

December 1, 2015

Honorable Richard Pan
Chair, Senate Select Committee on Children With Special Needs
State Capitol, Room 4070
Sacramento, CA 95814

RE: ARCA Testimony December 1, 2015 Senate Select Committee on Children with Special Needs

Honorable Senator Pan:

The Association of Regional Center Agencies (ARCA) represents the network of 21 independent non-profit regional centers that coordinate services for, and advocate on behalf of, over 280,000 Californians with developmental disabilities, which include intellectual disability, autism, cerebral palsy, epilepsy, and conditions closely related to or requiring services similar to intellectual disability.

The developmental services system currently serves individuals in those five categories, but its origins were focused on only intellectual disabilities, what used to be called “mental retardation”. In 1969, in response to the grassroots advocacy of parents of individuals with developmental disabilities, the Lanterman Act was signed into law and established that “[the] State of California accepts a responsibility for persons with developmental disabilities and an obligation to them which it must discharge.” Today, these twenty-one regional centers work in conjunction with community-based service providers under contract with the state Department of Developmental Services to provide services to individuals with developmental disabilities as an alternative to institutional care. The state’s Supreme Court found in 1985 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.” This is the cornerstone of California’s community-based developmental services system, what many advocates refer to as “*our* Lanterman Act.” This entitlement sets California apart, and once made it a national leader. The state’s lack of investment in the service system now leaves it lagging far behind other states and falling further back each year.

The Function of ARCA

The mission of ARCA is to promote, support, and advance regional centers in achieving the intent and mandate of the Lanterman Developmental Disabilities Services Act in providing community-based services that enable individuals with developmental disabilities to achieve their full potential and highest level of self sufficiency. ARCA promotes the continuing entitlement of individuals with developmental disabilities to all services that enable full community inclusion. ARCA is also an active participant in the development of public policy and legislation, and provides communication, education, and training to its regional center members across the State of California.

Overview of Regional Center Services for Children and Youth

Regional centers are independent, nonprofit agencies that are the official point of entry to the state's service system for people with developmental disabilities and their families. Infants and toddlers (age 0 to 36 months) who are at risk of becoming developmentally disabled or who have a developmental delay may also qualify for intensive intervention services through the state's Early Start Program. For more than 280,000 Californians with developmental disabilities or in the Early Start Program, their regional center is where service starts. Included in this number are over 130,000 children under the age of eighteen. Businesses called "service providers" contract with centers to provide the many services and supports needed throughout an individual's life. This enables them to lead full, integrated lives in communities of their choosing. Each person's needs, goals, and services are described in an individual program plan (IPP) or individualized family service plan (IFSP). Regional centers' most visible role is to identify, coordinate, and monitor those services, but they also provide:

- Assessment, diagnosis, and referrals;
- Lifelong individualized planning and case management;
- Assistance in finding and accessing community and other resources;
- Payment for services included in the IPP/IFSP for which other funds are not available;
- Advocacy for the protection of legal, civil, and service rights;
- Early intervention services (Early Start) for at-risk infants and their families;
- Supports to help ensure individuals can remain within their family home;
- Planning, placement, and monitoring for 24-hour out-of-home care;
- Training and educational opportunities for individuals and families;
- Community education about developmental disabilities; and,
- Development of new services to better meet individual needs.

Funding Structure and Distribution

Regional centers work under contracts with the Department of Developmental Services. Funding for community-based developmental services is divided into two parts that work in tandem to both meet individuals' needs and fulfill state and federal mandates. The Purchase of Service (POS) budget allows regional centers to secure services for individuals from community service providers. The Operations (OPS) budget provides funding for assessment, service coordination, clinical services, quality assurance, programmatic functions, and administrative responsibilities, all of which are required to fulfill federal and state mandates. Funds allocated for POS can only be used for the direct benefit of specific individuals supported by the regional center.

Regional centers use person-centered planning to identify the services and supports needed by individuals and their families to implement each person's IPP, or for children under the age of three, their IFSP. For children and youth, these IPPs and IFSPs are developed by a planning team that includes the individual, the individual's parents, his or her regional center service coordinator, service providers, and others as appropriate or as invited by the individual or the individual's parents. The plan describes the supports and services the individual needs, and identifies who will provide and pay for those services. This process is time-consuming, but allows for the greatest customization of each individual's services to best meet his or her needs, while taking into account his or her preferences, culture, and lifestyle. This type of individualized needs-based determination has been the standard in California for decades and is consistent with recent federal guidance that requires a separation between service planning and service provision functions.

These services are funded through a combination of state and federal money. Approximately 40% of the system's funding comes from federal funding sources, which require the state to assure the federal government that certain requirements are being met related to quality service provision, individual choice, caseload ratios, and the health and safety of the individuals being supported. As the Lanterman Act established an entitlement for developmental services, California provides these valuable services to individuals regardless of family income or eligibility for Medi-Cal. In recent years, however, families have been increasingly expected to participate in the cost of certain services; the amount they contribute is based on their income level. Some families opt to pay for services themselves outright or to not participate in regional center services at all or based on the new requirements the system imposes on service provision. Some developmentally disabled individuals go without needed services because the service does not exist or is at capacity.

Current Challenges and Barriers

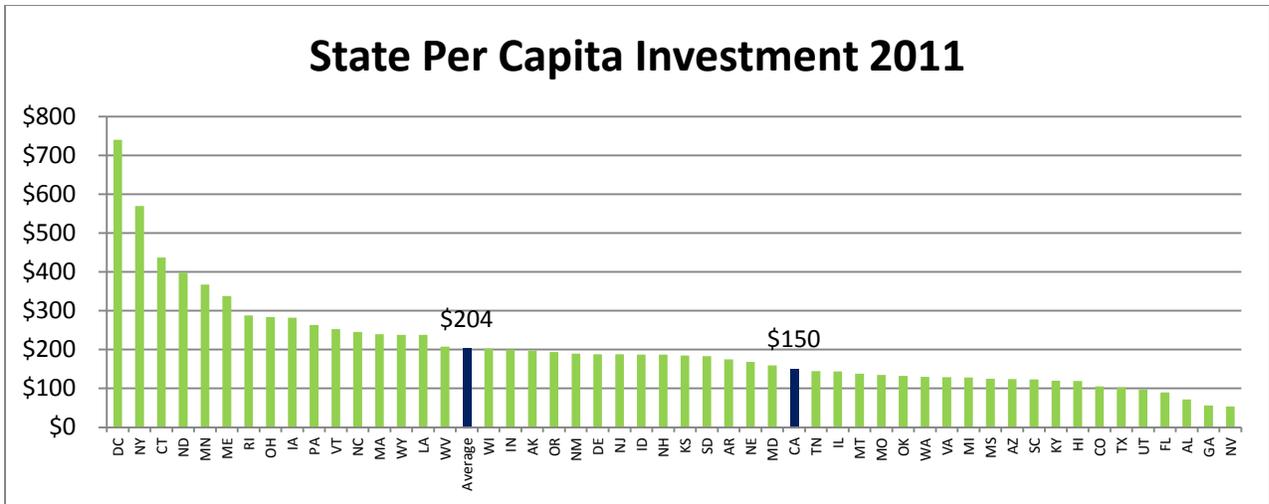
Years – and in some cases decades – of stagnant and reduced funding levels for service provider rates and regional center operations have left regional centers and their community partners all trying to do significantly more with far less. This underfunding is the result of various freezes and cuts that have been made in response to state Budget challenges for several decades. This problem was exacerbated by cuts made since 2008.

During the Great Recession, the community-based developmental services system sustained over \$1 billion in cuts, the largest of any health and human services program. In response, difficult choices were made that negatively impacted the service system. Some of these choices, such as limitations on respite care and funding for camp, put additional pressure on families supporting children with developmental disabilities at home – the very group that the Lanterman Act was designed to support. Additionally, from July 2009-January 2015 funded services were eliminated for infants and toddlers with less significant delays, which significantly hampered their ability to catch up to same age peers. Funding for this program has now been restored, but thousands of children missed out on crucial services during this time.

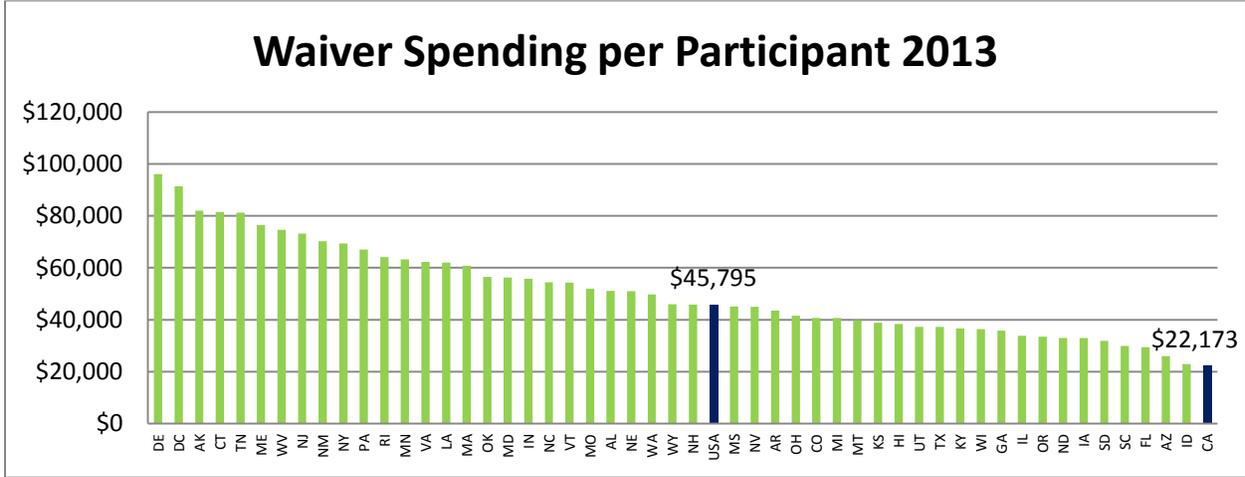
These cuts destabilized the developmental services system and have significantly compromised its ability to meet all of its obligations to individuals served, their families, and the federal government. Service provider rates and regional center operations funding suffer from chronic underfunding that threatens service quality, federal funding, and most importantly, the health and safety of the over 280,000 individuals served by the system today.

State law intends that services “maximize opportunities and choices for living, working, learning, and recreating in the community.” However, regional centers cannot always offer the most appropriate service for the individual's needs, only what is available given the current environment.

In 2011, California invested \$150 per resident of the state in its developmental services system. In contrast, the average state expended \$204 per resident, 36% more than California's investment.



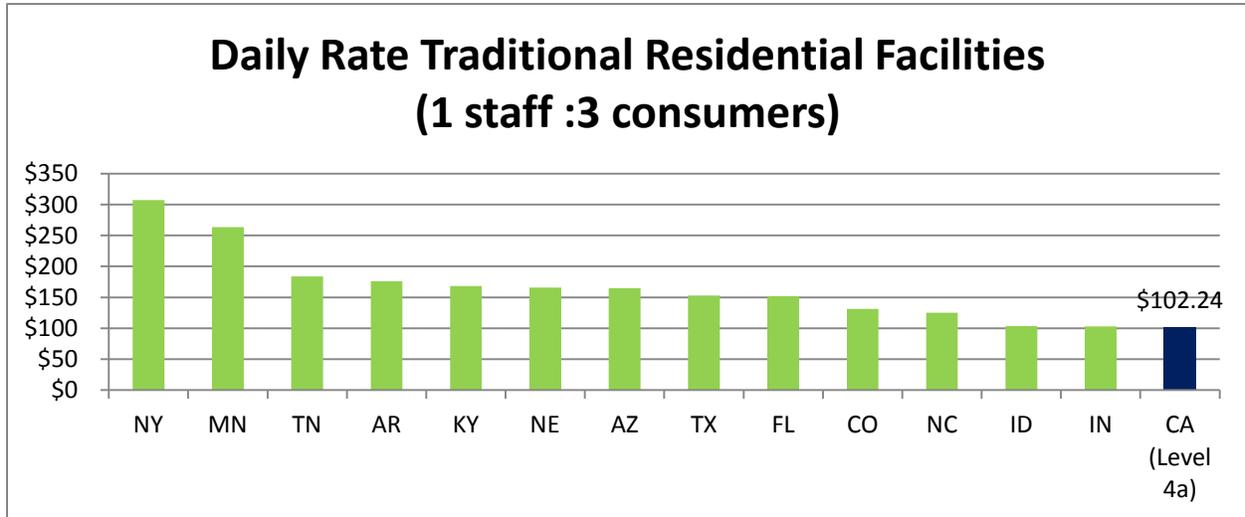
It is clear that California devotes less than average funding for developmental services for each resident of the state. The obvious question is what this means for the support that each individual served by the system receives. The simple answer is that California’s financial commitment, even when considering only community services for individuals eligible for the Medicaid Waiver (those with the greatest impact from their disability and eligible for Medi-Cal), is the lowest of any state in the nation. The average investment nationally is *more than double* California’s expenditure.



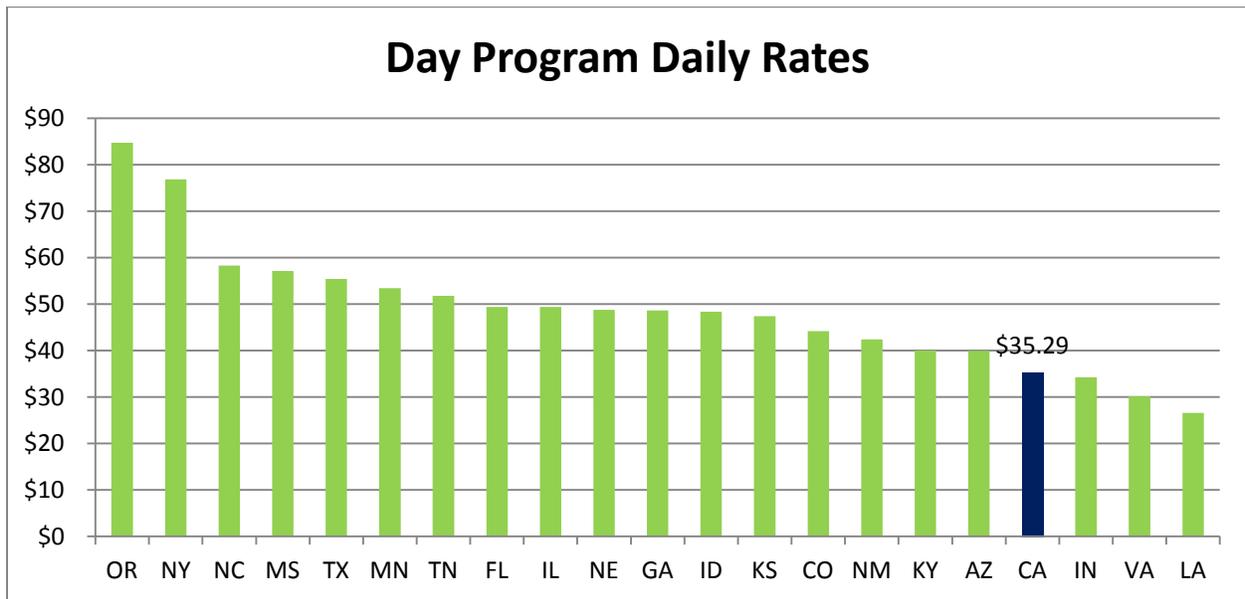
Community Service Provider Rates

ARCA consulted with Norm Davis from Davis Deshaies, a national expert on rate-setting procedures in developmental services. Mr. Davis examined California’s community developmental services rates and compared them to rates for similar services in other states taking into account the high cost of living and of doing business in the state. He examined rates for residential facilities, day programs, and supported employment services, as those are core supports that are provided in many other states using largely the same service models as California offers. While day programs and supported employment providers serve only adults and are beyond the purview of this committee, it is important to keep in mind that developmental disabilities are lifelong conditions and that children, youth, and their families need the assurance that a stable adult services system is waiting for them when the time comes.

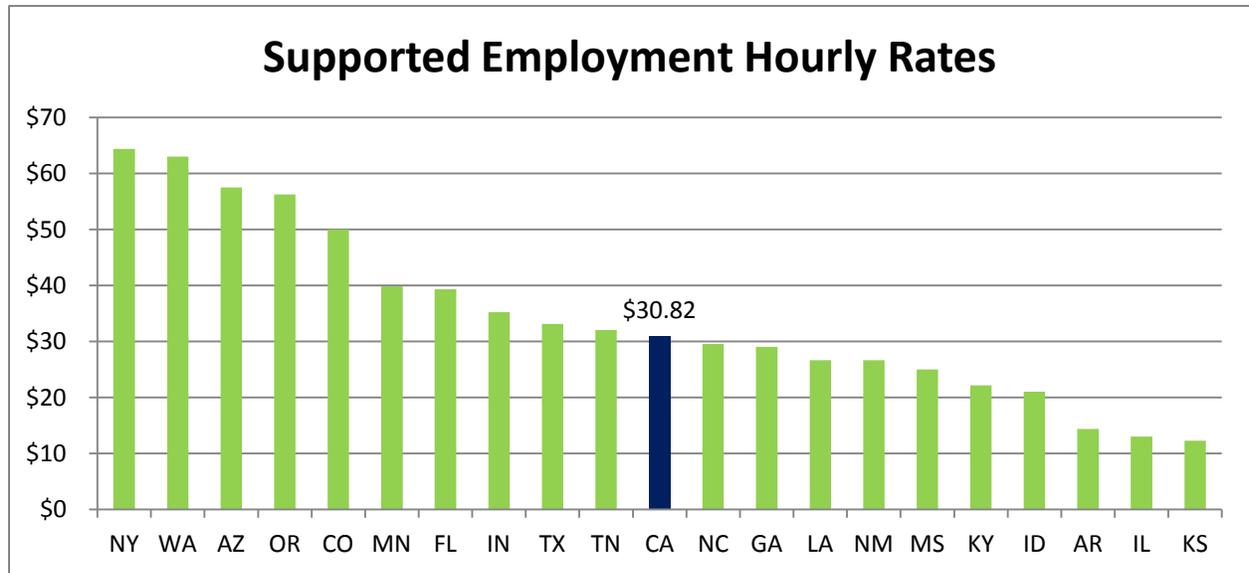
California’s residential rates have not kept pace with inflation. Data supplied by Mr. Davis that is displayed graphically below shows that states such as New York and Minnesota now fund similar facilities at rates two and a half to three times the California rate. California’s rate for this service is most comparable to rates paid in Indiana and Idaho, which are smaller states with lower costs of living.



California’s current rate for Work Activity Programs is \$35.29 per day per individual, with rates for some other day programs also less than \$37.00 per individual per day. Data from Mr. Davis that appears graphically below illustrates that Oregon and New York have rates that are more than double California’s daily rate for these services.

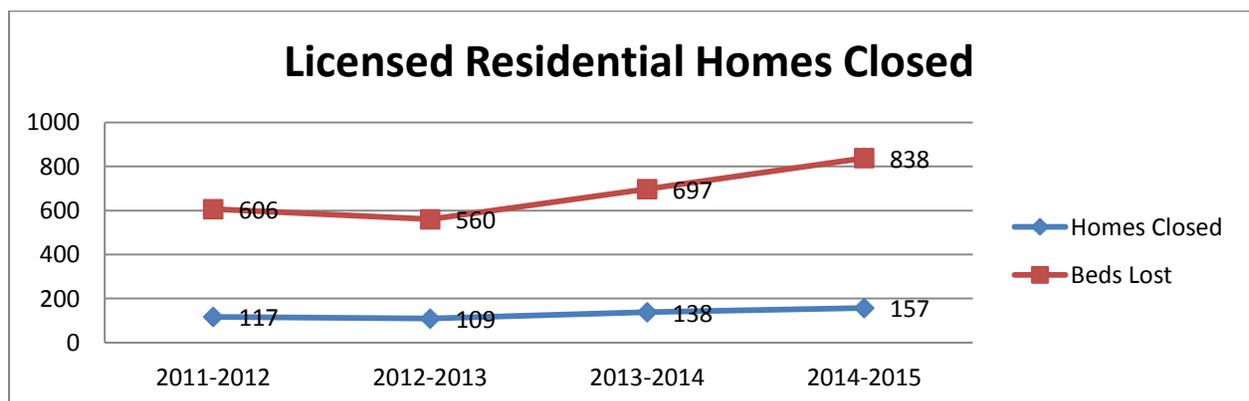


Data supplied by Mr. Davis that is displayed graphically below demonstrates that while California's rate for supported employment is less than \$31 per hour, New York, Washington, Arizona, and Oregon all have rates that exceed \$56 per hour, which is almost 83% higher than California's rate for this same service.

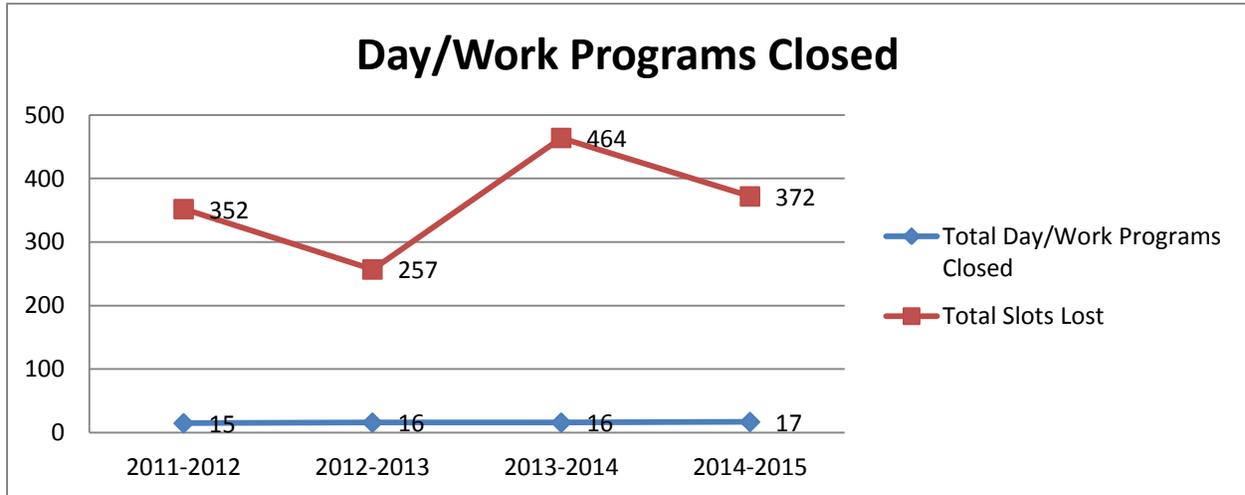


Due to higher real estate and labor costs, including the nation's highest worker's compensation premiums, California is a more expensive state to do business in. Additionally, California's picture is complicated by fifty-eight counties that represent affluence and poverty, densely packed cities and rural agricultural land, and industries ranging from farming to shipping to government to high-tech sectors. Other government programs take these geographic differences into account. For instance, cash aid amounts provided to CalWorks beneficiaries by the Department of Social Services are geographically adjusted with beneficiaries in California's sixteen counties with the highest cost of living receiving approximately 5% greater amounts than those elsewhere in the state.

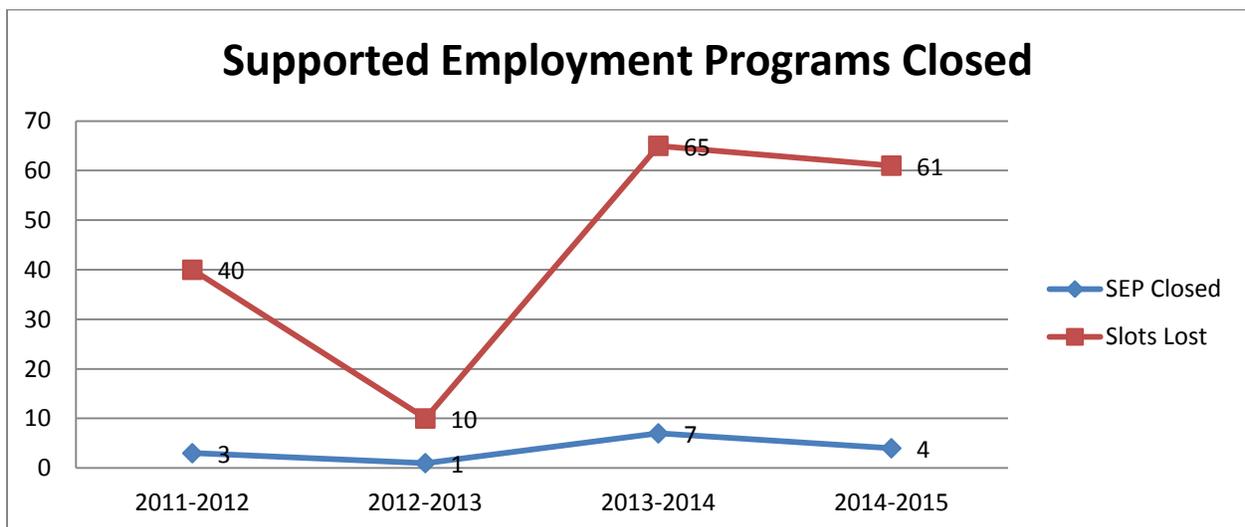
All told, regional centers report the closure of 521 homes since the beginning of Fiscal Year 2011-2012, which represents a loss of over 2,700 available beds. This is the type of loss that limits choice and opportunity for individuals in need of a safe and structured place to live, particularly for children who cannot remain in the family home.



Regional centers report that since the beginning of the 2011-2012 Fiscal Year 64 day and work programs have closed their doors, which is a loss of over 1,400 opportunities for individuals to interact with peers and their communities on a daily basis. These numbers also include many individuals with developmental disabilities that are no longer participating in paid employment opportunities.

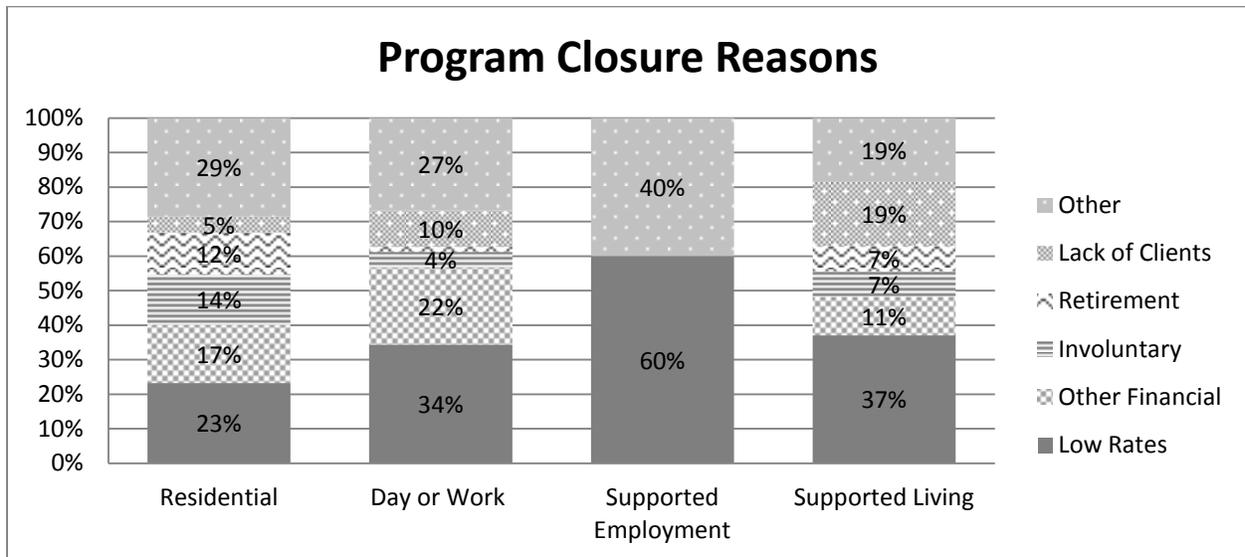


Since the beginning of the 2011-2012 Fiscal Year 15 supported employment programs have stopped providing this service, which is a loss of 176 opportunities for individuals to be supported to work in integrated community settings alongside nondisabled peers.



In a recent survey of regional centers, the reasons given for recent program closures are fairly consistent and are displayed graphically below. The leading identifiable reason for program closure was low rates. A closer examination of the data reveals, however, that the bulk of involuntary program closures due to

service quality can also be traced back to insufficient rates due to factors such as staff turnover and the inability to replace leaving staff members with new staff members of equal qualifications.



Regional Center Operations Funding

A survey conducted by The National Association of State Directors of Developmental Disabilities Services in 2005 indicated that 32 of 37 states responding had caseload ratios of less than 1:59. California was in the 1:60 to 1:99 range with two other states (see the chart below).

Estimated Caseload Ratios – 2005	
Caseload Ratio	Number of States
<1:20	2
1:20 - 1:29	3
1:30 - 1:39	15
1:40 - 1:49	5
1:50 - 1:59	7
1:60 - 1:99	3
>1:100	2

The CityGate study in 1999 found that based on expected client characteristics as for Fiscal Year 1999-2000, the overall caseload ratio needed in California’s developmental services system was 1:53. Since then, the number of clients with complex needs have increased dramatically.

In 2014, service coordinators made up approximately 54% of the regional center workforce, and the Core Staffing Formula sets the position’s salary at \$34,032 statewide. The current state equivalent salary is \$50,340. Individual regional centers must compete with local counties for skilled case management staff. In Contra Costa County the salary for similar positions is \$63,401; in Mono County it is \$61,716. In addition to higher pay, counties offer a comprehensive benefits package, sometimes even including the

repayment of employees' student loans, that regional centers are unable to match. Had the budgeted annual salary for the service coordinator position kept pace with inflation, it would now be in excess of \$61,000 per year. Similarly, the benefit amount assumed in the Core Staffing formula is 23.7% compared to the state's current rate of approximately 48%. The reality of budgeted salaries and benefits for service coordinators falling far below state or county equivalents leaves regional centers no choice but to pay more (the average salary paid by regional centers is \$46,121) by hiring fewer service coordinators and other critical employees and using that money for more realistic salary and benefit levels. In both 2014 and 2015, regional centers reported employing over 660 fewer service coordinators statewide than they need to meet required caseload ratios. By 2014 no regional center was able to meet all mandated caseload ratios. Many individuals require intensive case management to seek appropriate services from other agencies such as schools, the Social Security Administration, or programs such as In-Home Supportive Services. It is oftentimes the intensive case management that they receive that prevents them from needing to access more regional center funded services. In direct response to short-sighted underfunding for critical case management support, the need for additional funded services may increase for many individuals.

Changing Populations

Ten years ago a study conducted by Braddock and Hemp concluded that major cost-drivers in California's developmental services system include the transition of services from institutional to community settings and youth aging-out of the school system. These fundamental service needs, in conjunction with increasing rates of autism, must inform today's rate and service development policies. For instance:

- Individuals once served in developmental centers are being successfully supported in community settings at a cost lower than the average for developmental centers, but still higher than the average support cost for an individual in the community. California Health and Human Services Secretary Diana Dooley convened a task force two years ago to address this transition; the group noted the need to stabilize and increase the capacity of the community services system to adequately support all individuals with complex needs.
- With the assistance of individualized services and clinical support, individuals with intensive psychiatric and behavioral support needs are increasingly being served in community-based settings. To come to fruition, these services require not only the development or modification of services to address those specialized concerns, but take a great deal of collaboration and cross-training with agencies whose primary mission is not the service of individuals with developmental disabilities. Additionally, service providers' ability to succeed often hinges on being able to spend time working with families to help them understand and support their family members.
- A number of individuals with developmental disabilities, including youth, find themselves involved in the criminal justice system. These individuals can have co-occurring diagnoses, such as substance addiction, mental illness, or both. Serving these individuals necessitates significant resource development. But it also requires coordination with criminal justice agencies, other treatment and care systems, and regional center service providers to support these individuals to remain within, or return to, the community.
- The cost to support individuals rises sharply as they exit school settings. In the next three years, nearly 25,000 developmentally disabled individuals statewide will leave the educational system, requiring regional centers to provide services previously obtained in school settings, or entirely new services, such as adult day programs or supported employment.

- Individuals with autism oftentimes require customized supports to be successful, which frequently cost more than standard available services. While only 12% of individuals over age 22 served by regional centers are diagnosed with autism, this number jumps to almost 35% for individuals age 18-21, who will be exiting the school system soon.

Innovative models to serve these populations are costly to develop and require rates above artificially-capped limits. Until 2003 regional centers could help providers start programs to address unmet needs through the request for proposal (RFP) process. That option has since been ended for all but the small number of individuals either leaving, or being deflected from entry into, developmental centers or other institutional settings. As a result of long-term rate stagnation, providers do not have the cash reserves or borrowing ability to meet the initial costs of establishing needed programs. In the exceedingly rare cases when they do, they work with the understanding that in many instances the reimbursement rate for the service will not cover their operating expenses, largely as a result of rates being limited beginning in 2008 to the lower of either the regional center or statewide median rate for a service, regardless of the anticipated cost to provide it. Consequently, new and innovative programs are difficult to develop. Many times regional centers issue RFPs for needed services and are unable to locate or interest any qualified applicants to meet identified needs. California prides itself on not having waiting lists for services. Yet individuals and their families have identified needs, with inadequate or no services available to meet them. People are, essentially, waiting for something that is either in short supply or non-existent.

As California's population continues to diversify, the system must serve more individuals in ways that are responsive to and respectful of their language, ethnicity, geography, or family economic situation. Developing new, or augmenting traditional, service models to meet these various needs is essential in order to ensure that individuals of diverse backgrounds can be well-served. Community service providers and regional centers strive to provide services in a variety of languages and settings to accommodate this growing need, but there is no additional funding earmarked to offset the costs associated with customizing service delivery to ethnically diverse and other-language populations. As with other service developments and expansions, identifying providers to serve specific populations is virtually impossible given the existing rate structures.

Priorities for Advancing the System

California's developmental services system is severely underfunded as a result of years of neglecting to make needed investments to sustain it. Steps need to be taken to put the system back on track and ensure the health and safety of the persons served. Three areas that need to be of immediate focus are:

- *Stabilize System Funding* - The service delivery system, including service provider agencies and regional centers, is currently unable to provide services and supports needed to protect the health and safety of individuals and support their integration into the mainstream life of the community. The Lanterman Coalition, of which ARCA is a member, represents various groups touched by developmental disabilities in California (self-advocates, families, service providers, and advocates). The Coalition agrees that service provider rates and regional center operations should receive an immediate 10% increase, and 5% annual increases to provide a measure of system stability until sustainable rates and regional center operating funding formulas can be established, to ensure that needed supports continue to be available to Californians with developmental disabilities for years to come.
- *Commit to Fully Funding New Mandates* - The system must be agile in its response to changing expectations arising from a variety of sources, including shifting service populations and evolving federal, state, and local mandates. State and local changes to minimum wage, sick time

mandates, as well as new service requirements stemming from federal regulations, lead to considerable new costs. In order to meet increased expectations, there must be an explicit commitment to fully fund the impact of these changes for service providers and regional centers alike.

- *Reverse Failed Policies* - In response to state budget shortfalls in the past few years, DDS had to identify strategies to achieve targeted savings amounts. Several of the approaches identified have not achieved the anticipated savings levels and have actually increased fiscal pressures on service providers and regional centers. Fiscal strategies with no benefit added should be reversed. These failed policies that target families with minor children include:
 - Annual Family Program Fee – This program requires families of children not on Medi-Cal to pay an annual fee to DDS. The cost of administering the program likely exceeds the proceeds that it generates. Described by some advocates as a “disability tax,” the program acts as a significant artificial barrier between children and needed services.
 - Family support services – Regional centers are prohibited from purchasing services that support families to stay together, such as camp and social recreation services, and are limited in the amount of respite hours that can be provided. Those services support families who choose to maintain an individual with developmental disabilities in the family home – respecting personal choice and avoiding the need for a more expensive residential facility placement. These reductions have put tremendous additional strain on families who strive to maintain loved ones at home, rather than doing the right thing by supporting them to make a decision that best reflects their personal or cultural preferences. These changes have made it harder for families to maintain individuals at home.

Additional information about the challenges facing service providers can be found in the ARCA publication [Inadequate Rates for Service Provision in California](#). A similar ARCA publication titled [Funding the Work of California’s Regional Centers](#) provides comparable information about the challenges facing the regional center operations budget. Service provider rates and regional center operations funding suffer from chronic underfunding that threatens service quality, federal funding, and most importantly, the health and safety of the more than 280,000 individuals served by the system today. In order to carry out California’s ongoing commitment to individuals with developmental disabilities, significant ongoing investment must be made in the service system now.

Sincerely,

/s/Eileen Richey

Executive Director

Cc: Members, Senate Select Committee on Children with Special Needs
Cristina Jade Peña, Health Policy Analyst & Consultant
Darin Walsh, Deputy Chief of Staff, Office of Senator Richard Pan M.D.
Mark Newton, Deputy Legislative Analyst, Legislative Analyst’s Office
Meredith Wurden, Senior Fiscal and Policy Analyst, Legislative Analyst’s Office
Carla Castaneda, Principal Program Budget Analyst, Department of Finance
Teresa Calvert, Assistant Program Budget Manager, Department of Finance
Taryn Smith, Consultant, Senate Human Services Committee

Myesha Jackson, Chief Consultant, Assembly Human Services Committee
Michelle Baass, Consultant, Senate Budget Subcommittee #3
Jazmin Hicks, Consultant, Assembly Budget Subcommittee #1
Julie Souliere, Consultant, Assembly Republican Fiscal Office
Mary Bellamy, Consultant on Human Services, Assembly Republican Caucus
Chantele Denny, Human Services Consultant, Senate Republican Fiscal Office
Kirk Feely, Health Consultant, Senate Republican Fiscal Office
Joe Parra, Principal Consultant on Human Services, Senate Republican Caucus
John Doyle, Deputy Director, Department of Developmental Services
Mike Wilkening, Undersecretary, Health and Human Services Agency
Diana Dooley, Secretary, Health and Human Services Agency
Donna Campbell, Governor's Advisor, Health and Human Services