

**The Connecticut Applied Research Project  
Report Number 10**

**1990 Results of the CARC v. Thorne Longitudinal Study**

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## **The Connecticut Applied Research Project Reports Of the CARC v. Thorne Longitudinal Study 1985 to 1990**

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## 1. Introduction

This is a comprehensive report of 5 years of research on the well-being of CARC v. Thorne class members in Connecticut. This research was required by the 1984 consent agreement which settled the CARC v. Thorne litigation. In essence, it was intended to find out whether the people affected by the CARC v. Thorne class action lawsuit were actually better off because of it.

In a recent audit of this research project, Howard & Wyngaarden-Krauss (1989) made the following observations about the purpose of the Longitudinal Study:

Although there is no one statement of purpose used throughout documentation pertaining to the Longitudinal Study, we conclude that the original purpose of the Longitudinal Study was to allow the Department of Mental Retardation to measure the progress of class members as their circumstances changed as a result of the consent agreement. More specifically, the Longitudinal Study was viewed as a way of describing and monitoring the status of class members who moved into the community as a result of the consent decree (page 9-10).

Howard and Wyngaarden-Krauss are independent consultants with many years of experience in related deinstitutionalization efforts. We agree with the points they made in the paragraph quoted above. Therefore, as a comprehensive summary of this massive 5-year enterprise, we will focus on this single 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 than they were, 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 bar graph on the following page. 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.

In our original proposal to conduct this project, we wrote that two research designs would be employed, and a number of indicators of well-being would be measured. Here, we will use both designs and all of the quantitative measures of well-being to answer the central question. The two research designs are the “longitudinal” and the “matched comparison” designs. They will be fully described in the Methods section. The measures of well-being will also be described in the Methods section.

## 2. Methods

### 2.1 Background and Procedures

The Association for Retarded Citizens of Connecticut (CARC) and the state signed a consent decree in the CARC v. Thorne case in 1984. The settlement emphasized a preference for community placement of the class members. Included in the settlement was a provision for monitoring of the well-being of the CARC v. Thorne class members, both before and after they moved to community settings. This was the reason for the creation of the present project, the Connecticut Applied Research Project (CTARP), also called the CARC v. Thorne Longitudinal Study.

We hired and trained local professionals and students (each of whom was experienced in relevant human services) to visit each class member, and to complete our quantitatively oriented survey forms. The survey forms were designed jointly by the Department of Mental Retardation (DMR) and Conroy & Feinstein Associates (CFA), adapting the prior work of Temple University and the California Department of Developmental Services. The measures selected had all been tested at least once for reliability and validity. The forms used in 1990 are included in this report in Appendix 1.

The first round of visits and data collection was completed in February of 1986. A baseline report was delivered to DMR in May 1986 (CTARP Report Number 3). The second round of data collection was completed in November of 1986. The visits were staggered with regard to the 1985 round so that, for each person, the two visits were roughly a year apart. A report was delivered to DMR in May 1987, presenting an analysis of changes from the previous year (CTARP Report Number 5).

The third round of data collection began in June 1987 and all forms were received in Philadelphia by October, 1987. The third round resulted in CTARP Report Number 7. The fourth round began in February and was completed in October of 1989. CTARP Report Number 8 was delivered in January of 1990.

The present report arises from our fifth annual round of comprehensive individual data collection. Members of our project team have once again visited every known class member at their homes. We have again collected extensive data about each person, using residential staff knowledge and records. We have also interviewed every consumer who was willing and able to talk to us. In all, we visited 1335 members of the CARC v. Thorne class.

Training for the data collectors took place on a Friday evening and a Saturday in March of 1990. The training was organized by our in-state project coordinator, Ms. Julie Townsend. In this session, we explained the aims of the project, but, on the advice of the scientists who performed the audit of the Longitudinal Study, we did not review the details of the results of the past 4 years. This was suggested in order to reduce the possibility of bias among the data collectors; by knowing what was found before, they could conceivably be more inclined to look for the same things again.

The CFA training for data collectors is intended to accomplish three ends: explain the purpose of project, explain how each collector is expected to complete his/her assignment, and familiarize the collectors with the instrument package. Our instruments are designed to be self-explanatory as much as possible. Instructions and rules for each section are printed on the forms themselves. Thus only a few hours of study are necessary. Past problems with specific sections or items are discussed, and then assignments are given out and the field work begins.

Data collectors initiate contact with service providers to make appointments. They are trained to be flexible, and to avoid interference with routines and schedules. Providers are told what kind of information we will be seeking, what documents will be needed, and how long it will take.

In every case, we interview the staff person or other care giver who knows the class member best. In the course of 15 years of research in 12 states, we have 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).

In addition to the field data collection, the project includes a family survey component. Addresses of parents, close relatives, or guardians are obtained during the field visits. Mailing labels are generated from this information, and we send a survey package to each family. The package contains an introductory letter, a survey form, and a stamped return envelope. The survey is very brief, consisting of just 24 questions, in simple wording.

## **2.2 Instruments**

There are three primary data collection instruments in the Longitudinal Study. We will describe them briefly here for the record. They are reproduced in Appendix 1.

## **Instrument 1: The CIER**

The first and most important of the three instruments is the Connecticut Individual Evaluation Report (CIER). It was developed by combining, modifying, and adding to, several other instruments already known to be reliable and valid. One CIER is collected for each class member.

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 originally covered adaptive behavior, challenging (maladaptive) behavior, vocational behavior, and medical status. We modified some of these items, removed some, and added some.

The adaptive behavior section of the CIER contains 46 items relating to: motor abilities, independent living skills, communication skills, social/emotional skills, and cognitive skills. When the item scores are summed, an adaptive behavior sum score is produced. Dividing that number by the total possible score (which is 209 points) and multiplying by 100 converts the raw score to a percentage of the total scale possible, and this scale score ranges from 0 to 100.

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

Items on demographics, other disabilities, family contact, medications and health, integration, productivity, services received, and consumer satisfaction, were all taken from the Behavior Development Survey package that we designed for use in Pennsylvania. We also modified sections on the Overall Plan of Service (OPS), case management, and individual program goals.

The Social Presence Scale was developed specifically for the CTARP. It was tested in 1985 and revised in 1986. Information is collected about the frequency of opportunities for interaction between class members and non handicapped people other than staff. The scale assesses the frequency of opportunities for interaction with non-handicapped peers. It does not measure the intensity or quality of interactions.



Some significant modifications to the CIER were made for the 1990 data collection, although behavioral and demographic items were unchanged. The most important change was the elimination of a number of items that were found to be less objective, and more “compliance” oriented than the outcome oriented information we had been collecting all along. These items had been taken from Connecticut's Individual Review instrument. Unfortunately, they were too subjective and too time-consuming to be valuable to the Longitudinal Study. For example, one item read:

The individual does not demonstrate signs that might suggest over-medication or the need for medical evaluation.

Not only did this item combine two separate concepts into one, a severe error in survey methodology, but it called for a level of medical judgment that our data collectors were not prepared to make. The result was that the Yes-No responses were being made very subjectively.

Equally important, these process-oriented items were diverting resources from the main question of the project, which was to find out in what ways people's well-being had improved, and how much. These items were oriented more toward determining whether the service process was being conducted according to standards of best practice. As important as that function is, it is not the central purpose of the Longitudinal Study.

Secondly, the individual program goals and the services sections were combined and simplified. Page 12 of the 1990 form, headed Services, gives 17 categories of developmentally oriented services. For each service, data collectors must ascertain whether that service is prescribed in the OPS, which is a very objective determination. Then they must seek any convincing evidence, either verbal from staff (such as a clear and thorough description of how and when they render the service), or in records. If they are receiving the service, the data collectors then simply asked the staff respondent's opinion about whether the amount of the service was enough to meet the individual's needs.

The Day Program/Employment section was simplified in 1990, because residential staff were having trouble telling us details of how the person spent his/her time when they were away from the residence.

On page 16, we added a section headed “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 offers something to compare to. It captures how often people visit with friends or neighbors, go shopping, go to a restaurant, and so on. As an index of integration, we believe it is very useful. It also asks how satisfied the person is with how often they get to do each activity. We recently used this scale in the National Survey of People with Developmental Disabilities, and so we also have this scale for more than 14,000 people.

We deleted our Consumer Interview because of the appearance of a new scale by Schalock (1989), the Quality of Life Questionnaire or QOLQ. It begins on page 17 of the CIER. It looked so promising that we made the very difficult decision to abandon our own interview. Our own interview, which we had been collecting unchanged for two cycles of data collection, might have had the advantage of showing changes over time. However, in our previous report (CTARP Report Number 8), we did not detect any significant changes over a nearly 1 year period. This suggested that it would not necessarily be a mistake to change instruments. Moreover, the QOLQ had been used in several other areas of the United States, and also in other countries.

Like our own, the QOLQ is designed as a direct interview of the consumer. However, the QOLQ makes a significant departure from previous interview instruments in that whoever knows the individual best (staff, relative, friend) is permitted to supply responses if the individual cannot. We at CFA had resisted such approaches for years because of concern about reliability, and also about fostering a tendency to speak for others, which might be detrimental to staff's image of the people they serve.

Schalock seems to have shown that, at least for people who can speak, close staff persons will answer the same way the people do. He and his colleagues have reported quite acceptable reliability levels between staff and the individuals themselves. Although this does not prove that the same is true when staff answer for people who cannot communicate at all, it at least provides some confidence. Moreover, rather than fostering a negative tendency, asking staff to try to tell us what they think an individual would say if s/he could talk may turn out to be a very healthy (albeit difficult) exercise.

The 1989 version of the scale is composed of 40 questions arranged in four sections: Satisfaction, Competence/Productivity, Empowerment/Independence, and

Social Belonging/Community Integration. We have collaborated closely with Dr. Schalock in our preliminary analyses of the Connecticut data, by bringing him to Philadelphia in December to examine the properties of the scale when used with a severely disabled group of people. The members of the CARC v. Thorne class are considerably more severely disabled than previous QOLQ respondents.

### **Instrument 2: Site Review Package**

Unlike the CIER, one Site Review Package is 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 collects information about the size of the immediate environment experienced by the consumers who live there. For community service providers, it also collects the size of the provider agency overall. In case the setting is a congregate care facility, the overall size of the facility is collected. These items are related to the considerable theoretical interest in the “ideal” and most “cost-effective” size of settings and of providers. With this information, Connecticut could in the future explore the questions of whether group homes of different sizes result in different quality of life and different costs.

The Staff section is designed to capture the intensity of staffing at the home, plus the average longevity of the staff who work at the home. This year, we added items to get the average starting salary, and whether the staff are unionized or not.

The Physical Quality index has been used consistently since 1985. It is a general measure of how pleasant, comfortable, and attractive the home is.

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 is composed of only 10 items, all intended the degree to which the routine of life is regimented as opposed to individualized.

Basic Life and Safety Issues are checked in the Site Review package, not because we intend to report on them in our research findings, but rather because our presence at the residential site offers an opportunity to help protect people from

dangerous situations. We simply check on fire alarms, fire drills, staff training in first aid, and so on. These findings are reported directly to DMR, and are not a part of this report.

Site Reviewer Impressions are the purely subjective feelings of our data collectors about six dimensions of the quality of life. The six dimensions are: 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.

Special Concerns are recorded in an open-ended format on a blank sheet. Any area not covered in the rest of the site review, but seems to be a threat to the well-being of the people at the site, is mentioned here. The information is not used in the research project, but is reported to DMR for possible action.

Positive Comments are also recorded on the last page of the package, so that things that are positive and exemplary about the site can be expressed.

### **Instrument 3: Family Survey**

The 1985 family survey form was designed by modifying and shortening the survey that was used in the Pennhurst Longitudinal Study in Pennsylvania. Because of long experience with family surveys in that work, most of the questions were reworded for clarity and brevity. Only a few questions remained directly comparable to questions on the Pennhurst instruments.

In the 1986 survey form, we made significant modifications, such as changing the wording of most items, and collecting more detail about family visits. The 1986 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.

In 1990, we used exactly the same instrument as in 1986, because we wanted to assess changes between the earlier data and the 1990 round. A copy of the family survey instrument is included in Appendix 1.

### **2.3 Methods: Statistics**

Inferential statistics are designed to tell us whether we can make inferences from samples to populations. In this report, for the longitudinal analyses, we are dealing with a population and not a sample: all CARC v. Thorne class members who have moved from congregate care to community living situations. For those analyses, there is often therefore 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 use and report the statistical tests, for those who may find them useful or interesting.

However, in our matched comparison and family attitudes analyses, we are dealing with samples. Therefore we report the statistical tests and results with care.

In all cases in this report, we will attempt to de-emphasize the mathematics, and will instead stress pictorial representations of the findings that will be understandable by, and useful to, the widest possible audience.

### **3. Results**

#### **3.1 Description of People Who Moved from Congregate to Community Care**

The Longitudinal Study has 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.

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

The movers also experience other disabilities. A total of 11% of them have a severe or total vision loss, 3% have a severe or total loss of hearing, and 30% use a wheelchair. In the health area, 3% "would not survive without 24 hour medical personnel," and another 6% "have a life-threatening condition that requires rapid access to medical care." A history of seizures, but none currently, is reported for 17%, and another 18% have had seizures during the past year.

All in all, these descriptions demonstrate that these people, who have moved into the community over the past 5 years, are very seriously disabled, they are aging, and many of them have more than one disabling condition. These are 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 our measurements of how the quality of their lives has changed.

It is also important to show where these movers lived in 1985.

<b>Where the Movers Lived in 1985</b>	<b>#</b>	<b>%</b>
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.

Two important descriptors of the movers' current situations are the type of place they are living in, and what they are doing during the day. The following table shows what kind of residential settings the movers are living in.

<b>Type of Community Placements of the Movers</b>	<b>#</b>	<b>%</b>
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%

Clearly, Connecticut has relied most heavily on the group home model, with 72% of the movers living in group homes of 4 or more beds, of which about a third are ICF/MR certified. The smaller model, or CLA group home, with 3 or fewer beds, has received more recent attention, and 22% of the movers live in a CLA.

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 attend a Community Experience Program, which is geared to help them learn skills that will enhance their adaptation to, and productivity in, the community at large. A fourth are in sheltered employment, in which they earn wages.

Most remarkable is the fact that nearly a fifth of the movers are 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. Of the 839, 459 were Pennhurst class members, and only 1 of them was in supported employment. (Strangely enough, however, Philadelphia had a higher proportion of people in competitive employment positions: 9 out of 459 class members and 25 out of 380 non-class members.)

### **3.2 Longitudinal Results**

The longitudinal research design looks for changes over time. In the CARC v. Thorne Longitudinal Study, we first collected data in 1985, and we have done so each year since then. In this report, we will concentrate on changes between 1985 and 1990. As always, the changes we have measured are oriented toward the question of whether people are “better off” now than they were at the beginning of the study.

One of the most 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 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 have used a scale of adaptive behavior that is 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 graph on the following page.

However, it is more important to judge the practical significance of the findings in this study. As noted previously, the t-test and other statistical tests like are designed to tell us whether we are safe in generalizing findings from a sample to a population.

In this study, we are dealing with the entire population of CARC v. Thorne class members. It is perfectly proper to say that the 4.5 gain is exactly that, and that statistical tests are unnecessary. But how big is 4.5 points? From our experience, the answer is that it is a major gain, and it is in line with our findings in other states' deinstitutionalization experiences. Here are the average initial adaptive behavior gains upon deinstitutionalization in three states:

Pennsylvania	8%
Louisiana	8%
New Hampshire	5%

It is important to keep in mind, however, that the other studies used different behavior scales, with somewhat different kinds of individuals, and different community service systems. We interpret the findings in Connecticut as remarkably consistent with findings in other states. People who have moved out of congregate care are now doing considerably more for themselves, as opposed to having things done for them.

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 preceding 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 are dealing with a population and not a sample, inferential statistics are not strictly necessary. Therefore, any changes that are measured, should be thought of as real. Again, we raise the issue of the practical significance of a 1.2 point change in challenging behavior. In the service delivery system as it is currently configured, this means that people have displayed somewhat fewer challenging behaviors in the community than they did previously in congregate care settings. Moreover, over a period of many years, such gains would add up, and would become clearly noticeable improvements.

Our instruments do attempt to measure how and why such changes have occurred, in terms of the Overall Plan of Service process and the actual delivery of services in areas where goals have been set. In the area of adaptive behavior the answer is twofold. Increases in adaptive behavior are attributable either to the expression of previously learned skills or the learning of new skills.

The case of food preparation is a prime example of the former. Some individuals may have learned years ago how to prepare food. However, at Mansfield there is no opportunity to prepare food, as all food is brought in on trucks. Because the CIER measures what an individual does do, not what s/he could do, can do or might do, the person would not receive credit for preparing food. When the individual moves to the community and prepares lunch each day, the score on that particular item would increase. In this case, the individual has gained points by being able to express previously learned skills. Likewise, skill acquisition is measured through an increase in the adaptive behavior sum score.

The situation in the area of challenging behavior is not quite so clear. There is not consensus in the field about why individuals display challenging behavior. Challenging behavior has been called everything from attention-seeking behavior to expression of pain and boredom to learned institutional behavior. In any case, we know as the result of studies in several states that the expression of challenging behavior does decrease when individuals move from congregate care to community settings. However, the measured change seems to be of smaller magnitude than in the area of adaptive behavior.

In addition, we know that our measure of challenging behavior is less reliable than that of adaptive behavior. Both interrater and test-retest reliability coefficients are weaker in this area than in the adaptive behavior dimension. In other words, two respondents are less likely to agree about an individual's challenging behavior, and the same respondent is less likely to be consistent over

time in rating an individual's challenging behavior. The effect of this is that genuine changes in challenging behavior are more difficult to detect than in adaptive behavior; in the jargon of information theory, the challenging behavior scale has more “noise” in its “signal.”

In spite of the aforementioned difficulties in measuring and explaining challenging behavior, the longitudinal data indicate that the CARC v. Thorne class members are better off in this area.

Another measure of whether people are better off relates to the area of medications received. The CIER collects information about the name, dosage, prescribing practitioner, and purpose of each medication received by individuals. It is then possible to calculate the total number of prescribed medications an individual receives each day. Vitamins, topical ointments and any over the counter medications are excluded from this section.

In 1985, these 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, physicians often prescribe independent of one another, resulting in individuals receiving more medication than when they lived in congregate care settings. It is possible, if requested by DMR, to provide a more in depth analysis of the types and quantities of medications received by class members.

Another dimension of health status is the extent to which individuals have medical needs. The question on the CIER was, “In general, how urgent is this person's need for medical care?” The responses are displayed in the following table.

<b>Level of Medical Need</b>	<b>1985</b>	<b>1990</b>
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%

Interestingly, the table indicates that medical needs have increased overall, with fewer people having no serious medical needs. We hypothesize that this increase in need for medical care may be a result of increasing age among the class members. This area may warrant further investigation, and if DMR desires we can examine other areas in the health domain as well.

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 DD Act, productivity is 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 measure of productivity that has been used throughout the CARC v. Thorne Longitudinal Study is income.

Specifically, we ask how much money the individual earns 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 represents almost a 500% increase since 1985. While some may argue that this 500% increase does not result in a significantly enhanced quality of life for the individuals involved, we would argue that this represents 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.

In terms of the types of day program/employment in which people were involved both in 1985 and 1990, the results are as follows:

<b>Type of Day Program</b>	<b>1985</b>	<b>1990</b>
Community Experience	44.2%	33.3%
Sheltered Employment	20.0%	25.0%
Supported Work	1.4%	17.8%
Senior Citizen Programs	98	18%
Other	22	4%
Competitive Employment	9	2%
No Day Program	6	1%

A third of the movers attend a Community Experience Program, which is geared to help them learn skills that will enhance their adaptation to, and

productivity in, the community at large. A fourth are in sheltered employment, in which they earn wages.

Most remarkable is the fact that nearly a fifth of the movers are 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. Of the 839, 459 were Pennhurst class members, and only 1 of them was in supported employment. (Strangely enough, however, Philadelphia had a higher proportion of people in competitive employment positions: 9 out of 459 class members and 25 out of 380 non-class members.)

### **3.2 Longitudinal Results**

The longitudinal research design looks for changes over time. In the CARC v. Thorne Longitudinal Study, we first collected data in 1985, and we have done so each year since then. In this report, we will concentrate on changes between 1985 and 1990. As always, the changes we have measured are oriented toward the question of whether people are “better off” now than they were at the beginning of the study.

One of the most 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 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 have used a scale of adaptive behavior that is 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 graph on the following page.

However, it is more important to judge the practical significance of the findings in this study. As noted previously, the t-test and other statistical tests like are designed to tell us whether we are safe in generalizing findings from a sample to a population.

In this study, we are dealing with the entire population of CARC v. Thorne class members. It is perfectly proper to say that the 4.5 gain is exactly that, and that statistical tests are unnecessary. But how big is 4.5 points? From our experience, the answer is that it is a major gain, and it is in line with our findings in other states' deinstitutionalization experiences. Here are the average initial adaptive behavior gains upon deinstitutionalization in three states:

Connecticut	4.5%
Pennsylvania	8.1%
Louisiana	8.4%
New Hampshire	5.2%

It is important to keep in mind, however, that the other studies used different behavior scales, with somewhat different kinds of individuals, and different community service systems. We interpret the findings in Connecticut as remarkably consistent with findings in other states. People who have moved out of congregate care are now doing considerably more for themselves, as opposed to having things done for them.

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 preceding 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 are dealing with a population and not a sample, inferential statistics are not strictly necessary. Therefore, any changes that are measured, should be thought of as real. Again, we raise the issue of the practical significance of a 1.2 point change in challenging behavior. In the service delivery system as it is currently configured, this means that people have displayed somewhat fewer challenging behaviors in the community than they did previously in congregate care settings. Moreover, over a period of many years, such gains would add up, and would become clearly noticeable improvements.

Our instruments do attempt to measure how and why such changes have occurred, in terms of the Overall Plan of Service process and the actual delivery of

services in areas where goals have been set. In the area of adaptive behavior the answer is twofold. Increases in adaptive behavior are attributable either to the expression of previously learned skills or the learning of new skills.

The case of food preparation is a prime example of the former. Some individuals may have learned years ago how to prepare food. However, at Mansfield there is no opportunity to prepare food, as all food is brought in on trucks. Because the CIER measures what an individual does do, not what s/he could do, can do or might do, the person would not receive credit for preparing food. When the individual moves to the community and prepares lunch each day, the score on that particular item would increase. In this case, the individual has gained points by being able to express previously learned skills. Likewise, skill acquisition is measured through an increase in the adaptive behavior sum score.

The situation in the area of challenging behavior is not quite so clear. There is not consensus in the field about why individuals display challenging behavior. Challenging behavior has been called everything from attention-seeking behavior to expression of pain and boredom to learned institutional behavior. In any case, we know as the result of studies in several states that the expression of challenging behavior does decrease when individuals move from congregate care to community settings. However, the measured change seems to be of smaller magnitude than in the area of adaptive behavior.

In addition, we know that our measure of challenging behavior is less reliable than that of adaptive behavior. Both interrater and test-retest reliability coefficients are weaker in this area than in the adaptive behavior dimension. In other words, two respondents are less likely to agree about an individual's challenging behavior, and the same respondent is less likely to be consistent over time in rating an individual's challenging behavior. The effect of this is that genuine changes in challenging behavior are more difficult to detect than in adaptive behavior; in the jargon of information theory, the challenging behavior scale has more “noise” in its “signal.”

In spite of the aforementioned difficulties in measuring and explaining challenging behavior, the longitudinal data indicate that the CARC v. Thorne class members are better off in this area.

Another measure of whether people are better off relates to the area of medications received. The CIER collects information about the name, dosage, prescribing practitioner, and purpose of each medication received by individuals. It

is then possible to calculate the total number of prescribed medications an individual receives each day. Vitamins, topical ointments and any over the counter medications are excluded from this section.

In 1985, these 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, physicians often prescribe independent of one another, resulting in individuals receiving more medication than when they lived in congregate care settings. It is possible, if requested by DMR, to provide a more in depth analysis of the types and quantities of medications received by class members.

Another dimension of health status is the extent to which individuals have medical needs. The question on the CIER was, “In general, how urgent is this person's need for medical care?” The responses are displayed in the following table.

Reported Level of Medical Need	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%

Interestingly, the table indicates that medical needs have increased overall, with fewer people having no serious medical needs. We hypothesize that this increase in need for medical care may be a result of increasing age among the class members. This area may warrant further investigation, and if DMR desires we can examine other areas in the health domain as well.

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 DD Act, productivity is 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 measure of productivity that has been used throughout the CARC v. Thorne Longitudinal Study is income.

Specifically, we ask how much money the individual earns 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 represents almost a 500% increase since 1985. While some may argue that this 500% increase does not result in a significantly enhanced quality of life for the individuals involved, we would argue that this represents 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.

In terms of the types of day program/employment in which people were involved both in 1985 and 1990, the results are as follows:

<b>Type of Day Program</b>	<b>1985</b>	<b>1990</b>
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%

There are three major implications of the data in this table. First, the percent of individuals involved in supported employment skyrocketed from 1.4% in 1985 to 17.8% in 1990. Second, 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). Third, 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 is clear from these data that the state of Connecticut has made a significant commitment to the outcome of productivity for CARC v. Thorne class members.

In 1986, we began to collect the revised Social Presence Scale for each class member. Information was collected about the frequency of opportunities for

interaction between class members and non-handicapped people other than staff. The Social Presence Scale measures only one dimension of integration, that of presence. The scale does not, however, measure participation in the community. The scale simply records how often, and with how many other consumers, the individual has been in the presence of people without disabilities. Responses are coded for both the number of consumers present, and by the type of setting in which the event occurred. The types of setting included:

- Home or other person's home or neighborhood;
- Recreational settings;
- Commercial settings;
- Day programs or jobs; and
- Transportation.

The most straightforward way to present the data is to simply add up all numbers, which yields the total number of events during the previous week. 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 2 interactions per week in congregate care settings. Insofar as integration is one of the important goals of deinstitutionalization, this finding should be interpreted as strong evidence that class members who have moved to the community are much better off now than they were in 1985.

One of the ultimate goals of deinstitutionalization is to move individuals from large, segregated settings to smaller, integrated settings in the community. For the individuals who moved from congregate care, the average size of the setting they came from was 20.7 people. The integrated community settings averaged 4.7 individuals ( $t=28.6$ , 565 df,  $p < .0001$ ). In future analyses, these data will enable us to address the issue of size of residential setting as it relates to the quality of care delivered.

Increased contact with families is another dimension that might be considered as a valued outcome. We added items about frequency in 1986. Specifically, we asked how often the family visited the class member and how often the class member visited with family either at their home or on outings. The range of responses was as follows:

- 5 Never
- 4 Twice a year or less
- 3 About every three months
- 2 About once a month
- 1 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 3.7 to 3.4 ( $t=5.4$ , 361 df,  $p<.0001$ ). On the same scale, the frequency of class member visits to the family increased from 4.2 to 4.0 ( $t=4.4$ , 361 df,  $p<.0001$ ).

This was the first time that we detected significant increases in family contact associated with deinstitutionalization. These changes were small and may not be of much practical significance, but they are of some theoretical interest. Early speculation among observers of deinstitutionalization, in Pennsylvania and elsewhere, was that family contact would increase after people returned to communities. However, our findings in other states have consistently failed to show any significant increase. Our explanation was that active families continued to be active wherever their relatives lived, and uninvolved families remained uninvolved. Here, we have at last seen an increase in family contact, which, although small, is a positive outcome.

Another dimension of “better off” that we have measured during the course of the study is the quality of the environment in which class members live. The two major instruments used were the Group Home Management Schedule (GHMS) and the Physical Quality Instrument (PQ). The GHMS measures the extent to which the environment is individualized to meet the specific needs of class members versus regimented to meet the needs of an “average” person. The GHMS is scored so that higher scores represent 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 average setting was more individualized in 1990 than in 1985.

The Physical Quality Instrument is completed after the site reviewer walks through the residential setting. Ratings are based on the physical pleasantness of the site. The 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 much more pleasant than the average congregate care setting.

At the end of each site review data collectors were asked to complete 6 subjective questions that were each scored on a scale of 1 to 10. Another way to look at the impact of deinstitutionalization is from the site reviewers's perspective over time. Each of the questions was asked about the setting in which the class member lived in 1985 and again in 1990. The results are displayed in the table below.

<b>Item</b>	<b>1986</b>	<b>1990</b>	<b>Signif</b>
1. Overall, how would you rate this site (1=poor, 10=excellent)?	5.4	7.9	.0001
2. How would you rate the quality and quantity of food in the refrigerator and cupboards (1=poor, 10=excellent)?	5.8	8.2	.0001
3. How do you perceive staff-consumer/consumer-staff interactions (1=cold, impersonal, 10=warm personal)?	7.2	8.3	.0001
4. How do you perceive consumer-consumer interactions (1=unfriendly, 10=friendly)?	5.0	6.8	.0001
5. What are staff's expectations for consumers regarding growth (1=pessimistic, 10=enthusiastic)?	5.5	7.8	.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)?	4.1	6.4	.0001

As these data demonstrate, on each and every question, site reviewers concurred that the community settings were far better than the congregate care settings from which people came.

### **3.3 Matched Comparison Results**

Scientifically, the longitudinal design by itself provides reasonably high confidence in the results. In order to achieve even higher confidence, however, the matched comparison design is needed. The longitudinal design enables us to be certain that the movers are now better off than they were in 1985 in most of the measured areas. But perhaps the stayers are also better off. Then we could not say that the deinstitutionalization “caused” the movers' improved quality of life.

To control for this possibility, we can perform a “twins” study. For each mover, we try to find a “stayer” with extremely similar characteristics. A stayer is

a person who was living in a congregate care facility in 1985, and still is in 1990. (There are 340 such people.) Then, if we find different outcomes, we can be much more confident that the reason for the differences is the fact that the movers were treated differently from the stayers; the movers were deinstitutionalized and the stayers were not.

We cannot simply compare all 569 movers to all 340 stayers, because they have different characteristics. The phenomenon called “creaming,” which is common in deinstitutionalization and other innovative social programs, refers to a tendency to select people thought to be “most likely to succeed” for community placement.

By looking backward in time to 1985, we find that the people who have thus far moved from congregate facilities into community settings started out with slightly higher adaptive behavior scores than those who remained in congregate care. They also had less challenging behavior and a less urgent need for medical care than the people who still in congregate care.

In fact, we tested for 1985 differences in several characteristics between the movers and the stayers. 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,  $p=.001$ ). These initial behavioral differences are portrayed in the graph on the following page. 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. Rather, we needed a “matching” process, to control for those important initial differences between movers and stayers.

The matched comparison design asks this question: “If we take two very similar people, one who was placed into the community and one who remained 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. We would automatically be able to predict that whatever

happened to the movers would also happen to the stayers, later, when they went to the community. Matching is the “next best” research design to enable us to make such a prediction.)

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 can be matched is the fact that the groups are different. In adaptive behavior, for example, the stayers are lower functioning; therefore some of the lowest functioning people simply do not have “twins” who have moved to the community.

This leads to the major methodological weakness of the matched comparison design. When we complete the matching, 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, for example, 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.

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.

It was important to be certain that our matching process worked perfectly, so we performed tests on the two groups of 124 stayers and their 124 mover “twins” to see if they were different in any way back in 1985. 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.

Then the real question was addressed: “Given that the two groups started out looking like 'twins,' did they have different outcomes?” That is, did they become different by 1990, after the movers moved?

In 1990, the two groups are significantly different on several variables. Most importantly, the movers scored a 47 in adaptive behavior and the stayers scored a 41 ( $t=2.09$ , 242 df,  $p=.038$ ). The change is depicted in the graph on the following page.

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 are significantly higher in adaptive behavior than the stayers. This difference can almost certainly be attributed to the fact of community placement.

In a similar fashion, we examined the challenging behavior score, to see if the two groups differ in 1990. The movers average 81 and the stayers 80 points. This one point difference did not reach statistical significance, so we are not able to conclude from the matched comparison analysis that similar people have different outcomes in reduction of challenging behavior. Statistically, their outcomes look about the same.

We had two different measures of integration on the CIER data collection form in 1990. 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 on the left hand side of the graph on the following page.

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 can be interpreted as showing 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 graph on the following page.

In the future, it would be interesting to compare the Connecticut findings on this scale to the original Harris survey, which included 1000 Americans with disabilities and 1000 Americans without disabilities. It would also be useful to

compare findings with the results of National Survey of Americans with Developmental Disabilities (Conroy, Feinstein, Lemanowicz, Devlin, & Metzler, 1990). This survey collected face to face interviews with more than 15,000 Americans with developmental disabilities.

Another important outcome measure we wanted to examine was derived from the Quality of Life Questionnaire (Schalock, 1989). The QOLQ scale combined measures of satisfaction, productivity, independence, and integration, as reported by the individual or their surrogate. A higher score on the each component of the scale indicates what the scale's authors believe to be a higher "quality of life." The graph on the following page shows the results for movers and stayers on each of the four subscales.

Incidentally, 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.

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 indicates that the people living in the community enjoyed a greater "quality of life" than similar people who still lived in congregate care settings.

There were three questions about staff that were of interest to us. Findings on all three are shown in the graph on the following page. 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 very subjective rating ( $t=3.03$ , 239 df,  $p=.003$ ). While 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 an 8.9 and stayers' staff an 8.1 ( $t=4.17$ , 243 df,  $p<.0001$ ). Staff in the community gave slightly higher ratings than staff in congregate care settings.



Another subjective item rated by staff was a 1 to 5 scale which addressed “the progress made by this person in the past year.” A “1” meant they regressed a lot, and “5” meant they progressed a lot. The movers' staff persons rated an average of 4.3 on this item, compared to a 3.7 for the stayers' staff ( $t=5.06$ , 244 df,  $p<.0001$ ). For the graph, these numbers were doubled so that they could be seen on the same scale as the other two staff questions. While both of these average ratings indicated progress, the trend again was that movers had higher ratings for staffs' perceptions of progress.

The following variables were examined in 1990, and we were unable to detect a significant difference between movers and stayers.

- Number of weeks since the DMR case manager visited this person at the residence.
- Number of medications taken daily.
- Hours per week physically present at the day program.
- Frequency of visits from family members.
- Frequency of visits to family members.
- Earnings per week.

The first bulleted item, weeks since DMR 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 is a major change from past practices, at least in the congregate care settings. Now people in institutions are being visited just as often as people in group 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 made a lot of progress in this area since 1985. The groups were also not different in earnings per week, again 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 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.

There was no significant difference in earnings between the two groups in 1990. This is curious given that, overall, movers increased their earnings from an average of \$2.00 per week to an average of \$10.00 per week. One possibility is that

the use of the mean as a measure of central tendency may be misleading. The mean is sensitive to extreme values, and, in the matched comparison design, there were a few individuals with earnings of \$200.00 per week. The earnings of those individuals would affect the mean.

Another measure of central tendency that could be used is the median, which represents the point above which and below which 50% of the cases fall. Because in our sample more than half the people were earning no money, the median was zero for both groups, in both 1985 and 1990.

Perhaps it would be more informative to report the proportion of people who are earning money. For the movers, 10% were earning money in 1985, and 27% earned money in 1990 (chi-square=11.4,  $p=.0007$ ). For the stayers, only 8% of the people earned money in 1985, compared to 23% in 1990 (binomial,  $p=.0009$ ). A greater proportion of people earned money in 1990, for both groups. Therefore, the mean is still the most appropriate measure of central tendency with these data.

Medical needs 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.

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. This leaves us with the tentative conclusion that medications might have actually increased slightly among the 569 movers in the longitudinal design, but that the increase was not large enough to detect in the smaller sample of 126 movers in the matched comparison design. This measure, "number of medications administered daily," also included a wide variety of prescribed medications. An interesting area for future analysis at a more detailed level would be changes in the use of drugs associated with significant risk, such as the neuroleptics.

Another health-related variable we examined was the number of months since the last general medical checkup. On the average, movers had a medical

checkup 5 months ago, and stayers 6 months ago ( $t=2.01$ , 243 df,  $p=.045$ ). While movers have had more recent medical checkups than stayers, both time periods were well within the limits of good medical practices.

Another indicator of well being is service delivery 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 on the following page.

There was no difference between movers and stayers on the total number of services received. Taken together, the 248 people in this matched comparison had 1357 services recorded on our data collection forms. In both groups, if a service was in the OPS, it was almost certain to be reported that the service was being provided. We found only 5 instances (out of 1357 delivered to 248 people) in which a service was planned, but reported as “not enough.”

There were some interesting differences between the two groups in the type of services being received. The graph on the following page shows the number of people in each group, movers and stayers, who were receiving each of the 17 types of formal developmentally oriented service. The graph is sorted according to which services were most commonly received by the movers.

Starting at the top of the graph, we see that stayers were slightly more likely to have medical/nursing services specified in the OPS, but that 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, and these were not surprising findings.

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. Corresponding, near the bottom of the graph, we see that the services of a recreation therapist were much more likely to be received by stayers in their congregate care facilities. Apparently, there has been significant emphasis in the

recreation area in Connecticut's training schools and regional center, including recruiting the professional therapists.

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

Moving to variables addressed on the site review, 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 are in smaller residential units.

There were two environmental scales to compare in 1990. One is the Group Home Management Scale (GHMS), which was intended to measure the degree to which the routine of life is regimented as opposed to individualized. 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 is a 30 point scale, the 4 point difference is actually quite substantial. It is represented in the graph on the following page.

The second environmental scale was the Physical Quality (PQ) scale, which measured the physical pleasantness of the setting. The average PQ score for movers was 68, compared to 54 for the stayers ( $t=12.17$ , 231 df,  $p<.0001$ ). This can be interpreted as showing that movers lived in more pleasant settings than stayers. In fact, movers were better off than stayers on both of our environmental scales, as symbolized in the graph on the following page.

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 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 10 times more statistically significant than the usual .05 level). For whatever value these subjective impressions may have, then, the evidence is clearly and strongly in favor of community settings.

### **3.4 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. Whenever there was any indication that family members would not want to be included in a mail survey, we left this section of the CIER blank. 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 translates into a response rate of 46%, which was slightly less than the 50% rate we had obtained in 1986.

For this report, we will restrict the analysis in two ways. First, we will limit consideration to the families who responded both in 1986 and in 1990, because we are looking for change over time. We will use the 1986 survey data, rather than the original 1985 data, because the 1986 survey form was exactly the same as the 1990 one. (We revised the survey significantly after the 1985 round.)

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

We are focusing in this report on the people who lived in congregate care in 1985, and had moved to the community by 1990. Therefore, for this analysis of changes in family perception, we are restricting our analysis of the family survey to 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 “movers” related to these 101 families were:

- 69 people who moved from Mansfield to Group Homes;
- 17 people who moved from Regional Centers to Group Homes;
- 10 people who moved from Nursing Homes and Homes for people who are aged to Group Homes;
- 3 people who moved from Mansfield to Community Training Homes;
- 1 person who moved from Mansfield to a living situation that our data collector had to characterize as “other”;
- 1 person who moved from a Nursing Home to a living situation that our data collector had to characterize as “other.”

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

This distribution is also represented in the pie chart on the following page.

The items on the family survey fell into four groups of issues: Satisfaction and Quality, Security and Permanence, Visits, and Attitudes About Individual Development.

### 3.4.1 Satisfaction and Quality

The family survey contained nine items 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.

The table below presents a 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 are always favorable in the table.

<b>Quality Dimension</b>	<b>1986</b>	<b>1990</b>	<b>Change</b>
Adequate Privacy	3.15	3.93	0.78
Happy: Day Prog.	3.91	4.08	0.17
Satis: Day	4.33	4.54	0.21
Trust Staff	3.89	4.15	0.26
Turnover No Problem	2.94	3.22	0.28
Medical Care Good	3.76	4.07	0.31
Food Good	3.81	4.14	0.33
Happy: Residence	3.89	4.25	0.36
Satisfied: Residence	4.15	4.64	0.49

The pattern that emerged was that families were 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 column headed "Changes" shows which of the families' perceptions appear to have changed the most since community placement. The perception that the class member has adequate privacy was the largest change, with satisfaction with the residence coming in second.

To summarize the findings with regard to perceptions of quality and satisfaction, families are more satisfied with community residential and day settings than they were with the previous congregate care settings. They also believe their relatives are happier with both residential and day programs. Families are now more trusting of staff, less concerned about turnover, less concerned that they are not getting the medical care they need, they believe their relatives are getting better food, and they believe their relatives have more privacy in their community homes.

Interestingly, of the families who answered the question “Would you like your relative to move into a small community based setting such as a group home or a community training home?” in 1986, 49% were either neutral to the idea or opposed to it. Obviously, most of these families have now changed their minds.

### 3.4.2 Security and Permanence

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 is 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.

### 3.4.3 Visits

In an effort to find out whether patterns of contact with families would change with deinstitutionalization, we included two questions about visits:

- (6) How often were you able to visit your relative in the past year?**
- (7) How often did your relative come to visit you in the past year?**

Visiting patterns remained practically unchanged among the families of the movers. Both pre and post move, the average frequency of family visits to the person was midway between once a month and once every 3 months. Visits of the person to the family's home averaged between once every 3 months and once or twice a year, and was closer to the latter.

We have been studying deinstitutionalization for more than 15 years, and this result has been consistent. In general, it seems that families that visited frequently at the institution continue to do so at the group home; those that did not visit frequently at the institution also do not visit frequently at the group home. Community placement does not appear to affect the pattern of family visits in Connecticut, just as it did not in our studies in Pennsylvania, New Hampshire, Colorado, California, and Louisiana.

### 3.4.4 Growth

We asked families about their attitudes toward the continued development of their relatives. We included two items, worded somewhat differently:

- (11) My relative has learned just about all he/she is ever going to learn about taking care of his/her own needs.**
- (17) My relative is continually learning to do more for him/herself.**

Both items were answered according to how much the family agreed with the statement, with a “1” meaning “Disagree Strongly” and a “5” meaning “Agree Strongly.” The responses to these items seemed to show contradictory results. The graph on the following page shows the results for both items.

On the first item, families actually increased in their agreement with the statement that their relative had “learned all he/she is ever going to learn about taking care of his/her own needs.” On the average, they changed from an agreement score of 2.99 (almost exactly neutral) to 3.28 (slightly on the side of agreement). The change was statistically significant ( $t=2.21$ , 87 df,  $p=.029$  two-tailed), although it was fairly small. From this item alone, one might infer that families had come to believe somewhat more strongly that their relatives had “leveled off,” having learned everything they would ever be able to learn, given their individual potentials.

On the other item, however, families appeared to show a distinctly different view. They increased their agreement with the idea that their relative was “continually learning to do more for him/herself.” The average agreement level changed from 3.41 to 3.70, which was also significant ( $t=2.78$ , 87 df,  $p=.007$  two-tailed).

The two responses would appear to be contradictory. One cannot have “leveled off” at the same time that one is “continually learning.”

We believe the answer may lie in the phrasing of the first of the two items: “...learn about taking care of his/her own needs.” Prior studies have indicated that the earliest and most rapid behavioral gains from deinstitutionalization are in the area of basic self-care (Temple University, 1988). In later years, attention tends to shift to more complex behaviors, such as manners and social appropriateness. Families who witnessed this rapid gain may have concluded that their relatives had indeed achieved their full potential for “taking care of their own needs,” but they may have interpreted this phrase to mean things like eating, dressing, grooming, and bathing.

In the subsequent question, then, the increase in agreement may not have been contradictory. The observation that their relative was “continually learning to do for him/herself” may have referred to the more complex skills that were being learned after the initial basic self-care skill acquisition that seems to be associated with living in community based settings.

There may be other interpretations of these apparently paradoxical results, but, in any case, the results are intriguing. Continued attention to the attitudes of families is essential, if the community of service professionals is to fully understand their feelings about the “developmental model” and the dominant concept of “active treatment.”

## 4. Summary and Interpretations

The Connecticut Applied Research Project (CTARP), also called the Longitudinal Study of CARC v. Thorne Class Members, has visited 1298 class members in 1985, 1342 in 1986, 1344 in 1987, 1335 in 1989, and 1335 in 1990. The project has collected quantitative data about each person in the class in each year. The central, although not the only purpose of this project, has been 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 report 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 two major research designs, both aimed at the question of whether people are “better off.” But the two 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. On occasion, the two designs can lead to slightly different answers, because they were asking slightly different questions. For example, our findings about earnings demonstrated this fact. The longitudinal design revealed that the 569 movers were better off in 1990 than they had been in 1985, because they were earning much more money than before. But the matched comparison design revealed that the 124 matched movers were not significantly better off than their 124 “twins” who were still in congregate care.

These findings were not contradictory. Deeper analysis revealed that, in the matched design, both movers and stayers were earning more in 1990 than they had been in 1985; what happened was that both groups increased by about the same amount. The conclusion of the matched comparison, then, was that the matched movers were not any better off than the matched stayers in terms of earnings. This finding, however, could be fully understood only when combined with the longitudinal finding. This illustrates the value of using both designs.

Overall, our findings about the well-being of these people are 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. (The family survey results given in this report were longitudinal, but are summarized in a separate column for emphasis.)

**Individual Outcomes  
Associated With Deinstitutionalization:  
Connecticut’s Mansfield Class Members, 1985-1991**

<b>Outcome Measure</b>	<b>Matched Comparison</b>	<b>Longitudinal Design</b>	<b>Family Survey</b>
Adaptive Behavior Improvement	Strong Positive	Strong Positive	
Challenging Behavior Improvement	No Change	Positive	
Intensity of Medical Needs	No Change	Negative	
Reduced Daily Medications	No Change	Negative	
Increased Earnings	No Change	Positive	
Day Program Productivity	Positive	Strong Positive	
Subjective Quality Ratings	Strong Positive	Strong Positive	
Individualized Treatment	Strong Positive	Strong Positive	
Physical Quality of Residence	Strong Positive	Positive	
Social Presence (Integration)	Strong Positive	Strong Positive	
Harris Integration Scale	Strong Positive		
Quality of Life Questionnaire	Strong Positive		
Frequency of Case Manager Visits	No Change	Positive	
Staff Like Their Jobs	Positive		
Staff Like Working With Person	Positive		
Staff Think Person Has Progressed	Positive		
Family Visits to Person	No Change	Positive	No Change
Person Visits with Family	No Change	Positive	No Change
Family Satisfaction, Residence			Strong Positive
Family Satisfaction, Day Program			Positive
Family Perception: Happiness, Home			Strong Positive
Family Perception: Happiness, Day			Positive
Family Trust In Staff Competence			Positive
Family Concern About Staff Turnover			Positive
Family Perception: Quality of Food			Positive
Family Perception: Personal Privacy			Strong Positive

From the sheer number of “Strong Positive” and “Positive” outcomes, it is clear that the findings support a compelling inference that the class members are much better off in their new community homes.

In fact, there are only two negative findings to be reported. One negative aspect is that the number of daily medications has increased slightly from 1985 to

1990 in the longitudinal design. The 569 people we have tracked during their move from institution to community are receiving a higher number of daily medications now in the community than they did in 1985 in congregate care settings.

While this finding is disturbing, it seems to be a general pattern for all class members, both movers and stayers. The matched comparison analysis shows that there is 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.

The only other negative finding is 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 is slightly greater now than it was in 1985 in congregate care settings. Again, the matched comparison design reveals no difference between movers and stayers in 1990. The urgency of medical needs seems to have increased for both movers and stayers, although for neither group was the change statistically significant.

The area of medical needs may warrant further investigation for all class members; the situations of class members in both congregate care and community settings appear to have worsened slightly since 1985. It is possible that both of the groups are being affected by the aging process, which may be causing more need for medications and more intense medical needs. It should also be restated that both of these health-related negative findings are statistically significant, but small in magnitude.

In every other dimension we have measured, people are much better off, better off, or the same in 1990 as they were in 1985. In both the matched comparison and longitudinal designs, people are better off in terms of adaptive behavior than they were in 1985. This finding mirrors those from other states with a small variation in the magnitude of change.

In the matched comparison design, the two groups do not differ significantly in 1990 in challenging behavior. In the longitudinal design, however, there is a significant improvement in this dimension. Again, this finding is quite similar to those in other states. The typical pattern has been incremental annual changes, which when added together over several years, produce 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 that these authors have watched develop over the past 5 years in Connecticut is the area of employment. On almost every element measured within the employment/day program domain, positive results have been obtained. People are experiencing more valued employment/day program experiences, are earning more money (both movers and stayers), and have more opportunities for integration with non-handicapped people during day programs/employment.

Both the longitudinal and the matched comparison design show dramatic increases in our measures of social presence and social integration. The members of the class are much more integrated after moving from congregate care to community settings.

On Schalock's new Quality of Life Questionnaire, the matched comparison reveals that movers consistently receive higher ratings than matched stayers. To the degree that this scale is reflective of the elusive concept of quality of life, people who have moved to the community are better off.

Case management has evidently evolved considerably during the course of this study. The longitudinal design reveals that case managers are visiting the movers more often than they used to. The matched comparison design shows that this is true for both movers and matched stayers; case managers are 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 are better off than they were before, and better off than similar people who are still awaiting community placement. We also infer that community residential settings are clearly "better" than congregate care facilities in all the environmental dimensions we have measured.

With regard to the frequency of family contact, often thought to be a valued outcome of returning to the community, our findings are mixed. Certainly family visits have not decreased. The matched comparison design shows that matched

movers and stayers have about the same level of contact with their families. The two variants of the longitudinal design, staff report and family report, show different conclusions. The staff reports indicate that families are visiting more often in the community than they did in the institutions, but the family self-reports say that they do not visit any more frequently now than they did before.

The difference may be related to the fact that the families who responded to the family survey both times appear to be unusual. They had more frequent contact with their relative to begin with than the typical family, according to the average frequencies reported by staff. This makes them less likely to increase their already high frequency of contact with their relative.

The rest of the family-oriented items are addressed only by the family survey. Family satisfaction with their relative's home in the community is 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. Now that their relatives are out in the community, the satisfaction of the families is even higher than it was.

Satisfaction with their relative's day program is also greater in 1990 than it was in 1986 in congregate care. We equate this higher level of family satisfaction with their relative being "better off." Families believe their relatives are now "happier" than they were, both with their homes and with their day programs. On every measure related to quality on the family survey, ratings have increased significantly for the people who have moved to the community. Clearly, the families of the movers believe strongly that these members of the CARC v. Thorne class are better off living in the community.

In summary, the evidence from 5 years of study, using three different research approaches, is very clear and consistent. The answer to the question originally posed for this project is this: the people who have thus far moved from congregate care to community settings are, 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 should be offered to every class member as soon as possible.



## 5. Future Directions

With this report, we conclude the current set of obligations to track the well-being of the CARC v. Thorne class members. Several options are available for future activity to assess Connecticut's progress toward the goals set in the consent agreement. One of the options is to consider this the end of the project, in the belief that all the important questions have been answered. As long as all parties agree, there would be nothing inherently wrong with this option. The authors of this report, having studied the deinstitutionalization process in Connecticut for nearly 6 years, certainly do not believe that the results are going to be much different for the last few hundred class members who are still awaiting community placement.

However, the possibility exists that things might be different in the future. This possibility is supported by the fact that some proposals have suggested that some class members will have to stay in congregate care for an indefinite period of time. Questions about this proposal remain: Why? How were these people selected? How do we know they won't benefit from community placement as others have? Isn't it useful to keep tracking both these people and the people already in the community for the next several years at least?

These issues lead to two possible futures for the longitudinal study's efforts: continue the study, or continue the study at a level of effort significantly less than in past years. Instruments and procedures could be streamlined so that the cost of the entire study would be reduced by about a third. Alternatively, the data collections could be shifted to every other year instead of every year, which would cut expenditures in half.

There are obvious benefits to some variety of continuation. This study has produced the largest and longest lasting base of scientific information about Connecticut's citizens with mental retardation yet amassed. Completely abandoning it would be short sighted, particularly since the results have been so positive.

Some form of continuation of the project might be feasible. We believe that, at an absolute minimum, we should make full use of the data that are already in hand. The present report has focused almost entirely on the people who moved from congregate to community care. We have not dealt here with the 5 year history of the people who have remained in congregate care. There are a number of other

topics which could not be analyzed here, but which should be extracted from our existing data base as soon as possible, before the data become outdated.

We have composed a preliminary list of topics for a series of brief reports that we think would be very helpful to the Department and other interested parties. A selection of these reports could be produced within relatively low resource requirements. This list follows.

## **Suggested Brief Reports to Make Use of the Existing Data**

1. The well-being of the people who are still awaiting community placement, and changes since 1985.
2. Variations in quality across types of community residential setting, including state-operated versus private, family-like versus group home, and small versus large.
3. Detailed analysis of patterns of utilization of psychotropic and other medications.
4. Patterns of staff retention, turnover, and job satisfaction by type and size of community residence in Connecticut.
5. What environmental and staff variables seem to result in the most rapid behavioral progress?
6. Detailed examination of staffing patterns, ratios, pay scales, and retention across setting types.
7. Systems level description of the type of “flag” situations seen most often, and in what kind of settings, with an analysis of what happened after we reported the flags.
8. Variations in residential per diems, with analyses that could reveal: people who are in settings much more expensive than their characteristics would seem to warrant; settings with unusually low and high costs, compared to other similar settings; formulas for rate setting that would be more closely related to the characteristics and needs of the individuals being served; and cost-effectiveness comparisons of the various community living options.
9. A fully detailed report of the 1990 family survey, including analysis of opinions of families of stayers.
10. Detailed analysis of the stability of residential situations of class members. This would involve examination of all kinds of movement among class members over the past 3 years, including short and long term alterations in living situation, and the reasons for the movements.
11. A closer look at the people who moved into congregate care during the study period.
12. A full examination of the degree and patterns of integration of class members, as compared to people in community living in other states, and also as compared to Americans with any kind of disability, and as compared to the general public (the latter two to be derived from the 1986 Harris poll of Americans with disabilities).

13. Technical review of the Quality of Life Questionnaire's utility and psychometric properties, with recommendations for future utilization of this and similar approaches to the measurement of quality.

In summary, options for future directions of the longitudinal study of CARC v. Thorne class members range from complete cessation to full continuation:

1. Cease all activity;
2. Make maximum use of existing data, but collect no new data;
3. Continue analysis and data collection, but scale back the effort either by streamlining data instruments or by going to every other year;
4. Continue the entire project until the community placement process is essentially finished.

Political and economic forces will tend to make options 1 and 2 more favorable to state government, while 3 and 4 are more desirable for advocates and plaintiffs in the CARC v. Thorne case. Our own view is that option 2 is the absolute minimum that is sensible or justifiable, and that option 3 would adequately represent the interests of all parties. We do not recommend continuation of the full-scale effort as an annual process, because we have learned a great deal from our field efforts; we would be comfortable with a simplification of our instrument package, or with a reduction in the frequency of our visits to class members.

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## APPENDIX 1: 1990 Longitudinal Study Instrument Package

-SIB  
-SIL