Deinstitutionalization of People with Mental Retardation and Developmental Disabilities in the United States:

Was This Good Social Policy?

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Purposes of this Paper

The purposes of this paper are to present, explain, and support the following facts and opinions:

1) **Research Shows Multiple Benefits of Community Placement:** Twenty-five years of developmental disabilities research literature on movement from institutional to community settings indicates that, on the average, people experience major enhancements in dozens of quality of life indicators. The literature is remarkably consistent in this area. A handful of recent reports on mathematical models of mortality, led by one researcher in California (Strauss), claimed an increased risk of mortality in community living. However, Lakin (1998) later showed these reports to be based on erroneous data, scientifically unfounded, and contradicted by other published studies. No other researchers have been able to replicate the findings of Strauss and his colleagues. The sum total of rigorous studies over a 25 year period provides conclusive evidence of the superiority of community living. In 1997 and 1998, my staff individually visited 1,125 people of the more than 2,300 people who moved out of California's Developmental Centers and moved to community homes under the terms of the Coffelt settlement. We will show some of the results of that body of work, which resulted in 17 formal public reports. Their qualities of life were enhanced, they were more independent, they displayed less challenging behavior, their homes were more pleasant, and their families believed that they were far "better off" than they were in the developmental centers.

2) **Deinstitutionalization in Developmental Disabilities Must be Clearly Differentiated from Deinstitutionalization in the Mental Health Field:** The deinstitutionalization of nearly 100,000 American citizens with developmental disabilities has been highly successful. This is a very different experience from the nation's failure to support people with mental illness who have left mental health institutions.

3) **Family Attitudes Change Dramatically:** Families (parents, siblings, other relatives, guardians, best friends) of people living in institutions overwhelmingly supported the continued existence of those institutions, and the continued placement of their relatives in them. However, in cases in which people moved to the community (either over family objections, or after the family's objections have been accorded a formal hearing and they have agreed to trial placements), the families' attitudes changed dramatically toward acceptance and support of community living. Even the most vocal opponents of community placement became ardent supporters of community living once it had been experienced. Recent work in Oklahoma has shown the most dramatic changes in family opinions yet documented (Conroy, 1999). The same changes have occurred among California's families, as well (Conroy & Seiders, 1998).

4) **The Theory of the "Must Stay" Group is Not Supported:** There are four classic reasons given for keeping people in large segregated settings: severe retardation, challenging behavior, medical fragility, and advanced age. These reasons have been convincingly discredited by carefully controlled studies of community placement, by evidence from total closures during the past 25 years, by the fact that 10 states are now entirely free of public institutions as a living option, and by the pattern of recent placements out of developmental centers in California.

5) **Community Support Systems are More Cost Effective than Institutional Systems:** All studies published thus far are consistent. Community service models are less costly than institutional models. It must be recognized, however, that this is because staff salaries and benefits are significantly lower in community service systems than in institutional ones. Hence, the most appropriate conclusion is that community services do cost less, but they should not. Moreover, community services are able to obtain Federal reimbursement at the same rate as developmental centers in California.

6) The Research Findings Are Remarkably Consistent: The research on the question of institutional versus community based care is very unusual. It is consistent and compelling. The only exception of which I am aware is the mortality studies performed by Strauss, which has been fundamentally discredited by Lakin, and has also been repudiated by his own University colleagues and by his mentor.

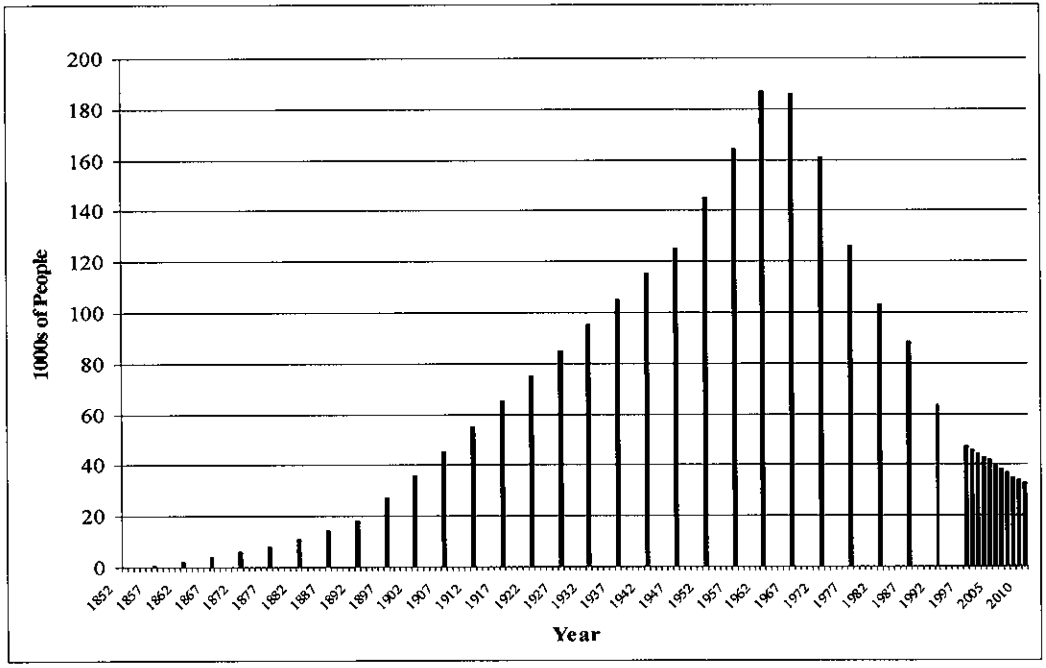
7) Community Living is Not Without Problems and Requires Protections: The clear and compelling scientific evidence on the benefits of community living should not be construed to mean that every single individual will be better off in every way, and at all times, in a community setting. Problems must be expected, and to the extent possible, they must be anticipated and prevented through carefully considered protective orders, monitoring, and quality assurance feedback systems, just as in the Pennhurst decision and other subsequent orders and settlements.

1) Research Shows Multiple Major Benefits of Community Placement.

In the past 20 years, a body of literature has developed on deinstitutionalization of people with developmental disabilities. It shows what happens to the quality of life of people with developmental disabilities when they move from large congregate care settings to community living. (Craig & McCarver, 1984; Haney, 1988; Larson & Lakin, 1989 and 1991.) This body of literature is remarkably consistent. Without contradiction, it demonstrates that people are "better off" in most ways when they leave large congregate care settings for community living in small, family-scale homes. Correspondingly, the satisfaction and perceptions of quality among parents and other family members rise.

Deinstitutionalization is far from new, and very far from untested. The graph below shows what has been happening to institutional populations in the United States since 1850.

150 Years of Institutional Care in America
1000s of People in State Operated Public Institutions



As the graph shows, the past 30 years have seen the population of America's public institutions for people with mental retardation reduced from about 190,000 to fewer than 45,000. The process is continuing, although it has slowed greatly since a new administration took office in 2001. Nearly every state mental retardation authority has concluded that no human being, regardless of degree of disability, "needs" to be isolated, segregated, or grouped with hundreds of "similar" people.

Since nearly 150,000 people have already experienced the move from institution to community, there has been ample opportunity to study the phenomenon. Many research groups have been involved in this work. Some of my own work will be summarized below, in order to provide the Court with the detailed reasons for my opinion in the current case.

The measurable benefits from moving to the community can be summarized. The central question of studies of the outcomes of community placement has been: "Are people better off, worse off, or about the same?" The phrase "better off" inherently implies the notion of "quality of life." However, nearly all people have their own complex of factors that they believe contribute to "quality of life." Usually their beliefs are not explicit, but rather, they form an internal set of values and judgments that are not always clearly defined. In this situation, the best available scientific approach is to address as many aspects of "quality of life" as are reliably measurable. Some of the dimensions of "quality of life," or outcomes, that social scientists know how to measure reasonably well include:

- independence
- productivity
- integration
- access to the places and rhythms of mainstream American life
- access to services when needed
- health
- health care utilization
- health care satisfaction
- mental health
- mental health care utilization or mental health care satisfaction
- friendships
- physical comfort
- privacy
- individualized treatment
- freedom from excessive restraints (physical, chemical, and authoritarian)
- respect for dignity and human rights by staff and others
- support for Choice making and learning to make choices
- personal satisfaction with multiple aspects of life
- satisfaction of the family members and "circles of friends" who care about the person
- the overall "locus of control" of the pattern of life; power, control, choice, self determination.

When multiple aspects of quality of life, or outcomes, are measured in a social program, the results are likely to be "mixed." A given social intervention may improve peoples' lives in some areas, while diminishing them in others, and leaving still other areas unchanged. This is a typical result, for example, in the field of substance abuse treatment programs.

However, the research literature on community versus institutional living has <u>not</u> been "mixed." Through the assessment of all of these quality of life dimensions, my research in 18 states, and the research of other scientists in America, has consistently shown numerous benefits consistently associated with community placement. Furthermore, the results have been extremely powerful, in that improvements have been documented in nearly every measurable outcome dimension. Research in other nations (Australia, Canada, Denmark, England, France, Ireland, the Netherlands, New Zealand, Norway, Sweden) has revealed remarkably consistent findings associated with institutional closure (Mansell & Ericsson, 1996).

In the following pages, I will briefly summarize the results of some of the largest and longest lasting studies of deinstitutionalization outcomes yet conducted: the Pennhurst Longitudinal Study (Pennsylvania), and the Mansfield Longitudinal Study (Connecticut). These two studies are of special interest because both culminated in total closure of the institution, with nearly all residents moving to community settings. At the end of this section, I will summarize other large-scale studies of community placement processes in California, New Hampshire, New Jersey, North Carolina, Oklahoma, Kansas, and Indiana.

I: Pennsylvania: Pennhurst Longitudinal Study Results:

In the Pennhurst Longitudinal Study, I was asked by the United States Department of Health and Human Services to study the effects of the district court's orders in Halderman v. Pennhurst, 446 F.Supp. 1295 (E.D. Pa. 1978). This Order resulted in the transfer of all of the people living in a large state institution in Pennsylvania to small, supervised community living arrangements (CLAs) in the communities from which they originally came. Since 1978, my colleagues and I have individually monitored the well being of each of the plaintiff class members -- more than 1,700 people -- every year. Following is a summary of the results of the study through 1992 (the last year in which I directly supervised the project).

A. The People:

1154 people lived at Pennhurst on the date of Judge Raymond J. Broderick's historic Order of March 17, 1978. My team immediately visited every one of those people, and collected information about characteristics, abilities, behavior, health, and service needs. These people (and other Pennhurst class members) are still being tracked. Every person is visited every year, and every family is sent a survey. We know more about their quality of life over the past decade and a half than any other group of people with disabilities in history. Their characteristics at the beginning, in 1978, were as follows:

Characteristic	**Average**
Average age	39
Average years at Pennhurst	24
Percent male	64%
Percent nonverbal	50%
Percent with seizures	33%
Percent not fully continent	47%
Percent with aggressive behaviors	40%
Percent labeled severe or profound	85%

B. The Community Model:

Three person Community Living Arrangements (CLAs) were the predominant program models in Pennsylvania at that time. These were either detached houses or apartments, and almost all were of existing housing stock. A day program was arranged before placement for every person. The staffing varied as seen below:

- Some shift staffing and some live-in;
- (later became almost entirely shift);
- 90% non-profit provider entities.
-

C. Additional Court Protections:

- Special low-caseload Case Managers (1 to 30);
- Consistent format to IHPs, with multiple reviews;
- Requirements for independent monitoring (including the Pennhurst Study itself).

D. Development Toward Increased Independence (See Adaptive Behavior Development graph) The graph below depicts the average increase in adaptive behavior over the course of the eight study years, that is, once people moved from institution to community. In fact, a direct quote from one Pennhurst Study report stated, "The adaptive behavior growth displayed by people who moved to CLAs under this court order [was] literally 10 times greater than the growth displayed by matched people who are still at Pennhurst.

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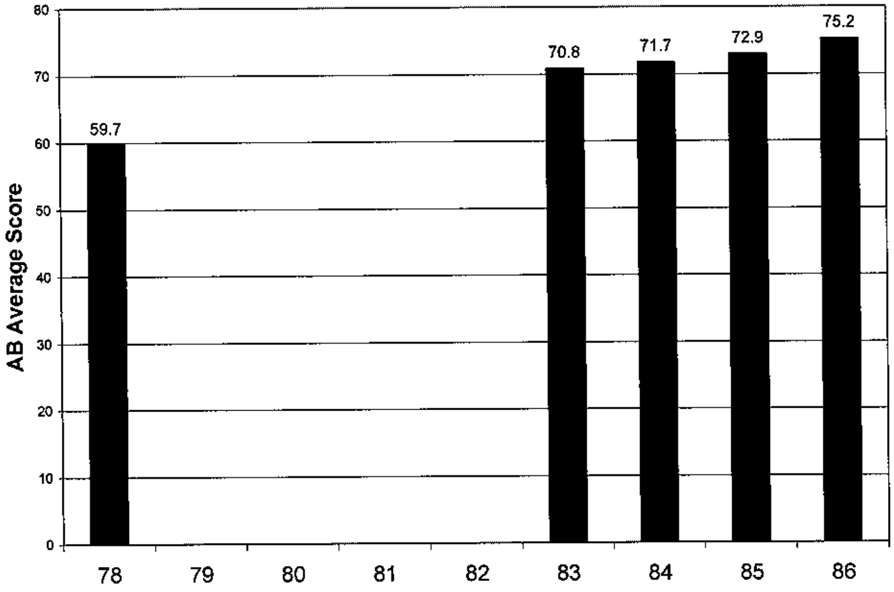
Pennhurst Longitudinal Study:
Adaptive Behavior Development 1978-1986

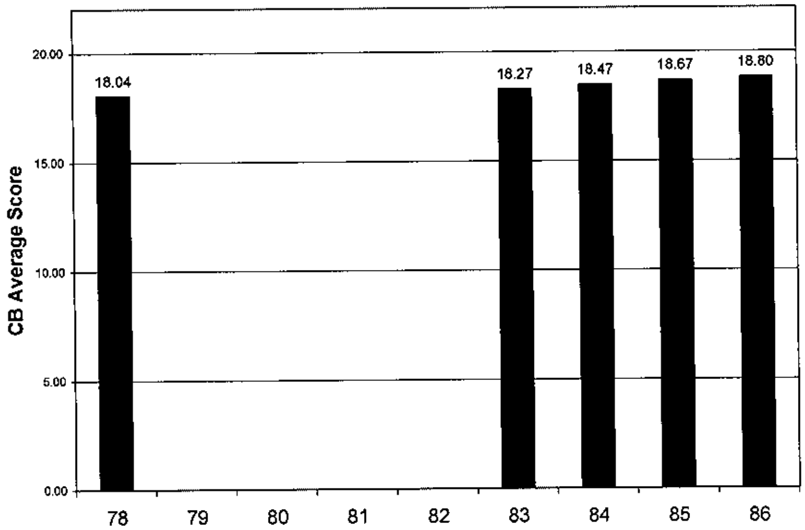


- In addition to the encouraging findings with respect to adaptive behavior, later study revealed positive gains in self-care skills that continued to improve the longer the people lived in the community:Upon placement, average gain 9%;
- 3 years after placement gain of 12%;
- Most recent measurement,(1992) gain of 14%.

E. Challenging Behavior: The improvements are shown on the graph headed "Improvements in Challenging Behavior." Moreover, the following findings accrued in later years:

- Average improvement in challenging behavior area upon placement 1%;
- 3 years after placement 3%;
- Most recent measurement, 1992, 6%.

Pennhurst Longitudinal Study:
Improvements in Challenging Behavior



F. Qualities of Environments

Scales utilized included Normalization, Individualization, the 1979 version of the standards of the Accreditation Council for Mental Retardation and Developmental Disabilities, and Physical Quality. Results from all scales improved sharply and significantly upon community placement.

G. Consumer Satisfaction

One aspect of the Pennhurst Study included repeated interviews with 56 people who were able to communicate. About a third of those people reliably said they were happy at Pennhurst, and wanted to stay there. After the moves, about two thirds reliably said they were happy in their new community homes, and wanted to stay in them. The number of people reporting satisfaction with aspects of life in the community was approximately double what was found in the institution. There were no areas of decreased satisfaction over the entire course of the study.

H. Amount of Service

People who moved to the community began to receive more hours of developmentally oriented service per month than similar people who stayed at Pennhurst (225 hours per month versus 189 hours per month). Hence we concluded that, on an overall index of amount of service, the movers were better off.

I. Health and Health Care

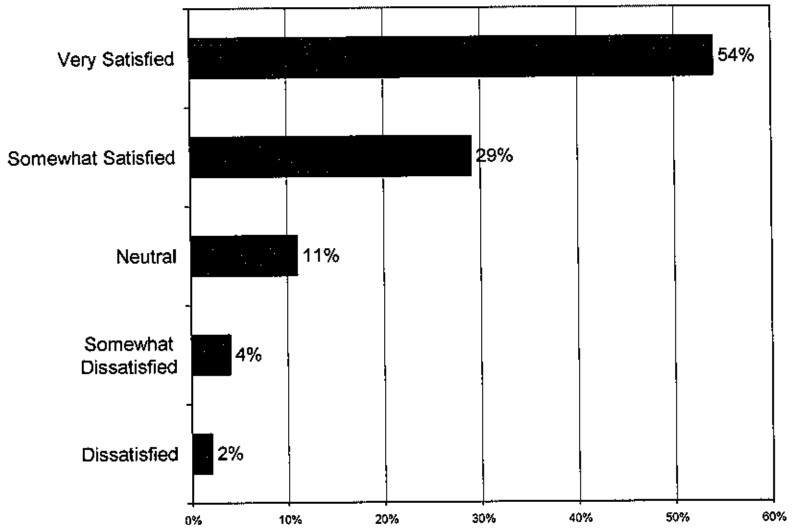
Indicators of health remained stable across the entire length of the study. Use of medications decreased slightly after community placement.

J. Day Activities

The proportion of people taking part in an active day program increased from about a third at the beginning of the study while living at Pennhurst to practically 100% at the end after having moved to the community.

K. Family Satisfaction: Initially, in 1979, the families of the people at Pennhurst were very satisfied with the institution.

Pennhurst Longitudinal Study:
Initial Family Satisfaction with the Pennhurst Institution



These same families were also quite strongly opposed to community placement. At the beginning, 83% of families reported satisfaction with Pennhurst, and 72% opposed movement to the community.

Pennhurst Longitudinal Study:
Initial Family Attitudes About Community Placement (1979

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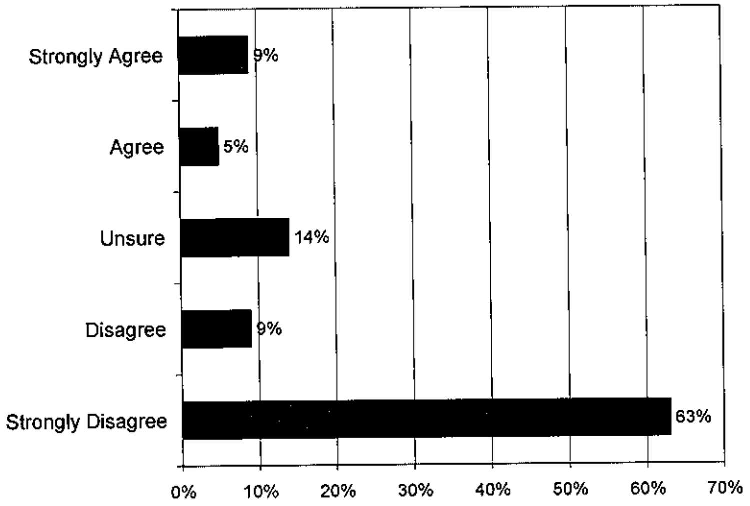
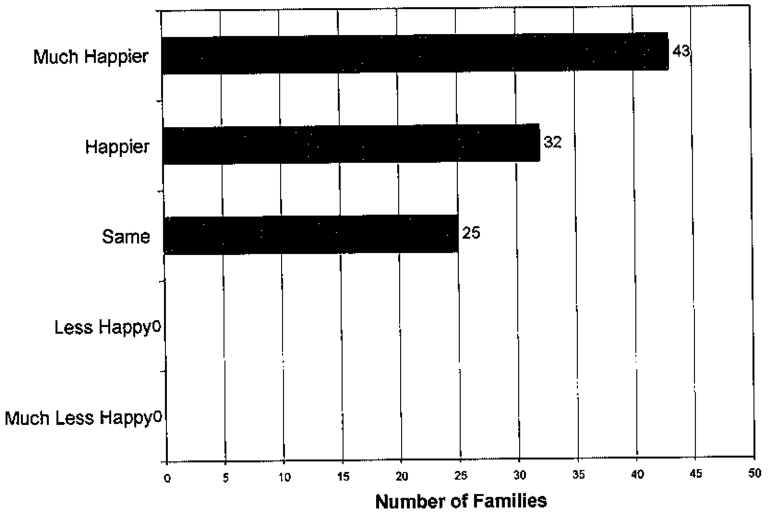
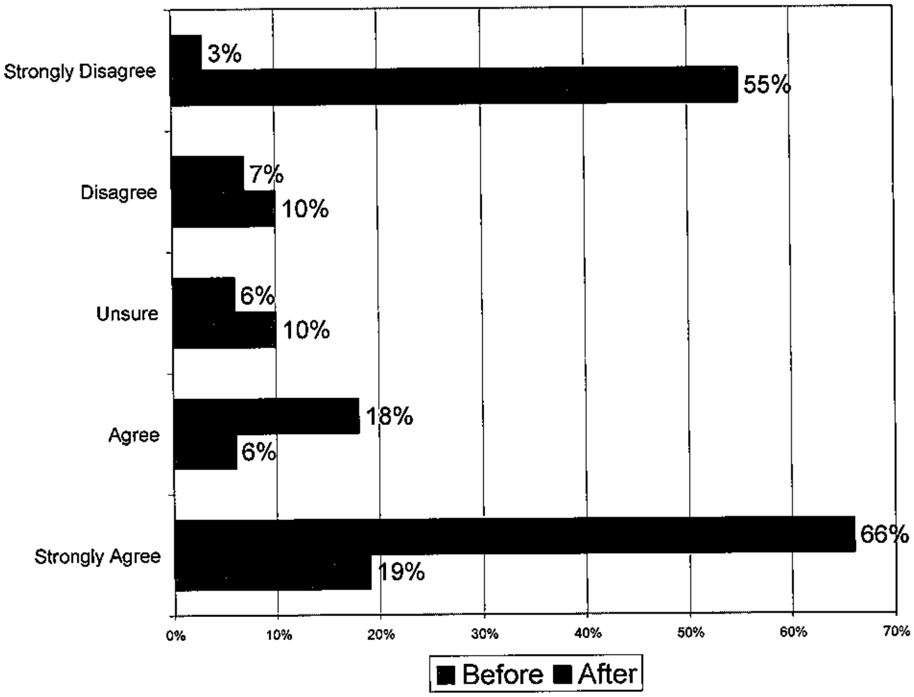


When surveyed later, however, these families had radically changed their views. When asked whether they thought their relatives were happier or less happy since moving, not a single family rated their family member as being "less happy" or "much less happy". As shown in the 1991 survey results below, 75% of families thought their family member was happier. Not a single family believed their relative was less happy in the community. Other related analyses showed that the strong prevailing attitude had shifted to support for community living.

Pennhurst Longitudinal Study:
"Has Your Relative's General Happiness Changed Since Moving to the Community?"



Pennhurst Longitudinal Study:
Agreement With the Idea of Community Living, "Before and After"



The graph shows a dramatic change in attitudes about relatives living in the community. This analysis was performed with 134 families who completed our surveys both in 1979 and again in 1984.

Some of the most compelling findings in the study were the verbatim comments of the families after deinstitutionalization. These comments frequently included expressions of surprise that they (the parents) had ever opposed community placement in the first place, coupled with surprise at the magnitude of improvements in the qualities of their loved ones' lives.

In a 1991 community survey of these same families, the results from 420 responding families concerning their overall satisfaction with community living were:

Very Satisfied	Somewhat Satisfied	Neutral	Somewhat Dissatisfied	Very Dissatisfied
65% (272)	25% (104)	4% (18)	5% (20)	1% (6)

L. Neighbor Acceptance

About three fourths of neighbors never find out there is a group home in their neighborhood. Of those who do know, only about half had any negative reactions, and those tended to vanish by a year to a year and a half.

M. Costs

The total public cost of serving the people who moved to Community Living Arrangements (CLAs) was significantly less than for the matched people still at Pennhurst (about $110 per day versus $129 per day at Pennhurst). However, the fiscal burden shifted sharply from Federal to state sources for the people who went to CLAs. Because Federal funds were being used for Pennhurst but not for CLAs, the state contributed about $57 per day for people at Pennhurst, and about $98 per day for people in CLAs.

Today, community programs are just as able to obtain Federal Medicaid funds as are institutions, primarily through the Waiver program. California is a major participant in these Waiver programs. Hence, the old disincentive for states to support community services is gone.

N. Synopsis of the Pennhurst Longitudinal Study

The 5 years of the Pennhurst Study led to the conclusion that, on the average, the people deinstitutionalized under the Pennhurst court order were better off in practically every way measured. For the people who moved from Pennhurst to small community residences, results were conclusive.

Since the end of the Federal study, my group continued to monitor the well-being of the Pennhurst class members with state, local, and University support. The positive outcomes have not only been maintained, they have continued to increase. For example, the class members have become continually more and more independent since moving to community homes. Year after year, their challenging behaviors have decreased.

The Pennhurst research led me to try to replicate the study in other states, with and without Court involvement. Replication is at the heart of science. I have been fortunate in this regard. The Pennhurst research has been replicated, extended, and refined, in many other states. Some of these will be described below, particularly the Mansfield Longitudinal Study in Connecticut, the Applied Research Project in New Hampshire, the Quality Assurance Project in Oklahoma, the Winfield Closure Study in Kansas, the Quality Tracking Project on Institutional Closures in Indiana, and the Quality Tracking Project related to the Coffelt settlement in California.

II. Connecticut: Mansfield Longitudinal Study:

In Connecticut, my associates and I followed 1,350 class members in CARC v. Thorne, No. H-78-653(TEC) (D. Conn.) to measure their well-being. A tracking project of this kind was required by the consent decree entered in that case in 1985. At the beginning of the study, most class members were in congregate care settings: state institutions, state regional centers, and private nursing homes. Between 1985 and April, 1990, approximately 600 persons received community placements under the consent decree.

The CARC class was typical of the population of public institutions in America. The average age was 46; 53% were male; their average adaptive behavior score before placement was 45 on a scale of 1 to 100; and their average score in challenging behavior was 79 on a scale of 1 to 100. About 7% of the class had a hearing loss, 15% had no vision, 21% had seizures, and 20% had serious medical needs. Approximately 69% of the persons who received community placements under the Court order were labeled severely or profoundly retarded, compared to 75% of the CARC class as a whole. This showed that community placement included people with the most intense needs, rather than being restricted to people gifted with higher ability levels.

We completed three major research designs in Connecticut. The three studies were (1) changes in well-being from pre-move to post-move; (2) comparison of changes in well being among people who moved versus extremely similar (matched) people who did not move; and (3) surveys of parents, other next of kin, next friends, and guardians.

The overall results of five years of study of the people deinstitutionalized in Connecticut are summarized in the table on the following page.

INDIVIDUAL OUTCOMES
ASSOCIATED WITH DEINSTITUTIONALIZATION
Connecticut's Mansfield Class Members, 1985-1991

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

This table shows, from three separate studies over a 5-year period, that the people who moved from institution to community were significantly better off in most of the dimensions that we knew how to measure.

On the average, class members in CARC v. Thorne who received community living arrangements under the Court's order made significant gains in adaptive behavior after placement in the community. Moreover, people labeled profoundly retarded made the greatest proportional gains: more than 28 percent (Stull, Conroy, & Lemanowicz, 1991). The longitudinal research design also showed that people who moved to community settings decreased their challenging behaviors during the years of the study.

In the area of social integration, movers began with 3.1 events per week of being in the presence of nonhandicapped peers when living at the institutions. They increased to 23.0 events per week in the community. We also found an inverse relationship between the size of a community living setting and the degree of social integration experienced by its residents.

Residents of smaller homes experienced more opportunities to be in the presence of nonhandicapped persons (Conroy, 1992).

In 1988-89, only 29 members of the CARC class had experienced even a short-term placement in a psychiatric facility, regional center or institution. This suggested that there was little or no need to maintain the institutional setting; it was often suggested that the institution should be maintained as the "backup" for people whom the community had difficulty handling.

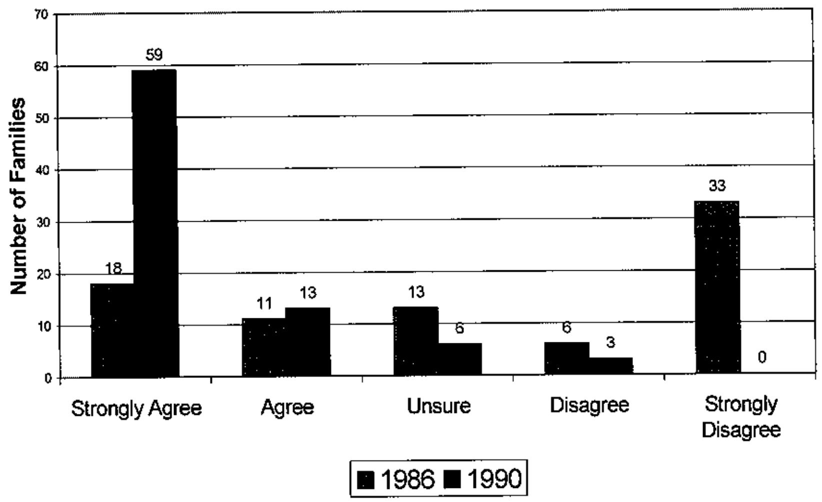
Members of the CARC class who received community placement received medical care of an appropriate frequency. The average class member had seen a physician within the preceding 5 months, and a dentist within 4 months. These frequencies compared favorably with figures for the general public.

During the course of our studies in Connecticut, we saw the cost of care at the Mansfield institution rise to $290 per person per day, more than double the cost of services in the community. Even at that funding level, the quality of life in the institution could not come close to matching what was available in the community for very similar people. We did find that quality had improved measurably in the institution, such as in the areas of social integration and increased earnings, but in no area were the gains as large as they were for people who moved from institution to community.

We also found that people who had resided in community settings during the entire course of the study had made significant gains in many areas of quality of life dimensions, including adaptive behavior, challenging behavior, social integration, productivity, earnings, satisfaction, and family satisfaction.

Just as in the Pennhurst Study, the families of the CARC class members opposed community placement at first, but later shifted to strong support. The graph below shows the extent of attitude change among all of the Mansfield parents whose adult children moved from institution to community, and who answered both of our mail surveys in 1986 and 1990.

Mansfield Longitudinal Study:
Changes in Family Attitudes Re: Community Placement



From all the results reported above, I concluded that many improvements occurred in the lives of people receiving services in Connecticut. By far the greatest improvements were seen among the people who moved from institution to community.

III. Brief Reviews of Other Relevant Community Placement Studies

A. New Hampshire

From 1981 onward, I have been involved in studying the process of deinstitutionalization in **New Hampshire** (Bradley, Conroy, Covert, & Feinstein, 1986; Conroy, Dickson, Wilczynski, Bohanan, & Burley, 1992). In January of 1991, the Laconia State School and Training Center closed. New Hampshire thus became the first state in which no citizen with a developmental disability lived in a state institution.

All of the people who remained at Laconia, a facility with a long and honorable history, are now living in community settings. Most of the last remaining group of people had serious behavioral or medical/health challenges. Up until the final year, many state officials appeared to believe that the institution would always be necessary for some people. In the end, New Hampshire elected to demonstrate the opposite. That is, even the most "medically fragile" people are now living and thriving in small, homelike settings. This achievement has an important place in the history of developmental disabilities. New Hampshire was the first state to show that communities can support all people, regardless of the severity of their disabilities.

I am continuing to perform studies and evaluations in New Hampshire to the present day. I see compelling evidence that even the most "difficult" people have been afforded the necessary supports in community settings. The overall evaluation of my 16 years of research in New Hampshire can only be that all people can, and do, live in the community, and that their lives are indisputably far better on the average. Case studies, "stories," and living examples are readily available. I would recommend contacting Mr. Donald Shumway, current director of the human services agency, for further information.

B. New Jersey

In **New Jersey**, the Johnstone Training and Research Center closed in 1992. I headed a 3 year project to track the former residents and the qualities of their lives. Two thirds of the Johnstone people went to other state developmental centers (institutions). One third went to community settings. The conclusions of the research were that both groups had experienced improvements in many dimensions of quality, but the movers to community settings were by far the most improved. Moreover, the care for the people who moved to other institutions wound up costing more than Johnstone, while the care for people who moved to community homes cost less than Johnstone. I wrote that "Future closure planning should, according to this and past research, employ deinstitutionalization rather than reinstitutionalization as its primary strategy" (Conroy & Seiders, 1994).

C. Oklahoma

Since 1990, I have been working on a statewide quality assurance system in **Oklahoma** that covers 3,700 people -- everyone receiving intensive services in the state. Among these 3,700 people are approximately 1,000 Class Members in the Homeward Bound v. Hissom Memorial Center litigation and consent agreement. In 1995, I found and reported that the outcomes for the 520 "Focus Class Members" (those who lived at Hissom on or after May 2,

1985) Jim, when did they move? were in many ways the strongest and most positive I had ever obtained (Conroy, 1996). These extraordinarily positive outcomes were associated with a "new" kind of community living arrangement. Nearly all of the Focus Class Members went from Hissom, not into "group homes," but rather into individually designed "supported living" situations. Practically no one had more than two roommates, and most had only one or none. This method of deinstitutionalization was unique in America. It also turned out to be the most successful. A summary table of the outcome results is shown below.

Hissom Outcomes Study Summary & Interpretation:
"Are Focus Class Members Better Off Now Than They Were Before?"

Quality Dimension	Answer
Adaptive Behavior	Yes
Choice-Making	Yes
Challenging Behavior	Yes
Productivity	Yes
Integration	Yes
Developmental Services	Yes
Family Contacts	Yes
Medications	Yes
Health Care	No Change
Satisfaction	Yes
Overall Conclusion	**Yes**

The table clearly shows that the people who left Hissom are better off in nearly every way measured, and worse of in no dimension.

More recently, we surveyed the families of these same people by mail (Conroy, 1999). Just as in the other studies, families told us that their feelings about community living had changed.

Oklahoma Outcomes Study of Hissom Class Members:

Family Feelings About Community Living, "At First" and "Now"

The graph shows that only a handful of these 301 families are now opposed to community living for their relatives (a total of 3, to be exact). We also asked these families to rate their relatives' qualities of life "Then" and "Now," with "Then" referring to the time when they lived at the Hissom institution. The results were the most dramatic we had yet seen in any of our studies, and they are depicted in the following graph.

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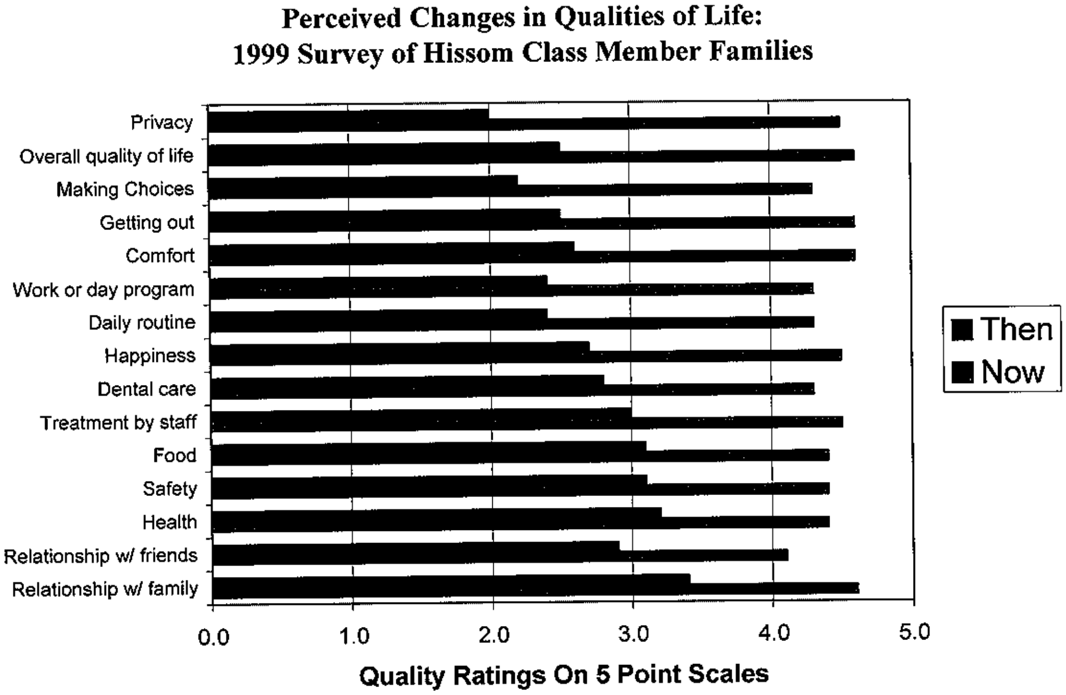

Each one of the differences between perceived quality "Then" and "Now" was statistically significant, and also very large in magnitude. This was powerful evidence of the eventual satisfaction experienced by families of people who moved from institutions to community homes.

D. North Carolina

I have also been tracking the well-being of more than 1,200 people with dual diagnoses in **North Carolina**. These members of the Thomas S. class are people who had mental retardation, and also had either a psychiatric diagnosis or a brush with the law that resulted in placement into a psychiatric facility. Hundreds of the Thomas S. class members have moved to new community homes. Despite widespread misgivings about their potential behavior problems, they are doing extremely well in their new community homes, with no evidence of criminal activity or "recidivism." In fact, they have made such progress that I am now working with the state to suggest that the Court's supervision might be relaxed. The Thomas S. class members are more integrated, more satisfied, better served, more independent, receiving less medication, and much more likely to be working and earning money. This project has strongly suggested that serious behavior "problems," even criminal histories, need not prevent people from flourishing in well supervised community homes. The placement process was so successful that the judge recently dismissed his own Order, concluding that all the original goals of the Thomas S. action had been achieved.

E. Kansas

My company was selected to track the process of closing the Winfield State Hospital in **Kansas.** For the 200 people who moved from institution to community in that effort, we measured qualities of life before and after the move. The following table summarizes the results of our 2 years of study.

Summary of Kansas Outcomes at Year One

Quality Dimension	Results	Outcome
Adaptive Behavior Scale	Significant 1.7 point gain (5% up)	**Very Positive**
Orientation Toward Productive Activities Scale	Large gain 1.7 to 11.5 points	**Very Positive**
Challenging Behavior	Modest 2.7 point gain (3% improvement)	**Positive**
# of Services in Individual Plan	Up from 5.2 to 8.2	**Positive**
Hours of Day Program Services	Up from 4 to 18 hours per week	**Very Positive**
Hours of Developmental "Programming" in Home	Down from 10 hours to 6 hours per week	**Negative(?)**
Integration	Large increase from 3 to 31 outings per month	**Very Positive**
Choice making	Up 50% from 27 to 40	**Very Positive**
Qualities of Life Ratings	Up from 68 to 78 (Now to Now)	**Very Positive**
Qualities of Life Perceptions of Changes	Up in every area but one – dental (Then & Now)	**Very Positive**
Staff Job Satisfaction	Up by 1.2 points out of 10	**Very Positive**
Staff Like Working With This Person	Up by 1.4 points out of 10	**Very Positive**
Staff Get Sufficient Support	Up 1 point (3.7 to 4.7, still low)	**Positive**
Staff Pay Rate	Down $4000	**Mixed**
Health Rating	Up from 3.5 to 3.8 out of 4	**Positive**
Health by Days Ill Past 28	Down from 3.2 to 0.8 days/28	**Very Positive**
Medications, General	Down from 5.7 to 4.9	**Positive**
Medications, Psychotropic	Down from 18 people to 6	**Very Positive**
Doctor Visits Per Year	Down from 22 to 6	**Unclear**
Dental Visits Per Year	Down from 2.3 to 0.5	**Negative**
Family Contacts	Up from 7 to 18 contacts per year	**Very Positive**
Individualized Practices Scale	Up from 47 to 72 points	**Very Positive**
Physical Quality Scale	Up from 76 to 86 points	**Positive**
Normalization	Large increase	**Very Positive**
Subjective Impressions of Visitors	Up on 4 out of 5 dimensions	**Positive**
Total Public Costs	Down about 15% From $109,000 to $91,000	**Positive**

This table revealed a clear pattern of positive outcomes, tempered by two that were interpreted as negative: a decrease in the number of hours per week of formal day program activity, and a drop in the frequency of visits to a dentist. Although many of these people moved into large 8 person group homes, their outcomes were still positive. These outcomes were not as dramatic as those seen in Oklahoma, but nevertheless, we were able to conclude with confidence that these people were "better off" in their new community homes than they had been at the Winfield institution. Moreover, there was no perceived decrement in the quality of health care.

F. Indiana

For the past year, we have been tracking the outcomes of closing two state institutions in **Indiana**, which affected approximately 300 people. Even at 6 months post-movement, when many elements of the community service system were still in flux, the people were found to be "better off" in most ways.

Statistical Summary of Indiana Outcomes at Six Months

Quality Dimension	Pre	Post	Change	Outcome
Adaptive Behavior	48.4	50.2	1.8	Positive
Orientation Toward Productive Activities Scale	30.9	28.8	-2.1	Neither
Challenging Behavior	70.2	67.6	-2.6	Negative
Elements of the Planning Process	51.3	73.6	22.3	Positive
Progress Reported Toward IP Goals	59.7	70.2	10.5	Positive
Hours of Developmental "Programming"	43.5	68.3	24.8	Positive
Number of Services in Individual Plan	4.8	4.6	-0.2	Neither
Hours of Day Program Services	13.8	15.7	1.9	Neither
Earnings	8.6	3.4	-5.2	Negative
Number of Friends Reported	4.2	6.0	1.8	Positive
Choice making	31.4	47.4	16.0	Positive
Integration	9.4	29.6	20.2	Positive
Qualities of Life Ratings (Now-Now)	65.8	78.2	12.4	Positive
Staff Job Satisfaction	7.8	9.0	1.2	Positive
Staff Like Working With This Person	8.2	9.1	0.9	Positive
Staff Get Sufficient Support	3.2	4.2	1.0	Positive
Number of Daily Medications	4.5	5.0	0.5	Negative
Number of Psychotropic Medications	0.5	0.4	-0.1	Positive
Health Rating	3.7	4.1	0.4	Positive
Health by Days Ill Past 28	1.0	0.5	-0.5	Neither
Doctor Visits Per Year	21.4	7.4	-14.0	Unclear
Dental Visits Per Year	1.9	1.2	-0.7	Unclear
Relative Visits Person Here At This Home	7.1	18.0	10.9	Positive
Individualized Practices Scale	57.7	78.9	21.2	Positive
Physical Quality Scale	57.9	75.6	17.7	Positive
Normalization	37.7	75.9	38.2	Positive

The table shows three negative findings. Two of them (challenging behavior and earnings) were interpreted as temporary, and are expected to move in a positive direction as the system becomes more mature. All of the other changes experienced by the 191 people represented in the table were positive. These Movers are indeed "better off," even at 6 months post-placement, and the most reasonable hypothesis is that the qualities of their lives will show further improvement in the years to come.

IV. California: The Quality Tracking Project

I am currently heading a project that is tracking the quality of life outcomes experienced by more than 2,300 people in **California** who have been affected by the Coffelt settlement. Thus far, the project has resulted in 20 reports, 17 of them intended for public distribution. These reports present data on the well-being of people who have moved out of California's institutions since the settlement (e.g., Conroy & Seiders, 1995a and 1995b; Conroy & Seiders 1996; Conroy & Seiders, 1998; Conroy 1996). These analyses employed multiple research designs, including pre-post, matched comparison, nonequivalent comparison groups with analysis of covariance, and family surveys.

A complete summary of the 17 public reports is provided following this section. The summaries are intended to reflect the breadth of measures, research designs, and methodologies employed. The summaries show a compelling tendency to reach the same conclusions from all the designs and methodologies: although deinstitutionalization in California has had its problems, they have been far outweighed by the benefits to the people in terms of the qualities of their lives, their satisfaction, their families' satisfaction. In other words, regardless of the design and methods utilized, the results show similar patterns: these people are "better off" in the community than they were in Developmental Centers.

All of this work was based on face to face visits with the people and their caregivers, during which we collected our battery of reliable measures of qualities of life and qualities of care. Each year, we visited a sample of the "Movers" (the people who moved from developmental centers to community homes). We also annually surveyed every known close relative or guardian.

The table below shows that, in the work performed up until December of 1998, we had conducted 4,051 visits with Movers. The table shows the pattern of our individual visits over the years. The abbreviation CTG refers to the "Community Target Group," those who were originally living with relatives, but encountered difficulty and/or a need for additional supports. The "Movers" are the people who moved from Developmental Centers to community homes. The "Stayers" are people who continued to live in Developmental Centers.

Year	**Movers**	**CTG Members**	**Stayers**	**Totals**
1994-95	286	21	855	1,162
1995-96	451	38	395	884
1996-97	723	67		790
1997-98	1,125	90		1,215
Totals	2,585	216	1,250	4,051

Our average visit to each person took 77 minutes at the person's home. This work offers a very large database for determining whether movement from institutions to community homes was "good" or "bad" for these people. It is important to state clearly, however, that our work has sought the answer to our question **"Are people better off?"** in an aggregate manner. That is, we were attempting to find out if the average experience was positive.

Our findings have been clear, definitive, and compelling. But that does not mean that every person's experience was positive. In fact, we know of many that were not. Part of our role in California was to immediately report back to the Department of Developmental Services when we found a person who was not doing well, or not receiving the services to which he or she was entitled.. (This aspect of the Project was called the Quality Feedback Summary, or "rapid feedback" system.) This work continues today.

The following Table of Outcomes is from our Final Report of the first 5 years of our monitoring.

Outcome Summary Table
Results of the Coffelt Quality Tracking Project
1,125 "Movers," 1993 to 1998

DIMENSION	OUTCOME
CAPABILITIES (Adaptive Behavior)	Significantly increased self-care abilities. Movers are now doing more for themselves, requiring less assistance.
SOCIAL BEHAVIOR	Sharply increased socially appropriate behavior (decreased challenging behavior), more than in other studies.
SELF-DETERMINATION	Increased choice making, but the increase was small. Much more can be done in this area.
SERVICES	Increased number of services in written plan, sharply higher goal attainment reports from staff.
PRODUCTIVITY	Increased day program hours, but decreased earnings and number of people employed. Much more needs to be done in the area of employment and productive activities.
INTEGRATION	Average number of outings to integrated settings per week doubled for Movers.
STAFF ATTITUDES	Job satisfaction, plus "How much do you like working with this person," were both higher in community homes.
CONSUMER SATISFACTION	Consumers (and surrogates) reported significant increases in **all** 14 dimensions of quality of life. Of the 261 people who answered the question "Would you rather go back to live at a DC?" only 17 said "Yes, Definitely."
FAMILY SATISFACTION	The closest relatives of the Movers (surveyed annually by mail) perceived significant increases in **all** 14 dimensions of relative's quality of life.
HEALTH & HEALTH CARE	Health care was reported to be more difficult to obtain in community than DC, but just as high in quality. Slight tendency toward increased use of psychotropic meds.
QUALITIES OF ENVIRONMENTS	All research designs showed enhanced Physical Quality, Individualized Treatment, and Normalization.
PUBLIC COSTS OF SERVICE & SUPPORT	Decreased by 45% (suggesting serious underfunding of community services in California).

A brief verbal summary in paragraph format is provided below.

1. Positive Outcomes: California's Coffelt class members are better off because of the settlement of the lawsuit. More than 2,300 people have moved from institution to

community living, and their lives have on the average been enriched measurably and significantly in terms of self-care abilities, appropriate social behavior, opportunities for choice making by the person and unpaid allies, integration, services delivered through the individual planning process, hours of day program per week, attainment of individual goals, individualized treatment, physical quality of their home environments, consumer satisfaction, and family satisfaction.

2. Negative Outcomes: Fewer class members have paid jobs in the community than they did while living in Developmental Centers, and they are on the average earning less money from paid work than they did while living in Developmental Centers. Moreover, the prevalence of sedative and psychotropic medication utilization has increased slightly since moving to the community. These are the only negative outcomes detected during the four years of this study.
3. Balance: The balance of positive and negative outcomes is weighted heavily toward the positive.
4. Cost: The total public cost of supporting people in California's community service system is much lower than the Developmental Center cost. In 1996, community costs averaged about $55,000 per person per year, while Developmental Center costs averaged about $100,000. Both costs are higher now, but the difference persists. These costs were computed for similar people, and the difference definitely cannot be explained by differences in the people served in institution and community.
5. Conclusion: The ultimate conclusion is inescapable: The Coffelt settlement brought about enormous social benefits to people with mental retardation. This did not require extra money; it was done at much lower cost than the Developmental Centers would have spent.
6. Policy: The movement of people out of institutions and into small integrated community homes should continue.

The overall conclusion of the years of the Quality Tracking Project is that class members' lives have been significantly enriched in nearly all of the measured dimensions of quality. Improvements have been documented in independence, productivity, integration, self-control of challenging behavior, satisfaction, self-determination, achievement of individual goals, physical quality of the homes, individualized treatment within the homes, and family perceptions of quality of life. Very few class members, and just as few families, would like to "go back" to Developmental Centers. All of this has been accomplished with far fewer public dollars than were required in Developmental Centers. The data from this project imply that the proper targets for future quality enhancement activity are medication use, expansion of support models in directions other than the ICF/MR funding stream, employment, and Choice making/self-determination.

Obviously, the evidence from more than 4,000 personal visits and the objective scientific assessments leads to the conclusion that the Coffelt Movers' lives have been significantly enriched. There can be little debate about this conclusion, because there is simply no credible scientific evidence to the contrary.

There will, of course, be "horror stories" in community service systems of the kind reported by the San Francisco Chronicle in 19____. But for every "horror story," the scientific evidence demonstrates repeatedly that there are many more "success stories,." not only in CA, but in IN, NH, OK, PA, and CT, among others.

I believe that it is a dangerous error to permit unscientific sensationalism to guide public policy. The simple fact of the matter is that the California deinstitutionalization has been a great success for the great majority of the people involved, as it has been for those involved in Oklahoma and elsewhere.

Summary of the 17 Reports from the California Quality Tracking Project

This is a summary of the 17 formal reports we produced from 1994 to 1998 as part of the Coffelt Quality Tracking Project. Three of these are in the process of publication in academic journals, and two have been accepted. ???? What's the difference??? Five of these reports have been reformatted and are being published in academic journals.

Report Number 1 was a status report on field data collection activities, and contained no data or other information on quality of life among the Coffelt class members.

Report Number 2, **Quality of Life Among Institutionalized and Deinstitutionalized People in California: Preliminary Findings, 1994,** was submitted in February, 1995. It detailed a matched comparison design of 57 Movers and 57 Stayers. Findings showed that the Movers expressed higher levels of satisfaction, perceived that their lives had improved, andexperienced more integration, active goals, progress, and services. Both groups had high quality of health care and similar utilization of medications.

Report Number 3, **Quality of Life Between Institutionalized and Deinstitutionalized People in California: Intermediate Findings, 1994-1995,** was submitted in April, 1995. It extended the matched comparison design to larger groups, 118 Movers and 118 Stayers. The findings were entirely consistent with those of Report Number 2. The Movers were far more integrated, were much more satisfied with their homes, believed their lives had sharply improved, received larger quantities and varieties of services, and lived in places that were measurably more normalized and physically pleasant. However, their opportunities to make choices were no greater than for Stayers, and the Movers were more likely to be taking neuroleptic medications. The total public cost of supporting the Movers was about $54,000 per person per year, while the cost for a Stayer was about $92,000. Together, Reports 2 and 3 provided extremely strong evidence of the cost-effectiveness of community living in California. *Report Number 3 was reformatted for submission to a peer-reviewed journal, and was accepted for publication in 0Oct. 1998.*

Report Number 4 was a collection of graphs, called a Chartbook, intended for internal DDS discussion purposes only. It was not a formal report, but was created at the request of the project officer to stimulate internal consideration of the difference among the Developmental Centers.

Report Number 5, **Coffelt Community Target Group Class Members: Results of the 1994-95 Round of Visits and Interviews**, was submitted in September, 1995. It was a qualitative, formative analysis of 21 of the 26 Community Target Group (CTG) members. These individuals were living with relatives but needed out of home placements and supports. The study was intended to guide future interventions and actions. According to the analyses, the CTG members had very positive experiences as a result of their movement into community residences. Further, their families believed that they and their relatives were better off because of the interventions they experienced.

Report Number 6, **Patterns of Community Placement: The First 15 Months of the Coffelt Settlement** was submitted in October, 1995. It described people who moved from Developmental Centers to community living during the first 15 months (4/93-6/94) of implementation of the Coffelt Settlement Agreement. Representative samples of Movers and Stayers were drawn and visited. Comparisons of qualities of life were performed for 246 Movers and 828 Stayers, and a post-only family survey was used to elicit input from family members of the Movers. The outcome indicators revealed that people who moved were clearly better off in their new community homes. Additionally, families of the Movers perceived significant improvements. Their approval of community living more than doubled.

Report Number 7, **Reliability of the Personal Life Quality Protocol**, was submitted in December, 1995. It supported the inference that the Coffelt project data are generally being collected accurately, objectively, and reliably. **Report 7 was reformatted and split into two separate manuscripts for submission to peer-reviewed journals.Both are now in the review process.**

Report Number 8, **Patterns of Community Placement II: The First 27 Months of the Coffelt Settlement,** was submitted in February, 1996. It contained analyses of: quality of life for nonequivalent comparison groups of Movers and Stayers; a longitudinal pre-post analysis of changes in quality of life for 34 people who moved into community settings; descriptive data of mental health and crisis intervention supports; reasons for 13 returns to Developmental Centers; features and quality of supported living; mortality; and costs. Findings indicated that the 438 Movers were better off in many ways, such as being in settings of higher physical quality, being more integrated, and being more satisfied with their living arrangements and staff. Seventy seven percent of those who could respond noted that they felt good or very good about living in their current community residence. Statistically significant improvements were reported in qualities of life such as comfort, happiness, food, health, and safety. However, results were not as positive with respect to Choice making, health care, and medications.

The pre-post test results indicated that the 34 people who moved into community living experienced an improved quality of life in the areas of health, running their own lives, family relationships, seeing friends, getting out, happiness, comfort, and safety. In addition, significant improvements were noted in adaptive behavior, challenging behavior, quantity of services received, progress on individual goals, and level of integration. On the other hand, self-determination and individualized treatment did not increase, and Movers received antipsychotic drugs at a higher rate than that of the Stayers.

Twenty eight people who moved into supported living situations reflected increases in self-determination and quality, above that of other community settings. Moreover, preliminary data indicated that movement to community did not increase mortality among class members when compared to the statistical expectation for large congregate care settings. Finally, cost data showed that community care in California costs about half as much as institutional care. In several other deinstitutionalization studies, community costs were about 75% those of institutional costs, suggesting that California's community reimbursement rates are relatively low.

Report Number 9, **Impacts of the Coffelt Settlement on Community Target Group Members in 1995-96**, was submitted in May, 1996. It provided a quantitative description of the members of the Community Target Group (CTG), and a qualitative sense of what happened to the CTG group during the second full year of implementation of the Coffelt Agreement. In general, the group believed their qualities of life had improved in 10 out of 10 areas in that one year period. In fact, the CTG group experienced more self-determination than the Movers did. They were more likely to have choices in their new homes and to have choices about daily activities. CTG members were better off because of their involvement with the Coffelt Agreement, and much better off than they would have been if admitted to Developmental Centers.

Report Number 10, **Qualities of Life Among Coffelt Class Members who Moved from Developmental Centers to Community Homes, 1993-1995**, was submitted in September, 1996. This Report compared qualities of life of 455 Movers and 395 Stayers using analysis of covariance. Consistent with other reports (Reports 2, 3, & 8), the qualities of life assessed were considerably higher among the Movers, even while controlling for their differences from the Stayers. *This report was accepted for publication The reference is: Conroy, J., & Elks, M. (in press).* Tracking qualities of life during deinstitutionalization: A covariance study. *Education and Training in Mental Retardation and Developmental Disabilities.*

Report Number 11, **Results of the 1995-96 Coffelt Family Survey**, was submitted in October, 1996. Completed surveys from 48% of the Movers' families were analyzed to determine if they believed the move from Developmental Center to community housing was a good thing for their relative. The ratings showed a clear and strong belief that community placement was a good thing. Many families changed their minds about opposing community placement. A large majority of families were pleased with community supports, wanted them to continue, and would not think of returning their relatives to Developmental Centers. Report Number 11 was reformatted for submission to a peer-reviewed journal, is now in the process of consideration for publication. Didn't you say at beginning that all 5 had been accepted?

Don't know why it's greenReport Number 12, Patterns of Community Placement III: The Third Year of Coffelt Implementation, presented a series of analyses of the qualities of life experienced by class members who left Developmental Centers. Two thirds of the people who moved carried the "severe" or "profound" mental retardation label. Nevertheless, they became significantly more independent, sharply reduced their challenging behaviors, received more services and supports than they did in the DCs, , they became much more integrated into the mainstream of American life in terms of outings, and, for those who could and would communicate with our Visitors, reported themselves to be much happier in the community than they had been at the DC. In addition, their their closest caregivers reported far more "progress toward goals in the past year" than had been the case in the DCs.

In this report, we also examined supported living, presented an analysis of the Family Survey, and revisited the comparative costs issue. Supported living was associated with increased choice, individualization, and self-determination than other types of setting. The family survey revealed very strong satisfaction with community living, coupled with the perception that their relatives' lives had improved in 10 out of 10 areas of quality. Many families had undergone a remarkable change of heart about institutional versus community living for their relatives. On the issue of costs, we found again that community supports were only 54% of the DC costs.

There were problems and cautions noted in the report. In the community, psychotropic and sedative medications tended to be overused. There was little emphasis in the community on supported and competitive employment. The class members on the average had not increased their opportunities to make their own life choices, even with the assistance of unpaid friends and relatives. Nearly all decisions were still being made by professionals and paid staff. True community connections had not yet emerged for many people. Health care in the community was also problematic, because it was rated as harder to find and not as good as in the DCs. Finally, although the overall benefits were large, a number of people reported loneliness in their new community homes.

Report Number 13, **Mental Health and Crisis Services for Coffelt Class Members, 1996-1997**, from April 1997, examined mental health, crisis intervention, and medical emergency supports among 774 class members in their community homes. The Coffelt settlement mandated capacity building among the Regional Centers, so that crises could be handled effectively within the community support system. Mental health supports were rendered to 35% of our sample, and of them 22% received medications monitoring, 11% received other supports, and 2% were not sure what the service had been. Recipients of such supports were higher in adaptive behavior, and displayed more challenging behavior, than the average class member. Only 28 people were reported to be in need of, but not receiving, one or more mental health services or supports, usually counseling. There were 24 people who experienced a crisis episode in the past year that involved relocation of the person from his/her residence. Nearly three fourths of these events involved violence or uncontrolled behavior. After hours phone calls to Regional Centers received the highest satisfaction ratings, and emergency rooms the lowest.

Report Number 14, **Results of the 1996-1997 Coffelt Family Survey** (April 1997), provided the final results of the 1996-1997 Family Survey. The 218 completed surveys made up a 53% response rate from a single mailing, which was quite acceptable. Families perceived positive changes in every one of 14 distinct areas of quality of life. The largest quality enhancements were reported in "Privacy," "Happiness," "Comfort" "Overall Quality of Life," and "Getting Out and Around." These improvements did not vary by level of disability, implying that people with severe impairments were perceived to have benefited just as much as others. Families also reported that they had been considerably more opposed to community placement, when they first heard about it, than they were "now," at the time of the survey. This meant that many families have changed their minds, and their opposition has sharply diminished. Of the 203 Movers' families surveyed, only 7 continued to say they were "Strongly Against" community living for their relatives. Only 19 said they would prefer that their relatives moved back to a Developmental Center.

We also presented the verbatim responses of the 203 families to our four open-ended questions. The 1996-1997 Family Survey findings left little room for doubt: families, although many were originally apprehensive, were generally very pleased with community supports, wanted them to continue, and would not think of returning their relatives to Developmental Centers.

Report Number 15, **Impacts of the Coffelt Settlement on Community Target Group Members in 1996-1997**, extended the findings of Report Number 9 to a total of 66 CTG members we visited in this round. The results confirmed and strengthened the conclusions of Report 9. CTG members were helped greatly by the Coffelt interventions, believed their qualities of life had improved, and were clearly better off than they would have been if they had gone into DCs.

Report Number 16 was an internal working document that contained individual class member names. Therefore, it was not appropriate for dissemination. Its purpose was to permit a working group to view the utility of our newly designed Quality Feedback System data.

Report Number 17, **Patterns of Community Placement IV: The Fourth Year of Coffelt Implementation,** was submitted in January, 1998. This report contained a pre-post analyses of changes of quality of life for 91 people who moved into community settings, and quality of life and satisfaction for nonequivalent comparison groups of Movers and Stayers. In this report, we also examined people in supported living, the issue of quality in small ICFs/MR versus Waiver Homes, and an analysis of the 1997-98 Family Survey.

The pre-post results indicated that 91 people who moved into community living experienced significant improvement in the following areas: adaptive behavior, challenging behavior, quantity of services received, progress on individual goals, level of integration, self determination, individualized treatment, normalization, and satisfaction. Because the Pre-Post design is the strongest one among the six that COA has used during the course of this work, these findings were very important. Combined with the parallel findings from the other research methodologies, we felt justified in having high confidence in their veracity.

Findings among 1,073 Movers indicated that they were better off in many ways than were the Stayers. The Movers experienced significant increases in all 14 areas of quality of life that were measured on the Quality of Life Changes scale. Compared to the Stayers, theMovers were somewhat higher in self-care abilities and displayed somewhat less challenging behavior. In addition, the Movers resided in settings that were of higher physical quality, felt more satisfied with their living arrangements and staff. Also, of the Movers who could respond, 78% indicated that they felt good or very good about living in their current community home.

Analyses of people in supported living arrangements showed that these settings were more conducive to choice making, integration, and self-determination. The supported living model was also being used to support people with major behavioral challenges.

The comparison of similar groups living in ICF/MR settings and Waiver settings provided strong evidence that Coffelt class members who were Waiver recipients were enjoying program qualities and outcomes that were significantly superior to those experienced by similar people living in Intermediate Care Facilities (ICFs/MR).

The 1997-98 Family Survey showed that families perceived their relatives' lives had improved significantly in the 14 out of 14 areas of quality assessed. The families expressed high satisfaction; 76% reported that they felt happy or very happy with their relatives' community homes.

Selected portions of Report 17 were reformatted and submitted for publication in an academic journal in the summer of 1998. ????Current Status????

Report Number 18, **Selected Findings of the Coffelt Quality Tracking Project** was submitted in June, 1998 and examined several topics of interest among the 1215 class members we visited that year. The first topics of interest involved mental health care, crisis intervention, and medical emergency supports among 1159 class members in their community homes. Mental health supports were delivered to 26% of our sample. Simple medication monitoring was provided to 12%, and services and supports other than or in addition to medication monitoring were provided to 5%. Nine percent of the respondents were reported to receive both medications monitoring as well as some other types of services or supports. Recipients of such supports were higher in adaptive behavior, but displayed more challenging behavior, than the average class member. Only 22 people were reported to be in need of, but not receiving, one or more mental health services or supports. Mental health counseling and therapy were the most common unmet needs reported.

There were 49 people who experienced a crisis episode during the t year of interest that involved relocation of the person from his/her residence. Supplemental supports received the highest satisfaction ratings, and incarceration the lowest.

The second topic of interest concerned the well being of the Coffelt class members known as the Community Target Group (CTG). In general, the group believed their qualities of life had improved significantly in 12 out of 13 areas assessed over the one year period. In fact, the CTG group experienced more self-determination than did the Movers. Staff reported high levels of job satisfaction both in general and working directly with the CTG members. The analysis of the CTG members provided compelling evidence that they arewere 1) better off than they would have been without the Coffelt intervention and 2) much better off than they would have been if they were living in Developmental Centers.

Report 18 also examined the class members who now live in large congregate settings, plus the situations of class members under age 18.

Report Number 19, **The Coffelt Quality Tracking Project: The Results of Five Years of Movement From Institution to Community**, was a summary document intended for wide distribution. It contained a succinct Executive Summary, and was written in a style for broad audiences. It contained no new analyses beyond those presented in prior reports. This was the "final report" of the first four years of the Quality Tracking Project.

Report Number 20, **Patterns of Coffelt Placement Practice and Indicators of System-Wide Quality**, was a description and summary of elements of individual and systemic feedback loops that we hoped would be ongoing in order to protect peoples' rights and entitlements. First, we broke down quality indicators by Regional Center to test for variations in quality. We found substantial variations in the characteristics of the class members across the RCs (age, percentage minority, challenging behavior, and adaptive behavior). Some RCs focused on bringing only the most capable people out of Developmental Centers, while other RCs brought out people with very limited functional abilities. For example, the "percent labeled profound" among Coffelt Movers in the RCs ranged from 16% to 95%. These variations made direct comparisons of quality indicators across the RCs difficult. The comparisons could be made, but only with great care and caution. We demonstrated a method for fair comparison of RCs in this Report.

This Report also summarized the individual information we provided to DDS in our Quality Feedback System. We produced individual class member "report cards" in February of 1998. We provided one "report card" for each of the 1,215 Coffelt class members we visited. On these "report cards" we included both positive and negative quality dimentions, such as having gained a great deal in independence skills in the past year (positive) or not having an Individual Plan (negative). These individual "report cards" were distributed to the 21 RCs with a request for feedback about actions taken to remedy undesirable situations or to congratulate consumers and providers for excellence.

Summary Statement on the Empirical Evidence on California's Deinstitutionalization Movement

In all of the studies summarized above, we have found that the Movers, as in other studies, experienced major gains in many areas of quality of life dimensions. A major study conducted by Berkeley Planning Associates has replicated and strongly confirmed our results (BPA, 1998). We have also found that community care in California costs a great deal less, even for similar people, than institutional care. The cost analyses included consideration of transportation, day programs, health care, and other relevant "hidden" costs. However, I have consistently raised concerns about the overuse of psychotropics, the lack of attention to vocational programs, and the serious underfunding, of community programs.

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Following the above 17 reports, COA was contracted to conduct three more years of study of the outcomes of community placement for the 2,400 people who moved. In this work, we visited every person once a year for three years. The executive summary of this project is reproduced below. The findings were remarkably consistent with all of the earlier work: the "Movers"were, on the average, significantly better off than when they were in institutions – and in a variety of important ways. These included freedom, choice, self-are skills, reduced challenging behaviors, integration, service provision, and so on. Moreover, their families believed they were much better off than they were before in all 14 of quality of life dimensions assessed.

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

Executive Summary

This is the final report of the 3 year Coffelt Quality Tracking Project. The report is concerned with the well-being of more than 2,200 Californians with developmental disabilities who moved out of Developmental Centers, mostly during the 1990s, and who now reside in community homes. There has always been one central question this project has been designed to answer: Are they better off?

A very clear answer has emerged from both this and the previous body of 5 years of work, which was often called the Coffelt Study. With five separate research designs and more than 25 formal deliverable reports, we conclude that the answer was a strong "Yes."

For the people who moved out of Developmental Centers under the Coffelt settlement agreement, careful monitoring was very important. Most of these people carried the labels "severe" or "profound" mental retardation, and more than half were not able to use language. They were very vulnerable people, and as the law that created the Quality Tracking Project stated,[1] California had a definite responsibility to watch out for their well-being after they left state-operated facilities.

However, the final Project was also designed to do much more than answer that single central question. Procedures used in the previous Project had become a firmly established part of California's monitoring of community programs for people with developmental disabilities. For every one of the people we visited in the last year, we not only collected quality of life data, but also we completed a Quality Feedback Summary form which summarized things in each person's life that demanded a "second look" by Regional Centers, case managers, families, and/or other advocates and allies. This system was created so that problems could be detected and addressed quickly. Our Quality Feedback Summaries were FAXed or quickly mailed to our Regional Center contacts for review and action.

The Report is presented in five major results sections: Three Years of Family Surveys, Pre-Post Analyses from 1994 to 2002, Quality Feedback Summaries, Analyses of Quality Changes in the Community from 2000 to 2002, and Feedback About the Visitors and the Process of Data Collection.

Family Opinions

For the first time the information obtained from the families of the Movers has been placed at the front of the report. The Family Survey data from the entire past 3 years has been combined into one large analysis. These findings were given precedence in this report because they and should continue to be an important contributor to public policy. As noted in the Lanterman Act,

> **A consumer of services and supports, and where appropriate, his or her parents, legal guardian, or conservator, shall have a leadership role in service design. §4501**

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[1] That section of the law is reproduced herein as Appendix A.

Moreover, the Family Survey findings have been quite dramatic. Families have changed their opinions over these last 9 years toward favoring community living. On the whole, they have been extremely satisfied with the community situations of their relatives. They believed their relatives have sharply better qualities of life now in 14 out of 14 dimensions. The overwhelming majority of families would not want their relatives to return to a Developmental Center.

From a list of 30 dimensions of quality of life and service, the 5 valued most highly by families were, in this order: Health, Freedom From Abuse, Safety, Medical Attention, and Comfort.

Are They Better Off Than They Were in Developmental Centers?

Using the Personal Life Quality protocol, the study team collected data on the qualities of life of many of the Movers (the people who eventually moved from Developmental Centers to community homes) back in 1994. We visited them again eight years later visited them again, and were able to compare qualities of life and service in institution and community.

The findings strongly supported the findings that the Movers were, indeed, better off in the community than they were in Developmental Centers. From among 21 major indicators of quality, these 11 changed significantly for the better:

Progress Reported Toward Individual Plan Goals
Choice making
Integration
Reduced Challenging Behavior
Qualities of Life Ratings in 14 Dimensions
Individualized Practices Scale
Hours of Day Program Services
Number of Services in Individual Plan
Staff Like Working With This Person
Staff Job Satisfaction
Staff Get Sufficient Support

Some of these dimensions of quality reflected essential intents of the Lanterman Act, and the improvements in those dimensions were very large. For example, the Lanterman Act mandates an individual planning process that results in specific written goals for each person. Our results showed that reported progress toward individual goals increased from 46 out of 100 points back at the Developmental Center, to 77 out of 100 points in the community.

The increases in opportunities for choice making are also large --- 14 points on a 100 point scale. This positive outcome was closely associated with another Lanterman Act mandate:

Consumers of services and supports, and where appropriate, their parents, legal guardian, or conservator, should be empowered to make choices in all life areas.

The Quality of Life ratings that were collected for people when they were living in Developmental Centers averaged 71 points, whereas in the community they averaged 80 points out of a possible 100. Moreover, the scale taps 10 dimensions, including health, safety, happiness, and family relationships, and all 10 weresignificantly higher now than before.

For the Movers who could be directly interviewed (about 20%), the vast majority expressed the belief that their lives had improved greatly and they were very happy with their community homes. They, too, were clear in their strong feelings that they did not want to return to a Developmental Center.

Despite these positive gins, there were four areas in which people were not better off. People were not seeing the dentist as often as before, they are earning even less money per week on the average (although this was always a very low figure, about $5 per week, and now it is down to about half that when assessed), there was a perception that health care was not quite as good as it used to be, and it appeared that people (and those who answered for the people) reported fewer close friends than before (down from an average of 3 to 2).

When combined with the opinions of the families, the weight and breadth of the scientific evidence strongly supported California's decision to provide community homes for the more than 2,000 people who left institutions. Combined with the knowledge that the community supports were less costly than the Developmental Centers,we inferredence this to be good social policy.

Quality "Report Cards"

For each visit to a Mover, a special form was completed that recorded carefully selected situations. A Working Group with broad representation selected exactly which situations would be on this "report card." (We called it the Quality Feedback Summary.) Both positive and negative situations were represented. These "report cards" were individually delivered to the appropriate Regional Centers so that they could help remediate the negative situations, and give congratulations for the positive situations.

The most frequently reported negative situationswere: that no unpaid people were involved in the person's life; that a person was allowed very little opportunity to participate in his or her life choices; and the person was receiving three or more psychoactive medications.

The most common positive reports were that people were treated very much as individuals. That is, they had freedom to move about their communities (with support) almost whenever they wanted, and their perceptions about their qualities of life were dramatically higher than when they lived in institutions.

By counting how many positive and negative things were in each person's report card, we derived an index that could be compared across groups, such as by type of living situation or by Regional Center. In this report, we presented an analysis of these "report card" quality indicators across Regional Centers. The variations were large. As such, this technique may hold tremendous potential for system improvement.

Changes in Quality from 2000 to 2002

On the issue of quality changes within the community over the 3 year period, we reviewed the last year's findings, reported on another year of data, and attempted objective interpretation. Last year's findings were generally replicated by the new year of data. However, the negative trends that appeared in last year's data did notemerge. InFor example, the apparent decrease in Adaptive Behavior from 2000 to 2001 was not observed in 2002.

The pattern of changes over 3 years is complex. The most encouraging changes among 10 key indicators were: that the average time spent in Day Activities had been increasing; treatment of people as individuals had been increasing; our measure of person-centered planning had been increasing; and people's opportunities for choice making have been increasing. For each of the negative trends observed last year, this final year of data show that the people remained roughly the same or improved in a lot of dimensions.either got better or did not get worse.

The Process of Visiting the Movers

At each visit a postcard was left for the person or the person's closest staff to "rate" the Visitor and the survey process. The ratings showed that the Visitors were overwhelmingly: considerate in scheduling, were on time for appointments, tried diligently to communicate directly with the people with disabilities, respected the time and space of others in the home, and were pleasant and courteous. The open ended comments on the postcards showed that the people and their staff found the visits to be non-threatening, professional, interesting, and even enjoyable. Many commented that they hoped the process continues.

Summary of Outcomes
For 179 Movers in California

Quality Dimension	Pre	Post	Change	Outcome
Progress Reported Toward IP Goals	45.7	77.0	31.3	Positive
Number of Services in Individual Plan	6.1	9.0	2.9	Positive
Hours of Day Program Services	23.7	28.4	4.7	Positive
Earnings	5.20	2.54	-2.66	Negative
Number of Close Friends Reported	3.3	2.3	-0.9	Negative
Integration	14.0	27.2	13.1	Positive
Qualities of Life Ratings (Now 1994-Now 2002)	71.4	80.2	8.8	Positive
Staff Job Satisfaction	8.8	9.3	0.5	Positive
Staff Like Working With This Person	8.3	9.5	1.2	Positive
Staff Get Sufficient Support	4.1	4.6	0.5	Positive
Number of Daily Medications	4.8	5.2	0.4	Not Signif.*
Number of Psychotropic Medications	0.4	0.4	0.0	Not Signif.*
Health by Days Ill Past 28	0.5	0.7	0.2	Not Signif.*
Perceived Quality of Health Care (Staff responses)	4.7	4.3	-0.3	Negative
Doctor Visits Per Year	37.4	14.9	-22.5	Unclear
Dental Visits Per Year	2.3	1.7	-0.6	Negative
Relative Visits Person Here At This Home	11.6	9.0	-2.7	Not Signif.*
Individualized Practices Scale	61.7	69.5	7.9	Positive
Adaptive Behavior	44.8	45.3	0.5	Not Signif. *
Challenging Behavior	68.0	78.3	10.3	Positive
Choice making	31.7	45.8	14.1	Positive

* “Not Signif.” means the change did not attain statistical significance at the .05 level by Paired t-test and is therefore not labeled as either positive or negative.

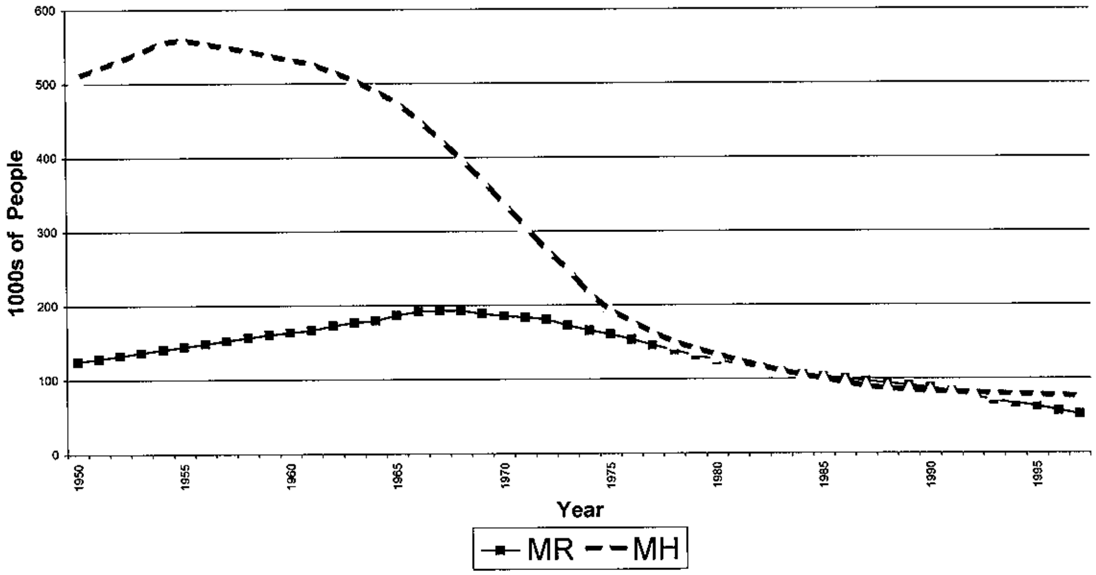
2) Deinstitutionalization in the Developmental Disabilities Field Must be Clearly Differentiated from Deinstitutionalization in the Mental Health Field.

Many people, including national radio and television commentators, have failed to recognize this fact:

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

I believe the misunderstanding is largely due to the confusion of mental health/mental illness with mental retardation. State institutions for mental illness have experienced an entirely different, and devastatingly negative, depopulation movement (Bassuk & Gerson, 1978, *Scientific American*). The graph below contrasts the depopulation of mental health institutions against the deinstitutionalization of public institutions for people with mental retardation.

**Deinstitutionalization in the United States:
Mental Retardation vs. Mental Health, 1950-1997**



Deinstitutionalization of people with mental illness was done hastily, without outside supports, and largely with reliance on the "new miracle drugs" approved by the FDA in 1955 (e.g., the chlorpromazine derivatives, such as Haldol, Mellaril, Thorazine, and so on). The phrase "dumping" came from the fact that tens of thousands of people were simply "discharged" with 30 days of "miracle drug" with no place to live, no job or daytime activities, and no support or assistance to reestablish family relationships. These procedures were led by policy makers in

California during the 1960s and 1970s. These policies continued and spread to other states as a "solution" to overcrowded institutional settings that were unable to deliver adequate clinical services. The result has been a national disgrace, including a major portion of the problem called "homelessness" (Alexander, 1996) and criminal recidivism. As Alexander wrote,

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

I believe that it is absolutely essential that the court understand the stark difference between the national record in mental health versus that for mental retardation and developmental disabilities. Jim, might also want to mention the huge difference in the **numbers** of MH people hospitalized from 1960 about 1978 and the rapid decline through the year 1980 when the number of MH hospitalized roughly equals the number MR/DD institutionalized. Also must note the strark diff in # of MH people hosp 1960 – 1976 vs MR/DD. Without any social policy or supoorts, depopulation of MH instutions was bound to be disastrous from the get go.

In the case of people with developmental disabilities, moving from large institutions to small community homes has been <u>extremely</u> successful.

3) **Family Attitudes Change Dramatically**

It is well established that the majority of families of people living in institutional settings are convinced that their relatives are receiving good care, and that they are in the best possible situations for them (Spreat, Telles, Conroy, Feinstein, & Colombatto, 1987).

For decades, however, some researchers have openly questioned the strength of parental defense of the institution's quality and appropriateness. Klaber (1969) surveyed parents of people in institutions in Connecticut. He found that more than three fourths of them were convinced of the excellence of the facilities. As he summarized, *"The parents...were convinced of the excellence of the facilities in which their children were placed ... The praise lavished on the institutions was so extravagant as to suggest severe distortions of reality in this area."*

Although parents and other family members approve of the institution, and reject the idea of community movement, these attitudes are not necessarily unalterable. I first detected the phenomenon of dramatic attitude changes in the Pennhurst Longitudinal Study (Conroy & Bradley, 1985). Before community placement, the great majority of families opposed movement of their relatives into CLAs. After community placement, the proportion of families strongly favoring community placement rose dramatically, from less than 20% to over 60%. Similar results were obtained in the Mansfield Longitudinal Study in Connecticut. Tabular and graphical summaries of the overwhelming changes in family attitudes have already been presented.

In addition, it is important to note that radical family change in feelings about community living have recently been documented by other respected researchers in California (Berkeley Planning Associates, 1998). Their table VII-3 of "How Families Saw Community Placement: *Then and Now*" replicates our own Table 20 of Report 17 (Conroy, Seiders, & Yuskauskas, 1998) to within a few percentage points in practically every cell, and shows even stronger post-relocation satisfaction than we found (89% vs. 83%). Hence there can be little question of the high family satisfaction with California's community alternatives to Developmental Centers.

4) The Theory of the "Must Stay" Group is Not Supported

There are four classic reasons given for keeping people in large segregated settings. These have been almost completely discredited by carefully controlled studies of community placement, by the evidence from total closures during the past 15 years, and by the pattern of recent placements out of Southbury itself. The four reasons have been:

1. People with limited adaptive behavior skills, such as those labeled "severe" or "profound," cannot benefit from community homes.
2. People who exhibit severe challenging behaviors when living in institutional settings cannot be handled in community settings.
3. People with extraordinary medical needs can only be properly cared for in large, centralized, hospital-like settings with doctors and nurses on staff.
4. People who are of advanced years, and have lived in a given institution for essentially their entire lives, do not want any other kind of home, would not benefit from a new home because of their age, and should basically be left where they are.

All four of these rationales have been called into serious question by the research, and even more strongly by the total-closure research data. Pennhurst, Mansfield, Laconia, Hissom, and other institutions have been closed without moving people to other institutions. In these and other closures, community services systems have been created that provide excellent supports for people of all kinds. Today, 40% of America's institutions have been closed, and nearly all of the rest have been downsized. There are now ten states that have completely eliminated institutions as an option.

In these instances, <u>everyone</u> moved into the community. This included people who are "low functioning," who, in my research, tended to benefit the most in some important ways. When people who are labeled severely or profoundly retarded move into family-like community settings, they often showed even greater gains, proportionally, in adaptive behavior than persons labeled mildly and moderately retarded. No support exists for the proposition that some people are "too low functioning" to succeed in the community. In fact, empirical evidence supports the contrary (Conroy & Bradley, 1985; Stull, Conroy, & Lemanowicz, 1990). , Studies have shown time and again that the gains made by persons with severe and profound disabilities upon moving to small community homes from large institutions are initially rapid and immediate and continue to improve over time.

The figures for institutional populations nationwide show that roughly 85% of institutional residents are labeled severely or profoundly retarded (Amado, Lakin, & Menke, 1990). In New Hampshire, the Laconia State School closed in 1990, and 78% of its population was labeled severely or profoundly retarded. Pennhurst is closed, and nearly all of its residents are in community settings, yet 86% of its population was labeled severely or profoundly retarded. The overwhelming evidence that level of disability does not preclude a person from experiencing benefits from moving from a large, group-oriented "facility" to a small, individual-oriented "home" is overwhelming Of the 373 people my team tracked out of Mansfield Training School during our study, 82% were labeled severely or profoundly retarded. They are doing extremely well also.

The research findings are conclusive, and form the basis for my opinion in this regard: level of disability does not provide a rational basis for keeping anyone in a large congregate care setting.

There is also a data base for rejecting the second rationale for continued institutionalization. The evidence is based on the experiences of people who displayed very serious challenging behaviors while living in the institution, and continued to do so for weeks, months, or years in community settings, but who now, removed from unnecessary restrictions and/or deprivation and/or abuse, have radically changed the way they act toward themselves and others. We know that, on the average, community movement will tend to reduce challenging behaviors. But this facet of the argument is aimed at the extreme cases, those who appear to present a danger to self and/or others -- people with "severe reputations" (Smull, 1995).

Common sense and concern for the safety of the community must, in theory, lead to defining certain kinds of behaviors that should not be "risked" even in a 24 hour supervision situation in the community. Serious criminal behaviors that could harm others would certainly provide a rational cause for considering non-integrated service settings. Although even such cases have been successfully supported in community settings (Smull, 1995), certain risks should not be taken until such time as a service provider is demonstrably able to provide acceptable levels of safety.

The third "must stay" group, people with urgent medical needs, have clearly been served well in community based settings. Many such people received community homes and supports in the Mansfield deinstitutionalization. Among the 957 people my team visited in 1990 in their community homes, 67 were described as "Would not survive without 24 hour medical personnel," or "Has life-threatening condition that requires rapid access to medical care." These 67 people were doing quite well in their community homes at that time. It would be of great interest to visit them today, to see whether or not their health has changed after 7 to 10 years of community living.

More recently, I have witnessed what I perceive to be extremely high quality and medically safe community homes in Oklahoma (August 1995), for people with tracheotomies, ventilator assistance, and non-oral feeding methods. Many of the Hissom class members in Oklahoma have very serious medical needs. These are being met in small community based supported living situations. I believe these people are receiving more individualized and more humane support than before, by a wide margin. People with such extraordinary challenges benefit even more than others from individual, one to one attention, whether it is medical, social, behavioral, or friendship. I do not believe that health care on a "ward" or any large unit can possibly compare to the quality provided in these individually designed supported living situations. There are videotapes of high intensity health care settings available through the Panel of Monitors appointed by Judge James Ellison.

The final rationale for keeping people in institutional settings is advanced age and the notion that the institution has become "home" for many people. However, data from within my own extensive research has demonstrated that people over 80 years of age have moved out of institutions, have adapted to the change, and even thrived in their new community homes. Many of those who can communicate have reported a major change from fear of the unknown (often exacerbated by well-meaning institutional staff) to delight with new experiences and new opportunities. Of the 957 Mansfield class members my team visited in community homes in 1990, 156 were age 60 or over, 16 of them were 80 or over, and one person was 93.

For this report, I returned to the Mansfield data base, and calculated the gains in independent functioning experienced by younger and older "Movers." For the people who moved from congregate care to community settings between 1985 and 1990, the average gain on the 100 point "Adaptive Behavior scale," our measure of independent functioning, was 4.1 points. For those under 60, the average gain was 3.9, while for those 60 and over, the average gain was 4.7 points. The older Movers actually benefited more in this outcome dimension than the younger Movers.

Finally, however, society must decide what is the right thing to do when a person has spent a lifetime in one setting, has been shown several new options, and continues to make an informed judgment that living in a large segregated setting is what he/she wants. It does seem abundantly clear, however, that that person's parents and relatives must not be permitted to unilaterally make such a decision. If the person cannot speak, then a person centered planning team is the only correct way to approach the future. Relatives, if given community veto power, would have prevented nearly all of the extraordinary benefits that have accrued to over 100,000 Americans in the past 30 years, primarily because of fear of the unknown. No single party can be given veto power over something that has so clearly benefited the vast majority of people who have experienced it.

The experience of deinstitutionalization of people with developmental disabilities demonstrates that it is possible to place all residents of a state institution into small, integrated residential settings in the community. Deinstitutionalization can be accomplished without adverse "relocation" effects upon consumers. When placements are made deliberately and with the involvement of families and consumers in the process, there is no evidence of "relocation trauma," that might produce increased mortality and morbidity, after community placement (Conroy & Adler, 1995). Moreover, community placements have consistently been shown to be cost-effective. My opinion is, therefore, that the four classic reasons for keeping people in large, segregated, isolated, institutional settings has not been supported by the "data." In fact, the "supposed data supporting the four classic reasons, does precisely the opposite: it supports moving these individuals out of institutions and into the community.

5) Community Support Systems are More Cost Effective than Institutional Systems

Community service models are less costly than institutional models. All studies published thus far are consistent (Ashbaugh, 1984; Conroy & Bradley, 1985; Jones, Conroy, & Lemanowicz, 1984; Nerney & Conley, 1982). It must be recognized, however, that this is, at least in part, because staff salaries and benefits are significantly lower in community service systems than in institutional ones. Hence, the most appropriate conclusion is that community services do cost less, but they should not.

Moreover, community services are able to obtain Federal reimbursement at the same rate as STS, primarily through the so called Medicaid Waiver program. California is an active participant in the Waiver program, and hence community supports can receive the same rate of Federal support as the institution.

The Medicaid Waiver regulations required that each state that was granted a Waiver must cause to be conducted an Independent Assessment every three years. The regulations specified that the assessment must cover quality of care, access to care, and cost-effectiveness. This is the same type of Medicaid Waiver which has been used to fund movement of persons to the community in California.

To date, more than 100 Independent Assessments of Home and Community Based Waivers have been performed in the area of developmental disabilities. Perhaps the most telling point about the costs of community living is this: not a single Independent Assessment has yet concluded that institutional care has been more cost-effective than community care. This holds true across the more than 45 states that have been granted waivers, including California. The formal reports of these Independent Assessments are filed at the headquarters of the Health Care Financing Administration. These Independent Assessments comprise a formidable body of knowledge about the quality and cost-effectiveness of Waiver services.

Nationally, the average cost of an institutional setting is about $98,000 per person per year (NASDDDS). The average inclusive cost of community supports, usually group homes plus day programs plus transportation plus case management and administration, is less than $60,000.

In the Mansfield study, the cost of the institution grew to double the cost of community care toward the end. During the majority of the downsizing process, community costs averaged between 75% to 85% of institution costs. In Pennsylvania, the community cost was approximately 85% of institution costs. In New Hampshire, the figure was 86%. In California, the ratio is about 55% (which I have characterized as an "underfunded" community service system).

There can no longer be any serious doubt that community services are more cost effective than institutional systems. The reasons for this are well understood. Staff salaries and benefits are at the heart of the difference in costs. Moreover, it is often noted that larger settings should enjoy "economies of scale," but anyone who has studied economics will know that there are also inevitable "diseconomies of scale" that arise in organizations that are too large. My opinion is that, when we are in the business of creating homes for people, those diseconomies begin to set in at about size 4.

6) The Research Findings Are Remarkably Consistent

As already mentioned, Larson & Lakin (1989 and 1991) undertook a meta-analyses of all rigorous studies of deinstitutionalization's impacts on independent functioning, and on family satisfaction. They are currently updating their 1989 analysis of studies on independent functioning. They found complete consistency in the literature. No researchers have yet found that people become more dependent when they move to the community. One report found no change, and all the others found significant improvement.

Similarly, no researchers have found families to be less satisfied with community homes than with the institution, even though families tended to be very satisfied with institutional care as long as their relatives were in institutions. The following table shows many, but not all, of the community placement processes that have been scientifically studied, with a small description of what took place.

State	Time Period	Notes
Arizona	1992-1997	Closed Ft. Stanton 1996, one WHAT? left
Arkansas	1983-86	Slow depopulation studied by Rosen (1985)
California	1993-1998	Coffelt settlement, 2400 movers, largest and fastest in history
Connecticut	1985-1994	Mansfield closed 1994
Louisiana	1980-1998	Gary W. or "Texas Children" lawsuit brought 600 back to LA, and then into community
Maine	1990	Pineland closed, only one Center left
Michigan	1975-1995	Plymouth Center and others closed during 20 year buildup of community capacity, led by Macomb-Oakland Regional Center; only 250 people with mental retardation still in institutions, largest state to be almost institution-free
Minnesota	1980-1998	Rapid downsizing of all facilities, closure of some
New Hampshire	1992	Became first state to have no citizen in a public institution
New Jersey	1988-1998	Johnstone closed 1991, North Princeton closed 1997
New Mexico	1996	Became institution-free with closure of last public facility
New York	1994	Governor announced goal of no institutions by 2000 (not currently keeping up with goal)
North Carolina	1991-1998	Thomas S. lawsuit resulted in movement of nearly 1,000 people with dual diagnoses out of Psychiatric Hospitals
Oklahoma	1988-1992	Hissom Memorial Center closed under court order, but ahead of schedule, with the best outcomes yet measured anywhere (Conroy, 1996)
Pennsylvania	1978-1987	Took 9 years to close Pennhurst, most closely studied closure of all time
Rhode Island	1995	Became institution-free after a long policy of community placement
Vermont	1996	Became institution-free
West Virginia	1985-1998	Continual gradual process of placement and closure

The following table offers further evidence of the consistency of findings across studies. As Larson & Lakin (1989) found in their meta-analysis of all rigorous studies, adaptive behavior (independent functioning) was found to increase in deinstitutionalization studies. In our own deinstitutionalization studies, we found a pattern of increasing independence according to how many years people have been out in the community.

State	# of Years	Time-1 Average Adaptive Behavior Score	Time-2 Average Adaptive Behavior Score	Gain on 100 Point Scales
Pennsylvania	14 years	39.8	50.2	10.4
New Hampshire	8 years	53.0	62.3	9.3
Louisiana	7 years	56.2	64.2	8.0
Oklahoma	6 years	41.3	47.4	6.2
Connecticut	5 years	49.5	54.0	4.5
California	3 years	44.7	46.7	2.0
North Carolina	2 years	52.7	54.8	2.2
Kansas	1 year	33.1	34.8	1.7
Indiana	.5 year	46.4	48.8	2.4

One of the primary goals of all services and supports for people with developmental disabilities is to permit and assist them to learn, grow, develop, and achieve the highest level of independence of which they are capable. The results in the table above provide compelling evidence that people grow, learn, and develop over long periods of time once they move out of institutions. The more the years of community living, generally the higher is the gain in independence. These outcomes are strong, favorable, and consistent with all published research literature.

7) Community Living is Not Without Problems, and Requires Protections

It is clear that the overwhelming majority of people can be expected to have very positive experiences with community living. Yet it must be recognized that a small proportion of people will have serious difficulties in the community. The evidence must be examined carefully to see what proportion of people will have difficulties, what kinds of difficulties, whether we can predict which people will have difficulties, and therefore whether it is possible to prevent even those relatively infrequent difficulties. Finally, a balanced analysis must compare the proportion of people who have difficulty in the community to the proportion of people who have difficulty in the institution.

There are certain protections that appear to be very important for people who move from institution to community. My colleagues and I studied these protections for many years in the Pennhurst experience, and found that the people who enjoyed these protections fared far better than their non-class-member who did not have these protections. These special protections were: case management requirements, a specific individualized planning process and format, and monitoring (Sokol-Kessler, Conroy, Feinstein, Lemanowicz, & McGurrin, 1983).

These older terminologies translate readily into more modern terms: support coordination, person-centered planning, and quality assurance. With such protections, I believe favorable outcomes for the Southbury residents who move from institution to community will be obtained in the great majority of cases. Moreover, for people who do experience difficulties, such protections should guarantee early detection and intervention to remedy problems.

The importance of a quality monitoring system is not just to find out "whether the court was right" when the entire process is completed. It is equally (and possibly more) important to be able to detect flaws during the process. In my opinion, any Order or Settlement in the Southbury case should include a requirement for "formative evaluation" and quality monitoring to be conducted and any problems to be remedied promptly, thus ensuring quality services for class members. This mechanism must be founded on individual outcomes and quality of life measurement. There is no interest in this era in certifying or accrediting "programs" or "facilities." We have the technology and the experience necessary to cost-effectively monitor each individual's situation and progress.

The topic of abuse and neglect fits into the assertion that community living is not without problems. It is often asserted that it is easier to detect and remedy abuse in a tightly controlled environment such as a developmental center. I have never seen a shred of evidence for this contention. In contrast, I have seen dozens of investigations, both sociological and criminal, in which Developmental Centers have been accused of generating a "culture of immunity and/or silence" in which staff can do whatever they like without fear of reprisal (see, for example, the record of undercover State Police placements on staff at Pennhurst and at Western Center). On the other hand, abuse occurs in community settings as well. The best question would probably be, "In which type of setting is there less abuse and neglect?" To my knowledge, that question has never been answered satisfactorily by research, primarily because the vast majority of abuse is known to be "covered up" in institutional settings, and may also be covered up in the community.

I do believe that the classic experiment conducted by Zimbardo and colleagues at Stanford in 1971 is relevant to the question of abuse in large, segregated settings where power is given to one group over another (Haney, Banks, & Zimbardo, 1973). In that experiment, young male students at Stanford were specifically selected as well-adjusted and mentally healthy. They were randomly assigned to the role of either guard or inmate in a simulated prison situation. All participants knew that this was an experiment, and indeed, the simulated prison was constructed in the basement of the psychology building on the college campus. Nevertheless, half of the inmates were removed from the experiment early because of serious psychological reactions including submissiveness, depression, self-doubt, and loss of hope. The entire experiment, designed to last several weeks, was halted at 6 days because of abuse inflicted by the student "guards" upon the student "prisoners," which was not only of a serious nature, but it was purposefully hidden from the investigators and their video cameras.

Zimbardo concluded that, among other things, the ability to depersonalize the inmates was crucial to the guards' ability to treat them as less than human. This phenomenon is intensified as settings become larger and larger, and is diminished in small settings. In my opinion, in a very small setting, care "givers" simply cannot perceive care "receivers" as faceless non-individuals in a group.

One important protection against abuse is a rigorous quality assurance system, including the following components: (a) values-based quality assessments conducted, in part, through frequent visits to consumers by parties independent of the service provider; (b) quality enhancement, including technical assistance and training for providers; and (c) corrective remedies and sanctions where required.

One related question that continually arises is "What is it about community living that accounts for the clearly established superiority in so many qualities of life?" The reasons why these benefits have been observed so consistently are becoming increasingly clear. The major reason is simply the smaller size of community homes. I believe that the organizational and economic literatures are completely clear on the conclusion that small group size for daily work and functioning produces higher satisfaction, productivity, and efficiency. This conclusion arises from a multitude of studies of human activity across a variety of settings. Gooding and Wagner (1985)provide the best summary of 100 years of this research .

Specifically in the field of developmental disabilities, Klaber (1969) was the first to point out the importance of small units for daily living and functioning. Since that time, researchers in developmental disabilities have continually added to the understanding that smaller living units are associated with higher quality of life and better outcomes, and these research findings have been documented in my own doctoral dissertation (Conroy, 1992). Research has also shown that simply "breaking up" institutional wards into smaller "walled off" subunits is emphatically not the same as moving to genuinely smaller homes (Harris, Veit, Allen, & Chinsky, 1974).

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Deinstitutionalization of People with Mental Retardation and Developmental Disabilities in the United States:

Was This Good Social Policy?

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Purposes of this Paper

The purposes of this paper are to present, explain, and support the following facts and opinions:

1) **Research Shows Multiple Benefits of Community Placement:** Twenty-five years of developmental disabilities research literature on movement from institutional to community settings indicates that, on the average, people experience major enhancements in dozens of quality of life indicators. The literature is remarkably consistent in this area. A handful of recent reports on mathematical models of mortality, led by one researcher in California (Strauss), claimed an increased risk of mortality in community living. However, Lakin (1998) later showed these reports to be based on erroneous data, scientifically unfounded, and contradicted by other published studies. No other researchers have been able to replicate the findings of Strauss and his colleagues. The sum total of rigorous studies over a 25 year period provides conclusive evidence of the superiority of community living. In 1997 and 1998, my staff individually visited 1,125 people of the more than 2,300 people who moved out of California's Developmental Centers and moved to community homes under the terms of the Coffelt settlement. We will show some of the results of that body of work, which resulted in 17 formal public reports. Their qualities of life were enhanced, they were more independent, they displayed less challenging behavior, their homes were more pleasant, and their families believed that they were far "better off" than they were in the developmental centers.

2) **Deinstitutionalization in Developmental Disabilities Must be Clearly Differentiated from Deinstitutionalization in the Mental Health Field:** The deinstitutionalization of nearly 100,000 American citizens with developmental disabilities has been highly successful. This is a very different experience from the nation's failure to support people with mental illness who have left mental health institutions.

3) **Family Attitudes Change Dramatically:** Families (parents, siblings, other relatives, guardians, best friends) of people living in institutions overwhelmingly supported the continued existence of those institutions, and the continued placement of their relatives in them. However, in cases in which people moved to the community (either over family objections, or after the family's objections have been accorded a formal hearing and they have agreed to trial placements), the families' attitudes changed dramatically toward acceptance and support of community living. Even the most vocal opponents of community placement became ardent supporters of community living once it had been experienced. Recent work in Oklahoma has shown the most dramatic changes in family opinions yet documented (Conroy, 1999). The same changes have occurred among California's families, as well (Conroy & Seiders, 1998).

4) **The Theory of the "Must Stay" Group is Not Supported:** There are four classic reasons given for keeping people in large segregated settings: severe retardation, challenging behavior, medical fragility, and advanced age. These reasons have been convincingly discredited by carefully controlled studies of community placement, by evidence from total closures during the past 25 years, by the fact that 10 states are now entirely free of public institutions as a living option, and by the pattern of recent placements out of developmental centers in California.

5) **Community Support Systems are More Cost Effective than Institutional Systems:** All studies published thus far are consistent. Community service models are less costly than institutional models. It must be recognized, however, that this is because staff salaries and benefits are significantly lower in community service systems than in institutional ones. Hence, the most appropriate conclusion is that community services do cost less, but they should not. Moreover, community services are able to obtain Federal reimbursement at the same rate as developmental centers in California.

6) **The Research Findings Are Remarkably Consistent:** The research on the question of institutional versus community based care is very unusual. It is consistent and compelling. The only exception of which I am aware is the mortality studies performed by Strauss, which has been fundamentally discredited by Lakin, and has also been repudiated by his own University colleagues and by his mentor.

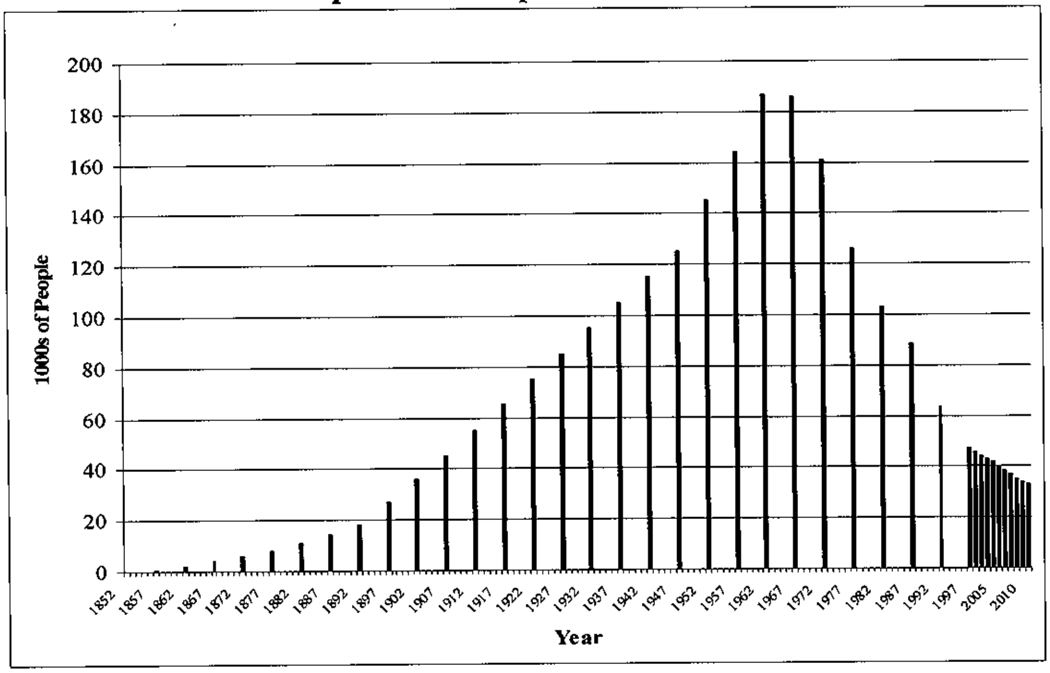
7) **Community Living is Not Without Problems and Requires Protections:** The clear and compelling scientific evidence on the benefits of community living should not be construed to mean that every single individual will be better off in every way, and at all times, in a community setting. Problems must be expected, and to the extent possible, they must be anticipated and prevented through carefully considered protective orders, monitoring, and quality assurance feedback systems, just as in the Pennhurst decision and other subsequent orders and settlements.

1) Research Shows Multiple Major Benefits of Community Placement.

In the past 20 years, a body of literature has developed on deinstitutionalization of people with developmental disabilities. It shows what happens to the quality of life of people with developmental disabilities when they move from large congregate care settings to community living. (Craig & McCarver, 1984; Haney, 1988; Larson & Lakin, 1989 and 1991.) This body of literature is remarkably consistent. Without contradiction, it demonstrates that people are "better off" in most ways when they leave large congregate care settings for community living in small, family-scale homes. Correspondingly, the satisfaction and perceptions of quality among parents and other family members rise.

Deinstitutionalization is far from new, and very far from untested. The graph below shows what has been happening to institutional populations in the United States since 1850.

150 Years of Institutional Care in America
1000s of People in State Operated Public Institutions



As the graph shows, the past 30 years have seen the population of America's public institutions for people with mental retardation reduced from about 190,000 to fewer than 45,000. The process is continuing, although it has slowed greatly since a new administration took office in 2001. Nearly every state mental retardation authority has concluded that no human being, regardless of degree of disability, "needs" to be isolated, segregated, or grouped with hundreds of "similar" people.

Since nearly 150,000 people have already experienced the move from institution to community, there has been ample opportunity to study the phenomenon. Many research groups have been involved in this work. Some of my own work will be summarized below, in order to provide the Court with the detailed reasons for my opinion in the current case.

The measurable benefits from moving to the community can be summarized. The central question of studies of the outcomes of community placement has been: "Are people better off, worse off, or about the same?" The phrase "better off" inherently implies the notion of "quality of life." However, nearly all people have their own complex of factors that they believe contribute to "quality of life." Usually their beliefs are not explicit, but rather, they form an internal set of values and judgments that are not always clearly defined. In this situation, the best available scientific approach is to address as many aspects of "quality of life" as are reliably measurable. Some of the dimensions of "quality of life," or outcomes, that social scientists know how to measure reasonably well include:

- independence
- productivity
- integration
- access to the places and rhythms of mainstream American life
- access to services when needed
- health
- health care utilization
- health care satisfaction
- mental health
- mental health care utilization or mental health care satisfaction
- friendships
- physical comfort
- privacy
- individualized treatment
- freedom from excessive restraints (physical, chemical, and authoritarian)
- respect for dignity and human rights by staff and others
- support for Choice making and learning to make choices
- personal satisfaction with multiple aspects of life
- satisfaction of the family members and "circles of friends" who care about the person
- the overall "locus of control" of the pattern of life; power, control, choice, self determination.

When multiple aspects of quality of life, or outcomes, are measured in a social program, the results are likely to be "mixed." A given social intervention may improve peoples' lives in some areas, while diminishing them in others, and leaving still other areas unchanged. This is a typical result, for example, in the field of substance abuse treatment programs.

However, the research literature on community versus institutional living has <u>not</u> been "mixed." Through the assessment of all of these quality of life dimensions, my research in 18 states, and the research of other scientists in America, has consistently shown numerous benefits consistently associated with community placement. Furthermore, the results have been extremely powerful, in that improvements have been documented in nearly every measurable outcome dimension. Research in other nations (Australia, Canada, Denmark, England, France, Ireland, the Netherlands, New Zealand, Norway, Sweden) has revealed remarkably consistent findings associated with institutional closure (Mansell & Ericsson, 1996).

In the following pages, I will briefly summarize the results of some of the largest and longest lasting studies of deinstitutionalization outcomes yet conducted: the Pennhurst Longitudinal Study (Pennsylvania), and the Mansfield Longitudinal Study (Connecticut). These two studies are of special interest because both culminated in total closure of the institution, with nearly all residents moving to community settings. At the end of this section, I will summarize other large-scale studies of community placement processes in California, New Hampshire, New Jersey, North Carolina, Oklahoma, Kansas, and Indiana.

I: Pennsylvania: Pennhurst Longitudinal Study Results:

In the Pennhurst Longitudinal Study, I was asked by the United States Department of Health and Human Services to study the effects of the district court's orders in Halderman v. Pennhurst, 446 F.Supp. 1295 (E.D. Pa. 1978). This Order resulted in the transfer of all of the people living in a large state institution in Pennsylvania to small, supervised community living arrangements (CLAs) in the communities from which they originally came. Since 1978, my colleagues and I have individually monitored the well being of each of the plaintiff class members -- more than 1,700 people -- every year. Following is a summary of the results of the study through 1992 (the last year in which I directly supervised the project).

A. The People:

1154 people lived at Pennhurst on the date of Judge Raymond J. Broderick's historic Order of March 17, 1978. My team immediately visited every one of those people, and collected information about characteristics, abilities, behavior, health, and service needs. These people (and other Pennhurst class members) are still being tracked. Every person is visited every year, and every family is sent a survey. We know more about their quality of life over the past decade and a half than any other group of people with disabilities in history. Their characteristics at the beginning, in 1978, were as follows:

Characteristic	**Average**
Average age	39
Average years at Pennhurst	24
Percent male	64%
Percent nonverbal	50%
Percent with seizures	33%
Percent not fully continent	47%
Percent with aggressive behaviors	40%
Percent labeled severe or profound	85%

B. The Community Model:

Three person Community Living Arrangements (CLAs) were the predominant program models in Pennsylvania at that time. These were either detached houses or apartments, and almost all were of existing housing stock. A day program was arranged before placement for every person. The staffing varied as seen below:

- Some shift staffing and some live-in;
- (later became almost entirely shift);
- 90% non-profit provider entities.
-

C. Additional Court Protections:

- Special low-caseload Case Managers (1 to 30);
- Consistent format to IHPs, with multiple reviews;
- Requirements for independent monitoring (including the Pennhurst Study itself).

D. Development Toward Increased Independence (See Adaptive Behavior Development graph) The graph below depicts the average increase in adaptive behavior over the course of the eight study years, that is, once people moved from institution to community. In fact, a direct quote from one Pennhurst Study report stated, "The adaptive behavior growth displayed by people who moved to CLAs under this court order [was] literally 10 times greater than the growth displayed by matched people who are still at Pennhurst.

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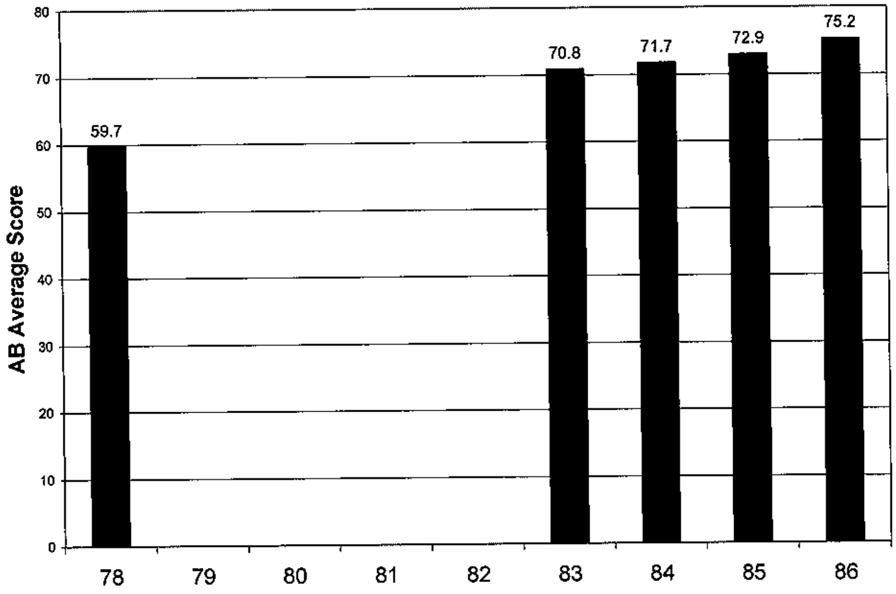
Pennhurst Longitudinal Study:
Adaptive Behavior Development 1978-1986

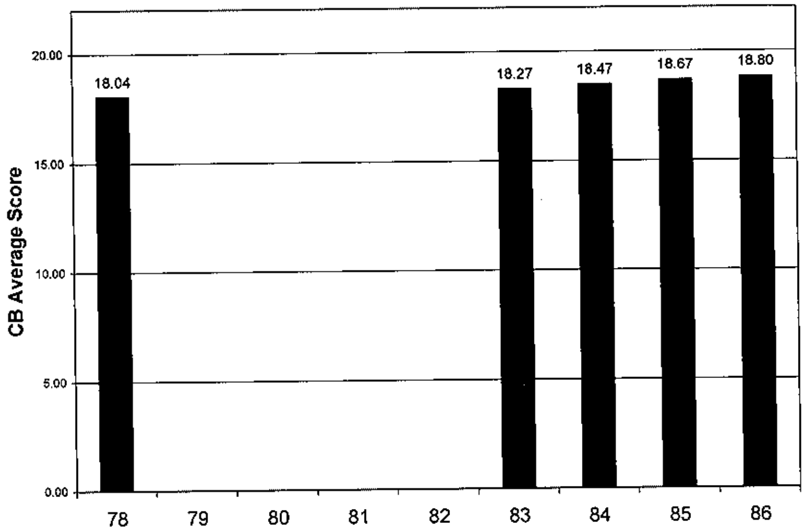


- In addition to the encouraging findings with respect to adaptive behavior, later study revealed positive gains in self-care skills that continued to improve the longer the people lived in the community:Upon placement, average gain 9%;
- 3 years after placement gain of 12%;
- Most recent measurement,(1992) gain of 14%.

E. Challenging Behavior: The improvements are shown on the graph headed "Improvements in Challenging Behavior." Moreover, the following findings accrued in later years:

- Average improvement in challenging behavior area upon placement 1%;
- 3 years after placement 3%;
- Most recent measurement, 1992, 6%.

Pennhurst Longitudinal Study:
Improvements in Challenging Behavior



F. Qualities of Environments

Scales utilized included Normalization, Individualization, the 1979 version of the standards of the Accreditation Council for Mental Retardation and Developmental Disabilities, and Physical Quality. Results from all scales improved sharply and significantly upon community placement.

G. Consumer Satisfaction

One aspect of the Pennhurst Study included repeated interviews with 56 people who were able to communicate. About a third of those people reliably said they were happy at Pennhurst, and wanted to stay there. After the moves, about two thirds reliably said they were happy in their new community homes, and wanted to stay in them. The number of people reporting satisfaction with aspects of life in the community was approximately double what was found in the institution. There were no areas of decreased satisfaction over the entire course of the study.

H. Amount of Service

People who moved to the community began to receive more hours of developmentally oriented service per month than similar people who stayed at Pennhurst (225 hours per month versus 189 hours per month). Hence we concluded that, on an overall index of amount of service, the movers were better off.

I. Health and Health Care

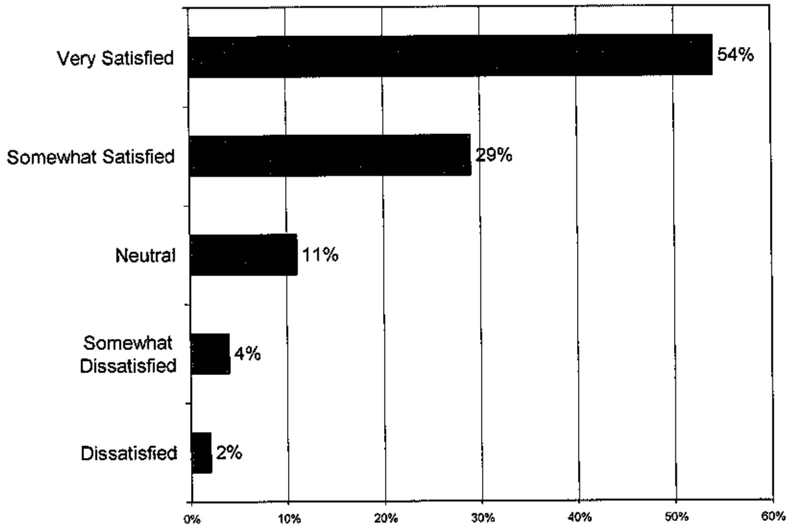
Indicators of health remained stable across the entire length of the study. Use of medications decreased slightly after community placement.

J. Day Activities

The proportion of people taking part in an active day program increased from about a third at the beginning of the study while living at Pennhurst to practically 100% at the end after having moved to the community.

K. Family Satisfaction: Initially, in 1979, the families of the people at Pennhurst were very satisfied with the institution.

Pennhurst Longitudinal Study:
Initial Family Satisfaction with the Pennhurst Institution



These same families were also quite strongly opposed to community placement. At the beginning, 83% of families reported satisfaction with Pennhurst, and 72% opposed movement to the community.

Pennhurst Longitudinal Study:
Initial Family Attitudes About Community Placement (1979

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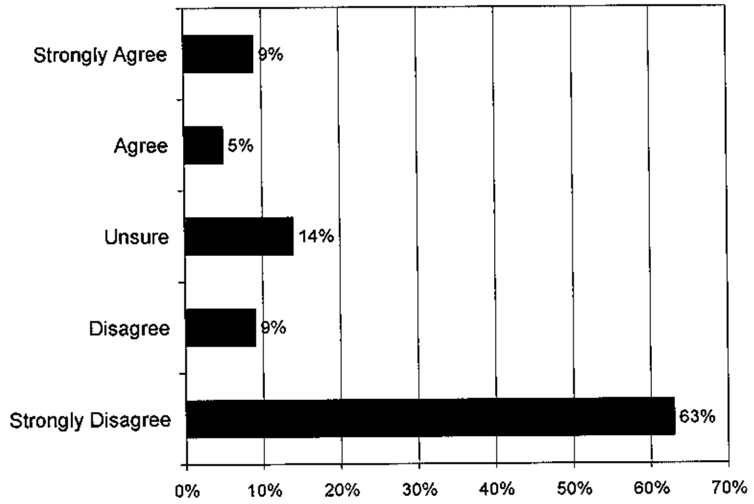
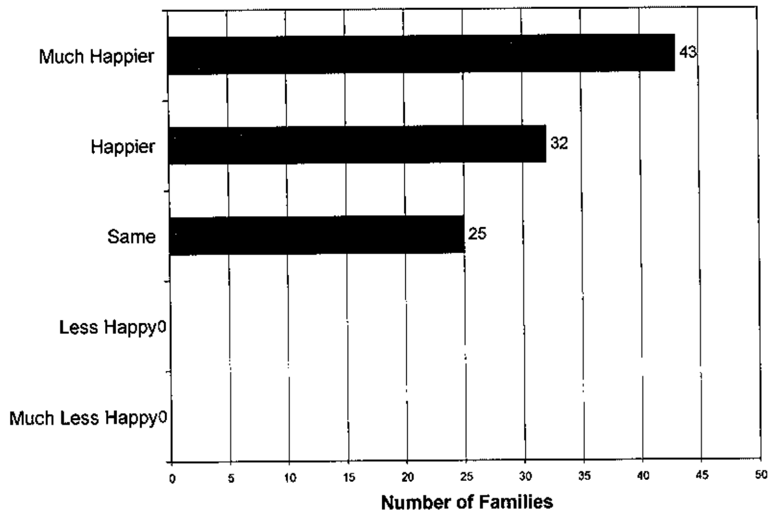
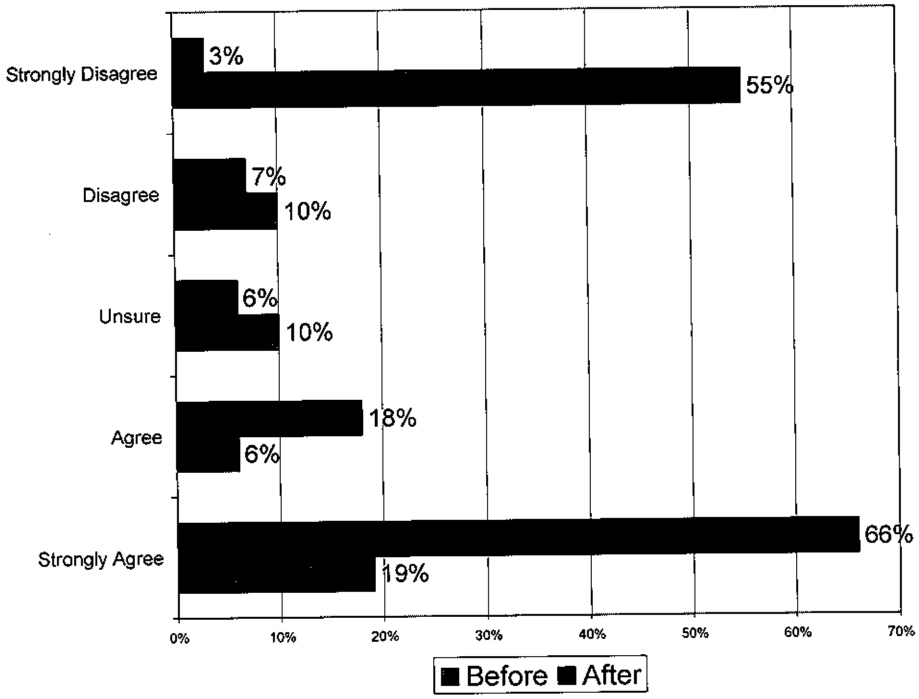


When surveyed later, however, these families had radically changed their views. When asked whether they thought their relatives were happier or less happy since moving, not a single family rated their family member as being "less happy" or "much less happy". As shown in the 1991 survey results below, 75% of families thought their family member was happier. Not a single family believed their relative was less happy in the community. Other related analyses showed that the strong prevailing attitude had shifted to support for community living.

Pennhurst Longitudinal Study:
"Has Your Relative's General Happiness Changed Since Moving to the Community?"



Pennhurst Longitudinal Study:
Agreement With the Idea of Community Living, "Before and After"



The graph shows a dramatic change in attitudes about relatives living in the community. This analysis was performed with 134 families who completed our surveys both in 1979 and again in 1984.

Some of the most compelling findings in the study were the verbatim comments of the families after deinstitutionalization. These comments frequently included expressions of surprise that they (the parents) had ever opposed community placement in the first place, coupled with surprise at the magnitude of improvements in the qualities of their loved ones' lives.

In a 1991 community survey of these same families, the results from 420 responding families concerning their overall satisfaction with community living were:

Very Satisfied	Somewhat Satisfied	Neutral	Somewhat Dissatisfied	Very Dissatisfied
65% (272)	25% (104)	4% (18)	5% (20)	1% (6)

L. Neighbor Acceptance

About three fourths of neighbors never find out there is a group home in their neighborhood. Of those who do know, only about half had any negative reactions, and those tended to vanish by a year to a year and a half.

M. Costs

The total public cost of serving the people who moved to Community Living Arrangements (CLAs) was significantly less than for the matched people still at Pennhurst (about $110 per day versus $129 per day at Pennhurst). However, the fiscal burden shifted sharply from Federal to state sources for the people who went to CLAs. Because Federal funds were being used for Pennhurst but not for CLAs, the state contributed about $57 per day for people at Pennhurst, and about $98 per day for people in CLAs.

Today, community programs are just as able to obtain Federal Medicaid funds as are institutions, primarily through the Waiver program. California is a major participant in these Waiver programs. Hence, the old disincentive for states to support community services is gone.

N. Synopsis of the Pennhurst Longitudinal Study

The 5 years of the Pennhurst Study led to the conclusion that, on the average, the people deinstitutionalized under the Pennhurst court order were better off in practically every way measured. For the people who moved from Pennhurst to small community residences, results were conclusive.

Since the end of the Federal study, my group continued to monitor the well-being of the Pennhurst class members with state, local, and University support. The positive outcomes have not only been maintained, they have continued to increase. For example, the class members have become continually more and more independent since moving to community homes. Year after year, their challenging behaviors have decreased.

The Pennhurst research led me to try to replicate the study in other states, with and without Court involvement. Replication is at the heart of science. I have been fortunate in this regard. The Pennhurst research has been replicated, extended, and refined, in many other states. Some of these will be described below, particularly the Mansfield Longitudinal Study in Connecticut, the Applied Research Project in New Hampshire, the Quality Assurance Project in Oklahoma, the Winfield Closure Study in Kansas, the Quality Tracking Project on Institutional Closures in Indiana, and the Quality Tracking Project related to the Coffelt settlement in California.

II. Connecticut: Mansfield Longitudinal Study:

In Connecticut, my associates and I followed 1,350 class members in CARC v. Thorne, No. H-78-653(TEC) (D. Conn.) to measure their well-being. A tracking project of this kind was required by the consent decree entered in that case in 1985. At the beginning of the study, most class members were in congregate care settings: state institutions, state regional centers, and private nursing homes. Between 1985 and April, 1990, approximately 600 persons received community placements under the consent decree.

The CARC class was typical of the population of public institutions in America. The average age was 46; 53% were male; their average adaptive behavior score before placement was 45 on a scale of 1 to 100; and their average score in challenging behavior was 79 on a scale of 1 to 100. About 7% of the class had a hearing loss, 15% had no vision, 21% had seizures, and 20% had serious medical needs. Approximately 69% of the persons who received community placements under the Court order were labeled severely or profoundly retarded, compared to 75% of the CARC class as a whole. This showed that community placement included people with the most intense needs, rather than being restricted to people gifted with higher ability levels.

We completed three major research designs in Connecticut. The three studies were (1) changes in well-being from pre-move to post-move; (2) comparison of changes in well being among people who moved versus extremely similar (matched) people who did not move; and (3) surveys of parents, other next of kin, next friends, and guardians.

The overall results of five years of study of the people deinstitutionalized in Connecticut are summarized in the table on the following page.

INDIVIDUAL OUTCOMES
ASSOCIATED WITH DEINSTITUTIONALIZATION
Connecticut's Mansfield Class Members, 1985-1991

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

This table shows, from three separate studies over a 5-year period, that the people who moved from institution to community were significantly better off in most of the dimensions that we knew how to measure.

On the average, class members in CARC v. Thorne who received community living arrangements under the Court's order made significant gains in adaptive behavior after placement in the community. Moreover, people labeled profoundly retarded made the greatest proportional gains: more than 28 percent (Stull, Conroy, & Lemanowicz, 1991). The longitudinal research design also showed that people who moved to community settings decreased their challenging behaviors during the years of the study.

In the area of social integration, movers began with 3.1 events per week of being in the presence of nonhandicapped peers when living at the institutions. They increased to 23.0 events per week in the community. We also found an inverse relationship between the size of a community living setting and the degree of social integration experienced by its residents.

Residents of smaller homes experienced more opportunities to be in the presence of nonhandicapped persons (Conroy, 1992).

In 1988-89, only 29 members of the CARC class had experienced even a short-term placement in a psychiatric facility, regional center or institution. This suggested that there was little or no need to maintain the institutional setting; it was often suggested that the institution should be maintained as the "backup" for people whom the community had difficulty handling.

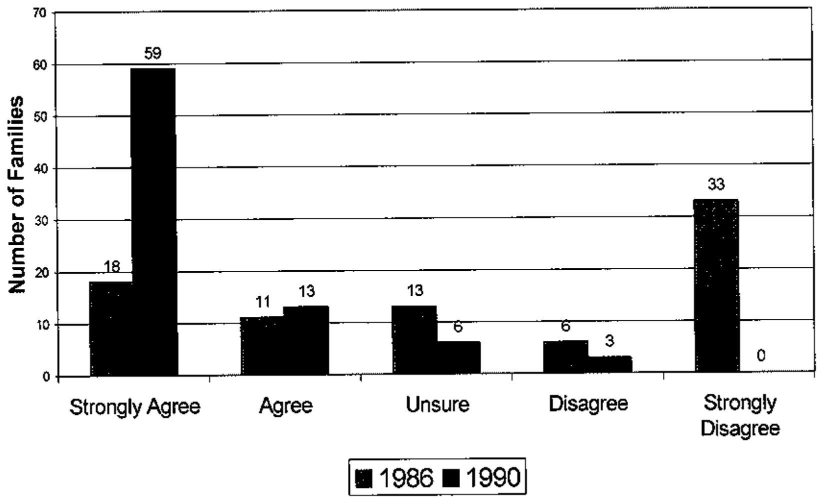
Members of the CARC class who received community placement received medical care of an appropriate frequency. The average class member had seen a physician within the preceding 5 months, and a dentist within 4 months. These frequencies compared favorably with figures for the general public.

During the course of our studies in Connecticut, we saw the cost of care at the Mansfield institution rise to $290 per person per day, more than double the cost of services in the community. Even at that funding level, the quality of life in the institution could not come close to matching what was available in the community for very similar people. We did find that quality had improved measurably in the institution, such as in the areas of social integration and increased earnings, but in no area were the gains as large as they were for people who moved from institution to community.

We also found that people who had resided in community settings during the entire course of the study had made significant gains in many areas of quality of life dimensions, including adaptive behavior, challenging behavior, social integration, productivity, earnings, satisfaction, and family satisfaction.

Just as in the Pennhurst Study, the families of the CARC class members opposed community placement at first, but later shifted to strong support. The graph below shows the extent of attitude change among all of the Mansfield parents whose adult children moved from institution to community, and who answered both of our mail surveys in 1986 and 1990.

Mansfield Longitudinal Study:
Changes in Family Attitudes Re: Community Placement



From all the results reported above, I concluded that many improvements occurred in the lives of people receiving services in Connecticut. By far the greatest improvements were seen among the people who moved from institution to community.

III. Brief Reviews of Other Relevant Community Placement Studies

A. New Hampshire

From 1981 onward, I have been involved in studying the process of deinstitutionalization in **New Hampshire** (Bradley, Conroy, Covert, & Feinstein, 1986; Conroy, Dickson, Wilczynski, Bohanan, & Burley, 1992). In January of 1991, the Laconia State School and Training Center closed. New Hampshire thus became the first state in which no citizen with a developmental disability lived in a state institution.

All of the people who remained at Laconia, a facility with a long and honorable history, are now living in community settings. Most of the last remaining group of people had serious behavioral or medical/health challenges. Up until the final year, many state officials appeared to believe that the institution would always be necessary for some people. In the end, New Hampshire elected to demonstrate the opposite. That is, even the most "medically fragile" people are now living and thriving in small, homelike settings. This achievement has an important place in the history of developmental disabilities. New Hampshire was the first state to show that communities can support <u>all</u> people, regardless of the severity of their disabilities.

I am continuing to perform studies and evaluations in New Hampshire to the present day. I see compelling evidence that even the most "difficult" people have been afforded the necessary supports in community settings. The overall evaluation of my 16 years of research in New Hampshire can only be that <u>all</u> people <u>can</u>, and do, live in the community, and that their lives are indisputably far better on the average. Case studies, "stories," and living examples are readily available. I would recommend contacting Mr. Donald Shumway, current director of the human services agency, for further information.

B. New Jersey

In **New Jersey**, the Johnstone Training and Research Center closed in 1992. I headed a 3 year project to track the former residents and the qualities of their lives. Two thirds of the Johnstone people went to other state developmental centers (institutions). One third went to community settings. The conclusions of the research were that both groups had experienced improvements in many dimensions of quality, but the movers to community settings were by far the most improved. Moreover, the care for the people who moved to other institutions wound up costing more than Johnstone, while the care for people who moved to community homes cost less than Johnstone. I wrote that "Future closure planning should, according to this and past research, employ deinstitutionalization rather than reinstitutionalization as its primary strategy" (Conroy & Seiders, 1994).

C. Oklahoma

Since 1990, I have been working on a statewide quality assurance system in **Oklahoma** that covers 3,700 people -- everyone receiving intensive services in the state. Among these 3,700 people are approximately 1,000 Class Members in the <u>Homeward Bound v. Hissom Memorial Center</u> litigation and consent agreement. In 1995, I found and reported that the outcomes for the 520 "Focus Class Members" (those who lived at Hissom on or after May 2,

1985) Jim, when did they move? were in many ways the strongest and most positive I had ever obtained (Conroy, 1996). These extraordinarily positive outcomes were associated with a "new" kind of community living arrangement. Nearly all of the Focus Class Members went from Hissom, not into "group homes," but rather into individually designed "supported living" situations. Practically no one had more than two roommates, and most had only one or none. This method of deinstitutionalization was unique in America. It also turned out to be the most successful. A summary table of the outcome results is shown below.

Hissom Outcomes Study Summary & Interpretation:
"Are Focus Class Members Better Off Now Than They Were Before?"

Quality Dimension	Answer
Adaptive Behavior	Yes
Choice-Making	Yes
Challenging Behavior	Yes
Productivity	Yes
Integration	Yes
Developmental Services	Yes
Family Contacts	Yes
Medications	Yes
Health Care	No Change
Satisfaction	Yes
Overall Conclusion	**Yes**

The table clearly shows that the people who left Hissom are better off in nearly every way measured, and worse of in no dimension.

More recently, we surveyed the families of these same people by mail (Conroy, 1999). Just as in the other studies, families told us that their feelings about community living had changed.

Oklahoma Outcomes Study of Hissom Class Members:

Family Feelings About Community Living, "At First" and "Now"

The graph shows that only a handful of these 301 families are now opposed to community living for their relatives (a total of 3, to be exact). We also asked these families to rate their relatives' qualities of life "Then" and "Now," with "Then" referring to the time when they lived at the Hissom institution. The results were the most dramatic we had yet seen in any of our studies, and they are depicted in the following graph.

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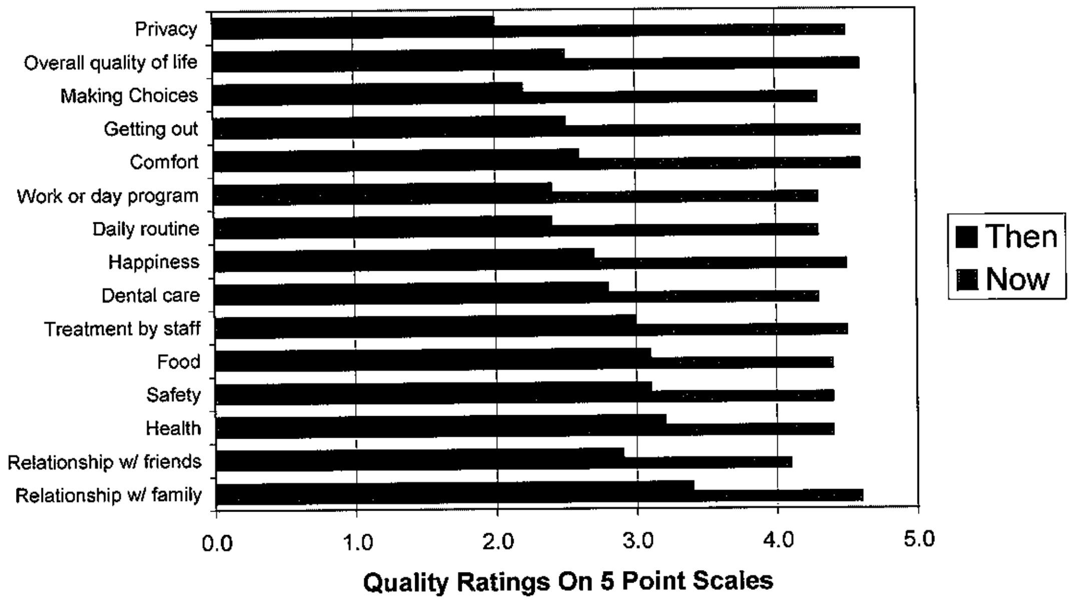
Perceived Changes in Qualities of Life:
1999 Survey of Hissom Class Member Families



Each one of the differences between perceived quality "Then" and "Now" was statistically significant, and also very large in magnitude. This was powerful evidence of the eventual satisfaction experienced by families of people who moved from institutions to community homes.

D. North Carolina

I have also been tracking the well-being of more than 1,200 people with dual diagnoses in **North Carolina**. These members of the Thomas S. class are people who had mental retardation, and also had either a psychiatric diagnosis or a brush with the law that resulted in placement into a psychiatric facility. Hundreds of the Thomas S. class members have moved to new community homes. Despite widespread misgivings about their potential behavior problems, they are doing extremely well in their new community homes, with no evidence of criminal activity or "recidivism." In fact, they have made such progress that I am now working with the state to suggest that the Court's supervision might be relaxed. The Thomas S. class members are more integrated, more satisfied, better served, more independent, receiving less medication, and much more likely to be working and earning money. This project has strongly suggested that serious behavior "problems," even criminal histories, need not prevent people from flourishing in well supervised community homes. The placement process was so successful that the judge recently dismissed his own Order, concluding that all the original goals of the Thomas S. action had been achieved.

E. Kansas

My company was selected to track the process of closing the Winfield State Hospital in **Kansas.** For the 200 people who moved from institution to community in that effort, we measured qualities of life before and after the move. The following table summarizes the results of our 2 years of study.

Summary of Kansas Outcomes at Year One

Quality Dimension	Results	Outcome
Adaptive Behavior Scale	Significant 1.7 point gain (5% up)	**Very Positive**
Orientation Toward Productive Activities Scale	Large gain 1.7 to 11.5 points	**Very Positive**
Challenging Behavior	Modest 2.7 point gain (3% improvement)	**Positive**
# of Services in Individual Plan	Up from 5.2 to 8.2	**Positive**
Hours of Day Program Services	Up from 4 to 18 hours per week	**Very Positive**
Hours of Developmental "Programming" in Home	Down from 10 hours to 6 hours per week	**Negative(?)**
Integration	Large increase from 3 to 31 outings per month	**Very Positive**
Choice making	Up 50% from 27 to 40	**Very Positive**
Qualities of Life Ratings	Up from 68 to 78 (Now to Now)	**Very Positive**
Qualities of Life Perceptions of Changes	Up in every area but one – dental (Then & Now)	**Very Positive**
Staff Job Satisfaction	Up by 1.2 points out of 10	**Very Positive**
Staff Like Working With This Person	Up by 1.4 points out of 10	**Very Positive**
Staff Get Sufficient Support	Up 1 point (3.7 to 4.7, still low)	**Positive**
Staff Pay Rate	Down $4000	**Mixed**
Health Rating	Up from 3.5 to 3.8 out of 4	**Positive**
Health by Days Ill Past 28	Down from 3.2 to 0.8 days/28	**Very Positive**
Medications, General	Down from 5.7 to 4.9	**Positive**
Medications, Psychotropic	Down from 18 people to 6	**Very Positive**
Doctor Visits Per Year	Down from 22 to 6	**Unclear**
Dental Visits Per Year	Down from 2.3 to 0.5	**Negative**
Family Contacts	Up from 7 to 18 contacts per year	**Very Positive**
Individualized Practices Scale	Up from 47 to 72 points	**Very Positive**
Physical Quality Scale	Up from 76 to 86 points	**Positive**
Normalization	Large increase	**Very Positive**
Subjective Impressions of Visitors	Up on 4 out of 5 dimensions	**Positive**
Total Public Costs	Down about 15% From $109,000 to $91,000	**Positive**

This table revealed a clear pattern of positive outcomes, tempered by two that were interpreted as negative: a decrease in the number of hours per week of formal day program activity, and a drop in the frequency of visits to a dentist. Although many of these people moved into large 8 person group homes, their outcomes were still positive. These outcomes were not as dramatic as those seen in Oklahoma, but nevertheless, we were able to conclude with confidence that these people were "better off" in their new community homes than they had been at the Winfield institution. Moreover, there was no perceived decrement in the quality of health care.

F. Indiana

For the past year, we have been tracking the outcomes of closing two state institutions in **Indiana**, which affected approximately 300 people. Even at 6 months post-movement, when many elements of the community service system were still in flux, the people were found to be "better off" in most ways.

Statistical Summary of Indiana Outcomes at Six Months

Quality Dimension	Pre	Post	Change	Outcome
Adaptive Behavior	48.4	50.2	1.8	Positive
Orientation Toward Productive Activities Scale	30.9	28.8	-2.1	Neither
Challenging Behavior	70.2	67.6	-2.6	Negative
Elements of the Planning Process	51.3	73.6	22.3	Positive
Progress Reported Toward IP Goals	59.7	70.2	10.5	Positive
Hours of Developmental "Programming"	43.5	68.3	24.8	Positive
Number of Services in Individual Plan	4.8	4.6	-0.2	Neither
Hours of Day Program Services	13.8	15.7	1.9	Neither
Earnings	8.6	3.4	-5.2	Negative
Number of Friends Reported	4.2	6.0	1.8	Positive
Choice making	31.4	47.4	16.0	Positive
Integration	9.4	29.6	20.2	Positive
Qualities of Life Ratings (Now-Now)	65.8	78.2	12.4	Positive
Staff Job Satisfaction	7.8	9.0	1.2	Positive
Staff Like Working With This Person	8.2	9.1	0.9	Positive
Staff Get Sufficient Support	3.2	4.2	1.0	Positive
Number of Daily Medications	4.5	5.0	0.5	Negative
Number of Psychotropic Medications	0.5	0.4	-0.1	Positive
Health Rating	3.7	4.1	0.4	Positive
Health by Days Ill Past 28	1.0	0.5	-0.5	Neither
Doctor Visits Per Year	21.4	7.4	-14.0	Unclear
Dental Visits Per Year	1.9	1.2	-0.7	Unclear
Relative Visits Person Here At This Home	7.1	18.0	10.9	Positive
Individualized Practices Scale	57.7	78.9	21.2	Positive
Physical Quality Scale	57.9	75.6	17.7	Positive
Normalization	37.7	75.9	38.2	Positive

The table shows three negative findings. Two of them (challenging behavior and earnings) were interpreted as temporary, and are expected to move in a positive direction as the system becomes more mature. All of the other changes experienced by the 191 people represented in the table were positive. These Movers are indeed "better off," even at 6 months post-placement, and the most reasonable hypothesis is that the qualities of their lives will show further improvement in the years to come.

IV. California: The Quality Tracking Project

I am currently heading a project that is tracking the quality of life outcomes experienced by more than 2,300 people in **California** who have been affected by the Coffelt settlement. Thus far, the project has resulted in 20 reports, 17 of them intended for public distribution. These reports present data on the well-being of people who have moved out of California's institutions since the settlement (e.g., Conroy & Seiders, 1995a and 1995b; Conroy & Seiders 1996; Conroy & Seiders, 1998; Conroy 1996). These analyses employed multiple research designs, including pre-post, matched comparison, nonequivalent comparison groups with analysis of covariance, and family surveys.

A complete summary of the 17 public reports is provided following this section. The summaries are intended to reflect the breadth of measures, research designs, and methodologies employed. The summaries show a compelling tendency to reach the same conclusions from all the designs and methodologies: although deinstitutionalization in California has had its problems, they have been far outweighed by the benefits to the people in terms of the qualities of their lives, their satisfaction, their families' satisfaction. In other words, regardless of the design and methods utilized, the results show similar patterns: these people are "better off" in the community than they were in Developmental Centers.

All of this work was based on face to face visits with the people and their caregivers, during which we collected our battery of reliable measures of qualities of life and qualities of care. Each year, we visited a sample of the "Movers" (the people who moved from developmental centers to community homes). We also annually surveyed every known close relative or guardian.

The table below shows that, in the work performed up until December of 1998, we had conducted 4,051 visits with Movers. The table shows the pattern of our individual visits over the years. The abbreviation CTG refers to the "Community Target Group," those who were originally living with relatives, but encountered difficulty and/or a need for additional supports. The "Movers" are the people who moved from Developmental Centers to community homes. The "Stayers" are people who continued to live in Developmental Centers.

Year	**Movers**	**CTG Members**	**Stayers**	**Totals**
1994-95	286	21	855	1,162
1995-96	451	38	395	884
1996-97	723	67		790
1997-98	1,125	90		1,215
Totals	2,585	216	1,250	4,051

Our average visit to each person took 77 minutes at the person's home. This work offers a very large database for determining whether movement from institutions to community homes was "good" or "bad" for these people. It is important to state clearly, however, that our work has sought the answer to our question **"Are people better off?"** in an aggregate manner. That is, we were attempting to find out if the average experience was positive.

Our findings have been clear, definitive, and compelling. But that does not mean that every person's experience was positive. In fact, we know of many that were not. Part of our role in California was to immediately report back to the Department of Developmental Services when we found a person who was not doing well, or not receiving the services to which he or she was entitled.. (This aspect of the Project was called the Quality Feedback Summary, or "rapid feedback" system.) This work continues today.

The following Table of Outcomes is from our Final Report of the first 5 years of our monitoring.

Outcome Summary Table
Results of the Coffelt Quality Tracking Project
1,125 "Movers," 1993 to 1998

DIMENSION	OUTCOME
CAPABILITIES (Adaptive Behavior)	Significantly increased self-care abilities. Movers are now doing more for themselves, requiring less assistance.
SOCIAL BEHAVIOR	Sharply increased socially appropriate behavior (decreased challenging behavior), more than in other studies.
SELF-DETERMINATION	Increased choice making, but the increase was small. Much more can be done in this area.
SERVICES	Increased number of services in written plan, sharply higher goal attainment reports from staff.
PRODUCTIVITY	Increased day program hours, but decreased earnings and number of people employed. Much more needs to be done in the area of employment and productive activities.
INTEGRATION	Average number of outings to integrated settings per week doubled for Movers.
STAFF ATTITUDES	Job satisfaction, plus "How much do you like working with this person," were both higher in community homes.
CONSUMER SATISFACTION	Consumers (and surrogates) reported significant increases in **all** 14 dimensions of quality of life. Of the 261 people who answered the question "Would you rather go back to live at a DC?" only 17 said "Yes, Definitely."
FAMILY SATISFACTION	The closest relatives of the Movers (surveyed annually by mail) perceived significant increases in **all** 14 dimensions of relative's quality of life.
HEALTH & HEALTH CARE	Health care was reported to be more difficult to obtain in community than DC, but just as high in quality. Slight tendency toward increased use of psychotropic meds.
QUALITIES OF ENVIRONMENTS	All research designs showed enhanced Physical Quality, Individualized Treatment, and Normalization.
PUBLIC COSTS OF SERVICE & SUPPORT	Decreased by 45% (suggesting serious underfunding of community services in California).

A brief verbal summary in paragraph format is provided below.

1. Positive Outcomes: California's Coffelt class members are better off because of the settlement of the lawsuit. More than 2,300 people have moved from institution to

community living, and their lives have on the average been enriched measurably and significantly in terms of self-care abilities, appropriate social behavior, opportunities for choice making by the person and unpaid allies, integration, services delivered through the individual planning process, hours of day program per week, attainment of individual goals, individualized treatment, physical quality of their home environments, consumer satisfaction, and family satisfaction.

2. Negative Outcomes: Fewer class members have paid jobs in the community than they did while living in Developmental Centers, and they are on the average earning less money from paid work than they did while living in Developmental Centers. Moreover, the prevalence of sedative and psychotropic medication utilization has increased slightly since moving to the community. These are the only negative outcomes detected during the four years of this study.
3. Balance: The balance of positive and negative outcomes is weighted heavily toward the positive.
4. Cost: The total public cost of supporting people in California's community service system is much lower than the Developmental Center cost. In 1996, community costs averaged about $55,000 per person per year, while Developmental Center costs averaged about $100,000. Both costs are higher now, but the difference persists. These costs were computed for similar people, and the difference definitely cannot be explained by differences in the people served in institution and community.
5. Conclusion: The ultimate conclusion is inescapable: The <u>Coffelt</u> settlement brought about enormous social benefits to people with mental retardation. This did not require extra money; it was done at much lower cost than the Developmental Centers would have spent.
6. Policy: The movement of people out of institutions and into small integrated community homes should continue.

The overall conclusion of the years of the Quality Tracking Project is that class members' lives have been significantly enriched in nearly all of the measured dimensions of quality. Improvements have been documented in independence, productivity, integration, self-control of challenging behavior, satisfaction, self-determination, achievement of individual goals, physical quality of the homes, individualized treatment within the homes, and family perceptions of quality of life. Very few class members, and just as few families, would like to "go back" to Developmental Centers. All of this has been accomplished with far fewer public dollars than were required in Developmental Centers. The data from this project imply that the proper targets for future quality enhancement activity are medication use, expansion of support models in directions other than the ICF/MR funding stream, employment, and Choice making/self-determination.

Obviously, the evidence from more than 4,000 personal visits and the objective scientific assessments leads to the conclusion that the <u>Coffelt</u> Movers' lives have been significantly enriched. There can be little debate about this conclusion, because there is simply no credible scientific evidence to the contrary.

There will, of course, be "horror stories" in community service systems of the kind reported by the San Francisco Chronicle in 19____. But for every "horror story," the scientific evidence demonstrates repeatedly that there are many more "success stories,." not only in CA, but in IN, NH, OK, PA, and CT, among others.

I believe that it is a dangerous error to permit unscientific sensationalism to guide public policy. The simple fact of the matter is that the California deinstitutionalization has been a great success for the great majority of the people involved, as it has been for those involved in Oklahoma and elsewhere.

Summary of the 17 Reports from the California Quality Tracking Project

This is a summary of the 17 formal reports we produced from 1994 to 1998 as part of the Coffelt Quality Tracking Project. Three of these are in the process of publication in academic journals, and two have been accepted. ???? What's the difference??? Five of these reports have been reformatted and are being published in academic journals.

Report Number 1 was a status report on field data collection activities, and contained no data or other information on quality of life among the Coffelt class members.

Report Number 2, **Quality of Life Among Institutionalized and Deinstitutionalized People in California: Preliminary Findings, 1994,** was submitted in February, 1995. It detailed a matched comparison design of 57 Movers and 57 Stayers. Findings showed that the Movers expressed higher levels of satisfaction, perceived that their lives had improved, andexperienced more integration, active goals, progress, and services. Both groups had high quality of health care and similar utilization of medications.

Report Number 3, **Quality of Life Between Institutionalized and Deinstitutionalized People in California: Intermediate Findings, 1994-1995,** was submitted in April, 1995. It extended the matched comparison design to larger groups, 118 Movers and 118 Stayers. The findings were entirely consistent with those of Report Number 2. The Movers were far more integrated, were much more satisfied with their homes, believed their lives had sharply improved, received larger quantities and varieties of services, and lived in places that were measurably more normalized and physically pleasant. However, their opportunities to make choices were no greater than for Stayers, and the Movers were more likely to be taking neuroleptic medications. The total public cost of supporting the Movers was about $54,000 per person per year, while the cost for a Stayer was about $92,000. Together, Reports 2 and 3 provided extremely strong evidence of the cost-effectiveness of community living in California. *Report Number 3 was reformatted for submission to a peer-reviewed journal, and was accepted for publication in 0Oct. 1998.*

Report Number 4 was a collection of graphs, called a Chartbook, intended for internal DDS discussion purposes only. It was not a formal report, but was created at the request of the project officer to stimulate internal consideration of the difference among the Developmental Centers.

Report Number 5, **<u>Coffelt</u> Community Target Group Class Members: Results of the 1994-95 Round of Visits and Interviews**, was submitted in September, 1995. It was a qualitative, formative analysis of 21 of the 26 Community Target Group (CTG) members. These individuals were living with relatives but needed out of home placements and supports. The study was intended to guide future interventions and actions. According to the analyses, the CTG members had very positive experiences as a result of their movement into community residences. Further, their families believed that they and their relatives were better off because of the interventions they experienced.

Report Number 6, **Patterns of Community Placement: The First 15 Months of the <u>Coffelt</u> Settlement** was submitted in October, 1995. It described people who moved from Developmental Centers to community living during the first 15 months (4/93-6/94) of implementation of the <u>Coffelt</u> Settlement Agreement. Representative samples of Movers and Stayers were drawn and visited. Comparisons of qualities of life were performed for 246 Movers and 828 Stayers, and a post-only family survey was used to elicit input from family members of the Movers. The outcome indicators revealed that people who moved were clearly better off in their new community homes. Additionally, families of the Movers perceived significant improvements. Their approval of community living more than doubled.

Report Number 7, **Reliability of the Personal Life Quality Protocol**, was submitted in December, 1995. It supported the inference that the <u>Coffelt</u> project data are generally being collected accurately, objectively, and reliably. **Report 7 was reformatted and split into two separate manuscripts for submission to peer-reviewed journals.Both are now in the review process.**

Report Number 8, **Patterns of Community Placement II: The First 27 Months of the <u>Coffelt</u> Settlement,** was submitted in February, 1996. It contained analyses of: quality of life for nonequivalent comparison groups of Movers and Stayers; a longitudinal pre-post analysis of changes in quality of life for 34 people who moved into community settings; descriptive data of mental health and crisis intervention supports; reasons for 13 returns to Developmental Centers; features and quality of supported living; mortality; and costs. Findings indicated that the 438 Movers were better off in many ways, such as being in settings of higher physical quality, being more integrated, and being more satisfied with their living arrangements and staff. Seventy seven percent of those who could respond noted that they felt good or very good about living in their current community residence. Statistically significant improvements were reported in qualities of life such as comfort, happiness, food, health, and safety. However, results were not as positive with respect to Choice making, health care, and medications.

The pre-post test results indicated that the 34 people who moved into community living experienced an improved quality of life in the areas of health, running their own lives, family relationships, seeing friends, getting out, happiness, comfort, and safety. In addition, significant improvements were noted in adaptive behavior, challenging behavior, quantity of services received, progress on individual goals, and level of integration. On the other hand, self-determination and individualized treatment did not increase, and Movers received antipsychotic drugs at a higher rate than that of the Stayers.

Twenty eight people who moved into supported living situations reflected increases in self-determination and quality, above that of other community settings. Moreover, preliminary data indicated that movement to community did not increase mortality among class members when compared to the statistical expectation for large congregate care settings. Finally, cost data showed that community care in California costs about half as much as institutional care. In several other deinstitutionalization studies, community costs were about 75% those of institutional costs, suggesting that California's community reimbursement rates are relatively low.

Report Number 9, **Impacts of the Coffelt Settlement on Community Target Group Members in 1995-96**, was submitted in May, 1996. It provided a quantitative description of the members of the Community Target Group (CTG), and a qualitative sense of what happened to the CTG group during the second full year of implementation of the Coffelt Agreement. In general, the group believed their qualities of life had improved in 10 out of 10 areas in that one year period. In fact, the CTG group experienced more self-determination than the Movers did. They were more likely to have choices in their new homes and to have choices about daily activities. CTG members were better off because of their involvement with the Coffelt Agreement, and much better off than they would have been if admitted to Developmental Centers.

Report Number 10, **Qualities of Life Among Coffelt Class Members who Moved from Developmental Centers to Community Homes, 1993-1995**, was submitted in September, 1996. This Report compared qualities of life of 455 Movers and 395 Stayers using analysis of covariance. Consistent with other reports (Reports 2, 3, & 8), the qualities of life assessed were considerably higher among the Movers, even while controlling for their differences from the Stayers. *This report was accepted for publication The reference is: Conroy, J., & Elks, M. (in press).* Tracking qualities of life during deinstitutionalization: A covariance study. *Education and Training in Mental Retardation and Developmental Disabilities.*

Report Number 11, **Results of the 1995-96 Coffelt Family Survey**, was submitted in October, 1996. Completed surveys from 48% of the Movers' families were analyzed to determine if they believed the move from Developmental Center to community housing was a good thing for their relative. The ratings showed a clear and strong belief that community placement was a good thing. Many families changed their minds about opposing community placement. A large majority of families were pleased with community supports, wanted them to continue, and would not think of returning their relatives to Developmental Centers. Report Number 11 was reformatted for submission to a peer-reviewed journal, is now in the process of consideration for publication. Didn't you say at beginning that all 5 had been accepted?

Don't know why it's greenReport Number 12, Patterns of Community Placement III: The Third Year of Coffelt Implementation, presented a series of analyses of the qualities of life experienced by class members who left Developmental Centers. Two thirds of the people who moved carried the "severe" or "profound" mental retardation label. Nevertheless, they became significantly more independent, sharply reduced their challenging behaviors, received more services and supports than they did in the DCs, , they became much more integrated into the mainstream of American life in terms of outings, and, for those who could and would communicate with our Visitors, reported themselves to be much happier in the community than they had been at the DC. In addition, their their closest caregivers reported far more "progress toward goals in the past year" than had been the case in the DCs.

In this report, we also examined supported living, presented an analysis of the Family Survey, and revisited the comparative costs issue. Supported living was associated with increased choice, individualization, and self-determination than other types of setting. The family survey revealed very strong satisfaction with community living, coupled with the perception that their relatives' lives had improved in 10 out of 10 areas of quality. Many families had undergone a remarkable change of heart about institutional versus community living for their relatives. On the issue of costs, we found again that community supports were only 54% of the DC costs.

There were problems and cautions noted in the report. In the community, psychotropic and sedative medications tended to be overused. There was little emphasis in the community on supported and competitive employment. The class members on the average had not increased their opportunities to make their own life choices, even with the assistance of unpaid friends and relatives. Nearly all decisions were still being made by professionals and paid staff. True community connections had not yet emerged for many people. Health care in the community was also problematic, because it was rated as harder to find and not as good as in the DCs. Finally, although the overall benefits were large, a number of people reported loneliness in their new community homes.

Report Number 13, **Mental Health and Crisis Services for Coffelt Class Members, 1996-1997**, from April 1997, examined mental health, crisis intervention, and medical emergency supports among 774 class members in their community homes. The Coffelt settlement mandated capacity building among the Regional Centers, so that crises could be handled effectively within the community support system. Mental health supports were rendered to 35% of our sample, and of them 22% received medications monitoring, 11% received other supports, and 2% were not sure what the service had been. Recipients of such supports were higher in adaptive behavior, and displayed more challenging behavior, than the average class member. Only 28 people were reported to be in need of, but not receiving, one or more mental health services or supports, usually counseling. There were 24 people who experienced a crisis episode in the past year that involved relocation of the person from his/her residence. Nearly three fourths of these events involved violence or uncontrolled behavior. After hours phone calls to Regional Centers received the highest satisfaction ratings, and emergency rooms the lowest.

Report Number 14, **Results of the 1996-1997 Coffelt Family Survey** (April 1997), provided the final results of the 1996-1997 Family Survey. The 218 completed surveys made up a 53% response rate from a single mailing, which was quite acceptable. Families perceived positive changes in every one of 14 distinct areas of quality of life. The largest quality enhancements were reported in "Privacy," "Happiness," "Comfort" "Overall Quality of Life," and "Getting Out and Around." These improvements did not vary by level of disability, implying that people with severe impairments were perceived to have benefited just as much as others. Families also reported that they had been considerably more opposed to community placement, when they first heard about it, than they were "now," at the time of the survey. This meant that many families have changed their minds, and their opposition has sharply diminished. Of the 203 Movers' families surveyed, only 7 continued to say they were "Strongly Against" community living for their relatives. Only 19 said they would prefer that their relatives moved back to a Developmental Center.

We also presented the verbatim responses of the 203 families to our four open-ended questions. The 1996-1997 Family Survey findings left little room for doubt: families, although many were originally apprehensive, were generally very pleased with community supports, wanted them to continue, and would not think of returning their relatives to Developmental Centers.

Report Number 15, **Impacts of the Coffelt Settlement on Community Target Group Members in 1996-1997**, extended the findings of Report Number 9 to a total of 66 CTG members we visited in this round. The results confirmed and strengthened the conclusions of Report 9. CTG members were helped greatly by the Coffelt interventions, believed their qualities of life had improved, and were clearly better off than they would have been if they had gone into DCs.

Report Number 16 was an internal working document that contained individual class member names. Therefore, it was not appropriate for dissemination. Its purpose was to permit a working group to view the utility of our newly designed Quality Feedback System data.

Report Number 17, **Patterns of Community Placement IV: The Fourth Year of Coffelt Implementation,** was submitted in January, 1998. This report contained a pre-post analyses of changes of quality of life for 91 people who moved into community settings, and quality of life and satisfaction for nonequivalent comparison groups of Movers and Stayers. In this report, we also examined people in supported living, the issue of quality in small ICFs/MR versus Waiver Homes, and an analysis of the 1997-98 Family Survey.

The pre-post results indicated that 91 people who moved into community living experienced significant improvement in the following areas: adaptive behavior, challenging behavior, quantity of services received, progress on individual goals, level of integration, self determination, individualized treatment, normalization, and satisfaction. Because the Pre-Post design is the strongest one among the six that COA has used during the course of this work, these findings were very important. Combined with the parallel findings from the other research methodologies, we felt justified in having high confidence in their veracity.

Findings among 1,073 Movers indicated that they were better off in many ways than were the Stayers. The Movers experienced significant increases in all 14 areas of quality of life that were measured on the Quality of Life Changes scale. Compared to the Stayers, theMovers were somewhat higher in self-care abilities and displayed somewhat less challenging behavior. In addition, the Movers resided in settings that were of higher physical quality, felt more satisfied with their living arrangements and staff. Also, of the Movers who could respond, 78% indicated that they felt good or very good about living in their current community home.

Analyses of people in supported living arrangements showed that these settings were more conducive to choice making, integration, and self-determination. The supported living model was also being used to support people with major behavioral challenges.

The comparison of similar groups living in ICF/MR settings and Waiver settings provided strong evidence that Coffelt class members who were Waiver recipients were enjoying program qualities and outcomes that were significantly superior to those experienced by similar people living in Intermediate Care Facilities (ICFs/MR).

The 1997-98 Family Survey showed that families perceived their relatives' lives had improved significantly in the 14 out of 14 areas of quality assessed. The families expressed high satisfaction; 76% reported that they felt happy or very happy with their relatives' community homes.

Selected portions of Report 17 were reformatted and submitted for publication in an academic journal in the summer of 1998. ????Current Status????

Report Number 18, **Selected Findings of the Coffelt Quality Tracking Project** was submitted in June, 1998 and examined several topics of interest among the 1215 class members we visited that year. The first topics of interest involved mental health care, crisis intervention, and medical emergency supports among 1159 class members in their community homes. Mental health supports were delivered to 26% of our sample. Simple medication monitoring was provided to 12%, and services and supports other than or in addition to medication monitoring were provided to 5%. Nine percent of the respondents were reported to receive both medications monitoring as well as some other types of services or supports. Recipients of such supports were higher in adaptive behavior, but displayed more challenging behavior, than the average class member. Only 22 people were reported to be in need of, but not receiving, one or more mental health services or supports. Mental health counseling and therapy were the most common unmet needs reported.

There were 49 people who experienced a crisis episode during the t year of interest that involved relocation of the person from his/her residence. Supplemental supports received the highest satisfaction ratings, and incarceration the lowest.

The second topic of interest concerned the well being of the Coffelt class members known as the Community Target Group (CTG). In general, the group believed their qualities of life had improved significantly in 12 out of 13 areas assessed over the one year period. In fact, the CTG group experienced more self-determination than did the Movers. Staff reported high levels of job satisfaction both in general and working directly with the CTG members. The analysis of the CTG members provided compelling evidence that they arewere 1) better off than they would have been without the Coffelt intervention and 2) much better off than they would have been if they were living in Developmental Centers.

Report 18 also examined the class members who now live in large congregate settings, plus the situations of class members under age 18.

Report Number 19, **The Coffelt Quality Tracking Project: The Results of Five Years of Movement From Institution to Community**, was a summary document intended for wide distribution. It contained a succinct Executive Summary, and was written in a style for broad audiences. It contained no new analyses beyond those presented in prior reports. This was the "final report" of the first four years of the Quality Tracking Project.

Report Number 20, **Patterns of Coffelt Placement Practice and Indicators of System-Wide Quality**, was a description and summary of elements of individual and systemic feedback loops that we hoped would be ongoing in order to protect peoples' rights and entitlements. First, we broke down quality indicators by Regional Center to test for variations in quality. We found substantial variations in the characteristics of the class members across the RCs (age, percentage minority, challenging behavior, and adaptive behavior). Some RCs focused on bringing only the most capable people out of Developmental Centers, while other RCs brought out people with very limited functional abilities. For example, the "percent labeled profound" among Coffelt Movers in the RCs ranged from 16% to 95%. These variations made direct comparisons of quality indicators across the RCs difficult. The comparisons could be made, but only with great care and caution. We demonstrated a method for fair comparison of RCs in this Report.

This Report also summarized the individual information we provided to DDS in our Quality Feedback System. We produced individual class member "report cards" in February of 1998. We provided one "report card" for each of the 1,215 Coffelt class members we visited. On these "report cards" we included both positive and negative quality dimentions, such as having gained a great deal in independence skills in the past year (positive) or not having an Individual Plan (negative). These individual "report cards" were distributed to the 21 RCs with a request for feedback about actions taken to remedy undesirable situations or to congratulate consumers and providers for excellence.

Summary Statement on the Empirical Evidence on California's Deinstitutionalization Movement

In all of the studies summarized above, we have found that the Movers, as in other studies, experienced major gains in many areas of quality of life dimensions. A major study conducted by Berkeley Planning Associates has replicated and strongly confirmed our results (BPA, 1998). We have also found that community care in California costs a great deal less, even for similar people, than institutional care. The cost analyses included consideration of transportation, day programs, health care, and other relevant "hidden" costs. However, I have consistently raised concerns about the overuse of psychotropics, the lack of attention to vocational programs, and the serious underfunding, of community programs.

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Following the above 17 reports, COA was contracted to conduct three more years of study of the outcomes of community placement for the 2,400 people who moved. In this work, we visited every person once a year for three years. The executive summary of this project is reproduced below. The findings were remarkably consistent with all of the earlier work: the "Movers"were, on the average, significantly better off than when they were in institutions – and in a variety of important ways. These included freedom, choice, self-are skills, reduced challenging behaviors, integration, service provision, and so on. Moreover, their families believed they were much better off than they were before in all 14 of quality of life dimensions assessed.

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

Executive Summary

This is the final report of the 3 year Coffelt Quality Tracking Project. The report is concerned with the well-being of more than 2,200 Californians with developmental disabilities who moved out of Developmental Centers, mostly during the 1990s, and who now reside in community homes. There has always been one central question this project has been designed to answer: Are they better off?

A very clear answer has emerged from both this and the previous body of 5 years of work, which was often called the Coffelt Study. With five separate research designs and more than 25 formal deliverable reports, we conclude that the answer was a strong "Yes."

For the people who moved out of Developmental Centers under the Coffelt settlement agreement, careful monitoring was very important. Most of these people carried the labels "severe" or "profound" mental retardation, and more than half were not able to use language. They were very vulnerable people, and as the law that created the Quality Tracking Project stated,[1] California had a definite responsibility to watch out for their well-being after they left state-operated facilities.

However, the final Project was also designed to do much more than answer that single central question. Procedures used in the previous Project had become a firmly established part of California's monitoring of community programs for people with developmental disabilities. For every one of the people we visited in the last year, we not only collected quality of life data, but also we completed a Quality Feedback Summary form which summarized things in each person's life that demanded a "second look" by Regional Centers, case managers, families, and/or other advocates and allies. This system was created so that problems could be detected and addressed quickly. Our Quality Feedback Summaries were FAXed or quickly mailed to our Regional Center contacts for review and action.

The Report is presented in five major results sections: Three Years of Family Surveys, Pre-Post Analyses from 1994 to 2002, Quality Feedback Summaries, Analyses of Quality Changes in the Community from 2000 to 2002, and Feedback About the Visitors and the Process of Data Collection.

Family Opinions

For the first time the information obtained from the families of the Movers has been placed at the front of the report. The Family Survey data from the entire past 3 years has been combined into one large analysis. These findings were given precedence in this report because they and should continue to be an important contributor to public policy. As noted in the Lanterman Act,

> **A consumer of services and supports, and where appropriate, his or her parents, legal guardian, or conservator, shall have a leadership role in service design. §4501**

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[1] That section of the law is reproduced herein as Appendix A.

Moreover, the Family Survey findings have been quite dramatic. Families have changed their opinions over these last 9 years toward favoring community living. On the whole, they have been extremely satisfied with the community situations of their relatives. They believed their relatives have sharply better qualities of life now in 14 out of 14 dimensions. The overwhelming majority of families would not want their relatives to return to a Developmental Center.

From a list of 30 dimensions of quality of life and service, the 5 valued most highly by families were, in this order: Health, Freedom From Abuse, Safety, Medical Attention, and Comfort.

Are They Better Off Than They Were in Developmental Centers?

Using the Personal Life Quality protocol, the study team collected data on the qualities of life of many of the Movers (the people who eventually moved from Developmental Centers to community homes) back in 1994. We visited them again eight years later visited them again, and were able to compare qualities of life and service in institution and community.

The findings strongly supported the findings that the Movers were, indeed, better off in the community than they were in Developmental Centers. From among 21 major indicators of quality, these 11 changed significantly for the better:

Progress Reported Toward Individual Plan Goals
Choice making
Integration
Reduced Challenging Behavior
Qualities of Life Ratings in 14 Dimensions
Individualized Practices Scale
Hours of Day Program Services
Number of Services in Individual Plan
Staff Like Working With This Person
Staff Job Satisfaction
Staff Get Sufficient Support

Some of these dimensions of quality reflected essential intents of the Lanterman Act, and the improvements in those dimensions were very large. For example, the Lanterman Act mandates an individual planning process that results in specific written goals for each person. Our results showed that reported progress toward individual goals increased from 46 out of 100 points back at the Developmental Center, to 77 out of 100 points in the community.

The increases in opportunities for choice making are also large --- 14 points on a 100 point scale. This positive outcome was closely associated with another Lanterman Act mandate:

Consumers of services and supports, and where appropriate, their parents, legal guardian, or conservator, should be empowered to make choices in all life areas.

The Quality of Life ratings that were collected for people when they were living in Developmental Centers averaged 71 points, whereas in the community they averaged 80 points out of a possible 100. Moreover, the scale taps 10 dimensions, including health, safety, happiness, and family relationships, and all 10 weresignificantly higher now than before.

For the Movers who could be directly interviewed (about 20%), the vast majority expressed the belief that their lives had improved greatly and they were very happy with their community homes. They, too, were clear in their strong feelings that they did not want to return to a Developmental Center.

Despite these positive gins, there were four areas in which people were not better off. People were not seeing the dentist as often as before, they are earning even less money per week on the average (although this was always a very low figure, about $5 per week, and now it is down to about half that when assessed), there was a perception that health care was not quite as good as it used to be, and it appeared that people (and those who answered for the people) reported fewer close friends than before (down from an average of 3 to 2).

When combined with the opinions of the families, the weight and breadth of the scientific evidence strongly supported California's decision to provide community homes for the more than 2,000 people who left institutions. Combined with the knowledge that the community supports were less costly than the Developmental Centers,we inferredence this to be good social policy.

Quality "Report Cards"

For each visit to a Mover, a special form was completed that recorded carefully selected situations. A Working Group with broad representation selected exactly which situations would be on this "report card." (We called it the Quality Feedback Summary.) Both positive and negative situations were represented. These "report cards" were individually delivered to the appropriate Regional Centers so that they could help remediate the negative situations, and give congratulations for the positive situations.

The most frequently reported negative situationswere: that no unpaid people were involved in the person's life; that a person was allowed very little opportunity to participate in his or her life choices; and the person was receiving three or more psychoactive medications.

The most common positive reports were that people were treated very much as individuals. That is, they had freedom to move about their communities (with support) almost whenever they wanted, and their perceptions about their qualities of life were dramatically higher than when they lived in institutions.

By counting how many positive and negative things were in each person's report card, we derived an index that could be compared across groups, such as by type of living situation or by Regional Center. In this report, we presented an analysis of these "report card" quality indicators across Regional Centers. The variations were large. As such, this technique may hold tremendous potential for system improvement.

Changes in Quality from 2000 to 2002

On the issue of quality changes within the community over the 3 year period, we reviewed the last year's findings, reported on another year of data, and attempted objective interpretation. Last year's findings were generally replicated by the new year of data. However, the negative trends that appeared in last year's data did notemerge. InFor example, the apparent decrease in Adaptive Behavior from 2000 to 2001 was not observed in 2002.

The pattern of changes over 3 years is complex. The most encouraging changes among 10 key indicators were: that the average time spent in Day Activities had been increasing; treatment of people as individuals had been increasing; our measure of person-centered planning had been increasing; and people's opportunities for choice making have been increasing. For each of the negative trends observed last year, this final year of data show that the people remained roughly the same or improved in a lot of dimensions.either got better or did not get worse.

The Process of Visiting the Movers

At each visit a postcard was left for the person or the person's closest staff to "rate" the Visitor and the survey process. The ratings showed that the Visitors were overwhelmingly: considerate in scheduling, were on time for appointments, tried diligently to communicate directly with the people with disabilities, respected the time and space of others in the home, and were pleasant and courteous. The open ended comments on the postcards showed that the people and their staff found the visits to be non-threatening, professional, interesting, and even enjoyable. Many commented that they hoped the process continues.

Summary of Outcomes
For 179 Movers in California

Quality Dimension	Pre	Post	Change	Outcome
Progress Reported Toward IP Goals	45.7	77.0	31.3	Positive
Number of Services in Individual Plan	6.1	9.0	2.9	Positive
Hours of Day Program Services	23.7	28.4	4.7	Positive
Earnings	5.20	2.54	-2.66	Negative
Number of Close Friends Reported	3.3	2.3	-0.9	Negative
Integration	14.0	27.2	13.1	Positive
Qualities of Life Ratings (Now 1994-Now 2002)	71.4	80.2	8.8	Positive
Staff Job Satisfaction	8.8	9.3	0.5	Positive
Staff Like Working With This Person	8.3	9.5	1.2	Positive
Staff Get Sufficient Support	4.1	4.6	0.5	Positive
Number of Daily Medications	4.8	5.2	0.4	Not Signif.*
Number of Psychotropic Medications	0.4	0.4	0.0	Not Signif.*
Health by Days Ill Past 28	0.5	0.7	0.2	Not Signif.*
Perceived Quality of Health Care (Staff responses)	4.7	4.3	-0.3	Negative
Doctor Visits Per Year	37.4	14.9	-22.5	Unclear
Dental Visits Per Year	2.3	1.7	-0.6	Negative
Relative Visits Person Here At This Home	11.6	9.0	-2.7	Not Signif.*
Individualized Practices Scale	61.7	69.5	7.9	Positive
Adaptive Behavior	44.8	45.3	0.5	Not Signif. *
Challenging Behavior	68.0	78.3	10.3	Positive
Choice making	31.7	45.8	14.1	Positive

* "Not Signif." means the change did not attain statistical significance at the .05 level by Paired t-test and is therefore not labeled as either positive or negative.

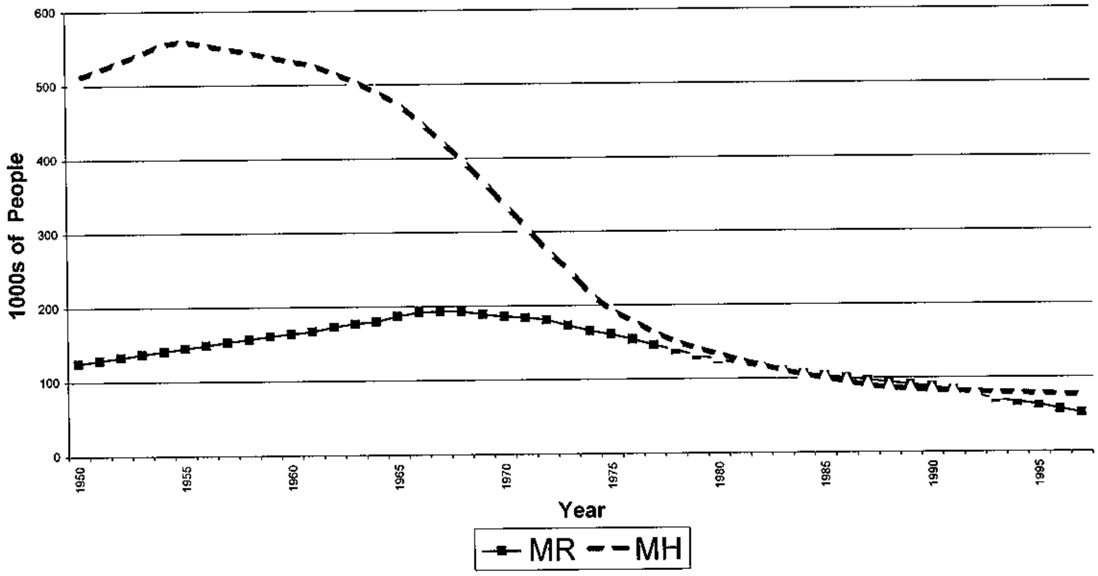
2) Deinstitutionalization in the Developmental Disabilities Field Must be Clearly Differentiated from Deinstitutionalization in the Mental Health Field.

Many people, including national radio and television commentators, have failed to recognize this fact:

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

I believe the misunderstanding is largely due to the confusion of mental health/mental illness with mental retardation. State institutions for mental illness have experienced an entirely different, and devastatingly negative, depopulation movement (Bassuk & Gerson, 1978, *Scientific American*). The graph below contrasts the depopulation of mental health institutions against the deinstitutionalization of public institutions for people with mental retardation.

Deinstitutionalization in the United States:
Mental Retardation vs. Mental Health, 1950-1997



Deinstitutionalization of people with mental illness was done hastily, without outside supports, and largely with reliance on the "new miracle drugs" approved by the FDA in 1955 (e.g., the chlorpromazine derivatives, such as Haldol, Mellaril, Thorazine, and so on). The phrase "dumping" came from the fact that tens of thousands of people were simply "discharged" with 30 days of "miracle drug" with no place to live, no job or daytime activities, and no support or assistance to reestablish family relationships. These procedures were led by policy makers in

California during the 1960s and 1970s. These policies continued and spread to other states as a "solution" to overcrowded institutional settings that were unable to deliver adequate clinical services. The result has been a national disgrace, including a major portion of the problem called "homelessness" (Alexander, 1996) and criminal recidivism. As Alexander wrote,

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

I believe that it is absolutely essential that the court understand the stark difference between the national record in mental health versus that for mental retardation and developmental disabilities. Jim, might also want to mention the huge difference in the **numbers** of MH people hospitalized from 1960 about 1978 and the rapid decline through the year 1980 when the number of MH hospitalized roughly equals the number MR/DD institutionalized. Also must note the strark diff in # of MH people hosp 1960 – 1976 vs MR/DD. Without any social policy or supoorts, depopulation of MH instutions was bound to be disastrous from the get go.

In the case of people with developmental disabilities, moving from large institutions to small community homes has been <u>extremely</u> successful.

3) **Family Attitudes Change Dramatically**

It is well established that the majority of families of people living in institutional settings are convinced that their relatives are receiving good care, and that they are in the best possible situations for them (Spreat, Telles, Conroy, Feinstein, & Colombatto, 1987).

For decades, however, some researchers have openly questioned the strength of parental defense of the institution's quality and appropriateness. Klaber (1969) surveyed parents of people in institutions in Connecticut. He found that more than three fourths of them were convinced of the excellence of the facilities. As he summarized, *"The parents...were convinced of the excellence of the facilities in which their children were placed ... The praise lavished on the institutions was so extravagant as to suggest severe distortions of reality in this area."*

Although parents and other family members approve of the institution, and reject the idea of community movement, these attitudes are not necessarily unalterable. I first detected the phenomenon of dramatic attitude changes in the Pennhurst Longitudinal Study (Conroy & Bradley, 1985). Before community placement, the great majority of families opposed movement of their relatives into CLAs. After community placement, the proportion of families strongly favoring community placement rose dramatically, from less than 20% to over 60%. Similar results were obtained in the Mansfield Longitudinal Study in Connecticut. Tabular and graphical summaries of the overwhelming changes in family attitudes have already been presented.

In addition, it is important to note that radical family change in feelings about community living have recently been documented by other respected researchers in California (Berkeley Planning Associates, 1998). Their table VII-3 of "How Families Saw Community Placement: *Then and Now*" replicates our own Table 20 of Report 17 (Conroy, Seiders, & Yuskauskas, 1998) to within a few percentage points in practically every cell, and shows even stronger post-relocation satisfaction than we found (89% vs. 83%). Hence there can be little question of the high family satisfaction with California's community alternatives to Developmental Centers.

4) The Theory of the "Must Stay" Group is Not Supported

There are four classic reasons given for keeping people in large segregated settings. These have been almost completely discredited by carefully controlled studies of community placement, by the evidence from total closures during the past 15 years, and by the pattern of recent placements out of Southbury itself. The four reasons have been:

1. People with limited adaptive behavior skills, such as those labeled "severe" or "profound," cannot benefit from community homes.
2. People who exhibit severe challenging behaviors when living in institutional settings cannot be handled in community settings.
3. People with extraordinary medical needs can only be properly cared for in large, centralized, hospital-like settings with doctors and nurses on staff.
4. People who are of advanced years, and have lived in a given institution for essentially their entire lives, do not want any other kind of home, would not benefit from a new home because of their age, and should basically be left where they are.

All four of these rationales have been called into serious question by the research, and even more strongly by the total-closure research data. Pennhurst, Mansfield, Laconia, Hissom, and other institutions have been closed without moving people to other institutions. In these and other closures, community services systems have been created that provide excellent supports for people of all kinds. Today, 40% of America's institutions have been closed, and nearly all of the rest have been downsized. There are now ten states that have completely eliminated institutions as an option.

In these instances, everyone moved into the community. This included people who are "low functioning," who, in my research, tended to benefit the most in some important ways. When people who are labeled severely or profoundly retarded move into family-like community settings, they often showed even greater gains, proportionally, in adaptive behavior than persons labeled mildly and moderately retarded. No support exists for the proposition that some people are "too low functioning" to succeed in the community. In fact, empirical evidence supports the contrary (Conroy & Bradley, 1985; Stull, Conroy, & Lemanowicz, 1990). , Studies have shown time and again that the gains made by persons with severe and profound disabilities upon moving to small community homes from large institutions are initially rapid and immediate and continue to improve over time.

The figures for institutional populations nationwide show that roughly 85% of institutional residents are labeled severely or profoundly retarded (Amado, Lakin, & Menke, 1990). In New Hampshire, the Laconia State School closed in 1990, and 78% of its population was labeled severely or profoundly retarded. Pennhurst is closed, and nearly all of its residents are in community settings, yet 86% of its population was labeled severely or profoundly retarded. The overwhelming evidence that level of disability does not preclude a person from experiencing benefits from moving from a large, group-oriented "facility" to a small, individual-oriented "home" is overwhelming Of the 373 people my team tracked out of Mansfield Training School during our study, 82% were labeled severely or profoundly retarded. They are doing extremely well also.

The research findings are conclusive, and form the basis for my opinion in this regard: level of disability does not provide a rational basis for keeping anyone in a large congregate care setting.

There is also a data base for rejecting the second rationale for continued institutionalization. The evidence is based on the experiences of people who displayed very serious challenging behaviors while living in the institution, and continued to do so for weeks, months, or years in community settings, but who now, removed from unnecessary restrictions and/or deprivation and/or abuse, have radically changed the way they act toward themselves and others. We know that, on the average, community movement will tend to reduce challenging behaviors. But this facet of the argument is aimed at the extreme cases, those who appear to present a danger to self and/or others -- people with "severe reputations" (Smull, 1995).

Common sense and concern for the safety of the community must, in theory, lead to defining certain kinds of behaviors that should not be "risked" even in a 24 hour supervision situation in the community. Serious criminal behaviors that could harm others would certainly provide a rational cause for considering non-integrated service settings. Although even such cases have been successfully supported in community settings (Smull, 1995), certain risks should not be taken until such time as a service provider is demonstrably able to provide acceptable levels of safety.

The third "must stay" group, people with urgent medical needs, have clearly been served well in community based settings. Many such people received community homes and supports in the Mansfield deinstitutionalization. Among the 957 people my team visited in 1990 in their community homes, 67 were described as "Would not survive without 24 hour medical personnel," or "Has life-threatening condition that requires rapid access to medical care." These 67 people were doing quite well in their community homes at that time. It would be of great interest to visit them today, to see whether or not their health has changed after 7 to 10 years of community living.

More recently, I have witnessed what I perceive to be extremely high quality and medically safe community homes in Oklahoma (August 1995), for people with tracheotomies, ventilator assistance, and non-oral feeding methods. Many of the Hissom class members in Oklahoma have very serious medical needs. These are being met in small community based supported living situations. I believe these people are receiving more individualized and more humane support than before, by a wide margin. People with such extraordinary challenges benefit even more than others from individual, one to one attention, whether it is medical, social, behavioral, or friendship. I do not believe that health care on a "ward" or any large unit can possibly compare to the quality provided in these individually designed supported living situations. There are videotapes of high intensity health care settings available through the Panel of Monitors appointed by Judge James Ellison.

The final rationale for keeping people in institutional settings is advanced age and the notion that the institution has become "home" for many people. However, data from within my own extensive research has demonstrated that people over 80 years of age have moved out of institutions, have adapted to the change, and even thrived in their new community homes. Many of those who can communicate have reported a major change from fear of the unknown (often exacerbated by well-meaning institutional staff) to delight with new experiences and new opportunities. Of the 957 Mansfield class members my team visited in community homes in 1990, 156 were age 60 or over, 16 of them were 80 or over, and one person was 93.

For this report, I returned to the Mansfield data base, and calculated the gains in independent functioning experienced by younger and older "Movers." For the people who moved from congregate care to community settings between 1985 and 1990, the average gain on the 100 point "Adaptive Behavior scale," our measure of independent functioning, was 4.1 points. For those under 60, the average gain was 3.9, while for those 60 and over, the average gain was 4.7 points. The older Movers actually benefited <u>more</u> in this outcome dimension than the younger Movers.

Finally, however, society must decide what is the right thing to do when a person has spent a lifetime in one setting, has been shown several new options, and continues to make an informed judgment that living in a large segregated setting is what he/she wants. It does seem abundantly clear, however, that that person's parents and relatives <u>must not</u> be permitted to unilaterally make such a decision. If the person cannot speak, then a person centered planning team is the only correct way to approach the future. Relatives, if given community veto power, would have prevented nearly all of the extraordinary benefits that have accrued to over 100,000 Americans in the past 30 years, primarily because of fear of the unknown. No single party can be given veto power over something that has so clearly benefited the vast majority of people who have experienced it.

The experience of deinstitutionalization of people with developmental disabilities demonstrates that it is possible to place <u>all</u> residents of a state institution into small, integrated residential settings in the community. Deinstitutionalization can be accomplished without adverse "relocation" effects upon consumers. When placements are made deliberately and with the involvement of families and consumers in the process, there is no evidence of "relocation trauma," that might produce increased mortality and morbidity, after community placement (Conroy & Adler, 1995). Moreover, community placements have consistently been shown to be cost-effective. My opinion is, therefore, that the four classic reasons for keeping people in large, segregated, isolated, institutional settings has not been supported by the "data." In fact, the "supposed data supporting the four classic reasons, does precisely the opposite: it supports moving these individuals out of institutions and into the community.

5) Community Support Systems are More Cost Effective than Institutional Systems

Community service models are less costly than institutional models. All studies published thus far are consistent (Ashbaugh, 1984; Conroy & Bradley, 1985; Jones, Conroy, & Lemanowicz, 1984; Nerney & Conley, 1982). It must be recognized, however, that this is, at least in part, because staff salaries and benefits are significantly lower in community service systems than in institutional ones. Hence, the most appropriate conclusion is that community services do cost less, but they should not.

Moreover, community services are able to obtain Federal reimbursement at the same rate as STS, primarily through the so called Medicaid Waiver program. California is an active participant in the Waiver program, and hence community supports can receive the same rate of Federal support as the institution.

The Medicaid Waiver regulations required that each state that was granted a Waiver must cause to be conducted an Independent Assessment every three years. The regulations specified that the assessment must cover quality of care, access to care, and cost-effectiveness. This is the same type of Medicaid Waiver which has been used to fund movement of persons to the community in California.

To date, more than 100 Independent Assessments of Home and Community Based Waivers have been performed in the area of developmental disabilities. Perhaps the most telling point about the costs of community living is this: not a single Independent Assessment has yet concluded that institutional care has been more cost-effective than community care. This holds true across the more than 45 states that have been granted waivers, including California. The formal reports of these Independent Assessments are filed at the headquarters of the Health Care Financing Administration. These Independent Assessments comprise a formidable body of knowledge about the quality and cost-effectiveness of Waiver services.

Nationally, the average cost of an institutional setting is about $98,000 per person per year (NASDDDS). The average inclusive cost of community supports, usually group homes plus day programs plus transportation plus case management and administration, is less than $60,000.

In the Mansfield study, the cost of the institution grew to double the cost of community care toward the end. During the majority of the downsizing process, community costs averaged between 75% to 85% of institution costs. In Pennsylvania, the community cost was approximately 85% of institution costs. In New Hampshire, the figure was 86%. In California, the ratio is about 55% (which I have characterized as an "underfunded" community service system).

There can no longer be any serious doubt that community services are more cost effective than institutional systems. The reasons for this are well understood. Staff salaries and benefits are at the heart of the difference in costs. Moreover, it is often noted that larger settings should enjoy "economies of scale," but anyone who has studied economics will know that there are also inevitable "diseconomies of scale" that arise in organizations that are too large. My opinion is that, when we are in the business of creating homes for people, those diseconomies begin to set in at about size 4.

6) The Research Findings Are Remarkably Consistent

As already mentioned, Larson & Lakin (1989 and 1991) undertook a meta-analyses of all rigorous studies of deinstitutionalization's impacts on independent functioning, and on family satisfaction. They are currently updating their 1989 analysis of studies on independent functioning. They found complete consistency in the literature. No researchers have yet found that people become more dependent when they move to the community. One report found no change, and all the others found significant improvement.

Similarly, no researchers have found families to be less satisfied with community homes than with the institution, even though families tended to be very satisfied with institutional care as long as their relatives were in institutions. The following table shows many, but not all, of the community placement processes that have been scientifically studied, with a small description of what took place.

State	Time Period	Notes
Arizona	1992-1997	Closed Ft. Stanton 1996, one WHAT? left
Arkansas	1983-86	Slow depopulation studied by Rosen (1985)
California	1993-1998	Coffelt settlement, 2400 movers, largest and fastest in history
Connecticut	1985-1994	Mansfield closed 1994
Louisiana	1980-1998	Gary W. or "Texas Children" lawsuit brought 600 back to LA, and then into community
Maine	1990	Pineland closed, only one Center left
Michigan	1975-1995	Plymouth Center and others closed during 20 year buildup of community capacity, led by Macomb-Oakland Regional Center; only 250 people with mental retardation still in institutions, largest state to be almost institution-free
Minnesota	1980-1998	Rapid downsizing of all facilities, closure of some
New Hampshire	1992	Became first state to have no citizen in a public institution
New Jersey	1988-1998	Johnstone closed 1991, North Princeton closed 1997
New Mexico	1996	Became institution-free with closure of last public facility
New York	1994	Governor announced goal of no institutions by 2000 (not currently keeping up with goal)
North Carolina	1991-1998	Thomas S. lawsuit resulted in movement of nearly 1,000 people with dual diagnoses out of Psychiatric Hospitals
Oklahoma	1988-1992	Hissom Memorial Center closed under court order, but ahead of schedule, with the best outcomes yet measured anywhere (Conroy, 1996)
Pennsylvania	1978-1987	Took 9 years to close Pennhurst, most closely studied closure of all time
Rhode Island	1995	Became institution-free after a long policy of community placement
Vermont	1996	Became institution-free
West Virginia	1985-1998	Continual gradual process of placement and closure

The following table offers further evidence of the consistency of findings across studies. As Larson & Lakin (1989) found in their meta-analysis of all rigorous studies, adaptive behavior (independent functioning) was found to increase in deinstitutionalization studies. In our own deinstitutionalization studies, we found a pattern of increasing independence according to how many years people have been out in the community.

State	# of Years	Time-1 Average Adaptive Behavior Score	Time-2 Average Adaptive Behavior Score	Gain on 100 Point Scales
Pennsylvania	14 years	39.8	50.2	10.4
New Hampshire	8 years	53.0	62.3	9.3
Louisiana	7 years	56.2	64.2	8.0
Oklahoma	6 years	41.3	47.4	6.2
Connecticut	5 years	49.5	54.0	4.5
California	3 years	44.7	46.7	2.0
North Carolina	2 years	52.7	54.8	2.2
Kansas	1 year	33.1	34.8	1.7
Indiana	.5 year	46.4	48.8	2.4

One of the primary goals of all services and supports for people with developmental disabilities is to permit and assist them to learn, grow, develop, and achieve the highest level of independence of which they are capable. The results in the table above provide compelling evidence that people grow, learn, and develop over long periods of time once they move out of institutions. The more the years of community living, generally the higher is the gain in independence. These outcomes are strong, favorable, and consistent with all published research literature.

7) <u>Community Living is Not Without Problems, and Requires Protections</u>

It is clear that the overwhelming majority of people can be expected to have very positive experiences with community living. Yet it must be recognized that a small proportion of people will have serious difficulties in the community. The evidence must be examined carefully to see what proportion of people will have difficulties, what kinds of difficulties, whether we can predict which people will have difficulties, and therefore whether it is possible to prevent even those relatively infrequent difficulties. Finally, a balanced analysis must compare the proportion of people who have difficulty in the community to the proportion of people who have difficulty in the institution.

There are certain protections that appear to be very important for people who move from institution to community. My colleagues and I studied these protections for many years in the Pennhurst experience, and found that the people who enjoyed these protections fared far better than their non-class-member who did not have these protections. These special protections were: case management requirements, a specific individualized planning process and format, and monitoring (Sokol-Kessler, Conroy, Feinstein, Lemanowicz, & McGurrin, 1983).

These older terminologies translate readily into more modern terms: support coordination, person-centered planning, and quality assurance. With such protections, I believe favorable outcomes for the Southbury residents who move from institution to community will be obtained in the great majority of cases. Moreover, for people who do experience difficulties, such protections should guarantee early detection and intervention to remedy problems.

The importance of a quality monitoring system is not just to find out "whether the court was right" when the entire process is completed. It is equally (and possibly more) important to be able to detect flaws during the process. In my opinion, any Order or Settlement in the Southbury case should include a requirement for "formative evaluation" and quality monitoring to be conducted and any problems to be remedied promptly, thus ensuring quality services for class members. This mechanism must be founded on individual outcomes and quality of life measurement. There is no interest in this era in certifying or accrediting "programs" or "facilities." We have the technology and the experience necessary to cost-effectively monitor each individual's situation and progress.

The topic of abuse and neglect fits into the assertion that community living is not without problems. It is often asserted that it is easier to detect and remedy abuse in a tightly controlled environment such as a developmental center. I have never seen a shred of evidence for this contention. In contrast, I have seen dozens of investigations, both sociological and criminal, in which Developmental Centers have been accused of generating a "culture of immunity and/or silence" in which staff can do whatever they like without fear of reprisal (see, for example, the record of undercover State Police placements on staff at Pennhurst and at Western Center). On the other hand, abuse occurs in community settings as well. The best question would probably be, "In which type of setting is there less abuse and neglect?" To my knowledge, that question has never been answered satisfactorily by research, primarily because the vast majority of abuse is known to be "covered up" in institutional settings, and may also be covered up in the community.

I do believe that the classic experiment conducted by Zimbardo and colleagues at Stanford in 1971 is relevant to the question of abuse in large, segregated settings where power is given to one group over another (Haney, Banks, & Zimbardo, 1973). In that experiment, young male students at Stanford were specifically selected as well-adjusted and mentally healthy. They were randomly assigned to the role of either guard or inmate in a simulated prison situation. All participants knew that this was an experiment, and indeed, the simulated prison was constructed in the basement of the psychology building on the college campus. Nevertheless, half of the inmates were removed from the experiment early because of serious psychological reactions including submissiveness, depression, self-doubt, and loss of hope. The entire experiment, designed to last several weeks, was halted at 6 days because of abuse inflicted by the student "guards" upon the student "prisoners," which was not only of a serious nature, but it was purposefully hidden from the investigators and their video cameras.

Zimbardo concluded that, among other things, the ability to depersonalize the inmates was crucial to the guards' ability to treat them as less than human. This phenomenon is intensified as settings become larger and larger, and is diminished in small settings. In my opinion, in a very small setting, care "givers" simply cannot perceive care "receivers" as faceless non-individuals in a group.

One important protection against abuse is a rigorous quality assurance system, including the following components: (a) values-based quality assessments conducted, in part, through frequent visits to consumers by parties independent of the service provider; (b) quality enhancement, including technical assistance and training for providers; and (c) corrective remedies and sanctions where required.

One related question that continually arises is "What is it about community living that accounts for the clearly established superiority in so many qualities of life?" The reasons why these benefits have been observed so consistently are becoming increasingly clear. The major reason is simply the smaller size of community homes. I believe that the organizational and economic literatures are completely clear on the conclusion that small group size for daily work and functioning produces higher satisfaction, productivity, and efficiency. This conclusion arises from a multitude of studies of human activity across a variety of settings. Gooding and Wagner (1985)provide the best summary of 100 years of this research .

Specifically in the field of developmental disabilities, Klaber (1969) was the first to point out the importance of small units for daily living and functioning. Since that time, researchers in developmental disabilities have continually added to the understanding that smaller living units are associated with higher quality of life and better outcomes, and these research findings have been documented in my own doctoral dissertation (Conroy, 1992). Research has also shown that simply "breaking up" institutional wards into smaller "walled off" subunits is emphatically not the same as moving to genuinely smaller homes (Harris, Veit, Allen, & Chinsky, 1974).

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