

**SUSTAINING THE ENTITLEMENT FOR THE  
DEVELOPMENTAL SERVICES SYSTEM:**

**A REGIONAL CENTER PERSPECTIVE**

**ADOPTED BY THE BOARD OF DIRECTORS  
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SUSTAINING THE ENTITLEMENT  
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PURPOSE

In 1969, the state of California passed the Lanterman Mental Retardation Services Act. This act authorized the creation of a statewide network of community-based agencies to provide or coordinate services and supports for individuals with mental retardation throughout the lifespan. The mission of these organizations was to enable individuals with developmental disabilities to live full, productive and satisfying lives as active members of their communities. In 1985, the California Supreme Court ruled that the Lanterman Act defined an entitlement – that is, a basic right to necessary services and supports that the State had a corresponding basic obligation to provide.

Social and economic changes occurring since the passage of the Lanterman Act in 1969 have made it increasingly difficult for the State to ensure funding that is adequate to implement the entitlement defined in the Act. Given the repeated economic fluctuations in California over the last 20 years, it would seem unrealistic to expect the State to guarantee to fully fund an entitlement that is broadly defined according to individual need and continually expanding due to innovations in services and rising client<sup>1</sup> and family expectations. Therefore, it is critical to carefully examine the factors contributing to the tension between the entitlement and the State's limited resources and consider possible changes to the Act that would moderate cost escalation, better ensure equity, and result in an entitlement program that is sustainable given the State's financial resources.

The board of directors of Frank D. Lanterman Regional Center is and always has been strong a supporter of the Lanterman Act and the entitlement that it bestows on Californians with developmental disabilities. It is for this reason that five years ago we adopted the initial version of this position paper. We have watched with increasing concern as the State has struggled to contain costs while repeatedly failing to address the core structural problems that are undermining the foundation of the entitlement. During the ensuing five years, these structural problems have continued to grow and we now face a crisis, with a community-based service system that is under extreme stress and has its very existence threatened.

Organization of this Paper

The first section of this paper provides a description of regional centers and the individuals they now serve. This is followed by a history of the Lanterman Act and the regional center system, and a discussion of the evolution of the entitlement and how it is financed.<sup>2</sup> The history section in Part II provides a context for the discussion in Part III that explores the changes in the service system, target population, and financing that have created a tension between the expanding entitlement and increased competition for finite financial resources in the State.

The focus of the discussion in Part III is on services purchased by regional centers for clients and their families. It is these services that consume by far the largest portion of the regional center

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budget – currently 85 percent. The remaining 15 percent is devoted to regional center operations, including staff salaries, rent, equipment, and supplies. This paper concludes with a series of recommendations for changes that would enable the state to more reliably predict the cost of the entitlement and enable regional centers to more effectively manage the funds they receive while better ensuring equity in the distribution of those funds.

We intend the term equity as used in this document to have two meanings. The first relates to fairness across regional centers, meaning that all clients should be given access to the same level and types of services no matter which regional center is coordinating their services. The second refers to fairness across clients within a regional center. In other words, we believe that clients with similar needs receiving services from the same regional center should receive similar levels and types of services regardless of their own or their family's ability to advocate on their behalf. Later in the document we introduce the concept of a standardized assessment tool that could be used to more equitably determine support needs.

## The Vision of the Lanterman Act

The individuals involved in the development of this paper strongly support the vision of the Lanterman Act. We embrace the vision of Frank D. Lanterman, Jerome Waldie, their colleagues in the California Legislature, and a large number of committed parents and professionals that children and adults with developmental disabilities should be afforded the opportunity to live independent, productive and normal lives in the community. Because of their vision and commitment, California created a community-based system of services and supports for individuals with developmental disabilities that has become a model for the rest of the United States. Further, the discussion that follows emphasizes the importance of ensuring that service models are cost-effective and achieve outcomes for individuals – values also embodied in the Act – and that services are provided in a way that is both fair and equitable. This paper emphatically rejects a return to the outmoded and archaic service models of the past. Rather, it endorses the development of innovative models that are individualized and increase opportunities for individuals to be included with their non-disabled peers in all aspects of their lives.

It is possible to support the concept of an entitlement and, at the same time, support the establishment of standards defining how the entitlement should be managed, including reasonable expectations regarding a family's financial responsibility for their child with a developmental disability. The goal of this paper is to contribute to a constructive dialogue that, it is hoped, will result in changes to the system so the entitlement can be sustained for future generations. Given the virtual certainty that the State's current dismal economic climate will continue for the next several years, it is critical at this time to consider all reasonable alternatives and put forward a comprehensive set of recommendations that, taken together, will provide for an entitlement program that is sustainable in the long term.

The original version of this paper was written in 2003 and since then has been periodically updated to include consideration of ongoing economic and political events in California. Since the paper was originally published, the financial situation has become increasingly bleak and the State is again facing a budget deficit of substantial proportions. At the same time, there have been no serious attempts to address most of the structural problems contributing to the continuing cost

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escalation within the regional center system. The issues have not changed and the analyses and recommendations in the original paper are as relevant now as when it was written.

Several cost saving strategies have been implemented by the State, including stricter eligibility criteria, parent cost sharing for some services, a freeze on rate increases to community-based service providers, and unallocated reductions to regional center budgets. While the first three strategies are regarded as having resulted in cost savings, the rate freezes – which are now in their fifth year and have been made permanent – have had serious negative consequences on the community service system. Further, unallocated reductions have both failed to achieve the required savings and contributed to increasing inequities across regional centers. The State is now faced with a crumbling infrastructure within the community-based service system, brought about by prolonged failure to address the core structural problems facing the developmental services system, and a benefit program that is increasingly inequitable both within and across regional centers.

## A Regional Center Perspective

As the title indicates, this paper is written from a regional center perspective. Given their mandated role of system coordinator among individuals with developmental disabilities and their families, community service providers, generic agencies, and state and federal agencies, the regional centers have a unique vantage point from which to view the developmental services system. Regional centers serve children and adults across the lifespan with all qualifying conditions, from all ethnic and socio-economic groups, and from vastly different geographic areas of the State. They identify, coordinate, and monitor a broad range of services provided through networks of hundreds, and in many cases thousands, of individuals and organizations. While certainly not the only perspective of consequence, the views of the regional center should be given careful consideration during the development of policy affecting the delivery of developmental services.

## PART I: WHAT IS A REGIONAL CENTER?

A regional center is a community-based non-profit corporation chartered in state law (Welfare & Institutions Code Section 4400 et. Seq.) and operating under contract with the state Department of Developmental Services (DDS). A regional center has as its mission to enable individuals with developmental disabilities to live more independent, productive, and normal lives, and to minimize the risk of developmental disabilities and ameliorate developmental delays in infants and young children who are at risk for developmental disabilities.

A developmental disability is a condition that originates before a person reaches age 18, is expected to continue indefinitely, and constitutes a substantial impairment. Five categories of disability are specified in state law: (i) mental retardation<sup>3</sup>; (ii) cerebral palsy; (iii) epilepsy; (iv) autism; and (v) disabling conditions closely related to mental retardation or requiring services similar to those required by a person with mental retardation.

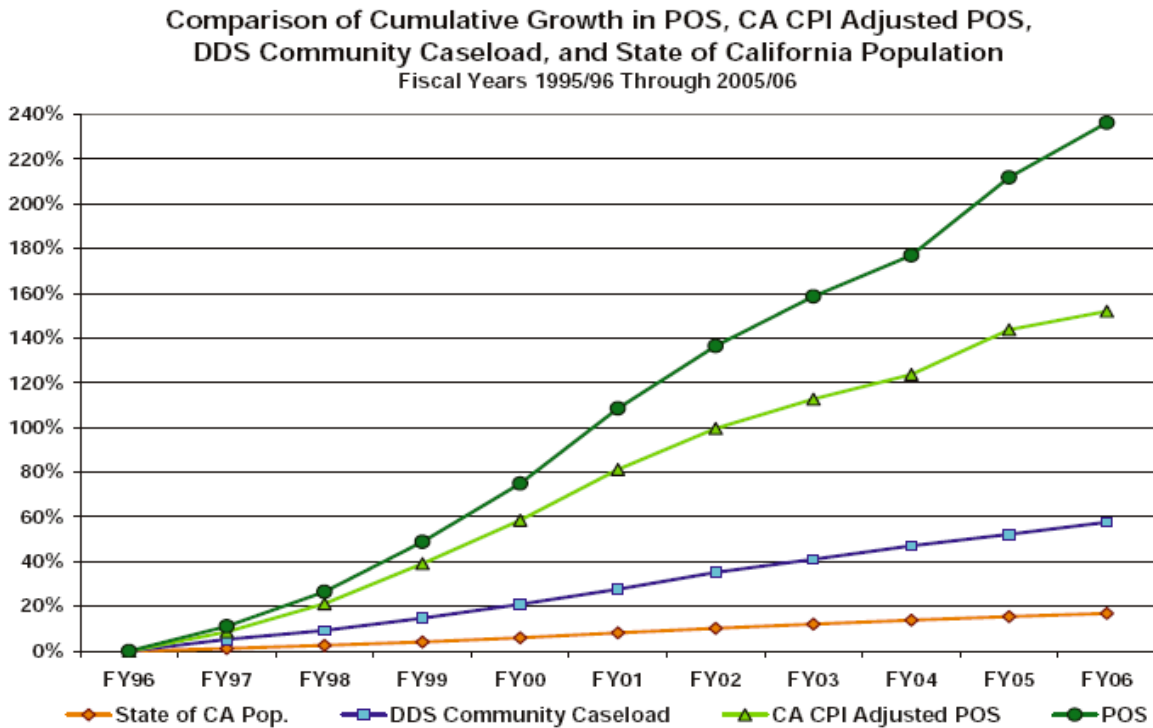
There are 21 regional centers in California, each serving a designated geographic area. They accomplish their mission through the coordination and provision of services and supports in accordance with the mandates of the Lanterman Developmental Disabilities Services Act and the Early Intervention Services Act. Specifically, the services provided directly by regional centers consist of: intake and assessment for diagnosis and eligibility determination; individualized planning and coordination of services; advocacy; family support; assurance of service quality through monitoring, auditing, technical assistance and training to its service providers; and resource development. All services provided directly by regional centers are provided without regard to family income. The same is true for the vast majority of services purchased by regional centers for clients and families. The exception to this general rule is a cost-sharing requirement for families whose minor children live in a licensed home and for families receiving certain services for their minor children.<sup>4</sup> The regional center program is funded through a combination of state and federal funds, totaling approximately \$3.6 billion system wide for fiscal year 2007-08.

Regional centers currently serve more than 230,000 individuals throughout the lifespan. Approximately 40 percent of people served are children birth to 13 years of age, and another 17 percent are adolescents and young adults aged 14 to 21. Fully 47 percent of clients served are individuals with mental retardation while an additional 29 percent have mental retardation coupled with one or more of the other developmental disabilities – epilepsy, cerebral palsy, or autism. Although autism, either alone or coupled with another disability, presently affects about 17 percent of the regional center client population, the number of individuals diagnosed with this disorder increased in California by 338 percent between December 1996 and December 2006. The vast majority (94.8 percent) of children under 18 years of age live at home with their families, as do 51.2 percent of adults. Only 1.1 percent of individuals with developmental disabilities now reside in state developmental centers.<sup>5</sup>

The regional center population has been increasing at a rate significantly higher than overall increases in the state's population. For example, from Fiscal Year 1995/96 through 2005/06 the number of persons served by the California Department of Developmental Services increased 58 percent, while California's general population grew by approximately 17 percent. The cost of purchasing services for clients has increased even more rapidly. During this same period, the

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cumulative growth rate for purchase of service dollars in the regional center system was approximately 236 percent. Adjusted for changes in the California Consumer Price Index (CA CPI) the increase was nearly 152 percent. The graph below provides a summary of the increase in the state population, the regional center population, and purchase of service (POS) spending over that period.



(DDS *Fact Book*, Tenth Edition, April 2008)

Most of the services purchased by regional centers on behalf of clients and their families are provided by independent service providers under contract with regional centers. These individuals and organizations provide a wide range of services and supports, including, for example, residential care, day programs, respite, transportation, and behavior management. Regional centers also work with “generic” agencies that have an obligation to serve the general public to ensure that regional center clients receive benefits and services to which they are entitled. These agencies include local school districts, mental health departments, Medi-Cal, the Social Security Administration, and the state Department of Rehabilitation.

## Part II: DEVELOPMENT OF REGIONAL CENTERS AND THE ENTITLEMENT

In California, parents of children and adults with developmental disabilities, as well as professionals working in the field, are intensely passionate about the “entitlement” defined in the Lanterman Act and they value it highly. To understand why this is so, it is necessary to understand the history of the Lanterman Act and the development of the regional center system. (See footnote 2.)

Prior to the establishment of the regional center system that began with two pilot projects in 1966, the only service or support provided by the state to children and adults with developmental disabilities was custodial care in large state institutions for people with mental retardation – if the families were able to find an opening. At that time, approximately 13,000 individuals lived in such institutions and another 3,000 were on the waiting list for placement.

If they chose to care for a child with developmental disabilities at home, families were essentially on their own. With the exception of very limited post-hospital care in licensed homes in the community for individuals who could not return to their family homes, there were no community services and few if any school programs. In response to this situation, parents engaged in self-help, establishing voluntary organizations to create day activities for children and adults and group homes as alternatives to the state hospital.

### The Creation of Regional Centers

In 1965, the California Legislature passed landmark legislation (AB691 Waldie) to establish as a pilot a community-based alternative to institutional care for people with mental retardation. These organizations, called regional centers, were to be the mechanism through which services in the community were coordinated. The Act called for a shift in the State’s responsibility for individuals with mental retardation from the point where they enter a state hospital to the point where they are diagnosed. In urging passage of the bill, Governor Pat Brown stated that a major goal in establishing the first two regional centers was, “...education and rehabilitation, not merely protection and custody...If [individuals with mental retardation] can become more self-sufficient and productive, some may become taxpayers and more active participants in our society. In any event, they will require less expensive services from society than if they were totally dependent.”

In their first year of operation, the two pilot regional centers served 559 people who were on the waiting list for state hospital placement. The first year’s budget was less than \$1 million, for an average service cost of \$1,728 per person. Following a positive evaluation of these pilots, the Legislature expanded the model statewide. The system eventually grew to 21 regional centers, chartered in state law (AB 225, the Lanterman Mental Retardation Services Act) but operated as private non-profit corporations under contract with the State.

By 1975, the regional center system was serving nearly 34,000 individuals with a budget of \$48 million. The population of state institutions had fallen by almost 22 percent, to 10,200. During these years, the program was funded almost entirely by state general funds, and each regional center was given an annual budget allocation. Sometimes, centers’ allocations were insufficient to meet service needs, and DDS would seek supplemental appropriations from the Legislature. For their

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part, centers found it necessary to establish priorities for services and waiting lists for new clients or for services that were not of an urgent nature.

## Expansion of Regional Centers: Building on Success

During the decade 1975-85, the eligibility for regional center services was expanded to include categories of developmental disabilities beyond mental retardation, and the governing legislation was amended as the Lanterman Developmental Disabilities Services Act. A requirement for an individualized planning process was also added, as was specification of client/family rights, including the right to appeal any decision made by a regional center.

The service model during this period was generally one of structured programs that served groups of individuals who fit predetermined criteria. Although located in the community, these programs were typically segregated. Services included group homes, sheltered workshops and day activity centers, and transportation to these settings. Family support in the form of respite service was added in 1977.

By 1985, the annual regional center budget had risen to \$318 million and the centers were serving 78,000 clients. The state hospital population continued to decline, to 7,100 people, a decrease of nearly 50 percent from the peak in 1965.

In the early 1980s, state budget deficits resulted in reduced funding for regional centers. Centers were required by DDS to implement cost-saving strategies such as establishing service priorities, making categorical cuts in services, and maintaining waiting lists in order to keep their doors open and provide services for the entire year. In response, the Association for Retarded Citizens (ARC) brought suit against DDS and the regional centers, arguing that the Lanterman Act was an “entitlement to services” and that these cost-saving strategies were illegal.

The California Supreme Court agreed, holding that the Lanterman Act “defines a basic right and a corresponding basic obligation...[T]he 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.” The Court further held that, “The rights of developmentally disabled persons and the corresponding obligations of the State toward them under the Lanterman Act are implemented in the Individual Program Plan (IPP).” **It is the IPP, said the Court, that defines the entitlement for each individual, and the services and supports listed in that document must be provided.** At the same time, however, the Court stated, “It is simply not the case that the Act fails to establish a maximum of services to which the developmentally disabled person is entitled....[We] conclude that it grants the developmentally disabled person the right to be provided at state expense with only such services as are consistent with its purpose.” The purpose referenced by the Court is to provide individuals with developmental disabilities the services that will enable them to lead more independent and productive lives.

Equally important in the ARC decision was the Supreme Court’s conclusion that regional centers may spend no more money than is appropriated by the Legislature. Furthermore, the Court concluded that, “so long as funds remain, the right must be implemented in full; as soon as they are exhausted, it can no longer be implemented, but may be financed through an additional

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appropriation if the Legislature so chooses.” Alternately, the Court noted that the Legislature could resolve any fiscal crisis by reducing the entitlement. This decision created the “great dilemma” for regional centers that exists to this day. The dilemma is how to provide all the services and supports mandated by an individually and broadly defined entitlement to all eligible clients throughout the term of the contract and not exceed a limited appropriation.

## Bringing Federal Funds into the System

Another event occurring in 1985 had a significant impact on regional centers’ funding and operations. Before 1985, regional centers were almost entirely state-funded. That year, however, the State was approved to participate in the federal Home and Community-Based Waiver (HCBW) program. The HCBW program grew over subsequent years to bring in hundreds of millions of dollars in federal funds annually. At the same time, it brought to regional centers a large number of regulation-based compliance requirements. It also required regional centers to vendor virtually all service providers satisfying minimum DDS requirements to ensure client and parent choice. As has been demonstrated repeatedly in health care, increasing the number of providers of a service can result in a corresponding increase in utilization of that service and the increase may not be directly correlated with need. This same dynamic has been observed in developmental services. This vendoring requirement became a significant cost driver, making it increasingly difficult for regional centers to manage the scope and amount of services purchased. The proliferation of some types of service providers also made it virtually impossible for regional centers to enforce standards for service quality in these service areas.

The HCBW program generated a significant influx of federal dollars, but the State made the decision that these funds would offset general funds going to regional centers rather than supplement regional center budgets. Access to supplementary funding would have better enabled regional centers to keep pace with inflation and other costs for service providers and for regional centers. Over the years, regional centers’ inability to do this has had a deleterious effect on the quality of services provided to clients and their families and, in some cases, has resulted in service providers closing their doors.

The decade following 1985 was a time of significant social and economic change that resulted in increasing tension between the entitlement and budget realities. Changes occurred in the economic condition of the State and nation and in the service model for individuals with developmental disabilities. As is discussed below, during the period 1985-95, legislation would broaden the entitlement, increase the types and number of services regarded as necessary and appropriate for individuals with developmental disabilities, and lead to increased expectations on the part of clients and their families regarding the definition of service “need.”

## Unallocated Reductions as a Budget Tool

In 1991, owing to a nationwide recession, California’s budget deficit exceeded \$1.5 billion. The State implemented a budget methodology called “unallocated reduction” that required regional centers to prepare expenditure plans outlining how they would reduce their budgets by a specific percentage but still meet all mandates of the Act. This strategy relied on voluntary cooperation of clients, families, and service providers, with each regional center working with its own community to create a unique expenditure plan in accordance with guidelines issued by DDS. DDS retained the

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authority to disapprove all or part of a plan. Regional centers were also required to develop service funding guidelines and submit them to DDS for approval.

Unallocated reductions were used repeatedly in years of budget shortfalls and contributed to inequity in funding across regional centers. As is discussed later, this was because regional centers that were already spending less per client had to meet the same criteria for reductions as centers with higher per client expenditures.

In 1992, the budget situation worsened and the state deficit grew to nearly \$11 billion. As a result, regional centers lost 23 percent of their funding. The state Legislature enacted SB 485 in an attempt to ensure access to services within the limits imposed by the budget while maintaining the entitlement to services. This bill stated in part, “In order to ensure that services to eligible clients are available throughout the contract period, regional centers shall administer their contracts within the level of funding available within the annual Budget Act...Regional centers shall implement innovative, cost-effective methods of service delivery.”

SB 485 also required parents to provide for their child with a developmental disability as they would for a child without a disability. Finally, it waived certain regulatory requirements, thereby giving centers authority as well as flexibility to more effectively manage their budgets. This authority ended in January of 2001 when the Legislature failed to extend SB 485 (i.e., the legislation was allowed to “sunset”). The provision for parental financial responsibility was also allowed to sunset in 2001, but it was reinstated, effective October 1, 2008.

## De Facto Expansion of the Entitlement

During 1992, as regional centers were being asked to make unallocated reductions equivalent to 23 percent of their purchase of services budget, the Legislature passed a bill (SB 1383) that made important changes to the Lanterman Act. This bill updated the philosophy and embraced the concept of “empowerment,” giving clients and families more choice and more authority to make decisions about their lives. The changes were presented to the legislature as a change in the Act’s philosophy and values only, and one that should not be viewed as expanding the entitlement. Partly for this reason, the legislation was never subjected to a careful analysis to determine its fiscal impact.

What SB 1383 did, in fact, was greatly increased the range of services and supports available to clients and families and resulted in a significant expansion of the entitlement due to a rise in expectations among clients and their families. It added to the Lanterman Act two new service directions which were to have significant cost implications in years to come.

The first provision of SB 1383 was an endorsement of services provided in “natural environments” to promote community integration. These services utilized strategies such as trained aides providing individual support to children and adults with developmental disabilities that would allow them to be included in activities with non-disabled peers in integrated environments. The second was “supported living,” providing “opportunities for adults with developmental disabilities, regardless of the degree of disability, to live in homes that they own or lease with support available as often and for as long as it is needed.” (Section 4689) At the time SB 1383 was passed, most adults with developmental disabilities lived with their families or in licensed homes in the

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community, although a relatively small number were living on their own with modest support, called “independent living” services. Supported living constituted a profound change in that it proposed that any person, regardless of type or severity of disability or support needed, could also live on his or her own. DDS represented the addition of supported living as being “cost neutral,” but supported living is significantly more expensive than alternatives in many cases. By 2008, nearly 20,000 adult clients across the state (17.6% of the adult regional center population) were living in their own homes or apartments with support from the regional center.

In 1993, adding to the complexity of the funding situation in developmental services in California, the State enacted SB 1085, authorizing California’s involvement in the federal Part H Early Intervention Program (Early Start) for infants and toddlers. California already had a well-established early intervention program serving infants and toddlers with developmental disabilities and children considered to be at-risk. This decision to accept federal funding resulted in access to a wider range of services for children and their families. Federal regulations included an exhaustive list of services and supports that were required to be provided under the program. In addition, although the federal government allowed states to assess parental fees, the State chose not to implement such a policy. At the same time, regional centers were prohibited from seeking reimbursement from a family’s health insurance program, except with the parents’ expressed consent. Finally, parents were given great latitude in identifying what their children’s needs were and what services they should receive. The increase in number and kinds of services provided to each child resulted in a corresponding increase in costs in the Early Start program. Again, no careful assessment of the fiscal impact of this program expansion was completed.

## Accelerating De-institutionalization

In 1993, the State settled a class action lawsuit, *William Coffelt, et al. v. Department of Developmental Services, et al.* that required a further reduction in the population of developmental centers. As a consequence, DDS established the Community Living Options Initiative that called for moving 2,000 residents of developmental centers into the community over five years. The cost of this initiative was estimated to be one-third of a billion dollars, most of which was to be funded by an expansion of the HCBW program. This decision increased the State’s reliance on federal funds and imposed additional compliance requirements on regional centers’ direct services and operations.

By 1995 the developmental center population had fallen to 5,100 and regional centers were serving nearly 130,000 people. The annual budget for regional centers had risen to more than \$941,515,000, for an average cost of \$7,300 per person. By that time, more than 50 percent of funding for regional centers came from federal financial participation, although that percent would fall in subsequent years to its current 35 percent. As the end of 2008 approaches, the developmental center population has fallen to approximately 2,500 residents.

## Increasing Inequities in Service Rates

In 1998, a bill was passed in the California Legislature requiring DDS to address the inequities in the rate system applied to developmental services. That bill, SB 1038, called upon DDS to engage stakeholders in a “system reform” effort to address structural and rate reforms aimed at developing equitable and cost-effective payment systems based on performance and client outcomes.

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Importantly, a mandate in this effort was to create and implement a comprehensive quality management system that could provide clear criteria for evaluating and improving the quality of services provided. By 2001, this reform process was stalled and remains so.

The state fiscal crisis of the early 1990s resulted in long-term unintended consequences to the regional center system. Despite the fact that the State eventually recovered from the recession and went on to have large budget surpluses and a strong economy for a number of years, the regional center system did not benefit proportionately from the years of plenty. The unallocated reductions in the budget appropriations were never fully restored in subsequent years, and in some measure they continue to this day.

Rate freezes for most community-based services were instituted in 2003 and were made permanent in February 2008 in a special session of the state legislature. In the 2007-08 budget year, an additional freeze was placed on programs reimbursed under the negotiated rate system, a system intended to fairly compensate new and innovative types of services for which traditional rate models are inappropriate. In July of 2008, certain programs for which regional centers had previously negotiated rates became subject to a new rate structure. Henceforth, new programs in this category will receive a rate equal to the median of similar programs in the regional center area or the median of those programs statewide, whichever is lower.

Some increases in payments to providers have been granted for specific purposes related to changes in programs (e.g., reducing staff to client ratios). There have also been changes in the minimum wage, and other increases, such as a 25 percent increase to supported employment providers (subsequently reduced to 15%), which have been in response to political pressures or strong advocacy. Residential providers sometimes have received increases in SSI, although sometimes these increases have not been “passed through” by the State. What has been lacking is a realistic and measured approach to funding that recognizes the real costs of doing business and the effects of inflation. This chronic problem has affected service quality as well as availability, as some providers have been forced out of business.

The repeated use of the unallocated reduction methodology created increasing disparities in purchase of service funding across regional centers. This was due to the wide variation in regional center expenditure plan proposals and the varying degrees of success in plan implementation that was highly dependent upon community support. In addition, this cost-saving methodology magnified the existing disparity in purchase of service spending across regional centers. For example, the projected per capita spending for 2002-03 reported by the 21 regional centers ranged from a low of \$7,300 to a high of \$13,900.<sup>6</sup> When, in that year, DDS allocated \$52 million in required savings across regional centers, it did so proportionally based solely on the number of clients rather than on per capita spending.

## Recognizing Inequities in the Regional Center System

In 1997, the Legislature authorized the Bureau of State Audits to conduct an audit of the budget and allocation process used by DDS to fund regional centers. The Bureau concluded from the audit that the process did not ensure that clients throughout the State have equal access to needed services. The report concluded that insufficient state funding and more than \$106 million in budget cuts in four years had undermined the success of the system. Subsequently, the Legislature mandated that

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DDS determine the reasons for the lack of equal access and make recommendations to correct the problem. While several studies were conducted to address the Legislature's concerns, there has never been a resolution concerning this issue.

More recently, additional funding to regional centers has been provided piecemeal by the State for specific purposes. For example, additional funds have been allocated to allow regional centers to meet federal requirements for individuals participating in HCBW and Early Start, to provide intensive early intervention services for children with autism, and to continue the movement of state developmental center residents into the community. At the same time, regional centers remain under-funded in core services and programs.

The state fiscal crisis in 2002-03 created an unprecedented shortfall in revenues and a budget deficit estimated to be more than \$30 billion. As a partial response to the crisis, DDS proposed the establishment of "statewide service standards" for regional centers – a proposal that was widely rejected by advocates and some providers as signaling the death knell of the entitlement. As a result, the Legislature once again chose to use the failed methodology of unallocated reductions, asking regional centers to develop expenditure plans that would reduce spending in the system by \$52 million.

In response to this request, some centers not only met their goal but also generated additional savings. In contrast, other centers failed to achieve the required savings while some incurred even greater deficits. As a result, the Department of Developmental Services was forced to return to the Legislature and request two supplemental allocations – one for \$30 million and a subsequent one in the amount of \$44 million.

## The Current Situation

The fiscal situation in California continued to worsen into 2003-04. Partly as a result of this, a campaign was undertaken to recall Governor Gray Davis. Arnold Schwarzenegger was elected governor in October of 2003 on a platform promising to solve the budget crisis and bring more jobs to California.

In November of 2003, the new governor put forth his first proposals to deal with the fiscal crisis. His proposals for health and human services, including developmental services, were seen as draconian. For example, he proposed suspending the Lanterman Act, capping the number of individuals who could become eligible for regional center services each year, instituting waiting lists for services, and eliminating certain categories of services, such as respite. Other cuts proposed by the governor were aimed at programs outside of developmental services, but would have had a significant impact on the many regional center clients who use services provided by those programs. These proposals included limiting enrollment and instituting other cost-saving measures in the "lifeline" programs of Medi-Cal, In-Home Supportive Services, and California Children's Services.

These proposals were roundly rejected by regional center clients, families, and advocates, as well as the general public, and the governor sought alternative ways to save money in developmental services. The alternative proposals were presented to the public on January 10, 2005, in the 2004-05 state budget.

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The governor prefaced his proposals for the regional center system with seven key principles:

1. Everyone who is eligible should be entitled to necessary services.
2. There should be a share of cost for those who can afford to pay.
3. Services should be provided in the least costly manner possible.
4. Regional centers should be able to manage available resources in such a fashion as to ensure the health and safety of all clients.
5. Allowable services and rates need to be clearly defined.
6. Only necessary services and reasonable administrative costs should be funded.
7. Individuals with developmental disabilities should have the opportunity to live in the most integrated and least restrictive setting possible.

He also stated that, while putting forth some recommendations for cost savings, he was asking “clients, stakeholders, regional centers, and the Legislature...to facilitate the necessary changes and prevent the need for more drastic cost control measures in the future.”

The specific proposals put forth by the governor included:

- A co-payment from families who can afford to pay
- A requirement that services be provided in the least costly manner possible
- Creation of meaningful service standards to allow regional centers to prioritize and manage the resources provided through the budget process
- Once standards have been developed, development of standard rates, set by DDS, for all services purchased by regional centers
- An unallocated reduction in funding for regional center administration

With the exception of a parental cost-sharing requirement, the recommendations made by the governor were not implemented. The financial challenges facing the State at that time exist still. The 2008-09 deficit for the State is estimated to be as high as \$17.2 billion, and significant deficits are expected to continue for several more years.

For the 2008-09 budget year, the governor proposed that all state departments be subject to a 10 percent across the board reduction in funding. He also proposed additional cost-saving measures for developmental services, including making permanent the rate freeze for community providers, expansion of the Family Cost Participation Program to a greater number of services, including services provided under the Early Start program, and a 10 percent reduction in reimbursement to supported employment programs.

In February of 2008, the governor called a special session of the Legislature to deal with the worsening budget situation and a number of the proposed cost-cutting strategies were approved for immediate implementation. These included prohibition on the use of purchase of services funds for new program development, a permanent rate freeze for community providers, expansion of the Family Cost Participation Program to families receiving Early Start services, and new restrictions on rates for programs with which regional centers traditionally negotiated rates.

An additional cost-cutting strategy, originally planned for implementation in 2008 but now delayed, is a Self-Directed Services (SDS) program. Under this program, clients receive a global budget

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which they can use to purchase non-segregated services and supports of their choosing. A client's global budget is equal to either 90 percent of the average amount spent on his services and supports in the prior two years or 90 percent of the average (mean) amount spent on clients whose support needs are similar to those of the client. We do not address the SDS program in this paper because its implementation has been delayed, there are no final regulations to guide it, and the federal government has not yet approved the state's Medicaid Waiver application for the program. At the same time, it should be noted that this program, once implemented, will perpetuate many of the inequities discussed in this paper.

The governor and Legislature continue to look for strategies to contain costs, but, in her report of February 2008, the Legislative Analyst has made it clear that the State has a serious structural deficit problem that can no longer be addressed by the "easy" (temporary) solutions used in the past. The Legislative Analyst also criticized the across the board 10 percent reduction as an alternative to establishing priorities for programs and services. In tacit recognition of the gravity of the current situation and the failure of past attempts to solve the problems, the legislature has asked DDS to submit an exhaustive list of options to contain the developmental services budget.

After record-breaking partisan wrangling, the California legislature finally approved the 2008-09 budget on September 19, 2008, a full 81 days after the start of the budget year. This budget expanded the Family Cost Participation Program to cover Early Intervention services and reduced the income at which families are responsible for the entire cost of the service from 2,000% to 1,000% of the federal poverty level. The legislation also authorized regional centers to implement "funding committees" to ensure that purchase of services funds are expended appropriately.

The Legislature – aided by several administrations – has set up unrealistic expectations for the developmental services system by promulgating changes to the Lanterman Act and related legislation without realistically assessing their cost implications. Advocates contribute to this situation by asking for expansion of services without acknowledging their cost implications. For example, in 2008, although the state was faced with a massive budget deficit, a bill was put forth in the Assembly (AB 2424) that would have mandated changes in the individualized planning process. According to official estimates, this bill would have added tens of millions of dollars to operating costs of regional centers as well as undetermined increases in purchase of services. The bill (which was never approved) was strongly endorsed by advocate organizations who insisted that it would have no cost implications.

Meanwhile, interest groups persist in attempting to govern by initiative without seriously considering the financial consequences of their actions on the state budget as a whole. Problems created by these dynamics are exacerbated by equally unrealistic expectations among advocates and some clients and families who have come to take for granted that the entitlement will always be there to meet all of their needs.

We are committed to sustaining the entitlement of the Lanterman Act. This can only be achieved, however, if we undertake to seriously and realistically address the current challenges to the system through thoughtful analysis and development of sound policies. To do otherwise is to allow continued deterioration of the community-based service system that will be extremely difficult to reverse and will result in increasing inequities and unaddressed needs. The Legislature must seize the opportunity at this critical juncture to make the investment in rational system change that

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ensures fairness, cost-effectiveness, and accountability in the context of a community-based service system that is sustainable for future generations of individuals with developmental disabilities and their families.

PART III: ISSUES AND RECOMMENDATIONS

In this section, we discuss a series of factors that have come to limit the capacity of regional centers to effectively carry out their mandates. We also offer a series of recommendations intended to address these factors with a goal of improving service quality, ensuring equity, and limiting the cost escalation that, increasingly, threatens the future of the community-based system intended to serve people with developmental disabilities and their families.

In deliberations leading up to the development of this paper, concepts and techniques of managed health care emerged in the discussion and were perceived as having potential for addressing some of the challenges faced by the developmental services system. Consequently, some of the recommendations that follow are proposed as potentially useful if the State were to choose to adopt a more managed approach to developmental services.

Systems for managing the delivery and financing of health services have evolved out of necessity. They are responses to the real and profound inadequacies in U.S. health care and a growing realization that the country can no longer support a health care system that allows virtually uncontrolled access to increasingly costly high-technology interventions at the expense of basic health care for everyone. Many of the strategies developed by managed care organizations to ensure more equitable distribution of finite health care dollars have been measurably effective in improving access and quality and containing costs.

The parallels between health services and developmental services – in terms of the challenges they face – are clear. For example, in both systems costs are increasing significantly faster than the growth in the population and in inflation. These costs are driven by factors such as the expanded availability of services that increases utilization often in the absence of necessity, and costly new service modalities, some of unproven effectiveness, that are increasingly sought out by clients and families. It is reasonable, therefore, to take advantage of the lessons learned in health care and consider the application of management techniques that have demonstrated usefulness in holding down costs and increasing accountability. An overarching recommendation, then, is for the Legislature to carefully examine structures and strategies used by health care organizations to manage utilization, cost, and quality and determine their usefulness if applied to the regional center system.

Issue 1. While the Lanterman Act defines an entitlement that is non-prescriptive, highly individualized, and uncapped, it is funded through an annual budget appropriation that is finite and vulnerable to economic downturns.

The Lanterman Act describes an entitlement that has evolved to be essentially unlimited. There is no defined benefit as there is with most entitlements. Rather, for each client, it is the Individual Program Plan that defines the entitlement. Individuals with developmental disabilities have a right, granted by legislation and strengthened by judicial action, to whatever services and supports are needed to enable them to lead a more independent and productive life in the community. From an economic perspective, the current policy framework presents extreme challenges to regional centers attempting to effectively manage this entitlement.

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The broadness is especially evident with regard to services for children. The Act outlines a wide range of services that may be provided to ensure that families are able to maintain their children at home. For example, Section 4646 of the Lanterman Act provides: “the IPP shall include a family plan component which describes those services and supports necessary to successfully maintain the child at home. Regional centers shall consider *every possible way to assist families* [emphasis added] in maintaining their children at home....” The services required to keep a child at home are described as including any and all that “maximize opportunities and choices for living, working, learning, and recreating in the community (Section 4640.7).”

While the goals of the Act are addressed by an increasingly broad and expensive array of services and supports, the State has established no service standards or priorities. All services in a client’s IPP are viewed as equally important when funding decisions are made. In addition, state and federal mandates aimed at empowering parents and ensuring choice have greatly expanded their role in deciding what services and supports are necessary for their children.

Without a clearer definition of the entitlement, the rising expectations of families will result in a continued expansion of what is considered a *necessary* service, particularly among parents who are more highly educated. As a result, oftentimes, children of these parents receive proportionately more services than the children of less advantaged families. For example, one regional center that reports expenditures by health district found that the poorest district was home to 20 percent of the regional center client population living at home but consumed only 15 percent of its purchase of service budget for that client group. Several studies have also revealed disparities in service use and expenditures related to ethnic and cultural differences.<sup>7</sup>

The service coordination process is intended to ensure that all clients receive the services required to meet the purposes of the Act, but increasingly the differences in parents’ expectations and their abilities to advocate successfully for their children result in inequities in the provision of services. This matter could be partially addressed if regional centers had a reliable and objective way of assessing service need at the individual client level. Some see potential in an instrument called the Supports Intensity Scale, and its usefulness for this purpose is being piloted in a number of settings. Plans call for the Client Development Evaluation Report (CDER) to determine need in context of the Self-Directed Services program, but there is no evidence that this instrument is a valid tool when used for this purpose.

Juxtaposed with this increasingly broadly defined entitlement is the annual budget with set appropriations that is vulnerable to economic downturns. Economic downturns are cyclic, but the state Legislature has generally not chosen to fully restore earlier cuts to regional centers in times of surplus. Furthermore, the system of state control includes significant compliance requirements but gives regional centers no effective tools for managing their purchase of service spending. In 1991, with SB 485, the State gave regional centers increased authority and flexibility that allowed them to manage their budgets more effectively, but these legislative changes “sunset” in January of 2001.

Issue 2. The cost of the entitlement continues to increase due to the shifting model of service provision which requires the creation of more costly individualized, integrated services, the utilization of which is driven by the principles of client/family preferences and choice.

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Since the promulgation of the Lanterman Act, the model that guides service delivery for individuals with developmental disabilities has changed radically from one of institutionalized (segregated) custodial care to one based on the “inclusion” mandate – emphasizing full participation for individuals with developmental disabilities in the community. During this time, the variety of services and supports available to people in the community has continued to expand and the corresponding cost per individual has increased markedly. In addition, advances in knowledge and innovations in technology, combined with a lack of rigorous criteria for vrending services, have resulted in a large number of new service types, some of which are very costly and sometimes of unproven effectiveness. A brief discussion of two services sheds some light on the dynamics of the cost increases.

Supported living. A major service innovation has been supported living, wherein a person with a disability receives the full range of services and supports that are necessary for him to live on his own in the community. Individuals qualify for supported living regardless of the nature and extent of their disabilities and receive support “as often and for as long as it is needed.” Furthermore, it is intended that “the consumer’s preference shall guide decisions concerning where and with whom he or she lives (Section 4689).”

This innovation has provided opportunities for individuals with disabilities that would have been deemed impossible in the early days of the Lanterman Act, and certainly before that time. People with severe disabilities in need of assistance for virtually every aspect of personal care and activities of daily living can now live on their own in the community. These are individuals who, as recently as 20 years ago, would have been institutionalized and regarded as unable to live in the community.

While few would argue against the least restrictive environment, the supported living option comes with significant costs. The expectation originally put forth by DDS was that supported living would be “cost-neutral.” The reality, however, is significantly different in many cases. For example, supported living for someone with severe disabilities can cost more than \$250,000 per year. An alternative for many people could be a negotiated rate licensed home. While still expensive, costs in such a setting would be moderated by the fact that the clients share the residence with two or three others. In a system with finite financial resources, choice must be balanced against economic realities.

Intensive services for children with autism. Research has demonstrated that intensive early intervention services for young children with autism is a wise investment that can improve quality of life and offset service and support costs for these children later in life. Such services include comprehensive behavior-based programs focused on communication and social skills.

These comprehensive programs are expensive, both because they are intensive (typically 25-30, but sometimes up to 40 hours per week) and because their costs cover the services of technically trained interventionists providing the service, as well as professionals supervising the interventionists. The cost of intensive behavior programs can exceed \$100,000 per year. Most children receiving these intensive services also receive ancillary services such as occupational therapy, physical therapy, and speech and language services.

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The number of children receiving intensive autism services has increased significantly over the past five years due to the growth in incidence of autism, rising awareness among parents and professionals about the value of these services, and increased demand for the services from parents. Additional increases in the number of children entering Early Intervention can be expected as a consequence of the October 2007 report from the American Academy of Pediatrics recommending that all children be screened for autism at 18 and 24 months.<sup>8</sup>

The Lanterman Act explicitly endorses the use of innovative and cost-effective alternatives for the provision of services and supports, and a number of regional centers have been successful in implementing such strategies. For example, some centers have developed group approaches to give parents basic skills and knowledge in behavior management, with one-to-one interventions being used to supplement this training based on the needs of the client and family. The group modality is potentially useful for delivery of a wider range of services for clients and families. In many areas of human service, group modalities have been shown to be at least as good as, and generally more cost-effective than, individual modalities for delivering services.

Some regional centers have been very successful at utilizing integrated community resources in place of traditional regional center providers, as is called for by the Lanterman Act's "inclusion mandate" and as is strongly endorsed by the federal government through its requirement that early intervention services be provided in "natural environments." Regional centers encourage the use of programs such as typical neighborhood preschools rather than segregated center-based infant development programs. These "typical" programs generally have more competitive rates than the traditional segregated programs and have the advantage of increasing opportunities for children with disabilities to interact with their non-disabled peers. Further, research has demonstrated that serving children in natural environments benefits not only the child but also the family.

There are extra costs to providing services for children with disabilities in natural environments. For example, children with disabilities participating in the typical programs may require one-to-one support and the providers in these programs require training or mentoring from experts in inclusion. The extra support is very often faded out after a period of time, however, and the training of providers builds capacity within the community to serve additional children with disabilities.

**Recommendation 1. Clearly specify the services included in the "benefit package" defined by the entitlement and develop uniform service standards and priorities so that these services are authorized equitably across regional centers and across clients with similar needs.**

More specificity in the definition of the benefit would ensure greater equity in regional center spending than is currently achieved through the individual planning process alone. The promulgation of standards would also provide an excellent opportunity to promote resource development and service provision shaped by the principles of inclusion, cost-effective innovation, and prevention. Finally, statewide standards, coupled with a standardized method of assessing support needs, would ensure that individuals with similar needs would qualify for similar services no matter which regional center serves them. Any such system, however, must be dynamic, allowing for change in response to advances in knowledge and technology.

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Issue 3. Through the IPP process, the Lanterman Act gives parents a leadership role in determining what services will be provided to their children with disabilities. At the same time, the law has been inconsistent with regard to the requirement that parents have a financial responsibility to provide for their child with a disability as they would for a non-disabled child.

The Lanterman Act is explicit in giving parents, through the IPP process, a significant role in determining what services will be provided to their children by the regional center. For example, the Act describes the planning process and services provided by the regional center as being “centered on the individual and the family...and [taking] account of the needs and preferences of the individual and the family (Section 4648).” Further, it mandates that clients and their parents should “be empowered to make choices in all life areas (Section 4501).” The Act also gives families broad rights to appeal if they believe the regional center is not offering them adequate assistance.

The entitlement defined by the Lanterman Act has differed historically from virtually all other federal and state entitlement programs in its lack of requirements for cost-sharing or means testing for income eligibility. For many years, the single exception to this was a requirement for cost-sharing for the small number of parents whose children live out-of-home. In January 2005, an additional cost-sharing requirement was implemented for families receiving respite, camp, or day care for their children. In October 2008, the Legislature voted to expand this program to include Early Start services, and lower the income threshold at which parents were required to pay 100% of the cost of the service.<sup>9</sup>

Research focused on health and social services has demonstrated that consumers who are required to pay a reasonable share of cost of services are more likely to value the services they receive and less likely to utilize unnecessary services. It has also been shown, however, that cost sharing set at too high a level can result in underutilization and have a negative impact on health status.

Until the provision “sunset” in January of 2001, the Lanterman Act required regional centers to “...take into account, in identifying the consumer’s service needs, the family’s responsibility for providing similar services to a child without disabilities (Section 4791).” The elimination of this provision resulted in regional centers paying for a variety of services that parents themselves would be obligated to pay for if their children did not have a disability. Typical of these were recreation and enrichment activities such as art, music, and camp. Families often asked regional centers to pay for these services regardless of their own financial resources. As a result of the 2008-09 budget negotiations, this provision for parental responsibility was reinstated.

Before the Lanterman Act, the only responsibility the State accepted for individuals with developmental disabilities was to provide institutional care. The Act gave the State “a responsibility for persons with developmental disabilities and an obligation to them which it must discharge (Section 4501).” Without a clear statement about parental financial responsibility for their child with a disability, some families will interpret this provision to mean that the State has the responsibility to meet all of the service and support needs for individuals with developmental disabilities, with no corresponding financial obligation on the part of parents.

Recommendation 2. **Maintain the provision in the Lanterman Act regarding parental financial responsibility for their child with a developmental disability.**

This provision, which “sunset” in 2001 and was reinstated in 2008, moderates purchase of service spending while appropriately recognizing a family’s responsibility for their child with developmental disabilities.

Recommendation 3. **Ensure that the expanded requirement for cost sharing for families of minors, based on their ability to pay, does not create a financial hardship for families or otherwise constitute a barrier to needed services.**

Families are required to share in the cost of services for a child if the child is under the age of 18 and lives in a licensed facility or if the child is under age 18, not eligible for Medi-Cal, and receives specific services, such as respite and day care. In both cases cost sharing is means tested so it does not create hardships for parents. The impact of recent changes to the Family Cost Participation Program (i.e., expanding it to additional services and lowering the income threshold) should be carefully monitored to ensure that they do not create barriers to needed services.

Issue 4. The Lanterman Act provides an ambiguous definition of the entitlement and a broad appeal provision that allows clients and families to appeal virtually any decision made by a regional center. These two factors contribute to an environment that encourages families to appeal and administrative law judges to exercise broad discretion in interpreting law and regulation in their fair hearing decisions – decisions that result in de facto expansion of the definition of the entitlement.

The Lanterman Act gives clients and families broad appeal rights. For example, Section 4710.5 states: “Any applicant for or recipient of services, or [his/her] authorized representative, who is dissatisfied with any decision or action of the service agency which he or she believes to be illegal, discriminatory, or not in the applicant or recipient’s best interests shall...be afforded an opportunity for a fair hearing.” While the right to appeal is critical to ensure fair and impartial application of any benefit program, this provision gives wide berth to parents who are unhappy with any aspect of their relationship with the regional center.

Combined with the unlimited right to appeal is the ambiguity in the Lanterman Act as to the definition of the entitlement, as described above. Because of this ambiguity, the entitlement is subject to wide ranging and inconsistent interpretation by administrative law judges (ALJ) presiding over fair hearings. Judges use sometimes overly broad discretion in deciding appeals and issue decisions that in effect expand the definition of the entitlement. In some circumstances judges have abused this discretion and granted an appellant more than was requested or something that was not

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part of the original appeal. At other times, because of the lack of definition in the wording of the Act, judges have incorrectly interpreted its provisions out of a desire to provide relief to a family.

The performance of administrative law judges is not viewed as an issue solely in the developmental services system. In February 2008, a federal class-action lawsuit was filed in San Diego County alleging that state officials who decide disputes between parents and school districts over special education services are unqualified and inadequately trained.

While fair hearing decisions do not set legal precedents, they sometimes are treated as though they do when cited in later service requests or appeals. As a result, they may by de facto cause expansion of the entitlement when advocates disseminate decisions – for example, via the Internet – in order to encourage other parents to use them in their dealings with the regional center as though they were precedential.

There is no review of individual judges' decisions prior to their release by the Office of Administrative Hearings (OAH). In addition there is no provision for administrative review by the Department of Developmental Services or authority for the director of DDS not to certify a decision. The only alternative open to regional centers or families who disagree with a decision is to appeal the decision in Superior Court, a costly and time-consuming process.

**Recommendation 4. Establish a system for administrative review of OAH decisions to ensure that hearing officers correctly interpret applicable laws.**

While the right of clients and families to appeal should be protected, fairness requires that DDS have a right to review decisions of OAH hearing officers. DDS currently has the authority to review a regional center's decision to de-vendor a service provider. This would seem a reasonable model to extend to OAH decisions.

Issue 5. Generic resources often fail to meet their rightful obligation to regional center clients. This is due to a lack of a clear legislative mandate of generic services vis-à-vis regional centers, a lack of adequate funding of these generic services, and a perception among the generic agencies that the regional centers have the "deep pockets." As a consequence, regional centers are increasingly called upon to pay for these services as the payor of last resort.

The Lanterman Act mandates that regional centers be the payor of last resort, after generic services or (for clients over the age of 3) private insurance. Only if there is no other source of funding is the regional center obligated to purchase a service. While this responsibility is clearly stated in the Lanterman Act, the legal obligation that other agencies, such as mental health, have for individuals with developmental disabilities is not clearly specified in law.

Because of their own under funding or because they perceive regional centers as being relatively well-funded, generic agencies are increasingly unable or unwilling to serve individuals with developmental disabilities. For example, although a recent initiative resulted in an increase in funding for new services for the public mental health system in California, existing services continue to be severely under-funded. Partly as a result of this under funding and partly as a result

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of their historic unwillingness to serve clients of the regional center, public mental health agencies are failing badly to meet the needs of regional center clients.

More notable, however, is the failure of the relatively well-funded school districts to provide education and related services in accordance with the requirements of the federal Individuals with Disabilities Education Act (IDEA). Schools frequently fail to fully inform parents about what the school's responsibilities are under IDEA and the parents are left to believe – incorrectly – that the regional center is the agency that should be providing a service.

Administrative law judges have contributed to this problem by making decisions based on a misinterpretation of IDEA. For example, in some cases ALJs have ordered regional centers to fund 100 percent of behavior modification and discrete trial training services for children with autism when at least some of those services fall under the obligation of the local school district as required by IDEA. In some of these cases, families have been unhappy with the service provider or the type of services offered by the school district, and the ALJ has ordered the regional center to fund all of what the family requested, notwithstanding what was available from the school district. In other cases, the school district has offered to provide half or less of the recommended services and the regional center has been ordered to fund the balance.

Such orders demonstrate disregard for the fact that IDEA requires the school district to provide all services necessary to afford the child a free appropriate public education. Such services can include behavioral services and any other service necessary to bring the child to the point where he can benefit from his educational program. For example, in the case of Battle v. Commonwealth of PA (3<sup>rd</sup> Cir. 1980) 629 F.2d 269, the court specifically stated that “[w]here basic self help and social skills such as toilet training, dressing, feeding, and communication are lacking, formal education begins at that point. If the child masters these fundamentals, the education moves on to more difficult but still very basic language, social and arithmetic skills, such as counting, making change, and identifying simple words.”

Recommendation 5. **Clearly specify in the respective laws governing state-funded agencies the mandates of those agencies regarding their responsibilities for people with developmental disabilities. Provide a clear process for dispute resolution in situations where there is disagreement between a generic agency and the regional center about the locus of responsibility for a service in an individual case, and include a provision that allows regional centers to recoup costs for a service if the resolution is that a generic agency is responsible.**

The regional center is the “payor of last resort” and, for this reason, would pay for a disputed service while any such resolution process takes place. Currently, there is no clear process for resolving disagreements.

Issue 6. Parent and client choice is a significant determiner of which services become vendored and which services are purchased.

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The Lanterman Act authorizes regional centers to purchase services or supports “from any individual or agency which the regional center and consumer or...his or her parents, legal guardian, or conservator, or authorized representative determines will best accomplish all or any part of that consumer’s program plan.” Further, the highest preference is to be given to “those services and supports which would allow minors...to live with their families, adult persons...to live as independently as possible in the community, and that allow all consumers to interact with persons without disabilities in positive, meaningful ways.” (Section 4648.)

Frequently, parents independently identify a service that they believe will be beneficial for their child. They may learn about the service from other parents, from the Internet, at a workshop, or as a result of the marketing efforts by the service provider. Some parents request a list of all services the regional center provides.

Out of a true belief in a service or a sense of urgency to find something that will help their child, parents may ask the regional center to purchase that service. Because of the requirement of federal financial participation that clients and families have a choice of services and providers, the regional center is then obligated to vendor the service provider as long as that provider meets the minimum standards established by the State. These standards generally address credentials of individual professionals and structural and process aspects of programs. Such standards rarely are high enough to result in a service provider being denied vendorization nor, certainly, to ensure that the services are of reasonable quality or will be effective in achieving desired outcomes.

As designed, the IPP process is a rational one, wherein input is provided by the client and family, regional center service coordinator and other professionals, and service providers. Services are chosen to achieve desired outcomes specified in the IPP. Everyone involved agrees on the plan and “signs off” on it. The process does not always occur as designed, however. Often families hear about a new service after the IPP meeting has occurred and believe it will benefit their child. They request the service independent of the IPP process, or even begin the service and ask the regional center to fund it retroactively. Since regional centers are prohibited from funding services retroactively, the denial of funding may result in an appeal.

When parents independently select services for their children without the participation of knowledgeable professionals, they place themselves in the position of making decisions about quality and effectiveness that they may not be qualified to make. There is a legitimate role for clinical and other professional expertise in decision-making in developmental services, just as there is in health care. Particularly as services become more technically advanced, it is increasingly important for parents and professionals to work collaboratively in determining which services are appropriate for addressing the goals and objectives of the IPP for a particular child. Further, a requirement to vendor any willing provider prevents regional centers from making judgments about the relative quality of service providers and prevents them from determining with whom they do business.

**Recommendation 6. Give regional centers authority to establish standards for vending service providers within their respective service areas that exceed Title 17 regulatory requirements.**

Current regulations establish minimum criteria to qualify for vending, and once a service provider achieves vendor status, the regional center is generally obligated to use that provider at the request of a family or client, regardless of the quality of services provided.

Issue 7. The current methods used by DDS to determine rates for services contribute to underfunding and inequities in reimbursement across programs. This is making it increasingly difficult for regional centers to find and retain providers who will work for the rates currently offered and deliver services of reasonable quality.

Rates for many client services and supports are determined by the State using strategies that contribute to a reimbursement system that is inequitable. Generally, rates set by DDS are based on rates of existing similar programs. Typically, a new program will receive a rate somewhere near the mean of the highest and lowest rates being paid for existing programs of that type. In previous years, this initial rate was considered “temporary” and, after 12 months, the Department would set a permanent rate, based on an unaudited statement of costs submitted by the program. This is no longer true. The temporary rate becomes the de facto permanent rate, whether or not it covers the actual program costs. Further, rates have essentially been frozen for five years.

Theoretically, a program may receive periodic cost-of-living adjustments (COLA) based on a percent determined by the Legislature. COLA amounts over the years have not kept established programs at parity with new programs, however. As a consequence, the longer a program has been in existence, the lower its rate becomes relative to other programs providing the same service.

If a very old program stops providing services and is replaced by a new program, the new program will almost certainly receive significantly higher rates. For example, the lowest rate currently paid for a day program is \$26.83 per day. A new program opening to provide the same service (conceivably to the very same clients) would receive \$46.91 per day. One Southern California day program provider which had received the same rate – \$26.85 per day per client – for 10 years was unable to sustain programming on that rate and closed its doors. Services to its clients were transferred to a new provider whose rate was set at \$42.61.

In recent years, regional centers have negotiated rates for certain types of services. These tend to be more individualized, integrated services that are increasingly sought out by clients and families. Typical examples are supported living services and programs offering individualized community inclusion activities as an alternative to site-based day programs. This authority has allowed regional centers to reimburse programs for the real costs of doing business. Recently, however, DDS capped the rates that can be negotiated for these innovative services. Under this provision, new programs receive the median of local programs of the same type or the statewide median, whichever is lower. Rate policies will drive older providers out of business and limit regional centers’ ability to develop the new resources that come about as a result of increases in knowledge and technology.

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The Lanterman Act contains provisions describing a rational process for DDS to determine reasonable rates for community providers. This process is intended to ensure that rates continue to reflect increases in the actual costs of providing services. The Act also states, however, that rate increases are contingent upon annual budget appropriations.

**Recommendation 7. Retain regional centers' authority to negotiate rates with providers based on agreed-upon state guidelines that provide a reliable framework for negotiations.**

Regional centers are informed about the economic situation in their local areas. Giving them the authority to negotiate rates at the local level would result in increased equity across providers and rates that reflected the real costs of doing business. State guidelines would provide a rational structure for defining legitimate costs. Such authority would also allow regional centers to find more innovative and cost-effective ways of providing services and supports.

**Recommendation 8. Complete the process of "system reform" to achieve an equitable and cost-effective rate system for selected services based on performance and client outcomes.**

It is appropriate for the State to continue setting rates for certain services – in particular, residential services – while allowing for regional variations. At the same time, however, these rates must be adequate to ensure the survival of excellent residential providers. The State is currently seeking to standardize rates statewide. They should take this opportunity to complete the system reform process begun in 1998 that was intended to transition the community service system to a performance-based, consumer outcome model. While rates will increase in some cases for some programs, implementation of other recommendations discussed in this document will yield moderate savings as well as raise the level of quality of services being provided. Keeping monies generated by waiver programs in the regional center system would help offset rate increases

**Issue 8. The regional center has limited capacity to ensure the quality of services it purchases for clients.**

While the Lanterman Act gives regional centers a general responsibility for monitoring the "quality and cost-effectiveness" of services they purchase, their staffing patterns provide them with insufficient human resources to establish and carry out effective quality management programs. The core staffing formula used by DDS to determine funding for regional centers provides for two types of regional center employees whose activities are intended to address issues of quality. One is the fiscal monitor whose activities, while of great importance, are arguably unrelated to service quality. The other is quality assurance (QA) staff whose designated responsibilities relate only to monitoring the quality of licensed residential services.

QA staff members are required by law to monitor residential services twice a year, in unannounced visits. In addition, every three years they conduct a thorough review of each facility and its residents' records. This more comprehensive review is also mandated and is announced. In 2005,

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DDS added the monitoring of work programs to the responsibilities of regional centers, but provided no additional resources for this activity. There is no corresponding requirement and no designated staff for monitoring services such as day activities, supported living services, or services provided by specialists or professionals.

Because of their close involvement with their clients' lives, service coordinators cooperate with QA staff in the monitoring of residential and work programs. Due to their mandated responsibilities, however, these individuals have limited time to give to this QA role. Further, they generally have neither the skill set nor the focus to carry out a monitoring activity independently.

Regional centers have no effective authority for engaging service providers in activities aimed at raising the level of quality above the minimum regulatory requirements. Furthermore, given the outdated rate structure for many services, there is little financial incentive for providers to cooperate, especially if these activities add to the cost of providing services. Providers who do not wish to participate may point to the minimum requirements for vendoring stated in the California Administrative Code and claim they are not obligated to perform above that level. Some centers have organized voluntary quality improvement activities for program services, including supported living, residential, and day programs. But these centers have had to base their activities on the willingness of service providers to cooperate.

Parent choice of the type required under federal financial participation is also a powerful force in ensuring that services continue to be used, even in the absence of evidence that they are providing high quality services or are successful in achieving desired outcomes. Providers who are judged to be inadequate by regional centers can lose their vendorization, but the process for achieving this is long and costly for regional centers. In addition, providers have appeal rights which significantly increases both the time and cost of the process.

DDS attempted for five years to promulgate service standards which could have provided regional centers with some ability to manage the purchase of services in ways that ensured equity, fairness, and achievement of desired outcomes. Strong opposition from advocates and other interest groups repeatedly defeated this initiative, however.

The Lanterman Act was amended in the early 1990s to require regional centers to be accountable for specific outcome-based performance objectives. Through these objectives, regional centers are asked to demonstrate that they are helping clients "achieve life quality outcomes" and "meaningful progress above the current baselines (Section 4629)." In contrast, no such requirements apply to providers who serve regional center clients and their families. The result is a system under which regional centers wishing to improve the quality of services they purchase must persuade service providers that achieving a higher level of quality will work to their advantage.

**Recommendation 9. Give regional centers authority to develop standards for service quality and use these standards to identify “preferred” providers.**

The implementation of quality standards would give regional centers a measurable way to identify “quality” service providers who could then receive priority in the referral process. At the same time, it is critical that this strategy be coupled with rates of payment that reflect providers’ real costs of doing business. The most recent application that the State submitted for the Home and Community-Based Waiver program included a comprehensive quality management program which has not been implemented. Further, the model created for system reform also contains a thorough discussion of service quality and ways to ensure it. These two documents would seem to provide an appropriate basis for restarting the discussion about quality management.

**Issue 9. There is no mechanism to ensure that new service modalities are effective.**

Interventions intended to address medical, psychological, or other developmental challenges should be subjected to scientific study of their effectiveness before they are used routinely. The standard method for addressing the question of effectiveness is a carefully designed study employing service providers carefully trained to deliver the intervention in a standardized manner, patients or clients selected to receive the intervention according to explicit qualifying criteria, and a random process to assign these people to treatment conditions. An intervention is usually considered appropriate for general use if its effectiveness has been demonstrated in at least one study reported in a peer-reviewed journal, and if this success has been replicated at least one time in another setting.

The “gold standard” for this type of research is the treatment-control study in which outcomes for subjects receiving a service are compared with control subjects who receive no service. This model is not acceptable in context of this discussion, because it would not be considered acceptable, example, to provide no treatment to a child with autism. For this reason, the preferred model is to assess the relative effectiveness of two or more commonly used interventions.

Many of the interventions most often requested by parents and purchased by regional centers, particularly for young children with autism, have not been subject to rigorous research and have little empirical support. For example, Floortime is an increasingly popular intervention which is regarded as a promising practice, but it is not supported by a sound research base. At the same time, much promising research has been done in the search for causes of autism. In California, for example, several University of California campuses and Stanford University are active in this type of research.

History provides numerous examples of services of unproven value (e.g., chelation therapy, facilitated communication) that have been accepted by some or many for a period of time and used to treat individuals with developmental disabilities. Parents’ opinions about the appropriateness of a new or unproven intervention for their child may be based on anecdotal evidence from other parents or unconfirmed claims of people who provide the intervention. Their willingness to use such interventions may be related to strong desire to improve the quality of life for their child and

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their family. Because parents are given the lead in creating their child's IPP and in determining which services are most likely to achieve the objectives in the plan, these opinions – no matter what their validity – can significantly influence what is purchased.

The Lanterman Act includes wording that would seem to give regional centers authority to use effectiveness as a criterion in purchasing services. For example, Section 4646 (a) mandates that the “provision of services to consumers and their families be effective in meeting the goals stated in the IPP...and reflect the cost-effective use of public resources.” Similarly, Section 4648 (a) (5) states that selection of a provider should consider the “provider's ability to deliver quality services or supports which can accomplish all or part of the consumer's individual program plan.” Finally, Section 4648 (a) (7) affirms that “No service or support provided by any agency or individual shall be continued unless... reasonable progress toward objectives has been made.” While, in theory, these provisions give regional centers authority for ensuring effectiveness of services, centers have neither the resources nor the technical capacity to conduct rigorous evaluation of effectiveness of new or unproven interventions.

In situations where regional centers do consider effectiveness as a criterion when purchasing a service in a particular case, their decisions must withstand scrutiny in a fair hearing if parents choose to appeal. Especially when a service is new and evidence is inconclusive, hearing officers may give the benefit of the doubt to parents.

A model that regional centers could use for conducting such evaluations is one used in the health care industry. Most health care organizations use a procedure called *technology assessment* to evaluate requests for new, experimental, or otherwise unproven interventions. (The word “technology” as used here applies primarily to clinical interventions.) Formal technology assessments are conducted by professionals who are recognized experts in the field. They include careful reviews of published studies, to the extent that they exist, findings of government panels, and surveys of the opinions of experts in the particular clinical area.

Because technology assessment mechanisms are carefully designed to conform to principles of scientific rigor, and because they are based on the best available professional opinions and empirical evidence, they are usually perceived as fair. Consequently, their decisions tend to be accepted both by clients and by health care professionals. In addition, they are generally accepted as credible evidence in due process (appeals) hearings. A formal technology assessment process could be an effective way of balancing the frequently competing interests of effectiveness and parent choice.

To create an effective technology assessment function within a single regional center (and pay for it out of operations funds) would not be financially feasible. It would be feasible, however, to achieve this on a statewide basis. DDS could establish an independent or university-based Technology Assessment Committee that could be the primary mechanism for determining if and when a new technology should be included in the benefit package.

The California Legislature has established an excellent precedent for a state level independent review of technology. It is found in the Independent Medical Review process funded and maintained by the state Department of Managed Health Care. If a similar mechanism were established to evaluate new or unproven technologies in developmental services, the cost to the

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State could be more than offset by the dollars saved through the elimination of interventions that fail to demonstrate effectiveness.

It should be noted that the Autism Advisory Committee to California's Superintendent of Public Instruction, in its August 2007 report,<sup>10</sup> recognized the importance of information dissemination when it called for creation of "a statewide clearinghouse for information on the findings of educationally related research-based recommended practices to support children with autism...."

**Recommendation 10. Develop a statewide Technology Assessment Committee that can be used by the State to determine when and if new or unproven service modalities should be included in the benefit package covered by the Lanterman Act. Any such entity should be either university-based or an independent free-standing entity.**

If independent evaluations were made, they would need to be perceived as fair by service providers and families and they would need to stand up to scrutiny in fair hearings. The technology assessment process as used in health care organizations is an appropriate model to achieve these ends.

Issue 10. Regional centers have limited capacity to determine objectively if a given service is necessary, appropriate, and effective in the individual case.

The results of the type of scientific study described above reveal whether or not an intervention is effective when used in a controlled environment (e.g., with appropriate patients/clients being treated by specially trained providers following a strict protocol). An intervention that has been shown to be effective under such ideal circumstances may turn out to be ineffective when used outside of the controlled setting. This may be because the service provider lacks competence in the intervention, because the service is not necessary or is not appropriate for the person receiving it, or the parent or other caregiver is not capable of participating in delivering the intervention as required by the model.

Regional centers have ongoing responsibilities to address these two issues for all clients receiving services. While technology assessment gives an answer to the question of whether a particular service modality has been demonstrated to be effective under highly structured conditions, it does not answer the question as to whether the service is effective as typically delivered by a specific service provider and parent in a "real world" setting. These questions of provider competence, necessity and appropriateness of the service for the client, and a parent's ability to participate in service delivery are especially relevant to new services such as intensive behavioral services for children with autism. These services are typically delivered by a non-credentialed provider who is supervised by a more highly qualified professional. The child's parent is also expected to play a role in delivering the intervention, and the parent's ability to comply may be affected by his or her commitment to the process, time constraints, and technical ability. These factors may have a significant impact on the effectiveness of the service.

To answer this question of provider competence, a regional center would need to have access to qualified professionals who could review the service provider's qualifications – considering

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education, credentials, and experience – as well as the provider’s typical work products. The latter is typically done in the form of document review or direct observation of interventions.

With regard to the second question – Is the service necessary and appropriate in this case? – a center typically makes a decision based on a written assessment, in many cases completed by the same service provider who will provide the service if it is determined to be necessary and appropriate for the client. Rarely does an assessment conclude that a child does not need an intervention. Similarly, a decision about whether a service is leading to achievement of the stated objectives is made on the basis of a progress report submitted to the regional center by the same provider and reviewed by a regional center clinician.

Parents’ judgments about a service and whether it is helping their child can be colored by the personal relationship they have with the service provider. Such relationships can make it difficult for a parent to objectively evaluate the extent to which a service is helping his or her child or to be willing to switch to another service provider with whom no relationship exists.

Each type of situation possesses serious potential for conflict of interest, involving as it does a service provider making recommendations that have direct financial implications for him. The service provider may overstate the client’s need for the service or the progress that has been made. This may be due to his desire to provide that service or in response to the wishes of family members who are hopeful, perhaps in the absence of evidence, that the service will help their child. There may be a genuine disagreement between the service provider and the regional center clinician about the necessity for the service or the appropriateness of continuing that service. Finally, due to time constraints on regional center clinicians, many services are not subject to professional review.

In a case where the regional center makes a decision not to authorize a service in the face of a recommendation to the contrary from the service provider, parents frequently initiate an appeal. The hearing officer is faced with weighing one professional opinion (the regional center clinician) against another (the service provider). In practice, the emphasis in the Lanterman Act on honoring the wishes of the family frequently becomes the determining factor in the appeal.

One way to address this situation is to use independent assessors to evaluate necessity, appropriateness, and progress. In practice, centers have found it difficult to identify clinicians willing to restrict their practice to assessments, since it is much more financially advantageous for them to be involved in direct service provision. Using service providers to review one another’s services also has not proven to be a viable option. Providers hesitate to make negative judgments about their colleagues’ work.

The model of an independent arbiter, or peer reviewer, would seem appropriate for use by regional centers to address disagreements between their clinical staff and service providers. This strategy could be used to avoid fair hearings or it could be used as a part of the appeal process. It could also conceivably be used to address questions of provider competence. The volume of such questions would be greater than the questions addressed through formal technology assessment, and would also be simpler to answer. Consequently, it would be reasonable to organize regional peer review committees (perhaps through local universities) for this purpose. The aforementioned Independent Medical Review process provides a model for this structure.

Recommendation 11. **Develop regional peer review resources that could be used by regional centers, clients and families to solicit independent opinions on the necessity, appropriateness, or effectiveness of services in individual cases. This process could be used to obviate the need for a fair hearing, or it could be a resource for fair hearing officers to assist them in the decision-making process.**

A model of an independent professional arbiter or peer reviewer would seem to be useful to address these questions at the individual provider or client level. Regional centers currently find it difficult to find professionals among their network of service providers who are willing to play this role.

Issue 11. The use of unallocated reductions as a cost-saving strategy during financial crises has proven to be a failed approach. It places the responsibility for reducing spending solely on individual regional centers rather than on the Legislature that could create an equitable policy framework with statewide application. At the same time, since all other policies stay in place in the face of unallocated reductions, regional centers have neither flexibility nor authority to enforce implementation of such a plan or to use other, more effective strategies for reducing spending.

Regional centers have only the goodwill of their communities on which to rely when budget shortfalls make it necessary to implement expenditure plans. Although a powerful force, goodwill is not enough. Since their initial use to control costs in 1991, unallocated reductions have failed to achieve the necessary savings and, further, have contributed to inequity in funding across regional centers. In the past, in response to the state's requests for unallocated reductions, some families have stepped forward and expressed their willingness to reduce the level of services they receive or do whatever else is necessary to help the regional center through its crisis. Other families take the position that they will resist any attempts by the regional center to solve the problem by reducing services to their children, claiming that the Lanterman Act gives the state a responsibility to provide the services regardless of its financial situation.

The decision to use unallocated reductions as the strategy for controlling spending forces citizen boards, many of whom are themselves clients and parents of clients, to make ad hoc decisions in the absence of policy direction that should be forthcoming from the Legislature. Because the Legislature has failed to fulfill its proper role, regional center boards repeatedly shoulder the burden for solving a financial crisis that deserves a system-wide solution to ensure equity. They are placed in the untenable position of asking clients or parents to reduce or forego services that they or their children need.

While requiring regional centers to work with their communities to develop plans for reducing spending, DDS retains the authority to reject such plans. Centers are left with a responsibility to reduce costs but no authority either to enforce the reductions or to use more effective strategies to reduce spending. As discussed earlier, expenditure plans proved to be unsuccessful in the budget crisis of the early '90s. Further, they lack fairness and equity because some regional center communities are able to rise to meet the challenge of reducing spending while others are not.

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The state must provide regional centers with a realistic uniform policy framework that has statewide application. Given the current structure of the disabilities service system, it is only the state that has the capacity to establish statewide service standards and funding priorities, and hold regional centers and their communities accountable for their implementation. (See Recommendations 1 and 7.)

## Conclusion

These recommendations, taken together, provide a realistic uniform policy framework and effective tools for addressing the structural problems which represent a serious threat to the viability of the development services system. They would facilitate movement of the system in a positive direction by moderating cost escalation, allowing the State to better predict the growth of the program from year to year, and better ensuring equity within and across regional centers. In the end, they would contribute significantly to ensuring that the system created by the Lanterman Act will be sustained for future generations.

FOOTNOTES

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<sup>1</sup> In this paper, we refer to individuals who receive regional center services as clients. When quoting sections of the Lanterman Act, we use the term consumer, as originally used in that legislation.

<sup>2</sup> An expanded discussion of the history of regional centers and the developmental services system is found in the publication, *Reaffirming the Commitment...Realizing the Vision*, available from Frank D. Lanterman Regional Center. A profoundly human perspective on this history is found in the video, *We're here to speak for justice*, also available from this regional center.

<sup>3</sup> “Intellectual disability” is now considered the appropriate term for describing people who in the past were referred to as having mental retardation. This paper continues the use of the term mental retardation since this is the terminology used in the Lanterman Act.

<sup>4</sup> Legislation signed by the Governor in February of 2008 continues this cost-sharing program on a permanent basis and expands it to additional services.

<sup>5</sup> Department of Developmental Services, *Fact Book*, Ninth Edition, June 2007.

<sup>6</sup> These disparities continue to increase. While in 2002-03 the highest per capita amount was 190 percent of the lowest, in 2006-07 the highest was 205 percent of the lowest.

<sup>7</sup> See, for example, C. Harrington & T. Kang, *Disparities in Service Utilization and Expenditures for Individuals with Developmental Disabilities*. National Institute on Disability and Rehabilitation Research, Report #H133G050358.

<sup>8</sup> Plauch, C., & Johnson, A. (2007). Identification and evaluation of children with autism spectrum disorders. *Pediatrics*, 120 (5), 1183-1215.

<sup>9</sup> Children who qualify for coverage under the Medi-Cal program, either because of family income or through institutional deeming, are exempt from the Family Cost Participation Program.

<sup>10</sup> California Department of Education, Superintendent of Public Instruction Autism Advisory Committee. *A Call for Action: Improved Services for Children with Autism Spectrum Disorders*, August 30, 2007.