

Executive Summary

The Coffelt Longitudinal Study: The Results of Four Years of Movement From Institution to Community

Final Report (Number 19) Of the 5-Year Coffelt Quality Tracking Project California Department of Developmental Services

Contract Number HD390158

Submitted to: Delores Murrey, Ph.D., Manager Quality Assurance & Program Support Branch Quality Assurance Section CA Department of Developmental Services 1600 Ninth Street Room 340 Sacramento, CA 95814

Submitted by:

James W. Conroy, Ph.D., Jeffrey X. Seiders, and Anita Yuskauskas, Ph.D.
The Center for Outcome Analysis 1062 East Lancaster Avenue Suite 15E
BrynMawr.PA 19010 610-520-2007, FAX 5 271, e-mail jconroycoa@aol. com

July, 1998

Acknowledgements

It is appropriate to recognize the contributions of many stakeholders during the past four years of our work. At Protection & Advocacy Incorporated, the attorneys who successfully conducted the litigation continued their advocacy by staying closely involved with the research and quality tracking activities. We wish to thank Ellen Goldblatt, Catherine Blakemore, Eric Gelber, and Kim Swain in particular. At the Department of Developmental Services, we thank many individuals, particularly former Director Denny Amundsen for his courage and vision during the years of the Coffelt deinstitutionalization. And we thank the more than 50 Visitors who worked for us during these years, who conducted more than 4,000 face to face Visits with Coffelt class members, faithfully recording extensive data about the qualities of their lives, their satisfaction, and their well-being. The most important acknowledgement, of course, must go to the more than 2,000 California citizens who are members of the Coffelt class, and whose lives have been powerfully affected by the lawsuit, the settlement, and by advocates on all sides

Executive Summary: Four Years of the Coffelt Quality Tracking Project

This final report of this phase of tracking the well being of the Coffelt class members offers an Executive Summary which condenses the findings of all prior reports. The Summary ends with comments on problems, issues, and recommendations based on thousands of hours of research, involvement in the legal situation, oversight of the monitoring process, review of media

attention, and more than 4,000 face to face visits with class members, lasting an average of 96 minutes each. The Summary is therefore longer than usual.

The main body of this Final Report attempts to condense thousands of pages of reports and thousands of visits and family surveys into a non-technical, widely readable format. The most important results are summarized in a single Outcomes Table, and then each outcome area is discussed in terms of what we have presented in all prior reports.

Prior Reports

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

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

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

Report Number 4: was a collection of graphs, called a Chartbook, intended for internal DDS discussion purposes only.

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

they and their relatives were better off because of the interventions they experienced.

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

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

Report Number 8: Patterns of Community Placement II: The First 27 Months of the Coffelt Settlement was submitted in February, 1996. It contained analyses of: quality of life for nonequivalent comparison groups of Movers and Stayers; a longitudinal pre-post analysis of changes in quality of life for 34 people who moved into community settings; descriptive data of mental health and crisis intervention supports; reasons for 13 returns to Developmental Centers; features and quality of supported living; mortality; and costs. Findings indicated that 438 Movers were better off in many ways, including being in settings of higher physical quality, being more integrated, and being more satisfied with their living arrangements and staff. Seventy seven percent of those who could respond noted that they felt good or very good about living in their current community residence. Statistically significant improvements were reported in qualities of life such as comfort, happiness, food, health, and safety. However, concerns were raised with choice making, health care, and medications. The pre-post test results indicated that 34 people who moved into

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

Twenty eight people who moved into supported living situations reflected increases in self-determination and quality, above that of other community

settings. On another note, cost data showed that community care in California costs about half as much as institutional care. In several other deinstitutionalization studies, community costs were about 75% of institutional costs, suggesting that California's community reimbursement rates are relatively low. Concerning mortality rates, preliminary data indicated that movement to community did not increase mortality among class members when compared to the statistical expectation for large congregate care settings.

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

Report Number 10: Qualities of Life Among Coffelt Class Members who Moved from Developmental Centers to Community Homes, 1993-1995 was submitted in September, 1996. The Report compared qualities of life of 45 Movers and 395 Stayers using analysis of covariance. Consistent with other Reports (Reports 2, 3, & 8), the qualities of life were considerably higher among the Movers, even while controlling for their differences from the Stayers. This report was submitted to a journal for peer review, and has been accepted: Conroy, J., & Elks, M. (In Press). Tracking qualities of life during deinstitutionalization: A covariance study. *Education and Training in Mental Retardation and Developmental Disabilities*.

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

Report Number 12: Patterns of Community Placement III: The Third Year of Coffelt Implementation presented a series of analyses of the qualities of life experienced by class members who left Developmental Centers. Two thirds of the people who moved carried the "severe" or "profound" mental

retardation label. Nevertheless, they became significantly more independent, sharply reduced their challenging behaviors, they received even more services and supports than they did in the DCs, their closest caregivers reported far more "progress toward goals in the past year" than had been the case in the DCs, they became much more integrated into the mainstream of American life in terms of outings, and, for those who could and would communicate with our Visitors, reported themselves to be much happier in the community than they had been at the DC.

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

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

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

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

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

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

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

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

The pre-post results indicated that 91 people who moved into community living experienced significant improvement in adaptive behavior, challenging behavior, quantity of services received, progress on individual goals, level of integration, and self determination, individualized treatment, normalization, satisfaction. Because the Pre-Post design is the strongest one among the six that COA has used during the course of this work, these findings were very

important. Combined with the parallel findings from the other research methodologies, we are justified in having high confidence in their veracity.

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

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

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

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

Report Number 18: Selected Findings of the Coffelt Quality Tracking Project was submitted in June, 1998 and examined several topics of interest among the 1215 class members we visited this year. The first topic of interest involved mental health, crisis intervention, and medical emergency supports among 1159 class members in their community homes. Mental health supports were delivered to 26% of our sample. Simple medications monitoring was provided to 12%, and services and supports other than or in addition to medications monitoring were provided to 5%. Nine percent of the respondents were reported to receive both medications monitoring as well as some other types of services or supports.

Recipients of such supports were higher in adaptive behavior, and displayed more challenging behavior, than the average class member. Only 22 people were reported to be in need of, but not receiving, one or more mental health services or supports. Mental health counseling and therapy were the most common unmet needs reported.

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

The second topic of interest concerned the well being of the Coffelt class members known as the Community Target Group (CTG). The Community Target Group is composed of Coffelt class members who had difficulty in their living situations in the community, and received assistance to find new residential alternatives. This year we visited 89 CTG members and once again discovered that many enjoy similar qualities of life as the Movers.

In general, the group believed their qualities of life had improved significantly in 12 of 13 areas in a one year period. In fact, the CTG group experienced more self-determination than the Movers did. Staff report high levels of job satisfaction both in general and working directly with the CTG members. The analysis of the CTG members provides compelling evidence that they are 1) better off than they would have been without the Coffelt intervention and 2) much better off than they would have been if they were living in Developmental Centers.

The third topic of interest provided a brief description of class members who live in large congregate settings. The fourth and final topic looked at children (class members under age 18) that were visited last year and provided a descriptive summary of their characteristics and situations.

What We Have Learned: Outcomes and Remaining Issues

Outcomes

- 1. Positive Outcomes:** California's Coffelt class members are better off because of the settlement of the lawsuit. More than 2,000 people have moved from institution to community living, and their lives have on the average been enriched measurably and significantly in terms of self-care abilities, appropriate social behavior, opportunities for choice making by the person and unpaid allies, integration, services delivered through the individual planning process, hours of day program per week, attainment of individual goals, individualized treatment, physical quality of their home environments, consumer satisfaction, and family satisfaction.
- 2. Negative Outcomes:** Fewer class members have paid jobs in the community than they did while living in Developmental Centers, and they are on the average earning less money from paid work than they had while living in Developmental Centers. Moreover, the prevalence of sedative and psychotropic medication utilization has increased slightly since moving to the community. These are the only negative outcomes detected during the four years of this study.
- 3. Balance:** The balance of positive and negative outcomes is weighted heavily toward the positive.
- 4. Cost:** The total public cost of supporting people in California's community service system is much lower than the Developmental Center cost. In 1996, community costs averaged about \$55,000 per person per year, while Developmental Center costs averaged about \$100,000. Both costs are higher now, but the difference persists. These costs were computed for similar

people, and the difference definitely cannot be explained by differences in the people served in institution and community.

5. Conclusion: The ultimate conclusion is inescapable: The Coffelt settlement has brought about enormous social benefits to people with major mental retardation. This did not require extra money; it was done at much lower cost than the Developmental Centers would have spent.

6. Policy: The movement of people out of institutions and into small integrated community homes should continue.

Remaining Issues

1. Underfunding: The cost of community supports is too low. Other deinstitutionalizations have been cost-efficient, but at the level of about 80% of institutional costs, not 55%. Community service providers in New Hampshire, Connecticut, or Pennsylvania would refuse to do business at the per diem reimbursement rates that California pays. California could have experienced even more positive outcomes from the Coffelt process, if the community service system had not been so seriously underfunded. This underfunding results in poor staff salaries and benefits, which can result in high turnover. (Note that the average duration of relationships with "whoever knows the class member best" is 2.5 years, which is not as bad as many critics of community care would claim.) Dollars must follow people in future deinstitutionalization efforts. Any dollars saved must go back into the service system to assist families who are receiving less support than they need.

2. Lack of Employment: Only 34 of the 1215 people visited this year were involved in supported employment. Only 3 were competitively employed, and only 1 had a full time job. The Coffelt process has not emphasized real jobs for real wages sufficiently. Similar people in Oklahoma who left institutions are involved in supported employment at the rate of 40%. There are hundreds of Coffelt class members who could work, and most would like to work.

3. Overreliance on Congregate Care: The "group home" model typified by the ICF/MR funding stream is not the best way to support people. Future development in California should stress supported living, with choices offered to people and their unpaid allies. Only 51 of 1215 class members visited this year are in supported living situations. This is not the level of emphasis envisioned in the Coffelt settlement agreement, and it needs to be changed.

4. Self-Determination: The most disappointing outcome of the Coffelt community movement has been the very small increase in power wielded by the class members and their unpaid allies/families/friends/guardians/conservators. Professionals controlled nearly every life decision in the Developmental Centers, and they are still controlling nearly every life decision in California's community service system. Future efforts to support people in communities must adhere to the principles of self-determination so that the overwhelming professional dominance over every life decision can be diminished. Power should move toward people and their

loved ones as much as possible. There are now 29 states involved in self-determination projects, and California is not one of them. This places California in the back rows of the "state of the art."

5. Medications: The community health care system tends to prescribe more of the powerful psychotropic and sedative medications for class members than the Developmental Centers. This issue needs to be addressed, and we are aware that efforts are under way.

6. Media Attention: Recent media attention has been devastatingly negative, and thoroughly unjustified. DDS leadership needs to counter that negative attention with courage and scientific evidence. California's political leadership should join in the effort to inform the public that the Coffelt community movement has been overwhelmingly successful, cost-effective, and welcomed by the families and the consumers involved. We recommend that the reports in this series be presented to the media in a series of press releases, briefings, and conferences