

**Independent Evaluation of California's
Self-Determination Pilot Projects:
Second Year Interim Findings**

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Executive Summary

**If people gain control,
Their lives will improve
and
Costs will go down.**

Can this basic hypothesis of the self-determination initiative be proved in California? That is certainly the hope of the authors of the legislation that mandated the pilot projects and of the many stakeholders who have worked so hard to redesign systems, facilitate choice, and implement person-centered plans. 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.

This interim evaluation report presents quantitative and qualitative data generated to date by the Center for Outcome Analysis and our preliminary analyses of selected findings. It is important to remember, as illustrated by the Demographics section, that each of the pilots are unique, they serve people with differing characteristics, they use different designs for their support and fiscal systems, and they operate in very different physical environments. To explain these differences we have included regional center profiles that include Project Vision, Participant Selection Process, Project Operations, Budgets, instances of internal Organizational Change, and a summary of Qualitative Findings.

The interim outcomes for the participants are positive. We have observed statistically significant positive changes at one or more regional centers in adaptive behavior, control of challenging behavior, elements of the planning process, perceptions of overall quality of life, decision making, and integrative activities. Our preliminary cost analyses suggest that self-determination has tended to keep costs steady, after the initial individual budget amount is set. The number of people reporting individual budgets has more than tripled and the service categories for expenses are shifting.

The final evaluation report, to be completed after another round of interviews, will yield even more information about the pilots, their systems, and their outcomes.

Introduction

The year 2001 marked the official end of the Robert Wood Johnson Foundation's national self-determination initiative. It also marked the mid-point of the California self-determination pilot projects. California is one of 42 states that are now engaged in some level of developing, testing and implementing self-determination strategies. California is the only state where self-determination was mandated by the legislature. In last year's report, we provided a brief history of self-determination in the United States and a chapter that related the beginnings of self-determination in California. Those documents are appended to this report as Appendices A and B.

The evaluation design calls for three visits to the pilot participants 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. The results from the third slice of time visits will be included in the final report.

Last year's report included the characteristics of the self-determination participants and a discussion of the model designs selected by the three regional centers. 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 to measure changes since the first visit.

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. They then selected their participants in different

ways and proceeded to implement different models of self-determination with differing strategies. The non-equivalent comparison group can really only be compared to the self-determination participants at the ELARC pilot. For that reason refer to the comparison group throughout the report as “The ELARC Comparison Group.”

Focus groups were used again this year to gather attitudes and opinions regarding the progress of the pilots. We also gathered and reviewed policy statements and other literature from the various sites. For the first time, we gathered and analyzed financial information for the participants. We compared their purchase of service expenditures over the past four years and examined the levels of federal reimbursement.

This report describes changes in the things that we can measure for the pilot project participants. The findings are strong and positive.

Methods

Methods 1: Qualitative

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 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 this effort is 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 are then cross-referenced with the quantitative data to present a total picture (see Morgan, 1998 for a discussion about combining methodologies).

Qualitative data for this evaluation report were obtained from focus groups, individual stories, and media articles from the pilot projects. In particular, the focus group participants were asked about:

- the shifting of power,
- the choices for implementing self-determination,
- changes in professional roles and boundaries,
- outcomes experienced by organizations,
- transition plans for organizational change,
- conflicts associated with change,
- leadership qualities that enhance project implementation, and
- comparisons between individual and organizational outcomes.

The topic guide for the individual stories included:

1. Why did you want to participate (benefits)?
2. Describe briefly how self-determination has progressed for you (conflicts, disagreements, etc.):
3. How did your services and supports change as a result of your participation (type, usage, etc.)?
4. Do you feel there are any risks to self-determination?
5. What changes has self-determination made for you/your family?
6. What have been the outcomes of self-determination for you?
7. Are you satisfied with self-determination?

Qualitative information for this evaluation was collected in July and August 2001. A state level focus group, consisting of eight representatives from various departments of the California Department of Developmental Services and the Association of Regional Center Agencies was held in July 2001. If stakeholders were unable to participate in formal focus groups, the desired information was gathered through other methods, such as phone interviews and regular regional center meetings. The Table below details the methods used.

Table 1

	Eastern Los Angeles Regional Center	Tri-Counties Regional Center	Redwood Coast Regional Center
<u>Consumers/Families</u>	Focus Group with 3 consumers/2 support staff and 2 family members (with Spanish translation provided by the ELARC Training Department)	As part of information meeting with 6 consumers/1 support staff, 1 parent, 3 regional center staff and consultant	As part of monthly participant potluck with 5 consumers, 4 family members, 3 support staff, 1 advisory committee member, 3 regional center staff
Regional Center staff	Focus group with 10 members of the Self-Determination team, including Area Board 10	As part of the internal Self-determination meetings with 12 service coordinators, 5 branch managers, 3 pilot leadership staff/consultant	Focus group with 3 service coordinators
<u>Service Providers</u>	As part of information meeting with 4 staff representing 2 service providers	Phone interviews and communication with 3 service providers in pilot	Phone interviews and communication with 3 service providers in pilot

Fourteen structured interviews were conducted with key informants. The following from each of the pilots were invited to participate: an Advisory

Committee representative, the Area Board Director, and the following regional center staff: project coordinator, case management leadership staff, service coordinator/service broker, fiscal contact, and Executive Director. The following statewide representatives were invited: leadership from the Department of Developmental Services, the Organization of Area Boards, the Association of Regional Center Agencies, and Senate Select Committee.

Qualitative information collected for this evaluation included audiotapes and transcripts of the focus group meetings, facilitator observation notes and interviewer notes. In keeping with the qualitative methodology, the information was inductively analyzed for general themes. Those themes constitute the Qualitative Results in this report.

Methods 2: Quantitative

Quantitative Methods: 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 Project¹ with those of the national self-determination framework. The more than 2,000 people who left Developmental Centers during the 1990s, who are in our database, will form an immensely valuable point of comparison and benchmark for future analyses of the qualities of life of the self-determination participants.

1 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.

The main component of the quantitative approach was the Personal Life Quality Protocol © (available upon request). This package and its component instruments have been described in the literature and have been submitted to multiple tests of reliability.² Following is a more detailed description of the component instruments and their purposes.

The Center for Outcome Analysis (COA) package of measures of qualities of life is generally called the Personal Life Quality Protocol. Many of the elements of this package evolved from the Pennhurst Longitudinal Study (Conroy & Bradley, 1985). Pennhurst Class members have been visited annually since 1978. An extensive battery of quality-related data has been collected on each visit. Over the years, other groups have been added to the data base, such as all 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.

The battery of instruments was based on the notion that "quality of life" is inherently multidimensional (Conroy, 1986). It is essential to measure many kinds of individual outcomes to gain an understanding of what aspects of quality of life have changed over time (Conroy & Feinstein, 1990a). Modifications made to the battery of instruments over the years have been based on the concept of "valued outcomes" (Conroy & Feinstein, 1990b; Shea, 1992). Professionals may value some outcomes most highly, such as behavioral development; parents and other

² 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.

relatives may value permanence, safety, and comfort more highly; and people with mental retardation may value having freedom, money, and friends most highly. The goal in our research on deinstitutionalization, and later in self-determination, has been to learn how to measure aspects of all of these "valued outcomes" reliably.

The measures used in 2001 include behavioral progress, integration, productivity, independence, earnings, opportunities for choicemaking, individual plan status and content, friendships, health, health care, medications, amount and type of developmentally oriented services, satisfaction of the people receiving services, self-perceived qualities of life now compared to a year ago, satisfaction of next of kin, physical quality, individualized practices, staff longevity, staff attitudes, staff job satisfaction, program costs, and individual budget status. 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 prepared (Conroy, 1995; Dodder, Foster, & Bolin, 1999; Fullerton, Douglass, & Dodder, 1999).

Behavior

The behavioral measures were contained within the California Client Development Evaluation Report. The adaptive behavior measure is composed of 52 items. The challenging behavior scale is composed from 14 items. The CDER adaptive behavior measure has been reported to have good reliability under certain circumstances (Harris, 1982). It should be noted that this is not a direct test of adaptive behavior, but rather a rating scale in which the opinions of knowledgeable third party informants are taken as descriptions of adaptive behavior.

Productivity

Productivity was reflected by earnings, by the amount of time engaged in daytime activities that were designed to be productive (adult day activities, vocational training, workshops, supported and competitive employment), and by the amount of time reported to be engaged in developmentally oriented activities in the home. Through the instrument package estimates were made of the amount of each of 17 services delivered in the preceding 4 weeks, such as dressing skills training, occupational therapy, and behavioral interventions.

Many versions of the PLQ also contain the “Orientation Toward Productive Activities” scale, composed of 12 simple items concerning being on time, showing enthusiasm about work, keeping a job, and getting promotions. This scale has not yet been subjected to reliability testing. It did, however, show significant increases during the first New Hampshire implementation of self-determination, and also during deinstitutionalization in Indiana, so there is some reason to believe that it is sensitive to meaningful changes.

Choice Making

The scale of 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). (A separate form was recently developed for people living with their families rather than being supported by paid

staff. In that form, the power balance is measured between the person and the relatives.)

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 very high when the time interval was corrected for (.97).

Indicators of the Individual Planning Process

Most PLQ versions now include the “Elements of the Planning Process” scale, which is 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 occurred, as well as a snapshot of the content 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 plan.

Individual Budgeting

This section is designed to collect information about the money utilized to support the person. If the person has a traditional support system, then the section captures the traditional estimates of residential and day program per diems, plus

public entitlements such as SSI, plus estimates of other expenditures for transportation and other costs. If the person has an individual budget, then the section captures how that budget is being spent, as well as what kind of control(s) the person exerts over that money. In either case, getting cost information for an individual often requires a phone call to an administrative office.

Connections with Family and Friends

This section collects the name and address of the person's closest relative, so that we can send a mail survey about perceptions of quality. It also collects the frequency of several kinds of contact with family members. The number of friends is counted, however the person defines friends. 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 to respond. Surrogates (usually staff persons) were "whoever knew the participant best on a day to day basis." On this scale, approximately 85% of the responses 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 among people with developmental disabilities has been 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 of the PLQ as the one section where no surrogates

are permitted. This section is intended to capture the person's thoughts, and none other.

So much of the rest of the PLQ can be collected from third parties who know the person well, that it is fitting that there is one place where we who are "listening" to the data will know that this is directly from the focus person. The Personal Interview is left blank if we fail to find a way to communicate with the person. That may be 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 by third parties. And, in the final analysis, we must have one place that is set apart, and only the focus people themselves can put their thoughts and feelings into it.

The Personal Interview is primarily designed as five point scales, which can be asked as two Either-Or questions. (For example, "How is the food here? Good? 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 best overall question design for many purposes is Either-Or, because most people can answer it easily, and it is not threatened by the problems of the Yes-No format. There are also open-ended items throughout the Personal Interview, and answers to these are written down 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?")

Health and Health Care

The indicators of health and health care were simple and straightforward. Intensity of medical needs was rated by staff informants on a four-point scale. Problems involved with getting health care for the person were rated on a three-point scale (No Problems, Minor Problems, Major Problems). Number of days of restricted activity because of health problems, number of medications received daily, and percent receiving psychotropic medications, were scored as raw frequencies.

Size of Home

The size of the home was measured by the response to the question "How many people who have developmental disabilities live in this immediate setting?" This was not necessarily a direct measure of quality or outcome, but the size of the setting has been investigated extensively as an important contributor to quality of life (Balla, 1976; Baroff, 1980; Conroy, 1992; Lakin, White, Hill, Bruininks, & Wright, 1990).

Individualized Treatment

The Individualized Practices Scale was used as an indicator of individualized versus group-oriented practices in the home. This instrument was derived from the work of Pratt, Luszcz, and Brown (1981), which was based on the Resident Management Practices Inventory developed by McLain, Silverstein, Hubbel, and Brownlee (1975). The Inventory was an adaptation of the Child Management Scale from the pioneering work of King, Raynes, and Tizard (1971) on measurement of resident-oriented versus staff-oriented practices. The Group Home Management Scale was administered during interviews with individuals familiar with the residential practices in the home, and took about 5 minutes to complete. Devlin (1989) reported interrater reliability of .78 and test-retest of .86.

Subjective Impressions

The Visitor Subjective Impressions were subjective ratings on a scale of 1 to 10 about overall perceptions of the quality of the residential site, quality of food found in the refrigerator and cupboards, quality of staff-consumer interactions, quality of consumer-consumer interactions, expectations of staff regarding consumers' potential for growth and development, and the degree to which the setting was oriented toward research and measurement. The visitors made these ratings after being in each home for an average of 3 hours. Reliability of these essentially subjective ratings has not been adequately tested. They remain as subjective impressions, and should be interpreted with caution.

Service Delivery Process

A few simple items were collected to reflect the involvement of the service coordinator according to records. Examples were; a recording from the log book of the service coordinator's last visit; the presence of an up-to-date IPP at the time of the visit; and the presence of the Day Program Plan at the home.

The PLQ also contained an instrument to capture the type and amount of formal services rendered to the person. Estimates were made of the amount of each of 17 services delivered in the preceding 4 weeks, such as dressing skills training, occupational therapy, and behavioral interventions.

The most recent PLQ package developed for the self-determination evaluation contains a new section on the Person-Centered Planning Process. One scale is designed to measure the degree to which the planning process had the characteristics of "person-centeredness." Another captures the membership of the planning team, according to paid or unpaid, invited or not invited by the focus person, and family member or not. Another page captures each goal, desire, or preference in the Plan, plus the degree to which each goal is being addressed by formal or informal supports, and the extent of progress seen thus far toward the goal. These new elements have not been subjected to reliability testing yet.

Quantitative Methods: Procedures

The project recruited and trained local professionals, paraprofessionals, and advocates to perform a data collection visit with each person in the sample. These data collectors, called “Visitors,” functioned as Independent Contractors. They were paid a fixed rate for each completed interview. Here are the written instructions from our Personal Life Quality Protocol that we provide to the visitors:

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

1. The person (to attempt a 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.

Visitor training and mentoring was conducted by Sherry Beamer, MSW. A crew of fifteen interviewers collected the data for this evaluation, including Sherry Beamer. Two of the interviewers are bilingual in English and Spanish and one interviewer is bilingual in English and Chinese. A Spanish interpreter was used for one interview at RCRC, and a translation company was used for one comparison group interview in Cantonese at ELARC. Twelve of the fifteen Visitors were experienced in using the PLQ from their work on related projects and last year’s data collection for this evaluation. Three new Visitors were recruited and trained for the Redwood Coast Regional Center area. The “training” was really a refresher session, designed to answer any confusions and questions that had arisen, as well

as to go over in detail the differences between the self-determination form of the instrument and the form used for the study of deinstitutionalization in California. Training for the three new Visitors consisted of an introduction to the project, a role-playing exercise and/or accompanied visit, and a review of the instrument and purposes sections of the protocol. A detailed, question by question PLQ training session was recorded on CD by Dr. Conroy and made available to the Visitors. Sherry Beamer monitored the Visitors on a weekly basis. The interviews were purposefully scheduled for July and August 2001 to allow as much time as possible between the 2000 and the 2001 visits.

Each visitor was responsible for scheduling appointments and completing an assignment of visits. Visitors were instructed emphatically to respect programmatic needs, and work around them. No person's daily schedule was to be disrupted by these visits. In the visits in California's self-determination work, the visits ranged from 60 to 270 minutes, with an average of 109 minutes. The amount of information collected, in relation to the relatively short duration of the visits, is worthy of comment. We are able to collect reliable quantitative data on dozens of qualities of life in a very short time, with very little intrusion into peoples' lives.

Purchase of Service and Waiver Records

In the course of conducting the PLQ visits, COA visitors record each participant's Unique Client Identifier (UCI) number. After all the data were entered, COA extracted a list of participant names with matching UCIs. This password protected list was sent to DDS Information Services with a request for Purchase of Service expenditures and a breakdown of waiver billable claims. We also requested financial information from the pilot sites, all of whom had developed their own internal systems for tracking pilot financial data. The

problem with the data for this report is that regional centers have six months from the time of service to submit claims to DDS. Therefore, expenses for the fiscal year ended June 30, 2001 can be submitted as late as December 2001. Only one regional center reported that all their claims had been submitted to DDS at the time of our report. We therefore decided to use data from fiscal years 1998 through 2000 for most of the fiscal analyses. The final report will encompass the full year of expenses for fiscal year 2001. A secondary concern was a desire to eventually analyze individual budgets according to the participants' self-determination start dates. The data we have are organized in 6 month blocks of time and we will be receiving the official start dates from all the regional centers so that those kinds of analyses can be included in the final report.

Qualitative Results

EASTERN LOS ANGELES REGIONAL CENTER (ELARC)

Project Vision

The Eastern Los Angeles Regional Center self-determination pilot is guided by the vision that “people with disabilities will determine their own futures, with appropriate assistance from families and friends.”³ ELARC’s board reportedly 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 implement the Lanterman Act and its own mission. The Board also felt that the pilot could be used as a tool to track how money is spent in the region. The amount of money spent per-capita has been a board issue for a long time. A recent Purchase of Services Variance study for Californians with developmental disabilities shows that minorities, especially Hispanic consumers, spend less money on a per capita basis.

Participant Selection

ELARC’s population is culturally diverse, composed of 64% Hispanic, 17% Caucasian, and 9% Asian consumers. These facts, plus ELARC’s commitment to providing culturally competent and sensitive services, were major factors in the design of its pilot project. One of the questions they hope to answer is why utilization rates for residential services are so low. Is there truly a preference for natural support systems among certain minority groups, or do people just not want available service models?

³ Exhibit B: 1.d.4. Compatible with the vision and principles articulated by the Self-Determination Steering Committee

ELARC chose four specific culturally diverse groups from which to draw a random sample for the self-determination pilot.⁴ In addition, participants were selected according to age and level of service characteristics. At the beginning of the pilot, a large random sample of people, representing each of the target groups, was invited to an informational meeting on self-determination. After this meeting, people were randomly selected, according to the selected target groups, and invited to join the pilot. Participation was voluntary. It took almost two years to enroll the complete group of participants. ELARC reserves the right to ask participants to leave the pilot, but this option has not been exercised. As of June 2001, there are thirty-two participants in the ELARC pilot, with eight people representing each of the following groups:

- Children with high medical needs
- Children with autism
- Adults 22 – 35 years old
- Adults over 35 years old

ELARC reports that it took longer than anticipated to finalize the pilot group because it was often difficult to agree on individual budgets. Some families were hesitant to sign off on the plan, fearful that their plan/budget would not offer sufficient support in case of changes in life circumstances. For others it was difficult to commit increased personal time to participate.

Project Operations

Organizationally, the ELARC pilot is staffed by the project funds with:

- One Full-time Self-Determination Service Coordinator who works with the 32 participants by coordinating planning and budgeting meetings,

⁴ Exhibit B: 1.c.1. *Who* participated in the pilot projects?

- writing the plans and budgets, and ongoing plan and budget support as requested.
- One Part-time fiscal monitor who creates the monthly budget, compiles the data, sends participants monthly budgets, tracks individual budgets, tracks Service Broker usage, compiles statistical data (e.g. averages by the target groups), and sets up and cancels services.
 - One Part-time supervisor, who also works as the Training and Information Manager.
 - Support brokers
 - Project Consultant⁵

After participants were officially enrolled in the self-determination pilot, they were “transferred” from the caseload of their prior Service Coordinator to the newly designated Self-Determination Service Coordinator. The DDS mandated upper limit for Service Coordinator caseloads is 62 individuals. ELARC chose to have one person assume responsibility for the 32 self-determination participants only, to assure more personalized service.⁶

The original Self-determination Service Coordinator was promoted in the second year of the pilot to an agency training position. Both the former and current Self-Determination Service Coordinators speak English and Spanish. In the first year, if consumers spoke a language other than English or Spanish, their original Service Coordinator continued membership in their circle of support to provide interpreter services. In the second year, this is not the practice. In-house staff at ELARC are now requested to assist the few people who need this kind of support.⁷

⁵ Exhibit B: 1.c.3. How are funds being used in self-determination?

⁶ Exhibit B: 1.c.1. **How** did patterns of support, paid and unpaid, change as a result of participation?

⁷Exhibit B: 1a. Detailed description of the development, implementation, and management of each pilot project...and any subsequent revisions.

ELARC assisted the participants to develop a pool of ten Service Brokers who are prepared to provide the following services per the participants' choice and requests:

- Assistance in developing and maintaining a circle of support.
- Assistance in planning life and future based on choice and variety.
- Coordinate services by finding providers and resources to meet changing needs and choices.
- Assist in planning and managing allotted budget including setting up and maintaining the most cost-effective use of available funding.
- Assist in locating, developing and utilizing natural and generic resources.
- Advertise, recruit and assist in pre-screening all potential service providers.
- Assist in developing and coordinating person-centered planning and budget meetings.
- Maintain a working relationship, emphasizing quality, collaboration and partnership among participants, ELARC and Fiscal Intermediary.
- Maintain case record for each consumer detailing the services being utilized.
- Complete required documentation and submit to ELARC for review.
- Provide monthly updates to ELARC service coordinator advising of any important issues regarding a change in the plan, including health status and provider issues.

The fiscal intermediary serves as the employer of record to withhold and file taxes, provide professional liability coverage, and to ensure compliance with fair labor standards for participants who working with individuals providing them personal services. The cost for the fiscal intermediary is shared with Tri-Counties Regional Center. Payment forms for personal services are submitted to ELARC, then a check is cut to the fiscal intermediary who pays the person and assures payroll deductions. The fiscal intermediary currently charges 30% of each dollar

spent for its services. It is anticipated that this cost will decrease as the use of the fiscal intermediary services increases.⁸

There are currently some quality assurance issues with the fiscal intermediary around timely payments, accuracy of payroll reporting, and adequate documentation. ELARC and TCRC staff recently conducted an audit of their services. ELARC developed the fiscal intermediary job description with the assistance of its consultant. Research was conducted on community fiscal intermediaries, with costs ranging up to 50% of each dollar spent. Community fiscal intermediaries were also leery of providing this service with the anticipated risk in covering personal services to people with developmental disabilities. The current fiscal intermediary is a human resources consulting group that specialized in supported living services. They were recruited to provide the service.

The cost of the Service Broker is not currently paid for out of the participant's individual budgets, but out of ELARC's operations budget. Less than one third of the participants are using service brokers, and each one is being used to help secure services. One service broker is assisting a gentlemen to "find his voice" by going out to give presentations and speak with legislators. ELARC staff feel this service "is developing a side of him that could lead to employment possibilities." Another service broker is assisting a family who is monolingual Chinese who receive funding to support their adult son to use the budget funds responsibility and to fill out billing forms correctly. As well, this broker is helping this man to market his art in local venues, like coffeehouses. A few of the service brokers started to provide educational advocacy, which the regional center felt was a service that should be paid for separate from the service broker role.

⁸ Exhibit B: 1.b: Detailed description of the development, implementation, and management of each strategy used to achieve self-determination.

The Self-determination Service Coordinator holds monthly support groups so that she can be accessible in a number of ways to the consumers and their families. The ELARC pilot convenes an internal self-determination team meeting, typically each month, that is attended by representatives of various agency departments including finance, case management, resource development, training and executive management. Staff members report how valuable these team meetings are as a forum for input on self-determination procedures and practices from the perspective and expertise of various agency functions.⁹

Training has been a strong focus of the ELARC pilot and a consultant was hired to provide the majority of the training sessions.¹⁰ Now that the original self-determination service coordinator has been promoted to the training department, her expertise with self-determination will be used there. Currently she runs a monthly self-determination study group with 16 service coordinators, each one representing a case management unit at ELARC. They review cases and discuss how case management would differ if the principles of self-determination were used, practice filling out the accounting forms, and “shadow” the current self-determination service coordinator on his planning and budgeting meetings. The training department recently put together a Resource Guide of services for purchase available through the regional center, including new services that are being used through self-determination. This is proving to be an invaluable resource for participants, service brokers, and ELARC service coordinators. There is concern with the amount of resources that will need to be allocated to keep the guide current.¹¹

⁹ Exhibit B: 1.c.2. What resources do participants put together to achieve self-determination? How are conflicts and disagreements among players resolved? What strategies are used to achieve desired outcomes? How do the policies, procedures, and practices of participants, DDS, pilot projects, vendors affect these outcomes?

¹⁰ Exhibit B: 1.b. Detailed description of the development, implementation, and management of each strategy used to achieve self-determination

¹¹ Exhibit B: 1.c.2 What strategies are used to achieve desired outcomes?

There has been ongoing training with the participants and their service brokers on filling out the accounting forms. Community training for service providers was co-developed with the Area Board and includes a review of the self-determination principles, the new roles of the service broker and fiscal intermediary, and discussion on how agencies can flourish with self-determination by providing situations that:

- Help people have good lives not just good programs
- Are values driven as opposed to rules governed
- Are creative, flexible and fluid
- Are proactive rather than reactive
- Involve people who use services in everyday decision making and long range planning¹²

Budgets

The individual budget amounts are set by comparing prior year costs to the target group's aggregate mean to define an amount, then the person centered plan further defines the budget.¹³ ELARC is collecting internal qualitative and quantitative data to track purchase of service trends.¹⁴ They are collecting narrative stories and plan to compare the amount of money budgeted, the amount of money spent, and the service codes used, compared to prior spending.¹⁵

Participants are spending their budgets on one-time purchases or on adjusting their current services. ELARC staff observe:¹⁶

¹² Exhibit B: 1.d.4. Compatible with the vision and principles articulated by the Self-Determination Steering Committee;

¹³ Exhibit B: 1.c. Evaluation and discussion, for each pilot project in general and by each self-determination strategy

¹⁴ Exhibit B: 1.c.2. What strategies are used to achieve desired outcomes?

¹⁵ Exhibit B: 1.c.3. What are the *costs and cost benefits* of the pilot project models? **How** do these compare, individually and on an aggregate level, with pre-self-determination costs? Do the actual costs of services to regional centers and providers change? **How** are funds being used in self-determination and how is that different/same from previous utilization?

“This is partly an awareness that this could go away . . . people are choosing to modify a bathroom, get a door opener, or a squeeze machine for a child with autism. We’re seeing traditional services with a twist. Everything will stay the same, except someone is hiring their neighbor to take their son to the day program instead of relying on the day program’s transportation. Or people will choose to use some of their respite dollars for a co-pay on medication. Most people are doing things that they haven’t been able to do before, like taking their child to counseling. A lot of money is spent on camps, one-to-one aides for camp and recreation. It does blur the line on parental responsibility. We’re watching that but erring on their judgment. We have one family with two teenagers that go out with their church group and perform for the homeless. They also perform at different cultural festivals. They purchased the services of a music therapist, who suggested they buy a karaoke machine so they could hear their own voices, and perform with it. There is no way this would be purchased under regular services.”

Below are some reflections from participants and families on how they are using their individual budgets:

“One of the things my nephew used to mention all the time is that he wants his own room...that he doesn’t want to share his own room. He’s been living in his group home a long time, and we are planning to have him purchase his own home, and I would come live with him. In the meantime, although the group home staff have been challenging to work with, they have constructed an extra bedroom. His roommate has moved to the extra bedroom, and he has his own room. He’s really proud of his room and his privacy, He has his own closet with his own clothes and no one can touch them. One of the care providers came in his room and was trying to show to someone else his drawers and things and he said “no.” This new option came about because he’s been able to voice his needs, and they have been listed and acted on. His opinion really counts now. Attitudes have changed drastically. Before, especially with the care providers, there was a lot of animosity and struggles for control and power. Now the staff ask how we are doing when they acted like they hated us before. There’s a better working relationship, it’s a lot easier and friendlier. They even bought a television for him. The whole attitude of how they provide services and supports to him has changed.”

“I’ve had to fire a lot of staff, which was hard, because of the way they acted. They didn’t listen to me, or weren’t pleasant because they were having trouble at home and brought their problems to work with them.”

“One of my goals is to spend less money than the year before. I’m trying to set some things up for myself, and then I will need less money for my everyday life. This is not just about spending a lot of money. I know better what I need and how to use the money better.”

¹⁶ Exhibit B: 1.c.1. How did patterns of support, paid and unpaid, change as a result of participation?

Organizational Change

Except for those who choose or need the services of a fiscal intermediary to serve as the employer of record for personal services, ELARC has created a self-determination accounting system that is different than its typical Purchase of Service accounting system. This is being provided in part because the Advisory Committee would like ELARC to be prepared to provide this service to people should self-determination expand. Shorter and simpler forms for payment have been created with different check cutting and tracking systems.

Participants and ELARC staff agree that the payment forms are difficult to use, especially for those who do not read well or who do not speak English. Even though the forms have been translated into Spanish and Chinese, there have still been difficulties with forms being filled out correctly and in a timely manner. ELARC staff report that many participants feel that if they turn in the forms incorrectly, the regional center will automatically correct the forms for them. However, ELARC intends that people take on this responsibility and complete the forms correctly, with the help of service brokers as necessary. The forms have been redesigned a few times, and are currently in another period of revision due to recent difficulties with timely vendor payment.¹⁷

Developmental Disabilities Board Area X has been a partner for ELARC in helping to steer the pilot. The relationship with the Area Board is described by many as a “synchronicity of philosophy.” The Area Board is sharing the time of one of its Community Program Specialists to conduct vendor training and to assist in problem solving with vendors. The pilot has influenced some of their priorities as well. As an example, they will be hosting consultants from the Center for Self-

¹⁷ Exhibit B: 1.c.2. How do the policies, procedures, and practices of participants, DDS, pilot projects, vendors affect these outcomes?

determination to provide intensive training and mentoring to assist a small group of interested people with developmental disabilities to start micro-enterprises.¹⁸

Qualitative Findings

Service Coordinators report feeling that self-determination is a challenge for some cultural groups who want the “professionals” (in this case the regional center) to tell them what to do. They also discussed high levels of family participation in some cultural groups. The awareness of cultural differences has resulted in regional center staff referring more often to families rather than just the person with a disability, although the person remains the primary focus. Overall, the service coordinators observe that the regional center service system has created a dependency for people, but participants are learning enough in a year to free themselves from the system and look to the community, friends and family for support. They also noted that individual personality differences affect the self-determined level of each participant.¹⁹

One residential provider feels that self-determination is not for everyone, and that the regional center should have conducted a case review, with input from vendors, on who would be appropriate for the self-determination program. In the case of their resident, whose family was part of his circle of support who decided he should participate, the vendor feels it is “not appropriate for this person to be making these decisions,” especially about moving from the group home into a home with his aunt and exploring a decrease in psychotropic medications. As well, they feel his circle of support is too limited to be healthy for him, and that they should be represented in his circle of support. They feel they have not been

¹⁸ Exhibit B: 1.c.3. How are funds being used in self-determination and how is that different/same from previous utilization?

¹⁹ Exhibit B: 1.c.1. How did patterns of support, paid and unpaid, change as a result of participation?

consulted at all after a long-term relationship providing services to the client, and that the regional center has not respected their relationship with him.

The vendors feel that they assume some risk and liability by agreeing to serve participants in the self-determination pilot. They feel they can't speak up for what they need to be reimbursed to provide service and must be willing to take what the regional center offers to keep their business open. Now that vendors are no longer in control of submitting payment paperwork, they are receiving late payments. Their experience is that service brokers provide an extra person to deal within the payment process and that this is not efficient. They observe that families do not seem concerned that vendors are not being paid on time.

There is quite a bit of concern at ELARC about its ability to continue to finance the self-determination pilot at the current level. The lack of funds for expansion of the project has caused some to lose their "gung ho" attitude. Some ELARC staff like to say, "the toothpaste is out of the tube" – that the agency can never return to pre-self-determination days. There is a feeling that even if self-determination does not continue in its present form, regional center business will be better because of the pilot. There are some self-determination cynics, people who have worked in the regional center for years and seen trends come and go, who are labeling the pilot as the latest failed trend. Participants are clear about wanting self-determination to continue, but feel it is not for everyone. Some of the most important aspects of self-determination that need to continue are flexibility, the service coordinator standing behind people, good communication with people with a variety of disabilities, and patience in working with people with disabilities.

TRI-COUNTIES REGIONAL CENTER (TCRC)

Project Vision

Tri-Counties Regional Center planned their pilot with an emphasis on the core principles of self-determination (freedom, support, authority, responsibility) to be reflected in:

- Person centered planning
- Consumer and family control of individual budgets
- A variety of support, planning, coordination options, and clearly identified responsibilities for all parties²⁰

TCRC started to experiment with self-determination before the legislated pilots as a result of its strategic planning process. It began testing self-determination with two families whose children have extraordinary medical needs as a strategy to aid TCRC in putting its agency vision into practice: “People with developmental disabilities will live as full and active members of their community.” In May 1999 the board for TCRC approved the following Service Policy:

²⁰ Exhibit B: 1.d.4. Compatible with the vision and principles articulated by the Self-Determination Steering Committee;

POLICIES AND GUIDELINES - 18000

SERVICE POLICY

SELF DETERMINATION PILOT PROJECT

The Tri-Counties Association for the Developmentally Disabled, Inc. (TCADD) is committed to ensuring inclusion, participation, and community belonging for persons with developmental disabilities. TCADD and the Tri-Counties Regional Center (TCRC) endorse the vision that people with disabilities will determine their own futures, and, in keeping with this vision, have chosen to participate in a Self-Determination Pilot Project.

The Self-Determination Pilot Project will apply the following principles in working with consumers, and where appropriate, their families and/or conservators:

Right to Plan (Freedom and Supports): They shall have the right to plan a life with both natural and publicly funded supports and services as necessary to live life as full and active members of the community.

Authority to Act: They shall have the authority to control the decisions and resources provided under this Pilot Project to meet all or some of the objectives in their Individual Program Plan.

Responsibility for Decisions: They shall accept responsibility and liability for their decisions and for their use of public resources under this Pilot Program to meet the objectives identified in their Individual Program Plan.

TCADD and TCRC understand that the Self-Determination Pilot will be experimental in nature, that procedures will be developed to implement the Pilot Project, and that there may be modifications to these procedures as a result of lessons learned during implementation.

To the extent practicable, however, procedures will be consistent with the following tenets: Participants in the Pilot Project will be representative of the TCRC consumer caseload. Participants will be precluded from purchase of any services or supports that are either illegal or medically harmful. All purchases of goods and services through this Pilot Project shall be for the benefit of the person with disabilities.

The Pilot Project will be fiscally neutral over the aggregate of participants.

Approved May 1, 1999 by the Tri-Counties Association for the Developmentally Disabled, Inc.

Participant Selection

There are currently thirty participants in the TCRC pilot. Twelve were signed up the first year and nine in the second and third years. TCRC randomly selected two groups of people, children and adults living and not living in their family home, who were invited to informational meetings to learn about self-determination and to make a decision about participating.²¹

A number of stakeholders in the TCRC pilot feel that the random selection was not a good strategy for judging the real viability of the program. It is felt that parents and adults who are frustrated by the system and have a clear idea of different services would have been better participants for the pilot.

Eight potential participants “dropped out”, are considering dropping out, or never started with the pilot. Three people/families had difficult life circumstances, (including a death) that prohibited them from participating. Four did not see or understand the benefit of self-determination. One was adamantly opposed to the cost neutral budget setting methodology.²²

Project Operations

Organizationally, the TCRC pilot is staffed by the pilot funds with a full-time Fiscal Assistant and Consultant. The Fiscal Assistant sets up “vendorization” paperwork, assures budgeted services are authorized by the plan and that services are paid for, monitors the use of services, assures mandated quality assurance functions, processes monthly invoices, verifies and audits service providers,

²¹ Exhibit B: 1.c.1. Who participated in the pilot projects?

²² Exhibit B: 1.c.3. What are the similarities and differences in cost? How do the policies, procedures, and practices of participants, DDS, pilot projects, vendors, affect these outcomes?

assures yearly “rollover” of services, provides technical and on-call assistance to the participants, oversees the use of TCRC operations dollars for the pilot and helps to provide internal consistency between TCRC’s fiscal, case management and resource development departments and functions. Supervision for the pilot is provided by TCRC through the Community Services Department. In the second year of the pilot the supervision was extended to the Consumer Services Branch Managers.²³

TCRC has a part-time staff member, a Michael Smull Master Trainer, who assures that Essential Lifestyle Planning is the strategy used at TCRC to complete Individual Program Plans. She assisted in designing the in-house format for the self-determination plans. TCRC leadership wanted broad implementation of the pilot throughout the agency because self-determination is a business practice that TCRC was testing through their strategic plan. When participants signed up for the pilot, their Service Coordinator was asked to join them in the pilot. If this was not possible, other volunteer Service Coordinators were available to the participants.²⁴

These kinds of voluntary initiatives have often been a sticking point for the Service Coordinators union. There are eleven Service Coordinators, which means that some service coordinators have multiple self-determination participants on their caseload. TCRC also wanted to test if Service Coordinators could perform both their typical case management function as well as the functions of service brokers. Service Coordinators have been given no relief from their average caseloads of 62 people. The Service Coordinators, Branch Managers and pilot leadership staff are invited to periodic meetings to share the successes of self-determination and to problem solve any barriers to self-determination.

²³ Exhibit B: 1.c.2. What strategies are used to achieve desired outcomes?

A pool of service brokers is developing, as Service Coordinators are finding that they cannot fulfill the complete service broker's role, especially for participants who need assistance in developing specialized, individualized services. TCRC's consultant assisted in designing a service broker recruitment and training effort. TCRC is expecting half to two thirds of their participants to soon be using the services of a broker. Broker services will be purchased through individual participant budgets.²⁵

Many involved in the TCRC pilot state that creative thinking on the part of the Service Coordinator is key to the success of self-determination. The TCRC pilot consultant is now available to participants and/or Service Coordinators who would like some technical assistance with creative thinking. The consultant is available to visit participants who have not made any changes to their services to see if a different form of facilitation in planning may assist them, or to determine that they are truly satisfied with the plan they had put together for themselves before self-determination. Below are the words of one of the Service Coordinators who has worked with some families to make dramatic changes:²⁶

“For me I feel I have more of a partnership relationship than I have with other families on my caseload because I don't have to sit inside of a 'box.' I'm not looking at people to see what service policies they fit into – I'm listening and discussing options. I've not having to say 'no.' Families feel in control. In our usual system we have to go back many times through our exception process to make things happen creatively. With self-determination, there's a twenty-four hour turnaround. Initially it takes a lot of work for families to be more empowered, but I don't think anymore than my usual work.”

²⁴ Exhibit B: 1.a. Detailed description of the development, implementation, and management of each pilot project, including whether the pilot project met the expectations expressed in their proposal, and any subsequent revisions.

²⁵ Exhibit B: 1.c.4. What effect does participation in self-determination have on the types and amounts of services and support utilization?

²⁶ Exhibit B: 1.c.1 How did patterns of support, paid and unpaid, change as a result of participation?

Budgets

Historical expenditures, as opposed to allocations, are used as the basis for the TCRC budgets. If families have requests for an allocation that exceeds the historical costs, then the Service Coordinator uses the traditional exception process at TCRC, described in the Service Policy below. One Service Coordinator reported that it took him seventeen meetings to get the original plan, budget and necessary documents signed for one of the participants on his caseload. This was in part because the participant wanted a budget allocation beyond the historical allocation, and he needed to access the exception process. The participant wanted to include horseback riding services and clinical professionals were called in to make a final decision. Service Coordinators resoundingly loathe the exception process because it is lengthy and requires several levels of approval. Most Service Coordinators will work hard to find generic services and other options before pursuing the exception process.

Except for those who choose or need the services of a fiscal intermediary who serves as the employer of record for personal services, TCRC uses its Fiscal Assistant to process payments for services through TCRC's self-determination pilot with a simpler package of forms than the usual TCRC system uses. The fiscal intermediary serves as the employer of record to withhold and file taxes, provide professional liability coverage, and to ensure compliance with fair labor standards for participants who working with individuals providing them personal services. This fiscal intermediary is shared with Eastern Los Angeles Regional Center. The fiscal intermediary currently charges 30% of each dollar spent for its services. It

was anticipated that this cost would decrease as the use of the fiscal intermediary services increased.²⁷

There are currently some quality assurance issues with the fiscal intermediary around timely payments, accuracy of payroll reporting, and adequate documentation. ELARC and TCRC staff recently conducted an audit of their services. TCRC developed the fiscal intermediary job description with the assistance of its consultant. Research on costs for community fiscal intermediaries revealed rates as high as 50% of expended dollars. Some community fiscal intermediaries were leery of providing this service to people with developmental disabilities because of the anticipated risk in covering personal care services. The fiscal intermediary function is currently the responsibility of a human resources consulting group that specialized in supported living services. The group was recruited to provide the service.

Participants and TCRC pilot leadership are not satisfied with the current fiscal tracking system. Participants are receiving updates up to three months after bills are submitted for payment, making it difficult for people to be more independent in self-managing their spending. There was a sudden increase of requests to spend down budgets at the end of last fiscal year, which seems to have been due in part to the fact that participants were spending their money conservatively because they did not have timely accounting information. Some Service Coordinators believe the year-end requests may have also been due to a lack of quality planning that did not address some priority needs.

²⁷ Exhibit B: 1.c.4. What effect does participation in self-determination have on the types and amounts of services and support utilization?

Organizational Change

Stakeholders in the TCRC pilot are noting signs of organizational and local systems changes:²⁸

“ Self-determination has already influenced our current system. My supervisor (Branch Manager) has changed his thinking, and he’s learning rapidly. The results from the individualized day program we created for the one participant have been so empowering that now the Branch Manager is thinking that we should be doing more of this. He’s thinking that this should no longer be an exception to our policy, but part of our day program policy. We are also negotiating with the Department of Rehabilitation to agree to dual services so that people can get funding for work services, and the regional center can provide support socialization. Traditional rehabilitation services are brainstorming and finding creative solutions to getting people with physical disabilities to work.”

²⁸ Exhibit B: 1.c.2. What difference does self-determination make, for participants, families, providers, regional centers, area boards, the Department of Developmental Services?

Policies and Guidelines - 10101

SERVICE POLICY GUIDELINES

Purchase of supports and/or service

Tri-Counties Regional Center is committed to assisting individuals with developmental disabilities and their families in securing those supports and services which will maximize opportunities and choices for living, learning, working, and pursuing recreational activities in their community.

Tri-Counties Regional Center will purchase supports and/or services for consumers which:

- prevent developmental disabilities or minimize the effects of a developmental delay or disability;
- protect the health and safety of individuals with developmental disabilities;
- prevent or minimize the institutionalization and dislocation of individuals with developmental disabilities from family and community;
- enable individuals with developmental disabilities to approximate the pattern of everyday living of non-disabled persons of a similar age;
 - lead to more independent, productive and normal lives in their community; and
 - prevent significant regression of the individual's functioning level.
- In accordance with the Lanterman Developmental Disabilities Services Act, supports and services may be purchased for a consumer only under the following circumstances:
 - when he/she has special needs associated with a developmental disability or a condition determined by the planning team to present a risk of developing a developmental disability;
 - when the consumer is a minor and the needs are beyond those parental responsibilities normally associated with raising or providing for a minor in his own home;
 - when it has been determined by the consumer's planning team, through the person centered planning process, that such supports and services are necessary to accomplish all, or any part, of a consumer's Individual Program Plan;
 - when such supports and services are identified in the Individual Program Plan and are linked to one or more consumer outcomes;
 - after public resources, as well as other sources of funding available to the consumer, have been used to the fullest extent possible to implement and/or coordinate the supports and services identified by the planning team;

- from a provider of supports and services who is vendored or otherwise authorized by the Department of Developmental Services to provide such supports and services and who adheres to the quality standards set forth by Tri-Counties Regional Center, the Department of Developmental Services and California regulations relating to the provision of supports and services;
- when the rate to be paid is in accordance with the rates established by the Department of Developmental Services or by contract with Tri-Counties Regional Center;
- when, unless otherwise specified, the regional center has approved and authorized the support and/or service prior to the purchase date;
- when the request is for a continuation or renewal of a purchased support or service, such continuation or renewal will be contingent upon consumer/family satisfaction and upon reasonable progress in having achieved the outcome(s) stated in the Individual Program Plan.

Tri-Counties Regional Center will authorize funding for supports and/or services for eligible consumers without regard to race, color, creed, national origin, citizenship, gender, age, or condition of physical or mental handicap.

Tri-Counties Regional Center will not authorize use of purchase of service funds for any support and/or service available through any other resource. This includes all public and/or private resources available to the consumer and family.

The Planning Team, through the Individual Program Planning process, will specify the types and amounts of supports and/or services to be purchased by the regional center. Tri-Counties Regional Center will not authorize or continue authorization of funding for any support and/or service that is not documented on the consumer's Individual Program Plan.

Authorization of funding for specific supports and/or services will be continued when the consumer, or when appropriate the consumer's family or other legal representative, and the regional center service coordinator agree that reasonable progress has been made toward objectives for which the service provider is responsible.

Tri-Counties Regional Center will not authorize funding for any form of program therapies, drugs or special services considered by recognized professionals to be experimental and/or potentially harmful to the individual. The expected outcome from the purchase of any support and/or service must be both clinically and fiscally an effective use of public funds.

Disagreements between the consumer, or when appropriate the consumer's family or other legal representative, and the regional center representative will be resolved through the Fair Hearing process.

Exception Policy:

Tri-Counties Regional Center recognizes that some individual needs are so unique that they may not be addressed in this Service Policy and may require an exception. Such requests for an exception to a Service Policy will be made through the Planning Team Process.

Approved July 11, 1998 by the Tri-Counties Association for the Developmentally Disabled, Inc.

Qualitative Findings

The parent who is opposed to the budget setting process is concerned with her child's historical data. The way she understands the current system, as she needs a service, e.g. respite, she is able to have it authorized, whether she uses the entire amount or not. In self-determination, the amount actually expended is used, which is less than the historically authorized amount. Her adult child has been ill for the last few years, and therefore her actual use of services has been lower than the authorization. This mother does not feel comfortable working with historical expenditure data because of this situation. Her interpretation is that she would need to purchase services that she doesn't need in order to get a self-determination budget that she feels comfortable with. This seems absurd to her.

One adult participant had difficulty expressing her confusion with the self-determination pilot, and her group home provider spoke on her behalf. Reportedly, she prefers trusted, known situations and does not react well to changes in her daily routines. The idea of potential life changes through self-determination seemed to frighten her. One father reported that all he wanted was "mechanical legos" for his son, and that he was being told this was not possible and he didn't understand how that fits with his understanding of self-determination. Two families are not feeling supported by their Service Coordinators to make self-determination a reality. One family feels the burden of the requested responsibility to make things happen, when they feel that is the role of the regional center. One single mother with an adult child with significant disabilities feels overwhelmed. She desperately needs respite services, but is unable to recruit staff at the wage level she has to offer.²⁹

One Service Coordinator believes that no one in the pilot is exploiting state funds. Participants seem willing to give back money they

²⁹ Exhibit B: 1.f. Identify, assess, and discuss system level changes needed to readily and successfully improve and expand self-determination.

have not spent because they understand that it will be used for the good of others. They also understand that mismanaging their budgets may end the pilot. They feel their participation in the pilot is a privilege.

Vendors who are participating with the pilot have great hope for the work although they are experiencing mixed responses of success. They find that excellent person centered planning is key; without this different needs may not be discovered. Some vendors feel that planning skills are not consistent across the many service coordinators who are involved with self-determination and that is reflected in inconsistent participant success. In some cases, the only obvious difference for the vendor is that there is a different billing format.³⁰

There are many examples of how TCRC's self-determination pilot has relieved, and in some cases added to, the stress of caring for family members with disabilities, as evidenced in the individual stories.³¹ One Service Coordinator who is working with monolingual Spanish speaking families reports that self-determination has been a cultural struggle. Hispanic families do not always feel they have permission to take power, and the Regional Center is seen as the place with the power. Questions of family responsibility in providing for any child's enrichment, whether they have a disability or not, have made some branch managers "squirm" in their new role of "approving" the budgets and plans. Below are narratives about a monolingual Spanish speaking family, and a family who is struggling to support an adult daughter as she gains independence:

"Legal services for citizenship were provided for the mother out of the child's budget. This has resulted in a tremendous change for the family. The mother feels better; this has given her tremendous hope and a 'burst of energy' to take charge of her life – she wasn't

³⁰ Exhibit B: 1.c. 2. What difference does self-determination make, for participants, families, providers, regional centers, area boards, the Department of Developmental Services?

³¹ Exhibit B: 1.c.4. What effect does participation in self-determination have on the types and amounts of services and support utilization?

following through on the citizenship before. She was poor and living with her child with a disability with her parents, which was an abusive situation. She now has a place of her own and will soon be able to get a job and benefits and have a very different life.”

“One of my families has been disgruntled with me because I am trying to empower their adult daughter. I need to advocate for her first – they will always be second. I can’t get past that to real partnership – no matter what I do. The daughter is in her own apartment; she has a peer who is paid to support her four nights a week, and they hang out; they’ve known each other for a long time. They work on their budgets, cooking, diets. She fired her other support agencies – they just didn’t work well.”

There is quite a bit of concern about the potential for expansion at TCRC, especially in light of the Governor’s decision to decrease funding. As one consumer commented:

“Regional centers are so cautious because they fear they can’t handle the changes, so they often offer false promises. Instead they could take leadership and say ‘here’s something we believe in and were going to do it!’”

A Service Coordinator noted:

“No additional expenses were spent on me. My gut tells me that this work can be absorbed into the regional center, even though this seems to be a front loaded process. Certainly a caseload of 45 would make more sense. It would sadden me tremendously if self-determination were nuked – it works so much better. It makes so much sense. Most of the people I work with would benefit from this. It doesn’t make sense not to do this!”

REDWOOD COAST REGIONAL CENTER (RCRC)

Project Vision

The Redwood Coast Regional Center believes that the self-determination values (freedom, support, authority, responsibility) are only realized through the person centered planning process. In order for people to exercise true freedom and authority, people must have choices that allow a full range of options.³²

Executive Staff report that the self-determination pilot afforded RCRC a mechanism to apply their vision statement, revised in June of 1999, to its agency practices. RCRC's vision statement is:

Redwood Coast Regional Center is committed to providing a wide array of services and supports to people who have developmental disabilities, individuals at risk for disabilities, and families of people with developmental disabilities. We stand ready to work with consumers to educate each other and the community on the ongoing issues surrounding disability rights. We expect all interactions with consumers, our staff and the community at large will be conducted in an open, honest, and flexible manner.

In the Spring of 1998, a formal statement of vision was developed through a collaboration of consumers, families, staff, and directors. It reads:

³² Exhibit B: 1.d.4. Compatible with the vision and principles articulated by the Self-Determination Steering Committee

OUR VISION...

It is the vision of Redwood Coast Regional Center that all people in our community, including individuals with developmental disabilities, will live, learn, work, travel, and play in the best, most inclusive environments.

We envision strong, healthy individuals and families whose emotional resources are renewed and supported by community and regional center. We envision full access to a complete array of health services throughout life.

We envision a system of services and supports that is determined by the individuals served. We envision a process that is complementary to the individual's own life, and which does not intrude upon the person's chosen lifestyle. We envision people residing in the living arrangement of their choice. We recognize that life is made meaningful by loving, being loved, and having friends and relationships. We acknowledge that life is enhanced by contribution, responsibility and the opportunity to learn new ideas and to engage in new experiences, including educational opportunities, social interactions, and work activities. We envision a system of services and supports which acknowledge the person's age, lifestyle preferences and culture, and which is fluid and ever changing.

We envision all people being empowered to communicate with their own minds and hearts to determine their supports and services.

We also subscribe to a vision which represents the highest commitment to excellence. We envision a commitment to honesty, compassion, trustworthiness, flexibility, responsiveness, accountability, accessibility, creativity and a passion for community service. We envision a joyful and supportive environment in which trust is the cornerstone of all interactions, humor is appreciated and everyone participates fully in teamwork. We envision one community. We value diversity and honor individuals.

We strive to be accessible, to be knowledgeable; to be accountable, to accomplish tasks in a timely and effective manner, and to offer and receive feedback formally and informally on in fulfilling our mission and realizing our vision. We envision all members of the support community having

access to adequate resources, including funding, in order to provide desired services and supports. We envision a collaboration between members of the community which creates a whole of services and supports which is greater than the sum of its component contributors. We acknowledge that shared learning, communication and planning activities will provide the greatest benefit for those individuals we mutually serve, as well as for our respective members. We envision a culture in which all members of the community are respected, supported, honored, and recognized for their diverse contributions and valued services.

We envision educational efforts which focus on teaching relationship rather than care giving; which teach support rather than control; which teach communication rather than regulation. We promote informed exploration and risk taking, with opportunities for feedback. We envision individual and community satisfaction as the standard by which all services are measured.

Participant Selection

As of July, 2001, there are 29 participants enrolled in the RCRC pilot, and 17 of those have signed person centered plans and individual budgets. It was decided that the pilot would be implemented in Mendocino County, one of the four counties served by RCRC. A computerized random sample of regional center clients was identified and they were invited to self-determination informational meetings. It took three random invitation and information series for 29 participants to choose to participate in the self-determination pilot. RCRC key staff feel that it took so much effort to find the participants because people are satisfied with their regional center services, or because they were not aware of the benefits of self-determination. In hindsight, they feel they could have let interested people self-select for participation without a random sampling method. Participants can choose to leave the self-determination pilot at any time and return to their usual regional center process.³³

Project Operations

Organizationally, the RCRC pilot is staffed by the pilot funds with a full-time Self-determination Project Manager and a full-time Service Broker. A consultant was used briefly to assist in setting up fiscal intermediary services.³⁴

When participants sign up with the self-determination pilot, they maintain their relationship with their Service Coordinator because so many people have long term relationships with their coordinator. This practice allows the Coordinators to share valuable information as part of the circle of support. Another reason for maintaining the relationships is that Service Coordinators at RCRC are often

³³ Exhibit B: 1.c.1. Who participated in the pilot projects?

³⁴ Exhibit B: 1.c.2. What resources do participants put together to achieve self-determination?

providing families with Individual Educational Planning support. The Service Broker, formerly a RCRC Service Coordinator, takes the lead in planning, developing the budget and assisting in implementing the person centered plan. She reports that the process of planning and budgeting takes about four months per participant and includes an average of 13 meetings and about 40 hours of her time.³⁵

Some RCRC staff expressed frustration with the length of time it is taking for the self-determination pilot to progress. Service Coordinators report that some families need to go slowly in order to understand the self-determination concept and to identify the important issues in their lives. They report that time to become comfortable with the philosophy and the shift in responsibility and power is especially crucial for Latino families.

The Service Broker feels that her role is different in that she is a “powerless party” in the planning process. She describes her role as giving people information, helping them to do the things they need to do and only offering her ideas and opinions when asked. She feels that the self determination planning process is much more involved than her previous work as a Service Coordinator. Her goal is to assist people to develop goals from their dreams, but she finds that people need to begin with doing a little research on their dreams. The Service Broker 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.³⁶

³⁵ Exhibit B: 1.b. Detailed description of the development, implementation, and management of each strategy used to achieve self-determination.

³⁶ Exhibit B: 1.b. Detailed description of the development, implementation, and management of each strategy used to achieve self-determination.

Budgets

Once the person centered plan is completed, a draft budget is attached and compared with the person's previous year expenses. If a participant had no regional center funds allocated in the previous year, or if the budget needs adjustments due to emergencies or unanticipated service needs, the Budget Planning Review Committee finalizes the plan and budget. Anticipated reasons for utilizing the Budget Review Committee are:

- Person is age 18 – 22 and transitioning from high school
- Person is new to the area or regional center
- Lack of vendored services available
- Desired support services do not meet traditional service standards or vendor categories
- Changes in service needs due to life changes, e.g. aging or changes in medical condition

The Budget Review Committee includes:

- Redwood Coast Regional Center representative: Executive Director or Associate Executive Director
- Area Board 1: Executive Director or designee
- Local Advisory Committee: President or designee
- Redwood Coast Regional Center Consumer Advocate
- Redwood Coast Regional Center Director of Consumer Services

The Project Manager submits requests for a Budget Review Committee meeting, to be convened within seven days. The person, family, Service Brokers, and others chosen by the person/family attend the meeting. Three members of the committee are needed for a review to take place.³⁷

³⁷ Exhibit B: 1.c.2. What strategies are used to achieve desired outcomes?

The Project Manager has been spending a majority of her time this year working out the fiscal issues. She reports the Executive Director is very supportive of the pilot and has told her to do what it takes to make the pilot happen. An example of this is the using the outside fiscal intermediary when it became clear to the manager that building an in-house fiscal system seemed would not match the self-determination principles.

RCRC staff report that they figure out from the budgets what people need to get through the first two months of their plan and that amount is sent to the fiscal intermediary. Participants spend according to their plans and the person sends the bill to the fiscal intermediary. The fiscal intermediary uses the participant's plan as a guide and if the submission for payment makes sense it is processed. Typical regional center service codes are not used in this system, but the fiscal intermediary has a simple accounting system that reports what people are purchasing. The Project Manager audited the fiscal intermediary after three months and found the system to be working well.³⁸

Participants and self-determination project staff find this system immediate, responsive, and accountable. As an example, one young man wanted to go to camp, but respite was in his plan. The cost for camp was \$64. He called the fiscal intermediary and asked her to pay for camp for him. The fiscal intermediary called and double-checked with RCRC and then paid the bill. As RCRC self-determination staff reflect:

“So here’s a person controlling his own life – he didn’t call us to say he needed more money – he didn’t even think to do this.”

³⁸ Exhibit B: 1.c.4. What effect does participation in self-determination have on the types and amounts of services and support utilization?

Organizational Change

Monthly potlucks are arranged for and by the participants at the RCRC Ukiah office to share in their excitement about the pilots and to support each other in their life plans. The newest self-determination participant was a former resident of Ukiah, and has been living at the Sonoma Developmental Center for a portion of his adult life. One of the other members asked the service broker to share with him that he will be his friend and guide when he moves back to Ukiah, as he remembers how lonely he was when he moved there and how long it took for him to make friends. A number of the participants are located approximately two hours away from the Ukiah office. RCRC has teleconference equipment in its Fort Bragg office for its telemedicine program, and this technology is being experimented with to bring people together throughout the county for the potlucks. At the July potluck, one of the members brought a dramatic and touching video tape from his high school graduation. He had advocated for ramps on both sides of the stage and a standing wheelchair as his dream was to walk across the stage at his graduation.

RCRC has experienced limited participation from the traditional regional center vendors in self-determination efforts. Few attended the public information sessions. A few participated in the evaluation process. RCRC management notes that no vendors have gone out of business due to self-determination. Vendors were part of the community process to develop the vision statement. When disagreements³⁹ come up with vendors, RCRC staff find it is “magical” how turning back to the vision statement helps in solving problems. It is RCRC’s experience that the combination of the vision statement and the self-determination

³⁹ Exhibit B 1.c.2. How are conflicts and disagreements among players resolved?

pilot is transforming traditional, segregated services into services that are more client centered.⁴⁰

Both the leaders of the Area Board and the regional center agree that working relationships have improved because complaints are being resolved. Both hope that self-determination will become available to a larger group of people and therefore further reduce complaints. The Self-determination pilot has given the Area Board Director the freedom to work on more proactive and integrated community resource development (e.g. drug and alcohol and hunger and poverty issues) in the communities of RCRC instead of focusing on resolving consumer complaints with the regional center.⁴¹

The Project Director looks forward to increased progress next year as participants and their families become more familiar with the process;

“Families are planning six months after the first plan begins. They’re already planning the second year...once the folks get the idea that this is their life when they’re planning their budget, it’s kind of an ongoing thing.”

There are mixed opinions among the leadership of the RCRC project regarding safeguards. One train of thought is that the best safeguard is assuring that people with disabilities have caring people in their lives and control over who comes into their home, who sleeps next to them, and who helps with their money. The other train of thought is that because people with disabilities historically experience higher rates of abuse, it is the system’s responsibility to put systems, like regular visitation, in place to assure safety.⁴²

⁴⁰ Exhibit B: 1.c.2. What difference does self-determination make, for participants, families, providers, regional centers, area boards, the Department of Developmental Services?

⁴¹ Exhibit B: 1.c.2. How are conflicts and disagreements among players resolved?

⁴² Exhibit B: 1.d.3. Included adequate safeguards for ensuring freedom from exploitation, abuse, neglect, and harm

Qualitative Findings

Some staff report having “taxpayer twinges” from the practices of self-determination. One service coordinator has a participant on her caseload who needs to take a day off work from a low paying job to take his daughter to a medical specialist. He has included reimbursement for his wages in the family budget. The service coordinator is nervous that many other people will request such support. A manager expressed some concern about self-determination budget funds being used for a spa and swimming pool for someone who needs minor physical therapy. The participant was unable to successfully attend the local community gym because of negative reactions to her disability.

Self-determination staff suggest that many service coordinators are positive about self-determination because it has not yet had an effect on their jobs. There is an enduring feeling that the project could backfire. There is concern among the leadership of the regional center that self-determination cannot be accomplished without substantially decreasing caseloads. One manager recently conducted a basic analysis of how much time Service Coordinators have available to spend with consumers after their benefit time is subtracted from their required 1:62 caseload. The result was 1.5 hours per month, less time than the Service Broker has been spending with the self-determination participants. Staff feel that 1.5 hours per month is not sufficient time to implement the vision of the agency. Service Coordinators feel that excessive Medicaid documentation requirements keep them from having the time to fill some of the service broker functions.⁴³

Service Coordinators describe the plans completed with the participants and the Service Broker as complete, thoughtful and innovative, especially in their area that is known for having limited resources. They also find that the plans are

⁴³ Exhibit B: 1.c.4. What effect does participation in self-determination have on the types and amounts of services and support utilization?

visually different and “beautiful,” with the cover page filled with clip art that people select to reflect what is important to them about their life and plans. They report that the plans are written in language that people can understand, and do not include the jargon that is typical of traditional plans. Service Coordinators find that these plans are not “stashed away” and are in fact used by the participants. They find the Service Broker to be very responsive to each of the participants.⁴⁴

The Review Committees have been a positive experience. It has only been convened a few times for requests of a few thousand dollars each. Members describe the meetings as “hearty and enlightening – a real change” from the typical regional center process of reviewing exceptional requests. The committee is not “intrusive – they feel that the details of people’s lives are none of their business. Their attitude is that the planning has been done well and that people don’t need to submit details of their private lives to receive a fair review. All the requests make sense when you look at someone’s life. But because this is a pilot, we will keep our eyes on unusual things, like swimming pool cleaning services, golf carts, down payments on phones, and cell phones. The committee has been helpful at pointing out that sometimes people need more than requested because they don’t want the plan to fall apart after six months over unanticipated costs.”

One vendor who is a therapist reports wonderful progress for people because they feel empowered. Because she has a good sense of self, one client is now pursuing a life long ambition to find her daughter who was taken from her years ago. Another woman often felt timid, excluded and invisible in her neighborhood. She is now feeling empowered from regularly making decisions and wrote to the governor about the need for self-determination. She is also hosting a barbecue at her apartment. The vendor reports how different this outcome is from her

⁴⁴ Exhibit B: 1.c.2. What difference does self-determination make, for participants, families, providers, regional centers, area boards, the Department of Developmental Services?

“typical” regional center system experiences with “crazy making procedures” that make people wait long periods for responses to requests for help.

Another more traditional service provider is concerned about the way vendors are being treated within the self-determination pilot. She feels that vendors are in business to help people; that there is a supportive vendor community in Mendocino County, but that vendors are being treated like adversaries, like they are “trying to rip people off.” As a matter of course, the service broker was attempting to negotiate lower rates, when those are the rates this vendor feels are necessary to stay in business. She feels that participants are being given the message to be empowered and to take charge of their services, but are not being given the practice to handle that situation in a diplomatic matter. The vendor feels that participants need to consider that the people who are working with them are part of their team, and if they treat them disrespectfully people will not want to work with them⁴⁵.

There is concern at RCRC as to whether the pilot will continue and/or expand because of the lack of state dollars. There is some feeling that if RCRC employed Service Coordinators who are truly able to be a “powerless party,” that it would not take as much effort to prepare the organization to expand self-determination in the agency. RCRC Service Coordinators are currently uncomfortable with implementing the new RCRC Purchase of Service guidelines that give much less direction of how to authorize services on behalf of people with developmental disabilities. The guidelines were recently revised in response to the agency vision and Lanterman Act amendments. The guidelines are much more

⁴⁵ Exhibit B: 1.c.2. How are conflicts and disagreements among players resolved?

open to consumer and family choice than in the past, and self-determination practices are even more open ended than these guidelines.⁴⁶

SUMMARY OF STATE LEVEL FOCUS GROUPS AND INTERVIEWS

Our discussions with state level leaders about the self-determination pilot projects focused on systems issues. Some DDS staff feel that they need to give the pilots the freedom to problem solve implementation problems. Their hope is that leadership will come from the participants, consumers, and families who receive services from the regional centers as they are the people who will benefit from a new way of doing business.

There is some disagreement among the pilot leaders with regard to the state's role in facilitating the self-determination initiative. Some expressed concern about expanding the pilot project without statewide consistency in implementation strategies. Some are looking to the Department of Developmental Services to solve process and policy issues such as the question of saving or carrying forward individual budget surpluses or the time consuming financial rollover process that does not match participants' budget calendars. As one manager stated:

“There’s not enough pureness to the guiding principles – it needs a more structured bureaucracy I hate to say. If things go this way with some regional centers saying that we already do self-determination, and we all do different things, what will we become? Unless someone takes the lead and has the leadership, that I think needs to come from the Department, I don’t think self-determination will happen.”

⁴⁶ Exhibit B: 1.d.5. Met pilot outcomes, as defined by the local advisory committee; and
6. Consistent with the philosophy, values, and requirements expressed in the Lanterman Act.

Another major topic at the state level was the importance of person centered planning and what needs to be changed to make sure that everyone has the support they need to develop and implement good plans. Many view person centered planning as the first step toward self-determination for participants, a way to help them start to think outside of the traditional developmental disabilities service system and to focus on what is truly important in their lives. There is concern that management staff at the pilots report that it takes an average of 13 meetings and/or 40 hours to develop a plan. This is a problem because Service Coordinators have an average maximum of 18 hours to spend with people/families each year. As one Department employee pointed out:

“We must not lose sight of our mission in California which is to promote as much self-determination as possible for everyone, whether or not it includes individual budgets. Everything we do should be aimed at people being self-determined.”

There is a sense that the pilots are indicating that self-determination is a resource heavy program, and worry about that kind of message to the legislature. In defense of the concept, many believe that the small sample of participants in the pilots does not allow for measurement of economies of scale.

The self-determination stakeholders in California, participants and professionals, are committed to continue the pilot projects and to resolve the major systems issues so that expansion becomes a viable recommendation.

Personal Stories

“Call Us Back Next Year To Find Out What’s Really Happening.”

Pete and his Mom were interviewed for last year’s report. They described Pete’s life to date and their expectations for the self-determination project. Her appropriate closing comment, quoted above, has become the sub-title for this section.

Pete was seventeen years old last year when he and his family decided to become involved with self-determination. He is a strong advocate for himself and for others with disabilities, concentrating on issues that are important to people who use wheelchairs. One of Pete’s major goals was to walk across the stage at his high school graduation. In typical fashion, he found a way to accomplish his goal despite his cerebral palsy.

Pete began by lobbying the school for ramps (that’s ramps plural) because he wanted people in wheelchairs to cross the stage like everyone else, not have to make a u-turn and exit by the single ramp. The principal and the wood shop surprised him by installing three ramps. Pete’s wheelchair repairman lent him a stand up chair for the special day. Pete was so excited that he forgot to lower the chair and proudly rode off the stage, in a standing position, clutching his hard earned diploma.

Post graduation, Pete attended Camp Rubber Soul and was chosen to participate in the California Governor’s Committee for Employment of Disabled Students. This youth leadership forum was held at California State University in Sacramento.

Self-determination has not made Pete a strong advocate, he did that for himself, but he does say that the project has helped open doors to more opportunities. Pete's latest goal is to purchase a new computer with more voice activated programs. He would also like to have his own racecar but knows that for now he must be content with hanging out with his racer friends at the local track. He has many friends in his community and, like most eighteen year olds, is looking forward to moving out of his family home.

Warren is a 24 year old man who is described by his Mom as "quite a guy." He has lived longer with his terminal illness than anyone else on record. Warren's parents had just about given up on regional center services, despite the expensive and long term support that Warren needed. "We were taking a lot of time off work and our jobs were in jeopardy." They decided to try self-determination because it offered more choices.

The first year on the road to self-determination has included several major milestones. Warren recently acquired a Dynovox communication device, an item his family had spent at least four years arguing with insurance companies to purchase. When he started using this new talking device he had only three choices," yes," "no," and "I want." Those limited choices mirror the service choices open to him before the self-determination pilot. Warren and his family were not using their authorized family vendored respite and in home support hours because they could not find staff they trusted. They could have said "yes" to services that did not suit their needs, they did say "no," but they continued to hope that someone would listen when Warren says "I want."

Warren's Dynovox now has links to 121 options with special pages and phrases for his day program and his family. His self-determination support broker helped him and his family write a job description and a want ad, and to pre-screen and interview staff. The broker reports that she handled most of the process on the first round but that the family has now completed the process twice on their own and only need to call her for advice. They now have more options in selecting support than when they were dependent on an agency to recruit and train personnel. The support broker also helped them to allocate their hours and funds so that they could increase staff wages from \$7.79 per hour to \$11.20 per hour.

Warren also used his individual budget funds to purchase a wheelchair lift for the family van. This not only increases his opportunities for getting out into the community but also preserves the health (and backs) of his Mom and Dad who are his primary caregivers. Warren has hired a physical therapist, of his own choice, who comes to his home. According to his Mom, this makes a big difference because Warren will work harder with someone he likes.

Warren's plans for next year include renovations to the family bathroom, another choice that will give him more independence and facilitate caregiving for his family and support staff. Warren and his family continue to plan for the future despite his diagnosis, they will continue to break records for survival.

“Things are so much better now because of the self-determination program.”

Warren's Dad

“Thanks to self-determination we have less stress. We have people in our home we trust. Our case worker is responsive to every phone call. Any disabled person

or their family should all have this service because there are single moms that need this service. Everyone needs this - it's good for all. You don't get lost in the system this way. We had been lost for 19 years. The door has been opened for us, and we're running through it. Warren's Mom

Allan is really happy with his decision to participate in the self-determination project. He is a 28 year old man who has mild mental retardation and who has been receiving supported living services. He was having trouble meeting his expenses with the salary he earned at a sheltered workshop.

During his first year of self-determination, Allan re-allocated the fees formerly paid to a workshop and hired an old job coach to help him find a landscaping job. He has since changed to a janitorial position and is happy that he has the freedom to make such choices and to select the person he wants to help him. With the help of his circle of support, Allan has learned to budget his money and to pay his bills on time.

In Allan's own words "It's nice to have someone there for me." Self-determination has given him the confidence to voice his dreams and to act on his decisions. "I used to be quiet and now I speak up for myself." Finally, Allan ended fiscal year 2001 with a balance of \$4,274 in his budget. Allan's story illustrates the basic hypothesis of the self-determination initiative "If people gain control, their lives will improve and costs will go down."

"I am really happy. We (people with disabilities) need the support to make it in the world." Allan

Quantitative Results

One of the most important goals of the self-determination evaluation was specified in Exhibit B of the contract. It was deemed urgent to learn about the differences and similarities among the three self-determination pilot efforts. In this Results section, we break down our analyses by pilot project to search for patterns of differing outcomes, if any. Overall, we are also interested in testing the three-part “operational definition” of self-determination:

- Power shifts
- Lives get better
- Costs stay the same or go down

First, we will examine the evidence about shifting power. Next, we will analyze the Personal Life Quality data for evidence about changes in qualities of life and qualities of service and support. At the end of this Results section, we examine several kinds of fiscal analysis, all of which should be considered preliminary, seeking evidence of changes in the costs of supports delivered by the developmental disabilities system.

We must note that this Results section does not contain all the analyses we have performed. In a number of areas, we conducted intensive investigations, and simply found no evidence of change or significance. In order to maintain the focus of this interim report on the most important issues, we chose to avoid extensive reporting on factors that showed no impacts (thus far) of self-determination. Examples of these apparently unaffected dimensions include number and depth of friendships, types of day activities (although two people did become self-employed

and one person got a competitive job), injuries, allegations of abuse, patterns of medication utilization, and patterns of health care utilization.

At this point in time, we have obtained comprehensive data for 80 people before most of them became fully involved in self-determination (back in early 2000), and during their involvement (mid-2001). Some people declined to participate in the interview process at one time or the other, and some just could not schedule their data collection visit by the time this report was prepared. A few people who were in the participant group last year have ceased involvement, so they could not be included here. The numbers of people included in these analyses are shown in the table below.

Table 2
Number of People for Whom We Now Have “Before-And-During” Data

	TCRC	RCRC	ELARC	ELARC Comparison	Total
Number	20	24	22	14	80

As the table shows, we do not have complete before-and-during data for all 30 people at each pilot site. This is because of several reasons listed above. Also, because the numbers in each group are below 30, we have performed all of our statistical tests using both the parametric and the non-parametric approaches.⁴⁷

⁴⁷ The usual parametric tests, such as the classical Student’s *t*-test, assume either large numbers (at least) 30, or normal distributions with homogeneity of variance. Below 30, non-parametric tests are generally more appropriate. For this report, we have performed both, and have found that the two tests produce almost exactly the same results in each analysis. We report the appropriate test(s) for each analysis. The parametric tests are more familiar and they lend themselves to the more conservative interpretation.

Demographics

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).

Table 3
Average Ages of Participants, Broken Down by Regional Center Pilot

	SD Participants	TCRC	RCRC	ELARC	ELARC Comparison
Age	25.1	23.2	34.6	20.8	29.2

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

The average age varied from just under 21 years of age to almost 35 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 Comparison, showing the percentage in each group who were male.

Table 4
Gender Breakdown by Pilot Regional Center: Percent Male

	SD Participants	TCRC	RCRC	ELARC	ELARC Comparison
Number of Males	51	15	19	17	8
Percent Male	77%	75%	79%	77%	57%

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

The percentage of males was more than half in all groups, yet the variations across the Regional Centers and Comparison Group were not statistically significant by nonparametric tests.

The table below 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.

Table 5
Ethnic Breakdown by Pilot Regional Center

	SD Participants	TCRC	RCRC	ELARC	ELARC Comparison
Caucasian	53%	60%	75%	23%	14%
African-American	3%	5%	0%	5%	0%
Hispanic or Latino	35%	35%	21%	50%	57%
Native American	2%	0%	4%	0%	0%
Asian	8%	0%	0%	23%	21%
Other	0%	0%	0%	0%	7%

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 makes sense because ELARC is in an urban setting with large proportions of non-Caucasian citizens.

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.”

Table 6
Level of Mental Retardation Label (If Any) by Pilot Regional Center

	SD Participants	TCRC	RCRC	ELARC	ELARC Comparison
Not Labeled	36%	40%	39%	29%	25%
Mild	31%	35%	28%	29%	42%
Moderate	9%	5%	6%	14%	17%
Severe	14%	5%	6%	29%	0%
Profound	5%	10%	6%	0%	8%
No Level Assigned	7%	5%	17%	0%	8%

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

For the most part, most of the responses were consistent from Regional Center to Regional Center, and even between the Self-Determination participants and the 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 settings within which the people were living. We collapsed all answers into three broad categories: “Group Home,” “Supported or Independent Living,” and “With Family.”

Table 7
Living Situations of the Participants by Regional Center Pilot

	SD Participants	TCRC	RCRC	ELARC	ELARC Comparison
Group Home	14%	25%	4%	14%	21%
Supported or Independent Living	24%	25%	29%	18%	14%
With Family	62%	50%	67%	68%	64%

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

The largest percentage of people was living “With Family.” Any variations across the Regional Centers, and between the Self Determination and 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” in a list of secondary disabilities.

Table 8
Percentages of People Reported to Have “Major Disabilities” by Regional Center Pilot

	SD Participants	TCRC	RCRC	ELARC	ELARC Comparison
Ambulation	22%	30%	10%	27%	17%
Autism	18%	25%	10%	18%	33%
Behavior: Aggressive	8%	10%	5%	9%	25%
Behavior: Self Abusive	2%	0%	0%	5%	8%
Brain Injury	13%	10%	17%	14%	0%
Cerebral Palsy	11%	10%	5%	18%	8%
Communication	32%	40%	19%	36%	17%
Dementia	0%	0%	0%	0%	0%
Health Problems	23%	20%	14%	33%	17%
Hearing	3%	10%	0%	0%	0%
Mental Illness	3%	0%	5%	5%	8%
Physical Disabilities	11%	10%	5%	18%	0%
Seizures	15%	10%	19%	14%	0%
Substance Abuse	2%	5%	0%	0%	0%
Swallowing	3%	0%	0%	9%	0%
Vision	13%	10%	9%	18%	8%
Other Disabilities	7%	7%	0%	0%	0%

None of these variations across the RCs were significant by Analysis of Variance or Kruskal-Wallis nonparametric tests.

Within the Self Determination participants, the two most frequently reported areas of “Major Disability” were “Communication” and “Health Problems.” In the Comparison group, the two secondary disabilities with the highest percentages of people with reported “Major Disabilities” were “Autism” and “Aggressive Behavior.” Tri-Counties Regional Center had the highest levels of respondents experiencing major problems with “Ambulation,” “Autism,” “Communication” and “Health Problems.” Redwood Coast Regional Center had the highest percentages of people reported to have “Brain Injuries” and “Seizures.” ELARC had high percentages of people with “Major Disability” in “Ambulation,”

“Autism,” “Communication,” and “Health Problems.” The Comparison Group reported the highest levels of severe disability due to “Ambulation,” “Autism,” “Aggressive Behavior,” and “Communication.” No one was reported as having a major disability due to “Dementia.” None of these variations were statistically significant by Analysis of Variance or the nonparametric statistical tests.

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.”

Table 9
Guardianship/Conservatorship Percentages by Regional Center Pilot

	SD Participants	TCRC	RCRC	ELARC	ELARC Comparison
No Guardian	39%	27%	30%	23%	20%
Guardian or Conservator	60%	73%	70%	77%	80%

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

The majority of respondents, across all groups, report that they have a guardian or conservator. We will cross check this data by Regional Centers prior to submitting the final report. This finding is consistent across Regional Center groups as well as between the Self Determination participants as a whole and the Comparison group. The variations found were not significant by Chi-Square and other nonparametric tests.

Adaptive Behavior

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?”

Table 10
Average Adaptive Behavior Scale Scores by Regional Center Pilot

Group	Time A	Time B	Percent Change
SD Participants	67.4	69.5	3.1%
TCRC*	59.7	66.7	11.8%
RCRC	80.2	78.9	-1.5%
ELARC	61.3	62.3	1.7%
ELARC Comparison	67.1	70.0	4.3%

* Indicates statistical significance at the .05 level.

The increase in the scale score was statistically significant only for the Tri-Counties site. The increase showed statistical significance using both parametric and nonparametric tests.

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 B using parametric statistical tests. However, the increase for the Self-Determination participants from 67.4 at Time A to 69.5 at Time B did show statistical significance when using nonparametric tests. It should be noted that the sample size for the Self-Determination participant group was 63 people; therefore, the reporting of the results of the parametric statistical test offers the more conservative interpretation. The average participant may have slightly increased his/her adaptive behavior over the past year and a half, but we cannot confirm this statistically.

Challenging Behavior

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 B are shown in the table below.

Table 11
Average Challenging Behavior Scale Score Changes by Regional Center Pilot

Group	Time A	Time B	Percent Change
SD Participants	85.5	87.3	2.1%
TCRC*	82.9	89.3	7.8%
RCRC	92.3	89.8	-2.7%
ELARC	81.2	83.0	2.3%
ELARC Comparison	84.5	86.3	2.1%

* Indicates statistical significance at the .05 level.

Examining the changes in challenging behavior scores across the Regional Center Pilot sites, statistical analyses revealed a significant increase in the scale scores for Tri-Counties Regional Center. Redwood Coast Regional Center showed a decrease in the scale score, indicating a decreased ability of the participants at that regional center to control challenging behavior, although this decrease was not statistically significant. East Los Angeles Regional Center showed moderate gains in both the Self Determination and the Comparison groups, though not at a statistically significant level.

The question of whether the participants are “better off” in terms of reduced challenging behavior yielded mixed results. The answer seemed to be “Yes” in one of the pilots, and “No Change” in the others.

Elements of the Planning Process

On page 24 of the Personal Life Quality Protocol is the scale entitled “Elements of the Planning Process.” This scale attempted to quantify the extent to which the planning process was carried out in a “person-centered” manner. The average scores on the 16 items provided a quick and reasonably accurate look at how the planning process was taking place across the pilot sites. This scale too 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.

Table 12
Average Elements of the Planning Process Scale Score by Regional Center Pilot

Group	Time A	Time B	Percent Change
SD Participants*	71.9	84.6	17.6%
TCRC	79.6	77.7	-2.4%
RCRC*	69.4	91.9	32.3%
ELARC*	71.3	81.4	14.1%
ELARC Comparison	54.6	55.9	2.4%

* 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 average scores for the entire group increased significantly (up 17.6%). The increases at Redwood Coast and East Los Angeles Regional Centers were statistically significant, using both parametric and nonparametric tests. The changes at Tri-Counties and the Comparison group were not significant. Thus the average self-determination participant experienced enhancement of the person-centered planning process, while the average Comparison group member did not.

Quality of Life Changes

This 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 ("Then") and during involvement with self-determination efforts ("Now"). 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.

We compared the respondents' perceptions of the quality of their lives both at Time A and at Time B. At both times, we asked them to rate the quality of their lives both a year ago and now. When analyzing changes in their perceptions from "Now" at Time A and "Now" at Time B, we found that for the Self-Determination participants, there was a significant increase in their ratings. Unfortunately, there were not enough valid pairs to analyze the changes in the Comparison group's ratings from "Now" at Time A to "Now" at Time B.

Table 13
Perception of Quality of Life From “Now” to “Now”
By Regional Center Pilot

Group	Time A	Time B	Percent Change
SD Participants*	74.8	81.4	8.9%
TCRC	77.1	81.8	6.0%
RCRC*	74.2	84.3	13.6%
ELARC*	73.8	78.9	6.8%
ELARC Comparison	No valid pairs		

* Indicates statistical significance at the .05 level.

All Regional Center pilot site participants showed increases in their ratings of quality of life from "now" at Time A to "now" at Time B. These increases were significant for the participants at Redwood Coast and East Los Angeles Regional Centers. Again, there were no valid pairs to compute statistical tests on the Comparison group for this scale.

Table 14
Perception of Quality of Life From “Then” to “Now”
By Regional Center Pilot

Group	Time A	Time B	Percent Change
SD Participants*	63.2	81.6	29.1%
TCRC*	68.3	83.4	22.1%
RCRC*	64.5	83.2	29.0%
ELARC*	58.7	78.9	34.4%
ELARC Comparison	No valid pairs		

* Indicates statistical significance at the .05 level.

We also examined respondents' ratings of the quality of their lives at Time B, asking them to rate the quality of their lives "now" and their perception of the quality of their lives "before self-determination." On this measure the participant

groups at all three Regional Center pilots showed statistically significant increases. The “pooled” score for the Self-Determination participants as a group showed a statistically significant increase from Time A to Time B as well. Once again, there were no valid pairs to compare for the Comparison group on this scale.

Every one of the perceived changes in 14 life areas was statistically significant. The five largest perceived changes among the participants were in these areas:

1. Running my own life
2. Overall quality of life
3. Getting out and going places
4. Happiness
5. Treatment by paid support providers

It may be of interest to note that these changes in perceived qualities of life were the largest this research team has thus far observed in similar research in a dozen states. Therefore a strong interpretation is warranted: the participants and their allies report themselves to be much better off than they were before self-determination. The second part of the operational definition of self-determination, that quality of life will improve, is convincingly supported by these findings.

Choicemaking

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.

Table 15
Decision Control Inventory for All People Scale Score
By Regional Center Pilot

Group	Time A	Time B	Percent Change
SD Participants*	80.9	88.9	9.9%
TCRC	64.3	83.1	29.2%
RCRC	80.0	92.8	16.0%
ELARC	89.5	90.4	1.0%
ELARC Comparison	68.7	64.8	-5.7%

* Indicates statistical significance at the .05 level.

The first Decision Control Inventory Scale is intended to be completed for all people. Self-Determination participants showed a statistically significant increase in choicemaking from 80.9 at Time A to 88.9 at Time B.⁴⁸ For the Comparison group, the results showed a 4-point decrease in choicemaking from Time A to Time B. This decrease was statistically significant using parametric tests, but not while using nonparametric tests; nonparametric statistical tests are the most appropriate to use in this case because there were only four people in the Comparison group with scores on the Decision Control Inventory to be compared.

The second Decision Control Inventory score in the questionnaire was specifically intended for people living with their families. This scale measures choicemaking power between the focus person at one end of the continuum and their family at the other end.

⁴⁸ None of the pilot site changes reached statistical significance simply because there were so few people in the analysis. In the first round of data collection, two data collectors erroneously completed only one of the two Decision Control Inventories, rather than both.

Table 16
Decision Control Inventory for People living with Family
Scale Score by Regional Center Pilot

Group	Time A	Time B	Percent Change
SD Participants	44.5	42.0	-5.7%
TCRC	21.5	15.2	-29.3%
RCRC*	66.4	50.0	-24.7%
ELARC*	28.6	43.8	53.0%
ELARC Comparison	49.5	42.1	-15.0%

* Indicates statistical significance at the .05 level.

Analyzing the changes in this scale across the four groups revealed decreases for the ELARC Comparison group, the Redwood Coast group and the Tri-Counties group; however, only the decrease at Redwood Coast was statistically significant. The scores for the people at ELARC increased from Time A to Time B, and this increase was also statistically significant. On this scale, there were decreases for both the Self-Determination participants as a group and the Comparison group, but these decreases were not statistically significant.

The data from this “family power scale” presented a rather complicated pattern. It would appear that at two of the sites, people living with family tended to surrender some control over their choices to their relatives. Yet at one site, individual power increased sharply. We cannot delineate the reasons for these contrasting findings, but we invite ideas and suggestions. The findings certainly call for further investigation in the future.

Overall, the first part of the operational definition of self-determination was supported by the Decision Control Inventory findings. For the people with data from the first version of the scale, which measured the possession of power between professionals and the participants (and their freely chosen allies), there was about a 10% shift in power away from paid professionals and toward the

people. Thus we obtained clear evidence that a shift in power did in fact take place, on the average, in these self-determination pilot projects. The strength of the conclusion was buttressed by the fact that no power shift was observed among the Comparison Group members.

Integrative Activities

The 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 B.

**Table 17
Number of Integrative Activities Per Month by Regional Center Pilot**

Group	Time A	Time B	Percent Change
SD Participants	43.2	47.6	10.1%
TCRC*	26.8	40.6	51.5%
RCRC	53.6	64.0	19.5%
ELARC	47.0	37.1	-21.0%
ELARC Comparison	39.8	39.9	0.2%

* 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, Redwood Coast and the Comparison group showed increases from Time A to Time B; however, only the increase at Tri-Counties was statistically significant. The East Los Angeles group

showed a 10-point drop in the total number of integrative activities per month from Time A to Time B, although this drop did not achieve statistical significance using either parametric or nonparametric tests.

Between the Self-Determination participants as a group and the Comparison group, analysis revealed no significant differences in the total number of integrative activities a month from Time A to Time B.

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 one site, there was a large increase, at one site a modest increase, and at one site a modest decrease. Since the results were mixed, and the overall group increase of 10% did not reach significance, this was a tentative and carefully qualified positive finding, strengthened somewhat by the fact that no change was observed among the Comparison Group members.

Reasons for Participation

In each visit with participants, we asked this question:

17. WHY? Brief description of why this person (and friends, relatives, support providers) decided to take part in Self-Determination efforts.

The following table shows the participants’ answers. We present this table without comment so that readers can examine the answers and form their own impressions of the variety of reasons people give, last year and this year, for getting involved in self-determination. We also are not breaking this table down by pilot site, because that would tend to increase the risk that a reader might be able to identify who said what.

Table 18
Answers to “Why We Decided to Take Part in Self-Determination”

Time A, Year 2000, Before or Very Early in Self-Determination	Time B, Year 2001, During Self-Determination Implementation
	They were told to participate by a case worker.
Felt would help him control his life better.	Because I was picked to do it and they need someone to use as an example, I wanted to help out.
	We had a case manager, and he suggested it.
I think that they were randomly chosen	Wanted to do this my whole life. So I can do what I want to do, etc. Hire my own staff, etc.
It's in his best interest	
Mom's idea so things can change for the better wants him to be more and get out of isolation	Thought it was very good and that he was chosen for this. I hope he will be able to get help.
Unknown	[Name] asked me if I'd like to a wood shop on my own, and I didn't have the money for it.
Self determination makes us a lot more free we do not have to use no darn agencies.	Because I could hire and fire whoever I wanted. The agencies don't listen to the consumer.
Sounded like a good idea because I will be in control of my own money. In charge of money management	I thought it would be interesting to see how to manage my own money.
I like to make my own choices, I think it's good for me to know such things	Give me things to do.
I thought it was a good idea for me to learn these things. Budgeting, taking care of my own bills.	[They] explained to [her] & it was her choice to participate.
I can do what I want with my money; learn to budget my money.	Getting to know people. Always had pizza at meetings.
	Take part in anything that helps.
Control of my own money	To see how far I can go, how can it help me.
	Wanted a house
	I thought I'd give it a try. I was having a lot of staff problems.
He says, "I would like to be my own supervisor."	I don't like [agency]. I wanted control over staff.
I want to learn how to live on my own and to get help to move.	To learn how to pay my bills.
Hope it will help to get her the things she needs.	Because the father wants to insure his safety, comfort, and health if he is able to.
It is going to help him.	
	Mother enthusiastic.
	Support provider suggested.

	Focused money on the child is imperative. Gives the issue of choice control to the family
	They were convinced to be a part of self determination but the don't want to continue in the project.
Parents felt it was in his best interest.	[The regional center] chose this family at random. Family felt it would be good for them.
Allow them to get to a single individual program of controls.	We thought it would help us get things that we could not get before. It also give more choices.
Believe they are best qualified to make decisions in their son's interest.	Innovative and something new.
	Likes to make decision for ourselves and her well-being.
We need to be able to close and pay whom ever we want for respite care	School [is elsewhere] - no services here. Need him to live there [Monday through Friday]. More opportunities.
Parents are older. Wanted him to develop skills so he could take care of himself when they're gone.	
They told us it would be better	[He] wanted more choices.
Thought it might be helpful for her to get a computer.	
Good for him to take care of bills and make decisions.	He is my son, better choices.
	To see if we could create a better program for him.
Because I thought it might help me in the long run.	Thought it would be fun.
	To start own business.
Because there's more control over the programs that he is able to access.	No other options.
To give him greater [choice] of activities and funds to carry them out.	Flexibility, potential for addressing his needs more effectively.
Because it was offered. A good plan to get on with his life.	
Wanted to start my own business; I want to have my own office someday.	Employment desires otherwise available [are] too limiting.
Good for her to learn to take care of herself in future.	
I want to upgrade, I want to make a better life, I want to learn how to use a computer.	Upgrade life.
Cause the program will pay more attention to him.	They explained the project to us and it was a new project for the community.
Interested in his goals.	
Previous program wasn't working.	He is high functional. We saw it as a better way to attain services for him when he comes of age.

They wanted to participate.	Because we have the opportunity to decide what he needs and we wanted to take advantage of that.
The freedom.	
Wanted to be able to be creative with his day program due to high turnover of staff at day program.	We felt it would benefit him so we could be creative with his money; so we could choose other services that may be outside the regional center vendors.
Like the idea of knowing how much money there is to support him.	I always want to try new things, nothing was approved though. I could have more control for him.
We don't want to feel like beggars anymore. We want control over resources we want good services [tailored to his needs].	
For freedom [from] authorities.	
We have many needs and regional center won't pay for it all; self determination will help when to get things [get tight].	Because he had the authority to use the money, and he is the one who knows best and understands.
Were unhappy with some of the vendors provided by regional center. Wanted more freedom.	A different approach to meeting his needs.
Great opportunity to explore options and his abilities.	To explore the opportunities available to him.
Lots of services; his needs don't fit into vendored services available through regional center.	[Name] is so high functioning that a lot of authorized services weren't applicable.
To get more money and support to meet his needs, he was getting programs he didn't need.	Because the family can best use the money to where the person needs most.
I want to make the decisions about what [she] needs regional center isn't much help.	Planning for independence when kids are older. More of "real-life" experience.
Make own decisions about what's best for [him].	
So [he] can have a direct role in selection of the programs he needs -- also identify other resources.	Because he was not receiving the services that he needs.
[She] was asked if she wanted to participate and she agreed.	
I wanted more of a say for services that she could get.	I like the idea...of us getting to decide what we need; to say what my child needs.

Wishes

On every visit, we ask the person “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 down 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.

Table 19
Answers to the Question “If you had one wish, what would you wish for?”

Time A: Year 2000 Before or Very Early in Self-Determination	Time B: Year 2001 During Self-Determination Implementation
I would like to visit my nephew.	
None	I'd wish to never work again, but it would be nice not to have to work again!
He would like to have his own dog some day.	More money.
Move back in with mother.	Could not think of one.
	Things are great!
Wish I could live by myself.	Own the world.
	To buy a lot of old comic books.
Wishes he could go on a train ride.	To be married to my girlfriend.
Wish I could afford a bigger apartment.	I would be working in my own woodshop [making dollhouses.]
Getting a lot of money to buy whatever I want.	A job, I don't care where I work, I just want a job.
A yacht I could live on.	For a million dollars.
Have a good steady job and a drivers license.	Move to Ventura.
Wish he could win the lottery.	To move out with my friend.

Live out in the country.	To lose weight and look like the picture of me when I was 18 years old.
	Move to Arizona, marry [boyfriend.]
A new VCR.	To visit my family, but they don't follow through with their promised visits.
I want to live in my own.	Move out of town - get away from family who order me around.
	To be rich.
	Live forever.
Have my own house and a new car.	To win the lotto and buy the house, have a job and work full-time so not to be on public money.
Go find a girlfriend.	To get married, and have two kids, maybe a little girl.
	Car
New case for my guitar.	
No answer	To have more choice, and more toys.
I was on the NASCAR circuit.	Race car.
A swing set.	
Drive in NASCAR.	Do not know.
All the transformers in the world (action figures).	Wish for more wishes, more friends, and to write with more skill.
To have some fun; to live here.	I wish that the holidays are coming.
Good musician in the world.	
Go to college.	
Can see better.	To visit Hong Kong and Shanghai, China.
Can't think of one.	
Brother to not come home again.	I would wish for a hundred wishes, then I could have more time to make up my mind.
A million dollars.	
A million dollars.	
I don't know, having a car.	Living on my own.

Individual Budgets

We asked each person and his/her closest ally if they had an “individual budget.” At Time A, only 9 people thought they had an individual budget, 39 did not, and 19 did not know. At Time B, 40 people reported having an individual budget, 10 did not, and 16 did not know. This showed that many participants had

obtained individual budgets, and that they were aware of this fact. No one in the Comparison Group reported having an individual budget at either time.

For people who were aware of their individual budgets, we asked how they were spending the dollars. We collected this information in seven categories. We analyzed the data to reveal percentages spent by category as shown in the following table.

Table 20
Percentages Spent in Seven Categories

45%	8B. Personal support in the home (staff, personal care attendants, home health aides, support coordinators, etc.)
27%	8D. Supported work, education tuition, adult day activity, community experience program
8%	8G. Other
7%	8E. Therapies (psychological, physical, occupational)
6%	8F. Recreation, entertainment, vacations, buying leisure items such as televisions, stereos, exercise equipment, or luxuries
4%	8A. Housing (including rent, mortgage, utilities, food, household supplies, etc.)
3%	8C. Transportation of all kinds

The largest portion of the expenditures, nearly half, was to purchase personal supports in people’s homes. The next largest category was for day activities of all kinds. The third largest category was “Other,” which should not be surprising in a flexible self-determination effort. Many individually determined purchases may not easily fit into pre-established categories.

Costs: Preliminary Findings

The operational definition⁴⁹ of self-determination in its simplest form is this:

- Power shifts
- Lives get better
- Costs stay the same or go down

In this section, we report on three ways in which we have thus far tested the third part of the theory, the notion that self-determination is a fiscally conservative process.

At the outset, it is important to state explicitly some unique facts about the California implementation of self-determination, and some limitations of the available fiscal research strategies.

First, California's service system in general is unusually low in expenditures when compared to all the other states. For example, the 1999 data from the University of Minnesota place California 49th of 51 in average HCBS Waiver cost per person (\$15,198 compared to the national average of \$31,949.) There may be many reasons for this, but it is a fact, and it follows that we really should not expect cost reductions in such a system. We believe that it is more reasonable to look for costs to stay the same, or to increase less rapidly than they otherwise would have.

Secondly, the California implementations of self-determination have not emphasized people in high cost situations. Some people in residential settings have been included (about 15%), but most participants live in their own homes or

⁴⁹ An operational definition is one which is stated in terms that can be observed, measured, or tested via "operations" in the empirical world.

with relatives. Self-determination is believed by its developers to be appropriate for everyone, but the greatest impacts are expected when applied with people whose lives have been overly controlled, professionally dominated, and even “oppressed.” In particular, the largest cost impacts are expected with people whose supports are very costly. Again, therefore, it would not be reasonable to expect major cost reductions among people who are living in their own homes or with relatives.

The first limitation of our cost analyses is that the complete array of human service expenditures for all the people in the project are simply not available, and could not be obtained even with doubled resources. This analysis cannot include expenditures of public schools, vocational rehabilitation, acute medical care, HUD housing assistance, food stamps, public assistance, SSI, SSDI, Title XX programs, and the wide variety of other social programs and services that people might be tapping into. Some analysts would argue that we should not include these public costs, because they are outside the control of the individuals and the developmental services agencies. It is a fact that funding for people with disabilities in America is fragmented and complex. One person could theoretically receive support from 10 funding streams and programs. In an ideal world, self-determination would begin by adding up all the public dollars from all sources, take control over the entire pot of money, add one’s private resources, and plan one’s life from there. This scenario is not reasonable in current service systems.

What we do have is Purchase of Service (POS) expenditures for the participants (and for the comparison group of ELARC non-participants). We feel it is important to state clearly that Purchase of Service dollars may not be the only sources of public supports in these people’s lives, and that is a limitation of our analyses.

The second limitation of our cost analyses is that we cannot use the most recent expenditure data, from January to June of 2001. Regional Centers are permitted up to 6 months to submit this information to DDS, and therefore the data for 1/2001 to 6/2001 are incomplete. We will, however, be able to use that time period in our final report next year. At this time, the best alternative is to use the most recent complete POS data, which is for July to December of 2000.

The third limitation of our cost studies is that we are not yet able to use an analytical technique suggested by DDS, in which each person's expenditures would be traced for 12 months before the self-determination start date and 12 months after the start date. We do not yet have each person's start date by the criterion of the day the individual budget was approved and signed. We did collect from the participants themselves what they thought their start date was, but they used varying criteria for defining "start." We should be able to try this analytical technique for the final report next year.

A fourth limitation of this cost research is that it may be that Regional Center costs are higher for the participants than for others. In particular, case manager involvement may be much more intense when self-determination, person-centered planning, and individual budgeting are required. We suspect this is probably true. We have not included estimates of this possibility in the present analyses, and that too is a limitation.

For this second interim report, we have performed four kinds of analysis of the POS costs of the participants and the comparison group:

1. A slice-of-time "before and during" analysis of POS costs;
2. A longitudinal examination of expenditures over a four year period;
3. An examination of HCBS Waiver utilization within the POS data.
4. A tabulation of the Service Codes most often utilized in POS billing before and during self-determination.

1. Slice-of-Time “before and during” analysis of POS costs.

DDS supplied POS expenditures by month for the participants and the comparison group from July 1997 to June 2001. An excellent way to use these data was the usual “before and during” design that we have employed in other states. This method compared aggregated individual expenditures from July to December of 1998, before anyone had an individual self-determination budget, to expenditures between July and December of 2000, when most participants had a signed and approved budget.

The results of this analysis are shown in the following table.

Table 21
POS Expenditures in Two Six-Month Periods, Before and During Self-Determination⁵⁰

	Average Costs 7/98 to 12/98	Average Costs 7/00 to 12/00	Percent Change
TCRC Participants	6687	8993	34%
RCRC Participants	5102	6351	24%
ELARC Participants	7767	9018	16%
ELARC Comparison Group	5366	7479	39%

The table shows that all expenditures increased over this two year period. The three pilot projects displayed varying levels of costs to begin with, and also varying degrees of cost increase. Perhaps the most important element of the table is the comparison between the ELARC participants and the ELARC Comparison

⁵⁰ The table is adjusted for Consumer Price Index fluctuations. The data are reported in constant dollars based on the latter half of year 2000.

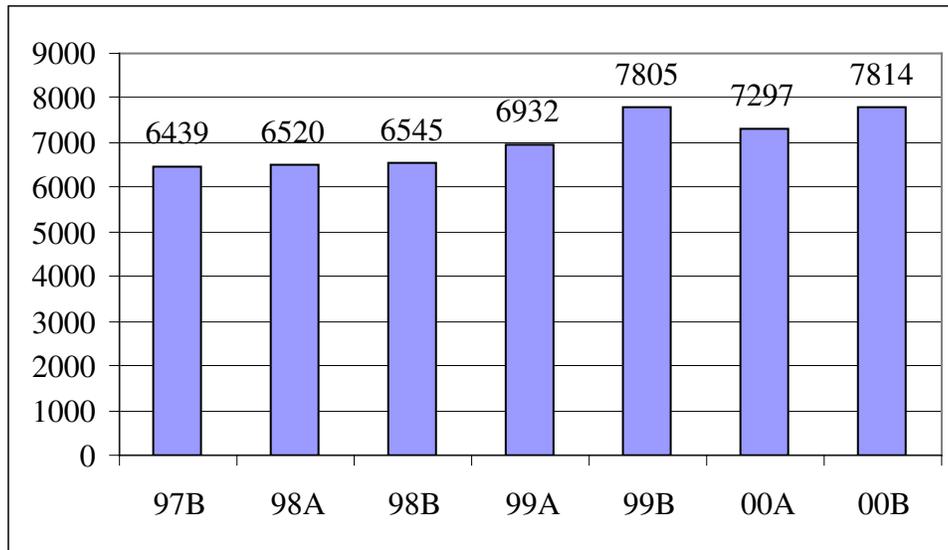
Group. While the participants increased their spending by 16%, the non-participants increased theirs by 39%, more than double the participants' percentage increase. Moreover, the percentage increase among all three pilot RCs was lower than that observed for the comparison group.

We regard this as reasonably persuasive evidence that the self-determination implementations in California have thus far displayed fiscally conservative practices. This analysis suggests that more would have been spent in the absence of self-determination. In the future, should this conclusion be accurate, California will spend considerably more to support people (as much as twice as much the rate of increase) if it does not adopt the self-determination approach.

2. A longitudinal examination of expenditures over a four year period

In this analysis, we plotted average inflation-adjusted expenditures for all the self-determination participants over time. The time periods were calculated in 6 month intervals to minimize monthly variations in billings and reimbursement. The result of this analysis is shown in the graph below.

Graph 1
POS Expenditures Over Time for the Self-Determination Participants



The labels at the bottom of the graph show the 6 month time intervals, with 97B meaning the second half of 1997, and 98A meaning the first half of 1998. Most of the self-determination participants began their involvement somewhere around the latter half of 1999, although not all obtained individual budgets by then.

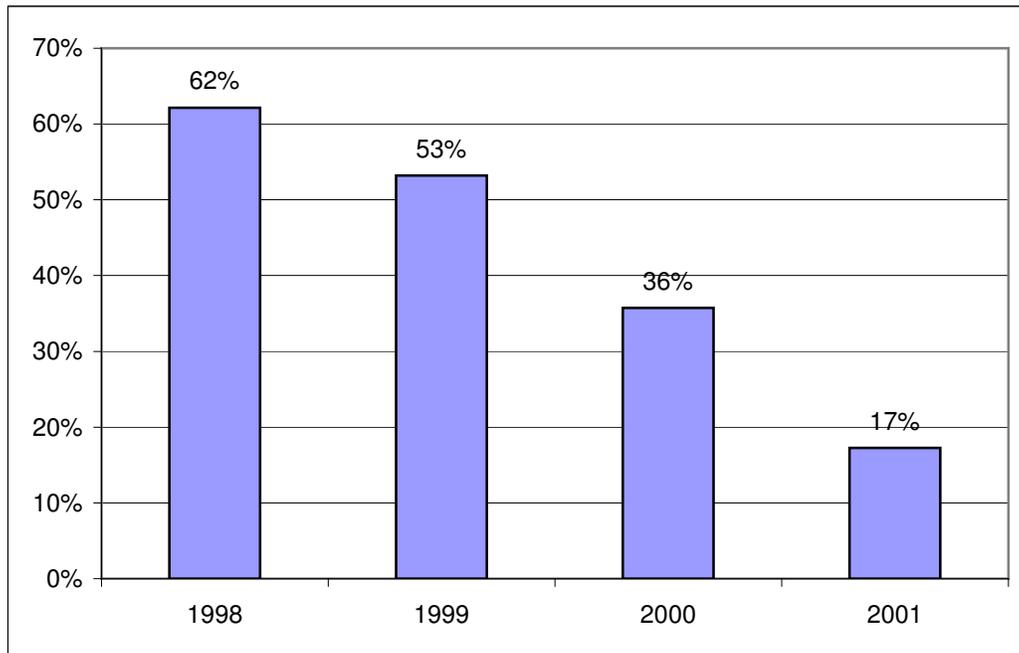
We see a slight increase in average costs around the time self-determination work began, in late 1999. But then there appears to be a slight decrease after the initial work, so that the bar representing average expenditures in the first half of 2000 is somewhat smaller than the bar to its left. By the second half of 2000, the average expenditures are almost exactly what they were in late 1999.

Although very preliminary, this graph suggests that self-determination has tended to keep costs steady, after the initial individual budget amount is set. This may be interpreted as a second piece of evidence of the cost-neutrality and/or fiscal conservatism of the self-determination pilot projects.

3. An examination of HCBS Waiver utilization within the POS data.

DDS provided both POS and Waiver-reimbursed costs for the participants and for the Comparison Group members. It was of interest to determine how the federal Waiver reimbursement program was utilized in the self-determination pilots. The graph below shows the overall pattern of Waiver utilization over time.

Graph 2
Percentage of POS Costs Reimbursed by the HCBS Waiver Program
For the Self-Determination Participants, from 1998 to 2001



Clearly, the self-determination pilot projects have been reducing reliance on Federal dollars for the self-determination experiment. The table below provides more detail, broken down by Regional Center site.

Table 22
Total POS Expenditures and Waiver Expenditures Within POS

Group	1997-1998	1998-1999	1999-2000	2000-2001	% Change in Overall Spending
TCRC POS	284,213	300,177	354,704	379,259	33%
TCRC Waiver	187,729	220,118	161,023	65,700	
TCRC Percent Waiver	66%	73%	45%	17%	
RCRC POS	110,456	130,787	205,513	188,191	70%
RCRC Waiver	82,126	86,803	69,170	61,834	
RCRC Percent Waiver	74%	66%	34%	33%	
ELARC POS	256,025	341,114	373,532	361,291	41%
ELARC Waiver	98,401	103,966	103,622	32,883	
ELARC Percent Waiver	38%	30%	28%	9%	
ELARC Comparison POS	181,177	226,021	309,748	300,368	66%
ELARC Comparison Waiver	72,067	55,536	69,208	85,766	
ELARC Comparison Group Percent Waiver	40%	25%	22%	29%	

For this analysis, we were primarily interested in the percentage of costs that were reimbursed by the Waiver program. The absolute amounts of money spent were not important here, only the relative amounts. Hence here we could use 2000-2001 data, even though we know the numbers were incomplete.

The rows showing “Percent Waiver” are of primary interest. For each Regional Center pilot, the percentage of costs reimbursed under the Waiver program went steadily downward. (Some of the 1997-1998 Waiver figures are very high, higher than California’s 52% reimbursement rate in 1999.) The steady decreases in Waiver utilization were probably related to conscious choices made by the Self-Determination Steering Committee, related to the state’s relationship with Federal overseers of the Waiver program.

Even for the Comparison Group, Waiver reimbursement decreased. We are not aware of any explanation for this phenomenon. But the decrease in the Comparison Group was much smaller than in the three self-determination pilot groups.

A secondary finding in the table is in the column at the right, which shows the percentage of increase in average spending per person from 1997-1998 to 2000-2001. Again, the exact numbers are not important here. The only intention is to show, once again, evidence that spending increased less among the participants than among the Comparison Group members, who increased by 66%.

4. Tabulation of the Service Codes most often utilized in POS billing before and during self-determination

As a preliminary investigation of how funds were being utilized, we examined data from 4 years of POS expenditures. Each expenditure is tagged with a “Service Code” that indicates the category of the transaction. Because of the enormous amount of information about services purchased each month over 4 years, with amounts, Regional Centers, and numbers of billings, we prepared a very simplified “first look” at changes in the pattern of service categories used in the billings for the self-determination participants.

The two tables below show the five largest expenditure service codes in 1998 for the participants, before self-determination began, and the same for 2001.

Table 23
Service Codes most often utilized in POS billing before Self-determination

1998	Percent of POS Expenditures in this Category	Number of Billings in This Category
915 Residential Facility Serving Adults-Staff Operated	21%	8
510 Adult Development Center	11%	12
520 Independent Living Program	9%	12
892 Training and Habilitation Service	9%	2
420 Respite Service-Family Member	5%	21

Table 24
Service Codes most often utilized in POS billing during Self-determination

2001	Percent of POS Expenditures in this Category	Number of Billings in This Category
997 Self-Determination Pilot Project (Gen Ledger Acct 01007-65070)	48%	31
915 Residential Facility Serving Adults-Staff Operated	8%	5
515 Behavior Management Program	6%	3
24 Purchase Reimbursement	4%	14
510 Adult Development Center	4%	5

As self-determination evolved, the California pilot sites came to the conclusion that a specific Service Code for self-determination purchases would contribute to flexibility in purchasing nontraditional supports and services. Thus Code 997 (Self-Determination Pilot Project) began to be utilized in 2000.

Now Code 997 appears to account for almost half of the POS expenditures for the participants. The project implementers knew that this increased convenience in billing might sacrifice some ability to analyze exactly what the

participants were purchasing. Further investigation of purchasing patterns, therefore, will have to be done at the individual level. The state POS database will be of limited utility in such analyses.

Recommendations for System Level Changes

The three self-determination pilot projects in California were developed and implemented by an extraordinary group of committed stakeholders. People with disabilities and their families agreed to try the program, even though many had years of negative experiences and broken promises in trying to organize support services. State and Regional Center administrators had the courage to assume leadership roles in a project designed to limit their own power and control. Fiscal policy makers and staff brought their expertise to the planning tables to help make the system more responsive to individual needs. Service coordinators, trainers, therapists, residential and vocational staff suspended disbelief in a desire to improve the quality of life for the people they support everyday. Provider agencies assumed new risks and agreed to share responsibilities.

The spirit of commitment exhibited in the California pilots is typical of self-determination initiatives across the country. All the people involved are stakeholders in the true meaning of the term. The people with disabilities and their families are the obvious beneficiaries of an improved service system but all the other players, the administrators, the accountants, the service brokers and coordinators have a vested interest as well. Their values, their aspirations, their daily routines, and their careers are enhanced through self-determination.

The three regional centers involved in the pilots have bravely followed through on their designs and gathered valuable qualitative and quantitative data on multiple strategies for facilitating self-determination. They have experienced delays, false starts, and even a few dead ends. But that is the nature of a pilot project and they are to be commended for their good will, energy and stamina.

Preliminary recommendations for systems change are primarily related to money; tapping into federal reimbursement, setting the amounts for individual

budgets, strategies for supporting individuals and families to allocate their resources, processes for managing accounts payable and receivable, and vendor contracts. Everyone knew from the beginning that moving the money was going to be one of the most difficult aspects of the pilot projects. Accountability and responsibility are important but it seems that many stakeholders have allowed the fiscal complexities to overwhelm the spirit of self-determination.

It is necessary to educate individuals and families and service coordinators about budgets but they do not have to become accountants. Many people who chose human services as a career have a strong aversion to spreadsheets and bookkeeping. The emphasis on the fiscal infrastructure across the various models has created unnecessary barriers to progress. It is our recommendation that the fiscal people concentrate on developing the internal systems that work best for them without bringing the dialogue to people who really have no interest or expertise in making such decisions. It is obvious from the time and energy devoted to the pilot strategies that the fiscal staff have a clear understanding of the principles and values of self determination and they can be trusted to develop a technical system that does not inhibit individual choice or freedom.

A second recommendation involves training. California is obviously committed to the principles of person centered planning. This can be dangerous if the plan is not joined with an individual budget. People who engage in person centered planning need the authority to allocate resources according to the plan. Otherwise, the circle of support and the planning team become stagnant, people become frustrated and stop participating and people with disabilities and their families are back where they started, maybe even a little worse off as they have been encouraged to envision a dream that is out of reach. The fear of budgets and money should not deter service brokers and coordinators from talking about money. It is not fair to let people assume that whatever they want is a possibility.

The amount of public funds available has to be part of the conversation from the first meeting.

A second training issue related to control and freedom. The qualitative data collected for this evaluation presented a disturbing thread. There were many comments about “taxpayer twinges” and concerns about what would happen if “others found out” etc. This kind of control is the antithesis of self-determination. This attitude is even more alarming when you consider that the majority of participants are receiving less than \$20,000 per year in public support. If the families had placed them in developmental centers the cost to California would be in excess of \$150,000 per year. In that light, it is hard to imagine concern about a father who needs to be reimbursed for a day’s wages to take his child to a specialist. The alternative would be to have a much higher paid service coordinator take the child, an alternative that would not benefit the child or the family. The best way to combat this attitude is to have people with disabilities and families present their stories at conferences, trainings etc. Service coordinators need to know that people can be trusted and that in the majority of cases, their solutions are cheaper and more beneficial than those presented by systems.

Another recommendation regards vendors. The provider agencies have not generally been included in the self-determination pilots. It is understandable that systems have to be developed that are primarily responsive to the needs of participants and funding sources, but it is more than time to invite the providers to the policy making table. Although provider agencies are concerned about the viability of their businesses, they are in most cases operated by caring professionals who share the commitment to improving life quality for people with disabilities. The excellent providers can lend their experience and imagination to families and regional centers to design new and improved ways of providing service.

References

- Arndt, S. (1981). A general measure of adaptive behavior. *American Journal of Mental Deficiency, 85*, 554-556.
- Balla, D. (1976). Relationship of institution size to quality of care: A review of the literature. *American Journal of Mental Deficiency, 81*, 117-124.
- Baroff, G. S. (1980). On "size" and the quality of residential care: A second look. *Mental Retardation, 3*, 113-118.
- Berg, B.L. (1989). *Qualitative research methods for the social sciences*. Boston, MA: Allyn & Bacon.
- Conroy, J. (1986). *Principles of quality assurance: Recommendations for action in Pennsylvania*. Position paper submitted to the Pennsylvania Office of Mental Retardation. Philadelphia: Temple University Developmental Disabilities Center/UAP.
- Conroy, J. (1992). *Size and Quality in Residential Programs for People with Developmental Disabilities*. A Dissertation Submitted to the Temple University Graduate Board in Partial Fulfillment of the Requirements for the Degree Doctor of Philosophy. Philadelphia: Temple University.
- 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. Rosemont, PA: The Center for Outcome Analysis.
- Conroy, J., & Bradley, V. (1985). *The Pennhurst Longitudinal Study: A report of five years of research and analysis*. Philadelphia: Temple University Developmental Disabilities Center. Boston: Human Services Research Institute.
- Conroy, J., & Feinstein, C. (1990a). A new way of thinking about quality. In: V. Bradley and H. Bersani (Eds.) *Quality assurance for individuals with developmental disabilities: It's everybody's business*. Baltimore: Paul H. Brookes.
- Conroy, J., & Feinstein, C. (1990b). Measuring quality of life: Where have we been, where are we going? In: R. Schalock and M. Begab (Eds.) *Quality of life: Perspectives and issues. Monograph Number 12*. Washington: American Association on Mental Retardation.
- Devlin, S. (1989). *Reliability assessment of the instruments used to monitor the Pennhurst class members*. Philadelphia: Temple University Developmental Disabilities Center.
- Dodder, R., Foster, L., & Bolin, B. (1999). Measures to monitor developmental disabilities quality assurance: A study of reliability. *Education and Training in Mental Retardation and Developmental Disabilities, 34, 1*, 66-76.
- 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.
- Harris, C. (1982). *An interrater reliability study of the Client Development Evaluation Report*. Final report to the California Department of Developmental Services.

- King, R., Raynes, N., & Tizard, J. (1971). *Patterns of residential care: Sociological studies in institutions for handicapped children*. London: Routledge and Kegan Paul.
- Kirk, J. & Miller, M.L. (1986). *Reliability and validity in qualitative research*. Beverly Hills, CA: Sage.
- Krueger, R.A. (1989). *Focus groups: A practical guide for applied research*. Newbury Park, CA: Sage.
- Lakin, K.C., White, C.C., Hill, B.K., Bruininks, R.H., & Wright, E.A. (1990). Longitudinal change and interstate variability in the size of residential facilities for persons with mental retardation (Brief Report No. 28). *Mental Retardation*, 28, 343-352.
- Lemanowicz, J., Levine, R., Feinstein, C., & Conroy, J. (1990a). *Evaluation of the well-being of non-class members living in the community in 1990: The results of Temple monitoring in Philadelphia*. Project Report 90-2 to the Philadelphia Office of Mental Health and Mental Retardation. Philadelphia: Temple University Developmental Disabilities Center/UAP.
- McLain, R., Silverstein, A., Hubbell, M., & Brownlee, L. (1975). The characterization of residential environments within a hospital for the mentally retarded. *Mental Retardation*, 13, 24-27.
- Merton, R.K. (1987). The focussed interview and focus groups. *Public Opinion Quarterly*, 51, 550-566.
- Moos, Lemke, & Mehren (1979). Multiphasic Environmental Assessment Procedure. Palo Alto, CA: Social Ecology Laboratory.
- Morgon, D.L. (1988). *Focus groups as qualitative research*. Newbury Park, CA: Sage.
- Morgon, D.L. (1998). Practical strategies for combining qualitative and quantitative methods: Applications to health research. *Qualitative Health Research*, Vol.8, No.3, 362-376.
- Nihira, K., Foster, R., Shellhaas, M., & Leland, H. (1974). *AAMD Adaptive Behavior Scale, 1974 Revision*. Washington DC: American Association on Mental Deficiency.
- Patton, M. Q. (1982). *Practical evaluation*. Newbury Park, CA: Sage.
- Patton, M.Q. (1987). *How to use qualitative methods in evaluation*. Newbury Park, CA: Sage.
- Pratt, M., Luszcz, M., & Brown, M. (1981). Measuring dimensions of the quality of care in small community residences. *American Journal of Mental Deficiency*, 85, 188-194.
- Shea, J. R. (1992). From standards to compliance, to good services, to quality lives: Is this how it works? *Mental Retardation*, 30, 143-149.
- Sigelman, C.K., Budd, E.C., Spanhel, C.L., Schoenrock, C.J. (1981). When in doubt, say yes: Acquiescence in interviews with mentally retarded persons. *Mental Retardation*, 19, 53-58.
- Straw, M.K. & Marks, K. (1995). Use of focus groups in program development. *Qualitative Health Research*, Vol. 5, No.4, 428-443.
- Straw, R.B. & Smith, M.W. (1995). Potential uses of focus groups in federal policy and program evaluation studies. *Qualitative Health Research*, Vol. 5, No.4 421-427.

Taylor, H., Kagay, M., & Leichenko, S. (1986). *The ICD Survey of Disabled Americans*. Conducted by Louis Harris and Associates. New York: The International Center for the Disabled, and Washington, DC: National Council for the Handicapped.

Appendix A: Brief History of Self-Determination in the United States

Brief History of the Self-Determination Movement in the United States

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 ⁵¹
- 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

⁵¹ Conroy, J. (1995). *Independent Evaluation of the Self-Determination Project, Sixth Quarterly Report*, February 1, 1995 to April 31, 1995.

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 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.⁵² 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.

⁵² Yuskas, 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 B: The Beginning of Self-Determination in California

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.”