

**CALIFORNIA'S SELF-DETERMINATION PILOT PROJECTS
FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES**

MAY 17, 2002

DEPARTMENT OF DEVELOPMENTAL SERVICES
COMMUNITY SERVICES AND SUPPORTS DIVISION
COMMUNITY DEVELOPMENT BRANCH



STATE OF CALIFORNIA
GRAY DAVIS, GOVERNOR

HEALTH AND HUMAN SERVICES AGENCY
GRANTLAND JOHNSON, SECRETARY

DEPARTMENT OF DEVELOPMENTAL SERVICES
CLIFF ALLENBY, DIRECTOR

TABLE OF CONTENTS

EXECUTIVE SUMMARY	i
INTRODUCTION	
C Legislative Mandate.....	1
C Background.....	2
Department Implementation	
C Statewide Self-Determination Steering Committee.....	2
C Regional Center Pilot Projects Implementation.....	3
Pilot Projects	
C Eastern Los Angeles Regional Center / AB X.....	4
C Redwood Coast Regional Center / AB I.....	7
C Tri-Counties Regional Center / AB IX	10
C Kern Regional Center / AB XII	13
C San Diego Regional Center / AB XIII	16
Contract Evaluation of Pilot Projects	
C Summary of Report to the Department.....	17
Findings	
C Satisfaction of Participants	21
C Individual Budgets	21
C Ownership of Equipment/Property	22
C Underserved Population.....	23
C Regional Center Operations	23
C Determining what is reasonably related to IPP objectives	25
C Regional Center as payer of last resort.....	26
C Income and Tax consequences Of Self-Determination.....	26
C The Home and Community-based Services (HCBS) Waiver	27
C Management Information System Requirements.....	27
Recommendations to the Legislature	28
Appendix A	
C Welfare and Institutions Code Section 4685.5	A-1
Appendix B	
C Principles of Self-Determination.....	B-1
C Individual Planning.....	B-2

Executive Summary

INTRODUCTION

Senate Bill 1038 (Chapter 1043, Statutes of 1998, Thompson) established three self-determination pilot projects in California. The pilots are a collaborative effort between each regional center and area board. The original pilots are Redwood Coast Regional Center and Area Board I, Tri-Counties Regional Center and Area Board IX, and Eastern Los Angeles Regional Center and Area Board X. Kern Regional Center and Area Board XII and San Diego Regional Center and Area Board XIII submitted Assembly Bill 637 proposals (Chapter 623, Statutes of 1993) and have joined the pilot effort.

Self-determination is based on the principles of freedom (to plan a life with necessary supports), authority (to control a certain sum of dollars), support (to arrange resources and personnel to assist with living in and becoming a part of the community), and responsibility (to accept a valued role in the community and to be accountable for spending public dollars). It is an approach to service delivery that has garnered international and bipartisan support and, in addition to California, is being piloted in a number of states. (See Appendix B for further description of each principle.)

IMPLEMENTATION IN CALIFORNIA

Shortly after SB 1038 was enacted (September 1998), the Department of Developmental Services (Department) brought together the Statewide Self-Determination Steering Committee, consisting of the executive directors of the pilot regional centers and area boards, along with representatives from the Organization of Area Boards, the Association of Regional Center Agencies, and the Senate Select Committee on Developmental Disabilities and Mental Health. The Committee, which meets on a quarterly basis, designed the vision and principles which would guide the implementation of self-determination in California. Recognizing that the value of a pilot project lies in experimentation within an agreed upon framework, the Steering Committee established guidelines for the required project proposals.

The Steering Committee also recognized the need for a comprehensive study of the pilot efforts. The Center for Outcome Analysis, which is conducting similar studies in a number of states, was hired to evaluate the pilots. Their study will give us valuable information on what it takes to make self-determination work in California, the most successful model, system changes that need to occur, and the costs (and cost/benefits) of self-determination.

Each self-determination pilot is advised and directed by a local advisory group. The local advisory groups consist of consumers, family members, service providers, and other interested community members. Consequently, each pilot has a unique approach to self-determination. For example, all pilots adhere to the general principles of self-determination but have different target populations. Eastern Los Angeles Regional Center and Area Board X, for example, have a multi-cultural focus, while Kern Regional

Center and Area Board XII have offered self-determination to all consumers in two very rural counties. Target populations and the use of support people unique to self-determination efforts, such as fiscal intermediaries and support brokers, vary across the pilots. However, each pilot encounters similar, fundamental issues. These issues are discussed in detail In our **FINDINGS** section, and more information can be found in the Center for Outcome Analysis Report and in each of the local advisory group reports.

FINDINGS

PARTICIPANT SATISFACTION

- C Participants report that they are happy with self-determination, and that they experience more freedom and responsibility in controlling the direction of their services and their life choices.

INDIVIDUAL BUDGETS

- C Through the use of an individualized budget, self-determination involves establishing limits on the amount of funding. California is the only state in which an individual with a developmental disability has an entitlement, or a categorical right, to services, once eligibility is established. While other states can limit services or cap expenditures for services to individuals with developmental disabilities, by law, California cannot.
- C Designing a participant's individual budget is not a simple task and is inextricably linked to intensive, high quality person-centered planning. Each pilot is committed to designing a fair and equitable way to determine the amount of the individual budget while also seeking to meet the mandate for cost neutrality. To date, no fair hearings have been sought over the amount of an individual budget and all pilots are cost-neutral in the aggregate.

UNDERSERVED POPULATION

- C Comprehensive person-centered planning is essential to self-determination. The pilot projects are substantiating, through extensive person-centered planning, that some Californians with developmental disabilities have unmet service needs. To some extent, these costs may be offset by potential savings realized by others using self-determination and, the more comprehensive person-centered planning may help identify generic services available for the unmet service needs.

REGIONAL CENTER OPERATIONS

- C Good self-determination requires intensive person-centered planning, collaboration, and follow along support. Based on the first year of planning, It appears that to effectively handle intensive person-centered planning, with a caseload of 1:62, the regional center has to be very careful regarding when to enroll participants in self-

determination. Although we do not have firm data, it appears that in subsequent years of participation, participants are taking the lead on the person-centered-planning and the role of the case manager is somewhat lessened.

- C Service brokers and fiscal intermediaries do not replace existing regional center staff or resources B they complement them. These functions could represent new costs to the system unless changes are made to existing regional center operational structures. Whether funding could shift, with more people self-determining their services, remains an open question. In order to address this issue, the pilots are experimenting with efficiencies of scale and evaluating current changing procedures.

DETERMINING WHAT IS REASONABLY RELATED TO IPP OBJECTIVES

- C The pilot projects often face complex and potentially precedent-setting "what is reasonably related?" decisions. With California's entitlement to these services, it may be difficult to place a limit on an individual budget, so long as a proposed service or support can reasonably be related to an IPP objective.

REGIONAL CENTER AS PAYER OF LAST RESORT

- C Participants ask to use self-determination funds to pay for services that are the obligation of another agency, often because of dissatisfaction with, or delay in provision of, services by that agency. The Lanterman Act places clear limits on the use of regional center funds when other publicly funded resources are available. If we agree that individual budget funds can be used for these purposes, how do, or should they, affect construction of the individual budget?

INCOME AND TAX CONSEQUENCES OF SELF-DETERMINATION

- C In some cases, participants are using a fiscal intermediary (FI) to handle regular bill payments and to provide employee related services such as payroll, deductions and tax filing matters. Pilots must decide who pays and how to pay for the fiscal intermediary services and are experimenting with varying methods of payment. Several pilots are paying all or part of the FI fee with regional center operations funds. For those whose fee is only partly paid by the regional center, the balance is paid through the individual budget. The KRC/AB XII pilot in Inyo and Mono counties includes funds for the FI in development of the individual budget.

THE HOME AND COMMUNITY-BASED WAIVER SERVICES (HCBS) WAIVER

The extent to which the Home and Community-based Services Waiver (Waiver) can support self-determination is unknown. Some of the issues the Department is researching include:

- C The specific manner in which our Waiver would need modification in order to capture funding for self-determined services and supports, including fiscal intermediary and support broker services.
- C How to define and assure that services and service providers used in self-determination meet Waiver criteria.
- C Whether the Waiver will allow for different rates for the same service. In self-determination, for example, participants are encouraged to negotiate rates with their vendors, in an effort to free up money for other services. The same vendor may charge a different rate to the regional center.

MANAGEMENT INFORMATION SYSTEM REQUIREMENTS

- C The accounting system currently used by regional centers to report and claim expenditures does not readily accommodate reporting of expenditures on an individual basis as is required for self-determination. Should self-determination expand, a system that is compatible with reporting requirements of the Department and waiver billing requirements will be required. The Department team responsible for development of the new California Developmental Disabilities Information System (CADDIS) is aware of these needs and will incorporate changes to accommodate self-determination.

RECOMMENDATIONS

Assembly Bill 430 (Chapter 171, Statutes of 2001, Cardenas) extended the self-determination pilot projects to January 1, 2004. The Department recommends that the pilot projects continue, without expansion within the existing projects or to other catchment areas, and that funding for any future continuation or expansion be explored through the budget process.

#####

CALIFORNIA SELF-DETERMINATION PILOT PROJECTS

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.

INTRODUCTION

In September 1998, Senate Bill 1038 (Chapter 1043, Statutes of 1998, Thompson) was signed, authorizing the planning and implementation of three self-determination pilot projects. This document is in response to the mandate to issue a report to the Legislature no later than January 1, 2001, on the status of those three self-determination pilot projects.

Since September 1998, two other regional centers and area boards have created independent self-determination pilots through approval of alternative service delivery models (AB 627, Chapter 623, Statutes of 1993). This report also includes information about these pilot projects.

LEGISLATIVE MANDATE

SB 1038 added Section 4685.5 to the Welfare and Institutions Code and required:

- C Effective January 1, 1999, the Department of Developmental Services (Department) conduct a three-year self-determination pilot project that would enhance the ability of an individual 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 and, to the extent possible, test a variety of approaches to self-determination.
- C \$750,000 be allocated for administrative and evaluation costs in three regional center catchment areas. (Note: An additional \$500,000 was allocated in Fiscal Year 1999-00.)
- C The pilot projects take place at Tri-Counties Regional Center, Eastern Los Angeles Regional Center, and Redwood Coast Regional Center, with the provision that another regional center could be substituted if one of the named regional centers did not participate.
- C The Department develop and issue a request for proposals (RFP) and that consumers, families, regional centers, advocates, and service providers be consulted during development of the RFP and in the selection of pilot areas.

- C Each pilot demonstrate joint regional center and area board support and establish a local advisory committee made up of consumers, family members, advocates, and community leaders. The advisory committee is to reflect the multicultural diversity and geographic profile of the catchment area.
- C By September 1, 2000, the local advisory committees submit a report to the Department with recommendations for the continuation and expansion of the pilots.
- C The Department issue a report to the Legislature no later than January 1, 2001, with the status of each pilot and recommendations with respect to continuation and expansion.
- C Welfare and Institutions Code Section 4685.5 remains in effect until January 1, 2002, unless a later enacted statute, extending or deleting the sunset date, becomes effective on or before January 1, 2002.

Appendix A contains the language of Section 4685.5 of the Welfare and Institutions Code.

BACKGROUND

Self-determination is an international initiative. California's first attempt to introduce this concept was through an unsuccessful application for a Robert Wood Johnson Foundation self-determination grant in July 1996. Legislation (SB 1038) was later introduced to establish three pilot projects in California. The three regional centers named in this legislation, in partnership with their area boards, were responsible for start up of the three pilots.

A longitudinal study of the effects of self-determination is under way. The contract for this evaluation was awarded to The Center for Outcome Analysis (COA). COA is also conducting studies of the Robert Wood Johnson Foundation self-determination pilot projects.

California's definition of self-determination is: Adults with developmental disabilities¹ or families of children with developmental disabilities, with the support of family, friends and professionals, taking charge of their future by gaining control over the services, supports and resources that they need. (See Appendix B for additional information regarding self-determination principles, individual planning and support structure.)

¹ International use of the term self-determination refers to individuals with any disability, however, California's focus for its pilot projects is on individuals with developmental disabilities.

DEPARTMENT'S IMPLEMENTATION

STATEWIDE SELF-DETERMINATION (SD) STEERING COMMITTEE

The Statewide SD Steering Committee consists of members that represent the five pilot regional centers and area boards, Department staff, and representatives from the Organization of Area Boards, the Association of Regional Center Agencies, and the Senate Select Committee on Developmental Disabilities and Mental Health. Consumers, families, advocates and service providers were consulted during the development of the pilots.

Statewide SD Steering Committee meetings began in December 1998. This committee did extensive research on methods used in other states and received information, instruction and assistance from nationally known experts in self-determination. Using this information, the vision, principles and implementation plan for the self-determination proposals were developed. The implementation plan also includes statements defining the roles and responsibilities of each participating agency and a statement about the use of public funds.

The Statewide SD Steering Committee reviewed and approved each of the proposed pilot project implementation plans. Once the Statewide Steering Committee was established, issues and questions that emerged from the pilots were presented to the Committee for discussion and direction.

REGIONAL CENTER PILOT PROJECTS IMPLEMENTATION

The regional centers and area boards, with knowledge gained through the Statewide Steering Committee and their own studies, began implementation of their pilot projects in the Spring of 1999. Each pilot works with a local advisory committee to establish direction, make policy decisions, and guide pilot efforts.

As required by Welfare and Institutions Code Section 4685.5(h), each local steering committee was required to report to the Department on recommendations for the continuation and expansion of the pilot projects. They were asked by the Department to address the following:

- C Summarize the self-determination pilot in relationship to the implementation plan, noting progress through June 30, 2000.
- C Based on your assessment of progress, what are the next steps in your area, including continuation and/or expansion of the pilot?

The following pages provide an at-a-glance summary for each pilot. A complete report from each self-determination pilot project is available upon request.

Note: Definitions for the terms Fiscal Intermediary and Support Broker, as used in the following pages, are found in Appendix B, Pages B-2 and B-3.

SUMMARY

EASTERN LOS ANGELES REGIONAL CENTER (ELARC) AREA BOARD X

TARGET POPULATION

A series of information sessions were held after which 175 potential participants indicated an interest. From that pool, 32 individuals were randomly selected to participate. Efforts were made to ensure that the groups were representative of ELARC's ethnic composition and geographic profile. Participants were drawn from the following target groups:

- Ⓒ Children age three (3) to fifteen (15) with the diagnosis of autism.
- Ⓒ Children age three (3) to fifteen (15) with high medical needs.
- Ⓒ Adults age twenty-two (22) to thirty-five (35).
- Ⓒ Adults over age thirty-five.

Proposed number of participants: 32

Number of signed Participant Agreements as of November 1, 2000	28	Number of IPPs completed with budgets approved as of November 1, 2000	17
--	----	---	----

HIGHLIGHTS

The Regional Center and/or the Area Board:

- Ⓒ Submitted an implementation plan for the self-determination pilot project that was approved on May 21, 1999.
- Ⓒ Conducted informational meetings for target populations with verbal and written information available in Mandarin, Cantonese, Spanish and English. Thirty-two participants were randomly selected from 175 attendees requesting inclusion in the project.
- Ⓒ Began conducting person-centered plans and developing individual budgets in January 2000.
- Ⓒ Conducted training for the ELARC and Area Board X Boards of Directors, vendors, service brokers, the community, and other regional centers. Presented at Cal-TASH (California: The Association for Persons with Severe Handicaps), California AAMR (American Association on Mental Retardation), Los Angeles Self-Advocacy Conference, California State-wide Self-Advocacy Conference, Area Board IV, Area Board IX, and San Diego Parent IEP (Individual Education Plan) Day conferences.

Regional Center Service Coordinator

- C Assigned all participants to one regional center service coordinator who works solely with these individuals and families.

SERVICE BROKER

- C Recruited and contracted with ten independent service brokers. Service brokers are paid by the Regional Center.

FISCAL INTERMEDIARY

- C Signed a contract with a fiscal intermediary agency in June 2000. This agency also accepts employer responsibilities for participant's employees and is paid by the Regional Center.

FINDINGS

SATISFACTION OF PARTICIPANTS

Participants state that they have a greater sense of freedom, authority, and choice. Family members indicate that they feel like they are in partnership with the Regional Center and are more confident in assuming their new responsibilities. Because most of the details are worked out early on, during comprehensive, person-centered planning sessions, many problems that created conflicts in the past are avoided. Families have indicated that they feel this will lead to fewer meetings and fair hearings. They feel supported by the Regional Center.

PERSON-CENTERED PLANNING (PCP) / INDIVIDUAL PROGRAM PLAN (IPP)

Comprehensive PCP sessions, under the self-determination model, have taken anywhere from 6 to 16 hours to complete and have identified service needs not previously discovered or met. For example, service purchases that had been authorized and funded but never used because of a lack of providers (i.e., LVN nursing care) have been identified. With their self-determined budgets, many participants are choosing services and supports outside of the traditional array offered by Regional Center providers.

INDIVIDUAL BUDGETS

The most challenging process undertaken so far has been the development of each participant's individual budget in accordance with the person-centered plan. Individual budget amounts are developed by reviewing the individual's Purchase of Service (POS) costs from the previous year in conjunction with a review of the target group's aggregate mean POS costs from the previous year. The range between the individual's costs and the group average serves as the basis for the budget. The exact amount from within that range is developed based upon individual needs as identified in the person-centered plan. Budget ranges were increased when service needs not previously discovered were found or when funded services were not used due to a lack of providers.

REGIONAL CENTER RESOURCES

Attitudes and approaches relating to traditional models of service coordination and service delivery have been challenged. Many difficult and complex issues have been addressed and solved in new and innovative ways.

Service coordination under self-determination is vastly different, more personal and more time consuming, requiring up to triple the staff time expended under the traditional model. Other key staff, in areas such as accounting, resource development, management information systems, and quality assurance, are devoting additional time to self-determination while simultaneously maintaining all traditional operations. A one-half time project manager position (to oversee the project) and a one-half time fiscal monitor position were created for the project.

The Regional Center has also provided extensive training to all stakeholders and Regional Center staff in order to assure the success of self-determination. This training is essential to ensure that key staff truly understand and embrace new roles, those in the community gear up for innovation, and participants understand their own responsibilities.

RECOMMENDATIONS

The local advisory committee recommends that the Eastern Los Angeles Regional Center and Area Board X continue their self-determination pilot project. They also encourage expansion to other regional centers.

Summary Redwood Coast Regional Center (RCRC) Area Board I

TARGET POPULATION

A pool of participants was chosen by a random sample of consumers in Mendocino County. The sample was reviewed to ensure that it was representative of the consumers in the pool based on age, residential type and location, type of disabilities, marital status, gender and legal status.

Proposed number of participants:	30	Limited to Mendocino County
Number of signed Participant Agreements as of November 1, 2000	26	Number of IPPs completed with budgets approved as of November 1, 2000 5

HIGHLIGHTS

The Regional Center and/or the Area Board:

- C Submitted an implementation plan for the self-determination pilot project that was approved on May 21, 1999. A project manager was hired in October 1999.
- C Hired a consultant who researched issues relative to employment that consumers would face as employers. He developed related materials and a video that will be used for future training.
- C Supports a participant focus group that meets monthly to share experiences and information.

Regional Center Service Coordinator

- C Participants will continue to receive support from their Regional Center service coordinator who is also part of the planning process.

Service Broker

- C The service broker works with all 30 participants. Once the consumer identifies what he/she wants, the service broker works with him/her to find resources and determine how much time and money it will take to accomplish the goals.

Fiscal Intermediary

- C A local, private fiscal intermediary is contracted by RCRC to pay participant's bills up to the amount of each person's annual budget. Up to 25% of the budgeted funds are transferred to the fiscal intermediary when the person's plan is implemented. This

enables participants to pay for services as needed without waiting to invoice and be reimbursed by the Regional Center. Fiscal reports are made to the participant and service broker.

FINDINGS

SATISFACTION OF PARTICIPANTS

Redwood Coast participants feel their lives have changed for the better with self-determination. They find that their freedom and authority often change how people interact with them. A group of participants plan to meet monthly to continue the sharing of experiences they enthusiastically discussed at their first meeting. The mother of an adult participant stated that self-determination "provided the mechanism to create services that really fit with his life@.

PERSON-CENTERED PLANNING (PCP) / INDIVIDUAL PROGRAM PLAN (IPP)

Both the support services broker and the regularly assigned service coordinator support participants during the planning process. Participants are deciding how they want their team to be involved and asking who is willing to take on particular activities. They are eagerly taking on the leadership role. Person-centered planning in a self-determination context is taking longer than other planning processes. Service options for persons in the "traditional" system are already researched, developed and approved by Regional Center staff and other agencies and have rates and standards that are already developed. Under self-determination, the research, development and service negotiations are done on an individual level.

INDIVIDUAL BUDGETS

The budget is developed based on a projection of the amount of funds needed to accomplish the person's plan, and a review of the prior year expenditures with adjustments for any service provider rate increases. If the projected amount exceeds the amount allocated for the individual's budget, the team works together to prioritize support needs and develop strategies to meet the essential and preferred support needs within the allocated amount. The individual budgeting process is causing people to consider choices thoroughly and work hard to stay within their personal allocation.

A budget review process was established to help finalize budgets for individuals who may not have a realistic purchase of service history because of life changing events, choices, or transition from adolescent to adult services.

Some things the Regional Center has learned during the planning process include:

- C When people are paying for services from their own budget, the consequences for unacceptable quality come swift and hard. In one case, the provider was fired within three weeks because the participant was not satisfied with the services provided.

- C People are asking what they are getting for the money they're spending.
- C People are surprised at the amount of money that is being spent on their services.
- C The freedom and authority of consumers often change how people interact with them.

REGIONAL CENTER RESOURCES

This project reports that planning takes much longer and ongoing support will necessitate lower caseloads. The planning process is taking place over a period of three to four months, sometimes with up to 40+ hours in meetings and other tasks relating to planning and budgeting.

RECOMMENDATIONS

More time is needed to learn about how self-determination will impact consumers and the service delivery system. An extension of the project for an additional year beyond the end date would enable RCRC consumers to have at least two years experience with the self-determination planning process. Consumers need at least a full year to gain experience with self-direction and control in order to gauge the impact on their lives, their ability to determine their futures, and their satisfaction with the piloted processes.

Expansion is needed in the area of addressing the population residing in the State Developmental Centers. RCRC proposes adding up to five participants to the project (who originally lived in Mendocino County) who are currently residing in a developmental center.

SUMMARY
TRI-COUNTIES REGIONAL CENTER (TCRC)
AREA BOARD IX

TARGET POPULATION

This pilot project focused on two general populations:

- C Individuals, both adult and children, who are not living in the family home. Potential participants were randomly selected from those who received funding for services during the prior year.
- C Individuals, both adult and children, who are living in the family home. Potential participants were chosen through a stratified random sample of: 1) families whose children have behavioral challenges; 2) families whose children have medical challenges; 3) families whose adult children live at home; and 4) families whose children do not fit into the other three groups.
- C Proposed number of participants: 36
- C Number of signed Participant Agreements as of November 1, 2000 20 Number of IPPs completed with budgets approved as of November 1, 2000 20

HIGHLIGHTS

The Regional Center and/or the Area Board:

- C Submitted an implementation plan for the self-determination pilot project that was approved on May 21, 1999.
- C Hired and trained a fiscal assistant to provide individualized budget tracking and project operations cost tracking.
- C Executed a contract with a fiscal intermediary.
- C Hosted and developed training activities for the first California Self-Determination Conference in conjunction with the Santa Barbara Interagency Coordination Council which is made up of school representatives, Department of Rehabilitation representatives, and local service providers.
- C Distributes a quarterly self-determination newsletter specifically developed for participants.

Regional Center Service Coordinator

- C TCRC service coordinators have assumed the role of support broker for self-determination participants in addition to their traditional case management services.

SERVICE BROKER

- C Three options are available for procuring services: 1) TCRC service coordinators can serve as the service broker; 2) the family or consumer can secure a service broker; or 3) the family can serve as the service broker.
- C External service broker services have not yet been developed, however, the Regional Center will be offering service broker training for interested community individuals.

FISCAL INTERMEDIARY

- C TCRC directly pays independent contractors (e.g., professionals) or traditional service providers or directly purchases goods for consumers.
- C The fiscal intermediary is used for payment of payroll, tax withholding, worker's compensation and liability insurance and is paid from the individual's budget.

FINDINGS

SATISFACTION OF PARTICIPANTS

Families and consumers have verified that the process of taking control is life affirming. They report that they now feel like they are in control of their lives and that they have been able to structure services to fit their needs rather than changing their needs to fit the services available. Other families and consumers have heard about the project and are interested in this option.

PERSON-CENTERED PLANNING (PCP) / INDIVIDUAL PROGRAM PLAN (IPP)

Even consumers who continued their current service options reported that, through the person-centered planning and budget development process, they felt they were really listened to. Staff doing the person-centered planning are finding that many previously authorized services have not been purchased, perhaps due to lack of available providers (i.e., nursing services). The PCP process is also identifying unmet service needs and inequities in expenditures among like groups.

INDIVIDUAL BUDGETS

Individual budgets are established based on historical purchase of service expenditures with adjustments for partial year expenditures, service provider rate adjustments, natural life transitions that weren't reflected in the prior year budgets, and changes in medical or behavioral needs.

REGIONAL CENTER RESOURCES

A number of issues have emerged in the implementation of the self-determination pilot project that will require creative solutions for self-determination to move forward as an option for all consumers and families. Some of these issues are:

- C *Who pays for the support broker?* Existing resources in regional center budgets do not allow for support brokers. TCRC's experiment with having service coordinators provide the support brokerage has produced some mixed results. Service coordinators are quite able to perform broker activities but lack the time required to broker services given current caseloads. Additional operations dollars are needed to either lower caseloads or buy the support broker function (i.e., include support broker dollars in the consumers' individual budgets).
- C *How is the individual budget set?* The issue of how to establish equitable individualized budgets is one of the most pressing issues in self-determination. Especially critical is deciding how to fund previously unmet needs.
- C *Unbundling large service contracts.* Under the current service system a regional center can frequently purchase services in block amounts that afford significant savings. Support brokers and families are finding that they are unable to purchase services for the rates TCRC receives.

RECOMMENDATIONS

- C The Department of Developmental Services should do a study to determine the additional costs of adding a support brokerage function to regional centers providing self-determination services.
- C The Department should develop standard procedures for setting individual budgets.
- C The Department should find ways to roll unused self-determination dollars across fiscal years to allow the redistribution of these funds for unmet service needs identified through the person-centered planning process.
- C TCRC and Area Board IX are committed to the expansion of the self-determination project. They further recommend that adequate funding be provided for any new participants. These funds are essential to provide the support brokerage, individual budget tracking, bill payment, and enhanced case management, which have reduced the burden on families, enabled individuals of all disability levels to participate in SD, and made the pilot project successful.

SUMMARY

KERN REGIONAL CENTER (KRC) AREA BOARD XII

TARGET POPULATION

The Kern Regional Center serves a large geographic area. In two rural counties, Inyo and Mono, difficulty in securing services and providers is a common experience. Thus, Kern and Area Board XII agreed to open self-determination to all 127 consumers and families in Inyo and Mono Counties.

C	Number of signed Participant Agreements as of November 1, 2000	12	Number of IPPs completed with budgets approved as of November 1, 2000	12
---	--	----	---	----

HIGHLIGHTS

Kern Regional Center proposed to implement a self-determination pilot project through approval of alternative service delivery methods (AB 627, Chapter 623, Statutes of 1993). The proposal was approved on April 5, 2000, with a requirement that they follow the Statewide Self-Determination Steering Committee agreements used by the other self-determination pilot projects. Since KRC was not named as a participant in SB 1038, they do not share in the appropriated funding.

The Regional Center and/or the Area Board:

- C Held a series of trainings for the participants and community in both Bishop and Mammoth Lakes.
- C Held trainings for Regional Center staff, both in the Bishop office and at the main office in Bakersfield.

REGIONAL CENTER SERVICE COORDINATOR

- C A service coordinator in the Bishop office is designated as the self-determination liaison.

SERVICE BROKER (FACILITATOR)

- C The service broker is chosen by the consumer or family and paid from the individual budget. In some cases, the family is acting as their own service broker and not incurring service broker costs.

FISCAL INTERMEDIARY (FACILITATOR)

C The fiscal intermediary (facilitator) is paid from the individual budget. The regional center is experimenting with several options for providing this service, including the use of parents as a fiscal intermediary.

FINDINGS

SATISFACTION OF PARTICIPANTS

Participants and families are taking personal responsibility for their person-centered planning, with some families volunteering to be their own service broker and fiscal intermediary at no cost to the pilot project. Participant satisfaction level appears directly correlated with the participant's understanding of the overall process. One family, who learned of housing options through the person-centered process, has purchased their first home. Another family, through the PCP process, learned about in-home supportive services and local work options and now has these services in place.

PERSON-CENTERED PLANNING (PCP) / INDIVIDUAL PROGRAM PLAN (IPP)

The process of person-centered planning has taken longer than anticipated. Although very time consuming, the person-centered planning process will most likely be the most critical component in the success of self-determination in California. It is common for the PCP process to require multiple meetings and take up to ten hours to complete, not including the actual writing of the plan, securing resources, and related paperwork duties. Service needs not previously discovered or funded are being identified through the PCP process.

INDIVIDUAL BUDGETS

Individual budgets are developed using historical costs with adjustments for today's needs (as identified in the PCP process) including needs not previously identified.

Participants are beginning to make creative and responsible determinations of services and supports. Many participants are continuing with established services while some of the plans are using services not currently vendored. The requests have been largely within the established budgets and also consider the use of generic and natural supports.

Many parents are requesting services that are the responsibility of the school district, (i.e., speech therapy, occupational therapy, and physical therapy). Although the parents are generally clear that these services are the responsibility of the school district, they are tired of the struggle to obtain these services from the school. Similar issues are emerging from adult participants who are dissatisfied with services for job training and related supports through another public agency required to provide those services.

In response to the school services issue, the Regional Center sponsored a full day special education advocacy training seminar for the entire community in both Inyo and Mono Counties. The goal was to empower parents of participants as to their rights to special

education services and to decrease the use of self-determination funds for services that are clearly the responsibility of the local education agencies.

REGIONAL CENTER RESOURCES

Area Board XII is providing a staff person to facilitate and coordinate the development and implementation of the pilot project. KRC reimburses Area Board XII for those services.

A number of barriers were identified that include staffing issues, consumer and family education issues, lack of fiscal and service facilitators, the need for multiple and lengthy person-centered planning meetings, and issues related to the geographic nature of Inyo and Mono Counties. One of the steps taken is the extensive training offered to staff, participants and families, the community, and service providers.

The Regional Center is finding that comprehensive person-centered planning may not have been taking place as originally intended by the Lanterman Act. Secondary to this finding is the availability of funding for well-trained staff and adequate time for staff to complete the person-centered planning process. It appears that the need for high levels of staffing may diminish as plans are completed and participants become more aware of their plans, resources, and new responsibilities.

In addition, the Regional Center purchase of service expenditures are increasing to provide for newly identified service needs.

RECOMMENDATIONS

It is the consensus of the local advisory committee that the self-determination pilot should be continued in both Inyo and Mono Counties. Kern Regional Center is prepared to and may expand self-determination processes to include individuals who live outside of Inyo and Mono Counties on a selective, individual basis.

The local advisory committee, the Regional Center, and the Area Board all feel that it is too early to make a recommendation about the immediate successful expansion of self-determination to all persons with developmental disabilities in California.

SUMMARY

SAN DIEGO REGIONAL CENTER (SDRC)

AREA BOARD XIII

San Diego Regional Center and Area Board XIII proposed to implement a self-determination pilot project through approval of alternative service delivery methods (AB 627, Chapter 623, Statutes of 1993). The proposal was approved on June 30, 2000, with a requirement that they follow the Statewide Self-Determination Steering Committee agreements used by the other self-determination pilot projects. Since SDRC was not named as a participant in Senate Bill 1038 (Chapter 1043, Statutes of 1998, Thompson), they do not share in the funding appropriated by the bill.

Since SDRC was so recently approved, they were not required to submit a report and recommendations to the Department.

Summary

INDEPENDENT EVALUATION OF CALIFORNIA'S SELF-DETERMINATION PILOT PROJECTS: FIRST YEAR FINDINGS

THE CENTER FOR OUTCOME ANALYSIS (COA)

The COA is under contract with Eastern Los Angeles Regional Center to conduct an independent analysis of the California self-determination pilot projects. This contract provides for two interim reports (September 1, 2000, and September 1, 2001) in addition to a final report due March 1, 2002.

COA has collected data about the participants' lives when they were just beginning to take part. Therefore, COA cannot yet conclude with confidence that power has shifted, lives have improved, or costs have changed. To do that, they must visit the people again after they have had some experience with self-determination. They will do so in the next project year. Nevertheless, the early indications are strong that individuals and families are enthusiastic, committed, and they believe their lives are already beginning to improve.

WHO PARTICIPATES IN THE PILOT PROJECTS?

Each of the pilot projects took a different approach to identifying potential participants. In general, pilots focused on underserved populations (ELARC/AB X and TCRC/AB IX), a third (KRC/AB XII) offered self-determination to anyone in two rural counties, and the RCRC/AB I pilot constructed a random sample within Mendocino County. While in other states self-determination has been used as a means to move people out of congregate living arrangements (and/or clear waiting lists), most California participants live in their parents' home (60%).

Characteristics of Participants²

Characteristics	TCRC N = 31	RCRC N = 18	KERN N = 35	ELARC N = 28	TOTAL N = 112
Average Age	26	35	31	22	25
Sex					
Male	55%	78%	63%	79%	67%
Female	45%	22%	37%	21%	33%

² A complete description of participants is found in the Center for Outcome Analysis report, which is available upon request.

REPORT TO THE CALIFORNIA LEGISLATURE

Characteristics	TCRC N = 31	RCRC N = 18	KERN N = 35	ELARC N = 28	TOTAL N = 112
Ethnicity					
White	77%	67%	79%	14%	60%
Black	6%	0%	3%	0%	3%
Hispanic	13%	28%	12%	61%	27%
Native American	3%	6%	6%	0%	4%
Asian	0%	0%	0%	21%	5%
Other	0%	0%	0%	4%	1%
Developmental Disability ³					
No Mental Retardation	42%	11%	33%	42%	35%
Mild Mental Retardation	42%	61%	45%	29%	43%
Moderate Mental Retardation	10%	22%	12%	7%	12%
Severe Mental Retardation	3%	6%	3%	11%	6%
Profound Mental Retardation	0%	0%	6%	7%	4%
MR present/No label	3%	0%	0%	4%	2%
Autism	13%	0%	6%	14%	9%
Cerebral Palsy	16%	17%	3%	18%	13%

Where Participants Live

Setting	Number	Percent
Congregate	7	6%
Supported Living	10	9%
Independent Living	16	14%
Parents= Home	67	60%
Relatives= Home	8	7%
Other Settings	4	4%

³ Total exceeds 100% because an individual may have more than one diagnosis.

Total:	112	100%
---------------	-----	------

COA has looked at common themes occurring among the pilot projects. Excerpts of responses by participants, Regional Center and Area Board staff, Steering Committee members and others to COA questions about self-determination follow.

WHAT DIFFERENCE DOES SELF-DETERMINATION MAKE?

IN GENERAL

A majority of the respondents to a COA inquiry believe that self-determination is a better and easier way for people with developmental disabilities to receive needed services and supports. However, a number of respondents also feel that self-determination is not for everyone and that dual systems of self-determination and "traditional" service coordination will be inevitable.

FOR PARTICIPANTS

Families and consumers feel lucky to have been chosen for the self-determination pilot. Central to participants successfully planning for and managing their individual budgets is a changed relationship with the regional center service coordinator. They like handling their service dollars and the responsibility that comes with it. They feel in charge of their life and services. Most agree that good person-centered planning is occurring through the self-determination pilots; they have options and choices available to them. They have hope for a different lifestyle.

The COA survey of families shows that they believe their relatives' lives have already improved in several ways: opportunities to make choices, qualities of work or day program, getting out and around, safety, relationship with family, and happiness.

FOR SERVICE PROVIDERS

The service broker strategy is not well understood by the vendor community. They question if the service broker is a duplication of regional center service coordination.

Service providers have not been very involved in the pilots. Although they lack an understanding of how self-determination is operating in the pilots, many service providers are concerned that self-determination will not look much different than current practice and they perceive that the regional centers will still be in control.

Service providers are also concerned about how self-determination may negatively affect their business operations and the quality of services provided. They are concerned about people receiving services from people who don't have the quality assurance that agencies can provide, such as monitoring, supervision, staff training, and employee protections. They are also concerned that their high turnover rates may increase further if consumers and families hire staff away from their agencies.

FOR REGIONAL CENTERS, AREA BOARDS AND THE DEPARTMENT

Some Regional Center staff and administrators report that self-determination is bringing their staff back to the "touchstone" of what brought them to the disability profession. However, other Regional Center staff are experiencing some strain in implementing flexible service delivery for self-determination within their agencies that have a history of providing less than flexible service options. Many regional center staff feel that self-determination is a radical idea; that it's about giving money to people.®

Respondents believe that the pilots are a good strategy to learn how to provide self-determination in California. A lot of the system leaders look forward to public policy direction on the limits of self-determination such as how will personal choice be balanced with the outcomes stated in the Lanterman Act and public sentiment on the use of taxpayer dollars.

COSTS AND COST-BENEFITS OF THE PILOT PROJECT MODELS

The pilot projects have not been in place long enough to allow for a fair analysis of these issues.

In general, respondents feel that families are taking personal responsibility for their individual dollars and are developing quality, creative services at less cost. As a group, families and consumers are not demanding excessive amounts of financial support.

FINDINGS

SATISFACTION OF PARTICIPANTS

Participants report that they are happy with self-determination. They experience more freedom and responsibility in controlling the direction of their services and their life choices. While all changes are not dramatic, even small changes make a significant difference for participants. As the following vignettes illustrate, self-determination is making positive changes in people's lives⁴:

Eric had a traditional day program with transportation. If he wasn't ready when transportation came, he'd be left behind for the day and he would behaviorally demonstrate his dissatisfaction. If he was ready and transportation came late he would demonstrate his dissatisfaction. Then he couldn't go to the day program because of his "behaviors"! With self-determination, this doesn't happen any more. With the help of family and his service broker, he now has his own day activities, doing what he wants, when he's ready.

When Tony wanted change, it came swiftly. He had been unhappy with the services he was getting. He'd also asked for a job change that never happened. Upon receiving his budget, he fired his support agency and hired a person to work directly for him. He wanted a new job and with help from his new support person he found one that he loves.

In limiting the number and length of the pilot projects, we can presume that the Legislature understood that California's current service delivery system would need to change in order to implement self-determination. Although California's experience is only 12 years old, we are able to identify a number of key issues which need resolution before significant expansion can occur.

INDIVIDUAL BUDGETS

Having responsible control over a known sum of money, and the support to purchase services and supports, is central to self-determination. Designing a participant's individual budget is not a simple task and is inextricably linked to intensive, high quality, person-centered planning.

Pilot regional centers have been able to readily integrate the notion of an individual budget with the Individual Program Plan (IPP). Each pilot, though, has grappled with designing a fair and equitable way to determine the amount of the individual budget while also seeking to meet the mandate for cost neutrality. This is not unique to California's experience for

⁴ Names are changed to protect confidentiality.

self-determination; project directors in other states also note the need for an objective way to determine the needed amount of funding.

The pilots have addressed cost neutrality for individual budgets in several ways.

- C Each pilot looks at past year expenditures and uses that history as a guide in preparing a budget.
- C Several have done extensive review not only of the past expenditures, but of past service authorizations that may or may not have been used in order to determine if the budget is reasonable.
- C Each pilot has a review process for proposed budgets that exceed established targets.
- C Most participants receive a monthly report showing real and estimated expenditures and the amount remaining in the individual budget. This helps regional centers and participants track over/underspending.

California is the only state in which an individual with a developmental disability has an entitlement, or a categorical right, to services, once eligibility is established. There is no maximum amount of services or expenditures established at which services are no longer provided. This entitlement is established by law in the Lanterman Developmental Disabilities Act. While other states can limit services or cap expenditures for services to individuals with developmental disabilities, by law, California cannot.

While the entitlement to services and supports can be regarded as an open-ended entitlement, regional center budgets are not. Indeed, regional centers labor under a legislative mandate to stay within their budgets. The inherent contraction between these two mandates — open-ended entitlement within a closed budget — poses a particularly thorny issue for the self-determination pilots because an individual budget, by definition, involves setting a cap on the amount of funding⁵.

OWNERSHIP OF EQUIPMENT/PROPERTY

California's constitution states that the Legislature does not have the power to make any gift, or to authorize the making of any gift, of any public money or thing of value to any individual. In keeping with this mandate, certain purchases or property with a value of \$5,000 or more must be inventoried by the regional center and have a tag attached identifying the item as property of the State of California. This includes computer equipment, cell phones, camera equipment, etc. An exception is adaptive equipment such as wheelchairs and other mobility devices, durable medical equipment, and communication devices purchased solely because of a person's unique needs.

For example, an individual has an IPP objective to purchase a computer to use for budgeting, e-mail contact with the service broker and fiscal intermediary, school projects,

⁵ It is important to note that participants still have their fair hearing appeal rights and could challenge the budget amount. To date, no participants have gone to mediation or fair hearing.

etc. Purchase of the computer is included in that individual's self-determination budget. When purchased, the regional center is required to affix an inventory tag identifying the computer as state property.

This "tagging" of equipment as state property when purchased with self-determination funds is seen by some as an unnecessary intrusion into the lives of those self-directing their services. Some consumers have expressed apprehension that, since tagged items belong to the state, they can be taken away at any time. It also seems to be at cross purposes with the self-determination principles of freedom and authority. Individuals gain the freedom to plan their lives and the authority to control their money — then an inventory tag is placed claiming that an item is the property of the state.

UNDERSERVED POPULATION

One reason self-determination is so welcomed by participants is that it offers the opportunity to truly individualize services and supports. No matter how comprehensive the array of services and the talents of providers, there is always a need for customized services. Traditional services are designed to meet the needs of an aggregate group and may be less adaptable to meet individual needs that include everything from unique behavior challenges to enriching ethnic and cultural environments.

The pilot projects are substantiating that some Californians with developmental disabilities have unmet service needs. There are a number of reasons for the unmet needs. The ELARC/AB X pilot project is finding that some racial and ethnic group members had significant amounts of encumbered, but unspent funding, because culturally appropriate services were in short supply. The KRC/AB XII pilot was located in the very rural counties of Inyo and Mono because the sparse population did not support development of some traditional services. The TCRC/AB IX project is finding that some participants want to stay with current providers, but rearrange how the service is provided.

Pilot projects credit the thoroughness of the person-centered planning process with identifying unmet service needs. Uncovering these needs also poses a dilemma to the pilot regional centers because the pilots are mandated to be cost neutral. Further expansion could create a purchase of services budget impact for the regional centers as new, unmet needs for services are uncovered.

To some extent, these costs are offset, individually and in the aggregate, by potential savings realized by identifying generic services available and by the timely provision of needed services. The Department, Regional Centers, Area Boards, and participants will continue to work toward aggregate cost neutrality for the self-determination pilots.

REGIONAL CENTER OPERATIONS

The above discussion on unmet needs underscores the central importance of person-centered planning. Failure or difficulty is invited without full attention to detail at the beginning — to help participants understand their roles and responsibilities, plan their goals and objectives, and develop their budgets. With a budget in hand, person-centered planning is needed to secure providers, goods and services, track expenditures, and allocate resources.

Good self-determination requires intensive person-centered planning, collaboration, and follow along support. In the first year of self-determination, unless participants were moved into the project in several stages, case management role could not be effectively handled with a caseload of 1:62.

The Tri-Counties/AB IX pilot is implementing self-determination within the current caseload requirements. They are able to do so by timing the number of participants entering the pilot.

One of the issues being tracked by the project evaluation is whether this trend continues the second year and beyond for those continuing with self-determination. It does seem that the case management demands may be different for the second year of self-determination.

In the Eastern Los Angeles/AB X pilot, for example, participants who are going into their second year of self-determination have done significant planning and budget estimation before meeting with the service coordinator. Thus, the service coordinator is spending less time on the second year planning.

Self-determination also adds a new dimension with the use of service brokers and fiscal intermediaries. As noted in the Redwood Coast pilot project report, service options for persons in the "traditional" system are already researched, developed and approved by the regional center or generic agencies and have established rates and standards. Under self-determination, the research, development and service negotiations are done anew on an individual basis.

Service brokers and fiscal intermediaries do not replace existing regional center staff or resources B they complement them. The relationship of the service broker to the participant is usually as an employee of the participant. This allows more individual attention. Additionally, it may open resources that may not be available through a regional center because of regulatory requirements or other restrictions on service development. A fiscal intermediary outside of the regional center furthers the self-determination principles regarding authority and control of funds. Once the individual budget is set, the participant can direct payments from their budget.

Who pays for the cost of these services? The legislative funding for the three original pilot projects provided some relief to regional center operations. Each pilot has contributed significant matching funds or in-kind services. Some pilots are paying for the service broker and fiscal intermediary functions directly, while others are building this cost into the

individual budget. Whether funding could shift to pay for these costs, with more people self-determining their services, remains an open question. However, the pilots are experimenting with efficiencies of scale, changing procedures, and other methods to address this funding issue.

DETERMINING WHAT IS REASONABLY RELATED TO IPP OBJECTIVES

After reviewing self-determination efforts in other states, the Statewide Self-Determination Steering Committee established three "rules" for the use of individual budget funds (public funds). The money budgeted is to be used:

1. In a way that is legal.
2. In a way that does not cause physical harm.
3. To buy what is reasonably related to the IPP or IFSP objectives.

The first two "rules" are relatively easy to define. Number three is not. Sometimes it is difficult to determine what is reasonably related to an IPP or IFSP objective because reaching self-determination goals often means purchasing services outside the "box". And it is likely that some of the "boxes" have been constructed to help manage the closed end budget, others to avoid conflict with the "gift of public funds" restrictions, and others based on best practices.

The Lanterman Act contains several references to the Legislative intent regarding the IPP document. One reference is that "*provision of services to consumers and their families be effective in meeting the goals stated in the individual program plan, reflect the preferences and choices of the consumer, and reflect the cost-effective use of public resources.*" Another charges the Department to monitor regional centers to assure that services contained in an individual's IPP are provided.

The pilot projects often face complex and potentially precedent-setting *what is reasonably related?* decisions. Some examples are listed below:

- C Is it allowable to pay vehicle registration and car insurance for someone who has agreed to be the primary transportation person in a rural area?
- C A person changes how his services are provided, saving hundreds of dollars a month in service costs. He/she previously incurred credit debt to purchase furniture and household goods for an apartment. Can some of the savings be used to pay part of the debt so the individual has some financial stability?
- C A child is unable to attend therapy and other necessary appointments because the parent (and sole transportation provider available) has an unpaid traffic ticket. Does this ticket get paid so the child can receive services included in the IFSP?

In other states piloting self-determination, what is purchased with the individual budget does not pose such difficulties because the total amount of the budget, as well as the types

of services that can be purchased, can be limited. For these states, establishing the budget is the significant hurdle. Once the budget is established, participants in those states arrange and rearrange their proposed purchases to maximize their value, and even the most creative person may still have unmet needs. However, with our entitlement to services, it may be difficult to place a limit on an individual budget, so long as a proposed service or support can reasonably be related to an IPP objective.

REGIONAL CENTER AS PAYER OF LAST RESORT

The Lanterman Act envisioned inclusiveness for individuals with developmental disabilities long before inclusive practices were common. Individuals with developmental disabilities were entitled to access any publicly funded service available to Californians. Regional center case managers help identify and access these services; if no service is available, the regional center is able use its funding to secure it. In essence, regional centers are designed to be payer of last resort.

In spite of the elegance and promise of this design, regional centers often face the dilemma of requests to provide funds for services that another agency is obligated to provide. For instance, school districts are obligated to provide a variety of services to children with special educational needs. For parents of these children, the process of obtaining these services is often an emotional and exhausting challenge of hearings and other legal actions. Not wanting to face a delay in needed services, some parents are requesting to use their individual budgets to pay directly for these services.

In other cases, it may be expressed as a desire to use the individual budget to pay for specialty health services in lieu of finding medical, dental or mental health care professionals who will accept the Schedule of Maximum Allowances or Medi-Cal rate.

The Lanterman Act limits the use of regional center funds when other resources are available through publicly funded agencies. Given how these actions conflict with the intent of the Lanterman Act, and the potential budget impact, pilots have struggled with these requests. With self-determination and control over an individual budget, the dilemma of when, and whether, to pay for these services has to be carefully and seriously considered. Under self-determination, is the regional center still payer of last resort or, since individuals determine their own services, can they override this mandate? If we agree that individual budget funds can be used for these purposes, how do, or should they affect construction of the individual budget?

INCOME AND TAX CONSEQUENCES OF SELF-DETERMINATION

Prior to self-determination, it is doubtful that most regional center consumers and family members gave much thought to the "business" side of being an employer. The regional center entered into a contract with the service provider and the service provider's administrative staff handled many of these issues. Now that some participants are the official employers of those who provide their services, it is especially important that responsibilities relating to employer/employee relationships and employment related taxes

and deductions are handled correctly. An individual may choose to do this him/herself⁶. However, a fiscal intermediary, chosen and directed by the individual, not only handles regular bill payment, but also employee payroll, deductions and tax filing matters. Pilots must decide who pays for and how to pay for fiscal intermediary services and are experimenting with varying methods of payment⁷.

THE HOME AND COMMUNITY-BASED SERVICES (HCBS) WAIVER

Reimbursements to California for services provided for Waiver-eligible individuals average about \$500 million per year. Eligible Waiver services are traditionally based on a medical model with strict accountability rules. Although the Department is investigating how to amend our Waiver to include self-determination, it is not covered in the current Waiver. The Department is conducting a "pilot within the pilot" to test the extent to which our Waiver would need modification in order to capture funding for self-determined services and supports.

Some of the issues the Department is researching include:

- C The specific manner in which our Waiver would need modification in order to capture funding for self-determined services and supports, including fiscal intermediary and support broker services.
- C How to define and assure that services and service providers used in self-determination meet Waiver criteria.
- C Whether the differing rates that are negotiated between participants and their providers for the same types of services will be allowed for Waiver billing instead of the one rate or average rate now used.

Health Care Financing Administration is reported to be in the process of developing written policy directions relating to the Waiver and self-determination. We do not have a clear picture of what will be allowed by HCFA, but intend to work closely with our Federal partner when amending our Waiver.

MANAGEMENT INFORMATION SYSTEM REQUIREMENTS

The accounting system currently used by regional centers to report and claim expenditures does not readily accommodate reporting of expenditures on an individual basis. It is set up to capture the expenditures of service providers who report expenditures by service code (i.e., Supported Living Service, Day Program, etc.) for each individual they serve. Each pilot has set up its own method of tracking and reporting individual expenditures and

⁶ The Department and pilot projects are working closely with the Internal Revenue Service (IRS), California Employment Development Department (EDD), California Franchise Tax Board and the Social Security Administration to learn how to structure self-determination funding to minimize chances of unexpected income, tax, or employer related consequences to participants.

⁷ Typically, the regional center would not act as the fiscal intermediary for payroll and employee tax matters because of a conflict of interest of being both the employer and the fund source.

budgets. This is possible because of the short term of the pilots and the relatively small number of participants. Should self-determination expand, a system that is compatible with reporting requirements of the Department and HCFA's Waiver billing requirements will be required.

The Department is presently engaged in long-range development of a management information system that will allow integration of information from all of its reporting sources.

The Department team responsible for development of the new California Developmental Disabilities Information System (CADDIS) is aware of the needs to track individual budgets and other data for self-determination, and will incorporate changes to accommodate self-determination. CADDIS is expected to be operational in June 2003.

RECOMMENDATIONS TO THE LEGISLATURE

Assembly Bill 430 (Chapter 171, Statutes of 2001, Cardenas) extended the self-determination pilot projects to January 1, 2004. The Department recommends that the pilot projects continue, without expansion within the existing projects or to other catchment areas, and that funding for any future continuation or expansion be explored through the budget process.

Our report, and those of the pilot projects and the Center for Outcome Analysis, outlines many unresolved issues that will require creative and collaborative efforts to resolve. Before we can expand self-determination, the significant policy issues discussed in this report need to be addressed. The projects and the Department will continue to work toward resolving issues identified in this report and toward implementation of self-determination in the most efficient, effective and cost neutral manner possible.

Additionally, while needed changes to the administrative efforts central to our service delivery, such as an amendment to the HCBS Waiver and modification of our MIS systems, are already in progress, these changes must be operational prior to full-scale expansion.

We are keenly aware that many members of our constituency are looking forward to the availability of self-determination in their area. We are also mindful that, for self-determination to flourish, we must build a system that is wrapped around the values of self-determination — and this takes time and the ability to make changes based on what we have learned.

#####

Appendix A

Welfare and Institutions Code Section 4685.5

Added by SB 1038, Chapter 1043, Statutes of 1998

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.

#####

Appendix B

PRINCIPLES OF SELF-DETERMINATION

The principles of self-determination used by the Robert Wood Johnson Foundation were adapted by the Statewide Self-Determination Steering Committee for use by California's self-determination pilot projects⁸. The four principles are:

1. Freedom. The ability for individuals with freely chosen family and or friends to plan a life with necessary support rather than purchase a program;
2. Authority. The ability for a person with a disability (with a social support network or circle if needed) to control a certain sum of dollars, consistent with limits delineated in the Self-Determination Steering Committee's *Use of Public Funds*,⁸ in order to purchase these supports;
3. Support. The arranging of resources and personnel B both formal and informal B that will assist an individual with a disability to live a life in the community rich in community association and contribution; and
4. Responsibility. The acceptance of a valued role in a person's community through competitive employment, organizational affiliations, spiritual development and general caring for others in the community, as well as accountability for spending public dollars in ways that are life-enhancing for people with developmental disabilities.

It is understood that the responsibility for using public funds wisely do not infringe on the consumers right to:

- C Make informed choices in matters which affect their quality of life including where and with whom to live, favorite people with whom to socialize, and meaningful daily activities including paid work;
- C Be treated with dignity and respect and supported in making and keep friendships, close relationships and circles of support;
- C Be fully included into the mainstream life of their natural communities and have expanding opportunities for full and equal participation in spiritual, recreational and leisure activities with persons with and without disabilities, and homes in regular neighborhoods;

⁸ The Self-Determination Steering committee adopted these principles from the *Beyond Managed Care: Self-Determination For People with Disabilities*, RWJ Foundation, First Edition, 1996, Thomas Nerney and Donald Shumway.

- C Have children receive services and supports that are valued by their families and enrich their quality of life;
- C Pursue futures of their own design, supported by flexible, creative, individually tailored services and supports in a coordinated statewide system.

INDIVIDUAL PLANNING

All self-determination starts with comprehensive individual planning. Each of the following steps is critical to an individual's success.

- C Choice. The individual or family of a minor child chooses to participate in self-determination.
- C Development of an Individual Program Plan (IPP) (for adults) or an Individual Family Service Plan (IFSP) (for minor children) through person-centered planning that shows, in detail, the needs, preferences, hopes and dreams of the individual or family and that includes self-determination as a preference.
- C Development of an individual budget that provides an appropriate amount to support meeting the goals and objectives of the IPP or IFSP.

General Definition: One intent of self-determination is to turn over control of a specific amount of funds to the consumer and/or family. Consumers then have the freedom to purchase services from a variety of sources. A consumer can gain the experience of making personal choices, and hopefully, relationships that will be helpful for future decision-making. Individual budgets are developed by the consumer, family or circle of support. The funding agency representatives may or may not be a part of this budget planning group. In California, regional center staff will help develop the budget.

- C Having a fiscal intermediary to accept and pay out state and Federal monies that may not be issued directly to an individual or family receiving services and to provide other budgetary help when needed.

General Definition: A fiscal intermediary manages funds, makes payments, and accounts for expenditures made on behalf of the consumer as directed by the consumer, family, or circle of support. The fiscal intermediary is not a direct service provider, but handles the business end of securing services and supports. A fiscal intermediary can be a nonprofit agency, a payroll service, an individual, or any organization that the individual, family, or circle of support selects. A fiscal intermediary must be able to provide payroll services, bill payments, benefit administration, contract negotiation, rate setting functions, and record keeping services. Without a fiscal intermediary, the individual or family could be affected

by state and Federal labor laws, be responsible for filing tax records, and have additional obligations with regard to the Social Security Administration.

- C Having a support broker who, if help is requested, can find or develop individualized services and supports and help in many different ways to reach IPP and IFSP goals and objectives.

General Definition: A support broker is the individual or agency who arranges for the specific services and supports a consumer and/or family needs. The broker acts on behalf of the consumer as his or her personal "agent" to arrange these services and supports. The broker helps define the needs and life dreams, provides information about resources, identifies potential providers (regardless of funding source), arranges contracts for services, and evaluates the effectiveness of the services and supports. One of the key principles of self-determination is the shifting of power and control from the funding agency to the consumer. Ideally, to avoid a conflict of interest, the broker should not be a provider of direct services nor should he or she have fiscal responsibilities, e.g., allocation of funds, bill payments, etc. If one organization performs both functions, great care must be taken to delineate staff roles and to provide ongoing training to instill the central percepts of self-determination, independence, service coordination, case management, fiscal intermediary, and service broker.