

**Progress Report:
Quality of Life Evaluation
of People with Developmental Disabilities
Moving from Developmental Centers into the Community**

**Semi-Annual Report
(Year 2) ¹**

Submitted to:

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Table of Contents

SUMMARY	1
HISTORICAL BACKGROUND	3
FIELD WORK	8
ACTIVITY REPORT	8
PROJECTIONS	13
PRELIMINARY DESCRIPTIVE DATA	15
CHARACTERISTICS OF THE 1,025 MOVERS	15
PERCEIVED QUALITY OF LIFE CHANGES	18
PERSONAL INTERVIEW	22
REFERENCES	24
APPENDIX A	25

Summary

The Center for Outcome Analysis (COA) is conducting a long-term Quality Tracking Project on behalf of the California Department of Developmental Services (DDS). The project focuses on the lives and well-being of the more than 2,000 Californians who moved from Developmental Centers (large segregated public institutions) to community homes (small, community-integrated, privately operated homes) since 1993.

The work is being performed under contract with DDS, pursuant to legislation contained in the Welfare & Institutions Code 4418.1 (see Appendix A for the text of the law). The intent of the legislation, and COA's work, is to ensure that these people are receiving necessary services and supports. In general, the work is designed to answer the question: "Are these people better off" in their new community homes than they were at the institutions?

The project methodology includes annual face to face visits with each person in his or her community home. The Project also surveys each person's closest relative (or guardian or conservator) by mail or any other method they select. In both the individual and the family surveys, we collect measures of qualities of life such as health and health care, independence, friendships, productive activities, integration, and opportunities for choice.

COA submits two major reports for each year of the study: a semi-annual field progress report in January and a final annual report in July with data analysis and recommendations. This semi-annual field progress report is one of a series. It documents progress for the first half of the second year of the study and describes the field work from July 1, 2000 through mid-January, 2001.

The purpose of this report is to present a comprehensive progress report on the status of the project, to present characteristics of the people who moved from institutions to communities (the “Movers”), to review the implementation of the project methodology, and to report any observed positive or negative trends. This report gives a preview of the annual report, describing the numbers of people we have visited, the kinds of living arrangements they utilize, and other demographic information. This report also reviews the status of COA’s field operations, describing our coordinators and visitors, the supports and barriers they encountered in the course of their work, and the type and number of field reports filed to date.

This report does not fully address the questions of whether the people are better off and whether they are receiving the supports and services they need. These are the questions that are addressed and answered in the final annual report. This is simply a brief review of our progress in conducting the visits and collecting the data that are necessary to answer the questions posed by the legislature in Welfare and Institutions Code section 4418.1.

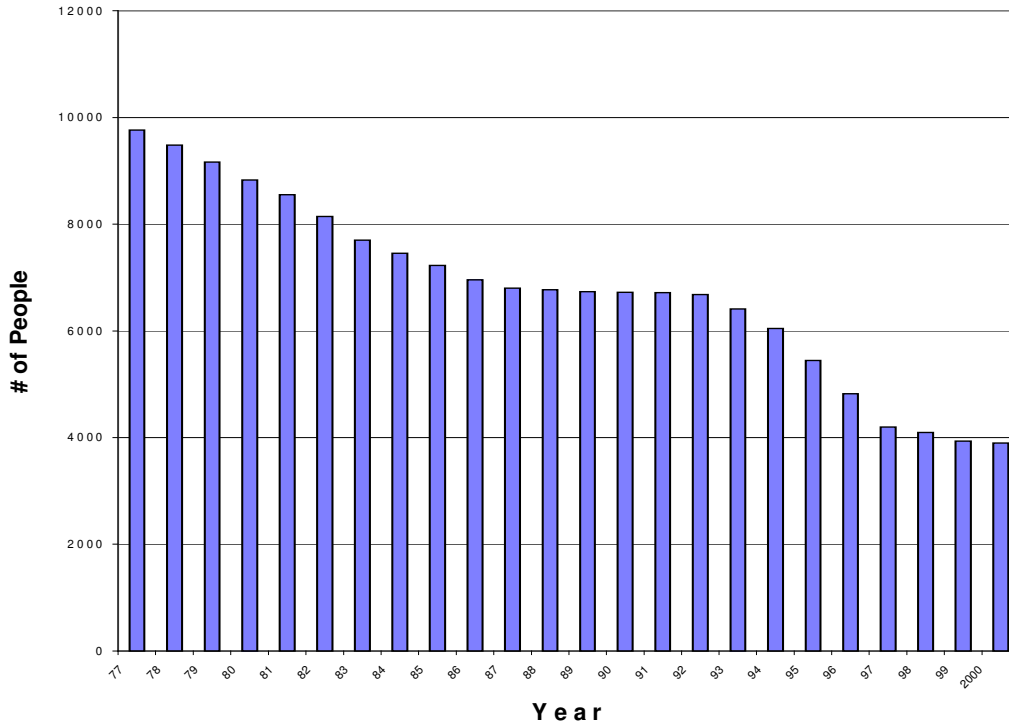
The following sections detail our work to date. In summary, 1,805 visits were completed and data from 1,094 of those visits were entered into the computer database. In addition 1,686 Quality Feedback Summaries were completed and copied to the appropriate Regional Centers. Another 741 visits were conducted at people’s day programs, and 536 Family Surveys were mailed.

Historical Background

The principle and the practice of deinstitutionalization for people with developmental disabilities have been operative in the United States since 1969. Its history has been turbulent, producing avid supporters and fervent opponents. At different times it has stalled, advanced at a measured pace, or accelerated almost beyond the capabilities of community systems. Fortunately, most aspects of deinstitutionalization have been documented in depth, allowing those who study the literature to design experience-based systems for future implementation.

Figure 1 tracks the history of deinstitutionalization in California. Advocates and policy makers espoused deinstitutionalization as early as the late 1970s and early 1980s. The process slowed throughout the eighties, most likely because the development of viable community options did not keep pace with the demand for deinstitutionalization from the Developmental Centers. Approximately equal numbers of discharges and new admissions resulted in a stable census for the Developmental Centers during the 1980s and early 1990s.

Figure 1
Deinstitutionalization in California:
Declining DC Populations



A sharp increase in community placement began in 1993 and continued through 1997. This was the direct result of the 1990 class action, Coffelt v. DDS litigation. This suit was filed on behalf of William L. Coffelt and 12 other named plaintiffs in order to make non-institutional community homes more readily available. By 1997, more than 2,300 people had moved out of California Developmental Centers, most into small, single family homes in residential neighborhoods.

After this massive relocation program was accomplished, however, the decrease in Developmental Center populations nearly stopped. As Figure 1 shows, there has been virtually no change in DC populations since

1997. This halting of movement from institution to community was related to several factors, among which were:

- Research on mathematical models of mortality suggested higher “adjusted risk of mortality” in community settings (including parental homes) over the risk estimated in DCs;
- The San Francisco Chronicle published a series of 24 articles in 1997 on mortality and other “severe problems” in the community service system;
- The Director of DDS resigned under the pressure of the Chronicle’s criticism, thus removing progressive leadership that favored movement toward the community services envisioned by the Lanterman Act;
- Court cases instigated by the pro-institutional group (California Association of State Hospital Parent Councils for the Retarded or CASH/PCR) and the ARC of California’s pro-institutional board, resulted in temporary moratoria on community placement for un-represented consumers residing at Fairview Developmental Center.
- The Coffelt litigation reached a final settlement, which reduced the pressure on DDS and the Defendant Regional Centers to bring people out of DCs;
- Community service providers may have expanded rapidly, sometimes stretching the limits of growth, and needed time to consolidate their expansion.

Interestingly, all of these reasons for the slowing of California’s conversion efforts are now dissipated, diminished, or discredited.

Later attempts to replicate the mortality studies failed to obtain the results reported by the original researchers (e.g., O’Brien & Zaharia, 1998). Contradictory articles appeared in major journals (e.g. Conroy & Adler, 1998). Finally, a fatal error in counting deaths was found and reported by Lakin (1999): all of the California mortality studies were founded upon a significant undercounting of deaths in Developmental Centers.

The Chronicle series was submitted to the Pulitzer board for consideration. A large number of objections were filed, and the Chronicle

did not win the award. The principal author left the Chronicle and California.

At the present time, the leadership of DDS is facilitating a “system reform” effort that is moving California back onto the path of community options. The system reform resolutions thus far drafted leave no long-term role for Developmental Centers in California’s future.

The court cases that slowed or stopped community placements, e.g. Richard S. vs. DDS et al., have been decided strongly in favor of affording people the option of community rather than institutional living.

While the settlement of the Coffelt class action litigation may have slowed community placement initiatives, and providers may have necessarily grown rapidly, there are now movements afoot in California that would reinvigorate the transition from DC to community supports. “Project Butterfly” is a joint effort of four Regional Centers to work with DDS to bring their citizens back home from DCs. The mission statement of Wing of the Butterfly Project is:

Identify, develop and recommend effective tools and processes for:

- *assessing and planning the transition of developmental center residents into the community*
- *capturing uniform information on individual baselines and outcomes*
- *sharing stories to educate the public and develop support.*

Our primary objective is to enhance quality of life for people with developmental disabilities through person-centered planning and partnership building.

This is the first time, to our knowledge, that local agencies have demanded that their citizens be permitted by the state to come home. All major past deinstitutionalization efforts have resulted either from litigation or from top-down policy initiatives.

It is possible that California will soon undergo continued DC downsizing. The people who live in DCs and their families may be offered opportunities to see, visit, and experience community homes. It remains to be seen what choices will be made by the people and their allies. In any case, the present Quality Tracking Project and/or its successor project(s) is mandated by law to track all the people who leave DCs, and to monitor their well-being. This is a very positive policy. It means that California will always be in possession of the hard scientific data necessary to determine whether the community movement produced good outcomes. Therefore California will always be able to judge whether these actions comprised good social policy.

Field Work

Activity Report

Work began promptly in July of 2000. The list of people to be visited was assembled by COA from the prior year's list of people visited plus people we attempted to visit but could not. The list included names, addresses, phone numbers and other pertinent individual information.

People were divided into two lists: the Movers Group, composed of individuals who had lived in an Institution and moved starting in 1993, and the Community Target Group composed of people who had never lived in an institution. The Movers list included 2,466 people and the Community Target Group included 62 people for a total of 2,528 people. Visitors were instructed to start with last year's unreachable folks and the 133 new people that were added by DDS. It should be noted that DDS sent COA two different lists combining a total of 256 'new' people to be visited. However, the three Field Coordinators alerted COA that 123 of these 256 additional people had already been identified and visited by COA in the previous year. COA resolved this matter by isolating only the 133 people who were 'true' add ins and scheduled them to be visited.

The three Field Coordinators divided the list among themselves according to Regional Centers, so that each RC would have a single point of contact with COA. Regional Centers were divided into three areas as follows:

Abbreviation	Regional Center Name	COA Area
CVRC	Central Valley RC	Central
KRC	Kern RC	Central
TCRC	Tri-Counties RC	Central
ACRC	Alta RC	North
FNRC	Far Northern RC	North
GGRC	Golden Gate RC	North
NBRC	North Bay RC	North
RCEB	East Bay RC	North
RCRC	Redwood Coast RC	North
SARC	San Andreas RC	North
VMRC	Valley Mountain RC	North
DDC (RCOC)	Developmental Disabilities RC (Orange County RC)	South
ELARC	Eastern L.A. RC	South
FDLRC	Lanterman RC	South
HRC	Harbor RC	South
IRC	Inland East RC	South
NLACRC	North L.A. County RC	South
SCLARC	South Central L.A. RC	South
SDRC	San Diego RC	South
SGPRC	San Gabriel/Pomona RC	South
WRC	Westside RC	South

The Central area was responsible for approximately 600 visits, the South for 800, and the North for 1100. These numbers are given as approximate because there was movement from one Area to another. The three Field Coordinators were in constant communication with one another, so that a person who had been in one Area the year before, but had moved into another Area, could be reassigned rapidly.

The three Field Coordinators became so familiar with the visiting process, and so skilled in making adjustments, that no central coordination function was necessary. From COA's perspective, the removal of our State Coordinator in the spring of 2000 posed absolutely no difficulties for the project. In fact, the Field Coordinators report higher efficiency and timeliness in the absence of the State Coordinator function.

The Southern Area employed an average of 11 Visitors, the North 11, and Central 6. These Visitors were trained in PLQ administration and procedures by the Field Coordinators. Field Coordinators assigned individual interviews to the Visitors on a geographic basis, again so that Regional Centers would have a single point of contact with COA in nearly every case. In each Area, more Visitors were trained than were actually needed. This ensured backups for Visitors who dropped out for various personal reasons.

At this writing, more than 90% of the people have been Visited. COA has 1,805 PLQs in house, and 1,094 have been entered into our statistical package for analysis. By the end of March, all Visits will be completed, and all data will be entered. Our draft final report is due on May 25. We will have two full months to compile and complete the draft final report.

The Field Coordinators report relatively simple and straightforward field activities. Regional Centers and provider agencies are reasonably familiar with this process by now, and cooperation has been generally excellent. When overnight stays were necessary Field Coordinators reviewed and approved travel expenses.

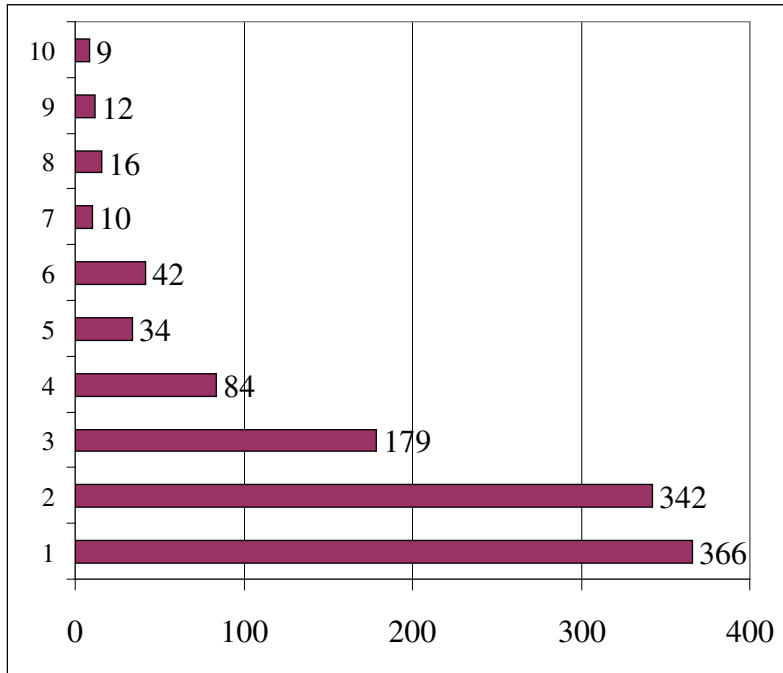
Our Visitors are instructed to obtain access to the person, the person's records, and "whoever knows the person best." Field Coordinators unanimously report that the best respondent for knowing about all aspects of an individual's life is usually the QMRP or House Manager. These respondents have full knowledge of individual lives, all the way from behavior to choice making and individual planning. The process of obtaining information for the PLQ is reported to be smooth and efficient, although not easy. The Field Coordinators have devoted substantial time to reviewing the quality of incoming PLQs, and following up with Visitors to

remind and retrain them on COA's rules and procedures for accurate completion of the forms.

The PLQs took an average of 79.64, or roughly 80 minutes of on-site time to complete. There was a great deal of variation around this average. The minimum time for completion was 30 minutes, and the maximum was 340 minutes (5 hours and 40 minutes). The standard deviation was 27 minutes. These figures exclude breaks, interruptions, and down time. It also does not count the time Visitors spend reviewing the form after leaving, checking answers for consistency, and ensuring readability. For the wealth of outcome and quality of life information obtained, an 80 minute visit once a year could be interpreted as a very modest "investment" with a very positive "payoff."

In the year 2000, we included a page called the Contact Log. Visitors were instructed to note all the contacts made during the process of scheduling and completing a PLQ. The average Visit required 2.5 preliminary contacts in order to conduct and complete a PLQ Visit. The graph below shows how many contacts were required for the people in our preliminary data set.

Figure 2
Number of Contacts Necessary to Schedule and Complete Visits



The bar graph shows that, for 366 people, only one preliminary contact was needed. This preliminary contact was almost always done by telephone. For another 342 people, two preliminary contacts were needed. At the extreme, 9 people required 10 preliminary contacts before the Visit could be completed.

The Principal Investigator interviewed all three Field Coordinators in preparation for this Report. The final question in the interview was “What suggestions do you have to make the process go better next year?” The consistent feeling was that this project’s field work is now operating at maximum efficiency. No major suggestions were offered. Minor

suggestions included 100% reliability as to timely payment of Visitors, shortening the PLQ instrument package, and testing video conferencing methods to keep Visitors in close touch with project supervision.

Projections

All 2,528 residential PLQ visits are scheduled for resolution by the end of March, 2001. By resolution we mean that all people will be located and identified, but not all people will be physically visited.

It is understood that some people will not be visited by the end of the work year, because some will have moved, graduated from the human service system, died, a few may refuse to be included, and others may fail to keep three or more appointments.

The day service visits will be completed by Mid-April 2001. We have been extremely careful to avoid intrusion into peoples' work environments if they are holding real jobs in the competitive employment market. (There are only about 20 such people.) Such intrusion at the work site would be inappropriate and unjustified. In any case, the necessary information can be collected at the home for these people. There is no reason to intrude on their job sites.

For most of these people, we can obtain complete information about day activities from the residential site. As noted above, this is also true for people with real jobs. About half of the peoples' day activities are provided by the same vendors that provide the residential program, hence thorough information about the day services is readily obtained during the residential visits. We expect that separate day service data collection visits will only be needed for 600 to 800 individuals.

These scheduled completion dates will permit analysis of the full data set to begin in April 2001. Draft results will be available at the end of May 2001. Final results will be delivered by the end of the contract year. Some family survey returns are likely to extend beyond June 30, 2001. However, we have already begun to send out the first wave of family survey forms. About 500 people will be covered in this first wave. We will have fairly complete family survey data available before the end of the contract year.

Preliminary Descriptive Data

Characteristics of the 1,025 Movers

At the time of this writing, we have completed visits with 1,805 people affected by the Coffelt settlement agreement. This progress report reflects the 1,025 Movers that have been entered in our database to date. Table 1 shows the distribution of basic characteristics among the 1,025 Movers, including sex, ethnicity, average age, and label for level of mental retardation.

Table 1
Characteristics

Percent Male	61.6%
Percent Minority	28.1%
Average Age	42.4
Percent Mild	17.3%
Percent Moderate	10.5%
Percent Severe	12.3%
Percent Profound	56.9%

The people are 61% male. The people are reported to be about 30% minorities. The average age of the people is 42 years. About 70% of the people are labeled severely or profoundly mentally retarded.

Table 2 shows the disabilities other than mental retardation that the people report as major conditions.

Table 2
Secondary Disabilities

Ambulation	30.5%
Autism	10.8%
Aggressive Behavior	35.9%
Brain Injury	8.6%
Cerebral Palsy	21.6%
Communication	63.9%
Dementia	1.3%
Major Health Problems	31.2%
Hearing	6.1%
Mental Illness	24.2%
Physical Disability	20.3%
Seizures	35.3%
Self Abuse	23.1%
Substance Abuse	2.2%
Swallowing	8%
Vision	12.2%
Other	15.6%

Communication and aggressive behavior difficulties are the most frequently reported secondary conditions. The people display multiple major secondary disabilities. Other areas include ambulation, major health problems, and seizures.

Table 3 depicts the current living situations of the 1,025 people.

Table 3
Current Homes

Type of Residence	Number	Percent
ICF/DD-N 4-6 BEDS, NURSING	227	22.1%
ICF/DD-N 7-15 BEDS, NURSING	12	1.2%
ICF/DD-H 4-6 BEDS, HABILITATIVE	251	24.5%
ICF/DD-H 7-15 BEDS, HABILITATIVE	3	0.3%
CCF L2 OWNER	4	0.4%
CCF L2 STAFF	3	0.3%
CCF L3 OWNER	17	1.7%
CCF L3 STAFF	52	5.1%
CCL L4-A/STAFF	7	0.7%
CCF L4-B/STAFF	3	0.3%
CCF L4-C/STAFF	26	2.5%
CCF L4-D/STAFF	9	0.9%
CCF L4-E/STAFF	8	0.8%
CCF L4-F/STAFF	51	5.0%
CCF L4-G/STAFF	59	5.8%
CCF L4-H/STAFF	39	3.8%
CCF L4-I/STAFF	144	14.0%
ADULT FOSTER CARE	1	0.1%
FOSTER CARE, DEPT OF SOC SRVCS	1	0.1%
ADULT FAMILY HOMES SB1730	5	0.5%
SUPPORTED LIVING >21 HRS WK	58	5.7%
SUPPORTED LIVING 11-20 HRS WK	1	0.1%
SUPPORTED LIVING 0-10 HRS WK	1	0.1%
INDEPENDENT LIVING	6	0.6%
IN PARENT'S HOME	16	1.6%
IN OTHER RELATIVE'S HOME	6	0.6%
IN FRIEND'S HOME	3	0.3%
OTHER COMMUNITY SETTING	12	1.2%
Total	1,025	100.0%

In our data, the most common type of community home was the ICF/DD-H (4-6 Beds). The ICF/DD-H (4-6 Beds) served 24.5% of the people in our sample. The ICF/DD-N (4-6 Beds) was next, with 22.1%, and was followed by CCF Level 4-I Staff with 14%. If we combine categories, 48% of people are in some variety of ICF, and 41% are in some kind of CCF.

Perceived Quality of Life Changes

A key element of the Personal Life Quality protocol is the perceived quality of life changes section. It is important to note that these changes are *perceived*, changes as the respondent sees them. There are fourteen questions that may be answered by the focus person or by the person who knows the person best. For the purpose of this report, we have analyzed the answers of the two respondent groups separately.

Table 4

Quality of Life Changes
 “Then” (Back at the DC) and
 “Now”(In the Community Home)
Answered by Focus Person
N = 138

	Then	Now	Change	t	Sig.
Health	3.07	4.06	0.99	-8.386	0.000*
Running my own life	2.39	4.08	1.69	-13.688	0.000*
Family relationships	2.87	3.55	0.68	-7.383	0.000*
Seeing friends	2.69	3.99	1.30	-10.764	0.000*
Getting out	2.46	4.13	1.67	-12.432	0.000*
What I do all day	2.58	4.00	1.42	-11.509	0.000*
Food	2.61	4.30	1.69	-12.847	0.000*
Happiness	2.35	4.26	1.91	-16.629	0.000*
Comfort	2.47	4.31	1.84	-15.579	0.000*
Safety	2.56	4.41	1.85	-15.001	0.000*
Treatment by staff	2.68	4.35	1.67	-13.060	0.000*
Dental care	2.91	3.75	0.84	-7.291	0.000*
Privacy	2.26	4.06	1.80	-14.329	0.000*
Overall Quality of Life	2.50	4.18	1.68	-14.087	0.000*

* Indicates significance a .05.

When the questions related to quality of life “Then” (back at the DC) and “Now” were answered in their entirety by the focus person (N = 138), all 14 dimensions, including “Overall Quality of Life” increased significantly from “Then” to “Now”. The largest increases were in “Happiness” (1.91), “Safety” (1.85), and “Comfort” (1.84). The smallest increases, from “Then” to “Now”, were in “Dental Care” (.84) and “Family Relationships” (.68).

Table 5
Quality of Life Changes
“Then” (Back at the DC) and
“Now”(In the Community Home)
Answered by the Person Who Knows the Focus Person Best
N = 822

	Then	Now	Change	t	Sig.
Health	3.66	4.23	0.57	-14.752	0.000*
Running my own life	3.19	3.92	0.73	-17.004	0.000*
Family relationships	2.77	3.14	0.37	-7.622	0.000*
Seeing friends	3.22	3.92	0.70	-15.445	0.000*
Getting out	3.37	4.24	0.87	-18.100	0.000*
What I do all day	3.49	4.33	0.84	-18.157	0.000*
Food	3.78	4.50	0.72	-16.420	0.000*
Happiness	3.58	4.51	0.93	-19.259	0.000*
Comfort	3.78	4.68	0.90	-19.293	0.000*
Safety	4.11	4.76	0.65	-15.407	0.000*
Treatment by staff	4.03	4.79	0.76	-16.777	0.000*
Dental care	3.73	4.33	0.60	-14.280	0.000*
Privacy	3.41	4.38	0.97	-18.393	0.000*
Overall Quality of Life	3.68	4.54	0.86	-18.766	0.000*

* Indicates significance a .05.

When the same quality of life questions were answered, by the person who knows the focus person best, again, all 14 dimensions increased significantly from “Then” to “Now”. The overall increases were not as large, but the increases were statistically significant at the .05 level. The largest increases were in the areas of “Privacy” (.97), “Happiness” (.93) and “Comfort” (.90). The areas with the smallest increases were “Family Relationships” (.37) and “Health” (.57).

In comparing the two respondent groups, it is interesting to note that two of the three largest areas of increased quality of life matched (happiness and comfort.) Similarly, one of the two smallest areas of increased quality of life matched (Family Relationships.)

The “Quality of Life Changes” scale is reproduced on the following page for reference.

Quality of Life Changes

To Be Answered by the Person OR the Respondent Who Knows the Person Best

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Obtain ratings of each quality of life for this person THEN, BACK AT THE DC, and NOW, IN THE COMMUNITY HOME.

If the person can't answer, accept answers from whoever knows the person best. These surrogate respondents may not have first hand knowledge of conditions back at the DC, but we will accept their perceptions based on what they have read, heard, and been told by the person (and others close to the person). If the surrogate respondent really cannot comment on conditions at the DC, leave that column blank.

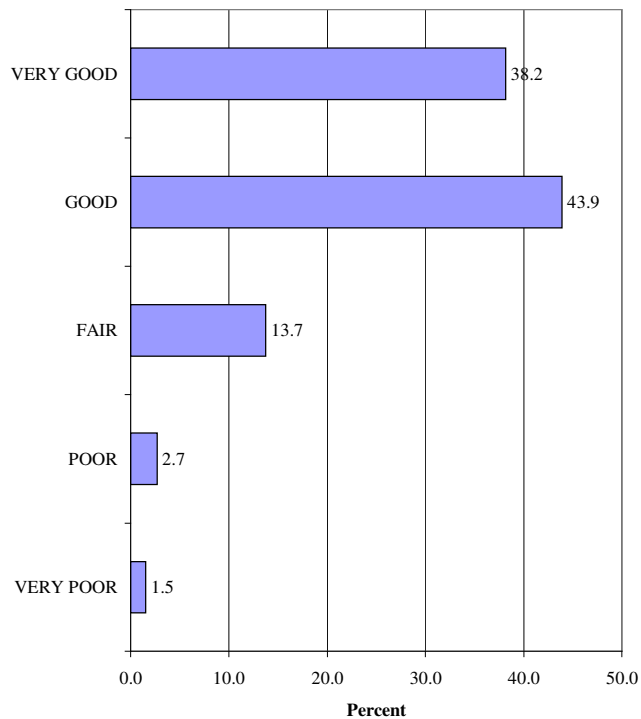
- 1 = Very Bad**
- 2 = Bad**
- 3 = OK**
- 4 = Good**
- 5 = Very Good**

	THEN, BACK AT THE DC	NOW, IN THE COMMUNITY HOME
1. Health	1T. _____	1N. _____
2. Running my own life, making choices	2T. _____	2N. _____
3. Family relationships	3T. _____	3N. _____
4. Seeing friends, socializing	4T. _____	4N. _____
5. Getting out and getting around	5T. _____	5N. _____
6. What I do all day	6T. _____	6N. _____
7. Food	7T. _____	7N. _____
8. Happiness	8T. _____	8N. _____
9. Comfort	9T. _____	9N. _____
10. Safety	10T. _____	10N. _____
11. Treatment by staff/attendants	11T. _____	11N. _____
12. Dental care	12T. _____	12N. _____
13. Privacy	13T. _____	13N. _____
14. Overall quality of life	14T. _____	14N. _____

Personal Interview

This section of the Personal Life Quality protocol is reserved for direct responses from focus people who can and will communicate with the COA visitor. Figure 3 is based on the responses of the 262 people who were able to do so.

Figure 3
How Do You Feel About Living Here?



The majority of the 262 people who responded (82%) said that they felt “Good” or “Very Good” about their current living situation. Only 1.5% of the people responded “Very Poor.” This demonstrated relatively high satisfaction levels. These responses from the people themselves will be compared to the family responses at the end of this contract year. In prior

years, both the individuals and their families strongly agreed that community homes are preferable to institutions.

References

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Appendix A

Legislative Authority for the Quality Tracking Project

Welfare & Institutions Code 4418.1

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