
The Results of Deinstitutionalization
in the State of Connecticut, 1985-1990

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Introduction

This is a comprehensive report of 5 years of research on the well-being of more than 500 people who moved from institutions to community settings. The people lived in Connecticut, a state on the east coast of the United States. They were members of a group called CARC v. Thorne class members.

In the late 1970s, a lawsuit was filed by the Connecticut Association for Retarded Citizens (CARC) against the Governor (Mr. Thorne) and many other state officials and agencies. The lawsuit alleged that conditions at the state's institutional settings, particularly the Mansfield Training School, were below even the most minimal acceptable standards of quality. It further alleged that to keep people in such an institutional setting, while hundreds of other similar people were already living and thriving in community homes, would be discriminatory and unjust.

After several years of litigation, a Federal magistrate approved a settlement agreement that strongly supported the plaintiffs' contentions. The settlement conceded that people should be given every opportunity to move to homes that were more integrated and more like typical family homes in regular neighborhoods. However, the settlement also stipulated that a major longitudinal study should be mounted to track the progress and well-being of the people during and after the move.

This report contains the final results of that study. The entire effort can be characterized as focusing on one simple research question:

Are the people who were living in large, segregated, congregate care facilities in 1985, and are now living in community based settings, better off or worse off than they were, and in what ways and how much?

In 1990, representatives of the Longitudinal Study visited 1335 class members at their homes, and collected quantitative data about their lives. This report, however, concentrates on the 569 people who were living in large, segregated congregate care facilities in 1985, but had moved into community settings by 1990.

It is important to note, however, that the number 569 does not fully represent the tremendous overall achievements of Connecticut in changing toward a community based residential service system. The best reflection of that is a different statistic, the percent in congregate care in 1985 and in 1990. In 1985, 79% of all CARC v. Thorne class members lived in segregated congregate care facilities, and 21% were in community settings. In 1990, only 28% of class members live in congregate care, and 72% are in the community. This remarkable accomplishment is symbolized in

the Figure 1 bar graph. In reading this report, which is about 569 class members, it is important to keep in mind that these are not the only people whose lives have been affected by the CARC v. Thorne consent decree. (As of the date of this writing, the major institution involved in the case, the Mansfield Training School, is closed. Practically all of the people who once lived there have moved to new homes in the community.)

We used three research designs and a long list of measures, or "indicators," of quality of life, to assess changes in the well-being of the people who moved. The three research designs were the "longitudinal," the "matched comparison," and the "family survey" designs. They will be fully described in the Methods section. The measures of well-being will also be described in the Methods section.

Methods

Procedures

CFA staff hired and trained local professionals, advocates, and students (each of whom was experienced in relevant human services) to visit each class member, and to complete our quantitatively oriented survey forms. In the training for data collectors, we explained the general aims of the project, but we did not provide details of the results of the past years. This was intended to reduce the possibility of bias among the data collectors. The CFA training for data collectors was intended to accomplish three ends: explain the purpose of project, explain how each collector was expected to complete his/her assignment, and familiarize the collectors with the instrument package. The instruments were designed to be self-explanatory as much as possible. Instructions and rules for each section were printed on the forms themselves. Thus only a few hours of study and role-playing were necessary. Past problems with specific sections or items were discussed, and then assignments were given out and the field work began.

Data collectors initiated contact with service providers to make appointments. They were trained to be flexible, and to avoid interference with routines and schedules. Providers were told what kind of information would be sought, what documents would be needed, and how long it would take. In every case, the goal was to interview the staff person or other care giver who knew the class member best. In the course of 15 years of research in 12 states, we clearly established that direct care staff can give accurate and reliable information about the individuals with whom they work closely on a daily basis (Devlin, 1989).

The first round of visits and data collection was completed in February 1986, the second round in November 1986, the third in October 1987, the fourth in October 1989, and the fifth and final round of in November 1990. In 1990, we visited 1335 members of the CARC v. Thorne class.

In addition to the field data collection, the project included a family survey component. Addresses of parents, close relatives, or guardians were obtained during the field visits. We sent a survey package to each family. The package contained an introductory letter, a survey form, and a stamped return envelope. The survey was very brief, consisting of just 24 questions, in simple wording.

Instruments

We assembled a battery of instruments specifically for this project. There were three packages of instruments: one for each individual, one for each home setting, and one for each family. The individual instrument package was the Connecticut Individual Evaluation Report (CIER). One was completed for each person visited. The package oriented at the setting rather than the individual was the Site Review Package. One of these packages was completed for each home visited; if several people lived at one home, only one Site Review Package was completed. Each family was offered an opportunity to complete a family survey.

This battery of instruments is based on the dual notions that "quality of life" is inherently multidimensional (Conroy & Feinstein, 1990a), so there are many kinds of outcomes to measure, and that "valued outcomes" may be different for different people (Conroy & Feinstein, 1990b; Shea, 1992). Professionals may value some outcomes most highly, such as behavioral development; parents and other relatives may value permanence, safety, and comfort more highly; and people themselves may value having freedom, money, and friends most highly. The goal in the CFA body of work and related efforts has been to learn how to measure aspects of all of these "valued outcomes" reliably.

Taken together, the measures in the 1990 battery included behavioral progress, integration, productivity, earnings, status of each person's written habilitation plan, health, health care, medications, amount and type of developmentally oriented services, satisfaction of the people receiving services, satisfaction of next of kin, physical quality, individualized practices, staff attitudes, and program cost. 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; Conroy, 1994; Conroy & Seiders, 1994).

The individual package, or Connecticut Individual Evaluation Report (CIER), was developed by combining, modifying, and adding to, several other instruments already known to be reliable and valid. The behavioral items of the CIER were modified from the State of California Department of Developmental Services' Client Development Evaluation Report (1978). The California instrument covered adaptive behavior, challenging (maladaptive) behavior, vocational

behavior, and medical status.

The adaptive behavior section of the CIER contained 46 items relating to: motor abilities, independent living skills, communication skills, social/emotional skills, and cognitive skills. When the item scores were summed, an adaptive behavior sum score was produced, which was scaled to range from 0 to 100.

The CIER also contained 11 items on challenging behaviors, including aggression, running away, hyperactivity, etc. These 11 items were summed to produce a challenging behavior total score. The scores were again cast in terms of a 0 to 100 point scale; a higher score indicated fewer challenging behaviors.

The behavioral items from the original California instrument were tested for interrater reliability by Harris (1982). In a study including 750 people in a variety of settings, the interrater reliability of the adaptive and challenging behavior items fell almost entirely in the range from .70 to .95, although no average or overall score was given. For item reliabilities, such figures are well within the acceptable range. We used prior years' data (1985 and 1986) in Connecticut to examine test-retest reliability. The correlation between the 1985 and the 1986 adaptive behavior scale scores was .94; for the challenging behavior scale it was .66. A third kind of reliability, internal consistency, was tested in the 1986 data, and the results were .97 for adaptive and .80 for challenging.

Items on demographics, other disabilities, family contact, medications and health, integration, productivity, services received, and consumer satisfaction, were all taken from the package that we had been using for many years in Pennsylvania.

There were two measures of integration and inclusion. The Social Presence Scale was developed specifically for the Connecticut project. It was tested in 1985 and revised in 1986. Information was collected about the frequency of opportunities for interaction between class members and non handicapped people other than staff. It was interpretable as "how many times per week a person got out into integrated settings." These could include movies, grocery stores, banks, restaurants, sports events, parks, and so on. A second measure of integration was "Integrative Activities." This scale was taken from the 1986 Louis Harris poll of Americans with disabilities (Taylor, Kagay, & Leichenko, 1986). The Harris organization conducted 1000 telephone interviews with adults with disabilities, and another 1000 interviews with non-disabled members of the general population. This scale thus offered something to compare to. It captured how often people visited with friends or neighbors, went shopping, to a restaurant, and so on. Both of these scales really measured only half of the total dimension of integration. If integration was composed of presence in the mainstream of community life and activity,

plus participation in the mainstream, then these scales only captured "presence." More research will be needed to produce reliable measurement approaches to integration's participation/inclusion aspects.

We included Schalock's (1989), Quality of Life Questionnaire or QOLQ as our individual interview. The QOLQ had been used in several other areas of the United States, and also in other countries (Schalock, Keith, Hoffman, & Karan, 1989). The QOLQ is designed as a direct interview of the person or whoever knows the person best. The 1990 version of the scale was composed of 40 questions arranged in four sections: Satisfaction, Competence/Productivity, Empowerment/Independence, and Social Belonging/Community Integration.

Unlike the CIER, one Site Review Package was collected for each residential setting, rather than for each person. There are certain facets of well-being that cannot be tied to any one individual, but only to the home, such as the physical quality of the home. In 1990, the package had eight sections: Size, Staff, Physical Quality, the Group Home Management Scale, Basic Life and Safety Issues, Site Reviewer Impressions, Special Concerns, and Positive Comments.

The Size section collected information about the size of the immediate environment experienced by the people who lived there. For community service providers, it also collected the size of the provider agency overall. In case the setting was a congregate care facility, the overall size of the facility was collected. These items were related to the considerable theoretical interest in the "ideal" and most "cost-effective" size of settings and of providers.

The Physical Quality Index (PQI) was modified from Seltzer's (1980) instrument, which was in turn a derivative of portions of the Multiphasic Environmental Rating Procedure (Moos, Lemke, & Mehren, 1979). It was a measure of how home-like and pleasant the setting was. It was completed after the visiting data collector had walked through the residence, rating each room on dimensions such as cleanliness, odors, condition of the furniture, individualized decorations, and overall pleasantness. Interrater reliability of the PQI was reported as .81, with test-retest at .70 (Devlin, 1989).

The Group Home Management Scale was adapted from a scale developed by King, Raynes, & Tizard (1971) in England, and applied in international research by Balla (1976) and his colleagues at Yale. It was composed of only 10 items, all intended to measure the degree to which the routine of life was regimented as opposed to individualized.

Site Reviewer Impressions were the purely subjective feelings of our data collectors about six dimensions of the quality of life. The six dimensions were: overall rating of the perceived overall quality of the residential site, quality of food found in the refrigerator and cupboards,

quality of staff-consumer interactions, quality of consumer-consumer interactions, expectations of staff regarding individuals' potential for growth and development, and the degree to which the setting is oriented toward measurement and accountability. These ratings were given at the end of each site review, after the data collectors had met the people, learned a great deal about them and the program, and had toured the home.

The 1986 and 1990 Family Survey form contained 24 items. The areas covered were demographics, satisfaction with services, perceived happiness of the class member, frequency of contact, feelings about permanence, and beliefs about the person's potential for development.

Analyses

Inferential statistics are designed to tell us whether we can make inferences from samples to populations. In this study, for the longitudinal analyses, we were dealing with a population and not a sample: all CARC v. Thorne class members who moved from congregate care to community living situations. For such analyses, there is no real need for inferential statistics. Any differences among groups or across time can be interpreted as real, and the only interpretation necessary is practical: how large and how meaningful is the difference? We nevertheless used and reported the statistical tests, for those who might find them useful or interesting. However, in our matched comparison and family attitudes analyses, we were dealing with samples. Therefore we reported the statistical tests and results with care.

Results

Description of the People Who Moved from Congregate to Community Care

The Longitudinal Study collected complete data about 569 class members who moved from congregate care facilities to community living situations between 1985 and 1990. For convenience in this report, these people will be referred to as "movers". Their counterparts who remained in institutional settings will be called "stayers".

The movers were 51% male and 49% female. Their reported ages ranged from 22 to 93, with a mean age of 47. Their levels of retardation broke down as 44% profound, 29% severe, 16% moderate, and 11% mild. These were clearly people who were neither young nor mildly disabled. Under this consent decree, in a 5 year period, fully 73% of community placements were people labeled severely or profoundly retarded.

The movers also experienced other disabilities. A total of 11% of them had a severe or total vision loss, 3% had a severe or total loss of hearing, and 30% used a

wheelchair. In the health area, 3% "would not survive without 24 hour medical personnel," and another 6% had "a life-threatening condition that requires rapid access to medical care." A history of seizures, but none currently, was reported for 17%, and another 18% have had seizures during the past year.

All in all, these descriptions demonstrated that the people who moved into the community were very seriously disabled, they were aging, and many of them had more than one disabling condition. These were emphatically not the kind of people who would have been described as "easy to serve in the community" in the past. This is an important point to keep in mind in evaluating how the quality of their lives has changed.

The following table shows the kinds of facilities from which the movers came.

Where the Movers Lived in 1985

	#	%
Mansfield Training School	375	66%
Regional Center - On Campus	80	14%
Skilled Nursing Facility	67	12%
Home for the Aged	35	6%
General Intermediate Care Facility	9	2%
Southbury Training School	3	1%

Most of the movers came from Mansfield, but a third came from other congregate care facilities. The following table shows what kind of residential settings the movers were living in 5 years later, in 1990.

Type of Community Placements of the Movers

	#	%
Group Home, Non ICF/MR* (4 or more beds)	264	46%
Group Home, ICF/MR* (4 or more beds)	148	26%
Community Living Arrangement (3 or fewer beds)	127	22%
Supervised, Supported, or Cooperative, Other	19	3%
Community Training Home	11	2%

* ICF/MR stands for a Federal funding program that is part of the Social Security Act, called the Intermediate Care Facilities for [People With] Mental Retardation program.

The following table shows the kinds of daytime activities in which the movers are now engaged.

Type of Community Day Programs of the Movers

	#	%
Community Experience Program (CEP)	189	33%

Sheltered Employment (SHELT)	142	25%
Supported Work (SUPP)	101	18%
Senior Citizen Programs	98	18%
Other	22	4%
Competitive Employment	9	2%
No Day Program	6	1%

A third of the movers attended a Community Experience Program, which was geared to help them learn skills that would enhance their adaptation to, and productivity in, the community at large. A fourth were in sheltered employment, in which they earned wages.

Most remarkable was the fact that nearly a fifth of the movers were in supported work placements, a figure that other parts of the nation would envy. In Philadelphia, for example, of the 839 people we monitored in 1990, only 9 were in supported employment.

Longitudinal Results

The longitudinal research design looks for changes over time. In this section, we will concentrate on changes between 1985 and 1990. One of the important ways in which people with mental retardation can become "better off" is to achieve their own potential for independence. Independent functioning is a very easy and reliable quantity to measure. In line with the definitions used by the American Association on Mental Retardation (Grossman, 1983), we use the term "adaptive behavior" to represent this dimension. As noted earlier, we used a scale of adaptive behavior that was known to be highly reliable and valid.

The 569 movers had an average adaptive behavior score of 49.5 in 1985, when they were living in congregate care facilities. In 1990, out in their new community homes, their average score was 54.0. This gain of 4.5 points was highly statistically significant ($t=11.5$, 568 df, $p<.0001$). The change in adaptive behavior is shown on the left hand side of the Figure 2 graph.

The practical significance of this gain may be judged by placing it in the context of results from our research results in other states.

- o Pennsylvania -- 8% (7 years)
- o Louisiana -- 8% (7 years)
- o New Hampshire -- 5% (5 years)
- o Connecticut -- 4.5% (5 years)

We interpret the findings in Connecticut as remarkably consistent with findings in other states. People who moved out of congregate care gained in adaptive behavior, and, considering time spans, they appeared to be gaining at about the same rate as did people in other community placement efforts.

In the area of challenging behavior, the average score in congregate care settings in 1985 was 79.0, and in 1990 in the community the average score was 80.2, indicating a 1.2 point gain in the area of challenging behavior ($t=1.5$, 556 df, $p=.061$, one-tailed). This small change is represented on the right hand side of the Figure 2 graph. As in the adaptive behavior domain, a higher score is desirable, indicating fewer challenging behaviors. This gain almost reached the most commonly used criterion for statistical significance, which is that p be less than .05.

However, as mentioned previously, because we were dealing with a population and not a sample, inferential statistics were not strictly necessary. Therefore, any changes that were measured should be thought of as real, and our task is to interpret the practical significance of a 1.2 point change in challenging behavior. It meant that people displayed somewhat fewer challenging behaviors in the community than they did previously in congregate care settings. Although noticeable for some people, the changes would be minor for most. Moreover, over a period of many years, such gains would add up, and would become clearly noticeable improvements.

Another measure of whether people are better off is health, and one indicator of general health is the use of medications. In 1985, the movers received an average of 1.6 different medications each day. In 1990, the average number of medications increased to 1.9 ($t=4.2$, 564 df, $p<.0001$). This increase may be a cause for concern, yet it is not dissimilar from what we have observed in other states. Many people contend that in the community people are receiving more appropriate medical care and that the medications received are needed. Others argue that medical care in the community is fragmented and lacks coordination. Hence, two physicians may often prescribe independently of one another, causing people to receive more medication than when they lived in congregate care settings.

Another indicator of health status was this item: "In general, how urgent is this person's need for medical care?" The responses are displayed in the following table.

	1985	1990
Would not survive without 24 hour medical personnel	1.9%	3.2%
Has life-threatening condition that requires rapid access to medical care	5.3%	5.7%
Needs visiting nurse and/or regular doctor's visits	36.4%	41.7%
Has no serious medical needs	54.8%	49.4%

Statistically, the changes were not significant.

However, the slight increases in the "Would not survive..." and "Needs visiting nurse..." categories might be related to aging of the group.

Another valued outcome for all citizens, and stated explicitly in the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987, is productivity. In the Act, productivity was defined as "engagement in income-producing work by a person with developmental disabilities which is measured through improvements in income level, employment status, or job advancement, or, engagement by a person with developmental disabilities in work which contributes to a household or community." The primary measure of productivity that was used throughout the Longitudinal Study was income.

Specifically, we asked how much money the individual earned in an average week. In 1985 the average among the 569 movers was \$2.06; by 1990, this average had increased to \$10.02 (t=9.3, 543 df, p<.0001). This represented almost a 500% increase over the 5 years. It could be argued that this 500% increase did not mean a significantly enhanced quality of life, we would argue that it did represent a significant shift in the income producing opportunities afforded Connecticut citizens with disabilities. This shift away from segregated, non-paid opportunities, to integrated, income-producing opportunities, is illustrated in the table below.

	1985	1990
Community Experience	44.2%	33.3%
Sheltered Employment	20.0%	25.0%
Supported Work	1.4%	17.8%
Competitive Employment	0.5%	1.6%
Opportunities for Older Adults	0.2%	15.7%
Generic Senior Citizen Prog.	0.0%	1.8%
School Programs	5.4%	0.0%
Other Day Programs	8.5%	3.7%
No Day Program	18.2%	1.1%

The most noticeable fact in the table was that the percent of individuals involved in supported employment skyrocketed from 1.4% in 1985 to 17.8% in 1990. In addition, the proportion of older adults involved in senior citizens' programs jumped from 0.2% in 1985 to 17.5% in 1990 (including generic senior citizen programs). Finally, in 1985, 18.2% of the class members (102 individuals) had no day program/employment whatsoever. In 1990 that number dropped to 1.1% (6 individuals). It was clear from these data that the class members had made great strides in terms of spending time productively.

A measure of the valued outcome of integration (actually opportunities for integration rather than actual integration) was the Social Presence Scale. In 1986, in

congregate care settings, the average score was 2, and in 1990 in the community, the average score was 16 ($t=18.4$, 462 df, $p < .0001$). The average class member in 1990 experienced, on the average, 2 opportunities for interaction with individuals without disabilities per day, as opposed to about 2 interactions per week in congregate care settings. Insofar as integration was one of the important goals of deinstitutionalization, this finding was strong evidence that class members who moved to the community were much better off.

One of the goals of deinstitutionalization was to move individuals from large, segregated settings to smaller, integrated settings in the community. The average size of the immediate living areas in congregate care was 20.7 people. In the community, the average size of immediate living areas 4.7 people ($t=28.6$, 565 df, $p < .0001$). Obviously, the movers had moved to smaller settings.

Increased contact with families was another dimension that might be considered as a valued outcome. The measurement scale was:

- 1 Never
- 2 Twice a year or less
- 3 About every three months
- 3 About once a month
- 5 About once a week or more

The frequency of family visits to the class member increased on this scale after people moved out into the community, from an average of 2.3 to 2.6 ($t=5.4$, 361 df, $p < .0001$). On the same scale, the frequency of class member visits to the family increased from 1.8 to 2.0 ($t=4.4$, 361 df, $p < .0001$).

Another dimension of "better off" that was the quality of the home environments. The GHMS measured the extent to which the environment was individualized to meet the specific needs of class members, versus regimented into uniform rules for all. The GHMS was scored so that higher scores represented more individualized settings. In the congregate care settings in 1985 the average GHMS score was 5.3, and in the community in 1990 the average score was 16.5 ($t=36.84$, 391 df, $p < .0001$). In other words, the movers were experiencing much more individualized treatment in their homes in the community than they had at the institutions.

The Physical Quality Instrument average score in 1985 in congregate care settings was 60.6, and in 1990 in the community the average score was 67.8 ($t=11.4$, 532 df, $p < .0001$). The average community setting was rated as considerably higher in physical quality than the average congregate care setting.

The Site Reviewer Impressions, although subjective, were intended to capture the personal impressions of the

experienced visitors. The results are displayed in the table below.

1. Overall, how would you rate this site (1=poor, 10=excellent)?
1985 = 5.4 1990 = 7.9 sig. = <.0001
2. How would you rate the quality and quantity of food in the refrigerator and cupboards (1=poor, 10=excellent)?
1985 = 5.8 1990 = 8.2 sig. = <.0001
3. How do you perceive staff-consumer/consumer-staff interactions (1=cold, impersonal, 10=warm personal)?
1985 = 7.2 1990 = 8.3 sig. = <.0001
4. How do you perceive consumer-consumer interactions (1=unfriendly, 10=friendly)?
1985 = 5.0 1990 = 6.8 sig. = <.0001
5. What are staff's expectations for consumers regarding growth (1=pessimistic, 10=enthusiastic)?
1985 = 5.5 1990 = 7.8 sig. = <.0001
6. To what extent is this setting oriented toward measurement, research and scientific approaches (1=not at all, 10=as much as I've ever seen)?
1985 = 4.1 1990 = 6.4 sig. = <.0001

As these results demonstrated, on each and every question, site reviewers believed that the community settings were considerably better than the congregate care settings from which people came.

Matched Comparison Results

Scientifically, the longitudinal design by itself provided reasonably high confidence in the results. The matched comparison design lent one more level of scientific control to the investigation (Campbell & Stanley, 1966). The longitudinal design enabled us to learn that the movers were better off in the community than they were in 1985 in most of the measured areas. But perhaps the stayers were also better off, because the institutions had also improved during the 5 years. If so, then we could not infer that the deinstitutionalization "caused" the movers' improved quality of life.

To check for this possibility, we needed to compare the changes experienced by the movers and the stayers. We knew the movers had improved in many aspects of quality of life, and the next question was whether the stayers had done the same. However, a simple comparison of the outcomes of all 569 movers to the 340 stayers could be misleading, because the characteristics of the movers and the stayers were somewhat different.

In adaptive behavior, the movers' average score in 1985 was 49, and the stayers' average was 40 ($t=6.99$, 907 df, $p<.0001$). The average challenging behavior score was also different for the two groups, with movers scoring a 79, and

stayers a 74 ($t=3.51$, 890 df, $p=.001$). The movers also had less urgent need for medical care than the stayers in 1985 ($t=4.86$, 906 df, $p<.0001$). No significant differences were found between the movers and the stayers for age and gender. However, the differences between the two groups in adaptive behavior, challenging behavior, and medical needs indicated that the two entire groups should not be compared directly.

To control for the differences between movers and stayers, we performed the matched comparison, or "twins," analysis. For each mover, we tried to find a "stayer" with extremely similar characteristics. A stayer was a person who was living in a congregate care facility in 1985, and still was in 1990. (There were 340 such people.) Then, if we found different outcomes for movers and stayers, we could be much more confident that the reason for the differences was the move, since other factors (such as age and level of functioning) had been "held constant" by the matching.

The matched comparison design asks this question: "For two very similar people, one placed into the community and one remaining in congregate care, did any aspects of their quality of life turn out differently?" (This is, in essence, an attempt to get closer to the truly ideal scientific design, which is random assignment. If people were selected for placement completely at random, then the stayers and the movers would inevitably have almost exactly the same characteristics overall. Matching is the "next best" research design to random assignment.)

We attempted to find a match for each of the 340 stayers in the pool of 569 movers. The characteristics we matched were adaptive behavior, challenging behavior, medical needs, and age. For each stayer, we tried to find a mover with these characteristics:

- o adaptive behavior within 10 points of the stayer's;
- o challenging behavior within 5 points of the stayer's;
- o age within 10 years;
- o same rating of degree of medical needs.

We were able to find perfect matches for 124 of the stayers, using these criteria. The reason that not everyone could be matched perfectly was the fact that the groups were different. In adaptive behavior, for example, the stayers were lower functioning. Although some very low functioning people had moved to the community, there were not as many; so there were not enough very low functioning community "twins" to find a perfect match for every stayer.

This explains the only major methodological weakness of the matched comparison design. With any matching process, the groups we are left with will no longer be perfectly representative of the populations from which they were selected. The matched stayers will be somewhat higher in adaptive behavior than the average of the entire group of 340 stayers. The matched movers will be somewhat lower than the average for the entire group of 569 movers. Confidence in our ability to generalize findings to the entire

populations is often strong, but still imperfect. This weakness in the matched comparison design explains why we have performed both a longitudinal and a matched comparison design. As noted earlier, the longitudinal design has certain weaknesses too. Together, however, the two designs complement one another. The weakness of the longitudinal design is controlled by the matched comparison design, and vice versa. If we obtain similar results from both designs, then we are justified in being extremely confident in the validity of our findings.

We tested for the adequacy of the matching process. The t-tests revealed no significant differences between the two groups in 1985 on any of the four matching variables. This meant the matching process was successful.

Knowing that the matched movers and stayers started out basically the same, we were able to take the next step, which was to test for differences 5 years later, when one group was out in the community and their "twins" were still in institutions.

In 1990, the two groups were significantly different on several variables. In adaptive behavior, the movers averaged 47 in adaptive behavior and the stayers scored a 41 ($t=2.09$, 242 df, $p=.038$). The change is depicted in the Figure 3 graph. The two groups started out in 1985 with exactly the same average adaptive behavior score. But 5 years later, after the movers went to the community, the movers were significantly higher in adaptive behavior than the stayers.

In a similar fashion, we examined the challenging behavior score, to see if the two groups differed in 1990. The movers averaged 81 and the stayers 80 points. This one point difference did not reach statistical significance. Statistically, their outcomes were about the same.

We had two different measures of integration. One measure, the Social Presence Scale, counted the number of contacts the individual had with non-handicapped people in a week. On this measure, the movers averaged 13 and the stayers 5 ($t=5.26$, 246 df, $p<.0001$). Clearly, the people living in the community were having more contact with non-handicapped people than similar people still living in congregate care settings. This result is shown graphically in the Figure 4 graph. The second measure of integration was a scale that summarized how frequently the person engaged in seven socially integrative activities (visiting people, supermarket, restaurant, church/synagogue, shopping center, tavern, and bank). This measure was taken from the 1986 Harris Poll of Disabled Americans. On this scale, the movers scored 35 and the stayers scored 17 ($t=9.98$, 239 df, $p<.0001$). This showed that the movers engaged in these seven activities much more frequently than similar people who stayed in congregate care settings. The movers were better off than the stayers on both of our measures of integration. Both findings are summarized in the Figure 4

graph.

Another outcome measure was the Quality of Life Questionnaire (Schalock, 1989). The QOLQ scale combined measures of satisfaction, productivity, independence, and integration, as reported by the person or his/her surrogate. Higher scores on the components of the scale indicated what the scale's authors believed to be a higher quality of life. The QOLQ scale does permit surrogates to answer the interview questions when the class members cannot. In the case of the 248 people included in this matched comparison study, staff answered all or most of the questions in 89% of the cases; 11% of the class members answered all or most of the questions themselves. The graph in Figure 5 shows the results for movers and stayers on each of the four subscales.

Each of the differences between movers and stayers favored the movers, and each difference was significant beyond the .05 level (by t-tests). Computing total scale scores, the movers averaged 76, and the stayers 69 ($t=4.42$, 172 df, $p<.0001$). This indicated that the people living in the community enjoyed higher quality of life, as measured by this questionnaire, than similar people who still lived in congregate care settings.

There were three questions about staff attitudes to compare. Findings on all three are shown in the graph in Figure 6. In the first question, on a 1 to 10 scale, staff were asked to rate "How much do you like this job?" The community-based staff of the movers averaged 9.1, and the congregate care staff of the stayers averaged 8.6, on this subjective rating ($t=3.03$, 239 df, $p=.003$). Although staff in both groups gave high ratings on this item, staff for the movers gave slightly higher ratings. In a related item, staff were asked to rate "How much do you like working with this person," on the same 1 to 10 scale. Again, the ratings were high, with the movers' staff scoring 8.9 and stayers' staff 8.1 ($t=4.17$, 243 df, $p<.0001$). Staff in the community gave slightly higher ratings than staff in congregate care settings. Another item rated by staff was a scale which addressed "the progress made by this person in the past year." A "1" meant they regressed a lot, and "10" meant they progressed a lot. The movers' staff persons rated an average of 8.6 on this item, compared to 7.4 for the stayers' staff ($t=5.06$, 244 df, $p<.0001$). Both of these average ratings indicated progress, but the trend again was that movers had more favorable outcomes.

There were some indicators of quality and services that showed no significant differences between movers and stayers.

- o number of weeks since the case manager visited.
- o number of medications taken daily.
- o level of need for medical care.
- o hours per week physically present at the day program.
- o frequency of visits from family members.

- o frequency of visits to family members.
- o earnings per week.

The first bulleted item, weeks since case manager visited, was the same for movers and stayers. This indicated that movers and stayers were receiving case manager visits with similar frequency. This was a major change from past practices, at least in the congregate care settings. In 1990, people in institutions were being visited just as often as people in community homes. Movers and stayers spent about the same amount of time at day programs in 1990, which implied that the congregate care facilities must have sharply increased the availability of day programs since 1985. The frequency of visits from family to the class member was the same for stayers in congregate care facilities as it was for movers to community settings. Stayers and movers also had the same frequency of visits by the class member to the family. The groups were also not different in earnings per week, suggesting that the congregate care facilities must have worked very hard to "catch up" to the pay earned by the movers, who historically had more integrated and more lucrative work opportunities available to them.

The health indicators were interesting in that the longitudinal analysis appeared to show a trend toward increasing need for medical care over time, which might indicate declining health. In the matched comparison design, however, statistical tests showed that movers and stayers were equally in need of health care 1985 and again in 1990. Similarly, we were unable to confirm a statistically significant change over time on this variable, for either the movers or the stayers. We therefore conclude that the matched comparison does not confirm the evidence of declining health seen in the longitudinal analysis. We also conclude that there have been no changes in medical needs over time, for either group. Similarly, the matched comparison analysis failed to detect a difference in the number of medications being given daily to movers and stayers, and thus did not confirm the longitudinal finding of increased medications among the movers.

Another indicator of well being was the service delivery pattern as prescribed in the Overall Plan of Services. For each of 17 services, information was recorded about whether the service was in the OPS, whether the service was delivered and whether the amount was sufficient. Information was only collected for those services that were formally structured and scheduled. The service received most frequently by both groups was Medical/Nursing, and more stayers received that service than movers. A graph of the number of stayers and movers receiving each type of service is presented in Figure 7, and it is sorted according to the most frequently reported services among the movers.

Starting at the top of the graph, stayers were slightly more likely to have medical/nursing services specified in

the OPS, but overall, medical/nursing was in almost everyone's written plan. In the community, hygiene skills training was the second most common, and it was sharply more common than in the congregate care settings. Appropriate social behavior training and communication skills training were the next most frequently prescribed in both types of setting. Community living and domestic skills training, however, were far more prevalent among the movers. Recreation skills training (defined as a service designed by a recreation therapist but delivered by a direct care staff person) was far more common among stayers. Correspondingly, near the bottom of the graph, the services of a recreation therapist were more likely to be received by stayers. Apparently, there was significant emphasis in the recreation area in Connecticut's institutional settings.

Below the recreation skills bars, eating and mobility service patterns were similar for movers and stayers. Movers tended to get more training in sensorimotor skills and dressing skills. Speech therapy and physical therapy were about equally common for movers and stayers. Occupational therapy and counseling/psychotherapy, although not very common services, were more common in the community than in congregate care settings. Finally, at the bottom of the graph, cognitive skills training was more often received by stayers than movers.

Moving to environmental quality indicators, we compared the size of the immediate residential setting for movers and stayers. On the average, stayers were living in immediate proximity to 11 people; for movers, the figure was 4 ($t=16.74$, 246 df, $p<.001$). Obviously, the people who moved into the community were in smaller residential units.

On the GHMS (Group Home Management Survey), the movers' community settings averaged 14, and the stayers' congregate care settings averaged 10 ($t=5.49$, 182 df, $p<.0001$). This indicated that movers lived in more individualized settings than the stayers. Because the GHMS was a 30 point scale, the 4 point difference was actually quite substantial. The second environmental scale was the Physical Quality Index (PQI), which measured the physical pleasantness of the setting. The average PQI score for movers was 68, compared to 54 for the stayers ($t=12.17$, 231 df, $p<.0001$). This showed that movers lived in more pleasant settings than stayers. In fact, movers were better off than stayers on both environmental scales, as symbolized in the Figure 8 graph.

As in the longitudinal analysis, the purely subjective opinions of our data collectors were examined. There were six ratings, all on 10 point scales. The results are shown in the Figure 9 graph on the following page. Ratings assigned to the movers were higher on all six items, and every difference was significant beyond the .005 level (meaning considerably more statistically significant than the usual .05 level). For whatever value these subjective impressions may have, the

evidence was clearly and strongly in favor of community settings.

Family Survey Results

When the CIER instruments were collected in 1990 during the site visits, we also collected the full name and mailing address of the parents, close relatives, or guardians of each class member. We were able to obtain 1157 addresses for the 1335 class members. The remainder of class members either had no close family or the family did not desire contact. When the survey was complete, we had obtained 424 valid survey forms. In addition, 226 packages were returned to us because of some variety of bad or outdated address. This translated into a response rate of 46%, which was typical of single-round mail surveys of this type (Conroy, 1992).

There were 255 families who responded to the survey both in 1986 and 1990. Of those 255, 101 were in congregate care in 1986, but had moved to community settings by 1990, as shown in the following table.

	In Congregate Care in 1990	In Community in 1990
In Congregate Care in 1986	58	101
In Community in 1986	5	91

This analysis concerns the 101 people at the upper right of the table. The 101 families, relatives, or guardians in this analysis are those who responded to both surveys and whose relatives were among the 569 "movers."

The people who responded to the family survey, and who were part of our group of 101, were often mothers, but almost equally often siblings or mothers and fathers responding together. The distribution of relatives was:

Mother	28
Sister or Brother	24
Mother & Father Together	23
Father	12
Guardian or Advocate	8
Other	6

The items on the family survey fell into four groups of issues: satisfaction and quality, security and permanence, visits, and attitudes about individual development. Nine items were related to satisfaction and quality of life. They were:

- (4) Overall, how satisfied are you with the place where your relative is now living?
- (5) Overall, how satisfied are you with what your relative

does during the day (day program, school, or work)?

(8) How happy do you think your relative is with his/her living situation?

(9) How happy do you think your relative is with what he/she does during the day?

(12) I trust the ability of the staff who work with my relative to handle almost anything that comes up.

(14) Staff turnover at the program where my relative lives is a major problem.

(16) My relative often does not get the kind of medical care he/she needs.

(18) The food at the place where my relative lives is good quality.

(19) My relative has little or no privacy where he/she lives.

Figure 10 is a graphic summary of the changes in these nine items from 1986 to 1990. All of these changes were statistically significant (by paired t-tests, using the .05 level of significance criterion). For items that were worded negatively, we reversed the scoring system so that higher numbers were always favorable on the graph. Families were very highly satisfied with their relatives' congregate care facilities in 1986. However, they reported even higher satisfaction with community services in 1990. The fact that every item increased significantly demonstrated that the effect was very strong and uniform.

The Figure 11 graph headed "Magnitude of Changes" shows which of the families' perceptions appeared to have changed the most since community placement. The perception that the class member had adequate privacy was the greatest change, with satisfaction with the residence coming in second.

Because it is well recognized that security and permanence are at or near the top of the list of families' concerns about their relatives' lives (Latib, Conroy, & Hess, 1984), the family survey included three items concerning permanence. They were:

(13) The funding for places like the one my relative lives in is secure and permanent.

(15) The agency that runs my relative's home will still be in business 5 years from now.

(20) It is very important to me that I have the major say about what happens to my relative.

There was no significant change in any of these three items from 1986 congregate care to 1990 community living. On the funding item, families on the average were 'in between' agreement and disagreement that funding was secure and permanent. Actually, this was an interesting finding. One might have expected higher confidence in the "bricks and mortar" of the old "tried and true" congregate care facilities than in the new community home models. This was

not the case. Confidence in funding was just about the same when people moved out into the community. The question about whether the relatives' service provider would still be in business 5 years in the future also did not change. Again, one might have expected a decrease in confidence on this item. Training Schools and Regional Centers might have been perceived as more stable than group homes. This did not turn out to be true. On the average, families tended to feel weak agreement with the 5 years statement. Finally, families did not change in their initially very strong concern that "It is very important that I have the major say about what happens to my relative." This concern was initially strong, and it remained strong even after community placement. The mean score on the 5 point scale was 4.13 in 1986, and 4.27 in 1990.

To summarize the family survey findings, families were more satisfied with community residential and day settings than they were with the previous congregate care settings. They also believed their relatives were happier with both residential and day programs. Families of community movers were more trusting of staff, less concerned about turnover, less concerned that they were not getting the medical care they need, they believed their relatives were getting better food, they believed their relatives had more privacy in their community homes, and they had just as much confidence in the permanence of the community homes as they previously did in the institutional settings. They continued to want to have a strong and respected voice in determining what happened to their loved ones.

Summary

The Longitudinal Study of CARC v. Thorne Class Members was responsible for visiting 1298 class members in 1985, 1342 in 1986, 1344 in 1987, 1335 in 1989, and 1335 in 1990. The project collected quantitative data about each person in the class in each year. The central, although not the only, purpose of this project was to provide scientific information about the well-being of the people who moved out of large congregate care settings, and moved into small community based programs.

This article has focused on people who were visited in 1985, and were living in congregate care settings, and who then moved to community settings, and were visited again in 1990. We applied three major research designs (longitudinal, matched comparison, and family survey), all aimed at the question of whether people were "better off." But two of the designs approached the question in slightly different ways. The longitudinal design asked whether people who moved into the community were better off in 1990 than they had been in 1985. The matched comparison design asked whether people who moved into the community were better off in 1990 than very similar people who were still

in congregate care.

When both designs yield similar findings, we can be very confident in the validity of the results. Overall, our findings about the well-being of these people were extremely clear. The results of the entire study have been summarized on the following page. The table is organized according to the three major components of the project: matched comparison, longitudinal, and family survey. We have rated each finding as follows:

- ++ Extremely positive finding
- + Positive finding
- 0 Neutral finding
- Negative finding
- Extremely negative finding

CONSUMER OUTCOMES
ASSOCIATED WITH DEINSTITUTIONALIZATION
Connecticut, 1985-1990

	Matched Comparison Design	Longitudinal Design	Family Survey
Adaptive Behavior Improvement	++	++	
Challenging Behavior Improvement	0	+	
Intensity of Medical Needs	0	-	
Reduced Daily Medications	0	-	
Increased Earnings	0	+	
Day Program Productivity	+	++	
Subjective Quality Ratings	++	++	
Individualized Treatment	++	++	
Physical Quality of Residence	++	+	
Social Presence (Integration)	++	++	
Harris Integration Scale	++		
Quality of Life Questionnaire	++		
Frequency of Case Manager Visits	0	+	
Staff Like Their Jobs	+		
Staff Like Working With Person	+		
Staff Think Person Has Progressed	+		
Family Visits to Person	0	+	0
Person Visits with Family	0	+	0
Family Satisfaction, Residence			++
Family Satisfaction, Day Program			+
Family Perception: Happiness, Home			++
Family Perception: Happiness, Day			+
Family Trust In Staff Competence			+
Family Concern About Staff Turnover			+
Family Perception: Quality of Food			+
Family Perception: Personal Privacy			++

From the sheer number of "+" symbols, it is clear that the findings were very positive.

In fact, there were only two negative findings to be reported. One negative aspect was that the number of daily medications increased slightly from 1985 to 1990 in the longitudinal design. The 569 people we tracked during their move from institution to community were receiving a higher number of daily medications in the community than they did in 1985 in congregate care settings. However, this finding seemed to be a general pattern for all class members, both movers and stayers. The matched comparison analysis showed that there was no difference between movers and stayers in the number of daily medications taken in 1990; the number of daily medications increased for both movers and stayers between 1985 and 1990. This suggested that the effect may

have been a simple function of aging.

The only other negative finding was the increased urgency of medical needs between 1985 and 1990 in the longitudinal design. For the 569 movers, the reported intensity of medical care needed was slightly greater in 1990 than it was in 1985 in congregate care settings. Again, the matched comparison design revealed no difference between movers and stayers in 1990. The urgency of medical needs seemed to have increased for both movers and stayers, although for neither group was the change statistically significant.

In every other dimension we measured, people were either no worse off or considerably better off in 1990 than they were in 1985. In both the matched comparison and longitudinal designs, people were better off in terms of adaptive behavior than they were in 1985. This finding mirrored those from other states with a small variation in the magnitude of change. In the matched comparison design, the two groups did not differ significantly in 1990 in challenging behavior. In the longitudinal design, however, there was a significant improvement in this dimension. Again, this finding was quite similar to those in other states. The typical pattern has been incremental annual changes, which when added together over several years, produced significant changes. Over the 5 year period, class members who moved to the community experienced a small (1.2 point) yet significant improvement in challenging behavior.

One of the most significant areas of improvement over the 5 years in Connecticut was the area of productivity and vocational activity. On almost every element measured within the employment/day program domain, positive results were seen. People were experiencing more valued employment/day program experiences, were earning more money (both movers and stayers), and had more opportunities for integration with non-handicapped people during day programs/employment.

Integration was affected dramatically by deinstitutionalization. Both the longitudinal and the matched comparison design showed sharp increases in our measures of social presence and social integration. The members of the class were much more integrated after moving from congregate care to community settings.

On Schalock's Quality of Life Questionnaire, the matched comparison revealed that movers consistently gave higher ratings than matched stayers. To the degree that this scale was reflective of the elusive concept of quality of life, people who moved to the community were better off.

Case management evidently evolved considerably during the course of this study. The longitudinal design revealed that case managers were visiting more often than they used to. The matched comparison design showed that this was true for both movers and matched stayers; case managers were visiting more often than before, both in congregate and

community settings.

The matched comparison design included new questions for staff about how they like their job, how they like working with the specific class member, and whether they have seen progress in the class member. All three results favored the movers over the stayers.

The second group of outcomes were related more to the residential environments than to individuals. Both research designs showed strong superiority of the community settings on all measures. We conclude that class members in the community were better off than they were before, and better off than similar people who were still awaiting community placement. We also infer that community residential settings were clearly "better" than congregate care facilities in all the environmental dimensions we measured.

With regard to the frequency of family contact, often thought to be a valued outcome of returning to the community, our findings were mixed. Certainly family visits have not decreased. The matched comparison design showed that matched movers and stayers had about the same level of contact with their families.

The family survey showed that family satisfaction with the relative's new home in the community was significantly greater than their previous satisfaction with congregate care living units. It should be emphasized that prior satisfaction with the congregate care settings was high, and that about half of the families in our analysis initially opposed community placement for their relatives. Once their relatives were out in the community, the satisfaction of the families was even higher than it was before. Satisfaction with their relative's day program was also greater in 1990 than it was in 1986 in congregate care. On every measure related to quality on the family survey, ratings improved significantly for the people who moved to the community. Clearly, the families of the movers believed strongly that these members of the CARC v. Thorne class were better off living in the community.

In summary, the evidence from 5 years of study, using three different research approaches, was very clear and consistent. The question originally posed by this project was:

Are the people who were living in large, segregated, congregate care facilities in 1985, and are now living in community based settings, better off or worse off than they were, and in what ways and how much?

The answer to this question is:

The people who moved from congregate care to community settings were, on the average, much better off in almost every way we know how to measure.

We must conclude that the opportunity to live and work in regular communities, and to construct regular lives, should be offered to every class member as soon as possible.

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