

How Are They Doing?

**Year 2000 Report of the Quality of Life Evaluation
Of People with Developmental Disabilities
Moving from Developmental Centers into the Community
(The “Quality Tracking Project”)**

Final Report

(Year 1)¹

Submitted to:

Mr. Dale Sorbello, Manager
Regional Center Branch
Community Services Division
Department of Developmental Services
1600 Ninth Street,
Room 322 (MS3-10)
Sacramento, CA 95814

Submitted by

James W. Conroy, Ph.D., Jeffrey X. Seiders, M.S., and Marguerite Brown, M.S.
The Center for Outcome Analysis
1062 Lancaster Avenue
Suite 18C
Rosemont, PA 19010
610-520-2007, FAX 5271, e-mail outcomeanalysis@aol.com

April, May, and June, 2000

¹ Prepared Pursuant to Contract Number HD989038 from 1999 to 2002 in the Amount of \$1,410,515

Acknowledgment

The authors wish to acknowledge and thank the 2,204 people who allowed us into their homes and workplaces to find out “how they are doing.” We also thank the 21 Regional Centers for their cooperation, the staff of the vendor agencies who made time for our visits, and all the relatives who took time to complete our mail survey. In gratitude, we dedicate our work and this report toward the goal of a constantly improving system of supports for people in their communities and their families.

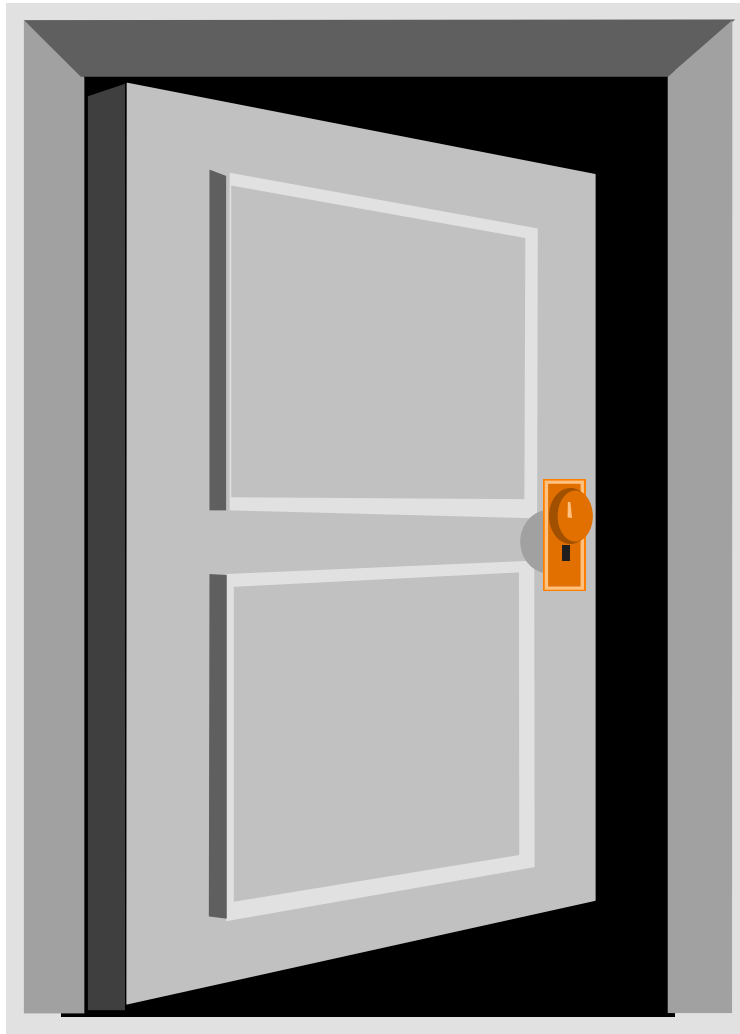


Table of Contents

Executive Summary	1
Historical Background	4
Prior Tracking and Monitoring of the <u>Coffelt</u> Movers.....	Error! Bookmark not defined.
Methods	Error! Bookmark not defined.
Participants: The People in this Study	Error! Bookmark not defined.
Results of the Field Work: A Population, Not A Sample	Error! Bookmark not defined.
Instruments	Error! Bookmark not defined.
Procedures for Field Work and Data Collection.....	Error! Bookmark not defined.
Results	Error! Bookmark not defined.
Results 1: Characteristics of the Movers.....	Error! Bookmark not defined.
Results 2: Family Contacts	Error! Bookmark not defined.
Results 3: Friendships	Error! Bookmark not defined.
Results 4: Individual Planning	Error! Bookmark not defined.
Results 5: Day Activities, Employment, and Earnings.....	Error! Bookmark not defined.
Results 6: Choicemaking and Self-Determination	Error! Bookmark not defined.
Results 7: Integrative Activities	Error! Bookmark not defined.
Results 8: Health, Health Care, and Medications.....	Error! Bookmark not defined.
Results 9: Personal Interviews	Error! Bookmark not defined.
Results 10: Perceived Quality of Life Changes.....	Error! Bookmark not defined.
Results 11: Qualities of the Homes.....	Error! Bookmark not defined.
Results 12: Family Survey, Preliminary.....	Error! Bookmark not defined.
Family Survey: Participants	Error! Bookmark not defined.
Families' Perceptions of Quality.....	Error! Bookmark not defined.
Involvement and Communication	Error! Bookmark not defined.
Valued Outcomes.....	Error! Bookmark not defined.
Results 13: "Before and After" Qualities of Life	Error! Bookmark not defined.
Adaptive Behavior	Error! Bookmark not defined.
Challenging Behavior	Error! Bookmark not defined.
Progress Reported Toward Individual Plan Goals.....	Error! Bookmark not defined.
Number of Services in Individual Plan	Error! Bookmark not defined.
Hours of Day Program Services.....	Error! Bookmark not defined.
Earnings	Error! Bookmark not defined.
Number of Friends Reported	Error! Bookmark not defined.
Choicemaking	Error! Bookmark not defined.
Integration.....	Error! Bookmark not defined.
Qualities of Life Ratings (Now 1994-Now 1999).....	Error! Bookmark not defined.
Staff Job Satisfaction	Error! Bookmark not defined.
Staff Like Working With This Person	Error! Bookmark not defined.
Staff Get Sufficient Support.....	Error! Bookmark not defined.
Number of Daily Medications.....	Error! Bookmark not defined.
Number of Psychotropic Medications.....	Error! Bookmark not defined.
General Health Rating	Error! Bookmark not defined.
Health by Days Ill in Past 28 Days	Error! Bookmark not defined.
Quality of Health Care	Error! Bookmark not defined.
Doctor Visits Per Year.....	Error! Bookmark not defined.
Dental Visits Per Year	Error! Bookmark not defined.
Relative Visits Person Here At This Home.....	Error! Bookmark not defined.
Individualized Practices Scale	Error! Bookmark not defined.
Results 14: People Living In Congregate Care Settings	Error! Bookmark not defined.

Appendices

Appendix A:

**Prior Reports of The Center for Outcome Analysis On the well being of
People Who Moved From Developmental Centers to Community Homes in
California**

Appendix B:

The Year 2000 Personal Life Quality Protocol

Appendix C:

The Year 2000 Family Survey

Appendix D:

Full Statistical Table of Outcomes For the Pre-Post Research Design

Appendix E:

**Responses to Open-Ended Questions in the
Year 2000 Family Survey**

Executive Summary

This is the report of the first year of our three year contract designed to find out about the lives of more than 2,000 California citizens with developmental disabilities. These are people who moved out of California's Developmental Centers, also called institutions, between 1993 and 1999. They moved into new homes in regular neighborhoods all over California. *How are they doing?* Was this change good for them, or have they been harmed? In other words, all of our research and analysis is aimed at one central and ultimate "outcome" question: *Are they better off?*

Perhaps the most important aspect of the project is that fact that we were able to include everyone. We did not draw "a sample." We attempted to locate and visit every single one of the 2,322 people that moved out of institutions and was still reported to be "active" on the community caseloads of the Regional Centers. We can now talk about the people who moved, the "Movers," in a very concrete and confident manner. We attempted to visit everyone. *No one "fell through the cracks."* We located every single person, and completed Visits with 92% of them.

As the data in this Report make clear, these people are indeed better off. In fact, they are on the average much better off. They are better off in most of the ways that we know how to measure, such as behavior, independence, integration, choicemaking, health, medications, friendships, family contacts, daily activities and engagement, physical quality, individual planning, individualized treatment, perceived qualities of life, and satisfaction.

There are a host of subsidiary questions in this research, such as: In what way(s) are they better off or worse off? How much? If they are better off, there

may still be problems and things that could be made better; what are they? Are there any major unmet needs? This report is designed to answer the majority of these questions.

This project was mandated by the California legislature in 1997. The legislation is contained in the Welfare & Institutions Code 4418.1. It reads as follows:

- (a) The Legislature recognizes that it has a special obligation to ensure the well-being of persons with developmental disabilities who are moved from state hospitals to the community.
- (b) To ensure that persons with developmental disabilities who are moved from state hospitals to the community are receiving necessary services and supports, the department shall contract with an independent agency or organization for the tracking and monitoring of those persons, including all persons moved as a result of the *Coffelt v. State Department of Developmental Services* settlement agreement and any persons moved after the terms of that agreement have been met.
- (c) The contractor shall be experienced in all of the following:
 - (1) Designing valid tracking instruments.
 - (2) Tracking the quality of community programs, including outcome-based measures such as health and safety, quality of life, integration, choice, and consumer satisfaction.
 - (3) Tracking the quality and appropriateness of community placements for persons moving from large institutions into community settings.
 - (4) Developing data systems.
 - (5) Data analysis and report preparation.
- (d) The contractor shall measure consumer and family satisfaction with services provided, including case management and quality of life, including, but not limited to, health and safety, independence, productivity, integration, opportunities for choice, and delivery of needed services.
- (e) The information maintained for each person shall include the person's name, address, nature of disability, medical condition, scope of community-based services and supports, and the annual data collected by the contractor.
- (f) The contractor shall meet with each person, and the person's family, legal guardian, or conservator, when appropriate, no less than once a year to discuss quality of life and observe the person's services and supports. In cases where the consumer is not capable of communicating his or her responses and where there is no family member, guardian, or conservator involved, the contractor shall meet with no less than two persons familiar with the consumer. Additionally, the contractor shall interview staff and friends who know the consumer best and review records, as appropriate.
- (g) If the contractor identifies any suspected violation of the legal, civil, or service rights of an individual, or if the contractor determines that the health and welfare of the individual is at risk, that information shall be provided immediately to the regional center providing case management services, the client rights advocate, and to the department.
- (h) The department shall monitor the corrective actions taken by the regional center and maintain a report in the person's file. The consumer and, when appropriate, his or her parents, legal guardian, or conservator, shall be provided with access to the person's file and be provided with copies of all reports filed with the regional center or department relative to them.
- (i) The department shall establish a task force, including representatives from stakeholder organizations, to annually review the findings of the contractor and make recommendations regarding additional or differing criteria for information to be gathered by the contractor in future interviews.
- (j) As of July 1, 1998, and annually thereafter, the contractor shall provide a report to the Governor, the Legislature, and the department outlining the activities and findings of this process. The reports shall be public and shall contain no personally identifying information about the persons being monitored.

The Center for Outcome Analysis (COA) was selected to perform this work under contract with the Department of Developmental Services. The work began in mid-1999. We have now completed face-to-face Visits with 2,143 people who moved from Developmental Centers to community homes. Our Visits averaged 83 minutes. This Report shows what we have learned from these Visits and from the people who allowed us into their lives for these brief times. In the next 2 years, these people will be Visited annually.

Historical Background

Since April 1993, California's Developmental Centers² have been reduced in population by more than 2,300 people. Most of the reduction has been accomplished by helping people move into small, integrated homes in regular neighborhoods. This has been the most rapid movement of people with mental retardation and other developmental disabilities from institution to community in history. Most of these 2,300 people moved during a 4-year period between April 1993 and April 1997.

California's achievement can now be placed into the context of the national experience of deinstitutionalization. By comparison, it took 10 years to move 1,154 people from Pennhurst Center (a Pennsylvania institution near Valley Forge) to new community homes.³ The Pennhurst closure was one of the most hotly contested and extensively studied of its kind. Yet it progressed much less rapidly than what has happened in California. Similarly, the other famous community placement examples moved slowly in comparison to the California action (Connecticut, Michigan, New Hampshire, New York, Oklahoma). In these well-known cases, states moved no more than 300 people per year, and usually fewer. In California, the rate exceeded 500 per year.

The driving force in California's efforts was a lawsuit filed in 1990, which came to be known as Coffelt v. DDS⁴. In February 1990, a lawsuit was filed by William L. Coffelt Jr. and 12 other named plaintiffs in order to make non-

² Developmental Centers are large, segregated public institutions for people with mental retardation and other developmental disabilities. They are to be distinguished from institutions for people with mental illness.

³ Conroy, J., & Bradley, V. Conroy, J. W., & Bradley, V. J. (1985). *The Pennhurst Longitudinal Study: A report of 5 years of research and analysis*. Pennhurst Study Report PC-85-1. Philadelphia: Temple University Developmental Disabilities Center/UAP. Boston: Human Services Research Institute.

⁴ Coffelt v. Department of Developmental Services, No. 91-6401 (Cal. Super. Ct. Jan 19, 1994), MPDLR 185.

institutional community homes more readily available. This class action lawsuit resulted in a 1993 settlement agreement, in which the parties agreed to:

... increase the availability of quality, stable, normalized, integrated community living arrangements so that persons with developmental disabilities can obtain treatment and habilitation services and supports in the least restrictive environment; can achieve the most independent, productive and normal lives possible; can have the opportunity to be integrated into the mainstream life of their home communities; and can, with the assistance of services and supports, approximate the pattern of everyday living available to persons without disabilities of the same age (Coffelt v. DDS, 1994, p 3).

According to the terms of the Coffelt settlement, at least 2,000 California citizens who have developmental disabilities were to be affected over a 5-year period. Some would be assisted in finding an alternative to being placed into a State Developmental Center, and others, who were experiencing difficulties in their community living situations, would receive additional or different supports in order to resolve those difficulties. Most of the Coffelt class members, however, were to be people who moved from state Developmental Centers (DCs) to homes in communities.

California met the obligations of this settlement agreement ahead of schedule. By 1997, more than 2,300 people had moved out of institutions. Many other deinstitutionalizations were also hastened by court action, such as those in Pennsylvania (Pennhurst), New York (Willowbrook), and Oklahoma (Hissom). Nevertheless, the Coffelt deinstitutionalization stands as the largest and most rapid among them.

Deinstitutionalization is not a new phenomenon. In the field of developmental disabilities, it has been proceeding since 1969, and has been remarkably well studied, evaluated, and documented. There has, however, been

considerable confusion between deinstitutionalization in the mental health field and deinstitutionalization in the mental retardation field.

The misunderstanding is largely due to the confusion of mental illness with mental retardation. State institutions for people with mental illness have experienced an entirely different, and devastatingly negative, depopulation movement.⁵

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 anti-psychotic drugs including Haldol, Mellaril, Thorazine, and so on). The phrase “dumping” came from the fact that tens of thousands of people were simply “discharged” with a 30-day supply of “miracle drug” with no place to live, no job or day activity, and no support to reestablish family relationships. In a summary statement of the nation’s early experience with deinstitutionalization in the mental health field, Alexander (1996) wrote:⁶

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

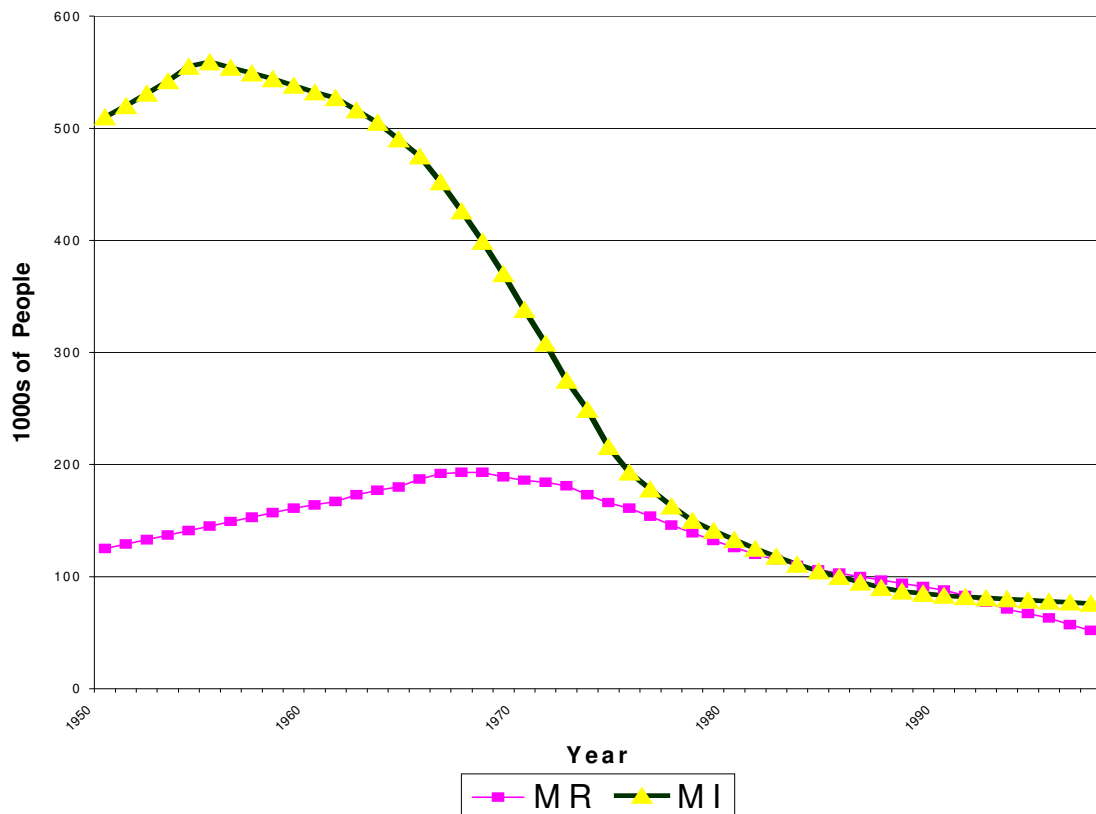
The result in the mental health field was a national disgrace, according to Bassuk & Gerson (1978).

Figure 1 compares the two trends toward deinstitutionalization. The upper line shows the depopulation of mental health institutions since 1950, which was

⁵ Bassuk, E.L., & Gerson, S. (1978). Deinstitutionalization and mental health services. *Scientific American*, 238, 46-53.

⁶ Alexander, R. Jr. (1996). The quality of life of persons with severe emotional disability: a review of empirical studies. *Journal of Health & Social Policy*, 7:4 9-22, 1996.

Figure 1
Deinstitutionalization in the United States:
Mental Retardation vs. Mental Illness, 1950-1998



clearly far more precipitous than the relatively gradual shrinkage of institutions for people with mental retardation in the lower line.

Figure 1 shows how different the two trends have been. Most citizens, and many families, who are skeptical of deinstitutionalization, formed their opinions with regard to the mental health debacle.

It is important to 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. There is a large body of research evidence available to support this conclusion. Much of the best evidence was summarized in a meta-analysis performed by Larson & Lakin (1989).

The historical context of California was similar to that of the nation as a whole, but with one difference that may have been significant. California was deeply engaged in deinstitutionalization of its Developmental Centers in the late 1970s and early 1980s. Toward the middle and end of the 1980s, though, the process slowed. The availability of appropriate community options appeared to have ceased its rapid increase. This fact is shown in Figure 2. The community placement movement had, in effect, ceased in net terms. Although community placements were occurring, new admissions were keeping the overall Developmental Center census constant. Although the reasons for litigation like Coffelt v. DDS are multiple and complex, this graph provides one of the simplest and most understandable foundations for understanding the Coffelt litigation.

Figure 2
Deinstitutionalization in California: Declining DC
Populations

