

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

**Semi-Annual Report
(Year 1) ¹**

Submitted to:

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Executive Summary

This document is a mid-year progress report on a project mandated by the California legislature in 1997. The legislation is contained in the Welfare & Institutions Code 4418.1. It reads as follows:

- (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.

The purpose of this legislation was to ensure that people with developmental disabilities are receiving the necessary services and supports, all with an eye toward a single question: “Are these people better off?”

Within this central question were many subsidiary questions, including the ways in which peoples’ qualities of life changed, how much, whether people were receiving the services and supports that were promised when they moved, and whether any problems had arisen that could be addressed quickly and effectively.

The Center for Outcome Analysis (COA) was selected to perform this work under contract with the Department of Developmental Services. The work began in mid-1999. By the time of this writing, the vast majority of the necessary field work has been completed.

This mid-year report is intended to summarize what has been accomplished, give a brief overview of the characteristics of the people who have been visited thus far, and set the stage for the annual report that will be prepared as directed by the legislature. The annual report will answer the questions about the well-being of the “Movers” (people who moved from an institution to community since April of 1993) The present report is intended to demonstrate that the work is well under way and on target for the production of the required information in an annual report.

As of this writing, 1,768 visits have been completed and the data have been entered for computer scrutiny. Descriptive analyses are presented in the Results section of this report. In addition, 1,616 Quality Feedback Summaries have been prepared and sent to the appropriate Regional Centers. Visits were conducted with people at their day activities where necessary, and there have been more than 600 such visits. Family surveys have already been mailed out to the relatives of the first 800 people visited.

We are now in the process of final collection of data from the last few available people. Data entry will be completed for the primary Personal Life Quality data within 3 weeks. In all, the project is on track for timely completion of the Annual Report.

Historical Background

Since April 1993, California's Developmental Centers have been reduced in population by more than 2,400 people. Most of the reduction has been accomplished by helping people move into small integrated homes in regular neighborhoods. Most of these people moved during the period between April 1993 and April 1997.

California's achievement can now be placed into the context of the national experience of deinstitutionalization. In the case of the Pennhurst Center (a Pennsylvania institution near Valley Forge) more than 1100 people moved to new community homes.² The Pennhurst closure was one of the most hotly contested and extensively studied of its kind. Similarly, other famous community placement processes have been studied and documented (Connecticut, Louisiana, Michigan, Minnesota, New Hampshire, New York, North Carolina, Oklahoma). California's experience with court-ordered community placement has been similar in many ways to these prior events. California does stand out in sheer numbers. The California deinstitutionalization movement has been the largest and most rapid ever implemented.

The driving force in California's efforts was a lawsuit filed in 1990, which came to be known as Coffelt v. DDS³. In February 1990, a lawsuit was filed by William L. Coffelt Jr. and 12 other named plaintiffs in order to make non-institutional community homes more readily available. This class action lawsuit resulted in a 1993 settlement agreement, in which the parties agreed to:

² Conroy, J., & Bradley, V. Conroy, J. W., & Bradley, V. J. (1985). *The Pennhurst Longitudinal Study: A report of 5 years of research and analysis*. Pennhurst Study Report PC-85-1. Philadelphia: Temple University Developmental Disabilities Center/UAP.

³ Coffelt v. Department of Developmental Services, No. 91-6401 (Cal. Super. Ct. Jan 19, 1994), MPDLR 185.

... increase the availability of quality, stable, normalized, integrated community living arrangements so that persons with developmental disabilities can obtain treatment and habilitation services and supports in the least restrictive environment; can achieve the most independent, productive and normal lives possible; can have the opportunity to be integrated into the mainstream life of their home communities; and can, with the assistance of services and supports, approximate the pattern of everyday living available to persons without disabilities of the same (Coffelt v. DDS, 1994, p 3).

According to the terms of the Coffelt settlement, at least 2,000 California citizens who have developmental disabilities were to be affected over a 5 year period. Some would be assisted in finding an alternative to being placed into a State Developmental Center, and others, who were experiencing difficulties in their community living situations, would receive additional or different supports in order to resolve those difficulties. Most of the Coffelt class members, however, were to be people who moved from state Developmental Centers (DCs) to new homes in communities.

California met the obligations of this settlement agreement ahead of schedule. By 1997, more than 2,300 people had moved out of institutions. Many other deinstitutionalizations were also hastened by court action, such as those in Pennsylvania (Pennhurst), New York (Willowbrook), and Oklahoma (Hissom). Nevertheless, the Coffelt deinstitutionalization stands as the largest and most rapid among them.

Deinstitutionalization is not a new phenomenon. In the field of developmental disabilities, it has been proceeding since 1969, and has been remarkably well studied, evaluated, and documented. There has, however, been considerable confusion between deinstitutionalization in the mental health field and deinstitutionalization in the mental retardation field.

The misunderstanding is largely due to the confusion of mental illness with mental retardation. State institutions for people with mental illness have experienced an entirely different, and devastatingly negative, depopulation movement.⁴

Deinstitutionalization of people with mental illness was done hastily, without supports, and largely with reliance on the “new miracle drugs” approved by the FDA in 1955 (the anti-psychotic drugs including Haldol, Mellaril, Thorazine, and so on). The phrase “dumping” came from the fact that tens of thousands of people were simply “discharged” with a 30 day supply of “miracle drug” with no place to live, no job or day activity, and no support to reestablish family relationships. In a summary statement of the nation’s early experience with deinstitutionalization in the mental health field, Alexander (1996) wrote:⁵

Following the deinstitutionalization of persons with serious mental illness from state hospitals, many persons with serious mental illness did not receive the care that they needed and encountered unexpected negative experiences. Among the negative experiences were frequent rehospitalizations, involvement in the criminal justice system, and homelessness.

The result in the mental health field was a national disgrace, according to Bassuk & Gerson (1978).

Figure 1 compares the two trends toward deinstitutionalization. The upper line shows the depopulation of mental health institutions since 1950, which was clearly far more precipitous than the relatively gradual shrinkage of institutions for people with mental retardation in the lower line.

⁴ Bassuk, E.L., & Gerson, S. (1978). Deinstitutionalization and mental health services. *Scientific American*, 238, 46-53.

⁵ Alexander, R. Jr. (1996). The quality of life of persons with severe emotional disability: a review of empirical studies. *Journal of Health & Social Policy*, 7:4 9-22, 1996.

Figure 1
Deinstitutionalization in the United States:
Mental Retardation vs. Mental Illness, 1950-1998

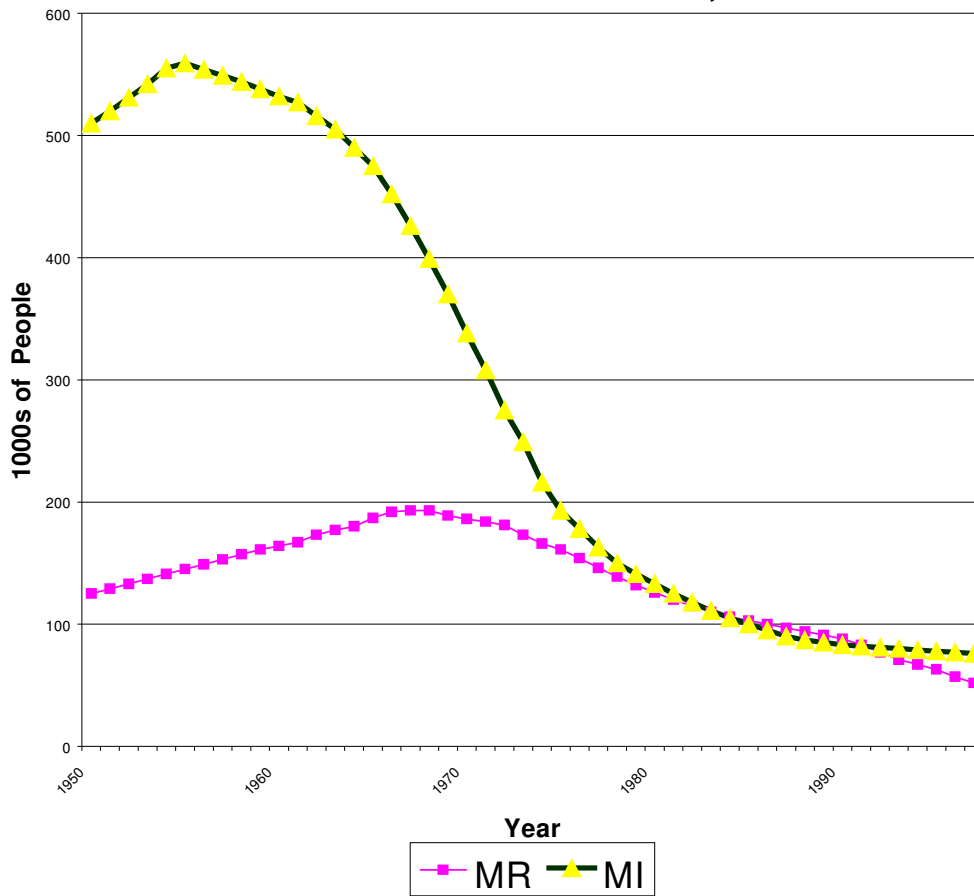


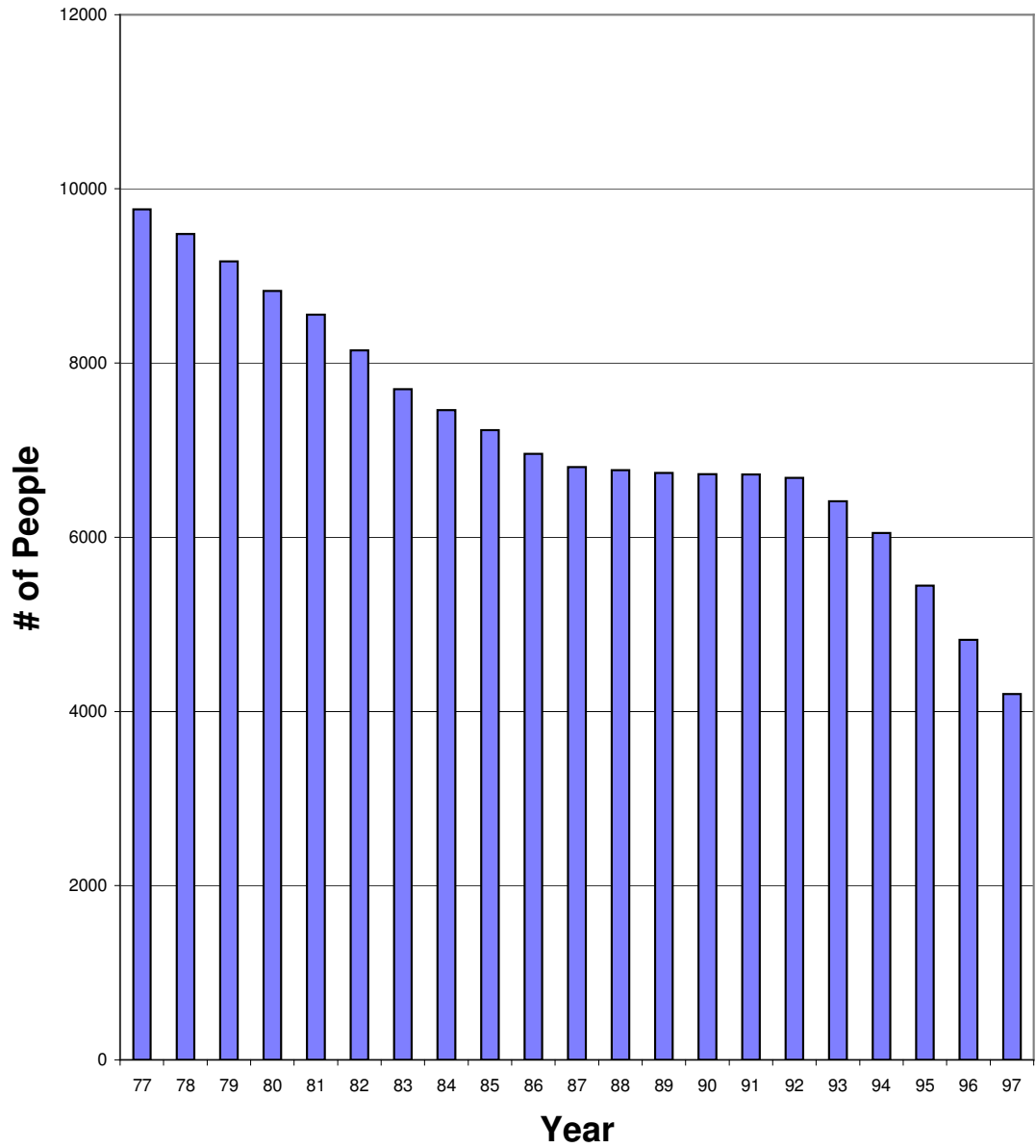
Figure 1 shows how different the two trends have been. Most citizens, and many families, who are skeptical of deinstitutionalization, formed their opinions with regard to the mental health debacle.

It is important to understand the stark difference between the national record in mental illness, versus that for mental retardation and developmental disabilities. In the case of people with developmental disabilities, moving from large institutions to small community homes has been extremely successful. There is a large body of research evidence available to support this conclusion. Much of the best evidence was summarized in a meta-analysis performed by Larson & Lakin (1989).

The historical context of California was similar to that of the nation as a whole, but with one difference that may have been significant. California

was deeply engaged in deinstitutionalization of its Developmental Centers in the late 1970s and early 1980s. Toward the middle and end of the 1980s, though, the process slowed. The availability of appropriate community options appeared to have ceased its rapid increase. This fact is shown in Figure 2. The community placement movement had, in effect, ceased in net terms. Although community placements were occurring, new admissions were keeping the overall Developmental Center census constant. Although the reasons for litigation like Coffelt v. DDS are multiple and complex, this graph provides one of the simplest and most understandable foundations for understanding the Coffelt litigation.

Figure 2
Deinstitutionalization in California:
Declining DC Populations



Methods

The purpose of any Methods section in a scientific report is to enable others to replicate our research using exactly the same methodology. This requires us to describe what we did and what we measured in enough detail to permit future researchers to duplicate our methods, and see if they arrive at similar conclusions. This section therefore describes the instruments we have used to measure qualities of life, and the procedures by which we assigned the work to our Visitors (data collectors) and implemented the data collection process.

Instruments

COA's package of measures of qualities of life is generally called the **Personal Life Quality** protocol (PLQ). Many of the elements of this package evolved from the Pennhurst Longitudinal Study (Conroy & Bradley, 1985). Pennhurst Class members have been visited annually since 1978. An extensive battery of quality-related data has been collected on each visit. Over the years, other groups have been added to the data base, such as all people living in Community Living Arrangements in Philadelphia who were not members of the Pennhurst Class.

Prior to the present work in California, the PLQ package had also been applied in deinstitutionalization studies and quality assurance systems in Arkansas, Colorado, Connecticut, Florida, Georgia, Louisiana, Maryland, Minnesota, New Hampshire, New Jersey, North Carolina, and Texas, as well as in Canada, France, and Australia. Most recently, COA's PLQ approach has been selected as the primary method for evaluating the impacts of self-

determination in the 29 participating states funded by the Robert Wood Johnson Foundation.

This comprehensive battery of instruments was based on the notion that "quality of life" is inherently multidimensional (Conroy, 1986). It is essential to measure many kinds of individual outcomes to gain an understanding of what aspects of quality of life have changed over time (Conroy & Feinstein, 1990a).

Modifications made to the battery of instruments over the years have been based on the concept of "valued outcomes" (Conroy & Feinstein, 1990b; Shea, 1992). Professionals may value some outcomes most highly, such as behavioral development; parents and other relatives may value permanence, safety, and comfort more highly; and people with mental retardation may value having freedom, money, and friends most highly. The goal in our research on deinstitutionalization, and later in self-determination, has been to learn how to measure aspects of all of these "valued outcomes" reliably.

The primary instrument package for this project is called the Personal Life Quality protocol or PLQ. It includes measures of independence, productivity, choice making, integration, friendships, behavioral progress, health, health care utilization, health care quality ratings, case management, activities and supports, individual planning, environmental qualities, and satisfaction. The PLQP used in this year's work was reviewed by a Task Force in 1999. It is available from the authors of this report and from DDS.

The reliability of the PLQP was explored in detail in Report Number 7 in the previous series, with very positive results (Conroy, 1995). The components have been subjected to other reliability tests over the years, as well (Devlin, 1989; Fullerton, Douglass, & Dodder, 1996; Isett & Spreat,

1979). The components of the PQLP have been shown to be highly objective, scientific, and reliable. The dimensions measured in the PLQP were derived from many years of interviews with services users, parents, other family members, service providers, and other stakeholders, about what is really important in peoples' lives.

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

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

- characteristics of the home environment (e.g. staffing)
- physical quality of the home environment
- individualized treatment in the home environment
- normalization in the home environment
- costs of the service/support elements
- family/next friend opinions and satisfaction

The Task Force that was convened for this project recommended that the tool utilize symbols, pictures, and/or simple language in our interviews with the focus people. Our Personal Interview was, in fact, constructed in simple language and tested more than 30,000 times across the country. We decided to use that simple-language instrument for the current project.

The Task Force also recommended that we ask questions concerning the staff of the homes, such as turnover, wages, and benefits. We did include questions about longevity for the staff, and also questions about how long a staff person has worked with the specific person being interviewed. COA has found this question to be more relevant to the quality of service delivery, and more individualized, than asking how long a person has been employed by an agency. COA collected specific wage and benefit information in California in 1995. The questions were (and had to be) optional, and the majority of staff chose not to respond. The people who did respond were unsure of their exact benefit packages. We have many alternative sources of information on staff wages and benefits, including our past data, corrected for inflation. We chose to include questions that in our experience resulted in usable data.

The second component of our instrumentation is the Family Survey. This form was derived from 20 years of work surveying the families of

people in institutions and communities. The first such survey was conducted with families of people living at Temple University's Woodhaven Center in 1975. The Pennhurst Longitudinal Study produced the next generation of family surveys, followed by versions adapted for Arizona, Arkansas, Connecticut, Colorado, Georgia, Massachusetts, New Hampshire, New Jersey, North Carolina, Oklahoma, and Texas. The 1996-97 California Coffelt Family Survey form, developed in 1993, was included in Report 12 as Appendix B. It was first sent to families of Coffelt Class Members in 1994, and every year thereafter. The results of the Family Surveys were summarized in Reports 6, 8, and 11, 12, and 14. For the current 3 year project, we will present the results of family surveys annually.

Procedures for Field Work and Data Collection

This section provides the details of our field activities, that is, what we have done in order to complete visits with approximately 1,800 individuals thus far.

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

This package is composed of many measures, scales, instruments, and interview items. Practically all of the information collected in this package is related to quality of life. In order to complete the package, you must have access to:

1. The person (to attempt a 5 to 15 minute direct interview)
2. The person's home (for a 5 to 10 minute tour and observation)
3. Whoever knows the individual best on a day to day basis (average 45 minutes)
4. The person's records, including medical records

5. In some cases, a health care professional (about 5-10 minutes)
With access to these five sources of information, you should in most cases be able to complete this package within the range of 60 to 90 minutes.

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

Each visitor was responsible for scheduling appointments and completing an assignment of visits. Visitors were instructed emphatically to respect programmatic needs, and work around them. No person's daily schedule was to be disrupted by these visits. In our community work this year, the average visit thus far has taken 82 minutes. The shortest visit took 20 minutes, the longest 250 minutes (4 hours and 10 minutes). The amount of information collected, in relation to the relatively short duration of the visits, is worthy of comment. We are able to collect reliable quantitative data on dozens of qualities of life in a very short time, with very little intrusion into peoples' lives.

Defining Tracking Areas

We defined three Tracking Areas to maximize cost and labor efficiency in data collection. Factors in making these divisions included travel distance for Visitors, communication between Area Coordinators and Visitors, and coordination between Visitors and regional centers. The 21 Regional Centers were divided into 3 Tracking Areas.

- Northern Area: Alta, North Bay, East Bay, San Andreas, Far Northern, Golden Gate, Redwood Coast, and Valley Mountain Regional Centers.
- Central Area: Central Valley, Kern, and Tri-Counties Regional Centers.
- Southern Area: Eastern LA, North LA, Orange County, Lanterman, Harbor, Inland, Westside, San Diego, San Gabriel/Pomona, and South Central LA Regional Centers.

Visitors and Area Coordinators

Area Coordinators were selected according to experience and location. Essential attributes for the job included sensitivity to people with developmental disabilities, flexibility in scheduling (for the convenience of consumers and those who support them), and familiarity with the areas to be covered. A major responsibility for Area Coordinators was the ability to minimize travel time and expenses by geographically matching Visitors and their assignments. Proximity among Visitors was also important for facilitating team building and scheduling training and monthly project meetings. Coordinators and their assignments were as follows:

- | | |
|--------------------|----------|
| 1. Susan Scott: | Northern |
| 2. Nancy Pallanes: | Central |
| 3. Rod Rhodes: | Southern |

Visitors were recruited in a variety of ways, including soliciting persons who had participated in previous studies. The primary requirement for selection was excellent interpersonal skills. Experience with and sensitivity to people with disabilities were required. The Principal

Investigator, Project Manager, and Area Coordinators all provided ongoing supervision and training.

Dr. Conroy, President of COA, conducted a full day of training for the Southern and Central area Visitors, and another full day for the Northern and Central area Visitors. He covered interview techniques, specific training on the PLQ and Day Service Instruments, how to complete the Quality Feedback Summary and the “Perceived Violations of Rights and/or Immediate Threats to Health or Safety” form, and definitions and discussions of important terms such as Individual Program Plan, Person-Centered Planning, and Case Management. In addition, the rules of privacy and confidentiality were explained and stressed. It was made clear that any violations of the right to confidentiality of the people being visited would be grounds for dismissal.

As an adjunct to training, the newly hired Visitors accompanied Area Coordinators on visits to observe interviewing techniques. For quality assurance, Area Coordinators also observed Visitors. The first training for northern California was held (at DDS in Sacramento) on August 28, 1999 and the second for southern and central California (in Arcadia) on August 29, 1999.

COA Visitor training focused on building the skills necessary for completing the interviews and stressed the importance of maintaining a position as an impartial recorder. Visitors were encouraged to establish a rapport with participants but were also cautioned against allowing personal bias or opinion to influence data collection. A total of 40 Visitors received COA orientation and training. Upon receipt of the official list from DDS, initial Visitor assignments were distributed.

Monthly meetings were convened to provide on-going training and to allow Visitors to share experiences and techniques. Topics included abuse reporting, questions about the PLQ and the other instruments, general interviewing etiquette, and scheduling concepts emphasizing flexibility and minimal intrusion. Visitors were reminded to present themselves as Visitors, not as inspectors. This approach was intended to set the desired tone for interviews and create a feeling of openness that facilitated quality data collection. Completed PLQs were collected at the monthly meetings, invoices were submitted and new assignments were distributed.

Curriculum highlights of the 10-9-99 Monthly Visitors meeting included:

- Face to Face interview for the personal interview section of the PLQ (p.38). This section captures direct information from the focus person rather than from any surrogate respondent.
- Alternative Means of Communication. Discussed examples of people who do not speak but who have developed alternate modes of communication e.g. answering yes and no questions; nodding/shaking head; blinking once for yes and twice for no.
- Obtain input from the service provider prior to beginning the personal interview regarding the most effective way to elicit information from the consumer. This might involve including a support person as part of the personal interview if the consumer's physical or emotional needs warrant this.
- Role-playing the various techniques mentioned previously.
- Visitors were instructed to abandon an interview ONLY if they attempted the above techniques and were still unable to obtain responses.

Quality Assurance and Quality Feedback

Area Coordinators were responsible for ongoing spot-checking the quality of the incoming data. Area Coordinators verified the validity of

incoming data by taking every 20th PLQ and telephoning the “primary respondent” who was interviewed. A varying set of 10 questions from the PLQ was asked to assure that the responses obtained on the PLQ did in fact match the answers given by phone. The questions were varied by the Area Coordinators so that Visitors could not predict which questions would be checked. This routine form of quality assurance resulted in the conclusion that the data collected by the Visitors met or exceeded professional standards for survey research. Coordinators detected no instances of fabricated, falsified, or carelessly collected data.

1,616 Quality Feedback Summaries had been prepared and forwarded to the appropriate Regional Centers by February 20, 2000. The Project Manager had personally visited 14 of the 21 Regional Centers to discuss the meaning and utility of these documents. The following table breaks down the QFS forms delivered thus far (as of 2/23/2000) by Regional Center.

Name RC	RC CODE	10/15/99	11/15/99	12/15/99	1/15/00	2/15/00	TOTAL
ALTA	364	15	34	1	0	0	50
CVRC	367	0	17	83	40	38	178
EBRC	380	29	0	25	13	0	67
ELARC	373	1	25	5	22	23	76
FNRC	363	0	0	1	0	0	1
FDLRC	360	0	28	6	25	8	67
GGRC	361	0	49	14	0	0	63
HRC	375	0	18	0	1	20	39
IRC	369	2	5	16	114	107	244
KRC	372	0	37	29	27	5	98
NBRC	371	39	39	3	0	0	81
NLARC	378	0	8	39	2	2	51
RCOC	368	40	30	23	16	23	132
RCRC	370	0	0	0	0	0	0
SARC	365	18	23	13	4	19	77
SDRC	362	10	40	42	5	3	100
SAPRC	379	0	8	37	9	11	65
SCLARC	374	0	27	11	12	35	85
TCRC	366	0	0	1	32	34	67
VMRC	377	0	9	2	0	6	17
WRC	376	0	14	24	10	10	58
TOTAL		154	411	375	332	344	1616

The List of People to be Visited

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 2,334 people and the Community Target Group included 91 people for a total of 2,425 people.

Visits

When scheduling appointments, Visitors were careful to set a time that would be convenient and the least intrusive for the participants. Visitors requested that relevant documents be available on the day of the visit. Visitors also completed Quality Feedback Summaries, which addressed areas of positive or negative concerns. The deadline for submission of these forms to the regional centers was 45 days from the date of the visit.

However, since COA emphasized the urgency of this feedback, a system was established to direct Visitors or Area Coordinators to send a copy of the report directly to the Regional Center and to forward the original to the COA Sacramento office. This process prevented undue delay in conveying essential information.

The Perceived Violations of Rights form was developed to note serious violations such as abuse or neglect and was submitted directly to DDS as well as to the appropriate regional center. To date only two reports of such perceived violations have been filed.

Visitors scheduled a second appointment with consumers who had outside day services. A five page form was used at this visit.

Projections

All 2,425 Residential PLQ visits are scheduled for resolution by the end of March, 2000. By resolution we mean to make explicit the fact 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. We anticipate a completion rate exceeding 80%.⁶

The day service visits will be completed by Mid-April. 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 about 600 to 800 individuals.

These scheduled completion dates will permit analysis of the full data set to begin in April. Draft results will be available at the end of May. Final results will be delivered by the end of the contract year. Some family survey returns are likely to extend beyond June 30. However, we have already begun to send out the first wave of family survey forms. About 800 people will be covered in this first wave. The next wave will be sent out in early

⁶ 80% was the completion rate achieved by Berkeley Planning Associates in a prior project noted in footnote 2 below. This figure was accepted and praised in writing by the Division of Quality Assurance of DDS. This is therefore a demonstrably acceptable completion rate for this project.

April. This way, we will have fairly complete family survey data available before the end of the contract year.

Upon completion of this first year of effort, we will be in a very strong position to answer the legislature's primary policy question: **Are the people with developmental disabilities who moved from developmental centers to the community receiving necessary services and supports?**

Results

Results 1: Characteristics of the 1,729 people

At the time of this writing, we have completed visits with 1,768 people affected by the Coffelt settlement agreement. This group includes 1,729 “Movers,” that is, people who moved out of Developmental Centers, and 39 members of the Community Target Group. In our final analyses at the completion of the data collection, we will report on the “Movers” only as required by Welfare and Institutions Code, Section 4418.1. Table 1 shows the distribution of basic characteristics among the 1,729 people, including sex, ethnicity, average age, and label for level of mental retardation.

Table 1
Characteristics

Percent Male	61.1%
Percent Minority	29.2%
Average Age	41.4
Percent Mild	17.8%
Percent Moderate	9.4%
Percent Severe	14.9%
Percent Profound	55.4%

The people are 61% male. The people are reported to be about 30% minorities. The average age of the people is 41 years. Seventy percent 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	27.2%
Autism	8.5%
Aggressive Behavior	24.1%
Brain Injury	7.0%
Cerebral Palsy	14.6%
Communication	57.4%
Dementia	1.3%
Major Health Problems	21.9%
Hearing	4.7%
Mental Illness	18.0%
Physical Disability	13.5%
Seizures	21.4%
Self Abuse	17.6%
Substance Abuse	1.3%
Swallowing	8.3%
Vision	13.6%
Other	7.7%

Communication and ambulation difficulties are the most often reported secondary conditions among the people. The people display multiple major secondary disabilities. Other areas include aggressive behavior, major health problems, seizures, and mental illness. Table 3 depicts the current living situations of the 1,729 people.

**Table 3
Current Homes**

Type of Residence	Number	Percent
Porterville DC	7	.4%
Sonoma DC	7	.4%
Agnews DC	1	.1%
Fairview DC	1	.1%
State Mental Hospital	1	.1%
ICF/DD >15 Beds	17	1.0%
Skilled Nursing Facility	16	.9%
Board And Care Home	1	.1%
Hospital, Acute Care	1	.1%
ICF/DD 4-15 Beds	18	1.0%
ICF/DD-N 4-6 Beds, Nursing	313	18.1%
ICF/DD-N 7-15 Beds, Nursing	17	1.0%
ICF/DD-H 4-6 Beds, Habilitative	455	26.3%
ICF/DD-H 7-15 Beds, Habilitative	14	.8%
CCF L1 Owner/Staff	11	.6%
CCF L2 Owner	7	.4%
CCF L2 Staff	10	.6%
CCF L3 Owner	29	1.7%
CCF L3 Staff	52	3.0%
CCF L4-A/Staff	25	1.4%
CCF L4-B/Staff	8	.5%
CCF L4-C/Staff	26	1.5%
CCF L4-D/Staff	10	.6%
CCF L4-E/Staff	12	.7%
CCF L4-F/Staff	66	3.8%
CCF L4-G/Staff	127	7.3%
CCF L4-H/Staff	61	3.5%
CCF L4-I/Staff	265	15.3%
Teaching Family Model	2	.1%
Foster Care, Dept Of Social Services	3	.2%
Adult Family Homes SB1730	4	.2%
Supported Living >21 Hrs Wk	66	3.8%
Supported Living 0-10 Hrs Wk	1	.1%
Independent Living	12	.7%
In Parent's Home	29	1.7%
In Other Relative's Home	6	.3%
In Friend's Home	1	.1%
Other Community Setting	27	1.6%
Total	1,729	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 26.3% of the people in our sample. The ICF/DD-N (4-6 Beds) was next, with 18.1%, and was followed by CCF Level 4-I Staff with 15.3%, and so on. However, if we combine categories, 46% of people are in some variety of ICF, and 41% are in some kind of CCF. The table also shows that 52 people were found to be living in large-scale congregate settings.

Results 2: Quality of Life Changes

Figure 1 provides the results from the “Quality of Life Changes” scale, which 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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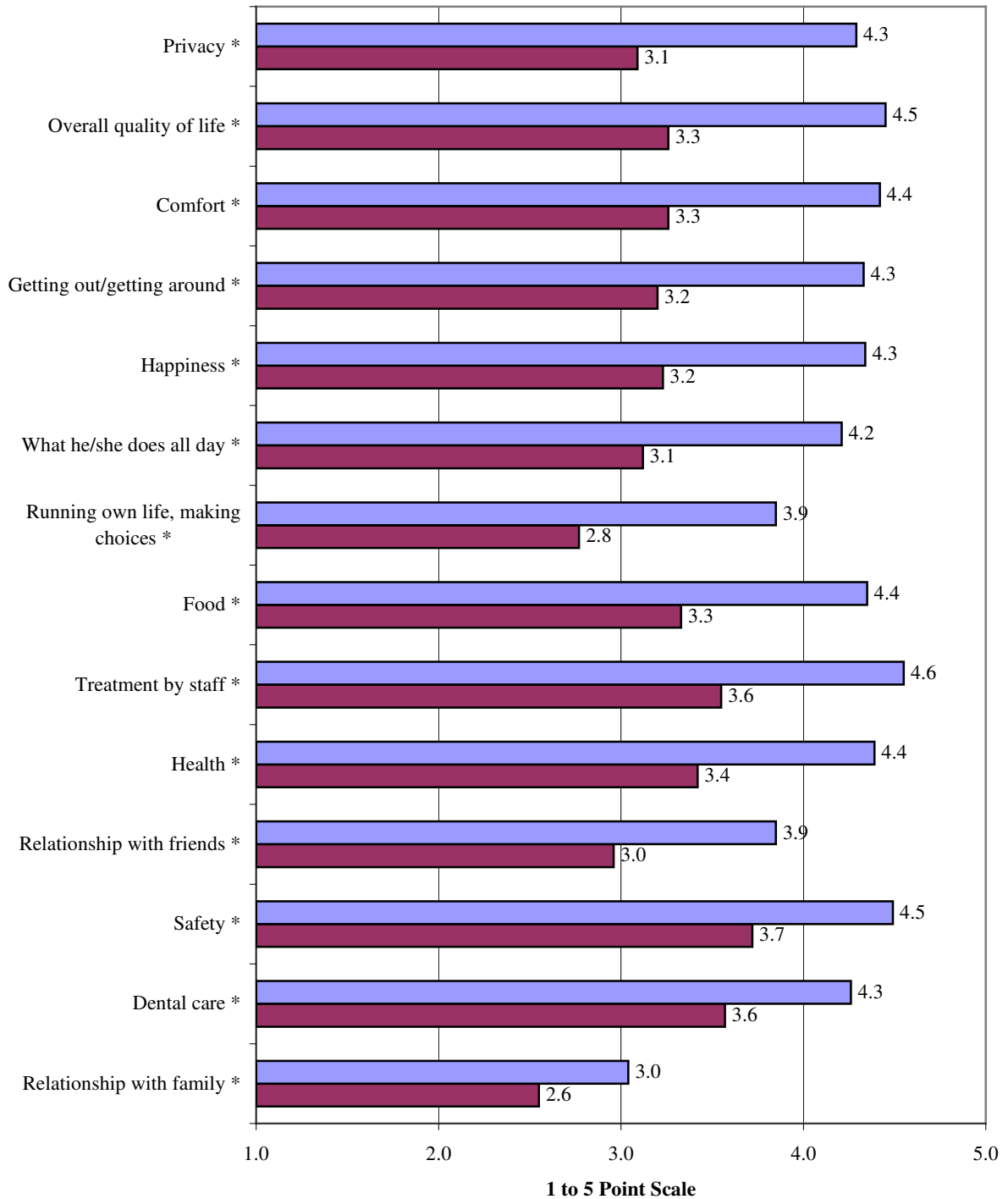
Obtain ratings of each quality of life for this person THEN, BACK AT THE DC, and NOW, IN THE COMMUNITY HOME.

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. _____

Figure 1
Qualities of Life, Then and Now
(Perceptions of Community Staff)



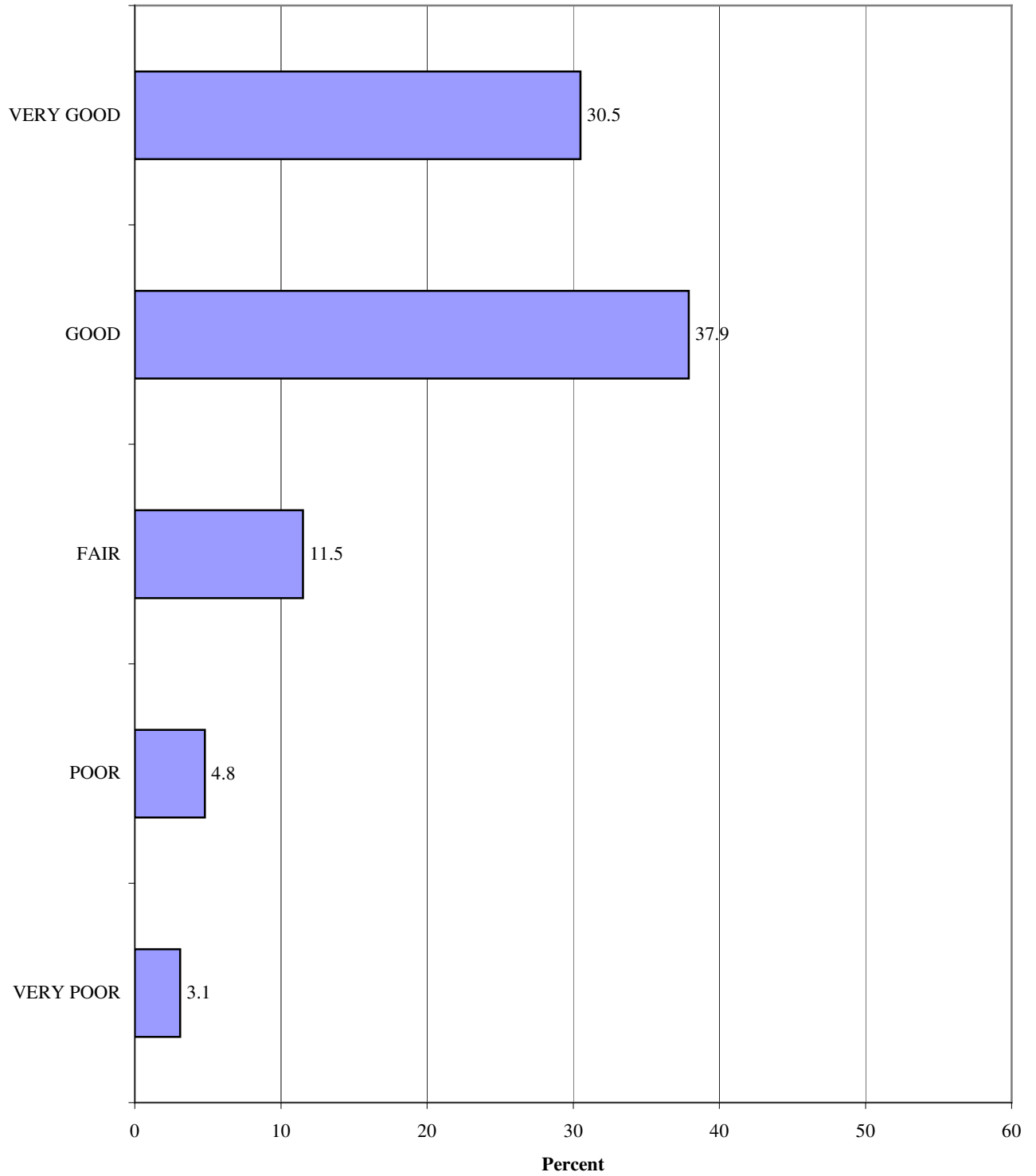
* Significance = <.001|

Figure 1 shows that there were 14 statistically significant perceived improvements in qualities of life out of 14 quality areas for the people. At the left of the graph, asterisks have been inserted to show the level of statistical significance. The single asterisk means highly significant, below .001. The largest reported change was in “Privacy,” “Comfort,” and “Overall quality of life.”

Results 3: Consumer Satisfaction

Figure 2 is based on the responses of the 535 people who were able and willing to communicate with our interviewers.

Figure 2
"How Do You Feel About Living Here?"



The majority of the 535 people who responded, 68%, said that they felt “Good” or “Very Good” about their current living situation. Only 3.1% of the people responded “Very Poor.”

Discussion

These preliminary results strongly suggest that the results of the annual visits will be very similar to those obtained in prior years. That is, the final conclusions are likely to support the inference that the vast majority of people are doing quite well in their new community homes. According to the data shown in Figure 1, they are “better off” in 14 out of 14 life areas than they had been when living in Developmental Centers.

At this time, it would be premature and imprudent to go beyond these simple preliminary statements. Within another 4 weeks, we will have a draft version of our final annual report, with data from all visits included.

