Patterns of Community Placement IV: The Fourth Annual Report on the Outcomes of Implementing the Coffelt Settlement Agreement

Report Number 17
Of the 5-Year Coffelt Quality Tracking Project
California Department of Developmental Services

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Executive Summary

This Report presents our most recent findings about the well-being of Coffelt Class Members who have moved from Developmental Centers to community homes. We have conducted face to face visits with nearly half of the approximately 2,300 people who have moved since the Coffelt settlement implementation began. During each visit, we have measured dozens of aspects of their quality of life. We have also surveyed their closest relatives by mail.

In summary, the results of all our Reports to date indicate that California citizens who moved from Developmental Centers to community living arrangements under Coffelt are on the average much better off than they would have been if they had remained in Developmental Centers. These cumulative positive outcomes demonstrate that the movement of people from institution to community under the Coffelt settlement has been successful. Because we are reporting on the average outcomes of more than 1,000 people, we must acknowledge that some people have had minor and major difficulties with the transition to community living. For example, we found that a few people had moved back into Developmental Centers after having a troubled experience in a group home. However, the data show that those difficulties were experienced by only a small minority of the Coffelt class members. Despite the continuation of debates in political, media, and advocacy arenas, the scientific information about quality of life stands uncontested. These people are far better off than they were before, and far better off than they would have been had they stayed in Developmental Centers.

Even the recent work by Strauss and colleagues on mortality does nothing to contradict our strong findings. Mortality is not a good "stand-in" for measurement of quality. There is no "stand-in" for outcomes such as independence, productivity, integration, support amounts, support appropriateness, engagement, comfort, safety, satisfaction, and happiness. On these true quality of life outcome measures, the Coffelt Movers' lives have been significantly enhanced.

Moreover, the mortality issues raised by Strauss et al. are far from resolved. An article recently accepted by the peer-reviewed journal *Mental Retardation*, written by the senior author of this report, shows that mortality probability among the people who left Pennhurst Center in Pennsylvania actually decreased. Community living was associated with higher survival rates than the institution.

Longitudinal Findings

In this year's work, we have completed visits with 1,073 people who moved from institution to community under the terms of Coffelt. (We have also visited other class members, but they will be described in a separate report). Of the 1,073 Movers, 91 were also visited back in 1994, when they were still living in Developmental Centers. (Many of the 1,073 were also visited in the intervening years as well as part of this project.) Seeing people "before and after" living in the institution enables us to examine changes in the qualities of their lives since moving to their new community homes. We can now make inferences about whether those 91 people are better off or worse off than they were in Developmental Centers, in what ways, and how much. These 91 people provide our strongest scientific evidence of changes in qualities of life, and are therefore the primary focus of this Report.

1. Adaptive Behavior

The Movers improved significantly in adaptive behavior, also called independent functioning or self-care skills. The improvement was about 2 points on a scale of 100. This conclusion is based on results obtained from California's standardized and highly reliable measure of self-care and independent functioning. We collected the behavioral data by directly interviewing whoever knew the class member best on a day to day basis, and the interrater reliability of these data was found to be .97. Conclusions about gains in self-care skills are therefore made with confidence.

2. Challenging Behavior

The Movers improved sharply in challenging behavior, displaying the most rapid improvements this research team has witnessed in similar evaluations (including, for example, people tracked from the Thomas S. Class in North Carolina, the Pennhurst Class in Pennsylvania, and the Hissom Class in Oklahoma). The improvement was about 6 points on a scale of 100.

3. Developmentally Oriented Services

The Movers appear to be receiving a greater quantity and variety of developmentally oriented services than they were before, according to their Individual Program Plans.

4. Reported Progress Toward Individual Goals

Staff working most closely with the Movers reported on the progress seen in the Class Member during the preceding year. When at Developmental Centers, the average staff rating was 47 on a scale of 100 points. The average community staff rating was 78. This implies that much more progress is occurring in the community, and this is consistent with the behavioral outcomes noted above.

5. Integration

Integration is measured as the number of times per month Class Members went out to places where they were in the presence of non-disabled citizens. The measure nearly doubled. Insofar as integration and inclusion are explicit goals of the Lanterman Act, this must be interpreted as an extremely positive outcome.

6. Self-Determination

The Decision Control Inventory is a measure of self-determination. It measures the extent to which people make their own decisions in daily life, with the support and assistance of unpaid friends or loved ones, as opposed to having decisions made by paid staff. This measure increased significantly, but only went up from 31 to 36 points on a scale of 100. This is a relatively small improvement, in the experience of this research team. It may be inferred that community programs in California would benefit from extensive and intensive training in consumer rights, empowerment, choice making, and self-determination.

7. Antipsychotic Medications

Among the 91 Movers, there are now 24 people being given antipsychotic medications, whereas there were 15 before. Although this does not reach statistical significance, it is in keeping with past findings of increased utilization of neuroleptic and other powerful medications in the community. The number of people reportedly being given sedatives or hypnotics is up from 5 to 26. These medication issues are urgent, and must continue to be the focus of DDS investigation, training, and policies.

Experiences of 1,073 Movers

We have analyzed the characteristics and qualities of life of all 1,073 Movers (people we saw who moved from institution to community under Coffelt) who we visited in the past year. The 1,073 Movers are somewhat higher in self-care abilities than those still in Developmental Centers. The Movers also display somewhat less challenging behavior. Nevertheless, almost three fourths are labeled either "severely" or "profoundly" retarded. We can therefore conclude that the Coffelt deinstitutionalization has not been a process of placing only the "higher functioning" people into community living. Following is a summary of our findings for the 1,073 Movers.

1. Personal Interviews and Satisfaction

The Class Members who were willing and able to complete an interview (with whatever assistive devices or techniques they needed) told us they were extremely happy in their new community homes, happier than they had been in the Developmental Centers, and generally very satisfied with many aspects of their lives. We found strong satisfaction among 302 of the 1,073 Movers who were able and willing to be interviewed. Only 4 out of 302 described their living situations as "Very Poor," while 120 said "Very Good."

2. Qualities of Life, A Year Ago and Now

The Class Members, or those who knew them best, rated their qualities of life in 13 areas, "A Year Ago" and "Now." The data revealed significant increases in every one of the 13 areas, by either of two methods of analysis (pre-post and recollection).

3. Community Staff

Staff in community programs said they "liked working with" the Class Member more than did the DC staff. Community staff also appeared to have as broad or broader a battery of training as the DC staff.

4. Physical Quality of the Home

The Movers' new community homes received significantly higher physical quality ratings than did the Developmental Centers, including comfort, cleanliness, decor, and attractiveness.

5. Open Ended Comments

The open ended section of the protocol revealed a large number and variety of positive statements about community homes, and relatively few negative statements. For example, people liked having opportunities to listen to music and watch television, have relationships with family and friends, and choose foods. They disliked lack of choice related to staff, roommates, and daily activities.

6. Supported Living Settings

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

7. Comparison of similar groups living in Waiver settings and ICF/MR settings

This comparison produced 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 (ICFsMR). We believe this can and should be taken into consideration in considering future policy on Waiver and ICR/MR funding patterns. This finding is relevant to the recent HCFA survey of 91 people in Waiver settings in California.

Family Survey Results

In this project, we have made extensive efforts to obtain the opinions of each class member's closest relatives. Again this year, we mailed a survey form to every person's closest known family member, in order to find out what their opinions of the community placement process had been. Of the 1,406 people in our original sample, we were able to obtain 570 valid addresses of relatives by the time of this writing. (This shows, sadly, that many class members have no family involved in their lives at all.) Although responses are still coming in from this survey, we report herein the findings from the first 185 responding relatives of Movers.

The primary interest in the survey is whether the families believe the class members' lives have become better, worse, or stayed the same since moving to the community. The "Quality of Life - THEN and NOW" scale asks families to estimate 14 qualities of life before the move, and after the move. In all 14 quality areas, families reported that they perceived enhancements in the class members' lives. All 14 were statistically significant. The three largest increases were in "Privacy," "Getting Out and Getting Around" and "Happiness." It is clear that most families have very positive feelings about the movement to the community.

When they first heard about the possibility of community placement, many families were skeptical. About 42% recalled being distinctly opposed to the idea at first. Now, after it has happened, the opposition is down to 5%. To be sure, those 5% should be followed up and efforts made to correct situations, but this large reduction in family opposition shows that the program has been seen by families as successful and beneficial.

The 1998 Family Survey findings leave 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.

Quality Feedback System

Since the beginning of the Quality Tracking Project, we have maintained that some of the information we collect should be utilized at the individual level, in addition to the ongoing aggregate analyses we have been performing. For example, we believe that when we visit a person, and find that the person has no day program, we should promptly report this to DDS for transmission to the Regional Center and the service provider. This year, for the first time, we have implemented a Quality Feedback System. For each person we visited, we produced a simple 2 page "report card" noting both positive and negative findings from the visit. The items on this "report card" were selected jointly by representatives of ARCA, DDS, P&A, and COA.

This new development in our work is now providing rapid feedback on both negative and positive situations in individual lives. This mechanism has the potential of alerting the system to individual problems early, and possibly preventing them from becoming emergencies. For example, we are reporting each person who is living in a home that is very low on the Individualized Practices Scale. Homes that are treating people as groups rather than as individuals are in need of technical assistance. If they receive it, qualities of life such as satisfaction and self-determination may be expected to increase.

Feedback about successes is also part of the Quality Feedback System. For example, we are reporting individuals whose opportunities to control their own lives (with assistance from unpaid circles of friends if needed) is unusually high in comparison to their adaptive behavior skill levels. The entire system stands to learn a great deal from such examples of excellence.

Moreover, it is common sense that any service provider that is enabling such state of the art practices should be notified and congratulated.

These are only a few examples of the Quality Feedback System. We obtain a wealth of individual information when we conduct our Visits. A few more examples of the kind of individual information are: adaptive behavior, challenging behavior, service types and amounts, physical quality of the home, integration, choicemaking, and satisfaction. With feedback, a system can move toward continuous enhancement of quality. Without feedback, a system can only move in random directions.

Introduction

This is the 17th report of the Coffelt Quality Tracking Project, which arose from the Coffelt Settlement Agreement. The Agreement called for an independent analysis of the health, well being, and quality of life of the individuals affected by the Coffelt Agreement. The highlights of the 16 prior Reports are provided in Appendix A.

In summary, the results of all our Reports to date indicate that California citizens who moved from Developmental Centers to community living arrangements under Coffelt are on the average much better off than they would have been if they had remained in Developmental Centers. These cumulative positive outcomes demonstrate that the movement of people from institution to community under the Coffelt settlement has been successful. Because we are reporting on the average outcomes of more than 1,000 people, we must acknowledge that some people have had minor and major difficulties with the transition to community living. For example, we found that a few people had moved back into Developmental Centers after having a troubled experience in a group home. However, the data show that those difficulties were experienced by only a small minority of the Coffelt class members. Despite the continuation of debates in political, media, and advocacy arenas, the scientific information about quality of life stands uncontested. These people are better off than they were before, and better off than they would have been had they stayed in Developmental Centers.

The clear fact is that Coffelt class members are more independent, more integrated, more satisfied, display less challenging behavior, and live in better quality homes, at which the staff's job satisfaction is higher, and who like working with these individuals more than Developmental Center staff (by their own reports).

These important quality of life changes have been shown by matched comparison of qualities of life (twin studies), by mathematical techniques to control for differences between Movers and Stayers (analysis of covariance), by static group comparisons without controlling for differences (nonequivalent comparison groups), and by pre-post measurements of qualities of life. In addition, families of the Movers are very highly satisfied with community living, have sharply reduced their initial skepticism and resistance, and only a handful would ever even think of seeing their relatives return to a Developmental Center.

Even the recent work by Strauss and colleagues on mortality does nothing to contradict our strong findings. Despite their creation of “adjusted mortality ratios” through complex mathematical models, it is simply indefensible to suggest that mortality is a good “stand-in” for measurement of quality. There is no “stand-in” for outcomes such as independence, productivity, integration, service intensity, and satisfaction.

It should be noted that four of our prior reports have been submitted to peer-reviewed journals, and one has already been accepted for publication.

There are political aspects of the Coffelt community placement process, which have risen to the level of debate in the California Senate, and indeed, nationally. These Reports of the Coffelt Quality Tracking Project are not the place to discuss political disputes. Our concern is whether the people themselves are benefiting from movement from DC to community, as the Court anticipated they would. The evidence is clear that movement out of Developmental Centers makes excellent social policy, from both the quality of life and the economic perspectives.

The primary purpose of Report Number 17 is to broaden previously reported results by incorporating additional people into our sample. We have visited 1215 people, of whom 1073 were “Movers” thus far this year. This Report concerns the 1073 Movers.

As in Report Number 12, we will examine the issue of “skimming,” which refers to a common practice of selecting the most capable people for community placement. This phenomenon has been observed in many in past deinstitutionalization processes (Conroy, 1977; Conroy, Lemanowicz, & Bernotsky, 1991; Prouty & Lakin, 1995). However, the effect is not as powerful today as it once was, because there are very few people left in DCs who could be described as “high functioning” (Stancliffe & Lakin, 1996). We will compare the characteristics of 1073 community Movers to our baseline sample of Developmental Center residents.

Next, we undertake a pre-post analysis of changes in quality of life. The pre-post analysis includes 91 people who moved into community settings during the past 3 years, who were living in DCs when we first visited them. In this analysis, each person serves as his or her own "control." The power of this analysis is that we can directly observe whether each person is better off, worse off, or about the same, and in which ways. This "before and after" analysis is the strongest scientific evidence of improved qualities of life that we have, and that is why this Report places it in such a prominent position.

We then examine the results of the personal interviews. We include every open ended comment made by the Movers in Appendix B. Although only about a fourth of the Class Members were able or willing to communicate with our visitors, their voices and their feelings are very important. We must, however, recognize that their voices do not necessarily speak for those who cannot communicate their feelings. Yet at the same time we must try to obtain the feelings of as many people as we possibly can. For those who cannot communicate through traditional channels, the present body of work includes measures of dozens of dimensions of quality of life that do not depend on communication ability, such as comfort, behavioral growth, integration, and health.

Because of a recent critical report by the Health Care Financing Administration (HCFA) concerning California's Medicaid Waiver program, we are adding a new chapter to this Report. The new chapter examines the quality of the homes and services provided under the ICF/MR program versus the Waiver program. The HCFA critique suggested that the flexible, community oriented, non-medically dominated Waiver program has led to lower quality than would be expected under the ICF/MR program. Our data do not confirm the HCFA findings; in fact, our analyses support the opposite conclusion.

Methods

The 1996-97 Sample

For the 1996-1997 year, we selected a stratified random sample of 1422 people. The 1422 people were composed of the groups shown in Table 1.

Table 1
The Design of the 1996-1997 Community Sample

Group	Number	Percent
93-96 MOVER ("Old")	723	50.8%
96-97 MOVER ("New")	592	41.6%
93-96 CTG ("Old")	67	4.7%
96-97 CTG ("New")	40	2.8%
Total in Sample	1422	100.0%

The 93-96 Movers are people who left Developmental Centers earlier in the Coffelt process, and whom we have visited in their new community homes before. The heading 93-96 CTG refers to Community Target Group members who were visited before. This year, we added 592 new Movers, and 40 new CTG members, to our Coffelt community sample.

At the time of this writing, we have completed face to face visits with 1215 of these 1422 people. This is nearly half of all the people who have moved from Developmental Centers into community settings during the 48 month period from 4/93 to 4/97. Many of these people were visited last year, and some the year before as well. Of the 1422, however, 16 people were in the DDS data base twice, leaving only 1406 individuals in our sample. There were 191 Class Members (Movers and CTG) in our sample who we were unable to visit. The reasons are shown in Table 2.

Table 2
191 Class Members Who Could not be Visited

Reason	Number
Could not be reached in three attempts	84
Deceased	64[1]
Returned to DC or State Hospital	*20
Moved out of state	15
Refused to be interviewed	8
Total	191

* this figure represents only those not interviewed in the institution, not all persons returned and residing in the institution during the data collection period.

While a 100% completion rate is desirable, in practice it simply is not possible. Because the system of care is dynamic and people are moving from place to place, leaving the state, having scheduling conflicts, changing or disconnecting telephone numbers, or simply resistive to the whole notion of being interviewed, some number of interviews will not be conducted in the time allotted. However, all visitors were instructed to make *at least* three attempts at conducting a face to face interview, and in many cases many more attempts were, in fact, made.

During this data collection period there were at least two other statewide data collecting efforts occurring at the same time in California. This led to some confusion on the part of some providers about the exact purpose of the requested visit, occasionally leading to disputes about whether or not a given consumer had already been interviewed or a given program site visited. And while most of these situations were overcome and the data collected, it tended to slow down the scheduling process for visitors.

Also, during this data collection period several situations were brought to the attention of the Project Manager by visitors that were of some immediate concern. These situations usually involved observations made during a visit to a program site or home. In each case the regional center was immediately notified by telephone and the situation described in detail. In all

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[1] Among 1406 Movers, across 4 years (1994, 1995, 1996, and 1997), this number of deaths is not extraordinary. DDS maintains its data base as everyone who moved whether they later died or not. Hence our samples contain people who died during the 4 years. 64 deaths among 1406 Movers over 4 years translates to a mortality rate of 1.1%, which is about half of California's 1996 Developmental Center mortality rate, which was approximately 2.2%.

circumstances similar information was included in QFS rapid feedback reports for follow-up and monitoring.

Design of this Year's Primary Analysis

The primary analytical technique for this Report is simple pre-post, or "before and after." Because we visited more than 800 people in Developmental Centers in 1994, and some of those people have moved to the community, we are now able to look for "before and after" changes in qualities of life among Movers. There are now 91 people for whom we now have such pre-post data.

By itself, the simple pre-post design would not be conclusive. It is always possible that factors other than movement from DC to community could have "caused" any changes we might detect. However, in conjunction with the matched comparison design (Reports 2 and 3), the covariance design (Report 10), and the family surveys (Reports 6, 8, 11, and 14), we can have very high confidence in the overall findings. Because all the different research designs have produced essentially the same results, it is extremely unlikely that they are flawed or misleading.

In addition to the pre-post design with 91 Movers, we will present selected findings from the entire group of 1073 Movers. We will also present results from the individual interviews with all Class Members in our sample. Finally, we include the results of a comparison of qualities of life for similar people who live either in an ICF/MR setting or a Waiver home.

Instruments

The primary instrument package of the Coffelt Quality Tracking Project is called the Personal Life Quality Protocol or PLQP. It includes measures of independence, productivity, choice making, integration, friendships, behavioral progress, health, health care utilization, health care quality ratings, case management, activities and supports, individual planning, environmental qualities, and satisfaction. The PLQP was originally attached to Report 2 as an Appendix, and is available from the authors.

The reliability of the PLQP was explored in detail in Report Number 7 in this series, with very positive results (Conroy, 1995). The components have been subjected to other reliability tests over the years, as well (Devlin, 1989; Fullerton, Douglass, & Dodder, 1996; Isett & Spreat, 1979). The components of the PQLP have been shown to be highly objective, scientific, and reliable. The dimensions measured in the PLQP were derived from many years of interviews with services users, parents, other family members, service providers, and other stakeholders, about what is really important in peoples' lives.

The instrument package contains dozens of measures of quality of life and outcomes. Some of them are:

- power to make one's own life choices (with support if needed)
- self-care skills and skill development (adaptive behavior)
- vocational skills and skill development
- challenging behaviors and reduction of such behaviors
- stability of living and working environments
- attitudes and experience of primary caregivers
- health
- health care utilization patterns
- health care satisfaction
- use (versus overuse) of medications
- earnings
- hours per week of productive activity
- individual planning process timeliness
- individual planning process usefulness
- individual planning process degree of "person-centeredness"
- case manager involvement and quality of support
- integration
- relationships with neighbors
- friendships
- family contacts and family relationships
- opportunities for intimate relationships
- having a financial interest in the home
- satisfaction with home
- satisfaction with work
- satisfaction with leisure time

- satisfaction with services rendered (including case management)
- individual wishes and aspirations
- size of the home environment
- characteristics of the home environment (e.g. staffing)
- physical quality of the home environment
- individualized treatment in the home environment
- normalization in the home environment
- costs of the service/support elements
- family/next friend opinions and satisfaction

The second component of our instrumentation is the Family Survey. The Coffelt Family Survey form was derived from 20 years of work surveying the families of people in institutions and communities. The first such survey was conducted with families of people living at Temple University's Woodhaven Center in 1975. The Pennhurst Longitudinal Study produced the next generation of family surveys, followed by versions adapted for Arizona, Arkansas, Connecticut, Colorado, Georgia, Massachusetts, New Hampshire, New Jersey, North Carolina, Oklahoma, and Texas. The 1996-97 California Coffelt Family Survey form, developed in 1993, was included in Report 12 as Appendix B. It was first sent to families of Coffelt Class Members in 1994, and every year thereafter. The results of the Family Surveys were summarized in Reports 6, 8, and 11, 12, and 14.

Procedures for Data Collection

The project recruited and trained local professionals, paraprofessionals, and graduate students to perform a data collection visit with each person in the Coffelt project sample. These data collectors, called "visitors," functioned as Independent Contractors. They were paid a fixed rate for each completed interview. Here are the written instructions from our Personal Life Quality Protocol that we provide to the visitors:

> *This package is composed of many measures, scales, instruments, and interview items. Practically all of the information collected in this package is related to quality of life. In order to complete the package, you must have access to:*
> 1. *The person (to attempt a 5 to 15 minute direct interview)*
> 2. *The person's home (for a 5 to 10 minute tour and observation)*

3. *Whoever knows the individual best on a day to day basis (average 45 minutes)*
4. *The person's records, including medical records*
5. *In some cases, a health care professional (about 5-10 minutes)*

With access to these five sources of information, you should in most cases be able to complete this package within the range of 60 to 90 minutes.

Training for the Visitors was conducted by the Project Manager. The training consisted of an introduction to the project, a role-playing exercise, and a review of the instrument sections and purposes. Field supervision was provided on site during the first few days of visits.

Each visitor was responsible for scheduling appointments and completing an assignment of visits. Visitors were instructed emphatically to respect programmatic needs, and work around them. No Class Member's daily schedule was to be disrupted by these visits. In our community work this year, the average visit took 77 minutes. The amount of information collected, in relation to the relatively short duration of the visits, is worthy of comment. We are able to collect reliable quantitative data on dozens of qualities of life in a very short time, with very little intrusion into peoples' lives.

Collection of such solid information about peoples' qualities of life and outcomes is amply justifiable on an annual basis. There is absolutely no substitute for individual data on quality. No amount of licensing, performance indicators, or accreditation can compare to the utility and precision of individual outcome measurement. As systems move toward person centered planning, they must also move toward person centered evaluation and quality assurance systems.

Results

Results 1: Characteristics of the Movers

In the fourth year of this project, we visited 1125 Movers. However, there were 22 people who had returned to a Developmental Center, 4 who had moved to a mental health institution, and 12 who had moved to a large ICF/DD, 12 who had moved to a Skilled Nursing Facility, and 2 who had moved to a nursing home. This left 1073 people who were living in small (fewer than 15 beds) community homes when we visited. The 52 people who were visited in large scale congregate care facilities should be the subject of further investigation, but in the present report, we will restrict our analyses to people who moved to community settings. Table 3 provides details of the varieties of homes into which the 1125 people moved.

Table 3
Current Homes of the 1125 Movers

Type of Residence	Number	Percent
Large Scale Congregate Care		
Porterville Developmental Center	12	1.1
Sonoma Developmental Center	2	0.2
Agnews Developmental Center	2	0.2
Lanterman Developmental Center	2	0.2
Fairview Developmental Center	4	0.4
State Mental Hospital	4	0.4
ICF/DD, more than 15 beds	12	1.1
Skilled Nursing Facility	12	1.1
Nursing Home	2	0.2
Community Homes <= 15 beds		
ICF or SNF (4 to 15 beds, Generic)	3	0.3
ICF/DD (4 to 15 beds)	12	1.1
ICF/DD-N (4 to 6 beds, Nursing)	227	20.2
ICF/DD-N (7 to 15 beds, Nursing)		
ICF/DD-H (4 to 6 beds, Habilitative)	248	22.0
ICF/DD-H (7 to 15 beds, Habilitative)	6	0.5
CCF (Community Care Facility) LEVEL 1	3	0.3
CCF LEVEL 2 Owner	6	0.5
CCF LEVEL 2 Staff	13	1.2
CCF LEVEL 3 Owner	23	2.0
CCF LEVEL 3 Staff	69	6.1
CCF LEVEL 4-A/Staff	6	0.5
CCF LEVEL 4-B/Staff	3	0.3
CCF LEVEL 4-C/Staff	32	2.8
CCF LEVEL 4-D/Staff	5	0.4
CCF LEVEL 4-E/Staff	10	0.9
CCF LEVEL 4-F/Staff	53	4.7
CCF LEVEL 4-G/Staff	87	7.7
CCF LEVEL 4-H/Staff	54	4.8
CCF LEVEL 4-I/Staff	121	10.8
Foster Care, Foster Family Agency- DDS Funded	4	0.4
Adult Family Homes defined by SB1730	3	0.3
Supported Living, >21 hrs/wk support	37	3.3
Supported Living, 11-20 hrs/wk support	1	0.1
Supported Living, 0-10 hrs/wk support	2	0.2
Independent Living	18	1.6
In Parent's Home	21	1.9
In Other Relative's Home	3	0.3
Homeless or sleeps in shelter for homeless	1	0.1
Other	2	0.2
TOTAL	1125	100.0

It is important to note that our sample was stratified, and the percentages in Table 3 do not reflect the percentages for the entire Coffelt Movers group of more than 2,000 people. We had special interest in certain categories of community living, such as supported living, and therefore stratification was necessary.

In our sample, the most common type of community home was the ICF/DD-H (4-6 Beds). The ICF/DD-H (4-6 Beds) served 22.0% of the Movers in our sample. The ICF/DD-N (4-6 Beds) was next, with 20.2%, and was followed by CCF Level 4-I Staff with 10.8%, and so on. The three categories of Supported Living combined to a total of 3.6% of the total community homes for the Movers. For the entire population of Coffelt Movers, the percentage was similar (about 3% according to recent DDS figures).

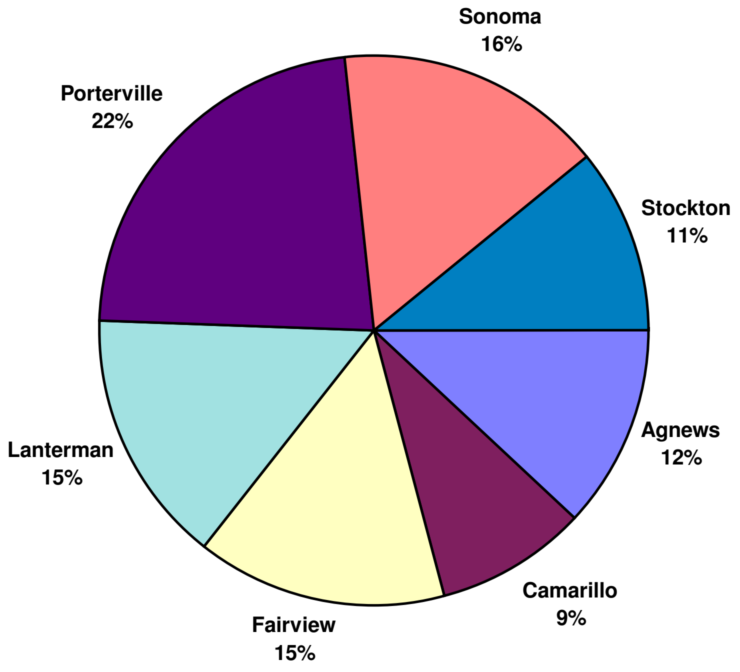
Table 3 shows that 51 people were found to be in large scale congregate settings. For clarity, we have left out these 51 Movers for the remainder of the Report. These 51 Movers, however, should be targeted for future investigation by DDS, because it was not the intent of Coffelt to have people move from one form of congregate care to another and we must make sure that their settings are appropriate to their needs. This leaves us with 1073 true Movers to community homes.

Table 4 and Figure 1 below show the DCs from which the Movers came.

Table 4
Prior DC Homes

Developmental Center	**Percent**
Agnews	12%
Camarillo	9%
Fairview	15%
Lanterman	15%
Porterville	22%
Sonoma	16%
Stockton	11%
Total	100%

Figure 1
Prior DC Homes



Porterville contributed the largest number of people in our sample of Movers, with 22%. The smallest number of people came from Camarillo. Our sample in this Report closely mirrors the total number of people who have moved from DCs to community homes under Coffelt.

Table 5 shows the distribution of basic characteristics among the 1073 Movers, including sex, ethnicity, label for level of mental retardation, average age, average adaptive and challenging behavior scores, and secondary disabilities. For comparison, the parallel data for our baseline sample of 828 people in DCs are included.

Table 5
Characteristics of 1073 Movers and 828 Baseline Stayers

	Movers	**Stayers**
Percent Male	59.5%	60.6%
Percent Minority	30.5%	21.8%
Percent Mild	18.1%	8.4%
Percent Moderate	8.5%	7.1%
Percent Severe	13.4%	14.0%
Percent Profound	58.0%	68.4%
Average Age	38.6	37.8
Average Adaptive Behavior	48.5	38.2
Average Challenging Behavior	78.4	69.8
ADDITIONAL MAJOR CONDITIONS		
Ambulation	27.6%	35.9%
Autism	9.5%	6.2%
Aggression	26.3%	24.6%
Brain Injury	8.2%	12.8%
Cerebral Palsy	15.9%	12.4%
Communication	59.1%	68.2%
Dementia	0.9%	2.4%
Major Health Problems	16.8%	34.8%
Hearing	4.5%	8.0%
Mental Illness	14.2%	13.2%
Physical Disability	13.7%	23.3%
Seizures	21.2%	31.2%
Self Abuse	19.9%	17.6%
Substance Abuse	2.1%	1.4%
Vision	14.3%	20.5%
Other	3.2%	8.0%

The distribution of gender closely mirrors the DC population. Minorities have been somewhat more likely than Caucasians to be selected for community placement - the DC population is reported to be about 22% Minorities, while the Movers are about 30% Minorities. [2]The average age of the Movers and the Stayers is about 38 years. About 71% of the Movers are labeled severely or profoundly mentally retarded, while the figure for DCs is 82%. Similarly, the average adaptive behavior score is higher among Movers than Stayers (48.5 versus 38.2), showing that the Movers have somewhat higher ability levels. The difference in challenging behavior is not as pronounced, with 78.4 for Movers versus 69.7 for Stayers. The Movers have somewhat fewer, and somewhat less severe, challenging behaviors.

Communication and ambulation difficulties are the most often reported secondary conditions among the Movers. The Movers display multiple major secondary disabilities. However, in several areas, the Stayers have even more disabilities. These areas include ambulation, brain injury, communication, dementia, hearing, major health problems, physical disability, seizures, vision and “other” disabilities.

The general pattern is clear: the Movers are somewhat higher in adaptive behavior skills than the Stayers, somewhat less likely to display challenging behaviors, and somewhat less likely to have a series of secondary disabilities. This means that “skimming” is occurring, but it is important to note that its magnitude is far less than in years past. Fully 71% of the Movers have the severe or profound label. It can no longer be said that community placement is being restricted to the “high functioning” people. California, under Coffelt, has assisted many hundreds of people with severe disabilities to move to, live in, and adapt to, community living arrangements.

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[2] This fact should be taken into account in any future comparison of institution versus community services, especially health care and mortality, since it is well known that ethnicity is related to health care practices and quality. None of the studies thus far produced by the University of California at Riverside have included ethnicity in their mathematical models of mortality.

Results 2: Are the Movers Better Off Than They Were at DCs?

The central question of any evaluation of a social intervention is "Are people better off?" In prior reports, we approached this question in several ways, with several designs. First, we used matched comparison, to test whether "similar" Movers and Stayers experienced different qualities of life. Second, we used analysis of covariance to control for differences between groups, and then to test for differences in quality when group characteristics were controlled for.

Now we have the ability to address the question more directly. Of the 1073 Movers, we visited 91 back in 1994, when they were still living in Developmental Centers. We can now examine what, if any, qualities of their lives have changed as a result of community placement. The terminology used to describe such analyses includes pre-post, test-retest, before-and-after, and longitudinal.

The number of people in the analysis, 91, is large enough for studies of this kind. For example, a peer-reviewed article on Movers from Pennhurst (Conroy, Efthimiou, & Lemanowicz, 1982), was based on a similar number of people, 70 class members. Moreover, the 91 people are similar to the average person living in a DC. The 91 Movers' average adaptive behavior score in 1994 was 44.7, not far above the overall DC average of 38.2. The 91 Movers' challenging behavior average was 68.1, not far below the overall DC average of 69.8.

An important facet of this pre-post design is that, for the pre data collection, our principal informants were DC staff. Later, in the community, the informants were community staff. Any differences in <u>their</u> perceptions of quality cannot be attributed to community bias, because both points of view were incorporated in the analysis.

The 91 people moved into the types of community settings shown in Table 6.

Table 6
Living Situations of 91 Pre-Post Movers

Type of Home	**Number**
ICF/DD-N (4 to 6 beds, Nursing)	19
ICF/DD-H (4 to 6 beds, Habilitative)	24
CCF LEVEL 1 Owner/Staff	1
CCF LEVEL 2 Staff	1
CCF LEVEL 3 Owner	1
CCF LEVEL 3 Staff	5
CCF LEVEL 4-A/Staff	2
CCF LEVEL 4-F/Staff	3
CCF LEVEL 4-G/Staff	7
CCF LEVEL 4-H/Staff	5
CCF LEVEL 4-I/Staff	14
Foster Care	1
Supported Living, >21 hrs/wk support	3
Supported Living, 0-10 hrs/wk support	1
Independent Living	2
In Parent's Home	2
TOTAL	91

Table 7 below presents a summary of results for a variety of important quality and outcome indicators for the 91 Movers. In this Table, the quality dimension is shown in the left hand column. The second column, headed "Pre: DC" shows the average score or rating for each quality dimension when the 91 Movers were still living in a Developmental Center. The third column, headed "Post: Community" shows their average scores when we visited them in their new community homes. The last column on the right shows the statistical significance level of each pre-post difference. The significance levels can be read as the likelihood that a difference that large could have happened by chance. For example, the significance of the adaptive behavior gain is 0.05, which means that a gain of this size (2 points) would happen by chance fewer than 5 times out of 100. The smaller the number, the higher the significance. We have presented the statistical significance in a simple fashion, with the highly significant differences marked by ** ($\underline{p} < .01$, i.e., the probability that the difference happened by chance is less than 1 in 100) and the significant differences marked by * ($p<.05$).

Table 7
Changes in Qualities of Life for 91 Movers

Quality Dimension	**Pre: DC**	**Post: Community**	**Signif. *=.05 **=.01**
Behavior			
Adaptive Behavior	44.7	46.7	*
Challenging Behavior	68.1	76.4	**
Medications and Health Care			
Number Receiving Antipsychotics	15	24	
Number Receiving Antidepressants	2	6	
Number Receiving Sedative/Hypnotics	5	26	**
Number Receiving Seizure Control Meds	33	34	
Number Receiving Digestive, Stomach &Bowel Meds	50	40	*
Number Receiving Other Daily Meds	79	25	**
Rating of Quality of Health Care	4.6	4.4	
Services			
Number of Services in Written Plan	6.1	7.8	**
Reported Progress on IHP Goals	47.3	77.1	**
Day Program Hours	24.3	26.6	*
Number Earning Any Money	31	16	
Average Earnings Per Week	$6.60	$1.10	*
Self-Determination and Integration			
Decision Control Inventory	31.5	36.3	*
Individualized Practices Scale	61.5	65.2	*
Integrative Activities Scale	13.6	30.3	**
Personal Interview and Satisfaction			
QOL Then and Now 1996	67.4	75.1	**
QOL Now 1994 and QOL Now 1996	71.1	80.6	**
Staff Indicators			
Staff Experience, Average Years	15.2	9.9	**
Staff Like Job	8.9	9.0	
Staff Like Working With This Person	8.0	9.0	**
Staff Training Received Out of 23 Areas	18.3	19.1	
Physical Quality Scale	64.7	74.5	**

Table 7 shows a number of positive outcomes. In general, the Table provides compelling evidence that these 91 Movers are better off in the community than they were in the DCs.

The first significant finding is the adaptive behavior gain. The Movers gained 2.0 points. This is a 9.5% gain from where they began (2.0 is 9.5% of their starting score of 44.7). The California results are similar to those reported in other studies. Gains in adaptive behavior after community placement are a consistent and uniform finding in the research literature (Larson & Lakin, 1989). In general, however, the longer people have been out of institutions, the greater the gains seen in adaptive behavior. Table 8 shows this pattern from seven of the studies we have performed.

Table 8
Adaptive Behavior Development In Several Deinstitutionalization Studies

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

Sources: Conroy, 1996b, Conroy & Bradley, 1985; Bradley, Conroy, & Covert, 1986; Lemanowicz, Conroy, & Gant, 1985; Conroy, 1986b; Conroy, Lemanowicz, & Bernotsky, 1991; Present Report; Dudley, Ahlgrim-Delzell, & Conroy, 1995.

The table shows a pattern of greater developmental progress among people who have been deinstitutionalized the longest. The Movers in California have not been out in the community very long. We would therefore expect to see continued adaptive behavior gains among California's Coffelt class members in future years of this project. We believe these early Coffelt adaptive behavior gains should be viewed as "only the beginning."

The second significant finding is the improvement in challenging behavior, from 68.1 to 76.4 points. (The higher score means less challenging behavior at Time-3). This is the largest change we have yet seen in deinstitutionalization work in such a short time. Table 9 provides comparisons with other states, again sequenced by the amount of time between the two measurements.

Table 9
Challenging Behavior Improvements In Several Deinstitutionalization Studies

State	**Number of Years**	**Time-1 Average Challenging Behavior Score**	**Time-2 Average Challenging Behavior Score**	**Gain on 100 Point Scales**
Pennsylvania	14 years	77.7	87.3	9.6
New Hampshire	8 years	79.6	78.6	-1.0
Louisiana	7 years	80.9	84.1	3.2
Oklahoma	6 years	89.7	93.5	3.8
Connecticut	5 years	79.0	80.2	1.2
California	**3 years**	**68.1**	**76.4**	**8.3**
North Carolina	2 years	87.7	89.4	1.7

In Table 9, the largest improvement in the challenging behavior area was in the Pennhurst study in Pennsylvania; however, this change of 9.6 points took 14 years to produce. The California change of 8.3 points happened between 1994 and 1997. If these findings remain stable over time, this will be some of the most compelling evidence of the quality of community supports yet produced by quantitative research.

Among these 91 Movers, there are now 24 people being given antipsychotic medications, whereas there were 15 before. Although this does not reach statistical significance, it is in keeping with past findings of increased utilization of neuroleptic and other powerful medications in the community. The number of people reportedly being given sedatives or hypnotics is up from 5 to 26. These medication issues are urgent, and must continue to be the focus of DDS investigation, training, and policies. These issues merit continual attention and monitoring.

Respondents, usually staff, were asked to give their rating of the overall quality of health care received by the person. At both times, ratings given for these 85 Movers were high – 4.6 out of 5 points at the DC, and 4.4 in the community. Although the change was small and not statistically significant, it was in a downward direction. Community staff are rating the quality of health care slightly lower than the former ratings given by DC staff. Again, in view of current concerns, health care in the community must receive strong attention and consideration. The Department's health care and wellness initiatives are much needed responses to this issue.

The Movers have more services in their written plans now than they did before, up from 6.1 services to an average of 7.8 services. This reflects increased attention to planned services to meet individual objectives. However, our recent work on the Self-Determination Project in New Hampshire revealed that the average number of goals actually decreased as individual and family empowerment increased, and project implementers felt that this was a sensible and favorable outcome (Conroy & Yuskauskas, 1996).

For each individual goal in the person's written program plan, we ask the staff who know the person best, "Have you seen any progress in the past year?" on this goal. The difference in staff perceptions of progress are quite dramatic, up from a rating of 47.3 (on a scale of 100 points with 100 meaning a great deal of progress on every goal) to a rating of 77.1. This is very strong evidence that the Movers are making significantly more progress toward their individual goals than they were when they lived back at their DCs.

Referring back to Table 7, we saw no significant change in the number of people who work for pay, and a significant decrease in earnings per week (averaged across the entire group). Enhancements in quality of life in the vocational and productivity area have yet to be evidenced in the Coffelt process. This is certainly an area in need of attention in California.

The Decision Control Inventory is a measure of self-determination. It measures the extent to which people make their own decisions in daily life, with the support and assistance of unpaid friends or loved ones, as opposed to having decisions made by paid staff. As Table 7 shows, this measure has increased significantly for the 91 Movers. In our prior research, this increase scale did not reach statistical significance. It should be noted, therefore, that we can now say the Coffelt class members are exercising more control over their own lives than they were before (with the assistance of their most trusted friends and family members where necessary).

A related measure, the Individualized Practices Scale, measures the extent to which people are treated as individuals, with consideration of their uniqueness, and with flexibility. This scale has been used internationally, and usually distinguishes very well between institutional and community settings, with community settings found to be more individual oriented rather than staff and management oriented (Balla, Butterfield, & Zigler, 1974; Conroy & Bradley, 1985). In California, the community settings are indeed associated with more individualization than were the DCs, however, the amount of difference is rather small (a 5 point increase from 61 to 65). Larger differences have been seen in some past studies (Conroy, 1995; Conroy, Lemanowicz, & Bernotsky, 1991). In the Connecticut study, DC scores averaged about 18 points, and community scores went up to about 55 points. Both DC and community scores in California are above 60 points. One possible interpretation is that California's DCs in 1998 are far more individualized than was Connecticut's Mansfield Training School in 1990. Whatever the correct interpretation may be, we believe that policy leadership and training programs should be mounted to address both the choicemaking and the individualization issue. Both issues are closely related to the person centered planning process, which is already the subject of considerable effort in California.

The next line in Table 7 displays the Movers' average levels of integration pre and post community placement. The rating has more than doubled, from 13.6 integrative events per month to 30.3. This is conclusive evidence that the Movers have sharply increased in their opportunities to go to places in which they are in the presence of non-disabled citizens. Insofar as integration is a fundamental value in supporting people with disabilities, and a prominent concern stated in the Lanterman Act, this is a strong positive outcome.

On every visit, we obtain access to whoever knows the Class Member best on a day to day basis, hence it is of interest to find out about those "close" staff members. In the DC, the average number of years of experience in the developmental disabilities field was 15.2 years, while in the community it was 9.9 years. Both staff groups liked their jobs about equally on a scale of 1 to 10 (8.9 DC and 9.0 community).

However, the community staff definitely expressed more affection for the Class Members on the next question, which was "How much do you like working with this person on a scale of 1 to 10?" The DC ratings averaged 8.0, and the community ratings averaged a full point higher, at 9.0. Although such indicators contain an element of subjectivity, it would certainly be important to most parents to have staff who report that they enjoy working with their son or daughter.

Surprisingly, Table 7 shows that the amount of training received by community staff is just slightly higher than the prior average for DC staff. Since the training data in DCs are 3 years old, however, this finding should be treated with caution – training efforts in DCs may have increased since then.

We ask each Class Member, or whoever knew the Class Member best on a day to day basis, what were the person's qualities of life "A Year Ago" and "Now" in 10 life areas. Ratings are given on 5 point scales in areas such as health, food, safety, comfort, and happiness. We asked these items at the DC in 1994, and again in the community in 1997. The 10 items are combined into overall scales of perceived quality. Two methods of analysis are under Personal Interview and Satisfaction in Table 7. The first relies on memory, by comparing the peoples' 1996 "Then and Now" answers. This analysis shows that people believe their lives are significantly better now than they were a year ago. The second method compares the ratings for "Now" back in the DCs to the ratings for "Now" in 1997 in the community. This method produces essentially the same result. People and/or the staff who know them best clearly believe that their lives are better in the community than they were back in the DCs. Moreover, the DC quality of life responses were generally provided by DC staff, so there can be little question of bias in these quality ratings.

The last line in Table 7 shows that the average ratings of Physical Quality (comfort, cleanliness, attractiveness, personalization, etc.) are significantly higher in the community than they were back at the DCs. This is perhaps surprising, since California operates some of the most physically pleasant DCs in the nation. Nevertheless, the ratings on this scale favored the new community homes over the former DC homes for these 91 Movers.

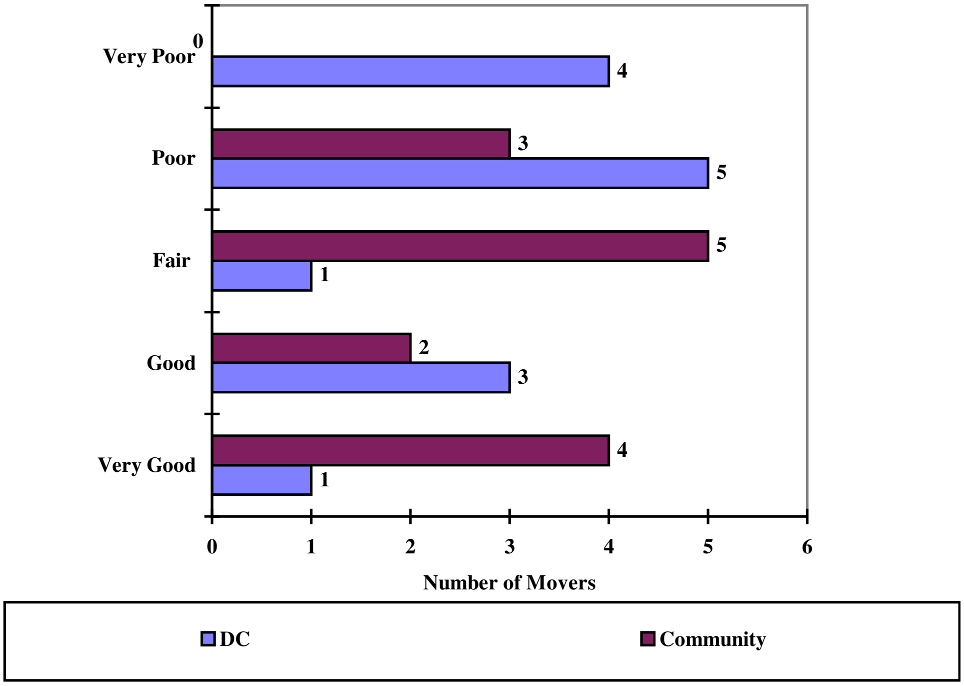
Results 3: Pre-Post Consumer Satisfaction

Among the 91 Movers discussed in the preceding section were 14 people who were able and willing to be interviewed by our visitors at both times. Their answers to the question "How do you feel about living here?" are placed in this separate Results section, because the numbers are so small. Yet the results are strong enough to merit inclusion in the report. Table 10 shows the peoples' answers at the DC and later in the community, an average of 3 years apart. Figure 3 makes the same point graphically.

Table 10
Consumer Satisfaction, Pre and Post
How Do You Feel About Living Here?

	DC	**Community**
Very Good	1	4
Good	3	2
Fair	1	5
Poor	5	3
Very Poor	4	0

Figure 2
Consumer Satisfaction, Pre and Post
How Do You Feel About Living Here?



The results were obvious. Back at the DCs, four people told us they felt “Very Poor” about their living situations. In the community, 3 years later, no one did. Despite the small numbers, these results tend to reflect the general experience of all 1073 Movers to community homes. Of the 1073 who we visited this year, 302 were able and willing to answer this question in the interview, and only **4** of them reported that they felt “Very Poor” about their living situations in the community.

Results 4: Satisfaction and Quality of Life For All 1073 Community Movers

During each visit, we attempt to interview the Class Member directly. In our 1073 visits, there were 302 people who were able to respond to the question "How do you feel about living here?" Responses were on a 5 point scale, from "Very Poor" to "Very Good." The Movers' answers are shown in Table 11.

Table 11
Responses to "How Do You Feel About Living Here"
From Coffelt Movers in 1997

Response	**Number**	**Percent**
Very Good	120	39.7%
Good	115	38.1%
Fair	42	13.9%
Poor	21	7.0%
Very Poor	4	1.3%
Total	**302**	**100.0%**

Obviously, satisfaction with community living is very high among the Coffelt Movers. Only 4 out of 302 people say they feel "Very Poor" about their new homes. Certainly they, and the 21 people who say "Poor" should be followed up, but overall, the Coffelt Movers who can communicate in an interview say they are happy with their new homes.

The "Quality of Life Changes" Scale asks each person to rate his/her quality of life "A Year Ago" and "Now." Ratings are given on 5 point Likert scales, and cover 13 dimensions of quality. On this scale, we permit surrogates to respond. Surrogates (usually staff persons) were "whoever knew the class member best on a day to day basis." On this scale, 85% of the responses were provided by surrogates. Table 12 shows the results for all 13 dimensions of perceived quality.

Table 12
Perceived Quality of Life Changes

Quality Area	"Then," A Year Ago	"Now," At Time of Visit	t Value	p Value	Amount of Change
Happiness	3.8	4.3	9.10	0.000	0.5
Getting out/getting around	3.6	4.1	9.80	0.000	0.5
Comfort	4.0	4.4	9.10	0.000	0.4
What he/she does all day	3.6	4.0	17.74	0.000	0.4
Overall quality of life	3.9	4.3	16.48	0.000	0.4
Relationship with friends	3.3	3.6	15.46	0.000	0.3
Dental	3.9	4.2	5.23	0.000	0.3
Running own life, making choices	3.2	3.5	16.26	0.000	0.3
Food	4.0	4.3	6.18	0.000	0.3
Safety	4.2	4.5	12.80	0.000	0.3
Treatment by staff	4.3	4.6	12.83	0.000	0.3
Health	3.9	4.2	13.46	0.000	0.3
Relationship with family	2.6	2.8	4.34	0.000	0.2

Figure 3
Perceived Changes in Quality of Life

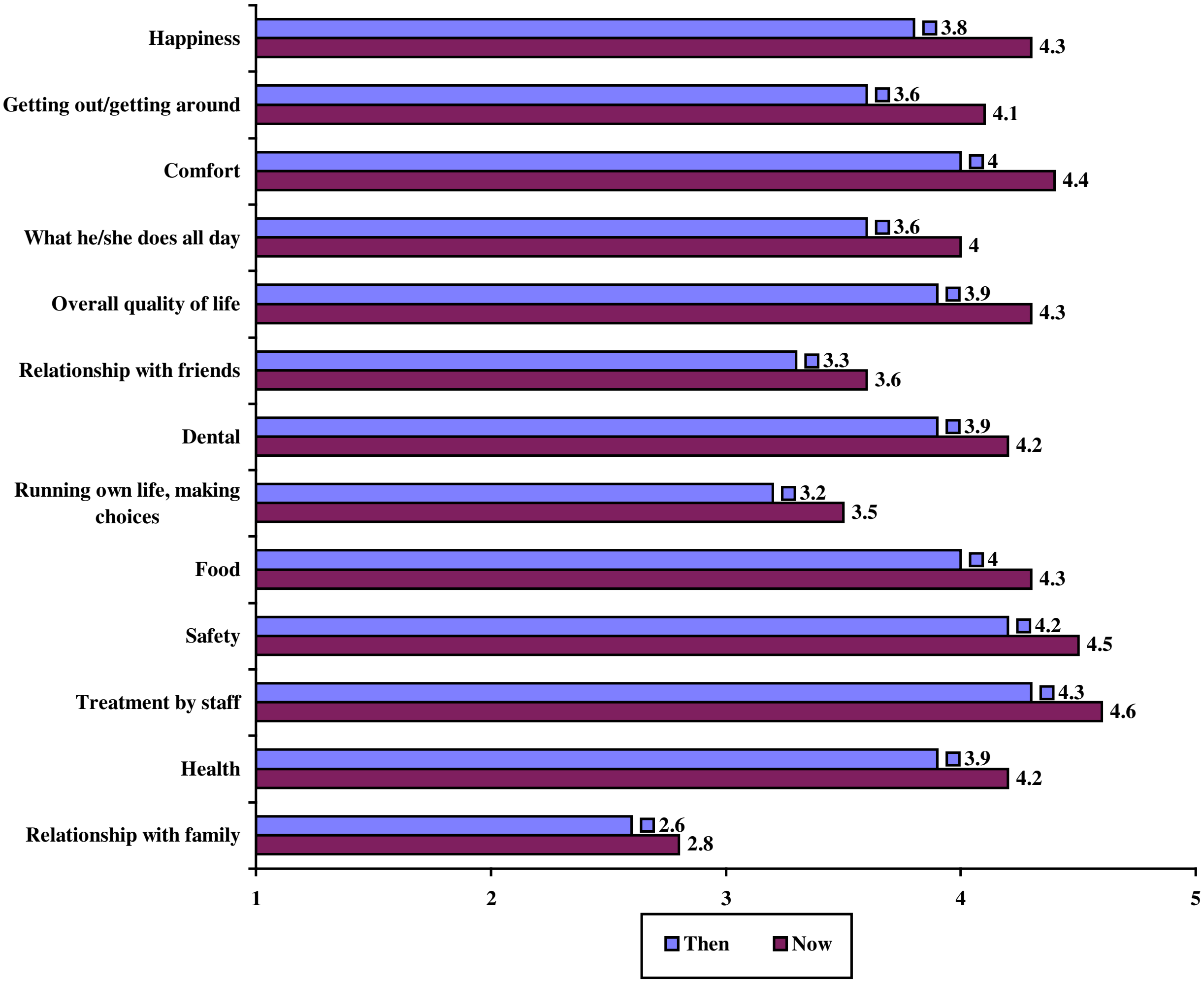


Table 12 and Figure 3 show that our informants perceived significant enhancements in <u>every one</u> of 13 qualities of life over the past year. The largest increase was in "Happiness," followed by "Getting Out and Getting Around."

Results 5: Open Ended Comments from the Movers

During each visit, we attempt to interview the Class Member directly. In our 1073 visits, there were 239 people who were able and willing to make comments in response to three questions: What do you like about living here, What do you not like about living here, and If you had one wish, what would it be? Included is the respondent question 'If wishes could come true, what would you wish for on behalf of this person in the coming year?' This was done to see if the individual's wish matches that made on behalf of the person who knows him or her best. These comments are reproduced in Appendix B.

Responses to the first question tended to deal with desires for increased self-determination, socialization, community accessibility, and nice staff. Specifically, people said they liked having freedoms, such as listening to music, watching television and videos, food choices, having their own room, and the ability to come and go. Socially, people liked having relationships with boyfriends or girlfriends, and the ability to make new friends. Many people enjoyed their relationships with staff. Finally, people commented on the physical location of their homes. They liked being closer to their families, being able to access community resources and, in contrast to institutional living, being able to have quiet. Moreover, some people expressed a wish to move to more independent settings, and public officials should identify these people and assure that a person centered planning process is in place to help people toward that goal.

When Class Members were asked what they did not like about living in their homes, the great majority said "nothing," that they liked everything about their living situation and had nothing negative to report. It is clear that people from California who have moved into community living are generally very happy and feel they have little to complain about. However, policy makers would be wise to attend to the areas of concern that were reported to us. Though they were few, there were some individuals who alluded to abusive or inadequate living situations. Specifically, those comments warranting attention include: screaming at night, people blow up and attack, they do bad things to me, staff gets rough with me, and one of housemates hits me.

Some people clearly did not feel comfortable responding to this question, for whatever reason. This in itself is noteworthy. Hesitation to respond to interview questions has been noted in other attempts to interview people with disabilities in their homes (see Speaking For Ourselves, 1996).

Finally, a lack of choice and self-determination was expressed by many, and this trend was noted in other data (see Results from the Decision Control Inventory). People either were not given choices about their daily activities, or about their staff, and were therefore dissatisfied. This year, for the first time, every person for whom opportunities to make choices and contribute to decisions about their lives was severely limited was reported, by name, to DDS. This new development in our work is just one aspect of the Quality Feedback System, which is now providing rapid feedback on both negative and positive situations in individual lives. This mechanism has the potential of alerting the system to individual problems early, and possibly to prevent them from becoming emergencies.

Each Class Member was asked "If you had one wish, what would you wish for?" The responses underscored that these people's desires are not unlike those of anyone else. Wishes for money, material possessions, freedom, marriage, owning a home, getting a job, and moving home with family, were among the responses. People on the whole had simple wishes that the current system has prevented them from realizing. Again, some of the responses were reflective of possible mistreatment or dissatisfaction. Those responses included: an abortion, get out of this dump, send friends to safety, get out of here, to die, move out of this house, and to sue Camarillo.

Overall, it is important to emphasize that, by and large, individuals were satisfied with their living situations. They had positive things to say about living in the community and about the changes they experienced after moving from the Developmental Centers. But many people expressed they wanted more. The degree to which the system learns from these reports, to increase individualization and flexibility, it will be more responsive to dreams and aspirations. This should result in more satisfied customers.

Results 6: People in Supported Living

What kinds of people have thus far moved to supported living settings, rather than to traditional ICF and group home settings? Among the 1073 Movers in our current data set, 40 (3.7%) are reported to be residing in supported living situations. The percentage of all Class Members who have moved into supported living is approximately 3.0%. Progress toward the Coffelt agreement's emphasis on the expansion of supported living models has been very slow.

We compared the 40 supported living Movers to 981 people who moved into other kinds of community settings. We left out independent living, and living in the home of a relative, from this analysis, in order to keep the comparisons interpretable. Table 13 displays some of the characteristics of the 40 supported living Movers compared to the other 981 Movers.

Table 13

Characteristics of People Who Moved to Supported Living

Characteristic	Movers to Supported Living, N=40	Other Movers, N=981	Signif. *=.05 **=.01
Percent Male	68%	59%	
Percent Minority	28%	30%	
Average Age	37.6	39.2	
Percent Mild	46%	15%	
Percent Moderate	21%	7%	
Percent Severe	23%	13%	
Percent Profound	10%	63%	
Average Adaptive Behavior	72.8	46.1	**
Average Challenging Behavior	75.1	78.2	
ADDITIONAL MAJOR CONDITIONS			
Communication	38%	62%	*
Aggression	40%	26%	**
Autism	23%	9%	**
Self Abuse	20%	20%	
Seizures	23%	22%	
Major Health Problems	18%	17%	
Mental Illness	13%	13%	*
Ambulation	8%	29%	**
Vision	8%	15%	*
Hearing	8%	5%	
Brain Injury	3%	9%	
Physical, Other than Ambulation	3%	15%	*
Cerebral Palsy	3%	17%	*
Inability to Swallow	3%	9%	*
Other	0%	3%	*
Substance Abuse	0%	2%	
Dementia	0%	1%	*

Table 13 shows that the people selected to move to supported living in this sample were about two thirds male, about the same as the other Movers. The supported living people were about equally likely to be minority group members as were the other Movers. The two groups had about the same average age. The supported living group was less likely to bear the label "profound" than other Movers, but more likely to have the “severe” label. Supported living people were 27 points higher in adaptive behavior than other Movers. Challenging behavior scores tended to be lower among the supported living group, meaning they tended to exhibit more challenging behavior than the other Movers.

The challenging behavior finding was intriguing, and was further emphasized by the analysis of secondary disabilities. Reports of aggression as a secondary disability were much more frequent among the supported living people than the other Movers (40% versus 26%). Most other secondary disabilities were not greatly different, although supported living people were more likely than other Movers to have a diagnosis of major autism (23% versus 9%), and they were less likely to have a major physical disability (3% versus 15%).

The pattern thus far emerging in Coffelt supported living placements is one of significantly higher functioning people with major problems related to aggressive behaviors.

Because of the interest in supported living models, examination of quality variables is warranted. Table 14 summarizes a series of analyses related to quality.

Table 14
Qualities of Life for People in Supported Living vs. Other Homes

Quality Dimension	**Supported Living N=40**	**Other Movers N=981**	**Signif. *=.05 **=.01**
Average Decision Control Score	65	32	**
Average Discrepancy, DCI vs. AB	-8	-14	**
Average Integration Score	54	26	**
Average QOL Rating "Then"	75	75	
Average QOL Rating "Now"	86	82	**
How do You Feel About Living Here? (5 Pt. Scale)	4.5	4.0	**
How is the Food Here?	4.2	4.1	
How do You Feel About the Staff Here?	4.5	4.1	*
Average Individualized Practices Score	83	65	**
Average Physical Quality Score	72	75	*
Average Normalization Score	82	78	
Percent on Antipsychotics	25%	29%	
Percent 'General Health Good/Excellent'	90%	84%	
Percent 'Health Care Very Easy to Get'	30%	26%	
Percent 'Health Care is Excellent'	36%	48%	
Median Number of Doctor Visits	8.0	11.0	
Median Number of Dentist Visits	2.0	1.0	
Subjective Visitor Impressions:			
How Happy Do You Think Person is?	7.9	6.9	**
Quality of Staff-Consumer Interactions	8.0	7.6	*
Quality of Consumer-Consumer Interactions	7.0	6.3	*
Staff Attitudes About Progress and Growth	7.6	7.2	
Would You Want A Relative to Live Here?	7.7	6.7	**

Caution is required in interpreting the differences in Table 14. For example, the difference in Decision Control Inventory scores is likely to be related to the group difference in adaptive behavior, not just to the differential effects of settings. In general, however, Table 14 suggests a supported living pattern of more choice, more integration, larger perceived enhancements in quality of life, more individualized living situations, and higher normalization. Note, however, that Physical Quality ratings are <u>lower</u> for people in supported living; this unexpected finding deserves future investigation.

The most dramatic difference in Table 14 is the Decision Control Inventory, our measure of self-determination. The scores of people in supported living are double those of people in other homes.

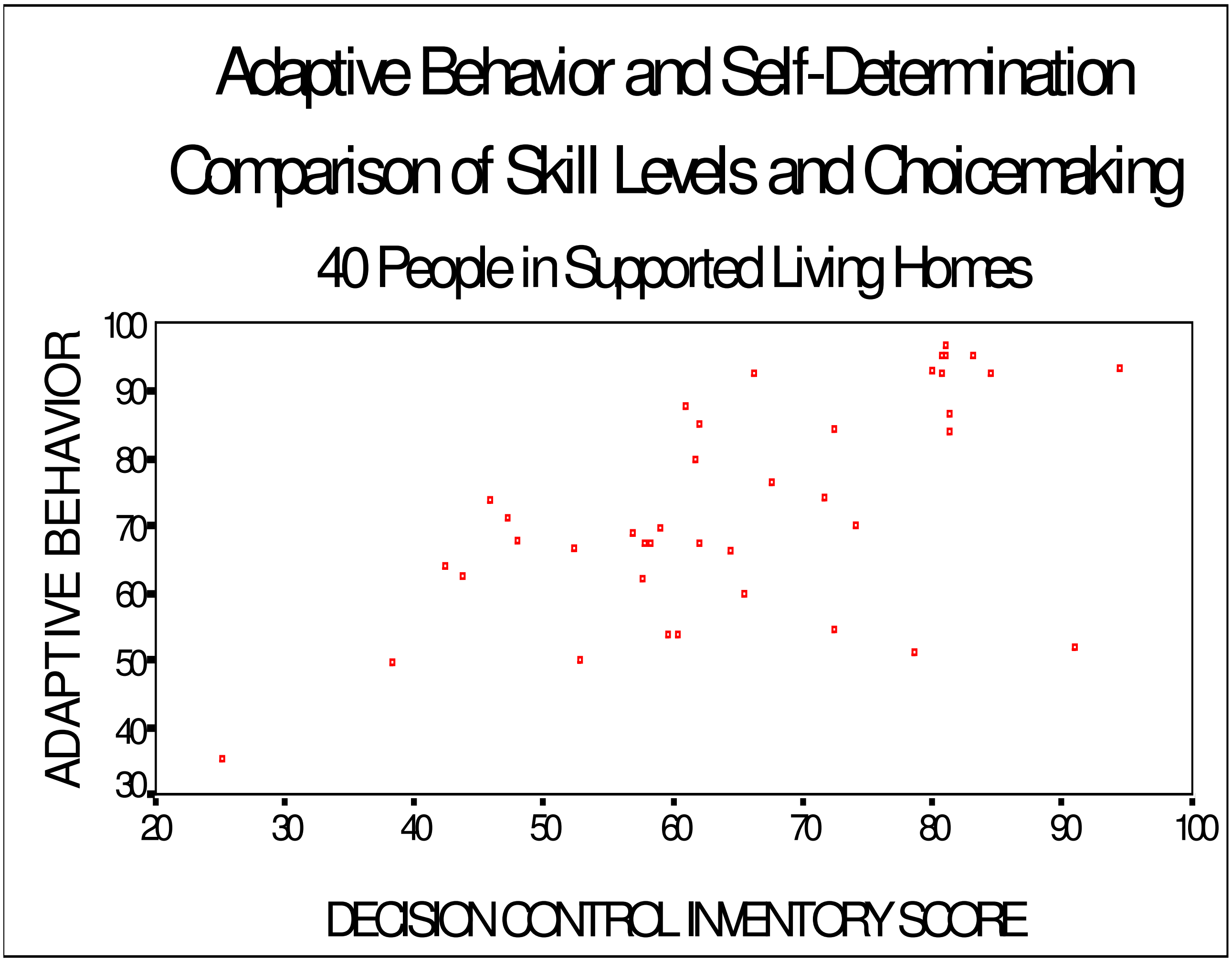
The health and health care lines in Table 14 show slight differences between supported living and other homes. The percentage of people in supported living who feel that their General Health is "Good" or "Excellent" is higher (90%) than those people living in other homes (84%). People in other homes received a higher median number of doctor visits while people in supported living received twice the median number of dentist visits.

At the bottom of Table 14 we can see the ratings of quality given by our visitors after each visit is completed. These are intended to be purely subjective. They are based on everything the visitor has learned in the visit, but there is no claim of reliability across different visitors. Despite their subjectivity, it is interesting to note that these ratings are highly correlated with many other indicators of quality. Table 14 presents these ratings, and they show that our visitors gave significantly higher ratings of quality to supported living settings in every area.

Table 14 also contains a new analysis, and it is one that we intend to explore further in the future. It is the second line, "Average Discrepancy, DCI vs. AB," which means the difference between a person's degree of self-determination and his level of adaptive behavior. Both scales, self-determination and adaptive behavior, are on 100 point metrics. By simply calculating the difference between the two scales, we obtain an index that reveals a person's self-determination power in relation to his independent functioning. Some people with very high adaptive behavior are in situations in which they make very few of their own decisions; conversely, some people with very limited adaptive behavior are in situations in which they (with the assistance and support of unpaid friends and loved ones) make a lot of their own decisions.

The Discrepancy index enables us to identify individuals who are at either extreme. The numbers in the second row show that people in supported living have a smaller discrepancy between their ability levels and the amount of choicemaking they enjoy (-7) than do the residents of other homes (-14). Figure 4 shows the relationship between adaptive behavior and self-determination for the 31 people in supported living.

Figure 4



On this type of graph, people at the upper left would be those with higher skill levels and with very little freedom of choice. They would probably be judged to be overly restricted. Notice that, among people in supported living, there are no such people, although there certainly are in the DCs and in group homes in general. At the lower right would be people with limited ability levels who enjoy a great deal of freedom. In the future, we hope that this new analytical technique will be used to identify people who are unusually restricted for their functional levels, and likewise, those who are unusually self-determined despite their skill level. This analysis will enable policy makers to work on remedies for the former, and to learn from the latter.

In view of the high national interest in supported living and adult foster care models (O'Brien, 1994), further study of these models in California is clearly needed. Moreover, in view of the documented success of such models, such as in Oklahoma (Conroy, 1995), California policy makers should consider a renewed and vigorous commitment to these models. Much of the Coffelt community expansion has been in the ICF/MR model – about 700 out of the first 1800 were placements into ICFs/DD, ICFs/DD-Habilitative, and ICFs/DD-Nursing facilities.

There is reason to believe that ICF models are associated with less individualization, more regimentation, and generally lower quality than are more integrated models such as supported living. In a recent peer-reviewed matched comparison study, we reported that 10 out of 35 outcomes and indicators of quality of life were lower in ICF funded settings than in Waiver funded settings (Conroy, 1996a). None of the indicators were higher in ICFs. Clearly, California's future direction should emphasize supported living and related models, not the ICF/MR model.

Results 7: Quality in Small ICFs/MR versus Waiver Homes

A recent investigation of California's Waiver program for people with developmental disabilities, conducted by the Health Care Finance Administration (HCFA), produced harshly critical findings (HCFA, 1997). This piqued our interest, because we have not seen evidence of poor quality among the Coffelt class members who have moved to Waiver settings. We decided to investigate further.

HCFA is responsible for two major funding streams for people with mental retardation and developmental disabilities. One is called the ICF/MR (Intermediate Care Facilities for [people with] Mental Retardation) Program, and the other is called the HCBS Waiver (Home and Community Based Waiver) Program. The ICF/MR program is founded in a medical model of care, and is derived directly from a nursing home and institutional mindset. Waiver programs were introduced in 1981 because of evidence that medical domination of care tended to result in overly costly and less person-centered situations. The intention of the Waiver program was to "waive" the extensive and medically oriented standards and inspection requirements linked to the

ICF/MR program. Under a Waiver, states could receive Federal financial assistance for individualized, flexible, non-medical, community based supports.

Since the origin of the Waiver program, all scientific evidence has supported the original evidence. Waiver programs result in cost savings and enhanced quality as compared to ICF/MR programs. The Waiver regulations required an "Independent Assessment" of the quality and cost-effectiveness of each state's Waiver (section 4442.11 of Medicaid regulations). To date, well over 100 Independent Assessments have been conducted. There is not a single negative finding. The Independent Evaluations are maintained in Baltimore at the central office of the Social Security Administration. It would therefore seem clear that people can be better served, and at less cost, in flexible, individually designed, non-medically dominated homes.

Nevertheless, HCFA undertook a review of California's Waiver program in 1997. It took almost 6 months to complete. When completed, a total of 91 California citizens had been visited. For a population of 35,000 Californians in the Waiver program, this corresponds to a "margin of error" of plus or minus about 11%.

Most important for our Coffelt work was the HCFA claim that their surveyors had found that *"Coffelt class consumers showed significant signs of loss of functional ability or health status since being placed in the community."* Since HCFA only visited 91 people, how many of them were Coffelt class members? Of the 35,000 Californians supported under the Waiver program, approximately 1200 are Coffelt class member Movers, or about 3%. If, as the HCFA report stated, the sample had been simple random, there would have been only about 3 Coffelt Movers in the HCFA sample. Other sources, however, report that the HCFA sample included 29 Coffelt Movers. In either case, the size of the sample was not sufficient to warrant major policy interpretations.

Because we possess data for so many Coffelt class members, we decided to compare quality in the Waiver to the small ICF/MR program. The small ICF/MR program has not been criticized by HCFA studies in California, hence we hypothesized that HCFA finds the ICF/MR program to be acceptable in quality.

The question of interest may be phrased as: "Do people supported by the ICF/MR experience any higher qualities of life than people supported via the Waiver model?" This question is perfectly amenable to quantitative investigation. However, it is very important that we compare qualities for people who are similar. The question can be rephrased more precisely as: **"For similar people, are there any differences in quality and/or outcomes between the ICF/MR program and the Waiver program?"**

At the outset, however, we must recognize that the people served in the ICFs/MR and the Waiver programs are significantly different. ICFs/MR serve people with fewer independence skills and fewer challenging behaviors, and Waiver homes serve people who are more independent but have more challenging behaviors. (We think future investigations should be aimed to find out why this is true --- it is certainly not true in ICF/MR and Waiver programs in other states such as Connecticut and Pennsylvania.) Comparisons of quality cannot proceed until these differences are controlled for. The comparisons would be "apples and oranges." The following Table shows the differences between the two overall groups of Coffelt movers.

Table 15
Differences Between the People Living in ICFs/MR and Waiver Homes

Setting Characteristic	ICF/MR N=447	Waiver N=490	Signif. **=.01
Adaptive Behavior	35	59	**
Challenging Behavior (High Score is Favorable, meaning less challenging behavior)	84	72	**
Age	39	38	

As Table 15 shows, the ICF/MR participants were significantly lower on adaptive behavior abilities than the Waiver participants. This meant that the ICF/MR participants were much less capable of independent self-care. The ICF/MR participants also displayed significantly less challenging behavior that the Waiver participants. Age was similar for the two groups.

When the groups we want to compare are different, there are at least three methods available to compare "apples to apples." One is the matched comparison method, which we have used in the past (the "twin study" method). Another is purely mathematical corrections for differences in groups (analysis of covariance). A third is what we call the "similar groups" method, in which we select two groups who have similar characteristics. For the present analysis, we have used the similar groups method, partly because in prior Reports in this series, we have already used the other two methods, and partly because it is simpler to describe and interpret.

The two similar groups were composed by selecting people with characteristics that were "in between" the ICF/MR and the Waiver groups. The best groups were those whose adaptive behavior scores ranged from 30 to 50, and whose challenging behavior scores ranged from 75 to 90. When this selection was performed, we were left with 49 people in ICFs/MR and 50 people in Waiver homes. The statistical tests showed that the two subgroups were now equivalent on the most important dimensions, as shown in the following Table.

Table 16
Characteristics of Similar Groups Living in ICFs/MR and Waiver Homes

Setting Characteristic	ICF/MR N=49	Waiver N=50	Signif.
Adaptive Behavior	40	41	0.188 NS
Challenging Behavior (High Score is Favorable, meaning less challenging behavior)	81	81	0.567 NS
Age	41	39	0.179 NS

For these similar groups, the important characteristics were not statistically different. Hence we could proceed to compare qualities of life and service between these two similar groups.

The results of our analyses for a series of outcome measures are shown in the Table below.

Table 17
Quality Comparisons in ICFs/MR and Waiver Homes For Two Groups of Similar Coffelt Class Members

	Average for ICF/MR Residents, N=49	Average for Waiver Residents, N=50	t	Signif. *=.05 **=.01
1. Integration Scale	18	**27**	2.38	*
2. Self-Determination Index	23	**32**	2.92	**
3. Physical Quality Scale	74	74	.29	
4. Individualized Practices Scale	59	**65**	3.50	**
5. Normalization Scale	73	77	1.44	
6. Adaptive Behavior Change During the Past Year	-.48	-.05	.18	
7. Challenging Behavior Change During the Past Year	3.75	**19.78**	3.05	**
8. General Health Rating	4.2	4.1	.70	
9. Number of Dentist Visits in Past Year	1.5	1.4	.95	
10. Number of Doctor Visits in Past Year	10.9	**17.7**	3.82	**
11. How Easy Is It To Get Medical Care Rating	4.0	3.5	1.91	
12. Percent of People Taking Psychotropic Medications	**16%**	34%	2.05	*
13. Quality of Life Overall Rating "Now"	78.9	**84.1**	2.65	**
14. Cost of Residential Program	$43,447	**$32,151**	7.58	**

The Table uses **boldface** to show dimensions on which one type of setting or the other came out superior. The Table presents the results of t-tests, which reveal whether the difference between the two groups' averages is statistically significant. One column gives the actual t value, and the last column gives the level of significance. Any significance below .050 is considered significant. Each line in the Table is discussed below.

1. The data from the Integration Scale, which counts the number of outings per week, showed that people in the Waiver homes tended to get out significantly more often than their similar peers in ICFs/MR.
2. The Self-Determination Index or Decision Control Inventory (DCI) shows that the Waiver group had significantly more control over making individual choices in their daily lives than the ICF/MR group.
3. The ratings of Physical Quality (comfort, cleanliness, attractiveness, personalization, etc.) were equal among both groups.
4. The Individualized Practices Scale, which measures the extent to which people are treated as individuals, indicates that the Waiver group found their settings to be significantly more individual oriented than the ICF/MR group.
5. On the Normalization Scale, there was no significant difference between the two groups.
6. For adaptive behavior, we found that 52 of the 99 people in this analysis had been visited the prior year in their community homes. Hence we were able to compute the amount of skill development or loss for those 52 people over the past year. There was no significant change in either group in either direction.
7. The challenging behavior results were quite different. The 3.75 point improvement among the ICF/MR group was not statistically significant (this fact is not shown in the Table). However, the 19.78 point improvement among the Waiver recipients was highly significant, and was significantly different from the ICF/MR group's gain. In this sample, challenging behavior outcomes were sharply superior among Waiver participants.
8. The General Health Rating was similar for the two groups, as both Waiver people and ICF/MR people indicated that their General Health was "Good." We interpret this to mean that the two groups enjoyed approximately the same overall level of health.
9. The average number of dental visits were about the same for both groups. However, the average number of doctor visits were different , with ICF/MR people averaging 10.9 visits and Waiver people averaging 17.7 visits per year. For people with similar ratings of general health, one must wonder why one group sees doctors nearly twice as often as the other.
10. On the item "How Easy is It to Find Medical Care for This Person?" the responses were similar with both groups indicating "Easy." The difference between the ICF/MR average of 4.0 on our 5-point scale and the Waiver group's average of 3.5 was not statistically significant. Hence we conclude that there is no overall difference in the ease or difficulty of obtaining health care in ICFs/MR versus Waiver homes.
11. The percentage of people taking psychotropic medications was significantly different between the two groups. We found that the percentage of Waiver people taking psychotropic medications was double that of the percentage of people in the ICFs/MR. We would generally interpret this as an indication of higher quality in the ICFs/MR; however, the most appropriate interpretation may not be that simple. Even though the groups are now similar in challenging behavior (both groups average 81 points), the Waiver group gained almost 18 points in the past year. It is possible that the use of psychotropic medications played an important role in these dramatic improvements among the Waiver recipients. The final word on the appropriateness of these medications will require further research and clinical investigations; the data available to us cannot settle this question.
12. The Overall Quality of Life Rating "Now," which is usually obtained from the person who knows the Class Member best and includes 14 dimensions of quality, showed that people in the Waiver settings were rated as having a significantly higher quality of life than their similar peers in the ICF/MR settings.

13. Finally, we examined the average cost of each placement. Our data source was the DDS reimbursement rates for each type of community home. It is well known that Waiver reimbursement rates are lower than ICF/MR rates. That is usually justified by the fact that the two programs serve very different kinds of people. However, the present analysis concerns two very similar groups of people. The Waiver costs average only 74% of the ICF/MR costs in this sample. This is a large and significant difference.

These findings are obviously quite different from the conclusions reached by HCFA (1997). Out of 13 important dimensions of quality, Waiver settings were superior on 6, and ICFs/MR were possibly superior on 1. Even that one, use of psychotropic medications, was tempered by the possibility that the medications may have been appropriate and useful, as judged by behavioral outcomes. In any case, the weight of these data clearly favor the Waiver settings in many areas of quality, for comparable people. Finally, the Waiver program's costs are considerably lower than those for ICFs/MR for comparable people. The data show that, for comparable groups of Coffelt class members, Waiver homes tend to yield higher quality, at lower cost, than the ICF/MR model.

We suggest that California policy makers use this information to support and defend its Waiver program. In the absence of continued growth in the Waiver program, the only option for future expansion of community living will be the outdated, overly medically oriented, overly regulated, ICF/MR model. We believe this would be unfortunate, both fiscally and programmatically.

Results 8: The 1998 Family Survey

Family Survey: Participants

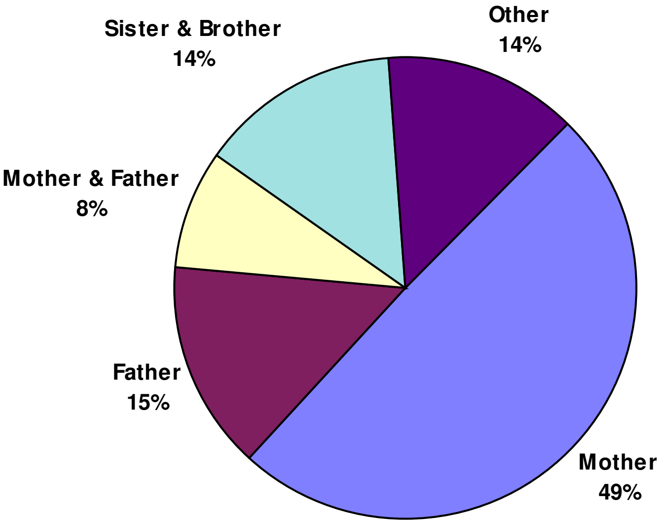
At the time of this writing, we have received survey responses from 205 of the 570 with valid addresses (36%). Of the 205 responses, 20 were from the Community Target Group members' families. They were not included in the analyses for the present report. This report is restricted to analyses of the families of Movers, people who moved from DCs to community homes in the first 51 months of Coffelt implementation.

Class Members' mothers were involved in completing the survey more than half of the time. The respondents were distributed as shown in Table 18 and Figure 5.

Table 18
Relationship of Family Survey Respondents to Class Members

Relationship	Number	Percent
Mother	90	49.2%
Father	27	14.8%
Mother & Father	15	8.2%
Sister & Brother	26	14.2%
Other	25	13.7%
Total	183*	100.0%

Figure 5
Relationship of Family Survey Respondents to Class Members



* Two families did not answer this question

Legal guardianship was claimed by 44 respondents (24.9%), legal conservatorship by 66 (37.3%), and no legal status by 67 (37.9%). (8 respondents were unsure, and left this item blank.) The family respondents' ages ranged from 21 to 87, with a mean age of 63. The families reported that their relatives had lived in DCs between 1 and 70 years, with an average of 23 years.

Families' Perceptions of Quality

The main focus of the family survey was on whether the families believed the class members were better off in the community than they had been in the Developmental Centers. We asked the families to describe their relatives' quality of life "Then" while living in a Developmental Center, and "Now" while living in their new situations in the community. The results are shown in Table 19 and Figure 6.

Table 19
Families' Perceptions of Qualities of Relative's Life

	Then At The DC	Now In New Home	p	Difference
Comfort	3.1	4.2	0.001	1.1
Dental	3.1	3.8	0.001	0.7
Food	3.3	4.1	0.001	0.8
Getting out/getting around	2.8	4.1	0.001	1.3
Happiness	2.8	4.1	0.001	1.3
Health	3.2	4.1	0.001	0.9
Making choices	2.6	3.7	0.001	1.1
Privacy	2.3	4.0	0.001	1.7
Relationship with family	3.6	4.2	0.001	0.6
Relationship with friends	3.0	3.8	0.001	0.8
Safety	3.4	4.1	0.001	0.7
Treatment by staff	3.5	4.4	0.001	0.9
What he/she does all day	2.9	4	0.001	1.1
Overall quality of life	3.0	4.2	0.001	1.2

Figure 6
Families' Perceptions of Qualities of Relative's Life

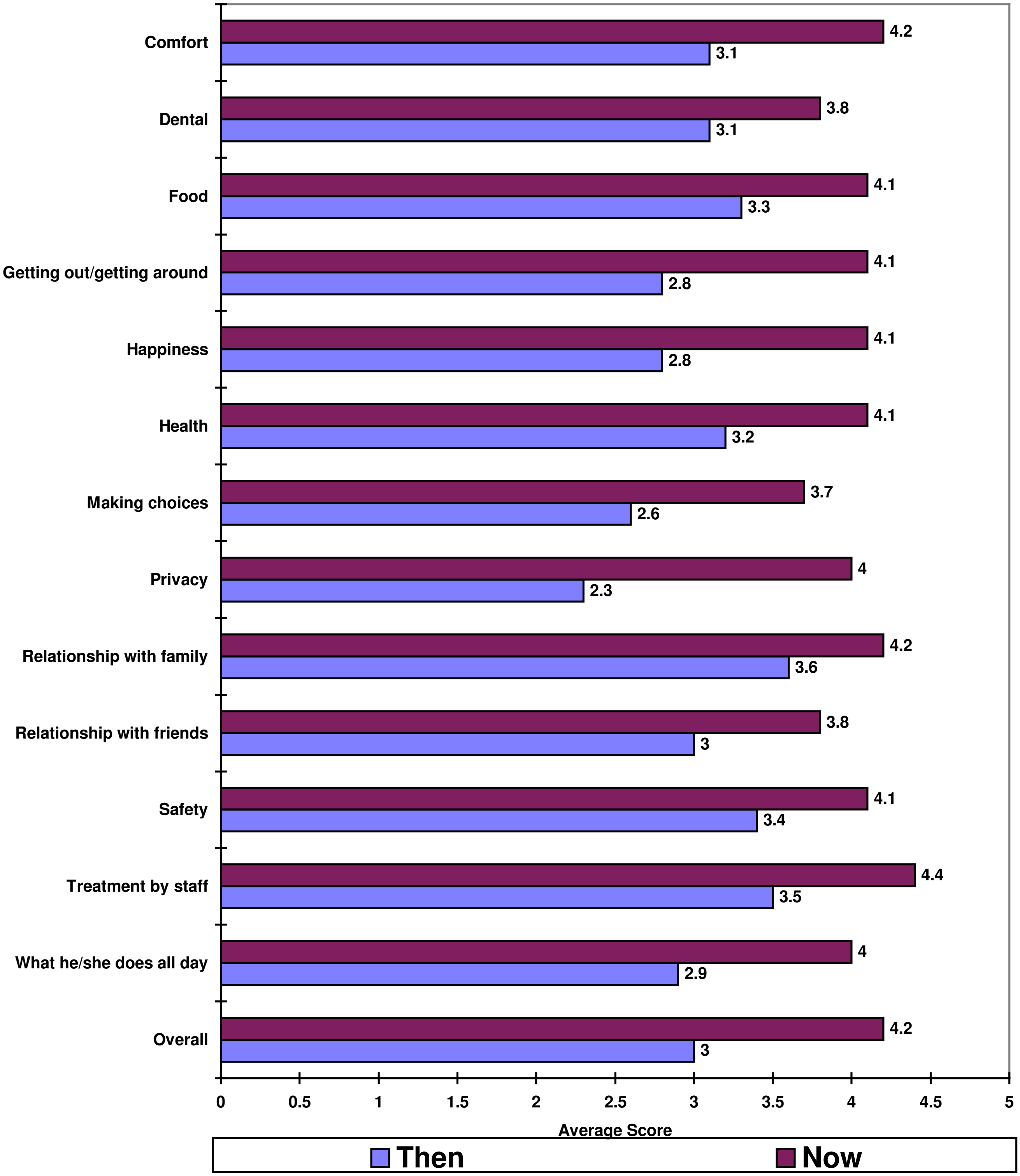


Table 19 provides the p values for the statistical test, which was the t-test. The p values represent the probability that changes of these magnitudes could have happened by chance. The value “0.001” means the probability was less than 1 in 1,000. The last column on the right shows the average amount of change on the 5 point scales of quality. From the right hand column, we can read that the largest perceived change in quality was a gain of 1.7 points in “Privacy.” Next were “Getting Out and Getting Around” and “Happiness” both (1.30).

Questions 8 and 9 in the Survey were about family reactions to the idea and the reality of community placement. Question 8 was: “When you first heard about the idea for your relative to move to a new home in the community, were you ‘for’ it or ‘against’ it?” Question 9 asked: “Now that it has happened, how do you feel about your relative living in a new home in the community?” Responses could range from Strongly Against to Strongly For, on a 5 point scale. The results of these two questions are presented in Table 20 and Figure 7.

Table 20
Families' Opinion About Community Placement When First Heard Idea, Versus Now

	At First	Now
Strongly Against	42	4
Against	31	5
In Between	29	20
For	35	54
Strongly For	37	91

Figure 7
Families' Opinion About Community placement When First Heard Idea, Versus Now

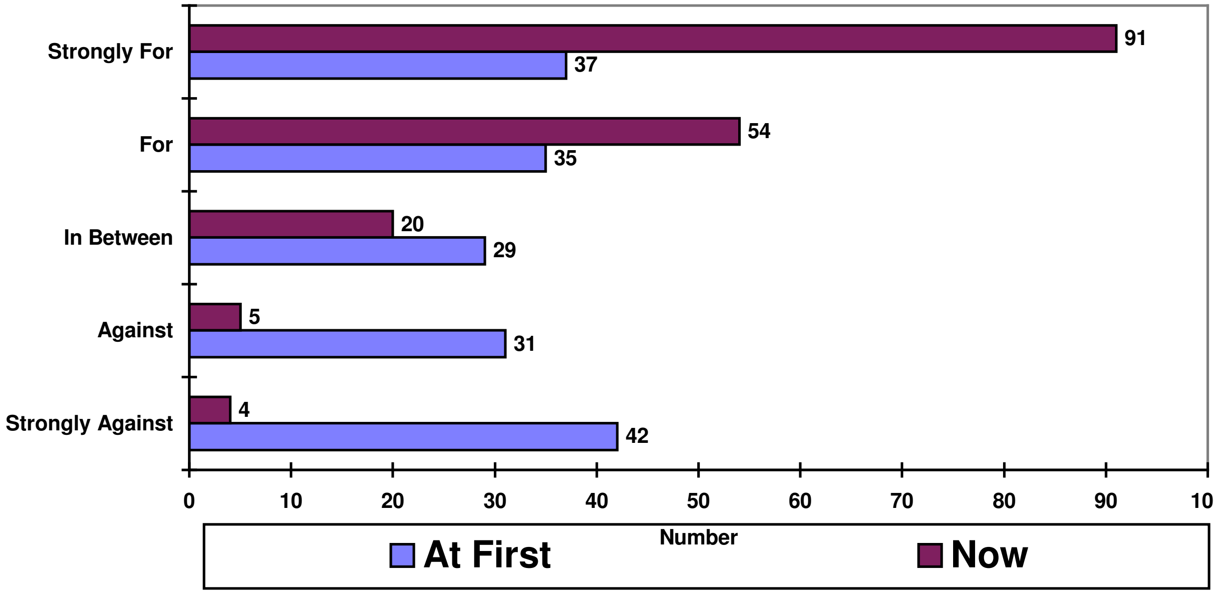


Table 20 shows that opposition to community placement decreased, and support increased. Before the move, 42 families strongly opposed the idea, and after it happened, the figure dropped to 4 out of the 185 families. The shift from opposition to support is clear in these data. Out of 185 families, only 9 now say they are against, or strongly against community living; before it happened, the number was 73. Similarly, the number of families who support or strongly support community living is up from 72 to 145. As has been reported in past studies (Larson & Lakin, 1991), there has been a large positive shift in these families' attitudes toward community living.

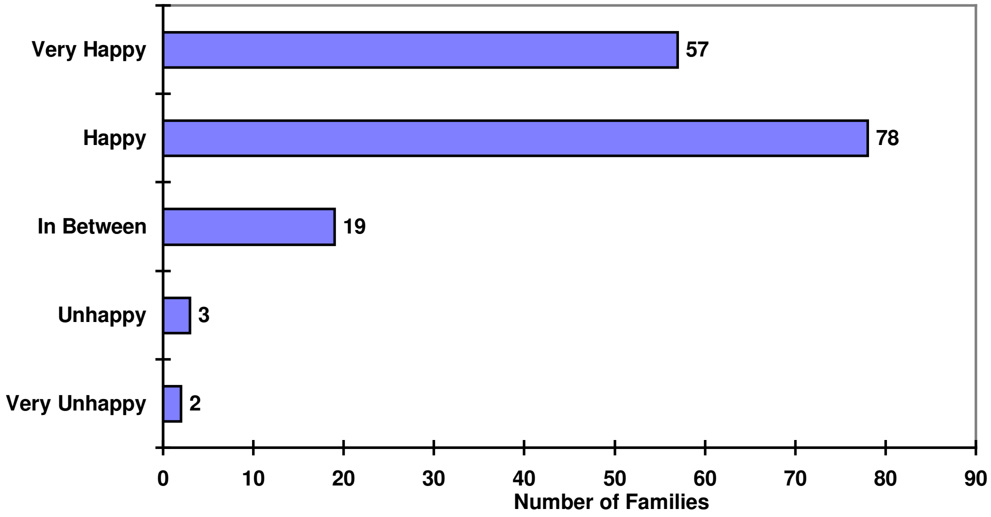
The change was dramatic for 64 of these families, who said they were either "against" or "strongly against" community placement when it was first suggested to them, but who now say they are either "for" or "strongly for" community living for their relatives. **Not one family moved in the opposite direction.**

To get the families' opinions about the class members' happiness in a different way, we asked "How happy do you think your relative is with his/her living situation?" Only 2 family respondents felt that their relatives were "Very Unhappy." Table 21 and Figure 8 show how many families answered with each rating.

Table 21
How Happy Do You Think Your Relative Is With His/Her Living Situation?

Rating	Number	Percent
Very Happy	57	36%
Happy	78	49%
Neither Happy Nor Unhappy	19	12%
Unhappy	3	2%
Very Unhappy	2	1%
	159	100%

Figure 8
How Happy Is Your Relative With His/Her Community Living Situation?



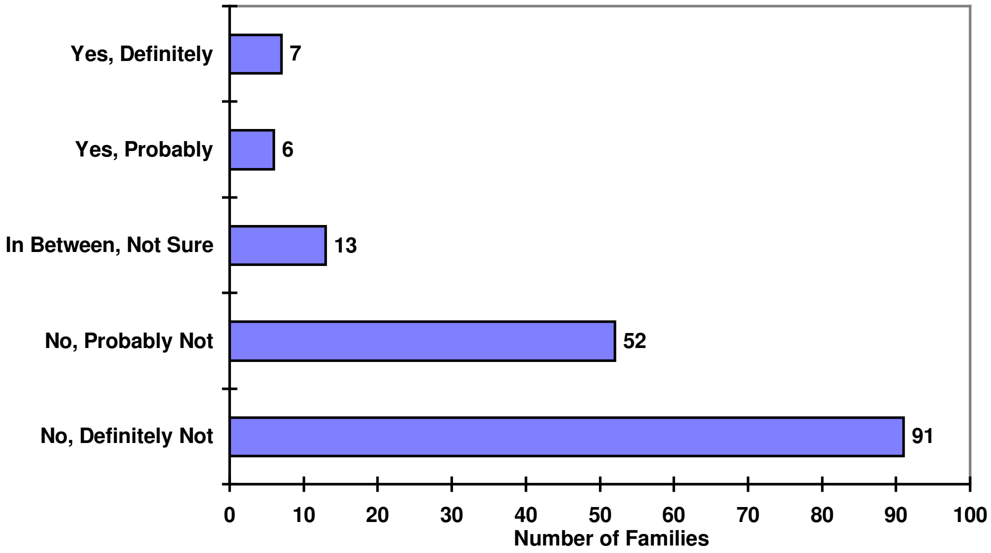
In a very direct question, we asked “If you could, would you have your relative leave his/her new community home and move back to a Developmental Center?” The results are shown in Table 22 and Figure 9.

Table 22
Would You Like Your Relative to Move Back to a DC?

	Number	Percent
Yes, Definitely	7	4.1%
Yes, Probably	6	3.6%
In Between, Not Sure	13	7.7%
No, Probably Not	52	30.8%
No, Definitely Not	91	53.8%
	169*	100.0%

* Sixteen families did not answer this question

Figure 9
Would You Like Your Relative to Move Back to the DC?



These responses clearly showed that the preference of the families was to continue with community living. However, there were 13 families who said they probably or definitely would like to see their relatives move back to a DC. The situations of these 13 individuals, and the opinions of their families, demand further investigation by DDS or the responsible Regional Centers.

Involvement and Communication

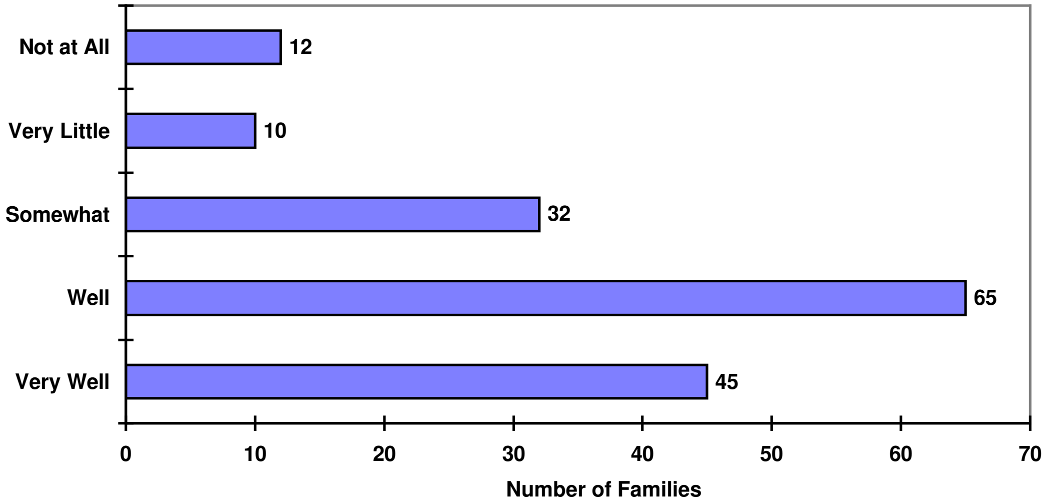
One of the most important things for families is whether or not their feelings are heard and respected. A pertinent question was, “Looking back, how well were you kept informed about what was happening with your relative during community placement?” Table 23 and Figure 9 gives a “report card” on this issue for the Regional Centers and DDS.

Table 23
How Well Were You Kept Informed?

	Number	Percent
Not at All	12	7.3%
Very Little	10	6.1%
Somewhat	32	19.5%
Well	65	39.6%
Very Well	45	27.4%
	164*	100.0%

* Twenty one families did not answer this question

Figure 10
How Well Informed Were You Kept During the Placement Process?



Although it is clear that most families felt that they had been kept well informed, it is also clear that a few families felt that the job could have been done better.

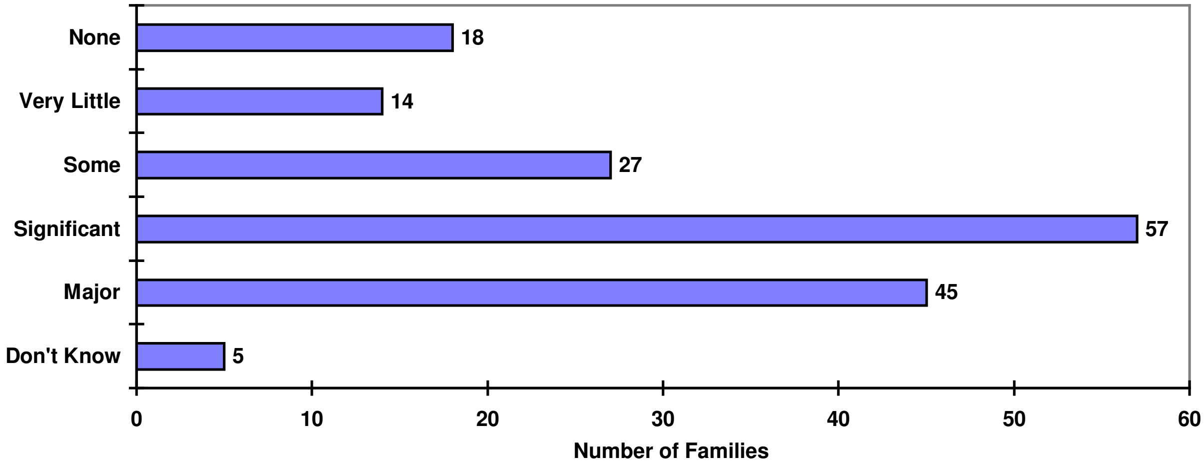
Similarly, we asked "How much attention was given to your opinion about what was best for your relative?" and received the responses shown in Table 24.

Table 24
How Much Attention was Given to Your Opinion?

	Number	Percent
None	18	10.8%
Very Little	14	8.4%
Some	27	16.3%
Significant	57	34.3%
Major	45	27.1%
Don't Know	5	3.0%
	166*	100.0%

* Nineteen families did not answer this question

Figure 11
How Much Attention was Given to Your Opinion During Placement?



This table supports the notion that DDS has given significant attention to family opinions during the Coffelt movement.

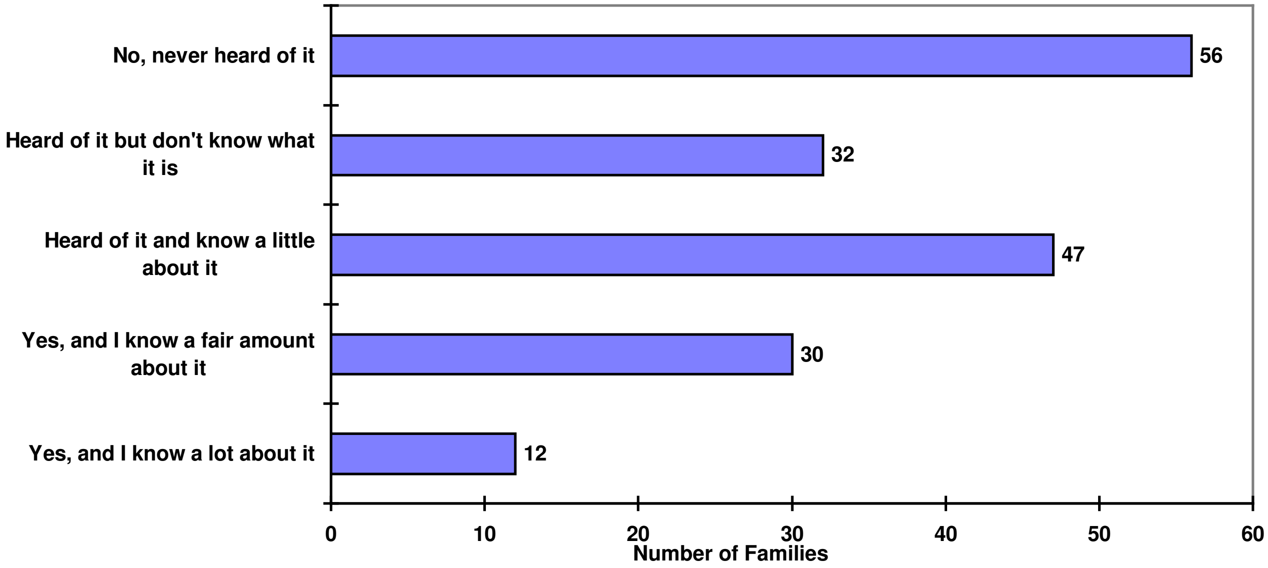
We were also curious to know whether the families were familiar with the Coffelt settlement, so we asked: "Have you heard of the Coffelt lawsuit or settlement agreement?" Table 25 depicts the results.

Table 25
Familiarity with Coffelt Settlement

	Number	Percent
No, never heard of it	56	31.6%
Heard of it but don't know what it is	32	18.1%
Heard of it and know a little about it	47	26.6%
Yes, and I know a fair amount about it	30	16.9%
Yes, and I know a lot about it	12	6.8%
	177*	100.0%

* Eight families did not answer this question

Figure 12
Have You Ever Heard of the Coffelt Lawsuit?



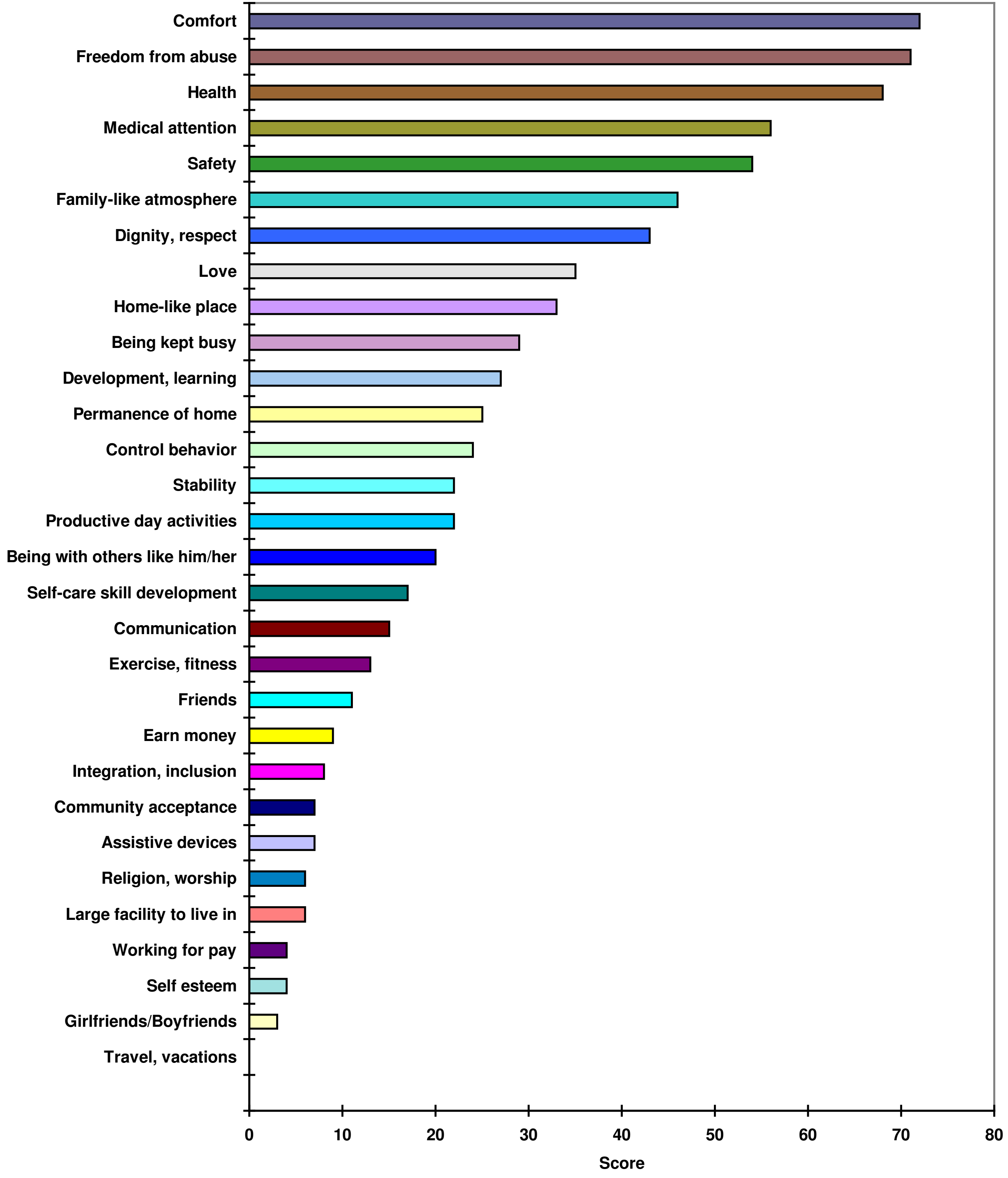
The table shows that families of people recently deinstitutionalized did not generally know very much about the Coffelt settlement. It would appear that the transitions of their relatives were largely done without the families being given extensive information about the lawsuit. The community placement movement may be inferred to be “user-friendly” in that sense.

Valued Outcomes

The Family Survey asked families to rank-order things important to them about their relative’s well-being. We provided a list of 30 areas of possible concern. They were asked to place a “1” next to the area of most importance, a “2” next to the second most important area, and so on down to the fifth most important area. We assigned weights to these rankings, and calculated which areas of quality and well-being received the highest ratings.

The results are shown in Figure 13. The graphed data showed that comfort, ranking first, was of the greatest overall importance to the families.

Figure 13
The Most Important Things for The Quality of My Relative's Life



Following Comfort, the next most valued outcomes were Freedom from abuse, Health, Medical attention, and Safety. In contrast, toward the bottom of the bar graph, it is clear that families did not attach much importance to Travel/vacations, Girlfriends/boyfriends, Self esteem or Earning money.

We believe that these findings are important, because they suggest differences in what families want for their loved ones, versus what professionals are currently advocating, versus what self-advocates themselves say is important to them. Some observers have found that professional values are currently much closer to those of self-advocates than are those of relatives (Speaking for Ourselves, 1996). In any case, in determining "what is best" for people, these different value systems need to be clarified and understood.

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Appendix A: Summary of the Past Reports of the *Coffelt* Quality Tracking Project

Summary of the Reports of the Coffelt Quality Tracking Project

(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 choicemaking, 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. 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 455 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 relative 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.)

Appendix B: Open Ended Comments from the Coffelt Movers

Type of home	**What do you like about living here?**	**What do you not like about living here?**
ICF/DD 7-15 BEDS	Staff	
ICF/DD 7-15 BEDS	Good food	I sleep poorly here
ICF/DD-N 4-6 BEDS, N	Have own radio	
ICF/DD-N 4-6 BEDS, N	I'm not locked up	
ICF/DD-N 4-6 BEDS, N	Staff food	Room/stretching
ICF/DD-N 4-6 BEDS, N		Lady cusses me
ICF/DD-N 4-6 BEDS, N	I go home every Saturday	Being teased
ICF/DD-N 4-6 BEDS, N	I like staff they treat me nice	
ICF/DD-N 4-6 BEDS, N	Going bowling	Hate food and clients
ICF/DD-H 4-6 BEDS, H	Nice	
ICF/DD-H 4-6 BEDS, H	Make things and go on outings	
ICF/DD-H 4-6 BEDS, H	Get to go out	
ICF/DD-H 4-6 BEDS, H	Good food, nice people	
ICF/DD-H 4-6 BEDS, H	Like one of clients	
ICF/DD-H 4-6 BEDS, H	Hockey party	
ICF/DD-H 4-6 BEDS, H	Peers, staff, food	
ICF/DD-H 4-6 BEDS, H	Likes bus to school	
ICF/DD-H 4-6 BEDS, H	I get my freedom	Get a real job
ICF/DD-H 4-6 BEDS, H	Friends/room	
ICF/DD-H 4-6 BEDS, H	Raymond	
ICF/DD-H 4-6 BEDS, H	They're good	
ICF/DD-H 4-6 BEDS, H	Play games	
ICF/DD-H 4-6 BEDS, H	Friends	
ICF/DD-H 7-15 BEDS, H	Catalogue w/paper	
CCF L1 OWNER/STAFF	Judy-counselor	
CCF L2 OWNER	Food, walking, and sitting around	No coke machine
CCF L2 OWNER	Like peers , see family.	
CCF L2 OWNER	We go on trips	
CCF L2 OWNER	Living with staff	
CCF L2 STAFF	Watching videos	Living w/old people
CCF L2 STAFF	Have own TV	
CCF L2 STAFF		Make me do things I don't want
CCF L3 OWNER	House	
CCF L3 OWNER	Go out places	See family more
CCF L3 OWNER		Getting new roommate
CCF L3 STAFF	Like outings	
CCF L3 STAFF	Recreation	Pick your pockets
CCF L3 STAFF	Like staff/food	One of housemates hits me
CCF L3 STAFF		People here
CCF L3 STAFF	Be by myself/private time	Can't stay up till 11 on weekends
CCF L3 STAFF	The food	
CCF L3 STAFF	Likes watching TV	
CCF L3 STAFF		See more mom
CCF L3 STAFF	Bowling, cook once in a while	
CCF L3 STAFF	Good food, help cook	
CCF L3 STAFF	I just like living here	
CCF L3 STAFF	Food, outings	

CCF L3 STAFF		Many rules
CCF L3 STAFF	It's OK	Do what I want
CCF L4-B/STAFF	Making ice and crushing soda cans	I'm too high functioning for here.
CCF L4-C/STAFF		People call me names , I get upset
CCF L4-C/STAFF	Nicer people	
CCF L4-C/STAFF	Independence and people here care	
CCF L4-C/STAFF	I like the people	Some clients get on my nerves
CCF L4-C/STAFF	Good days, good guys	
CCF L4-E/STAFF	Like staff	House too small
CCF L4-E/STAFF	Shopping by myself	
CCF L4-F/STAFF	Staff is nice	
CCF L4-F/STAFF	Good staff easy to talk to	People blow up and attack
CCF L4-F/STAFF	Going to program and I like rob	
CCF L4-F/STAFF	Going to store	
CCF L4-F/STAFF	Independence	
CCF L4-F/STAFF	See my family more	Miss my family
CCF L4-F/STAFF	Nice people	
CCF L4-F/STAFF		Too many rules
CCF L4-F/STAFF	Cookies	
CCF L4-F/STAFF	Staff	
CCF L4-F/STAFF	Staff	
CCF L4-F/STAFF	He can smoke	Wants own room
CCF L4-F/STAFF	These are my family	
CCF L4-G/STAFF	We go out places	Some don't like talking to me
CCF L4-G/STAFF	Nice staff	
CCF L4-G/STAFF	Go on outings	People yelling
CCF L4-G/STAFF	Food, staff	
CCF L4-G/STAFF	Staff nice and I love it	
CCF L4-G/STAFF	Go out in community	Rules too strict
CCF L4-G/STAFF	Freedom-go to store	Job w/more money
CCF L4-G/STAFF	Food & people	
CCF L4-G/STAFF	Staff helps out	Wash other people's dishes
CCF L4-G/STAFF	Good food	It's fair
CCF L4-G/STAFF	Staff, owners help her a lot	
CCF L4-G/STAFF	Food, roommate	
CCF L4-G/STAFF		Too big for house
CCF L4-G/STAFF	Close to mountain	
CCF L4-G/STAFF	Everything fine	Dislikes food
CCF L4-G/STAFF	More freedom	
CCF L4-G/STAFF	Nice environment	
CCF L4-G/STAFF	Quiet	
CCF L4-H/STAFF	One of the staff here	I get lonely
CCF L4-H/STAFF	Help with cleaning	
CCF L4-H/STAFF	People are nice	Screaming at night
CCF L4-H/STAFF	Own privacy	Living own house
CCF L4-H/STAFF	Sleep all I want	One client
CCF L4-H/STAFF	Like it a lot	
CCF L4-H/STAFF	I like dancing and drama	They do bad things to me
CCF L4-H/STAFF		Take meds, decide for self
CCF L4-H/STAFF	They give me money	I'm sick -- high blood pres.

CCF L4-H/STAFF	Clients staff	
CCF L4-I/STAFF	Nice staff	
CCF L4-I/STAFF	The food	
CCF L4-I/STAFF		Too many Camarillo people
CCF L4-I/STAFF	This is home	
CCF L4-I/STAFF	Going places	
CCF L4-I/STAFF	Melba	
CCF L4-I/STAFF	More freedom here	Staff gets rough w/me
CCF L4-I/STAFF	Food, going out	Like everything here
CCF L4-I/STAFF	Have own TV & music	Too many people
CCF L4-I/STAFF	I can do stuff	People telling you what to do
CCF L4-I/STAFF	Going out-circus	Circus
CCF L4-I/STAFF	Work	Watching TV
CCF L4-I/STAFF	Like staff	Wants more freedom
CCF L4-I/STAFF	People live here	
CCF L4-I/STAFF	One of staff	Rules/their attitude
CCF L4-I/STAFF	Good food, friends here	Former roommate
CCF L4-I/STAFF	Going out on weekends	
CCF L4-I/STAFF	The yard housemates	Family in Mexico
CCF L4-I/STAFF	Work	
CCF L4-I/STAFF	Doing work and getting paid	Move to San Jose
CCF L4-I/STAFF	Autonomy here	Don't like 1 peer
CCF L4-I/STAFF		CL made me upset
CCF L4-I/STAFF	Shopping	
CCF L4-I/STAFF	Job, boyfriend, dances	Can't stand out front
CCF L4-I/STAFF	Food, room, chores	Others confront me
CCF L4-I/STAFF	Care provider nice guy	On my own someday
CCF L4-I/STAFF	Like riding buses /taking walks	Being rushed out in mornings
CCF L4-I/STAFF	Everything	
CCF L4-I/STAFF	Going to school/doing my job	
CCF L4-I/STAFF	Staff	House too small
SUPP. LIVING >21 HRS	Own place to live	
SUPP. LIVING >21 HRS	Make own decisions	Watch money too much
SUPP. LIVING >21 HRS	Go out to eat	
SUPP. LIVING >21 HRS	Riding in the car	
SUPP. LIVING >21 HRS	Likes it here	Likes tom one w/card
SUPP. LIVING >21 HRS	Close to town	
SUPP. LIVING >21 HRS	Own space	No kitchen
SUPP. LIVING >21 HRS	Bill Vincent pooh	
SUPP. LIVING >21 HRS	Own room	
SUPP. LIVING >21 HRS	Watching baseball at park	
SUPP. LIVING >21 HRS	Look at window	
SUPP. LIVING >21 HRS	Not getting in trouble	
SUPP. LIVING >21 HRS	Puzzles	
SUPP. LIVING >21 HRS	Pretty neat here	
SUPP. LIVING 11-20 HRS	I'm on my own	
INDEPENDENT LIVING	No one pushes me around	Too small
INDEPENDENT LIVING	Everything	Kids make fun of me
INDEPENDENT LIVING	Can leave whenever he wants	Friends don't want to come over
INDEPENDENT LIVING	Watching people's court	High rent

INDEPENDENT LIVING	No staff bossing me around	It's hard dealing w/life
INDEPENDENT LIVING	Like being on own	
INDEPENDENT LIVING	Nice	
INDEPENDENT LIVING	My own boss	On own w/other people
INDEPENDENT LIVING	More things here	
INDEPENDENT LIVING	Nobody tells me what to do	
PARENT'S HOME	Dad takes care of me	
PARENT'S HOME	Cook own food	
PARENT'S HOME	Freedom	Chores
PARENT'S HOME	Family	
PARENT'S HOME	Loves living with family	Too many kids around
OTHER RELATIVE'S HOME	My friends/family/house	
OTHER RELATIVE'S HOME	Loves family	
OTHER COMM. SETTING	Nice place	

Responses to the question
"If you had one wish, what would you wish for?"
From Both the Class Member and the Primary Respondent
(Whoever knows the Class Member Best on a Day to Day Basis)

Type of home:	**Individual's wish**	**Respondent's wish**
ADULT FAM. HOMES	A baby	Live own apt.
CCF L1 OWNER/STAFF	Apartment	Live independently
CCF L1 OWNER/STAFF	Sue Camarillo	Acceptance
CCF L2 OWNER	Hard to say	Normalization
CCF L2 OWNER	Have fun, play softball	To be happy see more of family
CCF L2 OWNER	Live w/sister	Don't know
CCF L2 STAFF	Marry girlfriend	Commit to being independent
CCF L2 STAFF	Own Burger King	Ride a bull
CCF L2 STAFF	Own home 2 little girls	Eat right, lose weight
CCF L2 STAFF	Visit grandma	Grandmother to visit more
CCF L3 OWNER	Get out of here	Learn more safety
CCF L3 OWNER	Motor home	Go home w/mother
CCF L3 OWNER	Talking bird macaw	Not be physically disabled
CCF L3 STAFF	A hug	Better family relations
CCF L3 STAFF	Be more healthier	Keep doing well, maybe live on own
CCF L3 STAFF	Bird	Be happy, content in new home
CCF L3 STAFF	Brand new car & house	Learn to live on his own & have family
CCF L3 STAFF	Family for holidays	No seizures
CCF L3 STAFF	Get married	
CCF L3 STAFF	Go to Napa	Stop touch people
CCF L3 STAFF	Have own apt	To be independent
CCF L3 STAFF	Independence to live	Find a girlfriend
CCF L3 STAFF	Lamborghini	Go to independent living
CCF L3 STAFF	Live at home	Never touch children again
CCF L3 STAFF	Money	More volunteer work, have girlfriend
CCF L3 STAFF	My own boyfriend	Live independently
CCF L3 STAFF	New Soc. Worker	Paying job
CCF L3 STAFF	Own apartment	Establish a friendship
CCF L3 STAFF	Own apt -more money	Have his own apt
CCF L3 STAFF	See brother in Oakland	Medical care for prostate
CCF L3 STAFF	Total seizure control	Total seizure control
CCF L3 STAFF	Wishes his mom lived closer	More contact w/family
CCF L4-B/STAFF	Higher function facility	Learn to control behavior
CCF L4-C/STAFF	$1,000,000	Make it successfully , live happy
CCF L4-C/STAFF	Friends w/excitement	Family structure
CCF L4-C/STAFF	Live by beach	Stop bothering other clients
CCF L4-C/STAFF	Money	Reach 100 years old
CCF L4-C/STAFF	New life w/car and own place	Mom could visit him
CCF L4-C/STAFF	To live independently	Find her own place and be successful
CCF L4-E/STAFF	Be in own place	
CCF L4-E/STAFF	See dead parents	Not hurt anyone

CCF L4-F/STAFF	Better job & lot's of money	To see mom
CCF L4-F/STAFF	Have a nice girlfriend and place	Have the independence he wants
CCF L4-F/STAFF	Go home for Xmas	Family involvement
CCF L4-F/STAFF	I wish I had my life over again	Live in supported independent living
CCF L4-F/STAFF	Live on own	Better relationship w/family
CCF L4-F/STAFF	Make money	
CCF L4-F/STAFF	More soda	Complete independence
CCF L4-F/STAFF	Parents to still be alive	Learn to think past today
CCF L4-F/STAFF	Stop stealing cars	Relationship w/mom
CCF L4-F/STAFF	To smoke cigarettes	Get own apartment
CCF L4-G/STAFF	Be home w/family	Have own apartment
CCF L4-G/STAFF	Bicycle	Have car & drive it
CCF L4-G/STAFF	Cigarettes, coffee, soda	Get better job
CCF L4-G/STAFF	Get out of here	Honesty
CCF L4-G/STAFF	Get together w/x-girlfriend	Own apartment
CCF L4-G/STAFF	Go home w/mother	Get over diabetes
CCF L4-G/STAFF	Hit the lottery	Control anger
CCF L4-G/STAFF	Home to San Diego	Get over disabilities
CCF L4-G/STAFF	Ice cream	Could control himself
CCF L4-G/STAFF	Live w/parents	Family love her
CCF L4-G/STAFF	Money	Wish he could be well
CCF L4-G/STAFF	New job	Meaningful work
CCF L4-G/STAFF	New stereo	Be independent
CCF L4-G/STAFF	On my own	Independence
CCF L4-G/STAFF	Paul-love interest	To be independent
CCF L4-G/STAFF	Place of her own	Happiness, love in her family
CCF L4-G/STAFF	See stepmom more often	Move to an apartment
CCF L4-G/STAFF	To get married	
CCF L4-G/STAFF	To get married	Reunited w/family
CCF L4-H/STAFF	A car	More motivation
CCF L4-H/STAFF	A million $	Maintain good relationship
CCF L4-H/STAFF	Ask governor for more jobs	More attention from family
CCF L4-H/STAFF	Go back to Philippines w/family	Psychiatric symptoms disappear
CCF L4-H/STAFF	CD’s	No lymphoma
CCF L4-H/STAFF	Home to Mexico	Grant P & I
CCF L4-H/STAFF	I just don't know	Be w/family
CCF L4-H/STAFF	Invent great gifts	Interact w/family
CCF L4-H/STAFF	Like to write a book	Her family closer to her
CCF L4-H/STAFF	Live on own	Good supported living
CCF L4-H/STAFF	Live w/family	Walk
CCF L4-H/STAFF	New apartment	Develop/practice self care skills
CCF L4-H/STAFF	See sister	Stay here w/us
CCF L4-H/STAFF	Someplace warmer	Be reunited w/family
CCF L4-H/STAFF	Stay in group home	Stop smoking
CCF L4-I/STAFF	$1 buy a soda	Lose weight, get job
CCF L4-I/STAFF	An apartment by myself	Control over anger
CCF L4-I/STAFF	Be a clown in circus	Good physical health
CCF L4-I/STAFF	Celebrate birthday	Speak more clearly
CCF L4-I/STAFF	Circus	More time w/mother
CCF L4-I/STAFF	Coffee	Progress towards independence

CCF L4-I/STAFF	Have more food and money	Everything he wants for himself
CCF L4-I/STAFF	Family lived closer	More 1-1 attn. So she can do more
CCF L4-I/STAFF	Game show	Nintendo
CCF L4-I/STAFF	Get a good job	
CCF L4-I/STAFF	Get out of here	Drug free good health
CCF L4-I/STAFF	Go around the world	Girlfriend/sociability
CCF L4-I/STAFF	Go back home	
CCF L4-I/STAFF	Go home	Spend overnight w/family
CCF L4-I/STAFF	Go home to mom	Diminish aggression
CCF L4-I/STAFF	Go to past change things	Independent living
CCF L4-I/STAFF	Have 2 kids	Receive independent living
CCF L4-I/STAFF	Horse	Supportive living
CCF L4-I/STAFF	House of my own	Move into own home
CCF L4-I/STAFF	House/job	Take up hobby and be less intrusive
CCF L4-I/STAFF	I need time to figure it out	Some kind of contact w/family
CCF L4-I/STAFF	Job at Albertsons	Recognize behavior antecedents
CCF L4-I/STAFF	Leave this hospital	To see her family
CCF L4-I/STAFF	Live in Carmel	Take initiative in task analysis
CCF L4-I/STAFF	Live w/grandma	Stay w/grandma
CCF L4-I/STAFF	Live w/mom again	More progress
CCF L4-I/STAFF	Live w/parents in Mexico	Parents move back and die
CCF L4-I/STAFF	Living on my own	Safe, healthy year, improve goals
CCF L4-I/STAFF	Many years to kiss Vince	How to spend more time w/boyfriend
CCF L4-I/STAFF	Money to buy more clothes	Learn to control temper/get along
CCF L4-I/STAFF	Mother to visit	More trips/loves going out
CCF L4-I/STAFF	Move-don't like it here	Not need medication/ live on own
CCF L4-I/STAFF	My own place	More independent living situation
CCF L4-I/STAFF	New speaker for stereo	More independent
CCF L4-I/STAFF	No more seizures	
CCF L4-I/STAFF	Pregnant in 5yrs	Get behavior under control
CCF L4-I/STAFF	Shook head pointed at window	That he could be with us forever
CCF L4-I/STAFF	Stable environment	
CCF L4-I/STAFF	To die (true feeling?, not sure)	Get better
ICF/DD-H 4-6 BEDS, H	A cat	No seizures
ICF/DD-H 4-6 BEDS, H	A dog-Mexican food served here	She could move home
ICF/DD-H 4-6 BEDS, H	A pet	Live a normal life
ICF/DD-H 4-6 BEDS, H	A radio	No seizures
ICF/DD-H 4-6 BEDS, H	A TV	Electric equipment he wants
ICF/DD-H 4-6 BEDS, H	A van	Normal use of arms & legs
ICF/DD-H 4-6 BEDS, H	Airplane	Could talk
ICF/DD-H 4-6 BEDS, H	Car	Continue being stable
ICF/DD-H 4-6 BEDS, H	Coffee	Be able to see
ICF/DD-H 4-6 BEDS, H	Go out for b-day	Relationship w/mother
ICF/DD-H 4-6 BEDS, H	Live w/Millie care provider	Independent someday
ICF/DD-H 4-6 BEDS, H	Mom's phone bill to be paid	Gain self confidence
ICF/DD-H 4-6 BEDS, H	Papers	Be in contact w/family
ICF/DD-H 4-6 BEDS, H	To go with brother	Go see mother more
ICF/DD-N 4-6 BEDS, N	Custody of baby girl Anna	Control nicotine problem
ICF/DD-N 4-6 BEDS, N	Get a permanent outside job	Get eyesight and ambulation back
ICF/DD-N 4-6 BEDS, N	Live here in my own room	To walk

ICF/DD-N 4-6 BEDS, N	Live on own	More happiness, closer friends
ICF/DD-N 4-6 BEDS, N	Move to sisters	Dec aggression
ICF/DD-N 4-6 BEDS, N	New car	Have money, own car, travel
ICF/DD-N 4-6 BEDS, N	Stay w/mom	Control behavior
ICF/DD-N 4-6 BEDS, N	To talk	Get through menopause
ICF/DD-N 4-6 BEDS, N	To work	To be ambulatory
ICF/DD-N 4-6 BEDS, N	Unable to respond	Make improvements
ICF/DD-N 4-6 BEDS, N	Wants boyfriend back	Confidence
ICF/DD 4-15 BEDS	Own room	Live on his own
ICF/DD 4-15 BEDS	Let bygones to be bygones	Hope he gets own apartment
OTHER RELATIVE'S HOME	Always have money	
PARENT'S HOME	$1,000	
PARENT'S HOME	An abortion	Competent supported living
PARENT'S HOME	Car for mom	
PARENT'S HOME	Go to Graceland	She could walk
PARENT'S HOME	Go to Superbowl	
PARENT'S HOME	Have divorce, daughter back	
PARENT'S HOME	High school diploma	
PARENT'S HOME	Move to Washington	
INDEPENDENT LIVING	$1,000,000	
INDEPENDENT LIVING	$ + Better place to live	
INDEPENDENT LIVING	A 4 bedroom house	Full time work
INDEPENDENT LIVING	A radio	Complete independence
INDEPENDENT LIVING	Be rich	
INDEPENDENT LIVING	GED so can get regular job	
INDEPENDENT LIVING	Get out of this dump	
INDEPENDENT LIVING	Get tattooed & pierced	Stabilize living situation
INDEPENDENT LIVING	Girlfriend/wife	
INDEPENDENT LIVING	Move out of here	
INDEPENDENT LIVING	Own apt and a job	
INDEPENDENT LIVING	Own place & $	
INDEPENDENT LIVING	See GOD	
INDEPENDENT LIVING	To apt w/Stephanie	
INDEPENDENT LIVING	TV/VCR	
INDEPENDENT LIVING	Family to get back together	
INDEPENDENT LIVING	Work at Ross	Secure job
OTHER COMM. SETTING	License & car	Find cure for behavior
SUPP. LIVING >21 HRS WK	1,000 more wishes	Everything his heart desires
SUPP. LIVING >21 HRS WK	98 Buick Century	See things clearly
SUPP. LIVING >21 HRS WK	Buy a coke	Earn money at job he likes
SUPP. LIVING >21 HRS WK	Choo Choo train	Personal relationships beyond home
SUPP. LIVING >21 HRS WK	Father	Get a grip on impulse control
SUPP. LIVING >21 HRS WK	For a job and get hair done	Stabilize diabetes
SUPP. LIVING >21 HRS WK	Get 3 sons back	Independent living situation
SUPP. LIVING >21 HRS WK	Go on vacation	
SUPP. LIVING >21 HRS WK	Go to Disneyland	Trip to Disneyland
SUPP. LIVING >21 HRS WK	Go to Reno	Heal foot
SUPP. LIVING >21 HRS WK	GOD	Control inappropriate behaviors
SUPP. LIVING >21 HRS WK	Leave Marin county.	Go on vacation of his choice
SUPP. LIVING >21 HRS WK	Likes guy wants boyfriend	

SUPP. LIVING >21 HRS WK	Live here all life	More friends
SUPP. LIVING >21 HRS WK	More money	
SUPP. LIVING >21 HRS WK	New chair	Good trips new chair
SUPP. LIVING >21 HRS WK	Send friends to safety	Be healthier
SUPP. LIVING >21 HRS WK	Radio	Have a boyfriend
SUPP. LIVING 11-20 HRS WK	Stay in apartment	

Appendix C: 1998 Family Survey