Eight Years Later:
The Lives of People Who Moved From Institutions to Communities in California

Year 2001 Report of the Quality of Life Evaluation
Of People with Developmental Disabilities
Moving from Developmental Centers into the Community
(The "Quality Tracking Project")

Final Report
(Year 2) [1]

Submitted to:
The Honorable Gray Davis
The Honorable Steve Peace, Senate Budget and Fiscal Review Committee
The Honorable Dede Alpert, Senate Appropriations Committee
The Honorable Carole Mi~~d~~gden, Assembly Appropriations Committee
The Honorable Wesley Chesbro, Senate Select Committee on DD & MH
The Honorable Dion Aroner, Assembly Human Services Committee
Mr. Dale Sorbello, Department of Developmental Services

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Acknowledgment

The authors wish to acknowledge and thank the more than 2,000 people who allowed us into their homes and workplaces to find out how they were doing. We also thank the 21 Regional Centers for their cooperation, the staff of the provider agencies who made time for our visits, and all the relatives who took time to complete our mail survey. In gratitude, we dedicate our work and this report to people with disabilities and their families.

TABLE OF CONTENTS

Appendices

Executive Summary

The Quality Tracking Project of the California Department of Developmental Services is intended to track and monitor the well-being of more than 2,000 Californians with developmental disabilities who left institutions (Developmental Centers) since 1993. The origin of the project can be found in Welfare and Institutions Code 4418.1, which is reproduced below.

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.

The present Annual Report is the third one delivered in response to the law above. It is the second report prepared for the Governor, the Legislature, and the Department of Developmental Services, by the Center for Outcome Analysis.

Our primary goal in this Report is to answer the question "Are the people who moved better off than they were when living in Developmental Centers?" And, for the first time, we have explored a related question, "Are the people who moved into community homes better off than they were last year?" In other words, do they continue to grow, learn, and flourish year after year in the community? Our third purpose is to describe in quantitative, scientific terms what are the characteristics of the people and what are the qualities of life they experience in their new community homes? When appropriate, we also include comparisons to similar studies we have conducted in other states.

As for the first question, we find that the "Movers" (the people who moved from institution to community) have benefited considerably from community living. We attempted to conduct a visit with every single Mover, and we were successful with 2,170 of them (94% of all known Movers). The average visit lasted 79 minutes. We collected data and scales that have been very widely used, extensively tested, and are known to be reliable and valid. The data collected included measures of independence, behavioral challenges, choicemaking, friendships, integration, person-centered planning, health, service intensity, earnings, and both consumer and family satisfaction.

In this Report, we delineate exactly what has changed in the lives of 191 of the Movers compared to what their lives were like when they were living in Developmental Centers. We can do this because, back in 1994, we collected the same data for a random sample of 839 people living in Developmental Centers. Now, 7 years later, 191 of those 839 happen to be out in the community, and we now know how they are doing in dozens of ways.

The data show, with considerable clarity, that the Movers are better off than they were when living in a DC in 1994 in 11 of 21 major dimensions that we measured. Some of these are “integrative activities,” “individualized treatment,” “progress toward individual goals,” “opportunities for choicemaking,” “reduced challenging behavior,” and “perceived quality of life in 10 areas.” Families too are unexpectedly and overwhelmingly happy with community living, even those who formerly opposed the change. However, they are somewhat worse off in the “number of close friends,” the “staff perceptions of the quality of health care,” and the “frequency of dental care.” Moreover, very few people have become involved in competitive or supported employment. We suggest that the community system still needs attention in the areas of health and dental care, and employment and income generation, and also that systematic thought needs to be devoted to the issue of natural relationships with other than paid employees.

Our analyses over the years revealed that the earlier Movers experienced major behavioral gains – adaptive behavior increased, and challenging behavior decreased. The later Movers tended to show smaller gains. This led to a new analysis, for all the Movers, in which we examined changes in life from the year 2000 to the year 2001 for 1,912 Movers. We found that the average Mover actually lost ground in adaptive behavior in the past year in the community. We also found that the average Mover lost ground in the challenging behavior area too; that is, their challenging behavior increased. These findings, although small, were both highly significant, and both scales are sufficiently reliable to be virtually certain that something genuine is being measured.

This is the first time in 22 years of constant research by this team that such an outcome has been observed. We have never before seen people in community service systems lose skills and increase challenging behavior. However, the monitoring process put into place through Welfare & Institutions Code 4418.1 has resulted in early detection of these problems. A concerted effort to identify the reasons for these outcomes can surely result in quick and decisive action to arrest further decline. Without the kind of quantitative monitoring mandated by the Legislature for the present project, no one would even know that the average Mover has now begun to lose ground behaviorally.

At the same time that the Movers were experiencing the first behavioral decline, they were rapidly increasing their choicemaking opportunities. This apparently paradoxical finding is fully discussed in the second section of Pre-Post Results. We must proceed with considerable caution in trying to interpret the new findings. The new findings are mixed. Before we make a judgment about how "bad" or "good" these findings are, we must carefully study how people's lives have changed. If they are expressing fewer adaptive skills, and more challenging behaviors, while they have gained rapidly in controlling their own daily lives and decisions, then what exactly is the nature of the balance that seems to have shifted? How did this balance shift over the past year or two, and why? These are the questions that must be explored before any parties, on either side of the ever-present community versus institution debate, claim to know what these findings imply. We do not yet know what they imply.

Since 1995, the staff of the California Quality Tracking Project have been reporting to DDS that the community system is "underfunded." We repeat this refrain. The evidence has always been very clear. Other states have undergone very successful deinstitutionalization movements, and they too did it in ways that saved some money, and that money then went to support people and families who were in need. But, California was different from the other states.

California "saved" much more money than the other states as reported to DDS and the court in the Coffelt case in 1996 in Report 8 of the prior series.[2] For example, New Hampshire expended 86% of its institutional cost per person on community supports, Pennsylvania 85%, and Connecticut 80%. In contrast, California spent 55%. Other national studies have noted

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[2] Conroy, J. (1996, February). ***Patterns of Community Placement II: The First 27 Months of the Coffelt Settlemen*t**, Report Number 8 Of the 5-Year Coffelt Quality Tracking Project, California Department of Developmental Services

that California's fiscal effort with regard to funding community programs is low in comparison to other states.[3] It is difficult to draw precise fiscal comparisons with other states as each state develops and allocates resources from multiple funding streams. However, California's rating on several standard measures of fiscal commitment appears low. We will note again that there is danger in trying to save too much money on institutional to community transition initiatives.

Although we have evidence of a service system that may be troubled, in that two behavioral outcomes have slipped in the past year, it needs to be reiterated that the Movers are still much better off than they were at the Developmental Centers. Almost no one wants to go back. Only a few families would like their relatives to go back. The people themselves, and those closest to them, believe their lives are significantly better in 9 out of 10 ways we asked them about. The people who moved are far more integrated, and have much more of a role in making choices about their daily lives. There has been no major decrement in health and/or safety. The people and their families believe they are as healthy as ever, and as safe as ever.

The movement of more than 2,000 Californians from institutions to community homes was excellent social policy. However, the data deliver a clear warning that should not be ignored. The recent downturn in two behavioral outcomes needs to be understood, and analyzed in the context of other behavioral outcomes that were enhanced. The meaning and causes of the new findings must be explored in depth.

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[3] Braddock, D., Hemp, R., Bachelder, L., & Fujiura, G. (1995). The state of the states in developmental disabilities: Fourth edition. Washington, DC: American Association on Mental Retardation.

Methods

The purpose of a Methods section in a scientific report is to enable other researchers to replicate our findings. We describe exactly how we collected our data, the measurement tools we used, and the people we visited. Our own findings are enhanced by independent validation and so we are careful to furnish detailed information. This section therefore describes the technical aspect of our project from start to finish; the instruments we use to measure qualities of life; the procedures for Visitor assignments; data collection and analysis procedures; the family survey instrument.

Participants: The People in this Study

Our task, as set by the California Legislature and as detailed in our contract with Developmental Disability Services is to:

> ...conduct statewide evaluations annually of the quality of life of all persons with developmental disabilities who have moved from state developmental centers into community settings throughout the state commencing in April, 1993. The instrument to be used for the evaluation will be provided to Contractor by DDS, or approved by DDS. This instrument will measure consumer and family satisfaction with services provided, including case management and quality of life, including, but not limited to, community placement, health and safety, independence, productivity, integration, opportunities for choice, and delivery of needed services.

The population we visit is defined by the list furnished to us by DDS. In 2000 we began with a list of 2,458 people. These people were reported to be Community Target Group Members and all those who had moved from a developmental center between April 1, 1993 and June 30, 2000. In collaboration with our DDS Project Officers, we used the legislative mandate for our research to narrow the list to only those “persons with developmental disabilities who are moved from state hospitals to the community” (4418.1-(a)). We were unable to meet with 184 of those people for reasons ranging from death or incarceration to moved out of state, reducing the list to 2,274 people. We completed visits with 2,271 people. For the purposes of the analyses in this report, we removed 57 people who are listed as members of the Community

Target group and 47 people who have returned to developmental Centers. Our report therefore refers to 2,170 Movers.

Results of the Field Work: A Population, Not A Sample

In the executive summary, we explained that for the purposes of this project we did not use sampling. We included every individual in the Mover population, that is, all 2,170 Developmental Center residents who were known to DDS, who moved to the community from April 1, 1993 through June 30, 2000, and who continued to reside in the community at the time of our data collection.

The distinction between a sample and a population is scientifically important. A population is everyone in a certain group. A sample is a selected subgroup from that population. When we use a sample, we measure things and then attempt to "infer" that what we observe in the sample is also true for the population. The term "inferential" in the phrase "inferential statistics" means exactly that: inferential statistics help us infer something we measure in a sample to the whole population of which the sample is a part.

In the present study, we have included the entire population. ***Therefore inferential statistics are not strictly necessary***. The measurement results we obtain for this population simply "are what they are." We still have the ever-present problems of measurement imprecision, plus the fact that we could not complete visits with a few people, but all in all, the work reported here must be considered and treated as the population, not as a sample. (Nevertheless, some analysts and readers may find statistics useful as indicators of the magnitude of effects, so we will include them in this Report wherever helpful.)

This fact is also important in a very practical sense. It enables us, and the state of California, to say that we attempted to visit every single person who was affected by the Coffelt settlement and its aftermath. ***No one "fell through the cracks."*** For the second year in a row, we located every individual and documented their current living arrangement. We completed visits with 2,271 people. These visits took between 20 and 340 minutes. They averaged 79 minutes.

During these visits, we measured many aspects of the people's well-being and quality of life. We can now compare our findings to the results from last year and from now on we can detect any changes that might affect this population. This is the highest form of system accountability: to be accountable for the qualities of the individual lives of the people who are receiving services from the system.

We completed visits with 2,271 people. This was a "response rate" of **93.8%.** The most common reason for not completing a Visit was that multiple appointments were made and then broken. Our Visitors were instructed to stop after three appointments were broken by the person and/or the person's support personnel.

This response rate compared very favorably with the prior work of Berkeley Planning Associates or BPA [4], who reported two separate completion rates (80% on page i and 80.7% on page 1.10). Whichever figure was correct for the BPA study, our completion rate exceeded theirs by more than 12%. Our own Visitors exceeded their own previous completion rate of 92%

The major variable that we are studying in the lives of these 2,170 people is their place of residence. Therefore, we present the following Table 1 to illustrate the type and frequency of residential alternatives for the "Active Movers" visited this year.

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[4] Berkeley Planning Associates (1998). ***Quality Of Life For Persons With Developmental Disabilities Moving From Developmental Centers Into The Community.*** Sacramento: Department of Developmental Services.

Table 1
Detailed Living Situations of the 2,170 "Active Movers"

Type of Setting	Number	Percent
State Mental Hospital	1	0.0
ICF/DD > 15 Beds	15	0.7
Skilled Nursing Facility	21	1.0
Private Facility	5	0.2
Board and Care	8	0.4
Hospital, Acute Care	3	0.1
Nursing Home	5	0.2
Jail or Detention Center	2	0.1
ICF/DD 4 to 15 Beds	9	0.4
ICF/DD-N 4 to 6 Beds	361	16.9
ICF/DD-N 7 to 15 Beds, Nursing	16	0.7
ICF/DD-H 4 to 6 Beds Habilitative	509	23.8
ICF/DD-H 7-15 Beds Habilitative	10	0.5
CCF Level 2 Owner	6	0.3
CCF Level 2 Staff	7	0.3
CCF Level 3 Owner	43	2.0
CCF Level 3 Staff	85	4.0
CCF Level 4 A/Staff	23	1.1
CCF Level 4B/Staff	8	0.4
CCF Level 4C/Staff	45	2.1
CCF Level 4D/Staff	13	0.6
CCF Level 4E/Staff	16	0.7
CCF Level 4F/Staff	79	3.7
CCF Level 4G/Staff	159	7.4
CCF Level 4H/Staff	79	3.7
CCF Level 4I/Staff	341	15.9
Adult Foster Care	2	0.1
Foster Care Dept. of Social Services	2	0.1
Adult Family Home SB1730	10	0.5
Supported Living > 21 hours/week	115	5.4
Supported Living 11-20 hours/week	6	0.3
Supported Living 0-10 hours/week	4	0.2
Independent Living	30	1.4
In Parent's Home	43	2.0
Other Relative's Home	14	0.7
In Friend's Home	7	0.3
Other Community Setting	38	1.8
No description given	30	1.4
Total	2170	100.0

The names for types of settings in the table are taken from various California and Medicaid codes and titles that are used to describe residential living arrangements for people with disabilities. Some differ in the number of residents they accommodate e.g., ICF/DD-h 4-6 beds versus ICF/DD-h 7-15 beds. Others vary according to people's levels of disability and the related kinds of support and staff ratios that they require. For example, CCF Level 4-A/staff versus CCF Level 4-E/staff, and supported living services are classified according to the hours of support that people receive per week, e.g., Supported Living >21 hours versus Supported Living 0-10 hours.

It is important to note that the first eight lines of Table 1 record 60 people living in nursing homes, or other large, congregate care type facilities. These people were included because they were originally members of the group who moved from Developmental Centers to the community, "Movers", and so we feel it is necessary to track their subsequent moves. In addition, there is a detailed section on "Returnees", beginning on page 117, that describes the characteristics of 47 people who returned to developmental centers after community placement.

The distinctions noted in Table 1 are important for some analyses and are therefore included in this report. However, for most discussions of the characteristics and outcomes of the Movers, we have collapsed the 37 categories into the eight categories listed in Table 2.

Table 2
Broad Categories of Living Situations

Living Situation Category	Number	Percent
Congregate	60	2.8%
ICF (Small)	905	41.7%
CCF	904	41.7%
Foster Care	4	0.2%
Supported Living	125	5.8%
Independent Living	30	1.4%
Relatives' Homes	57	2.6%
Other	85	3.9%
Total	2,170	100.0%

The 60 people listed in the congregate living situation category were not technically living "in the community" at the time of our Visit. It is a generally accepted practice that any facility housing 16 or more individuals is not referred to as a "community" facility. This custom is legitimatized by several respected sources:

- Definitions established by regulations of the Health Care Financing Administration's ICF/MR (Small) Program, which was defined as "4 to 15 beds." Anything larger than that must obey the standards set for institutions.
- The National Residential Information Systems Project of the University of Minnesota (R.W. Prouty & K.C. Lakin (Eds.), *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 1998.* Minneapolis: University of Minnesota, Research & Training Center on Community Living, Institute on Community Integration. Their reports break all living situations into 15 and smaller versus 16 and larger.
- The fiscal tracking Project of National Significance of the University of Illinois at Chicago (Braddock, D., Hemp, R., Parish, S., & Westrich, J. (1998). *The state of the states in developmental disabilities: Fifth Edition.* Washington, DC: American Association on Mental Retardation.

Despite a national consensus that larger settings are not "community," we included all 2,170 Movers in our analyses. The basis for keeping the 60 congregate care people in these analyses was that they were, in fact, part of the Coffelt and subsequent deinstitutionalization initiatives. Wherever they wound up, they had to be tracked and included. Moreover, many such large settings could, in theory, be “appropriate” for some people. For example, the three people we visited in acute care hospitals were surely in them for good reason. And some or all of the 26 people in skilled or other nursing homes may have required that level of care. Hence we determined to include people in the congregate care settings. We think this produces the fairest picture of what happened to all the people who moved out of, and stayed out of, California’s Developmental Centers.

Table 3 shows a breakdown of current living types and the average number of people with disabilities living at each type.

Table 3
Average Sizes of Community Homes

Type of Home	**Average Number of People with Disabilities**
ICF/DD 4-15 Beds	6.9
ICF/DD-N 4-6 Beds, Nursing	5.9
ICF/DD-N 7-15 Beds, Nursing	9.6
ICF/DD-H 4-6 Beds, Habilitative	5.7
ICF/DD-H 7-15 Beds, Habilitative	10.3
CCF L2 Owner	4.0*
CCF L2 Staff	5.4
CCF L3 Owner	7.0*
CCF L3 Staff	7.8
CCF L4-A/Staff	7.3
CCF L4-B/Staff	5.0*
CCF L4-C/Staff	5.1
CCF L4-D/Staff	4.1
CCF L4-E/Staff	4.9
CCF L4-F/Staff	5.3
CCF L4-G/Staff	5.3
CCF L4-H/Staff	4.7
CCF L4-I/Staff	4.7
Adult Foster Care	3.5
Foster Care, Dept. Of Social Services	2.0
Adult Family Home SB1730	2.7
Supported Living >21 hours/week	2.2
Supported Living 11-20 hours/week	1.2
Supported Living 0-10 hours/week	1.3
Independent Living	2.5
Parent's Home	1.0
Other Relative's Home	0.9
Friend's Home	2.6
Other Community Setting	14.2

*The median rather than the mean was used for these types of homes because one or two people in these categories reported living with large numbers of people.

Table 3 shows that aside from the ICF homes, Other Community Settings has the largest average number of people with disabilities with an average of 14.2 residents. The next highest in average number of residents is CCF L-3 Staff at 7.8, followed by CCF L-4-A Staff at 7.3.

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 database, 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. 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 and was most recently selected as the instrument to track court mandated deinstitutionalization in Tennessee.

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 is included herein as **Appendix B**. 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 PLQ used in this year's work was reviewed by a Task Force in 1999.

The reliability of the PLQ 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, (Devlin, 1989; Fullerton, Douglass, & Dodder, 1996; Isett & Spreat, 1979). The components of the PLQ have been shown to be highly objective, scientific, and reliable. The dimensions measured in the PLQ 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 staff longevity, and also questions about how long staff have supported the specific person being visited. We also included optional wage questions.

The second instrument for this project is the Family Survey (**Appendix C**). This form was derived from 20 years of work surveying the families of people living in institutions and in 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 an Appendix. 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

The time and coordination necessary to schedule and complete individual visits with 2,170 people living in the community is enormous. The three Regional Coordinators for this project have perfected a system that is efficient and responsive to the needs of all stakeholders as well as to the time constraints of the project.

In the first year of the project, COA recruited and trained local professionals, paraprofessionals, and graduate students to Visit each person in the Quality Tracking Project and to collect the PLQ data. These data collectors, referred to as "Visitors", function as Independent Contractors. The majority of the Visitors returned for this year's round of visits. This continuity facilitates timely data collection as the Visitors utilize personal connections with the person to be visited, and often with family members or residential staff, to schedule visits.

Visitors are paid a fixed rate for each completed interview plus expenses for overnight trips or significant distances. The Visitor instructions from the PLQ are reproduced below:

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.

Visitor training was conducted in the first year by Dr. Conroy, 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. On site field supervision was provided by Regional Coordinators. New Visitors hired in year two were trained and directly supervised by their Regional Coordinators. Dr. Conroy hosted a two-day project meeting with all Regional Coordinators and Visitors in February, 2001 in Oxnard, California. The agenda for the meeting was a presentation of the results from Year One, a review of all instruments, and a question and answer session regarding instruments and methods. This meeting provided a forum for Visitors to learn from each other and to make suggestions to improve the instruments used by COA.

The data collection process begins with an updated list of Active Movers from DDS. The list is divided according to COA's three regions, North, Central and South, and distributed to the Regional Coordinators. The Regional Coordinators assign names to Visitors who are them responsible for scheduling and completing appointments. Visitors are trained to be sensitive to the schedules of the people to be visited and to the programmatic needs of staff. All visits are scheduled for the person's convenience, not our Visitor's convenience. Visitors can make appointments for evenings and weekends if that is what is preferable. The average length of a visit for this year was 79 minutes, down from an average of 83 minutes from last year. We collected reliable quantitative data on dozens of qualities of life in a very short time, with very little intrusion into peoples' lives.

Pre-Post Results for 191 Movers

Pre-Post Results 1: "Before and After" Qualities of Life

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

The "Pre-Post" Design

In prior reports, we approached these questions in several ways, with several designs.[5] First, we used matched comparison, to test whether "similar" Movers and Stayers experienced different qualities of life (Reports 2 and 3 of the first series of 20 Reports). Second, we used analysis of covariance to mathematically control for differences between Movers and Stayers, and then to test for differences in quality between the groups (Report 10). Third, we used "before and after" or "pre-post" measures of qualities of life for a group of people when they were still in DCs back in 1994, and again when they were out in their new community homes (Reports 7, 12, and 17 of the first series).[6]

What made this "pre-post" design possible was a decision we made back in 1994. Although not originally mandated by the Court or by DDS, we contended that we needed to collect "baseline data" for as many people as possible before they left DCs. We requested permission from Court representatives and DDS officials to rework our study designs so that

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

we could immediately visit as many DC residents as possible, and it was granted. Hence, back in 1994, we conducted data collection visits with as many DC residents as resources would permit. We visited 839 individuals in DCs, selected purely at random from the more than 5,000 DC residents.[7]

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

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

This year, we completed visits with 2,170 Movers (people who once lived in a DC, but now are living in the community). Included in that number, by pure random sampling, are 191 of the people who had been visited at their previous DC homes back in 1994. These 191 people are the topic of this chapter. We can now examine what, if any, qualities of their lives have changed since community placement.

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

[7] Sample drawn by DDS statistical program as simple random 15%.

Limitations of the Pre-Post Design

The number of people in the analysis, 191, is definitely large enough for studies of this kind. For example, a peer-reviewed article on Movers from Pennhurst (Conroy, Efthimiou, & Lemanowicz, 1982), was based on a smaller number of people who moved from institution to community (70). Many other published articles have relied on considerably smaller sample sizes.[8] For reference, the "sampling margin of error" for 191 out of 2170 people is, in the very simplest case, calculated as plus or minus 7%. This meets most professional standards for sample size and precision.

However, the 191 Movers who were in our original baseline of 839 people may have had different characteristics than those 648 people who remained in DCs. If so, this would limit our ability to generalize from the 191 to all the remaining people in DCs. In plain language, what has been observed to be true for the Movers so far may or may not be what is true for any future Movers. This will depend in part on whether the current Movers are "similar to" the future Movers. In Table 4 below, we can see that there is at least one significant difference between the 191 Movers in our sample and the 648 "potential future Movers" (in other words, the 648 Stayers).

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

Table 4
Tests of Initial 1994 Differences Between Movers and Stayers

	The 648 Stayers	The 191 Movers	Mean Difference	t	df	Significance (1-tailed)
Average Adaptive Behavior in 1994	36.5	45.9	-9.41	-5.07	301.9	0.0000
Average Challenging Behavior in 1994	70.4	68.0	2.48	1.46	353.8	0.1454
Average Age in 1994	38.0	36.6	1.46	1.32	400.4	0.1887

The table shows that the average Stayer started out in 1994 with a lower adaptive behavior total score than the average Mover, by 9.41 points. And on the extreme right of the adaptive behavior row, the figure "0.0000" means that this difference is large and almost certainly not something that happened by chance.[9] Thus the Movers in our sample were initially somewhat higher in self-care abilities and independent functioning than the Stayers, by about 9 points on a 100 point scale. Although highly significant, this difference was not overwhelmingly large. Yet even small differences in adaptive behavior, which is a very global and reliable measure, can influence many other aspects of life.

The second row of the table shows only a small difference in challenging behavior between the Movers and the Stayers, about 2 ½ points (this time with the Movers having more challenging behavior than the Stayers -- lower scores on this scale mean more challenging behaviors). That difference did not reach significance -- the figure at the extreme right of the row is not below the usual criteria of .0500 or .0100. The finding for age is similar. The difference of about 1½ years was not statistically significant.

Thus the tendency was for these 191 randomly identified Movers to be slightly higher functioning in adaptive behavior, to display somewhat more challenging behaviors, and to be slightly younger, than the average Stayer. But only the adaptive behavior finding was

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[9] Statisticians generally require that significance numbers fall below some arbitrary standard, usually 0.0500 or 0.0100.

significant. We think the proper conclusion is that our findings about these Movers should be interpreted as generalizable with caution. That is, what we find about the experiences of these 191 Movers over the past 7 years would likely have been similar for the other 648, if they had moved. However, this is not certain, and in some areas of quality, outcomes might have been different. In the text above, we have simply emphasized that we must be very careful about generalizing findings from one group to all kinds of other groups.

In addition to the above caution about generalization, the pre-post design suffers from another threat to validity. The pre-post design by itself does not answer the question "How do we know the Stayers haven't experienced the same kinds of changes in qualities of life as the Movers?" With the pre-post design by itself, the answer is that we don't. There is no "control group." A valuable addition to this study would be to conduct visits with the people who continue to live in Developmental Centers, the "Stayers", particularly the 648 people that we visited in 1994. This additional data would allow us to track their progress since 1994 and to compare it to the "Movers".

It is true that our past matched comparison and covariance designs did shed light on that issue, with the inference that the Stayers did not show similar changes.[10] Nonetheless, it needs to be said that the analyses in this Chapter by themselves are vulnerable to several threats to validity, even though these threats have already been diminished by other designs in the present body of work.

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[10] Incidentally, the best available design to settle this question would be a matched comparison study of change over time, which would require current visits with 191 Stayers who are "twins" (people still in DCs who have characteristics very similar to the 191 Movers). The cost of such a study would be under $40,000.

What Kind of Community Homes Are the 191 Movers Now Living In?

The 191 people moved into the types of community settings shown in Table 5.

Table 5
Current Homes of 191 Pre-Post Movers

Type of Community Setting	Number of People	Percent
9 ICF/DD >15 Beds	1	0.5%
10 Skilled Nursing Facility	2	1.0%
14 Nursing Home	1	0.5%
22 ICF/DD-N 4-6 Beds, Nursing	39	20.4%
23 ICF/DD-N 7-15 Beds, Nursing	1	0.5%
24 ICF/DD-H 4-6 Beds, Habilitative	47	24.6%
25 ICF/DD-H 7-15 Beds, Habilitative	4	2.1%
29 CCF L3 Owner	2	1.0%
30 CCF L3 Staff	10	5.2%
31 CCF L4-A/Staff	4	2.1%
32 CCF L4-B/Staff	1	0.5%
33 CCF L4-C/Staff	4	2.1%
36 CCF L4-F/Staff	6	3.1%
37 CCF L4-G/Staff	19	9.9%
38 CCF L4-H/Staff	4	2.1%
39 CCF L4-I/Staff	24	12.6%
43 Adult Family Homes SB1730	2	1.0%
44 Supported Living >21 Hrs Per Week	7	3.7%
47 Independent Living	2	1.0%
48 In Parent's Home	3	1.6%
50 In Friend's Home	1	0.5%
52 Other Community Setting	7	3.7%
Total	191	100.0%

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

Outcomes Summary

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

For example, there were 16 items on "getting out" and going on outings. The 16 items were combined into a single scale of how many times each person went out into integrated settings each month. This produced a simple measure of "how often people got out each month." If this measure increased between 1994 and 2001, then we would conclude that the level of "integrative activities" increased. That would be a positive outcome, insofar as reduced segregation is viewed as a good thing. For the Quality Tracking Project, we collected a series of measures related to quality of life and therefore to outcomes.

Table 6 presents a summary of results for a variety of important quality and outcome indicators for the 191 Movers.

Table 6
Summary of Outcomes
For 191 Movers

Quality Dimension	Pre	Post	Change	Outcome
Progress Reported Toward IP Goals	45.2	78.9	33.7	Positive
Number of Services in Individual Plan	6.1	8.9	2.8	Positive
Hours of Day Program Services	23.4	27.1	3.6	Positive
Earnings	5.2	4.1	-1.1	Not Signif. *
Number of Close Friends Reported	3.3	2.2	-1.1	Negative
Integration	14.0	27.6	13.7	Positive
Qualities of Life Ratings (Now 1994-Now 2001)	71.3	83.8	12.5	Positive
Staff Job Satisfaction	8.9	9.4	0.6	Positive
Staff Like Working With This Person	8.2	9.3	1.1	Positive
Staff Get Sufficient Support	4.1	4.6	0.5	Positive
Number of Daily Medications	4.9	5.0	0.1	Not Signif.*
Number of Psychotropic Medications	0.4	0.4	0.0	Not Signif.*
Health by Days Ill Past 28	0.5	0.9	0.4	Not Signif.*
Perceived Quality of Health Care (Staff responses)	4.7	4.4	-0.3	Negative
Doctor Visits Per Year	34.4	13.5	-21.0	Unclear
Dental Visits Per Year	2.2	1.5	-0.7	Negative
Relative Visits Person Here At This Home	8.4	7.3	-1.1	Not Signif.*
Individualized Practices Scale	61.7	67.4	5.8	Positive
Adaptive Behavior	45.7	45.0	-0.7	Not Signif. *
Challenging Behavior	68.0	78.0	9.9	Positive
Choicemaking	32.7	47.3	14.7	Positive

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

For each quality dimension in Table 6, we have presented the average score for Movers on that dimension prior to the move (in the column headed "Pre"). The column headed "Post" shows the average score in 2001, after moving into the community. Next, the column headed "Change" shows the average number of points of change that occurred in each dimension.

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

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

Table 6 lists outcomes for 21 quality dimensions that were compared from the pre (DC 1994) to post (community 2001) visits. There are 11 significantly positive outcomes, 3 significantly negative outcomes, 6 outcomes that are neither significantly positive nor negative and 1 outcome for which the comparison is unclear. In other words, for these 191 Movers, quality of life improved in half the ways measured, got worse for one seventh of the ways measured, and did not change for about a third.

In summary, the Table data support the inference that people's lives have improved in more than three times as many dimensions as they have declined. This leads to the conclusion that, at least for these 21 indicators of quality, moving out of institutions allowed these 191 people, on the average, to experience improvements in many qualities of their lives.

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

Progress Reported Toward Individual Plan Goals

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

As the table shows, the respondents at the DCs produced an overall scale score of 45.2 back in 1994, which can be interpreted as an average perception of a little below "No Change". In the community in 2001, the average rating was 78.9, which can be interpreted as an average perception of a little above "Some Progress". The difference is large. Since staff of the residences almost always answered these items, it can safely be concluded that community staff believe they are seeing a lot more progress than did institutional staff back in the DCs.

The proper conclusion is that these 191 Movers are "better off" than they were back in the DCs in terms of making progress toward the goals in their Individual Plans.

Number of Services in Individual Plan

The Personal Life Quality protocol (PLQ) contains a checklist of 15 traditional therapies, training programs, services, and supports that might be delivered via the residential program. The number of services for these Movers increased from 6.1 at the DCs in 1994 to 8.9 in the community in 2001. The increase of 2.8 services was statistically significant.

The proper conclusion is that these 191 Movers are receiving a wider range of services and support than they were back in 1994 at the DCs. Since we did not measure amount of services, however, we cannot comment on how much of each such service is being provided.

Hours of Day Program Services

We collected the number of hours per week of each of 17 types of day activities, from self-employment to community experience to school. The average number of hours of day program services of all types increased from an average of 23.4 hours per week back at the DCs to 27.1 hours per week in 2001 in the community. This increase of 3.5 hours is significant.

We conclude that community placement appeared to be related to a greater number of hours per week that people spend in some kind of "productive activity". Further research into changes in the distribution of types of day activities could be performed within the present data set, but is beyond the scope of this chapter.

Earnings

Comparison of average weekly earnings back at the DC to earnings in the community reveal a slight decrease, which is not statistically significant. The average amount in the DCs was $5.20 per week, and the average amount in the community is $4.10. Both of these figures are so low that they should engender a statewide discussion of the potential role of work and income generation for all Californians with developmental disabilities, whether in DCs or the community.

Last year, in Report 2 of this series, we found a different result. For the 178 Movers who were included in that analysis, average weekly earnings dropped from $4.80 in the DCs to only $1.60 in the community. That drop was statistically significant. Now, a year later, the significant drop is gone. This means that a fair number of people among the 191 Movers either began earning some small amount of income, or increased what they were earning.

This could be interpreted as a positive finding, in the sense that a previously negative outcome has been reduced to no change.

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

Number of Close Friends Reported

In 1994 in the DCs, and in 2001 in the community, we asked people how many "close friends" they had. The answers were usually given by whomever knew the person best. We did not define "close friends" for the respondents, we asked them to use their own definitions. Hence this item must be considered to be largely subjective as an indicator of quality of life.

From 1994 to 2001, the average number of close friends reported fell from 3.3 to 2.2. The decrease of 1.1 was statistically significant.

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

In our last annual report, Report 2, we also detected a drop in the average number of close friends from DC to community. However, that drop was not statistically significant (from 3.3 to 2.6). Now, measuring from 1994 to 2001, the decrease from 3.3 to 2.2 has become statistically significant. This suggests that some of the loss of friends may have taken place over the past year or two within the community. If so, that would be a very important finding, pointing to a rather urgent need to help people maintain and/or extend what relationships they have.

We suggest that the nature and depth of human relationships is an area in need of urgent concern and further investigation. Further investigations should study the proportion of friends in 1994 and in 2001 who were paid and unpaid, and friends with and without disabilities. A study of those variables and others such as levels of retardation, age, gender, and living arrangement may help to explain the drop in close friends that we have detected.

Integration

Our measure of Integrative Activities is simply a count of "how many times the person went out" and went to places where any citizen might go. The Movers increased their levels of integration from 14.0 to 27.6, indicating an additional 13.3 community events per month. This near doubling of integrative activities was statistically significant.

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

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

Qualities of Life Ratings (1994 and 2001)

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

We compared the ratings given by people and/or DC staff back in 1994 to those given by people and/or community staff in 2001. (The overall 100-point scale for this analysis was composed of only the 10 items used in 1994, to keep the scales comparable in 1994 and 2001). The average score increased from 71.3 to 83.8, for an increase of 12.5 points. This indicates that the Movers, or the people closest to them, perceived lower quality of life back in the DC, and considerably higher qualities of life in the community.

To reveal the largest perceived changes, we broke down the scale into its component items. Table 7 shows the results, sorted by the size of the change.

Table 7
Perceived Qualities of Life Reported by Person or Closest Others, Pre-Post

Dimension of Quality	1994 at DC	2001 in Community	Change	Statistical Significance
Food	3.6	4.4	0.8	0.0000
Comfort	3.9	4.5	0.6	0.0000
Getting out	3.5	4.1	0.6	0.0000
Happiness	3.8	4.4	0.6	0.0000
Running my own life	3.2	3.8	0.6	0.0000
Seeing friends	3.2	3.7	0.6	0.0000
Safety	4.2	4.7	0.5	0.0000
What I do all day	3.7	4.2	0.5	0.0000
Health	3.9	4.2	0.3	0.0000
Family relationships	2.8	2.9	0.1	0.1708

The table shows that 9 out of 10 dimensions of quality of life were rated higher in the current community homes than they were back at the DCs. The largest difference was in quality of food. The next largest differences were in comfort, getting out, happiness, and running my own life.

It is worth noting that the perceptions of health and safety went up as well. This may be a surprise to those who believe that living in the community carries with it a price to be paid in terms of diminished health and safety. These 191 Movers, and those closest to them, clearly do not agree with that contention.

The one element that did not change significantly was relationships with family. We speculate that those who had involved family members while at the DC continued to have them in the community, and those who did not have involved family members did not acquire them.

The proper conclusion from this is that the people and/or the staff closest to them reported their perceptions of quality back at the DC, and again 7 years later in the community – and the community ratings were considerably higher. These data strongly support the inference that the Movers are "better off" in their own eyes and the eyes of those close to them.

Staff Job Satisfaction

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

For "How much do you like your job?" on a scale of 1 to 10, the average response from developmental center staff was 8.9 and in the community it rose to 9.4. Community staff like their jobs more than did developmental center staff. This difference was significant.

Staff Like Working With This Person

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

On a scale of 1 to 10, the developmental center staff score averaged 8.2, and the community staff was significantly higher at 9.3. Community staff report enjoying working with each specific person significantly more than did the developmental center staff. We think the proper conclusion is that relationships with close staff members are better in the community than they were back at the DCs for these 191 Movers.

Do Staff Get Sufficient Support?

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

Number of Daily Medications

The average number of medications (including vitamins, minerals, and special supplements) administered daily stayed essentially the same, going from 4.9 to 5.0. This was not a statistically significant change (0.1). Incidentally, detailed analysis shows that the average number of "digestive, stomach, and bowel" medications has decreased significantly. This may be an indication of a change in dietary habits and medical management practices.

Number of Psychotropic Medications

The number of psychotropic medications remained the same. However, we must point out that in a sense this is a positive finding, because in our early studies, we found that the people who moved out of DCs in the mid-1990s actually experienced increases in psychotropic medications. This suggested that the community medical system was overmedicating people, perhaps out of lack of experience. Now we conclude that the 191 Movers are experiencing about the same probability of being given psychotropics in the community as they were in the DC.

Health by Days Ill in Past 30 Days

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

Quality of Health Care

The responses to the question "Overall, how good is the health care this person is getting?" revealed a negative and significant difference. Because this dimension was rated on a 1 to 5 scale, both the answers from 1994 in the DCs (4.7), and the answers from 2001 in the community (4.4), lie in the "Good" to "Excellent" range. However, the average rating in the community is significantly lower than the average rating back at the DCs.

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

Doctor Visits Per Year

The Movers' number of doctor visits per year decreased sharply from 34.4 to 13.5 times per year. This pattern has been documented as fairly standard in moves from institutions to the community.[11] However, the fact that they saw the doctor 21 less times in the community does not necessarily mean that either their health care or general health was negatively affected.

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[11] Hayden, M. F., & DePaepe, P .A. (1991). ***Medical conditions, level of care needs, and health related outcomes of persons with mental retardation: A Review***. Journal of the Association of Persons with Severe Handicaps, 16(4), 188-206.

There is no evidence from any of the data that people in the community need to see doctors more often than 13 times a year. We therefore interpreted this finding as neither positive nor negative, but rather "Unclear."

Dental Visits Per Year

The Movers' number of dental visits per year decreased, from 2.2 to 1.5. Because the dental profession recommends 2 visits per year, we interpret the significant decrease as a negative finding. (Although the 1.5 times per year rate is believed to exceed the frequency of general public visits to dentists.)

Relative Visits Person Here At This Home

The frequency of family contacts increased from 8.4 to 11.2 per year. This was not a statistically significant change. Again, this might be interpreted as "those that had family contacts in the DC continued to have them; those that had no family contacts did not acquire the.". Proximity may also play a part in this increase as a number of people may have been placed in community residences that were close to their family home.

Individualized Practices Scale

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

The Movers increased their score on this quality dimension from 61.7 to 67.4, and this increase of 5.8 points on a 100 point scale was statistically significant, but not very large.

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

Adaptive Behavior

For the first time in this body of work, the change in adaptive behavior between institution and community has become negative. Although the change is not statistically significant, this does represent a first. In more than 20 years of this kind of work in 10 states, this is the first time this research team has detected a skill loss, significant or not, for people who moved from institutional to community settings. We decided that this new finding was important enough to warrant a preliminary review of the entire California body of work since 1994. To follow up on this preliminary review, we will definitely need to investigate more deeply to try to understand the causes and the implications of these data.

Last year, in 2000, we conducted the same kind of pre and post analysis for 178 Movers whom we visited in the DC in 1994 and again in the community in 2000. In that analysis, there was an average gain of 0.6 points from the DC 1994 score in adaptive behavior. That was not significant. However, the fact that it was the first non-significant gain led us to wonder whether we might be seeing the leading edge of a trend. Hence we looked at the findings of all of our past pre-post comparisons for adaptive behavior change i.e., the results for each year of the study regarding the people that we interviewed in the DCs in 1994. The data are shown in Table 8. Although this table is complex, we believe it is necessary to present complete information because of the potential importance of the issues raised.

Table 8
Trends in Pre-Post Adaptive Behavior Findings Over the Years

Adaptive Behavior Measure	Baseline DC 1994	Community 2001	Change	Significant?
Report 8, 1996 34 Movers	48.9	51.4	2.5	Significant
Report 12, 1997 64 Movers	45.1	48.3	3.2	Significant
Report 17, 1998 91 Movers	44.7	46.7	2.0	Significant
Report 2, 2000 178 Movers	45.0	45.6	0.6	Not significant (1st time)
Report 4, 2001 191 Movers	45.7	45.0	-0.7	Not significant (2nd time, first loss)

In our earliest studies at the top of the table, in 1996, 1997 and 1998, we found significantly increased adaptive behavior among the Movers after they left the institutions. This is consistent with a large number of studies by many research groups, as documented in the meta-analysis performed by Larson & Lakin (1989).[12]

Moving down the table to the larger and more recent analyses, we see a fairly consistent trend toward less and less benefit, until at the bottom, the average outcome for the 191 Movers in 2001 is that they appear to have actually lost slightly in adaptive behavior skills. Since the change is not statistically significant, we cannot be certain that the apparent loss is valid. Nonetheless, the trend seems worthy of note. A graphic presentation may make this issue more clear. Chart 1 shows only the amount of change in adaptive behavior detected in the five California studies.

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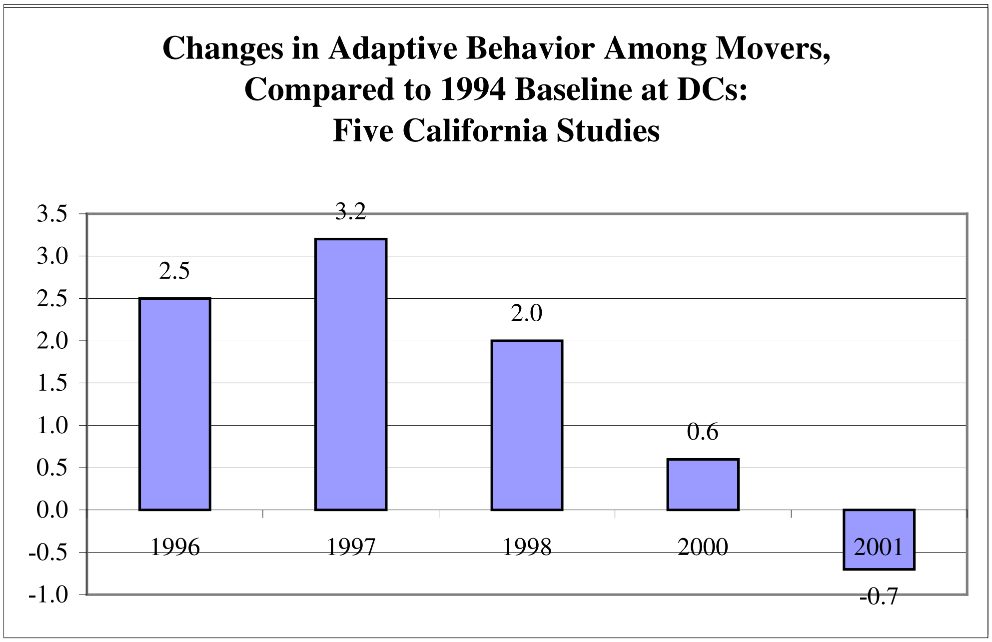
[12] Larson, S., & Lakin, C. (1989). ***Deinstitutionalization of persons with mental retardation: Behavioral outcomes.*** Journal of the Association for Persons with Severe Handicaps, 14, 324-332.

Chart 1



It is the trend that is of greatest interest. The chart suggests rather strongly that the early Movers enjoyed considerable benefits in terms of learning new self-care skills and becoming more independent, but that the later Movers did not. In fact, the data suggest, but do not prove, that there might have actually been a loss in adaptive behavior in the past year, not between DC and community, but <u>within the community</u>. This hypothesis is tested in the next section, in which we analyze changes in quality indicators from the year 2000 community visits and the year 2001 community visits.

Another way to attempt to interpret the adaptive behavior data is to compare it with parallel data from other states.[13] Table 9 shows the adaptive behavior results from several studies conducted by this research group.

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

Table 9
Adaptive Behavior Results From Several Deinstitutionalization Studies

State	# of Years	Time-1 Average Adaptive Behavior Score	Time-2 Average Adaptive Behavior Score	Gain on 100 Point Scales
Pennsylvania	14 years	39.8	50.2	10.4
New Hampshire	8 years	53.0	62.3	9.3
Louisiana	7 years	56.2	64.2	8.0
California	**7 years**	**45.7**	**45.0**	**-0.7**
Oklahoma	6 years	41.3	47.4	6.1
Connecticut	5 years	49.5	54.0	4.5
North Carolina	2 years	52.7	54.8	2.1
Kansas	1 year	33.1	34.8	1.7
Indiana	1 year	48.1	50.2	2.1

At this point, the California experience is unusual. In prior years, the California data fit rather neatly into the general national pattern. Now, in 2001, something has changed. We think it is urgent to find out what has changed, and why, and also what can be done about it. It is important to again state that this change is not statistically significant and that it would certainly not have been detected without the mandate from the California legislature to monitor the progress of the Movers. This data, although alarming in its implications, presents an opportunity for all stakeholders to review current policies and practices and to assure that community services are being implemented according to the spirit and the letter of the law.

Challenging Behavior

This dimension was measured according to the person's ability to control challenging behavior and so a higher score is a positive outcome. The 9.9 point increase in our current pre-post analysis is very high.

It is possible that the decrease in adaptive behaviors (although not statistically significant) and the major improvement with regard to challenging behavior are related. Programs that focus on adaptive behaviors are often more formal and regimented. In contrast, state-of-the-art programming for people with challenging behaviors relies more on prevention and positive reinforcement to produce safe and nurturing environments. The data on these two dimensions appear to support the hypothesis that the community programs for these 191 Movers have been designed to meet their specific needs in these areas. This is an area that should be investigated further.

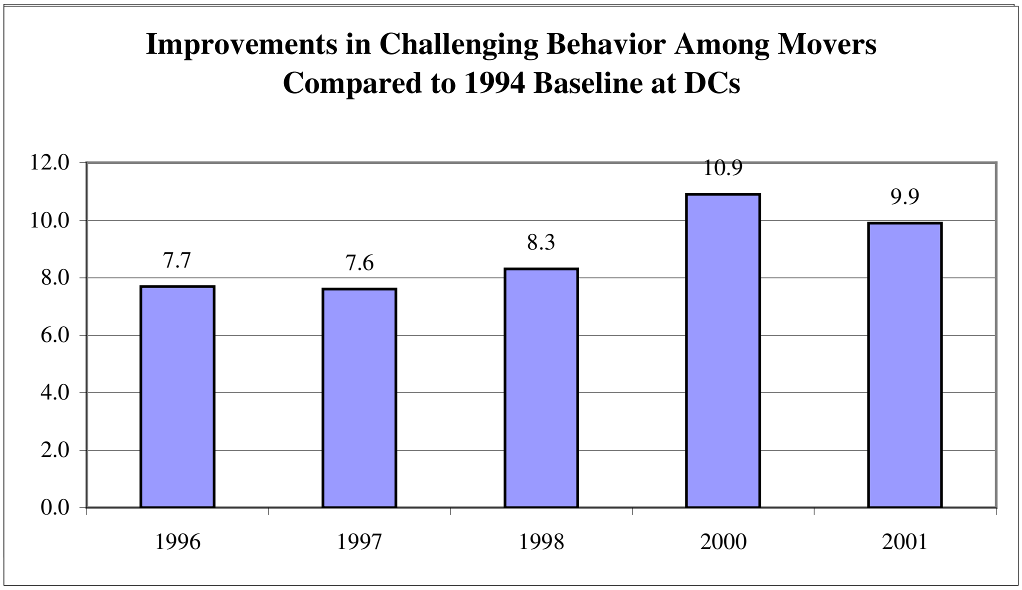
Because of the surprising findings in adaptive behavior, we decided to look at challenging behavior findings over the years in the same way. Table 10 shows the data.

Table 10
Trends in Pre-Post Challenging Behavior Findings Over the Years

Challenging Behavior Measure	Baseline DC 1994	Community 2001	Change	Significant?
Report 8, 1996 **34 Movers**	67.3	75.0	7.7	Significant
Report 12, 1997 **64 Movers**	69.7	77.3	7.6	Significant
Report 17, 1998 **91 Movers**	68.1	76.4	8.3	Significant
Report 2, 2000 **178 Movers**	67.6	78.4	10.9	Significant
Report 4, 2001 **191 Movers**	68.0	78.0	9.9	Significant Less than Year 2000

The table suggests that outcomes were progressively becoming more and more positive over the years, until this year. The 2001 average gain from deinstitutionalization has become less than the average gain we measured last year (10.9 to 9.9). Again, a chart may make this trend easier to see.

Chart 2



It is the downturn on the right that makes us suspect that there may have been very recent decrements in quality within the California community support system, at least for these 191 Movers.

To this research group, this finding is of major importance. As in the case of adaptive behavior, this gradual decline in the challenging behavior benefits associated with community placement may suggest that in the past year or two these 191 Movers have actually lost ground in this area. We decided to add a new chapter to this report, the chapter following this one, to explore this issue further. In the next chapter we present tests for changes in qualities of life between the Year 2000 visits and the Year 2001 visits, not just for the 191 Movers, but for all 2170 people in this study population.

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

Table 11
Challenging Behavior Results From Several Deinstitutionalization Studies

State	# of Years	Time-1 Average Challenging Behavior Score	Time-2 Average Challenging Behavior Score	Gain on 100 Point Scale
Pennsylvania	14 years	77.7	87.3	9.6
New Hampshire	8 years	79.6	78.6	-1.0
Louisiana	7 years	80.9	84.1	3.2
California	**7 years**	**68.0**	**78.0**	**9.9**
Oklahoma	6 years	89.7	93.5	3.8
Connecticut	5 years	79.0	80.2	1.2
North Carolina	2 years	87.7	89.4	1.7
Kansas	1 year	78.6	81.3	2.7
Indiana	1 year	70.5	67.9	-2.6

The proper conclusion is that these 191 Movers are far better off now, in the community, in terms of being able to control their own potentially challenging behavior. Yet the data still lead to intense concern about possible recent declines in this important quality dimension.

Choicemaking

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

Choicemaking opportunities as measured by the Decision Control Inventory increased from 32.7 points back at the DCs in 1994, to 47.3 points in the community in 2001. This increase of 14.7 points was highly statistically significant.

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

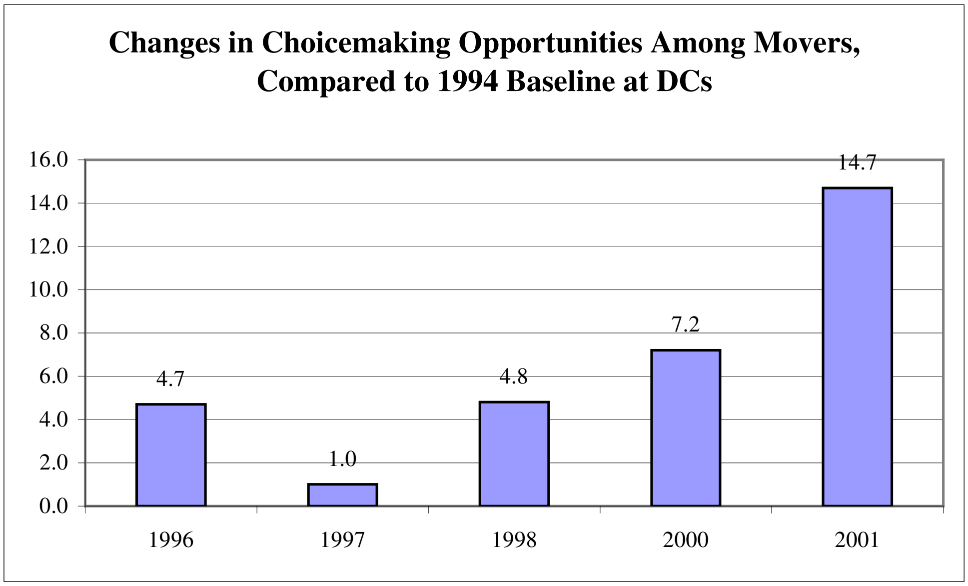
We are intrigued, however, that the large increases in choicemaking did not appear until recently in our studies. In the same format as in the two previous sections, Table 12 shows the choicemaking results of five pre-post analyses.

Table 12
Trends in Pre-Post Choicemaking Findings Over the Years

Choice Making Measure	Baseline DC 1994	Community 2001	Change	Significant?
Report 8, 1996 **34 Movers**	35.9	40.6	4.7	Not Significant
Report 12, 1997 **64 Movers**	33.6	34.6	1.0	Not Significant
Report 17, 1998 **91 Movers**	31.5	36.3	4.8	Significant (1st time)
Report 2, 2000 **178 Movers**	31.7	38.9	7.2	Significant (2nd time, larger)
Report 4, 2001 **191 Movers**	32.7	47.3	14.7	Significant (3rd time, still larger gain)

For the early Movers, the gains in opportunities to make choices were small and not statistically significant. In the third of the five studies, the gain was still small, but at least it reached significance. By the time of the fourth study in 2000, the gain was larger. Then the average gain more than doubled in 2001. The pattern may again be made more clear by a chart.

Chart 3



What could explain such a dramatic recent increase in the choicemaking scale? Several competing possibilities are available. They will be discussed after new analyses in the next chapter: changes in qualities of life <u>within</u> the community, from Year 2000 to Year 2001, for <u>all</u> the movers.

Chart 3

<u>Pre-Post Results 2: Last Year and This Year</u>

For the first time, we now have the ability to explore changes in the lives of the Movers from one year to the next, while they are living in the community. In the previous section, we studied changes in the Movers' lives from institution to community. In this section, we investigate changes from last year to this year. Has anything changed? Are people growing and learning? Is individual planning becoming more person-centered? Are people making more choices now than they were last year? There are many questions that can be posed, all aimed at the question "Is the entire service system any different now than it was a year ago?"

And, the ideal way to test this question is to determine whether the qualities of life of the people served in the system have changed.

Using this approach, we have attempted to further investigate some of the major issues raised in the previous section. These major issues involve adaptive behavior, challenging behavior, and choicemaking. These areas will be the focus of this section.

Before proceeding into those three areas, we note that we did test the entire battery of quality indicators to see what had changed since last year. In brief, we detected statistically significant changes in:

- Perceived Progress Toward Individual Goals (up 1.3 points on the 100 point scale)
- Number of Services in the Plan (up .4 services per person)
- Time Spent in Day Program (up .4 hours per week)
- Individualized Practices Scale (up 4.3 points on the 100 point scale)
- Elements of the Planning Process (up 4 points on the 100 point scale)
- Number of Friends (down 1.3 friends, to 8.8)
- Number of Doctor Visits Per Year (down .8 visits per year, to 11.7)

Five of these changes are favorable, one is unfavorable (Number of Friends), and one is unclear (Number of Doctor Visits). We will offer to prepare a full report on changes from year 2000 to year 2001 as part of the existing contract with DDS, within existing resources. For the present report, we wish to focus on what we see as the largest and most pressing issues.

In the previous section, we examined five separate pre-post analyses over the years of our work. We found reason to suspect that people's adaptive behavior abilities (also called self-care skills or independent functioning) might have begun to decline. It is extremely important to find out if this is true.

Our statistical test includes 1,912 Movers who were visited both in 2000 and 2001, and for whom complete data on the selected issues was available. We use the Student's t-test to ask whether the average adaptive behavior score this year is any different from the average score from last year. The answer is "Yes".

Table 13
Average Adaptive Behavior Changes Among 1,912 Movers
Year 2000 to Year 2001

Average for Year 2000	Average for Year 2001	Change	Significance
49.064	47.350	-1.7	0.000

The average Mover experienced a loss of 1.7 points on the adaptive behavior scale. This was very highly statistically significant, as symbolized by the "0.000" at the right of the table. Any number below 0.050 would be considered significant. The lower the number, the higher the significance. The probability that this decrease of 1.7 points is just a chance variation in the numbers is very close to zero.

Because adaptive behavior is such a highly reliable,[14] valid, global, and strongly predictive measure of individual functioning, we think this finding should be taken very seriously.

One might wonder whether a mere 1.7 point loss on a 100 point scale is really that serious. The answer is found in the long run. What would happen to people if such losses continued each year for 10 years? If our service system consistently produces small losses, people would lose 17 points in the next decade. In old and generally outmoded terminology, that loss would be more than enough to push a person from the mental retardation label "moderate" to the label "severe." In our data set, the average person with the label "moderate" has an adaptive behavior score of 64; the average person with the label "severe" has a score of 51. A loss of 17 points over 10 years would be devastating to a person's functional status.

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[14] In Report 7 of our earlier Coffelt series, we reported interrater reliability for the adaptive behavior scale as .97 or .98 depending on the calculation method. This is extremely high. It means that this is a very accurate measure. We also know that this measure correlates strongly with many other aspects of life, such as choicemaking, earnings, and integration. This means that it is an important measure that influences many aspects of people's lives.

That is why we feel a strong sense of urgency about this finding. Further investigation of causes and necessary actions are urgently needed.

Next, we performed the same kind of analysis for challenging behavior. Obviously, challenging behavior and its reduction is a very important aspect of people's lives. Challenging behaviors are also of great concern to service providers and families.

Table 14
Average Challenging Behavior Changes Among 1,912 Movers
Year 2000 to Year 2001

Average for 2000	Average for 2001	Change	Significance
78.614	77.106	-1.5	0.000

As seen in the table above, the average scores for the 1,912 Mover decreased by 1.5 points on the 100 point scale. On this scale, the higher the score the better the person is able to control challenging behavior. The 1.5 decrease means that people are displaying more challenging behaviors in 2001 than they were in 2000. The decrease was highly statistically significant.

This finding is also unusual in our experience. We have seen challenging behavior increase temporarily when people change homes, as happened in our 6-month post deinstitutionalization data in Indiana. However, those increases later vanished as people settled into their new homes. The increase we have measured in California, however, appears to be quite different. This is associated with people living in their homes, engaging in daily activities, and not obviously experiencing any major disruptions in their lives. It strongly suggests a systemic problem. In combination with the adaptive behavior finding, the evidence seems to us to be compelling. We do not know for certain, however, exactly what is (are) the nature of the problem(s).

At the same time that people were losing skills and increasing challenging behavior, a counterintuitive and paradoxical process was occurring. Average scores on the Decision Control Inventory, our measure of opportunities for choicemaking, were increasing rapidly. This scale is an important indicator of power shifting and progress toward self-determination.

Table 15
Average Decision Control Inventory Change Among 1,912 Movers
2000 to 2001

Average for 2000	Average for 2001	Change	Significance
43.077	47.345	4.3	0.000

The average score on the Decision Control Inventory <u>increased</u> significantly from 2000 to 2001, from 43.077 points in 2000 to 47.345 in 2001. The increase of 4.3 points is highly statistically significant, and it is also large. The entire self-determination movement has been at least partly fueled by the positive scientific findings from the original project in New Hampshire – and in that project, the observed gain on this same scale was only 4.1 points over an 18 month period. The observed increase among California's Movers is larger, and happened faster, than the power shift in New Hampshire. This too should be taken seriously, and on the surface, it appears to be a positive outcome.

Taken together, what do these three major changes over the course of 12 months mean? At this time, we can only brainstorm and speculate. It is urgent that we obtain explanations so that California can take action to halt any negative trends.

The first explanation that occurred to our team was a broad based acceptance of the principles of self determination which espouse personal choice and freedom. It is possible that in their zeal to convert the system, some people have moved too quickly and have decreased their focus on skill development activities. This kind of scenario could explain behavioral losses and increased choice.

A second possible explanation is the widely acknowledged crisis in the direct care labor pool. Low salaries and high turnover rates translate into poorly motivated and poorly trained staff. Recognizing the antecedents of challenging behavior and providing positive supports to prevent such behavior requires caring and well-trained staff. A direct care worker who does not have the benefit of such skills, or complete knowledge of the principles of self determination and person centered planning, may find it convenient to adopt the rhetoric of consumer choice and “let the people do what they want.”~~.~~[15] This could explain the increase in the choicemaking scale.

Either explanation fits at least some of the facts. A reading of Appendix D, which contains the notes and comments written by relatives in the 2001 Family Survey, tends to support the second explanation. There are many comments about the poor quality and the short tenure of direct care staff.

The details of the power shift reflected in our choicemaking scale also seem to support the second explanation. The top 10 changes in power from 2000 to 2001 were:

- *When to go to bed on weekdays*
- *What to have for dinner*
- *When to get up on weekends*
- *What to have for breakfast*
- *Choosing to decline activities*
- *What to do with relaxation time*
- *When to go to bed on weekends*
- *Taking naps in evenings/weekends*
- *What foods to buy*
- *Express affection*

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[15] Self-determination advocates would not favor the description given above. True self-determination is a very careful and responsible process of sharing power and control with a person and the person’s allies. Genuine self-determination requires Freedom, Authority, Responsibility, and Support.

It is our opinion that these activities are mainly related to direct care staff attitudes and actions. We should also note that in general, the above kinds of choices do not entail significant cost increases. At the other end of the Decision Control Inventory are the things that did not change.

- *Who goes with you on outings*
- *Time spent working or at day program*
- *Choice of house or apartment*
- *Choice of case manager*
- *Type of work or day program*
- *How to spend residential funds*
- *Whether to have pets in the home*
- *How to spend day activity funds*
- *Choice of people to live with*
- *Choice of furnishings*

These items seem to us to be “big” aspects of life – where you live, with whom you live, what you do during the day. In most traditional service systems, these items are controlled by administrative policies and personnel. These items also have significant financial implications depending on the choices people make. This pattern of change in the scale tends to support the idea that what is going on among the Movers in California in the past year is not actually self-determination, but rather simply a relaxing of authority over several “small” aspects of daily life.

Because the behavioral results were both unusual and unexpected, we wanted to begin preliminary investigations at slightly deeper levels. Based on past research by this team,[16] we wondered whether outcomes differed for people who lived in ICF/MR versus Waiver settings. We collapsed the long list of residential categories into Community ICF/MR and Waiver

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[16] Conroy, J. (1996). The Small ICF/MR Program: Dimensions of Quality and Cost. *Mental Retardation, 34 (1)***,** 13-26. Conroy, J. (1998). Quality in Small ICFs/MR Versus Waiver Homes. *TASH Newsletter, Valume 2, Issue Number 3, March 1998.*

settings, and excluded people who lived in large congregate settings. Next, we excluded people who had changed their type of home between 2000 and 2001. This left us with about 800 people who had been living in an ICF/MR for the entire year, and about 950 who had been in Waiver settings.

Before showing these preliminary results, however, it is extremely important to caution readers that this analysis is exploratory only. The people who live in ICFs/MR and Waiver settings are different kinds of people, with distinctly different characteristics. To drive this point home, we produced Table 16 of measures from the year 2000 round.

Table 16
Characteristics of People in ICF/MR and Waiver Community Settings, 2000

	ICF/MR, N=808	Waiver, N=957
Adaptive Behavior	35.0	60.0
Challenging Behavior	83.2	74.9
Choicemaking Scale	31.9	52.6
Quality of Life Scale	85.8	83.4
Integrative Activities	21.4	36.9

Notice the large difference in adaptive behavior, with the Waiver recipients having far higher levels of ability – 60 points versus 35 points. The Waiver recipients also displayed considerably more challenging behavior than the ICF recipients. (Higher scores are favorable on this scale, meaning <u>less</u> challenging behavior.)

These differences between the ICF/MR and the Waiver recipients means, for one thing, that direct comparisons between the two groups must be done judiciously and interpreted with great caution and conservatism. We proceed with a comparison here, because we are “looking for clues”. This is purely an exploratory attempt to see if any pattern might emerge that could lead toward an explanation of the recent findings.

With that caution, then, the following table breaks down changes in five quality indicators for the two groups.

Table 17

Changes In Quality Indicators, 2000 to 2001, for Two Groups: ICF/MR and Waiver

	ICF/MR, N=808	Waiver, N=957
Adaptive Behavior Change	-2.1	-1.0
Challenging Behavior Change	-1.6	-0.8
Choicemaking Change	5.5	3.4
Quality of Life Scale Change	-0.6	1.5
Integrative Activities Change	-2.6	3.0

While both groups lost some ground in adaptive behavior, the ICF/MR group's loss was twice the size of the Waiver group's loss. And because the ICF/MR group started out with much lower scores, their 2.1 point loss was a larger percentage of their skill repertoires.

Similarly, the loss in challenging behavior was about twice as large for ICF/MR recipients than Waiver recipients.

At the same time, the ICF/MR people gained more in Choicemaking, the opportunity to control many minor aspects of daily life and decisions, than did the Waiver people. This presents a pattern that is confusing to us. The mystery is only deepened when we note that the average Mover in an ICF/MR showed a slight decrease in overall quality of life ratings from our Quality of Life Changes scale, while the Waiver Movers showed an increase. Finally, Integrative Activities went down slightly for the ICF/MR Movers, while it went up for the Waiver Movers.

In the spirit of "looking for leads," then, we believe there is justification for much more in-depth and careful study of at least these two funding mechanisms. The funding mechanisms are tied to quite different methods of monitoring, licensing, and regulation, and these differences may be causing different emphases in daily service and support practices.

This exploration has not determined that either model is better than the other, because the people in the two models are so different in the first place. What we have done, again, is shown that this is an area that merits investigation.

This section closes with a reminder and a warning. The evidence is very clear and strong that the Movers are in most ways "better off" than they were in DCs. Moving people from institutions to community homes in California has been excellent social policy that benefited thousands of people. That fact has been established not only by the present research group, but also has been replicated by researchers at California State University, Berkeley Planning Associates, and the Citygate consulting organization.

However, we now have evidence that something is changing in the service system. There are many positive measurable changes in people's lives over the past year, but for the first time, we have seen two negative impacts on people's lives. We think these two areas, adaptive and challenging behavior, are important areas. Hence we suggest treating these findings as an "early warning system." The behavioral losses have just begun, as far as we can determine, in the past year or two. Our view is that these findings give California a chance to investigate further and weigh options carefully.

Descriptive Results for the 2,170 Movers

Descriptive Results 1: Characteristics of the Movers

We completed visits with 2,170 people who moved out of Developmental Centers as a result of the Coffelt settlement agreement and who were still in the community when we visited. We refer to this group as "Movers," that is, people who moved out of Developmental Centers and into community living situations. Table 18 shows the distribution of basic characteristics among the 2,170 people, including gender, minority status, average age, and label for level of mental retardation.

Table 18
Characteristics

Percent Male	61.5
Percent Female	38.5
Percent Minority	30.2
Average Age	41.6
Percent not labeled MR	2.0
Percent Mild	19.5
Percent Moderate	10.7
Percent Severe	13.7
Percent Profound	54.0

The population is 61.5% male and 30.2% minorities. The average age is 41.6 years old. About 68% percent of the people interviewed are labeled severely or profoundly mentally retarded, while approximately 30% are labeled mildly and moderately mentally retarded.

Marital status is another characteristic that is often used to describe people in the general population. The majority of the people in this study (98%) have never been married, but 22 people who are now single, reported that they had been married at some point, while 14 people said they are married now. We also asked if people had any children. The majority answered "no", but 53 people said they have children. Only 12 of the 53 reported parents list their children as dependents.

Many people with mental retardation also have secondary disabilities. This information can be important for developing current and long-range community resources. The people we visited reported the conditions shown in Table 19 as major secondary disabilities.

Table 19
Percent of "Movers" who Reported Major Secondary Disabilities

Ambulation	27.4
Autism	10.8
Aggressive Behavior	34.9
Brain Injury	7.2
Cerebral Palsy	17.9
Communication	60.7
Dementia	1.7
Major Health Problems	26.7
Hearing	5.3
Mental Illness	22.5
Physical Disability	15.7
Seizures	29.1
Self Abuse	23.5
Substance Abuse	2.3
Swallowing	7.9
Vision	13.1
Other	10.5

Communication, aggressive behavior, seizures, problems with ambulation, and major health problems are reported as the top five secondary disabilities. The least reported secondary disabilities were dementia, substance abuse, hearing problems, brain injury, and swallowing problems.

Descriptive Results 2: Family Contacts

A major concern in any deinstitutionalization initiative is the maintenance of family connections. In fact, planning for relocation and decisions regarding where people will live in the community are often made with the intent of reunifying families and providing opportunities for more contact. Our Visitors therefore ask how much and what kinds of family contact has occurred in the past year. The specific questions from page 11 of the PLQ are as follows:

10. What kinds of contact has this person had with any relatives during the past year, and about how many times?
About how often in the past year?
(Zero if none)

__________ 10a. Telephone calls
__________ 10b. Mail
__________ 10c. Relative visits person here at this home
__________ 10d. Person goes out with relative(s)
__________ 10e. Program Planning Meetings
__________ 10f. Consent for medical care

The results are shown in Table 20.

Table 20
Frequency of Contact with Relatives

Type of Contact	% With No Contact	Median For Those With Any Contact
Telephone calls	64%	12.0
Mail	74%	3.0
Relative visits person here at this home	63%	4.0
Person goes out with relative(s)	70%	6.0
Program Planning Meetings	80%	2.0
Consent for medical care	86%	1.0

The column headed "% With No Contact" shows that the majority of people had no contact with relatives in all of the listed categories. For example, approximately 80% of people had no contact with relatives in the past year via program planning meetings. For the 20% who did have relatives involved in program planning, the average (median) number of contacts was 2 in the past year.

The most common kind of contact with relatives was made by telephone, at about 12 times per year for the people who had any contact. To repeat, however, only 36% of the people had any telephone contact with relatives. The median number of 12 contacts per year is for those same 36% of the Movers who had phone contact.

Taken across all the forms of contact, more than 49% of the Movers were reported to have had no family contact of any kind in the past year. This showed that many of the Movers had no one in their lives other than paid professionals and direct care workers. These people were, and are, dependent on the "system" to safeguard their rights and well-being. This is in sad contrast with the fact that one of the most frequent responses given by the Movers to "If you had one wish" (see Results: Personal Interview below) was the wish for more contact with relatives.

Descriptive Results 3: Friendships

Many people measure their quality of life according to the numbers of friendships they enjoy.[17] This measurement is even more important for people with disabilities, like the Movers, who have not had years of community schooling and jobs to develop friendships in the ways that most people do. The PLQ addresses this serious issue beginning on page 12:

> **11. Number Of Friends:** About how many people in this person's life would you describe as friends? Do not count mere acquaintances (people one might say "Hi to, or wave to, but with whom there is no other interaction). Friends might include housemates, co-workers, schoolmates, other people with disabilities served by the residential or day program agency, direct care workers, case managers, support coordinators, therapists, churchgoers, neighbors, merchants (workers in any commercial store), letter carriers, law officers, advocates, guardians, etc.
>
> 11a. _______ number of friends
>
> 11b. _______ number of "close" friends (see next section for explanation)

This question was often answered by whoever knew the person best, usually a staff person. The following Table provides the results for both 11a and 11b.

Table 21
Number of Friends and Close Friends

	None	Average
11a. Friends	11.6	8.6
11b. Close Friends	29.3	2.6

Among the 2,170 Movers, 29% reported no close friends at all. The other 71% reported having an average of 2.6 close friends. We did not define "friend" or "close friend" for the people being interviewed. It is our procedure to allow the people being interviewed to make

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[17] R. Schalock and M. Begab (Eds.) ***Quality of life: Perspectives and issues*** (pp. 227-234). Monograph Number 12. Washington: American Association on Mental Retardation.

their own decisions regarding the definitions and degrees of friendship. The responses indicated that people have a clear understanding of friendship and that they do have friends.

The next section of the PLQ, the Close Friends Scale, begins on page 12 (see **Appendix B**). The matrix below was designed to capture the nature and intensity of relationships. Visitors asked people to describe their five closest friendships. Our analysis describes the percentages of friendships according to the type of relationship. The nature of these close friends was as shown in Table 22.

Table 22
Close Friends: Relationships

Relationship	Number	Percent of Responses
Relative	402	8.7
Staff of home	2066	44.6
Staff of day program	401	8.7
Other paid	145	3.1
Housemate	1094	23.6
Co-worker	185	4
Neighbor	78	1.7
Merchant	7	0.2
Other	257	5.5
Total responses	4635	100.0

The Table immediately reveals that most “close friends” were people who were paid to be in the person’s life (56.4% when we add rows 2, 3, and 4). The second most common choice was housemates at 23.6%. The third largest group was relatives at 8.7%. Respondents listed 257 friends (5.5%) as “Other,” the nature of the relationship was not known, and we could not tell whether they were paid or unpaid.

The data support an image of what the Movers considered to be close friends: mostly paid staff, and then the people they lived with (rarely by their own choice), followed by relatives. Outside of paid people, housemates chosen by others, and relatives, these people tended not to have many friends such as neighbors, co-workers, churchgoers, or other general members of the community. On the other hand, almost three out of four Movers were considered to have at least one close friend, and that would seem to be a positive finding.

If the future brings an increase in real community membership and inclusion, then we should expect to see a gradual increase in friendships with other than paid staff and housemates. Our database will enable us to test this hypothesis over the years to come.

Descriptive Results 4: Individual Planning

Since the mid 1970s and the beginnings of the movement towards individualized services, a person's plan has been a critical measure of quality services. Federal regulations for residential, employment, and educational services began to require individual plans so that active treatment and progress could be monitored. Today, the state of the art for individual plans includes a high degree of person-centered thinking and the inclusion of family members and friends in the planning process. Table 23 shows the personal plan status for the 2,170 people interviewed this year.

Table 23
Does The Person Have An Individual Plan?

	Number	Percent
0 No (if No, skip this section)	47	2.2
1 Yes, but no copy of it is kept here	83	3.8
2 Yes, and normally a copy would be here, but is not now	59	2.7
3 Yes, and a copy of it is here	1975	91.3
Information missing	6*	
Total	2170	100.0

* For 6 people of the 2,170, this item was left blank or an incorrect code was entered

Our data show that 91.3% of the Movers have individual plans and that a copy was available at the time of our Visit. There were only 47 people who did not have plans and that information was reported immediately to the proper Regional Center as part of our Quality Feedback System.

The next scale, on page 23 of the PLQ instrument, is "Elements of the Planning Process". This scale measures the degree to which a person's plan is person-centered. The first item is about the primary respondent's participation in the planning process. The results are listed in Table 24.

Table 24
How Was the Primary Respondent Involved in the Planning Process for This Person?

Value Label	# of People	% of People
Not at all	416	19.7
Somewhat	68	3.2
Half	43	2.0
Mostly	127	6.0
Completely	1459	69.0
Total	2113	100.0

*57 people left this question blank.

The first item asked whether the primary respondent, (the person or the person who knew the individual best) was involved in the individual planning process for the individual. The Table shows that the majority of our primary respondents (80%) were part of the planning team to some degree. However, approximately 20% were not involved at all. Those respondents were not asked to complete the rest of the items about the Elements of the Planning Process, because they would not have first hand knowledge of how things were done. For most people, then, we were able to find out a great deal about the nature of the planning process.

A review of the average scores on this five point scale provides an accurate summary of the status of the planning process for people with disabilities statewide. The results are shown in Table 25.

Table 25
Elements of the Planning Process:

Features of "Person-Centeredness"	Average
How involved in planning process?	3.0
Address long-term dreams?	3.5
Building a network of supports?	2.9
Meetings comfortable and relaxed?	3.7
Planning sessions scheduled as needed?	3.4
Process defined or regulated?	3.8
Process encourage creativity?	3.6
Process allow for conflict resolution?	3.6
Process flexible?	3.7
Does person have ultimate authority?	2.5
Process emphasize cooperation?	3.7
Process emphasize person's relationships?	3.1
Process consider money?	2.7
Does planning group have control over resources?	3.0
Do unpaid group members have real power?	2.6
Do you consider plan to be person-centered?	3.8

The data in Table 25 identify where the planning process was most "person-centered" and where it could use improvement. Two items were tied for the highest score at 3.8. They were: *Is the planning process defined or regulate*d? and *Do you consider the plan to be person-centered?*

The three lowest scores were recorded for: *Does the person have ultimate authority?* (2.5). *Do unpaid group members have real power?* (2.6). *Does the process consider money?* (2.7).

These answers seem to be contradictory in that the respondents feel strongly that the plans are person centered and yet they also report that the focus people do not have ultimate authority. The high score on the "defined or regulated" dimension also seems to be at odds with progressive notions of person-centered planning that are not governed by "one size fits all" rules and procedures. One explanation is that most respondents have accepted the philosophy of person centered planning and they see improvements from the past, even though the system needs to be more responsive to the actual preferences of the focus person.

The planning process was weakest on taking money into consideration, allowing the ultimate authority to reside with the person, and with the unpaid team members. These are three of the things that self-determination is specifically aimed at changing. Over the coming years, we will be looking for changes in these and other Elements of the Planning Process scale.

One of the most important aspects of a plan is the perception of the focus person, and those who are meant to implement it, regarding its utility. A plan is useless if the person and/or staff view it only as an annual requirement to be completed and filed away until the new year. Table 26 shows the percentages of how respondents rate a plan's usefulness.

Table 26
How Useful Is This Person's Plan?

Value	**Number of People**	**Percent**
Not at all useful	16	0.8
Not very useful	34	1.6
Somewhat useful	266	12.8
Very useful	1139	54.7
Extremely useful	600	28.8
Don't know or not applicable	27	1.3
Missing	88*	100.0
Total	2170	

* For 88 people of the 2,170, this item was left blank or an incorrect code was entered.

Table 26 shows clearly that the great majority of people (96.3%) consider their plan to be somewhat, very, or extremely useful. This is a credit to the system and to all stakeholders who participate in planning. Several other aspects of the planning process are of interest. For example, how many planning meetings took place during the past year for each person? The average (mean) was 3.3 and the median (half had more and half had less) was 4.0. More than three meetings per year can be viewed as a positive step because it can mean that a person's planning team is being flexible in responding to personal need, not solely the requirement for an annual meeting and an annual plan.

The approximate average length of these planning meetings was 1.5 (mean) and 1.0 (median) hours. The length of the meetings suggests adequate time to review progress and explore future goals and dreams. The planning teams were composed of about 6 people on the average (5.8 mean, 6.0 median). The average number of goals per plan was reported to be about 6 (6.2 mean, 5.0 median).

One of the basic principles of person-centered planning is to include the person in the meeting and to make accommodations to facilitate maximum participation. We measured the degree of participation for each person in the project, as shown in Table 27.

Table 27
Focus Person's Presence at the Planning Meetings

Response	Number	Percent
No	108	5.0
No, person chose not to be present	23	1.1
Yes, person present for small part	146	6.8
Yes, person present for most or all	1884	87.2
Total	2161	100.0

* For 9 people of the 2,170, this item was left blank or an incorrect code was entered.

As shown above, approximately 94% of the people visited had some level of participation in their plans. Non-participation was a relatively rare event. The Movers and the people who support them obviously place a high value on this element of the planning process.

On page 26 of the PLQ we ask about people’s “Top 5 Goals” (**Appendix B**). In Table 28, the goals are listed in the order of how often they were included in individual plans.

Table 28
How Often Were Various Goals Included in Plans?

Type of Goal	Number of Goals Out of the 9,283	Percent of the 9,283 Goals	Percent of the People
Other self-care	798	8.6	38.0
Eating	565	6.1	26.9
Grooming	519	5.6	24.7
Other sensory, motor or communication	451	4.9	21.5
Reduction of physical violence to self	433	4.7	20.6
Domestic activities	415	4.5	19.7
Bathing and/or washing	382	4.1	18.2
Reduction of physical violence	353	3.8	16.8
Personal health care	344	3.7	16.4
Other goals regarding reduction of challenging behavior	304	3.3	14.5
Use of non-verbal communication	282	3.0	13.4
Arm use and hand-eye coordination	266	2.9	12.7
Toileting	239	2.6	11.4
Develop skills in sports/athletic activities	237	2.6	11.3
Dressing skills	229	2.5	10.9
Reduction of hostility or threatening behavior	206	2.2	9.8
Reduction of stereotyped behavior	197	2.1	9.4
Reduction of disruptive behaviors	189	2.0	9.0
Use of money and purchasing	171	1.8	8.1
Reduction of rebelliousness	170	1.8	8.1
Reduction of property damage	159	1.7	7.6
Other leisure time goals	162	1.7	7.7
Ambulation improvement	149	1.6	7.1
Reduction of inappropriate verbalization	150	1.6	7.1
Use of verbal language	127	1.4	6.0
Group interaction	127	1.4	6.0
Reduction of inappropriate sexual behavior	107	1.2	5.1
One-to-one interaction	111	1.2	5.3
Other social skill goals	113	1.2	5.4
Develop hobby(s)	108	1.2	5.1
Reduction of running away	104	1.1	4.9
Reduction of clothing problems	90	1.0	4.3
Increase motivation to work	94	1.0	4.5
Awareness of others	79	0.9	3.8
Other work goals	88	0.9	4.2
Reduction of theft, stealing	70	0.8	3.3

Table 28
How Often Were Various Goals Included in Plans?
(continued)

Type of Goal	**Number of Goals Out of the 9,283**	**Percent of the 9,283 Goals**	**Percent of the People**
Other education goals	72	0.8	3.4
Learn to use community resources more independently	76	0.8	3.6
Mobility/Travel	61	0.7	2.9
Reduction of inappropriate interpersonal manners	43	0.5	2.0
Family interaction	51	0.5	2.4
Reduction of lying, cheating	34	0.4	1.6
Achieve a new or better work placement	36	0.4	1.7
Improve motivation to participate and learn in school	33	0.4	1.6
Learn to plan excursions	35	0.4	1.7
Obtaining generic community services	29	0.3	1.4
Learn the concept of working for pay	30	0.3	1.4
Learn specific job skills	31	0.3	1.5
Achieve mastery of specific academic skills	24	0.3	1.1
Vision: using glasses, correction of eye problems	14	0.2	0.7
Use of written language	15	0.2	0.7
Reduction of withdrawal	16	0.2	0.8
Reduction of hyperactivity	18	0.2	0.9
Manners, customs, politeness	20	0.2	1.0
Handling emergencies	11	0.1	0.5
Civic and legal duties	8	0.1	0.4
Sexual interaction	6	0.1	0.3
Learn job-seeking skills	7	0.1	0.3
Learn to use television appropriately	8	0.1	0.4
Understanding and use of numbers	3	0.0	0.1
Telling time	3	0.0	0.1
Use of telephone	2	0.0	0.1
Hearing: using hearing aid, correction of ear problems	4	0.0	0.2
Learn appropriate classroom behavior	3	0.0	0.1
Transfer to a more appropriate school placement	2	0.0	0.1
Total Number of Goals Reported	**9283**	**100**	

Table 28 has two percentage columns. The first represents the goal's percentage of the total 9,283 goals. For example, the goal with the highest percentage in that column was "Other Self-Care", meaning that 8.6% of the 9,283 reported goals were "Other Self-Care". The second percentage column lists the number of people in the population of 2,170 who selected that particular goal. In the case of "Other Self-Care", 38% of the respondents included that goal in their plans. The top three types of goals selected by the focus people and their planning teams all relate to basic self care. The fourth most common kind of goal was in the area of sensory, motor, and communication skills. The fifth was behavioral, aimed at reducing or preventing self-abusive behaviors.

It is interesting to note that some goals that were previously seen as "standard" in professional circles were rarely selected for this group. Examples are "Handling emergencies," "Learn job-seeking skills", and "Manners, customs, politeness".

Descriptive Results 5: Day Activities, Employment, and Earnings

One of the most important ways to look at quality for all people, and especially for people leaving institutions, is to ask, "What do they do all day?" It is important that people stay engaged, that they have something to do that is fulfilling to some degree, to have something that they can "look forward to" each morning. Page 29 of the PLQ recorded information about each person's involvement in work, day activities, and school. Table 29 summarizes how many of the Movers were involved in each type of day activity.

Table 29
Number and Percent of Movers Involved in Each Type of Day Activity

Type of Day Activity	Number of People Involved	Percent of the 2,170 Movers	Average Number of Hours
Adult Development Program	1247	57.5%	27
Vocational Rehabilitation	382	17.6%	25
Community Experience	364	16.8%	18
Sheltered Employment	115	5.3%	22
Other Day Activities	113	5.2%	26
Supported Employment	58	2.7%	22
Public School, Center-based	29	1.3%	26
Volunteer Work	24	1.1%	12
Regular Job	16	0.7%	26
Public School, Regular	14	0.6%	24
Senior Citizen Program/RC Funded	12	0.6%	27
Private School, Center-based	7	0.3%	22
Self Employed	6	0.3%	5
Adult Education	6	0.3%	10
Partial Hospitalization Program	4	0.2%	13
Private School, Regular	4	0.2%	14
Senior Citizen Program Generic	2	0.1%	2

For the Coffelt Movers, the most common type of day activity was an Adult Development Program (57.5%), and the second was Vocational Rehabilitation (17.6%). As the Table shows, very few people were involved in supported employment (2.7% or 58 people) or a regular job (0.7% or 16 people). The issue of most concern regarding day activities is that 116 people reported having zero hours per week of day activities. This number is an increase from last year's data in which 99 people reported no day program hours. This information was reported to the Regional Centers immediately following the interviews along with the stated reasons that are listed in Table 30.

Table 30
Reasons Given for Lack of Day Program

Refuses (10)
They said I don't belong there.
On a list to get a new day program, old one scaled down. (2)
Chooses not to participate. (3)
In-home activity center.
Because of seizures, it's difficult for him to participate in a day program.
Retired (6)
Not in day program due to being on a tube feeder.
Just moved, none yet.
Behavior problems due to fecal smearing at the day program.
Kept falling at day program.
Lost job. (2)
In jail. (3)
Trying to get a day program through resource center.
Quit his job a couple of weeks ago.
Became too difficult to handle, combative.
None apparently offered.
School was too stressful.
Behavior problems. (10)
Starting business.
Elopement risk, family living.
Too retarded and no verbal skills.
Health wise is unable to tolerate a day program. (2)
Client's choice (5)
Just fired from job and is just "hanging out."
Does not want to attend.
Totally dependent for all care, Mother feels it's better if she's at home.
Kicked out of last two day programs, looking for a new one.
No local program for his level of disability.
Broken legs and cataracts prevented her from going to a day program.
Lives with mother and she feels he should stay with her.
Physically unable to be cared for at local facility.
Says she doesn't want or need to attend a day activity.
Refused to attend day activity at level available.
Was just admitted to a drug rehab.
Recently hospitalized, recuperating.
Regurgitates continually and was removed.
Medical issues that prevent her.
Says he hurt his back.
Nobody will accept him at a day program. Case manager trying to find a program.

She will be attending an activity within a couple of weeks.
He refuses all attempts, there have been many.
Wants to make money at a job, but can't work around kids because of sexual behaviors.
AWOL behaviors prevent.
Still looking for a job.
Recovering from surgery.
He has aggressive behaviors and no one wants to work with him.
Lost job - looking right now for an evening job.
Physical disabilities prevent him from participating. (2)
Not since surgery last year.
Takes care of her baby.
Client doesn't want to go, he wants to fish.
Case worker hasn't signed him up yet.
In-home tutorial due to being wheelchair bound and can't talk.
Kicked out of last program.
This facility is beginning to discuss providing a day program.
Dropped from day program because of non-compliance. (2)
Not willing to participate recently.
Funding for his old program stopped, case manager looking for a new one.
He hasn't wanted one, moved frequently.
Lives with parents, they see no need.
Left job recently, waiting for a new placement.
Looking for work.
Unable to work due to health problems.
He is on his own and comes and goes as he pleases. Does not want a day program.
Fell at day program, broke arm. Removed until arm heals then place in a different one.
Level of retardation and health issues.
On the waiting list.

Many of the listed reasons for no day activity hours are perfectly valid, e.g., “Fell at day program, broke arm. Removed until arm heals then place in a different one” and “Takes care of her baby.” However, there are many responses that seem to indicate systemic problems. Many responses refer to challenging behaviors and an inability or unwillingness for these problems to be addressed in day programs. Examples of these responses are:

- Dropped from day program because of non-compliance
- He has aggressive behaviors and no one wants to work with him
- Nobody will accept him at a day program. Case manager trying to find a program that will
- Became too difficult to handle, combative

The next aspect of day activities that we examined was the level of integration that a person experiences during the day. One of the questions we use to measure integration is on page 30 of the PLQ:

5. DURING DAY ACTIVITIES, WORK, OR SCHOOL, HOW MUCH TIME DOES THE PERSON SPEND IN THE PRESENCE OF THE **PUBLIC**? (Do not count during transportation.)

Table 31
How Often In Integrated Settings During Day Activities

How Often Integrated	Number of People	Percent of People
None	279	13.5
Less than half	594	28.8
About half	650	31.5
More than half	273	13.2
All or nearly all	269	13.0
Total	2065	100.0
Response Missing	105	

As Table 31 shows, there was a fairly even distribution across the five levels of integration on this item. In all, about 58% of the Movers were reported to be “in the presence of” the public about half, or more than half, of the time.

When people move from institutions to the community there is an expectation that they will be able to engage in some form of income generating activities. We therefore ask people if they earned any money through their day activity. The average weekly earning figure, including all the people who made no money at all, was $5.93.

This year's data show that 470 of the 2,170 Movers (22%) earned money in the week preceding the visit (or a typical week). Of the 470 people who did make any money, the lowest weekly amount was 25 cents, and the highest was $260. We removed the data for the people who made no money at all, and looked at the averages again. The average (mean) for those who did make any money was $27.36. Another measure of the average is the median, which was $10.00. The median is the figure where half the earnings were below it and half were above it. For an unusual distribution, the median is a better measure than the mean, and earnings in this group were distributed very unevenly.

The picture that emerged was one of economic bleakness and scarcity. Less than a fourth of the Movers performed any work for pay, and for them, the amount of money earned was very small, the best indicator of the average was very low, about $10 per week or $520 per year.

Descriptive Results 6: Choicemaking and Self-Determination

The Decision Control Inventory, beginning on page 33 of the PLQ, measures who has power over 35 life areas such as clothes to wear, food to eat, places to go, and type of work or day program. The scale requires ratings from 0 to 10 on each dimension, with 0 meaning that paid staff made all decisions in that area, and 10 meaning that the focus person (and/or freely chosen unpaid allies) made the decisions in that area. A score of 5 or 6 means that decision making power is shared about equally. The 35 "0-to-10" scores can be combined into a single scale which we compute to a range from 0 to 100, with higher scores meaning more individual control over life choices, and therefore less professional domination. The Movers' average score on the Decision Control Inventory was 47.9 points out of 100.

Table 32 provides detail about which areas of choice people had more or less control over. Examination of these scores can provide guidance for provider agency staff and other support personnel who wish to enhance people's decision making skills.

Table 32
Details of Opportunities for Choicemaking

Life Control Area	Average Score
Taking naps in evenings	8.5
Freedom to decline activities	8.3
What to do with relaxation time	8.1
When to get up on weekends	7.8
When to go to bed on weekends	7.7
Express affection, including sexual	7.3
When, where and how to worship	7.3
When to go to bed on weekdays	7.0
Who you hang out with in and out of the home	6.7
What clothes to wear on weekends	6.2
What clothes to wear on weekdays	6.1
What to have for breakfast	5.2
What clothes to buy	5.1
What to have for dinner	5.1
Visiting with friends	5.1
Minor vices	4.9
Choosing restaurants	4.8
Choice of places to go	4.8
Time and frequency of bath	4.8
What to do with personal funds	4.6
Who goes with you on outings	4.0
What foods to buy	3.5
Type of work	3.4
Whether to have a pet in the home	3.2
Choice of house or apartment	3.1
Choice of furnishings	3.0
Amount of time spent working	2.9
How to spend day activity funds	2.8
Which service provider works with person	2.7
Choice of people to live with	2.5
Choice of support personnel: option to hire and fire	2.4
Choice of case manager	2.2
How to spend residential funds	2.1
Choice of agency's support person/staff	2.1
Type of transportation	1.9

These data showed that the highest average scores were in the choice to take naps in the evenings and to decline to take part in group activities. Following those were: what to do with relaxation time, when to get up on weekends and when to go to bed on weekends. These scores reflect the methods being used in community homes to support people who are in transition from hospital-like environments, with very strict medically oriented rules and regulations, to more flexible and individually tailored community homes.

The lowest scores in the table were equally informative. Movers in California do not yet participate very much in choices about hiring and firing support personnel, selecting case managers, spending residential funds, selecting what staff will work with them, or in types of transportation. These are major control issues that can shape lives in major ways. These are also areas that are targeted specifically in self-determination initiatives. If power shifts in future years in the California service system, data like these can reveal the change from the point of view of each individual service recipient.

Descriptive Results 7: Integrative Activities

The scale used to measure integration was taken from the Harris poll of Americans with and without disabilities (Taylor, Kagay, & Leichenko, 1986). Respondents were asked to report how often they engaged in a variety of community events in a typical month. Items on the scale included activities such as: visit with friends, go shopping, go to a place of worship, engage in recreation, etc. A second qualifier for our scale was events that involved the presence of people without disabilities. This tool simply counts the number of "outings" to places where there might be interaction with non-disabled citizens. It does not measure actual engagement or the degree of participation. Information regarding participation as well as presence might be revealed through an analysis of the close friends scale and types of individual goals.

Table 33
Types of Integrative Activities

Type of Outing	Average Number of Events Per Month
Visit with close friends	4.9
Go to a park or playground	4.7
Go to a shopping center	4.1
Visit a grocery store	4.0
Go to a restaurant	3.5
Use public transportation	1.9
Other kinds of getting out	1.8
Go to a movie	1.1
Go to church	0.8
Go to a library	0.7
Go to a bank	0.7
Go to a sports event	0.6
Go to a theater	0.6
Go to a post office	0.4
Go to a health or exercise club	0.3
Go to bars	0.1
Total	30.4

According to this scale, the Movers had opportunities for integrated activities an average of 30.4 times per month. The most frequent kind of integrated community activity reported by the focus people, or by those who knew them best, was visits to close friends, at an average of 4.9 visits per month. The next most frequent kind of outing was going to a park or playground, (4.7 times per month), followed by various kinds of shopping, to a shopping center (4.1 times per month) and to the grocery store (4.0 times per month). The least frequently reported activities were going to bars (0.1 times per month) and going to a health club (0.3 times per month). It will be interesting to track changes in this scale as people make more community connections and develop more individualized interests.

In the Integrative Activities section of the PLQ on page 34, we asked what kind(s) of transportation people had used during the past month. The results were as shown in Table 34.

Table 34
Types of Transportation Utilized

Type of Transportation	**% of People**
Car or van assigned to this home	72.9
Agency car or van	70.4
Staff member's car or van	49.4
Agency bus	30.9
Family member's car or van	24.7
Public transportation	19.9
Paratransit	18.3
Friend's car or van	7.7
Taxicab	4.8
Person's own car or van	1.7

The highest percentages of people had used a car or van assigned to their home (72.9%) or an agency car or van (70.4%) for transportation in the month preceding our visit. Many people (49.4%) had also been out in a staff member’s vehicle. The next types of transportation used were an agency bus or a family member’s car or van. Smaller groups of the Movers used public transportation (19.9%) and paratransit (18.3%). The least used forms of transportation were a friend’s vehicle, a taxicab or one’s own vehicle.

In one of the questions most indicative of freedom of movement, we asked:

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

The responses are listed in Table 35 and show a pattern of relatively high freedom to get out and about.

Table 35
Freedom to Travel at Will

# Times	# People	% of People
0	226	10.4
1	75	3.5
2	89	4.1
3	82	3.8
4	46	2.1
5	168	7.7
6	53	2.4
7	54	2.5
8	217	10.0
9	206	9.5
10	954	44.0
	2170	100.0

Remarkably, nearly half of the people (44%) were reported to be able to go out whenever they wanted to, even on the spur of the moment, 10 times out of 10.

The corresponding figure in an otherwise reasonably progressive service system in the Midwest was 19% for a total population of 786 people. The California Movers, then, enjoyed unusually high freedom of movement. This could be related to the cultural emphasis on vehicles in California, but the result was nevertheless intriguing and, in our view, positive.

Descriptive Results 8: Health, Health Care, and Medications

One of the strongest indicators of a quality support system is the maintenance of health and access to quality health care. Community capacity with regard to health care for people with disabilities is a vital factor in any deinstitutionalization initiative. The PLQ addresses these important issues in the Health Information section beginning on page 35. Table 36 shows the responses to the question "In general, how is this person's health?"

Table 36
How Is This Person's Health?

Rating	Number of People	Percent of People
Very poor	6	0.3
Poor	38	1.8
Fair	327	15.2
Good	1324	61.5
Excellent	457	21.2
Total	2152	100.0
Blank	18	

Almost 83% of the respondents felt that peoples' health was "Good" or "Excellent." Only 2.1% of the respondents felt that peoples' health was "Poor" or "Very Poor." Table 37 summarizes a series of analyses related to health care utilization.

Table 37
Indicators of Health Care Utilization

Health Care Dimension	
Average Dental Visits	1.50
Average Doctor Visits	6.07
Average Specialist Visits	4.77
Average Hospital Admissions	0.27
Average Emergency Room Visits	0.74
Receiving Antipsychotic Medication	581
Receiving Behavior Control Medication	812
Receiving Sleep Medication	182
Receiving Antidepressant Medication	217
Receiving Seizure Control Medication	924
Receiving Digestive Medication	1028
Receiving Chronic Health Condition Medication	827
Receiving Nutritional Supplements	1184
Receiving Other Daily Medication	751

Table 36 shows that the Movers had an average of 1.5 visits to a dentist and 6.07 visits to a doctor in the past year. Additional visits to specialists were made an average of 4.77 times in the past year. The table also shows the number of people receiving certain types of medications. Antipsychotic medication, for control of psychiatric symptoms, was received by 581 people. Behavior control medication was received by 812 people. Seizure control medication was received by 924 people. Another important health related question asked "How many errors in the administration of medications occurred in the past month?" Table 38 presents a list of responses.

Table 38
Number of Medication Errors in Past Month

Number of Medication Errors	Number of People	Percent of People
0	2080	98.3
1	26	1.2
2	4	0.2
3	2	0.1
5	1	0.0
6	2	0.1
20	1	0.0
Total	2116	100.0
Blank	54	

The great majority of Movers (98.3%) did not experience any errors in the administration of their medications in the month prior to our visit. However, there were 26 people who experienced at least one error in the past month. It is important to note that medication errors is one of the items that we include in our quality feedback summaries to the Regional Centers immediately following the visit. We also asked respondents to describe the most recent medication error. Their responses are presented in Table 39.

Table 39
Reasons for Most Recent Medication Errors

Describe most recent medical error
Didn't wake up in time for meds
He took medication at wrong time
There was a missed dosage in the afternoon, however there was no need for emergency room
Skipped giving an antibiotic for 5 days
Given a dose of pepsid when it had been discontinued
Gave coumadin 5 blood tests
There was a missed dosage in the afternoon. However, there were no significant problems
Received someone else's medications
He took someone else's medication at program
1 morning's doses missed, behaviors & trip to ER
Only 1/2 of regular dose given
New med order, missed on 1st dose
1 dose of propulsid missed
Missed one of her noon meds at cap
During day activity - did not receive depakote tablets
Client refused to take med. (resistive behavior)
Med. Omission
There was a missed dosage in the afternoon. No significant problems such as ER visit
There was a missed dosage in the afternoon
Not compliant when taking meds
PM doses given late
Forgot to give a pill, given soon after
Forgot to give one dosage
Refused meds 10/16 and 10/30 pm
Called pharmacy who instructed what to do
Forgot to take morning meds. Staff documented in chart
There was a missed dosage in the afternoon. There was no significant problem
There was a missed dose in the afternoon, no significant problems
He did not take 12 PM med. New staff did not send it to day program
Call the pharmacy to remind them that person is low on ibuprofen
He does not come back to the house for meds
Missed morning dose, nurse notified, no problems
Noon meds. Missed 1 week ago but given later

Table 40 illustrates the responses to the question “How easy is it to get health care?”

Table 40
Ease Of Getting Medical Care For This Person

Feeling	Number of People	Percent of People
Very difficult	65	3.1
Difficult	102	4.8
About average	372	17.7
Easy	974	46.2
Very easy	594	28.2
Total	2107	100.0

Table 40 show that over 74% of the respondents believed that it was “Easy” or “Very Easy” to obtain healthcare for the Movers. Only about three percent of the respondents felt that it was “Very Difficult.” Table 41 shows the responses to the question “Overall, how good is this person’s health care?”

Table 41
How Good Is The Health Care This Person Is Getting?

Feeling	Number of People	Percent of People
Very poor	4	0.2
Poor	5	0.2
Fair	97	4.6
Good	1207	56.7
Excellent	816	38.3
Total	2129	100.0

Table 41 shows that 95% of the respondents felt that the peoples’ quality of health care was “Good” or “Excellent.” Less than one percent of the respondent’s felt that the peoples’ quality of health care was “Very Poor.”

A very important aspect of any quality tracking and assurance program is monitoring allegations of abuse. Table 42 lists the respondents' descriptions of allegations of abuse in the past year.

Table 42
Allegations of Abuse in Past Year

Describe most recent allegation of abuse
No knowledge of previous problems no records
Accused mom of slapping, but it all worked out
Picked up stick & threatened house manager
Allegations of staff yelling at her. Tendency to make false allegations.
Episode of bus driver hitting. Bus driver was fired
Reported that resident was rolled over by staff while changing
Staff drug her on carpet, left rug burns
Mom made derogatory comments to regarding staff care (unfounded)
Says that staff at his old home started a fight with him.
Suspected physical abuse by prior care provider
Report of neglect filed because night staff member deserted his position.
Abuse was alleged in previous home
When returning from shopping with a group from the day activity staff
Lost control & as a result there were abrasions when brought under control
Sexual abuse allegation
Abuse by prior care provider
Alleged abuse at previous home
Abuse by prior care provider
Sexual advances from brother and his friend in sister's home.
Alleges that the administrator at the day program made an advance.
Allegedly sprayed disinfectant in her face. Employee dismissed
Someone heard her screaming and someone slapping her. It was investigated
Incident of rape by attacker when she snuck out. She is very proud of herself
Staff person raised her voice
Lost her wallet and asked if she would be spanked for it. Investigated.
He was whipped with a cord. Investigation resulted in arrest and conviction
Refuses to go to doctor appointments. Case worker filed a licensing report.
Staff member alleged he was hit on the arm by another staff member.
Old residence using my ss money for drugs. Reported to RC
Housemate grabbed him & caused abrasions & a bump on his head.
I don't want to talk about it
Mother took him out, ended up in ER. Social services was called.
Says staff are beating her up, calling her names and hitting her
Abuse at the day program, employee was terminated
Said staff at day program hit him. This resulted into investigation.
Multiple allegations against staff when she first moved.
Suspected of being involved in the sexual abuse of another patient.
Job coach allegedly pushed him from chair. Job coach terminated
Claimed a male peer forced him to have oral sex
Claims that a teacher attacked him. Charges pressed.
Called 911, said he needed to be straightened out
TV was stolen from room staff member staff
Former staff member pulled him to the bathroom by his feet no apparent injury
Claimed that staff hit him in the head. Finding was inconclusive.
Staff member grabbed her by the throat to lead her, no physical injury.
Physical abuse by day program staff

Descriptive Results 9: Personal Interviews

The personal interview is one of the most interesting sections of the PLQ. It records the opinions and comments of people with disabilities in their own words. As possible, this interview is conducted privately. Prime requisites for COA Visitors are experience in working with people with disabilities and demonstrated sensitivity to disability related interviewing factors such as non-verbal communication, short attention spans, repetitive physical and verbal mannerisms, limited vocabulary skills, and tendencies to agree or disagree regardless of question content. Visitor training includes instructions on gathering pre-interview information on these kinds of issues and on requesting methods and strategies for individual communication preferences. The location, timing and presence of a person who knows the focus person very well are additional factors that are considered in designing an optimal interview environment.

Visitors begin with an explanation of the purpose of the interview and assurances regarding confidentiality. Simple language is used to stress the fact that there are no wrong answers, that the interview is not a test or a licensing inspection, and that the Visitor will not tell anyone else individual answers. For example, "I will ask you a question like *how do you like the food here?* I will write down your answer but I will not tell your staff, house manager, case manager or anyone else what you said. When we finish our report, there will be a section that says something like *most of the people like the food, or 25% of the people don't like the food,* but no one will know what you said."

Visitors then gather general information and try to develop a rapport with the focus person. The person is free to come and go during the interview and to participate as much as possible. Visitors, with the assistance of the person who knows the focus person very well, make a judgment decision about when to try the personal interview.

Following are individual discussions of the questions on the personal interview. In this year's visits, 667 Movers were able to communicate directly with the Visitor and answer these questions. Most answers were recorded on a five-point scale, from very poor, poor, fair, to good, and very good. The remaining questions involved the use of a Likert scale, a yes, no or don't know choice. The respondents did not all answer every question so individual response numbers are presented. It is important to note that the PLQ often includes several questions on the same topic as a reliability tool. The questions do not follow each other in the personal interview but are grouped together in this report for ease of comparison.

Table 43
How do You Feel About Living Here?

Feeling	Number of People	Percent of People
Very poor	22	3.7
Poor	33	5.5
Fair	79	13.3
Good	259	43.5
Very good	202	33.9
Total	595	100.0

Table 43 shows that the majority of people (77.4%) answered good or very good to this question. This was followed by 13.3% who answered fair. The next level, poor, was the response of 33 people (5.5%). Only 22 people (3.7%) answered very poor. This question is very broad and of course may reflect a person's feelings about what occurred on the actual day of the interview. However, the percentage of positive responses indicates a significant level of satisfaction.

Table 44
Do You Want to Move Back to a Developmental Center?

Feeling	Number of People	Percent of People
Definitely not	312	67.0
Probably not	43	9.2
Maybe	42	9.0
Yes, probably	32	6.9
Yes, definitely	37	7.9
Total	466	100.0

The answers to this question were also significantly positive. Of the 466 people who answered, 76.2 % said they would definitely not or probably not choose to return to a developmental center. This majority was followed by 9 % of the respondents who answered maybe, and 14.8 % who answered probably or definitely yes. COA has found in other studies that people who consider a return to a developmental center often make that choice because of a personal connection that has been lost, either with staff or peers.

Table 45
Do You Want to Move?

Feeling	Number of People	Percent of People
No	301	55.2
Not sure	29	5.3
Yes	215	39.4
Total	545	100.0

This is a general question and a positive response could reflect a desire to move to a family home, to another community living arrangement, to a more independent community living arrangement or back to a developmental center. It is important to note that a desire to move does not necessarily reflect negatively on a provider or the service system. A desire to move may indicate personal growth and independence and a stable support system that has provided opportunities for developing community connections, and for learning personal choice and decision making.

There were three choices for this question, yes, no, and not sure. A total of 545 people answered and 301 (55.2%) answered no, they did not want to move. There were 215 people (39.4%) who did want to move and 29 people (5.3%) who were not sure.

A recommendation for further measurement and monitoring of changes in this question would include comparisons with the decision control inventory, especially with the, *who chose where and with whom you live,* questions.

Table 46
How is The Food Here?

Feeling	**Number of People**	**Percent of People**
Very poor	9	1.6
Poor	23	4.0
Fair	57	9.9
Good	287	49.8
Very good	200	34.7
Total	576	100.0

Approximately 84.5% of the 576 people who answered this question answered good or very good. It is apparent that most people feel that food in community programs in California is generally good. A description of food as fair was reported by 57 people, and 32 people answered poor or very poor. The negative responses are low but further study of those responses could be done with comparisons by provider agency and the decision control inventory scores.

Table 47
Please Let me Check-Did You Say The Food Here is Good or Bad?

Feeling	**Number of People**	**Percent of People**
Very poor	14	2.8
Poor	14	2.8
Fair	48	9.6
Good	258	51.6
Very good	166	33.2
Total	500	100.0

The responses to this question are consistent with the answers to the earlier food question. Fewer people (500 versus 576) answered this question but 84.8% reported that the food was good or very good, compared to 84.5% in the first question. There were 28 answers of poor and very poor in this group and 32 in the other question. The largest difference in answers was in the fair category, 48 for this question and 57 for the other.

Table 48
How do You Feel About The People You Live With?

Feeling	**Number of People**	**Percent of People**
Very poor	9	1.6
Poor	28	5.0
Fair	110	19.5
Good	221	39.3
Very good	91	16.2
Not applicable	104	18.5
Total	563	100.0

A total of 563 people answered this question. Of that number, 104 answered not applicable, most likely because they live alone. A majority (55.5%) felt good or very good about the people they live with. Unfortunately, there were 26.1% of the respondents who answered fair, poor or very poor to this question. It is hoped that future personal interviews will reflect an increase in satisfaction with housemates as people make more personal connections and are able to change their living arrangements through the individual planning process.

Table 49
Do You Have Enough Privacy?

Feeling	**Number of People**	**Percent of People**
Definitely not	21	4.2
Probably not	33	6.6
Maybe	49	9.8
Yes, probably	179	35.9
Yes, definitely	216	43.4
Total	498	100.0

An increase in privacy is an early and significant quality of life change for most persons moving from developmental centers to the community, and the 498 Movers who responded to this question reflect that trend. A significant majority (79.3%) reported that they definitely or probably have enough privacy. The next group of 49 people (9.8%) answered maybe and only 54 people (10.8%) said that they definitely, or probably, did not have enough privacy. This issue may be related to feelings about housemates and their levels of challenging behavior. This is another quality of life factor that would be expected to show positive growth in future surveys.

Table 50
How do You Feel About The People Who Work With You Here (the Staff)?

Feeling	**Number of People**	**Percent of People**
Very poor	8	1.6
Poor	7	1.4
Fair	66	13.2
Good	250	50.0
Very good	169	33.8
Total	500	100.0

Satisfaction with direct and indirect support staff is very important in measuring the overall life quality for a person moving from a developmental center to the community. This factor can make or break the development and implementation of individual plans and have a major impact on a person's general motivation and attitude toward community life.

The answers to this question were significantly positive. A total of 500 people answered this question and 419 of them (83.8%), answered that they felt good or very good about the people who support them. There were 66 respondents who answered fair (13.2%), and only 15, (3%) who felt poor or very poor about the people who work with them.

This level of satisfaction is very encouraging and is often an indication of quality staff recruitment and training. Further study of this issue would compare satisfaction levels by providers and staff job satisfaction.

Table 51
Are There a Lot of Rules You Have to Obey Here?

Feeling	**Number of People**	**Percent of People**
Definitely not	50	11.4
Probably not	49	11.2
Maybe	57	13.0
Yes, probably	138	31.6
Yes, definitely	143	32.7
Total	437	100.0

Rules, and an emphasis on compliance to rules, play a major role in congregate living arrangements. There is a need for structure in any specialized living arrangement, especially with regard to health, safety and preservation of personal privacy and property. However, a homelike atmosphere should incorporate these safeguards without the appearance of rigidity. This question was used to elicit a general feeling regarding the amount of rules.

The majority of the 437 respondents (64.3%) felt that there were definitely or probably a lot of rules. A smaller number (22.6%) reported that there definitely or probably were not a lot of rules. The remaining 57 respondents (13%) answered that maybe there were a lot of rules to obey.

Table 52
Are There Some Rules You Don't Like?

Feeling	**Number of People**	**Percent of People**
Definitely not	87	23.0
Probably not	94	24.9
Maybe	72	19.0
Yes, probably	81	21.4
Yes, definitely	44	11.6
Total	378	100.0

The transition from a large congregate facility to a small community home involves significant change. A total absence of rules, after many years of institutional life could be confusing and stressful. COA therefore included a follow up question to gauge the general attitude regarding existing rules. A majority of the 378 respondents (47.9%) stated that there were definitely not or probably not any rules that they did not like. There were 125 people (33%) who said yes, there definitely or probably were rules they did not like, while 72 people (19%) answered maybe.

Table 53
How do You Feel About Your Job, Day Program, Workshop, Etc.?

Feeling	**Number of People**	**Percent of People**
Very poor	17	3.6
Poor	27	5.7
Fair	65	13.7
Good	219	46.0
Very good	148	31.1
Total	476	100.0

The level of satisfaction with jobs and day programs has a strong impact on overall life quality. A significant number of the 476 respondents (77.1%) answered that they felt good or very good about their jobs. They were followed by 65 people (13.7%) who answered fair, and only 44 people (9.3%) who answered poor or very poor. A recommendation for further study is to compare this positive response rate with the number of people engaged in competitive employment, pay rates, and progress toward vocational goals.

Table 54
Do You Have Friends?

Feeling	**Number of People**	**Percent of People**
No friends	23	4.3
Just one	27	5.1
A few	137	25.7
Yes, some	161	30.2
Yes, a lot	185	34.7
Total	533	100.0

The PLQ asks several questions regarding friends because the answers yield rich information about a person's level of integration and satisfaction with the transition to community life. In the personal interview section, 64.9% of the 533 respondents stated that they had a lot, or some, friends. There were 50 people (9.4%) who reported having only one or no friends and 137 (25.7%) who said they had a few friends.

Table 55
Who is Your Best Friend?

Feeling	**Number of People**	**Percent of People**
Direct care staff	59	13.3
Paid professional	89	20.1
Advocate, guardian	1	0.2
Family member	49	11.1
Peer with a disability	201	45.4
Unpaid person without a disability	44	9.9
Total	443	100.0

It is interesting to note the categories of the people who are reported as best friends. For most people in the general population, a best friend is not someone who is paid to be in their lives. This is consistent with the friends noted by 55.3% of the 443 respondents, if the peer with a disability and the unpaid person without a disability categories are combined. A large number, (33.4%) of the people, listed direct care or paid professional staff as their best friend. The remaining 11.3% of respondents listed a family (including foster family) member, advocate or guardian as best friends.

Table 56
Do You Have a Special Friend, Like a Girlfriend or Boyfriend?

Feeling	**Number of People**	**Percent of People**
Definitely not	178	39.0
Probably not	30	6.6
Maybe	21	4.6
Yes, probably	68	14.9
Yes, definitely	159	34.9
Total	456	100.0

There were slightly more people who reported having a special friend than those who did not have a special friend. There were 227 people who answered probably yes or definitely yes to this question, and 208 who answered probably not or definitely not. The remaining 21 of the 456 respondents answered maybe. The opportunity to form intimate relationships was not widely available to people living in developmental centers. A future increase in the number of people reporting special friends could be viewed as a positive sign of community integration and personal independence. This is another area that would be interesting to study further, e.g., differences according to other variables such as levels of disability or employment status.

Table 57
Do You Get Lonely?

Feeling	Number of People	Percent of People
Yes, often	64	14.0
Yes, sometimes	166	36.2
In between	44	9.6
No or very rarely	57	12.4
No, never	127	27.7
Total	458	100.0

Many professionals and parents worry about the potential for loneliness in small community homes, especially for people who spent many years in an environment that included large numbers of peers and staff. A small majority of the 458 respondents (50.2%) felt that yes, they were often or sometimes lonely. There were 184 people (40.1%) who felt that they were never or very rarely lonely. Future trends with regard to this question should be monitored closely and cross-referenced with the sections on community outings and friendships.

Table 58
Do You Have a Pet?

Feeling	Number of People	Percent of People
No	364	71.0
Not sure	6	1.2
Yes, shared with others	86	16.8
Yes, my own	57	11.1
Total	513	100.0

Person centered plans, especially the sections that refer to wishes or dreams, often refer to pets. The opportunity to own a pet is sometimes the first obvious sign of choice, and for many it is a major element in creating a homelike environment. There are many reasons why it is difficult to include pets in community living arrangements, allergies, cost, and housemate preferences. The data indicate a low frequency of pet ownership. Only 57 of the 513 respondents (11.1%) had their own pet, while an additional 86 people (16.8%) shared pets. The great majority (72.2%) did not have a pet or were not sure.

Table 59
How Important is Having This Pet?

Feeling	**Number of People**	**Percent of People**
Not at all important	12	7.5
Not much	6	3.8
In between, not sure	16	10.1
Yes, some	39	24.5
Yes, very important	86	54.1
Total	159	100.0

The people who had pets (143) were asked to rate their pet's importance. The majority (78.6%) answered that having their pet was either very important or of some importance. A smaller group (11.3%) felt that their pet was not at all important or not of much importance. Finally, 10.1% of the pet owners were unsure of how they felt about their pet's importance.

Table 60
Would You Like To Have A Pet?

Feeling	Number of People	Percent of People
Definitely not	76	23.2
Probably not	22	6.7
Maybe	28	8.6
Yes, probably	70	21.4
Yes, definitely	131	40.1
Total	327	100.0

This question sought more information regarding choice and pets. The data would appear to indicate that there are people who want pets who do not have them. When asked if they want to have a pet, 201 of the 327 respondents (61.5%) answered probably or definitely yes. An additional 28 people (8.6%) said maybe they would like a pet and 29.9% answered probably or definitely not.

Table 61
When You Go Places (Field Trips, Shopping, Movies, Parks, Walks, or Any Other Outings), Who Picks Where You Go?

Feeling	Number of People	Percent of People
Others choose	59	13.9
Person has some say,	19	4.5
Person has little say	36	8.5
Person has major say	139	32.7
Person chooses	172	40.5
Total	425	100.0

The answers above are related to community integration and choice. The majority of the 425 respondents (73.2%) answered that they either choose where to go in the community or have a major say in where to go. There were 55 people (13%) who answered that they have little or some say in where to go and 59 people (13.9%) who reported that others choose where they go. Choices for community outings are often dependent on cost, transportation, staff ratios and housemate preferences. This is an important measure to be monitored and cross referenced with the decision control inventory and integration questions that appear elsewhere in the PLQ. A further recommendation would be to identify the 59 respondents for whom others make the choices and check their annual goals for training in choice making.

Table 62
Do You Like Going Out To Those Places?

Feeling	Number of People	Percent of People
Not at all	3	0.6
Not much	4	0.8
In between	20	4.1
Yes, some	92	19.1
Yes, very much	363	75.3
Total	482	100.0

The point of this question is to double-check the issue of choice making. Some people may report that they choose to go certain places. However, if they do not really like where they are going then the apparent choice may be the result of limited options. In this case, the data appear to support the fact that the 482 respondents are choosing to go to places they like. Their overwhelming (94.4%) answers were yes, some, or yes, very much. The remaining 5.5% of the answers were in between, not much or not at all.

Table 63
Would You Like To Go Out More Often, Or Less Often?

Feeling	Number of People	Percent of People
More often	358	74.7
About the same	91	19.0
Less often	30	6.3
Total	479	100.0

It seems that the residential providers are doing such a good job at identifying places that people like to go that the 479 respondents want to go out even more. The majority, (74.7%) want to go out more often and 19% are content with about the same amount of outings. There were only 30 people (6.3%) who answered that they want to go out less often.

Table 64
Do You Have Someone Who Visits You Called a Regional Center Case Manager?

Feeling	Number of People	Percent of People
No	30	6.1
Not sure	79	16.1
Yes	381	77.8
Total	490	100.0

Case management services are a crucial factor in community transition and stability. The majority of the 490 respondents, (77.8%) answered that yes, they are visited by a regional case manager. There were 79 people (16.1%) who were not sure and 30 people (6.1%) who said no. Further study of the 22.2% of these Movers who were not sure, or said no, could include cross-references to discharge dates and regional centers.

Table 65
Can You Call (reach) This Case Manager if You Need To?

Feeling	**Number of People**	**Percent of People**
No	44	9.1
Not sure	105	21.7
Yes	334	69.2
Total	483	100.0

It is important for people living in the community to understand that they can contact their case manager. For many people, the case manager may be the only contact that is independent of the residential provider agency. Although the majority of the 483 respondents (69.2%) said yes, they can reach their case manager, it is a concern that 105 people (21.7%) were not sure and 44 people (9.1%) said no. This may be a training issue, assuring people that they can contact their case manager and providing them with assistance with the phone to do so. It may also be indicative of a confusion between regional center case management and provider staff who may have similar titles, or who may perform functions that these Movers associate with case management.

Table 66
Does the Case Manager Help You?

Feeling	**Number of People**	**Percent of People**
Not at all helpful	11	2.8
Not helpful	18	4.7
Somewhat helpful	74	19.2
Helpful	167	43.3
Very helpful	116	30.1
Total	386	100.0

It is important that Movers view their case managers as helpful, as the kind of person they can turn to for support. Approximately 73.4% of the 386 respondents felt that their case managers were either helpful or very helpful. Only 7.5% of these people answered that their case managers were either not helpful or not at all helpful. The remaining 19.2% felt that their case managers were somewhat helpful. The responses to this question could also be further analyzed according to time in the community and by regional center.

Table 67
How Was This Interview Conducted?

Present	**Number of People**	**Percent of People**
Staff person was present	150	22.5
In private with the focus person	489	73.3
Other situation	28	4.2
Total	667	100.0

The final question on the personal interview asks if a staff person was present for the interview, if it was conducted privately, or if there were some other situation such as the presence of a friend or family member. There were 667 respondents, 73.3% of whom were interviewed privately. Staff were present for 22.5% of the interviews and 4.2% of the interviews were described as being conducted under some other situation.

If You Had One Wish….

The answers to the one wish question range from funny to heart breakingly sad. It is perhaps the one response that best illustrates how much the Movers are just like anyone else in our society. The wishes can be categorized in many ways, and many wishes fit more than one category. In general, they break down according to wealth or possessions (stuff), relationships, adventures, and homes. Within each category there is a wide range of wishes that may reflect levels of disability. The wishes that seem most related to being a Mover have to do, appropriately, with moving and being more independent. The best way to share the responses to these questions is with direct quotes. Below are selected wishes from the PLQs.

Wealth/Stuff
Brand new bowling ball and bag- I want to get a computer
Catalogs, to see what I'll get for Xmas & birthday
I want a car
Candy bars, cigarettes, box of candy, 6 pack of coke
A dollar and an alarm clock
I wish that I had one million dollars
Bigger refrigerator
A lot of money
To have a lot money
Millionaire
To go to Reno, gamble and make a lot of money
Radios, telephones, watch
Money lots of money
Wish I could have some cocoa
To get $100,000 and spend it on junk food
A new radio
Lots of money

I like to watch TV I like music
I wish that I had my own car
For a joint
Chocolate peanut cups, chocolate candy
A guitar
A car
A bike & a VCR
PJs with no buttons and pull over tops
I want to have a car, can you get me a car?

Relationships and Family
To be with my sister-in-law, go shopping and eat out and go to another school
To visit my family
I want to live with my sister
To take my girlfriend out someplace and talk to her
Get married
I wish I could have my kids back
To be with my parents
To have even more friends

House
A house out in the country
My own place
To be with my girlfriend and get an apartment
To buy a house of our own in Modesto
I wish that I could get my own place
For me and my family to get completely out of debt and to buy a mansion
Get own apartment with kids

Adventure and Experiences
I want to visit my friend in Hawaii
To go to another country (Mexico or something)
Meet Elvis
To meet Connie Francis
I wish for Alice in Wonderland
Wish I could have a vacation to Disneyland where I wouldn't have to worry
A letter from England and to go to England
To meet Aretha Franklin
To fly a hot air balloon

Go to the Bahamas
To get laid in Hawaii
To visit the city of Washington

Self Improvement

Get better job
Better job- more money
To be back on my own
To get out, to be released, to be a free man

Sad

Wants baby girl back
That I could walk
To have his brother & aunt come back (they both passed away)

Descriptive Results 10: Perceived Quality of Life Changes

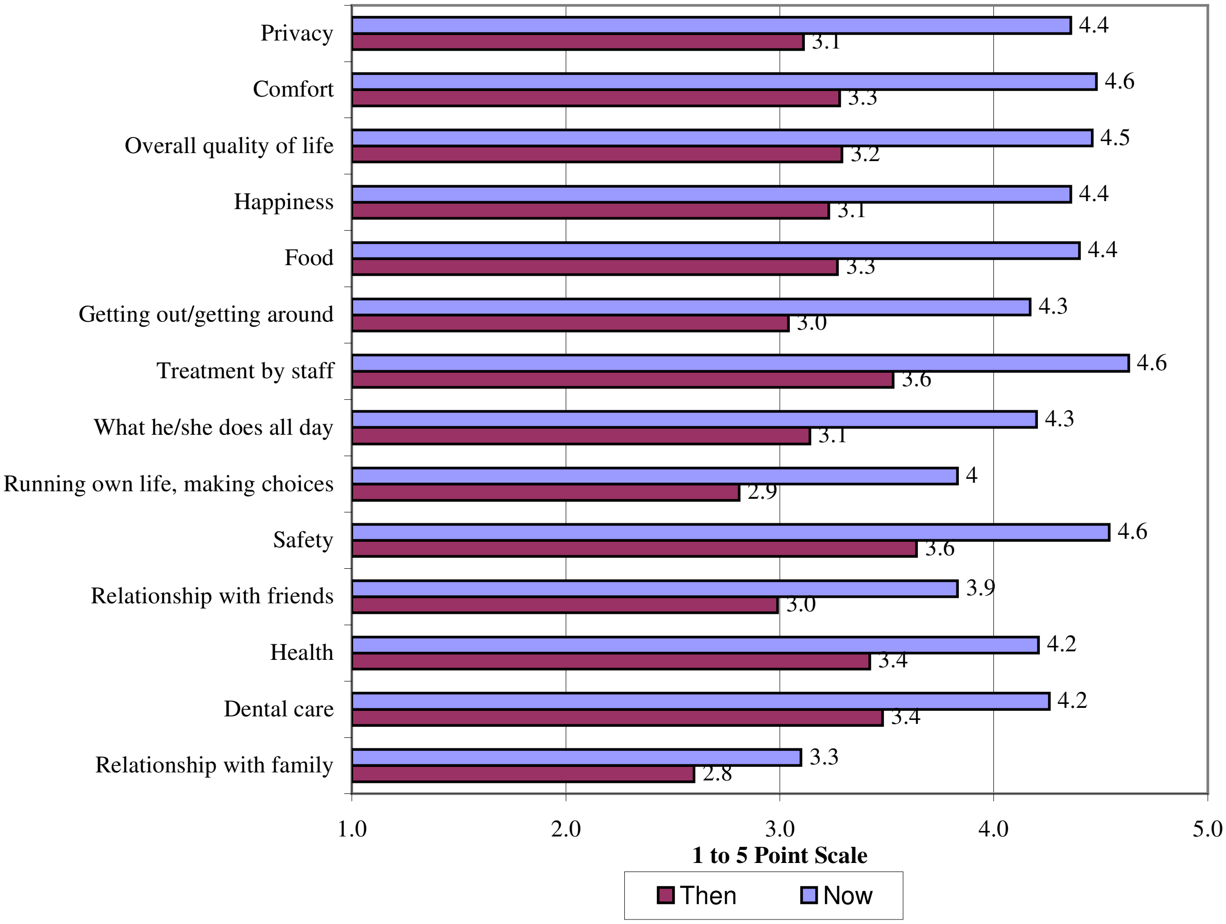
This scale addressed fourteen dimensions of quality of life, including health, friendships, safety, and comfort. The person, or whoever knew the person best, gave numeric ratings of the person's qualities of life at the developmental center (then) and in the community home (now). If the respondent did not have first hand knowledge of conditions at the developmental center, we accepted their perceptions based on what they had read, heard, and been told by the person and others close to the person. It is important to note that this scale measured perceptions only.

Table 68
Perceived Changes in Qualities of Life "Then" to "Now"

Quality of Life Dimension	Now	Then	Change	p
Relationship with family	3.3	2.8	0.5	0.000*
Dental care	4.2	3.4	0.8	0.000*
Health	4.2	3.4	0.8	0.000*
Relationship with friends	3.9	3.0	0.9	0.000*
Safety	4.6	3.6	1.0	0.000*
Treatment by staff	4.7	3.6	1.1	0.000*
Food	4.4	3.3	1.1	0.000*
Running own life, making choices	4.0	2.9	1.1	0.000*
What he/she does all day	4.3	3.1	1.1	0.000*
Getting out/getting around	4.3	3.0	1.2	0.000*
Overall quality of life	4.5	3.2	1.2	0.000*
Comfort	4.6	3.3	1.3	0.000*
Happiness	4.4	3.1	1.3	0.000*
Privacy	4.4	3.1	1.3	0.000*

Table 68 shows that the perceived changes in the fourteen quality of life areas were all positive and significant. The largest perceived changes were in privacy, happiness and comfort. The change in the perception of privacy was an expected result with a move from a large congregate living facility to a small community home, but it is interesting to note that along with the increased perception of privacy, people perceived increases in their levels of comfort and happiness. The next highest changes were in overall quality of life and getting out and getting around. The smallest recorded perceived change was in relationship with family. This is fairly consistent with our findings in other studies, and our findings in California as shown in Report 2. Family relationships may improve slightly with a move to the community, mainly due to proximity and improved access. However, people who had strong family ties while living in the developmental centers tended to maintain those same relationships. Unfortunately, the same pattern held true for those who had little family contact prior to their community move. Finally, it is important to note that there were also perceived positive changes in health and safety, two areas that are of great concern in planning and implementing deinstitutionalization initiatives.

Chart 4
Qualities of Life, Then and Now
(Perceptions of Community Staff)



Descriptive Results 11: Qualities of the Homes

There are three general measures of environmental quality in this study: the Individualized Practices scale, the Environmental Ratings scale and the Visitor's Subjective Impressions ratings. These scales are generally completed after the visit, based on the interview, observation, and a tour of the home. Table 69 shows the average scores on the Individualized Practices scale.

Table 69
Individualized Practices Scale

Weekend/Holiday Schedule	**Average Score**
Waking time	1.8
Bed time	1.9
Dinner time	0.9
TV, Radio and Music time	1.9
Weekday/Workday Schedule	
Waking time	1.0
Bed time	1.4
Dinner time	0.7
TV, Radio and Music time	1.7
General Activities	
Going to work/day program	1.1
Recreational trips	1.1
Shopping for food	1.4
Doctor, dental, psychiatric	1.7
Restaurants	1.0
Worship	1.3
Birthdays	1.8

The level of Individualized Practices was measured on a three-point scale ranging from 0 to 2. For weekend/holiday and weekday/workday schedules, a response of “0” indicated the selected time was fixed-same for all persons in the home. A response of “1” indicated the selected time was fixed-but with exceptions. A response of “2” indicated the selected time was flexible allowing for individual choice. On the weekend/holiday schedule, the average scores leaned toward a flexible environment with the exception of dinnertime. It seems that dinner was served at a fixed time during both weekend and weekday schedules but exceptions were permitted. During the weekday/workday schedule, the average scores were not quite as flexible as the weekend/holiday schedule but again, exceptions were allowed.

Under general activities, we found that on average, people celebrated birthdays and attended health care appointments individually. Going to work, recreational trips and going to restaurants tended towards being group activities, while shopping for food and attending worship services were more individualized.

Table 70 shows the average scores on the Environmental Ratings scale.

Table 70
Environmental Ratings

Location	Average Score
Describe person's own room	2.6
Describe the outside of the home	2.7
Describe the inside of the home	2.7
Describe the home's grounds	2.7
Describe the area around the home	2.7

The Environmental Ratings scale was measured on a five-point scale which ranged from 1 to 5, from very unpleasant, unpleasant, ordinary, pleasant, to very pleasant. On average, the scores rated between ordinary and pleasant.

On the Visitor's Subjective Impressions section, we asked five questions that were measured on a ten-point scale. The range was from 0 to 10 with a low score indicating a negative response and a high score indicating a positive response. A response of "5" indicated a neutral or in between position. The average ratings of the Visitors are shown below in Table 71.

Table 71
Visitor's Subjective Impressions

Question	Average Score
How happy do you think this person is?	7.3
Quality of staff/consumer interactions	7.9
Quality of consumer/consumer interactions	6.5
Staff attitudes and expectations	7.5
Want relative to live here?	6.6

The first question asked was "How happy do you think this person is?" The average score was a 7.3, indicating that the Visitors felt that the people were "happy". On the second question, "What is the quality of staff-consumer interactions?" the average score was a 7.9, indicating that the Visitors believed the quality of interactions was positive leaning towards "warm and personal".

The third question "What is the quality of consumer-consumer interactions?" was scored at 6.5, indicating "tolerant". The fourth question concerned staff attitudes and expectations about growth, progress, and development. Here, the average score was a 7.5 indicating optimism. The last question was, "If you had a close relative with a major disability, how would you feel about him or her living in this home?" The average score was a 6.6 indicating a more neutral position in reference to this question.

Returnees

In every deinstitutionalization project there are some people who do not have a successful transition to the community. In some cases, usually very few, the problems are resolved by the person returning to live at a developmental center. In this quality tracking project, COA continues to visit the people who have returned to developmental centers so that we can learn more about what caused the return and perhaps identify the kinds of community resources that may have prevented that return. In this year's study, there were 47 people that we visited at Developmental Centers. The numbers and current places of residence are listed in Table 72.

Table 72
People who Returned to Developmental Centers from the Community

Number	Developmental Center
9	Agnews
10	Fairview
1	Lanterman
17	Porterville
10	Sonoma
47	

A comparison of the characteristics of the returnees and the people who remained in the community reveals very few differences. Table 73 compares their major characteristics.

Table 73
Characteristics of the Returnees

Characteristic	**Community**		**Back in DC**	
Gender	N	%	N	%
Male	1335	60.3%	29	61.7%
Female	835	37.7%	16	34.0%
Ethnicity				
White	1512	68.3%	33	70.2%
African American	216	9.8%	6	12.8%
Hispanic	338	15.3%	6	12.8%
Native American	10	0.5%	0	0.0%
Asian	48	2.2%	0	0.0%
Filipino	12	0.5%	0	0.0%
Other	31	1.4%	0	0.0%
Level of MR Label				
Not labeled MR	42	1.9%	1	2.1%
Mild	413	18.6%	20	42.6%
Moderate	227	10.2%	8	17.0%
Severe	291	13.1%	6	12.8%
Profound	1144	51.6%	10	21.3%

The distributions by gender and ethnicity vary very little. The area that does appear to show differences is the levels of mental retardation. Note that 60% of the returnees are labeled mildly or moderately mentally retarded while only 29% of the Movers are similarly labeled. The trend is reversed for people with severe and profound mental retardation with only 34% of the returnees carrying that label compared to 65% of the Movers.

Do these numbers mean that the community system is designed to better support people with severe and profound disabilities? Further investigation shows that the returnees share additional distinguishing characteristics. Table 74 compares their status to that of the Movers who remained in the community with regard to major secondary disabilities.

Table 74
Secondary Disabilities Reported as Major

Secondary Disabilities	**Community**		**Back in DC**	
	N	%	N	%
Ambulation	593	26.8%	8	17.0%
Autism	233	10.5%	6	12.8%
Aggressive Behavior	757	34.2%	30	63.8%
Self Abusive Behavior	510	23.0%	14	29.8%
Brain Injury	156	7.0%	4	8.5%
Cerebral Palsy	387	17.5%	5	10.6%
Communication	1317	59.5%	14	29.8%
Dementia	37	1.7%	1	2.1%
Health Problems	579	26.1%	18	38.3%
Hearing	115	5.2%	3	6.4%
Mental Illness	489	22.1%	24	51.1%
Physical Disabilities	341	15.4%	4	8.5%
Seizures	631	28.5%	12	25.5%
Substance Abuse	50	2.3%	5	10.6%
Swallowing	172	7.8%	4	8.5%
Vision	285	12.9%	6	12.8%
Other(s)	227	10.2%	7	14.9%

The differences are not quite as stark as in the previous table but there is a discernible pattern. The returnees appear to have higher percentages of those kinds of disabilities that usually result in challenging or disruptive behavior. They include autism, aggressive and self-abusive behavior, brain injury, dementia, mental illness, and substance abuse.

Finally, we examined the comparative scores of the returnees and the Movers who stayed in the community on various other dimensions. The results are shown in Table 75

Table 75
Comparative Scores on Various Dimensions

Dimensions	Community Mean	Back in DC Mean
Age	41.74	38.21
Adaptive Behavior	48.42	58.95
Challenging Behavior	77.30	67.86
Progress on Goals	78.69	78.65
Number of Services	8.33	7.66
Day Program Hours	26.87	23.45
Earnings	5.93	21.66
Number of Friends	8.73	10.71
Decision Control Inventory	47.93	41.43
Integrative Events	29.62	15.68
Quality of Life Now	84.35	73.14
Staff Satisfaction	1.76	1.27
Like Working w/Person	9.31	9.00
Sufficient Support	4.55	4.64
Number of medications	4.84	4.79
Antipsychotic Meds	0.41	0.47
General Health	4.03	3.73
Illness Past 30 Days	0.87	2.73
Health Care Rating	4.33	4.68
Dentist Visits Past Year	1.50	1.78
Doctor Visits Past Year	11.84	45.80
Relative Visits to Home	8.30	9.57
Individualized Practice Scale	68.61	66.03

The scores on the dimensions listed in Table 75 reveal more information about the returnees. Their adaptive behaviors are higher than those of the larger Mover group. This can probably be explained by the fact that they are generally “higher functioning” as predicted by their mental retardation levels. They exhibit less control of their challenging behavior, have less opportunities for decision making, less integrative activities, and they report that their qualities of life are lower than in the past. On the positive side the returnees report having more friends and they make more money than the Movers in the community. The amount of doctor visits is also higher for the returnees. These differences are most likely a function of living in a congregate facility with daily interactions with large numbers of people. We can only assume that their higher earnings are due to large government contracts that are often available to Developmental Center contract workers. The amount of doctor visits is often higher in congregate care facilities since there is often on-site medical staff.

The respondents to our interview reported the following reasons for returns to developmental centers.

Table 76
Reasons for Return to Developmental Centers

Physical decline/ behaviors/ police involvement
Behavior
Due to health problems
Got out of jail
Progressive weight loss
Assaulted mother
Improved medical care
Health became too fragile
To Agnews to stabilize medically
Behavior and med problemss
Longer term placement / court ordered
Med and behavioral problems
Decompensation at previous home
AWOL & inadequate support for seizures
Aggression and destroying property
Behavior & running away
Increase in behavior
Aggressive behavior & destructive behavior
Aggressive behavior/ non-compliance
Aggression / self injury behavior increased
Unable to control in group home
Assaulted care provider
Had behavioral issues
Due to out of control community behavior
AWOL
Less restrictive environment
Behavioral problem
Behaviors too much to deal with in community
Behaviors became too much
Sexual behaviors were too much to deal with
Increased behavioral problems in community setting
Behaviors, put in psychiatric hospital
Family moved to Santa Rosa
Behaviors became too much/severely underweight
Needed better medical care
4 in home, could not accommodate health problems
Aggressive and self abusive behaviors

Reading the above list gives an overall impression of challenging behavior as the primary reason for failure to succeed in a community placement. There are Movers in the community who exhibit challenging behaviors and in many cases they are learning to control those behaviors. However, our overall findings regarding some loss of ability to control challenging behavior become even more serious if a major predictor for possible return to a developmental center is challenging behavior. A fuller analysis appears to be necessary. It would be interesting to pair these returnees with Movers who exhibit similar characteristics and to identify the differences in the supports they received in the community.

Family Survey

Participants

At the time of this writing, we have received survey responses from 291 of the 711 families for whom we received valid addresses (40.9%). Mothers completed the survey on their own almost half of the time (49.6%) and jointly with fathers on an additional 10.7% of the responses. The respondents were distributed as shown in Table 77.

Table 77
Relationship of Family Survey Respondents to Movers

Relation to Focus Person	Number	Percent
Mother	139	49.6
Father	40	14.3
Mother and Father	30	10.7
Sister or Brother	45	16.1
Other	26	9.3
Total	280	100.0

* Eleven families did not answer this question.

Legal guardianship was claimed by 61 respondents (23.6%), legal conservatorship by 106 (41.1%), and no legal status by 91 (35.3%). This item was left blank by 33 respondents who were unsure. The family respondents' ages ranged from 30 to 90, with a mean age of 63. The families reported that their relatives had lived in DCs between 0 and 65 years, with an average of 22 years.

Of the 243 family members who responded to the question of how often their relative had changed addresses since moving to the community, the average number of times reported was 1. The average number of times family members reported being able to visit their relative in the past year was 22 times, or roughly twice a month.

Perceptions of Quality

The primary purpose of the family survey was to determine if the families believed the Movers were better off in the community than they had been in the Developmental Centers. We asked the families to describe their relatives' quality of life "Then" while living in a Developmental Center, and "Now" while living in the community. The results are shown in Table 78.

Table 78
Families' Perceptions of Qualities of Relative's Life

Quality of Life Dimension	Now in Community	Then at DC	Change	p
Privacy	4.2	2.4	1.8	0.000*
Getting out and getting around	4.4	2.7	1.6	0.000*
Happiness	4.3	2.8	1.5	0.000*
Comfort	4.4	3.0	1.4	0.000*
Making choices	3.9	2.5	1.4	0.000*
Overall Quality of Life	4.3	3.0	1.4	0.000*
What he or she does all day	4.2	2.9	1.3	0.000*
Food	4.3	3.2	1.1	0.000*
Treatment by staff/attendants	4.5	3.5	1.0	0.000*
Safety	4.3	3.3	1.0	0.000*
Relationship with friends	3.9	2.9	1.0	0.000*
Dental	4.1	3.1	1.0	0.000*
Health	4.1	3.3	0.9	0.000*
Relationship with family	4.4	3.6	0.8	0.000*

* Indicates significance at the .05 level.

Table 78 provides the p values for the statistical test, which was the t-test. The p values represent the probability that changes of these magnitudes could have happened by chance. The value "0.000" means the probability was less than 1 in 1,000. The column labeled "Change" shows the average amount of change on the 5 point scale of quality. From this column we can see that the largest perceived change in quality was a gain of 1.8 points in

"Privacy". The next largest was in "Getting Out and Getting Around" with a gain of 1.6 points. These were followed by "Happiness" with a gain of 1.5 points, and "Comfort" with a gain of 1.4 points.

Questions 8 and 9 in the Survey were about family reactions to the idea and the reality of community placement. Question 8 was: "When you first heard about the idea for your relative to move to a new home in the community, were you 'for' it or 'against' it?" Question 9 asked: "Now that it has happened, how do you feel about your relative living in a new home in the community?" Responses could range from Strongly Against to Strongly For, on a 5-point scale. The results of these two questions are presented in Table 79.

Table 79
Families' Opinion About Community Placement When First Heard Idea, Versus Now

Response Category	**At First**	**Now**
Strongly against	16.1%	1.1%
Against	15.4%	2.6%
In between	17.6%	5.5%
In Favor	22.7%	31.0%
Strongly in favor	28.2%	59.9%
Total	100.0%	100.0%

Table 79 shows that opposition to community placement decreased, and support increased. Before the move, 16.1% of the families strongly opposed the idea, and after it happened, the figure dropped to 1.1%. The shift from opposition to support is clear in these data. Only 3.7% now say they are against, or strongly against, community living. Before the move, the percentage opposed was 31.5% (16.1%, "Strongly Against" and 15.4% "Against"). Similarly, the percentage of families who support, or strongly support, community living is up from 50.9% to 90.9%. The trend is obviously toward increased family support for the idea of community living for their relatives. The trend appears to get stronger the longer their family members are out of the Developmental Center.

To get the families' opinions about the Movers' happiness in a different way, we asked "How happy do you think your relative is with his/her living situation?" Table 80 shows how many families answered with each rating.

Table 80
How Happy Do You Think Your Relative Is With His/Her Living Situation?

Response Category	Number	Percent
Neither happy nor unhappy	31	11.0
Happy	102	36.3
Very happy	122	43.4
Don't know	26	9.3
Total	281	100.0

* Ten families left the item blank.

Not one family responded to this question with either "Very unhappy" or "Unhappy". Almost 80% said their relative was either "Happy" (36.3%) or "Very Happy" (43.4%). There were 10% of the respondents who did not know how to rate their relative's happiness or unhappiness. In a very direct question, we asked "If you could, would you have your relative leave his/her new community home and move back to a Developmental Center?" The results are shown in Table 81.

Table 81
Would You Like Your Relative to Move Back to a DC?

Response Category	Number	Percent
Yes, definitely	7	2.7
Yes, probably	3	1.1
In between	11	4.2
No, probably not	70	26.7
No, definitely not	171	65.3
Total	262	100.0

* Nineteen families left the item blank.

These responses clearly show that the preference of the families is to continue with community living. Ninety-two percent of the respondents said either “No, probably not” (26.7%) or “No, definitely not” (65.3%) in response to this question. There were only 10 families (3.8%) who said they probably or definitely would like to see their relatives move back to a DC. The situations of these 10 individuals, and the opinions of their families, may require further investigation by DDS or the responsible Regional Centers.

Satisfaction with Supports

Satisfaction with the Case Manager or Service Coordinator assigned to their relative is a major factor in a family’s overall satisfaction with supports. Table 82 provides a “report card” on this issue.

Table 82
How Satisfied Are You with Your Relative's Case Manager or Service Coordinator?

Response Category	Number	Percent
Very dissatisfied	16	6.5
Dissatisfied	9	3.6
In between	27	10.9
Satisfied	104	41.9
Very satisfied	92	37.1
Total	248	100.0

* Forty-three families did not answer this question.

When asked the question, "How satisfied are you with your relative's case manager or service coordinator, 79% of the families reported being either "Satisfied" (41.9%) or "Very Satisfied" (37.1%). A little over 10% of the families who responded to this question reported being either "Dissatisfied" (3.6%) or "Very Dissatisfied" (6.5%).

We asked family members to report how happy they felt their relative was with their job or other day program, Table 83 below shows the distribution of responses.

Table 83
How Happy Do You Think Your Relative is with Their Job or Other Day Program?

Response Category	Number	Percent
Very unhappy	2	0.7
Unhappy	3	1.1
In between	48	17.5
Happy	104	38.0
Very happy	78	28.5
Don't know	39	14.2
Total	274	100.0

*Seventeen families did not answer this question.

The responses were extremely positive with 66.5% of the families reporting that they felt their relative was either “Happy” (38.0%) or “Very happy” (28.5%). Only 1.8% of families responded that they felt their relative was “Unhappy” or “Very unhappy”. An additional 17.5% said they felt their relative was “in between”, neither happy nor unhappy with their job or other day program.

Person-centered planning has become a key element in providing services and supports for people with developmental disabilities across the nation. We asked the families to tell us whether or not they felt that their relative’s individual plan was “person-centered”.

Table 84
Is Your Relative’s Plan a Result of a “Person-Centered” Process?

Response Category	Number	Percent
Yes	156	62.4
No	20	8.0
Don't know	74	29.6
Total	250	100.0

* Forty-one families did not answer this question.

The majority of family members (62.4%) reported that “Yes”, their relative’s individual plan was the result of a person-centered planning process. Eight percent responded “No” to this question, while almost 30% responded to this question with “Don’t know”. Perhaps families in California, as is true of families in other states we have studied, need more information about the shift in service planning from a program-centered model to the newer person-centered approach.

Verbatim Comments

At the end of the family survey, we asked three open-ended questions:

- Please list one or more thing(s) that you like about your relative's current situation
- Please list one or more thing(s) that you are most concerned about with regard to your relative's current situation
- If you had one wish for your relative, what would it be?

These responses add substantial insight to the survey data. Some of the things that families liked about their relative's current situations were how home-like their relative's homes were, that the staff at the homes were caring and affectionate, that their relatives seemed very happy, that their relatives were closer to home, and that their relatives were in homes with less people then the situations they were in before.

Things that caused concern for family members about their relative's current situation included such things as the perception that staff turnover was a problem, that the direct care staff in the community made less money than the developmental center staff for more work, worries about the long-term stability of the homes, concerns about their relative's safety and health needs, and the lack of community activities and employment.

In terms of what families wished for their relatives, most of the wishes reflected a desire for their relatives to be safe and happy, for adequate community care to be continued, for the current placement and supports for their relatives to remain stable, and for their relatives to achieve their highest potential. Many families expressed the desire that their loved one would overcome their disability, be "normal", or be able to communicate verbally.

The verbatim responses of family members to these questions are presented in **Appendix D** and are grouped by family, in other words, in a glance across the three columns, one can see each family's responses to the three questions.

APPENDIX A

PRIOR REPORTS OF THE CENTER FOR OUTCOME ANALYSIS ON THE WELL BEING OF PEOPLE WHO MOVED FROM DEVELOPMENTAL CENTERS TO COMMUNITY HOMES IN CALIFORNIA

APPENDIX B

THE YEAR 2001 PERSONAL LIFE QUALITY PROTOCOL

APPENDIX C

THE YEAR 2001 FAMILY SURVEY

APPENDIX D

RESPONSES TO OPEN-ENDED QUESTIONS IN THE YEAR 2001 FAMILY SURVEY