Final Outcomes of the 3 Year California Quality Tracking Project

Year 2002 Report of the Quality of Life Evaluation Of People with Developmental Disabilities Moving from Developmental Centers into the Community
(The "Quality Tracking Project")

Final Report
(Report #6, Year 3) [1]

Submitted to:
The Honorable Gray Davis
The Honorable Wesley Chesbro, Senate Select Committee on DD & MH
The Honorable Steve Peace, Senate Budget and Fiscal Review Committee
The Honorable Dede Alpert, Senate Appropriations Committee
The Honorable Darrell Steinberg, Assembly Appropriations Committee
The Honorable Gilbert Cedillo, Assembly Subcommittee No. 1 on HHS
Mr. Dale Sorbello, Department of Developmental Services

Submitted by

James W. Conroy, Ph.D., Amanda Fullerton, M.S., and Marguerite Brown, M.S.
The Center for Outcome Analysis
201 Sabine Avenue
Narberth, PA 19072
610-668-9001, fax 610-668-9002

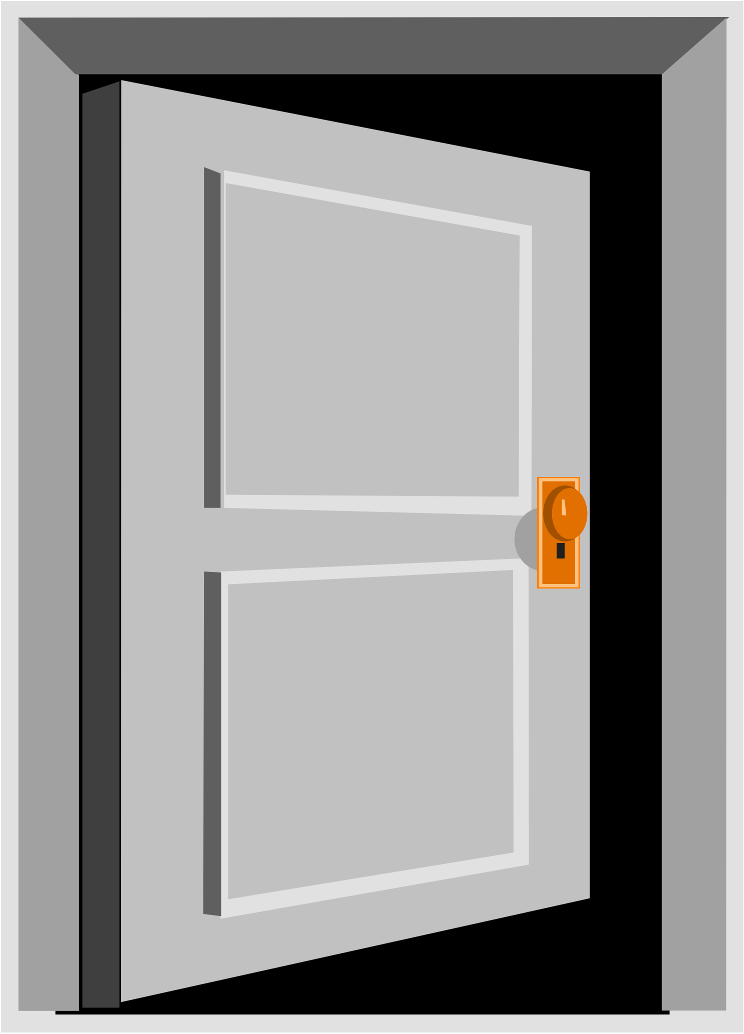
June 2002

---

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

Acknowledgment

The authors wish to acknowledge and thank the more than 2,000 people who allowed us into their homes and workplaces to find out how they were doing. And we offer a special thanks to their relatives who completed our surveys over the past three years.



Contents

Appendices

Executive Summary

This is the final report of the 3 year Quality Tracking Project. The report is concerned with the well-being of more than 2,200 Californians with developmental disabilities who moved out of Developmental Centers, mostly during the 1990s, and who now reside in community homes. There has always been one central question this Project has been designed to answer: Are they better off?

A very clear answer has emerged from both this and the previous body of 5 years of work, which was often called the Coffelt Study. With five separate research designs and more than 25 formal deliverable reports, we conclude that the answer is a strong "Yes."

For the people who moved out of Developmental Centers under the Coffelt settlement agreement, careful monitoring was very important. Most of these people carried the labels "severe" or "profound" mental retardation, and more than half were not able to use language. They were very vulnerable people, and as the law that created the Quality Tracking Project stated,[2] California had a definite responsibility to watch out for their well-being after they left state-operated facilities.

But the present Project was also designed to do much more than answer that single central question. Now this Project is firmly established as part of California's monitoring of community programs for people with developmental disabilities. For every one of the people we visited this year, we not only collected quality of life data, but also we completed a Quality Feedback Summary form which summarized things in each person's life that demanded a "second look" by Regional Centers, case managers, families, and/or other advocates and allies. This system was created so that problems could be detected and addressed quickly. Our Quality Feedback Summaries were FAXed or quickly mailed to our Regional Center contacts for review and action.

The Report is presented in five major results sections: Three Years of Family Surveys, Pre-Post Analysis from 1994 to 2002, Quality Feedback Summaries, Analyses of Quality Changes in the Community from 2000 to 2002, and Feedback About the Visitors and the Process of Data Collection.

Family Opinions

This year for the first time the information obtained from the families of the Movers has been placed at the front of the report. The Family Survey data from the entire past 3 years has been combined into one large analysis. The Family

---

[2] That section of the law is reproduced herein as Appendix A.

Survey findings are given precedence in this report because they can and should be an important contributor to public policy. As noted in the Lanterman Act,

> ***A consumer of services and supports, and where appropriate, his or her parents, legal guardian, or conservator, shall have a leadership role in service design. §4501***

Moreover, the Family Survey findings have been quite dramatic. Families have changed their opinions over these last 9 years toward favoring community living. They are on the whole extremely satisfied with the community situations of their relatives. They believe their relatives have sharply better qualities of life now in 14 out of 14 dimensions. The overwhelming majority of families would not want their relatives to return to a Developmental Center.

From a list of 30 dimensions of quality of life and service, the 5 valued most highly by families were, in this order: Health, Freedom From Abuse, Safety, Medical Attention, and Comfort.

Are They Better Off Than They Were in Developmental Centers?

Using the Personal Life Quality protocol, the study team collected data on the qualities of life of many of the Movers (the people who eventually moved from Developmental Centers to community homes) back in 1994. Now, 8 years later, we visited them again, and are able to compare qualities of life and service in institution and community.

The findings strongly support the inference that the Movers are, indeed, better off now than they were in Developmental Centers. From among 21 major indicators of quality, these 11 changed significantly for the better:

Progress Reported Toward Individual Plan Goals
Choicemaking
Integration
Reduced Challenging Behavior
Qualities of Life Ratings in 14 Dimensions
Individualized Practices Scale
Hours of Day Program Services
Number of Services in Individual Plan
Staff Like Working With This Person
Staff Job Satisfaction
Staff Get Sufficient Support

Some of these dimensions of quality reflected essential intents of the Lanterman Act, and the improvements in those dimensions were very large. For example, the Lanterman Act mandates an individual planning process that results in specific written goals for each person. Our results show that reported progress toward individual goals increased from 46 out of 100 points back at the Developmental Center, to 77 out of 100 points in the community.

The increases in opportunities for choicemaking are also large --- 14 points on a 100 point scale. This strong positive outcome is closely associated with another Lanterman Act mandate:

> ***Consumers of services and supports, and where appropriate, their parents, legal guardian, or conservator, should be empowered to make choices in all life areas.***

The Quality of Life ratings that were collected for people when they were living in Developmental Centers averaged 71 points, and now in the community they average 80 points out of a possible 100. Moreover, the scale taps 10 dimensions, including health, safety, happiness, and family relationships, and all 10 are significantly higher now than before.

For the Movers who could be directly interviewed (about 20%), the vast majority express the belief that their lives have greatly improved and they are very happy with their community homes. They, too, are clear in their strong feelings that they would not like to return to a Developmental Center.

However, there are four areas in which people are not better off. People are not seeing the dentist as often as before, they are earning even less money per week on the average (although this was always a very low figure, about $5 per week, and now it is down to about half that), there is a perception that health care is not quite as good as it used to be, and it appears that people (and those who answered for the people) now report fewer close friends than before (down from an average of 3 to 2).

When combined with the opinions of the families, the weight of the scientific evidence strongly supports California's decision to provide community homes for the more than 2,000 people who left institutions. Combined with the knowledge that the community supports were less costly than the Developmental Centers, the inference must be that this was good social policy.

Quality "Report Cards"

For each visit to a Mover, a special form was completed that recorded carefully selected situations. These were both positive and negative. These "report cards" were individually delivered to the appropriate Regional Centers so that they could help remediate the negative situations, and give congratulations for the positive situations.

A Working Group with broad representation selected exactly which situations would be on this "report card." (We called it the Quality Feedback Summary.) The most frequently reported negative situations are: that no unpaid people were involved in the person's life; a person is allowed very little opportunity to participate in their life choices; and the person is receiving three or more psychoactive medications.

The most common positive reports are that people are treated very much as individuals, people have freedom to move about their communities (with support) almost whenever they want, and the perceptions about their qualities of life are dramatically higher than when they lived in institutions.

By counting how many positive and negative things are in each person's report card, we derive an index that can be compared across groups, such as by type of living situation or by Regional Center. In this report, we present an analysis of these "report card" quality indicators across Regional Centers. The variations are large, and this technique may hold tremendous potential for system improvement.

Changes in Quality from 2000 to 2002

On the issue of quality changes within the community over the 3 year period, we review last year's findings, report on another year of data, and attempt objective interpretation. Last year's findings are generally confirmed by the new year of data. However, the negative trends that appeared in last year's data did not continue. In particular, the apparent decrease in Adaptive Behavior from 2000 to 2001 did not continue in 2002.

The pattern of changes over 3 years is complex. The most encouraging changes among 10 key indicators are: that the average time spent in Day Activities has been increasing; treatment of people as individuals has been increasing; our measure of person-centered planning has been increasing; and people's opportunities for choicemaking have been increasing. For each of the negative trends observed last year, this year's data show that they either got better or did not get worse.

The Process of Visiting the Movers

For each visit a postcard was left for the person or the person's closest staff to "rate" the Visitor and the survey process. The ratings show that the Visitors were overwhelmingly: considerate in scheduling, were on time for appointments, tried diligently to communicate with the people with disabilities directly, respected the time and space of others in the home, and were pleasant and courteous. The open ended comments on the postcards show that the people and their staff found the visits to be non-threatening, professional, interesting, and even enjoyable. Many commented that they hope the process continues.

Completion of the Year 2002 Visits

Our Visitors attempted to contact every person on the lists supplied by DDS. When the work was complete, we examined the ultimate resolution of these efforts. The original lists, with DDS duplicates removed by COA, has 2,487 names total. Our Visitors in the field found that 135 of these people were not available for visit, primarily because of death, or moving out of state, in previous years. So for the year 2001-2002, we had a "Visit Candidate" pool of 2,352 people. These were assigned in three geographic groups as follows:

Candidates for Visits in 2001-2002

North	1,016
Central	514
South	822
Total	2,352

Of the 2,352 candidates for face to face Quality Tracking Project Visits, our Visitors sent in Personal Life Quality (PLQ) protocols for all 2,352. Some of these Protocols could not be completed, however, for the reasons shown below.

Final Results of the Assigned Visits

	Frequency	Percent
1 Visit conducted and PLQ was completed	2,218	94.3%
2 Visit conducted, but could not complete the entire PLQ	2	0.1%
3 Person could not be found; Regional Center could not locate	10	0.4%
4 Person inactive, case closed by Regional Center	21	0.9%
5 Two or more appointments were broken by respondent(s)	1	0.0%
6 Deceased	30	1.3%
7 Moved out of state*	5	0.2%
8 Person was in a DC or Mental Hospital, visit not feasible	5	0.2%
9 Focus person was incarcerated in prison, visit not feasible	19	0.8%
10 Focus person was hospitalized, no resp. avail. complete PLQ	2	0.1%
11 Refused: Focus person refused to allow visit	10	0.4%
12 Refused: Caregiver(s) sup. focus person refused visit	6	0.3%
13 Any other reason, please describe	23	1.0%
Total	2,352	100.0%

Thus the completion rate in 2001-2002 was 94.3%.

There is another way to compute the completion rate. Out of the 2,352, only 2 visits resulted in incomplete Personal Life Quality (PLQ) protocols, another 10 people could not be found, 1 person broke two or more appointments, 10 people declined to take part, and for 6 people a caregiver refused on the person's behalf. The remainder of the non-completed Visits could not possibly have been completed anyway --- e.g., deaths and moved out of state. Hence by this approach there were a total of (2+10+1+10+6) 29 visits that theoretically could have been completed, but were not. That method of computation led to a response rate calculation of 98.7%.

Either figure, 94.3% or 98.7%, was judged acceptable. It was significantly higher than rates obtained by other research groups both within California and in other projects in other states.

Results 1: The Family Survey

The origin of this Quality Tracking Project can be found in Welfare and Institutions Code 4418.1. One section, reproduced below, specifically requires the measurement of consumer and family satisfaction.

> (d) The contractor shall measure consumer and family satisfaction with services provided, including case management and quality of life, including, but not limited to, health and safety, independence, productivity, integration, opportunities for choice, and delivery of needed services.

COA used the Personal Life Quality protocol (PLQ)[3] to measure consumer perceptions and satisfaction. Because the majority of the Movers do not live with their families, and therefore the families were not present when the COA visits were conducted, it was necessary to use another instrument to measure family satisfaction.

How the Family Survey Was Done

During each year of this project, we completed face to face visits with more than 2,000 Movers. During each interview, our Visitor attempted to complete the following section of the Personal Life Quality protocol:

---

[3] Included here as Appendix B.

WHO IS THIS PERSON'S CLOSEST RELATIVE, FRIEND, GUARDIAN, OR CONSERVATOR? WE WILL SEND A MAIL SURVEY TO THIS INDIVIDUAL EVERY YEAR.

0. Does this person have a relative who might respond to a survey about the person's well-being?
    1. No known relatives to survey
_____ 2. Yes, relatives are known, but THEY WANT NO CONTACT (we will NOT mail a survey to them)
    3. Yes

BE SURE TO GET COMPLETE ADDRESSES, INCLUDING ZIP CODES

PLEASE COMPLETE THIS ADDRESS EVEN IF THE PERSON LIVES WITH THE RELATIVE
WRITE COMPLETE ADDRESS DO NOT ABBREVIATE OR WRITE "SAME"

1. ______________________________ Name(s) of Relative, Friend, Guardian, or Conservator

2. ______________________________ Type of Relationship

3. ______________________________ Complete Mailing Address, Line 1

4. ______________________________ Complete Mailing Address, Line 2

5. __________ City or Town 6. __________ State 7. __________ Zip Code

8. __________ Telephone Number 9. __________ If Monolingual, What Language?

In each of the past 3 years, COA used the data from this section to mail a survey form[4] to the closest family member of each and every person.[5] Each year we found that only about half of the people had any known family.[6] In 2002, that figure was 1,084 out of 2,103. We mailed surveys to those 1,084 addresses and 145 were returned because the address was not valid. The family may have moved, or died, and no one close to the Mover had known about it or recorded the information at the person's home. Theoretically we might have been able to reach approximately 970 families in each of the three years. However, the real figure was closer to 800, simply because the last wave of the surveys was sent out in mid-

---

[4] The Family Survey Form is reproduced here in Appendix C.
[5] We also offered telephone or personal visits as alternatives to the mail survey.
[6] This in itself is an interesting finding, revealing the degree of disconnection experienced by these people.

May, and some family responses were not received in time to be included in our annual report.

This year, for the Final Report of three years of tracking quality, we have pooled the Family Survey data. We took all of the surveys received over the three years, and selected the most recent one received from each family. If a family had responded to all three surveys in 2000, 2001, and 2002, we kept the one from 2002 for this analysis.

Ultimately, this resulted in one large unduplicated Family Survey datafile that represented the opinions and feelings of 637 families. Because less than half of the Movers had any family (with valid addresses), it is accurate to say that over the three years of the study we obtained responses from more than 60% of the available families.

The controversy surrounding America's shift from institutional to community support systems is very intense. Family members on both sides of the issue have taken positions based on advocacy and values. Because of the Quality Tracking Project, California is now able to know with considerable certainty what most of the families of the Movers felt about the change from institution to community. This data should be very valuable and policy relevant in the coming years.

What Kinds of Relatives Answered the Surveys?

The 637 family members who responded to our survey are as varied as their relatives with disabilities. A brief description of their general characteristics may be helpful to establish a context for reading the survey results.

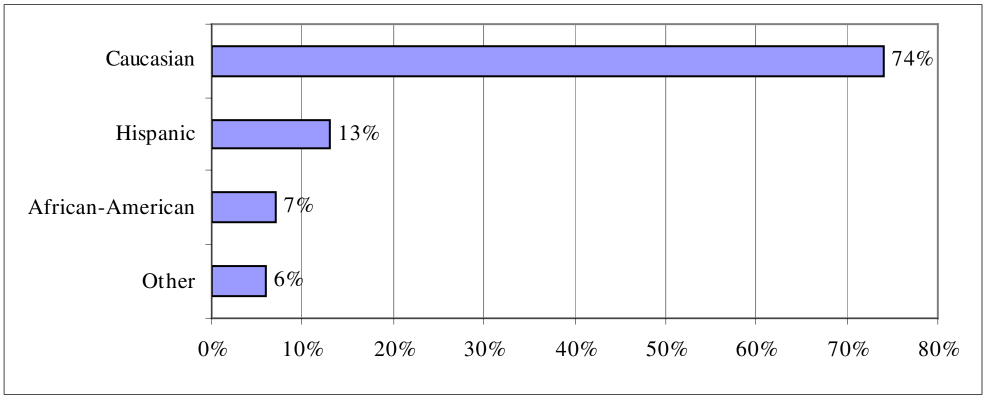
Approximately 70% of the respondents were parents, 20% were siblings and 10% were other relatives. In 60% of the cases, the family respondent was the legal guardian or conservator for their relative with a disability and the remaining 40% were not. The mean age for respondents who were not parents was 54; the mean age for respondents who were parents was 66. (The overall average age of respondents was 62). These demographics make it clear that for this group, the closest family members were elderly parents who were legal guardians or conservators.

The families reported that they visited their relatives a median of five times per year. In other words, half visited more than five and half visited less than five times per year. (Incidentally, we also asked this question of the people and their community staff during the PLQ data collection, and the answers from families and from people/staff corresponded very well --- the correlation between the two reports of number of visits was .88, a very high figure. This indicated that both parties were reporting accurately.)

The Movers

It is also important to have an understanding of the people with disabilities whose family members responded to our survey. The average age of the people with disabilities was 41 and they had spent an average of 22 of those years in Developmental Centers. Their race, level of mental retardation, and living arrangement are described below.

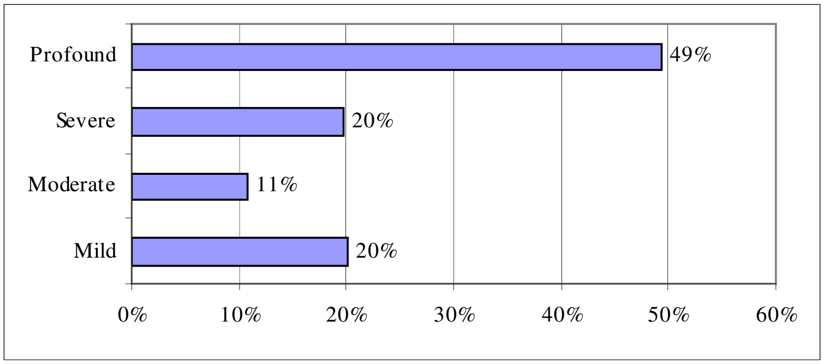
Racial Identity



This table shows that 74% of the Movers whose family members responded to our survey were Caucasian, 13% were Hispanic, 7% were African-American, and 6% reported other racial heritages, including Native American, Asian, Filipino, and other.

It has been customary in the field of developmental disabilities to describe people according to their levels of mental retardation. Although this practice has decreased in recent years, and in fact is a major point of contention for self-advocates, we include the levels of mental retardation labels, for those who had such labels, as a point of reference.

Levels Of Mental Retardation For Those Who Had Labels



As reported in the chart above, 69% of the people whose families responded to our survey were labeled as having severe or profound mental retardation. Only

31% were labeled as having mild or moderate mental retardation. These levels are interesting in light of past and present assumptions that people with severe or profound mental retardation are difficult to support in community settings. Readers should therefore keep these levels in mind when reading later sections that describe family opinions regarding life in the community for their relatives.

The next important item of descriptive information about the 637 Movers whose families responded to the survey is their type of community living arrangement.

Living Arrangements

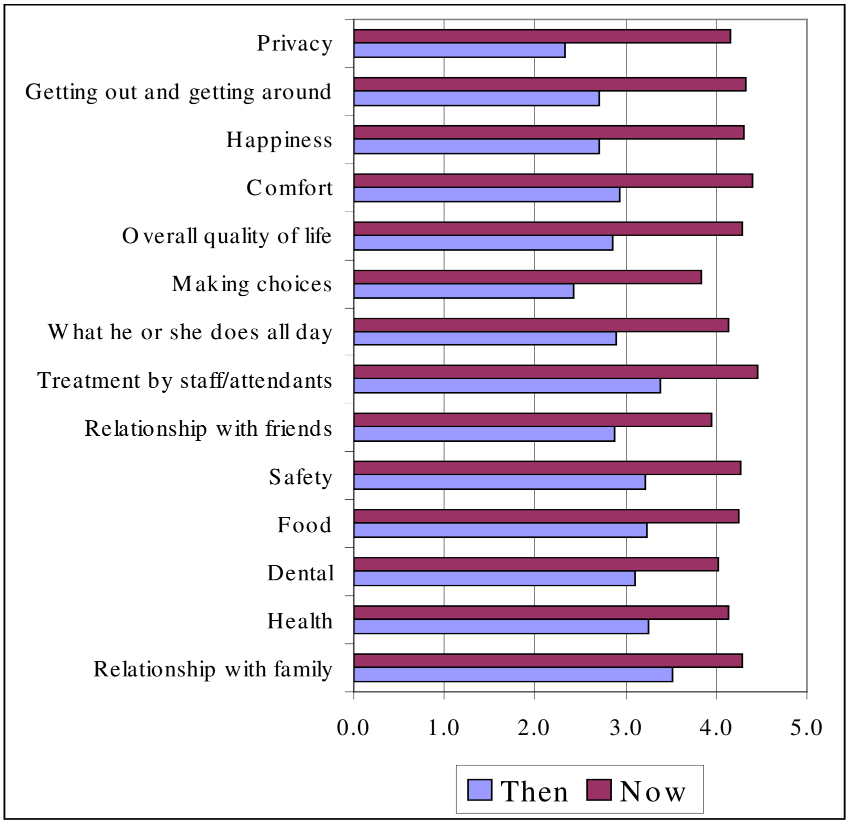
Living Arrangement	**Numbers of People**	**Percent of People**
Small Community Care Facility	395	62%
Small Community Care Facility Specialized for Nursing Care	99	16%
Foster Care	11	2%
Small Home for Child with Health Care Needs	19	3%
With Family	24	4%
Own Apartment/Home with Supports	36	6%
Some other kind of home in the community	48	8%
Nursing Home	5	1%
	637	100%

The chart above makes it clear that the majority (62%) of people with disabilities referred to in this survey lived in small community care facilities. The next highest category of living arrangement (16%) was small community care facilities with specialized nursing care. The living arrangement that was least utilized by this group (1%) was a nursing home and the next lowest (2%) was foster care. The remainder of the arrangements represented from 3% to 8% of the people with disabilities.

Do Families Believe Their Relatives are "Better Off?"

The desired goal of any social intervention is to improve the quality of life for the people involved with the intervention. Our Family Survey included several questions aimed at measuring the degree to which relatives felt that the quality of life for their family member with a disability had changed since their move from a developmental center to the community. The chart below shows family ratings of fourteen important measures of quality of life. The survey asked that they rate each quality of life dimension both THEN (when living at a developmental center) and NOW (while living in a community home.) A five-point rating scale was used to measure this outcome: Very Poor, Poor, In-Between, Good, and Very Good.

Qualities Of Life THEN And NOW



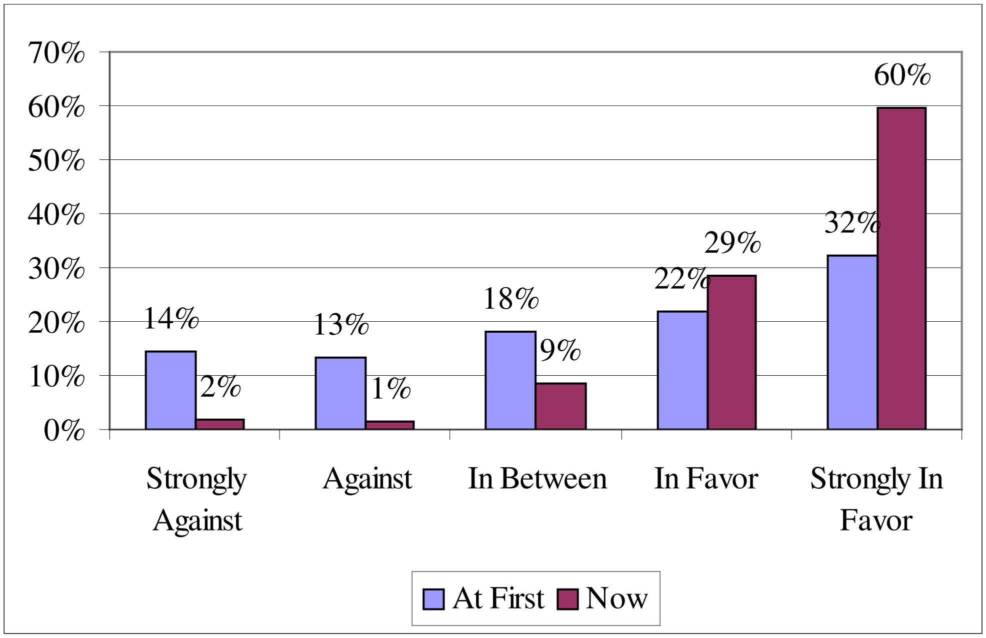
The results in the table above are a strong indication that families think their relatives are better off. Every one of these perceived improvements was highly statistically significant (p<.0001). The scores for NOW, with the exception of making choices, were between Good (4) and Very Good (5). The table not only shows satisfaction with current quality of life but also it shows a dramatic change in family perception of quality from life in the developmental center to life in the community.

The various qualities of life are listed from top to bottom according to the greatest changes as rated by the families. Privacy and Getting Out and Around showed the most improvement. The qualities that families felt had changed least were Health and Relationship with Family. These results are consistent with our findings in other studies and in other states. Enhanced privacy and more opportunities for getting out are obvious advantages of life in the community. At the other end of the table, we have found that people with disabilities who had good family relationships prior to community placement maintain those relationships and unfortunately, those who did not have good family relationships did not see any improvement after community placement. Families also reported little change in health status as the result of the move to the community. This is another pattern that we have observed, most likely because the medical model of developmental centers made quality healthcare a priority, and community support staff continued successful health maintenance strategies.

Have Families Changed Their Opinions About Community Living?

The philosophical foundation for developing and improving community support systems for people with disabilities is the belief that they will have more opportunities and better lives in the community. Many people, including parents and family members, have serious reservations about the feasibility of community placements for people with significant support needs. It is our opinion that most of these reservations arise from love and concerns for health and safety. We therefore felt it was important to ask families if their opinions about community placement changed, from the time they first heard about a move for their relative, to now, when their relative is living in the community. Again, we provided a five point scale for answers: strongly against, against, in between, in favor, strongly in favor.

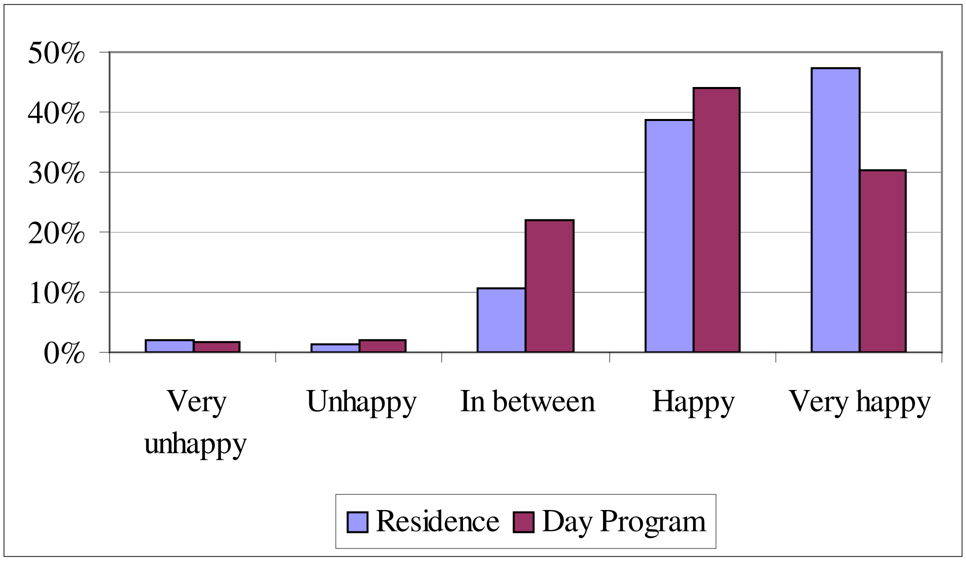
Change In Family Opinions About Community Placement



The results in the table above are dramatic. The percentage of family members strongly against community placement changed from 14% to 2%. Conversely, the percentage of those strongly in favor of community placement changed from 32% to 60%. A total of 89% of the 637 families who responded to our survey reported that they are now in favor or strongly in favor of community placement.

We expect that family opinions about community placement were largely based on their perceptions of their relative's happiness. We therefore asked how happy they think their family members are with their living arrangements and day programs.

How Happy Is Your Relative With His/Her Residence And Day Program?



Again, the results are overwhelmingly positive with 86% of the families reporting that their relative was either happy or very happy with the current community living situation. Only 3% of the people felt that their relative was very unhappy or unhappy. It is understandable that observing this level of satisfaction would cause families to think favorably about community placement.

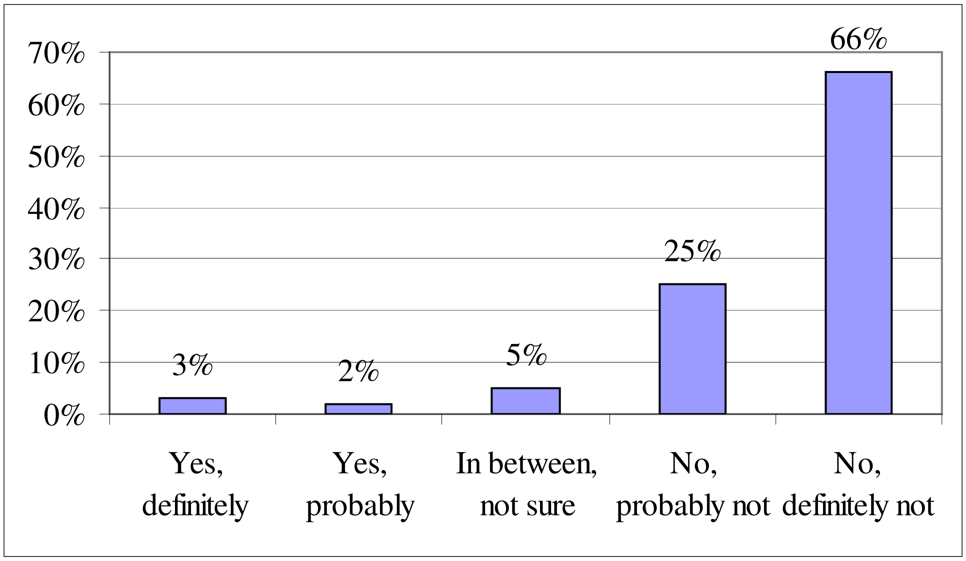
Satisfaction with where one lives is of primary importance but quality of life is also affected by how people feel about what they do all day. We also asked the families how happy they think their relatives are with their jobs or day programs.

As the chart shows, 74% of the family members who responded to our survey think that their relatives are happy or very happy with what they do during the day. Only 4% feel that their relatives are very unhappy or unhappy.

Do Families Want Their Relatives to Move Back to a Developmental Center?

Our last question aimed at measuring family opinions about whether or not their relatives are better off, was very direct. We asked if they would want their relative to move back to a developmental center.

If Possible, Would You Want Your Relative To Move Back To A Developmental Center?



The most frequent answer to this question, from the 637 families who responded to our survey, was a resounding NO. As illustrated in the table, 91% of the respondents said no, they would probably not, or no, they would definitely not, want their relative to move back to a developmental center. Only 5% of the respondents answered that yes probably, or yes definitely they would want their relative to move back to a developmental center.

Family Perceptions of Planning and Case Management

Our task, as specified in Welfare and Institutions Code 4418.1, included measuring family opinions about the process of community placement and case management. Our first question directed to this measurement was about how well families felt they were informed during the planning process. We asked that families answer this question using the five point scale listed in the following table.

How Well Were You Kept Informed About What Was Happening With Your Relative During Planning For Community Placement?

1. Not At All: Always found out about things after they happened	8%
2. Very Little: Usually found out afterward	7%
3. Somewhat: Sometimes knew, sometimes didn't	16%
4. Well: Usually knew in advance what was happening	36%
5. Very Well: Always informed in advance about what was being planned	32%

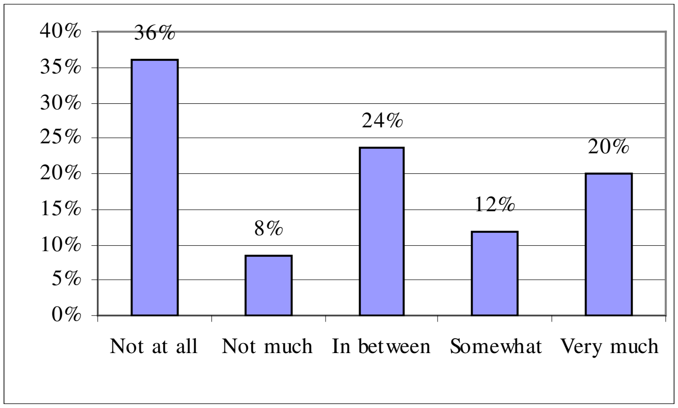
The majority (68%) of relatives who answered our survey reported that they were well, or very well, informed about what was happening regarding their family member's move to the community. Only 8% felt that they only found out about things after they happened and only 7% more reported that they usually found out about things afterward. These results are a tribute to the developmental center and regional center staff who worked together to assure smooth transitions to the community.

Next, we wanted to know how families felt about the annual planning process in the community. As specified in the Lanterman Act, §4646(a):

> It is the intent of the Legislature to ensure that the individual program plan and provision of services and supports by the regional center system is centered on the individual and the family of the individual with developmental disabilities and takes into account the needs and preferences of the individual.

In the spirit of the Lanterman Act, all community supports are supposed to emerge from an individual or person-centered planning process. We therefore asked families if they felt that their relatives' plans were the result of a person- centered planning process.

Is Your Relative's Individual Plan (IPP Or IHP) The Result Of A Person-Centered Planning Process?



The answers to this question were not positive. As illustrated above, only 32% of the respondents felt that their relative's plan was person-centered, and 44% felt that the plans were either not at all person-centered or not much person-centered.

This finding is puzzling because the results of our Personal Life Quality (PLQ) visits with the people with disabilities show a high rating for the extent to which plans are person-centered. There was zero correlation between the families' and the people's/staff's perceptions of how "person-centered" the planning process had been (r=.005, NS).

The fact that most Movers do not have relatives present and involved in their planning meetings coupled with the conflicting opinions regarding person-centered planning, point to a need for more communication and education regarding the planning process. The people with disabilities and the people who know them best on a day to day basis (usually staff) appear to understand the intent and implementation process for person-centered plans. On the other hand, the families, the majority of whom are not involved in the annual planning process, may not be as familiar with the steps and activities that result in an annual plan.

Our next set of questions related to family satisfaction with case management in the community. First, we wanted to know if the family members knew their relative's case manager.

Do You Know Your Relative's Case Manager Or Service Coordinator?

1 YES	76.0
2 NO	24.0
Total	100.0

In our opinion, a 76% positive response rate is very good. Considering that the families visit their relatives an average of five times a year, that the mean age for relatives is 62, and other variables such as case manager turn over and geographic proximity, it appears that families and case managers made strong efforts to become acquainted.

The next question asked families to rate their satisfaction levels with regard to case managers, using the five point scale in the table below.

How Satisfied Are You With Your Relative's Case Manager Or Service Coordinator?

Response	Percent
1.Very Dissatisfied	5.0
2. Dissatisfied	3.1
3. In Between, Neutral	12.2
4. Satisfied	43.0
5. Very Satisfied	36.7
Total	100.0

The results for this question were also positive, with approximately 80% of the respondents reporting that they were satisfied or very satisfied with their relatives' case manager or service coordinator. Only 8% of the respondents felt dissatisfied or very dissatisfied.

How Do Families Rate the Quality of the Service System?

It is also important to understand how families feel about the agencies that are supporting their relatives in the community. Therefore, we asked three questions about family interactions with community provider staff.

What Happens Now When You Contact The Agency That Serves Your Relative?

Response	Percent
1 Always Talk To A Different Person	4.2
2 Usually Talk To A Different Person	12.7
3 Get Thru To One Person Half The Time	8.1
4 Usually Talk To Same Person	52.9
5 Always Talk To Same Person	22.1
Total	100.0

Almost 75% of the respondents reported always or usually talking to the same person when they contact the community agency. This finding is very positive.

What Kind Of Person Do You Usually Talk To At The Agency?

Type of Person	Percent
1 Direct Care	61.8
2 Mid-Level Manager	14.9
3 Upper-Level Administrator	6.7
4 Assistant Director Of The Agency	1.6
5 Director Of The Agency	6.1
6 Other	8.8
Total	100.0

It is clear from the above table that most (76%) family contact is with direct care and mid-level managers. This is understandable as family contact is probably most common in the evenings and on weekends. It is also probable that the day-to-day kind of information that interests families is best obtained from the staff who support them directly.

In the last question about agencies, families were asked to use a five point scale (Very Poor, Poor, Fair, Good, Very Good) to rate the following kinds of contact with agencies that support their relatives.

Please Describe Your Contacts With The Agency

Type Of Contact	**Score**
Pleasantness (toward you)	4.5
Caring (toward your relative)	4.4
Familiarity with your relative	4.4
Listening to you and your concerns	4.3
Overall relationship between you and agency	4.3
Trust (do you trust the staff you talk to?)	4.3
Access (can you reach them easily?)	4.2
Telling you what's going on	4.1
Action (getting changes made when needed)	4.1

The ratings in the table above are consistently high. Every type of contact was scored between Good and Very Good.

What Do Families Value the Most?

The last scored question on the Family Survey asked relatives to choose and rank the five things that are most important to them about their relative’s well being. We provided a list of 30 dimensions of quality. We used a weighted scale to score the results. If a dimension was selected as the most important (number one), it received five points, if rated second, four points, etc. The scores in the table below are the total number of points received for each dimension.

Five Most Important Things

Dimension of Quality	Total Score
Health	1064
Freedom from abuse	701
Safety	690
Medical attention	635
Comfort	620
Love	586
Dignity, respect	398
Family-like atmosphere	338
Home-like place	335
Control behavior	296
Permanence of home	287
Development, learning	230
Being kept busy	201
Stability	196
Productive day activities	179
Being with others like him/her	138
Self-care skill development	138
Communication	131
Self esteem	104
Exercise, fitness	74
Religion, worship	74
Assistive devices	61
Community acceptance	60
Working for pay	57
Earn money	49
Friends	45
Integration, inclusion	38
Travel, vacations	23
Large facility to live in	19
Girlfriends/Boyfriends	16

The scores above are presented in descending order, with the items receiving the most points at the top of the table. The families who responded to our survey felt that the five most important things for their relatives' well-being were health, freedom from abuse, safety, medical attention, and comfort. The five areas of concern that received the lowest scores from the family respondents were girlfriends/boyfriends, large facility to live in, travel/vacation, integration/inclusion, and friends.

Family Comments

The last two items on the Family Survey were open-ended questions, designed to elicit personal feedback and to provide relatives with a place to express concerns not addressed through other questions in the survey. The questions and a discussion of the answers follow. Verbatim answers to these questions are listed in Appendix D.

If You Had One Wish For Your Relative, What Would It Be?

This question about wishes is also included in the PLQ survey and always generates interesting and often touching responses. The relatives who responded to this survey were fairly consistent in their choice of wishes.

Many wishes referred to their relatives' disability, including:
I wish he could communicate with me……A cure for autism……That he could speak……To be free from seizures…That she could be comfortable and free of pain……Better health.

Another frequently selected wish category was related to care and stability:
That her days be filled with activity and caring people……These good times continue……Kept safe from harm……Permanent safe situation……That his care taker can live as long as him……I wish he had remained in a larger institution where he would be safe and comfortable for the rest of his

life……That he can remain in the place he's living……That the people who work with my brother are filled with love and compassion.

Many families expressed the wish that their relative could live with them, or at least live closer to them:

To come home with her family……To have her with us……To come back home to live with me……To be re-united with family……I wish she could be closer to my home so I could make regular visits……That she could live at home with me……To live even closer to me……Come home.

A few respondents wished that their relatives were still living in developmental centers:

That she would be back at the developmental center because she lives too far away…… Return to (Developmental Center)

Finally, many family respondents expressed the wishes that all parents and relatives have for those they love:

To be happy……Just be loved……I hope that he is loved and feels it and that he is happy……Peace and happiness……A long happy life……To know he is loved……Be happy and content.

The last question on the family survey offered relatives the chance to communicate directly with state officials who will be reading this report.

Is There Anything You Would Like Us To Tell State Officials About Your Relative's Situation?

The family responses to this question indicated a concern not only for their own relatives but for other people with disabilities, for caregivers, and the system in general.

More than twenty respondents used this item to express their thanks for the support provided to their family member. Samples include:

Thank you for taking care of him……I would like to thank state officials for providing a system for those unable to do for themselves……Just thankful that he has loving people taking care of him……We are eternally grateful to the state of California for the wonderful care and love……I express gratitude.

Many relatives chose to communicate with state officials regarding staff wages and overall funding issues. Following are selected comments on this point:

Funding for community living should be increased……Tell them do not cut the fund. These people need help……Higher wages for staff and quality of life would much improve……Pay staff a livable wage and treat them like a professional with full benefits……More money is needed for better care……Please keep funding programs.

Finally, relatives expressed their positive and negative opinions about the quality of care for their relatives. There were more positive than negative comments. Following are some examples:

The program or home he's in now is the best thing that ever happened to him……We are fortunate to have gotten our child into an excellent placement, believe more homes like this one should be available…... There is a shortage of quality care homes……This care home is the best thing to happen to him, he is a real person and treated that way……They are great care providers. I have no worries now…… My sister seems to be thriving……I hate how there is always a change in staff…… I know that's a problem everywhere……Work programs are limited……Make sure homes are safe……Continue careful screening of caregiver……Less regulation paperwork for providers, so more time can be spent with consumers……Be very careful placing individuals in the

community……I would like better communication from the group home…… Maintain standards in group homes and check them out.

Results 2: Pre-Post Results for 179 Movers

Pre-Post Results: "Before and After" Qualities of Life

The central question of any evaluation of a social intervention is "Are the people who received the intervention better off?" In the case of California's recent deinstitutionalization initiative under the terms of the Coffelt settlement, this question is very appropriate. California's stakeholders deserve to know whether the people who moved from Developmental Centers (DCs) to community homes from 1993 to the present are better off, worse off, or about the same --- and, it is important to know in what ways and how much.

The "Pre-Post" Design

In prior reports, we approached these questions in several ways, with several designs.[7] First, we used matched comparison, to test whether "similar" Movers and Stayers experienced different qualities of life (Reports 2 and 3 of the first series of 20 Reports). Second, we used analysis of covariance to mathematically control for differences between Movers and Stayers, and then to test for differences in quality between the groups (Report 10). Third, we used "before and after" or "pre-post" measures of qualities of life for a group of people when they were still in DCs back in 1994, and again when they were out in their new community homes (Reports 7, 12, and 17 of the first series).[8]

---

[7] The ideal research design, as noted by Campbell (1969), would have been random assignment to "treatment" and "control" groups. Naturally, this was not feasible, because program implementers felt they should select people for placement according to their characteristics and perceived potential for community living, their wishes, and the wishes of their families.

[8] In a "fourth design," we surveyed the closest relatives, guardians, and conservators each year to obtain their opinions about comparative quality back at the DC and in the community.

What made this "pre-post" design possible was a decision we made back in 1994. Although not originally mandated by the Court or by DDS, we contended that we needed to collect "baseline data" for as many people as possible before they left DCs. We requested permission from Court representatives and DDS officials to rework our study designs so that we could immediately visit as many DC residents as possible, and it was granted. Hence, back in 1994, we conducted data collection visits with as many DC residents as resources would permit. We visited 839 individuals in DCs, selected purely at random from the more than 5,000 DC residents.[9]

This decision provided DDS and COA with a crucial advantage. For any of those 839 people who later moved out of DCs, we would then be able in any future year to measure any changes in the qualities of their lives, compared to when they lived at a DC.

If we had not collected this "baseline data" on quality of life for people in the DCs at the beginning of this social change, we would never have been able to answer the most fundamental and important questions: ***"Have the qualities of these peoples' lives changed, and if so, in what ways, in what direction, and how much?"***

This year, we completed more than 2,100 visits with Movers (people who once lived in a DC, but moved to the community). Included in that number, by pure random sampling, are 179 of the people who had been visited at their previous DC homes back in 1994. These 179 people are the topic of this chapter. We can now examine what, if any, qualities of their lives have changed since community placement.

---

[9] 15% Simple random sample drawn by DDS statistical program.

Limitations of the Pre-Post Design

The number of people in the analysis, 179, is definitely 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 smaller number of people who moved from institution to community (70). Many other published articles have relied on considerably smaller sample sizes.[10] For reference, the "sampling margin of error" for 179 out of 2218 people is, in the very simplest case, calculated as plus or minus 7%. This meets most professional standards for sample size and precision.

However, the 179 Movers who were in our original baseline of 839 people may have had different characteristics than the 660 other people who remained in DCs. If so, this would limit our ability to generalize from the 179 to all the remaining people in DCs. In plain language, what has been observed to be true for the Movers so far may or may not be what is true for any future Movers. This will depend in part on whether the current Movers are "similar to" the future Movers. As we found in the comparison of the 191 Movers with the 648 Stayers in Report 4, when we compare the 179 Movers in 2002 with the people who were in DCs in 1994 there was at least one significant difference between the 179 Movers in our sample and the 660 "potential future Movers" (in other words, the 660 Stayers). This difference, again, was a difference of approximately 9 points on adaptive behavior scale scores.

Thus the Movers in our sample of 179 people for the present report were initially somewhat higher in self-care abilities and independent functioning than the Stayers, by about 9 points on a 100 point scale. Again, we think the proper

---

[10] For example, see Aanes, D., & Moen, M. (1976). Adaptive behavior changes of group home residents. *Mental Retardation, 14,* 36-40.

conclusion is that our findings about these 179 Movers should be interpreted as generalizable with caution. That is, what we find about the experiences of these 179 Movers over the past 8 years would likely have been similar for the other 660, if they had moved. However, this is not certain, and in some areas of quality, outcomes might have been different. In the text above, we have simply emphasized that we must be very careful about generalizing findings from one group to all kinds of other groups.

In addition to the above caution about generalization, the pre-post design suffers from another threat to validity. The pre-post design by itself does not answer the question "How do we know the Stayers haven't experienced the same kinds of changes in qualities of life as the Movers?" With the pre-post design by itself, the answer is that we don't. There is no "control group." A valuable addition to this study would be to conduct visits with the people who continue to live in Developmental Centers, the "Stayers", particularly the 660 people that we visited in 1994. This additional data would allow us to track their progress since 1994 and to compare it to the "Movers".

It is true that our past matched comparison and covariance designs did shed light on that issue, with the inference that the Stayers did not show similar changes. Nonetheless, it needs to be said that the analyses in this Chapter by themselves are vulnerable to several threats to validity, even though these threats have already been diminished by other designs in the present body of work.

What Kind of Community Homes Are the 179 Movers Now Living In?

The 179 people moved into the types of community settings shown in the table below.

Current Homes of 179 Pre-Post Movers

Type of Home	Number	Percent
ICF/DD >15 BEDS	1	0.6
SKILLED NURSING FACILITY	2	1.1
PRIVATE FACILITY >15 BEDS	1	0.6
ICF/DD 4-15 BEDS	1	0.6
ICF/DD-N 4-6 BEDS, NURSING	42	23.5
ICF/DD-N 7-15 BEDS, NURSING	1	0.6
ICF/DD-H 4-6 BEDS, HABILITATIVE	43	24.0
ICF/DD-H 7-15 BEDS, HABILITATIVE	2	1.1
CCF L2 STAFF	1	0.6
CCF L3 OWNER	4	2.2
CCF L3 STAFF	11	6.1
CCF L4-C/STAFF	1	0.6
CCF L4-D/STAFF	1	0.6
CCF L4-E/STAFF	1	0.6
CCF L4-F/STAFF	3	1.7
CCF L4-G/STAFF	14	7.8
CCF L4-H/STAFF	5	2.8
CCF L4-I/STAFF	28	15.6
ADULT FAMILY HOMES SB1730	2	1.1
SUPPORTED LIVING >21 HRS WK	9	5.0
SUPPORTED LIVING 0-10 HRS WK	1	0.6
INDEPENDENT LIVING	1	0.6
IN PARENT'S HOME	2	1.1
OTHER COMMUNITY SETTING	2	1.1
Total	179	100.0

The table shows that four of these Movers are currently living in a congregate care setting, i.e., the first three rows. Nearly 100 are in some variety of federally assisted Medicaid ICF/MR setting. The rest are in a diverse set of community settings, with the preponderance in small community care facilities that receive federal financial assistance through the Medicaid Waiver. This general pattern reflects the fact that nearly all of the Coffelt Movers went to settings that were assisted by the federal Medicaid program --- about half via ICF/MR and about half via Waiver.

Outcomes Summary

For the quantitative part of our work, we visited hundreds of people with disabilities, interviewed hundreds of staff members, reviewed records, and toured homes and day programs. The data permitted us to analyze more than 700 items of information for each person. Most of these items were combined into scales for ease of interpretation.

For example, there were 16 items on "getting out" and going on outings. The 16 items were combined into a single scale of how many times each person went out into integrated settings each month. This produced a simple measure of "how often people got out each month." If this measure increased between 1994 and 2002, then we would conclude that the level of "integrative activities" increased. That would be a positive outcome, insofar as reduced segregation is viewed as a good thing. For the Quality Tracking Project, we collected a series of measures related to quality of life and therefore to outcomes.

The table below presents a summary of results for a variety of important quality and outcome indicators for the 179 Movers.

Summary of Outcomes
For 179 Movers

Quality Dimension	Pre	Post	Change	Outcome
Progress Reported Toward IP Goals	45.7	77.0	31.3	Positive
Number of Services in Individual Plan	6.1	9.0	2.9	Positive
Hours of Day Program Services	23.7	28.4	4.7	Positive
Earnings	5.20	2.54	-2.66	Negative
Number of Close Friends Reported	3.3	2.3	-0.9	Negative
Integration	14.0	27.2	13.1	Positive
Qualities of Life Ratings (Now 1994-Now 2002)	71.4	80.2	8.8	Positive
Staff Job Satisfaction	8.8	9.3	0.5	Positive
Staff Like Working With This Person	8.3	9.5	1.2	Positive
Staff Get Sufficient Support	4.1	4.6	0.5	Positive
Number of Daily Medications	4.8	5.2	0.4	Not Signif.*
Number of Psychotropic Medications	0.4	0.4	0.0	Not Signif.*
Health by Days Ill Past 28	0.5	0.7	0.2	Not Signif.*
Perceived Quality of Health Care (Staff responses)	4.7	4.3	-0.3	Negative
Doctor Visits Per Year	37.4	14.9	-22.5	Unclear
Dental Visits Per Year	2.3	1.7	-0.6	Negative
Relative Visits Person Here At This Home	11.6	9.0	-2.7	Not Signif.*
Individualized Practices Scale	61.7	69.5	7.9	Positive
Adaptive Behavior	44.8	45.3	0.5	Not Signif. *
Challenging Behavior	68.0	78.3	10.3	Positive
Choicemaking	31.7	45.8	14.1	Positive

* "Not Signif." means the change did not attain statistical significance at the .05 level by Paired t-test and is therefore not labeled as either positive or negative.

For each quality dimension in the table above, we have presented the average score for Movers on that dimension prior to the move (in the column headed "Pre"). The column headed "Post" shows the average score in 2002, after moving into the community. Next, the column headed "Change" shows the average number of points of change that occurred in each dimension.

Since many of these dimensions are measured on different scales, the amounts of change cannot always be compared directly. Therefore each dimension will be discussed individually below.

The final column headed “Outcome” shows whether the change in each dimension was positive or negative; that is, whether each represented an improvement or a decline in quality of life. Any findings that did not reach statistical significance are labeled “Not Signif.,” meaning that we are unable to conclude that any real change occurred. The label “Unclear” means that the direction of the change cannot be obviously identified as positive or negative, e.g., are 13.5 doctor visits per year “worse” than 34.4, or are 34.4 visits excessive? A coherent argument can be constructed that 13.5 visits, on the average, shows sufficient access to health care and is not “worse” than 34.4. The opposite argument can also be made. Hence our conclusion is “Unclear”, and the reader may draw his or her own inference on such an outcome.

The table above lists outcomes for 21 quality dimensions that were compared from the pre (DC 1994) to post (community 2002) visits. There are 11 significantly positive outcomes, 4 significantly negative outcomes, 5 outcomes that are neither significantly positive nor negative and 1 outcome for which the comparison is unclear. In other words, for these 179 Movers, quality of life improved in half the ways measured, got worse for one seventh of the ways measured, and did not change for about a third.

In summary, the Table data support the inference that people’s lives have improved in more than three times as many dimensions as they have declined. This leads to the conclusion that, at least for these 21 indicators of quality, moving out of institutions allowed these 179 people, on the average, to experience improvements in many qualities of their lives.

Following are individual explanations and implications for each of the 21 indicators of quality.

Progress Reported Toward Individual Plan Goals

For each of the top five goals in each person's Individual Plan, we asked "Has there been any progress toward this item in the past year?" Responses are given on a five point scale: Major Loss, Some Loss, No Change, Some Gain, Major Gain. These five point scales are combined across the five goals, and we construct an overall scale of progress toward goals. This overall scale is computed so that it can potentially range from 0 to 100.

As the table shows, the respondents at the DCs produced an overall scale score of 45.7 back in 1994, which can be interpreted as an average perception of a little below "No Change". In the community in 2002, the average rating was 77.0, which can be interpreted as an average perception of a little above "Some Progress". The difference is large. Since staff of the residences almost always answered these items, it can safely be concluded that community staff believe they are seeing a lot more progress than did institutional staff back in the DCs.

The proper conclusion is that these 179 Movers are "better off" than they were back in the DCs in terms of making progress toward the goals in their Individual Plans.

Number of Services in Individual Plan

The Personal Life Quality protocol (PLQ) contains a checklist of 15 traditional therapies, training programs, services, and supports that might be delivered via the residential program. The number of services for these Movers increased from 6.1 at the DCs in 1994 to 9.0 in the community in 2002. The increase of 2.9 services was statistically significant.

The proper conclusion is that these 179 Movers are receiving a wider range of services and support than they were back in 1994 at the DCs. Since we did not measure amount of services, however, we cannot comment on how much of each such service is being provided.

Hours of Day Program Services

We collected the number of hours per week of each of 17 types of day activities, from self-employment to community experience to school. The average number of hours of day program services of all types increased from an average of 23.7 hours per week back at the DCs to 28.4 hours per week in 2002 in the community. This increase of 4.7 hours is significant.

We conclude that community placement appeared to be related to a greater number of hours per week that people spend in some kind of "productive activity".

Earnings

Comparison of average weekly earnings back at the DC to earnings in the community reveal a decrease, which is statistically significant. The average amount in the DCs in 1994 was $5.20 per week, and the average amount in the community in 2002 is $2.54. Both of these figures are so low that they should engender a statewide discussion of the potential role of work and income generation for all Californians with developmental disabilities, whether in DCs or the community.

In Report 2 of this series, we found the same result. For the 178 Movers who were included in that analysis, average weekly earnings dropped from $4.80 in the DCs to only $1.60 in the community. That drop was statistically significant. Now, two years later, the significant decrease in earnings is still present.

As we have consistently stated in Reports 2, 3, 8, 12, and 18 of the previous series, and Report 2 of this series, the data support the strong conclusion that California's community services system is sorely in need of attention to supported and competitive employment options, and to more innovative options for generation of income such as micro-enterprises.

Number of Close Friends Reported

In 1994 in the DCs, and in 2002 in the community, we asked people how many "close friends" they had. The answers were usually given by whoever knew the person best. We did not define "close friends" for the respondents, we asked them to use their own definitions. Hence this item must be considered to be largely subjective as an indicator of quality of life.

From 1994 to 2002, the average number of close friends reported fell from 3.3 to 2.3. The decrease of 1.0 was statistically significant.

Friendships are rapidly becoming recognized as a very important dimension of quality, and one that has often been under-emphasized or even ignored by traditional human service systems. Hence this negative finding should be interpreted to be an important one. We suggest that friendships, relationships, and community connections might be considered as a dimension for close monitoring by families, service providers, regional centers, advocates, and also for policy makers in DDS, the legislature, and the judiciary.

In Reports 2 and 4 of this series, we also detected a drop in the average number of close friends from DC to community. The drop in Report 2 was not statistically significant; however, by Report 4 measuring from 1994 to 2001, the decrease had become significant, and in the present report we see that trend continue. This suggests that some of the loss of friends may have taken place over the past year or two within the community. If so, that would be a very important finding, pointing to a rather urgent need to help people maintain and/or extend what relationships they have.

We suggest that the nature and depth of human relationships is an area in need of urgent concern and further investigation. Further investigations should study the proportion of friends in 1994 and in 2002 who were paid and unpaid, and friends with and without disabilities. A study of those variables and others such as levels of retardation, age, gender, and living arrangement may help to explain the drop in close friends that we have detected.

Integration

Our measure of Integrative Activities is simply a count of "how many times the person went out" and went to places where any citizen might go. The Movers increased their levels of integration from 14.0 to 27.2, indicating an additional 13 community events per month. This near doubling of integrative activities was statistically significant.

Although integration is an expected result of movement to the community, this outcome is strong evidence that the Movers have sharply increased their opportunities to go to places in which they are in the presence of citizens without disabilities. Insofar as integration is a fundamental value in supporting people with disabilities, and a prominent issue in the Coffelt Settlement, this is a major outcome.

For future investigation, we would recommend a full analysis of the integrative activities in relation to the close friends scale and the individual goals. Such a simultaneous investigation might yield more insight about complex relationships among Individual Planning, relationships, and community activities. The present database is sufficiently rich to permit such a thorough analysis.

Qualities of Life Ratings (1994 and 2002)

The measures in this study include a scale of perceived qualities of life. Fourteen dimensions of quality of life are addressed including health, friendships, safety, comfort, etc. The person, or whoever knew the person best, gave numeric ratings of the person's qualities of life at the developmental center. (Back in 1994, there were only 10 dimensions of quality in the scale, so only 10 of the 14 can be compared pre and post.) In subsequent interviews, the person, or whoever knew the person best, gave ratings of the same qualities of life.

We compared the ratings given by people and/or DC staff back in 1994 to those given by people and/or community staff in 2002. (The overall 100-point scale for this analysis was composed of only the 10 items used in 1994, to keep the scales comparable in 1994 and 2002). The average score increased from 71.4 to 80.2, for an increase of 8.8 points which was highly significant statistically. This indicates that the Movers, or the people closest to them, perceived lower quality of life back in the DC in 1994, and considerably higher qualities of life in the community in 2002.

To reveal the largest perceived changes, we broke down the scale into its component items. The table below shows the results, sorted by the size of the change.

Perceived Qualities of Life Reported by Person or Closest Others, Pre-Post

Life Area	"Pre" at DC 1994	"Post" in Community 2002	Change	Significance
Food	3.6	4.3	0.7	0.000
Seeing friends	3.2	3.9	0.7	0.000
Comfort	3.9	4.6	0.6	0.000
Getting out and around	3.5	4.1	0.6	0.000
Running own life	3.2	3.8	0.6	0.000
Family relationships	2.7	3.3	0.6	0.000
Happiness	3.8	4.3	0.5	0.000
What I do all day	3.7	4.2	0.5	0.000
Safety	4.2	4.7	0.5	0.000
Health	3.9	4.2	0.3	0.000

The table shows that 10 out of 10 dimensions of quality of life were rated higher in the current community homes than they were back at the DCs. The largest difference was in quality of food. The next largest differences were in seeing friends, comfort, getting out and running my own life.

It is worth noting that the perceptions of health and safety went up as well. This may be a surprise to those who believe that living in the community carries with it a price to be paid in terms of diminished health and safety. These 179 Movers, and those closest to them, clearly do not agree with that contention.

The one element that did not change significantly in our analysis in Report 4 last year was relationships with family. We speculated that those who had involved family members while at the DC continued to have them in the community, and those who did not have involved family members did not acquire them. We see this year in this report that even this dimension of quality has shown a significant increase.

The proper conclusion from this is that the people and/or the staff closest to them reported their perceptions of quality back at the DC, and again 8 years later in the community – and the community ratings were considerably higher. These data strongly support the inference that the Movers are "better off" in their own eyes and the eyes of those close to them.

Staff Job Satisfaction

A critical factor in rating the quality of life in residential programs is staff. Do they like their jobs? Do they like working with this person specifically? Do they feel they receive sufficient support from administration to do their jobs effectively?

For "How much do you like your job?" on a scale of 1 to 10, the average response from developmental center staff in 1994 was 8.8 and in the community in 2002 it rose to 9.3. Community staff like their jobs more than did developmental center staff. This difference was significant.

Staff Like Working With This Person

The question "How do you feel about working with this person?" is believed to be very important for people with disabilities. Staff who like their jobs, and who like working with the individual, would seem likely to render better support.

On a scale of 1 to 10, the developmental center staff score averaged 8.3 in 1994, and the community staff was significantly higher at 9.5 in 2002. Community staff report enjoying working with each specific person significantly more than did the developmental center staff. We think the proper conclusion is that relationships with close staff members are better in the community than they were back at the DCs for these 179 Movers.

Do Staff Get Sufficient Support?

When asked “Do you feel you receive sufficient support from administration to do your job?” the staff responses were fairly high in both settings. On a 5-point scale, the response was 4.1 from developmental center staff and 4.6 from community staff. Although both groups reported feeling supported, the ratings were higher in the community than they were in the developmental centers. The proper conclusion is that current community staff feel more supported in 2002 than did DC staff back in 1994.

Number of Daily Medications

The average number of medications (including vitamins, minerals, and special supplements) administered daily stayed essentially the same, going from 4.8 to 5.2. This was not a statistically significant change (0.4). Incidentally, detailed analysis shows that the average number of “digestive, stomach, and bowel” medications has decreased significantly. This may be an indication of a change in dietary habits and medical management practices.

Number of Psychotropic Medications

The number of psychotropic medications remained the same. However, we must point out that, in a sense, this is a positive finding because in our early studies, we found that the people who moved out of DCs in the mid-1990s actually experienced increases in psychotropic medications. This suggested that the community medical system was overmedicating people, perhaps out of lack of experience. Now we conclude that the 179 Movers are experiencing about the same probability of being given psychotropics in the community as they were in the DC.

Health by Days Ill in Past 30 Days

Another method used to measure general health is taken from national health surveys: "Number of days of restricted activity because of illness within the past 30 days." This health quality indicator did not change significantly, indicating that people's general health had neither improved nor diminished.

Quality of Health Care

The responses to the question "Overall, how good is the health care this person is getting?" revealed a negative and significant difference. Because this dimension was rated on a 1 to 5 scale, both the answers from 1994 in the DCs (4.7), and the answers from 2002 in the community (4.3), lie in the "Good" to "Excellent" range. However, the average rating in the community is significantly lower than the average rating back at the DCs.

One potential explanation for the decrease in the perceived rating of health care is problems with locating specialists and doctors in the community who have experience in working with people with disabilities. This is an area that has begun to be monitored closely via various DDS policies and actions, such as the Wellness Initiative. We interpret our finding as evidence that this attention to health care in the community needs to continue.

Doctor Visits Per Year

The Movers' number of doctor visits per year decreased sharply from 37.4 in the DC in 1994 to 14.9 times per year in the community in 2002. This pattern has been documented as fairly standard in moves from institutions to the community.[11] However, the fact that they saw the doctor 22.5 less times in the

---

[11] Hayden, M. F., & DePaepe, P .A. (1991). ***Medical conditions, level of care needs, and health related outcomes of persons with mental retardation: A Review***. Journal of the Association of Persons with Severe Handicaps, 16(4),

community does not necessarily mean that either their health care or general health was negatively affected. There is no evidence from any of the data that people in the community need to see doctors more often than 14 times a year. We therefore interpreted this finding as neither positive nor negative, but rather "Unclear."

Dental Visits Per Year

The Movers' number of dental visits per year decreased, from 2.3 to 1.7. Because the dental profession recommends 2 visits per year, we interpret the significant decrease as a negative finding. (Although the 1.7 times per year rate is believed to exceed the frequency of visits to dentists by the general public.)

Relative Visits Person Here At This Home

The frequency of family contacts decreased from 11.6 to 9.0 per year. This was not a statistically significant change. Again, this might be interpreted as "those that had family contacts in the DC continued to have them; those that had no family contacts did not acquire them."

Individualized Practices Scale

This scale lists 15 items that are related to staff management practices, and it is designed to reveal the extent to which people are treated as individuals versus a management style in which "the same rules apply to everyone". The scale tends to reflect people's opportunities to engage in non-group activities and their options for making independent scheduling decisions within a group living arrangement.

188-206.

The Movers increased their score on this quality dimension from 61.7 to 69.5, and this increase of 7.9 points on a 100 point scale was statistically significant and larger than the increase reported in Report 4 of this series which was an increase of 5.8 points.

The topic of individualized supports may benefit from further investigation, because similar deinstitutionalizations in several other states have been associated with larger enhancements of individualized practices. A much larger increase on the Individualized Practices Scale occurred recently among 183 Indiana citizens who moved out of Developmental Centers. The Indiana Movers showed a statistically significant gain of 25 points on the Individualized Practices Scale after one year of life in the community.

Adaptive Behavior

From 1994, when these Movers lived in Developmental Centers, to 2002 in the community, there was an increase on the Adaptive Behavior scale from 44.8 to 45.3, or about half a point on the CDER's 100 point scale. However this increase was not statistically significant. It is therefore best interpreted as no change.

Another way to attempt to interpret the adaptive behavior data is to compare it with parallel data from other states.[12] The table below shows the adaptive behavior results from several studies conducted by this research group.

---

[12] As far as we are aware, only COA possesses a national database that permits such cross-state comparisons.

Adaptive Behavior Results From Several Deinstitutionalization Studies

State	# of Years	Time-1 Average Adaptive Behavior Score	Time-2 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
California	**8 years**	**44.8**	**45.3**	**0.5**
Oklahoma	6 years	41.3	47.4	6.1
Connecticut	5 years	49.5	54.0	4.5
North Carolina	2 years	52.7	54.8	2.1
Kansas	1 year	33.1	34.8	1.7
Indiana	1 year	48.1	50.2	2.1

At this point, the California experience is unusual. Nearly all past studies of deinstitutionalization found significant increases in adaptive behavior. Now, in California, that is not the case.

This finding may generate discussions and consideration of the goals of services in California under the Lanterman Act. In one passage, the Act notes the importance of increasing independence among service recipients:

> The Legislature finds that the mere existence or the delivery of services and supports is, in itself, insufficient evidence of program effectiveness. It is the intent of the Legislature that agencies serving persons with developmental disabilities shall produce evidence that their services have resulted in consumer or family empowerment **and in more independent, productive, and normal lives** for the persons served.[13]

Thus, services that help people become progressively more independent are certainly desirable. Yet in our work with the California Movers, we have

---

[13] Section 4501.

documented very strong positive outcomes in other areas, such as reduction of challenging behaviors and increased opportunities to participate in life choices.

Challenging Behavior

This dimension was measured according to the person's ability to control challenging behavior and so a higher score is a positive outcome. The 10.3 point increase in our current pre-post analysis is very high and is statistically significant.

It is possible that the apparent cessation of adaptive behavior growth and the major improvement with regard to challenging behavior are related. Programs that focus on adaptive behaviors are often more formal and regimented. In contrast, state-of-the-art programming for people with challenging behaviors relies more on prevention and positive reinforcement to produce safe and nurturing environments. The data on these two dimensions appear to support the hypothesis that the community programs for these 179 Movers have been designed to meet their specific needs in these areas. This is an area that should be investigated further.

Before leaving the challenging behavior dimension, it is important to underscore the fact that California's Movers appear to have experienced the largest improvements ever documented in such research. The following state comparison table shows this fact.

Challenging Behavior Results From Several Deinstitutionalization Studies

State	# of Years	Time-1 Average Challenging Behavior Score	Time-2 Average Challenging Behavior Score	Gain on 100 Point Scale
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
California	**8 years**	**68.0**	**78.3**	**10.3**
Oklahoma	6 years	89.7	93.5	3.8
Connecticut	5 years	79.0	80.2	1.2
North Carolina	2 years	87.7	89.4	1.7
Kansas	1 year	78.6	81.3	2.7
Indiana	1 year	70.5	67.9	-2.6

The proper conclusion is that these 179 Movers are far better off now, in the community, in terms of being able to control their own potentially challenging behavior.

Choicemaking

The scale for measuring opportunities for choicemaking is called the Decision Control Inventory. It is composed of 35 ratings of the extent to which minor and major life decisions are made by paid staff versus the focus person and/or unpaid friends and relatives. Each rating is given on a 10 point scale, where 0 means the choice is made entirely by paid staff/professionals, 10 means the choice is made entirely by the focus person (and/or unpaid trusted others), and 5 means the choice is shared equally. This is the same scale being used by the Robert Wood Johnson Foundation in its National Evaluation of Self-Determination in 29 states. In fact, the scale was originally created by COA in order to measure the impacts of self-determination in people's lives.

Choicemaking opportunities as measured by the Decision Control Inventory increased from 31.7 points back at the DCs in 1994, to 45.8 points in the community in 2002. This increase of 14.1 points was highly statistically significant. And it was large. The average gain among California's self-determination participants, 1999 to 2002, was 5.3 points.

This positive outcome may reflect major differences between institutional and community life. The Movers, despite their levels of disability, have shown a consistent pattern of growth in their ability and opportunity to make choices, with the support and assistance of valued friends and allies. This outcome may also be an indication of provider and staff commitment to independence as a valued goal.

The table below shows the changes in the individual items of the Decision Control Inventory, sorted by magnitude of change.

Analysis of Changes in Decision Control Inventory Items From 1994 to 2002

Life Area	Pre in DC 1994	Post in Community 2002	Change	Significance
What to have for breakfast*	2.0	4.8	2.8	0.000
What to have for dinner*	2.0	4.7	2.7	0.000
Choice of house/apartment*	0.6	3.3	2.7	0.000
What food to buy*	0.8	3.5	2.7	0.000
What clothes to buy*	2.9	5.1	2.2	0.000
Whether to have a pet in the home*	1.1	3.3	2.2	0.000
Choice of places to go*	2.7	4.8	2.1	0.000
When to go to bed on weekdays*	4.5	6.6	2.1	0.000
Choosing restaurants*	2.1	4.0	2.0	0.000
When to go to bed on weekends*	5.5	7.2	1.7	0.000
Time and frequency of bath*	2.6	4.3	1.7	0.000
What to do with relaxation time*	6.1	7.8	1.7	0.000
When to get up on weekends*	5.8	7.4	1.6	0.000
Visiting with friends*	3.6	5.1	1.5	0.000
Choice of case manager*	0.6	2.0	1.4	0.000
Minor vices*	3.3	4.6	1.3	0.001
Choice of people to live with*	1.4	2.6	1.3	0.000
Express affection*	5.1	6.2	1.2	0.003
Transportation to/from day program/job*	0.8	2.0	1.1	0.000
Type of work or day program*	2.5	3.5	1.1	0.000
Taking naps in evening*	6.9	7.9	1.0	0.004
Choice of service agency*	1.1	2.1	1.0	0.001
Choice of support person/staff*	1.2	2.0	0.8	0.006
Amount of time spent working*	2.3	3.1	0.8	0.016
Choosing to decline activities*	7.4	8.2	0.8	0.020
What to do with personal funds*	4.3	4.9	0.6	0.034
What clothes to wear on weekdays*	4.9	5.5	0.6	0.042
Choice of furnishings/décor	2.8	3.3	0.5	0.083
What clothes to wear on weekends	5.1	5.5	0.4	0.124

*Indicates statistical significance at the .05 level.

All 35 dimensions of the Decision Control Inventory show increases from 1994 to 2002, and 33 of the 35 were statistically significant. The only non-significant changes were in the choice of furnishings or décor for the home and the choice of what clothes to wear on weekends. The areas which showed the largest increases for these 179 Movers in California from 1994 to 2002 were: what to have for breakfast, what to have for dinner, choice of house or apartment, what food to buy and what clothes to buy.

This strong positive outcome is related to one of the principal mandates of the Lanterman Act:

> Consumers of services and supports, and where appropriate, their parents, legal guardian, or conservator, should be empowered to make choices in all life areas.[14]

The Decision Control Inventory is a direct and reliable measure of the extent to which people and their unpaid allies are participating in making major and minor life choices. The 14 point gain on this scale should be viewed as one of the strongest and most important positive outcomes of deinstitutionalization in California.

Personal Interview

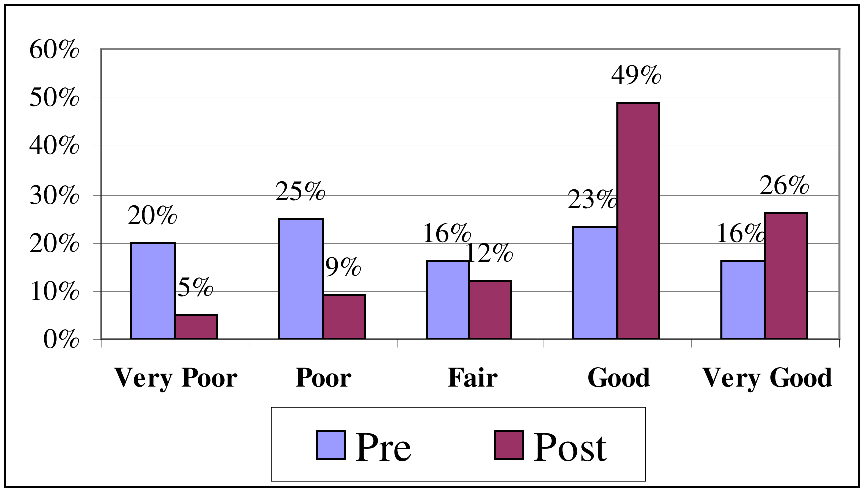
We asked the individuals with developmental disabilities a series of questions designed to measure their feelings about the quality of their lives. The Personal Interview section of the Personal Life Quality (PLQ) protocol can only be answered by the person with a disability themselves; in this section we allow no surrogate responses. One of the most important issues involved in the deinstitutionalization movement is the feelings the individuals themselves have about their lives and their living arrangements.

The graph below illustrates the feelings of the people we interviewed when we asked them how they liked where they were living back in 1994 in the DC, and when we asked the same question in 2002 when they were living in the community.

---

[14] Section 4501.

1994 (DC) and 2002 (Community) Responses to Personal Interview Question "How Do You Feel About Living Here?"



The graph makes clear the shift in consumer satisfaction with their living arrangements, with large percentages of people who felt "very poor", "poor" and "fair" about their living arrangements in 1994 shifting to feeling "good" and "very good" about their living arrangements in 2002. In many ways, this information could be seen as being the most important finding of this section. The people who are most affected by deinstitutionalization say that they feel more satisfied with their community homes in 2002 than they felt with living in the DCs in 1994. It is also interesting to note the changes in the wishes of the Movers that were reported in 1994 and the wishes reported in 2002. In 1994, there were 30 wishes that involved wanting to move out of the Developmental Centers, whether that be moving in with family or with roommates, or living independently. These types of wishes were by far the most frequently reported wishes. In 2002, the wishes range from getting married and having children, to going on vacation, to getting more satisfying and higher paying jobs. In fact, there are only three wishes in 2002 that reflect wanting to move at all, and those three involve the wish to move into more independent situations. Clearly, the people themselves feel they are “better off” in their current living situations in the community than they did in 1994.

Results 3:
Positives and Negatives from the Quality Feedback Summaries

Following each visit, COA Visitors are trained to complete the Quality Feedback Summary (QFS) form. A copy is included here as Appendix E. This device was designed in 1997 via a process that included broad input from advocacy agency, Regional Center, and DDS personnel. A Work Group was convened and the question was:

> ***Given that COA staff are going to visit and collect extensive data for more than 2,000 people in the next several months, exactly what things (both positive and negative) should be reported back to the Regional Centers directly after each visit?***

The Working Group studied this question and selected which situations related to service and life quality needed to be reported quickly to the Regional Centers. After this initial Working Group determination, field tests and revisions took place. Since 1997, several rounds of minor revisions have occurred, each time intended to make the form easier to use and to understand.

The QFS was designed as a "tickler" or "flag" system. Its purpose was to provide, not findings of fact or "deficiencies," but rather "reminders" or "flags" for further scrutiny. The spirit in which the system was designed and implemented was that the COA Visitors could identify situations that might benefit from a "second look" by a case manager, a Regional Center specialist, the family, or the vendor.

The QFS was not punitive --- in fact, it was designed intentionally to include reporting of good, high quality items. Thus the QFS was set up to quickly report situations of concern to Regional Centers and to identify items of excellence for recognition and possible replication.

In essence the QFS was a "flag" system for things that might be important for Regional Centers to know about, study further, and perhaps take action.

An example of a situation that the Working Group deemed "important" and worthy of rapid feedback to the Regional Center was from page 24 of the Personal Life Quality protocol:

Item 14. PLAN'S USEFULNESS is rated as 1, Not At All Useful (Positive: 5, Extremely Useful)

That is, if the person (or the front line people who worked with the person) said the person's Individual Plan was useless, then the Regional Center would find that out right away.

In all, the QFS contains 37 such "reportable" negative situations. It also contains 11 positive items, such as the finding that perceptions of qualities of life are significantly higher than they were in the past.

The QFSs are like individual "report cards" covering matters believed, by consensus of the Working Group, to be very important. The QFS is a convenient way to summarize selected critical findings from each Personal Life Quality protocol, and to forward that information to Regional Centers for action. (A copy of each QFS also went to DDS.)

Origin of the Quality Feedback Summary System

The QFS process was designed to address the following particular part of the legislation that authorized this project:

> (g) If the contractor identifies any suspected violation of the legal, civil, or service rights of an individual, or if the contractor determines that the health and welfare of the individual is at risk, that information shall be provided immediately to the regional center providing case management services, the client rights advocate, and to the department.
>
> (h) The department shall monitor the corrective actions taken by the regional center and maintain a report in the person's file. The consumer and, when appropriate, his or her parents, legal guardian, or conservator, shall be provided with access to the person's file and be provided with copies of all reports filed with the regional center or department relative to them.
>
> (From Welfare & Institutions Code 4418.1)

In fact, the QFS system goes beyond the requirement above. It actually gets at specific conditions of high and low quality, so that the service system can have a chance to make individual corrections when necessary, and to give rewards for good outcomes.

Quality Feedback Summaries Completed by Regional Center

For every person visited by the Quality Tracking Project, a QFS form is completed. In this project year, we received 2,220 QFS forms. They broke down by Regional Center as follows:

Number of Movers	Regional Center Abbreviation	Regional Center
221	CVRC	Central Valley RC
210	SARC	San Andreas RC
167	RCEB	East Bay RC
149	GGRC	Golden Gate RC
149	NBRC	North Bay RC
145	IRC	Inland East RC
131	KRC	Kern RC
122	TCRC	Tri-Counties RC
117	DDC (RCOC)	Developmental Disabilities RC (Orange County RC)
116	ACRC	Alta RC
94	SDRC	San Diego RC
85	VMRC	Valley Mountain RC
75	HRC	Harbor RC
63	FNRC	Far Northern RC
63	SCLARC	South Central L.A. RC
63	WRC	Westside RC
57	SGPRC	San Gabriel/Pomona RC
51	NLACRC	North L.A. County RC
49	FDLRC	Lanterman RC
49	ELARC	Eastern L.A. RC
44	RCRC	Redwood Coast RC
2,220		

This table reflects the numbers of Movers who went to each of the 21 Regional Centers. The largest number of people, 221, went to Central Valley RC. The smallest number, 44, went to Redwood Coast. The average Regional Center has brought 106 people out of Developmental Centers since the Coffelt settlement began in 1993.

Interestingly, the largest number of people moving from Developmental Centers to community homes was Central Valley Regional Center. This is interesting because Central Valley was not among the original four “Defendant

Regional Centers," the ones named in the Coffelt litigation (East Bay, Golden Gate, North Bay, and San Andreas). The legal pressure to bring people out was probably less intense for Central Valley than for the four Defendant Regional Centers. Yet Central Valley actually accomplished more placements.

Incidence of Negative Situations from the Quality Feedback Summaries

What were the negative situations or "red flags" most often observed in the community? The following table shows the 5 "red flags" that were observed and reported most often.

Number of People with Red Flags	Quality Indicator
1,118	Item 8. None of the PLANNING PARTICIPANTS are invited or unpaid
455	Decision Control Inventory: All or nearly all (25 plus) of the ratings are below 5.
302	Item 10 PRESCRIBED DAILY MEDICATIONS: Person is receiving 3 or more medications for which the purpose is described as either 1 (Control of Psychiatric Symptoms) OR 2 (Behavior Control, Calming).
155	Integrative Activities During the Past Month: Person got out fewer than 5 times total in the past month
149	Item 18. ACCESS TO TRANSPORTATION: Answer is "0," person could never go somewhere on the spur of the moment

The most common "red flag" situation was that the person had no unpaid people involved in the individual planning process. This happened for 1,118 out of 2,220 people. Recommendations for unpaid involvement in individual planning originally arose from modern thinking about self-determination and possible conflicts of interest for paid planning participants. For each person visited, the COA Visitor completed this matrix:

8. PLEASE CATEGORIZE THESE CURRENT **PLANNING PARTICIPANTS**:

Number of Paid Personnel	**Number of Unpaid Relatives**	**Number of Unpaid Non-Relatives**	
8A __________	8B __________	8C __________	**Number invited by the person and/or the person's circle of friends**
8D __________	8E __________	8F __________	**Number not invited by the person and/or the person's circle of friends**

From this matrix, the Visitor was able to determine when a person had no unpaid members on the planning team. Although not an immediate threat or a health and safety issue, the Working Group that selected this as a "red flag" item believed that it was related to quality in a significant way. Since each and every one of the 1,118 people so identified was reported to the appropriate Regional Center, it became possible to suggest action --- such as alerting the case manager and the provider to make extra effort to get someone from outside the "service system" to help the person with life planning.

The next most common flag, with 455 people, was very low opportunity for choicemaking as measured by COA's Decision Control Inventory. The Decision Control Inventory measures choicemaking, power, and/or freedom from unwarranted professional domination.

455	Decision Control Inventory: All or nearly all (25 plus) of the ratings are below 5.

The Visitors completed this scale for each person, and in so doing, were able to identify people for whom practically all major and minor decisions were being made by agency staff, with little or no room for input from the person or the person's family and friends. This too had been determined by the Working Group to be an important indicator of quality in modern service systems. Again, it became possible via the QFS for Regional Centers to work with providers around these 455 people to re-examine the degree of choice and freedom accorded to them. In theory, this kind of re-examination could lead toward a lessening of overly strong professional domination.

The third flag occurred for 302 people: receiving three or more prescribed daily medications with behavioral or psychotropic effects.

302	Item 10 PRESCRIBED DAILY MEDICATIONS: Person is receiving 3 or more medications for which the purpose is described as either 1 (Control of Psychiatric Symptoms) OR 2 (Behavior Control, Calming).

The Working Group identified this as a situation of concern because of the known risks of polypharmacy. Drug interactions can be complex and dangerous. By receiving notice of these situations, Regional Center staff could investigate and study whether each person's medication regimen had been medically prescribed and confirmed to be medically sound.

The fourth flag, with 155 people, concerned integrative activities. The Working Group felt it was important to know which people "never got out," to identify those who simply languished around the house and never went anywhere for activities or recreation.

155	Integrative Activities During the Past Month: Person got out fewer than 5 times total in the past month

It was counted as negative if the person got to go on fewer than five outings in the past month. Knowing which people rarely got to go anywhere permitted managers and vendors to reconsider plans for activities and recreation for the 155 individuals and to identify possible causes such as low staff ratios or the need for specialized transportation.

The fifth most common flag was found for 149 people, and came from this item on the PLQ:

> 18. ACCESS TO TRANSPORTATION: If this person wanted to go somewhere on the spur of the moment (beyond walking distance), how many times out of 10 would he/she be able to? If this person does not communicate such wants phrase the question as "If someone unpaid wanted this person to be able to go somewhere on the spur of the moment". Count only trips that are within 1 hour of home.
>
> _____ times out of 10

A negative situation was defined as a "zero" on this item, meaning that the person never had the freedom or the option to go somewhere on the "spur of the moment." The Working Group felt this reflected something fundamental about freedom and self-determination within the service system. Although group living situations necessarily limit individual freedoms, the complete absence of spontaneous ability to go places was determined to be important to report.

Those, then, were the 5 most common of the 37 red flags. For the remaining 32 red flags, the following table provides the number of people who received each kind of red flag, based on the results of the 2,220 Visits with Movers.

Number of Negatives	Quality Indicator
143	Item 11. Number Of Friends: Person is reported to have no friends at all.
131	Item 6A. HOW MANY PEOPLE LIVE IN THIS HOME? Answer is 10 or more.
120	ALLEGED ILLEGAL BEHAVIORS: If any item 5A through 5H has a “2”.
119	Item 3. IF DAY PROGRAM HOURS TOTAL TO ZERO, PLEASE EXPLAIN WHY (e.g., retired): Explanation is incomplete or insufficient, situation needs closer scrutiny.
107	Individualized Practices Scale: 7 or more of the 15 items are rated “0” (Positive: 7 or more rated “2”)
87	Item 3. DENTIST VISITS: Person has not been to any dentist in the past year
80	Item 5. One or more incidents of a behavioral crisis requiring chemical restraint in the past year.
77	Item 4. One or more incidents of a behavioral crisis requiring physical restraint in the past year.
71	Item 4 PLAN DATE: Plan is more than a year old.
68	Item 11: “No” or “0,” person was not present for the planning sessions
59	Item 6. One or more crisis episodes in the past year resulting in the person spending one or more nights in another place?
45	Item 20. ALLEGED ABUSE: One or more events of abuse, mistreatment, or neglect have been alleged to have been experienced by this person in the past year
44	Item 15. WEIGHT GAIN OR LOSS: Has this person gained or lost weight within the past year? Answer is “1 Significant Gain (more than 10%)” or “5 Significant Loss (more than 10%)”
41	Item 3, Elements of the Planning Process, none of the responses are above a “2.” (Positive: none of the responses are below “5”)
38	Item 8. One or more admissions to a psychiatric hospital in the past year
38	Item 1. How do you feel about living here? Answer given is “1 Very Poor” or “2 Poor”
31	Item 1. Does the person have an Individual Plan? Answer given is “0 No” or “1 Yes, but no copy of it is kept here”
28	Item 19. INJURIES: 3 or more injuries happened in the past year
23	Item 18. If person has no individual goals in current plan.
21	Item 12. How do you feel about your [job, school, day program, workshop, etc.]? Answer given is “1 Very Poor” or “2 Poor”
20	Item 14. PLAN'S USEFULNESS is rated as 1, Not At All Useful (Positive: 5, Extremely Useful)
18	Environmental Ratings: Any one of the first 5 items are rated “1” (Positive if rated “5”).
16	Item 8. How do you feel about the people who (work with you / assist you) here (the staff)? Answer given is “1 Very Poor” or “2 Poor”
13	Item 1: How happy do you think this person is? Rating given is “0” or “1” (Positive: “9” or “10”)
11	Item 2. Quality of recent mental health services/supports is rated as 0, indicating Poor. (Positive if 10 indicating excellent).
9	Item 1. GENERAL HEALTH: Person’s general health is rated as 1, “Very Poor”
9	QUALITY OF LIFE CHANGES: Scanning the scale shows that life “Now” is in most ways worse than it was “Then.” To be precise, 7 or more items have gone down, and no more than 2 have gone up (Positive: 7 or more have gone up, and no more than 2 have gone down)
8	Item 2. HOW MANY TIMES IN THE PAST YEAR HAS THIS PERSON MOVED (CHANGED ADDRESSES)? Negative = response is 3 or more. (No positive.)
8	Item 29. Is there anything else you'd like to say? Answer is anything negative or alarming.
7	Item 11.MEDICATION ERRORS: Have there been any errors in the administration of medications in the past month?
6	Item 4A. DOCTOR VISITS: Person has not been seen by any doctor in the past year
2	Item 18. RESPONDENT OPINION: Overall, how good is the health care this person is getting? Response is 1 “Very Poor” or 2 “Poor”

A few general observations may be derived from this table. There were 143 people who were reported to have “no friends” at all. It would seem that a quality service system would make efforts, even for people with the most significant disabilities, to find someone who would fill some aspect of the role of friend. This can be extremely difficult, yet nonetheless, the assumption in the QFS is that it is always important to ask about friendships, so that the system will not forget about some people who are badly isolated and unconnected.

There were 131 people living in large settings, with more than 10 people. Some of these were nursing homes, which may have been appropriate for some people. Others were in DCs, having returned to them from their community homes. The point was that each such situation demanded a “second look” to make sure it was appropriate for the person’s current needs.

For 120 people, behaviors had occurred during the past year that might have been deemed illegal. This would certainly bear looking into.

For 119 people, zero hours per week were being spent in a job, school, or day program. The explanation(s) given on site were incomplete or inadequate. We accept reasons such as retired, lost job, or on waiting list. This was not supposed to happen. These 119 situations should have been investigated after the QFS forms made their way to the Regional Centers.

Moving down the table, there were 71 people for whom the Individual Plan was more than a year old. Individual Plans are supposed to be updated at least annually. For people not receiving this attention, a second look was certainly needed.

There were 45 people for whom there had been some kind of allegation of abuse or neglect in the past year. While it was likely that case managers already knew about most of these allegations, the QFS provided a double check so that no such allegation would “fall through the cracks.”

Sudden weight gain or loss has long been used by the health professions as a reliable indicator of serious threats to health. So here, the QFS identified 44 people who had gained or lost more than 10% of their body weight in the past year. Some of these events might have been positive (e.g. successful dieting), but again, the Working Group felt that such an event should be scrutinized.

For the 38 people who said they really did not like the place where they lived, the QFS “second look” could have been important. We hope that some of those people are now in places more to their liking since their feelings were reported directly to their Regional Centers.

There were 28 people with 3 or more injuries in the past year. These people needed to have their situations looked into to assure that abuse was not being reported as injuries and to discern any patterns that would indicate prevention measures.

For 13 people, there was reason to believe that they were very unhappy with their entire situation in life. For 9 people, health was reported to be Poor or Very Poor. Negative overall quality of life change, from the time they lived in a developmental center, until now when they live in the community, was indicated for another 9 people. Eight people had changed residences 3 or more times in the past year. Six people had not seen a doctor in the past year, and 2 people were reported to be receiving Poor or Very Poor health care. All of these constituted potential situations of concern that needed to be looked at.

It may be of special interest to note that the three flags least often seen concerned health care: medication errors in the past month; no doctor visits in the past year; and respondent feels that overall health care is poor or very poor. This suggests that getting health care in the community in California is perceived to be a fairly smooth process that seems to be working well.

Incidence of Positive Situations from the Quality Feedback Summaries

As noted above, the QFS contained positive, not just negative, reportable situations. There were 11 positive situations included in the reporting form. All 11 of these "green flags," and the number of people for whom they were found, are shown in the following table.

Number of Green Flags	Quality Indicator
1,366	Individualized Practices Scale: Positive: 7 or more rated “2”
1,065	Item 18. ACCESS TO TRANSPORTATION: Positive: “10,” person could always go out on spur of moment
941	QUALITY OF LIFE CHANGES: Scanning the scale shows that life “Now” is in most ways better than it was “Then.” To be precise: 7 or more have gone up, and no more than 2 have gone down
825	Decision Control Inventory: Positive: Most of the ratings are above 5
812	Item 14. PLAN'S USEFULNESS is rated as: 5, Extremely Useful)
678	Integrative Activities During the Past Month. Positive: person got out more than 40 times total
549	Item 3, Elements of the Planning Process, Positive: none of the responses are below “5”
532	Environmental Ratings: Positive: Any one of the first 5 items are “5”.
532	Item 1: How happy do you think this person is? Positive: Rating given is “9” or “10”
355	Item 2. Quality of recent mental health services/supports is rated as 10 indicating excellent
302	Item 8. PLANNING PARTICIPANTS are invited or unpaid . Positive: more than half are invited or unpaid

More than half of the Movers (1,366) obtained very high scores on the Individualized Practices Scale, an instrument COA has been using since the 1970s.

1,366	Individualized Practices Scale: 7 or more of the 15 items are rated “0” (Positive: 7 or more rated “2”)

This scale measures the extent to which people are treated as unique individuals, rather than as members of a group in a “one size fits all” mentality. So many people received this “green flag,” however, that in future years we will probably want to raise the bar a bit.

Another 1,065 people, or almost half, were reported to be able to “go somewhere on the spur of the moment” 100% of the time.

1,065	Item 18. ACCESS TO TRANSPORTATION: Answer is “0,” person could never go somewhere on the spur of the moment (Positive: “10,” person could always go out on spur of moment)

This meant that 1,065 people lived in community care facilities, or other kind of homes, that not only had access to a vehicle and a driver, but also operated with enough flexibility to accommodate a person's request for an individual, unplanned outing.

For 941 people, the Quality of Life Changes scale indicated that life was much better than it had been back at the Developmental Center.

941	QUALITY OF LIFE CHANGES: Scanning the scale shows that life "Now" is in most ways worse than it was "Then." To be precise, 7 or more items have gone down, and no more than 2 have gone up (Positive: 7 or more have gone up, and no more than 2 have gone down)

The Quality of Life Changes scale asked for quality of life ratings in 14 dimensions (e.g. health, happiness, integration, friends, choicemaking) when living in the DC versus now, living in the community. This finding of 941 very large improvements was in stark contrast to the 9 people for whom life had "gotten much worse" since coming to community homes as indicated by "red flags" on this item.

The Decision Control Inventory measures choicemaking, power, and/or freedom from unwarranted professional domination.

825	Decision Control Inventory: All or nearly all (25 plus) of the ratings are below 5. (Positive: Most of the ratings are above 5)

There were 825 people out of the 2,220 who had a great deal of freedom and control of their own lives. In this era of concern about self-determination for people with developmental disabilities, this is a very strong indicator of quality. We hope the people, their families, and their vendors were notified and congratulated.

For 812 people, the Individual Plan was reported to be "Extremely Useful."

812	Item 14. PLAN'S USEFULNESS is rated as 1, Not At All Useful (Positive: 5, Extremely Useful)

This was an indicator of the general quality of the individual planning process.

There is a scale in the Personal Life Quality protocol called "Elements of the Planning Process." It is composed of 16 items, each on 5 point scales, about how "person-centered" the planning process was for the individual being Visited. This scale reflects one of the core mandates of the Lanterman Act about individual planning:

> It is the intent of the Legislature to ensure that the individual program plan and provision of services and supports by the regional center system is centered on the individual and the family of the individual with developmental disabilities and takes into account the needs and preferences of the individual. §4646(a)

549	Item 3, Elements of the Planning Process, none of the responses are above a "2." (Positive: none of the responses are below "5")

For 549 of the Movers, the planning process was reported to be extremely person-centered. All the ratings were 5s. These commendable situations were reported to the Regional Centers on the QFS forms.

On a subjective rating of how happy the person seemed to be, 532 were reported to be extremely happy – a 9 or a 10 on a 10 point scale.

532	Item 1: How happy do you think this person is? Rating given is "0" or "1" (Positive: "9" or "10")

Granted, this was a completely subjective rating by the COA Visitor. Nonetheless, it might have some validity in relation to everyday notions about what constitutes quality.

For people who received mental health supports, 355 reported that their mental health care was "Excellent."

355	Item 2. Quality of recent mental health services/supports is rated as 0, indicating Poor. (Positive if 10 indicating excellent).

These 355 people gave 10 out of 10 points to their rating of the quality of mental health service they received recently.

Finally, for 302 people, their planning teams were well represented with unpaid friends, family members, and allies.

302	Item 8. None of the PLANNING PARTICIPANTS are invited or unpaid (Positive: more than half are invited or unpaid)

For these 302 Movers, more than half of the planning team was unpaid. This was formulated as an indicator of quality because of the current belief that service planning is better when team membership is balanced between paid professionals and unpaid members who are only present because they care about the individual. Many believe that unpaid members tend to remain in a person's life longer and to offer perspective on the simple, common sense aspects of building a decent life.

The Quality Feedback Summary "Scale Score"

The QFS has 37 items that could be rated negatively, and 11 that could be rated positively. For each person, it is easy to conceive that getting all 37 negative "red flags" would almost certainly mean that the person was in a very bad situation altogether. Similarly, getting all 11 positive "green flags" would be a strong indicator that the person was in a very good situation.

We calculated how many red flags were reported for each of the 2,220 people.

Number of Red Flags	How Many People	Percent of People
0	476	21.4%
1	760	34.2%
2	535	24.1%
3	229	10.3%
4	102	4.6%
5	55	2.5%
6	18	0.8%
7	22	1.0%
8	11	0.5%
9	5	0.2%
10	3	0.1%
11	2	0.1%
13	1	0.0%
15	1	0.0%
Total	2,220	100.0%

For about a fifth of the people (476 or 21.4%), <u>zero</u> red flags were observed. For another 760 (34.2%), only <u>one</u> red flag occurred. And so on, until we see that one person in the group had a total of 15 red flags (surely an indicator of trouble).

Moving down the table, the implication is that the more the red flags, the worse the quality of the person's situation.

Similarly, we counted the number of green flags observed for each person.

Number of Green Flags	How Many People	Percent of People
0	150	6.8%
1	310	14.0%
2	442	19.9%
3	400	18.0%
4	279	12.6%
5	203	9.1%
6	143	6.4%
7	84	3.8%
8	58	2.6%
9	43	1.9%
10	53	2.4%
11	55	2.5%
Total	2,220	100.0%

For 150 people, no green flags were observed. On the other end of the spectrum, 55 people had all 11 green flags. It seems obvious that, in some important ways, the 55 were experiencing higher quality than the 150.

In principle, then, the more "green flags," and the fewer "red flags," the "better" the quality of the person's life and service situation. So a person who got 10 green flags and only 2 red flags would be interpreted to be better off than a person who got 2 green flags and 10 red flags.

This means that, for each of the 2,220 people, we can calculate one single indicator of many (but not all) dimensions of life and service quality. We simply count how many red and green flags were reported for each person, and find the difference. If a person got 5 more green than red flags, that would be good. Conversely, if a person got 12 more red flags than green, that would be bad. The key to this approach is the concept of discrepancy. We are computing the balance between "good" and "bad" things in each person's life.

To visualize this, the following table shows four hypothetical people

	QFS Red Flags	QFS Green Flags	**QFS Discrepancy Score**	QFS Quality Verbal Description?
Fred	10	0	**-10**	Bad
Ellen	5	5	**0**	Fair
Bert	3	7	**+4**	Better
Susan	1	10	**+9**	Best

Fred had lots of red flags, and no green flags. The discrepancy was minus 10. He had 10 more reds than greens. His situation was relatively bad. Ellen got the same number of reds and greens. Her situation was somewhere in between. Bert got 4 more greens than reds, and so his situation would be interpreted as better than either Ellen or Fred. And Susan, with 9 more greens than reds, would be seen as the best off among the four.

A QFS discrepancy score was computed for each of the 2,220 people visited this year. Now that every one of the 2,220 has an "overall quality indicator score," it becomes possible to compare quality across geographic regions, program types, level of functioning, and anything else we find interesting.

For the present report, an analysis of variations in this QFS quality indicator across geographic regions was performed.

Regional Center Code and Name	**Average Number of QFS Red Flags Per Person**	**Average Number of QFS Green Flags Per Person**	**Discrepancy Between QFS Reds and Greens**	
372 KRC	1.35	6.68	5.33	The highest rating
361 GGRC	1.18	6.36	5.17	
365 SARC	1.12	5.30	4.18	
369 IRC	0.86	3.65	2.79	
367 CVRC	1.20	3.99	2.78	
376 WRC	1.29	3.79	2.51	
378 NLACRC	1.96	4.41	2.45	
368 RCOC	1.91	3.44	1.52	
360 FDLRC	1.94	3.43	1.49	
374 SCLARC	1.90	3.14	1.24	
377 VMRC	1.84	2.78	0.94	Right in the middle
380 RCEB	2.20	3.02	0.83	
370 RCRC	1.73	2.55	0.82	
366 TCRC	1.34	1.89	0.55	
364 ACRC	1.96	2.26	0.30	
375 HRC	2.24	2.44	0.20	
371 NBRC	1.87	2.05	0.18	
363 FNRC	2.32	2.32	0.00	
379 SGPRC	2.26	1.93	-0.33	
362 SDRC	2.17	1.72	-0.45	
373 ELARC	3.24	2.59	-0.65	The lowest rating
Total	1.66	3.58	1.93	Average for All RCs

For three Regional Centers at the bottom of the table, the average Mover had more red flags than green flags. Insofar as this QFS data collection was based on best practice thinking, and reliable data collection instruments, one is constrained to conclude that these three Regional Centers are most in need of assistance --- because the people who moved from Developmental Centers to these communities are not getting the level of support and therefore the opportunities for high qualities of life as are the people being supported by the Regional Centers at the top of the table.

The policy implication of this finding is that, given limited resources for training and technical assistance about how to support the people who came out of institutions, the areas most in need of assistance are probably those at the bottom of the table. The others need help in varying degrees as we move upward in the table. At the top of the table are the Regional Centers that might be enlisted to provide technical assistance to the others.

Results 4: Quality Changes Over the Past 3 Years

The primary original purpose of the Quality Tracking Project and the Coffelt study that preceded it was to find out whether people who left Developmental Centers were "better off" in their new community homes. That question has been repeatedly and reliably answered in the affirmative. The movement of Californians with developmental disabilities out of institutions, and into community homes, during the 1990s, was an excellent and successful social policy.

The current Quality Tracking Project has now visited nearly every Mover three times in their community homes. (And many were visited several times before this 3 year project as well.) Last year, Project staff undertook a new analysis: examination of changes in qualities of life within community living. In 2001, we asked a new question: are these people's lives continuing to improve, now that they have been in the community for several years?

In our last annual report (Report #4 of this series), we found evidence of changes in life quality from 2000 to 2001 that were mostly positive, but a few negative outcomes gave cause for some concern. In this section, we will review last year's findings, report on another year of data, and attempt once again to interpret the findings in an objective manner.

Positive Within-Community Changes from 2000 to 2001

- Perceived Progress Toward Individual Goals (up 1.3 points on the 100 point scale)
- Number of Services in the Plan (up 0.4 services per person)
- Time Spent in Day Program (up 0.4 hours per week)
- Individualized Practices Scale (up 4.3 points on the 100 point scale)
- Elements of the Planning Process (up 4.0 points on the 100 point scale)
- Decision Control Inventory (up 4.3 from 43.1 to 47.4 on the 100 point scale)

Negative Within-Community Changes from 2000 to 2001

- Number of Friends (down 1.3 friends, to 8.8)
- Number of Doctor Visits Per Year (down 0.8 visits per year, to 11.7)
- Challenging Behavior (down 1.5 from 78.6 to 77.1 on the 100 point scale)
- Adaptive Behavior (down 1.7 points from 49.1 to 47.4 on the 100 point scale)

The last item was potentially the most alarming. The idea that people were beginning to lose functional skills would suggest declining quality throughout the service system. To the extent that maximizing self-care skills and independence was an important goal, a reliable decline in abilities across a large number of people would certainly be cause for concern.

After Report 4 was submitted, COA found a mathematical error in part of the statistical programming used on the data. Correcting this error changed the adaptive behavior loss to 1.3 points rather than 1.7.

Subsequently, DDS researchers explored the data and found suspicious items in the CDER data. For a few behavioral items, some people had gone from the highest possible score to the lowest possible score in just one year. That did not seem likely to have been accurate. The three items that were most suspicious were these:

63. Receptive Sign Language
99 Skills not needed (R5)
1 Does not respond to signs or finger spelling
2 Responds to one to nine signed basic survival words (stop, restroom, come, etc.) as well as other common signs (simple commands, food, clothing, etc.)
3 Responds to signed complex commands made up of two or more parts ("Go to the bathroom and bring me a towel")
____
4 Responds to signed complex commands, directions and explanations with a combination of signs and simple finger spelling
5 Responds to signed questions (3 or more words) with a combination of signs and finger spelling

64. Expressive Sign Language
99 Skills not needed (R7)
1 Does not sign or imitate signs
2 Imitates sign language but makes no meaningful signs
3 Makes one to nine signs independently to indicate a need
4 Makes ten or more signs independently to indicate needs
____
5 Makes twenty or more signs independently to indicate needs and/or simple conversation
6 Makes fifty or more signs, finger spells simple words and makes simple sentences
7 Signs and finger spells independently in carrying on conversations as well as expressing needs

65. Expressive Communication with Aids (Includes all types of specialized devices which allow or facilitate communication)
99 Aids not needed (R4)
1 Does not communicate with aids
2 Communicates single words or ideas
____
3 Forms short sentences; combines subject and verb
4 Communicates combinations of sentences and groups of ideas together

All three of these items were potentially confusing. We analyzed them very carefully across the years, and found sufficient evidence to justify removing them from our Adaptive Behavior scale computations.

We have gone back into our datafiles all the way to the baseline Developmental Center data from 1994, and have recalculated the Adaptive Behavior scales without including these three items. We also reanalyzed data from past reports, and consistently found small alterations in Adaptive Behavior numbers, without changing the basic nature of the findings. That is, some past analyses would be changed a few tenths of a point, but the basic finding of behavioral progress (or lack of it) remained significant and intact.

This was also true in the analysis from Report 4 of Adaptive Behavior loss from 2000 to 2001. Even with these modifications and corrections, the fundamental finding of behavioral regression from 2000 to 2001 remained intact. It was a smaller regression when recomputed, but still highly statistically significant.

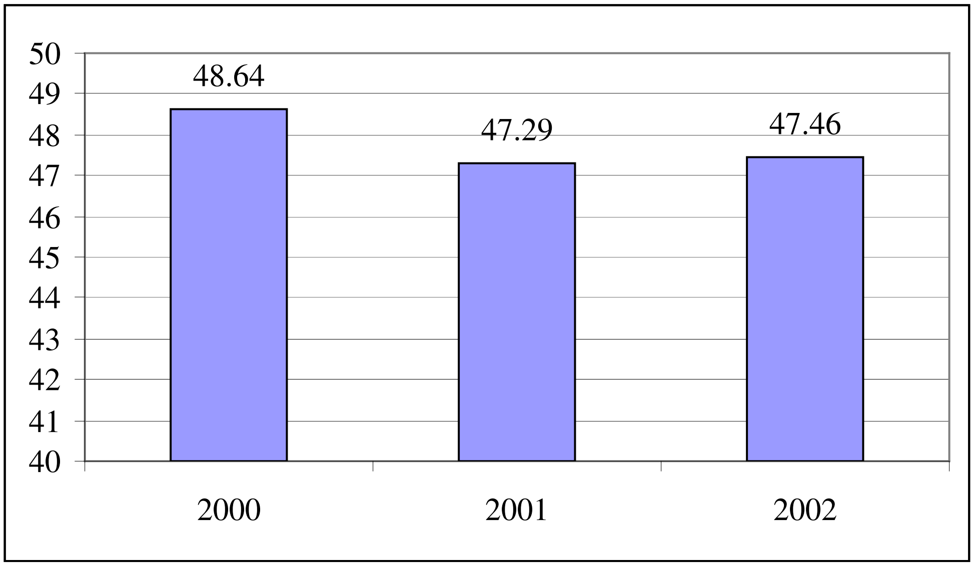
These 3 behavioral items were among the 13 (out of the 52 on the CDER) that DDS researchers routinely exclude from their analyses. These items are referred to as the "Not Needed" items, because they may be measuring skills that are not needed in certain environments, e.g., cooking skills are not needed in Developmental Centers.

COA has not followed that practice because of differing research interests. COA has been interested in documenting growth in all kinds of skills, and particularly when people move from one kind of environment to another. Our analyses cannot exclude skills such as Bedmaking, Household Chores, Dishwashing, and Basic Medical Self-Help, because they are skills that are valued and needed in community settings.

Hence COA is now computing Adaptive Behavior without the 3 suspicious items, but we continue to include the other 10 "Not Needed" items. This is because in our research they are needed, and they are not associated with problems in scoring.

Now we can return to the issue of declining Adaptive Behavior scores within the community. By selecting all the people who we visited in 2000, 2001, and 2002, we made this graph:

Adaptive Behavior Changes in the Community



Using the updated Adaptive Behavior scale scores, there was a drop of 1.35 points from 2000 to 2001, which was statistically significant. Then, from 2001 to 2002, there was an increase of 0.16 points, which was not statistically significant. (The overall change from 2000 to 2002 was also significant.)

If these findings really reflected a genuine phenomenon, then one would conclude that the Movers, on the average, lost a little ground 2 years ago, but this downward trend did not continue. That should be interpreted as good news.

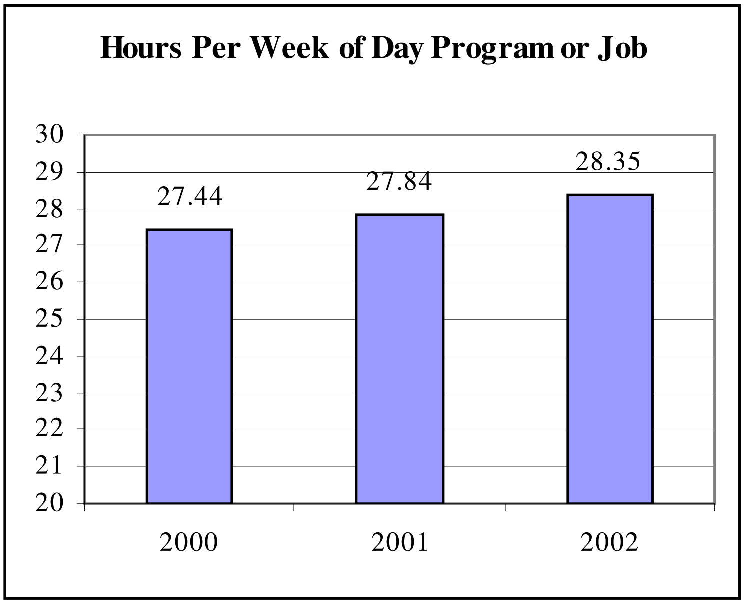
Now we can examine the other indicators of quality that we utilized in Report 4. They are shown in the following table, with average scores for all the Movers in 2000, 2001, and 2002.

Changes in Qualities of Life: 2000, 2001, 2002

Dimension of Quality	2000	2001	2002	Pattern
Perceived Progress Toward Goals	77.68	78.87	77.55	Up, then down
Number of Services in the Plan	8.15	8.52	8.40	Up, then down
Time Spent in Day Program	27.44	27.84	28.35	Up, then up again
Individualized Practices Scale	63.59	68.01	69.42	Up, then up again
Elements of the Planning Process	79.84	84.51	84.62	Up, then up slightly
Decision Control Inventory	42.25	46.62	47.27	Up, then up slightly
Number of Friends	9.99	8.65	8.84	Down, then up slightly
Number of Doctor Visits Per Year	12.41	11.65	13.43	Down, then up
Challenging Behavior	78.49	77.01	78.07	Down, then up
Adaptive Behavior	48.64	47.29	47.46	Down, then up slightly

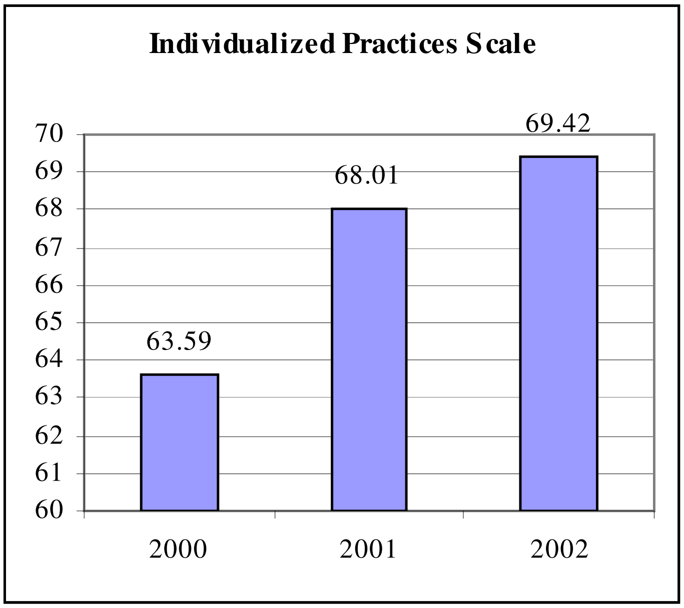
In the right hand column of the table are simple interpretations of the pattern of changes over time. For example, the first row, *Perceived Progress Toward Individual Goals*, shows numbers that went up from 2000 to 2001, then back down. By converting some of the most interesting findings into graphs, we can visualize these patterns.

The *Time Spent in Day Program* findings seem to these authors to be both interesting and important.



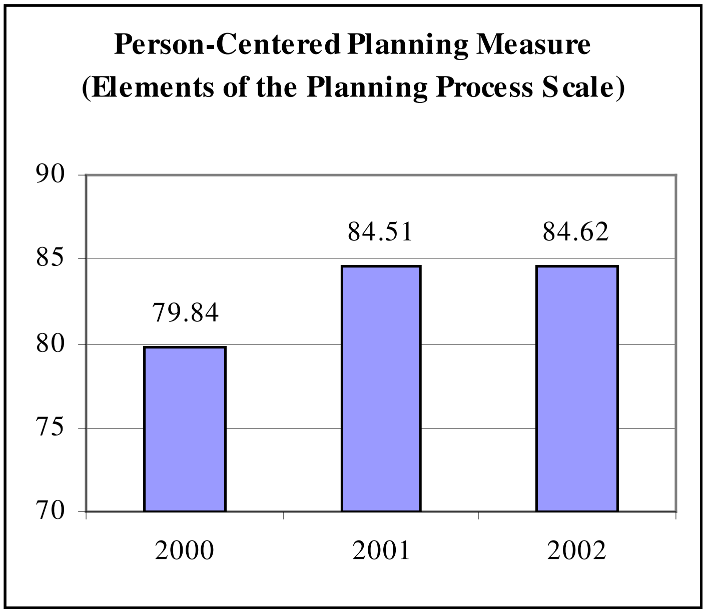
There is a steady increase in the average number of hours per week of day program or job. We already know that these Movers have experienced very little emphasis on integrated employment opportunities (from all of our past Reports), so this gradual increase in activities would seem to be a step in the right direction.

The Individualized Practices Scale is a measure of the degree to which people are being treated as individuals with unique characteristics and needs. (As opposed to being treated in a one-size-fits-all mentality.)



The graph shows a pattern of consistent increases in this indicator of service quality. That is a very encouraging finding. Note, however, that the graph is scaled to emphasize the changes; these year to year changes are just a few points. Nonetheless, a few points improvement per year would be a very positive outcome.

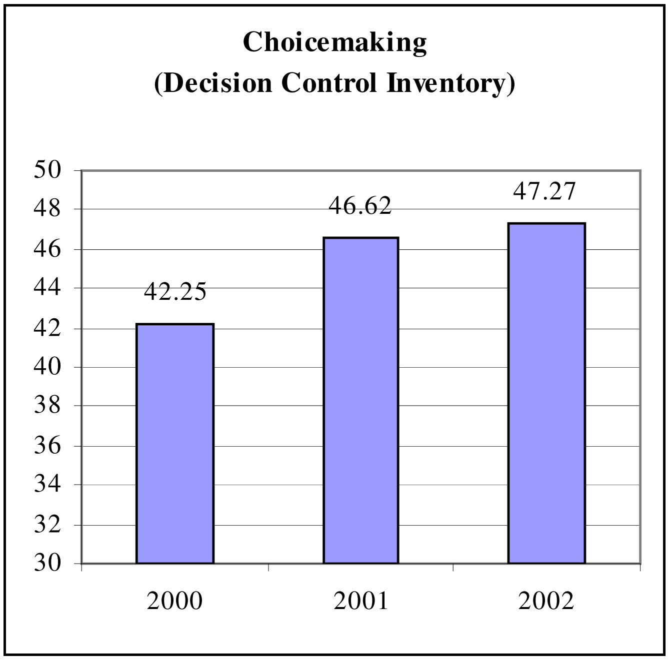
The Elements of the Planning Process scale is designed to measure the degree to which individual planning has been conducted in a person-center manner, as is strongly encouraged by the Lanterman Act.



Person-Centered Planning Measure
(Elements of the Planning Process Scale)

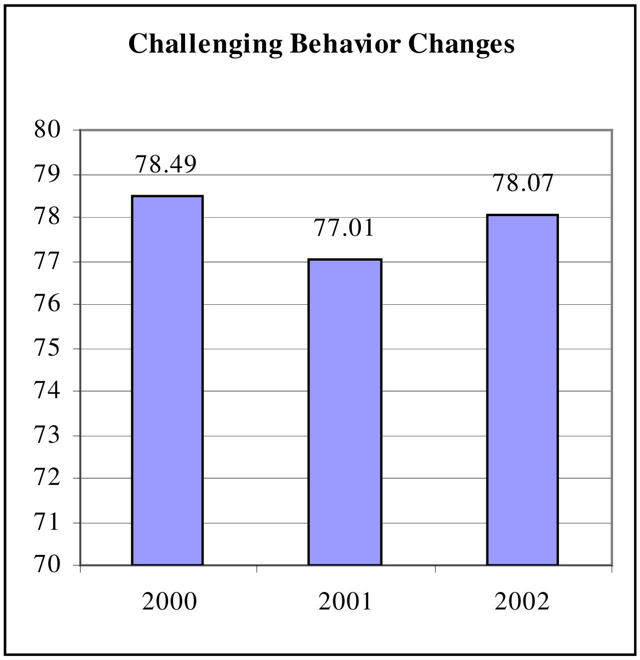
By this index, it appears that the service system that supports these more than 2,000 Movers has become more person-centered. That, too, is a highly desirable outcome.

The Decision Control Inventory measures power sharing between paid workers and the person along with the person’s unpaid allies. As such, it is the most widely used and best known measure of self-determination in use. This scale has been increasing for the people in their community settings.



The data show a pattern of progress since 2000. This strongly suggests that, insofar as self-determination is related to quality, the system that supports these Movers has been improving.

The final dimension to be discussed here is challenging behavior. Last year, we reported that scores had gone down about 1.5 points (and lower scores are undesirable). Now we add another year to the observations:

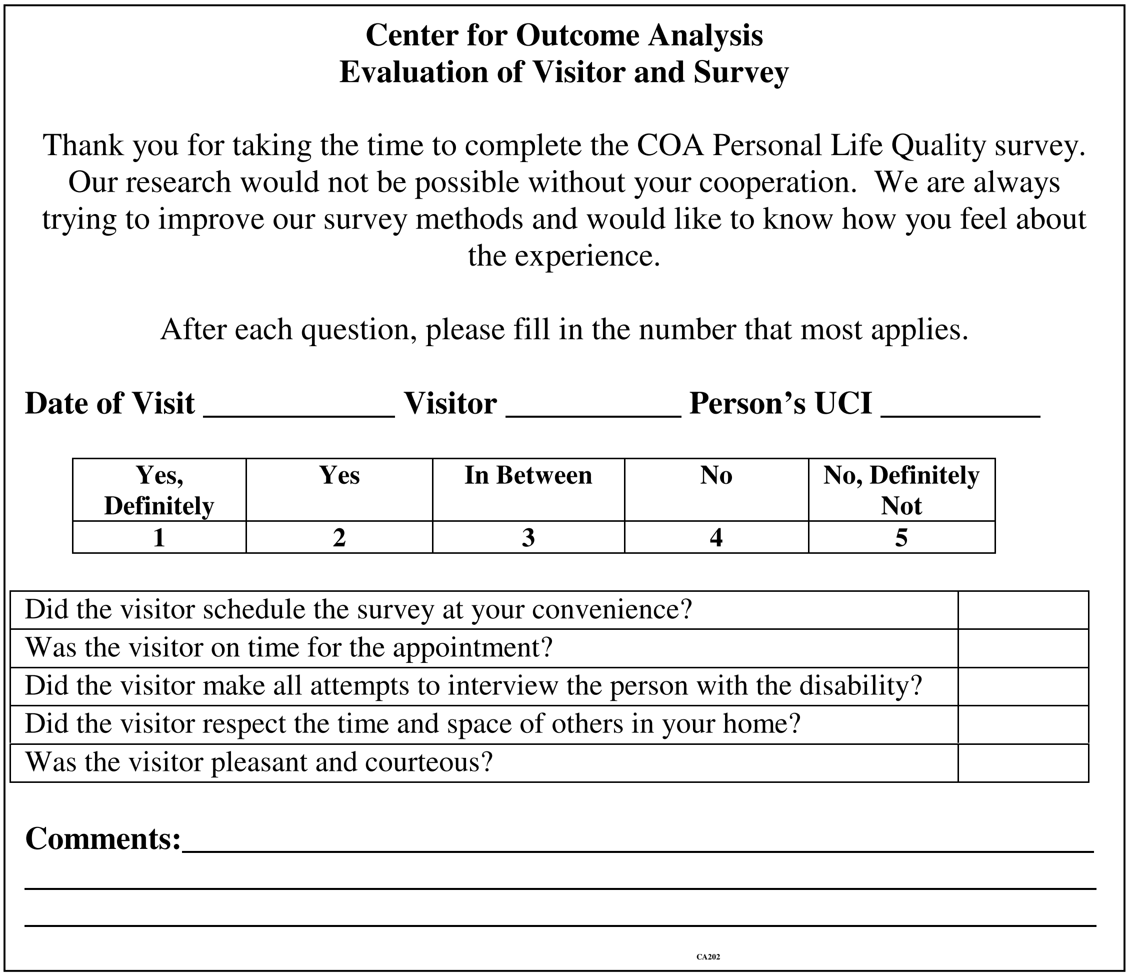


The data now suggest that the drop in scores last year is beginning to be reversed. Again, this is encouraging because the downward trend did not continue.

In all, this year's reexamination of the quality concerns we raised in Report 4 has produced evidence that is generally encouraging. For the most part, the negative trends did not continue, and for the most part, the positive trends did continue. All of this should probably be taken as support for the inference that the community service system that supports these more than 2,000 Movers is reasonably stable, and in some ways, gradually improving.

Results 5: Feedback About the Visitors

The COA Visitors gave the person or the person's support staff a post card at the end of the visit. This post card was designed for the person or the person's staff to "rate" the visitor. There were five questions on the post card.



Center for Outcome Analysis
Evaluation of Visitor and Survey

Thank you for taking the time to complete the COA Personal Life Quality survey. Our research would not be possible without your cooperation. We are always trying to improve our survey methods and would like to know how you feel about the experience.

After each question, please fill in the number that most applies.

Date of Visit ____________ Visitor ___________ Person's UCI __________

Yes, Definitely	Yes	In Between	No	No, Definitely Not
1	2	3	4	5

Did the visitor schedule the survey at your convenience?	
Was the visitor on time for the appointment?	
Did the visitor make all attempts to interview the person with the disability?	
Did the visitor respect the time and space of others in your home?	
Was the visitor pleasant and courteous?	

Comments:____

____

____

CA202

After the Visitor left, the person and/or the person's closest allies were to complete the card and drop it in the mail. The cards were already stamped with first class postage. They were addressed, not to COA, but to an independent company (Community Services Systems), which compiled them.

These post card feedback forms have some importance as an indicator of how the process of Visiting more than 2,000 Californians was received. Were the Visitors highly professional, and were the Visits pleasant or a burden?

A total of 334 feedback cards were received. The responses in percentage form are tabulated below.

	Yes, Definitely	**Yes**	**In Between**	**No**	**No, Definitely Not**
Did the Visitor schedule the survey at your convenience?	93.1%	4.5%	1.8%	0.0%	0.6%
Was the Visitor on time for the appointment?	91.6%	5.4%	0.6%	0.3%	2.1%
Did the Visitor attempt to interview the person with the disability?	93.2%	1.5%	2.2%	0.6%	2.5%
Did the Visitor respect the time and space of others in your home?	98.5%	0.0%	0.9%	0.0%	0.6%
Was the Visitor pleasant?	97.9%	0.0%	1.2%	0.0%	0.9%

Obviously, the COA Visitors received very high marks from the people and the staff in the field. The handful of negative ratings enabled questions to be asked of the Visitor in question, to assure that negative events would not be repeated.

The post cards also contained a space for open-ended comments about the Visitor or the process. The comments received have been sorted by their overall intent --- Positive, Negative, or Neutral. They are reproduced below.

Comments About Visits and Visitors Received on Feedback Post Cards

Positive (127)

A breath of fresh air, kind & caring- need more like him
A very kind person
Absolutely wonderful. Kind & considerate. We loved his visit
Accommodating, professional & friendly man. Asset to agency
All went well
B. was a very nice man, enjoyed meeting him.
Clients non-verbal, she observed & interacted w/ client
Continue your good work
Courteous & pleasant disposition. straight to the pt.
Did excellent job
Does a great job & is very pleasant & respectful
Efficient & friendly; very professional, a pleasure
Enjoyed the survey
Everything was good
Everything was good
Excellent
Excellent
Friendly, respectful & established good rapport w/ consumers
Good job
Great
Great!!
Have a nice day
Have a nice day
He was great.
Hope to see her next year
I really enjoy S.'s company. She's good at what she does
I was very pleased w/ the interviewer. She was pleasant & professional.
Interview was excellent. Thank you
Interviewed well with all staff & clients
Interviewer appeared to have knowledge of her clientele
Interviewer pleasant & understanding for concerns of consumer
Interviewer was very good. She knew how to communicate
Interviewer was very personable, professional & thorough.
It went very well
Knowledgeable/ continue your research for handicap
Liked D., let's work hand in hand for clients needs
Liked her. All evaluators have been fun.
Look forward to each visit
M. was very nice.
M.'s visit was unique & pleasant in things discussed
Ms. D. was very good & pleasant, we need more like her
Nice meeting & talking to you.
Nice to have the same research consult 3yrs, so pleasant
Outgoing, friendly & easy to talk to
Overall pleasant
Overall rating - very good
Patient & understanding to let client express himself

Pleasant
Pleasant & knowledgeable
Pleasant, knowledgeable & accommodating. A+ experience.
Please continue to hire people like S.
Pleasure to work with
Punctual & precise, an excellent evaluation.
R. has been courteous, professional, helpful & sensitive.
R. is pleasant.
Respectful & pleasant to work with; appeared knowledgeable
S. always makes everybody here feel terrific
S. delightful & knows how to do interviews quick & efficient
S. is a delight, competent, polite, understanding & complimentary
S. is a huge asset & deserves compensation!
S. is a very nice person
S. is terrific. looking forward to seeing her next yr.
S. is wonderful & should get an immediate raise!
S. was a real nice lady. I enjoyed her visit.
S. was pleasant & did her job well.
S. was pleasant & very concerned about person's welfare
S. was pleasant, concise & knowledgeable. A pleasant visit.
S. was very pleasant & made the survey a wonderful experience for all
S. was wonderful
She is excellent.
She is very thorough & complete
She was excellent
She was excellent
She was friendly, pleasant & understanding
She was great. very patient & repeated question.
She was very good
She was very good
She was very kind, patient & professional.
She was very pleasant & nice
She was very pleasant to speak with & extremely professional
She was very pleasant. Made client very comfortable.
She's a delight & well organized. Made all comfortable.
She's great! This survey redundant to other agencies.
Some of the questions require an assumption.
Surveyor very pleasant. We had an enjoyable time together
T. is a pleasant person & easy to work with & gets the job done
T. was very pleasant & accommodating
T. was very pleasant. She did a great job with survey
Thanks for the survey.
The survey is great
Very cordial, cooperative & good to work with.
Very efficient.
Very enjoyable.
Very friendly & knowledgeable. Easy to talk to made me comfortable
Very friendly & professional
Very friendly & professional
Very friendly interviewer
Very good
Very good experience
Very good job
Very good job
Very helpful & efficient.
Very knowledgeable about developmental disability

Very natural with clients
Very nice
Very nice & mannerly
Very nice & patient. Stafff glad T. did evaluation
Very nice an excellent evaluation
Very nice lady
Very nice man, seemed very caring for clients needs
Very personable. Made survey very relaxed & respectful.
Very pleasant
Very pleasant
Very pleasant & happy to talk to. Respects client.
Very pleasant & knew what she was doing
Very pleasant man
Very pleasant to work with. Genuine concern for clients
Very pleasant, nice attitude & very considerate
Very pleased w/ visitor, her time was right for me & home.
Very polite & interested in client.
Very professional. demonstrated dignity & respect for patients
Very very polite person
Visit & interview was a success. Interviewer was patient & good
Visitor was pleasant, mannerly& interesting to talk 2.
Visitor was prompt, polite & courteous to all.
Visitor was very friendly & pleasant.
We enjoyed having the interviewer in our home.

Negative (8)

Came in groggy & used the bathroom to move bowels
Appt was 2:45 called at 7:00 came 7:30 said car trouble
I think the meeting was too long
It would be better not to schedule all 6 clients in 1 visit.
Question/process is redundant
Seemed hurried, had to take time for questions.
She was impatient & annoyed if we asked questions
Was late due to went to old address

Neutral (11)

Clients are non verbal & incapable of such questions
Clients were non-verbal; unable to talk personally
No comment
No comment
No comment
None
The consumers here are non-verbal
This client has no means of communicating.
We would appreciate a month's notice for the interview
Would have liked to schedule survey w/ 1-2 wks notice
Would like 1-2 weeks notice

In all, 127 of the comments were positive, and only 8 were negative. This provides evidence that the data collection process was done in a pleasant, professional manner that was generally very well received by both consumers and service providers.

Appendix A

Welfare & Institutions Code 4418.1

Appendix B

The Personal Life Quality Protocol

Appendix C

The Family Survey Form

Appendix D

Family Comments

Appendix E

The Quality Feedback Summary Form