

CONTROLLING REGIONAL CENTER COSTS

*Report to the Legislature
Submitted to fulfill the requirements of Section 102.5,
Chapter 188, Statutes of 2007*

Prepared by the
Department of Developmental Services
1600 9th Street
Sacramento, California 95814

December 2007

TABLE OF CONTENTS

EXECUTIVE SUMMARY	1
INTRODUCTION.....	6
I. BACKGROUND.....	7
A. History of Regional Centers	7
B. Regional Center Eligibility.....	8
C. Demographics	10
D. Regional Center Services.....	11
E. Community Services System	14
F. Entitlement to Services.....	15
G. Regional Center Budget	16
H. Budget Expenditure History and Current Pressures	18
I. Federal Fund Sources.....	27
J. Expenditures from a National Perspective	33
II. PRIOR YEARS' COST-CONTAINMENT PROPOSALS.....	34
Regional Center Operations (OPS) Budget Cost-containment Proposals	35
A. Eliminating Hospital Liaison Positions	35
B. Reducing Frequency of Individual Program Plan Reviews	35
C. Extending Regional Center Assessment Timelines	35
D. OPS Budget Reductions and Expenditure Plans	36
E. Discontinuing Regional Center Salary Indexing	37
F. Increasing Service Coordinator-to-Consumer Caseload Ratios.....	38
G. Modifying the Personnel Funding Formula	39
Purchase of Services for Consumers Budget Cost-containment Proposals	39
A. Priorities for Regional Center Expenditures.....	39
B. AB 40X (Chapter 16, Statutes of 1983-84) Regulations.....	40
C. POS Budget Reductions/Expenditure Plans.....	40
D. Purchase of Service Standards	43
E. 2003-04 Mid-year Reduction Proposals.....	44
F. Revision of Eligibility Definition	44
G. Family Cost Participation Program	45
H. Long-term Cost-containment Strategies.....	46
I. Regional Center Contract Language	47

J.	Start-up Funding Freeze	48
K.	Program Rate Freezes/Restrictions.....	49
III.	IMPENDING COST-CONTROL OPTIONS	53
A.	Rate/Service Code Standardization Project.....	53
B.	Self-Directed Services Waiver.....	54
C.	Supported Living Services Regulations.....	55
D.	Autism Spectrum Disorders Best Practice Guidelines	56
IV.	ADDITIONAL COST-CONTROL OPTIONS	58
	Control Options that Reduce or Curtail Services	58
A.	Consolidate Regional Centers	58
B.	Outsource Regional Center Billing Transactions.....	59
C.	Increase Service Coordinator-to-Consumer Caseload Ratios	60
D.	Consolidate Quality Assurance Evaluation Processes	61
E.	Reduce or Eliminate Clients' Rights Advocacy Services	63
F.	Establish a Definition for "Cost-effective"	64
G.	Redefine "Substantial Disability"	66
H.	Eliminate the Fifth Category of Developmental Disability	67
I.	Adopt Cost-containment Regulations	68
J.	Limit the Scope of Allowable Regional Center Purchases	69
K.	Downsize and/or Reconfigure Large Residential Facilities.....	69
L.	Cap Non-employment-Related Day Programming	71
M.	Change Transportation Services	72
N.	Update the Parental Fee Schedule	75
O.	Revise the Family Cost Participation Program.....	76
P.	Apply Means Testing to All Consumers and Services.....	77
Q.	Decrease Provider Rates	79
R.	Limit Regional Center-Funding to Consumers Enrolled in the Waiver ..	80
S.	Cap Enrollment and Establish Waiting Lists	81
T.	Eliminate Early Start Services for "High-risk" Children	82
U.	Establish Specific Criteria for Early Start Eligibility	83
V.	Eliminate Services to School-age Children	84
W.	Increase Regional Centers' Utilization Review Authority	86
	Long-term Options that Improve Service Outcomes.....	87
A.	Increase Employment Opportunities for Consumers	87
B.	Expand Availability of Affordable and Accessible Housing.....	89

C.	Leverage Developmental Center Land to Expand Housing for Consumers Living in the Community.....	90
D.	Expand Access to Preventative Medical and Dental Services	92
E.	Maximize Generic Resources.....	95
V.	CONCLUSION	96

EXECUTIVE SUMMARY

On January 6, 1966, the state Department of Public Health entered into contract with two private agencies to operate the first regional centers. The regional center concept reflected a public-policy shift in serving persons with developmental disabilities in California. Until this time, virtually all services for residents with developmental disabilities were provided in state-operated institutions. In contrast, the regional centers were community-based non-profit organizations charged with providing services and supports necessary to allow individuals to remain in their local communities. The two pilot regional center projects were very successful and, about a decade later, the last of the existing 21 regional centers was established. The success of the regional center system in creating community-based alternatives to institutional care is demonstrated by the decline in the overall state developmental center (institutional) population. The resident population in developmental centers numbered over 13,000 and was climbing when the first regional centers were established – the developmental centers' population today is about 2,700 despite the expanding general state population.

Regional centers provide or fund a wide range of services. These services include information and referral; assessment and diagnosis; individualized planning; service coordination; acquisition of services and supports included in a consumer's individual planning document; assistance in finding and accessing community and other resources such as community health, recreation and social services; resource development; advocacy for obtaining needed services; early intervention services for infants and their families; genetic counseling; family support; planning, placement, and monitoring of 24-hour out-of-home care; training and education; and community education. Services are provided without charge except for (1) a monthly fee charged to families who place their minor children out of home, and (2) a share-of-cost requirement for families with a child, age 3 through 17, who is not on Medi-Cal and living at home and receiving respite, day care, or camping services.

With a current-year budget of \$3.6 billion, regional centers serve about 230,000¹ children and adults with developmental disabilities. About 28,000² of these individuals are infants and children under age three. Most consumers reside with family members but about 55,000³ reside in licensed and unlicensed out-of-home living arrangements. Most consumers under age 22 attend public schools and those over 22 receive day/work and transportation services funded by the regional centers. Individuals' service needs are identified through a comprehensive assessment and planning process that includes the individual and his or her family, as appropriate. The regional center assigns a "service coordinator" to each eligible individual. The service coordinator's primary role is to ensure the services on the Individual Program Plan (IPP) are obtained, either first through other publicly- or privately-funded agencies or, in the absence of other such resources, through regional center funding.

In 2006, the Department engaged the services of an independent contractor (Acumen) to review and analyze regional centers' expenditures. Several charts reflecting their findings in pertinent areas are included. In fiscal year 1993-94, regional center expenditures per consumer averaged \$6,633 per year, including \$791 in contract-based expenditures (expenditures that cannot be easily separated out by individual consumer). Before fiscal year 1997-98, expenditures per consumer grew at 3 percent per year (inflation adjusted) or less. However, between fiscal years 1996-97 and 2000-01 annual growth rates ranged from 8 to 11 percent, with the largest increase occurring between fiscal years 1997-98 and 1998-99. By fiscal year 2002-03, per consumer expenditures leveled off. Since fiscal year 2003-04, inflation-adjusted per capita expenditures have been nearly constant, except for the shift of the Department of Rehabilitation's

¹ "Monthly Consumer Caseload Report - Regional Center Caseloads by Consumer Status through November 2007," December 11, 2007, <http://www.dds.ca.gov/FactsStats/docs/Nov07_Caseload.pdf> (December 17, 2007). Includes Status Codes 0, 1 and 2 (At-Risk Infants, Diagnosis & Evaluation and Active Consumers).

² Ibid.

³ "Demographics of persons Served by DDS – Persons with Status Codes 1, 2 and 8 on Client Master File as of December 1995 Compared to December 2005," *Fact Book*, Ninth Edition, Department of Developmental Services, Information Services Division, June 2007, p. 5. Includes Community Care, SNF/ICF, ILS/SLS, and Other categories. Does not include consumers living in state developmental centers.

Habilitation Services Program and budget to the Department of Developmental Services in 2004.

There are many factors potentially contributing to the regional center budget growth, including:

- New consumers (an average of about 7,500 new consumers were added annually during the past decade).⁴
- Developmental center residents moving into the community.
- Transfer of the Department of Rehabilitation's Habilitation Services Program to the Department of Developmental Services.
- Budget augmentations for rate increases and minimum wage adjustments.
- Increase in consumers with autism spectrum disorders.
- Increase in consumers with dual diagnoses (developmental disability and mental illness).
- Erosion of generic service options, e.g., availability of clinicians willing to serve consumers on Medi-Cal.
- Aging parents who are no longer able to care for their family member at home.
- Consumers' increasing longevity.
- Program and service enhancements to meet minimum federal quality of care requirements.
- Consumers transitioning from public-school-funded programs to regional center-funded programs after local educational agencies are no longer statutorily required to provide services.

The growth rate in regional center expenditures, beyond what would be predicted by costs for adding new consumers alone, is driven by many of the factors operating within the existing or base regional center consumer population, as noted above. For example, expenditures for the base population increase due to the transition of children from public-school funding to regional center funding, aging parents who require

⁴Ibid.

increasing support to maintain their adult children at home or who require their children to be placed out of home, increasing longevity of consumers requiring more support services, etc. Approximately 25 percent of consumers account for 82 percent of all regional center expenditures. Regional center costs for out-of-home living arrangements (supported living, community care facilities, etc.) constitute the centers single largest area of expenditure.

The Department's success in securing additional federal funding has helped slow state General Fund growth in the program. This is particularly evident with the federal Home and Community-based Services Waiver program where federal reimbursements have increased, from \$373.5 million to \$895.7 million annually, since 2000-01.

Legislation chaptered on August 24, 2007, required the Department of Developmental Services (Department) to "*...develop a plan of options for consideration by the Administration and the Legislature to better control regional center costs of operating and providing state-supported services.*"⁵ This report contains not only the options for consideration to fulfill the basic reporting requirement but background information necessary to inform discussions about these options. Since fiscal year 1982-83, there have been numerous efforts to impose budgetary cost-controls on the developmental services system. These efforts reflect the many budget crises the state has encountered in the last 25 years. The success of past cost-containment efforts or proposals, which are cataloged in the body of this report, has been mixed. Proposals proffered have addressed many areas including eligibility for services, the scope of services, rates of payment, and the process by which service requests are reviewed and authorized. The state Supreme Court decision affirming that the Lanterman Developmental Services Act conferred an entitlement to services was a public-policy benchmark that has figured prominently in cost-containment discussions since its issuance in 1985.

⁵ Chapter 188, Statutes of 2007 (Assembly Bill 203, Sec. 102.5).

In addition to describing the state's past cost-containment efforts, the report includes impending and new cost-containment options for consideration. Among these options are proposals that would result in fundamental system reform in several areas, such as housing and employment. It is these options which offer the greatest hope for achieving responsible long-term cost containment while promoting more independent and productive lives for Californian's with developmental disabilities consistent with the Lanterman Developmental Disabilities Services Act and U.S Supreme Court Olmstead decision.⁶

⁶ "Olmstead v. L.C. and E.W." is a U.S. Supreme Court decision involving Title II of the federal Americans with Disabilities Act. The Supreme Court held, in a 6-3 ruling, that *"states are required to place persons with mental disabilities in community settings rather than institutions when the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities."* The federal Centers for Medicare and Medicaid services subsequently noted in a communiqué to states that Olmstead challenges states to prevent and correct inappropriate institutionalization and to review intake and admissions processes to assure that persons with disabilities are served in the most integrated setting appropriate."

INTRODUCTION

The Department of Developmental Services (Department) prepared this report to fulfill the requirements of Section 102.5, Chapter 188, Statutes of 2007 (AB 203), as follows:

SEC. 102.5. (a) (1) The State Department of Developmental Services shall develop a plan of options for consideration by the Administration and the Legislature to better control regional center costs of operating and providing state-supported services. The options shall provide program efficiencies while protecting clients.

(2) The plan developed pursuant to paragraph (1) should include a wide range of options, with an analysis of advantages and disadvantages of each.

(b) The department shall submit the plan developed pursuant to subdivision (a) to the Joint Legislative Budget Committee and the fiscal and policy committees of the Legislature no later than October 1, 2007.

Having an awareness of the community-based system of services for persons with developmental disabilities is necessary for understanding and evaluating the cost-containment options contained in this report. Therefore, the reader is first provided, in the **Background** section, information on the purpose, structure, budget, and expenditures of the developmental services system. In addition, the state Supreme Court decision directly affecting the budgeting and cost-control efforts related to this system is briefly summarized. The next section, **Prior Years' Cost-containment Efforts**, describes the specific efforts over the past 25 years to manage or control expenditures within the developmental services program. Next is the "**Options**" section which identifies "...options for consideration by the Administration and the Legislature to better control regional center costs of operating and providing state-supported services." This section includes options not previously implemented or presented to the Legislature. The final section consists of a short **Conclusion**.

I. BACKGROUND

A. History of Regional Centers

The regional center program was initiated by the Legislature through Assembly Bill 691, Chapter 1242, Statutes of 1965. This legislation advanced the findings of two study groups, the Study Commission on Mental Retardation and the Subcommittee on Mental Health Services of the Assembly Ways and Means Committee, which had reviewed the needs, available services and problems of people with "mental retardation."⁷ The purpose of these first two regional centers was to pilot the concept of providing local, community-based services for persons with "mental retardation" (hereinafter referred to as developmental disabilities) who otherwise would require services in the burgeoning state hospitals (hereinafter referred to as state developmental centers) which housed more than 13,000 people and had a 3,000 person waiting list. Until passage of the bill establishing the regional center program, the state developmental centers were the only service option for many parents who had exhausted their emotional and financial resources in caring for their family member with developmental disabilities.⁸

On January 6, 1966, the State Department of Public Health entered into contracts with two private agencies to operate the first regional centers: Children's Hospital of Los Angeles to serve Los Angeles County, and the San Francisco Aid for Retarded Children to serve the counties of Alameda, Contra Costa, Marin, San Francisco, and San Mateo. These regional centers initiated services to their first consumers in mid-March 1966. The *Lanterman Mental Retardation Services Act of 1969* (AB 225), providing for the statewide expansion of the regional center network of services. By 1976, the existing statewide network of 21 regional centers was in place. The creation and expansion of the regional center system occurred in the context of federal lawsuits and new laws affirming the constitutional rights of persons with developmental disabilities to treatment in the least restrictive environment and provision of services in the most normalizing settings possible.

⁷ "Regional Centers for the Mentally Retarded – the First Two Years", State of California, Department of Public Health, Bureau of Mental Retardation Services, June, 1969, p. 1.

⁸ Ibid.

A key decision made by the framers of the regional center system was that regional centers be locally-governed organizations responsive to, and representative of, the needs of the individuals residing in their local service area. Assembly Bill 225 expressed this sentiment, as follows "*...the services required of a regional center are of such a special and unique nature that they cannot be satisfactorily provided by state agencies. Therefore, private nonprofit community and local public agencies shall be utilized for the purpose of operating regional centers to the end that the unique relationship which these agencies enjoy with both the mentally retarded and their families and the providers of services in the community may enable the mentally retarded to receive service in the most direct, efficient and effective manner possible.*"⁹ All of the regional centers are incorporated as Internal Revenue Code section (501)(c)(3) nonprofit organizations with a board of directors representing the regional center's service area. The composition of the governing board includes consumers, family members, and other individuals whose qualifications are prescribed by law.¹⁰

Legislation enacted in 1977 established, as a separate state department, the Department of Developmental Services.¹¹ Today the Department directly operates five state developmental centers, two smaller community Intermediate Care Facility/Developmentally Disabled residential programs, and oversees the 21 regional centers.

B. Regional Center Eligibility

Regional centers were originally established and structured to serve persons with "mental retardation" only. Legislative action in 1973 expanded the conditions qualifying for regional center services to include cerebral palsy, epilepsy, and other neurological handicapping conditions closely related to mental retardation or to require treatment

⁹ Chapter 1594, Statutes of 1969 (AB 225, Sec. 38100).

¹⁰ Wel. & Insti. Code Sec. 4622.

¹¹ Chapter 1252, Statutes of 1977 (Senate Bill 363).

similar to that required for mentally retarded individuals.¹² Autism, the final qualifying condition for regional center services, was added in 1975.¹³

Regional centers are, by state law and regulation, responsible for determining eligibility for services.¹⁴ To be eligible for regional center services, a person must have a disability that: (1) originates before an individual attains age 18, (2) is expected to continue indefinitely, and (3) presents a "substantial disability." The law defines substantial disability as the existence of significant functional limitations in three or more areas of seven major life activities, as determined by a regional center, and as appropriate to the age of the person. The major life activities considered in this evaluation include self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency. The individual's disability must be attributable to one of the following: mental retardation, cerebral palsy, epilepsy, autism, or a disabling condition closely related to mental retardation or requiring similar treatment. The last eligibility category condition listed, "*a disabling condition closely related to mental retardation or requiring similar treatment*," is commonly known as the "fifth category" of eligibility. The state's definition of developmental disability does not include other conditions that are solely attributable to a psychiatric, physical or learning disability and is more restrictive than the federal definition. For example, the state's definition of developmental disability requires that the individual's disability originate before age 18, whereas the federal definition sets the age at 22.¹⁵

Infants and toddlers (age 0 to 36 months) who are at risk of having a developmental disability or who have a developmental delay may also qualify for services.¹⁶ Also,

¹² Chapter 546, Statutes of 1973 (Assembly Bill 846, Sec. 16).

¹³ Chapter 694, Statutes of 1975 (Senate Bill 363).

¹⁴ Wel. & Insti. Code Sec. 4642-4643, and California Code of Regulations, Title 17, Sections 45000-45002.

¹⁵ 42 United States Code, Chapter 144, Subchapter I, Sec. 15002 (8)(A)(ii).

¹⁶ Government Code Sec. 95014.

individuals at risk of having a child with a developmental disability may be eligible for referral for genetic diagnosis, counseling, and other prevention services.¹⁷

C. Demographics

Regional centers provide ongoing services to children and adults who meet the eligibility requirements described above, **Regional Center Eligibility**. At the end of November 2007, regional centers were serving 229,384 individuals with developmental disabilities. Of this number, 28,376 were high-risk or at-risk¹⁸ infants and children under age three and 9,221 were prospective consumers undergoing diagnosis and evaluation.¹⁹ Males constitute 61.2 percent of those served by the regional center, and 50.4 percent of the entire consumer population is over age 18.²⁰

The following chart shows the living arrangements for regional center consumers:

Living Arrangement	Percent of Total
Home of Family Member or Guardian	73.1
Community Care Facility	12.2
Independent or Supported Living Program	8.7
Skilled Nursing or Intermediate Care Facility	4.0
State Developmental Center	1.2
Other	0.7
Total	100 ²¹

¹⁷ Wel. & Insti. Code Sec. 4642.

¹⁸ “High-risk infants and children” are those whose genetic, medical, or environmental history is predictive of a substantially greater risk for developmental disability than that for the general population (Wel. & Insti. Code Sec. 4642).

¹⁹ “Monthly Consumer Caseload Report - Regional Center Caseloads by Consumer Status through November 2007,” loc. cit.

²⁰ Department of Developmental Services, Information Services Division, July 31, 2007 (Job 5235), and the Department of Developmental Services “Monthly Consumer Caseload Report: Regional Center Caseloads by Consumer Status through October 2007.”

²¹ Due to rounding, total is actually 99.9 percent.

D. Regional Center Services

For eligible individuals, the regional centers provide, coordinate, and/or fund many services and supports including, but not limited to, the following:

- Information and referral
- Assessment and diagnosis
- Individualized planning
- Service coordination
- Purchase of services and supports included in the individual program plan²²
- Assistance in finding and accessing community and other resources
- Advocacy for implementing the individual's program plan
- Early intervention services for at-risk infants and their families
- Genetic counseling
- Family support
- Planning, placement, and monitoring of 24-hour out-of-home care
- Training and education
- Case finding and outreach

There is no charge for diagnosis and assessment of eligibility. Once eligibility is determined, services and supports are also free regardless of age or income with two exceptions. First, there is a requirement for parents to share in the cost of 24-hour out-of-home placements for children under age 18. Secondly, there is a parental share-of-cost requirement for consumers age 3 through 17 who are living at home and receiving respite, day care, or camping services. Parents' share of cost depends on the parents' ability to pay.

²² The "individual program plan" is a written plan developed jointly by the regional center and the planning team, as defined in Wel. & Insti. Code 4512(j). The plan identifies services and supports, as defined in Wel. & Insti. Code 4512(b), to promote the individual's community integration, independence, and productivity. The plan must contain goals and objectives, the type and amounts of services to be purchased, service start dates, and other detailed information required by Wel. & Insti. Code 4646.5.

Regional centers are required by law to provide services in the most cost-effective way possible.²³ They must first seek and access all other resources to meet consumers' and families' needs, including services provided or funded by "generic" resources, before using regional center funds. A generic resource is a service provided by an agency that has a legal responsibility to serve all members of the general public and is receiving public funds for providing such services.²⁴ Examples of generic agencies or services include local education agencies, In-home Supportive Services, Medi-Cal, Social Security, vocational-rehabilitation services, county mental health services, etc.

The regional center uses a planning process to develop an "individual program plan" (IPP) for each person found eligible for ongoing regional center services. For children age 0 to 36 months, the planning process results in an "individualized family service plan" (IFSP). The plan is developed by the consumer, parents, or guardian of a minor child, or conservator (or authorized representative), anyone else invited by the consumer or authorized representative, and regional center staff. The IPP, or IFSP, identifies goals and the services and supports needed to reach those goals. It lists who will provide the services and supports and who will pay for them. All services listed in the IPP or IFSP will be provided either through a generic agency, natural supports,²⁵ a regional center vendor,²⁶ or directly by the regional center.

The following chart shows the distribution and respective service area of each of the 21 regional centers:

²³ Wel. & Insti. Code Sec. 4659.

²⁴ Wel. & Insti. Code Sec. 4644(b).

²⁵ "Natural supports", as defined in Wel. & Insti. Code 4512(e), means personal associations and relationships typically developed in the community that enhance the quality and security of life for people, including, but not limited to, family relationships, friendships reflecting the diversity of the neighborhood and the community, associations with fellow students or employees in regular classrooms and workplaces, and associations developed through participation in clubs, organizations, and other civic activities.

²⁶ A "vendor" is a person and/or business that meets the regulatory requirements for providing services to regional center consumers and has been issued an identifying number by the regional center.

Department of Developmental Services Regional Centers

(Colors correspond to areas served by each Regional Center)



E. Community Services System

As noted earlier, regional centers are mandated to access generic and other services for consumers and families before expending regional center funds. There are both fiscal and philosophical reasons for this mandate. The backdrop precipitating the Lanterman Act was the devaluation of people with developmental disabilities, with the attending discrimination and segregation, which limited their access to services commonly available to others. This problem was noted in the 1969 report on the first two pilot regional centers, as follows: *"One of the two major principles guiding Regional Center operation is that of integration of the mentally retarded into the community. The statewide study groups had found that mentally retarded persons were often denied services for which they were eligible because they were retarded . . ."*²⁷ The regional center mandate to pursue available public services before expending their funds is one means for redress.

Despite heavy reliance on accessing alternative resources, the special service and support needs of people with developmental disabilities are such that the needs cannot always be met through generic resources. In such cases, the regional centers are required to develop and fund needed services and supports. Thus, regional center consumers receive services from a broad array of public and private providers or vendors. The services and supports a regional center consumer may receive include early autism treatment, respite care, transportation to and from programs, work and day services, 24-hour residential care, behavioral training, and many more.²⁸ The regional centers currently use about 45,000²⁹ providers who participate in the service mix of publicly- and privately-funded organizations that comprise a complex community-based system of services and supports.

²⁷ "Regional Centers for the Mentally Retarded – the First Two Years," op. cit., p. 2.

²⁸ See Wel. & Insti. Code Sec. 4512(b) for the definition of "services and supports."

²⁹ This number represents all active vendors in fiscal year 06-07, including nearly 27,000 family members receiving vouchers for respite, day care, nursing, transportation, and/or diaper/nutritional supplements. This number does not include non-services claiming entities who are also vendorized for purposes of processing claims not related to the provision of services, e.g., personal and incidental reimbursements.

F. Entitlement to Services

Before 1985 there was uncertainty as to whether regional center consumers were entitled, under the Lanterman Developmental Disabilities Services Act, to the services and supports identified on their individual program plans. Clarity on this point occurred through litigation after the Department issued an October 14, 1982, directive to regional centers entitled "Priorities for Regional Center Expenditures." This directive intended to achieve cost savings by limiting regional center funded services to those that were "basic and essential." Consumer services identified in the guidelines as "basic and essential" included (1) a primary residence, (2) primary program services, (3) transportation services, (4) basic medical and health care, (5) in-home supportive services, and (6) primary prevention (see page 39, **Priorities for Regional Center Expenditures**).

The Association for Retarded Citizens of California, et al., filed suit against the Department seeking declaratory and injunctive relief alleging that the spending guidelines were not legal. The trial court granted a preliminary injunction and the Supreme Court found in favor of the Plaintiffs, noting *that "First, the regional centers and DDS have distinct responsibilities in the statutory scheme: that of the regional centers is to provide each developmentally disabled person with the services to which he is entitled under the Act; that of DDS is to promote the cost-effectiveness of the operations of the regional centers, but not to control the manner in which they provide services. Second, the Act defines a basic right and a corresponding basic obligation: the right which it grants to the developmentally disabled person is to be provided with services that enable him to live a more independent and productive life in the community; the obligation which it imposes on the state is to provide such services. . . . By requiring the regional centers in effect to cut back on services by category without regard to the individual client's IPP, the Priorities would have vitiated the IPP procedure, and with it the rights and obligations the Act defines. Because they would have radically altered the Lanterman Act and greatly impaired its scope, the Priorities are void."*³⁰

³⁰ Association for Retarded Citizens v. Department of Developmental Services (1985) 38 Cal.3d 384, 696 P.2d 150 [Mar. 1985]; 211 Cal. Rptr. 758.

The Supreme Court's decision finally settled the question as to whether regional center consumers were entitled, under the Lanterman Developmental Disabilities Services Act, to the services and supports identified on their individual program plans. Understanding this decision is important when evaluating options for cost containment.

G. Regional Center Budget

Regional centers receive virtually all of their funding from the state. This funding is budgeted and allocated in two distinct categories: operations (OPS) and purchase of services (POS). The OPS budget funds a regional center's costs related to personnel, insurance, leases, equipment, information technology, consultant services, independent financial audits, travel, office facilities, and other administrative/managerial expenses. Eighty-one (81) percent of the regional centers' OPS budget funds personnel who provide direct services to consumers and their families. These direct services include service coordination, assessment/diagnosis, money management, clinical services, etc. Therefore, reductions in regional centers' OPS budget directly impact the provision of direct services to consumers. The balance of the OPS budget, or 19 percent, funds all the regional centers' administrative costs and represents 2.3 percent of the entire (OPS and POS) regional center budget.³¹

The regional centers' personnel and related operational costs are budgeted through what is commonly referred to as the "core staffing formula." This formula, developed in the late 1970s, produces an operational budget appropriation that is then allocated to the 21 regional centers. The Department and the Association of Regional Center Agencies jointly develop the methodology for apportioning the budgeted funds to the regional centers. The relative percentage of the total regional center budget expended for Operations has shown a steady decrease over the years.

The regional centers' POS budget reimburses vendors for services provided to consumers and their families. All such expenditures must be consistent with, and

³¹ Based on the fiscal year 2007-08 budget data prepared by the Department of Developmental Services, Estimates Section, September 7, 2007.

reflected in, the consumer's individual program plan. The primary areas of expenditure for POS funds include residential services, adult day programs including work, supported living and related services, transportation, respite, infant program services, and behavioral services (including early autism treatment). Regional centers may not unilaterally transfer funds between the OPS and POS categories.

In the current fiscal year, the mean average regional center cost of serving all individuals in the community is estimated to be \$16,165. This compares to a mean average cost of \$275,970³² to serve an individual in a state developmental center. However, this not a perfect "apples-to-apples" comparison since there are other costs consumers may incur in the community which are not included in regional centers' expenditures, e.g., In-home Supportive Services, Vocational Rehabilitation, Medi-Cal, etc. Also, other factors such as consumers' living arrangements, their severity of disability, and family involvement are relevant considerations when comparing such costs.

The following chart summarizes the regional centers' budget for the current fiscal year:

CATEGORY	FY 2007-08 ENACTED BUDGET <i>(Dollars in thousands)</i>
Operations	\$497,556
Purchase of Services	3,084,481
Early Intervention Program	20,095
TOTAL	\$3,602,132
Federal Reimbursements	(\$1,194,890)
Federal Trust Fund	(52,494)
Program Development Fund	(1,265)
Public Transportation Account	(128,806)
General Fund	(2,224,677)

³² Based on the Department's 2007-08 enacted budget.

H. Budget Expenditure History and Current Pressures

This section includes information showing growth of the developmental services system, factors contributing to this growth, and the demographic, programmatic, and governmental actions which have influenced regional center expenditures. Except where noted, the following chart shows actual regional centers' **expenditures** (not budgeted funds) in POS and OPS since 1980-81:

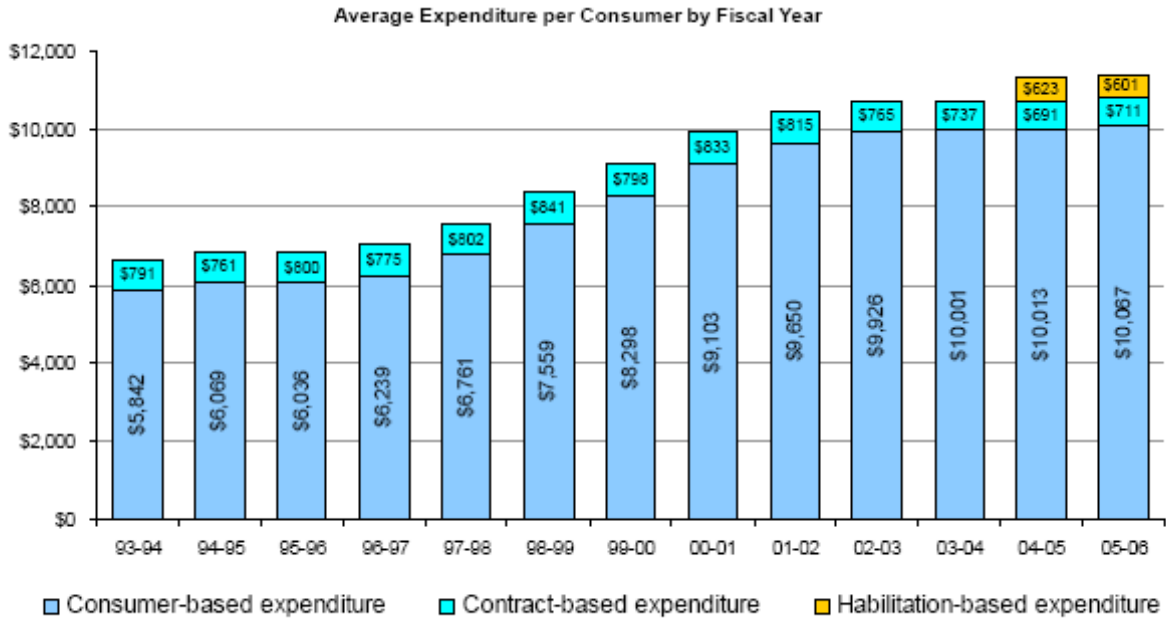
REGIONAL CENTERS' EXPENDITURE HISTORY			
PURCHASE OF SERVICES AND OPERATIONS BUDGET³³			
FISCAL YEAR	TOTAL	CHANGE	% CHANGE
1980-81	\$195,500,000		
1981-82	203,500,000	\$8,000,000	4.1%
1982-83	215,100,000	11,600,000	5.7%
1983-84	221,900,000	6,800,000	3.2%
1984-85	279,500,000	57,600,000	26.0%
1985-86	328,000,000	48,500,000	17.4%
1986-87	369,900,000	41,900,000	12.8%
1987-88	403,700,000	33,800,000	9.1%
1988-89	460,200,000	56,500,000	14.0%
1989-90	529,000,000	68,800,000	15.0%
1990-91	574,325,000	45,325,000	8.6%
1991-92	616,410,000	42,085,000	7.3%
1992-93	669,996,000	53,586,000	8.7%
1993-94	742,767,000	72,771,000	10.9%
1994-95	839,843,000	97,076,000	13.1%
1995-96	943,027,000	103,184,000	12.3%
1996-97	1,045,990,000	102,963,000	10.9%
1997-98	1,167,934,000	121,944,000	11.7%
1998-99	1,400,196,000	232,262,000	19.9%
1999-00	1,623,036,000	222,840,000	15.9%
2000-01	1,888,346,000	265,310,000	16.3%
2001-02	2,106,833,000	218,487,000	11.6%

³³ Expenditures exclude State Mandates; actual expenditures through 2005-06 are from the 2007-08 Governor's Budget (prior-year amounts); actual expenditures for 2006-07 are from the 2006-07 year-end statements; projected expenditures for 2007-08 are from the 2007-08 enacted budget.

REGIONAL CENTERS' EXPENDITURE HISTORY			
PURCHASE OF SERVICES AND OPERATIONS BUDGET³³			
FISCAL YEAR	TOTAL	CHANGE	% CHANGE
2002-03	2,298,749,000	191,916,000	9.1%
2003-04	2,478,564,000	179,815,000	7.8%
2004-05	2,689,197,000	210,633,000	8.5%
2005-06	2,884,286,000	195,089,000	7.3%
2006-07	3,314,749,000	430,463,000	14.9%
2007-08	3,602,132,000	287,383,000	8.7%

The next chart shows average POS expenditures per consumer. These expenditures are adjusted for inflation using the Consumer Price Index to reflect real dollars in fiscal year 2005-06. Costs for the Habilitation Services Program are excluded to ensure consistent measures over time since this program and budget were transferred from the Department of Rehabilitation to the Department of Developmental Services in fiscal year 2004-05. When growth in expenditures exceeds growth in enrollment, average expenditures per consumer are increasing. In fiscal year 1993-94, expenditures per consumer averaged \$6,633 per year, including \$791 in contract-based expenditures (expenditures purchased in "bulk" that cannot be easily separated out by individual consumer). Before fiscal year 1997-98, expenditures per consumer grew at 3 percent per year (inflation adjusted) or less. However, between fiscal years 1996-97 and 2000-01 annual growth rates ranged from 8 to 11 percent, with the largest increase occurring between fiscal years 1997-98 and 1998-99. By fiscal year 2002-03, per consumer expenditures leveled off. Since fiscal year 2003-04, inflation-adjusted per capita expenditures have been nearly constant, except for the shift of the Department of Rehabilitation's Habilitation Services Program to the Department of Developmental Services.

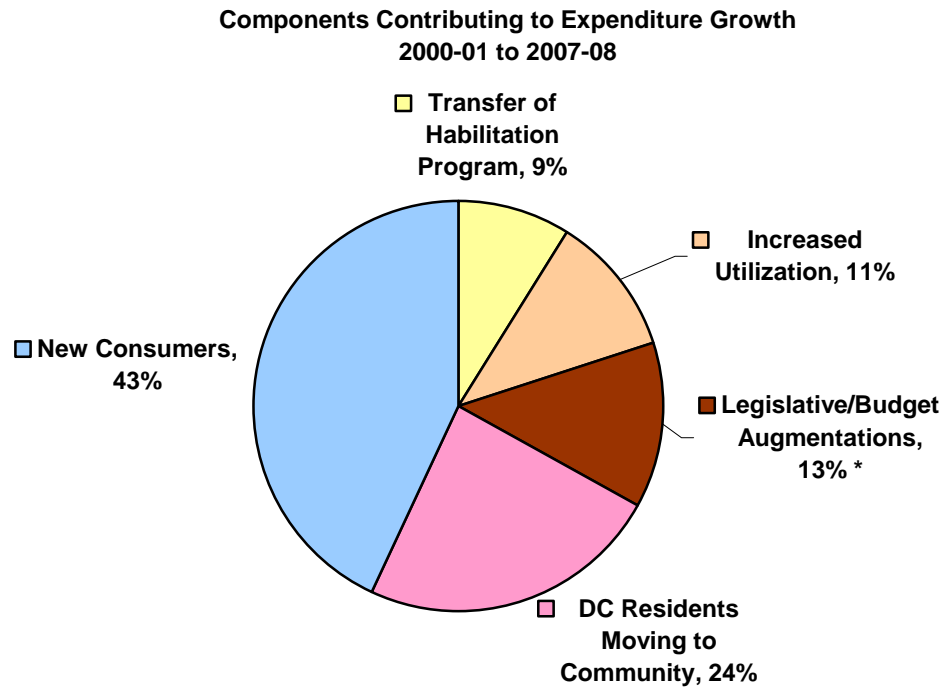
Average inflation-adjusted expenditures per consumer grew between fiscal year 1995-06 and 2002-03, but remained fairly constant since fiscal year 2003-04 (Source: Acumen)



A significant factor contributing to the increased growth from 1997-98 through 2000-01 was the cost associated with responding to a federal audit of the state’s Home and Community-based Services Waiver (Waiver). This audit identified concerns with the quality of services being provided to individuals enrolled in the Waiver. The state’s plan of correction required a significant infusion of funds to address the federal government’s concerns. For example, the payment rates for 24-hour licensed residential programs serving most of the Department’s consumers who live out of home had not been increased for a decade. The federal government’s audit identified a need to improve the quality of these residential programs. The state’s corrective actions included increasing rates and establishing a mandated training program for the direct support staff working in these programs. Other issues identified in the audit were also addressed by the state, most of which required significant funding. These corrective measures had to be taken before the federal government would renew the Waiver. The specific cost increases occurred over several years beginning in fiscal year 1998-99. However, this investment to address federal audit concerns stanching the loss of

federal funding which was estimated to be \$933 million (see pages 28-29, Home and Community-based Services Waiver).

The Department's contractor, Acumen, analyzed actual regional center expenditures to determine the primary reasons for growth in the overall (POS and OPS) regional center budget. The following chart identifies these reasons and their relative contribution, in percentages, to the growth:



* Includes, for example, the a 3% provider rate increase, the minimum wage increase adjustment, 21 % supported employment program rate increase, and others.

As shown above, the dominant cost drivers in the regional center budget the past seven years have been the addition of new consumers and costs of moving state-developmental-center residents into the community. There are also other factors affecting growth in the regional centers' budget, as follows:

- Increase in Consumers with Autism Spectrum Disorders: Autism is a complex developmental disability characterized by the presence of markedly abnormal or

impaired development in social interaction and communication and a markedly restricted repertoire of activity and interests. Manifestations of the disorder vary greatly depending on the developmental level and chronological age of the individual. Symptoms usually manifest before age three. Health care providers think of autism as a "spectrum" disorder, a group of disorders with similar features. One person may have mild symptoms, while another may have serious symptoms, but they both have an "autism spectrum disorder."³⁴

As of October 1, 2007, nearly 19 percent of regional center consumers over three years of age have an autism diagnosis, compared to 10.6 percent on June 30, 2001. About 60 percent of regional centers' net population growth in each of the past three years is attributable to consumers with an autism diagnosis. Expenditures for consumers with autism are greater, for every age group. In fiscal year 2005-06, the mean average POS cost for a child diagnosed with autism (3-18 years of age) was \$6,993, compared to \$3,447 for the same age group of children without autism. For consumers over age 19, the mean POS is \$26,047 for consumers with autism and \$15,935 for those without autism. This trend is showing no signs of abating.

- Generic Services Resource Limitations: There is an insufficient pool of qualified clinical and health care providers who will accept government insurance, but regional centers must pay for the service if the generic service cannot be accessed or is unavailable. This problem is especially acute in such areas as specialized therapeutic services, speech and language therapy, occupational therapy, physical therapy, and oral health care. A special problem exists with respect to early autism treatment where both local education agencies and regional centers have a role in funding. Some recent fair hearing decisions may portend a trend where regional centers are increasingly being identified as the responsible party in disputes regarding the agency responsible for funding costly early autism treatment services.

³⁴ Autism Spectrum Disorders (ASD), United States Department of Health and Human Services, National Institute of Child Health and Development, September 6, 2007, <<http://www.nichd.nih.gov/health/topics/asd.cfm>> (November 14, 2007).

The net effect of this will be to shift an increasing share of the funding responsibility for these services from local education agencies to the regional centers.

- Increase in Consumers with a Dual Diagnosis: The number of consumers with a dual diagnosis (mental illness and developmental disability) has increased 48 percent from July 1, 2001 through July 1, 2006, or from 12,600 to 18,700.³⁵ Such consumers require more intensive services and supports. The average annual regional center expenditure for serving a consumer with a dual diagnosis is over 100 percent greater than a consumer without a dual diagnosis, or about \$20,477 versus \$9,800 per year.³⁶
- Aging Population of Care Givers: The aging of parents or family members directly affects the demand for developmental services. About 73 percent (168,000) of all consumers reside in the home of a parent or guardian. As of 2004, it was estimated that California had about 76,000 consumers residing with caregivers who are over 60.³⁷ An aging caregiver may require an increased level of services and supports to maintain their family member in the home. When these caregivers die, or are no longer able to support their loved ones, alternative living arrangements must be developed or located. Almost all forms of out-of-home care are more costly than supporting a person in their own home. The Department's data clearly show that the percentage of consumers living out of home increases as they age.³⁸
- Increased Consumer Longevity and Neonatal Survival Rates: The demand for services is affected by an increase in the life expectancy of people with developmental disabilities and, not surprisingly, medical advances and improved

³⁵ Department of Developmental Services, Information Services Division, Data Extraction Unit, "Dual Diagnosis in Active DDS Population with CDERs," J5395, November 13, 2007.

³⁶ Department of Developmental Services, Information Services Division, Data Extraction Unit, "Comparison of Average POS Dollars Spent on Consumers Ages Three & Up with Dual Diagnosis Versus without Dual Diagnosis," J5043, November 16, 2007.

³⁷ David Braddock, et al., *The State of the States in Developmental Disabilities – 2005*, Department of Psychiatry and Coleman Institute for Cognitive Disabilities, The University of Colorado, p. 60.

³⁸ Department of Developmental Services, Information Services Division, Data Extraction Unit, *Eleven Year history of Proportion of Consumers Living out-of-Home by Age*, J5411, November 29, 2007.

care have dramatically increased consumers' life expectancies. Braddock observed that "...the mean age at death for persons with mental retardation was 66 years in 1993—up from 19 years in the 1930s and 59 in the 1970s (Janicki, 1996). The mean age at death for the general population in 1993 was 70 years. Longevity has also increased dramatically for persons with Down syndrome. Average age at death for persons with Down syndrome in the 1920s was 9 years; it rose to 31 in the 1960s and to 56 in 1993 (Janicki, Dalton, Henderson, & Davidson, 1999)."³⁹ Consumers' increasing longevity means that services and supports will be provided, not only for a relatively longer period of time, but the needs will be greater or of higher intensity especially during the later years.

A related trend is the steady decrease in state's neonatal mortality rate since 1980.⁴⁰ For example, advances in neonatal care have resulted in improved survival rates of extremely low birth weight infants; however, "... concerns have been expressed that these improvements may produce an increase in neurodevelopmental morbidity among survivors. A number of studies now document the prevalence of a broad range of neurologic, behavioral, and intellectual impairments at school-age in children who were born in the early era of neonatal intensive care."⁴¹ These infants and toddlers, who may be developmentally delayed or at-risk for having a developmental disability, are served by the regional centers.

- Consumers' Transition from Public Schools: A school-age child generally has his/her programming and treatment needs met by the public schools until age 22 during which time regional centers retain responsibility for service coordination, family-support services, and non-education-related services. However, when these children leave public school many of their service and programming needs become the financial responsibility of the regional center. The first of the following two charts

³⁹ Braddock, op. cit., pp. 59-60.

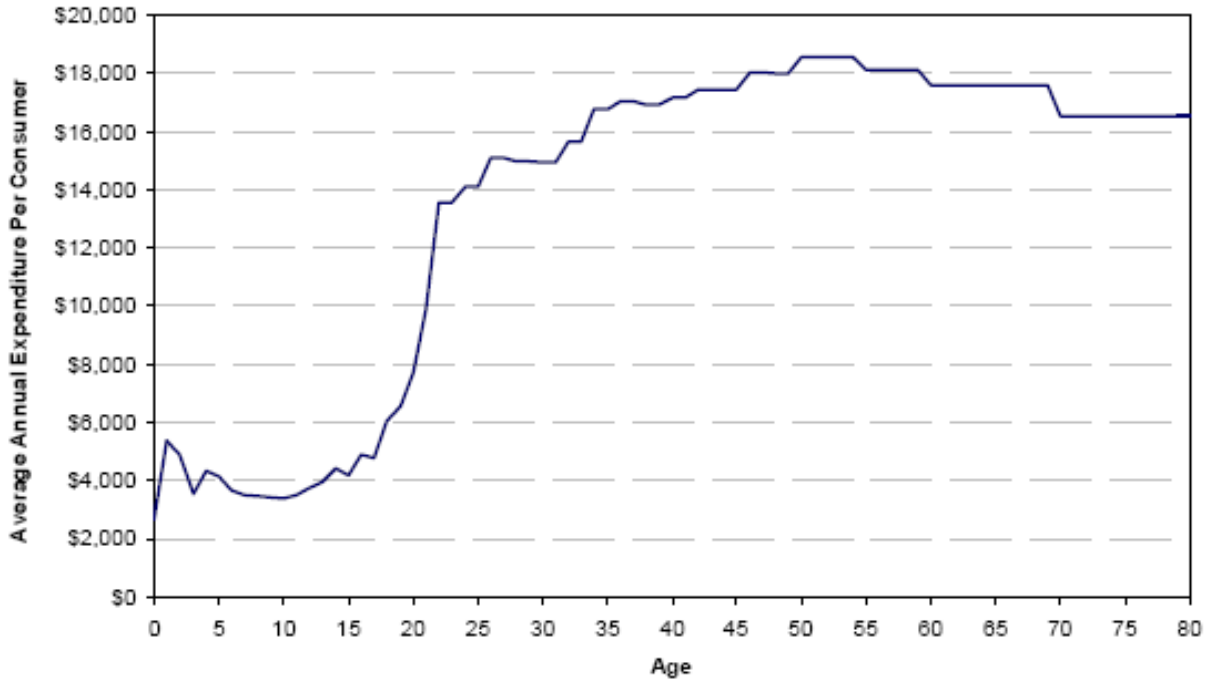
⁴⁰ Department of Health Care Services, Center for Health Statistics, Office of Health Information and Research, "TABLE 1-4. Comparison of Vital Statistics Rates, California and United States, 1980-2004 (By Place of residence)," n.d., <<http://www.dhs.ca.gov/hisp/chs/OHIR/tables/datafiles/vsofca/0104.pdf>> (December 28, 2007).

⁴¹ Saroj Saigal, MD, et al., "School-Age outcomes in Children Who Were Extremely Low Birth Weight From Four International Population-Based Cohorts," *Pediatrics*, October 2003, p. 943.

shows the significant increase in regional centers' costs resulting from consumers transitioning from public-school to regional center funding. The second chart compares the average cost of services for individuals by disability and age. Particularly evident are the increased costs of services across all disability groups upon exiting public school, with the cost of serving individuals with autism significantly greater than those without autism. This is an especially important consideration since, as discussed earlier in this report, there is an escalation in the number of children with ASD and they represent an increasingly significant percentage of regional centers' new cases.

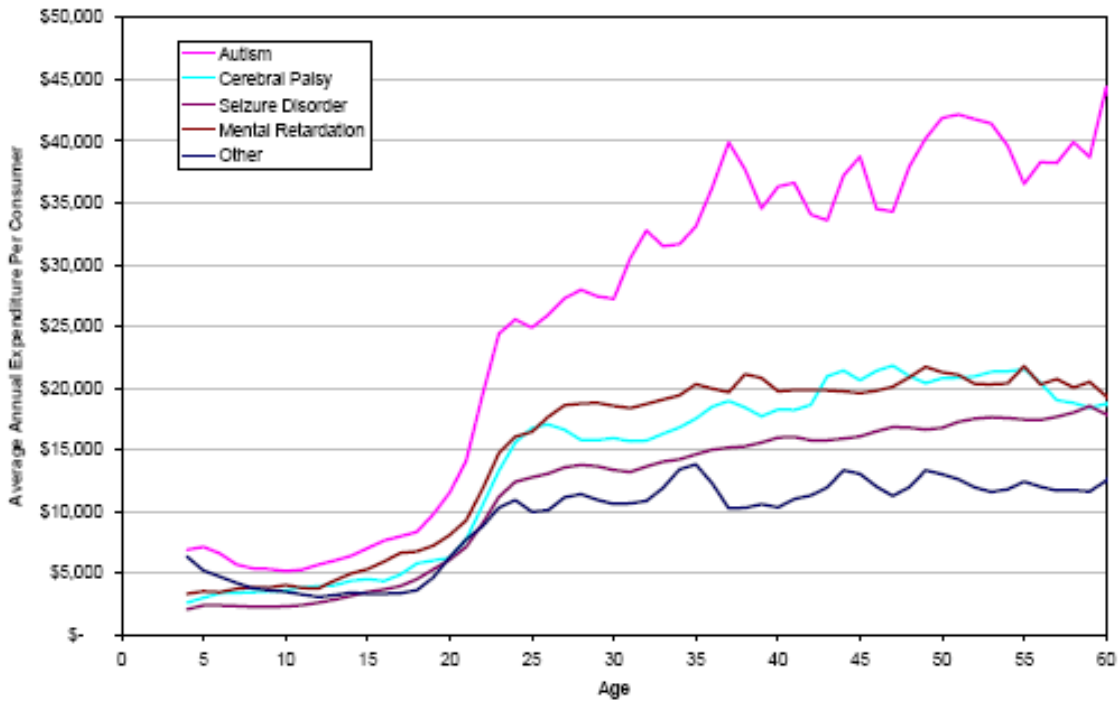
Per consumer expenditures jump as consumers leave school and costs shift to regional centers

Average Expenditures by Age in FY 2005-06



Across every age group, expenditures per consumer are higher for those with autism

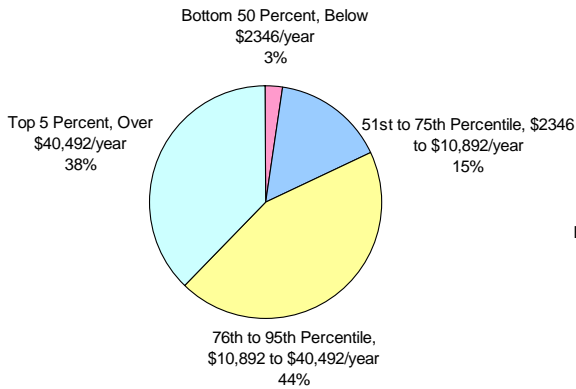
Average Annual Expenditures per Consumer by Age and by Diagnostic Group, FY2005-06



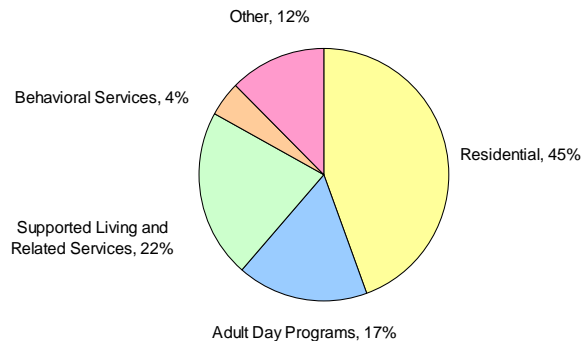
The following two pie charts prepared by Acumen show actual consumer expenditure utilization and the dominant expenditure areas. As noted earlier, approximately 25 percent of consumers account for 82 percent of all regional center expenditures, and regional center costs for out-of-home living arrangements (supported living, community care facilities, etc.) constitute the centers single largest area of expenditure.

Expenditure Utilization

Consumers Differ Widely In Expenditures Per Year:
The Top 5% Account for 38% of Expenditures
Distribution of Total Expenditures by Consumer Spending Percentiles, 2005-06



Residential Services and Supported Living Services Dominate
Expenditures Incurred by the Most Expensive 5%
Expenditure Distribution Among Top 5% of Customers by Annual Costs, 2005-06



Source: Acumen, LLC

I. Federal Fund Sources

Ensuring the state is receiving the maximum amount of federal funding to which it is entitled is essential, and the Department has sought to do this. The primary federal fund sources supporting the services and supports provided by regional centers include the following: Home and Community-based Services Waiver (Waiver) and related administration costs, Targeted Case Management (TCM) and related administration costs, Title XX Block Grant, and the Early Start Part C Grant. The Self-directed

Services Home and Community-based Services Waiver is not currently a fund source but is expected to become an increasingly significant fund source once the program is implemented. There are other federal fund sources reflected in the Department's budget, however, they are not described below since their contribution is negligible to the overall budget.⁴² The federal government also shares in the cost of Medi-Cal and In-home Supportive Services and persons with developmental disabilities are frequent beneficiaries of these services. However, this section addresses only those fund sources included in the Department's budget with the exceptions as noted above. A description of each of the primary federal fund sources included in the Department's budget follows.

1. Home and Community-based Services Waiver - Medicaid (Medi-Cal in California) is a jointly-funded, federal-state health insurance program for certain low-income and needy people. Nationwide, it covers individuals including children, the aged, blind, and/or disabled, and people who are eligible to receive federally assisted income maintenance payments. In 1981, President Reagan signed into law the Medicaid Home and Community-based Services Waiver program, section 1915(c) of the Social Security Act. Prior to the passage of this legislation, Medicaid long-term care benefits were limited to institutional facilities: hospitals, nursing facilities, intermediate care facilities for persons with mental retardation. The legislation provided a vehicle for states, for the first time, to offer services not otherwise available through their Medicaid programs to serve people in their own homes and communities. Waivers afford states the flexibility to develop and implement creative alternatives to placing Medicaid-eligible individuals in hospitals, nursing facilities, or intermediate care facilities for persons with developmental disabilities. The Waiver program recognizes that many individuals at risk of being placed in these facilities can be cared for in their homes and communities, preserving their independence and ties to family and friends at a cost no higher than that of institutional care.

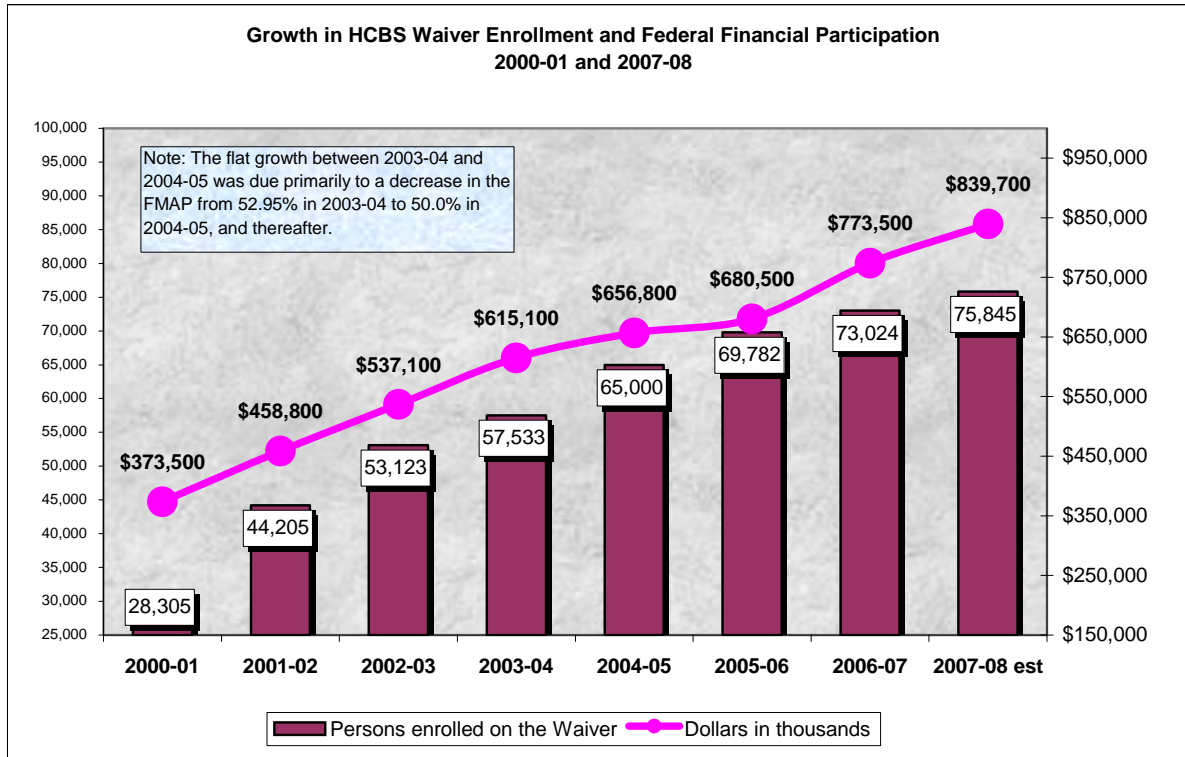
⁴² Vocational Rehabilitation/Work Activity Program, Foster Grandparent Program, and Real Choice Systems Change Grant.

California's first Waiver specifically for persons with developmental disabilities was approved in November 1982, effective retroactively to July 1, 1982. The initial cap was set at 3,360 people and increased until enrollment achieved 35,105 in September of 1992. In 1997, the federal Health Care Financing Administration (now known as the Centers for Medicare and Medicaid Services (CMS)) conducted its first major review of the state's Waiver and found serious deficiencies primarily involving the health and safety of people with developmental disabilities enrolled in the Waiver, financial accountability, and Waiver administration. In response to these findings, the state negotiated with the federal government to implement a series of initiatives necessary to continue in the Waiver program. The new initiatives were designed as permanent infrastructure improvements targeted at improving the overall quality of the service system. The federal government, however, froze Waiver enrollments as of December 1997 until the state demonstrated each regional center had implemented these changes. As a consequence, attrition of those enrolled on the Waiver and who could not be replaced from December 1997 until October 2000, reduced the caseload by 5,600 people. The cumulative impact of this enrollment freeze cost the state an estimated \$933 million in lost federal funds.⁴³ This significant funding loss underscores the importance of meeting federal quality assurance standards in the developmental services system lest the savings achieved through cost-containment measures is dwarfed by subsequent losses in federal reimbursement.

In September 2001, CMS approved a new five-year Waiver application. Tied to the approval were assurances from the state that previous quality issues identified by CMS regarding monitoring, risk management, clinical services, case management ratios, and provider enhancements would continue to be met. The state's current Waiver, approved effective October 1, 2006, has an enrollment cap of 80,000 (effective October 1, 2007) which increases annually until capping at 95,000 in fiscal year 2010-2011.

⁴³ "Estimate of Lost Federal Financial Participation Due to CMS Freeze on Enrollments," Department of Developmental Services, Community Operations Division, Federal Programs Section, October 23, 2007.

The following chart shows the growth in Waiver enrollments and Federal reimbursements.



A cumulative total increase of \$1,480,000,000 in federal funding from the Waiver has been realized since fiscal year 2000-01. Also, since June 1990 California has enrolled more consumers on the Waiver than any other state in the nation.⁴⁴

2. Targeted Case Management – Targeted Case Management (TCM) is defined in federal law as services which will assist an individual eligible under the Medicaid (Medi-Cal in California) State Plan in gaining access to needed medical, social, educational, and other services.⁴⁵ States may target case management services to specific classes of individuals and/or to individuals who reside in specified areas. Persons with developmental disabilities served by the regional centers are identified as such a "targeted" group in the State Plan. Under TCM, regional centers receive

⁴⁴ K. Charlie Lakin, op. cit., p. 108.

⁴⁵ Sections 1905(a)(19) and 1915(g)(2) of the Social Security Act.

federal funding for providing eligible case management services to consumers who are Medi-Cal beneficiaries. Capturing the federal funding under this program requires case managers to time study daily to those eligible activities. The total billable units are accumulated at each regional center monthly, transmitted to the Department, and billed based on the regional center's specific user fee schedule. There is a 50 percent state General Fund matching requirement for the TCM program, including administrative costs.

3. Title XX Block Grant – The state has received federal Title XX Block Grant funds for social services since 1981. Each state has wide discretion in determining the range of services to be provided and how the funds are to be distributed. There is no state match requirement for these funds. In California, the program is administered by the Department of Social Services. The Department of Developmental Services receives about \$204 million in such funds annually which it uses as fund source for its programs, as appropriate. Federal law establishes the following five service goals for the Title XX Block Grant:

- Achieving or maintaining economic self-support to prevent, reduce or eliminate dependency;
- Achieving or maintaining self-sufficiency, including the reduction or prevention of dependency;
- Preventing or remedying neglect, abuse or exploitation of children and adults unable to protect their own interests, or preserving, rehabilitating or reuniting families;
- Preventing or reducing inappropriate institutional care by providing for community-based care, home-based care, or other forms of less intensive care; and
- Securing referral or admission for institutional care when other forms of care are not appropriate or providing services to individuals in institutions.

Included in the Title XX Block Grant are funds for children under age 18 whose family income is less than 200 percent of the official poverty level (as defined by the federal Office of Management and Budget) applicable to a family of the size involved. This distinct allocation, known as Temporary Assistance for Needy Families (TANF), is used as a fund source for a variety of program areas consistent with the goals of the program. \$56 million of the \$204 million Title XX allocation is associated with TANF. The Department's May Revision Estimate shows the budget categories to which all the Title XX funds are allocated.⁴⁶

4. Early Start Part C Grant – Part C of the federal *Individuals with Disabilities Education Act* (IDEA) provides funding for serving families and their children with developmental delays, disabilities, or conditions which place children at high risk of disabilities from birth to under age three years. The program, known as Early Start in California, is administered according to federal Department of Education regulations and state regulations.^{47 48} The Department of Developmental Services is the state's lead agency for preparing the annual grant application and for receiving and administering the federal funds. Part C grant funds are used to pay costs for the additional federal requirements imposed by the Part C program. The Department allocates a significant portion of the federal funding to regional centers for local program operation and, through an interagency agreement with the state Department of Education, provides \$14.4 million for local education agency programs and services. The federal government determines each state's annual Part C allocation, which covers a small portion of the total cost of early intervention services in California. Although there is not a state General Fund matching requirement for the program, there is a maintenance-of-effort requirement to which the state must adhere.⁴⁹

⁴⁶ Department of Developmental Services, Regional Centers 2007-08 May Revision, page E-23.2.

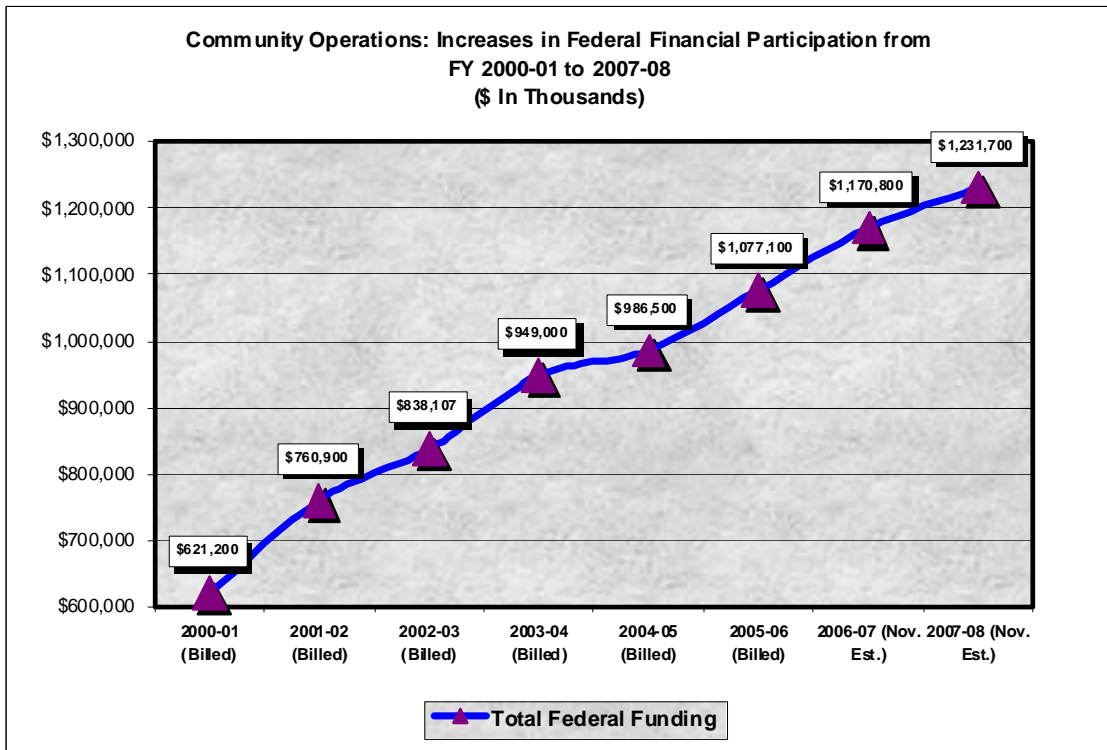
⁴⁷ Title 34, Code of Federal Regulations, Sections 303.1 through 303.654.

⁴⁸ California Code of Regulations, Title 17, Sections 52000 through 52175.

⁴⁹ Title 34, Code of Federal Regulations, Sec. 303.124(b) states "the total amount of State and local funds budgeted for expenditures in the current fiscal year for early intervention services for children eligible under this part and their families must be at least equal to the total amount of State and local funds actually expended for early intervention services for these children and their families in the most recent preceding fiscal year for which the information is available."

In 1999-00, the federal financial participation and related state General Fund match totaled \$0.6 billion and represented about 39 percent of the total regional center budget. However, in 2007-08 the federal financial participation and related General Fund match represents about 55 percent of the estimated expenditures of the regional centers' total budget.⁵⁰ This illustrates the Department's concerted efforts to maximize federal funding in recent years.

The following chart shows the combined growth of these four primary federal fund sources from fiscal year 2001-02 through the current year:



J. Expenditures from a National Perspective

California's annual budget for supporting persons with developmental disabilities in the community is significant. However, any discussion about cost containment is incomplete without understanding California's financial commitment from a national perspective, or compared to other states. The primary source for this comparative data

⁵⁰ Department of Developmental Services, Regional Centers 2007-08 May Revision, p. B-17.

is contained in the publication, "The State of the States in Developmental Disabilities." In this regularly issued report, calculation of a state's "fiscal effort" is the measure used to compare and rank states. Fiscal effort is defined as "...a state's spending for MR/DD services per \$1,000 of total state personal income." Based on the most recent available data, California's fiscal effort for community-based services is \$2.97, or rank 34 among all states and the District of Columbia. The national average fiscal effort is \$3.52.⁵¹

Another measure used for comparing states' expenditures is the average expenditure for each Medicaid Home and Community-based Services Waiver participant. A recent report reveals that "The national average expenditures for HCBS per recipient in FY 2006 (total HCBS expenditures divided by average daily recipients) was \$39,818. Among the states with the highest per recipient expenditures in 2006 were Alaska (\$66,516), Delaware (\$93,379), Maine (\$83,916), New Mexico (\$67,172), Rhode Island (\$76,126) and Tennessee (\$78,302). The states with the lowest per recipient expenditures were California (\$20,373) [rank 48 among all states], Mississippi (\$18,771) and North Dakota (\$20,279)."⁵²

II. PRIOR YEARS' COST-CONTAINMENT PROPOSALS

Many strategies for more effectively controlling regional center expenditures have been attempted over the years and recounting these past efforts is useful for informing future deliberations. This section describes these prior years' strategies, their success, and current status. Organized into two parts, the first part of this section addresses actions taken to reduce costs in the regional center OPS budget. The second part addresses actions taken to reduce regional center POS expenditures.

⁵¹ State of the States in Developmental Disabilities, University of Colorado, 2007 (preliminary data). The fiscal effort values and rankings were updated 9/12/07 and are subject to slight changes when all states' data are verified.

⁵² K. Charlie Lakin, Kathryn Alba, and Robert W. Prouty, "Utilization of and Expenditures for Medicaid Institutional and Home and Community-Based Services," In R.W. Prouty, Gary Smith & K.C. Lakin (Eds.), *Residential services for persons with developmental disabilities: Status and trends through 2006*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. August 2007, p. 108.

Regional Center Operations (OPS) Budget Cost-containment Proposals

A. Eliminating Hospital Liaison Positions

The fiscal year 1983-84 budget transferred case management services performed by regional center staff for consumers residing in state developmental center to developmental center staff. Prior to this time, regional centers were funded to regularly attend individual program plan meetings and visit the regional center's consumers residing in state developmental centers. The regional center OPS budget was reduced accordingly. At one time, regional centers were allocated one position for every 60 consumers residing in the developmental centers. This number was later increased to 120 and then eliminated altogether in fiscal year 1983-84. A small number of similar positions (one position for every 400 developmental center consumers) were subsequently reestablished in the core staffing formula and continue into the present.

B. Reducing Frequency of Individual Program Plan Reviews

Senate Bill 1045 (Chapter 93, Statutes of 1991) reduced the required frequency for reviewing consumers' individual program plans from once a year to no less often than once every three years. This change was permanent and continues to the present. However, individuals enrolled in the federal Home and Community-based Services Waiver (Waiver) must continue to have annual individual program plan reviews. The number of individuals currently enrolled in the Waiver is approximately 73,000.

C. Extending Regional Center Assessment Timelines

Regional centers have mandated timelines for completing their assessment of prospective consumers and for developing an individual program plan or individualized family service plan for those found eligible for services.⁵³ The timeline for completing the assessment phase of the process for consumers over age three has intermittently been extended from 60 to 120 calendar days for many years to generate savings in regional center personnel costs. This change was first enacted in fiscal year 1992-93 through an urgency statute (Senate Bill 485, Chapter 722, Statutes of 1992) which sunset July 1, 1996. This action was implemented again in fiscal year 2002-03 and,

⁵³ Wel. & Insti. Code Sec. 4642 and 4643, and Government Code Sec. 95016.

through subsequent legislative actions, has continued into the current fiscal year. The savings associated from this action derive from the reduced number of regional center clinical personnel needed for performing the required assessments. The Governor's Budget for 2008-09 assumes continuation of the longer assessment period.

D. OPS Budget Reductions and Expenditure Plans

The budget for regional centers' OPS has sustained numerous unallocated reductions over the years, some of which have been restored and others not. The first unallocated reduction in the regional centers' OPS budget occurred in fiscal year 1982-83 (\$2.2 million General Fund). Budget act language required the Department to establish expenditure priorities for regional centers to ensure they maintained expenditures within the amount budgeted.⁵⁴ These Department-developed priorities for controlling costs were invalidated by the state Supreme Court in their 1985 ruling in the *Association for Retarded Citizens v. Department of Developmental Services* litigation, as described on page 15, **Entitlement to Services**.

The next unallocated reduction occurred in fiscal year 1991-92. This reduction was followed by unallocated reductions in each fiscal year thereafter through 1995-96. Unallocated reductions were again instituted in fiscal years 2002-03, 2003-04, and 2004-05. Regional centers achieved the reductions in OPS in fiscal year 1991-92 and following through a variety of means including, but not limited to:

- increasing service coordinator-to-consumer caseload ratios
- reducing qualifications for new service coordinator employees
- employee layoffs
- temporary regional center closures, some between seven and 14 days with the provision of on-call emergency services
- relinquishing money management or representative payee services for consumers receiving SSI/SSP benefits
- reducing work hours
- employee furloughs

⁵⁴ Assembly Bill 21, the Budget Act of 1982, Item 4300-101-001, Provision 8.

- reduced employee training
- increasing employees' benefit premiums
- renegotiating lease/rental costs
- consolidating/closing offices
- contracting out additional services
- reduced travel, communication, consultant, legal, and other general administrative expenses
- freezing hiring and cost-of-living/salary increases

The regional centers' proposals for achieving the required reductions were incorporated into expenditure plans which the Department was required to review and approve, as appropriate. More information about expenditure plans is contained on page 40, **POS Budget Reductions/Expenditure Plans**. The cumulative total of unallocated reductions made to the regional centers' OPS budget since fiscal year 1991-92 is \$60.7 million, of which \$17.1 million continues.⁵⁵

E. Discontinuing Regional Center Salary Indexing

The methodology for budgeting regional centers' personnel costs is formula driven. The methodology calculates the number and type of personnel or positions theoretically needed for a regional center to comply with its mandated and contractual obligations. A position's salary in the formula is linked to the mid-range state salary for the equivalent state position based on when the regional center position was added to the formula. Until fiscal year 1991-92, whenever state employees received a cost-of-living adjustment the formula was kept current by updating the formula to maintain salary equivalency with comparable state positions. This policy of indexing regional centers' personnel budget increases to state employee cost-of-living adjustments continued through fiscal year 1990-91. In fiscal year 1991-92, the policy changed when the state ceased providing regional centers cost-of-living adjustments for their personnel costs; this policy has continued through the current fiscal year. Illustrating the fiscal impact of

⁵⁵ History of Unallocated Reductions and Restorations, Dept. of Developmental Services, Regional Centers 2007-08 May Revision.

this policy change is the regional center "Revenue Clerk" position, which is linked to the state equivalent position classification of "Accounting Technician." The annual mid-range salary for the state Accounting Technician position is currently \$31,272, whereas the formula uses an annual mid-range salary of \$18,397, which reflects the Accounting Technician annual mid-range salary as of fiscal year 1990-91. Based on caseload and other factors, the budgeting formula calculates the number of positions a regional center needs to perform the specified function(s) for which the Revenue Clerk positions are allocated. This number is then multiplied by the salary in the formula. In this instance the salary remains equivalent to the state's Accounting Technician in fiscal year 1990-91, or \$18,397, which is about 59 percent of the current annual mid-range salary for the state Accounting Technical position. To some extent, this discrepancy exists in all the regional center positions across the budgeting formula.

F. Increasing Service Coordinator-to-Consumer Caseload Ratios

The Lanterman Developmental Disabilities Services Act prescribes specific service coordinator-to-consumer caseload ratio standards that regional centers must observe. These ratios were established in response to an adverse federal audit of the state's Waiver, as described on pages 28-29, **Federal Fund Sources, 1. Home and Community-based Services Waiver**. To generate savings, legislation changed these requirements for non-Waiver consumers commencing January 1, 2004.⁵⁶ These changes (1) increased the maximum number of cases of consumers a regional center service coordinator may carry on his/her caseload from 62 to 66 for individuals who are not otherwise enrolled in the Home and Community-based Services Waiver or under age three, and (2) increased the maximum number of consumers a regional center service coordinator may carry on his/her caseload from 45 to 62 for consumers who have moved from a state developmental center since April 14, 1993, provided the consumer has lived continuously in the community for at least 12 months. The savings associated with these changes were, and continue to be, reflected in the regional centers' OPS budget. The Governor's Budget for 2008-09 assumes continuation of the 1 to 66 caseload ratio.

⁵⁶ Chapter 230, Statutes of 2003 (Assembly Bill 1762, Sec. 4640.6 (c)(3-4)).

G. Modifying the Personnel Funding Formula

In addition to the change in service coordinator ratios described immediately above, the budget for fiscal year 2003-04 imposed an additional OPS reduction linked to modifications in the core staffing formula. These modifications (1) increased the service coordinator-to-supervisor ratio from 1:8 to 1:10, and (2) increased the support staff-to-professional ratio from 1:4 to 1:6.

Purchase of Services for Consumers Budget Cost-containment Proposals

A. Priorities for Regional Center Expenditures

The Budget Act of 1982, Item 4300-101-0001, Provision 3, required the Director of the Department to issue guidelines as a way to absorb a \$4.7 million (\$2.2 million OPS; \$2.5 million POS) unallocated reduction in the regional center budget. This budget bill language stated:

3. Notwithstanding any other provision of law, the Director of the Department of Developmental Services shall establish guidelines for the expenditure of funds budgeted for the regional centers program.

The Department prepared and issued the required guidelines on October 14, 1982, which were to be in effect through June 30, 1983. The goal of the guidelines was to achieve cost savings by limiting regional center funded services to those that were "basic and essential." Consumer services identified in the guidelines as "basic and essential" included (1) a primary residence, (2) primary program services, (3) transportation services, (4) basic medical and health care, (5) in-home supportive services, and (6) primary prevention. The guidelines also included recommended methods for achieving OPS cost savings. The legality of the guidelines was litigated and the state Supreme Court voided them, as described on page 15, **Entitlement to Services**.

B. AB 40X (Chapter 16, Statutes of 1983-84) Regulations

Confronted with a \$1 billion state budget deficit, legislation (Section 26 of Chapter 16, Statutes of 1983-84, First Extraordinary Session) was enacted directing the Department to adopt emergency regulations to (1) provide standards for the consistent provision of services and related administrative practices by regional centers throughout the state, (2) govern the allocation of resources among regional centers, and (3) establish standards for the individual program planning and implementation process as set forth in Division 4.5 (commencing with Section 4500) of the Welfare and Institutions Code. The legislation, Assembly Bill 40X, was an urgency statute with Section 26 and the attending regulations remaining in effect until July 1, 1984.

The legislative intent for these regulations was *"...to ensure that regional centers administer the annual contract pursuant to the provisions of the emergency regulations and within the level of funding available pursuant to Section 4633 of the Welfare and Institutions Code."* The regulations (California Code of Regulations, Title 17, Subchapter 3, *Regional Center Budget Deficit Controls*) which were filed August 24, 1983, (1) included general parameters for approving consumer purchase requests, including documentation and provider progress report requirements, (2) required a review of all consumers' individual program plans and prioritization for services to be reduced or terminated if necessary to eliminate a projected regional center or statewide deficit, (3) authorized the Department to request a "plan of action" from one or more regional centers to resolve a projected deficit and to reallocate funds among regional centers, (4) set forth the requirements for the contents, review process, modification, and implementation of plans of action, (5) established standards for 16 purchase of service categories, and (6) provided an exceptions process for extraordinary individual circumstances.

C. POS Budget Reductions/Expenditure Plans

The budget for regional centers has sustained numerous unallocated reductions over the years, some of which have been restored and others that have not. The first unallocated reduction in the regional centers' POS budget occurred in fiscal year 1982-

83 (\$2.5 million, as described on page 39, **Priorities for Regional Center Expenditures**. The next unallocated reductions occurred in fiscal years 1991-92, 1992-93, 1993-94, and 1994-95. Unallocated reductions were again instituted in fiscal years 2002-03, 2003-04, and 2004-05. The cumulative total of unallocated reductions made to the regional centers' POS budget since fiscal year 1991-92 is \$195.6 million in total funds.⁵⁷

Imposition of the unallocated reduction in fiscal year 1991-92 was accompanied by Senate Bill 1045 (Chapter 93, Statutes of 1991) which provided for the expenditure plan process as the means by which the regional centers were to absorb the reduction. This was an urgency statute due to the significant state budget deficit. Each regional center was required to develop and submit a detailed plan to the Department describing how it intended to absorb the unallocated reduction and provide services to eligible consumers throughout the contract term within the limitation of the funds allocated. The law required that the regional center conduct a public hearing to receive comments on the plan before submitting it to the Department for review and approval. The plans were required to emphasize (1) the use of innovative and cost-effective methods of service delivery, (2) maximizing all alternative funding sources, and (3) operations expenditure reductions before reducing non-supervisory, case management personnel. Senate Bill 1045 also (1) reduced the required frequency for reviewing consumers' individual program plans from at least annually to once every three years, with a corresponding reduction in funding, and (2) authorized the Department to temporarily adopt, amend, or suspend regulations on an emergency basis to allow regional centers to implement their cost reduction plans. The regulations, however, could not impose any categorical reductions in service. The state's ongoing budget difficulties led to a continuation of the expenditure plan process for three succeeding fiscal years: 1992-93, 1993-94, and 1994-95. The legislative vehicle for this extension was Senate Bill 485 (Chapter 722, Statutes of 1992, an urgency statute). The expenditure plan process achieved the

⁵⁷ Department of Developmental Services, *History of Unallocated Reductions and Restorations*, Regional Centers 2007-08 May Revision.

required fiscal-year savings and the expenditure plan provisions of Senate Bill 1045 were repealed as of July 1, 1996.

In each of these three years the regional center system sustained unallocated budget reductions in OPS and POS. Senate Bill 485 granted the Department additional authority to require a regional center to take any actions deemed necessary to achieve the required savings in its OPS budget. These actions could include, but were not limited to, requiring regional centers to: centralize billing and other fiscal and administrative functions, reduce office space by reconfiguring service coordinators' work locations, freeze or reduce levels of pay for managerial or supervisory personnel, contract out for specified functions currently performed directly by the regional center, and seek Medi-Cal provider status for regional center personnel performing reimbursable activities. The expenditure plan provisions of Senate Bill 485 were repealed as of July 1, 1996. Some of the expenditure plan proposals developed by the regional centers included the following:

- Negotiating payment reductions with providers
- Increasing the use of employment-related services funded by the Department of Rehabilitation
- Expanding the use and development of Medi-Cal-funded Adult Day Health Care programs
- Implementing uniform holiday schedules among day programs
- Converting community care facilities to Medi-Cal-funded facilities
- Using lower cost vouchers for purchasing respite, day care, nursing, diapers, and nutritional supplements
- Increasing mobility training
- Establishing new day program sites to reduce transportation mileage and attending costs
- Establishing "preferred providers" for services
- Negotiating voluntary reductions in services
- Soliciting voluntary contributions for services

- Providing group services in lieu of individual services in such areas as behavioral treatment, independent living training, etc.
- Aggressively pursuing generic services, e.g., In-home Support Services, Early and Periodic Screening, Diagnosis and Treatment (EPSDT), special medical waivers, etc.
- Seeking voluntary contributions from families

D. Purchase of Service Standards

In the latter part of fiscal year 2001-02, the Department proposed trailer bill language that required the development of regulations to standardize the purchase practices of regional centers beginning in fiscal year 2002-03. The proposed trailer bill language mandated the promulgation of regulations within 90 days after passage of the trailer bill. The trailer bill language and draft regulations, known as "statewide purchase of service standards" were widely distributed, posted on the Department's website, and the subject of five community meetings in May and June to obtain input. Among other things, the proposed standards included limits on specified services, prohibited specific purchases, and set standards regional centers were to use in reviewing, processing, and approving purchase of service requests. The Legislature did not approve the proposed trailer bill language.

The proposed fiscal year 2003-04 budget included another unallocated reduction (\$100 million General Fund; \$136.5 million total funds) to help address a statewide budgetary shortfall. To accomplish this reduction, proposed trailer bill language was put forth during the Legislature's mid-year spending reduction session. The Legislature deferred action on that trailer bill language until the regular budget session. During legislative subcommittee budget hearings, the Department shared the specific service standards to be implemented pursuant to the trailer bill language. The savings generated by the service standards was to be realized through provider payment reductions in specified service categories, service efficiencies, elimination of selected services, and by freezing service-level changes for Alternative Residential Model facilities. This version of the standards included a sunset date of July 1, 2007. The Legislature rejected the service

standards approach and a reduced unallocated reduction of \$10 million was implemented instead.

In March and April 2004, the Department distributed for public comment a revised version of the POS service standards trailer bill and regulations for implementation in fiscal year 2004-05. A public meeting was held with stakeholders in March 2004, and revisions were made in response to the public input. This version of the standards did not propose eliminating any service categories nor include any provider rate reductions. The proposed trailer bill language and accompanying standards were not approved by the Legislature.

E. 2003-04 Mid-year Reduction Proposals

In November 2003, when the state was in the midst of a severe budget crisis, the Administration proposed reducing and controlling costs in the developmental services program by (1) capping the regional center caseload as of December 31, 2003, (2) establishing waiting lists for services, (3) requiring regional centers to live within their budgets and giving them the authority to deny, modify, reduce or terminate services to any consumer, including existing consumers with services listed on an individual program plan, and (4) eliminating specified "non-core" regional center-funded services, including respite services. These proposals were withdrawn about a month later.

F. Revision of Eligibility Definition

The Department proposed amending the definition of 'developmental disability' prospectively beginning in fiscal year 2003-04. See page 8, **Regional Center Eligibility**, for the criteria used by regional centers for determining service eligibility. The definition of 'developmental disability' not only requires that the disability be attributable to specified conditions manifested before the person attains age 18, but that the condition be expected to continue indefinitely and to constitute a 'substantial disability' to the person. To meet the substantial disability test, regulations require that the regional center's assessment find "significant functional limitations" in the individual's major life activities which include his or her receptive and expressive

language; learning; self-care; mobility; self direction; capacity for independent living; and economic self sufficiency. However, the definition did not specify a minimum number of functional limitations that had to be present to meet the substantial disability test. The Department proposed amending the law permanently to require that a minimum of three significant functional limitations be present for the person to be deemed substantially disabled. This requirement is the same as that used for the federal definition of developmental disability. The Legislature adopted this proposal, which included budgetary savings derived from an estimated decrease in the individuals eligible for regional center services.⁵⁸

G. Family Cost Participation Program

Legislation enacted in 2004 established the Family Cost Participation Program (FCPP).⁵⁹ Prior to implementing the FCPP, regional center services had been available to consumers at no cost to families, with the exception of the Parental Fee Program for minors living in 24-hour, out-of-home facilities. With implementation of the FCPP, a parental share of cost is assessed for all new and existing regional center consumers ages three through 17 who are (1) not Medi-Cal eligible, (2) living at home, and (3) receiving respite, day care, or camping services.

The law requires that the family share-of-cost responsibility begin at 400 percent of the Federal Poverty Level and vary by income and family size. At the threshold level for participation, the family is assessed a five percent share of cost of the respite, day care, and camping services authorized by their child's individual program plan. The law further requires that the family's assessment be reduced if they have two or more children receiving regional center services. The cost participation amount is reduced by 25 percent if two children are regional center consumers; by 50 percent if three children are regional center consumers; and by 75 percent if four children are regional center consumers. Families with more than four children are exempt from the cost

⁵⁸ Chapter 230, Statutes of 2003 (Sec. 46, effective August 11, 2003).

⁵⁹ Chapter 228, Statutes of 1994 (Sec. 4783, effective August 16, 2004).

participation. The assessment schedule is based on a sliding scale and ranges from five to a maximum 80 percent of the cost of targeted services.

The FCPP commenced January 1, 2005. Program implementation began as new consumers entering the regional center system were assessed for the FCPP. Final FCPP regulations became effective on August 22, 2005.⁶⁰ This program will sunset on July 1, 2009, unless the sunset date is repealed or extended. The Governor's Budget for 2008-09 proposes to expand the program and eliminate the sunset. Please see page 76 for further details.

H. Long-term Cost-containment Strategies

For the fiscal year 2005-06 budget, the Department proposed trailer bill language (TBL) giving regional centers authority to more effectively control POS expenditures. The requirements would have been applied at the time of the development, scheduled review, or modification of a consumer's individual program plan or individualized family service plan. The proposal, which was to be phased in over three years, included language requiring regional centers to:

- Purchase services and supports from the least costly vendor who is able to meet the consumer's needs;
- Give preference for purchasing a service or support using a group modality, in lieu of a more costly individual intervention, if the consumer's needs could be met using the group modality;
- Establish an internal review process to ensure, before using regional center resources to fund purchase requests, the maximum use of generic resources, legal compliance, and the appropriateness as to the type, amount, duration and scope of clinical services;
- Take into account the family's responsibility for providing similar services to a minor child without disabilities when determining which services will be purchased by the regional center;

⁶⁰ California Code of Regulations, Title 17, Sec. 50243-50267.

- Provide a statement, at least annually, of regional center purchased services to the consumer (or parents/conservator) to ensure that services are delivered; and
- Purchase supported living services only if the projected annual regional center cost of a consumer's supported living arrangement does not exceed the average annual cost of supporting a consumer in a developmental center.

The proposed trailer bill language and associated budget proposal were not approved by the Legislature.

I. Regional Center Contract Language

For the fiscal year 2006-07 budget, the Department sought to exercise its contracting authority with the regional centers in negotiating contract language binding the regional centers to requirements similar to those contained in the trailer bill language proposed the prior fiscal year. This budget proposal was entitled "*Regional Center Contract Provisions to Control POS Expenditures.*" The proposed contract language sought to (1) require the use of the least costly vendor who will meet the consumer's needs, (2) clarify parents' responsibility for purchasing services, (3) specify the preference for using less costly group, as opposed to individual, services if the consumer's needs would otherwise be met, (4) ensure regional centers establish and use an internal review process prior to authorizing the purchase of services, and (6) prohibit the purchase of specific item/services that are in conflict with state and federal law and federal OMB circulars.

Negotiations with the Association of Regional Center Agencies Contract Committee (ARCA) commenced late in fiscal year 2005-06. However, the Legislature rejected the budget request for resources needed by the regional centers to implement the contract language. Moreover, ARCA opposed the proposed contract language so, even if budget resources had been made available, the negotiations would not have been successfully concluded.

J. Start-up Funding Freeze

Since the mid-1990s, regional centers have used POS funds for starting new programs for consumers. Prior to this time, permissible start-up fund sources were limited to the Program Development Fund, Community Placement Plan (CPP) funding, and special funds allocated for this purpose.^{61 62} This policy changed when the Coffelt Settlement Agreement⁶³ was being implemented and additional POS funding became available. The Department authorized those funds to be used for starting programs related to implementing the settlement agreement. The Department proposed prohibiting regional centers from using regular POS funding for starting new programs beginning in fiscal year 2003-04. The only exceptions included using funds for projects included in the regional center's approved CPP and, if necessary, to protect consumers' health or safety or in other extraordinary circumstances. All exceptions to the prohibition had to be approved, in writing, by the Department. The Legislature approved this proposal for fiscal year 2003-04 and it has been included in trailer bill language and renewed annually into the present fiscal year. The freeze was modified for fiscal year 2006-07 only to allow for the use of \$3 million in POS for start-up activities, subject to the Department's prior written approval, for outcome-based programs that (1) promote and provide integrated supported work options for individuals or groups of no more than three consumers, (2) promote and provide integrated social, civic, volunteer, or recreational activities, and (3) allows current providers to engage in new or expanded employment activities that result in greater integration, conversion from sheltered to supported work environment, self-employment, and/or increased consumer participation

⁶¹ Wel. & insti. Code Sec. 4677.

⁶² Wel. & insti. Code Sec. 4418.25. A "Community Placement Plan" is a plan prepared by regional centers setting forth its activities, time frames, and resource needs for transitioning state developmental center residents into the community. The plans, submitted to the Department for approval, are developed according to departmental guidelines and receive dedicated funding for (1) performing comprehensive individual assessments of developmental center residents, (2) developing and funding needed resources, (3) moving selected individuals from developmental centers to the community, and (4) deflecting individuals from developmental center admission.

⁶³ The Coffelt et al. v. California Department of Developmental Services et al. was a class action lawsuit filed on February 1990, and which resulted in a formal settlement agreement in January 1994. The settlement required the Department to reduce the number of individuals with developmental disabilities living in large state developmental centers by 2,000 over five years by expanding community-based services and supports.

in the federal Ticket to Work program.⁶⁴ The Governor's Budget for 2008-09 continues this freeze.

K. Program Rate Freezes/Restrictions

Effective fiscal year 2003-04, the state froze or restricted the rates for many regional center-funded programs. These freezes or restrictions were first imposed through a budget trailer bill and have been in effect continuously including the current fiscal year.⁶⁵ The Governor's Budget for 2008-09 continues these freezes. These provisions affect the following:

1. Contracted Rate Programs and Services – The rates for many types of programs are set through negotiations between the regional center and provider and incorporated in a contract. This freeze prohibited regional centers from increasing the rate paid to existing service provider of any of the following 11 high-growth services: supported living, transportation, socialization training, behavior intervention, community integration, community activities support, mobile day programs, creative art programs, supplemental day services, adaptive skill trainers, and independent living specialists. Newly vendored service providers continue to have a rate set through a negotiated process but their rates are also subject to the freeze once set. The statute contains an exceptions process whereby an increase can be negotiated if the regional center demonstrates that an exception is necessary to protect the consumer's health or safety and the Department has granted prior written authorization.

Exceptions to the freeze have included many services funded through the Miscellaneous category of the budget. However, the Governor's Budget for 2008-09 proposes to freeze these services. Other exceptions include (1) effective July 1, 2006, a three percent cost-of-living adjustment that was provided to service providers for which the Department sets rates (community care facilities, community-

⁶⁴ Chapter 74, Statutes of 2006, Sec. 57.

⁶⁵ Chapter 230, Statutes of 2003 (Assembly Bill 1762).

based day programs, habilitation services programs, respite agencies, and vouchered respite) and for specified contracted-services programs (supported living, transportation, and look-alike day programs), (2) funding for minimum wage increases, and (3) an augmentation for enhancing wages for direct care staff in day programs, work activity programs, and "look-alike" day programs that met specified criteria.

2. Service-level Changes – Most Department of Social Services-licensed residential programs serving persons with developmental disabilities operate under a rate methodology known as the Alternative Residential Model (ARM). Under this model, regional centers pay providers a supplement to the consumers' Supplemental Security Income/State Supplemental Payment (SSI/SSP). This supplement pays the provider for the additional services and programming not covered by the consumer's SSI/SSP. There are four levels of ARM facility rates – Levels 1 through 4. The Level 1 rate is SSI/SSP only. The rate for Levels 2 through 4 increases at each level based on additional staffing requirements which are to be aligned with the assessed needs of the individuals served. For example, individuals requiring more care and services are generally served in Level 3 and 4 facilities, whereas those individuals whose needs are relatively less are served in Level 1 and 2 facilities. On occasion, the care needs of a majority of the individuals served in a given facility increase beyond what the designated level of care in that facility can provide, e.g., aging consumers. In such instances, the regional center can increase the facility service level and the commensurate payment level of the provider. This change in law prohibits a regional center from changing a provider's ARM service level if the approval would increase the rate to be paid to the provider. The statute contains an exceptions process whereby an increase can be granted if the regional center demonstrates that the exception is necessary to protect the consumers' health or safety and the Department has granted prior written authorization. These rates have been frozen since fiscal year 2003-04 except for the three percent increase provided July 1, 2006, and appropriate minimum wage increases.

3. Permanent Payment Rates – The Department sets the rates for community-based day and all of the in-home respite service programs.⁶⁶ Newly vendored providers are given a temporary rate until such time as they have a cost history from which to establish a permanent rate. During the first 18 months of operation, the new provider must submit cost data for a 12-month continuous period of operation. The Department uses these data to set a permanent rate. This change in law prohibits the Department from setting a permanent rate if the rate would exceed the temporary payment rate. The statute contains an exceptions process whereby a permanent rate can be granted if the regional center demonstrates to the Department that the permanent rate is necessary to protect consumers' health or safety.

Effective July 1, 2004, the Department assumed responsibility for the Habilitation Services Program (HSP) from the Department of Rehabilitation.⁶⁷ Similar to the rate freeze in effect for community-based day programs, legislation was enacted prohibiting the Department from approving any rate adjustment for a specific HSP that would result in an increase in the rate to be paid.⁶⁸ This freeze has continued into the current fiscal year similar to the other temporary cost-containment measures. The HSP came to the Department with unrestored fiscal year 2003-04 rate reductions in the Supported Employment and Work Activity programs of 2.5 percent and 5 percent, respectively. However, the Supported Employment Program within the larger HSP was augmented to increase the job coach rate by 21 percent effective fiscal year 2005-06, in addition to receiving the three percent rate adjustment.

4. Program Design Modifications and Re-vendorizations – The rates for community-based day programs and in-home respite service agencies are set based on

⁶⁶ "Community-based day programs means those programs which provide services to individuals on an hourly or daily basis, but less than a 24-hour basis in the community rather than at a developmental center. Only the following types of services are community-based day programs: activity centers, adult development centers, behavior management programs, independent living programs, infant developmental programs and social recreation programs." (California Code of Regulations, Title 17, Sec. 54302(a)(16))

⁶⁷ Chapter 226, Statutes of 2003.

⁶⁸ Chapter 228, Statutes of 2004 (Senate Bill 103).

allowable costs, as defined in regulations. The program type, which sets forth the general program design and the staffing requirements, is a significant determinant in the rate-setting process. Programs may change their program design, which is most often related to altering their staff-to-consumer ratio, and/or seek to be vendored as another program type. These changes usually result in rate increases. This change in law, or freeze, prohibits the Department and regional centers from approving a provider's program design modification or re-vendorization that would result in an increase in the rate to be paid to the provider. The statute contains an exceptions process if the regional center demonstrates that the program design and/or re-vendorization is necessary to protect consumers' health or safety and the Department has granted prior written authorization.

5. Anticipated Rate Adjustments - Once a payment rate for a community-based day program has been set by the Department, adjustments to that rate can be made by the Department for either 'anticipated' or 'unanticipated' program changes. An anticipated program change is a service modification for which the vendor and/or the vendoring regional center can plan and expect to occur in the next fiscal year, such as relocation of the service due to an expiring facility lease or tenancy arrangement. Unanticipated rate adjustments are limited solely to mandated service adjustments due to (1) changes in, or additions to, existing statutes, laws, regulations or court decisions, and/or (2) emergency relocations as required to protect the health and safety of consumers. This change in law prohibits the Department from approving an anticipated rate adjustment that would result in an increase in the rate to be paid to the provider. The statute contains an exceptions process if the regional center demonstrates that the anticipated rate adjustment is necessary to protect consumers' health or safety.

6. SSI/SSP Pass-through Elimination – As described on page 50, **Program Rate Freezes/Restrictions, 2. Service-level Changes**, the residential service facilities for consumers residing in Alternative Residential Model (ARM) facilities have a rate composed of the consumer's Supplemental Security Income/State Supplemental

Payment (SSI/SSP) payment and a regional center supplement. The combination of these two fund sources comprises the rate for the particular ARM service level. The rate schedule is established by the Department and can only be changed by action of the Legislature. When cost-of-living adjustments are provided for SSI/SSP recipients, the state can decide whether to pass the increase through to ARM providers as a rate increase, or decrease the regional center supplement by the amount of the SSI/SSP increase and, thereby, keep the rate frozen and save state funds. Beginning in the 2003-04 fiscal year into the current fiscal year, the state has elected not to pass through any of the SSI/SSP cost-of-living adjustments to the ARM providers.

III. IMPENDING COST-CONTROL OPTIONS

The following are cost-containment options that are in various stages of development. They are expected to be implemented within the next 12 months; however, those requiring the promulgation of regulations may take longer due to the complexities of the state regulation development process.

A. Rate/Service Code Standardization Project

Regional centers negotiate rates with a wide range of service providers. However, there is little regulatory guidance on how these negotiations are to be conducted and few parameters governing how the rates are set and adjusted. In an effort to better understand and control costs in areas where rates are negotiated, the Department embarked on a multi-year project. The first step in this project involved developing and distributing three rate surveys to the regional centers. The surveys focused on high-growth service codes for which rates are negotiated between the regional center and service provider. Next, the Department engaged a consultant to analyze regional centers' use of these service codes and their rates. Based on the consultant's work, the Department expects to introduce one or more regulation packages addressing these areas, starting in 2008.

Estimated Annual General Fund Savings: Indeterminate. This option may dampen future growth in the affected service categories as the new cost and rate setting parameters are implemented. The costs avoided or savings realized will vary as a function of the timing and specifics of the regulations adopted.

B. Self-Directed Services Waiver

The Self-Directed Services (SDS) program is "*A means by which individuals who are eligible for state developmental disabilities services are empowered to gain control over the selection of services and supports, that meet their own needs.*" The SDS program is designed to "*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.*"⁶⁹ Although relatively new in California, SDS programs are implemented nationwide and have garnered bi-partisan and international support.

The objective of SDS programs is to allow people with disabilities to determine their own futures, with appropriate assistance from families and friends. Participants have increased control over the decisions and resources necessary to implement their individual program plan. Each participant has an individual budget to purchase specific services and supports to implement their program plan. The services and supports selected must be provided within an inclusive, community setting.

Subject to approval by the federal Centers for Medicare and Medicaid Services of a 1915(c) Waiver, beginning in fiscal year 2007-08, the Department will implement a Self-Directed Services (SDS) model of funding and service delivery that will cap individual budgets in exchange for increased consumer control over services. The Budget Act of 2005 contained trailer bill language to implement the SDS program.⁷⁰ Since then, the Department has continued to refine this program based on input from stakeholders. In the fall of 2006 and 2007, a series of meetings were held on a draft of the regulations and the Department has now revised the regulations in response to the public comments and plans to file with the Office of Administrative Law in early 2008.

⁶⁹ Wel. & Insti. Code Sec. 4685.7.

⁷⁰ Chapter 80, Statutes of 2005 (Sec. 15.5).

Enrollment of an estimated 100 consumers in the SDS Waiver program is to begin during the latter part of fiscal year 2007-08, reaching a maximum estimated Waiver enrollment of approximately 9,500 consumers over five-years. The individual budget allocation to consumers will result, in the aggregate, in a 10 percent cost savings; from this amount 5 percent will be established as savings to the state and 5 percent will be deposited into a risk pool for SDS participant's "unanticipated" needs. The Department is in the process of developing a SDS information system to track expenditures and capture federal reimbursement for both consumer services (50/50 match) and for administrative activities. If the waiver is approved, all services in the SDS program will be federally reimbursable, resulting in 100 percent of the services allowed to receive federal reimbursement for Waiver-eligible consumers.

Estimated Annual General Fund Savings: Approximately \$5.8 million.

C. Supported Living Services Regulations

Supported living was established as a statewide service with the passage of legislation in 1992.⁷¹ The supported-living concept had been tested through a state-funded pilot project, required by budget bill language in fiscal year 1990-91, and during a five-year, federally-funded grant known as Community Supported Living Arrangements which California received in October 1991 along with seven other states. Supported living services was a new service paradigm in which consumers, regardless of their degree of disability, had the opportunity to live in their own homes they would lease or buy. The Department promulgated emergency regulations to implement the new law, the final adoption of which occurred in 1996.⁷²

Supported living has proven to be a very important and frequently requested program which has grown to become the third most significant individual service option (exceeded only by residential services and adult day programs) in the regional centers'

⁷¹ Chapter 1011, Statutes of 1992 (Sec. 24 (4689), Senate Bill 1383).

⁷² California Code of Regulations, Title 17, Division 2, Chapter 3, Subchapter 19.

budget. Supported living rates are not set by the Department, but are determined by each regional center through individually negotiated contracts between the regional center and its vendored providers. In 2004, the Department analyzed the efficacy of this rate-setting approach through a review of cost data and face-to-face discussions with selected regional centers across the state. The Department concluded that individual negotiation of rates at the regional center level was an appropriate approach for rate setting, with a few exceptions. As a result of this review, the Department determined to retain the negotiated rate-setting process for setting rates but to amend the regulations to (1) provide more specific guidance to regional centers in negotiating cost-effective rates, (2) provide for increased equity in the treatment of consumers and vendors statewide, (3) assure consumers are not denied supported living services solely due to the nature and severity of their disabilities, and (4) increase departmental oversight and monitoring of supported living costs. Proposed regulatory changes have been prepared, reviewed with the public in several meetings, and are now pending finalization.

Estimated Annual General Fund Savings: Indeterminate. Savings or cost avoidance will vary as a function of timing and specific regulations adopted.

D. Autism Spectrum Disorders Best Practice Guidelines

As noted earlier in this report, the number of children diagnosed with Autism Spectrum Disorders (ASD) has increased significantly and the families of these children and clinicians are aggressively searching for promising approaches for treatment and intervention. Responding to this concern, the Legislature enacted a requirement for the Department to develop evaluation and diagnostic procedures for the diagnosis of ASD and to develop a training program for regional center clinical staff in the utilization of the diagnostic procedures.⁷³ These procedures were published in 2002.⁷⁴

⁷³ Chapter 171, Statutes of 2001 (Assembly Bill 430, Sec. 4643.3 (a)).

⁷⁴ Department of Developmental Services, "Autistic Spectrum Disorders – Best Practice Guidelines for Screening, Diagnosis and Assessment," 2002, <http://www.ddhealthinfo.org/documents/ASD_Best_Practice.pdf> (November 2007).

The diagnosis and assessment of individuals with ASD, and the intervention program management process, requires great expertise and the collaboration of trained and knowledgeable staff. After diagnosis, however, families and professionals serving children with ASD need an up-to-date and authoritative resource to help in identifying those treatment and intervention approaches demonstrated, by evidence-based research, to be efficacious. Moreover, since there is not a "one-size-fits-all" treatment regimen, programs must be designed and tailored to each individual. The absence of such evidence-based best-practice guidelines for treatment is causing confusion among service coordinators and providers, frustrating parents, and resulting in expenditures for treatments of questionable value.^{75 76 77} As part of the Department's ASD Initiative, it is facilitating the development of best practice guidelines based on evidence-based interventions. These guidelines should be available for dissemination in fiscal year 2008-09. Once published, professionals statewide involved in serving children with ASD will have up-to-date, evidence-based guidelines to use in their respective treatment settings. Such guidelines will help avoid the financial and human costs of potentially ineffective practices and will help assure families, whom are often very involved in the treatment process, that their efforts are helping achieve optimal results for their children.

Estimated Annual General Fund Savings: Indeterminate. Savings or cost avoidance will vary depending on when the guidelines are issued, their impact on current and future service delivery approaches, and effectiveness of the training effort.

⁷⁵ Shannon Kay and Stuart Vyse, "Helping Parents Separate the Wheat from the Chaff: Putting Autism Treatments to the Test," in John W. Jacobson, et al.[ed.], *Controversial Therapies for Developmental Disabilities – Fad, Fashion, and Science in Professional Practice*, Mahwah, New Jersey, Lawrence Erlbaum Associates, 2005, pp. 265-277.

⁷⁶ C. Steve Holburn, "Counter the Mistreatments for Autism with Professional Integrity," *Intellectual and Developmental Disabilities*, Vol. 45, Number 2, April 2007, pp. 136-137.

⁷⁷ Gina Green, Ph.D. & ASD Project Staff, "Autistic Spectrum Disorders: Guidelines for Effective Interventions", *Paper prepared for the Department of Developmental Services, ASD: Guidelines Project. 2007.*

IV. ADDITIONAL COST-CONTROL OPTIONS

In addition to the impending cost-containment options immediately preceding this section and those attempted in prior years, the following are further options for controlling or containing regional centers' growth in expenditures. All the options presented include, when possible, an estimated fiscal savings and all but a few would require statutory and/or regulatory changes to implement. These are "stand-alone" options, but they are not mutually exclusive in the sense that implementation of one option may interact with or impact one or more of the other options. Therefore, accounting for the potential interaction between options must be part of the public policy cost-containment discussion and analysis.

There are two parts in this section. The first part provides options that focus solely on cost savings and, as such, may result in the diminution or elimination of services. Most of these options could be implemented within a year, if agreed to by the Administration and Legislature on an urgency basis, and a few would require additional funding to implement. The second part includes options that have the potential of improving service outcomes. These options require an initial investment of funds and/or ongoing support. Pursuant to statute, each option includes advantages and disadvantages.

Control Options that Reduce or Curtail Services

A. Consolidate Regional Centers

There are 21 separate regional centers each serving an average of about 10,500 consumers. The geographic size of regional centers' service areas vary widely, with seven regional centers serving the densely populated county of Los Angeles and one regional center serving 10 less populous northern California counties. However, the basic responsibilities of all regional centers are the same.

This option would generate savings in the regional centers' Operations budget by consolidating some of the regional centers having contiguous boundaries and where such consolidations would be the least disruptive to consumers and their families, and to the affected regional centers. The savings for this option would be achieved through

economies of scale in staffing by reducing selected positions (e.g., one executive director instead of two) and reducing other expenses (e.g., supporting one governing board instead of two).

Advantages/Disadvantages: Advantages of this option include (1) reducing the Department's auditing and monitoring burden by reducing the total number of regional centers, (2) achieving some economy-of-scale efficiencies and cost savings. Disadvantages of this option include (1) the relatively limited savings generated could be offset by significant administrative costs related to consolidation activities, and efforts to address administrative complexities and legal issues involving the merging of union represented with non-represented regional centers, centers with different retirement and salary/benefit packages, etc., (2) service issues as consumers, families, and providers would have to deal with a significantly larger organization.

Estimated Annual General Fund Savings: The consolidation of two regional centers into one would save approximately \$486,000 General Fund, annually. This figure does not include any offsetting costs that may occur, as described above.

B. Outsource Regional Center Billing Transactions

As noted earlier in this report, regional centers have about 45,000⁷⁸ providers who participate in the service mix of publicly- and privately-funded organizations that comprise the state's community-based developmental services system. In the current year, regional centers will expend over \$3 billion, through an estimated six million billing transactions, to pay vendors for providing services and supports to consumers and their families.

Under this option, the claiming and billing function now performed by regional centers would be centralized and a single entity, under contract with the state, would assume

⁷⁸ This number represents all active vendors in fiscal year 06-07, including nearly 27,000 family members receiving vouchers for respite, day care, nursing, transportation, and diaper/nutritional supplements. This number does not include non-services claiming entities who are also vendorized for purposes of processing claims not related to the provision of services, e.g., personal and incidental reimbursements.

this role. The state would redirect the regional center funding now earmarked for performing these functions to a centralized billing entity at an overall reduced cost.

Advantages/Disadvantages: The advantage of this option is the limited cost savings and statewide consistency a centralized entity would provide in the billing transaction process. Disadvantages of this option include (1) potentially increased processing time for transactions possibly causing vendor cash flow problems, (2) less personalized attention to address unique problems regional center vendors and consumers/families often encounter, and (3) potential of eroding the regional centers' ability to ensure vendors' fiscal accountability.

Estimated Annual General Fund Savings: Indeterminate.

C. Increase Service Coordinator-to-Consumer Caseload Ratios

Every person found eligible for regional center services has a "service coordinator," or case manager, assigned to him or her. The role of a service coordinator includes preparing, implementing, and monitoring consumers' IPP, securing and coordinating consumer services and supports, and providing placement and monitoring activities.⁷⁹

Existing law specifies maximum service coordinator-to-consumer caseload ratios that must be observed, depending on an individual's particular age, placement status, and Waiver-eligibility.⁸⁰ The mandated ratios were increased commencing January 1, 2004 through June 30, 2008, as a temporary cost-containment measure. These ratios will revert July 1, 2008, absent legislative action, to the ratios in effect prior to January 1, 2004. The Governor's Budget for 2008-09 would remove the sunset date and continue the higher ratios. Based on data from a 2005 survey, the average national caseload ratio is about 1:40 for Waiver-eligible consumers.⁸¹

⁷⁹ Wel. & Insti. Code Sec. 4640.6 (d).

⁸⁰ Wel. & Insti. Code Sec. 4640.6 (c).

⁸¹ Robin Cooper, *Medicaid and Case Management for People with Developmental Disabilities*, National Association of State Directors of Developmental Disabilities, Inc., Alexandria, Virginia, 2006, p. 56.

This option would be to increase the caseload maximum for one or more of the categories of consumers specified in the chart below.

Category of Consumer	Service Coordinator-to-Consumer Ratios Prior to 1/1/04	Current Service Coordinator-to-Consumer Ratios 1/1/04 through 6/30/08
A. Under age 3	1:62	1:62
B. HCBS-Waiver enrollees	1:62	1:62
C. Consumers moved from DCs	1:45 (indefinitely)	1:45 (only for first 12 months after placement)
D. Consumers 3-17 living at home (not A, B, or C above)	1:62	1:66
E. All others (not A, B, C, or D above)	1:62	1:66

Advantages/Disadvantages: The advantage of this option is the cost savings associated with reducing regional center funding for service coordinators, their support staff, and associated operational expenses. Disadvantages include (1) reduced service coordinator quality assurance/monitoring of vulnerable individuals and (2) according to some regional centers, high caseload ratios diminish service coordinators' ability to advocate for and access alternative generic funding resources which, in turn, leads to increased purchase-of-service expenditures.

Estimated Annual General Fund (GF) Savings: Indeterminate. Savings would depend on the caseload ratio changes that would be made. For example, if the caseload was increased from 1:66 to 1:85 the savings would be \$24.4 million (\$18.5 million GF).

D. Consolidate Quality Assurance Evaluation Processes

Existing law requires that a "life quality assessment" be conducted with every regional center consumer who is living in a licensed out-of-home placement, supported living arrangement, or independent living arrangement.⁸² This program was implemented in July 1, 1998, after about a year of pilot testing. The Area Boards on Developmental Disabilities conduct the life quality assessments which are funded by the Department through an interagency agreement with the State Council on Developmental Disabilities.

⁸² Wel. & Insti. Code Sec. 4570.

The Legislature's intent for the life quality assessment program is "*...to remain informed regarding the quality of services in the area and to protect the legal, civil, and service rights of people with developmental disabilities. . .* "

The law also requires that every consumer placed from a state developmental center into the community be evaluated annually by an independent contractor.⁸³ The current independent contractor is California State University, Sacramento. The results of these evaluations are summarized in a report that is submitted directly to the Legislature by the contractor. This report or study is commonly known as the "movers' study." Thus, the same consumers have the quality of their care evaluated through two separate evaluation processes. These two evaluations are in addition to the regular oversight and monitoring conducted by the regional centers and the periodic state licensing agencies' reviews.

This option would consolidate the life-quality-assessment evaluation and the movers' study into a single evaluation process that is nationally recognized, programmatically up-to-date and less costly. The new evaluation process could be the National Core Indicators Project in which 25 states and some of California's regional centers are currently participating, or another comparable process. Expected cost savings through this consolidation is expected to be about 50 percent of current expenditures for the existing two evaluation processes.

Advantages/Disadvantages: Advantages of this option include (1) cost savings, (2) aligning the evaluation process with the outcomes identified in the federal Home and Community-based Services Waiver Quality Framework, and (3) using a more data-based measurement approach to assessing quality and performance. Disadvantages to this option include (1) individual consumers not being seen as frequently since the new process would likely rely on a stratified-random-sampling methodology, and (2) the potential layoff of staff.

⁸³ Wel. & Insti. Code Sec. 4418.1.

Estimated Annual General Fund Savings: Approximately \$2.8 million.

E. Reduce or Eliminate Clients' Rights Advocacy Services

Until January 1, 1998, each regional center was allocated funding for a clients' rights advocate position to perform advocacy services on behalf of the regional center's consumers and families. The Legislature transferred this function and the attending funding from the regional centers to an independent contractor selected by the Department through a competitive-bidding process.⁸⁴ These responsibilities are now performed by a single contractor, Protection and Advocacy, Inc. (PAI), through its Office of Clients' Rights Advocacy (OCRA). This option would reduce or eliminate state funding for OCRA. Some residual advocacy service would still be available through such sources as:

- Regional centers, which still retain a fundamental mandate for advocating for and protecting the civil, legal, and service rights of persons with developmental disabilities. They must also employ at least one consumer advocate.⁸⁵
- Area boards, which are required to ". . . *protect and advocate the rights of all persons in the area with developmental disabilities.*"⁸⁶ The boards also have specific authority ". . . *to pursue legal, administrative, and other appropriate remedies to ensure the protection of the legal, civil, and service rights of persons who require services or who are receiving services in the area.*"⁸⁷
- Protection and Advocacy Inc., which has a federal mandate and appropriation (prior to and independent of their CRA contract) to ". . . *protect and advocate the rights of individuals with developmental disabilities . . .*" and authority to ". . . *pursue legal, administrative, and other appropriate remedies or approaches to ensure the protection of, and advocacy for, the rights of such individuals . . .*" and to ". . . *investigate incidents of abuse and neglect of individuals with developmental disabilities.* . . ." ⁸⁸

⁸⁴ Chapter 294, Statutes of 1997 (Sec. 4433, Senate Bill 391).

⁸⁵ Wel. & Insti. Code Sec. 4648 (b)(1), 4640.6 (g)(2) and (7),

⁸⁶ Wel. & Insti. Code Sec. 4548 (b).

⁸⁷ Wel. & Insti. Code Sec. 4548 (d)(1).

⁸⁸ Title 42, United States Code, Chapter 144, Subchapter I, Part C, Sec. 15043 and Wel. & Insti. Code Sec. 4900, et seq.

- Private advocacy organizations representing specific interest groups.

Advantages/Disadvantages: The advantage of this option is in reducing program costs. The disadvantages of this option include (1) overall reduction of advocacy support system for families and consumers, (2) in some cases, the absence of CRA services will require regional centers to purchase advocacy services for consumers/families, and (3) reducing the ability of consumers/families to obtain services and supports from generic agencies which may lead to service gaps or increased regional center funding to pay for the service the generic service would otherwise have funded if effective advocacy services had been provided.

Estimated Annual General Fund Savings: If eliminated, \$5 million. If reduced, the amount of the reduction imposed would be the cost savings. The Governor's Budget proposes a 10 percent program reduction, saving \$512,000.

F. Establish a Definition for "Cost-effective"

In several places, the Lanterman Act identifies cost-effectiveness as a significant consideration when purchasing services and supports for consumers. For example, the statute's definition of *"services and supports for persons with developmental disabilities"* states, in part, that *"The determination of which services and supports are necessary for each consumer shall be made through the individual program plan process. The determination shall be made on the basis of the needs and preferences of the consumer or, when appropriate, the consumer's family, and shall include consideration of a range of service options proposed by individual program plan participants, the effectiveness of each option in meeting the goals stated in the individual program plan, and the **cost-effectiveness** of each option."*⁸⁹ The term is later used in expressing the Legislature's intent with respect to the individual program plan process, as follows: *"It is the intent of the Legislature to ensure that the individual program plan and provision of services and supports by the regional center system is centered on the individual and the family of the individual with developmental disabilities and takes into account the needs and*

⁸⁹ Wel. & Insti. Code Sec. 4512(b).

*preferences of the individual and the family, where appropriate, as well as promoting community integration, independent, productive, and normal lives, and stable and healthy environments. It is the further intent of the Legislature to ensure that the 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."*⁹⁰

The Lanterman Act does not define "cost effective." The Department's transportation service regulations define cost effective but this definition's applicability is limited to the transportation regulation subchapter and the definition is not useful for other services.⁹¹ It is, therefore, very difficult for planning team participants to apply the cost-effectiveness requirement absent an operational definition. This option would define and codify, in the Lanterman Act, the term "cost effective" thus providing a consistent standard for planning teams to use in applying the Lanterman Act's cost-effectiveness requirement.

Advantages/Disadvantages: Advantages of this option include (1) cost savings, (2) providing statewide consistency in applying the cost-effectiveness principle established in law, (3) giving the Administrative Law Judges who process regional center mediations and fair hearings needed guidance in adjudicating cases, and (4) ensuring the cost of services is given due consideration by planning teams which develop consumers' individual program plans. Disadvantages of this option are the possibility that the definition crafted inadvertently subverts the individualized needs determination process by overwhelming other relevant considerations during the planning process and the possible diminution of services over time.

Estimated Annual General Fund Savings: Approximately \$29.0 million.

⁹⁰ Wel. & Insti. Code Sec. 4646(a).

⁹¹ California Code of Regulations, Title 17, Sec. 58501(a)(6) defines "cost effective" as "Obtaining the optimum results for the expenditure."

G. Redefine "Substantial Disability"

As described on page 9, **Regional Center Eligibility**, to obtain regional center services requires that a person have a disability that (1) originates before an individual attains age 18, (2) is expected to continue indefinitely, and (3) presents a "substantial disability." The law defines substantial disability as the existence of significant functional limitations in three or more areas of seven major life activities, as determined by a regional center, and as appropriate to the age of the person. The major life activities considered in this evaluation include self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency. The individual's disability must also be attributable to one of the following: mental retardation, cerebral palsy, epilepsy, autism, or a disabling condition closely related to mental retardation or requiring similar treatment. To meet the substantial disability test, regulations require that the regional center's assessment find "significant functional limitations" in the individual's major life activities, as described. Until fiscal year 2002-03, however, the definition did not specify a minimum number of functional limitations that had to be present to meet the substantial disability test. The state amended the law, as a permanent cost-containment measure in fiscal year 2002-03, to require that a minimum of three significant functional limitations be present for the person to be deemed substantially disabled. This requirement is the same as that used for the federal definition of developmental disability.

This option would require, prospectively, that an individual have at least four significant functional limitations in the seven listed major life activities to meet the substantial disability test to qualify for regional center services. Under this option, Individuals with less disabling conditions would no longer qualify for regional center services.

Advantages/Disadvantages: The advantages of this option are (1) fiscal savings by reducing the growth in the number of new consumers eligible for regional center services, and (2) possible increased availability of service providers for those with more significant disabilities. The disadvantages of this option include (1) eliminating services to less disabled children and adults who might otherwise benefit from receiving regional

center services, and (2) impacts on other health, social service, and/or mental health service systems as the affected individuals/families seek alternative services.

Estimated Annual General Fund Savings: Approximately \$4.5 million, not including offsetting costs that may occur, as described above.

H. Eliminate the Fifth Category of Developmental Disability

The fifth category of eligibility, defined in law as "*disabling conditions found to be closely related to mental retardation or to require treatment similar to that required by for individuals with mental retardation,*" is a category used by regional centers for individuals with disabilities who do not meet one of the other defined categories of eligibility: mental retardation, cerebral palsy, epilepsy, or autism. About 5.9 percent⁹² of consumers served by regional center are eligible under the fifth category. See page 8, **Regional Center Eligibility**, for background information on the definition used to determine regional center eligibility.

This option would eliminate, prospectively, the fifth category as a qualifying condition for regional center eligibility. The revised definition would apply to all new applicants for regional center services, regardless of age.

Advantages/Disadvantages: The advantages of this option are (1) fiscal savings by reducing the growth in the number of new consumers eligible for regional center services, and (2) possibly increased availability of services for those with more significant disabilities. The disadvantages of this option include (1) eliminating services to a group of children and adults who might otherwise benefit from receiving regional center services, and (2) impacts on other health, social service, and/or mental health service systems as the affected individuals/families seek alternative services.

⁹²"Information on Developmental Disability Combinations," *Fact Book*, Ninth Edition, Department of Developmental Services, Information Services Division, June 2007, p. 19.

Estimated Annual General Fund Savings: Approximately \$10.7 million, not including offsetting costs that may occur, as described above.

I. Adopt Cost-containment Regulations

Except for the emergency regulations adopted in fiscal year 1983-84 pursuant to Assembly Bill 40X and repealed July 1, 1984, no comprehensive regulations governing regional centers' expenditures have been implemented. This option would mandate that the Department promulgate such regulations within the parameters and priorities set forth by enabling legislation. The regulations would supplant existing Department-approved purchase-of-service policies now used by regional centers. Such regulations could (1) provide needed definitions, (2) set forth general parameters for controlling costs, (3) require regional centers to limit services purchased to specified federal guidelines (applicable Office of Management and Budget circulars), (4) clarify the regional centers' role in reviewing and authorizing services to be funded by the regional center, (5) establish standards for purchasing the different types of services, etc.

Advantages/Disadvantages: Advantages of this option include (1) reducing program costs, (2) providing a public regulatory process to establish methods for controlling costs in a very complex system, and (3) establishing consistent statewide policies that regional centers would follow when purchasing consumer services. Disadvantages of this option include (1) the time required for developing and implementing such regulations would delay savings at least a year or more, and (2) depending on the outcome, the regulations may be portrayed as undermining or curtailing the entitlement to services.

Estimated Annual General Fund Savings: Indeterminate. Savings would depend on when the regulations are adopted and the particular policy changes included in the enabling statute.

J. Limit the Scope of Allowable Regional Center Purchases

Previous cost-containment efforts (e.g., **Priorities for Regional Center Expenditures, AB 40X Regulations, Purchase of Service Standards, and 2003-04 Mid-year Reduction Proposals**) sought to prohibit regional centers from purchasing specific types of services or to impose limits on various types of services. The services targeted for elimination or curtailment have included respite care for families, social/recreational activities such as camping and Special Olympics, and non-medical therapies such as music or art therapy. Prior attempts to prohibit or limit the purchase of specific service types have been unsuccessful. This option would be to review, identify, and prohibit regional centers from purchasing specific services that do not appear to clearly align or further the purposes of the Lanterman Act. Also, limits or parameters on the amount and/or frequency of selected services could be adopted. Such parameters would be based on available evidence-based research and/or best practice guidelines which would be used when developing consumers' IPP.

Advantages/Disadvantages: The advantages of this option include (1) limiting program costs, and (2) more clearly defining the entitlement to services. Disadvantages of this option include (1) encroaching on the individual needs determination process by bringing external guidelines into the process, (2) limiting the options for addressing IPP objectives, and (3) may be portrayed as undermining or curtailing the entitlement to services.

Estimated Annual General Fund Savings: Indeterminate. Savings would depend on the service(s) eliminated or curtailed, the process and timelines for implementation, and due process procedures afforded the affected individuals/families.

K. Downsize and/or Reconfigure Large Residential Facilities

The federal Centers for Medicare and Medicaid Services (CMS) normally allows a state to claim federal financial participation (FFP) for expenditures to support consumers in community care facilities licensed by the state Department of Social Services, if the consumers are enrolled in the Home and Community-based Services Waiver (Waiver).

During its 1997 review of the Waiver, CMS determined that it would no longer allow the state to claim FFP under the Waiver for consumers residing in such facilities if they were larger than 15 beds. These large facilities were considered to be an institutional model of service delivery and, therefore, in conflict with the purpose of the Waiver which is to prevent consumers from being institutionalized by supporting home and community-based services.

To minimize the loss of FFP, the Department revised language in its federal Waiver application to specify the conditions under which large facilities could be eligible to provide Waiver-reimbursable services. The new Waiver language stipulated that eligible large facilities will be ". . . settings where living quarters are scattered in the community at large, or may be in an arrangement similar to an apartment house or retirement community. The facilities shall also respect an individual's rights and dignity by providing: (1) Bedrooms which are shared by no more than two individuals, with one person in a bedroom being preferred, (2) Common living areas that are conducive for interaction between residents, and residents and their guests, (3) Residents the opportunity to make decisions on their day-to-day activities in their home and in the community, (4) Services which meet the needs of each resident, and (5) Residents the privacy necessary for personal hygiene, dressing, and being by themselves, if they choose." CMS approved this language.

In 1998, the Department, in collaboration with the Department of Health Services, reviewed all the large facilities statewide and identified those meeting the new conditions for receiving FFP as set forth in the Waiver. The Department subsequently provided regional centers funding for "downsizing" or modifying additional large facilities on a voluntary basis to encourage these facilities to become eligible for Waiver reimbursement. This voluntary program has resulted in 16 large facilities, affecting 600 licensed beds, being downsized and expenditures for the affected consumers becoming federally reimbursable under the Waiver. Another 21 large facilities, representing over 500 beds, certified as meeting the Waiver criteria for large facilities have been approved

for FFP.⁹³ However, there are other large facilities serving about 1,100 consumers that remain ineligible for FFP because they have not downsized or reconfigured to meet the requirements allowing for FFP.⁹⁴

This option would impose a statutory requirement (1) prohibiting, prospectively, regional centers from vrending, or placing consumers into, any large (greater than 15 beds) Department of Social Service-licensed facilities that do not qualify for Waiver reimbursement, and (2) mandating that existing large facilities ineligible for Waiver reimbursement to downsize or reconfigure their facilities to become Waiver certifiable within 36 months, or to face specified sanctions.

Advantages/Disadvantages: The advantages of this option include (1) increasing federal funding, (2) providing affected consumers more integrated and homelike living arrangements, and all the benefits such environments confer, as the large facilities reconfigure or downsize, and (3) promoting the intent of the Olmstead decision (see Footnote 6, page 5). The disadvantages of this option include (1) requiring one-time funding and several years to fully implement, and (2) disrupting some affected consumers/families who do not want to relocate.

Estimated Annual General Fund Savings: Approximately \$10.7 million (as a result of increased federal funding).

L. Cap Non-employment-Related Day Programming

Most regional center-funded day programs for adults operate five days a week and the consumers attend accordingly. The regional centers usually fund transportation to and from these programs. This cost-containment option would set a maximum weekly limit of attendance or funding for such day programs at four days a week (or 18 days per month), six hours a day, unless the services are directly employment related. The

⁹³ Department of Developmental Services, Community Operations Division, Residential Services Branch, *Downsizing Large Residential Facilities*, June 29, 2007.

⁹⁴ Department of Developmental Services, Information Services Division, Data Extraction Unit, Job 5265, September 12, 2007.

Habilitation Services Program, by definition, would not be affected by this option, since it is an employment-focused program. Cost savings would be generated by reducing the average days of such programs' operation with concomitant savings in transportation.

Advantages/Disadvantages: The advantages of this option include (1) cost savings, and (2) creating incentives for expanding community integrated consumer employment opportunities. Disadvantages include (1) requiring care givers, including regional center funded residential providers, to provide care and supervision an additional day per week for the affected consumers, (2) limiting the entitlement to services by contravening, or setting parameters for, decisions that are now the responsibility of the consumer's planning team, and (3) significant financial impact on existing service providers.

Estimated Annual General Fund Savings: Approximately \$107.5 million.

M. Change Transportation Services

Regional centers expend about \$200 million annually for transportation services which enable people with developmental disabilities to participate in programs and/or other activities identified in their IPP. The law gives regional centers the option to purchase transportation services through either competitive bidding (request-for-proposals) or through a non-competitive procurement process.

Consumers use a variety of transportation services including public transit; specialized transportation companies; day programs and/or residential vendors; and family member, friends, and others. Consumers working in community jobs often use low-cost fixed-route public transportation for commuting to and from work as opposed to higher-cost specialized transportation. Regional centers purchase transportation services directly or, in many instances, issue vouchers to families/consumers who secure their own services.

The following are options for reducing transportation costs:

(1) *Mandate that a regional center can only vendor a newly-developed or relocated program which has a site that is easily accessible to public transportation routes, or where arrangements have been made with the local public transit authority to provide service to the new location.* This option would reduce reliance on higher-cost specialized transportation services and promote consumers' use of public transportation services. Vendors may object to such a requirement in that it would limit their siting options.

(2) *Mandate that regional centers use the competitive-bid process for securing transportation services from a provider where the potential contract amount exceeds a specified dollar threshold.* The stringency of the existing competitive-bid process and associated workload are such that the use of the competitive-bid process is limited. With specialized expertise, regional centers could also provide oversight and performance evaluation activities to improve the quality and efficiency of transportation services. Unless carefully planned and executed, increasing the use of the competitive-bid process may create short-term disruptions in consumers' transportation services due to changing providers more frequently; however, savings could be significant.

(3) This option includes several elements, as follows:

- *Prohibit regional centers from purchasing transportation for children, except under extraordinary circumstances, e.g., family illness which prevents the family from transporting, one-time-only taxi service for essential medical appointments, etc.*
- *Require all adults to first be assessed for their ability to safely use publicly-funded transportation services before funding regional center contracted services.* Consumers having the ability to use public transportation would be funded for mobility training, if needed, but would not be eligible for regional center contracted transportation services.
- *Prohibit regional centers from purchasing contracted, door-to-door transportation when a residential and/or day program provider is available and has the potential to provide the transportation services for the provider's consumers.* Regional

centers would reimburse the providers for the cost of this additional service but at a rate less than traditional regional center-funded fixed-route contract services.

(4) *Mandate the transition of consumers, who currently participate in site-based day programs, into integrated community jobs through supported employment if at all feasible.* This option assumes that consumers in integrated community work settings would generally use public transportation services, if available. This option dovetails with the option on page 87, **Increase Employment Opportunities for Consumers**, and will further promote employment opportunities for consumers. This option may disrupt consumers' existing routines and those day program providers retaining site-based models of service delivery. Traditional site-based day programs would be impacted unless they adopted a more integrated, employment-focused model of service delivery.

Advantages/Disadvantages: Advantages of these options include (1) reducing regional center expenditures for transportation, (2) increasing consumers' opportunities for independence by promoting the use of public transportation which allows consumers, not only to participate in their day or work programs, but to engage in community social/recreational activities, and (3) reducing vehicle ride time for some consumers whose residential and/or day programs may begin transporting. Disadvantages of this option include (1) resistance from consumers and service providers who may find these changes very disruptive to established routines, (2) some families being concerned if a new transportation arrangement involved public transportation which they consider unsafe for their family member, and (3) significant impact on some existing transportation providers, especially those that primarily serve consumers.

Estimated Annual General Fund Savings: Indeterminate. Savings generated would depend on what, if any, of the options are adopted. The option mandating competitive bidding would require additional regional center resources.

N. Update the Parental Fee Schedule

The Parental Fee Program applies to parents of children under the age of 18 who live in any out-of-home care arrangement, whether in the community or a developmental center.⁹⁵ Parents are assessed a fee based on a sliding scale that varies by family size and income. The fee is the same regardless of where the child is placed out of home. The Department determines the parents' ability to pay, assesses the fee, and bills the parents monthly until the child turns 18. Revenues produced by this program are deposited in the Program Development Fund and used for developing expanded community resources.⁹⁶

Proposed changes to the schedule require the approval of the State Council on Developmental Disabilities.⁹⁷ The maximum fee may not exceed (1) the cost of caring for a normal child at home, or (2) the cost of services provided, whichever is less. The current Parental Fee was last adjusted in 1989, except for an increase in the maximum fee amount in 2003.

This option would adjust the Parental Fee Schedule in two ways. The first would be to raise the minimum income level upon which to base the fee to the current federal poverty level (FPL). Current FPL is \$17,170 for a family of three.⁹⁸ The current parental fee schedule has the lowest fee based on income of \$12,501. This will reduce the families subject to a fee by about 10 percent. The second change would be to adjust the fee schedule to reflect the most recent (2006) data available from the U.S. Department of Agriculture's survey on the cost of raising a child, adjusted for the CPI from the survey date to present. This would raise the maximum amount billable on families at all levels of income above the FPL and raise the cap from \$662 per month to approximately \$1,812 for the highest income families.

⁹⁵ Wel. & Insti. Code Sec. 4782 and 4784.

⁹⁶ Wel. & Insti. Code Sec. 4677.

⁹⁷ Wel. & Insti. Code Sec. 4677 (c).

⁹⁸ "Annual Update of the Health and Human Services Poverty Guidelines," *Federal Register*, Vol. 73, Number 5, Department of Health and Human Services, January 24, 2007, pp. 3147-3148.

Advantages/Disadvantages: The advantages of this option include (1) ensuring families with resources are reimbursing the state actual costs for which they would otherwise be responsible if their children were living with them, and (2) creating a disincentive for some families who otherwise may place their children out-of-home in costly publicly-funded living arrangements but for the liability of the parental fee. The disadvantages of this option include (1) imposing a significant increase on parents in a single year, and (2) the administrative workload to make these changes. Due to the significant level of increase, consideration should be given to multi-year phase-in of the fee increase.

Estimated Annual General Fund Savings: Indeterminate.

O. Revise the Family Cost Participation Program

The Family Cost Participation Program (FCPP) requires regional centers to assess and impose a share for the cost of respite, day care, and camping services to parents who have a child aged three through 17 living at home and not eligible for Medi-Cal.

Respite, day care, and camps were specifically chosen to be subject to the share-of-cost requirement since these services do not, generally, directly impact the health and safety or development of the consumer.

This program does not involve any fee or payment to the Department or regional center. After the child's IPP is completed, parents of children receiving any of the three services are assessed to determine if they are subject to the FCPP share-of-cost requirements. The family share of cost is based on a sliding scale and ranges from five percent to 80 percent of the cost of services. The family is informed of the number of units of service that will be their financial responsibility to pay directly to the provider. About 5,000 families are in the program and the estimated net annual General Fund cost savings/cost avoidance based on the current program is approximately \$3 million.

This option would modify the existing FCPP by (1) expanding the population of consumers subject to the share of cost by including Early Start consumers (consumers from birth to age three) who are living at home and not on Medi-Cal, (2) modify the

share-of-cost requirement from 5 percent to 10 percent for families earning between 400 and 500 percent of the Federal Poverty Level, and (3) increase the share of cost from 80 to 100 percent at 2,000 percent of the Federal Poverty Level.⁹⁹ There are a range of other options, and combinations of options, that could be considered, e.g., adjusting the share-of-cost percentage schedule, adding additional services, etc.

Advantages/Disadvantages: The advantages of this option include (1) reducing expenditures in the three affected service areas, and (2) requiring those with means to assume a greater share in the cost of services for their children. The disadvantages of this option include (1) potential increase in the placement of children into costly publicly-funded out-of-home living arrangements due to the increased financial and personal stress some families may experience, and (2) may be portrayed as undermining or curtailing the entitlement to the three services for families who have a 100 percent share of cost liability.^{100 101}

Estimated Annual General Fund Savings: This proposal is included in the Governor's Budget and assumed to save approximately \$920,000 in Fiscal Year 2008-09.

P. Apply Means Testing to All Consumers and Services

The only means testing applied to regional center-funded services are in the Family Cost Participation Program (FCPP) and the Parental Fee program. Both programs are described above starting on page 75.

Under this option, all adult consumers and families of minor children would be assessed a share of cost for all regional center-funded services, based on their ability to pay. This option is similar to the option on page 76, **Revise the Family Cost Participation Program**, except for including all adult consumers not on Medi-Cal and regardless of

⁹⁹ "Annual Update of the Health and Human Services Poverty Guidelines," loc. cit.

¹⁰⁰ David A. Cole and Luanna H Meyer, "Impact of Needs and Resources on Family Plans to Seek Out-of-Home Placement," *American Journal on Mental Retardation*, Vol. 93, No. 4, 1989, pp. 380-387.

¹⁰¹ D.A. Bruns, "Leaving Home at an Early Age: Parents' Decisions about Out-of-Home Placement for Young Children With Complex Medical Needs," *Mental Retardation*, Vol. 38, No. 1, February 2000, pp. 50-60.

their living arrangement. Thus, the key elements of this proposal would include (1) subjecting all regional center families with minors living at home who are not on Medi-Cal, and adult consumers (regardless of living arrangement) who are not on Medi-Cal, to a share-of-cost requirement, (2) using a share-of-cost requirement starting at 10 percent for families/consumers earning between 400 and 500 percent of the Federal Poverty Level, and (3) not providing regional center-funded services to any families or consumers whose income is at or above 2,000 percent of the Federal Poverty Level (\$204,200 for a single adult consumer, \$273,800 for a family of two, \$343,400 for a family of three, \$413,000 for a family of four, and so forth).¹⁰²

A maximum of 33 percent, or about 76,000, of the total population would potentially be affected under this option. The remaining consumers (about 147,000) are receiving full-scope or partial Medi-Cal benefits so would be exempted from the assessment based on their low incomes.¹⁰³

Advantages/Disadvantages: The advantages of this option are in (1) reducing program costs, and (2) requiring those with means to share in the cost of services. The disadvantages of this option include (1) potential increase in the placement of children into costly publicly-funded out-of-home living arrangements due to the increased stress some families may experience, (2) may be portrayed as undermining or curtailing the entitlement to services for those with a 100 percent share-of-cost liability, (3) working adult consumers may be less motivated to continue working to the extent their earnings increase their share-of-cost, and (4) the share-of-cost disincentive for purchasing needed services may lead to less favorable developmental and/or health outcomes for affected consumers and increased dependence on publicly-funded health, social, and developmental services in future years.^{104 105 106 107}

¹⁰² "Annual Update of the Health and Human Services Poverty Guidelines," loc. cit.

¹⁰³ Department of Developmental Services, Information Services, Data Extraction, J5351 Medi-Cal Pop by Age (Status 1 and 2 consumers).xls, October 31, 2007. All consumers' Medi-Cal coverage: 64% full-scope, 33% none, 3% partial. Under age 18 Medi-Cal coverage: 47% full-scope, 53% none, 0% partial. Over age 18: 81% full-scope, 14% none, and 5% partial.

¹⁰⁴ Lawrence H. Thompson, "The advantages and disadvantages of different social welfare strategies," *Social Security Bulletin*, Fall 1994, p. 8.

¹⁰⁵ Cole and Meyer, op. cit.

Estimated Annual General Fund Savings: Approximately \$26.0 million, not including any offsetting costs that may occur, as described above.

Q. Decrease Provider Rates

Following three years of rate freezes imposed as temporary cost-containment measures, a 3 percent cost-of-living increase was given to providers of specific program types for which the Department sets the rates (community care facilities, community-based day programs, work activity programs, and respite services) and for specific contracted-services programs (supported living, transportation, and look-alike day programs). These rate increases, effective July 1, 2006, were provided to staunch the erosion of programs' quality and prevent program closures while temporary provider rate freezes are continued for cost containment. This option would reduce regional center provider rates by a specified percentage to achieve cost savings.

Advantages/Disadvantages: The advantage of this option is in reducing program costs and, depending on the degree of reduction, savings could be obtained without curtailing services. With a significant reduction, disadvantages would include (1) diminution of service quality, (2) potential program closures with the resulting disruption of services to consumers and families, (3) a risk of federal sanctions and the attending loss of federal funding depending on the extent to which programs' service quality erodes, and (4) inconsistent with the intent of the Olmstead decision (see Footnote 6, page 5) if a weakened community provider network compromises individuals' opportunities to live in the community.

Estimated Annual General Fund Savings: Indeterminate. The amount of savings would depend on the rate reduction percentage(s), the programs affected, implementation date(s), and offsetting costs. The Governor's Budget assumes a 10 percent rate

¹⁰⁶ Bruns, op. sit.

¹⁰⁷ HeidiL. Strickler, "Interaction Between Family Violence and Mental Retardation," *Mental Retardation*, Vol. 39, No. 6, 2001, pp. 461-471.

reduction to the Supported Employment Program funded by regional centers, saving \$7.74 million General Fund in 2008-09.

R. Limit Regional Center-Funding to Consumers Enrolled in the Waiver

The Home and Community-based Services Waiver (Waiver) is described on pages 28-29. Under this program, the state is reimbursed 50 percent of all qualifying expenditures for services provided to Waiver-eligible consumers. There are about 73,000 consumers currently enrolled in the Waiver, or approximately one-third of the existing regional center population. This option would prohibit regional centers from purchasing services for any new consumers unless they are enrolled in the Waiver, thus ensuring a 50 percent federal share of reimbursement for all regional center purchase of service expenditures for new consumers. This would reduce General Fund expenditures accordingly.

Under this option, regional centers could only pay for services that are federally reimbursable. All consumers would continue to be eligible for intake, assessment, and service coordination; however, services would only be purchased for new consumers who are enrolled in the Waiver unless the consumer (1) is currently receiving regional center-funded services, whether enrolled in the Waiver or not; however, any new services requested must be federally reimbursable, (2) is living in a state developmental center and moves into the community, (3) is under age three, or (4) would have his/her health and safety, or least restrictive living arrangement, directly threatened absent the provision of regional center-funded services.

The total number of individuals receiving regional center-purchased services under this option could not exceed the cap in the approved Waiver, which currently is at 80,000 consumers and increasing annually up to a maximum 95,000 consumers as of October 1, 2010. If the cap were reached in a given year, rules would have to be established to determine who among the individuals waiting for services would receive services.

Advantages/Disadvantages: The advantages of this option include (1) maximizing federal funding, and (2) reducing program growth by limiting services primarily to low income consumers/families. Disadvantages of this option include (1) prospectively narrowing the entitlement to services to consumers who are enrolled on the Waiver only, except for the above-noted exceptions, (2) potential litigation around equity in access and services between existing consumers and new applicants for services, (3) increasing pressure on other publicly-funded health, education and social service programs to fill the service gap, (4) potential litigation if a waiting list for Waiver-eligible consumers has to be established because the Waiver-enrollment cap is reached,¹⁰⁸ and (5) some individuals not having the benefit of regional center-funded services will have less favorable developmental and/or health outcomes leading to increased dependence on publicly-funded health, social, and developmental services in future years.

Estimated Annual General Fund Savings: Approximately \$65.2 million, not including any offsetting costs that may occur, as described above.

S. Cap Enrollment and Establish Waiting Lists

Currently, an applicant for regional center services can receive such services once they are determined eligible and an IPP is developed. This cost-control option would cap or limit the number of new consumers, as determined through the annual budget process, eligible to receive regional center-funded services. All new consumers would continue to be eligible for intake, assessment and service coordination; however, regional center funding for other services would be subject to the availability of funding. Consumers whose services could not be funded due to budgetary constraints would be placed on a waiting list, which is done in some other states. This option would not apply to (1) consumers who are currently receiving regional center-funded services, (2) consumers now living in state developmental centers who move into the community, (3) consumers under age three, and (4) consumers whose health and safety, or least restrictive living

¹⁰⁸ Gary Smith, "Status Report: Litigation Concerning Home and Community Services for Persons with Developmental Disabilities," Human Services Resource Institute, May 29, 2006. This report may be reviewed at the following website link <http://www.hsri.org/docs/litigation052906.pdf>

arrangement, would otherwise be threatened absent the provision of regional center-funded services.

Implementation of this option would require that a risk/needs assessment be made during the IPP development process. Rules would be established to determine who among the individuals waiting for services would receive services. This "order of selection" policy would prioritize funding for services based on the date of application with exceptions for specific situations.

Advantages/Disadvantages: The advantages of this option are (1) the reduction of program and expenditure growth, and (2) the ability to focus limited resources on providing quality services to a smaller number of consumers. Disadvantages of this option include (1) eliminating the entitlement to services, (2) the need to increase regional center and/or Department resources to manage the waiting list process, (3) increasing pressure on other publicly-funded health, education and social service programs to fill the service gap, (4) potential litigation around equity in access and services between existing consumers and new applicants for services, and (5) some individuals not having the benefit of regional center-funded services will have less favorable developmental and/or health outcomes leading to increased dependence on publicly-funded health, social, and developmental services in future years.

Estimated Annual General Fund Savings: Approximately \$31.4 million, not including any offsetting costs that may occur, as described above.

T. Eliminate Early Start Services for "High-risk" Children

The existing Early Start Program serves infants and toddlers who (1) manifest a *developmental delay* in one or more specified areas, (2) have an *established risk* condition of known etiology or conditions with harmful developmental consequences, or (3) are at *high risk* of having substantial developmental disability due to a combination of biomedical risk factors.¹⁰⁹

¹⁰⁹ Government Code Sec. 95014(a).

Federal law requires states participating in the Early Start Program to serve infants and toddlers with developmental delays or those with established risk conditions. Serving children with *high-risk* conditions is optional. This option would be for the state to discontinue serving, prospectively, the high-risk children in its Early Start Program and to reduce expenditures accordingly.

Advantages/Disadvantages: The advantages of this option are (1) reduction of program and budget growth in regional centers, and (2) the ability to focus limited resources on those with more significant needs. Disadvantages of this option include (1) research showing the long-term cost benefits of early intervention services are such that the short-term financial gains from opting out of serving at-risk children would not be cost beneficial to the state, (2) contributions such impacts may have on child abuse rates and the placement of children into publicly-funded out-of-home living arrangements, and (3) the hardship families would experience by not receiving services.¹¹⁰

Estimated Annual General Fund Savings: Approximately \$35.9 million, not including any offsetting costs that may occur, as described above.

U. Establish Specific Criteria for Early Start Eligibility

As noted in the preceding option, the Early Start Program serves infants and toddlers who (1) manifest a *developmental delay* in one or more specified areas, (2) have an *established risk* condition of known etiology or conditions with harmful developmental consequences, or (3) are at *high risk* of having substantial developmental disability due to a combination of biomedical risk factors. General guidance has been provided as to what the established risk and high risk categories may include; however, regional centers retain a significant degree of latitude in the specific criteria they apply in making that determination. Under this option, the Department would establish more specific criteria for Early Start eligibility for the established and high risk categories. It is

¹¹⁰ Diefendorf, Cole, Bruns, Strickler, op. sit.

expected that the overall impact of implementing this criteria would be a reduction in the number of children eligible for regional center services. This would generate General Fund savings by reducing regional centers' need for Operations and Purchase of Service funding.

Advantages/Disadvantages - Advantages of this option include (1) cost savings, (2) making regional center-eligibility practices for Early Start consumers more consistent statewide, and (3) allowing regional center to focus services on those most in need. Disadvantages of this option include (1) excluding from Early Start those infants who, absent early intervention services, will increase demands on local school districts in the preschool programs once the children reach age three, and (2) may negate potential savings because of these children remaining or becoming dependent lifelong on publicly-funded programs and services, e.g., SSI/SSP, AFDC, regional center services, etc., because of not receiving early intervention services.

Estimated Annual General Fund Savings: Approximately \$4.2 million, not including any offsetting costs that may occur, as described above.

V. Eliminate Services to School-age Children

All individuals found eligible for regional center services are assigned to a "service coordinator." The service coordinator has primary responsibility for preparing, implementing, and monitoring consumers' individual program plans, securing and coordinating consumer services and supports, and providing placement and monitoring activities.¹¹¹ The law establishes maximum service coordinator-to-consumer caseload ratios regional centers must observe.¹¹² The specific ratios are determined by an individual's status (i.e., under or over age three, time since placed out of a state developmental center, and enrollment in the Home and Community-based Services). In the current-year budget, about 54 percent, or \$265 million, of the total regional center OPS budget is allocated for service coordinators and related support costs.

¹¹¹Wel. & Insti. Code 4640.6(d).

¹¹²Wel. & Insti. Code 4640.6(c).

Regional centers purchase fewer services for consumers who are attending public schools than those who are not because schools provide and fund the primary day and related transportation services for children. The regional centers' role is limited to providing service coordination and purchasing family support services. Regional centers also purchase developmental, therapeutic and treatment services/programs not otherwise the responsibility of the local education agency or other generic service.

This cost-containment option would eliminate, prospectively, the provision of service coordination and all regional center-funded services to consumers who are three years of age and older until they leave public schools (between 18 and 22 years of age). Exceptions would be made (1) where the child's health and/or safety would be threatened but for the provision of regional center services, including service coordination, (2) for children who are currently in out-of-home living arrangements or for new or existing children who require placement out of home, and (3) where service coordination is necessary for maintaining a child in his or her own home.

Advantages/Disadvantages: The advantages of this option are (1) cost savings, and (2) focusing the provision of services on those most in need, while maintaining a safety net of services based on the above criteria. The disadvantages of this options include (1) reducing the level of support for these consumers and their families will increase pressures on families to place their children out of home; however, the extent to which increased out-of-home placements would occur depends on the effectiveness of the regional centers in identifying and intervening in cases where such placements are likely absent the provision of appropriate services, (2) may negate potential savings because of these children remaining or becoming dependent lifelong on publicly-funded programs and services, e.g., SSI/SSP, AFDC, etc., because of not receiving services during their formative years. This option requires the federal government's review and approval of an amendment to the state's Waiver before implementation could proceed.

Estimated Annual General Fund Savings: Approximately \$320.0 million, not including any offsetting costs that may occur, as described above.

W. Increase Regional Centers' Utilization Review Authority

Apart from their role on the planning team which develops and reviews consumers' IPP and identifies needed services, regional centers are neither required nor authorized to conduct independent utilization reviews of consumers' regional center-funded services. Moreover, since the early 1990s amendments to the Lanterman Developmental Disabilities Services Act have diminished the regional centers' role in identifying, selecting, and reviewing services to be purchased or reauthorized. This option would expand the regional centers' authority and responsibility by requiring them to conduct utilization reviews of each regional center-funded service requested, or to be continued, to ensure all the following:

- The service is appropriate with respect to type, amount, frequency, duration, and effectiveness for the individual and/or family.
- The IPP appropriately documents the service requested.
- Alternative resources, including generic agencies and natural resources,¹¹³ are not available before expending regional center funds.
- The service is consistent with all applicable state and federal laws.

Advantages/Disadvantages: Advantages of this option include (1) reducing program costs, and (2) providing greater consistency and equity in services authorized.

Disadvantages of this option include (1) increasing regional centers' authority on the planning team, relative to other members, may not be viewed favorably by many consumers and families, (2) may be portrayed as undermining or curtailing the entitlement to services, and (3) shifting to a more "professionally-driven" and less

¹¹³ "Natural supports", as defined in Wel. & Insti. Code 4512(e), means personal associations and relationships typically developed in the community that enhance the quality and security of life for people, including, but not limited to, family relationships, friendships reflecting the diversity of the neighborhood and the community, associations with fellow students or employees in regular classrooms and workplaces, and associations developed through participation in clubs, organizations, and other civic activities.

consumer/family-focused needs determination process is inconsistent with national trends for service planning.

Estimated Annual General Fund Savings: Indeterminate.

Long-term Options that Improve Service Outcomes

A. Increase Employment Opportunities for Consumers

Working age people with disabilities are among the most unemployed and underemployed segments of our society. The vast majority of these individuals can work and want to work.¹¹⁴ At 18 percent, California ranks 34th in the percentage of consumers in supportive or competitive employment when compared to other states.¹¹⁵ The state Employment Development Department data below show the number of regional center consumers who had earned income, and the amount of earned income, during calendar year 2006.¹¹⁶ Based on this wage data, about 15.8 percent of the 111,381 regional center consumers over age 18 received earned income.¹¹⁷ The income earnings for two-thirds of the consumers averaged about \$121 per month.

2006 Annual Earnings	Number of Consumers	Total Annual Earnings	Average Annual Per Capita Earnings
\$0 – 99	986	\$51,401.69	\$52.
\$100 – 499.99	2,985	843,825.47	283.
\$500 – 999.99	2,039	1,465,888.46	719.
\$1,000 – 1,999.99	2,297	3,313,959.70	1,443.
\$2,000 – 2,999.99	1,421	3,516,041.72	2,474.
\$3,000 – 3,999.99	1,123	3,903,359.71	3,476.

¹¹⁴ The ARC, AAIDD, AUCD, UCP and NACDD, "Policy Seminar Fact Sheet - Employment," 2007, <http://www.thearc.org/NetCommunity/Page.aspx?&pid=367&srcid=217> (December 7, 2007).

¹¹⁵ Tarren Bragdon, "The Case for Inclusion: An Analysis of Medicaid for Americans with Intellectual and Developmental Disabilities," United Cerebral Palsy Association, 2007, p. 8.

¹¹⁶ California Employment Development Department, Employer Unemployment Insurance Wage Reporting Data, 2006.

¹¹⁷ 17,623 consumers divided by the number of consumers over age 18. Source for the number of consumers over 18 is the Department of Developmental Services, Information Services Division, Data Extraction Unit, J5235, July 31, 2007.

\$4,000 – 4,999.99	887	3,999,819.94	4,509.
> \$5,000	5,885	67,980,192.65	11,551
Total	17,623	\$85,074,489.34	\$4,824.

Both the mandated¹¹⁸ State Council on Developmental Disabilities' recent "Report to the Legislature and Governor on Employment" and the "California Governor's Committee on Employment of People with Disabilities' Comprehensive Strategy" identified a lack of public awareness about the benefits of employing youths and adults with developmental disabilities as a barrier to employment. Both also identified lack of knowledge on the part of regional centers, family members, and individuals of the complexities of public benefit work incentives. Often people with developmental disabilities do not seek out employment because they and their families do not know the impact of paid work on the individuals' benefits. Given adequate and accurate benefits-planning services, an individual who is gainfully employed can maintain critical aspects of benefits (such as maintaining SSI eligibility up to an income of nearly \$33,000 per year), increase his or her income and benefits, and expand options for socialization and community participation.

Under this option, regional centers would be required to assess all their adult consumers for employment and would link them to appropriate resources to secure work opportunities, including state employment.

Advantages/Disadvantages: The advantages of this option include (1) increasing employment opportunities for consumers, (2) long-term cost savings associated with individuals participating in supported employment, (3) increasing consumers' income, resulting in reducing consumers' reliance on publicly-funded benefits and services while increasing tax revenues, and (4) expanding the labor pool for employers.^{119 120} The

¹¹⁸ Chapter 397, Statutes of 2006 (Senate Bill 1270).

¹¹⁹ Derek E. Hemenway, M.S. and Faranak Rohani, Ph.D., "A Cost-Benefit Analysis of the Employment of People with Disabilities in Florida: Final Report," Report prepared for The Able Trust, Assessment & Evaluation, The Educational Services Program, Florida State University, December 1999, p. 5.

¹²⁰ Frank R. Rusch, "Benefit-cost analysis of supported employment in Illinois," *Journal of Rehabilitation*, May – June 1993.

disadvantage of this option is the need for limited resources required for implementation.

Estimated Annual General Fund Savings: Indeterminate. Net savings would vary depending on (1) the extent to which consumers choose to participate in supported employment, (2) availability of employment opportunities, (3) the years a consumer remains employed (the longer the more cost-beneficial), (4) extent of support required by the consumer, and (5) expenditures for consumers' existing services and supports.

B. Expand Availability of Affordable and Accessible Housing

Housing demand for persons with developmental disabilities in California will continue to increase as caregivers age and become unable to care for their disabled children (see page 18, **Budget Expenditure History and Current Pressures**, where this trend is described.

Currently, rates for licensed residential facilities include mortgage, lease, and/or rent costs. The regional center contributes a portion of the property costs through the rate, and the consumer contributes a much smaller portion through their monthly SSI/SSP. Because the housing is privately owned by a service provider, the public tax dollar investment is never recouped by the state. The property is "bought" repeatedly through the rate paid to the service provider.

This option is for the state to change the current financing structure of community housing for individuals with developmental disabilities to a "buy-it-once" strategy that will generate long-term savings. Under this option, public housing bond funds could be used for property acquisition and, when the property is paid off, the investment of public funds for housing through the facility rate would cease. The asset investment into the property is then available to leverage the acquisition of additional properties, or to create deeply subsidized rental housing. Under this housing model, which is similar to that being used in the Agnews Developmental Center closure and which would be

expanded statewide, the provision of service is separated from ownership of the housing; thus, a consumer does not have to move if the provider is changed.

Advantages/Disadvantages: Advantages of this option include (1) increasing the availability of affordable housing for consumers to meet future demand, (2) creating an affordable housing stock that will be available to consumers in perpetuity, (3) long-term cost savings to the state associated with consumer housing, (4) maintaining stability in consumers' living arrangements whenever a service provider is unable or unwilling to continue providing services, and (5) promoting the intent of the Olmstead decision (see Footnote 6, page 5). The disadvantage of this option is the need for initial resources and the impact on providers who would no longer own the property.

Estimated Annual General Fund Savings: Indeterminate

C. Leverage Developmental Center Land to Expand Housing for Consumers Living in the Community

As previously noted, there is an increasing need for affordable housing for consumers who are able and interested in living in their own homes or apartments. Such housing is more cost effective than receiving services in staff-operated, 24-hour licensed residential living arrangements. Affordable housing units are in short supply and often rely on subsidies, such as Housing and Urban Development (HUD) Section 8 vouchers. Unfortunately, it is not uncommon for HUD to have literally thousands of applicants for a few hundred allocated vouchers. Because of consumers' physical and medical needs, extensive modifications to existing units are often required to meet regulatory standards and/or attain successful living arrangements. Landlords of rental units are usually reluctant and often refuse to modify their units because of the impact on future marketability of their property.

This cost-containment option involves utilizing in other appropriate locations, a long-term lease development model used with Harbor Village at Fairview Developmental Center. Under this model, existing surplus state land is leveraged to develop consumer

housing in a community setting. The Harbor Village development was done through a long-term (55 years) ground lease, at no cost to the state. In replicating this model, the state would partner with a developer/investor to construct a residential community complex on state property. The developer/investor provides development and construction capital and ongoing management resources for the project while the state provides management oversight and the land assets on which the project is established. Upon expiration of the land lease, as is the case with Harbor Village, the state takes full ownership of the entire community complex.

The land is retained by the state and leased to the investors who develop the project. The developer collects payments from the market-rate homes (non consumer) during the time of the lease with the state. The state would use the value of the lease payments to subsidize rents and to make them accessible for prospective residents. The Harbor Village prototype has more than 550 such units, 120 of which are subsidized and used for consumers.

The Department of General Services has the authority to assist other state departments in accessing surplus land for the purpose of developing affordable housing. This cost-containment option could also authorize the Department to use other departments' surplus land to produce affordable housing for consumers statewide. The land would be made available to develop the housing that includes units restricted for consumers which will reduce long-term General Fund expenditures for consumers' living arrangements.

Advantages/Disadvantages: Advantages of this option include (1) increasing the availability of affordable housing for consumers to meet future demand, (2) creating an affordable housing stock that will be available to consumers in perpetuity, (3) maintaining stability in consumers' living arrangements whenever a service provider is unable or unwilling to continue providing services, (4) long-term cost savings to the state associated with consumer housing and significant appreciation of state assets, and (5) promoting the intent of the Olmstead decision (see Footnote 6, page 5). The

disadvantage of this option is the required commitment of state land for this purpose, the elimination of park-like areas surrounding the developmental centers, and the loss of immediate General Fund revenue from the sale of the property. (Note: The loss would be fully mitigated over the life of the project.)

Estimated Annual General Fund Savings: Indeterminate.

D. Expand Access to Preventative Medical and Dental Services

In his letter transmitting the National Institutes of Health 2002 "Blueprint to Improve the Health of Persons with Mental Retardation," the Secretary of Health and Human Services observed that *"Americans with mental retardation, and their families, face enormous obstacles in seeking the kind of basic health care that many of us take for granted . . . Individuals with mental retardation are more likely to receive inappropriate and inadequate treatment, or be denied health care altogether. Children, youth, and adults with mental retardation receive fewer routine health examinations, fewer immunizations, less mental health care, less prophylactic oral health care . . ."*¹²¹

There are many reasons people with cognitive disabilities face unique challenges to accessing health and dental care. Some of these reasons include (1) having only a limited number of practitioners who are adequately trained to work with this population, (2) most primary care providers serve a small number of patients with disabilities and, they may not develop adequate expertise in working with them, (3) providers being reluctant to work with persons with disabilities because their conditions are more complex compared to the general population and often involve multiple disorders requiring multiple medications, and (4) the physical location and services available from community clinics are often inaccessible to adults who also have mobility or sensory impairments.^{122 123}

¹²¹ National Institutes of Health, "Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental retardation," *Report of the Surgeon General's Conference on Health Disparities and Mental Retardation*, 2002.

¹²² Susan L. Parish and Alison Whisnant Saville, "Women With Cognitive Limitations Living in the Community: Evidence of Disability-Based Disparities in Health Care," *Mental Retardation*, Vol. 44, No. 4, August 2006, p.250.

Researchers have found that good oral health is linked to overall physical health and well being. Infants, toddlers, children, and adults with developmental disabilities are at high risk of poor oral health because of the type and frequency of medication use, their need for sedation for routine procedures, complex co-occurring health conditions, and a shortage of trained dental practitioners. As a result, consumers have many challenges in maintaining their oral health and, with their high incidence of dental problems, often suffer pain and discomfort. Research indicates that *"The population with disabilities has significantly higher rates of poor oral hygiene, gingivitis, and periodontitis than do members of the general population. There is a wide range of caries (tooth decay) rates among people with disabilities; but, overall, their rate is significantly higher than that of the general population."*¹²⁴ Untreated dental conditions may also lead to other costly sequelae such as systemic infections, cardiac disease, etc. Dentists usually accept only a limited number of patients with developmental disabilities since these consumers require additional time for common procedures and most dentists lack the training and familiarity with the unique treatment needs of consumers. The result is that Californians with developmental disabilities are often unable to access timely dental services, or may go without needed care, further compromising these consumers' oral health.

This option in the oral health area would be to reduce long-term General Fund costs by expanding upon a model of community-based oral health care that was originally piloted by several regional centers in fiscal year 1999-2000. This model relies on licensed dental hygienists (dental coordinators) to act as liaisons with community oral health professionals to identify and develop resources and to match the needs of the consumers with potential dental providers and clinics. Net cost savings would result by avoiding the high costs for restorative, surgical, and hospital-based dental treatment that otherwise will be required by the affected consumers.

¹²³ H. Barry Waldman and Steven P. Perlman, "Providing Dental Services for People with Disabilities: Why Is It So Difficult?" *Mental Retardation*, Vol. 40, No. 4, August 2002, pp. 330-333.

¹²⁴ H. Barry Waldman, Steven P. Perlman, and Mark Swerdloff, "Children with Mental Retardation/Developmental Disabilities: Do Physicians Ever Consider Needed Dental Care?" *Mental Retardation*, Vol. 39, No. 1, February 2001, pp. 53-55.

The following are some basic medical screening and prevention activities relevant to persons with disabilities:

- Routine physical exams
- Immunizations
- Preconception and prenatal care
- Cancer screening (Pap smears, mammography, sigmoidoscopy)
- Cardiovascular disease screening (blood pressure, cholesterol, smoking cessation, aspirin prophylaxis)
- Infectious disease screening (HIV, chlamydia)
- Other screening (hearing, vision)
- Disease management programs (obesity, diabetes, osteoporosis)
- Lifestyle and safety programs (diet, exercise, seat belts, bike helmets)

Limited resources prevent regional centers from engaging in the systematic planning and implementation efforts required to ensure all consumers have access to and benefit from these preventative services. To ensure consumers have access to preventative care the state could implement preventative health care measures such as (1) assisting in the recruitment of new physicians to care for persons with developmental disabilities, (2) assisting with the referral process to access appropriate health care providers, (3) following up with the individual and/or their care provider to insure appropriate services were provided, (4) acting as a liaison between the regional center, physician and/or managed care plan, (5) developing an inventory of local and regional health care services, and (6) providing consultation to service coordinators, providers, and consumers/families on identifying, accessing and funding health care services.

Advantages/Disadvantages: Advantages of this option include (1) increasing consumers' physical and dental health, and (2) long-term cost savings by avoiding the high medical and dental costs that otherwise result from a lack of preventative care.¹²⁵

¹²⁵ Mark L. Messonnier, Ph.D., et al., "An Ounce of Prevention . . . What Are the Returns?, Second Edition," *American Journal of Preventive Medicine*, Vol. 16, No. 3, 1999, pp. 248-263.

The disadvantage of this option is the need for resources to initiate the prevention efforts.

Estimated Annual General Fund Savings: Indeterminate.

E. Maximize Generic Resources

Existing law mandates that regional centers pursue services from alternative public and private sources, especially publicly funded or "generic" resources such as Medi-Cal.¹²⁶ However, there is often significant difficulty in accessing these other resources forcing the regional center to fund the service which would otherwise be provided by another agency. This shift can result in higher costs to the State due to lower federal or county matching ratios or higher rates for service. For example, in medical and dental service areas consumers having Medi-Cal should have all their basic medical needs met through the public insurance program. However, practitioners are often reluctant to serve consumers on Medi-Cal. The need is especially acute in medical specialty areas and for sedation dentistry which consumers often require. Thus, if consumers cannot obtain the service from such practitioners, or if the service cannot be provided in a timely manner, the regional center is obligated to fund the service pursuant to the IPP, often at a higher cost. Or in the case of the In-Home Supportive Services (IHSS) Program, the regional center may purchase support services pending the county's needs assessment or provider approval. Since IHSS costs are shared by the counties and regional center costs are not, more state resources are required.

This option would provide for (1) strengthening the requirements for publicly-funded agencies to serve persons with developmental disabilities, regardless of their degree of disability, consistent with the requirements of the public agency's mandate, and (2) having administrative law judges, employed by the Office of Administrative Hearings (Department of General Services), serve as impartial arbiters in inter-departmental disputes affecting regional center consumers. These judges would need the statutory authority to render decisions affecting multiple agencies. Under this option, local

¹²⁶ Wel. & Insti. Code Sec. 4659.

education agencies and Health and Human Service Agency departments would all be bound by decisions involving regional center consumer service disputes.

Advantages/Disadvantages: Advantages of this option include (1) reducing costly interagency disputes, (2) sparing families the costs and time required for multiple hearings, (3) providing children more timely services to address their health, developmental and/or educational needs, and (4) cost savings associated with reduced costs for generic resources and increased cost sharing with non-state entities. A disadvantage of this option is the additional costs generic agencies would experience for serving regional center consumers and the possible impact to the consumers if the current service providers are not covered by the generic resource.

Estimated Annual General Fund Savings: Indeterminate.

V. CONCLUSION

Since establishing the first two regional centers in 1966, California has made significant progress in developing its community-based system of services and supports for persons with developmental disabilities. The success of this system is reflected in the availability of regional center-funded services and supports for every California resident with developmental disabilities. This success also is demonstrated in the state's reduced reliance on large state-operated residential facilities. California now has fewer people residing in large institutions per capita than 31 other states.¹²⁷ This progress, however, has not been without its many challenges. Among the greatest of these challenges has been the State's fiscal crises which are evident when reviewing the prior years' cost-containment proposals which extend back as far as fiscal year 1982-83.

¹²⁷K. Charlie Lakin, Kathryn Alba, and Robert W. Prouty, "Status and Changes in State Residential Services," In R.W. Prouty, Gary Smith & K.C. Lakin (Eds.), *Residential services for persons with developmental disabilities: Status and trends through 2006*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. August 2007, pp. 9-10.

Reducing state General Fund expenditures in the developmental services system requires (1) narrowing the eligibility requirements for regional center-services, (2) reducing or eliminating services, (3) decreasing provider rates, (4) revising cost-sharing policies for beneficiaries, (5) altering existing, or creating new, models of service delivery and financing, (6) reducing consumers' dependence on regional center-funded services and supports, and/or (7) re-engineering existing business practices. This report provides options for each of these expenditure reduction approaches.

Key issues for consideration when deliberating methods for Regional Center expenditures include:

- About 82 percent of regional center expenditures are for services to 25 percent of consumers. These consumers are among the most medically and physically vulnerable state residents and they depend on state funding to maintain their health, safety, and well-being. Also, regional center expenditures for out-of-home living arrangements (supported living, community care facilities, etc.) constitute the centers single largest area of expenditure.
- Total regional center expenditures have grown in the past decade, from \$1.17 billion in fiscal year 1997-98 to an estimated \$3.6 billion in the current year. Meanwhile, the number of consumers during this time has grown from 141,534 to an estimated 230,000.
- The numerous factors that potentially impact regional center expenditures, many of which involve the existing or base regional center population, including (1) developmental center residents moving into the community, (2) transfer of the Department of Rehabilitation's Habilitation Services Program to the Department of Developmental Services, (3) legislative budget augmentations for rate increases and minimum wage adjustments, (4) increase in consumers with autism spectrum disorders, (5) increase in consumers with dual diagnoses (developmental disability and mental disability), (6) erosion of generic service options, e.g., availability of clinicians willing to serve consumers on Medi-Cal, (7) aging parents who are no longer able to care for their family member at home, (8) consumers' increasing

longevity, (9) program and service enhancements to meet minimum federal quality of care requirements, and (10) consumers transitioning from public-school-funded programs to regional center-funded programs after local educational agencies are no longer statutorily required to provide services.

- The U. S. Supreme Court Olmstead decision which requires states ". . . to place persons with mental disabilities in community settings rather than institutions . . ." ¹²⁸ because they potentially compromise the state's community-based system of services. The same is true with respect to the Lanterman Developmental Disabilities Services Act which sets forth the right of consumers to receive ". . . treatment and habilitation services and supports in the least restrictive environment . . ." and promotes ". . . opportunities for individuals with developmental disabilities to be integrated into the mainstream of life in their home communities." ¹²⁹
- Some options may increase cost pressures in other state and local health and human service agencies, and may lead to increasing numbers of consumers being placed in costly state developmental centers or other publicly-funded out-of-home living arrangements.
- The past 25 years of proposed or adopted cost-control options should be reviewed for their value in helping to formulate future proposals.
- Many existing cost-control options will sunset at the end of the current fiscal year, unless extended. The Governor's Budget for 2008-09 removes the sunset provisions.
- Though each of these options stands alone, they are not mutually exclusive in that implementation of one option may affect other options selected. Thus, potential interaction between options must be considered.

There are no simple solutions for reducing regional center expenditures. However, it is critical that discussions about cost containment are informed by an understanding of the existing system so that fiscally responsible decisions can be made while ensuring quality services for consumers and their families.

¹²⁸ OLMSTEAD V. L. C. (98-536) 527 U.S. 581 (1999), 138 F.3d 893.

¹²⁹ Wel. & Insti. Code Sec. 4501 and 4502(a).