

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

**Semi-Annual Report
(Year 3)**

Submitted to:

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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. In addition to the individual and family surveys, we distributed postcards inquiring about the data collection phase of the project; specific questions asked included: "Was the visitor on time for the appointment," and "Was the visitor pleasant."

COA submits two major reports for each year of the study: a semi-annual field progress report in February and a final annual report in June 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 third year of the study and describes the fieldwork from July 2001 through February 2002.

The purpose of this report is to present a comprehensive progress report on the status of the project, 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.

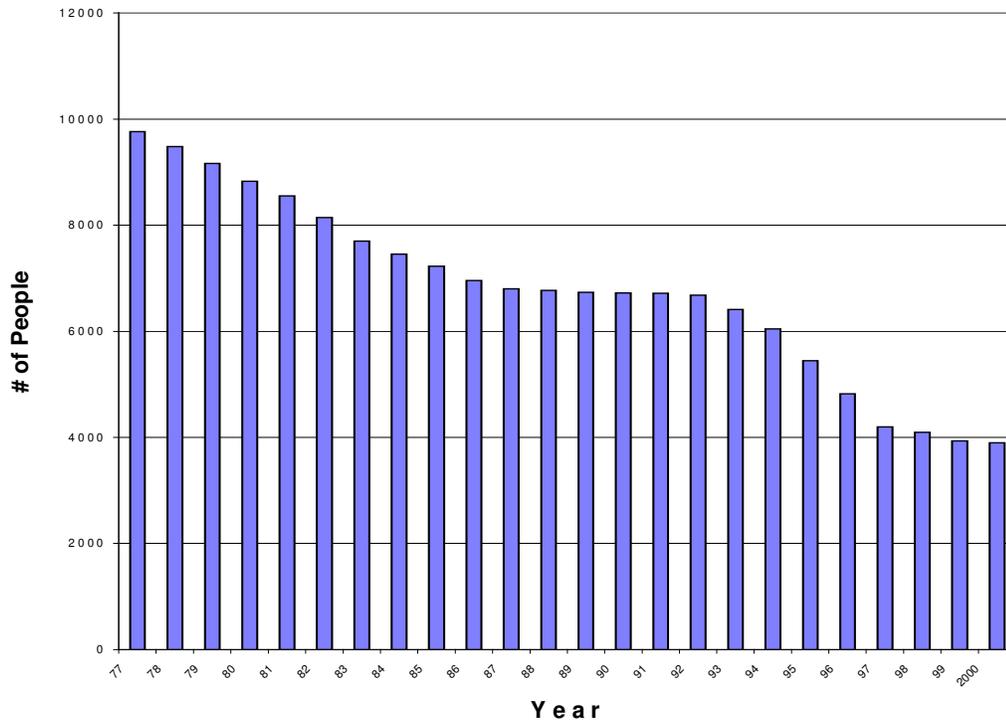
The following sections detail our work to date. In summary, 1,766 visits were completed and data from 1,510 of those visits were entered into the computer database. In addition, 1,595 Quality Feedback Summaries were completed, with copies sent to the appropriate Regional Centers. Another 1,022 visits were conducted at people's day programs, and 572 Family Surveys were mailed. A total of 278 visitor feedback postcards were received and entered into our database through February 2002.

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 manage 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.

Court cases, e.g. *Richard S. vs. DDS et al.*, that resulted from the stopping of community placements 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 the people and their allies will make. 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. California

can continue to measure, based on hard scientific data, whether community movement is producing good outcomes. California will always be able to measure whether these actions comprise good social policy.

Field Work

Activity Report

Work began promptly in July of 2001. 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. A total of 2487 people were contained on this list, with 2349 being carried over from last year and 139 added by DDS.

The three Field Coordinators divided the list among themselves according to Regional Centers, so that each Regional Center 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 Regional Center	Central
KRC	Kern Regional Center	Central
TCRC	Tri-Counties Regional Center	Central
ACRC	Alta Regional Center	North
FNRC	Far Northern Regional Center	North
GGRC	Golden Gate Regional Center	North
NBRC	North Bay Regional Center	North
RCEB	East Bay Regional Center	North
RCRC	Redwood Coast Regional Center	North
SARC	San Andreas Regional Center	North
VMRC	Valley Mountain Regional Center	North
DDC (RCOC)	Developmental Disabilities Regional Center (Orange County Regional Center)	South
ELARC	Eastern Los Angeles Regional Center	South
FDLRC	Lanternman Regional Center	South
HRC	Harbor Regional Center	South
IRC	Inland East Regional Center	South
NLACRC	North Los Angeles County Regional Center	South
SCLARC	South Central Los Angeles Regional Center	South
SDRC	San Diego Regional Center	South
SGPRC	San Gabriel/Pomona Regional Center	South
WRC	Westside Regional Center	South

The Central area was responsible for approximately 550 visits, the South for 850, and the North for 1000. 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. The Southern Area employed an average of 8 Visitors; the North has 9, and Central 6. Many of these visitors have continued to be part of the three-year study – offering continuity to the project. The Field Coordinators trained these Visitors in PLQ administration and procedures. 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 insured backups for Visitors who dropped out for various personal reasons.

At this writing, more than three-quarters of all scheduled visits have been completed. COA has physically received 1,766 PLQs, and 1,510 have been entered into our statistical package for analysis. By the end of March, we expect all Visits will be completed, and all data will be entered. The final draft report is due on May 17, giving us two full months to compile and complete that draft.

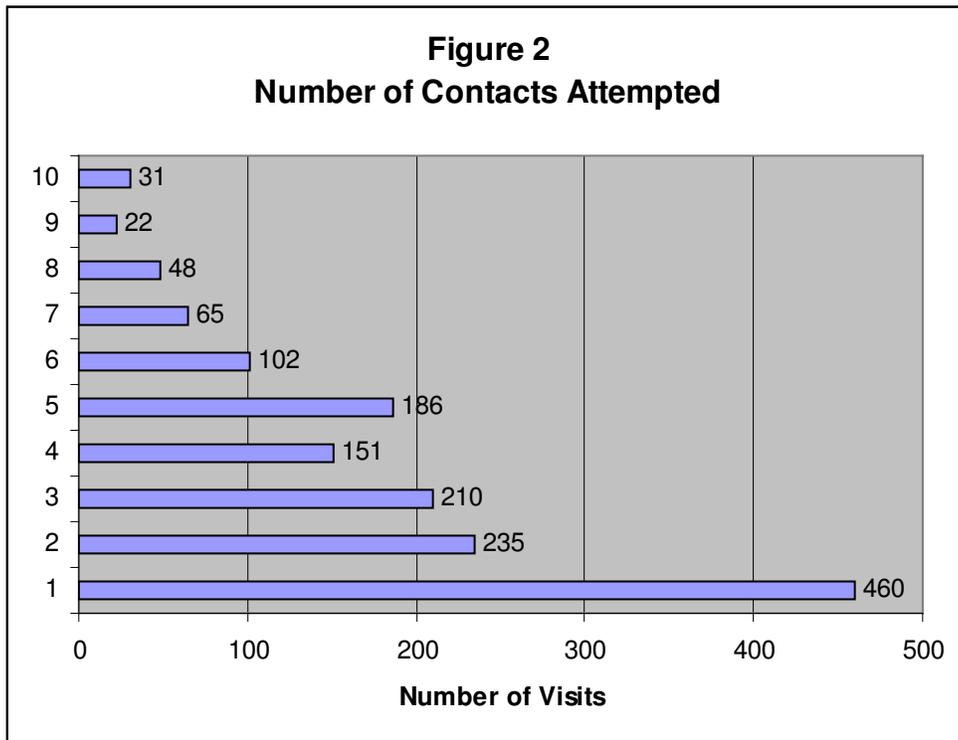
The Field Coordinators report relatively simple and straightforward field activities. Regional Centers and provider agencies are reasonably familiar with this process by now, and cooperation has been generally excellent. When overnight stays were necessary Field Coordinators reviewed and approved travel 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 person who knows the most about all aspects of an individual's life is usually the Qualified Mental Retardation Professional 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 always 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 75.4 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 195 minutes (3 hours and 15

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.”

Last year, we included a Contact Log in order to track the number of attempts at contacting consumers, before the Visitors considered the interview incomplete. This year, these data were useful in setting an importance list, in which consumers that were unable to be contacted last year were put on top of the Visitor’s lists. The average Visit required 3.3 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.



The bar graph shows that, for 460 people, only one preliminary contact was needed, while 235 consumers needed 2 preliminary contacts before the interview was completed. This preliminary contact was almost always done by telephone. At the extreme, 10 preliminary contacts were made for 31 people before the Visit could be completed.

Projections

All 2,487 residential PLQ visits are scheduled for resolution by the end of March 2002. By resolution we mean that all people will be located and identified.

The day service visits will be completed by Mid-March 2002. For most of these people, we can obtain complete information about day activities from the residential site. 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 2002. Draft results will be available by the middle of May 2002. Final results will be delivered by the end of the contract year.

Our first round of 572 family surveys was mailed in January. This number only includes families that wished to be contacted for this survey. By the end of the contract year, our family survey data will be more complete than in any year past. We will report all survey data that have been received by May 1, 2002.

Preliminary Descriptive Data

Characteristics

Table 1.
Demographics

Percent Male	60.9
Percent Minority	30.2
Average Age	43.0

From the 1510 Personal Life Quality Protocol's (PLQ's) we have received and entered so far, we have garnered important demographic information about the respondents. More than three-fifths (60.9%) of the respondents were male; 30.2% of the respondents were minority; and the average age of the consumers in this study was 43 years of age.

Table 2.
Label of Level of Mental Retardation

Label	Frequency	Percent
Not Labeled as Mentally Retarded	12	0.8%
Mild	265	18.4%
Moderate	139	9.6%
Severe	242	16.8%
Profound	771	53.5%
Retardation Present, No Level Assigned	13	0.9%
Total	1442	100.0%

More than one-half of the consumers surveyed (53.5%) were labeled as having Profound Mental Retardation. 18.4% of the respondent's level of mental retardation was classified as Mild, while 16.8% were given the label of Severely

Retarded. Less than 10% (9.6%) are described as Moderately Retarded, and less than 2% (.8% and .9%) are either Not Labeled as Mentally Retarded or No Level of Retardation Was Assigned to the respondent.

**Table 3.
Secondary Disabilities**

Major Disability	Frequency	Percent*
Ambulation	436	28.9%
Autism	146	9.7%
Aggressive Behavior	551	36.5%
Self Abusive Behavior	393	26.0%
Brain Injury	115	7.6%
Cerebral Palsy	312	21.5%
Communication	942	62.4%
Dementia	13	0.9%
Major Health Problems	444	29.4%
Hearing	65	4.3%
Mental Illness	341	22.6%
Physical Disability	231	15.3%
Seizures	479	31.7%
Substance Abuse	48	3.2%
Inability To Swallow Independently	134	9.2%
Vision	207	13.7%
Other	130	8.6%

* Numbers add up to more than 100% because respondents can give more than one answer.

Table 3 shows us the number of secondary disabilities reported that the respondent's classify as major in their lives. More than half of those surveyed (62.4%) reported a major disability with Communication. 36.5% have Aggressive Behaviors, while 26% have had Self Abusive Behaviors. Almost one-third of the

respondents (31.7%) have problems with Seizures, 29.4% have major non-specific Health Problems, and 28.9% reportedly were having Ambulation problems when interviewed. 22.6% were reported to have significant problems with Mental Illness, while 21.5% were reported to have Cerebral Palsy. All of the remaining disabilities pertained to less than 10% of the survey population.

**Table 4.
Current Homes**

Type Of Residence	Frequency	Percent
Porterville Developmental Center	15	1.0%
Sonoma Developmental Center	9	0.6%
Skilled Nursing Facility	13	0.9%
Private Facility >15 Beds	6	0.4%
Hospital, Acute Care	2	0.1%
Nursing Home	1	0.1%
Sierra Vista Developmental Center	4	0.3%
ICF Or SNF 4-15 Beds, Generic	4	0.3%
ICF/DD 4-15 Beds	9	0.6%
ICF/DD-Nursing 4-6 Beds,	296	20.7%
ICF/DD-Nursing 7-15 Beds,	12	0.8%
ICF/DD-Habilitative 4-6 Beds,	307	21.5%
CCF L1 Owner/Staff	1	0.1%
CCF L2 Owner	1	0.1%
CCF L2 Staff	9	0.6%
CCF L3 Owner	29	2.0%
CCF L3 Staff	58	4.1%
CCF L4-A/Staff	3	0.2%
CCF L4-B/Staff	4	0.3%
CCF L4-C/Staff	32	2.2%
CCF L4-D/Staff	17	1.2%
CCF L4-E/Staff	16	1.1%
CCF L4-F/Staff	34	2.4%
CCF L4-G/Staff	74	5.2%
CCF L4-H/Staff	45	3.1%
CCF L4-I/Staff	215	15.0%
Foster Care, Department Of Social Services	4	0.3%
Adult Family Homes as defined by SB1730	6	0.4%
Supported Living >21 Hrs Wk	116	8.1%
Supported Living 11-20 Hrs Wk	1	0.1%
Supported Living 0-10 Hrs Wk	10	0.7%
Independent Living	14	1.0%
In Parent's Home	26	1.8%
In Other Relative's Home	4	0.3%
In Friend's Home	2	0.1%
Homeless Or Sleeps In Shelter	1	0.1%
Other Community Setting	29	2.0%
Total	1429	100.0%

The largest percentage of respondents lived in “ICF/DD-Habilitative with 4-6 Beds,” (21.5%) and in “ICF/DD-Nursing with 4-6 Beds” (20.5%). When added together, nearly 44% people are housed in ICF’s, down from 48% last year. The

number of people living in CCF's this year dropped from 41% of the population last year to 37.6%.

Perceived Quality of Life Changes

**Table 5.
Perceived Quality of Life**

	Then	Now	Change	Significance
Health	3.2	4.1	0.9	0.000*
Running My Own Life, Making Choices	2.5	4.0	1.5	0.000*
Family Relationships	2.6	3.1	0.5	0.000*
Seeing Friends, Socializing	2.7	3.9	1.2	0.001*
Getting Out And Getting Around	2.5	4.3	1.8	0.000*
What I Do All Day	2.6	4.2	1.6	0.000*
Food	2.8	4.3	1.6	0.005*
Happiness	2.7	4.3	1.6	0.001*
Comfort	2.8	4.4	1.7	0.003*
Safety	2.9	4.4	1.5	0.000*
Treatment By Staff/Attendants	2.9	4.5	1.6	0.000*
Dental Care	3.2	4.1	0.8	0.000*
Privacy	2.5	4.3	1.8	0.000*
Overall Quality Of Life	2.7	4.4	1.7	0.000*

* Indicates significance at the .05 level, using a single tailed t-test.

The Quality of Life scale subjectively measures how the respondents feel about their lives when asked to compare “Then” to “Now.” We can then see if the respondents feel that their lives have gotten better lately, or worse. The items are scored from one to five, with one meaning “Very Bad,” and five meaning “Very Good.” All of the items this year experienced a positive gain from “Then” to “Now.” The greatest gain was seen in Privacy and Getting Out (both +1.8 points). Only Health, Family Relationships and Dental Care did not show a change of greater than a full point (+.9, +.5, and +.8, respectively). The people’s Overall

Quality of Life rose by an average of nearly two points (+1.7), this change can be equated to a person changing their view of life from Bad to Good.

Feedback Postcard

We have so far received 278 feedback postcards. These postcards were only sent to people who were not opposed to further contact from the visitors. Each had five questions focusing on the quality of the Visitor with regard to the interview. Following the tables for each item on the postcard is a selection of several comments written by the respondents on the postcards.

We feel these postcards are a very important part of our study, because one of the most readily given complaints about government-funded surveys, and our study in particular, is the inconvenience of the survey and a feeling of prying by the interviewers. Our data show these complaints to be completely unfounded in this particular project.

Typically, most people who take the time to fill out feedback forms do so in order to complain about service, or another aspect of their experience. The responses we received were overwhelming positive. Most people will not take the time to fill out a feedback form just to give positive feedback, but we found differently.

Table 6.
Did The Visitor Schedule The Survey At Your Convenience?

	Frequency	Percent
Yes, Definitely	261	94.6%
Yes, Probably	10	3.6%
In Between	4	1.4%
No, Definitely Not	1	0.4%
Total	276	100.0%

More than 98% of the respondents said that the Visitor was able to schedule the survey at a convenient time. Nearly 95% felt that the survey was scheduled in a manner that was “Definitely” convenient. Just a single person (.4% of the postcards received) felt that the survey was not scheduled conveniently for them.

Table 7.
Was The Visitor On Time For The Appointment?

	Frequency	Percent
Yes, Definitely	256	92.8%
Yes, Probably	15	5.4%
No, Probably Not	1	0.4%
No, Definitely Not	4	1.4%
Total	276	100.0%

Table 7 can be compressed into two categories, Yes and No. With respect to more than 98% of the consumers from whom we received a feedback card, the Visitor was on time for the scheduled appointment. In only five instances, the Visitor was late.

Tables 6 and 7 show us that these interviews can be reliably completed without causing undue stress on the respondent’s day and schedule.

Table 8.
**Did The Visitor Attempt To Interview
The Person With The Disability?**

	Frequency	Percent
Yes, Definitely	255	95.1%
Yes, Probably	3	1.1%
In Between	5	1.9%
No, Probably Not	2	0.7%
No, Definitely Not	3	1.1%
Total	268	100.0%

For certain parts of the survey instrument, it is essential that we attempt to interview the person rather than a surrogate (e.g. Personal Interview, to a lesser extent the Perceived Quality of Life scale, amongst others). That is why it is imperative that the interviewer attempt to interview the person. If this is not done, there is a chance that the surrogate may give different responses than the person him or herself. If the visitor cannot interview the person, one source of very important data, the Personal Interview, is skipped.

As we can see in Table 8, more than 96% of the respondents felt that the visitor made an attempt to communicate, and actually interview, the consumer. Only five respondents felt that little or no attempt was made.

Table 9.
Did The Visitor Respect The Time And Space Of Others In Your Home?

	Frequency	Percent
Yes, Definitely	271	98.9%
In Between	2	0.7%
No, Definitely Not	1	0.4%
Total	274	100.0%

Respecting the time and space of people that live with the interviewee is an intensively important part of the interviewing process. How people live in their own home is a matter of strict privacy, and we take great care not to disturb or invade the privacy of the person's housemates. In virtually all of the interviews (98.9%), the Visitor was noted respecting the time and space of the others in the home.

**Table 10.
Was The Visitor Pleasant?**

	Frequency	Percent
Yes, Definitely	271	98.2%
In Between	3	1.1%
No, Definitely Not	2	0.7%
Total	276	100.0%

More than 98% of the responses we received for this item said that the Visitor was pleasant during their interview. Only two respondents felt that the Visitor that met with them to conduct the interview was not pleasant. Three people reported an “In Between” feeling about the pleasantness of the interviewer; even considering this answer as negative, less than 2% of the interviews were unpleasant interactions for the respondents.

**Table 11.
Comments**

Was late due to went to old address.
Very nice man, seemed very caring for clients needs.
Absolutely wonderful. Kind & considerate. We loved his visit.
Clients non-verbal, she observed & interacted with client.
Punctual & precise, an excellent evaluation.
Seemed hurried, had to take time for questions overall pleasant.
We enjoyed having the interviewer in our home.
Visitor was prompt, polite & courteous to all.
Very polite & interested in client.
She is excellent.
Does a great job & is very pleasant & respectful.
[Interviewer] is pleasant, but question/process is redundant.

We have selected 12 comments from the pool of 112 submitted. These selected comments we felt were representative of all the comments received.

When reviewing the pool of potential comments, only five were found to offer something other than a positive comment (including No Comment).

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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.