

**Initial Outcomes of Community Placement
For the People Who Moved From Stockley Center**

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Executive Summary

We have now visited the people who moved from Stockley Center, one year after each person's move. We have collected a complete battery of individual information about the qualities of their lives, including independence, integration, productivity, health, safety, friendships, person-centered planning, satisfaction, and more. This report provides our findings in response to the grand question, "Are the people better off?"

The first report was a brief description of the characteristics and qualities of life of the people living at the Stockley Center in the summer of 2000, delivered as a PowerPoint presentation. Part of that report was the finding that 250 out of the 251 people then living at Stockley had been recommended for community placement. Now, nearly 50 have moved out into the community. Another finding in that report was that the people at Stockley were very similar to people in other states who had very successfully adapted to community living.

This second report is concerned with scientific, quantitative answers to the questions: "Are the people who moved out of Stockley better off, worse off, or about the same? In what ways? How much?" To answer these questions, we visited each person who had moved to the community since the summer of 2000. We measured dozens of aspects of quality of life and characteristics of service provision for each person. These same measures were collected in 2000, so that we could directly compare the quality of the Mover's lives from Then to Now. We used questionnaires and scales that have been used in many other studies over a period of 20 years. The reliability and validity of these measures is well established (Fullerton, Douglass, & Dodder, 1999).

Historically, the movement of people with developmental disabilities from institution to community has been one of the most successful social movements of

the baby boomer generation (Larson & Lakin, 1989, 1991). In contrast, in the field of mental illness, the nation's record in the 1960s and 1970s was disgraceful. (Bassuk & Gerson, 1978).

Our present study shows that the movement of people out of Delaware's only public institution has been associated with many benefits. The data support a very strong inference that the movement of people from the Stockley Center has been quite successful. The people are, on the average, "better off" now than they were while living at Stockley. In our opinion, the evidence is now more than strong enough to justify public announcements about Delaware's accomplishment, and to continue the trend of moving people from Stockley Center.

This report is only an initial review. It is important to note that the data we have collected can be utilized for far deeper and more detailed analyses than the overall outcomes reported herein. Brief reports can be requested for much finer grained explorations of behavior change, integration, case management practices, and so on. Moreover, a simple and inexpensive mail survey of the families in the near future would be an extremely cost-effective and valuable adjunct to the findings in this report. Finally, we recommend that the next step in studying the transition of Delaware citizens from institution to community be a detailed and rigorous analysis of the comparative costs of the two kinds of service models.

Purpose

The central question of this report is, “Are they better off?” We can now compare dozens of qualities of life measures for the people when they were at Stockley to the measures now, in their new homes. The specific primary questions for this Quality Tracking Project are:

- **Are the people better off, worse off, or about the same?**
- **In what way(s)?**
- **How much?**¹

These are the central questions about well being that any parent, friend, advocate, or caring professional must ask. Our research is designed to be formative (providing insights along the way) as well as summative (evaluating success at the end).

The decision to begin moving people from Stockley into the community was made for many complex reasons. Most stakeholders believed (partly on the basis of 20 years of past research) that lives would actually be enriched by movement from institution to community.

¹ The next urgent policy question will require a detailed analysis of the comparative costs of services in institution and community in Delaware.

Historical Context

Deinstitutionalization is not a new phenomenon. In the field of developmental disabilities, it has been proceeding since 1969, and has been remarkably well studied, evaluated, and documented. There has, however, been considerable confusion between deinstitutionalization in the mental health field and deinstitutionalization in the mental retardation field. The misunderstanding is largely due to the historical confusion of mental illness with mental retardation.

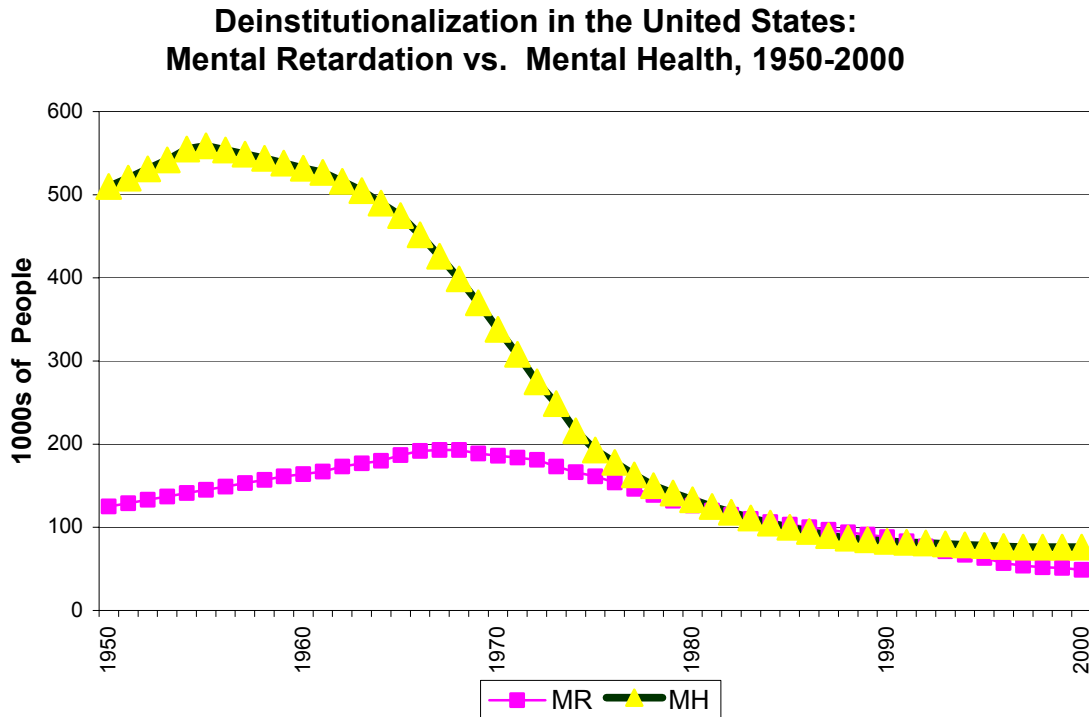
State institutions for people with mental illness experienced an entirely different, and devastatingly negative, depopulation movement during the 1960s and 1970s (Bassuk & Gerson, 1978). Deinstitutionalization of people with mental illness in the 1960s and 1970s was done hastily, without supports, and largely with reliance on the “new miracle drugs” approved by the FDA in 1955 (the anti-psychotic drugs including Haldol, Mellaril, Thorazine, and so on). In a summary statement of the nation’s early experience with deinstitutionalization in the mental health field, Alexander (1996) wrote:

Following the deinstitutionalization of persons with serious mental illness from state hospitals, many persons with serious mental illness did not receive the care that they needed and encountered unexpected negative experiences. Among the negative experiences were frequent rehospitalizations, involvement in the criminal justice system, and homelessness.

The result in the mental health field was a national disgrace, according to Bassuk & Gerson (1978).

The following figure compares the two trends toward deinstitutionalization. The upper line shows the depopulation of mental health institutions since 1950,

which was clearly far more precipitous than the relatively gradual downsizing of institutions for people with mental retardation as shown in the lower line.²



The figure above shows how different the two trends have been. Most citizens, and many families, who are skeptical of deinstitutionalization, formed their opinions with regard to the mental health debacle. Beginning in 1955, thousands of people with severe mental illness were released from public institutions with little more than 30 days of medications to support them. The term “dumping” was coined to describe this process in the 1950s, 1960s, and 1970s.

More recent experiences with mental health deinstitutionalization initiatives have been hailed as significant successes, such as the closure of Byberry in Philadelphia, PA. Still, it is important to understand the stark difference between the national record for mental illness, versus that for mental retardation and

² National and state data in this report were compiled into graphs and tables from several sources: Braddock et al, 2001, Lakin et al., 2002, and the National Center for Health Statistics.

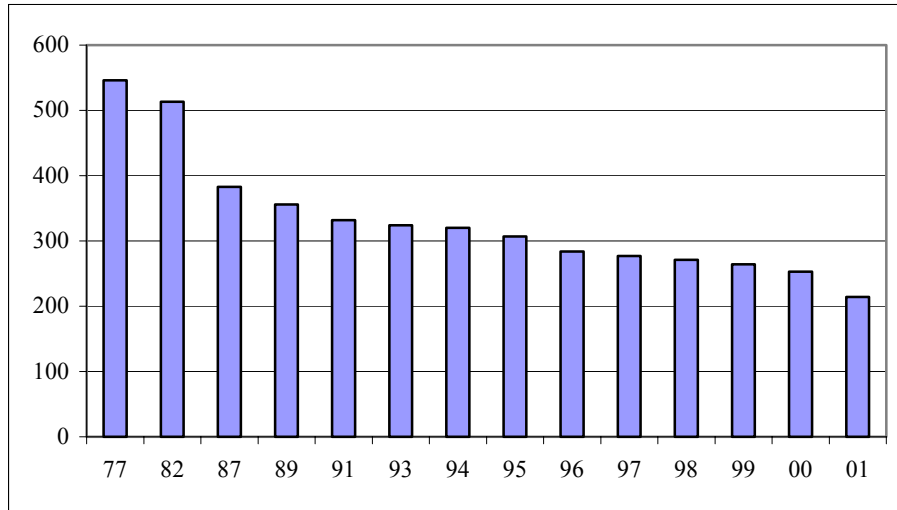
developmental disabilities. In the case of people with developmental disabilities, moving from large institutions to small community homes has been extremely successful. In fact, from the large body of research evidence now available, we are able to make this statement:

Deinstitutionalization of people with developmental disabilities in America has been one of the most successful and cost-effective social experiments in the past two decades.

For readers who care to review some of the extensive research literature on this topic, we have available thorough reviews of the largest and longest lasting studies of the impacts of deinstitutionalization in the mental retardation field. One such meta-analysis was performed by Larson & Lakin (1989).

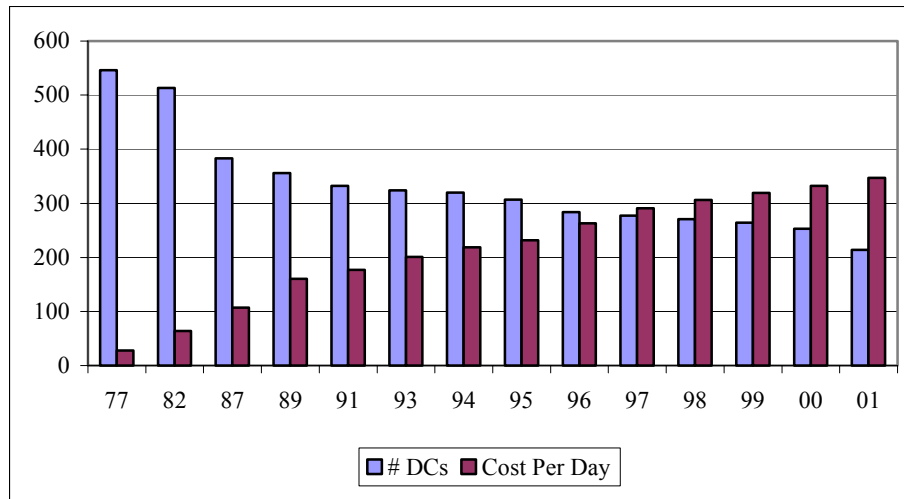
Delaware's involvement with institutional care for people with developmental and intellectual disabilities began in 1921 with the Stockley Center in Georgetown. Its population increased to a peak of approximately 600 people in the early 1970s. Following national trends, the movement of people from Stockley is part of a long process of downsizing in Delaware, beginning roughly in 1975. The decline of public institutional populations in Delaware is shown below.

Deinstitutionalization Trends in Delaware, 1977-2001



At the same time that populations were decreasing in Delaware's institutions, costs were rising.

Delaware Trends in Institutional Populations and Costs Per Person Per Day

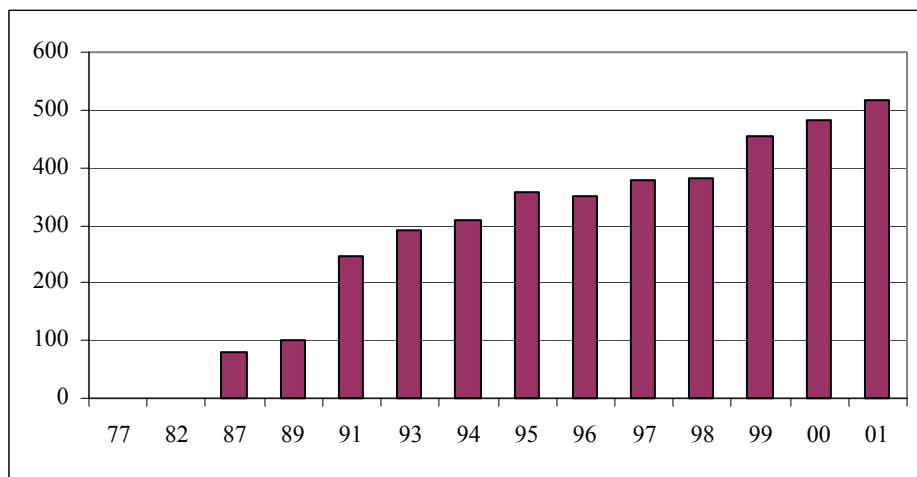


As the graph shows, the cost of supporting a person at Stockley has been rising steadily. And yet, to our knowledge, there is no hard evidence of increasing

quality of life for the people at Stockley.³ Efforts toward accreditation, licensing, ICF/MR standards, and the like are all commendable – but none of these approaches has measured or compared actual individual outcomes or qualities of life for all the residents – nor did they compare qualities of life to those of similar people living in community settings.

Community trends in Delaware have been clear and consistent. The following graph shows increasing reliance on Home and Community Based Waivers, which permit Federal Financial Participation to supplement Delaware’s state dollars.

**Increasing Use of Home and Community Based Waivers in Delaware
(Numbers of Participants by Year)**



The Delaware achievement can now be placed into the context of the national experience of deinstitutionalization and “communitization.” In the case of the nearby Pennhurst Center (a Pennsylvania institution near Valley Forge), more than 1,100 people moved to new community homes between 1978 and 1987. The

³ Delaware may wish to consider doing such a project, since the 2000-2001 baseline data on qualities of life at Stockley are readily available. It would not be difficult to collect new Personal Life Quality protocols for the people still living there, and see which if any quality of life indicators have been enhanced.

Pennhurst closure was one of the most hotly contested and extensively studied of its kind. Similarly, other famous community placement processes have been studied and documented as shown below.

Prior Studies of Closure and Deinstitutionalization

State	Time Period	Notes
Arizona	1992-1997	Closed Ft. Stanton 1996, one Center left
Arkansas	1983-1986	Slow depopulation studied by Rosen (1985)
California	1993-2002	Coffelt settlement, 2400 movers, largest and fastest in history
Connecticut	1985-1994	Mansfield closed 1994
Indiana	1996-2000	Northern Indiana and Newcastle closed
Kansas	1996-1998	Two state hospitals: Winfield and Topeka closed
Louisiana	1980-1998	Gary W. or "Texas Children" lawsuit brought 600 back to LA, and then into community
Maine	1990	Pineland closed, only one Center left
Michigan	1975-1995	Plymouth Center and others closed during 20 year buildup of community capacity, led by Macomb-Oakland Regional Center; only 250 people with mental retardation still in institutions, largest state to be almost institution-free
Minnesota	1980-1998	Rapid downsizing of all facilities, closure of some
New Hampshire	1992	Became first state to have no citizen in a public institution
New Jersey	1988-1998	Johnstone closed 1991, North Princeton closed 1997
New Mexico	1996	Became institution-free with closure of last public facility
North Carolina	1991-1998	Thomas S. lawsuit results in movement of nearly 1,000 people with dual diagnosis out of Psychiatric Hospitals
Oklahoma	1988-2003	Hissom Memorial Center closed under court order, but ahead of schedule, with the best outcomes yet measured anywhere (Conroy, 1996)
Pennsylvania	1978-1987	Took 9 years to close Pennhurst, most closely studied closure of all time
Rhode Island	1995	Became institution-free after a long policy of community placement
Vermont	1996	Became institution-free
West Virginia	1985-1998	Continual gradual process of placement and closure

What has resulted from this process of community placement? We at the Center for Outcome Analysis (COA) have measured dozens of qualities of life among the people affected by the community placement process in more than 15 states. Our research questions have been intentionally simple: Are they better off? In what ways? How much? At what cost?

These studies and Quality Tracking Systems have included more than 8,000 people, some of them for as long as 25 years. We have pursued our investigations with widely used and recognized measurement instruments and a variety of research designs (face to face key informant interviews and pre and post measurements of qualities of life). We have at all times striven for scientific objectivity to answer the question, “Are people better off?”

Where we have found positive outcomes, we have reported them scientifically. This report is intended to be brief, minimally technical, and graphically oriented, in order to make the findings accessible to the largest possible number of interested parties. Nevertheless, the report is founded on rigorous scientific and statistical analyses.

Methods

In this Methods section, we provide the information necessary for others to judge the scientific merits of what we measured, how, and why. The general purpose of a Methods section is to allow other scientists to replicate our work, to see whether they obtain similar results. Replication is the heart of the scientific method; any one study can be erroneous, but if other researchers in other places use the same procedures and get the same results, then we gain confidence in the findings. Secondly, a Methods section enables readers to immediately form judgements about whether we measured what is important, or measured those things in the right ways. The Methods section is composed of Instruments (the measurement devices), Procedures (how we collected the data), and Participants (what kinds of people were included).

Instruments: The Personal Life Quality Protocol

Our package of measures of qualities of life is generally called the Personal Life Quality Protocol (PLQ). Many of the elements of this 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. Over the years, other groups have been added to the database, such as all people living in Community Living Arrangements in Philadelphia, PA who were not members of the Pennhurst Class.

The battery of instruments was based on the notion that "quality of life" is inherently multidimensional (Conroy, 1986). It is essential to measure many kinds of individual outcomes to gain an understanding of what aspects of quality of life have changed over time (Conroy & Feinstein, 1990a). 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; while people with mental retardation may value having freedom, money, and friends most highly. The goal in our research on deinstitutionalization has been to learn how to measure aspects of all of these "valued outcomes" reliably.

The measures used in 2000 at Stockley included behavioral progress, integration, productivity, earnings, opportunities for choice making, Individual Planning and Supports status, health, health care, medications, amount and type of developmentally oriented services, satisfaction of the people receiving services. Some of the data collection instruments, and their reliability, have been described in the Pennhurst reports and subsequent documents (Conroy & Bradley, 1985; Devlin, 1989; Lemanowicz, Levine, Feinstein, & Conroy, 1990).

Behavior

In our data set, the California behavior scale called the Client Development Evaluation Report (CDER) was used. This behavior measure is composed of 52 adaptive behavior items and 14 challenging behavior items. The CDER adaptive behavior measure has been reported to have excellent reliability, and the challenging behavior scale has also been found to be acceptably reliable (Conroy, 1997; Harris, 1982). These scales are to be reported by third parties from their observation and experience. Both the adaptive and the challenging aspects of behavior are best treated as simple single scales rather than a complex set of subscales (Arndt, 1981).

Choice Making

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 same scale used by the Robert Wood Johnson Foundation in its National Evaluation of Self-Determination in 29 states. The interrater reliability of the Inventory was reported as .86 (Conroy, 1995).

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 very high when the time interval was corrected for (.97).

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.” In our experience, approximately 85% of the responses for this scale are provided by surrogates. The interrater reliability of the Quality of Life Changes Scale was found to be .76.

Health and Health Care

The indicators of health and health care were simple and straightforward. Intensity of medical needs was rated by staff informants on a five point scale. Problems involved with getting health care for the person were also rated on a five point scale (Very Difficult, Difficult, About Average, Easy, Very Easy). 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. Frequency of seeing physicians, of seeing specialists, of seeing dentists, of going to emergency rooms, and so forth were also included. The name and type of every medication was also collected.

Productivity

Productivity was reflected 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.

Many versions of the PLQ also contain the “Orientation Toward Productive Activities” scale, composed of 14 simple items concerning being on time, showing

enthusiasm about work, keeping a job, and getting promotions. This scale has not yet been subjected to reliability testing. It did, however, show significant increases during the first New Hampshire implementation of self-determination, so there is some reason to believe that it is sensitive to meaningful changes.

Size of Home

The size of the home was measured by the response to the question "How many people who have developmental disabilities live in this immediate setting?" This was not necessarily a direct measure of quality or outcome, but the size of the setting has been investigated extensively as an important contributor to quality of life (Balla, 1976; Baroff, 1980; Conroy, 1992; Lakin, White, Hill, Bruininks, & Wright, 1990).

Service Delivery Process

A few simple items were collected to reflect the involvement of the case manager according to records. Examples were the presence of an up-to-date Individual Plan at the time of the visit, and the presence of the Day Program Plan at the home.

In addition, the PLQ contains a section on Individual Planning and Supports. The Elements of the Planning Process scale is designed to measure the degree to which the planning process had the characteristics of "person-centeredness." Another scale captures the membership of the planning participants according to paid or unpaid, invited or not invited by the focus person, and family member or not. Another page captures each goal, desire, or preference in the Individual Plan, plus the degree to which each goal is being addressed by formal or informal supports, and the extent of progress seen thus far toward the goal. These new elements have not been subjected to reliability testing yet.

Procedures for Data Collection

The Center for Outcome Analysis recruited and trained people with extensive experience in working with people who have developmental disabilities to conduct a data collection visit with each person. These data collectors, called “Visitors,” functioned as Independent Contractors. They were paid a fixed rate for each completed interview. Below are the general instructions provided to our Visitors:

This package is composed of many measures, scales, instruments, and interview items. Practically all of the information collected in this package is related to quality of life. In order to complete the package, you must have access to:

- 1. The person (to attempt a direct interview of any length, usually 5 to 15 minutes)*
- 2. Whoever knows the individual best on a day to day basis (about 30 to 60 minutes)*
- 3. The person's records, including medical records (about 5 to 10 minutes)*
- 4. Sometimes, a health care professional familiar with the person (about 5-10 minutes)*

With access to these four sources of information, you will probably be able to complete this package within the range of 45 to 95 minutes.

The initial training for the COA Visitors was conducted by the Principal Investigator, with subsequent training by the Project Coordinator. The training consisted of an introduction to the project, a role-playing exercise, and a review of the instrument sections and purposes. Field supervision was provided on site during the first few days of visits.

Each visitor was responsible for scheduling appointments and completing assigned visits. Visitors were instructed emphatically to respect programmatic

needs, and work around them. No person's daily schedule was to be disrupted by these visits. In our community work, the average visit took 104 minutes. The amount of information collected, in relation to the relatively short duration of the visits, is worthy of comment. We were able to collect reliable quantitative data on dozens of qualities of life in a very short time, with very little intrusion into people's lives.

Annual collection of such solid information about people's qualities of life and outcomes is amply justifiable. There is absolutely no substitute for individual data on quality. No amount of licensing, performance indicators, or accreditation can compare to the utility and precision of individual outcome measurement. As systems move toward person centered planning, they must also move toward person centered evaluation and quality assurance systems.

Research Designs

The primary research design used in this report is the pre-post method. This method is also called "before and after." The pre-post method allows us to measure each person's many qualities of life while still living in a public institution, at baseline, and then visit and measure everything again after each person has moved into a community home. This method is intuitive and easy to understand.

Another research method used in this report is the external comparison. COA is able to compare the outcomes of deinstitutionalization in Delaware to outcomes among the thousands of people in other states where we have conducted research with essentially the same instruments. The advantage of this method is a direct way to establish external validity, one of the most central criteria in all of science.

If what we find in Delaware is very similar to what has been found in other states, then we may conclude with confidence that the deinstitutionalization phenomenon is fairly consistent in its outcomes. This lends a higher level of scientific credibility to the Delaware results.

Participants

There were a total of 251 people in the original survey conducted at Stockley. At the time of this writing, we had successfully completed one-year visits with 45 people whom we will refer to as Movers. We are presenting results on Movers who had been living in the community for one-year. These 45 Movers ranged in age from 37 to 77, with an average age of 50 years. The majority (70.5%) were male and 28.9% were minorities. Of the 45 people, one was unable to walk, five were reported to have serious aggression problems, there were three with severe self-abusive behaviors, eight with major seizure disorders, seven with no vision, and five with major health problems. Obviously, these 45 people experience a wide variety of severe disabilities.

Results

The ultimate quantitative questions posed by this project were, “Are these people better off, worse off, or about the same, and in what ways, and how much?” For the quantitative part of our work, we visited 45 people, interviewed staff members, and toured homes.

The data permitted us to analyze more than 700 items of information for each person. Most of these items were combined into scales for ease of interpretation. For example, there were 16 items on “getting out” and going on outings. The 16 were combined into a single scale of how many times each person went out into integrated settings each month. This produced a simple measure of “how often people got out each month.” If this measure went up, then we would conclude that the level of “integrative activities” increased. That would be a positive outcome as reduced segregation is viewed as a good thing. For this project, we collected a series of measures related to quality of life and therefore to outcomes.

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.

Demographics

Percent Male	70.5%
Percent Minority	28.9%
Average Age	50.3

As mentioned above, nearly three quarters of the 45 Movers were men, less than one-third were minority, and the average age was just over 50 years.

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 numbers of supports individuals require. The table below shows the percentages of people reported to have a “Major Secondary Disability” other than mental retardation.

Secondary Disabilities

Secondary Disability	Percent
Communication	40.00%
Seizures	22.20%
Vision	21.20%
Autism	18.20%
Mental Illness	15.60%
Health Problems	15.20%
Aggressive behavior	13.50%
Self abusive behavior	8.80%
Other Disability	7.10%
Hearing	6.10%
Ambulation	3.20%
Brain injury	3.20%
Cerebral palsy	3.20%
Dementia	3.10%
Physical Disability	0.00%
Substance Abuse	0.00%

The percentages of Movers who reported secondary disabilities varied according to the specific disability. The most commonly reported was Communication (40.0% of respondents), followed by Seizures (22.2%) and Vision (21.2%.)

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. The true description of self-determination includes decision making by families and friends who care about the person with a developmental disability. We therefore thought it was important to know the legal status of the 45 Movers. The table below shows the results.

Legal Status

	Number	Percent
Person has no guardian or is own guardian, not adjudicated incompetent	16	35.60%
Unrelated person is full guardian	12	26.70%
Parent/relative is full guardian	11	24.40%
Parent/Relative is limited guardian	5	11.10%
Unrelated person is limited guardian	1	2.20%

More than one-third (35.6%) of the Movers reported either not having a guardian, or being their own guardian. Unrelated persons were full guardians for 26.7% of the Movers and parents or relatives served as full (24.4%) or limited (11.1%) guardians. Only one person reported an unrelated person as a limited guardian.

We asked the Movers what kind of home they moved to after the institution, so we would be able to compare the Stockley Movers to other people we have followed. Their answers are shown below.

Type of Home

	Number	Percent
Supervised community residence (group home)	37	82.2%
Foster Home	8	17.8%

The table shows that 37 (82.2%) of the Movers were living in a Group Home when we interviewed them. The remaining eight Movers (17.8%) lived in Foster Homes.

We asked how many people with disabilities lived in each home (including the person we came to visit).

Number of People with Disabilities that Live in this Home

	Number	Percent
One Person	7	15.6%
Two People	4	8.9%
Three People	2	4.4%
Four People	31	68.9%
Five People	1	2.2%

Seven people (15.6%) reported being the only person with disabilities in their home. Four people lived with one other person with disabilities and two people lived with two others. The majority of Movers (68.9%) were living in four person homes when interviewed. Only one person (2.2%) was living in a five person home.

For the 37 people who lived in group homes, the average size of the homes was 3.7. This was interpreted as a positive finding because of the wealth of evidence in the scientific literature demonstrating that the size of group homes is

associated with quality, and in general, smaller homes produce better outcomes and qualities of life.⁴ For comparison, California's group homes that were created during the Coffelt deinstitutionalization averaged 6.0 people (median), and the outcomes we documented were not as positive as in Delaware.⁵

The average number of staff in these group homes was 5.3 full time, plus another 1.6 part time. Of course, the number of staff varied by the size of the home. The inference to be drawn is that the group homes that the Stockley Movers went to appeared to be reasonably well staffed and supervised. For comparison again, the larger group homes in California only had an average of 5.0 full time and 2.0 part time staff.

An adaptation of the California Client Development Evaluation Report (CDER) is a measure of independent functioning at the level of self-care skills. Below, we compare the change shown by the Delaware Movers to changes documented for similar Movers in other states. Because these Delaware changes occurred in only one year, there is reason to hope that there is still more learning potential to be tapped among these people.

⁴ Conroy, J. (1992). *Size and Quality in Residential Programs for People with Developmental Disabilities*. A Dissertation Submitted to the Temple University Graduate Board in Partial Fulfillment of the Requirements for the Degree Doctor of Philosophy. Philadelphia: Temple University.

⁵ Conroy, J., Fullerton, A., & Brown, M. (2002, June). *Final Outcomes of the 3 Year California Quality Tracking Project. Report #6 of the Quality Tracking Project for People with Developmental Disabilities Moving from Developmental Centers into the Community*. Narberth, PA: Center for Outcome Analysis.

Adaptive Behavior Development In Several Deinstitutionalization Studies

State	Number of Years	Time-1 Average Adaptive Behavior Score	Time-2 Average Adaptive Behavior Score	Gain On 100 Point Scale
Pennsylvania	14 years	39.8	50.2	10.4
New Hampshire	8 years	53.0	62.3	9.3
Louisiana	7 years	56.2	64.2	8.0
Oklahoma	6 years	41.3	47.4	6.2
Connecticut	5 years	49.5	54.0	4.5
California	3 years	44.7	46.7	2.0
North Carolina	2 years	52.7	54.8	2.2
Kansas	1 year	33.1	34.8	1.7
Indiana	1 year	48.1	50.2	2.1
Delaware	1 year	56.0	55.2	-.9

Sources: Conroy, 1996b; Conroy & Bradley, 1985; Bradley, Conroy, & Covert, 1986; Lemanowicz, Conroy, & Gant, 1985; Conroy, 1986b; Conroy, Lemanowicz, & Bernotsky, 1991; Present Report; Dudley, Ahlgrim-Dezell, & Conroy, 1995.

Delaware was the only group so far to fail to show an increase in the Adaptive Behavior table above. There could be any number of reasons for this, but as one can plainly see, larger gains are made the longer a person remains in the community. It is also important to note here that the change shown above for Delaware was not statistically significant, and therefore should be interpreted as no change.

The Orientation Toward Productive Activities Scale measures attitudes and behaviors related to productivity, including work, education, hobbies, volunteer work, self-improvement, etc. A few of the questions ask about waking up in the

morning, promptness, working well with others, and other skills necessary for vocational or employment success.

Productive Activities

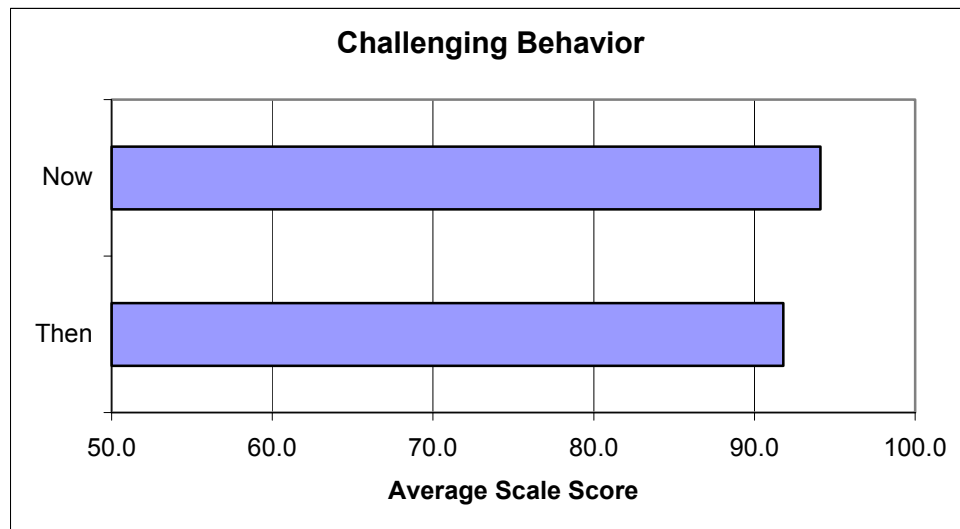
Then	Now	Change	Significance
36.4	41.2	4.8	0.035

The Delaware Movers showed a statistically significant improvement of 4.8 points (on a scale of 100) in the Orientation Toward Productive Activities Scale. This change shows that the Movers are making progress with regards to how they spend their days.

This next dimension was measured according to the person's ability to control challenging behavior, and so a higher score is a positive outcome. A score of 100 points would indicate no challenging behaviors. The Delaware Movers experienced an increase of 2.3 points on the challenging behavior scale after one year. This 10.3 point increase was statistically significant. Again, it may be of interest to compare these challenging behavior outcomes in Delaware to those we have obtained in other states. The table below shows these comparisons.

Challenging Behavior Improvements In Several Deinstitutionalization Studies

State	Number Of Years	Time-1 Average Challenging Behavior Score	Time-2 Average Challenging Behavior Score	Gain on 100 Point Scale
Pennsylvania	14 years	77.7	87.3	9.6
New Hampshire	8 years	79.6	78.6	-1.0
Louisiana	7 years	80.9	84.1	3.2
Oklahoma	6 years	89.7	93.5	3.8
Connecticut	5 years	79.0	80.2	1.2
California	3 years	68.1	76.4	8.3
North Carolina	2 years	87.7	89.4	1.7
Kansas	1 year	78.6	81.3	2.7
Indiana	1 year	70.5	67.9	-2.6
Delaware	1 year	91.8	94.1	2.3



The 45 Delaware Movers had very few challenging behaviors at Stockley and finished their first year in the community with even fewer challenging behaviors. It may be that absence of challenging behaviors was one of the criteria

for the first round of Stockley Movers. However, even this group managed to show statistically significant gains in this area after the move.

The Elements of the Planning Process Scale measures the degree to which the planning process is “person-centered.” This scale ranges from 0 to 100, with higher scores meaning that a higher level of “person-centered planning” is taking place. The results of the analysis of the Elements of the Planning Process scale for “Then” and “Now” are shown below.

Elements of the Planning Process

Then	Now	Change	Significance
62.0	71.0	9.0	0.038

The people who moved out of the Stockley Center scored an average of 62 points on the Elements of the Planning Process Scale “Then,” and their average scored increased 9 points when measured after they moved, or “Now.” This increase was statistically significant.

The Personal Life Quality Protocol also measures “Progress Towards Goals” on a 0 to 100 point scale. For each of the top five goals in each person’s Individual Plan, we asked “Has there been any progress toward this item in the past year?” Responses were given on a five point scale: Major Loss, Some Loss, No Change, Some Gain, Major Gain. These five point scales are combined across the five goals, and we construct an overall scale of progress toward goals. This overall scale is computed so that it can potentially range from 0 to 100. The results of this analysis are shown below.

Progress Toward Goals

Then	Now	Change	Significance
71.1	84.1	13.0	0.000

The 45 people included in this pre-post analysis scored an average of 71.1 points on the Progress Towards Goals scale “Then” or while at the Stockley Center, and their average score increased by 13.0 points when measured “Now”, or after they moved. This increase was highly statistically significant.

Average Length of the Planning Meetings

Then	Now	Change	Significance
1.7	1.5	-0.2	0.096

The average length of a the planning meetings got shorter for these people from “Then” to “Now,” but this decrease in the length of planning meetings was not statistically significant.

We also measured the average number of people who were invited to the planning meetings by the person receiving services and those who were present at the meetings but were not invited by the person. The table below shows the changes in the average number of invited and uninvited participants at the planning meetings from “Then” to “Now.”

Number of Planning Participants

	Then	Now	Change	Significance
Total	10.1	7.0	-3.1	0.000
Invited	5.1	5.3	0.2	0.395
Uninvited	3.4	2.8	-0.6	0.282

The average for the total number of planning participants decreased significantly from “Then” to “Now,” from about 10 participants to 7. The number of people who were invited to the planning meetings by the person receiving services remained essentially unchanged. Likewise, the 0.6 decrease in the average number of people who were present at the planning meeting but were not invited by the person receiving services showed no significant statistical difference.

Number of Services in Written Plan

Then	Now	Change	Significance
3.0	2.9	-0.1	0.400

The people who moved out of the Stockley Center showed essentially the same number of services in their written plans from “Then” to “Now.” The decrease shown above of 0.1 point was not statistically significant. This finding was interpreted as positive – there was no evidence that people in the community were receiving fewer services.

The Decision Control Inventory is made up of 35 items which measure the degree to which the person receiving services participates in the decision-making process for various everyday activities. Each items ranges from zero (Paid staff

make all choices) to 10 (person and/or family and friends make all choices). The items are then combined to make up the Decision Control Inventory scale score, which ranges from 0 to 100 with higher scores indicating higher participation in decisions of everyday life from the person and their (usually) unpaid allies. The results of the analysis of the overall scale score for the Decision Control Inventory and the item analyses from “Then” to “Now” are shown below sorted by the magnitude of change.

Decision Control Inventory

	Then	Now	Change	Significance
DCI Scale*	22.9	30.5	7.6	0.014
Choosing restaurants*	0.5	2.9	2.3	0.000
Choice of places to go*	1.0	2.9	2.0	0.000
How to spend day activity funds*	0.7	2.6	1.9	0.001
When to go to bed on weekends*	5.5	7.3	1.9	0.010
Whether to have pet in the home*	1.0	2.8	1.8	0.008
Choice of house or apartment*	0.0	1.8	1.8	0.001
Who goes with you on outings*	0.4	2.1	1.7	0.001
What foods to buy*	0.4	2.1	1.7	0.000
How to spend residential funds*	0.0	1.6	1.6	0.001
Minor vices*	0.7	2.2	1.5	0.008
Amount of time spent working or at day program*	0.6	2.0	1.3	0.013
Choice of people to live with*	0.2	1.5	1.3	0.004
When to go to bed on weekdays	5.6	6.9	1.3	0.056
When, where and how to worship*	2.9	4.1	1.2	0.046
Visiting with friends	1.5	2.4	0.9	0.138
Choice of furnishings	1.0	1.8	0.8	0.087
Type of work or day program	0.9	1.6	0.8	0.069
Express affection, including sexual	3.7	4.4	0.7	0.211
Choice of case manager*	0.0	0.6	0.6	0.024
Choice of support personnel*	0.0	0.6	0.6	0.037
Time and frequency of bath	2.7	3.2	0.5	0.262
Taking naps in evenings	7.0	7.4	0.4	0.284
Choice of which service agency works with person	0.0	0.3	0.3	0.109
What to do with personal funds	2.6	2.9	0.3	0.325
What to have for breakfast	2.7	3.0	0.3	0.340
What to have for dinner	2.6	2.9	0.3	0.347
What clothes to wear on weekends	4.7	4.1	-0.6	0.180
What clothes to buy	3.6	2.9	-0.8	0.125
What clothes to wear on weekdays	4.8	4.0	-0.8	0.089
What to do with relaxation time	5.1	4.3	-0.8	0.157
Who you hang out with*	4.5	2.5	-2.0	0.022
Choice to decline*	7.6	4.2	-3.5	0.000

* Indicates statistical significance at the .05 level.

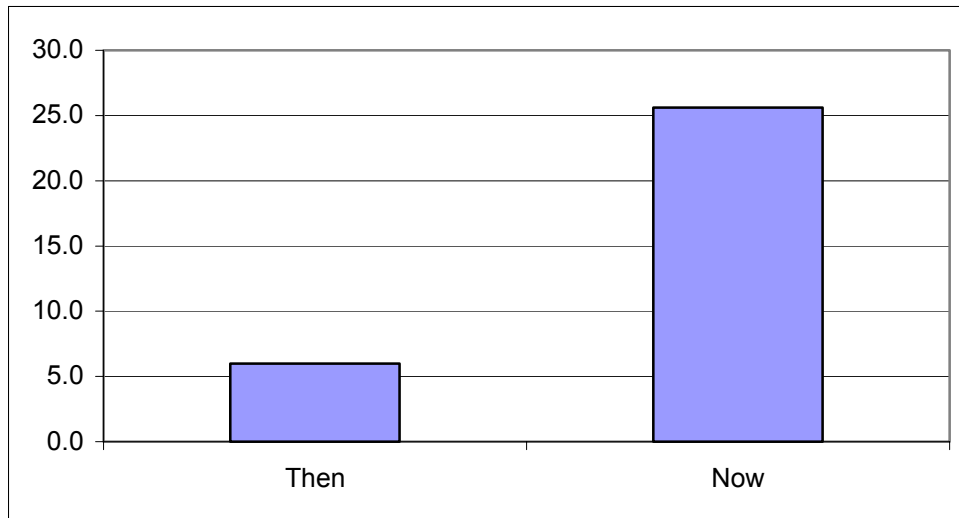
On the overall Decision Control Inventory scale score, the people who moved from the Stockley Center increased almost eight points (7.6) from “Then” to “Now.” This change was highly statistically significant. The item analysis

showed statistically significant changes in 17 of the 35 items. The areas of choice-making that showed the largest gains were “Choosing restaurants,” “Choosing places to go,” “How to spend day activity funds,” “When to go to bed on the weekends,” “Whether to have a pet in the home” and “Choice of house or apartment.” The areas which showed the least change, or even a negative change were, choice of “What clothes to buy,” “What clothes to wear on weekdays,” “What to do with relaxation time,” “Who you hang out with” and “Choice to decline” in scheduled activities.

Comparisons are particularly interesting in this outcome dimension. For example, the scores for Movers in California increased from 31 to 36 points. The Indiana Movers started at 32 points and wound up at 50 points after just one year. Then there is the original Self-Determination initiative in Keene New Hampshire, whose participants went from an already high score of 67 to a score of 72 in 18 months. The positive side of this comparison is that the Stockley Movers are likely to continue to show improvements year after year as the support system shifts more and more toward self-determination, supported living, and supported employment. We hope these future gains will be measured and documented.

COA’s Integrative Activities scale is intended to measure how many opportunities people have for contact with people without disabilities in a typical month. The scale is comprised of 16 items, and asks how often the focus person goes to restaurants, shopping malls, civic events, churches or synagogues, and other types of community activities. The following graph shows that the Movers increased significantly on this measure.

Average Number of Integrative Activities Per Month



In terms of participation in integrative activities in the community, the people who moved from the Stockley Center reported an average of about five integrative activities per month “Then,” or while living at the Stockley Center, which had increased dramatically to a little over 25 integrative activities per month when reported for “Now,” or after moving from the Stockley Center. Changes in individual types of integrative activities in the community for the Movers are shown in the table below.

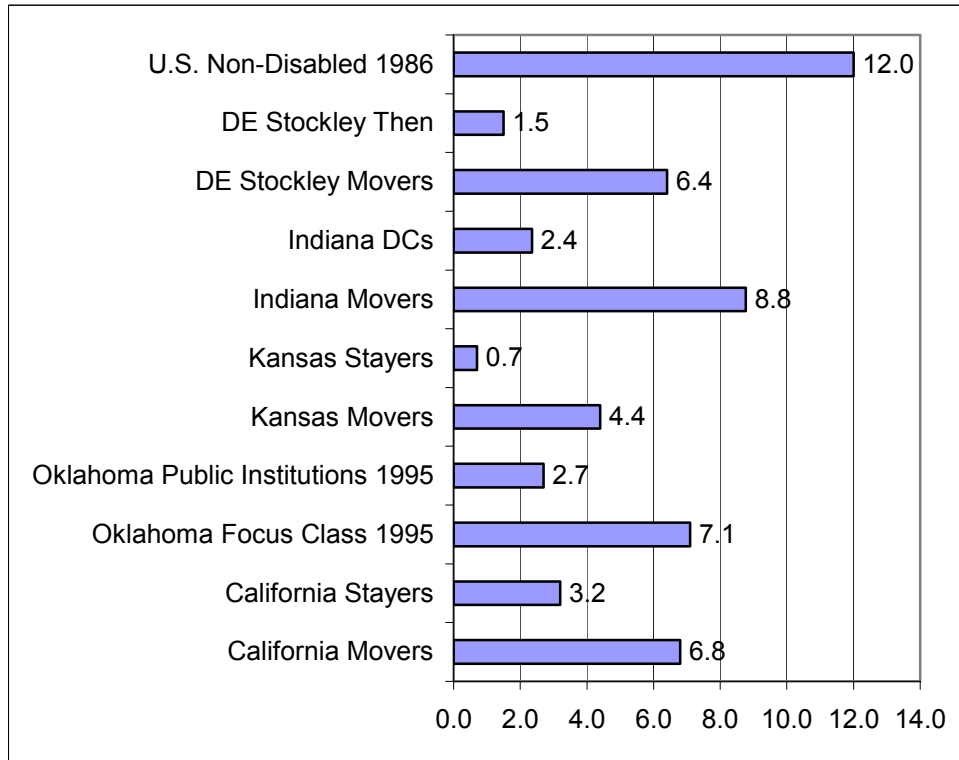
Integrative Activities Item Analysis

	Then	Now	Change	Significance
Go to a park or playground*	0.7	4.8	4.0	0.000
Go to a restaurant*	0.5	3.8	3.3	0.000
Go to a shopping center*	0.7	3.2	2.5	0.000
Use public transportation	0.0	2.3	2.3	0.076
Go to a bank*	0.0	2.0	2.0	0.000
Visit with close friends	2.1	4.0	1.9	0.127
Visit a grocery store*	0.4	2.1	1.7	0.000
Other kind of getting out	0.7	1.7	1.0	0.075
Go to a sports event	0.2	0.7	0.5	0.059
Go to church	0.8	1.1	0.4	0.134
Go to a movie	0.2	0.5	0.3	0.061
Go to a health or exercise club	0.0	0.3	0.3	0.115
Go to a post office*	0.0	0.2	0.2	0.045
Go to a theater	0.1	0.2	0.1	0.267
Go to bars	0.0	0.0	0.0	--
Go to a library	0.1	0.1	-0.1	0.211

The results shown above are sorted by the degree of change from “Then” to “Now.” Of the 16 types of integrative activities measured, all but one showed positive changes, while six of the areas showed statistically significant increases. These six areas were “Going to a park or playground,” “Going to a restaurant,” “Going to a shopping center,” “Going to a bank,” “Visiting a grocery store” and “Going to a post office.”

For context, the following chart shows data from the same scale from other states and service types. Please note that this graph shows integrative events per week rather than per month as in the text and charts above.

Comparison of Integrative Activities per Week



We can see that the experiences of the Movers are not dissimilar to those of Movers in other states. The Delaware Movers averaged over six activities per week. When compared to the four other states, this is just what we would expect to see. What is interesting to note is the large gain in activities the Movers have shown, nearly five activities a week gained. Only the Indiana Movers showed a larger gain of 6.4 activities per week.

The survey also asked the respondents how many times out of ten the person would be able to have access to transportation on the spur of the moment. Freedom and flexibility are important values for people learning to live outside of the institution. 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 ten on the scale. If they could never go anywhere on the spur of the moment, they would score a zero. The results on this scale of transportation access were as shown below.

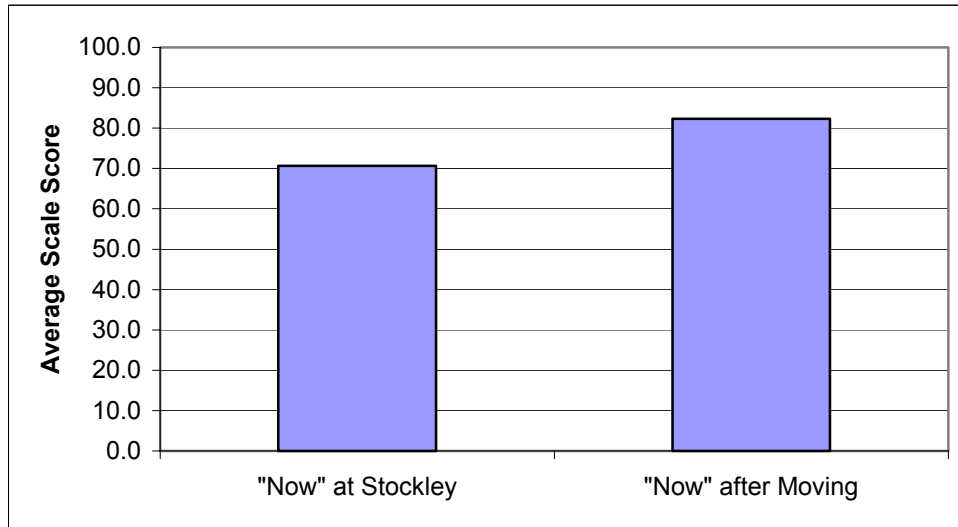
Access to Transportation

Then	Now	Change	Significance
0.4	5.1	4.7	0.000

Access to transportation showed a highly statistically significant increase from “Then” to “Now” for the people who moved from the Stockley Center. The averages on this question went from 0.4 times out of 10.0 at Stockley to 5.1 times out of 10.0 in the community. This demonstrated a large increase in freedom of movement – a central and universal value for any citizen.

The Perceived Qualities of Life Scale is made up of 14 items. These items ask the respondent to rate their quality of life from one (Very Bad) to five (Very Good) in areas such as health care, privacy, comfort, safety, food, care by staff or attendants and relationships. Respondents are asked to rate these items both for what they remember from “Then” and what they perceive “Now.” This allows the Center for Outcome Analysis to compare ratings at two points in time (“Now” from the pre-test and “Now” from the post-test) and from one point in time (comparing perceptions from “Now” to what is remembered from “Then”). The results of the first type of analysis are shown in the graph below.

Perceived Qualities of Life, Now to Now



The average score from “Now” at the pre-test (while people were at the Stockley Center) to “Now” at the post-test (after they’ve moved out of the Stockley Center) show an increase of over 11 points in people’s overall perception of their qualities of life. This increase was highly statistically significant. The same data are contained in the table below, along with the amount of change and its statistical significance.

Perceived Qualities of Life, Then to Now

Then	Now	Change	Significance
66.5	82.3	15.8	0.000

People’s perceptions of their qualities of life increased an average of almost 16 points on the 100-point scale. This difference was large and it was also highly statistically significant. Both of these analyses showed that people (and their

allies) believed that the qualities of their lives had significantly improved since moving from the Stockley Center.

We believe that the quality of a person's life can be greatly affected by the simple difference between either having or not having a friend. We therefore asked each person how many friends they had during both the first and second interview rounds. We can then directly compare the two numbers to see whether community living was conducive to making friends.

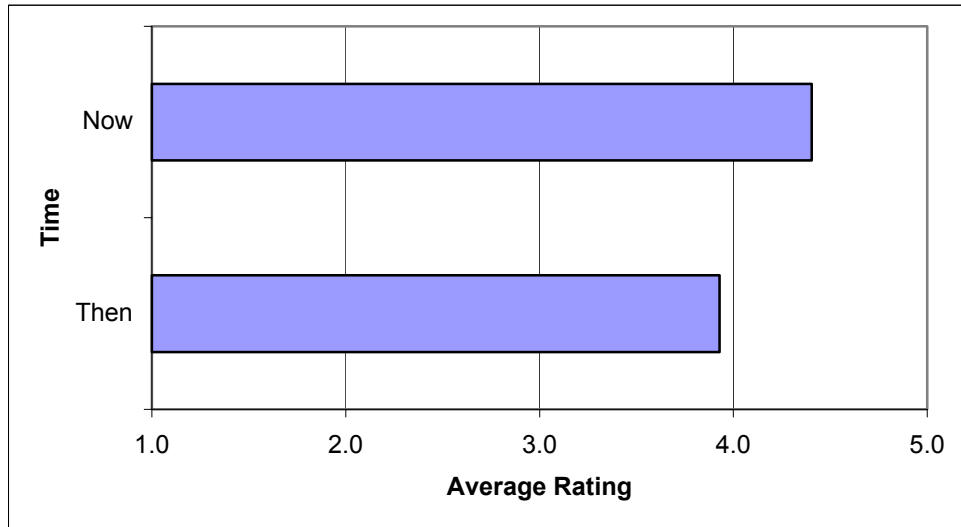
Number of Friends

Then	Now	Change	Significance
4.5	6.8	2.3	0.091

The people who moved out of the Stockley Center gained about 2 friends on average since moving, although this change was not statistically significant.

The next graph shows what is a relatively simple question with tremendous implications. We asked the Movers, both before and after the move, how they would rate their General Health. Not just how they were feeling today, but on a scale of one to five, how have they been feeling. An increase in this score means that the person feels they are generally in better health, while a decrease shows that they think the quality of their health declined since the move.

Ratings of General Health



These ratings showed a statistically significant increase, from a rating of 3.9 at “Then” to a rating of 4.4 “Now.”

The Need for Medical Attention scale includes 49 items, with questions ranging from issues of Ear Infections to Congestive Heart Failure. Each participant was asked if they had a minor or major need for medical attention in the areas listed. The scale ranges from one to three (with three meaning major medical attention needed for this area). We then averaged the scores and compared the Then and Now scores as shown below.

Need for Medical Attention

Then	Now	Change	Significance
1.2	1.1	0.0	0.435

The people who moved from the Stockley Center showed no change in their need for medical attention after moving.

The next table measures the number of reported days of illness in the last month. The question looks for days of restricted activities.

Illness in the Past 28 Days

Then	Now	Change	Significance
1.5	0.5	-1.1	0.230

The people who moved from the Stockley Center showed no significant change in the reported number of days ill in the past 28 days from “Then” to “Now.”

We measured the number of hospital admissions in the last year to see if people experienced more serious health conditions in the community, or the institution.

Number of Hospital Admissions

Then	Now	Change	Significance
0.3	0.1	-0.1	0.128

There was also no significant change in the number of hospital admissions from “Then” to “Now” for the people who moved from the Stockley Center.

It is common knowledge that finding quality medical care is not easy. For those with Developmental Disabilities, it can often be harder. Therefore, we asked the participants how they would rate their search for quality medical care on a five point scale, with five being Very Easy.

Process of Finding Medical Care

Then	Now	Change	Significance
4.3	4.2	-0.2	0.206

The 45 people who moved from the Stockley Center reported no changes in the difficulty of finding medical care from “Then” to “Now.”

A good, working relationship with one’s primary care doctor can make all the difference in the success or failure of one’s treatment. We measured this relationship on a simple one to five point scale, with five meaning a positive relationship.

Relationship with Primary Care Doctor

Then	Now	Change	Significance
3.7	3.9	0.2	0.110

These 45 movers also did not report any significant difference in their relationship with their primary care doctor from “Then” to “Now.”

We also tracked perceptions about the quality of the health care for the Movers to find out if there had been any changes since their moves into the community. The results follow.

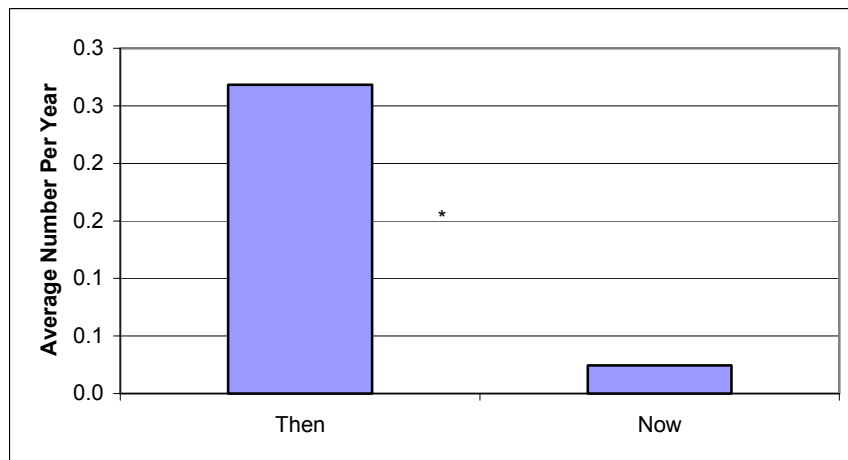
How Good is this Person’s Health Care?

Then	Now	Change	Significance
4.1	4.2	0.1	0.578

When asked to rate their health care from “Then” at the Stockley Center to “Now” after moving, the 45 Movers reported no significant difference, rating their health care essentially the same for both times.

Maintenance of health and safety is a major consideration in any transition and so in every interview we asked about the number of allegations of abuse in the last year. The chart below details the difference between numbers of allegations while at Stockley and the number documented in the community.

Allegations of Abuse



As shown in the chart, there was less than one (0.3) allegation of abuse per person per year while at Stockley. That number decreased after community placement to less than 0.1 per year. This is a very positive finding.

One of the most important parts of everyone's life is freedom. While this usually means freedom to make choices, it can occasionally mean freedom to move about at will. Below we compare the number of times restrictive procedures were used in the course of a year at Stockley with that number in the community.

Restrictive Procedures Used in the Last Year

Then	Now	Change	Significance
0.6	0.2	-0.4	0.104

Similar to the numbers on abuse, there were very few restrictive procedures used on these 45 people while at Stockley (0.6) and even less in the community (0.2). This very slight decrease did not reach statistical significance.

The following two tables were collected from the Personal Interview section. The questions in this section are asked only of the actual Movers. If the COA Visitor and the person could not figure out a way to communicate directly, this section was left blank. If appropriate, this part of the interview was completed in private.

Wishes

We asked each person, "If you had one wish, what would you wish for?"

The following are the responses we received.

A Cheeseburger, My Mom
A Radio- A Silver Band Watch
A Steak, Chicken, To Have A Girlfriend
Braid My Hair
Cake, Anything He Wants
Fried Chicken, Pepsi -Will I Ever Get To Earn It?
Go For A Car Ride Or A Bus Ride
Go To McDonald's Milkshake, French Fries, Hamburger
Have A Nice Day To See A Friend
I Don't Know
I Forget
I Would Like A Model Plane To Put Together And Fly
Like To Have \$2.00
May I Go On The Boardwalk?
Merry Christmas, Be A Nice Woman
More Candy- Peppermint Patties
More Magazines-
More Music
Orange Soda & Potato Chips
Out Of Here
Take A Ride
Take A Trip
To Be In Community Near My Dad
To Go Home With My Sister
To Have More Cars
To Live With Family, Sister

Comments

We also asked if there was anything else the people wanted to say, and those responses are given below.

I'm In A Bad Mood
I Got To Find My Way
I Want To Go On A Boat Ride
KFC- For Chicken"
Like To Have A Key
Like To Work With People Who Don't Complain
May I Go To The Canteen
Saw A Movie
Something About Santa Claus
T.T. Tapes, Markers, Crayons, Scissors. Paper
To Go To A Group Home, I'll Work.
To Go To Church

Concluding Comment

The Stockley Follow-Up Project was designed to find out whether the decision to move from an institutional model of supports to a community-integrated model was a good decision. In order to judge the merit of this decision, we need to answer this question: **“Are the people better off?”** This is the ideal way to judge the success of any social intervention. The quality of human life is the ultimate unit of accountability for human services.

We have visited the people affected by the decision twice - once while they lived at the Stockley Center, and again after they moved to community homes. We measured dozens of indicators of qualities of life and of services. We can now state with confidence that the Stockley Movers are indeed “better off.” Some of the ways in which they are “better off” include behavior, progress toward individual goals, decision-making, integrative activities, perceived qualities of life in 14 areas, person-centered planning, and indicators of general health. These are major and significant findings. We believe they validate the public policy of moving away from institutional care.

In addition to the primary question of whether people are “better off,” there are several subsidiary but important questions. One concerns the costs associated with the movement to community living. Does it cost more, less, or about the same to support a person in a community home? What accounts for the cost differences? In practically all prior studies, including more than 200 “independent assessments” of Medicaid Waivers, community costs have been found to be lower than public institutional costs, even for the same or comparable people. We hope in the near future to be permitted to conduct a cost study to supplement the outcome findings reported here. Only through proper tracking of costs will the State be aware of the money that could possibly be saved, and spent more wisely,

in the community. This kind of evidence will become crucial for development of public policy, as the pressures for full implementation of Olmstead mandates increase.

Another important subsidiary question concerns the feelings of the families of the people who moved from Stockley to community homes. After years and sometimes decades of having a relative live in a public institution, the decision to change is inevitably frightening and stressful. A family survey is another instrument that we suggest to fully document stakeholder perceptions.

One of the most important aspects of the Stockley Project is the fact that it is being done at all. It is a rare but welcome innovation when public officials voluntarily hold themselves accountable for individual well-being. When that well-being is being measured by an independent third party with proven methods and measurement techniques, the results would seem to be worthy of serious policy consideration.

All the evidence at our disposal leads toward the conclusion that many other Delaware citizens could benefit from the same kinds of changes that have been tracked in this project, namely, moving from segregated, isolated, institutional models of care toward community based and integrated supports. Community living is far from “perfect,” and is by no means free of frailties and problems. However, the simple fact is that these people, in spite of challenges encountered by some, are on the average much better off in their current community situations than they were while living at the Stockley Center.

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