

**Arizona's First Self-Determination Participants:
Descriptive Data from the Personal Life Quality Protocol**



Submitted by

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Introduction

The Nature of Self-Determination

The “theory” or “hypothesis” of self-determination has been stated quite simply:¹

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

In order to understand self-determination fully, these three elements of the hypothesis must be discussed in some depth.

If People Gain Control

The phrase “if people gain control” means several things. It means that focus people and their freely chosen allies gain power over life choices. The creators of the self-determination principles and practices believed that American service systems had moved much too far in the direction of professional domination of people’s lives.² Paid people were making all decisions, small and large, about every detail of the way people lived, worked, learned, and took part in leisure. The pendulum had swung too far.

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

¹ Conroy, J., Yuskas, A., & Spreat, S. (In Press). *Outcomes of Self-Determination in New Hampshire*. Under final review in JASH.

² 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.

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

In many parts of the country, service systems only have “group budgets.” Usually, for a person living in a traditional group home, the only way accounting procedures have attributed costs to individuals is by taking the cost of the facility and dividing it equally across the number of people living in the facility. This crude procedure has ignored individual differences in supports rendered, and also tends to ignore the complexities of the multiple funding streams that can be used to deliver needed supports: Medicaid funding through the ICF/MR program and the Waiver program, vocational rehabilitation services, housing assistance through several programs including HUD, Supplemental Security Income and other forms of income assistance, special education, Title XX programs, acute care medical assistance (Medi-Cal in California), and so on. Some observers have characterized the present American funding system for people with developmental disabilities as a bizarre patchwork that makes consideration of individual situations and expenditures very difficult indeed.

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

engaging and fulfilling opportunities possible within the predetermined amount of money available.

Individual budgeting has proven to be among the most difficult, and yet the most fundamental, of the preconditions for self-determination. Perhaps the thorniest problem is how to set a budget amount for people who are just entering the service and support system. What is “fair?” How can that be quantified? How much does one person and circle “deserve,” and why is that different from some other person and circle?

Their Lives Will Improve

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

In the situation of uncertainty about how the intervention will affect people’s lives, the only proper scientific approach is to measure a broad range of qualities of life. This was the purpose of collecting the Personal Life Quality protocol, which is described in the Methods section below. The basic idea is that, if self-determination has impacts, they might be felt in one or more of dozens of dimensions, such as:

- Power and opportunities for choicemaking,
- Composition of the planning team (proportion of unpaid and chosen members of the planning team)
- Individual plan status and content,
- Behavior
- Integration
- Productivity and earnings
- Health, health care, mental health care, medications
- Satisfaction

At this stage of our knowledge about how self-determination unfolds in different service systems, we do not know which dimensions of quality will be affected. Therefore we must measure all the dimensions we know how to measure, in order to determine which (if any) areas of quality of life display changes.

Costs Will Decrease

The third part of the self-determination “theory” is that “costs will decrease.” This hypothesis was originally based on the observation of three “case study participants” in the original work at Monadnock Developmental Services, Inc., in New Hampshire.³ Project implementers noticed that reduction of professional domination in the planning process seemed to be associated with a new tendency for teams to purchase precisely what was needed and wanted, and no more. This was believed to be in contrast with the traditional service system, in which all the built-in incentives forced service providers to make sure every dollar was spent at the end of the fiscal year, and that more was requested in each subsequent year.

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

Even this relatively progressive system was viewed as “traditional” by the originators of the self-determination demonstration. They believed that the Monadnock service system was, despite its advances, still guilty of excessively high costs and professional domination at the expense of genuinely connected and interconnected lives. The phrase “we have been spending money to avoid intimacy”⁴ was used to

³ Nerney, T., Crowley, R., & Conroy, J. (1993). Proposal to RWJF entitled “*Self-Determination for Persons with Developmental Disabilities: 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.*”

⁴ Nerney, T. (1995). Personal communication.

describe this radical belief structure. Some of the components of the originators' beliefs were:

- Non-professional control of resources will permit more precise purchasing of what people really want and need to “get a life”
- There will be a decreased reliance on the “one size fits all” mentality
- The inherently expensive congregate care models will diminish and someday may even vanish (congregate meaning a group of any size)
- A lessening of “over-service” will take place
- Increased utilization of natural and community based supports will emerge
- Some degree of escape from the traditional human services “vortex” of over-spending and over-controlling is to be expected
- All in all, when power moves away from traditional professional domination, the spending of tax dollars will decrease

Indeed, using two different accounting methods, we documented a reduction of between 12% and 15% in the total dollars necessary to support the original group of 45 participants in Monodnock.⁵

At this point, it is important to note that some self determination implementation models may be unable to fully test the three parts of the hypothesis. For example, if the participants are coming into self-determination from a waiting list, then there is no initial “cost of service,” and hence the costs cannot decrease. Moreover, for people already living at home, with family, in communities of their choosing, the likelihood that qualities of life will improve measurably is obviously less than for people who move from traditional congregate services to individual budgets and choice.

⁵ Conroy, J., & Yuskauskas, A. (1996, December). *Independent Evaluation of the Monadnock Self-Determination Project*. Submitted to the Robert Wood Johnson Foundation. Rosemont, PA: The Center for Outcome Analysis.

Implementing Self-Determination

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

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

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

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

- Freedom: The ability for individuals with freely chosen family and/or friends to plan a life with necessary support rather than purchase a program
- Authority: The ability for a person with a disability (with a social support network or circle if needed) to control a certain sum of dollars in order to purchase these supports
- Support: The arranging of resources and personnel – both formal and informal – that will assist an individual with a disability to live a life in the community rich in community association and contribution
- Responsibility: The acceptance of a valued role in a person’s community through competitive employment, organizational affiliations, spiritual development and general caring for others in the community, as well as accountability for spending public dollars in ways that are life-enhancing for persons with disabilities (pp. 4,5).

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

Methods

Instruments

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

The Protocol's subsections have been found to display strong reliability (Conroy, 1995; Devlin, 1989; Fullerton, Douglass, & Dodder, 1999). The subsections are designed to be sensitive to issues identified as important by self-advocates over the years. The dimensions of quality also cover the general areas specified as central outcomes in the Developmental Disabilities Act Amendments of 1987: Independence, Productivity, Integration, and Satisfaction. The elements of the Protocol have been described in detail in the literature (Conroy, 1996).

Design

This report examines the baseline data for 31 people visited in Arizona as part of the Self-Determination Project in 2000. The central question of any evaluation of a social intervention is "Are the people who received the intervention better off?" In the case of self determination initiatives, we want to be able to measure any changes in life quality that can be related to participation. It is therefore our preference to gather "baseline" data on participants before they actually begin self determination activities. We will then conduct the surveys again at some point in the future and be able to identify changes. This design will allow Arizona self-advocates, families, and policy makers to know whether the people who choose to become involved in self

determination are better off, worse off, or about the same --- and, to know in what ways and how much.

Results

Characteristics of the Participants

Table 1 shows the distribution of basic characteristics among the 31 people, including gender, minority status and average age.

Table 1.
Demographic Characteristics of the Participants

Characteristic	Percent
Percent Male	53.3
Percent Minority	38.7
Average Age	27.3

The participants were 53.3% male. Almost 40% of the participants (38.7%) were categorized as Hispanic, Native American or Other Minority. The average age of the participants was 27 years old.

Table 2 shows the distribution of mental retardation labels among the participants. Although the trend in the field is to put more credence in the utility of individual plans and assessments as opposed to such labels, it remains a point of interest to compare the distribution of the people included in the Arizona project with others across the country.

Table 2.
Label of Mental Retardation Distribution Among Participants

Label of Mental Retardation	Number	Percent
No MR	2	6.5
Mild	6	19.4
Moderate	8	25.8
Severe	4	12.9
Profound	2	6.5
Unknown	9	29.0
Total	31	100.0

Nine people (29%) in the sample were reported to have mental retardation, although the specific label was not known. Eight people (25.8%) were labeled as having “Moderate” mental retardation, 19.4% as having “Mild” mental retardation, 12.9% as having “Severe” mental retardation, and only 6.5% as having “Profound” mental retardation. In addition, 6.5% of the participants were reported as having no mental retardation label.

Many people with mental retardation have secondary disabilities. This information can be important for developing current and long-range community resources. The people we visited reported the conditions shown in Table 3 as major secondary disabilities.

Table 3.
Percentages of People with “Major” Secondary Disabilities

Category of Secondary Disability	Number	Percent
Ambulation	4	14.8
Autism	3	11.1
Aggressive Behavior	1	3.6
Self-Abusive Behavior	1	3.7
Brain Injury	2	7.4
Cerebral Palsy	6	21.4
Communication	9	33.3
Dementia	0	0.0
Health Problems	4	13.8
Hearing	0	0.0
Mental Illness	1	3.6
Physical Disability	4	14.8
Seizures	7	25.0
Substance Abuse	1	3.7
Vision	6	21.4
Other	7	26.9

Roughly one-third (33.3%) of the participants were reported as having a “Major Disability” in communication. Almost 15% (14.8%) of the participants had major disabilities in ambulation and physical disabilities, and 21.4% were reported to have cerebral palsy. Twenty-five percent of the participants were reported as having seizures as a major disability, and over 11% (11.1%) reported autism as a major disability. Over 20% (21.4%) of the participants were reported to have major vision impairments. Very small percentages of the 31 participants were reported as having aggressive types of behaviors (3.6%), self-abusive behaviors (3.7%) or mental illness (3.6%) as major disabilities.

Table 4 shows a breakdown of where the 31 participants live, and the percentage of participants who live in each type of setting.

Table 4.
Where do the 31 Arizona Participants Live?

Type of Home	Number	Percent
Own Home	2	6.7
Parents or Other Relatives Home	24	80.0
Supported Living in Community	1	3.3
Supervised Community Residence	1	3.3
Other	2	6.7
Total	30	100.0

* Type of residence was left blank on one individual.

Eighty percent of the people involved in the Arizona Self-Determination Project lived with their parents or with other relatives.

Participation in Self-Determination

As described in the design section, this round of visits was purposefully scheduled to gather baseline information prior to full participation in self determination activities. Table 5 is indicative of this strategy.

Table 5.
People Participating in Self-Determination in 2000

Response Category	Number	Percent
No	25	86.2
Yes	4	13.8
Total	29	100.0

The majority of the 31 people (86.2%) involved in this study were not formally participating in self-determination when we visited them in 2000.

Choice Making

An important aspect of self-determination is “Who has the power?” in individuals’ lives. The Decision Control Inventory measures who has power over 35 life areas such as clothes to wear, food to eat, places to go, and type of work or day program. The scale requires ratings from 0 to 10 on each dimension, with 0 meaning

that paid staff made all decisions in that area, and 10 meaning that the focus person (and/or his/her freely chosen unpaid allies) made the decisions in that area. A score of 5 or 6 means that decision making power is shared about equally. The 35 “0-to-10” scores can be combined into a single scale which we compute to a range from 0 to 100, with higher scores meaning more individual control over life choices, and less professional domination.

Table 6 below provides detail about which areas of choice people had more or less control over in 2000. Examination of these scores can provide guidance for provider agency staff and other support personnel who wish to enhance people’s decision making skills. Over time, this measure can pinpoint areas in which change in power is, or is not, occurring as people become more involved in self-determination.

Table 6.
Details of Opportunities for Choicemaking

Area of Control	Mean
What to do with personal funds	10.0
How to spend residential funds	10.0
Taking naps in evenings	9.6
When to go to bed on weekdays	9.6
When to go to bed on weekends	9.6
When to get up on weekends	9.6
What clothes to wear on weekends	9.5
How to spend day activity funds	9.5
Choice of furnishings	9.5
Express affection, including sexual	9.5
What clothes to wear on weekdays	9.3
Whether to have a pet in the home	9.2
Time and frequency of bath	9.1
Choice of house or apartment	9.1
Choice of people to live with	9.1
Choice of places to go	8.7
What to do with relaxation time	8.7
Choice to decline activities	8.7
Visiting with friends	8.6
Who goes with you on outings	8.6
Who you hang out with	8.6
What clothes to buy	8.6
Type of transportation to and from day program or job	8.2
Minor vices	8.2
Type of work or day program	8.0
What foods to buy	7.9
Choosing restaurants	7.8
What to have for dinner	7.7
When, where and how to worship	7.6
Choice of service agency	7.3
Choice of case manager	7.3
What to have for breakfast	7.2
Choice of agency support person	7.0
Choice of support personnel: option to hire and fire	7.0
Amount of time spent working or at day program	6.4

The Arizona participants' average score on the Decision Control Inventory was high at 85.1 points out of 100 when we visited them in 2000, indicating a relatively high degree of control over their lives. There were no items on the Decision Control Inventory that were scored below a mean of 6.4 out of 10 points. The lowest mean score (6.4) was in the area of choosing the amount of time spent working or at a day program. The other low scoring areas for Arizona participants were: having the option to hire or fire their support personnel, the choice of who their agency support person would be, the choice of what to have for breakfast, and a tie for fifth lowest mean score on the choice of case manager and the choice of service provider agency.

The thirty-one Arizona participants scored 10 out of 10 on the choice of how to spend their residential and personal funds. This finding is most likely the result of the fact that most of the participants (80%) live in a private home with parents or other relatives. The areas showing the next highest amount of control for the participants were in the choice of taking naps in the evenings, the choice of when to go to bed on the weekends and on weekdays, and the choice of when to get up on weekends. It is interesting to note that the Arizona participants scored very high (9.5) on the choice of how to spend their day activity funds and also on the choice of expressing affection, including sexual. This finding is interesting because most of the Arizona participants were described as not participating in self-determination in 2000, yet they already have power in the areas in which self-determination is theorized to increase power.

Day Activities and Earnings

One of the most important ways to look at quality for all people, and especially for people with disabilities, is to ask, "What do you do all day?" It is important that people stay engaged, that they have something to do that is fulfilling to some degree, to have something to "look forward to" each morning. Table 7 summarizes how many of

the participants were involved in each type of day activity and the average hours spent in each type of day activity.

Table 7.
Participation in Day Programs for the Participants

Type of Day Program	Number Involved	Mean Hours
Self-employed	0	-
Regular job	1	6.0
Supported Employment, Individual placement model	0	-
Supported Employment, Enclave model	0	-
Supported Employment, Mobile work crew	1	4.0
Sheltered Employment	1	35.0
Vocational Training	1	2.0
Non-vocational Activities	11	24.5
Senior Citizen Program	0	-
Partial Hospitalization	0	-
Volunteer Work	0	-
Community Experience	2	3.5
Public School, Regular	6	7.7
Public School, Separate building	1	4.0
Private School, Regular	0	-
Private School, Separate	0	-
Adult Education	0	-
Other Day Program	3	19.0
Total Day Program Hours	29	14.9

Eleven of the 31 people were involved in non-vocational types of day programs, and they were involved in these types of programs an average of 24.5 hours a week. One person had a “regular job” and worked at this job an average of six hours a week. One person averaged four hours a week on a mobile work crew, one person spent an average of 35 hours a week involved in sheltered employment. Seven people were in public school, six people attended regular classes in a public school, and one person attended classes in a separate building at a public school. Across the 29 out of 31 people who reported involvement in day program activities, the average number of hours spent per week was about 15 hours (14.9).

Twenty-five of the 31 participants were not earning any money at all. The six people who were earning money averaged \$33.25 per week. This finding is indicative of the nation wide crisis of unemployment and poverty for people with disabilities.

Integration

The scale used to measure integration was taken from the Harris poll of Americans with and without disabilities (Taylor, Kagay, & Leichenko, 1986). Respondents were asked to report how often people engaged in a variety of community events in a typical month. Events on the scale included activities such as: visit with friends, go shopping, go to a place of worship, engage in recreation, etc. A second qualifier for this scale was events that involved the presence of people without disabilities. This tool simply counts the number of “outings” to places where there might be interaction with non-disabled citizens. It does not measure actual engagement or the degree of participation. Table 8 describes the 31 participants in terms of their participation in integrative activities.

Table 8.
Integrative Activities

Type of Integrative Activity	Average Number of Events per Month
Visit with close friends	17.1
Visit a grocery store	4.2
Go to a restaurant	4.1
Go to church	1.7
Go to a shopping center	3.7
Go to bars	0.0
Go to a bank	0.4
Go to a movie	0.7
Go to a park or playground	2.0
Go to a theater	0.3
Go to a post office	1.3
Go to a library	0.5
Go to a sports event	1.4
Go to a health or exercise club	0.0
Use public transportation	2.3
Other kinds of getting out	1.8
Average Number per month	38.5

The 31 people participating in the Arizona Self-Determination Project were reported to go out to visit with their close friends an average of 17 times a month. They went out to restaurants and to grocery stores on average 4 times a month, or roughly once a week. They were reported to use public transportation a little over 2 times a month, went to parks or playgrounds twice a month and went to shopping malls almost 4 times a month. When we looked at the overall average number of events per month across all categories, we found that the people in Arizona get out to do some type of integrative activity a little more than once a day, with an average of 38.5 events per month.

Quality of Life, Then and Now

As part of the personal interview, we included an instrument called Quality of Life Changes. This scale asked the person to rate the quality of his/her life A YEAR AGO and then NOW. Ratings were presented on 1 to 5 point scales, with 1 being Very Bad and 5 being Very Good. This was the only part of the personal interview in which surrogates (usually residential staff) were allowed to give their opinions if the individual was unable or had difficulty. The ultimate answers were often the result of discussion. Ratings were collected for 13 dimensions of quality of life plus “Overall quality of life” and then combined into a Quality of Life Scale that ranges from 0 to 100.

In this analysis, we compared the “Before” and “Now” scale score for the people in Arizona. The 31 participants in Arizona had an average Quality of Life scale score of 72.5 when rating their perception of “A Year Ago”. When asked to rate their perception of their quality of life “Now”, the average score was 74.6. This difference was not statistically significant. It should be noted, however, that these two scores were from the peoples’ perceptions of their lives a year ago. In future visits we expect to see changes in this scale score as people become more involved in self-determination.

Individual Planning

To measure elements of the planning process in terms of “person-centeredness”, we included 16 items that describe aspects of the process that respondents rate on a 5-point scale, with 1 being “Not at all” and 5 being “Completely”. Table 9 shows the mean responses to these questions at baseline, in other words, at the first time we visited the 31 people in Arizona in 2000.

Table 9.
Elements of the Planning Process
In Three Samples

Planning Process Characteristic	Arizona	Ohio	Hawaii
Is the process flexible?	4.4	4.1	4.2
Does the process emphasize cooperation?	4.4	4.4	4.2
Does plan understand long-term dreams?	4.3	3.8	3.8
How involved in planning process?	4.2	4.4	4.1
Does the process encourage creativity?	4.2	3.6	3.7
Does the process emphasize the person's relationships?	4.1	4.0	3.7
Do you consider the plan to be person-centered?	4.0	4.1	4.0
Are meetings comfortable and relaxed?	3.9	4.4	4.2
Planning sessions scheduled as needed?	3.9	4.3	4.0
Conflict resolution?	3.9	3.9	4.1
Does plan build a network of supports?	3.5	3.2	3.4
Do unpaid group members have the real power?	3.4	4.1	3.7
Does the person have the ultimate authority?	3.1	4.1	3.4
Does the process consider money?	3.1	3.8	3.4
Does the planning group have control over resources?	2.6	3.9	3.1
Is the process defined or regulated?	2.3	3.5	4.5

The Planning Process appeared to show the most “person-centeredness” in terms of being flexible, emphasizing cooperation, and understanding the focus person’s long-term dreams. The Planning Process appeared to be the least “person-centered” when it came to the consideration of money, the planning group having control over resources, and the process being defined or regulated. The table also shows comparisons with elements of the planning process scores in Ohio and Hawaii at the time of our first visits.

Health Information

Respondents were asked to rate the quality of the health care they were receiving. The results are shown in Table 10.

Table 10.
Overall, How good is the Health Care Received?

Response Category	Number	Percent
Poor	3	9.7
Fair	6	19.4
Good	13	41.9
Excellent	9	29.0
Total	31	100.0

Over 70% (70.9%) of the respondents rated the health care they were receiving as either “Good” (41.9%) or “Excellent” (29.0%). Less than 10% (9.7%) rated the quality of the health care they were receiving as “Poor”.

Table 11.
Psychotropic Medication Usage Among Participants

Number of Psychotropic Medications	Number Receiving	Percent Receiving
Zero	27	87.1
One	2	6.5
Two	2	6.5
Total	31	100.0

Almost 90% of the 31 participants in Arizona were not taking any psychotropic medications. Two people (6.5%) were taking one psychotropic medication, and two people (again, 6.5%) were taking two psychotropic medications.

Satisfaction

We asked the participants how they felt about where they live. The results are presented in Table 12.

Table 12.
“How Do You Feel About Living Here?”

Response Category	Number	Percent
Very Poor	0	0
Poor	0	0
Fair	2	13.3
Good	5	33.3
Very Good	8	53.3
Total	15	100.0

The majority of the people who responded to this question, 86.6%, said they felt either “Good” (33.3%) or “Very Good” (53.3%) about where they were living. No respondents chose “Poor” or “Very Poor”, indicating that most are somewhat happy with their current living situation.

Friendships

Many people measure their quality of life according to the numbers of friendships they enjoy⁶. This measurement is even more important for people with disabilities, many of whom have not had years of integrated schooling and jobs to develop friendships in the ways that most people do.

The Close Friends Scale matrix was designed to capture the nature and intensity of relationships. Visitors asked people to describe their five closest friendships. Our analysis describes the percentages of friendships according to the type of relationship. The nature of these close friends is shown in Table 13.

⁶ R. Schalock and M. Begab (Eds.) *Quality of life: Perspectives and issues* (pp. 227-234). Monograph Number 12. Washington: American Association on Mental Retardation.

Table 13.
Close Friends Relationships

Relationship	Count	Percent of Responses	Percent of Cases
Relative	14	21.2	70.0
Staff of home	2	3.0	10.0
Staff of day program	13	19.7	65.0
Other paid	4	6.1	20.0
Housemate	1	1.5	5.0
Co-worker or schoolmate	16	24.2	80.0
Neighbor	6	9.1	30.0
Merchant	3	4.5	15.0
Other	7	10.6	35.0
Total	66	100.0	330.0

*Percentage of cases adds to more than 100 because the 31 people named more than one friend.

The median number of friends reported by the Arizona participants was 3 friends and 1 close friend. As can be seen in the table above, the largest percentage of people reported to be friends of the participants was co-workers or schoolmates. The next largest percentage of reported friends was relatives. Close to 30% of the friend relationships reported were either staff of the home (3.0%), staff of the day program (19.7%), or another type of paid relationship (6.1%).

If You Had One Wish...

In the personal interview, we ask the focus person, “If you had one wish, what would it be?” The answers range from funny to heart breakingly sad. It is perhaps the one response that best illustrates how much people with disabilities are just like anyone else in our society. The wishes can be categorized in many ways, and many wishes fit more than one category. In general, they break down according to wealth or possessions (stuff), relationships, adventures, and homes. The best way to share the responses to these questions is with direct quotes. Below are the verbatim responses from the Arizona participants who answered this question.

Wishes

A car
Able to drive
Be a good person
Bring Dad back
Go fishing, camping, pup tent, boat
Money
Nephews would listen to me
Not to have broken the ankle
Out of debt
To be good
To drive a car - driver's license. No drugs, no alcohol
To have my left eye back – I'd like to be like before
Walk and be more self dependent
Walk without walker
Want real Dad, movie stars, country stars

Discussion

The spirit of commitment exhibited by the stakeholders in the Arizona pilot project is typical of self-determination initiatives across the country. The people with disabilities and their families are the obvious beneficiaries of an improved service system but all the other players, administrators, care givers and other support staff have a vested interest as well. The hope is that shared values, aspirations, daily routines, and careers will be enhanced through self-determination.

The thirty-one self-determination pioneers in Arizona scored fairly well on health care and satisfaction with their living arrangements. This is to be expected as the majority of them live with their families. The areas that appear to need focused attention are control of resources and day program hours. Arizona is obviously committed to the principles of person centered planning, but plans must be linked with individual budgets. People who engage in person centered planning need the authority to allocate resources according to their plans. Otherwise, the circle of support and the planning team become stagnant, members become frustrated or stop participating and

people with disabilities and their families are back where they started, maybe even a little worse off as they have been encouraged to envision a dream that is out of reach. Opportunities for competitive employment and the development of micro-enterprises can be supported through individual budgets and hopefully make changes in the income and hours of productive activities for people with disabilities in Arizona.

It will be interesting to measure changes in these and other areas when a second round of interviews is conducted with the Arizona self-determination participants.

References

Abery, B. (1993). A conceptual framework for enhancing self-determination. In M. Hayden & B. Abery (Eds.), Challenges for a service system in transition: Ensuring quality community experiences for persons with developmental disabilities (pp. 345-380). Baltimore: Brookes Publishing Co.

Abery, B.; Rudrud, L.; Arndt, K.; Schauben, L.; Eggebeen, A. (1995). Evaluating a Multicomponent Program for Enhancing the Self-Determination of Youth with Disabilities. Intervention in School and Clinic, 30(3), Jan, 170-179.

Conroy, J., Yuskauskas, A., & Spreat, S. (In Press). Outcomes of Self-Determination in New Hampshire. Under final review in JASH.

Conroy, J. (1995). 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 and Advocacy, Inc. Ardmore, PA: Center for Outcome Analysis.

Conroy, J. (1996). 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. Submitted jointly to Oklahoma Department of Human Services and United States District Court, Northern District of Oklahoma. Ardmore, PA: 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.

Field, S., & Hoffman, A. (1994). Development of a model for self-determination. Career Development for Exceptional Individuals, 159-169.

Field, S., Hoffman, A., St. Peter, S.; Sawilowsky, S. (1992). Effects of disability labels on teachers' perceptions of students' self-determination. Perceptual & Motor Skills, 75(3), 931-934.

Fullerton, A. Douglass, M. & Dodder, R. (1999). A reliability study of measures assessing the impact of deinstitutionalization. Research in Developmental Disabilities, 20(6), pp. 387-400.

Jaskulski, T., Metzler, C., & Zierman, S. A. (1990). Forging a new era: The 1990 reports on people with developmental disabilities. Washington, DC: National Association of Developmental Disabilities Councils.

Jones, A., & Crandall, R. (1986). Validation of a short index of self-actualization. Personality and Social Psychology Bulletin, 12, 63-73.

Kishi, G., Teelucksingh, B., Zollers, N., Park-Lee, S., & Meyer, L. (1988). Daily decision-making in community residences: A social comparison of adults with and without mental retardation. American Journal on Mental Retardation, 92, 430-435.

Nerney, T., Crowley, R., & Conroy, J. (1993). Proposal to RWJF entitled "Self-Determination for Persons with Developmental Disabilities: 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."

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.

Nerney, T. & Shumway, D. (1996). Beyond managed care: Self-Determination for people with disabilities (first edition). (Available from the authors, University of New Hampshire, Institute on Disabilities, Durham, NH).

Stancliffe, R. (1995). Assessing opportunities for choice making: A comparison of self-report and staff reports. American Journal on Mental Retardation, 99, 418-429.

Wehmeyer, M. L. (1992a). Self-determination and the education of students with mental retardation. Education and Training in Mental Retardation, 27, 302-314.

Wehmeyer, M. L. (1992b). Self-determination: Critical skills for outcome-oriented transition services. The Journal for Vocational Special Needs Education, 39, 153-163.

Wehmeyer, M. L. (1993). Reliability and acquiescence in the measurement of locus of control with adolescents and adults with mental retardation. Psychological Reports, 75, 527-537.

Wehmeyer, M. L. (1994a). Perceptions of self-determination and psychological empowerment of adolescents with mental retardation. Education and Training in Mental Retardation and Developmental Disability, 29, 9-21.

Wehmeyer, M. L. (1994b). Reliability and acquiescence in the measurement of locus of control with adolescents and adults with mental retardation. Psychological Reports, 75, 527-537.

Wehmeyer, M. L., & Kelchner, K. (1995). Measuring the autonomy of adults with mental retardation: A self-report version of the Autonomous Functioning Checklist. Career Development of Exceptional Individuals, 18, 3-20.

Wehmeyer, M. L., & Kelchner, K., & Richards, S. (1995). Individual and environmental factors related to the self-determination of adults with mental retardation. Journal of Vocational Rehabilitation, 5, 291-305.

West, M. D., Rayfield, R. G., Wehman, P., & Kregel, J. (1993). Assessing self-determination of youth with disabilities: A conceptual framework and model. Unpublished manuscript.