

# **INFORMATION BRIEF**

## **UNIQUE FACTORS IMPACTING REGIONAL CENTERS' BUDGET GROWTH**



**Prepared by the  
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## UNIQUE FACTORS IMPACTING REGIONAL CENTERS' BUDGET GROWTH

The State of California funds community-based services for people with developmental disabilities<sup>1</sup> through 21 nonprofit corporations known as “regional centers.” Established in the late 1960s, the first two pilot regional centers provided a more cost effective and progressive service delivery alternative to the burgeoning state developmental centers. In recent years, the developmental-services system has faced increased scrutiny and criticism because of the growth in its budget, which is generally greater than the budget growth of other state-funded health and human services programs. This information brief describes some of the dynamics and unique characteristics of the developmental-services system that account for much of this budget growth.

Understanding the unique factors driving this system’s growth provides policy makers a crucial perspective necessary for making sound budget decisions. Lacking such information, some have concluded that the developmental-service system’s budget is “out of control” and in need of increasingly more rigid budget controls. National comparative expenditure data belie such assertions, however. For example, national metrics to gauge spending reveal that California: (1) ranks well below average, or 35<sup>th</sup>, when compared to other states in its “fiscal effort”<sup>2</sup> in total community spending for developmental services;<sup>3</sup> (2) ranks 43<sup>rd</sup> in its Home and Community-Based Services waiver (Waiver) funding per citizen of the general population;<sup>4</sup> (3) expends 31 percent less than the national average for supported-living and personal-assistance programs per citizen of the general population,<sup>5</sup> had an inflation-adjusted budget growth rate during 2004 to 2006 of about two-thirds of the national average growth rate;<sup>6</sup> and (4) expends only 72 percent of the national average for supported-employment programs per citizen of the general population.<sup>7</sup> The two developmental-services areas where California does exceed the national average in public spending include: (1) family support,<sup>8</sup> where the state ranks 21<sup>st</sup>, and (2) average daily spending per person in state-operated institutions, where the state expends 36 percent more than the national average.<sup>9</sup>

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<sup>1</sup> Wel. & Insti. Code §4512(a) "Developmental disability" means a disability that originates before an individual attains age 18 years, continues, or can be expected to continue, indefinitely, and constitutes a substantial disability for that individual . . . this term shall include mental retardation, cerebral palsy, epilepsy, and autism. This term shall also include disabling conditions found to be closely related to mental retardation or to require treatment similar to that required for individuals with mental retardation, but shall not include other handicapping conditions that are solely physical in nature.

<sup>2</sup> "Fiscal effort" is spending for developmental services per \$1,000 of aggregate statewide personal income.

<sup>3</sup> David L. Braddock, Richard E. Hemp, and Mary C. Rizzolo, "The State of the States in Developmental Disabilities," Department of Psychiatry, CU Denver School of Medicine, Coleman Institute for Cognitive Disabilities, University of Colorado, 2008, p. 59.

<sup>4</sup> Ibid., p. 26.

<sup>5</sup> Ibid., p. 37.

<sup>6</sup> Ibid., p. 8.

<sup>7</sup> Ibid., p. 41.

<sup>8</sup> "Family support" services (respite care, behavior management services, architectural adaption of the home, etc.), are designed to keep families from placing their relatives in out-of-home residential settings.

<sup>9</sup> Ibid., p. 55.

The following eight factors, many unique to the developmental-services system, account for much of the budget growth that does occur in the system:

1. Aging of Consumers and Parents

The definition for regional-center eligibility requires that the disabling condition originate before an individual attains age 18 and that the condition continue, or be expected to continue, indefinitely. This means that virtually all regional-center consumers (except for those in the Early Start Program, which serves children ages birth to three under a different eligibility definition) will be regional-center clients their entire lives. This fact has significant budgetary implications since there is a direct correlation between a consumer's age and regional-center expenditures. This phenomenon of aging consumers impacts expenditure growth in three primary ways.

**First**, the demand for regional-center-funded services is relatively limited for school-age children whose key programming needs are met by local education agencies. When these children leave school or graduate, however, responsibility for their services and funding shifts primarily to the regional centers. Nearly all of these individuals will require day/vocational programming, transportation, and related services. Moreover, many will begin moving from their parents' homes and require significant regional-center funding to support them in alternative living arrangements.

**Second**, as consumers' parents age, health and other age-related issues make it increasingly difficult for them to maintain their adult children in the home absent increasing regional-center-funded support. When these parents age beyond their care-giving capacity or pass away, regional centers usually become responsible for funding the consumers' alternative living arrangement. The number of consumers currently living with caregivers over age 60 is estimated to be about 77,000.<sup>10</sup> This phenomenon of aging caregivers is increasing the demand for regional-center-funded services, with a corresponding increase in expenditures.

**Third**, consumer longevity and neonatal survival rates have had a significant impact on increasing consumers' life spans; as a result, the length of time services will be provided and the type and intensity of the services increase, as well. Braddock, et al., observes: *"As persons with developmental disabilities live longer, they require services and support for longer periods of time. This directly impacts the finite capacities of state service delivery systems. The increased life expectancy of persons with developmental disabilities since 1970 accounts for a significant percentage of the increased demand for residential services in the states today. The likelihood of older persons with developmental disabilities living into their own retirement and outliving their family caregivers has increased substantially in recent years. This has stimulated a growing demand for additional services and supports. The need to provide these services is*

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<sup>10</sup> Ibid., p. 62.

*frequently unanticipated by federal, state, and local agencies, often resulting in a crisis situation . . .*<sup>11</sup>

Expenditure data confirm the impact of aging on the demand for services in California. In Fiscal Year 2007-08, the average annual purchase of service (POS) expenditure for consumers age 3 to 21 was \$6,703, while the average annual POS expenditure for consumers age 22 and above was \$20,192, or about three times as much. The net annual growth in the number of consumers served by the regional center has averaged slightly more than 5 percent per year over the past two decades. If all growth is ignored, the caseload remains constant, and the average POS expenditure for the two age groups remains the same, total POS expenditures will increase an average of \$90.9 million, or 3 percent, per year.<sup>12</sup> This growth is due entirely to the natural aging of consumers.

## 2. Growth in the Number of Consumers Served

As noted above, the net annual growth in the number of consumers served by regional centers has averaged slightly more than 5 percent per year over the past 20 years. The average state general population growth during this same period has averaged about 3 percent, or 67 percent less than the growth experienced by regional centers. A study commissioned by the Department of Developmental Services (DDS) concluded that 43 percent of POS budget growth since fiscal year 2000-01 to fiscal year 2007-08 is due to services for new consumers.<sup>13</sup> Though the regional-center caseload is growing at a rate faster than the general population, based on a conservative estimate of the prevalence of developmental disabilities in the general population (1.49 percent), regional centers are serving only about half of those in the state who would potentially qualify for services.<sup>14</sup>

## 3. Growth in the Number of Consumers with Autism

From December 2002 to December 2007 the number of consumers with autism increased by an average of 12.7 percent per year. This is more than triple the 3.4 percent average growth rate of all consumers during the same time period. In December 2002, only 12.4 percent of the consumers served by regional centers had a diagnosis of autism. By December 2007, the percentage had grown to 19.1 percent. Since 1987, there has been a twelve-fold increase in the number of individuals with autism served by regional centers; and, as reported by the DDS for the period from 1990 through 2000, “. . . *the number of persons with autism being served by regional centers rose 26 times faster than that of the general California population.*”<sup>15</sup>

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<sup>11</sup> Braddock, op. cit., pp. 62-63.

<sup>12</sup> “Growth in Purchase of Service Expenditures Due to Aging of Consumers,” Association of Regional Center Agencies, April 21, 2009.

<sup>13</sup> “Controlling Regional Center Costs,” California Department of Developmental Services, December 2007, p. 21.

<sup>14</sup> Sheryl A. Larson, et al., “Prevalence of Mental Retardation and Developmental Disabilities: Estimates from the 1994/1995 National Health Interview Survey Disability Supplements,” *American Journal on Mental Retardation*, Vol. 106, No. 3, 2001, p. 231.

<sup>15</sup> Andrew T. Cavagnaro, Ph.D., “Autistic Spectrum Disorders – Changes in the California Caseload – An Update: June 1987 – June 2007,” Department of Developmental Services, Sacramento, 2009, p. 9.

In all age cohorts, average annual POS expenditures for consumers with autism are higher than the average POS expenditures for consumers without autism. The following chart shows comparative fiscal year 2006-07 expenditures:

<b>AVERAGE REGIONAL CENTER EXPENDITURE PER CONSUMER<sup>16</sup></b>				
<b>Age Group</b>	<b>With Autism</b>	<b>Without Autism</b>	<b>\$ Difference</b>	<b>% Difference</b>
3 to 21	\$10,878	\$7,078	\$3,799	53.7
22 to 41	\$33,007	\$19,618	\$13,390	68.3
42 to 61	\$39,526	\$22,695	\$16,831	74.2
62 and Older	\$42,034	\$23,179	\$18,855	81.3

The DDS notes: *“Autism continues to be the fastest growing developmental disability in California . . .”* and *“Based on current projections, regional centers and developmental centers will be serving more than 50,000 people with ASD by September 2009. If the trend continues, DDS may serve as many as 70,000 people with ASD by June 2012. The biggest population boom is concentrated in young people . . . As the median age of this population decreased, the duration of service increases because state law mandates that services be provided for life for anyone who is eligible. A significant issue for this population is the increasing need for out-of-home residential services as these children reach late adolescence.”<sup>17</sup>* The report by the California Legislative Blue Ribbon Commission on autism spectrum disorders characterizes this dramatic and sustained rise in this disability as a “public health crisis” that is now affecting one in every 150 children.<sup>18</sup> Regional centers find themselves on the front line of this public health crisis, which has major budgetary and programmatic implications.

4. Placement of Consumers from State Developmental Centers

Regional centers were established to develop local community-based service systems as an alternative to costly state-operated institutions. A 1969 report to the Legislature about the first two pilot regional centers observed that *“Over the years, approximately 2,000 to 3,000 California families at the point where they were no longer able to care for their retarded member applied annually for services from one of the four State hospitals for the mentally retarded. Until 1965, the State hospital and post-hospital leave programs were the only alternatives open to families, whether or not hospital care was needed by the individual or desired by his family. During the 1965 legislative session, the Regional Center program was established to answer the pleas of families who were eager to keep*

<sup>16</sup> “Fact Book – Eleventh Edition,” California Department of Developmental Services, Information Services Division, Sacramento, October 2008, p. 28.

<sup>17</sup> Cavagnaro, op. cit., p. 1-2.

<sup>18</sup> “An Opportunity to Achieve Real Change for Californians with Autism Spectrum Disorders,” The California Legislative Blue Ribbon Commission on Autism Report, September 2007, pp. 7- 8.

*their mentally retarded family member home and/or in the community.*<sup>19</sup> Thus, from their inception, a primary regional-center function has been to deflect individuals from placement in state developmental centers (previously called “state hospitals”) and to transition those living in state developmental centers into the community. These deflection and placement activities are accomplished through the regional centers’ service coordination, referral, training, funding, crisis intervention, program development, and other related activities.

Regional centers’ placement efforts were amplified beginning in the mid-1990s with the filing of a class-action lawsuit by Protection and Advocacy, Inc., against DDS and other named plaintiffs, including regional centers. This suit culminated in the “Coffelt Settlement Agreement,” which required, among other actions, that regional centers place at least 2,000 people from the state developmental centers into the community over a five-year period, at a projected cost of \$334 million.<sup>20</sup> Disabilities Rights California (formerly Protection and Advocacy, Inc.) filed another class-action lawsuit in January 2002 that was settled in April 2009. This three-year settlement agreement involves approximately 2,300 regional-center consumers who live in developmental centers and 4,500 consumers who live in other large congregate institutions housing 16 or more in the community. Through a variety of requirements, the settlement seeks to promote the transition of individuals from large public and private residential facilities to more homelike community-living arrangements. The intent of these two settlement agreements is not inconsistent with federal policies that promote community-based alternatives and with a landmark June 1999 U.S. Supreme Court decision, *L.C. & E.W. vs. Olmstead (“Olmstead”)*, in which the Court ruled that keeping persons who could live in the community in institutional settings constituted discrimination under the Americans with Disabilities Act.

Data show that approximately 24 percent of the regional center POS budget growth since fiscal year 2000-01 is attributable to consumers’ moving from state developmental centers to the community.<sup>21</sup> In fiscal year 2007-08, the average POS expenditure for a consumer who had moved out of a developmental center since July 1992 was \$60,068,<sup>22</sup> compared to an overall average POS expenditure of \$13,350<sup>23</sup> for other consumers. Though this important regional-center function contributes to a higher budget-growth trend, regional centers’ success in placing and keeping people in the community more than offsets the budget growth that would otherwise be experienced by the state if these individuals were placed into and/or remained in more costly state developmental-center settings.

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<sup>19</sup> “Regional Centers for the Mentally Retarded – the First Two Years,” State of California, Department of Public Health, Bureau of Mental Retardation Services, June 1969, foreword.

<sup>20</sup> “Summary of Settlement Agreement: Coffelt, et al., v. DDS, et al.,” Protection and Advocacy, Inc., not dated, p. 1 summary.

<sup>21</sup> “Components Contributing to Expenditure Growth – 2001-00 to 2007-08,” Department of Developmental Services, Budget Analysis, presented to the California Senate Budget Subcommittee #3 during a May 7, 2007 hearing.

<sup>22</sup> “DC Mover POS in FY 07/08,” Department of Developmental Services, Data Extraction, J6062 Movers FY 08 POS and 9293-0708 Counts (2).xls, January 22, 2009.

<sup>23</sup> “Calculation of Per Capita Costs – FY 2007-08,” Association of Regional Center Agencies, May 13, 2009.

The regional-center “experiment” has been very successful, as evidenced by the steady decline in the number of individuals living in institutions and the closure of three large state developmental centers since the mid-1990s. In 1968, there were 13,355<sup>24</sup> individuals living in state developmental centers, and a legislative committee reported “...that thousands of children are on waiting lists for State hospitals...” Today the developmental centers serve only 2,301 individuals,<sup>25</sup> despite the state’s general population increase from 19.4 million in 1968 to about 38 million in 2009.<sup>26</sup> Thus, since the establishment of the first regional centers, the number of individuals in California residing in developmental centers has been reduced from one in 1,455 of the general population to one in 16,515 today. However, the costs of placing and maintaining individuals with medical and/or behavioral characteristics in the community are significant, albeit much less than serving these same individuals in state developmental centers.

5. Work Habilitation Program Transfer

Effective July 1, 2004, the Habilitation Services Program and associated funding were transferred to the DDS from the Department of Rehabilitation. At the time, this action increased DDS’s base budget by \$123.5 million. In addition to increasing the base budget, the HSP transfer accounted for 47 percent of the growth in the year of the transfer. An analysis of the regional centers’ budget growth must account for this significant program transfer or actual budget growth will be exaggerated.

6. Loss of “Generic” Resources

Developmentally disabled individuals depend on many other health and human services programs to meet their needs. However, the role of regional centers is such that regional centers usually become the “provider of last resort” when a public or private agency ceases providing a needed service. Some of these key agencies or programs upon which consumers rely include local education agencies, county mental health, Medi-Cal, In-Home Supportive Services, social services, etc. Many of these programs have sustained significant rate and budget reductions in recent years, and pressure for regional centers to fund the services that have been terminated or reduced has increased. For example, due to rate issues, there is an insufficient pool of qualified clinical and healthcare providers who will accept Medi-Cal for payment; however, 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 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. Regional centers report that they are increasingly being identified as the responsible party in interagency disputes regarding responsible for funding costly services

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<sup>24</sup> “Resident Population – State hospitals (DD Population only),” Department of Developmental Services, DC History Chart 1946 to present DD[1].

<sup>25</sup> <http://www.dds.ca.gov/DevCtrs/AllFacPop.cfm>, May 18, 2009.

<sup>26</sup> “California Statistical Abstract, Table B-1 — Population, Total & Civilian, California & the United States,” State Department of Finance, January 2009, [http://www.dof.ca.gov/HTML/FS\\_DATA/STAT-ABS/Toc\\_xls.htm](http://www.dof.ca.gov/HTML/FS_DATA/STAT-ABS/Toc_xls.htm), May 18, 2009.

for early autism treatment. This trend is shifting costs for these services from local education agencies to regional centers. This cost shifting is occurring in every health and human service agency program which is experiencing increasing fiscal pressure and/or budget reductions.

#### 7. Budget Increases Due to Governmental/Legislative Actions

The cumulative and ongoing impact of governmental actions on the developmental-services budget has been significant. Legislation enacted since the early 1990s has added new mandates, expanded services, reduced expenditure controls, and made other changes that have influenced budget growth. Most of these actions have advanced the interests of consumers and their families, but they have also increased expenditures.

The following are examples of these actions:

- a) Senate Bill (SB) 1383: Enacted in September 1993, this bill made numerous changes to the Lanterman Developmental Disabilities Services Act that significantly increased regional-center costs. Among other mandates, for example, SB 1383: (1) required that services be provided based on the needs and preferences of the consumer/family; (2) created and promoted a new individualized living arrangement (supported living), available to any consumer regardless of his/her disability level; (3) required regional centers to provide emergency and crisis intervention services; (4) required regional centers to fund facilitators; and (5) expanded the definition of "services and supports" to which eligible consumers/families are entitled. Though not easily quantified, this bill contributed significantly to regional-center budget growth.
  
- b) Senate Bill 1085: Enacted in September 1993, this landmark legislation, known as the *California Early Intervention Services Act*, established a mandate for regional centers and local education agencies to provide comprehensive services to infants and toddlers with developmental delays or those at risk of such delays. The requirements for this program are set forth in Part C of the federal *Individuals with Disabilities Education Act*, to which the state legislation conforms. Meeting the requirements of this program have been costly, while federal funding increases have been negligible. The fiscal year 1994-95 budget for this program for developmental services was \$21 million (100 percent federal funds).<sup>27</sup> Expenditures for this program are projected to be about \$400 million (\$350 million GF; \$50 million federal grant) for fiscal year 2009-10.<sup>28</sup> This represents a 19-fold increase in regional-center costs for this program since its inception.

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<sup>27</sup> "1994-95 Governor's Budget, Regional Centers, May Revision," Department of Developmental Services, Estimates Section, May 18, 1994, pp. A-1 and A-2.1. Note: The Dept. of Education received \$12 million of the \$33 million federal grant.

<sup>28</sup> "Restrict Eligibility Criteria for Early Start," Workgroup Budget Ideas document, Department of Developmental Services, p. 1.

- c) Adverse Federal Audit: In 1997, the federal Health Care Financing Agency (now known as the Centers for Medicare and Medicaid Services, or CMS) audited the state's Waiver program and identified numerous health/safety and financial deficiencies. Only after a multi-year corrective action plan requiring the infusion of substantial state General Fund dollars was the state able to meet CMS's requirements. **The DDS indicates that the state lost nearly \$1 billion of non-recoverable federal funding during this time.**<sup>29</sup> The corrective actions taken by the state to regain federal funding had a significant and ongoing impact on the developmental-services budget beyond normal growth, but these measures allowed the state to meet minimum federal quality-of-care requirements and successfully restored federal funding to the program.
- d) Senate Bill 1039 and Assembly Bill 2780: Enacted in 1997 and 1998, respectively, these bills required the DDS to review and approve all existing, new, and amended purchase-of-service policies and guidelines used by regional centers when determining the service needs of consumers. Regional centers established most of these policies in the early 1990s, with approval from the DDS, to reduce expenditures when the state was experiencing severe budgetary problems. Consistent with legislative intent, the DDS reviewed all regional centers' purchase-of-service policies and disapproved those that did not conform to existing law. However, no alternative budget-control mechanisms were enacted when these policies were eliminated, so regional centers' limited ability to manage or control expenditures was reduced further.
- e) Minimum Wage Increases: The payment rates for many service providers in the developmental-services system are predicated on or set at the minimum wage. These providers' rates, therefore, are increased as the minimum wage rises so providers can pay their employees the legal minimum wage. The state minimum wage has increased eight times in the past 12 years, from \$4.75 to \$8.00 per hour.<sup>30</sup> This represents a 68 percent increase in the wage rate and related costs. Minimum wage increases have increased budget growth, but this growth occurs only because the wage rates are so relatively low, not because of unrestrained spending.

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<sup>29</sup> "Controlling Regional Center Costs," Department of Developmental Services, December 2007, p. 29.

<sup>30</sup> <http://www.dir.ca.gov/IWC/MinimumWageHistory.htm>, May 11, 2009.

## **Conclusion**

Regional centers provide a safety net of services for Californians with developmental disabilities and their families. Their vital role, however, is not always understood by policy makers or the public. Even less well understood are the many factors contributing to regional centers' budget growth. It is ARCA's hope that this information brief narrows this knowledge gap and dispels the often-inaccurate assumptions that can result by looking at budget growth apart from the cost drivers.

California's budget for developmental services is impacted by a combination of demographic, medical, legal, and program trends that are increasing the demand for services, and which contribute to a budget-growth pattern that distinguishes it from most other state-funded health and human service programs. Therefore, the typical budget-reduction solutions that may be effective for other programs cannot achieve the same results in this system, but will, rather, disproportionately and adversely impact those who depend on this increasingly fragile service system. Budget-reduction approaches must recognize the growth dynamics and unique characteristics of this program so that changes achieve the desired results while minimizing unintended and harmful consequences, which may include longer-term General Fund outlays.

The developmental-services system has been impacted seriously by the state's continuing budget crises. ARCA understands, however, that the system must be part of the solution as the state confronts yet another, and perhaps the most enormous, deficit it has confronted to date. To this end, this information brief, in combination with ARCA's "*Budget Position Statement – Fiscal Years 2008-09 and 2009-10*" document, provide important background information and potential budget-reduction solutions that can assist policy makers in the difficult decisions ahead.