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SELECTED FINDINGS FROM TWO DECADES OF RESEARCH ON COMMUNITY VERSUS INSTITUTIONAL LIVING

The 12 tables and graphs that follow are about Pennsylvania's movement away from large, segregated settings for people with mental retardation and other developmental disabilities. The tables and graphs make these points:

1. **"The Decline of Institutions and Growth of Community Homes"**
The number of Americans living in state operated institutions has been falling for 25 years, and the trend is still continuing. Pennsylvania has a history of being a leader in the development of quality homes in communities.

2. **"PA State Center Discharges 1987 to 1994"**
In Pennsylvania in recent years, the momentum to decrease our reliance on institutional models has slowed considerably. In 1987-88, over 700 Pennsylvania citizens moved from State Centers to new homes in the community. In 1993-94, fewer than 100 moved.

3. **"The Pennhurst Longitudinal Study - Areas of Enhanced Quality of Life"**
From 1979 to 1985, the Federal government sponsored the largest study of movement to community living ever done. the Pennhurst Study. The study found improvements in almost every measurable quality of life dimension. This was the strongest evidence yet produced showing the vast superiority of community living.

4. **"Outcomes Associated with Deinstitutionalization, Connecticut, 1985-1990"**
Soon afterward, findings equally strong and consistent were produced in Connecticut.

5. **"Parallel Findings in Other States, 1975-1993"**
Over a 20 year period, every study found the same pattern as was found in Pennsylvania.

6. **"Pennhurst Longitudinal Study - Family Attitudes Toward Community Placement, Before and After"**
The parents of people in institutions favor the institutions, and nearly all strongly oppose movement to community homes. In the Pennhurst Study, we were able to ask parents how they felt **before and after.** The changes in their attitudes were dramatic.

7. “Pennhurst Class Members in 1991: Family Satisfaction with Community Homes”

After the end of the Federal Pennhurst Study, Pennsylvania continued to monitor the well-being of the Pennhurst class members. Every family has been surveyed every year. In 1991, 6 out of 472 families reported “Strong Dissatisfaction” with their relatives’ community programs. The fears of the families, although genuine and heartfelt at first, have almost completely vanished. Many families have difficulty remembering and understanding their initial resistance to community living. Hundreds of direct quotes are available from Temple University.

8. “Pennhurst Longitudinal Study -- Proportional Gains in Self-Care Skills by Level of Mental Retardation”

It is **not** true that only the “higher functioning” people benefit from movement to community living. In some ways, the most impaired people make the biggest gains.

9. “Would You Want to Go Live in a Group Home?”

In 1988, researchers visited and collected quality of life data for every person living in a State Center. An attempt was made to interview each of the 3,769 people. The question was asked “If a group home or apartment were developed for you, would you want to live there?” Of the 924 people who were able and willing to answer this question, **66.5% said “Yes**.”

10. “Adaptive Behavior Growth by Size of Community Home”

Some people believe that Pennsylvania’s community program has been very successful because the homes (CLAs) were kept **small**. Recent research in Oklahoma lends very strong support to this idea. People in larger homes did not make much progress over a 5 year period.

11. “Average Annual Cost by Size - PA CLAs and ICFs, 1995”

Some people believe that smaller settings cost too much. This is certainly not a powerful effect in Pennsylvania, if it is true at all. **Larger settings do not show much lower costs.**

12. “PA Residential Costs - Community Living Vs. State Centers, FY 95-96”

Even when all “hidden” costs are included, **the costs of supporting people in communities are far lower than in State Centers.**

SUMMARY: Although these charts and tables only show a very small fraction of the scientific data available, they are powerful and persuasive. If the community movement is accelerated, people will be much better off, their families will be happier, and total costs to the taxpayer will be lower.

Brief Summary of Deinstitutionalization Research Since 1985

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(V4.1)

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Purposes of this Report

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

1) I am qualified to provide facts and opinions in this matter: In addition to my C.V., I will summarize my experience and research as it specifically relates to the issues at hand in Messier v. STS.

2) Testimony, Depositions, Declarations, and Statements in the Past 4 Years: I have testified in six Court cases, and have provided depositions, declarations, or statements five times since 1993.

3) Research Shows Multiple Benefits of Community Placement: Twenty 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. There are no contradictory reports. A handful of recent reports on mathematical models of mortality, from one researcher in California, are severely flawed, and are strongly contradicted by other studies. The sum total of two decades of rigorous studies provides conclusive evidence of the superiority of community living

4) 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.

5) Family Attitudes Change Dramatically: Families (parents, siblings, other relatives, guardians, next friends) of people living in institutions overwhelmingly support the continued existence of those institutions, and the continued placement of their relatives in them. However, in cases in which people have 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 change dramatically toward acceptance and support of community living. Even the most vocal opponents of community placement have become ardent supporters of community living once it has been experienced.

6) The Theory of the "Must Stay" Group is Not Supported: The classic four reasons given for keeping people in large segregated settings (severe retardation, challenging behavior, medical fragility, and advanced age) have been convincingly discredited by carefully controlled studies of community placement, by the evidence from total closures during the past 15 years, by the fact that four states are now entirely free of institutions as an option, and by the pattern of recent placements out of Southbury itself.

7) 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 STS.

8) 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.

9) The Experiences and Well-Being of Seven People Who Moved from STS to Community in the Past 10 Years Will Provide Useful Examples to the Court: My study of the Mansfield class members happened to include seven people who lived at STS at some time between 1987 and 1990. They represent the full range of levels of mental retardation and age. All or nearly all of them are now in community homes. I have asked permission to follow up on these people, wherever they are, by examining their records and conducting an on-site visit to their homes via a trained observer. If permission is granted, I will report to the Court on the experiences of these former residents of STS.

1) I am qualified to provide facts and opinions in this matter.

I am President and Founder of The Center for Outcome Analysis, a not-for-profit firm founded for the purpose of research and policy analysis in the human services, with emphasis on programs that assist and support people with disabilities. I founded this company in 1985, and changed its name to its present one in 1994.

From 1975 to 1992, I was the Director of Research and Program Evaluation at the Institute on Disabilities of Temple University. My expertise is in applied research in the human services, including program evaluation, policy analysis, cost effectiveness analysis, and quality assurance systems. I began doing research in the developmental disabilities area in 1970, and have continued to work in this field since then. I have also performed studies in mental health, aging, child welfare, drug abuse treatment, education, housing, AIDS, immigration, criminology and prisons, and military/defense matters.

I have served as a Consultant to 18 federal agencies, and to more than 100 state and local agencies since 1970, and have been the Principal Investigator for 65 governmentally and privately funded grants and contracts. I have written more than 180 publications in the fields of disabilities, aging, child welfare, and other human service fields, including 14 articles in professional journals, 7 book chapters, and 162 formal deliverable research reports to government agencies.

I have participated in the delivery of 185 formal presentations, speeches, and papers in these fields at the local, state, national, and international levels since 1976, and was the lead or sole presenter for 120 of the 185. Interviews with me, and references to my work, have appeared in the New York Times, the Wall Street Journal, the Philadelphia Inquirer, the Chicago Tribune, WWDB Radio Philadelphia, WKYW Radio Philadelphia, Nightline with Ted Koppel, the ABC Evening News with Peter Jennings, and 60 Minutes with Ed Bradley.

When I began my research in the developmental disabilities field, I was strongly skeptical about the wisdom of deinstitutionalization. Even in the early 1970s, it was clear that deinstitutionalization of people with mental health problems had been an unmitigated disaster (Bassuk & Gerson, 1978).

My first public presentation of a scientific paper was a warning about the risks of relocation associated with deinstitutionalization (Newman & Conroy, 1976). My first published article (Conroy, 1977) was essentially a warning that deinstitutionalization of people with developmental disabilities was a bad idea. Data available at that time indicated a lack of community supports, and a "revolving door" pattern of releases and readmissions, similar to those already seen in the mental health field during the 1950s and 1960s. My second published paper was a study designed to assess the physical and behavioral risks of relocation (Cohen, Conroy, Frazer, Snelbecker, & Spreat, 1977).

Beginning in 1977, I was able to design and conduct comprehensive large-scale long-lasting studies of the precise outcomes of movement from institutions to communities in America. During the ensuing 20 years, the results of my work, and the results of the work of others, have been consistently contrary to my initial hypotheses.

Over the past 20 years, I have been certified as an expert witness in several court actions related to moving persons from institutions to community homes, including those in California, Connecticut, Florida, New Mexico, North Carolina, Oklahoma, Pennsylvania, and Tennessee.

On the following page is a summary of the extent of my research on deinstitutionalization, community living, and family attitudes/reactions. The table shows the number of people for whom I (and people under my direct supervision) have performed face to face visits and quality of life data collection, by state. The table also accounts for repeated visits to many of these people over the years. The table shows the number of families we have surveyed (not the number of responses received), and the numbers of family surveys sent out cumulatively over the years of each research project in each state.

Quality Tracking Activities Conducted by the President of The Center for Outcome Analysis Since 1975 Concerning Quality of Life Among People with Developmental Disabilities

	# Of People Visited	**# Of Visits**	**# Of Families Surveyed**	**# Of Family Surveys**	**# Of Years**	**Projects**
State						
AZ	220	220	220	220	1	1
AR	500	1500	500	1500	3	1
CA	1622	2342	500	1000	2	2
CO	350	700	350	700	2	2
CT	1330	5320	1330	3990	5	1
GA	30	30	590	590	1	1
LA	650	3250	650	1950	9	2
MA	260	520	260	520	2	1
MN	80	160	80	160	2	1
NH	606	1818	160	160	4	4
NJ	690	870	690	870	3	2
NY	1250	1250	1250	1250	1	1
NC	900	1800	900	1800	2	1
OK	3700	18500	3700	14800	5	1
PA-PC	1154	15028	1156	15028	15	2
PA-INST	4400	4400	4400	4400	1	1
PA-WAIVER	1637	1637	1637	1637	5	2
PA-OTHER	600	4200	600	4200	7	2
TX	600	1200	600	1200	3	1
NCS *	13076	13076	0	0	1	1
TOTALS	**33655**	**77821**	**19573**	**55975**	**74**	**30**

* NCS is the National Consumer Survey of people with developmental disabilities, performed in 1990 under Congressional mandate.

2) Testimony, Depositions, Declarations, and Statements in the Past 4 Years.

This is a list of cases in which I testified, or in which I provided a deposition, statement, or declaration, in the last 4 years.

Testimony:

Conroy, J. (March 1993). *Research on deinstitutionalization in the United States.* Expert testimony to the United States District Court of the Western District of Pennsylvania, in the case of Richard C., et al. v. John F. White, Jr., et al. Pittsburgh.

Conroy, J. (December 1993). *Statement of the Findings of James W. Conroy, Ph.D., from the Pennsylvania Office of Mental Retardation's 1992 Monitoring Data.* Expert testimony presented to Judge Raymond Broderick in the District Court of the Eastern District of Pennsylvania, bearing on contempt proceedings against the City of Philadelphia, as part of Halderman v. Pennhurst.

Conroy, J. (July, 1995). *Twenty years of research on the beliefs, feelings, and attitudes of families during deinstitutionalization.* Expert testimony presented to the Federal Court in People First v. Tennessee and the Arlington Developmental Center.

Conroy, J. (August 1996). *Individual Benefits of Implementing the Thomas S. Requirements: Strong Positive Outcomes.* Expert testimony presented to Federal Court in Thomas S. case in North Carolina, concerning motion to dismiss case on the basis of compliance with settlement provisions. (Deposition April 1996.) Charlotte, NC.

Conroy, J. (January 1997). *The Outcomes of Court Ordered Deinstitutionalization in America.* Expert testimony presented to Federal Court in People First v. Tennessee and the Clover Bottom, Nat. T. Winston, and Greene Valley Developmental Centers. Federal District Court, Nashville, TN.

Conroy, J. (July 1997). *Testimony in Support of the Proposed Settlement Agreement in Cramer v. Chiles.* Expert testimony presented to Federal Court Judge Wilkie Ferguson, Jr., Federal District Court, Ft. Lauderdale, FL.

Depositions and Declarations:

Deposition taken in People First v. Tennessee and the Arlington Developmental Center, June 1993. Deposition concerned 20 years of research on deinstitutionalization, particularly emphasizing studies of the families of people in institutions and their reactions to deinstitutionalization.

Declaration provided for Coffelt v. Department of Developmental Services, California, November 1993. Declaration was in support of proposed settlement. A supplementary Declaration was submitted to refute arguments submitted by the attorney represented certain proposed intervenors.

Deposition taken in Scott v. Snider, Pennsylvania, September 1994. Deposition concerned research on the health care services received by a sample of 8,000 Medicaid-eligible Pennsylvania children during 1992 and 1993, as part of an action concerning enforcement of the provisions of the Federal EPSDT (Early Periodic Screening, Diagnosis, and Treatment) legislation.

Deposition taken in Thomas S. case, North Carolina, April 1996. Concerned motion to dismiss case on the basis of compliance with settlement provisions. Charlotte, NC.

Deposition taken in CARC v. Tirozzi case involving discriminatory practices in special education in Connecticut. Testimony was based on ISSIS data base containing 8 years of data on more than 70,000 students.

3) 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 rises.

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, include:

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

When multiple aspects of quality of life, or outcomes, are measured, 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 not been "mixed." Through the assessment of all of these quality of life dimensions, my research in 16 states, and the research of other scientists in America, has consistently shown strong benefits 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, J., & Ericsson, K. (Eds.), 1996. *Deinstitutionalization and Community Living: Intellectual Disability Services in Britain, Scandinavia, and the USA.* London: Chapman and Hall.)

In the following paragraphs, 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 very large scale studies of community placement processes in California, New Hampshire, New Jersey, North Carolina, and Oklahoma. These studies all included analyses of cost-effectiveness in addition to the quality of life results.

Pennhurst Longitudinal Study Results: Pennsylvania

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 nearly 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, I and my colleagues have individually monitored the well-being of each of the plaintiff class members -- more than 1,700 person -- every year. Following is a summary of the results of the study through 1992 (the last year in which I directly supervised the project).

1. 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 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%

2. The Community Model:

Three person Community Living Arrangements (CLAs) were the predominant program model in Pennsylvania at that time. These were either detached houses or apartments, and almost all were existing housing stock.

Some shift staffing and some live-in;
(later became almost entirely shift);
90% non-profit provider entities;
A day program was arranged before placement for every person.

3. Additional Court Protections:

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

4. Behavior Change (See Adaptive Behavior Development Graph)

In addition to the information in the graph, later study produced these findings:
Average gain in self-care skills upon placement 9%;
3 years after placement 12%;
most recent measurement, 1992, 14%.

QUOTE from the Pennhurst Study report: "The adaptive behavior growth displayed by people who have moved to CLAs under this court order is literally 10 times greater than the growth displayed by matched people who are still at Pennhurst."

Challenging behavior improvements are also 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%.

5. Qualities of Environments

Scales measured included Normalization, Individualization, the 1979 version of the ACDD standards, and Physical Quality. All scales improved sharply and significantly upon community placement.

Four part graph here

6. Consumer Satisfaction

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.

7. 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.

8. Health and Health Care

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

9. Day Activities

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

10. Family Satisfaction (Please see attached graphs of "Initial Family Opinions" and "Has Relative's General Happiness Changed Since Movement to Community?")

At the beginning, 83% of families reported satisfaction with Pennhurst, and 72% opposed movement to the community. The graphs show dramatic changes in family attitudes after community placement. 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 recent 1991 community survey of these same families, the results from 500 responding families concerning their overall satisfaction with community living were:

Very Satisfied	Somewhat Satisfied	Neutral	Somewhat Dissatisfied	Very Dissatisfied
65%	23%	5%	5%	2%
(324)	(115)	(26)	(24)	(11)

11. 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.

Two part Pennhurst Family graph here

12. Costs (Please see graph above entitled "Who Pays?")

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. Connecticut is a major participant in these Waiver programs. Hence, the old disincentive for states to support community services is gone.

13. Synopsis

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, and extended, and refined, in many other states. Some of these will be described below, particularly the Mansfield Longitudinal Study in Connecticut.

Mansfield Longitudinal Study Results: Connecticut

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

KEY: The deinstitutionalized people are ...

++ = Much Better Off
+ = Better Off
0 = About The Same
- = Worse Off
-- = Much Worse Off

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. 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.

Families of CARC class members who received community placement were considerably more satisfied than the families of people who were still awaiting placement in the institutions. The first graph on the following page show 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. The second graph summarizes the level of satisfaction of all parents of people who moved to the community, as of 1990 (the second graph includes families who did not answer the 1986 survey).

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.

Double CT Mansfield Family Graph Here

Brief Reviews of Other Relevant Outcome Studies and Tracking Projects

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. 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 at the University of New Hampshire, formerly state director for mental health and mental retardation, for further information.

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).

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) were in many ways the strongest and most positive I had ever studied (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**	**Strength of Inference**
Adaptive Behavior	Yes	Strong
Choice-Making	Yes	Moderate
Challenging Behavior	Yes	Strong
Productivity	Yes	Strong
Integration	Yes	Strong
Developmental Services	Yes	Moderate
Family Contacts	Yes	Strong
Medications	Yes	Weak
Health Care	No	Weak
Satisfaction	Yes	Strong
Overall Conclusion	**Yes**	**Strong**

I have also been tracking the well-being of more than 1,000 people with dual diagnosis in **North Carolina**. These members of the Thomas S. class are people who had mental retardation, but 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, and, 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 medications, 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.

I am currently heading a project that is tracking the quality of life outcomes experienced by more than 2,400 people in **California** who have been affected by the Coffelt settlement. Thus far, the project has resulted in 13 major analyses of 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 1996). These analyses employed multiple research designs, including pre-post, matched comparison, nonequivalent comparison groups with analysis of covariance, and family surveys. All of this work relied on face to face visits with the people and their caregivers, collecting our battery of reliable measures, plus surveys of every known close relative or guardian.

In all of these studies, we have found that the Movers, as in other studies, have experienced major gains in many measures of quality of life. We have also found that community care in California costs a great deal less, even for similar people, than institutional care. The cost analyses include 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. The Court in California must continue to demand high quality programs.

Having raised the issue of costs, it is relevant to note that I have performed several studies of the cost-effectiveness of the so-called Home and Community Based Waiver Program (Pennsylvania, New Hampshire, and Oklahoma). The Medicaid Waiver regulations require that each state that is granted a Waiver must cause to be conducted an Independent Assessment every three years. The regulations specify 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 Connecticut.

As an example of a Waiver evaluation, in my work in **Pennsylvania** I studied a random sample of the more than 2,000 persons with developmental disabilities who moved from institutions to community living arrangements under the HCBS waiver (Conroy, Dickson, & Lemanowicz, 1989). I found that the persons placed under the waiver benefited greatly from the move. People became more able to do things for themselves. The average person placed under the Pennsylvania waiver immediately gained 7 percent in adaptive behavior. This was highly significant. Individual habilitation plan (IHP) goals were much more likely to be worked on in the community; 82% of written plan goals were fully implemented, and this was very high in comparison to similar measurements taken in institutional settings. Integrative experiences were far more common in the community. The people who moved to the community under Pennsylvania's waiver were in the presence of non-disabled persons an average of 4.7 times a week. For people at state centers at the time, the average was 0.5 times a week. Finally, the data showed that the average community living situation cost society about $13,000 less than an institutional placement for a similar person would have cost. This included "hidden costs" as well, and the report concluded that implementation of Pennsylvania's waiver resulted in lower total public costs than institutional living.

My Independent Waiver Assessment in Pennsylvania is but one example of the more than 100 Independent Assessments of Home and Community Based Waivers that 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 ever 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.

4) 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 two decades.*

I believe the misunderstanding is largely due to the confusion of 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*).

Deinstitutionalization of people with mental illness was done hastily, without supports, and largely with reliance on the "new miracle drugs" approved by the FDA in 1955 (the chlorpromazine derivatives, including 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 day activity, and no support to reestablish family relationships. This policy was led by policy makers in California during the administration of Governor Reagan. The policy continued and expanded when Reagan became President. The result has been a national disgrace, including a major portion of the problem called "homelessness."

I believe that it is absolutely essential that the court understand the stark difference between the national record in mental illness versus that for mental retardation and developmental disabilities. In the case of people with developmental disabilities, moving from large institutions to small community homes has been extremely successful.

5) **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.

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

The classic four reasons given for keeping people in large segregated settings 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 are called into serious question by the research, and even more strongly by the total-closure 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 five states that have completely eliminated institutions as an option.

In these instances, <u>everyone</u> has moved to the community. This includes people who are "low functioning," who in my research tend to benefit the most in some important ways. When people who are labeled severely or profoundly retarded move into family-like community settings, they show 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. Empirical evidence is directly to the contrary (Conroy & Bradley, 1985; Stull, Conroy, & Lemanowicz, 1990). In fact, 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 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 supports the inference 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." Of the 373 people my team tracked out of Mansfield Training School during our study, 82% were labeled severely or profound retarded.

The research findings are conclusive, and form the basis for my opinion in this regard: level of disability does <u>not</u> 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 how their health has changed or not changed after 7 to 10 years in 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, I also know as a factual matter that people over 80 years of age have moved out of institutions within my own research studies, and have adapted and thrived in 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 thus 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 cannot be supported by the facts.

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

All studies published thus far are consistent (Ashbaugh, 1984; Conroy & Bradley, 1985; Jones, Conroy, & Lemanowicz, 1984; Nerney & Conley, 1982). 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 <u>do</u> cost less, but they <u>should</u> not.

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

Nationally, the average cost of an institutional setting is about $88,000 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 7.

8) 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 so consistently been observed 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. The best summary of 100 years of this research was provided by Gooding and Wagner (1985).

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).

9) The Experiences and Well-Being of Seven People Who Moved from STS to Community Homes in the Past 10 Years Will Provide Useful Examples to the Court.

My study of the Mansfield class members happened to include seven people who lived at STS at some time between 1987 and 1990. They represent the full range of levels of mental retardation and age. They are not special or “selected” in any way that I know of. The only trait they have in common is that I happen to possess hard, scientific information on the qualities of their lives back in 1985, when they were all living in institutions.

All or nearly all of them are now in community homes. I have asked permission to follow up on these people, wherever they are, by examining their records and conducting an on-site visit to their homes via a trained observer. If permission is granted, I will report to the Court on the experiences of these former residents of STS. This is intended to provide the Court with useful examples of how former STS residents have fared in their movements to community homes. This may assist in supporting or refuting the claim that STS is needed as a sheltered, segregated, permanent home.

From my point of view, this part of my Report is not “essential,” but would certainly function as “case studies” that would serve to illustrate (or question) the results I have described above from following thousands of individuals from institutional to community living.

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EXCLUDED FROM REPORT:

The second reason that the benefits of movement to community are so clear and consistent is intertwined with the entire notion of integration and inclusion. The person who brought our institutional models of care from Germany to American in the 1850s later had reason to regret his role in that development. Samuel Gridley Howe said these words at the dedication of another new institution in New York in 1866:

> *Grave errors were incorporated into the very organic principles of our institutions ... which make them already too much like asylums; which threaten to cause real asylums to grow out of them, and to engender other evils.*
>
> *All great establishments in the nature of boarding schools, where the sexes must be separated; where there must be boarding in common, and sleeping in congregate dormitories; where there must be routine, and formality, and restraint, and repression of individuality; where the charms and refining influences of the true family relation cannot be had, ... all such institutions are unnatural, undesirable, and very liable to abuse. We should have as few of them as is possible, and those few should be kept as small as possible.*
>
> *Such persons [with disabilities] ... should be kept diffused among sound and normal persons. Separation, and not congregation, should be the law of their treatment; for out of their infirmity or abnormality there necessarily grow some abnormal and undesirable effects, and unless these be counteracted by education, they disturb the harmonious developments of character. These effects are best counteracted by bringing up the child among ordinary children, and subjecting him to ordinary social and family influences; but, on the contrary, they are intensified by constant and close association with children who are marked by the same infirmity or peculiarity ... We should therefore keep this truth in mind; and give it due weight when forming plans for the treatment of any special class of persons.*
>
> *As much as may be, surround insane and excitable persons with sane people, and ordinary influences; vicious children with virtuous people and virtuous influences; blind children with those who see; mute children with those who speak; and the like. People run counter to this principle for the sake of economy, and of some other good end, which they suppose cannot be had in any other way; as when they congregate the insane in hospitals, vicious children in reformatories, criminals in prisons, paupers in almshouses, orphans in asylums, blind children and mute children in boarding schools. Hence I begin to consider such establishments as evils which must be borne with, for the time, in order to obviate greater evils. I would take heed, however, against multiplying them unnecessarily. I would keep them as small as I could. I would take the most stringent measurements for guarding against those undesirable effects which lessen their usefulness; and for dispensing with as many of them as may be possible.*

Cost: Waiver mention, PLS explain cost graph, put new bullet in first page.

Rebuttal Report of James W. Conroy, Ph.D.
Re: Messier v. STS and the Family/Guardian Survey

February, 1998

(V1.3)

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Summary

This brief report is intended to question the utility of the results of the survey entitled "Criteria to Evaluate the Current Population of STS" conducted by the Defendants in this case. Defendants' Experts Walsh and Kastner both used the survey results to close their Expert reports. This was no doubt meant to lend strength and credibility to their contention that STS is an excellent facility that should be continued. Actually, this survey suffers from flaws so serious that the data from it are not worthy of such great reliance. Hence it is important to describe to the Court the serious shortcomings inherent in that survey. The points we will make in rebuttal to the survey results are as follows:

1. **Defendant Experts Walsh and Kastner relied very heavily on this survey in their closing remarks in their reports.**
2. **Parental satisfaction with institutions and corresponding opposition to deinstitutionalization is not new or surprising. It should be regarded as a "given."**
3. **There are 30 years of research literature on this matter.**
4. **The present survey was flawed, and tended to exaggerate the already high satisfaction levels that would be expected.**

I will first reproduce the exact quotes from the Defendant Experts on this matter, to show the high value they tried to attach to the survey. Then I will show that very high family satisfaction with institutions is exactly what we would expect at STS. Next I will show that the research literature leads to conclusions very different from those of Walsh and Kastner. Finally I will describe why this survey, although not worthless, is certainly not an adequate basis for inferring the quality of STS. Nor is this survey a sensible basis for public policy, such as the state's failure to request significant new funds for people to move from STS to the community.

1. Defendant Experts Walsh and Kastner relied very heavily on this survey in their closing remarks in their reports.

Reproduced below are the closing comments from the last paragraph of the 8/28/97 report of Dr. Walsh:

> *In early 1997 [sic], STS set out to listen to the voices of its constituents. In a survey, clients, families and guardians were asked to choose between continuing the placement of their loved one at Southbury or moving him or her to the community. The survey response rate was a surprising 97%, with 758 responses received. In many community surveys 50% response rates are considered good and 20% are acceptable. Despite the large number of respondents, this constituency spoke overwhelmingly in one voice – 734 of 758 responses (almost 97%) wished to have their loved one remain at the Southbury Training School. Apparently they feel the quality of life is good at Southbury, the programs delivered are what their loved ones need, and that, in the end, their family members are safe at this facility – at least in part, I think, because of some of the activities that have been reviewed in this report.*

The following comments are from the last section of the 9/1/97 report of Dr. Kastner:

> Customer Satisfaction
> *Perhaps the most important outcome in the field of health and human services is customer satisfaction. Recent data from state Medicaid agencies suggests that 80% to 85% of community residents enrolling in health maintenance organizations are satisfied with their care. In comparison, the Southbury Training School has a satisfaction rate of 96.8% meaning that if they were given a choice of staying or leaving, the vast majority of residents would prefer to stay. There can be no better testament to the quality of care at the Southbury Training School than this data [sic].*

By mentioning this survey in their closing comments, both experts showed that they placed a great deal of credibility and meaning in the survey. If the survey was not credible or meaningful, then their testimony and the development of their expert opinions is called into question.

2. Parental satisfaction with institutions and corresponding opposition to deinstitutionalization is not new or surprising. It should be regarded as a "given."

The overwhelming majority of parents of people in institutions have always favored the institution, and have distrusted community options. That should be regarded as a "given."

Parental satisfaction with Mansfield Training School in 1986 was very strong, too:

Satisfaction of Families of People at Mansfield Training School, 1986

	Number	Percent
Very satisfied	168	56%
Satisfied	79	26%
Neutral	27	9%
Dissatisfied	18	6%
Very dissatisfied	9	3%

Source: Conroy & Wang, 1987.

Only about 9% of families expressed any dissatisfaction. This was used at the time, in the Mansfield case, as indicating a 91% "satisfaction rate," just as the Southbury survey is being used now.

It is more interesting to extend the table above by adding the survey percentages for the people who had already left institutions by 1986.

Comparative Satisfaction of Families, CT, 1986

	MTS	Community
Very satisfied	56%	67%
Satisfied	26%	23%
Neutral	9%	4%
Dissatisfied	6%	4%
Very dissatisfied	3%	1%

Source: Conroy & Wang, 1987.

Satisfaction surveys typically produce high satisfaction findings. They become much more interesting when we have something to compare them to. In this case, satisfaction with MTS was very high indeed. However, it was even higher with community living.

Similarly, satisfaction among the families of people who lived at Pennhurst in 1979 was very strong:

Satisfaction of Families of People at Pennhurst Center, 1979

	Number	Percent
Very satisfied	253	54%
Satisfied	136	29%
Neutral	51	11%
Dissatisfied	23	5%
Very dissatisfied	9	2%

Source: Keating, Conroy, & Walker, 1980.

The phenomenon of high satisfaction with institutions is well known, well researched, and well recognized. We understand why this is the case. In their situations, we (all of us) might feel the same way. There is a very powerful need to believe that the institution is the best of all possible worlds for the sons, daughters, brothers, and sisters who have lived there for an average of more than 30 years. The initial decision to institutionalize was a wrenching and painful experience, and can only be justified the continuing belief that it was "for the best."

And it was "for the best," 30 years ago. Nearly all professionals, most particularly medical professionals, advised families of people with severe and profound mental retardation that places like Pennhurst, Mansfield, and Southbury were "the only right thing to do." And, at the time, they were.

The agony of our present dilemma with these institutions is that we have discovered a much better way to support these people, and the parents do not, will not, and indeed can not believe us. Decades ago, professionals told them Southbury was the right place, and promised them that this was a lifetime choice, never to be revisited. The vision offered to them was that their disabled relatives would be safe and cared for during their entire lifetimes.

It is not hard to see why these parents and other family members are now distrustful. The field of developmental disabilities has advanced a great deal, but these families are still relying on a decades old promise. No amount of debate or even visits to group homes and supported living arrangements will be sufficient to change their minds. In fact, the only thing ever shown to have an impact of family opinions is the actual experience of having their relatives move, improve, and flourish. But there can be no denying the pain and anguish they are experiencing, and this must be accorded its due respect, dignity, and empathy.

Parental resistance to community living was present in the Pennhurst case, it was present at Mansfield, and it was present at Laconia State School in New Hampshire (Covert, MacIntosh, & Shumway, 1994). Yet in 1992, New Hampshire became the first state to become completely free of public institutions for people with mental retardation. And there is no state with more satisfied, involved, and pleased families (Conroy & Yuskauskas, 1996). Today, there are five other states without institutions.

3. There are 30 years of research literature on this matter.

The research literature over the past 30 years has established the fact that families of people in public institutions are highly satisfied with these facilities. This is now to be considered as a "given." Nine state and local studies, which I will briefly review below, have been completely consistent in this finding. There has been only one national survey, and it shows exactly the same finding.

In one of the earliest studies, Klaber (1969) surveyed parents of people in institutions in Connecticut (including Southbury). He found that more than three fourths of them were very satisfied with the facilities. He concluded that **"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."**

Brockmeier (1975) reported similarly high levels of satisfaction, coupled with skepticism about community-based care, among families of people in Nebraska institutions.

Payne (1976) discovered the same situation in Texas. Payne was also the first to identify a "deinstitutional backlash." He characterized the backlash group as a loosely knit countermovement of various local and state-wide associations of parents organized in support of institutions as opposed to community residential facilities.

Willer, Intagliata, and Atkinson (1979) reported overwhelming satisfaction among families of institutionalized people in New York state. Meyer (1980) found that over 70% of families of people in an institution in Western

Pennsylvania were satisfied with the services provided by the facility, and they opposed the idea of community placement.

Keating, Conroy, and Walker (1980) found as part of the Pennhurst Longitudinal Study that 83% of families were "satisfied" or "very satisfied" with Pennhurst, even at the height of court and media criticism of Pennhurst. Moreover, 72% strongly opposed the idea of community placement.

Frohboese and Sales (1980) produced a superb legal analysis of the potential conflict among individuals, parents, and professionals in an article entitled ***"Parental Opposition to Deinstitutionalization: A Challenge in Need of Attention and Resolution."*** They reported that families in Nebraska believed the state institution to be the least restrictive alternative feasible for their relatives. They perceived greater freedom of movement, independence, and safety within the institution. The greatest concern expressed by these families about deinstitutionalization was their perception of the lack of permanence of the community settings. These authors also framed clearly the legal and ethical conflict between the rights of parents and the rights of people with disabilities.

Atthowe and Vitello (1982) detected similar feelings among families in New Jersey. In their survey, 54% expected no more than custodial care, and 91% said the institutional care was adequate or better. More than 80% wanted their relatives to remain in New Jersey's institutions.

Conroy (1984) surveyed the families of 1611 people living in institutions in Pennsylvania who had been "nominated" for movement to the community. No fewer than 91% of families were "satisfied" or "very satisfied" with institutional services, and 81% were "opposed" or "very opposed" to the idea of community placement.

Conroy (1987) found in Georgia that 72% of the families of people at Georgia Retardation Center were "Very Satisfied" with services provided to their relatives. They overwhelmingly opposed the idea of movement to community services.

There has only been one study of institutional family attitudes at the national level (Spreat, Telles, Conroy, Feinstein, & Colombatto, 1987). Spreat et al conducted a national survey of the families of people in public institutions. This study confirmed the fact that families of people in public institutions are highly satisfied with these facilities. Most families are opposed to changes, especially community placement. The survey revealed very high satisfaction with the institutional settings, plus resistance to community services. Overall, 61% of families rejected the idea of "a group home of about six beds, located in a regular residential area, staffed 24 hours so that clients are never left alone, and from which every client goes to a day program (school, workshop, job)." The survey also showed that resistance to community services was higher among families of people with the most severe impairments.

Because of court-ordered institutional closures such as Willowbrook and Pennhurst, it became possible in the 1980s to study changes in attitudes among the families of people who moved from institution to community. The nation's first report of changes in attitudes after movement from institution to community was published by Latib, Conroy, and Hess (1984). They surveyed Pennsylvania's Pennhurst families before and after community placement. They found that the families' initial opposition changed dramatically to overwhelming satisfaction with, and support for, community living.

Covert, Hess, and Conroy (1985) surveyed families after their relatives left the Laconia State School in New Hampshire. According to family recollections, only 38% had been "satisfied" or "very satisfied" with the situation at Laconia, whereas 84% said they were satisfied or very satisfied with their relatives' current community residences.

Conroy and Wang (1987) reported on Connecticut research tracking more than 1300 people. For people who moved from institutional to community settings, family satisfaction and the perceived happiness of the relative increased sharply.

Conroy, Lemanowicz, and Bernotsky (1991) extended the prior work of Conroy & Wang (1987). They surveyed the families of 101 deinstitutionalized people in Connecticut before and after community placement. The survey contained nine items related to quality of life and satisfaction (e.g., satisfaction with the home, with day program, food, privacy). All nine items increased significantly, with improved privacy and satisfaction with the residential setting showing the largest positive changes.

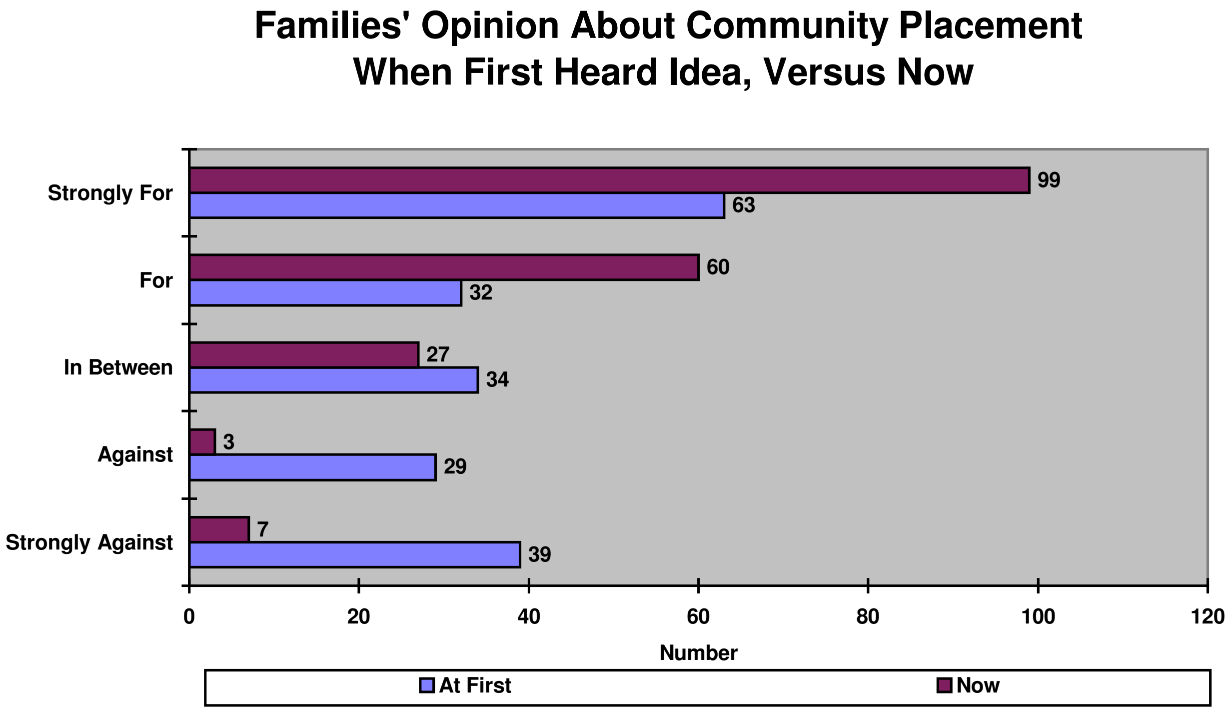
Grimes and Vitello (1990) examined the attitudes of 32 families of deinstitutionalized people who had been living in the community for 3 to 7 years. Preplacement data on these families (Atthowe & Vitello, 1982) had shown a high level of satisfaction with institutional services and strong opposition to community placement. The postplacement survey revealed a significant change toward more positive family attitudes toward deinstitutionalization.

Temple University's 1990 survey of all the families of people who once lived at Pennhurst (Lemanowicz, Levine, Feinstein, & Conroy, 1991) revealed that only 6 of the 420 responding families were "Strongly Dissatisfied" with community living. Most of the families wrote comments describing how surprised they were with the quality of life enjoyed by their relatives in community homes.

Many wrote that they were amazed that they had ever opposed the move from institution to community.

Larson and Lakin (1991) wrote a review article based on all of the family deinstitutionalization attitude studies of the preceding two decades. They performed a meta-analysis upon the results of 27 such studies which examined the attitudes and perspectives of parents of currently or formerly institutionalized people. Larson and Lakin summarized: "The clearest message in these studies is that the overwhelming majority of parents become satisfied with community settings once their son or daughter has moved from the institution, despite general predispositions to the contrary."

In California, The Center for Outcome Analysis has performed four years of surveys of the families of people who have moved from institution to community. These are the people affected by the Coffelt settlement agreement, under which more than 2,000 people moved out of institutions in just over three years. In the most recent survey (Seiders, Conroy, Elks, & Yuskauskas, 1997), the great majority of families reported that they were very satisfied with their relatives' new homes and situations, that they (the families) had changed their minds in the direction of favoring community living, that their relatives' qualities of life had improved sharply, that they believed their relatives were happier in the community, and that they did not want their relatives to return to institutions. Their graph of self-reported family attitude changes is reproduced below.



Source: Seiders, Conroy, Elks, & Yuskauskas, 1997.

In summary, the literature shows that family satisfaction with institutional care is very high, usually above 80% and often above 90% “approval” ratings. Of equal or greater interest is the fact that family satisfaction after movement to community homes is even higher, and that the vast majority of families “change their minds” after it happens.

4. The present survey was flawed, and tended to exaggerate the already high satisfaction levels that would be expected.

Given that we expect satisfaction ratings from families of people in an institution to be very high, the present survey’s finding of 96.8% approval needs to be examined more closely. From the weight of prior research, we would expect general family satisfaction to be above 80%, perhaps even about 90%. But 96.8% would be the highest such rating ever reported. Is there a reason for this? I believe there is, and it is to be found in three problems with the way this survey was conducted.

The first problem is the form of the question: “***Would you/your relative like to remain at STS?***” The answer to such a question, which does not provide any sense of options, almost has to be "Yes. There is no hint within that item of "as opposed to what?" Do they mean, as opposed to being discharged onto the streets? To become homeless?

By way of analogy, imagine that a person's mother is living in a nursing home. Neither the person nor the mother ever really wanted the nursing home, but the mother's health care needs had become life-threatening, to the point that 24 hour health care was simply necessary. Now a survey form arrives, in which the person is asked, "Do you want your mother to continue to live here?" Immediately, the first reaction has to be fear. "Is mother about to be discharged? We can't take care of her! What's going on?" The form has to be answered "Yes" until more is known about what they're really asking.

In that light, I find it amazing that even 24 family members had the courage to say "No" to the first survey question.

The second problem is that the current survey was tainted by the prior one, performed in 1993, by the Home and School Association. In the August 4, 1993 cover letter to that survey, Sally Bondy clearly raised the specter of Southbury closure. This is not proper scientific survey procedure. That cover letter, in my opinion, took and advised respondents to take a clear advocacy position. The taint would not vanish in the ensuing four years. It would remain a strong misgiving among the parents and other family members, who naturally care deeply about the well-being of their relatives at STS.

In the current (1996) DMR survey, there were other items after that first flawed item that explored level of interest in learning about options. I have not seen or heard any analysis of those items. But to quote the 96.8% "Yes" answers from the first item as though they represented an accurate measure of satisfaction or dissatisfaction with Southbury is simply not defensible.

The third problem is that more than 200 forms were completed by one person, Ms. Anne Rotzal. The STS Foundation served as guardian for approximately 212 people at the time of the survey, and according to my review of other depositions, 211 of them were completed with "Yes" checked on the first item. That, of course, artificially raised the "Yes" rate.

Moreover, in correspondence among STS Director Howley, Anne Rotzal of the STS Foundation and the Home and School Association, and Robert Lewis of the STS Foundation, it is very clear that Howley was frustrated by Ms. Rotzal's anti-community attitude and behavior. Yet Mr. Lewis responded that the Foundation's own consultants, Maze Masters, determined from a sample of 100 wards that 38% were appropriate for community placement (letter of June 22, 1995). Nevertheless, two years later, Ms. Rotzal filled out 212 forms for

Foundation wards, and determined that 211 (99.5%) were not appropriate for community placement. This kind of "blanket" approval of STS is grossly out of line with the need to consider each person's needs and desires individually.

A final but different kind of problem with this survey is that it provides only one part of the complete picture. Family surveys certainly have an important place in policy making and in quality assurance. However, they should never be considered in the absence of the other tools to inform policy. These include objective measures of quality and cost, plus the opinions and recommendations of interdisciplinary teams (or, better yet, person-centered planning circles), **plus the opinions of the people themselves**.

The opinions of the people must be given due weight, despite their cognitive disabilities. There is never any chance of providing a life of quality at STS for a person who hates living there. There must be options. In 1988, my group at Temple University visited all 4,693 residents of Pennsylvania's public institutions. There were 924 people who were able to respond to the question, "If a group home or apartment were developed for you, would you want to live there?" Of the 924, 231 (25.0%) said "No," 79 (8.5%) were not sure, and 614 (66.5%) said "Yes." Our interview contained check questions, to make sure these answers were reliable. Even under the most conservative restrictions and interpretations, a clear 58% of those who could answer the questions said they wanted to leave. This kind of "consumer survey" information must not be left out of our deliberations.

My group has just visited more than 1,000 people in California who left institutions in the past four years. Most of them were unable to respond to an interview in any format. Of the first 1,049 people to be visited, only about a fourth were able to respond to questions such as:

- How do you feel about living here?
- If you could, would you go back to live at a Developmental Center?

On the first item, 295 people were able to answer, and only 6 said "Very Poor." On the second, 219 responded, and only 8 reliably said they "Definitely" would like to return to an institution.

My purpose in reviewing these consumer surveys is to show that they are likely to produce very different results than the family/guardian survey. I believe the people at STS should be included in any and every effort to determine their fates. The current family/guardian survey was not designed to capture the opinions of the people who live at STS. By itself, a family/guardian survey may be interesting, but it certainly does not merit the degree of credibility and reliance assigned to it by Defendant Experts Walsh and Kastner.

The Position Statements of the Arc of the U.S. include a statement that defines seven levels of quality assurance (Arc/US, 1989). One of the seven is the opinions of the families, advocates, and friends; another is the opinions of the people themselves. Only a minority of the people at STS have a way to respond to an interview, but those who do should be given every possible opportunity to be heard, rather than to be spoken for.

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