

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

A REGIONAL CENTER PERSPECTIVE

**ADOPTED BY THE BOARD OF DIRECTORS
FRANK D. LANTERMAN REGIONAL CENTER**

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Preamble

The Board of Directors of Lanterman Regional Center has developed this paper out of a sense of urgency about the community-based system serving people with developmental disabilities. As we review the evolution of this system we cannot help but be concerned about the capacity of regional centers and the service provider community to continue to meet the needs of our clients and families. We first expressed our concern in the 2003 version of this paper in response to a crisis that had been building for more than a decade. Since that time, the situation for regional centers has gotten consistently worse along with the economic situation in the State, and every indication is that it will continue to deteriorate. We have now moved beyond crises to a new reality of limited government funding for all services, not just developmental services.

The community service system is breaking down. Rates are no longer sufficient to allow providers to retain competent staff and maintain adequate facilities. We have reached the point where funding will not allow the system to provide all clients with all services to which they have been entitled under the Lanterman Act. All parties, therefore, must come together, be open to change and agree on priorities and on what should be the responsibility of the State to provide. Absent additional funding, we see no alternative but to accept fewer services for which we pay a fair price and from which we can expect outcomes that enable our clients to be more independent and productive members of their communities.

Changes to the system cannot continue to be piecemeal as they have been in the past. We must take a step back and ask what is reasonable for a publicly-funded system to provide. Changes must also be fair to both current and future clients. For example, many clients currently served by regional centers would not be eligible if they applied for services today. Most importantly, we must stop practicing the denial that has allowed many of us to believe that things will get better if we just hang on a while longer.

We believe that the current situation provides us with an opportunity – to innovate, to reinvent and to adapt to the new reality. What we propose in this paper is not piecemeal change. Rather, it describes a framework for change that, we believe, can result in a fair and equitable system that will allow us to sustain a meaningful entitlement program that will deliver services that are high quality, economical and achieve desired outcomes.

SUSTAINING THE ENTITLEMENT
FOR THE DEVELOPMENTAL SERVICES SYSTEM:

A REGIONAL CENTER PERSPECTIVE

EXECUTIVE SUMMARY

Social change and economic fluctuations 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 as it is defined in the Act. This is the fifth revision of a paper first published in 2003 by the Board of Directors of Lanterman Regional Center. As in the past, it is intended to examine the factors contributing to the tension between the open-ended entitlement and the State's finite resources and consider possible changes to the Act that would clearly define an entitlement that is sustainable given the State's financial resources. The concerns expressed in the first version of the paper have grown with each revision to the point where we are witnessing the breakdown of the community service system. The urgency we feel is significantly greater than any time in the past.

The first section of the paper provides a description of regional centers and the people they serve. This is followed, in Part II, 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. The section documents the development of the system – from the two pilot regional centers serving 559 people who were on the waiting list for state hospital placement, to the current network of 21 centers serving more than 210,000 children and adults with developmental disabilities, 99 percent of whom live in the community.

Part III explores the changes in the service system, target population, and financing that have created the challenges to sustainability. The paper concludes with a series of recommendations for changes that it is believed 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. Implementation of these recommendations would also allow for the rebuilding of the crumbling community service system.

While supporting the concept of an entitlement and the vision of the Lanterman Act, the paper proposes the establishment of more comprehensive standards defining how the entitlement should be managed. Legislation passed in 2008 and 2009, for the first time, provided some structure to the entitlement and gave regional centers policy guidance that has allowed centers to more effectively manage costs. Still, these changes have fallen short of fully addressing the structural problems contributing to the continuing cost. Further, while achieving some cost savings, these changes have created even greater financial hardship for service providers and have done little to address inequities across regional centers. Given the certainty of continuing state budget shortfalls, it is critical at this time to consider all reasonable alternatives and put

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forward a comprehensive set of recommendations for substantive changes to the system so the entitlement can be sustained for future. These recommendations can provide a framework for future discussions about the challenges faced by the system and possible solutions.

Recommendations

An overarching recommendation 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.

Methods and strategies employed in managed health care have been demonstrated to be useful in containing costs while facilitating appropriate utilization. There are parallels across the two systems with regard to factors driving health costs and utilization, suggesting that these management techniques may be useful in developmental services.

Recommendation 1. *Further 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, and monitor compliance.*

Additional specificity in the definition of the benefit would ensure greater equity in regional center spending than is currently achieved. 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, combined with an objective process for determining individual need, would ensure that individuals with similar service needs would qualify for similar services no matter which regional center serves them.

Recommendation 2a. *Impose a moratorium on supported living while developing clear criteria for eligibility for the service and for exemptions, and enforce the cap on costs of this service as required by the Lanterman Act.*

Recommendation 2b. *Provide regional centers with support in their efforts to monitor the types and intensities of services provided to young children with autism. (See Recommendations 8 and 9.)*

The cost of the entitlement continues to increase due to the shifting model of service provision requiring the creation of more costly individualized services, the utilization of which is driven by the principles of client/family preferences and choice. Supported living for adults and intensive services for young children with autism, have been particularly costly and, without more effective management, their costs will surpass the capacity of the system to provide them to those for whom they are appropriate.

Recommendation 3a. *Expand the requirement for cost sharing, based on ability to pay, to all services provided to children living at home but ensure that the requirement does not create financial hardship for families or otherwise constitute a barrier to needed services.*

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Recommendation 3b. *Require families to enroll eligible infants and children in the Institutional Deeming Program.*

Recommendation 3c. *Require families to assume financial responsibility for transportation of their family member who lives at home unless they can demonstrate that doing so would result in financial hardship. Provide stipends to residential providers to transport residents to day programs.*

Recommendation 3d. *Develop a definition for financial hardship that can be used statewide.*

Virtually all public benefit programs are means tested or require cost-sharing by service users. The Lanterman Act provides for cost-sharing for parents of children under 18 living at home but not for all services. We see no reason why cost-sharing should not be extended to all services for children. We also see no reason why families should not be required to apply for Institutional Deeming for their eligible children since it provides an additional resource for them as well as additional federal funding for the state. Further, regional centers spend more than \$200 million dollars purchasing private transportation. Some centers have implemented voucher systems and made other accommodations that have resulted in significant savings, while others have made no such efforts.

Recommendation 4a. *Reinstitute the eligibility criteria for the Early Start Program that were in force prior to 2009.*

Recommendation 4b. *Investigate the impact of withdrawing from the federal early intervention program and funding the Early Start Program with Proposition 10 dollars.*

As a cost-saving strategy, the Budget Trailer Bill of 2009 significantly changed eligibility for the Early Start Program, making it more restrictive. Since early intervention programs have repeatedly been shown to yield a cost-benefit into adulthood, it would seem false economy to restrict eligibility for short term savings before the extent of an infant's or toddler's delays are fully understood. Withdrawing from the federal early intervention program, instituting more cost-effective interventions, and funding the program with Proposition 10 dollars would enable the State to adequately serve all children who would be eligible under the pre-2009 criteria.

Recommendation 5a. *Establish a system for administrative review of OAH decisions to ensure that hearing officers correctly interpret applicable laws and allow the Director of DDS to overturn decisions that result from an overly broad or incorrect interpretation of the Lanterman Act.*

Recommendation 5b. *Limit client and family right to appeal to services and supports in the benefit package.*

The broad appeal rights of the Lanterman Act combined with the ambiguity that remains in the definition of the entitlement contribute to an environment that encourages families to appeal and judges to exercise overly broad discretion in interpreting law and regulation in fair hearings.

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The right to appeal extends even to regional center decisions that implement recent legislative changes to the Act. Decisions that may be appealed by families are limited in both the Family Cost Participation program and the Prevention Program, but not relative to these other changes.

Recommendation 6. *Give regional centers authority to establish standards for vrending service providers that exceed Title 17 regulatory requirements and to develop standards for service quality that can be used to identify “preferred” providers based on performance.*

Current regulations establish minimum criteria to qualify for vrending, and once a service provider achieves vendor status, clients and families may choose to use that provider over the objections of the regional center. This makes client and family choice a greater determiner than provider competence or quality of services of which services become vrended and purchased. The implementation of quality standards would give regional centers a measurable way to identify “quality” service providers and make preferential referrals based on performance.

Recommendation 7. *Develop a rational system for determining provider rates based on the reasonable cost of services and for regular review to ensure that rates continue to cover costs.*

The current methods used by DDS to determine rates for services, combined with a series of rate freezes and rate reductions, have contributed to underfunding and inequities between old and new programs. This is making it increasingly difficult for regional centers to find and retain providers willing to work for current rates who can deliver services of reasonable quality.

Recommendation 8. *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.

Recommendation 9. *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.*

The Independent Medical Review Process maintained by the California Department of Managed Health Care is an effective resource for resolving disagreements between health plans and patients. A similar process for resolving disagreements between regional centers and families would be perceived as fair and independent by clients and families and could be a useful resource for fair hearing officers.

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Recommendation 10a. *Create a budget allocation methodology that is equitable and supports careful stewardship of public funds. A standardized instrument that assesses client support needs should be used in making per capita funding decisions.*

Recommendation 10b. *Enforce the clause in regional centers' contracts with DDS that requires regional centers to ensure that services "are provided within the funds identified in ...the contract" except in extraordinary circumstances.*

To control growth in the purchase of services, the State has traditionally used unallocated reductions and related cost-saving approaches without providing policy guidance to regional centers about how savings should be achieved. When centers have failed to achieve the required savings, the state has repeatedly provided supplemental funding. This action rewards centers that exceed their allocation by increasing their funding base for the following year. It also punishes centers that live within their budgets by lowering their funding base.

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 in a reasonable for future generations. Failure to address the challenges in a comprehensive way will result in breakdown in the community service system.

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SUSTAINING THE ENTITLEMENT FOR THE DEVELOPMENTAL SERVICES SYSTEM:

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PURPOSE

In 1969, the state of California passed the Lanterman Mental Retardation Services Act (AB225). This act authorized the creation of a statewide network of community-based agencies, called regional centers, to provide or coordinate services and supports for individuals with mental retardation throughout the lifespan. The mission of these organizations was to enable these individuals to live independent, productive and normal lives and be integrated into the mainstream of life in their home communities.

In 1985 in *Association of Retarded Citizens – California et al, Plaintiffs and Respondents, v. Department of Developmental Services et al, Defendants* (subsequently referred to as the ARC decision), 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 1969 have made it increasingly difficult for the State to ensure funding that is adequate to implement this entitlement.

Given the repeated economic fluctuations in California over the last three decades, 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 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 changes to the Act that could moderate cost escalation, better ensure equity, and result in an entitlement program that is sustainable given the State's financial resources. That is what this paper is intended to do.

The Board of Directors of Frank D. Lanterman Regional Center has always been a strong supporter of the Lanterman Act and the entitlement that it bestows on Californians with developmental disabilities. It is for this reason that seven 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 years, these structural problems have continued to grow. While the Lanterman Act underwent significant amendments in 2008 and 2009 to address some of these problems, the community-based service system continues to be under extreme stress and has its very existence threatened primarily due to inadequate funding.

Organization of this Paper

The first section of this paper provides a description of regional centers and the individuals they serve. This is followed in Part II 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. The history section provides a context for the discussion in Part III that explores the changes in the service system,

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target population and financing that have created a tension between the 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 budget – currently about 85 percent. The remaining 15 percent is devoted to direct services provided by the regional center and operations costs such as rent, equipment and supplies. This paper concludes with a series of recommendations for changes that we believe 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.

The Vision of the Lanterman Act

We strongly support the vision of the Lanterman Act and 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 became 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. We emphatically reject a return to the service models of the past and strongly endorse the development of innovative models that are individualized, that increase opportunities for individuals to be included with their non-disabled peers in all aspects of their lives and that are cost-effective and compatible with fiscal realities.

It is possible to support the concept of an entitlement while also supporting the establishment of standards defining how the entitlement should be managed. In previous versions of this paper we have taken this position in an attempt to promote a constructive dialogue about changes to the system that would allow the entitlement to be sustained for future generations. Given the virtual certainty that the State's dismal economic climate will take years to improve, 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.

In 2008 and again in 2009, in response to continuing fiscal challenges, the State amended the Lanterman Act in an attempt to address some of the structural problems inherent in the developmental services system. These change resulted in a somewhat clearer definition of the

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entitlement and some were consistent with recommendations made in previous versions of this paper.

Several of the changes made by the State focused directly on reducing costs. These include stricter eligibility criteria, parent cost sharing for some services, a series of rate freezes followed by rate reductions for community-based service providers and unallocated reductions to regional center budgets. While achieving cost savings in the short term, the actions against service provider rates have had serious negative consequences on the community service system. Further, funding reductions without accompanying policy guidance reflecting priorities have both failed to achieve the required savings and contributed to increasing inequities within the system. 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 offers a regional center perspective on the issues. Given our mandated role of system coordinator among individuals with developmental disabilities and their families, community service providers, generic agencies, and state and federal agencies, regional centers have a unique vantage point from which to view the developmental services system. We 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. We 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. The analyses and opinions expressed in this paper are those of the Board of Directors on Lanterman Regional Center. They do not represent the opinions of other regional centers or the Association of Regional Center Agencies.

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PART I: WHAT IS A REGIONAL CENTER?

A regional center is a community-based non-profit corporation chartered in state law (W & I Code, Section 4400 et seq.) and operated under contract with the state Department of Developmental Services (DDS). It 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; (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. Substantial impairment means the existence of significant functional limitations in three or more of the following areas of major life activity, as appropriate to the age of the person: self-care; receptive and expressive language; learning; mobility; self-direction; capacity for independent living; and economic self-sufficiency. When the Lanterman Act was written, eligibility required two or more areas of functional limitations. This requirement was changed in 2003.

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 (AB225) and the Early Intervention Services Act (SB1086). 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 most services purchased by regional centers for clients and families. The law provides for cost-sharing by families whose minor children live in a licensed home and for families receiving certain services for their minor children.

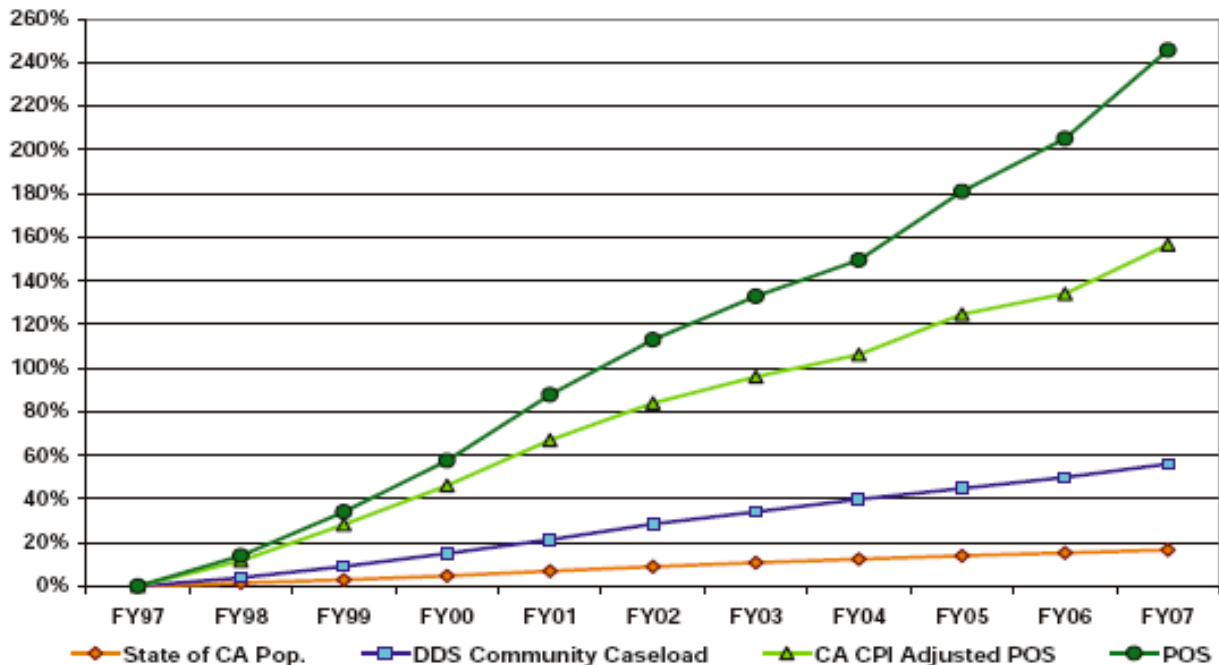
The regional center system is funded through a combination of state and federal funds, totaling approximately \$4.2 billion system wide for fiscal year 2010-11. Regional centers currently serve more than 240,000 individuals throughout the lifespan. Approximately 41 percent of people served are children birth to 13 years of age, and another 17 percent are adolescents and young adults aged 14 to 21. Fully 46 percent of clients served are individuals with mental retardation while an additional 28 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 19 percent of the regional center client population, the number of individuals diagnosed with this disorder increased in California by 321 percent between December 1997 and December 2007. The vast majority (96 percent) of children under 18 years of age live at home with their families, as do 55 percent of adults. Fewer than one percent of individuals with developmental disabilities now reside in state developmental centers.¹

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The regional center population has been increasing at a rate significantly higher than overall increases in the State’s population. For example, from 1/1/97 through 12/31/07 the number of persons served by the California Department of Developmental Services increased 59.6 percent, while California’s general population grew by approximately 18.1 percent.

The cost of purchasing services for clients has increased even more rapidly. Between 1997 and 2007, the cumulative growth rate for purchase of service (POS) dollars in the regional center system was approximately 246 percent while the community caseload grew by just under 60 percent. Adjusted for changes in the California Consumer Price Index (CA CPI) the POS increase was approximately 156 percent. The graph below provides a summary of the increase in the state population, the regional center population, and purchase of service spending over that period.

**Comparison of Cumulative Growth in POS, CA CPI Adjusted POS,
DDS Community Caseload, and State of California Population**
Fiscal Years 1996/97 Through 2006/07



(DDS *Fact Book*, Eleventh Edition, October 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 residential care, day programs, respite, transportation, and behavior management. Regional centers 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, county mental health departments, Medi-Cal, the Social Security Administration, and the state Department of Rehabilitation. They also work with voluntary community agencies such as the YMCA that serve the general public.

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Part II: DEVELOPMENT OF REGIONAL CENTERS AND THE ENTITLEMENT

In California, families of children and adults with developmental disabilities and professionals working in the field are 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.

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 admission.

If families chose to care for a child with developmental disabilities at home, they 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 established their own 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) 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 legislation 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 with a developmental disability. 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 a million dollars, for an average service cost of \$1,728 per person. Based on the success of the pilot program, 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.

Within a decade, the regional center system was serving nearly 34,000 individuals with a budget of \$48 million, and 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. Centers' allocations were sometimes insufficient to meet service needs, and DDS would seek supplemental appropriations from the

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Legislature. For their 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.

Expanding the Regional Center System

During the decade 1975-85, eligibility for regional center services was expanded to include other developmental disabilities, as discussed in Part II. The governing legislation, now called the Lanterman Developmental Disabilities Services Act, included a requirement for an individualized planning process and a statement of client/family rights, including the right to appeal regional center decisions .

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 as well as transportation to these settings. Family support in the form of respite service was added as a benefit 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 had declined 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 defined an entitlement to services and that these cost-saving strategies that denied people services 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 limiting the entitlement. This decision created a dilemma for regional centers that exists to this day: 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 fixed 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. This 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 including a process to ensure client and parent choice.

As the State interpreted the choice requirement, it obligated regional centers to vendor virtually any service provider satisfying minimum DDS requirements. As has been demonstrated in health care, increasing the number of providers of a service generally results 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. The 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 combined with the strong emphasis on parent choice and insufficient regional center staffing made it virtually impossible for centers to enforce standards for service quality in these service areas.

The HCBW program brought a significant influx of federal dollars, but the State used these funds to offset general funds going to regional centers rather than to 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 limitations. Changes occurred in the economies of the State and nation as well as in the service model for individuals with developmental disabilities. During this period, legislation expanded the entitlement, increased the types and number of services regarded as necessary and appropriate for individuals with developmental disabilities and led 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 describing 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

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to create a unique expenditure plan in accordance with guidelines issued by DDS. DDS retained the 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 and across-the-board cuts were used repeatedly over the next two decades. This strategy contributed to inequity in funding across regional centers. One reason was that centers with historically lower per client expenditures had to meet the same criteria for reductions as centers with higher per client spending. Secondly, regional centers that failed to live within their budgets were repeatedly “made whole” by the State through supplementary allocations.

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. In an attempt to ensure access to services within the limits imposed by the budget while maintaining the entitlement to services, the state Legislature enacted SB 485. 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.”

SB485 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 regional centers authority as well as flexibility to more effectively manage their budgets. This authority ended in January of 2001 when SB 485 was allowed to “sunset”. The provision for parental financial responsibility was also allowed to sunset in 2001, but it was reinstated in 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 SB1383 that made important changes to the Lanterman Act. This bill updated the philosophy of the Act 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 that were not to be viewed as expanding the entitlement. Partly for this reason, the Legislature passed the bill without analyzing its fiscal impact.

SB1383 actually 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 of these was an endorsement of services provided in “natural environments” to promote community integration. Such services utilized strategies such as trained aides providing individual support to children and adults with developmental disabilities so they could 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 community, although a relatively small number were

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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 level of support needs, 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 percent 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, 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. The decision to accept federal funding resulted in children and families gaining access to a wider range of services. Federal regulations included an exhaustive list of services and supports that were required under the program.

Although the federal government allowed states to assess parental fees for early intervention services, California 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 (DC) population had fallen to 5,100 and regional centers were serving nearly 130,000 people. (As of this writing, approximately 2,100 residents remain in the four developmental centers.) The annual budget for regional centers had risen to more than \$941,515,000, more than triple the amount of a decade earlier. 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 38 percent.

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Increasing Inequities in Service Rates

In 1998, a bill was passed in the California Legislature requiring DDS to address the inequities that had developed in the rate system applied to developmental services. (See the discussion of Issue 7.) 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. 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 service quality. By 2001, this reform process was stalled and has since been abandoned owing to the State’s fiscal situation.

California’s 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 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 July of 2008, certain programs for which regional centers had previously negotiated rates became subject to a new rate structure. Negotiated rates were intended to fairly compensate new and innovative types of services for which traditional rate models were considered inadequate due to the high level of need among the clients they served. Henceforth, new programs in this category would 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. Further, if regional centers were able to negotiate a rate lower than the median, they were instructed to do so.

In February of 2009, following five years of frozen rates, the Legislature passed an 18 month budget containing a 3 percent rate reduction (called a “discount”) for most service providers. This reduction was made retroactive – that is, effective for the entire 18 months. At the same time, the Legislature ordered DDS to achieve additional savings of \$100 million in regional center purchase of service budgets in 2009-10. The 3 percent reduction was continued in 2009-2010 and an additional 1.25 percent discount was added for the 2010-11 budget year.

Some increases in payments to providers have been granted for specific purposes related to changes in programs such as increase in staff-to-client ratios. There have also been changes in the minimum wage, and other increases, such as a 25 percent (subsequently reduced to 15 percent) increase to supported employment providers which have been in response to political pressures or strong advocacy. In the past, residential providers sometimes have received increases in the federal portion of SSI, but these increases have not been “passed through” by the State for four years. 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. Others, were it not for their fundraising efforts, would be forced to close their doors also.

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The repeated use of unallocated and across-the-board reductions 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 approach to budget reductions 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. 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 historical per capita spending. These disparities have continued to increase, thereby increasing the inequities resulting from this method. While in 2002-03 the highest per capita allocation for a regional center was approximately 190 percent of the lowest, in 2006-07 2010-11 the highest was more than 220 percent of the lowest.

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 that the process did not ensure that clients throughout the State have equal access to needed services and, further, 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 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, this matter has never been resolved.

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 services for young 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 resorted to across-the-board budget reductions with no accompanying policy guidance.

In responding to budget reductions, some centers not only met their goal but also generated additional savings. 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 totaling \$74 million to make the deficit centers whole.

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The fiscal situation in California continued to worsen into 2003-04. This and other factors resulted in a campaign to recall Governor Gray Davis. Arnold Schwarzenegger was elected governor in October of 2003 on a platform promising to solve the budget crisis.

In November of 2003, Governor Schwarzenegger 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 proposals, aimed at programs outside of developmental services, would also 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 Childrens Services.

The Governor’s 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 while preserving the entitlement. The alternative proposals, presented in January of 2005 included co-payments for families of minor children over age three, the creation of service standards, development of standardized rates for purchased services and an unallocated reduction in regional center administrative costs. While putting forth these recommendations for cost savings, he asked “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.” With the exception of a parental cost-sharing requirement, the recommendations made by the governor were rejected.

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 a February 2008 special session of the Legislature a number of the proposed cost-cutting strategies were approved for immediate implementation, outside of the budget cycle. These included prohibition on the use of purchase of services to develop new programs, 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.

Beginning to Define the Entitlement

The governor and Legislature continued to look for strategies to contain costs, but, in her report of February 2008, the Legislative Analyst made it clear that the State had a serious structural deficit problem that could 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 asked DDS to submit an exhaustive list of options to contain the developmental services budget.

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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 closed a funding gap of \$24.3 billion. It included an expansion of 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 Budget Act of 2009-10, describing an 18 month budget, was enacted in February of 2009. It included \$100 million in regional center cost containment measures resulting from significant changes to the Lanterman Act. The Governor also vetoed an additional \$50 million in purchase of services funding for services provided by regional centers to eligible children up to age 5. These services were eligible for funding from the California Children and Families Commission which was established by Proposition 10.

A deepening recession in 2009 required a subsequent budget amendment to deal with an additional \$24 billion budget gap, bringing the total for the year to \$60 billion. The amendment included a \$234 million cost containment target for the Developmental Services system. These savings were to result from a variety of proposals developed by DDS in cooperation with stakeholder groups.

The changes of 2009 constituted the first significant effort to shape the entitlement. They included stricter eligibility for early intervention services, limitations on the types of services that could be purchased for early intervention clients, increased cost-sharing for families (including expanded use of private insurance), and other limits on the types and amounts of services that could be purchased for clients over age 3. These changes allowed the DDS to achieve the savings goals set by the legislature.

The budget for 2010-11, agreed to after another record-setting delay, was signed in October of 2010. It closed a \$19.3 billion gap, bringing the total budget “solution” for the three year period to \$103.6 billion. This budget included an additional 1.25 percent across the board reduction to both regional centers and service providers.

As of this writing, the budget situation remains bleak and shows no signs of improving. The deep recession and accompanying unemployment have resulted in decreased revenues for the State and increased demands for unemployment compensation and other public benefits. The situation is not expected to improve until the next decade absent structural changes to the budget or increased tax revenues. Governor Brown has indicated that he will reopen the budget and make additional cuts. It is expected that this will include cuts to Developmental Services.

Looking Ahead

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 and how the State will pay for them. 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

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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 was never approved but 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 and the incoming administration must seize the opportunity at this critical juncture to make the investment in rational system change that 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.

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PART III: ISSUES AND RECOMMENDATIONS

In this section, we discuss in greater detail 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 goals of improving service quality, increasing equity, and limiting the cost escalation that threatens the future of the community-based system serving people with developmental disabilities.

In deliberations leading up to the development of this paper, concepts and techniques of managed health care emerged as having potential for addressing some of the challenges faced by the developmental services system. Systems for managing the delivery and financing of health services have evolved in response to the real and profound inadequacies in U.S. health care and a growing realization that the country can no longer support a 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 to manage health services have been measurably effective in improving access and quality and containing costs.

The parallels between health services and developmental services are clear. In both systems costs have increased 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 service users. 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. Changes to the Lanterman Act implemented in 2008 and 2009 have provided some structure for the benefit, but the entitlement is still highly individualized, and uncapped in many areas. At the same time, it is funded through an annual budget appropriation that is finite and vulnerable to economic downturns.

The changes implemented in 2008 and 2009 have provided a significant amount of structure for the benefit. It has capped some services, created stricter eligibility criteria for some and required increased use of generic resources prior to the regional center purchasing services. The changes also suspended the purchase of non-medical therapies pending the implementation of the Individual Choice Budget.

The benefit is still undefined in many areas, however. In addition, the Trailer Bill Language of 2009 allows for “exemptions” to a number of the new provisions. As discussed earlier, for each client, the entitlement is individualized based on what is written into the Individual Program Plan. From an economic perspective, the current policy framework still presents challenges to regional centers attempting to effectively manage this entitlement.

The expansiveness of the benefit 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

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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....” Further, 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 expansive array of services and supports, the State has established few service standards and no 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 the parent’s role in deciding what services and supports are necessary for their children.

Without additional clarification of the definition of the entitlement, what is considered a *necessary* service will remain subjective and will continue to be subject to disagreement between parents and regional centers. Such disagreements arise more frequently among parents of higher socioeconomic status (SES). Children of higher SES parents receive a disproportionate share of services. Several studies have revealed disparities in service use and expenditures related to ethnic and cultural differences which, in turn, are related to socioeconomic status.²

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 ability to advocate 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 has been tested within the State. DDS has engaged an independent consulting group to assist in the development of a tool to assess service need in the context of the Individual Choice Budget program once it is implemented.

Juxtaposed with the 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 imposes significant compliance requirements on centers but gives them 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. For example, centers were authorized to use vouchers to reimburse parents for certain purchases or to cover the cost of transporting their sons or daughters to day programs. Vouchers became a powerful tool for managing costs in some centers. Most of the changes resulting from B 485 were allowed to sunset in 2001, although the use of vouchers continues in some centers.

The Budget Trailer Bill language of 2009 began the process of defining the entitlement and the State should complete the process. It should develop additional service standards, create criteria defining exemptions to these policies, and ensure that all centers revise their funding policies consistent with the new requirements. Finally, the State should monitor implementation of the standards to ensure, for example, that one regional center does not have a disproportionate number of exemptions.

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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 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 help 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.

Recommendation 1. *Further specify the services included in the “benefit package” defined by the entitlement, develop uniform service standards and priorities so that these services are authorized equitably across regional centers and across clients and monitor compliance.*

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 services, the utilization of which is driven by the principles of client/family preferences and choice.

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 custodial care, it has evolved to emphasize inclusion and 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 person has increased markedly. In addition, advances in knowledge and innovations in technology, combined with a lack of rigorous criteria for vendoring services, have resulted in a large number of new providers and new service types, some of which are very costly and sometimes of unproven effectiveness.

The Lanterman Act has long contained provisions for innovative and economical means of meeting needs in the Individualized Program Plan, but choice has been the predominant value. The 2009 changes to the Act constrained choice to some extent due to the requirement for regional centers to use the lowest cost service that meets the client’s need. Still, for many of these new services, less costly alternatives do not exist. A 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 (Section 4689).” Furthermore, it is intended that “the consumer’s preference shall guide decisions concerning where and with whom he or she lives (Section 4689).” The Lanterman Act specifies no eligibility criteria for supported living for a person over the age of 18.

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

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activities of daily living can now live on their own in the community. As recently as 20 years ago, these individuals 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 can entail significant costs. For example, the cost of supporting clients with severe medical or behavioral challenges can exceed the cost of care in a developmental center. Title 17 [58617(a)(1)] of the California Code of Regulations states that the cost to the regional center for supported living should not exceed the cost required to support a client with similar support needs in a licensed home, but this provision has not been consistently enforced. The expectation originally put forth by DDS was that supported living would be cost-neutral, but the State did not conduct an analysis of the potential costs. An alternative to supported living for many people is a licensed home of an appropriate level. While still expensive, costs in such a setting would be moderated by the fact that the clients share the residence.

The Trailer Bill of 2009 included several changes related to supported living that were intended to control costs. For example, if two or more clients share a home, the regional center is required to use the same supported living provider for all clients in the home. In addition, the regional center is required to ensure that clients in supported living make maximum use of generic services for which they are eligible. These changes are reasonable but fall far short of adequately addressing the cost issues presented by a system in which supported living is seen as appropriate for all. The State has never had the discussion of the circumstances under which it is reasonable for public dollars to pay the cost of supported living for a person with a developmental disability who has extraordinary support needs. In a system with finite financial resources, we believe choice must be balanced against economic realities.

Intensive autism services. One of the fastest growing service costs has been 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, challenging behaviors and self-regulation. .

These comprehensive programs are expensive, both because they are intensive (regional centers typically purchase 15-20 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. Children receiving these intensive services may also receive ancillary services such as occupational therapy, physical therapy, and speech and language services.

The number of children receiving intensive autism services has increased significantly over the past five years due to the growth in the number of children diagnosed with autism, rising awareness among parents and professionals about the availability of these services and increased demand for the services from parents. Additional increases in the number of children entering Early Start and receiving intensive services can be expected as a consequence of the practice guidelines promulgated in 2007 by the American Academy of Pediatrics recommending that all children be screened for autism at 18 and 24 months.³

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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 as good as, and often more cost-effective than, individual modalities for delivering services. In support of this, the Trailer Bill Language of 2009 included a requirement that regional centers consider the use of group parent training in behavior services (including intensive services) prior to purchasing one-to-one interventions.

Recommendation 2a. Impose a moratorium on supported living while developing clear criteria for eligibility for the service and for exemptions and enforce the cap on costs of this service as required by the Lanterman Act.

Recommendation 2b. Provide regional centers support in their efforts to monitor the types and intensities of services provided to young children with autism. (See recommendations 8 and 9.)

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 parents' financial responsibility to provide for their child with a disability as well as a family's responsibility for an adult family member with a disability.

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 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 minor children live out-of-home. In 2005, an additional cost-sharing requirement was implemented for families receiving respite, camp, or day care for their children. The intent was to require cost-sharing for services that are of primary benefit to the family rather than only the client. In 2008, the Legislature expanded this program to include Early Start services and lowered the income threshold at which parents were required to pay 100 percent of the cost of the service. Finally, 2009 changes included in the Budget Trailer Bill required parents of children receiving Early Start services to utilize their private insurance before the regional center would purchase specified therapies. That legislation also limited circumstances under which the regional center would purchase transportation. Changes included the requirement that adults use

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public transportation if they are able and that centers not purchase private transportation for children unless it is necessary to allow the family to keep the child at home.

Transportation has been a significant cost driver for regional centers. Despite the 2009 changes, regional centers still spend more than \$200 million each year purchasing transportation. We believe that it is reasonable for families to assume financial responsibility for transportation of their family member of any age who lives at home unless they can demonstrate that doing so would result in a financial hardship. In cases of financial hardship, the regional center could reimburse the family for necessary transportation under a voucher program. Further, adult clients who are financially able should be required to purchase their own bus passes, and adults in supported or competitive employment should be required to obtain their own transportation to and from their job. Finally, residential providers should be required to transport their clients to day programs using a stipend reimbursement from the regional center. These strategies are eminently doable, having been implemented by Lanterman Regional Center for two decades. It is our belief that implementation of these policies statewide would result in savings of \$100 million in purchase of services funds – funds that could be invested in other necessary services. To ensure equitable application of these provisions, the State should also develop a clear definition of financial hardship.

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 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 and consistent statement about parental financial responsibility for their child with a disability, some families 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 little if any corresponding financial obligation on the part of parents.

Implementation of clear and reasonable limits on the regional center’s responsibility for providing services to children is necessary to ensure the public dollars are fairly expended. We see no rationale for selectively applying the requirement for cost sharing to specific services and would recommend its application to all services received by minors. The cost of services to children varies greatly depending upon the type and intensity of service, so a flat percentage copayment may not be the fairest way to implement cost participation for parents. Further, the impact of any system should be carefully monitored to ensure that it does not create barriers to needed services.

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An additional generic resource for families as well as a source of federal funds for the State is the Institutional Deeming program that provides Medicaid coverage for children who would not normally qualify for Medicaid because their parents' income is too high. Parents must complete an application process for their child to be enrolled in this program, but the State allows them to decline to apply. Those who decline generally do so because the application process requires them to disclose personal financial information. Regional centers are obligated to protect the confidentiality of personal – including financial – information for all clients and families. Given this, there is no justifiable reason for families to resist sharing such information with the regional center and for declining to apply for Institutional Deeming for their child.

Recommendation 3a. *Expand the requirement for cost sharing, based on ability to pay, to all services provided to children living at home but ensure that the requirement does not create a financial hardship for families or otherwise constitute a barrier to needed services.*

Recommendation 3b. *Require families to enroll eligible infants and children in the Institutional Deeming program.*

Recommendation 3c. *Require families to assume financial responsibility for transportation of their family member who lives at home unless they can demonstrate that doing so would result in a financial hardship, and provide stipends to residential providers to transport residents to day programs.*

Recommendation 3d. *Develop a definition for financial hardship that can be used statewide.*

Issue 4. The Trailer Bill language significantly changed eligibility criteria for the Early Start Program. As a result, high risk children and children with less significant delays no longer receive purchased therapies, only developmental monitoring and referral to community resources. Failure to provide early intervention services, while bringing small short-term savings, may result in increased costs to the State in future years.

While we believe that many of the changes made to the Act in 2008 and in the Budget Trailer Bill of 2009 will enhance the regional center's ability to manage the benefit of the Lanterman Act in a way that is fair and increases equity, we also believe that the changes to the Early Start program may well result in additional costs to the State in future years. The Trailer Bill limited eligibility for Early Start services and mandated regional centers to create Prevention Programs to serve infants and toddlers who in the past would have been served by Early Start but are not eligible under the new criteria which require higher levels of delay.

The Prevention Program provides no purchase of therapies or infant development services but does provide parent training, referral to community services and, most importantly, ongoing developmental monitoring. The number of children projected to qualify for the Prevention Program (and the corresponding savings to the state budget) was estimated to be 17,000, but the actual number as of September 2010 was slightly more than 3,000. This, it is believed, was due partly to the belief among referral sources as well as families that this new program offers no real benefit to

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infants and toddlers. In addition, we have found that some children who enroll in the Prevention Program develop additional delays before age 3 and transfer into Early Start. If these children had not enrolled in Prevention, they may not have had their delays detected and addressed until they reach school age.

Infants and toddlers should continue to be a priority for regional centers and for the State. Early intervention has been shown consistently to have substantial cost-benefit into clients' adulthood. The cost of Early Start services has been increasing consistently since the State joined the federal early intervention program, but the federal contribution remains constant. We recommend that the State study the consequences of disaffiliating from this program, and instituting more cost-effective strategies for providing needed services. These would include more extensive use of parent consultation models such as the Hanen "It Takes Two To Talk" program on language development in lieu of individual speech therapy. Such programs have been found to be cost-effective alternatives to individualized approaches. The State should also consider the use of Proposition 10 funding to support regional center early intervention programs beyond the amounts obtained from that program in the past two fiscal years.

Recommendation 4a. Reinstitute the eligibility criteria for the Early Start Program that were in force prior to 2009 and study the impact of disaffiliating from the federal early intervention program.

Recommendation 4b. Investigate the impact of withdrawing from the federal early intervention program and funding the Early Start program with Proposition 10 dollars.

Issue 5. The ambiguity that remains in the definition of the entitlement combined with the right of clients and families to appeal virtually any decision made by a regional center contribute to an environment that encourages families to appeal and administrative law judges to exercise overly broad discretion in interpreting law and regulation in their fair hearing decisions. Such decisions have resulted 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.

The recent changes to the Lanterman Act did not include any limitation on the rights of parents to appeal regional center decisions implementing these changes. They also gave the regional center executive director the right to grant exemptions to specific limitations for certain services. While some centers have created criteria clarifying when exemptions may be granted for certain services, there is no uniformity of criteria across centers. To comply with the spirit of the Budget Trailer Bill language, when denying all or part of a service, Lanterman Regional Center specifically informs

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families that they do not qualify for an exemption when this is the case and includes that provision when quoting the law supporting the denial.

Disability Rights California encourages parents to appeal any service reduction, even if made as a result of legislative changes. The knowledge that exemptions exist provides additional motivation for families to appeal. The legislature has, in the past, limited families' right to appeal based on legislative mandates. For example, decisions that may be appealed by families are limited in both the Family Cost Participation Program and the Prevention Program. Additional restrictions on what is subject to appeal are not unreasonable in light of the Legislature's clear intent to limit the scope of the entitlement.

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

Following implementation of the 2009 changes to the Lanterman Act, some regional centers have reported a corresponding increase in the consistency of judges' decisions and adherence to the intent of the law especially when dealing with these new aspects of the law. At the same time, there is still ambiguity elsewhere in the Act that provides opportunities for misinterpretation.

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 to overturn 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. While the right of clients and families to appeal should be protected, fairness requires that DDS have a right to review and overturn decisions of OAH hearing officers if they are based on flawed or overly broad interpretation of the Lanterman Act. The department 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.

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Recommendation 5a. *Establish a system for administrative review of OAH decisions to ensure that hearing officers correctly interpret applicable laws and allow the Director of DDS to overturn decisions that result from an overbroad or incorrect interpretation of the Lanterman Act.*

Recommendation 5b. *Limit client and family rights to appeal to services and supports in the benefit package.*

Issue 6. Parent and client choice is frequently a greater determiner of which services become vendored and which services are purchased than are provider competence or quality of services provided.

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 (Section 4648.)

Frequently, parents independently identify a service that they believe will benefit 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. 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 State’s interpretation of the federal requirement that 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 minimal standards established by the State. If a potential provider satisfies these regulatory criteria, a regional center is required to vendor it and a family may choose that provider over the objections of the regional center. Regional center service coordinators work with families to guide them to providers who have demonstrated a capacity to provide high quality services, but not all families can be persuaded to accept an alternative to their choice.

Existing standards generally address credentials of individual professionals and structural and process aspects of programs. Such standards rarely are discriminating enough to allow the regional center to deny a service provider vendorization. More importantly, due to insufficient staff, centers have limited oversight capacity to ensure that the services actually delivered by that provider once vendored are of reasonable quality and effective in achieving desired outcomes.

Regional centers have no effective authority for engaging service providers in activities aimed at raising the level of quality. Furthermore, given the outdated rate structure for many services, there is little financial incentive for providers to participate in quality improvement activities, 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 that their only obligation is to meet those requirements. Providers whose services are judged to be unacceptable 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.

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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 to signify agreement. 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 may then request the service independent of the IPP process. Some families have even begun the service and asked 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 innovative or 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.

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 ongoing quality management programs. Lanterman Regional Center has more than 1,100 vendored service providers from whom the center directly purchases services. (This is in addition to parents who are vendored so they may be reimbursed through a voucher system for services that they purchase independently for their sons and daughters.) Juxtaposed with this large number of providers is the core staffing formula used by DDS to determine funding for regional centers. This formula provides for staff to monitor quality of residential services and for other positions dedicated to quality assurance. These positions, however, are funded at a salary level that allows the center to maintain only a fraction of positions that would be required for effective monitoring.

QA staff members are required by law to monitor residential services twice a year. Until 2009, they were also required to conduct a comprehensive review of each facility and its residents’ records every three years. This review was eliminated by DDS as a cost-cutting measure. In 2005, the Department 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. They focus primarily on the needs of individual clients rather than quality issues related to programs. Further, they generally have neither the knowledge nor the focus to carry out a monitoring activity independently.

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A number of centers have developed quality standards in an attempt to establish a network of “preferred providers,” but the Lanterman Act provides no basis for them to enforce such standards. Regional centers should be given the authority to develop and enforce reliable and valid standards that they can use for deciding whether or not to vendor and subsequently use a provider. Alternatively, the State should collaborate with regional centers to develop a common framework for use as a basis for the development of such standards. The existence of meaningful standards would provide a foundation for ensuring that regional center clients receive appropriate care. With the authority to enforce quality standards, regional centers would still have a sufficient number of providers to ensure that the State could meet the federal requirement for client choice.

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 even though they have a more direct effect on the quality of clients’ lives. 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.

The National Core Indicators (NCI) system has shown promise as a tool for monitoring client outcomes and a mechanism for service providers to demonstrate accountability. The NCI program is a joint venture between the National Association of Directors of Developmental Disabilities Services and the Human Services Research Institute. It was launched in 1997 and is currently used in at least 28 states, including California. It was implemented in California as a result of the 2009 Budget Trailer Bill as a cost saving strategy. It employs nationally recognized performance and outcome indicators that enable state developmental disabilities agencies to track system performance and outcomes from year to year on a consistent basis and allow service providers to assess their own performance against other providers of the same service.

Recommendation 6. Give regional centers authority to establish standards for vrending providers that exceed Title 17 regulatory requirements and to develop standards for service quality that can be used to identify “preferred” providers based on performance.

Issue 7. The current methods used by DDS to determine rates for services, combined with a series of rate freezes and rate reductions, contribute to underfunding and inequities between old and new 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. DDS-established rates apply to residential, day, independent living and infant development services and 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. For the past eight years,

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however, DDS has not solicited cost statements and has allowed the temporary rate to become the permanent rate.

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 reasonable 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. If the regional center is able to negotiate a lower rate than either the local or statewide median, that is the rate that applies. Rate policies will drive older providers out of business and limit regional centers' ability to gain access the new resources that come about as a result of increases in knowledge and technology.

The financial situation has become particularly grave for residential service providers. Other than minimal increases for direct care wages, licensed homes have had no meaningful rate increases in more than 20 years. In 2008, they did receive a 3 percent increase, but this was followed in 2009 by the 3 percent reduction and in 2010 by an additional 1.25 percent reduction. These reductions applied to all services reimbursed under the median rate structure or under DDS-established rates, except to supported employment services.

The current residential rates were established in the late 1980s and were supposed to be periodically adjusted based on DDS surveys. These surveys have never been completed. The only rate increases received by these service providers consisted of the "pass-through" of the increase in their residents' SSI. For the last four years the State has failed to pass this increase along to residential providers. As a result of this debilitating funding situation, potential service providers are reluctant to develop new homes. Regional centers are also now faced with a number of licensed homes in foreclosure. Ten homes in Lanterman's area have closed since 2008. Eight of these homes closed because the rates were not adequate to justify the providers' continued operation. Closure of the remaining two was related directly to foreclosure by financial institutions.

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 costs of providing services. The Act also states, however, that rate increases are contingent upon annual budget appropriations. The community services system cannot survive without rational adjustments to rates to reflect the real cost of providing services.

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Recommendation 7. *Develop a rational system for determining rates based on the reasonable cost of service and for regular review to ensure that rates continue to cover costs.*

Issue 8. There is no mechanism to ensure that service modalities used to serve regional center clients are efficacious.

Interventions intended to address medical, psychological, or other developmental challenges should be subjected to scientific study to determine that they are *efficacious* (effective when delivered under controlled conditions) before they are used routinely in the community. The standard method for addressing this question 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 has been demonstrated to be efficacious 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, for 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 often requested by parents and purchased by regional centers, particularly for young children with autism, have not been subjected to rigorous research and have little empirical support. For example, the Developmental, Individualized, Relationship-based (DIR) Model of intervention is regarded as a promising practice, but it is not supported by a sound research base.

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 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 2009 changes to the Lanterman Act prohibit the “purchase of experimental treatments or therapeutic services or devices that have not been clinically determined or scientifically proven to be effective or safe or for which risks and complications are unknown.” The definition of experimental when applied to behavioral or other psychosocial services is, however, very imprecise and difficult to apply to many therapies.

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

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“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.” While, in theory, this provision gives 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 particular modality or service approach, parents frequently disagree with the decision. These 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 clinical 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.

Currently, there is no qualified body that has been designated to advise regional centers on which services are experimental. To create an effective technology assessment function within a single regional center and pay for it out of operations funds may not be financially feasible. It would be feasible, however, to achieve this on a statewide basis. DDS could establish an apolitical, 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. 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

It should be noted that the Autism Advisory Committee to California’s Superintendent of Public Instruction, in its August 2007 report, 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...”⁴

Recommendation 8. *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.*

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Issue 9. 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. 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 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 specific case 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 services for children with autism 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 skill level. These factors may have a significant impact on the effectiveness of the service.

To answer the question of provider competence, a regional center would need to have access to qualified professionals who could review the service provider’s qualifications – considering 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 question – Is the service necessary and appropriate in this case and, if so, at what intensity? – 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 will affect them financially. 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

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genuine disagreement between the service provider and the regional center clinician about the necessity for the service or the appropriateness of continuing that service. In addition, in cases of disagreement, parents frequently side with the service provider, questioning the regional center's motive for limiting a service.

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 number addressed through formal technology assessment, but the questions would be simpler to answer. Consequently, it would be reasonable to organize regional peer review committees (perhaps through local universities) for this purpose.

The California Legislature has established a precedent for independent review of individual episodes of care. 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 services provided through regional centers, the benefit would be cost savings in addition to increased effectiveness of services purchased.

Recommendation 9. *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.*

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Issue 10. To control growth in the purchase of services, the State has traditionally used unallocated reductions and related cost-saving approaches without providing policy guidance to regional centers about how savings should be achieved. When centers have failed to achieve the required savings, the State has provided supplemental funding.

Since their initial use to control costs in 1991, unallocated reductions and related strategies focusing on costs absent clear policy direction from the State have often failed to achieve the necessary savings and, further, have contributed to inequity in funding across regional centers. For example, 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. Regional centers have only the goodwill of their communities on which to rely when budget shortfalls make it necessary to implement plans for reducing purchase of service spending. Although a powerful force, goodwill is not enough.

This strategy of unallocated reduction is now being used with services providers in the form of across-the-board rate reductions without additional guidance about what providers should eliminate from their services. The decision to focus strictly on dollars rather than on providing regional centers or providers with effective tools for managing their budgets has provided a straightforward and simple solution for the California Legislature. At the same time, it forces citizen boards, many of whom are themselves clients and parents of clients, to make ad hoc decisions on spending purchase of service dollars in the absence of clear policy. 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.

Such strategies have been unfair and inequitable in other ways since centers that have been unable to meet the challenge of reducing spending have traditionally been "bailed out" at year end, giving them little incentive to implement cost-saving strategies that may be unpopular in their communities. Further, under such a system, centers that work successfully with their communities to implement cost-saving strategies are faced with the perverse incentive of having their funding base reduced while centers that overspend increase their base for the following year.

The State must provide regional centers with a realistic uniform policy framework that supports regional centers' efforts to control costs and has statewide application. Further, to ensure the effectiveness of any methodology that is implemented, the State should ensure that all regional centers live within their budget except in the face of extraordinary circumstances. 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.

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Recommendation 10a. *Create a budget allocation methodology that is equitable and supports careful stewardship of public funds. A standardized instrument that assesses client support needs should be used in making per capita funding decisions.*

Recommendation 10b. *Enforce the clause in regional centers' contracts with DDS that requires regional centers to ensure that services "are provided within the funds identified in ...the contract" except in extraordinary circumstances such as in a case of significant unanticipated client growth.*

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.

¹*Fact Book, Eleventh Edition.* Sacramento, California Department of Developmental Services, October 2008.

² 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.

³ Plauch, C., & Johnson, A. (2007). Identification and evaluation of children with autism spectrum disorders. *Pediatrics*, 120(5), 1183-1215.

⁴ 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.