Independent Evaluation of California's Self-Determination Pilot Projects

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Evaluation of Self-Determination Pilot Efforts in California
Executive Summary

The evidence from nearly three years of study of California's pilot projects on self-determination for people with developmental disabilities supports a positive conclusion: self-determination is highly beneficial to, and extremely welcome to, participants and their families. The evidence also indicates that self-determination is inherently fiscally conservative.

Moreover, California's developmental disabilities service system, as it has evolved under the Lanterman Act, appears to this research team to have more potential for self-determination than any other state. We therefore suggest that self-determination should be supported and expanded in California, with heightened fiscal and programmatic commitment from Sacramento. The evidence supports a policy to move the self-determination initiative the next level, beyond a small set of "pilot projects," and toward larger scale system efforts.

This Final Report provides the empirical bases for these conclusions. In this Executive Summary, we sketch in broad outline what we have learned from three small pilot sites of about 30 participants each.

This report required nearly three years of study, in which every participant and every participant's family was visited, interviewed, and surveyed, each year. The primary intent of the evaluation was to answer the fundamental question: "Has this made a difference in the lives of the participants?" In other words, does this new way of providing supports help people or not? Important additional questions involved how the efforts were designed, how they could be made better, and what it would take to expand this "experiment" to a larger implementation.

1. Synopsis

California is the only state thus far in which a self-determination effort was required by legislation. In 1997, the legislature passed a bill to start self-determination pilot projects at three of the 21 Regional Centers. Each Regional Center worked with 30 participants and families. An independent evaluator was selected to study the outcomes of this pilot effort. The evaluator visited each participant in each year, and collected information from the person, the family, and support providers. The evaluation included 30 people and families who wanted to participate, but who had to wait until later to get involved. This group served as a natural "comparison group." The evaluator also conducted extensive focus groups, key informant interviews, and collected individual "stories" during the years investigation.

The evaluation has produced very positive findings. Individual outcomes show evidence of rapid and significant benefits. Participants and their families really like the self-determination idea and the values that are part of it. They believe their lives have improved because of it. There have been barriers, problems, delays, paperwork, and cases of inflexibility, but despite all challenges, these complaints have been viewed as minor, and the overwhelming consensus is that California should continue and expand this innovation in providing supports to its citizens with developmental disabilities.

Most key informants believe that self-determination is in keeping with the ideals of the law that has structured California's entire developmental services system, the Lanterman Act. In fact, many believe that self-determination is an essential step in moving forward with the vision of the Lanterman Act: freedom, individual supports, and dignity through partnership.

The evaluator recommends that California now consider expanding its self-determination efforts beyond the "experimental" stage. This will require careful consideration of specialized case management, fiscal intermediary mechanisms, and innovative revisions to the fiscal management process. Given sufficient support, the evidence suggests strongly that California can become a national leader in moving toward the values of self-determination for people with developmental disabilities.

2. Major Finding: The Theory of Self-Determination is Supported

These three pilots began their work three years ago. They took time to get started. Sites took roughly a year to get up and running with 30 participants each. In the past two years, the efforts have grappled with a constant barrage of barriers, difficulties, and systematic impediments. Great progress has been made, and considerable reason for enthusiasm has been generated.

Normally, a "program evaluation" like the one summarized in this Report would extend another year or more, since the pilot sites took a year or more to get online. For a full three years of data on the efforts, we would have to wait another year or more, so that we could see what happened in the lives of the participants over a full three year experience. However, the excitement and enthusiasm for this initiative is apparently so high that an early evaluation report was demanded. An early report can be justified only because the present evaluation team has experience in evaluating self-determination's progress in dozens of other states over the past decade. Without the benefit of this team's history, context, and proven measurement techniques, the present early report would not have been feasible or sensible.

The reason for continued interest and enthusiasm about self-determination in California is probably the same as the reason for the rapid proliferation of the concept all over the country: it feels "right" to all or nearly all stakeholders, from participants to the general public. The theory seems to make good common sense, it adheres to fundamental American values, and it is characterized by concern for fiscal conservatism. In its clearest operational form, the theory of self-determination is this:

1. **If power shifts (carefully, gradually, responsibly, case-by-case) from paid professionals toward the people and their freely chosen allies,**
2. **Then lives will improve,**
3. **And costs will be the same or lower than they would be in the traditional professionally-dominated approach.**

Our evaluative work has focused primarily on finding out whether these three parts of the self-determination theory are supported by the evidence. If they are, then it follows that California policy should proceed toward self-determination. Better lives at the same or lower public costs is obviously a win-win proposition that should meet with universal support.

We measured the sharing of power between people (plus allies) and paid professionals by visiting each participant each year, and by collecting a power-measurement scale we developed specifically for our self-determination research during the past decade. The data from the visits show clearly that power <u>has</u> shifted measurably and significantly. On our 100-point scale, power shifted from paid professionals toward people and the allies (usually relatives) by about 5 points. This change was statistically significant, and rather large, considering that less than two years passed between measurements. Thus the first part of the theory has been supported.

The second part of the theory says that improvements in qualities of life will accompany the power shift. We applied measurement scales that have been used for more than two decades in dozens of major studies in the developmental disabilities field, again, via personal visits and data collection with all the participants. To strengthen our scientific evidence, we also included study of a

"Comparison Group" of people at one of the Regional Centers who did not participate in self-determination.

We found strong evidence to conclude that many qualities of life for participants and families did improve, and none got worse. Moreover, the subjective perceptions of quality of life indicated very strong changes for the better. People and their allies believe they are much better off in the self-determination paradigm than they were in the traditional approach.

The third part of the theory says that self-determination will not cause increases in public costs. The idea underlying this part of the theory is that people and their allies are themselves fiscally conservative, on the whole. Although exceptions do occur, the evidence shows that the great majority of people have purchased just what they need, and no more, when given real choice and control of resources. Over a three year period of observation, purchase-of-service costs increased for the self-determination participants, but they increased less than for the comparison group of non-participants. Thus our evidence strongly suggests that the cost-neutrality part of the theory is thus far true in California. The evidence further supports the inference that self-determination has been fiscally conservative, holding back cost increases that might otherwise have occurred.

However, a very large source of assistance for California's developmental services system is Federal funding via the Medicaid Waiver. For the self-determination experiments, the Federal Waiver program was consciously ignored. This was done in the belief that Waiver requirements and restrictions might have artificially limited flexibility by "disallowing" creative uses of public dollars. We found that, in fact, the self-determination participants sharply reduced their Waiver participation over the three years of the pilot projects. This situation must change if self-determination is to continue and expand. Self-determination has been applied in Waiver environments in many other states, and it can surely be done in

California. Since the Federal government will pay for more than 50% of California's approved community support costs, it should be obvious that no program that exists outside the Waiver can long survive. Self-determination must be made "Waiver friendly."

3. Major Finding: California has Unique Potential for Self-Determination

It is very important to note in this Summary that California's developmental services system appears to be uniquely suited to self-determination in several ways. First and foremost, individual budgets are an innate part of the California's system. Individual budgets are a necessary, although not sufficient, condition for self-determination. Budgeting for developmental disabilities services in traditional service systems has usually been done along a "program funding" model. In this model, money is paid to operate facilities and programs, rather than tying funds to individuals. California's approach is different. Money really can follow people in California, to a degree that many other states might envy. Thus the first precondition for self-determination, individual budgeting, poses a major stumbling block in many states, but is relatively easy to achieve in California.

Second, California's legal framework for developmental disabilities services is unique in that the Lanterman Act establishes an entitlement to services. In other states, services are only providing conditional upon available funding, and hence there are very long "waiting lists" in most states. In California, the law mandates that individual needs can and must be addressed. This makes the California system unusually favorable for self-determination thinking.

Third, California's developmental services system is unusually open to the concept of "self-vendorization," in which a person and/or a person's circle of friends can become an authorized provider of services. This can be quite important in the evolution of self-determination, which envisions micro-boards and microenterprises as options for support structures. Whereas the largest Federal assistance program, Medicaid, is by its nature a “provider payment system,” and not a system for providing funds for individual supports, the ease of vendorization in California can be a very significant advantage in making the system responsive to individual needs.

Trailing these three major advantages in California are several others that are important, but it remains to be seen how important they will become. The Sanchez v. Johnson litigation is designed to confront the issue of inequity of wages between institutional and community support workers. The future of community care is inextricably linked to the problem of low wages and high turnover rates. This national labor pool crisis is being addressed by litigation in California and nowhere else.

In a related vein, California has made unique progress toward involvement of organized labor in home and community based care systems. The In-Home Supportive Services or IHSS program for elders has been extensively organized by the Service Employees International Union. This is one force that will tend to increase wages for community support workers, a goal that seems to be universally accepted as desirable, although the sources of funds for decent salaries have not been easy to specify. The point is that, in California, the issue is being addressed to an unusual degree, and some progress has been made.

Another contributor to California’s unique receptivity to self-determination is its history of powerful judicial actions and decisions that favor individual community supports rather than congregate care and segregation. The receptivity to self-determination is its history of powerful judicial actions and decisions that favor individual community supports rather than congregate care and segregation. The Coffelt v. DDS experience resulted in the largest and most rapid shift from institutional to community living in history. Now another lawsuit, People First v.

<u>DDS</u>, has been filed. This new lawsuit can be expected to maintain the pressure on the legislature, DDS, and the Regional Centers to show preference for person-centered support designs rather than congregate models. This too is likely to favor the evolution of self-determination in California.

These unique California qualities, combined with our very positive scientific evidence, lead this evaluation team to conclude that the expansion and extension of self-determination is highly desirable in California. In order for expansion to succeed, however, it must be recognized that local implementers need resources for intensive person-centered planning, intensive case management and service coordination, and intensive fiscal management. Thus far, the three pilot sites have voluntarily extended resources to test and demonstrate the viability of self-determination. All three pilot sites expressed the view that expansion will require significant commitment to fund the necessary local efforts. This commitment is necessary during transition from one kind of service system to another. The future system, driven by self-determination, seems likely to be both beneficial and cost-effective, but getting there will require firm leadership and a relatively small and probably temporary amount of extra resources.

Elizabeth and her Family: Life is Good Once Again.

This story is from a family that was not a part of the original self-determination pilot projects. This family created their own self-determination out of whole cloth, within a system that was not designed for it. We think this story shows two things: first, such a transformation <u>is possible</u> within California's developmental services system. In most states, nothing like this could have happened. Second, this family wound up at the place that the self-determination movement is trying to permit and encourage for participants and families --- but with great struggle. In the future, self-determination thinking and policies could widen the trail that was first blazed by this courageous and determined family.

It was only six years ago that Elizabeth, born in July of 1981 with cerebral palsy, had only one option for living outside of her family home because of her fragile medical condition – a state-run institution where her spirit would die. This reality forced Liz's Regional Center case management team to develop a vision and think outside the confines of standard service delivery for people with developmental disabilities. As a result, an idea and a process slowly developed to create opportunities that would give Liz needed support in the community she knows, and allow her the freedom to live in a home of her own without feeling the fear of being cut off from the mainstream.

One of four children, Liz has always been an integral member of her family – her brothers and sister a huge part of her life. There were no family vacations or celebrations without Liz.

From the time Liz entered public education and through the 7th grade, she was mostly included in the regular classroom of her neighborhood school. She seldom saw the inside of a special education classroom – special education services supported her <u>and</u> her teacher. Liz was well known by her peers and her participation valued by hundreds of students on the school campus.

When she turned 13 her body started to betray her and her inclusion program at school wasn't working anymore, causing her to be isolated from friends and peers. The medical procedures were numerous, the convalescent periods long, and Liz never did regain the health she once had. In little more than a year, Liz lost her ability to swallow, and a g-tube was connected to her stomach so she could take in nutrition; her dislocated hips required surgery and confinement in a body cast for weeks; and, it took sixteen-hours to surgically place a rod in her back to straighten her spine.

Every operation begat more complications and Liz was now considered "medically fragile," requiring 24-hour care. Complex medical equipment and a hospital bed took over the teenager's room. Night after night, her parents Bruce and Louise took turns staying by Liz's bedside, ready to suction the fluid from her lungs that would easily take her life.

By this time the maximum allowable coverage under the family insurance had been reached for Liz, and although Medi-Cal agreed she was entitled to almost seven hours of nursing care per day, it was Liz's parents who were made responsible for finding the nurses to fill those hours. But there is a nursing shortage, and when nurses could be found they were unwilling to work at the Medi-Cal rates.

During their search for in-home nursing care, Liz's parents were finding Certified Nursing Assistants capable of caring for Liz's needs; however because of the severity of Liz's condition, Medi-Cal would not fund CNAs – a Catch-22 and the last straw that was about to cause the collapse of an entire family.

The burden of caring for Liz and her complex medical needs fell solely on her parents. As Louise reflects back on Christmas Day several years ago, she remembers recognizing for the first time exactly how much the overwhelming responsibility had taken a toll *on their lives. "I looked up at Bruce, saw his face, and knew then he was about ready to snap."*

Around the same time, self-determination was a new concept taking shape in a grassroots movement across the nation that allows people to maintain their rights as citizens and human beings in order to receive the services they need to live in their own home. Current policies, funding mechanisms and attitudes, tend to push people toward group homes, nursing homes, and institutions, and this was an unacceptable option for this family.

The Regional Center case management team started to look at what made sense to Liz and her family, developed a budget based on her medical needs, and placed the money in the hands of Liz's parents and said, "You control the money, you hire the people to support Liz, you pay the taxes, worker's compensation and insurance."

"At the time, we did not recognize this idea as cutting edge, we were just trying to find something that would work and we accidentally fell into self-determination," according to Bruce.

What took shape over the next two years developed slowly and, at times, capable nursing assistants were difficult to find. But by word of mouth Liz's parents developed a stable group of people that are loyal and love Liz. Bruce says it took a while, but at last "we got traction." If a shift problem occurs, the staff works it out amongst themselves.

More than a year ago a social worker came to Liz's family home for an interview in preparation for her move into supported living.

Bruce said, "We took the social worker into Liz's room. We told Liz this was the person helping us to get her a home of her own. The reaction on Liz's part was stunning. She understood the *concept of a home of her own. She smiled more than I've ever seen her smile at a stranger. In spite of her lack of consistent communication skills, she has told us her feelings about it. We are doing the right thing."*

Life is good once again.

Methods

Our evaluation design called for three visits to each pilot participant at three separate points in time; prior to beginning self-determination; at the mid-point of the pilot; and at the end of the pilot project. One hundred and twelve individual visits were conducted with each participant to establish baseline data regarding various qualities of life. Those visits were scheduled in the summer of 2000, to gather data that reflected the person's status prior to participation in self-determination. We returned to those people in the summer of 2001 and again in January of 2002 to measure change.

We also visited members of the "comparison group." This is a group of people drawn from the ELARC service population. It must be noted that this is not a scientific "control group" for the pilot projects. The pilot sites were chosen because they are very different. The three pilots selected their participants in different ways and proceeded to implementation with different strategies and procedures. The non-equivalent comparison group at ELARC is <u>best</u> compared to the ELARC participants, but can and will also be used as a benchmark for comparison to participants at the other sites. The characteristics of the participants in the three pilots were rather similar, hence it was deemed acceptable to employ the comparison group for all analyses.[1]

Stakeholder focus groups, composed of participants, families, advocates, vendors, regional center administrative and program staff, area board members, and DDS staff were convened in the first two years of the project, to elicit attitudes and opinions regarding the operations and the progress of the pilots. Qualitative methodology has a long history of application in program evaluation (Patton, 1987, 1982). Specifically, focus group research has been used in recent years as an

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[1] There was only one non-equivalent comparison group set up because of funding limitations.

efficient way to gather information from many people simultaneously (Morgan, 1988; Merton, 1987). Qualitative focus groups generate an understanding of multiple viewpoints (such as consumers, providers, advocates) in organization or policy analyses (Straw & Smith, 1995). Thus, when using qualitative focus groups in program evaluation, one can expect to,

a) provide a social context for the development of opinions and perceptions;
b) observe the language used by focus group participants and understand the meaning associated with its use;
c) identify potential problems in order to develop strategies to overcome them;
d) generate ideas that can be further tested using other research methods, and;
e) further enrich and explain important issues and concepts (Straw & Marks, 1995).

COA regularly uses qualitative focus groups as an evaluative tool. This method allows researchers to reach a large number of persons with limited resources. The intent of our efforts in this project was to understand the perceptions of multiple stakeholders regarding how self-determination may impact the current developmental disabilities service system in California. The materials generated from the qualitative evaluation were then cross-referenced with the quantitative data to present a total picture.

In the third round of evaluation, we used key informant interviews to answer the questions posed by the Statewide Steering Committee. We reviewed policy statements and other literature from the various sites throughout the project. In the second and third rounds we gathered and analyzed financial information for the participants. We reviewed the types of services participants purchased over the past four years and the costs of those services. In the last personal life quality interview we included a family survey. Finally, we selected two participants from each regional center and prepared stories to illustrate the personal impact of self-determination.

All of our quantitative data, including the family survey, can be compared to data collected with similar instruments for the evaluation of the Robert Wood Johnson Self-determination Initiative and for independent pilots in other states. See Appendix B for a brief history of Self-Determination in the United States.

Instruments

Together with the Statewide Steering Committee, COA adapted its general package of instruments utilized in the national evaluation of self-determination for use in California. Specifically for California, it was important to merge facets of the existing instrument being utilized for the Coffelt Quality Tracking Project [2] with those of the national self-determination framework. Our database includes more than 2,000 people who left Developmental Centers during the 1990s, and serves as an immensely valuable point of comparison and benchmark for future analyses of the qualities of life of the self-determination participants.

The main tool for our quantitative approach is the Personal Life Quality Protocol (PLQ). This package and its component instruments have been described in the literature and have been submitted to multiple tests of reliability. [3] The complete instrument used for this evaluation is attached as Appendix A.

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2 Conroy, J., & Seiders, J. (1998, June, revised October*). The Coffelt Quality Tracking Project: The Results of Five Years of Movement From Institution to Community. Final Report (Number 19) Of the Coffelt Quality Tracking Project*. California Department of Developmental Services. Submitted to: the California Department of Developmental Services and Protection & Advocacy Inc. of California. Rosemont, PA: The Center for Outcome Analysis.

[3] e.g., Conroy, J. (1995, January, Revised December). *Reliability of the Personal Life Quality Protocol. Report Number 7 of the 5 Year Coffelt Quality Tracking Project.* Submitted to the California Department of Developmental Services and California Protection & Advocacy, Inc. Ardmore, PA: The Center for Outcome Analysis. Also see: Fullerton, A. Douglass, M. & Dodder, R. (1999). A reliability study of measures assessing the impact of deinstitutionalization. *Research in Developmental Disabilities, Vol. 20, No. 6,* pp. 387-400.

Many elements of the PLQ evolved from the Pennhurst Longitudinal Study (Conroy & Bradley, 1985). Pennhurst Class members have been visited annually since 1978. An extensive battery of quality-related data has been collected on each visit. Over the years, other groups have been added to the data base, such as all 600 people living in Community Living Arrangements in Philadelphia who were not members of the Pennhurst Class, more than 3,000 people receiving supports in Oklahoma, 2,400 people who moved from institution to community in California, and 2,500 people involved in self-determination efforts nationwide.

Our battery of instruments is 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 to the 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 on self-determination, has been to learn how to measure aspects of all of these "valued outcomes" reliably.

The indicators of quality life and services measured for this evaluation include friendships, current capabilities and behavior, individual program plans, choice making, productive activities, integrative activities, health, and health care. Following are more detailed descriptions of the instruments.

Choice Making

The scale we use to measure choice making 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. The interrater reliability of the Inventory was reported as .86 (Conroy, 1995.)

Integration

The scale used to assess integration was taken from the Harris poll of Americans with and without disabilities (Taylor, Kagay, & Leichenko, 1986). It measured how often people visit with friends, go shopping, go to a place of worship, engage in recreation, and so on, in the presence of non-disabled citizens. The scale tapped only half of the true meaning of integration; if integration is composed of both presence and participation, then the Harris scale reflects only the first part. Presence in the community is a necessary but not sufficient condition for participation in the community. The scale simply counts the number of “outings” to places where non-disabled citizens might be present. The scale is restricted to the preceding month. The interrater reliability of this scale was reported to be very low when the two interviews were separated by 8 weeks, but when corrections were made for the time interval the reliability was high (.97.)

The Individual Planning Process

The PLQ includes a scale to measure the “Elements of the Planning Process”, designed to reflect the degree to which planning is carried out in a "person-centered" manner. The Individual Planning section also captures aspects of how and how often planning events occur, and a snapshot of the plan's content. This snapshot includes the nature of the top five goals in the plan, how much of the plan is addressed with informal supports, and the perceived amount of progress made toward each individual goal in the last year.

Connections with Family and Friends

This section collects the frequency of several kinds of contact with family members. The number of friends is recorded, based on the person's definition of friendship. The section concludes with the Close Friends Scale, which captures the characteristics and intensity of the person's five closest friendships.

Perceived Quality of Life Changes

The "Quality of Life Changes" Scale asks each person to rate his/her quality of life "A Year Ago" and "Now." Ratings are given on 5 point, Likert scales, and cover 13 dimensions of quality. On this scale, we permit surrogates (whoever knows the participant best on a day to day basis) to respond. In our experience approximately 85% of responses to this scale are provided by surrogates. The interrater reliability of the Quality of Life Changes Scale was found to be .76.

Personal Interview

One of the central problems in measuring quality of life for people with developmental disabilities is that many people cannot communicate with interviewers, whether by traditional verbal, or by any non-traditional, means. Hence many researchers have permitted surrogates to "speak for" the person. We reserve the Personal Interview section of the PLQ as the one section where surrogate responses are not permitted. This section is intended to capture the person's thoughts, and none other.

The Personal Interview is left blank if we fail to find a way to communicate with the person. This is unfortunate, yet it is mitigated by the fact that we still have all the dozens of other quality of life measures that can be collected from third parties. In the final analysis, we must have one place that requires first party thoughts and feelings.

The Personal Interview uses five point scales, which can be asked as two "Either-Or" questions. For example, 1) "How is the food here? Good? 2) "OK, would you say Good, or Very Good?" We know from the work of Sigelman et al. (1981) that "Yes-No" questions should be avoided when interviewing people with cognitive disabilities, because of the threats of acquiescence and nay-saying. The Personal Interview also contains open-ended questions. Answers to these are recorded verbatim for qualitative analysis. (Example: "What things are most important for you to be happy?" and "If you had one wish, what would you wish for?")

Some of the data collection instruments, and their reliability, were described in the Pennhurst reports and subsequent documents (Conroy & Bradley, 1985; Devlin, 1989; Lemanowicz, Levine, Feinstein, & Conroy, 1990.) Since that time, more detailed and rigorous reliability studies have been published (Conroy, 1995; Dodder, Foster, & Bolin, 1999; Fullerton, Douglass, & Dodder, 1999.)

Procedures

Purchase of Service Records

In the course of conducting the PLQ interviews, COA Visitors record each participant's Unique Client Identifier (UCI) number. Individual start dates were defined as the beginning of the first self-determination budget and were furnished by the Project Coordinators. After all the data were entered, COA extracted a list of participant names with corresponding UCIs and start dates. This password-protected list was sent to DDS Information Services with a request for Purchase of Service expenditures, by person, by month, beginning with the year prior to individual self-determination start dates. We also requested and received budget information from the pilot sites. Each site had developed its own internal system for tracking pilot financial data.

Quantitative Data Collection

The project recruited and trained local professionals, para-professionals, and advocates to perform a data collection visit with each participant. These data collectors, called "Visitors," functioned as independent contractors, and in most cases remained with the project from beginning to end. They were paid a fixed rate for each completed interview. Below are the Visitor instructions from our Personal Life Quality Protocol.

> 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 direct interview of any length, usually 5 to 15 minutes)
> 2. Whoever knows the individual best on a day to day basis (about 30 to 60 minutes)
> 3. The person's records, including medical records (about 5 to 10 minutes)
> 4. Sometimes, a health care professional familiar with the person (about 5 to 10 minutes)
>
> With access to these four sources of information, and after some practice sessions, you will probably be able to complete this package within the range of 45 to 95 minutes.

The Principal Investigator and the in-state Coordinator were responsible for training and monitoring the Visitors. A crew of fifteen interviewers collected the data for this evaluation. Two of the interviewers are bilingual in English and

Spanish and one interviewer is bilingual in English and Chinese. Twelve of the fifteen Visitors were experienced in using the PLQ from their work on other COA projects in California. Refresher sessions were held at the beginning of each new round of data collection to answer questions and to emphasize the differences between the self-determination form of the instrument and the form used by many for the study of deinstitutionalization in California. A detailed, question by question PLQ training session was produced on a CD and made available to the Visitors. The in-state coordinator monitored Visitor progress on a weekly basis.

Each visitor was responsible for scheduling appointments and completing assigned visits. Visitors were instructed to respect programmatic needs, and to work around them. No person's daily schedule was to be disrupted by these visits. The amount of information collected, in relation to the relatively short duration of the visits, is worthy of comment. We were able to collect reliable quantitative data on dozens of qualities of life in a very short time, with very little intrusion into peoples' lives.

Qualitative Data Collection

In the first two years of the study, COA's in-state Coordinator convened focus groups in all three regional center areas. Separate groups of consumers and family members, regional center staff, and provider representatives shared their experiences, concerns, and recommendations. In January 2002, the Principal Investigator and the Project Director conducted individual key informant interviews with project coordinators, regional center administrative and fiscal staff, service vendors, advocates and a representative of the Association of Regional Centers.

Additional information was gathered through participation in the Statewide Steering Committee meetings, the Project Coordinators Meeting, and attendance at a participant “Open Session” at ELARC. The personal stories of six participants' experiences in the California self-determination pilots were written by a consultant journalist who drew on material furnished by regional center staff, interviews by the in-state Coordinator and her own phone interviews with the people and their families.

Eddie: A life profoundly changed

Eddie Lyons was diagnosed with severe mental retardation at the age of three - little more than eighteen years ago. For most of the years to follow Eddie got on a bus every morning at 6:15 and spent over 2-1/2 hours going to and from school. During the day he sat in a classroom located at the back of the campus where he did nothing for most of five hours. Eddie was given few opportunities to socialize with other children, and was made to eat lunch alone.

Eddie lost his motivation to learn, was lonely without any friends, wasn’t known by his community, and there were no opportunities on the horizon to fill these voids in his life.

Over the years, once a pleasant and well-behaved child, Eddie transformed into an angry, self-abusive teenager. In response, the school isolated him further, identifying him as a disruption. Never did a teacher or an administrator think how Eddie might be really feeling as a fellow human being, nor was the intent behind the promise of the Individuals with Disabilities Education Act ever fulfilled.

Eddie’s mother Edna was weary from fighting the school district over the years. She felt defeated. “They never really cared." Edna and Eddie’s father Al pulled their son out of high school. “We made up our minds. We were just going to care for Eddie ourselves.”

As for the Regional Center, there was little that could be offered to support Eddie and his family – the location of the Lyons' home was too rural and remote and services were few and far between.

Even the Lanterman Act, the California law that promises Eddie the supports and services that will enable him to lead a more independent and productive life in the community, was an empty promise for the Lyons. They were ready to give up on the idea of getting help from public sources. According to Eddie's parents, "The very systems designed to educate and support Eddie in his life, cast him aside and said there was nothing that could be done.

Two years ago, at the height of their despair, the Lyons received a phone call from the Regional Center. On the other end was a worker with news that Eddie had been selected to participate in the self-determination pilot project.

"Somehow, she actually talked me into it," said Edna.

Over the following three months, a budget was established by looking at what traditional services might be for Eddie as an adult – a day program, behavioral supports, daily living skills training, diaper service, speech and language therapy, and transportation. This same level of resources was made available to purchase precisely the supports that would make life better for Eddie and his family.

Under self-determination the Lyons now had the control never afforded them in all these years. They were finally empowered to help Eddie create a new life and design the programs he needed to help him learn, as they knew he could.

Today, Eddie is an integral member of his community. His individualized day program includes Pat, who has experience in teaching life skills to people with the most profound disabilities.

Pat comes to the Lyon home several times a week to help Eddie learn. After a few games of basketball or a little music on the stereo, the two go hiking at the beach, swimming at the local pool with the aquatic therapist, join the drum circle to play music, and visit the youth center where Eddie has developed the friendships he has been missing for so long.

According to Edna, "We run into some of his friends around town. He has become a part of his own community. I have lived here for 30 years, but people didn't know my son." Now they do.

Pat seizes every teaching moment even when sitting in the coffee shop. He might point out to Eddie that others are whispering, and not speaking loudly, and ask him to observe common courtesies others demonstrate to one another. Eddie's behavior has improved significantly. He's learning how to use the toilet for the first time, and his attention span has increased from 15 seconds to 20 minutes at a time.

The speech therapist discovered that Eddie knows colors, the names of shapes like "triangle" and "boat."

"I didn't know," said Edna.

For the first time, Eddie moves his head to respond "yes" or "no." He is starting to formulate sounds with his lips, uses the computer, and puts puzzles together.

Not everything is perfect, and there are disagreements with the Regional Center at times over use of the money in Eddie's budget. But they work together now, toward what Eddie specifically needs. The Lyons now have hope that Eddie's life will never be underestimated in worth and ability again.

"It's made all of our lives better."

The life Eddie now deservedly enjoys, is not because of more money, the school system, or even the developmental services *system – it's because a family now has the power and authority to build a future for their son as a contributing, included and accepted community member.*

Jose and his family unit

Jose Sanchez was born in Mexico ten years ago. When he was one day old, his little body became wracked with seizures for reasons unknown at the time. The doctor prescribed Phenobarbital and unexpectedly Jose fell into a coma, not waking up for seventeen days.

As the days passed one by one, his mother Linda "almost went crazy" with worry. When he finally awoke, the "doctors took liquid from his spine, and did an ultrasound on his head," and neither test revealed the problem. Linda was handed her baby and told he was fine, although she sensed something was terribly wrong.

Jose was 10 months old and growing up normally – his speech was developing and he was starting to say "mom." He sat up independently in the bathtub, ate solid foods, was bearing weight and would soon be walking. Without warning, the seizures returned at a rate of 20 times per day. Every seizure left Jose crouching in a fetal position, his eyes barely open, his head limp, and his body hard.

Initially, doctors had no answers. "Jose stopped doing things normal children did," recalls Linda. He was no longer speaking or even trying, was unable to sit independently, bear weight, or eat solid food.

"I felt terrible. Everyone in the house was suffering." Soon Linda found herself caring almost exclusively for Jose and neglecting the emotional needs of her two older children. Jose's older sister, who was ten at the time, became seriously depressed and attempted suicide. Linda learned from talking to others that it is not uncommon for siblings of brothers or sisters with disabilities to feel forgotten and cast aside. Parents become overwhelmed

when there is little or no support, and a sense of "family" can be easily lost.

When Jose was seven years old, the Sanchez family moved to the United States. Linda doesn't speak much about her reasons for leaving Mexico. However, according to Paul, the family's Regional Center service coordinator, "In Mexico services for kids are limited. It isn't very much."

When they arrived in the United States, the Sanchez family was undocumented, spoke only Spanish, and on their own in an unfamiliar country. However, it didn't take long for Linda to connect Jose and their family to the Regional Center. Soon expenses for diapers and a summer camp were covered. However, Linda would not use respite services. "I could get respite before, but I never used it because they sent the worker." Jose does not easily become accustomed to strangers.

It wasn't long after Jose was accepted as a Regional Center client that the Sanchez family was notified of being randomly selected to participate in the self-determination pilot project, which was three years ago.

As I interviewed Linda through an interpreter, I got the feeling she is an uncomplicated person with good basic values and an appreciation of the family unit. I can honestly say, there isn't anything so profound about the Sanchez family experiences in self-determination that point to dramatic change in their lives like many of the other families I interviewed. I looked very hard, and at first was disappointed.

However, after a closer examination of Linda's words and my interviews with the service coordinators at the Regional Center, I realized the Sanchez family doesn't require much to feel supported.

The control Linda has over the use of the funds in the self-determination budget allows her to pay a family member Jose is familiar with to provide one hour of respite each day so she can attend school. Funds are also used to pay for the co-payment to the neurologist, Jose's seizure medication, and most recently a behavior specialist - Jose has become aggressive and self-abusive in recent months as a result of changes in his medication. Self-determination paid for a lawyer and fees to the Immigration and Naturalization Service so the Sanchez family could apply for permanent residence.

"Before the Regional Center would just give us our services - we made no decisions about them. Now we've worked and learned to be responsible to manage our budget. For example, I wanted to get really good diapers for Jose, so our Regional Center coordinator helped me find the company."

Although Linda considers self-determination a lot of responsibility, she still prefers it to the old way.

"This is better."

Results 1: Family Survey

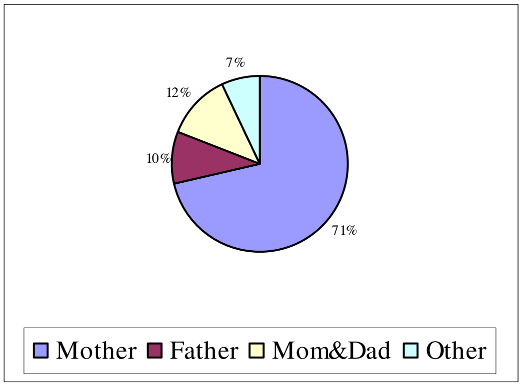
Family Opinions

The **California Self-Determination Family Survey** was administered during the face to face visits as part of the Personal Life Quality protocol. This Survey was essentially the same as the one we designed for the **National Self-Determination Family Survey** for the Robert Wood Johnson Foundation. The uniformity of the surveys permits national comparisons, so that we can obtain a rough "benchmark" about self-determination progress with regard to families in California versus the pilots in a dozen other states.

Who Responded to the Family Survey?

We completed data collection visits with 80 people this year, our third round of visits. Of these 80, 65 were participants (15 were in the Comparison Group), and of those 65, we were able to complete the ***Self-Determination Family Survey*** by direct interview with 41 relatives. The relatives were primarily mothers (71%), and another 12% were mothers and fathers answering together.

Relatives' Relationship to Participant



The average age of the family respondents was 47, while the average age of the self-determination participants themselves was 17. Of the 41 people for whom the Family Survey was completed, 37 lived with family and 4 lived in some kind of out-of-home setting. This reflected the general makeup of the self-determination participants in the California pilots: largely young adults living with family.

Family Awareness

The survey asked, *"Have you heard of Self-Determination for people with developmental disabilities?"* The responses were as shown in the following table.

Have You Heard of Self-Determination?

Response	%
1 No, never heard of it	0.0
2 Heard of it but don't know what it is	7.1
3 Heard of it and know a little about it	14.3
4 Yes, and I know a fair amount about it	26.2
5 Yes, and I know a lot about it	52.4
Total	100.0

All of the relatives had heard of self-determination, and about 93% knew at least something about it. This is significantly above the average from our ***National Survey of Families of People Involved in Self-Determination***, which was 81%. California's families were more likely to know about the efforts than were families in pilot projects in other states. This should be interpreted as indicative of relatively good outreach, training, and information sharing in the California pilots.

Similarly, for those who had heard of self-determination, most knew that their relatives were involved:

If You Have Heard of Self-Determination, Has Your Relative Been Involved?

Response	%
1 No	0.0
2 Yes, but very little	7.5
3 Yes, somewhat	17.5
4 Yes, significantly	15.0
5 Yes, very much	60.0

All of the families who had heard about self-determination knew that their relatives were involved. Once again, this exceeded the percentage found in our national survey (86%). This points again to relatively high family knowledge about the initiative in California.

Individual Budgets

An essential part of self-determination is having an individual budget. In most states and most service systems (especially residential and day services), group budgets and provider contracts existed. Self-determination presumes that one cannot control resources for one's life needs unless one knows what resources are available. This means that "money must be attached to, and follow, the person." In most states and service systems, this has never been achieved, even up to the present.

In the California self-determination pilots, families knew that individual budgets existed.

Does Your Relative Have An “Individual Budget”?

Response	%
1 No	0.0
2 Maybe not	0.0
3 Unsure	2.4
4 Maybe Yes	19.0
5 Positively Yes	78.6

These figures are in sharp contrast to the national findings. For the nation, fully 27% of families did not think there was an individual budget, or were unsure about it. In California, only about 2% were unsure. This finding suggests very strong progress in California toward individual budgeting, and toward family awareness of these budgets. Insofar as awareness of money is a necessary precondition for fully developed self-determination, this finding is very important. California’s pilots are far ahead of other states in this regard.

Every family that knew there was an individual budget believed they knew the amount. This too put California ahead of other states, because nearly half of families in other states who knew about individual budgets could not specify the amount. In California, the families reported an average amount of $19,125 per year, with a minimum of about $2,000 and a maximum of about $52,000.

Power

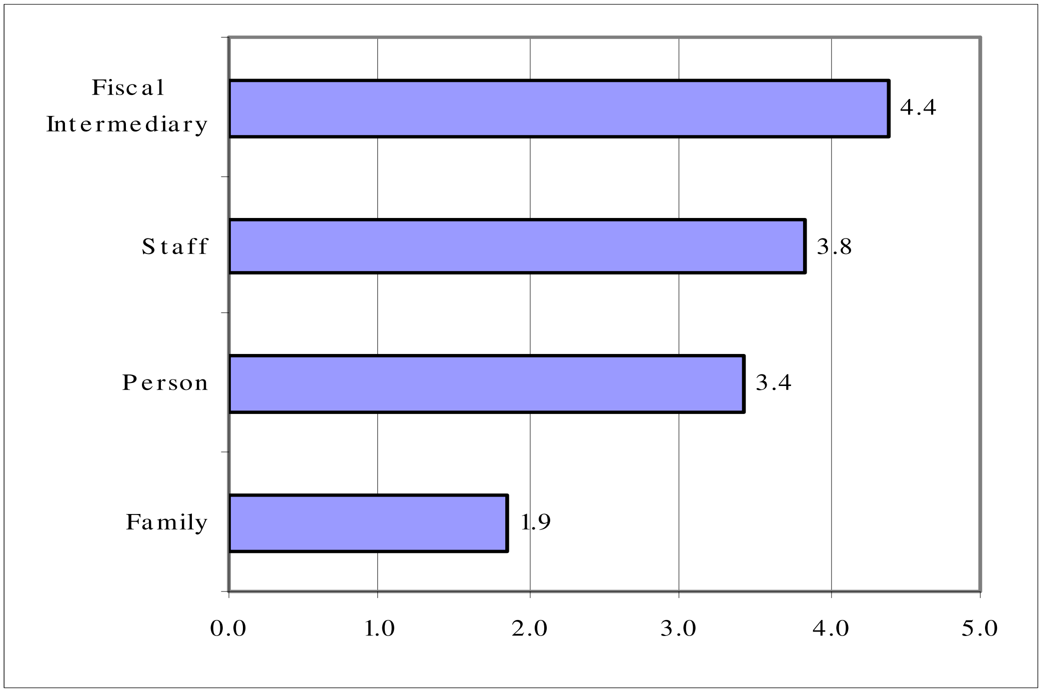
The most important questions in the Family Survey were about power. The first set of power questions asked *“Who controls the funds that are used to serve and support your relative?”* The answers were given on 5-point scales in four categories as follows:

(10) Who controls the funds that are used to serve and support your relative?
Please circle numbers in the boxes below.

10a. How much control over your relative's funds do **you** (or you with other relatives and friends) have?	10b. How much control does **your relative** have?	10c. How much control do **staff** of the service agency (if any) have?	10d. How much control does a **fiscal intermediary** (if any) have?
1 Complete or near complete	1 Complete or near complete	1 Complete or near complete	1 Complete or near complete
2 More than half	2 More than half	2 More than half	2 More than half
3 About half	3 About half	3 About half	3 About half
4 Less than half	4 Less than half	4 Less than half	4 Less than half
5 Little or none	5 Little or none	5 Little or none	5 Little or none
99 Not applicable	99 Not applicable	99 Not applicable	99 Not applicable

By looking at the average responses on these four items, we can easily compare the families' perceptions of where power is centered in the self-determination pilots.

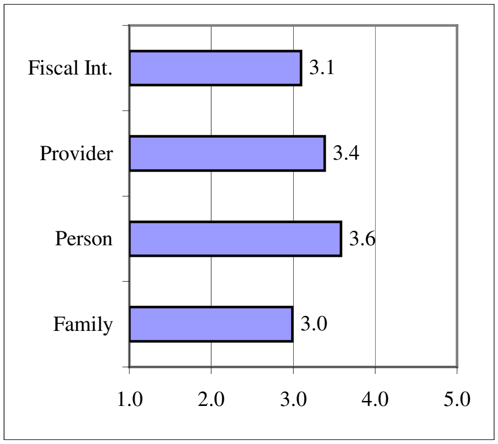
California Family Perceptions of Power Over Funds:
Lower Numbers Mean More Power



According to the families, then, they have more control over the funds than anyone else. And the difference is rather large. Moreover, the participants are perceived to have more power than paid staff or fiscal intermediaries. This, in our view, is very strong evidence that the shift in power over resources that is theorized by self-determination has really taken place among California's participants and families.

Data from our national survey will serve to underline this finding. The national survey graph below is quite different from the California graph above.

Contrasting Results from the National Survey:
Relatively Less Power for Families and Participants



Family perceptions of power-sharing are much more even among self-determination pilots all over the country. California's results are the strongest in terms of perceived family control over resources.

We asked similar questions about power over hiring and firing. An important part of self-determination <u>can</u> be authority over the people who are paid to provide supports to the participants.

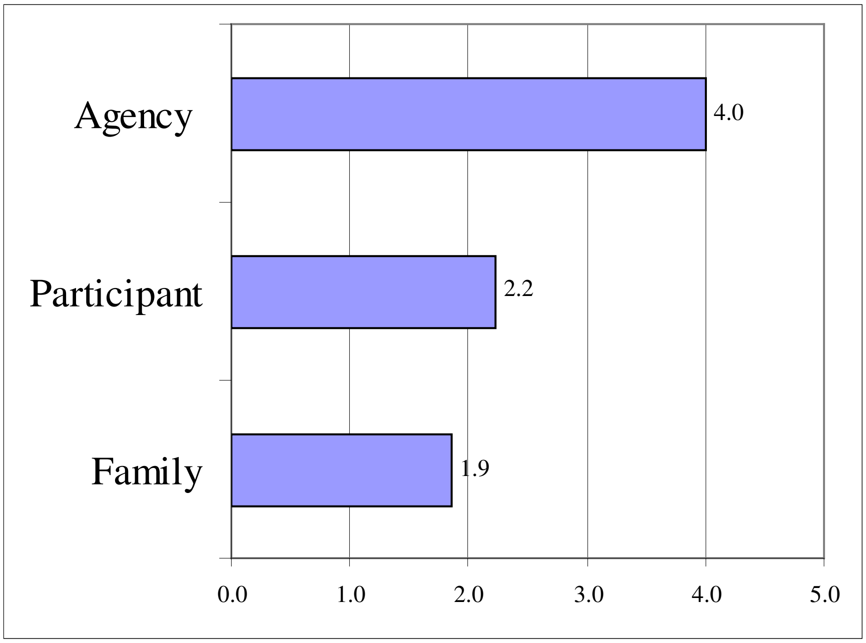
(11) Who has control over hiring and firing support staff?

Please circle numbers in the boxes below.

11a. How much control do **you** (or you with other relatives and friends) have over hiring and firing support staff for your relative?	11b. How much control does **your relative** have?	11c. How much control does a **provider agency** have?
1 Complete or nearly complete	1 Complete or near complete	1 Complete or near complete
2 More than half	2 More than half	2 More than half
3 About half	3 About half	3 About half
4 Less than half	4 Less than half	4 Less than half
5 Little or none	5 Little or none	5 Little or none
99 Not applicable	99 Not applicable	99 Not applicable

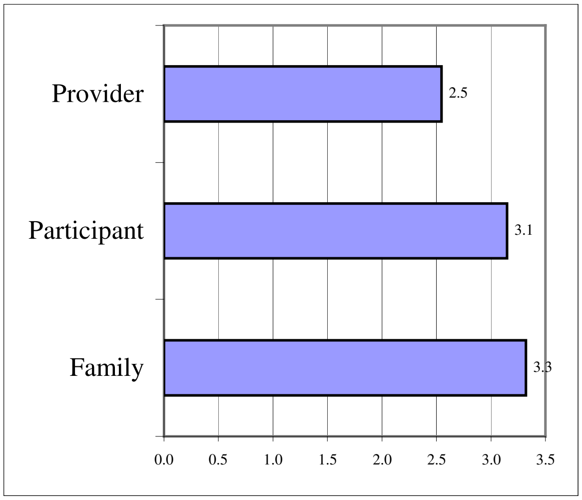
The results are shown in the following graph.

California Families' Perceptions of Power Over Hiring and Firing Staff



Again, lower numbers indicate <u>more</u> control over support staff. Insofar as self-determination is supposed to move power over support provision toward people and their freely chosen allies, this graph demonstrates marked success within the California self-determination pilots.

Comparative Data from the National Survey:
Providers Still Hold More Power than Participants or Families



On the national scene, families report on the average that service providers still have more hiring & firing power than they do, and more than the participants do. This sharply contrasts with the California results, in which the families and the participants appear to have more power than the paid professionals and vendor staff in the system. California's pilots thus outstrip the national average experience, and must be judged as more successful in this "hiring and firing authority" domain.

What's Important to Families?

We asked family members to rate what they felt were the "five most important things" for their relatives' well-being. The main utility of this question is to help planners and policy makers understand the value systems within which the families of self-determination participants are operating.

Families were asked to name their "top five," and these were translated into scores for each of 30 dimension of life quality. The scoring system allowed a maximum possible score of 200. The following table shows the results.

Family Ratings of "Most Important Things"

Quality of Life Dimension	Score
Health	102
Love	84
Safety	54
Communication	47
Dignity, respect	34
Development, learning	29
Self-esteem	29
Productive day activities	27
Medical attention	25
Self-care skill development	25
Friends	23
Comfort	17
Permanence of home	16
Religion, worship	14
Stability	14
Community acceptance	13
Family-like atmosphere	13
Being kept busy	12
Assistive devices	11
Freedom from abuse	10
Self-determination	10
Integration, inclusion	7
Choicemaking	6
Exercise, fitness	6
Supports for problematic behavior	5
Travel, vacations	5
Home-like place	4
Monitoring the quality of services	4
Working for pay	4
Being with other people with disabilities	3
Earn money	3
Girlfriends / Boyfriends	2
Large facility to live in	2

As the table shows, families rate health first and love second. Perhaps a fair translation of this finding would be that families hope most that their relatives stay healthy, and they are loved. Then, following at some distance behind these two primary values are safety, finding ways to communicate, dignity, learning, and self-esteem. Equally interesting are the values that are listed at the bottom of the table: large facilities, girlfriends/boyfriends, and earning money. These expressions of family values are not the same as values espoused by many professionals, and thus the unfolding of self-determination will have to include understanding and negotiation between and among families, participants, and professionals.

The Inclusion of Sarah and Susan

More than sixteen years ago, twins were born to the Kosalwats. Four months premature, both babies had enormous health issues and their disabilities would be life-long. Susan was blind from the oxygen she was given to save her life. Sarah almost died when her lungs collapsed.

Sarah and Susan's parents were both born and raised in Bangkok, Thailand where the culture includes the belief system that a child born with a disability committed a terrible sin in a previous life and the child is kept hidden at home.

The twins' birth seriously challenged their parents' heritage, culture, and values. With prayer, self-reflection, and time, the Kosalwats believe they glimpsed the purpose of their daughters' lives. They saw their family's opportunity to challenge the prejudices inherent in society by making their daughters visible, and not hidden.

Unfortunately, Sarah and Susan's experience with public education has been difficult. They found the school unwilling to support their inclusion in the regular classroom because "they were too mentally retarded." Other children on campus, driven by ignorance, mocked the twins because they were different.

When Sarah and Susan were ten years old the Kosalwats became aware of Regional Center services. Mrs. Kosalwat recalls feeling like, "We had everything in the world," when the Regional Center agreed to pay for services. However, the after-school daycare had no expertise in supporting the twins' needs and provided no solution. When mainstream summer camps rejected them, a camp for kids with disabilities was the only choice.

The Kosalwat family had little control over the outcome of their daughters' lives. They felt that Sarah and Susan were at the mercy of programs that did not fit them, and the personalities in a system that did not want to include them.

At a time when the Kosalwats were most frustrated, they were invited to participate in California's self-determination pilot project. With the proper planning, together with the family's vision, the twins now have opportunities that would not have otherwise been available. Barriers to inclusion at school still exist, but their lives outside of public education have improved dramatically.

Although it was hard at first to find the right ways to use public funds, many useful discussions ultimately clarified the family's goals. Consequently, the Regional Center service coordinator has been able to support the Kosalwats in thinking creatively as they developed individualized programs of inclusion for Sarah and Susan.

The Kosalwats have hired a personal assistant to accompany Susan in the community to support her participation in activities with peers, help her to improve articulation of the English language, and facilitate her increased knowledge of American culture.

For Sarah, the Kosalwats have hired a tutor who helps her with her homework. Mrs. Kosalwat indicates, "Our English is not very good, and we aren't able to help Sarah that much."

Self-determination has allowed adaptive swimming lessons for the twins, and singing lessons intended to train their voices, teach them posture, and give them self-esteem.

"Susan sings in the Thai language and I don't understand the words. But she carries you into the spirit of the music," according to Iris, the family service coordinator.

Prior to self-determination, policy restrictions would have prevented the Regional Center from considering or funding these non-traditional services.

As the Kosalwats see it, the results of self-determination for the twins are included lives, significantly improved self-images, and a confidence in their singing talents that has widely impacted a community.

The two girls made their first public appearance at a homeless shelter as 400 people were lined up waiting for food. They sang Amazing Grace, and God Bless America. When they were done, men, women, and children shouted out their joy, calling the twins "angels," and declaring them "gifts from God."

Sarah and Susan's popularity grew, the media were alerted, and the two of them became known throughout their community. They sang for the poor, the sad, and the sick wherever they could be found. They sang everywhere, except within the Thai community.

The tragedy of September 11th left no one untouched by feelings of loss, fear and devastation. It came as a surprise when Sarah and Susan were invited to sing at the Thai Temple – the first time people with disabilities were welcomed. The two girls sang America the Beautiful. That day, members of the Temple donated more than $4,000 to the families in New York who lost loved-ones.

The flexibility of self-determination has lifted many barriers for Sarah and Susan in becoming accepted members of their community. However, despite laws in the Individuals with Disabilities Education Act, the school still denies services, and in complete disregard of the Kosalwat family values, the twins are still segregated. The attitude of the school has forced the Kosalwats to spend funds in the self-determination budget to hire a personal *advocate to work with the school to implement the girls' educational plan.*

Sarah and Susan's continued exclusion at school hurts them deeply. They want to move somewhere different, where no one knows them and they can start over.

"There has been a lot of whispering going on in corners. It has been difficult for the family," according to service coordinator Iris.

"My girls are also learning how to forgive," said Mrs. Kosalwat.

Wang Chen: Unveiling Creativity

Wang Chen, an adult with severe disabilities, was born on February 26, 1970 and moved to the United States from the island of Taiwan in 1983 with his parents and younger sister. For this article, I interviewed Mrs. Chen, who speaks Cantonese, a dialect of Chinese. In retrospect, I understand there were likely many barriers to obtaining the information I was looking for, including my use of American slang, our different cultures, and how we each interpret life as it goes on around us. It was a wonderful experience, and an important reminder that California's developmental services system has a big responsibility in serving many people whose diversities are as much a part of their lives as their disabilities.

Wang's story, as told through his mother, illustrates how self-determination can integrate different cultures with an outcome that is respectful of individuals and their families. According to the Regional Center, Wang's supports were provided without exceeding the expense of traditional service delivery. What follows are Mrs. Chen's words through an interpreter.

Q What is Wang's disability?

A He cannot talk, and he cannot see anything. He can only see the light. Only a little bit of color.

Q What happened and when?

A In 1987, when he was in Texas. In the nighttime he was driving to a classmate's house to do homework. Someone hit him. Because of this accident he became a blind person and cannot talk. There was bleeding of a nerve in the brain. The doctor refused to do surgery. He said it could not help. I do not know why. Because my English is no good. I don't understand him.

Q ***How does Wang communicate?***

A *He uses Morse code.*

Q ***Did you teach him Morse code?***

A *Yes.*

Q ***How did you know Morse code?***

A *Because I am a Christian, so one day I prayed and a spirit talked to me and I learned there was such a thing I could teach him.*

Q ***So, Wang can tell you what he wants?***

A *Right now we are using the computer. We put the Morse code in the computer and the computer tells me what he is saying.*

Q ***Is he able to communicate different choices?***

A *He knows Mandarin, Cantonese and English.*

Q ***Did you teach him?***

A *He learned English before the car accident.*

Q ***When did you move to California?***

A *In March of 1988.*

Q ***How did you find out about the Regional Center?***

A *My friend from church.*

Q ***Was the Regional Center helpful?***

A *Yes, a lot.*

Q ***Tell me about Wang's day program.***

A *Before self-determination, we had services but could not get speech therapy. But now he can get speech therapy because we can control the budget from self-determination.*

Q. ***I understand Wang has a personal aide that brings him into the community instead of a traditional day program. What do they do?***

A *Wang uses a wheelchair. The aids loosen up the joints around the fingers, they feed him; they also help change his clothes* *when they get wet. Regarding transportation, they will make phone calls.*

Q ***Where do they go?***

A *We have two places. {Name of Service Agency} Art Center, where he is learning to draw, and enjoys it very much.*

Q ***The other place?***

A *Go to a movement center to train muscles and body movement, like physical therapy. If he goes swimming, the personal aide will accompany him. He doesn't swim, but exercises in the pool.*

Q ***Is it a public pool?***

A *YMCA. There are other people there swimming. So the one who aids him will explain to the other people in the pool. Introducing them to him.*

Q ***I heard Wang won a contest for his painting?***

A *Yes. Actually I go with him because I am helping him see around. I consider myself his eyes and I understand what he needs and I need to hold his hand. So I tell him whether it is the left or the right and then he chooses the color by himself. Then he tells me how to mix the color and then he determines by himself what he wants to draw. So actually in between we use the Morse code to communicate. The others that accompany him don't know how to interpret the Morse code.*

Q ***Does Wang have friends?***

A *Yes. Lots of friends. From the church, from daycare, the nurses, the neighbors and also friends of his sister. And, also people from Hong Kong, Seattle and San Francisco.*

Q ***How does he have friends from so far away?***

A *Because after they heard about our story they were so impressed they noticed he worked so hard they just wanted to write him.*

Q ***How did they hear about him?***

A *Because I made testimony in the church. So we went to many churches to make testimony.*

Q ***What was in your testimony?***

A *Testified to the work done by God. That we have received a lot of strength given by God and we never felt lonely and he always has hope.*

Q. ***Has self-determination been helpful?***

A *Very helpful.*

Q ***Would you ever want to go back to how it was before?***

A *I would like to maintain in the self-determination program.*

Q ***Is Wang happy?***

A *He is very happy. Now he can choose the service he wants so I can have more free time of my own.*

Q ***What are your hopes for Wang in the future?***

A *I hope he can manage to take care of himself.*

Q ***That he can live independently?***

A *Right now I'm just hoping.*

Q ***Do you think self-determination will help Wang live in his own home?***

A *Yes, I think so. Yes.*

Q ***Do you think Wang has the same dream for himself?***

A *Yes.*

Q ***Does he talk to you about wanting to live on his own?***

A *Yes.*

Regional Center **Q** ***Is life good?***

A *Very hard, very difficult. Very tired, but we have hope.*

According to Wang's Regional Center service coordinator, the traditional day program limited Wang's personal growth and development. Under self-determination his individualized program has created a big change in his creativity. "We had a meeting last week and he brought to the meeting a painting he made. He won a contest for the painting, and told me he plans on becoming an artist and show his art in a gallery."

Results 2: Cost Analyses

The third hypothesis of self-determination is that "***costs will be the same or lower than they would be in the traditional professionally-dominated approach***." We were able to test this part of the theory in several ways.

First, we asked people and their allies during our face-to-face visits how much their supports were costing. However, before self-determination began, almost no one knew the answer. Hence it was not possible to use participant-supplied data to examine changes from "before" to "during" self-determination.

It is worth noting that this lack of initial knowledge about money in itself was an intriguing finding. In the traditional service system, participants and their families rarely have any idea what their supports cost. This makes it impossible for service recipients to be "cost conscious." One of the most immediate effects of self-determination is to increase recipients' awareness of costs.

Fortunately, an alternative reliable source of cost information was available. We requested and obtained complete data on Purchase-of-Service (POS) expenditures, by person, by month, and by category, for a 4-year period extending before and after self-determination began. This information proved to be essential for accurate analysis of the cost impacts of self-determination.

POS data, however, reaches Sacramento up to 6 months after the expenditures occur at the Regional Centers. Hence the most recent complete POS data available to our team was through June of 2001. This longitudinal POS "paid claims" database, then, formed our primary source for overall examination of the cost hypothesis.

One form of fiscal analysis was suggested by DDS staff. This method was based on person-by-person "start dates." We calculated each person's expenditures for 12 months before, and 12 months after, self-determination began.

Each person in the pilots had his/her own unique start date. The agreed upon definition of when self-determination began, negotiated among the self-determination coordinators and DDS, was the date the parties signed off on the person's individual budget.

There were problems with this approach. The following table shows individual start dates, which were provided by the three pilot sites.

Start Dates for Self-Determination
By the Criterion of the Individual Budget Signoff

Month	# People Starting
Jan-00	12
Feb-00	0
Mar-00	2
Apr-00	1
May-00	2
Jun-00	3
Jul-00	13
Aug-00	4
Sep-00	2
Oct-00	3
Nov-00	3
Dec-00	2
Jan-01	5
Feb-01	3
Mar-01	2
Apr-01	2
May-01	2
Jun-01	1
Jul-01	10
Aug-01	1
Sep-01	7
Oct-01	3
Nov-01	1
Blank	7
Total	91

As the table shows, only 20 people began in or before June 2000. Our Purchase of Service data obtained from DDS in Sacramento can only be relied upon through June of 2001, because the POS data reporting is allowed to lag up to

6 months. Hence we can only be confident and sure of the POS data up to June 2001.

In order to tabulate individual expenditures for the 12 months preceding each participant's start date, and compare that to the 12 months after each individual's start date, as requested by our Sacramento Project Officer, we can only use the 20 people at the top of the table.

Performing this kind of analysis resulted in the table below.

One Form of Expenditure Analysis:
Dollars Utilized 12 Months Prior to Each Participant's Official Start Date (Acquiring Signed Individual Budget) and 12 Months After the Start Date *

The 12 Months PRIOR TO Each Person's Individual Budget Start Date	The 12 Months AFTER Each Person's Individual Budget Start Date	Change in Reported Expenditures	Percent Change in Reported Expenditures
$16,183	**$18,923**	**$2,741**	**17%**

*(Includes Only the 20 People Who Began Early Enough to Permit This Analysis)

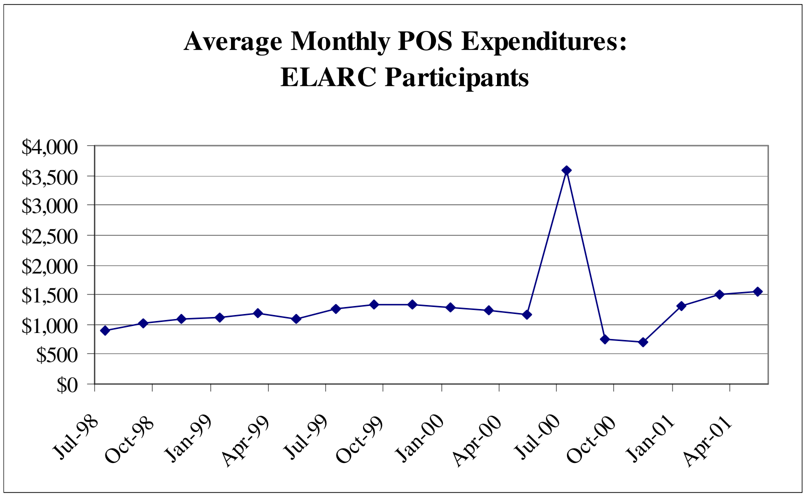
These 20 participants increase their expenditures by about 17% from "before" to the first 12 months "during" self-determination. This would suggest, without correcting for inflation, that costs went up somewhat for the self-determination participants.

However, we suggest that this analysis is flawed and should not be interpreted by itself. Its approach is limited in several important ways. First, it excludes most of the participants, who "started" after June of 2000. So it relies only on the first 20 participants' experience. Second, it does not take into account long-term trends. Third, it is not possible to compare this analysis to the experience of the Comparison Group, for whom there is no "start date." Thus we lose the scientific strength of the Comparison Group in this simple pre-post analysis.

We think a longitudinal analysis and "non-equivalent comparison group" analysis is equally, or perhaps more, informative. For this type of analysis, we calculate the average monthly expenditures for all the participants, and for the comparison group, across a four-year time span.

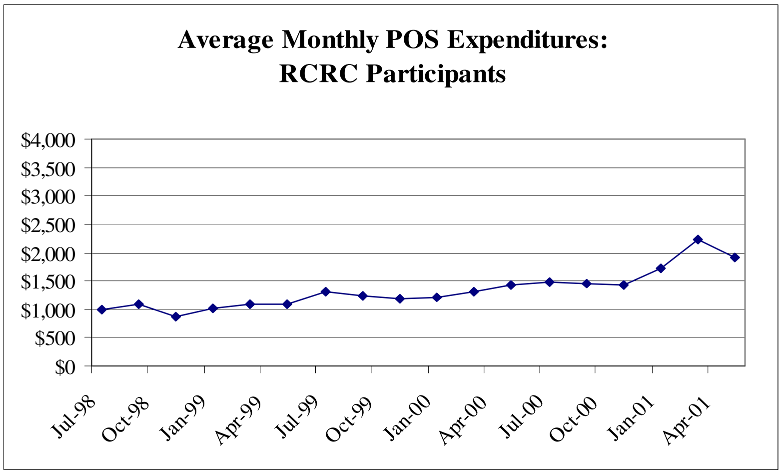
We know that all the participants in this study started their individual budgets in 2000 or 2001. Therefore any changes in average expenditures would show up in average monthly costs over the long run. By looking at trends for a long period, from July 1998 to June 2001, we can visualize any impacts of self-determination upon spending for the pilot participants.

We prepared four separate graphs of Purchase-of-Service expenditures for the self-determination participants at ELARC, RCRC, and TCRC, and also for the ELARC Comparison Group. These graphs are presented below.



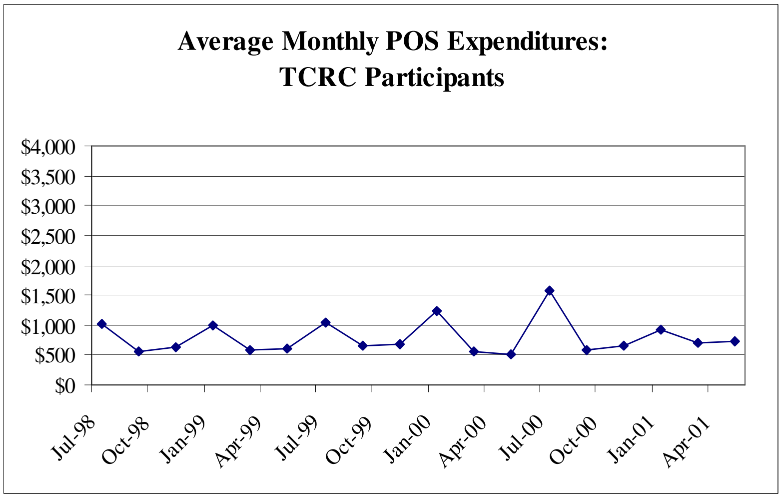
Start	End	Change
$908	$1,665	83%

This first graph shows the flow of dollars for the self-determination participants at ELARC. Over the months, the POS expenditures gradually rose, with an unusual “spike” in July of 2000. Ultimately, costs rose about 83% over the 4 years represented in this graph.



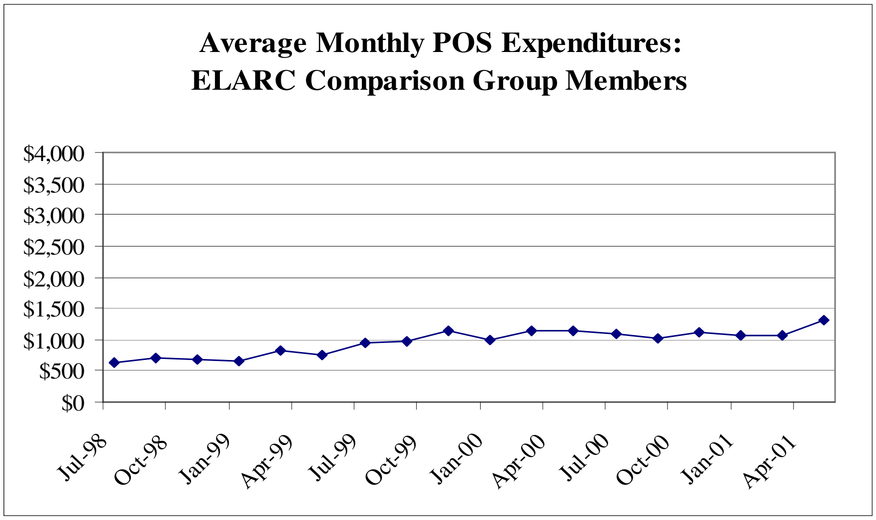
Start	End	Change
$1,001	$2,191	119%

The second graph shows the same thing for RCRC participants. Here, POS costs rose gradually, and by June 2001, they had increased by about 119%.



Start	End	Change
$1022	$786	-23%

At TCRC, the pattern was quite different. The POS data indicated a steady maintenance of costs over time, with a slight decrease. Costs in June of 2001 were about 23% lower than where they began in July of 1998.

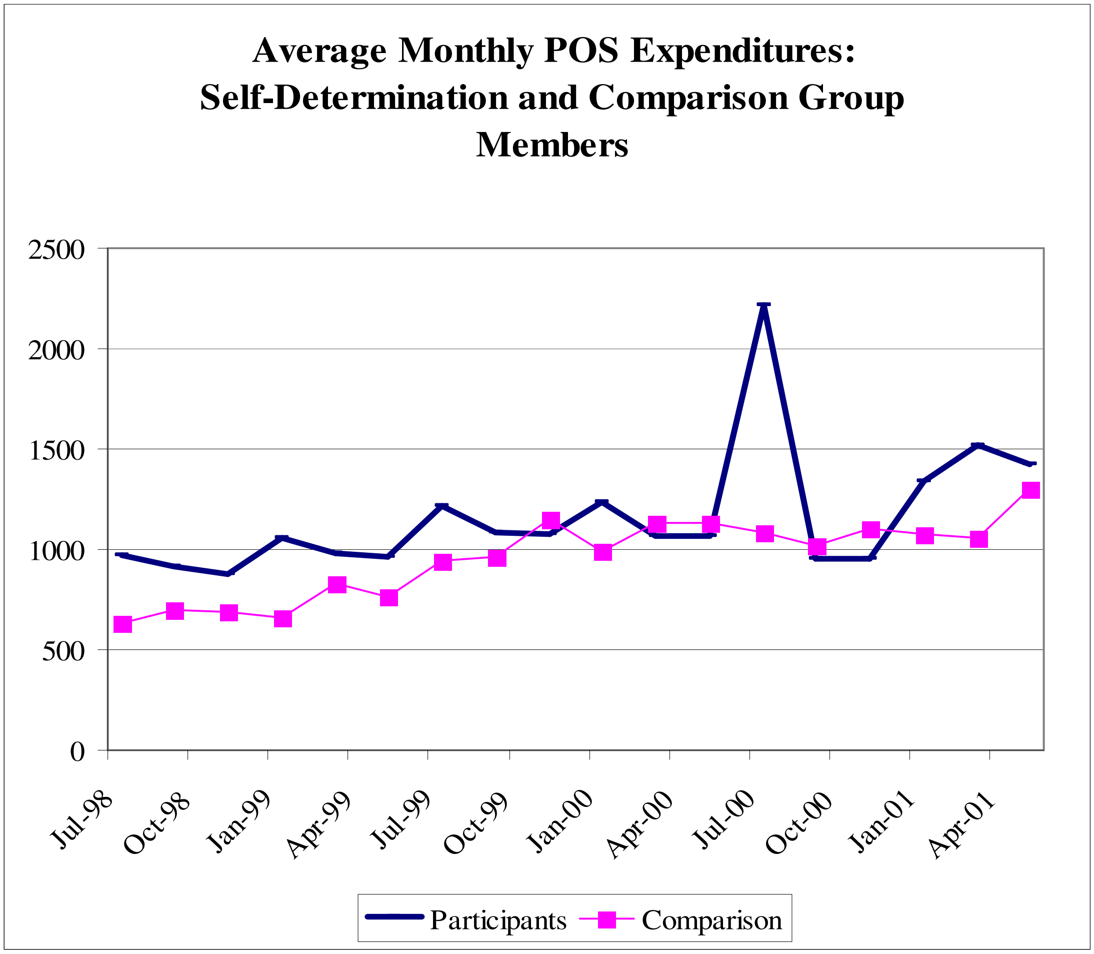


Start	End	Change
$632	$1,378	118%

The fourth graph shows how POS expenditures changed over time for ELARC Comparison Group members who were not involved in self-determination, but who were otherwise quite similar to the participants. Their average monthly costs went up by about 118%.

The four graphs taken together show that POS expenditures were generally increasing for all the groups except the TCRC participants. The most important finding is that the Comparison Group's costs were increasing too. In fact, the Comparison Group more than doubled its expenditures during the 4 years, considerably more than the overall increase for the self-determination participants.

The next graph shows the combined expenditures for the three self-determination pilot sites as compared to the expenditures of the Comparison Group. This graph reveals that the costs for non-participants were rising as fast or faster than the costs for the participants.



	Start	End	Change
Participants	$976	$1,581	62%
Comparison	$632	$1,378	118%

Remarkably, the pattern of change over time appears to have favored the participants insofar as fiscal conservatism is concerned. The participants at the three pilots averaged an increase of about 60%, while the non-participants in the Comparison Group showed an increase twice as large, or about 120% up from where they started.

Although the research design here is not perfect, conclusions do emerge from this analysis. It is possible that the Comparison Group members were not typical of the larger population of people who are not involved in self-determination. (We did test for demographic differences and found few.) There could be other reasons why the Comparison Group costs increased so sharply.

Nonetheless, these data lead rather inescapably to the inference that self-determination as it has evolved in California has not only been cost neutral, it has been fiscally conservative. The increases in costs that might have been expected in the absence of self-determination were slowed, perhaps even cut in half, by the creation of explicit individual budgets and the careful transfer of power to people with disabilities and their allies.

This is not the final word on the subject of the cost implications of self-determination. Analysis of data from these three relatively small pilot projects does not assure us that the results would be the same if the entire developmental services system with over 160,000 service recipients were converted to self-determination. Nevertheless, when placed side by side with our own rigorous findings in several other states, there is good reason to give credence to these findings. In New Hampshire, Michigan, Ohio, and Hawaii, we have obtained hard evidence that self-determination avoids cost increases, and in two of our studies (the ones that involved people in high cost congregate care settings), costs actually went down significantly.

The California fiscal data can best be interpreted as reasonably strong support for the notion that self-determination will slow the increase of costs in the future. At the same time, because quality of life and satisfaction measures have shown strong benefits associated with self-determination, it would seem that public policy should seriously consider self-determination as a major direction for the future in California.

Our final analysis of the cost implications of self-determination in California concerns the role of Federal Financial Participation, often referred to as “FFP.” Under the Medicaid program, the Federal government reimburses states for more than $25 billion per year in the costs of care and supports for people with developmental disabilities. As of the late 1990s, California qualified for 52% Federal Medicaid reimbursement of the costs of approved developmental disabilities services.

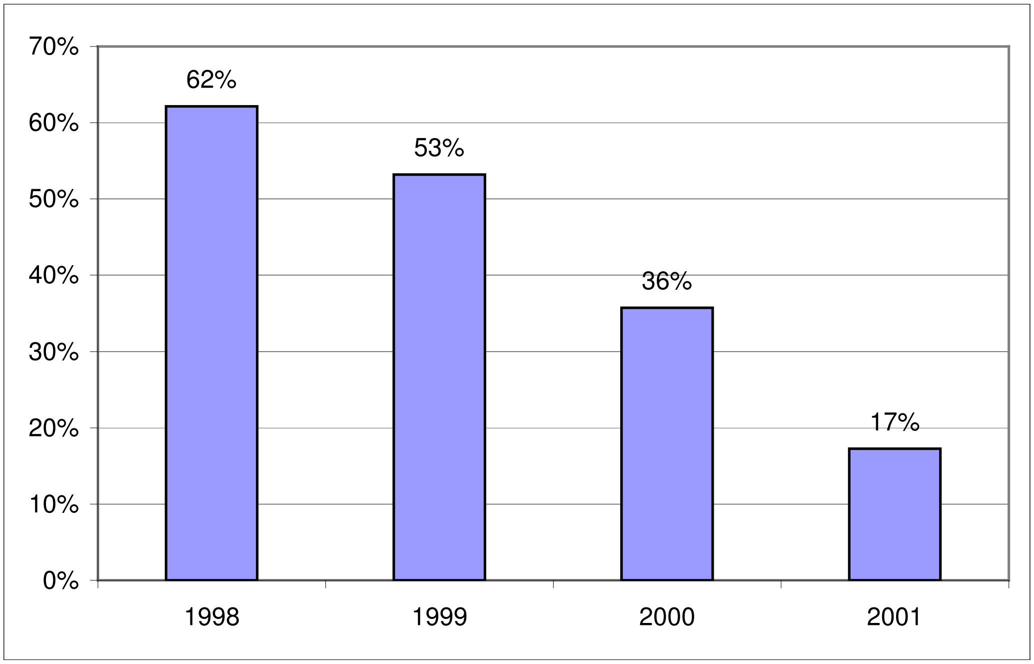
The most flexible and community-oriented part of the Medicaid program is generally called the Waiver program, shortened from the "Home and Community Based Services Waiver" program. Under this program, the Federal government's Social Security Administration, Centers for Medicaid & Medicare Services, administers payments to states to assist in providing supports for people with disabilities. The Waiver program is designed to be flexible, and it favors supports in community-based rather than congregate or institutional settings.

Because the Federal government contributes so heavily to community services for people with developmental disabilities, any programmatic initiative must take the Waiver program into account. Self-determination is no exception.

We learned from our key informant interviews and focus groups that California decided to "temporarily ignore" the Waiver program during the self-determination pilots. This decision was made in the belief that the Waiver program's strict categorical rules for reimbursement might artificially limit the flexibility and creativity of individual budgeting decisions. For example, an individual decision to use public dollars to purchase lessons in the language of one's family heritage might be difficult to put into a "Waiver reimbursement" category, but might be extremely productive in helping a person to become an active member of a "community," in this case, a cultural group.

Because the Waiver program is so important, we requested and obtained additional data on the participants' POS expenditures that were Waiver reimbursed. We graphed the results over time.

Percentage of POS Costs Reimbursed by the HCBS Waiver Program For the Self-Determination Participants, from 1998 to 2001



The graph shows that the California self-determination pilot participants have steadily decreased their Federal Waiver reimbursements over the years. In 1998, about 62% of their costs had been covered under the Waiver program, according to DDS fiscal data. By the middle of 2001, only about 17% was being covered.

This sharp decrease was understandable for a pilot project. However, if self-determination is to expand, it must become "Waiver-friendly." If thousands of people are to take part in self-determination in the future, then Federal Waiver reimbursement cannot be forfeited. There is simply too much money at stake.

Moreover, there is no ***a priori*** reason why self-determination expenditures cannot be made to qualify for Waiver FFP. Certainly other states, such as Michigan, New Hampshire, Hawaii, and Minnesota have grappled with this issue and met with success. Under its new leadership, CMS has demonstrated openness to expanded and flexible Waiver approaches. Despite California's history of

Federal oversight of its Waiver program, there is good reason to believe that cost-effective changes such as self-determination would be viewed favorably at this time.

If self-determination is to continue and/or expand in California, then ways must be found to fit expenditures into the Waiver framework. This can be done by modifying the Waiver(s) with CMS approval, and/or by instituting formal procedures for fitting creative expenditures into existing Waiver-approved service categories. We recommend that California stakeholders obtain the best available expert advice for accomplishing this goal, and move forward quickly.

Tony: "You don't get lost in the system this way"

Anthony "Tony" Whalley has a terminal illness. He turned twenty-five years old on February 12, 2002, and has lived more than two decades longer than doctors or statistics gave him. Tony's family attributes the unexpected years of life to "the Lord and lots of love."

Tony was diagnosed with Krabbe disease when he was six, a rare, degenerative, enzyme disorder of the central nervous system. The symptoms are seizures, difficulty in feeding, paralysis, deafness, blindness, and an eventual loss of mental and motor function. Typically children do not survive beyond two years of age.

Tony breathes through a tracheotomy tube in his neck, receives his food through a j-tube placed in his small intestine, wears a permanent catheter, and uses a wheelchair. His spine has been fused to keep his trunk upright, and he lost his voice at the age of five when his larynx was removed.

Despite Tony's personal care needs, he has always been an important member of the family unit. Placing him in a group home, or institution has never been a consideration for the Whalleys. Unfortunately, until two years ago, the only in-home support Tony and his family were authorized to receive by the Regional Center was twelve hours of respite services per month.

During most of Tony's life his aging parents and older brothers have cared for him. Seldom did the Whalleys take advantage of the respite support. The workers received a low rate of pay that the family compared to wages at a fast food restaurant. The family felt that there was no one qualified to care for Tony's complex needs *and afford him the respect and dignity he deserves as a human being and an adult.*

On December 28, 1998, Tony's mom Ellen had a cardiac arrest. Her heart stopped for eight minutes. She was brought back to life, but remained in a coma for four days.

During that time, nothing changed at home in the way of support. Tony and his father Ted were on their own as Ellen lay in the hospital bed not expected to live.

Four months later the Whalleys received word from the Regional Center that Tony was randomly selected to participate in the self-determination pilot project. They had just about given up on the regional center, despite the long-term support that Tony needed.

After an assessment was made to determine what traditional services would be appropriate, Tony and his parents identified goals through the person centered planning process. "We just want a normal life."

Tony has now acquired his first communication device and for the first time in twenty years can express his needs in a way others can understand. There would be no more fights with the insurance company. A week after getting the device, he transformed into a jokester – often waiting for his parents to leave the room and then announcing, "I need." When they return he grins from ear to ear. Tony has control and power for the first time. He has waited so long.

Monday through Friday a van picks Tony up in front of the Whalley home and brings him to a day program conveniently located five blocks away. Tony likes the structure of the program, the opportunity to be around people and hearing what they have to say, *and the outings in the community with his new friends. Ted said, "I don't like the program, but Tony loves to go, and that's important."*

Tony and his new physical therapist share a mutual respect. Therapy is personal and Tony does not like being intimately touched and manipulated when a good relationship is absent. Prior to self-determination, there was no choice in therapists – it was a "take who you get, like it or not," situation.

Several months ago, the Whalleys found someone to provide in-home support the whole family appreciates. Self-determination allows them to pay her enough, to give Tony time away from his parents and Ted and Ellen the freedom to actually think about taking a weekend off together. "It's been a long time."

Tony now has a lift for the family van and he can easily be transferred on and off which is crucial to his self-respect. It was an embarrassment for Tony as his parents struggled to get him in and out of the van. According to Ellen, "Even when we were younger, it wasn't the easiest thing in the world to push Tony in his wheelchair up and down that aluminum ramp."

Under self-determination, Tony's new service coordinator is helping the Whalley family feel empowered and in control of their lives. "I don't have to sit inside of a box. I'm not looking at Tony and his family to see what policies they fit into. I can listen to their needs and don't have to tell them their options are limited."

The family feels very strongly about the improvements. "Let there be no doubt Tony's life has improved dramatically, giving him more freedom and participation in the every day life most of us know and take for granted." He is not isolated at home or in an institution but wakes up to the beauty of each new day he is given. As his ability to communicate on his new device grows, all the *thoughts he's had over the years, and all the hopes and dreams he's been unable to express will come pouring out.*

"Things are so much better now."

Results 3: Questions from Exhibit B

The following results are presented according to the questions originally posed by the Statewide Steering Committee in its request for proposals for this evaluation. These questions were also incorporated in the evaluation contract with COA as Exhibit B.

In our first visits in the summer of 2000, we interviewed 112 people, including the ELARC Comparison Group. From that time until January 2002, pilots added new participants and some participants dropped out. In this report we are discussing the results for 77 people for whom we had 2000 and 2002 data (before and after self-determination participation.) The numbers of people from each pilot and the ELARC Comparison group are shown in the table below.

Number of People for Whom We Have "Before-And-After" Data

	TCRC	RCRC	ELARC	ELARC Comparison	Total
Number	19	21	23	14	77

Did the project meet expectations?

The project definitely met expectations with regard to testing the implementation of the principles of self-determination in the context of the California Developmental Disability Service System (See Appendix C for an overview of Self-Determination in California). All three regional centers demonstrated their commitment to the principles from the language and spirit of their proposals, through the strategies they employed, to the daily operations of the projects. Many respondents reported surprise that the level of commitment and excitement about self-determination has been sustained throughout the term of the pilots. Their feeling is that people who knew the most about self-determination prior to the project seem to have higher expectations and are hopeful that more progress will be made as the systems barriers are resolved. Several respondents reported that participants and families who only had a general idea that self-determination involved empowerment and control of funds have a very high satisfaction level.

How did your pilot work?

The three regional center pilot sites, Eastern Los Angeles, Redwood Coast, and Tri-Counties have devoted countless hours and resources to crafting systems that fit their particular region and populations. They have worked closely with the Department of Developmental Services (DDS) to assure consumer safety and access to necessary services, while identifying and confronting system barriers to consumer and family friendly services. It is important to remember, as illustrated by the demographic data, that each pilot is unique; the pilots serve people with differing characteristics, they use different designs for their support and fiscal systems, and they operate in very different physical environments. The pilot sites designed and managed the self-determination project according to their individual strengths and resources.

As the smallest regional center, Redwood Coast operated the pilot as a distinct entity, with new policies and procedures evolving according to the progress of the individual plans and budgets. The priority at RCRC was to replicate the self-determination strategies developed in New Hampshire and existing reporting and operating procedures were suspended or modified if they were in conflict with that priority.

RCRC recruited a new full time employee to coordinate the project and a full time Broker to work with 30 participants. A part time broker was hired later to help with developing the person-centered plans according to project timelines.

When participants signed up for the self-determination pilot, they maintained their relationship with their Service Coordinators because so many people had long-term relationships. The original design was to begin fiscal intermediary services in house and to outsource those functions later. This actually happened sooner than expected when it became obvious that the fiscal department did not have sufficient personnel to assume the additional duties required by the self-determination model. One company was hired to pay bills for participants and local employment agencies agreed to cover the employer of record function for staff hired by individuals.

RCRC began with each participant's person-centered plan and then the Project Coordinator worked with the person and the family to develop a draft budget. The draft budget was then compared with the person’s previous year expenses. If proposed budgets exceeded historical costs they were sent to the Budget Planning Review Committee. The Area Board and the local Project Steering Committee provided on-going support and direction to the pilot.

Stakeholders interviewed at RCRC are concerned about the future of the project as new allocations are not sufficient to cover the costs of the coordinator, brokers, and fiscal intermediaries. They are beginning to seek private funding to continue the project without additional regional center operating funds.

Tri-Counties Regional Center leadership wanted broad implementation of the pilot throughout the agency because self-determination was already being tested as part of the strategic business plan. The intent of this approach was to gather valuable information about how self-determination would work system wide. Existing personnel assumed project coordination duties and an in house fiscal assistant was assigned to conduct billing and accounting functions. The Fiscal Assistant developed a simpler package of forms to process payments for services through the pilot.

TCRC differed from the other sites in its decisions about service coordination. The administration wanted to test Service Coordinators' ability to perform both their typical case management functions and the new duties of service brokers. They also wanted a cross section of service coordinators to be trained in the principles of self-determination. Pilot participants therefore retained their existing service coordinators who continued to carry the average caseload of 62 people.

A key informant explained that service coordinators were not involved in the budget allocation process, in an attempt to avoid any conflict of interest between the roles of gatekeeper and advocate. TCRC used historical expenditures, as opposed to allocations, as the basis for individual self-determination budgets. Service Coordinators worked with participants and families to make creative decisions about how to spend the budget and they had access to a private consultant to help with individual cases.

Employer of record services were out-sourced to companies that were also contracting with ELARC participants. Key informants at TCRC reported plans to develop a pool of independent brokers to assist service coordinators with self-determination strategies. Broker services will be purchased through individual participant budgets in the future. They also plan to continue their emphasis on broad based training to educate more stakeholders in the successful strategies of self-determination.

The approach selected by the Eastern Los Angeles Regional Center fell somewhere in between those used by RCRC and TCRC. ELARC has a history of embracing pilot projects and chose to create a special unit for the project. An existing unit director was assigned to be Project Coordinator and one service coordinator was chosen to provide service to the 32 participants. ELARC hired a consultant to provide a self-determination overview to 95 service coordinators.

Several strong candidates applied for the position and informants report that many more were interested but were reluctant to give up serving the people on their existing caseloads. ELARC assisted the participants to develop a pool of ten independent Service Brokers to provide a menu of services according to individual choice. The cost of the Service Broker is currently paid for through ELARC's operations budget.

The ELARC fiscal department assumed responsibility for the accounting and billing functions of the Fiscal Intermediary. A key informant explained that they have made a great investment in self-determination by setting up an alternate accounting system for the pilot project, different than the standard Purchase of Service accounting system. Payment forms for personal services are submitted to ELARC, and then a check is cut to the fiscal intermediary who pays the person and assures payroll deductions. The local Advisory Committee supported this process so that ELARC will be prepared to provide this service to more people should self-determination expand. Shorter and simpler forms for payment have been created with different check cutting and tracking systems. Sample contract templates were developed for families and vendors.

The individual budget amounts were set by comparing prior year costs to the target group's aggregate mean to define a cost range, then the person-centered plan further defined the budget. Informants reported that finalizing the first budget usually involved three or four meetings but as participants know what to expect in subsequent years they may only need one meeting.

Employer of record duties were outsourced to an independent vendor and another vendor was added at the end of the project to provide choice to participants. ELARC also invested in a consultant to provide training for participants and brokers and hosts regular meetings for participants and interested parties to learn about self-determination.

Who participated in the pilot projects?

All three pilot projects selected participants through a random sample process because they wanted as much information as possible about how to implement self-determination for all people. COA received numerous comments about the selection process. Many stakeholders felt that the project would have proceeded more quickly if people who were already committed to the principles of self-determination were allowed to volunteer for the project. Another suggested option was selecting people who were known to be having problems receiving services in the traditional system. Finally, some respondents felt that the pilots should have selected people who had strong circles of support.

ELARC chose four specific culturally diverse groups from which to draw its sample. In addition, people were selected according to age, level of service need and ethnicity. It took almost two years to enroll 32 participants with the desired characteristics.

TCRC drew its sample from two groups of children and adults. A secondary factor for selection was residential arrangement (in or out of the family home.)

RCRC limited its random sample draw to Mendocino County. Selecting from the entire four county catchment area would have resulted in excessive travel time and costs for project staff. The 30 current participants and 2 waiting list people were selected from two draws of 100 people and a final draw of 50 people.

The following tables detail the characteristics of the participants in all three pilots. In the table below, the first column shows the average age of the Self-Determination participants in each of the Regional Center pilot sites "pooled," or combined. The remaining four columns show the average ages across the regional center pilot sites, including the Comparison group at the Eastern Los Angeles Regional Center (ELARC).

Average Ages of Participants, Broken Down by Regional Center Pilot

	SD Participants	TCRC	RCRC	ELARC	ELARC Comparison
Age	25.4	26.6	31.3	18.9	27.9

These variations were not significant by Analysis of Variance or Kruskal-Wallis nonparametric tests.

The average age of participants varied from just under 19 years of age to almost 32 years. The age differences among the Regional Centers were not statistically significant.

The table below shows the breakdown in gender for the Self Determination participants and the ELARC Comparison Group, showing the percentage in each group who were male.

Gender Breakdown by Pilot Regional Center:
Percent Male

	SD Participants	TCRC	RCRC	ELARC	ELARC Comparison
Number of Males	45	12	17	16	9
Percent Male	71.4%	63.2%	81.0%	69.6%	64.3%

These variations across the RCs were not significant by Chi-Square and other nonparametric tests.

All groups were more than 60% male, and the variations across the Regional Centers and Comparison Group were not statistically significant by nonparametric tests.

The next table shows the Ethnic Breakdown across all the groups. This table is useful to see if there are differences in the concentrations of ethnic groups in certain Regional Centers and also to see if the ethnicity of the participants is distributed in the same manner as the ethnicity of the Comparison group.

Ethnic Breakdown by Pilot Regional Center

	SD Participants	TCRC	RCRC	ELARC	ELARC Comparison
Caucasian	54%	68%	81%	17%	29%
African-American	2%	5%	0%	0%	0%
Hispanic or Latino	33%	26%	10%	61%	50%
Native American	3%	0%	10%	0%	0%
Asian	8%	0%	0%	22%	21%
Other	0%	0%	0%	0%	0%

These variations across the RCs were highly significant (p<.01) by Chi-Square and other nonparametric tests.

The largest percentages of Self-Determination participants in the Tri-Counties and Redwood Coast Regional Centers were Caucasian, while in both ELARC groups the largest percentages were Hispanic or Latino. These variations were highly significant by Chi-Square and other nonparametric tests. This difference makes sense because ELARC purposefully drew a sample that would reflect the cultural diversity of its general population.

The table below shows the differences in the distribution of labels of mental retardation across the Self Determination participants as a group, the participants broken out by Regional Center and the Comparison group. The consumers were grouped into six levels of diagnosis ranging from “Not Labeled with Mental Retardation,” to “Profound Mental Retardation.”

Level of Mental Retardation Label (If Any) by Pilot Regional Center

	SD Participants	TCRC	RCRC	ELARC	ELARC Comparison
Not Labeled	25%	11%	45%	19%	44%
Mild	30%	47%	15%	29%	33%
Moderate	7%	16%	0%	5%	11%
Severe	8%	5%	10%	10%	0%
Profound	12%	16%	5%	14%	11%
No Level Assigned	18%	5%	25%	24%	0%

These variations across the RCs were not significant by Chi-Square and other nonparametric tests.

For the most part, results were consistent from Regional Center to Regional Center, and even between the Self-Determination participants and the ELARC Comparison Group. The variations noted were not statistically significant by nonparametric tests. Most respondents answered either “Not Labeled with Mental Retardation,” or “Mild Mental Retardation.”

The table below shows the types of participant living situations. We collapsed all answers into three broad categories: “Group Home,” “Supported or Independent Living,” and “With Family.”

Living Situations of the Participants by Regional Center Pilot

	SD Participants	TCRC	RCRC	ELARC	ELARC Comparison
Group Home	0%	0%	0%	0%	0%
Supported or Independent Living	27%	36%	35%	11%	18%
With Family	73%	64%	65%	89%	82%

These variations across the RCs were not significant by Chi-Square and other nonparametric tests.

The largest percentage of participants lived “With Family.” Any variations across the Regional Centers, and between the Self-Determination and ELARC

Comparison Group, were not found to be statistically significant by Chi-Square and other nonparametric tests.

The table below shows the percentages of people reported to have a "Major Disability" other than mental retardation.

Percentages of People Reported to Have Secondary "Major Disabilities" by Regional Center Pilot

	Combined SD Participants	TCRC	RCRC	ELARC	ELARC Comparison
Ambulation	24%	26%	5%	39%	21%
Autism	10%	16%	0%	13%	29%
Behavior: Aggressive	5%	5%	10%	0%	14%
Behavior: Self Abusive	5%	0%	5%	9%	0%
Brain Injury	8%	0%	15%	9%	14%
Cerebral Palsy	19%	16%	15%	26%	21%
Communication	34%	53%	10%	39%	36%
Dementia	3%	0%	5%	4%	0%
Health Problems	12%	0%	10%	22%	14%
Hearing	7%	17%	0%	4%	7%
Mental Illness	7%	6%	5%	9%	0%
Physical Disabilities	16%	22%	5%	22%	7%
Seizures	13%	11%	20%	9%	14%
Substance Abuse	2%	0%	5%	0%	0%
Swallowing	7%	11%	0%	9%	21%
Vision	10%	16%	0%	13%	0%
Other Disabilities	13%	0%	13%	14%	18%

The two most frequently reported areas of secondary "Major Disability" among all Self Determination participants were "Communication" and "Ambulation." In the ELARC Comparison Group, the two secondary disabilities with the highest percentages of people with reported "Major Disabilities" were "Communication" and "Autism." Tri-Counties Regional Center had the highest levels of respondents experiencing major problems with “Communication” “Ambulation,” “Physical Disabilities” and “Hearing.” At Redwood Coast Regional Center the highest reported percentages of secondary disabilities were “Seizures” and “Brain Injury,” “cerebral Palsy,” and “other.” ELARC had high percentages of people with “Communication,” “Ambulation,” “Cerebral Palsy,” “health Problems,” and “Physical Disabilities.” The Comparison Group reported the highest levels of secondary disability due to “Communication,” “Autism,” “Ambulation,” “Cerebral Palsy,” and “Problems with Swallowing.”

The percentages of people with a guardian or conservator are shown in the table below. The possible responses have been collapsed into two categories: “No Guardian” and “Guardian or Conservator.”

Guardianship/Conservatorship Percentages by Regional Center Pilot

	SD Participants	**TCRC**	**RCRC**	**ELARC**	**ELARC Comparison**
No Guardian	42.9%	42.1%	66.7%	21.7%	28.6%
Guardian or Conservator	57.1%	57.9%	33.3%	78.3%	71.4%

These variations across the RCs were not significant by Chi-Square and other nonparametric tests.

The majority of respondents reported that they have a guardian or a conservator except at RCRC.

According to Arndt (1981), the best way to treat behavior instruments is as two simple additive scales, one reflecting adaptive behavior and the other challenging behavior (see below). The following table addresses the question, “Are people better off in terms of being able to do things for themselves?”

Changes in Adaptive Behavior Scale Scores by Regional Center Pilot

Group	Time A	Time C	Change
TCRC*	62.0	65.8	3.8
RCRC	81.5	74.2	-7.3
ELARC	56.4	57.3	0.9
ELARC Comparison	64.6	67.8	3.1

* Indicates statistical significance at the .05 level.

When examining the overall adaptive behavior scale scores by Regional Center Pilot site, we see that the increase in the scale score is statistically significant only for the Tri-Counties site. The increase shows statistical significance using both parametric and nonparametric tests.

Changes in Adaptive Behavior Scale Scores by Participants and Comparison Group

Group	Time A	Time C	Change
Self-Determination Participants	66.1	65.2	-0.8
Comparison Group	64.6	67.8	3.1

Looking at the changes in Self-Determination participants and the Comparison group (the people at East Los Angeles Regional Center who were not participating in Self-Determination), there were no statistically significant differences between the two groups when we compare the changes in Adaptive Behavior scores from Time A to Time C using parametric and nonparametric statistical tests. In other words, there was no change.

The Challenging Behavior scale is complementary to the Adaptive Behavior scale. It is composed of 14 items detailing various maladaptive behaviors. The table is based on a 100-point scale, with higher scores indicating less challenging behavior. For example, a person whose score is 100 is understood to have no maladaptive behavior. The results of the comparison of scores on the Challenging Behavior scale from Time A to Time C are shown in the table below.

Average Challenging Behavior Scale Score by Regional Center Pilot

Group	Time A	Time C	Change
TCRC	84.4	88.1	3.6
RCRC	92.6	93.0	0.4
ELARC	82.8	84.4	1.6
ELARC Comparison	84.2	89.6	5.4

Although each group improved slightly (higher scores are positive), none of the changes were significant.

Average Challenging Behavior Scale Score Changes: Participants and Comparison Group

Group	Time A	Time C	Change
Self-Determination Participants	86.3	88.2	1.9
Comparison Groups	84.2	89.6	5.4

Analysis revealed no significant differences between the Self-Determination participants and the Comparison Group on changes in challenging behavior scale scores, using both parametric and nonparametric statistical tests.

The question of whether the participants are “better off” in terms of reduced challenging behavior yielded neutral results; there were no changes.

Why did people want to participate?

The reasons for deciding to participate in the pilot are as varied as the participants themselves. Key informants speculate that some are natural pioneers or risk takers and eager to try something new. Others had just about given up on getting what they need from the traditional system and were willing to take one more chance. Many were attracted by the concept of personal control and authority. Several respondents explained that many people were hesitant to participate because of additional responsibilities, but that education about the process and information about how it could make their lives different convinced them to sign up. Finally, the general impression is that most participants trusted the advice of Regional Center staff that they have known for years. Individual responses to this question are listed below.

Answers to "Why We Decided to Take Part in Self-Determination"

Wanted more control / choice over his money
Father felt self-determination would enable her to create a more "personal" program.
Wanted to control his own life more -- get away from agency and work with best friend.
His care provider brought him to the meeting.
His mom heard about it and advised him to participate.
We thought it would help us better choose the caregivers and supportive devices that he needs.
Concerned that RC was going to get away from speech services -- went to a meeting in San Luis -- thought we'd have a better chance of funding speech therapy.
Her mother (conservator) was asked if she wanted to participate.
To enable funds to be tailored personally for his benefit.
Because it helps me out and I've been able to get creative and find ways to spend funds to assist in being more independent.
Suggested -- (told to participate).
Because it was a unique opportunity to be part of trying something new out -- having the control to get things done quicker.
Enables money to be directed to personal goals.
Because it's a great way to decide what's best for my child and I can use the money appropriately for her special needs.
I wanted to see what we could do to improve her life. But I still think it is RCs job to find services and supports.
Meet new friends, people – I am in charge now.
Do anything to help her.
Very reasonable idea // "person center" // more options, more control.
Met his needs.
To try it.
Offered new program // more options.
Fun, able to make own choices, different.
More options, wanted to start own business.
I like the program // more options.
No other programs working for him.
More options / do what he wants to do.
She was offered more options, more opportunities.
Sign of times / everything has changes / more options.
Getting upset, better to get out and get house for peace and quiet.

Maybe could really help him // more involved, more input // but still have last say.
Learn to manage own money and be independent.
Need to make some money. Might need to help starting own business.
More options to help my son.
Because they asked her what her dreams are.
$10,000 budgeted --> bicycle - 3 wheel.
Improve myself / "upgrade".
It seemed worthwhile to participate.
She wanted to be in control of her money // she also wanted to get help and the normal vendor system was not working.
I was not happy with service provider. Even though we put in the IPP what we wanted, it took forever to get or it simply was not in the budget. He is happy to have his freedom.
He won the toss with the computer -- so he said yes.
Believed that I could receive better services and become more independent with resources allocated to her.
It's important because it gives the individual more control of their lives and allows him to be himself and strengthens his character.
Gives him great flexibility, outside of day program. He now has a personal assistant 2 days a week. This is making a difference in his personality. This was not an option under the regular regional center rules.
I had no freedom to hire/fire whoever/whenever I wanted. I could buy stuff outside I needed that I wasn't able to afford before. It is a lot cheaper for the taxpayers. Because if I wasn't in the pilot program, I would have to use aid.
I am always looking for new therapies. Regular program is very difficult to get services. This way I have more freedom to make decisions for him.
I like the philosophy behind the person-centered project. You have freedom, authority and responsibility. We can set up our own plan.
Best use the money to the person's needs, because I live with my son every day and serve him every day; I know what he really needs.
They thought it would make taking care of his needs. During this time he moved into a group home and away from the family home.
Because when they explained what the project was, I thought it would be easier to get started with his services all around.
Because we were chosen; we had more services than before.
We wanted to tread new ground and see what benefits we could acquire through different approaches. Having to use only the vendors authorized through regional center wasn't optimum.
I know what her needs are and the regional center doesn't.
The freedom. I didn't have the freedom to change services or even create a new service.
Better opportunities to see what's out there.
Because I saw that there were a lot of advantages financially for her.
I can choose the service that my son really needs and best use of the money and it's relatively flexible to use the money.
To have flexibility. My son is high functioning and a lot of traditional vendored services not appropriate. Want to choose people to work with him, not have them assigned.
Because he wanted to become involved in everything having to do with him; to have more responsibilities and cooperate more.
Because I was randomly chosen and I was just called.
Because it caught my attention.
The person is eager to take part in self-determination program, but he is not enrolled in the program.

How did patterns of support change as a result of participation?

Patterns of support have changed. Several key informants reported that the individual attention of brokers and the budget setting process has resulted in some people realizing that they are eligible for additional services. In many cases the new kinds of support could have been purchased in the traditional system but it took the one to one broker support available through self-determination to make them a reality. Some respondents feel that others are utilizing former services at a higher rate because they have choices about schedules and personnel. Many of the professional staff we interviewed discussed their initial concern about what people would want and if it was possible to meet their wishes.

Many people, especially in the first year of participation, stayed with their existing services. The only thing that changed for them was the empowerment that came from the planning and budget process and their new responsibilities for record keeping. Others immediately left traditional services and hired their own staff or designed their own programs. What has changed for everyone is the details of supports and participants' feelings about how they choose, maintain, modify and change supports.

As part of the family survey, people were asked, *"Were there things or services or supports that you and your relative have been able to purchase via self-determination that you probably could not have gotten otherwise?"* Their answers, listed in the table below give details of the kinds of new services people purchased.

Examples of Flexible Purchasing

1	I rebuilt the bathroom for my son and it's more comfortable for him to take a shower now and he went to an art show for disabled persons to learn drawing.
2	I bought a computer through self-determination and I also wanted to buy a portable laptop as a communications device for my son.
5	Wheelchair lift for van. Probably saved dad from serious back injury.
6	Control of budget, get things (like a bike) that suit her needs better.
7	Personal advocate. Piano lessons. Voice training. Piano lessons. Help her concentrate and focus. Also, increase self-esteem.
8	Yes. Voice training and a personal advocate. Also, the assisted technology. Voice: it is a gift she has. It has enabled her to get involved in community and for community to accept her. The personal advocate is helping with school issues.
9	Replaced refrigerator/washer/stove. The appliances were old and broken. {Provider} would not have been able to provide that.
10	I get to go wherever I want, whenever I want because I have the freedom to control staff. Before the staff wouldn't support me and didn't respect my right.
11	One-on-one counselor: He enjoys seeing him, rather than seeing an appointed individual.
12	Sexual education: in the past year, there were two instances of inappropriate touching. I don't know how to deal and needed help. The class hasn't started yet. Med respite: I had surgery and needed help caring for him during recovery.
13	Durable medical equipments. He needs it and I have to go through so much to get certain equipment.
14	Not really. I have the same things.
15	Dental coverage outside of what is insured.
16	Computer. They would not have otherwise received. Helps with learning efforts.
17	A swing because he loves it since he was younger. That's his passion. I was as happy and as excited as he was when he got it.
18	He selected and bought his own bedroom set.
19	A stroller because it's higher than the wheelchair and easier to move her around.
20	Medicine.
21	Swing-set // swimming lessons.
22	With some unused funds from day program category, he was able to buy “HEPA” filters for his house to help with his allergies. This would not have been possible with the regular funding model.
23	They were probably there -- but now I am more aware of what is available.
27	Received funding for immigration papers, in order for him to become legal. He already has a social security number and is getting help with his legal residence here in the US.
28	Can't think of any.
29	Wheelchair -- but it's broken again.
30	Special wheelchair.
37	No changes since self-determination.
39	Reading interventions: a new computer and software to assist in his cognitive growth as well as recreation and leisure.

40	Her swing -- it's made for someone with special needs - bought for movement -- gives her pleasure and movement is good for her.
41	Only a few more respite hours than we had before.
42	Physical therapist, musicians coming to house. Trained the family, gave him relief and more mobility, strength. Increased interaction with family.
43	Art therapy -- would not have thought about it before as tool for lessening anxiety. Computer -- he is getting programs up, running and reading through it.
44	Someone to do fun things with in the community and travel.
45	Right to hire and fire. Flexibility to go to a farm.
48	Funds to go to driver's school, guitar lessons will be available but we just started.
49	Computer – helps with communication; concert tickets; 2 cd's
51	Swimming pool and spa. My son was asked not to come back to health club because of his behavior, but he needs to lose weight.
52	Golf cart to get around on.
53	Going to see Randy Travis // guitar lessons // My son is very interested in music.
55	For him to live in Ft. Bragg where his needs can be met.
58	Would have used private funds if program not available. Respite worker a "god-send"!
64	Equipment: we bought a feeder seat. Before, she was sitting in an infant carrier, which she has grown out of. The feeder seat provides more comfort. She can eat, exercise, etc., in it. Also, it's a lot easier to move than her chair.
65	Dental services. The insurance and regional center would not cover private dentist; had to go through state mental hospital. She had teeth cleaned with anesthesia.

These examples illustrate the wide variety and the high degree of flexibility in individually determined purchasing within the self-determination pilots.

Degree to which participants feel in control of their lives.

Almost every person interviewed by COA commented on the enthusiasm of the participants and their joy in being responsible for life decisions. The individual stories included in this report all highlight the benefits of control. One vendor described a mother's feeling of empowerment as she and her son came in to directly negotiate service changes. Prior to self-determination the request would have been channeled through a regional center service coordinator and may not have addressed all their priorities. In addition to such qualitative information about control, COA examined the California participants' feelings of control through quantitative methods.

The Decision Control Inventory 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 hold all power, and 10 meaning that the focus person (and his/her freely chosen unpaid allies) hold all the power. A score of 5 or 6 means that power is shared about equally. The 35 “0-to-10” scores can be combined into a single scale which we compute so that it can range from 0 to 100, with higher scores meaning more individual control over life choices and less professional domination. The following table shows changes in the scores on the Decision Control Inventory from “Then”, before self-determination, to “Now” or after self-determination began.

Changes in Decision Control Inventory Score
By Regional Center Pilot

Group	Then	Now	Change
TCRC*	78.3	83.5	5.2
RCRC*	85.9	95.6	9.7
ELARC*	83.8	85.0	1.2
ELARC Comparison	77.3	77.5	0.2

* Indicates statistical significance at the .05 level.

Participants in all three pilots significantly increased the power held by themselves and their allies. Members of the Comparison Group did not. This finding indicates that the first tenet of self-determination, power shifting toward people and their allies, was confirmed. The finding was strengthened by the lack of significant change in the Comparison Group. This finding is summarized in simpler form in the following table.

Decision Control Inventory Score
By Participants and Comparison Group

Group	Then	Now	Change
Self-Determination participants**	82.9	88.2	5.3
Comparison group	77.3	77.5	0.2

** Indicates statistical significance at the .01 level.

The overall power shift of about 5 points on our 100-point scale was about as large as we saw in the original self-determination demonstration in New Hampshire. In that pilot, in the mid-1990s, we documented a power shift of about 4 points. California's 5-point shift places its pilots among the states in which real power shifts have been measured.

What differences in types and amounts of services?

Key informants reported that participants were doing more with the dollars and being more creative. Services were being purchased outside of the traditional service system. Interviews in all three regional centers included positive stories of people who left traditional supported living programs and are now successfully managing their own staff. One person commented that an obvious change is people being able to schedule their hours according to their needs, especially evenings and weekends. We also heard of several cases where families were bringing staff into their homes instead of utilizing traditional day program services. For example, one broker arranged for people to get pedicures at a local salon in place of more expensive visits to the podiatrist. This was of course for people who were only going to the podiatrist to have their nails cut. These kinds of changes are clear indicators of increased freedom and authority for the participants.

The best way to gain an understanding of the differences in services and supports that have been made available to the self-determination participants is to review the person by person matrix of services and supports found in Appendix D. This matrix was prepared by the pilot Project Coordinators and shows each person's authorized supports in the year prior to self-determination and then in each subsequent year. The general pattern to be observed is movement away from clinical and aggregate kinds of programs toward more generic, creative, and hopefully more meaningful services that were selected by the participants and their allies.

What resources did participants put together to achieve self-determination?

Informants told us that participants were using old and new resources to implement their services. Many had hired staff from their former service vendors, others are trying to start their own businesses. One man had established a commercial Internet site and the consultant he hired to help with web design is now a valued member of his circle of support. We also heard positive reports of participants accessing opportunities to attend conferences and self-advocacy meetings. A vendor we interviewed commented on the fact that the independent brokers got things done much more quickly for people. All three pilot sites provided forums for participants and families to get together and share information and concerns. Key informants at ELARC and TCRC talked about the advantage of access to a consultant for person-centered planning and creative budgeting. The most important resources that people used to implement services were the family, friends, and staff who make up their circles of support. A person's plan is the best place to look for the numbers and kinds of people and resources they are using.

In the case of the pilots, COA used the "Elements of the Planning Process" scale to quantify the information received from the participants. The average scores on the 16 items provide a quick and reasonably accurate look at how the planning process took place across the pilot sites. This scale ranges from 0 to 100, with a higher score indicating a higher degree of "person-centered planning." The average scores across Regional Center pilot sites, as well as overall for the Self-Determination participants "pooled" and for the Comparison group are shown in the following table.

Average Elements of the Planning Process Scale Score by Regional Center Pilot

Group	Time A	Time C	Change
TCRC	78.2	76.0	-2.1
RCRC*	70.5	97.9	27.4
ELARC	72.0	75.0	3.1
ELARC Comparison	61.9	66.9	5.0

* Indicates statistical significance at the .05 level.

Analysis of the changes in Elements of the Planning Process scale scores for the participants at the three Regional Center pilot sites and the Comparison group showed that TCRC, which had the highest score at Time A, registered a non significant decrease, in other words, no change. The other groups showed increases but only the increase at RCRC was statistically significant, using both parametric and nonparametric tests. This indicates that person-centered planning has been increasing and becoming more effective within two of the pilots, and among the Comparison Group members, which suggests that the entire developmental services system may be moving in that direction. The change at Redwood, however, was dramatic, and may provide evidence of how much can be achieved in a short time with the proper leadership, attention, and training.

Average Elements of the Planning Process Scale Score by Participants and Comparison Group

Group	Time A	Time C	Change
Self-Determination Participants*	73.0	83.4	10.4
Comparison Group	61.9	66.9	5.0

* Indicates statistical significance at the .05 level.

Analysis of the changes in Elements of the Planning Process by participants and the Comparison group showed that average scores for the participants increased significantly (up 10.4). Thus the average self-determination participant experienced significant enhancement of the person-centered planning process, while the average Comparison group member did not. Again, the bulk of the positive change came from Redwood Coast's efforts, which sharply increased person-centered planning, according to our evidence.

How were conflicts and disagreements among players resolved?

The table of organization for the pilot project included the Statewide Steering Committee, the pilot Regional Centers and Area Boards, and the local Advisory Committees. There was no formal hierarchy or chain of command for decision making or project regulations. Key informants from all levels of the project commented on the sustained enthusiasm and the commitment to the principles of self-determination that were the foundation for project decisions.

The Statewide Steering Committee hosted regular meetings for project updates and to discuss strategies. Task forces were developed in response to specific issues such as the interfacing with UFS, Social Security, Medicaid, etc. The Project Coordinators held monthly conference calls that according to all reports were both informational and motivational. Many respondents commented on the high level of communication throughout the project. One key informant stated that the project is run by consensus.

We received many references to the high level of commitment from the Area Boards, Regional Center administrators and fiscal staff. Individual pilot sites developed their own internal procedures for decision making and problem resolution, but all were informal and based on a commitment to the experimental process and the quality of life for service recipients.

What strategies were used to achieve desired outcomes?

One key informant stated that the step-by-step process for self-determination is to 1) engage stakeholders in discussions about their needs; 2) educate them on the values and principles of self-determination; 3) develop trust through on going dialogue; 4) only then move on to honor individual participant wishes through the implementation process. The pilots followed these steps, beginning with broad based dissemination of information about the pilot projects and the principles of self-determination. Brokers and or service coordinators began with participants' existing person-centered plans and worked to develop and expand circles of support to help the participants to more clearly articulate their desires.

The Service Broker at RCRC found that a good starting point for many participants is to do a little research on their dreams. She does not use an agenda or particular format for the planning process as she feels it empowers the participants and families to identify their own priorities, strategies and desired outcomes. This process lets her get to know the people as she coaches them in technical skills like leading meetings.

A unique strategy used at TCRC was to have the Fiscal Assistant provide technical and on-call assistance to the participants, oversee the use of TCRC operations dollars for the pilot, and help to provide internal consistency between

TCRC's fiscal, case management and resource development departments and functions. Informants at TCRC related the benefits of having one person to coordinate these important operations. A second strategy used at TCRC was to provide a person-centered planning consultant to work with participants who did not have strong circles of support or family ties.

The ELARC Project Coordinator explained that they use the monthly self-advocacy group meeting for parents to hear first hand what can be accomplished. They also convene an internal self-determination team meeting, typically each month, attended by representatives of various agency departments including finance, case management, resource development, training and executive management. These meetings provide agency wide updates in the pilot and serve as a forum for cross department questions and issues. Finally, the training department at ELARC put together a Resource Guide of services available for purchase through the regional center, including new services that are being used in the self-determination project.

All the pilot projects found it necessary to provide training with participants, service brokers, and service coordinators in filling out the budget and accounting forms.

How do the policies, procedures, and practices of participants, DDS, pilot projects, vendors affect these outcomes?

The enabling legislation for this pilot purposefully allowed great latitude with regard to policies and procedures. Key informants from DDS, Regional Centers, Area Boards, and Vendor Agencies remarked on the wisdom of this approach, as they did not think that most of the successes could have been accomplished within traditional guidelines and procedures. The policies and procedures for service eligibility remained the same and all participants were required to sign a participant agreement. Other universal policies were that services be related to a person's disability, that nothing illegal was permitted, and that no harm should come to any participant. Within those broad parameters, Regional Centers were free to develop their own policies and procedures to implement the pilots in accordance with local needs and practices.

A Regional Center fiscal manager reported that everyone had been very supportive about "bending" procedures as long as the goal was in alignment with the vision and values statement. Although initially hesitant, she eventually understood that working outside the Medicaid and Title 17 rules would provide immediate benefit to participants and identify roadblocks for expansion of the project.

One respondent suggested a guide for parents, detailing their responsibilities, for example the need to update the purchase authorizations when changes are made in the personal plan. A service coordinator reported that one really positive aspect of the pilot was that working outside the traditional rules made her think more about how to develop the same kinds of services for people who are not in the self-determination project. She explained that she and her colleagues often question whether certain strategies only apply to people in the pilot or if they can be used for everyone.

A key informant at TCRC discussed a problem with amending Individual Program Plans (IPPs) every time participants made new decisions about how to spend their funds. The solution to this problem was to remove the budget line items from the IPP document, thus reducing paperwork for everyone involved.

The flexibility offered through the pilots was the source of many comments. One participant changed his health goal from membership in a health club to buying a treadmill for his home. Participants felt they could make things like this happen because there were no rigid procedures for the project. One service

Vendor reported that the contracts for the self-determination participants were processed more quickly than his traditional contracts and that the billing forms were actually easier to use.

The major procedural issue that came up over and over again in our interviews was the problem with individual budget start dates and fiscal year reporting. This issue resulted in the fiscal departments doing much of the self-determination budget tracking by hand. Each pilot dealt with the problem in its own way but it is a major technical piece that needs to be addressed prior to wide scale expansion.

Do the demographic, circle of support, locus of control, and service need characteristics of participants affect these outcomes?

Most of our respondents were in agreement that all of the factors listed above affect outcomes but that it is just about impossible to link factors directly to specific outcomes. ELARC made a special point of selecting a sample that would reflect the cultural diversity of its service population and include a sub-sample of children with autism, thereby acknowledging the importance of demographics and service need characteristics. One respondent mentioned that where people live in Los Angeles makes a big difference in what they will get and even in what they think they can get.

Several respondents reported that families who understood the system prior to self-determination or who had more active brokers or service coordinators took most advantage of the opportunities offered by the pilots. In reference to the locus of control, one respondent congratulated her pilot staff for their accessibility. She felt that services were put in place very efficiently because there were no long waits for meetings, decisions or next steps.

The Quality of Life scale addresses 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 before becoming involved with self-determination and during involvement with self-determination efforts. If the respondent did not have first hand knowledge of conditions prior to self-determination involvement, 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.

The table below shows the results of the analysis of peoples' perceptions of the quality of their lives from "Then" to "Now" at Time C.

Perception of Quality of Life From "Then" to "Now"
By Regional Center Pilot

Group	Then	Now	Change
TCRC*	70.0	80.3	10.3
RCRC*	71.3	86.0	14.7
ELARC*	66.7	77.8	11.1
ELARC Comparison*	69.6	78.0	8.4

* Indicates statistical significance at the .05 level.

On this measure, respondents' ratings of the quality of their lives from "then" to "now", the participant groups at all three Regional Center pilots and the Comparison Group showed statistically significant increases. This is a very positive finding, indicating that everyone involved in the pilot projects felt that the quality of their lives improved during the implementation of self-determination.

The table below shows a comparison of the quality of life change scores for the self-determination participants as a group and the Comparison Group.

Perception of Quality of Life From "Then" to "Now"
By Participants and Comparison Group

Group	Then	Now	Change
Self-Determination Participants*	69.2	81.3	12.1
Comparison group*	69.6	78.0	8.4

* Indicates statistical significance at the .05 level.

As in the table above, both groups showed statistically significant increases in their perceptions of quality from "Then" to "Now" at Time C.

What other factors affect these outcomes?

One Regional Center Administrator discussed the importance of provider relations. He described the new process of helping and encouraging providers to develop creative and customized services when everything the regional centers required before was about staying within well-defined boxes. He intends to work on this dilemma and provide technical assistance although he suspects that the good providers will make the transition easily.

A final factor that affects outcomes is personal leadership. Respondents from all pilots and at all levels referenced the commitment and work of individual stakeholders in really making the pilots work.

What are the costs and cost benefits of the pilot project models?

The consensus of opinion on cost is that it is always expensive to operate dual systems and that we probably need more time to actually determine the cost implications of self-determination. Informants report increased costs due to previously unidentified needs and the flexibility to spend funds in different ways. However, one respondent stated that actually providing people with what they need is less expensive in the long run.

One Project Coordinator felt that the costs of operating the pilot are high because of the time and effort in developing new systems but that the impact on purchase of service costs is negligible.

A Service Vendor suggested that a cost benefit to the project is that individuals have the chance to negotiate lower service rates rather than being locked in to the rates set by the Regional Centers.

How do these compare, individually and on an aggregate level, with pre-self-determination costs?

Please refer to the section of this report entitled, Results 2: Cost Analysis.

Do the actual costs of services to regional centers and providers change?

It was difficult for our respondents to separate the costs of running a dual system during the pilot project with the actual cost of providing services through a self-determination model. Many spoke to the high administrative costs involved in tracking individual budgets, providing technical assistance to families, and increased training opportunities for staff. There was also reference in several interviews to the additional meetings and related staff time involved in crafting a self-determination model, person-centered plan and budget. Although these factors increased costs, at least for the pilots, most respondents feel that it is worth the up front expense to enhance quality of life and shift power and responsibility to consumers.

Most Service Vendors we talked to reported that their costs will stay the same until there are a greater number of participants who are looking for customized services. One Vendor reported losing money because she did not change her family contract rates when she received a rate increase from the Regional Center.

How are funds being used in self-determination and how is that different/same from previous utilization?

Respondents report that because many consumers have decided to use services outside of the established service system, Vendors have to get used to the person making the service agreements. They have to learn to negotiate and communicate with the person and the family, not the Regional Center staff.

One Project Coordinator explained that many people retain their former services for the first year and then as they become more comfortable with decision making, they begin to consider changes in their day programs or living arrangements. She also noted that most of the people who were receiving money management services have stayed with that service.

A Fiscal Administrator told us that she still has concerns about fiduciary accountability and the appropriate use of taxpayer dollars, even though the great majority of purchases have been within acceptable guidelines. She worries that as the project expands it will be more difficult to monitor spending.

The table below shows the results from our quantitative data. Participants were asked to tell us what percentage of their individual budgets they spent in seven specific categories.

Percentages Spent in Seven Categories

Percent	Category
15%	Housing (including rent, mortgage, utilities, food, household supplies, etc.)
38%	Personal support in the home (staff, personal care attendants, home health aides, support coordinators, etc.)
3%	Transportation of all kinds
26%	Supported work, education tuition, adult day activity, community experience program
8%	Therapies (psychological, physical, occupational)
5%	Recreation, entertainment, vacations, buying leisure items such as televisions, stereos, exercise equipment, or luxuries
6%	Other

Within the self-determination rubric, the largest percentage of individual budget expenditures was in personal support in the home. The second largest percentage of expenditures was in the area of day activities, suggesting that people attempted to purchase opportunities for engagement and meaningful activities.

How do these costs and cost-benefits compare with a comparison group not participating in the pilot project?

Please refer to the section of this report entitled, Results 2: Cost Analysis.

What are the similarities and differences in costs?

Please refer to the section of this report entitled, Results 2: Cost Analysis.

Describe the development, implementation, and administration of the pilot project model(s) that best met the following conditions

As noted previously in this report, it is not possible to directly compare or rate the efforts of the three pilot projects because they were designed to be totally different. Although we can report the differences in their strategies, techniques, and operating procedures we cannot directly relate those differences to participant outcomes. There are just too many variables.

The ELARC Advisory Committee directed staff to meet with families, talk with them about creating a reasonable budget, and to have good reason for an expansive budget. We did what they advised, and it worked well. Our parent representative was very concerned about the participation of Asian American families. That concern led us to have a focus group with Asian American families to understand their perspective and to build self-determination in a way that works for them.

Key informants at the three pilot Regional Centers often referred to the Lanterman Act and their commitment to providing services in accordance with its values. In fact, we were told that the ELARC board decided to accept the offer from the Department of Developmental Services to be part of the self-determination pilot because they felt it would help the agency in implementing the Lanterman Act as well as ELARC's own mission. Another respondent explained that the Lanterman Act is all about working in partnership with people with disabilities to create life plans that lead them to outcomes to be part of the world they have a right to access. She felt that self-determination is a better and easier way for people to access their entitlements.

Embraced in the Lanterman Developmental Disabilities Services Act are the principles supporting the full inclusion of people with developmental disabilities into the mainstream of life in natural communities. A quantitative measure of compliance with the Lanterman Act is the frequency and quantity of participants' integrative activities.

COA's Integrative Activities scale is intended to measure how much opportunity for contact the consumer has with people without disabilities in the community in a typical month. The scale is comprised of 16 items, and asks how often the focus person typically goes to restaurants, shopping malls, civic events, churches or synagogues, and other types of community activities. The table below shows the average number of integrative activities per month across all types of activities listed for the groups at Time A and Time C.

Number of Integrative Activities by Regional Center Pilot

Group	Time A	Time C	Change
TCRC	28.8	43.6	14.8
RCRC*	55.1	80.6	25.5
ELARC	45.3	39.0	-6.3
ELARC Comparison	44.5	31.1	-13.4

* Indicates statistical significance at the .05 level.

Analysis of changes in the total number of integrative activities per month across the four groups showed that Tri-Counties and Redwood Coast showed increases from Time A to Time C; however, only the increase at Redwood Coast was statistically significant. The East Los Angeles group showed a 6.3-point drop in the total number of integrative activities per month from Time A to Time C, although this drop did not achieve statistical significance using either parametric or nonparametric tests. The East Los Angeles Regional Center Comparison Group dropped over 13-points in the number of integrative activities per month, but this drop also was not statistically significant.

The average number of integrative activities per month for the self-determination participant group as a whole and the Comparison Group are shown in the table below.

Number of Integrative Activities by Participants and Comparison Group

Group	Time A	Time C	Change
Self-Determination participants*	43.7	54.0	10.3
Comparison group	44.5	31.1	-13.4

* Indicates statistical significance at the .05 level.

Between the Self-Determination participants as a group and the ELARC Comparison group, analysis revealed a significant increase of over ten integrative activities a month for the participants in the self-determination pilots. The average number of integrative activities a month for the Comparison Group decreased from Time A to Time C, however this decrease was not statistically significant using either parametric or nonparametric tests.

The question "Are the participants better off in terms of getting out into integrated activities?" must at this time be answered with a cautious "Yes." At two sites, there were large increases, at one site a modest decrease, and in the Comparison Group a non-significant decrease. These results were mixed but overall the findings are positive as the increase in integrative activities for the Participants as a group was large and was statistically significant. This positive finding is strengthened somewhat by the fact that no change was observed among the Comparison Group members.

In accordance with the spirit of the Lanterman Act, we ask each participant, "If you had one wish, what would you wish for?" The responses are often as intriguing as they are revealing. The responses are shown in the table below. Our Visitors recorded these responses verbatim. Names and other identifying items have been removed where necessary to maintain confidentiality. Also, we do not report these data by Regional Center to minimize the risk of individual comments being identified. Again we offer no commentary on these responses, so that readers may form their own impressions. In general, though, it may be interesting to look for evidence of expanded wishes, greater aspirations, and/or broadened concepts of what a good life means.

"If you had one wish, what would you wish for?"

Time A	Time C
He would like to have his own dog some day.	Money but no work; does not want to work -- likes to just be at home.
	I wish I had a cure to make my diabetes better.
I would like to visit my nephew.	
Have a good steady job and a drivers' license.	To learn how to drive; to have a car!
Wish I could live by myself.	I would like to buy more cd's (music) with my self-determination money.
Wish I could afford a bigger apartment.	To own a car and to drive it.
Wish I could win the lottery.	I wish I could live in my own apartment and have support to live independently.
A yacht I could live on.	To spend more time with my girlfriend // to get married.
Move back in with my mother.	To continue to live in this house.
None	If I had a bigger budget, I could use it to buy more services like golf lessons and use it for college.
	Get married.
A new VCR.	See my daughter.
	Own house without stepfather.
I was on the NASCAR circuit.	Form my own NASCAR team .
	Be a millionaire.
	Better life and a hot tub
New case for my guitar.	Grand old Opry // Walton house.
I want to live in my own.	Go back to Disneyland and Knotts' Berry Farm .
	Go to Humboldt house.
	Live a long life.
Live out in the country.	Wish to live out in country and teach disabled kids how to ride horses.
	Go-cart.
A swing set.	
Drive in NASCAR.	Wish to live without back and foot pain.
Have my own house and a new car.	Buy my own home and give scholarships to individuals with disabilities and help kids through college.
To find a girlfriend.	A girlfriend, someone to talk to on the weekend.
Getting a lot of money to buy whatever I want.	
To have some fun, to live here.	I want money. I'd like to travel to Mexico and visit my relatives.
Best musician in the world.	I wish I could have some shoes.
Go to college.	A big house that I could live in with family and friends.
Can see better.	I wish to go to China to see the Olympic games in the year of 2008.
	Be in plays!

Get a job.	Magic pencil.
Can't think of one.	Own (navy jet) wart hog (jet).
Brother to not come home again.	I wish for a million wishes.
I forgot.	
Girlfriend.	
I would wish to walk.	Nothing; I have my own apartment.
	Not really able to state.
To go to a Disneyland hotel.	To go to Disneyland // to get married // to go into independent living.
To swim with the dolphins.	To swim with the dolphins.
I wish I had hamburgers.	I’d like to have an "RV".

Identify and discuss the pre-self-determination policies, procedures, organizational structures, professional relationships, etc., that changed, and those which did not change, for participants, regional centers, DDS, area boards, and vendors in order to successfully implement self-determination.

Key informants at DDS were in agreement that the pilot projects built on existing relationships to achieve their goals. They noted that all the Regional Center Directors have been very supportive in sharing resources and convening the local Advisory Boards. They were also appreciative of the joint conferences, training and technical assistance opportunities sponsored by Regional Centers and Area Boards. For example, the Area Board in Eastern Los Angeles shared the time of one of its Community Program Specialists to conduct vendor training and to assist in problem solving with vendors.

Respondents from the Area Board and the Redwood Coast Regional Center agreed that working relationships improved because consumer complaints were being resolved. All hope that self-determination will become available to a larger group of people and further enhance satisfaction. An Area Board informant felt that the Self-determination pilot’s role as a problem solver allowed the Area Board to work on more proactive and integrated community resource development (e.g. drug and alcohol and hunger and poverty issues.)

One fiscal manager that we interviewed felt that a real benefit of the project was that it forced fiscal and program people to work together and gain an understanding of how all their jobs impact peoples' lives.

Many respondents speculated on Vendors' reaction to the self-determination initiative. The general opinion as we heard it is that most were taking a wait and see attitude and hoping that it would not have a negative impact on their contracts, rates or workforce. We did interview several vendors who were providing services to pilot participants and most reported that the numbers were too small at this point to make a difference. One vendor did mention that he thought the paperwork and other responsibilities will be too burdensome for most families and that they will prefer to let agencies handle the administrative work.

Although the pilots were a small part of each Regional Center's operations, they seem to have had a large impact on attitudes. Respondents related many stories about families asking how they can join the project, service coordinators asking how they can support their caseloads in a self-determined way, sustained dialogue about the principles of self-determination, and a high level of interest in how it may expand and change the system.

Identify, assess, and discuss system level changes needed to readily and successfully improve and expand self-determination.

One respondent summed up the concerns about expansion by asking, "How do we make self-determination work in a system that wasn't designed for it?" The clear message from all respondents was that self-determination pilots have been a great experiment that have significantly changed the lives of the 90 participants, but how can it work for everyone? The major concerns and recommendations break down according to the following themes.

Accounting and Reporting:

Most respondents felt that self-determination can only expand if the stakeholders can find a way to modify standard system procedures for budget monitoring and reporting. The fiscal managers at each pilot related their concerns about the amount of staff time consumed by tracking individual budgets "by hand" and then trying to make them fit into UFS reports.

These problems are only amplified by the need to comply with IRS, Social Security, Wage and Labor and other regulatory systems. The Statewide Steering Committee has acknowledged this major issue and has formed a workgroup, composed of program, fiscal, and information systems personnel, to explore options for solutions.

Funding:

One administrator explained that the regional centers have been in a financial bind for the last ten years and that there really is no slack to assume additional costs. Key informants at all three regional centers raised concerns about the hidden costs of administering self-determination services. Additional fiscal staff, intensive training at all levels, new contracting procedures, and technical assistance are just a few of the categories that respondents identified. One administrator raised the issue of who pays for fiscal intermediary and broker services. Should these costs be part of the regional center operating budget or should they be assigned to individual budgets?

Individual Budgets:

Several informants suggested that DDS should issue guidelines for setting individual budgets prior to expansion. One key informant said that although it seems logical to base budgets on historical costs, that assumes that everyone has the resources to come up with a good plan within that range. Many stakeholders are seeking a formula that will be fair and defensible. Most pilot staff that we interviewed were comfortable with establishing a targeted budget range, based on individual historical expenses and average costs for similar services in the region.

Caseload Issues:

One informant stated that there is a statewide need to reduce caseload sizes, with or without self-determination. Many of the people we interviewed raised the issue of caseloads, especially in pilots where the service coordinator was assuming broker functions. The general opinion was that a standard caseload of 60 or more people does not allow a person to give the time and attention that is necessary to fully implement self-determination. In addition to time restraints, we also heard many concerns about the confusion of working in parallel systems, using one set of rules for some people and more flexible procedures for others.

Education and Training:

Key informants at every level referred to the importance of training for families, staff and the general public in understanding the principles of self-determination. All the pilots have made an investment in training and have plans to continue, expand, and share their network of consultants and technical assistants. One person recommended that interested families should have a mandatory orientation to understand the responsibilities and duties involved in the project.

Internal training for service coordinators was another universal theme from the respondents. Several informants mentioned the need for budget training in addition to learning new methods for supporting people through creative community building and circles of support.

Guidelines:

Most of our informants enjoyed the flexibility that was an integral part of the experimental pilot process but they are now worried about expansion and many expressed the need for guidelines to make implementation easier for stakeholders who may not have the same commitment and zeal for pursuing self-determination. Many respondents suggested guidelines for service coordinator and broker job descriptions, delineation of regional center as opposed to broker services and more clarity on exactly what kinds of services can be purchased

Choice:

The pilot sites made decisions about independent broker and fiscal intermediary services based on their project design and their existing resources. That fact was understood by most informants but we heard from many that expansion will require more choice for participants. The informants who were most concerned about adherence to the principles of self-determination warned about conflicts of interest if the regional centers continue to provide the core functions.

Public perception:

Finally, many respondents, especially administrators, were concerned about the public perception of self-determination. They fear that it is often portrayed as a "give away" program with no accountability. Respondents are asking for facts and reports to refute this position.

Julio: Living life with dignity and respect

Julio is 24 years old and was born with cerebral palsy. His physical disabilities are severe, and his speech is difficult to understand. However, he has a mind of his own, and a clear view of what he wants his life to include - the dignity of choice and the respect he deserves as a fellow human being.

I interviewed Julio over the telephone using an operator from the California Speech Relay Service - a skilled interpreter of Julio's speech. At times, it would take up to five minutes to interpret a word he was communicating, but he persevered without giving way to impatience and frustration. Unfortunately, he said, he has not always been afforded the same consideration. "Because of the way I look, people think I don't know anything."

Three years ago Julio made a decision to live on his own because he felt it was time - the same decision made by most young adults of the same age. He moved from his mother's house and into a duplex. The Regional Center identified a supported living agency to supply the necessary twenty-four hour support staff to care for his personal hygiene, transfer him in and out of his wheelchair, and help him keep his house clean. "I would surely stand up and do it myself if I were able."

However, he says that it wasn't uncommon for staff members to lounge around his apartment, eating, watching television, and then put him to bed early when he wasn't tired. The dust, dishes, and laundry would pile up. There were days when Julio was left without a single clean garment to wear. Julio's only recourse was in the use of his voice, but he felt that no one listened. When he called the supported living agency to complain he was met with, "Sorry, we *can't help you. We are shorthanded." This went on for more than a year, leaving Julio's quality of life out of his control.*

Two years ago, Julio was informed he was selected to participate in the self-determination pilot project. After the initial planning process, his budget was established based on the expense of traditional delivery of support services. Suddenly, he says, he was no longer at the mercy of an agency unwilling or unable to hear his concerns. "They didn't care."

Today, Julio's voice is heard loud and clear. He interviews, hires and fires support staff. He invites people to be a part of his life, and expects them to value his contributions to society, respect his personal choices, and not judge his humanness because of his physical needs. If a staff member can't live up to the basic considerations Julio desires, he dismisses them from his employment and hires someone who can.

"He is extremely happy, and has good people supporting him," according to Julio's Regional Center service coordinator.

However, Julio does have concerns about the future. "I am worried that I might need some things and I can't take money from my budget because if I do it won't last for my staff, like equipment for my wheelchair in case my Medi-Cal won't pay."

He also worries that self-determination will not be in his future because someone will "mess it up for the rest of us by asking to buy swimming pools and trips. Julio is a responsible adult. He pays his bills, goes to the grocery store and buys his own food, answers his own phone, makes doctor appointments, and takes seriously his responsibility in maintaining the integrity of self-determination. "I think that before anyone goes into self-determination they should know that it's a lot of responsibility."

Not long ago, Julio had a little money left in his budget, and he bought a computer. Since he loves to talk with people, and his speech is hard to understand, he expects the computer will open up a whole new world of communication for him. Julio's physical disabilities prevent him from using a conventional keyboard, so I asked what adaptive equipment he used and he said, "That is my secret."

I left my conversation with Julio knowing he was a man in control of his own life.

Appendix A: Personal Life Quality Protocol

Appendix B: Brief History of Self-Determination

The table below provides a condensed version of selected critical events in the unfolding of the self-determination movement.

- 1993 Original Proposal to Robert Wood Johnson Foundation (RWJF)
- 1994 Grants awarded to Monadnock Developmental Services, Keene, NH, and COA
- 1995 Preliminary 6-month evaluation outcomes at Monadnock show few significant changes[4]
- 1996 18 month outcomes show large and diverse positive outcomes
- 1996 Statewide expansion in New Hampshire begins with additional RWJF grant
- 1996 RWJF Decision to go National
- 1997 Grants to 19 States
- 1998 10 More Planning Grants
- 1998 National Evaluation Begins via COA and HSRI
- 1998 10 More States Join With State Funds (California via legislative action)
- 1999 Michigan shows strong positive results in COA outcome database
- 2000 Three year cycles of RWJF grants are completed (several states extend)
- 2000 Center for Self-Determination is initiated by all five creators of the initial New Hampshire demonstration, housed in Wayne County Michigan

Obviously, self-determination has spread rapidly across the country. Even today, however, the movement must be viewed as a "demonstration effort." The number of people across the country who are organizing their supports under the principles of self-determination including individual budgets that they and their freely chosen allies truly control is between 2,000 and 5,000, depending on the details of the estimation method. Although the number of people is small, most analysts believe the efforts have the strong potential to effect massive, even revolutionary, systems change.

A part of the reason for the rapid spread of the initiatives has been the availability of rigorous scientific data on the process and outcomes of self-determination. Originally, the Monadnock evaluation results were as surprising to the evaluators as they were compelling. Once it was established that self-determination could make a difference in people's lives, stakeholders at all levels appeared to begin to entertain the notion that, "If it can be done in a manner so

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[4] Conroy, J. (1995). *Independent Evaluation of the Self-Determination Project, Sixth Quarterly Report*, February 1, 1995 to April 31, 1995.

empowering and cost-effective, then we should try to move the system in that direction." However, the process of change does not appear to be easy.

Monadnock's grant from RWJF was $130,000 per year for 3 years, dropped into an agency with an annual budget of $12,000,000. (The grant funds could not be used for services/supports, only for coordination and training within the self-determination efforts.) The evaluators of the Monadnock project wrote in their original proposal for evaluation that their working hypothesis would be "no change." They contended that the self-determination model required fundamental changes in accounting methods and person-centered planning that probably could not be accomplished within a mere 3 years. Moreover, a large agency would probably not be able to change the basics of the way it conducted business merely because of one small grant.

When the extraordinarily positive outcomes appeared at 18 months, we learned that (at least in one demonstration site) the amount of money directed toward the initiative might not be a crucial factor in the success of such an initiative. Our quantitative results were compelling. Our qualitative findings lent more depth to the analysis by showing some of the levels of commitment, and the magnitude of the barriers faced by self-determination proponents. [5] The qualitative work led to the suggestion that belief and commitment on the part of the professionals who held so much power were far more important for achieving results than the amount of money in the grant.

The two major reports resulting from the Monadnock demonstration have provided one of the major driving forces in the expansion of self-determination. The present report, although only the first, and lacking true "before and after" data, should be seen in the context of ongoing rigorous testing and studying of the emerging new paradigm. We must constantly ask, not only, "Is this working," but also "Under what conditions does it work best, how can we improve what we are doing, what are the 'best practices' in this realm, what individually-based accounting and accountability procedures can effectively replace the morass of red tape in which we all find ourselves at this point in history?"

The brief history of important events above is presented primarily as a temporal and conceptual context for the California initiative.

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[5] Yuskauskas, A., Conroy, J.W., & Elks, M. (1997, May). *Live Free or Die: A Qualitative Analysis of Systems Change in the Monadnock Self-Determination Project.* Submitted to the Robert Wood Johnson Foundation, *Self-Determination* Initiative National Program Office. Ardmore, PA: The Center for Outcome Analysis.

Appendix C: The Beginning of Self-Determination in California

Unlike any other self-determination effort thus far in America, California's effort began in the legislature. We have seen efforts that were initiated by local agency professionals (e.g., New Hampshire), state officials (Wisconsin), Developmental Disabilities Councils (North Carolina), self-advocates (New York), and even by a community of service providers (Arizona). California is the only state in which the impetus for self-determination efforts came from the legislature.

We speculate that this unique development can be traced to the unusually progressive leadership of a small number of Senators and their staff members responsible for mental health and mental retardation. In any case, California's journey officially began with the legislation reproduced below.

The legislation authorizing and requiring the Self-Determination Pilot

BILL NUMBER: SB 1038
INTRODUCED BY Senator Thompson, February 27, 1997
(Coauthors: Senators Alpert, Solis, Vasconcellos, and Watson)
(Coauthor: Assembly Member Migden)

SEC. 13. Section 4685.5 is added to the Welfare and Institutions Code, to read:
4685.5.
(a) Notwithstanding any other provision of law, commencing January 1, 1999, the department shall conduct a three-year pilot project under which funds shall be allocated for local self-determination pilot programs that will enhance the ability of a consumer and his or her family to control the decisions and resources required to meet all or some of the objectives in his or her individual program plan.
(b) Local self-determination pilot programs funded pursuant to this section may include, but not be limited to, all of the following:

(1) Programs that provide for consumer and family control over which services best meet their needs and the objectives in the individual program plan.

(2) Programs that provide allowances or subsidies to consumers and their families.

(3) Programs providing for the use of debit cards.

(4) Programs that provide for the utilization of parent vendors, direct pay options, individual budgets for the procurement of services and supports, alternative case management, and vouchers.

(5) Wraparound programs.

(c) The department shall allocate funds for pilot programs in three regional center catchment areas and shall, to the extent possible, test a variety of mechanisms outlined in subdivision (b).

(d) Funds allocated to implement this section may be used for administrative and evaluation costs. Purchase-of-services costs shall be based on the estimated annual service costs associated with each participating consumer and family. Each proposal shall include a budget outlining administrative, service, and evaluation components.

(e) Pilot projects shall be conducted in the following regional center catchment areas:

(1) Tri-Counties Regional Center.
(2) Eastern Los Angeles Regional Center.
(3) Redwood Coast Regional Center.

(f) If any of the regional centers specified in subdivision (e) do not submit a proposal meeting the requirements set forth in this section or by the department, the department may select another regional center to conduct a pilot project.

(g) The department shall develop and issue a request for proposals soliciting regional center participation in the pilot program. Consumers, families, regional centers, advocates, and service providers shall be consulted during the development of the request for proposal and selection of the pilot areas.

(h) Each area receiving funding under this section shall demonstrate joint regional center and area board support for the local self-determination pilot program, and shall establish a local advisory committee, appointed jointly by the regional center and area board, made up of consumers, family members, advocates, and community leaders and that shall reflect the multicultural diversity and geographic profile of the catchment area. The local advisory committee shall review the development and ongoing progress of the local self-determination pilot program and may make ongoing recommendations for improvement to the regional center. By September 1, 2000, the local advisory committee shall submit to the department recommendations for the continuation and expansion of the program.

(i) The department shall issue a report to the Legislature no later than January 1, 2001, on the status of each pilot program funded by this section and recommendations with respect to continuation and expansion.

(j) Notwithstanding any other provision of law, as of January 1, 1999, of the balances available pursuant to Item 4300-490 of the Budget Act of 1998 for regional centers, the first seven hundred fifty thousand dollars ($750,000) is reappropriated for the purposes of implementing this section, and shall be available for expenditure until January 1, 2002.

(k) This section shall remain in effect only until January 1, 2002, and as of that date is repealed, unless a later enacted statute, that becomes effective on or before January 1, 2002, extends or deletes that date.

Legislative History:
PASSED THE ASSEMBLY AUGUST 31, 1998
PASSED THE SENATE AUGUST 31, 1998
APPROVED BY GOVERNOR SEPTEMBER 30, 1998
FILED WITH SECRETARY OF STATE SEPTEMBER 30, 1998

Reproduced below is an excerpt from the Legislative Counsel's Digest, describing the new law.

Brief summary of the intent of Sec. 13, Section 4685.5, from:

> LEGISLATIVE COUNSEL'S DIGEST
> SB 1038, M. Thompson. Developmental disabilities.
>
> Existing law, the Lanterman Developmental Disabilities Services Act (hereafter the act) requires the State Department of Developmental Services to contract with regional centers for the provision of various services and supports to persons with developmental disabilities.
>
> *[Intervening material omitted here.]…..*
>
> The bill would require the department to conduct a 3-year pilot project to provide funding to local self-determination programs that will enhance the ability of a consumer and his or her family to control the decisions and resources required to meet all or some of the objectives in his or her program plan.
>
> This bill would reappropriate $750,000 to the department from specified funds appropriated pursuant to the Budget Act of 1998 for these programs.

As noted in the legislation, proposals were required from the three selected Regional Centers as a condition of participation. DDS invited proposals in early 1999. All three Regional Centers named in the legislation chose to write proposals, and their proposals were received by May. All three began to implement their initiatives in mid-1999. Each Regional Center planned to involve approximately 30 people and their circles of support in the self-determination pilot.

Before the pilots were fully under way, the legislature appropriated another $500,000 for the pilot efforts.

Efforts are well under way at the three original pilot sites: East Los Angeles Regional Center, Redwood Coast Regional Center, and Tri-Counties Regional Center. A fourth site, Kern Regional Center, joined voluntarily without any additional funding, because of its leadership's apparent belief in the principles underlying self-determination. More recently, a fifth site, San Diego Regional Center, announced its intention to join the initiative.

As happened nationally, interest and excitement appear to be spreading relatively rapidly within California. As is to be expected in such a radical departure from past practices, there are also many observers who remain "friendly skeptics."

Nonetheless, the interest and commitment in California has extended from the initial action of the legislature to DDS, the Regional Center system, the Area Board system, advocacy organizations of all stripes (particularly self-advocates), and segments of the vendor community. The DDS website on self-determination characterizes self-determination as follows:

> *The intent of self-determination is to facilitate consumer and family control of public funds such that they have the freedom to develop and purchase their own services.*

The website further explains:

> *"Welcome to the Department of Developmental Services Self-Determination Home Page. This Home Page provides the reader with general information about the California Self-Determination (SD) Pilot Projects. The SD pilots will enhance the ability of consumers and/or their families to control the decisions and resources required to meet all or some of the objectives in their individual program plan. The SD pilots will explore methods of funding consumer services with various cost-effective, flexible service and support options. Consumer satisfaction will play an important role in evaluation of the SD pilots."*

Appendix D: Changes in Services and Supports