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The Deinstitutionalization of AMERICA

Following are excerpts from a comprehensive study *conducted* by James W Conroy, Ph.D. on the outcomes *of* moving people with developmental disabilities *from* institutions to communities in the United States. The activities and outcomes tracked in this report occurred between *1975-1*997. In the ensuing 22 years, Dr. Conroy and his *staff performed face-to-face* visits and collected quality of life data from over 33,000 participants during the course *of 77,821* visits.

Dr Conroy is president and founder *of* The Center for Outcome Analysis, a *not-for-profit firm founded* in 1985 for the purpose *of research and policy analysis in* human services, with emphasis on programs that assist and support people with disabilities. From 1975 to 1992, Dr Conroy was the Director of Research and Program Evaluation at the Institute on Disabilities *of* Temple University. *Dr.* Conroys expertise is in applied research in the human services, including program evaluation, policy analysis, cost effectiveness analysis, and quality assurance systems. Dr Conroy began doing research in the developmental disabilities area in 1970, and has continued to *work in* this field since then. He has also performed studies in mental health, aging, child welfare, drug abuse treatment, education, housing, AIDS, immigration, criminology and prisons, and military/defense matters.

Dr. Conroy has served as a consultant to 18 federal agencies, to more than *1*00 state and local agencies since 1970, and has been the Principal Investigator for 65 governmenttally and privately funded grants and contracts. He has 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 research reports to government agencies.

Interviews with Dr Conroy, and references to his *work,* have appeared in the New *York Times,* the Wall Street Journal, the Philadelphia Inquirer, the Chicago Tribune, Nightline with Ted Koppel, the ABC Evening News with Peter Jennings, and 60 Minutes with *Ed Bradley.*

Research Shoves 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 &r 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:

• independence * productivity

• integration

• access to the places and rhythms of mainstream life

• access to services when needed

• health

• health care utilization

• health care satisfaction

• mental health

• mental health care utilization and mental health care satisfaction

• friendships

• physical comfort

• privacy

• individualized treatment

• freedom from excessive restraints (physical, chemical, and authoritarian)

• respect for dignity and human rights by staff and others

* support for choice making and learning to make choices

• personal satisfaction with multiple aspects of life

• satisfaction of the family members and "circles of friends" who care about the person

• the overall "locus of control" of the pattern of life (by paid professionals and/or by the person and nonprofessional 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, Dr. Conroy's research in 16 states, and the research of other scientists, 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., &r Ericsson, K. (Eds.), 1996. Deinstitutionalization *and Community* Living: Intellectual Disability Services in Britain, Scandinavia, *and. the USA.* London: Chapman and Hall.]

The following paragraphs contain a brief summarization of 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).

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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 that section appears a summary of several other large scale studies of community placement processes in California, New Hampshire, New Jersey and Oklahoma. These studies all included analyses of cost effectiveness in addition to the quality of life results.

Pennhurst Longitudinal Study Results: Pennsylvania

The District Court's order in Halderman v. Pennhurst 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, Dr. Conroy and his colleagues have individually monitored the well-being of each of the plaintiff class members -- more than 1,700 persons -- every year. Following is a summary of the results of the study through 1992 (the last year in which Dr. Conroy directly supervised the project).

The adaptive behavior growth displayed by people who had moved to CLAs under this court order [was] literally 10 times greater than the growth displayed by people who were still at Pennhurst.

Behavior Change. Average gain in self-care skills upon placement: 9%; 3 years after placement: 12%; and most recent placement (1992): 14%. Average improvement in challenging behavior areas: 1% upon placement; 3% three years after placement; and 6% as of the most recent measurement (1992).

Consumer Satisfaction: The Pennhurst Study included repeated interviews with 56 people who were able to communicate verbally. 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.

Family Satisfaction: At the beginning, 83% of families reported satisfaction with Pennhurst, and 72% opposed movement to the community. However, there was a dramatic change in family attitudes after community placement. In a 1991 community survey of these same families, the results from over 500 responding families concerning their overall satisfaction with community living were: Very Satisfied (65%); Somewhat Satisfied (23%); Neutral (5%); Somewhat Dissatisfied (5%); and Very Dissatisfied (2%).

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).

Day Activities. The proportion of people taking part in employment or an active day program increased from about one-third at the beginning of the study to practically 100% at the end of the study in the community.

Costs: The total public cost of serving the people who moved to community living arrangements was significantly less than for the people at Pennhurst (about $110 per day versus $129 per day at Pennhurst). Today, community programs are just as able to obtain Federal Medicaid funds as are institutions, primarily through the Waiver Program,

The five years of the Pennhurst Study led to the conclusion that, on 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.

Mansfield Longitudinal Study Results: Connecticut

In Connecticut, Dr. Conroy and his associates followed 1,350 class members in CARC v. Thorne. to measure their well-being. 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 1990, approximately 600 persons received community placements under the consent decree.

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 significant needs, rather than being restricted to people gifted with high ability levels.

From three separate studies conducted over a 5-year period, the people who moved from institution to community were significantly better off in most of the dimensions that were measured. On the average, class members in CARC who received community living arrangements made significant gains in adaptive behavior after placement in the community. Moreover, people labeled profoundly retarded made the greatest proportional gains: more than 28%.

The study 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.

During the course of Dr. Conroy's studies in Connecticut, it was determined that the cost of care at the Mansfield institution rose to $290 per person per day, more than double the cost of services in the community.

Brief Summaries of Other Relevant Outcome Studies and Tracking Projects

New Hampshire: From 1981 onward, Dr. Conroy was 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 all people, regardless of the severity of their disabilities.

Dr. Conroy is continuing to perform studies and evaluations in New Hampshire.

New Jersey: In New Jersey, the Johnstone Training and Research Center closed in 1992. Dr. Conroy headed a 3 year project to track the former residents and the quality 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. Dr. Conroy wrote that "Future closure planning should, according to this and past research, employ deinstitutionalization rather than reinstitutionalization as its primary strategy" (Conroy & Seiders, 1994).

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Oklahoma: Since 1990, Dr. Conroy has been working on a statewide quality assurance system in Oklahoma that covers 3,700 people -- everyone receiving intensive services in the state. Among these 3,700 people are approximately 1,000 Class Members in the Homeward Bound v. Hissom Memorial Center litigation and consent agreement. In 1995, Dr. Conroy 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 he 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 deinstitutionalizalion turned out to be the most successful.

Quality Dimension Answer Strength of Inference

Adaptive	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

California: Dr. Conroy is 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 care givers, collecting a battery of reliable measures, plus surveys of every known close relative or guardian.

In all of these studies, Dr. Conroy and his associates found that the movers, as in other studies, have experienced major gains in many measures of quality of life. They 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, the Conroy group has consistently raised concerns about the overuse of psychotropic drugs, the lack of attention to vocational

programs, and the serious under funding of community programs. They concluded that the Court in California must continue to demand high quality programs.

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. Dr. Conroy first detected the phenomenon of dramatic attitude changes in the Pennhurst Longitudinal Study (Conroy &rBradley, 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.

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Community Living is Not Without Problems, and Requires Protections

One 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. Dr. Conroy believes 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 (1968) 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. 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, Alien, &r Chinsky, 1974).

For additional information on these studies, *contact Dr.* James *Conroy, The Center for Outcome analysis, at 615-520-2007, or send an e-mail to jconroycoa@aol.com*

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