

On the Brink of Collapse

The Consequences of Underfunding California's Developmental Services System



**Prepared by the
Association of Regional Center Agencies**

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On the Brink of Collapse

EXECUTIVE SUMMARY

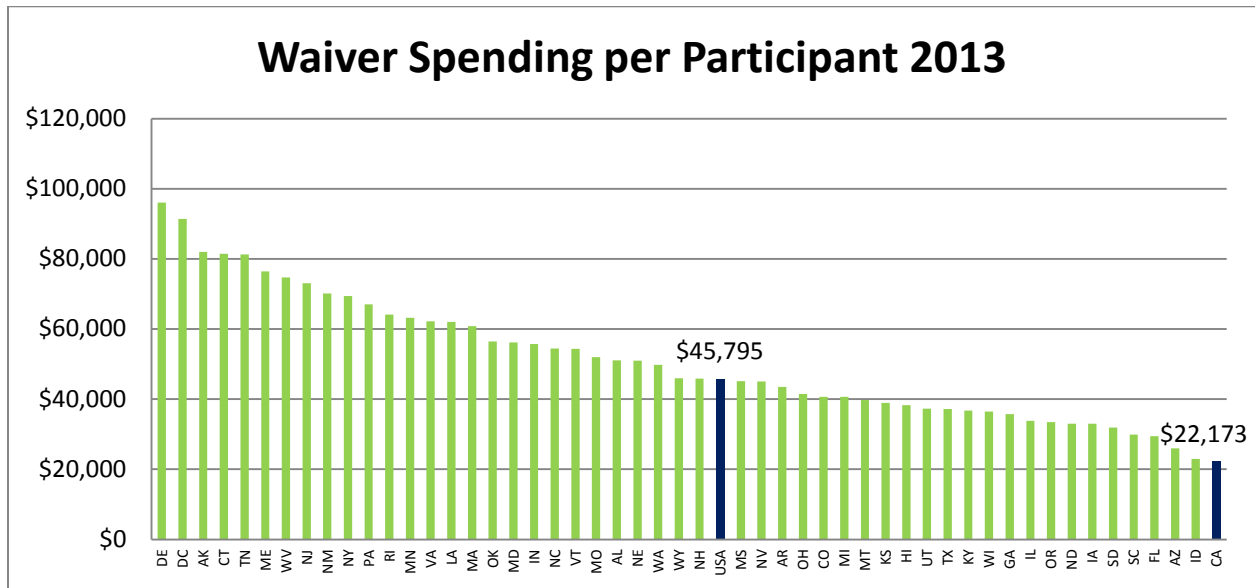
The Association of Regional Center Agencies (ARCA) represents the 21 regional centers in supporting and advancing the intent and mandate of the Lanterman Developmental Disabilities Services Act (the Lanterman Act). ARCA advocates on behalf of the nearly 280,000 individuals served by the regional centers statewide, and works in cooperation with other entities to promote services and supports for persons with developmental disabilities.

Regional centers and community service providers were established under the Lanterman Act in the late 1960's in order to offer individuals with developmental disabilities and their families an alternative to large, state-run institutional care. The basic goals of the system are straightforward: 1) enable infants and toddlers at heightened risk of developmental disability to reach their developmental potential; 2) support children with developmental disabilities to remain in their family homes; and, 3) provide services that allow adults with developmental disabilities to live as independently as possible in integrated communities of their choice.

Detailed descriptions of the decline in overall funding for California's community-based developmental services can be found in ARCA's recent publications titled *Funding the Work of California's Regional Centers* and *Inadequate Rates for Service Provision in California*. This paper focuses on the impact that decades of decreased funding levels have had on the availability of services and supports necessary to support individuals with developmental disabilities and their families. It also touches upon the decline in service outcomes as now the system can only strive to ensure that *some* service is provided rather than the *best* one for each individual.

1. The State of Our State

California's developmental services system has no waitlist and offers services to both individuals with more significant needs that qualify for federal funding as well as those with less significant needs who do not. In spite of its broader entitlement, California spends less on its developmental services system for each resident of the state than most other states in the nation. When taking into account the relative wealth of each state, California's performance is even lower and continues to decline. At this point, California spends *the least amount* of any state on services for each individual with a developmental disability that qualifies for community-based services eligible for federal funding (through federal/state agreements known as "Medicaid Waivers").

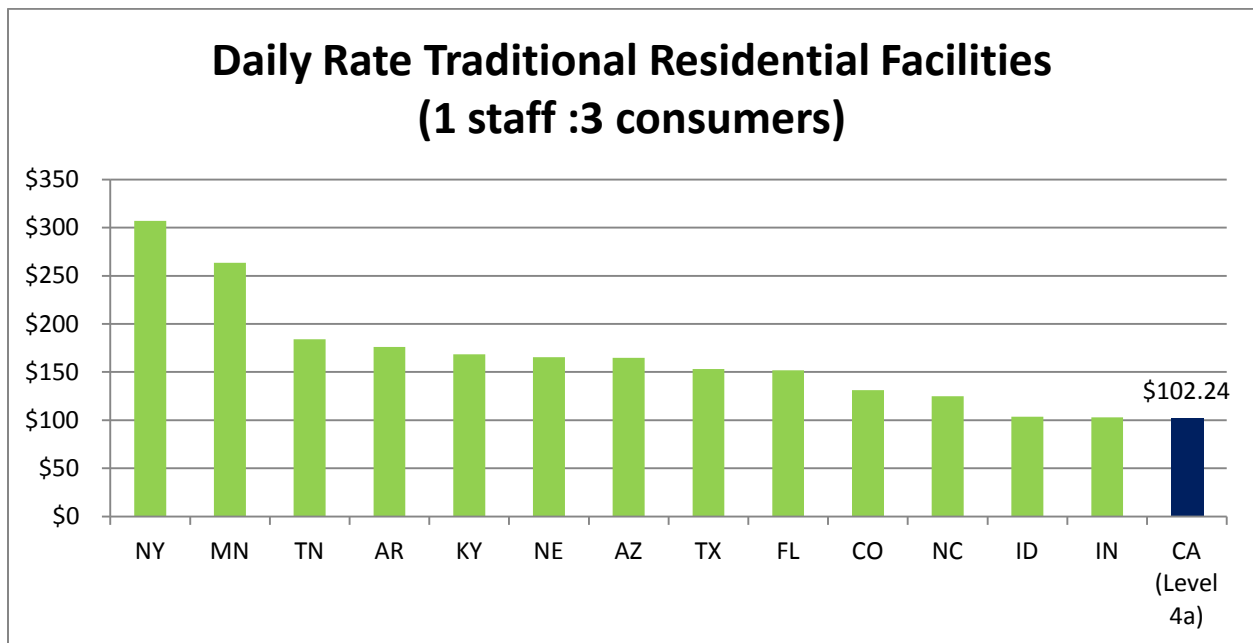


The Lanterman Act once made California a leader in services to individuals with developmental disabilities. After years of state and federal underfunding, California is falling behind in achieving key indicators of service and support outcomes to this population.

2. The Crumbling Foundation

California's developmental services system relies on a combination of regional center service coordination and community services to provide a meaningful alternative to institutional care for individuals with developmental disabilities. ARCA consulted with a national expert to compare service provider rates between different states for similar services, looking specifically at residential facilities, day and work services, and supported employment programs. In general, California's rates for these services fall behind other large or western states. The impact of this difference is exacerbated by California's high cost of living and other costs of doing business such as its highest-in-the-nation workers' compensation premiums. In most metropolitan areas examined, California's service rates were lower, but the cost of living was significantly higher.

For example, California's daily rate for traditional residential facilities (also known as "ARM Rate homes" in California) is approximately a third of the rate paid in New York State and is comparable to the rates paid in Indiana and Idaho, two states that are more rural and have lower costs of living. Additionally, most service rates do not include a geographic differential to account for the different cost of doing business in different regions of the state.



A similar review by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) in 2005 found that of thirty-seven states with available data, California's caseload ratios (service coordinators to individuals served) were among the highest. Salaries budgeted for these positions have not kept pace with inflation and cannot compete with those paid to similar professionals in the state.

California can no longer assure the federal government that sufficient services and supports are available to ensure the health and safety of Californians with developmental disabilities, putting billion of dollars of federal funds at risk. The most significant cost of underfunding the community service system for individuals with developmental disabilities, however, is the inability to access necessary services.

3. No Easy Choices

Without question, relative funding levels for California's community-based developmental services system have fallen in the last two decades, with the most precipitous decline seen during the Great Recession, which began in late 2007. Many service providers are now making the difficult choice to either trim service standards and expectations or to close up shop. The balance is beginning to tip with more providers each year deciding to discontinue services and inadequate numbers of new providers willing to fill the gap. Facing similar fiscal pressures, regional centers have no choice but to allow caseload ratios to climb above legally required levels and to spend less time proactively managing each case. Increasingly, these choices are leaving Californians with developmental disabilities without adequate services and supports to meet their needs and some without any service options at all.

4. Changing Times and Expectations

The Lanterman Act promised individuals with developmental disabilities, their families, and taxpayers a more personalized alternative to large, state-run institutional care and a system that aimed to promote and support independence and community integration. Now, the federal government has laid out similar expectations for developmental services nationwide. All states must ensure that by March 2019 they engage in robust service planning and provide services that offer ready access to the broader community.

Services provided in segregated settings with institutional qualities will no longer be eligible for federal reimbursement. Similarly, there is a renewed emphasis on making work opportunities available for adults with developmental disabilities as work is the foundation of relationships, identity, responsibilities, and increased independence. These system changes are potentially positive ones, but without resources will put additional fiscal pressure on community service providers and regional centers and run the risk of limiting choice and opportunity.

As service rates have failed to keep pace with inflation, service providers have been forced to pay their employees less for the work they do. Now, many direct support professionals are paid the minimum wage, despite a study in 2001 suggesting that a fair rate of pay at that time for direct support professionals was \$10.00-\$10.99 per hour, at a time that the state's minimum wage was \$6.25.^{i, ii} As federal, state, and local governments strive to improve the compensation for the lowest paid workers, community service providers face additional cost pressures. There is an increasing tension between needing to compensate employees fairly and lacking the resources to do so, which results in stress on financial resources and the inability to attract experienced staff.

SUMMARY

California has a long-standing philosophical commitment to providing quality services and supports to individuals with developmental disabilities in community-based settings but fails to provide sufficient resources to make this vision a reality. The service system now supports nearly 280,000 individuals with over 99% living outside of state-run institutional settings.ⁱⁱⁱ Nationally, there are models available that demonstrate how best to provide individualized services in each person's community. California's community service providers have the drive and skills to offer similar innovative services here. What the system lacks is the resources to make that vision a reality for the majority of people it serves. The state's lowest-in-the-nation funding for each individual with a developmental disability cannot support the vision of individuals, their families, the Lanterman Act, or the federal government.

It is with this challenge in mind that ARCA and its twenty-one member regional centers urge the Administration and the Legislature to adopt the Lanterman Coalition's three-pronged common sense approach to rebuilding California's community-based service system for individuals with developmental disabilities, which entails:

1. Providing community service providers and regional centers with a one-time 10% increase in funding to help stop the further decline of the system;
2. Work to reform funding for service rates and regional center operations to ensure that funding levels are adequate and sustainable; and,
3. The provision of annual 5% funding increases to the system until the funding reform strategies are implemented.

The path to stabilization of the service system is a clear one. California must take these steps in order to make its promise to individuals with developmental disabilities a reality.

PREFACE

The Association of Regional Center Agencies (ARCA) represents the 21 regional centers in supporting and advancing the intent and mandate of the Lanterman Developmental Disabilities Services Act. ARCA advocates on behalf of the nearly 280,000 individuals served by the regional centers statewide, and works in cooperation with other entities to promote services for persons with developmental disabilities. ARCA and its members are committed to ensuring that advancements that have been made in California over the last fifty years for individuals with developmental disabilities are sustained and continue.

In a 1963 speech, President John F. Kennedy noted that in caring for individuals with disabilities, “we have to offer something more than crowded custodial care in our state institutions.” By the mid-1960s California was housing more than 13,000 individuals with developmental disabilities in state hospitals, with many more on waiting lists for admission. At that time, families with a disabled child were given the choice between either institutional care or committing to care for, educate, and supervise the family member for the long term (oftentimes in secret) with no outside support.^{iv}

In response to the tenacity of a group of parents of children with special needs, California became a pioneer in 1969 when it created access for individuals with developmental disabilities to community services through the passage of the Lanterman Act. Limited first to serving individuals with an intellectual disability (then termed “mental retardation”), the aim of the Lanterman Act was a simple one: “to provide a network of services throughout the state so each mentally retarded person may attain the fullest intellectual, economic, social and health potential possible.”^v Regional centers were developed to be the first point of contact for families and to provide intake, assessment, resource development, and service coordination. The Lanterman Act noted:

Services should be planned and provided as a part of a continuum. A pattern of facilities and eligibility should be established which is so complete as to meet the needs of each retarded person, regardless of age or degree of handicap, and at each stage of his life’s development.^{vi}

The Lanterman Act afforded families a third option, maintaining their children at home with support and appropriate high quality services.

Community-based services and supports were largely ineligible for federal funding at that time, so the state paid the bulk of the cost of this program. In 1981, Congress authorized states to provide home and community services through their Medicaid programs (known as “Medi-Cal” in California) to individuals who would otherwise require institutional care.^{vii} This allowed California to begin receiving significant federal funding for its community-based system for individuals with developmental disabilities, and encouraged other states to develop similar programs. Now, more than thirty years later, every state in the nation (in addition to Washington, D.C.) provides community-based services to individuals with developmental disabilities in lieu of institutional care.

Services and eligibility vary from one state to the next. California’s entitlement to community-based services was solidified in a state Supreme Court decision in 1985. Consequently, the state continues to provide services to Californians with developmental disabilities regardless of their eligibility for Medi-Cal.^{viii} Most other states do not extend services to individuals who are not eligible for Medicaid. Most also cap the number of individuals that can be served, which creates significant waiting lists for services. Nationwide, over 300,000 individuals are on waiting lists for community-based services.^{ix} As a result of its service entitlement, California does not artificially limit the system’s enrollment through waiting lists, so a greater percentage of its population receives developmental services than in most other states.

Long-term funding shortfalls that were exacerbated by over \$1 billion in cuts during the five years of the Great Recession cumulatively have left California’s service system for individuals with developmental disabilities severely underfunded. In 1997 the Department of Developmental Services (DDS) noted in a report to the Legislature that service providers had come to the following conclusion:

The rate-setting methodologies are designed to work when rates are adequately funded. When rates are chronically underfunded, but program expectations are unchanged, an incongruity occurs that can not be sustained indefinitely. This is

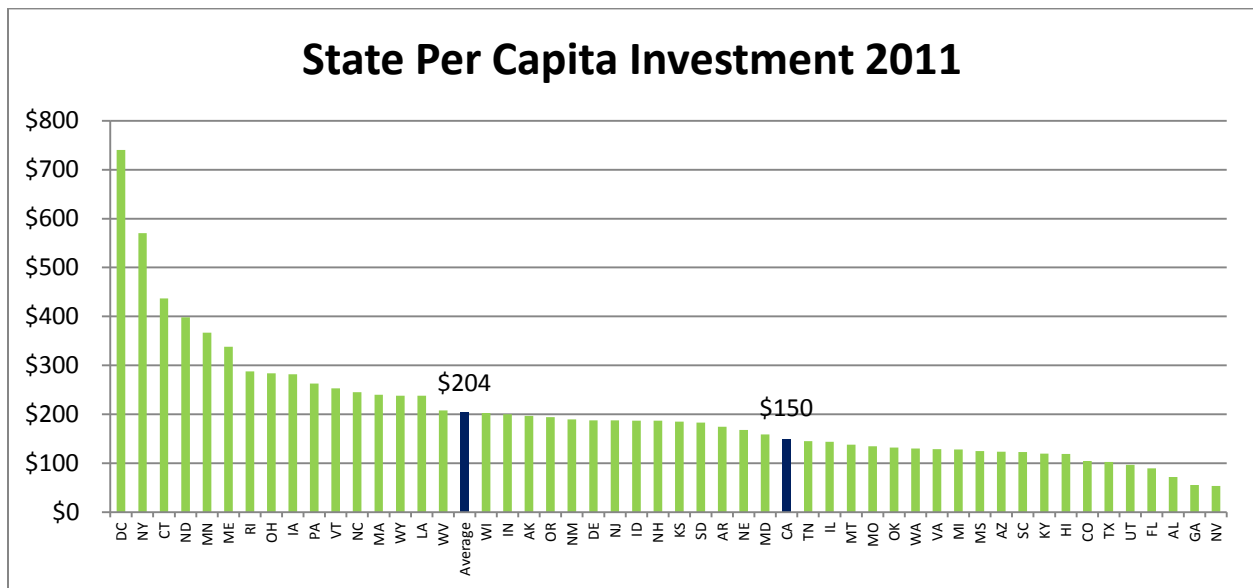
because the system is predicated upon rates that are related to service level needs of consumers. Eventually, the system must find a balance or collapse from its own contradictions (vendors leaving the business, refusing to respond to [Request for Proposals], or pressure to artificially upgrade program level). The correction can occur either in the expectations (programmatic demands) of a service, or at the funding end of the equation. If the state continues underfunding rates, the developmental disabilities service system will be forced to reformulate expectations of attainable goals. Better a less ambitious, but rationally functioning, system than one which promises far more than can be delivered.^x

California's community-based service system for people with developmental disabilities, once the pride of the nation, has fallen to the very bottom due to chronic underfunding and indifference. This underfunding has been noted repeatedly over the last two decades, and the system has been engaged in the struggle to manage the impacts and consequences of the underfunding since. Actions during the recent recession have pushed the community system to the tipping point and only immediate relief will prevent the collapse of the system, a system that has increasingly struggled under the weight of inadequate funding to provide appropriate services and supports to allow individuals to achieve meaningful, integrated lives in the community.

California's twenty-one regional centers are committed to ensuring that California keeps its promise to individuals with developmental disabilities and their families.

Part 1: The State of Our State

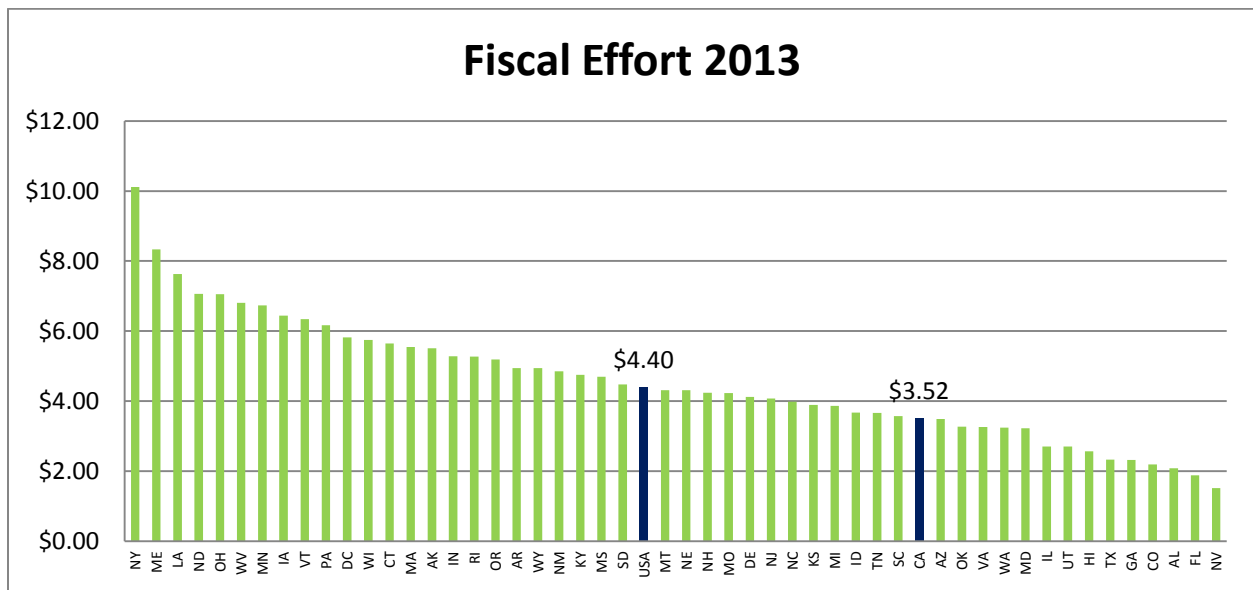
A scholar once asserted, “Don’t tell me where your priorities are. Show me where you spend your money and I’ll tell you what they are.”^{xi} One of the clearest ways to examine a state’s commitment to its developmental services system is to compare its financial investment in the system to the number of people living in the state. In 2011, California invested \$150 per resident of the state in its developmental services system. In contrast, the average state expended \$204 per resident, which is 36% more than California’s investment.^{xii}



Another way to evaluate a state’s commitment to its developmental services system is to examine the portion of its overall wealth it devotes to serving the population. One measure of a state’s wealth is the “total personal income”, which includes all of its residents’ earnings from employment or self-employment in addition to other income (i.e., rent and dividends).^{xiii} “Fiscal effort” calculates a proportion of the amount spent on the developmental services system to the state’s total personal income. Specifically, fiscal effort is a measure of how many dollars are committed to developmental services for every \$1,000 in personal income in the state. We would expect more affluent states to spend more overall on developmental services than those with less fiscal resources. Fiscal effort measurements adjust for that, letting one see if states will spend relatively

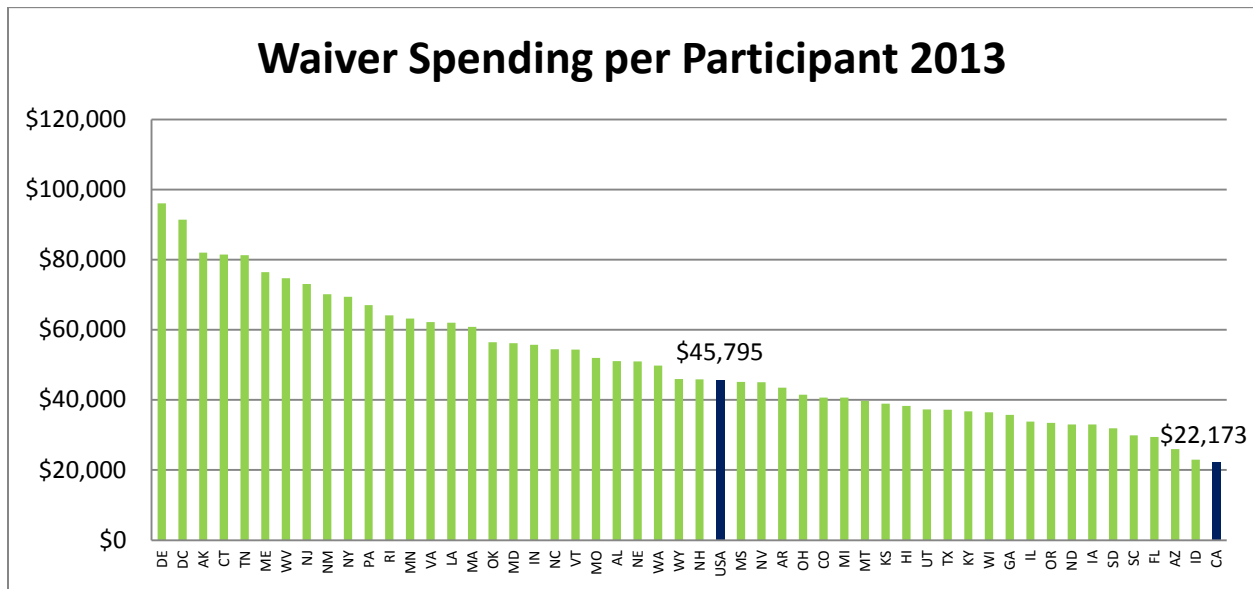
the same *percentage* of their wealth on their developmental services systems. When using fiscal effort as an indicator of commitment to developmental services, a report released in 2013 ranked California 34th in fiscal effort with spending \$3.77 for every \$1,000 in personal income. The average of each state's spending was \$4.62, which is 23% greater than California's fiscal effort level.^{xiv} At that time, approximately two-thirds of other states committed a greater share of their resources to supporting individuals with developmental disabilities than California.

A pre-publication release of the 2015 edition of this report has been widely distributed and analyzes available spending data from 2013. In the period of time from 2011-2013 spending on developmental services in California increased. However, California's spending on developmental services did not increase at the same rate that its personal income increased as the state climbed out of recession. This means that its fiscal effort actually *decreased* as its economy recovered. During that two year period, its fiscal effort fell almost 7% from \$3.77 to \$3.52. During that same time, California's level of commitment fell four slots (to 37th) in comparison to other states.^{xv}

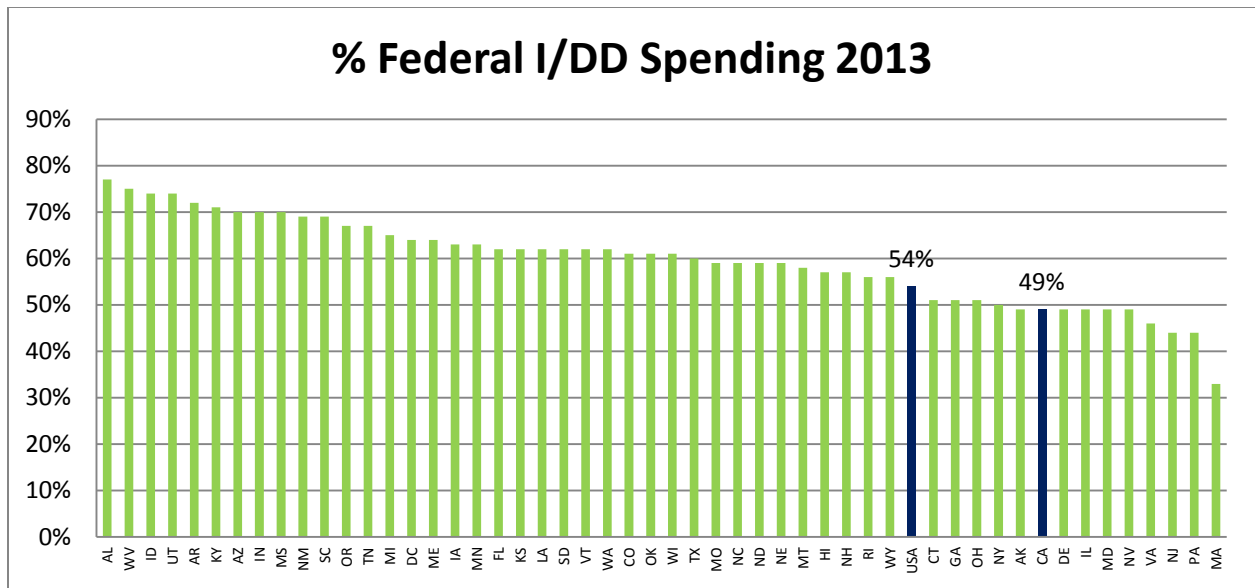


It is clear that California devotes less than average funding for developmental services for each resident of the state and a smaller percentage of its wealth on services for individuals with developmental disabilities than most other states. The obvious question

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 federal funding, is the lowest of any state in the nation. The average investment nationally is *more than double* California's expenditure.^{xvi}



This analysis is skewed without considering differences in federal funding for developmental services between states. The 2015 State of the States report provides information about the differing levels of federal support for the broad developmental services system in each state, including funds that flow from the Social Security Administration. The report notes that federal funding levels range from a high of 77% for Alaska's developmental services system to a low of 33% for Massachusetts' system. California's level is 49%, which falls almost 10% below the weighted average level of 54%.^{xvii}



The level of funding for services and supports to individuals has a direct impact on the outcomes each individual experiences. California and most other states participate in the National Core Indicators (NCI), a project that measures service outcome and satisfaction among recipients of developmental services. Data for the 2011-2012 Fiscal Year survey of adult consumers was recently released and showed that California's developmental services system falls behind national averages in several key measures.^{xviii, xix} For instance:

- 63% of respondents in California compared to 74% nationally reported that service coordinators call them back in a timely manner.
- 77% of respondents in California, compared to 83% nationally, reported they receive needed services.
- 19% of respondents in California, compared to 31% nationally, reported they participated in a self-advocacy event in the past year.

In December 2011, the midpoint of the 2011-2012 Fiscal Year, regional centers were supporting in excess of 130,000 adults.^{xx} This means that if California's services system had been performing at only average levels, nearly 8,000 more adults would have received needed services. Similarly, an additional 14,300 individuals went without timely

calls from service coordinators and 15,600 less participated in a self-advocacy event that would allow them to learn skills needed to speaking up for themselves in their communities. These are the real, tangible results of long-term underfunding.

Similarly, in the 2012-2013 Fiscal Year, California and ten other states participated in the Child Family NCI Survey. At that time, California's developmental services system was supporting in excess of 90,000 children.^{xxi} Results of that survey included:

- 44% of respondents in California, compared to 50% in other states, reported support workers always have the right training to meet their child's needs.
- 63% of respondents in California, compared to 55% in other states, reported that they had unmet service needs.
- 31% of respondents in California, compared to 60% in other states, reported that they always chose their child's service agency.^{xxii}

These results suggest that by falling short of average performance levels, California leaves 5,400 children without adequately trained support workers, 7,200 children without needed services, and 26,100 children without a meaningful choice between service providers. Some of this dynamic may be the result of too few service providers to meet the demand; another portion may be attributed to the requirement imposed in 2009 that an individual's needs be met by the least costly appropriate vendor, a move that artificially limited individual and family choice.^{xxiii} This change made funding considerations a bigger part of the vendor selection process than ensuring that services were the right fit for the individual and his or her family.

California made a commitment to individuals with developmental disabilities and their families decades ago. 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."^{xxiv} This is the cornerstone of California's developmental services system, what many advocates refer to as "*our*

Lanterman Act.” This entitlement sets California apart, and once made it a national leader. As illustrated above, the state’s lack of investment in the service system now leaves it lagging far behind other states and falling further back each year.

Underfunding of the system at all levels has a tangible and profound impact on individuals with developmental disabilities and their families. They face high staff turnover, waiting lists for programs, and the loss of viable service options. Worst of all, California’s broken promise leaves them feeling uncertain about the future.

“[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.”^{xxiv}

Part 2: The Crumbling Foundation

California's developmental services system was designed to provide comprehensive, lifelong assessment, planning, and services to individuals with developmental disabilities and their families. Regional centers provide diagnostic assessments and determine eligibility for the service system. An assigned service coordinator then meets with the individual and family to discuss their goals and needs related to the disability and then works with them to identify potential resources to help them. Some resources are available naturally in the community and others are arranged and funded by the regional center. Over time, the regional center, individual, family, and service providers review progress and make adjustments to the service plan to encourage continued improvement. All of this is done to ensure the best service match, highest service quality, and compliance with federal expectations.

Community service providers work in conjunction with regional center staff to provide many services to individuals with developmental disabilities and their families. For children, this may be the behaviorist who helps a family shape their child's behaviors and assist the child to be more integrated in their community. For adults, it may be the residential facility, job coach, or supported living provider who helps the individual to live, work, and develop greater independence within their community. Service provider rates and regional center operations budgets are set using a variety of mechanisms that were once based on the actual or presumed cost of providing services, but no longer are. For example:

- Many residential homes are reimbursed under the "alternative residential model" (ARM) rate, which was implemented in 1991 and provided varying levels of reimbursement based upon the level of support individuals required. A basic premise of this model was that homes would support six residents and the owner would realize a profit only when all six beds were occupied. Economic pressures and trends toward smaller homes challenge the viability of this model. In order to provide more individualized services, new residential development in many geographic areas has been limited to three or four beds, but this positive change makes the viability of this funding model even more challenging.

- Day and vocational services are the largest part of an individual's day, and are critical to increasing their skills and independence. Originally, most day and vocational service rates were based on the submission of a cost statement, a calculation of all the costs for the provider. Current reimbursement rates are only slightly higher than the Fiscal Year 1995-1996 costs. Since that time, inflation has driven up costs about 50%.^{xxv}
- Specialized programs serving individuals with complex behavioral, psychiatric, and/or medical needs negotiate their rates with regional centers. These rates were originally set based on a cost statement submitted to the regional center, followed by review and negotiation, but since 2008 these rates have been capped by median rates, many of which were adjusted downward in 2011. The median rates do not allow negotiation based on the actual cost of services, which means that cuts are required to some parts of proposed programs in order to fall under the capped rates. Less than half as many people are being served in developmental centers as in 2008, with most of those who have moved to community settings now relying on specialized negotiated rate services.^{xxvi, xxvii}
- Rates for supported employment services, which help individuals secure and maintain integrated community employment, are statutorily determined. They were decreased by 10% in 2008 and have never been reinstated despite increased costs in wages, benefits, and insurance.^{xxviii} A recent survey of individual supported employment providers indicates economic losses in both group and supported employment with fewer providers able to break even providing individual services.^{xxix}
- Regional center operations funding is largely determined by the Core Staffing Formula, which was implemented in 1980 and funded regional center positions at state equivalent salaries and benefit levels. The salaries were adjusted in tandem with state salaries until this practice was halted in 1991 and never resumed. Benefit levels were set at 23.7% in 1980 and have never risen, despite the fact that the state benefit level is now close to 48%. These freezes in combination with unallocated reductions to the formula that now amount to about 7% leave

regional centers unable to hire enough staff to carry out all of their functions.^{xxx,}

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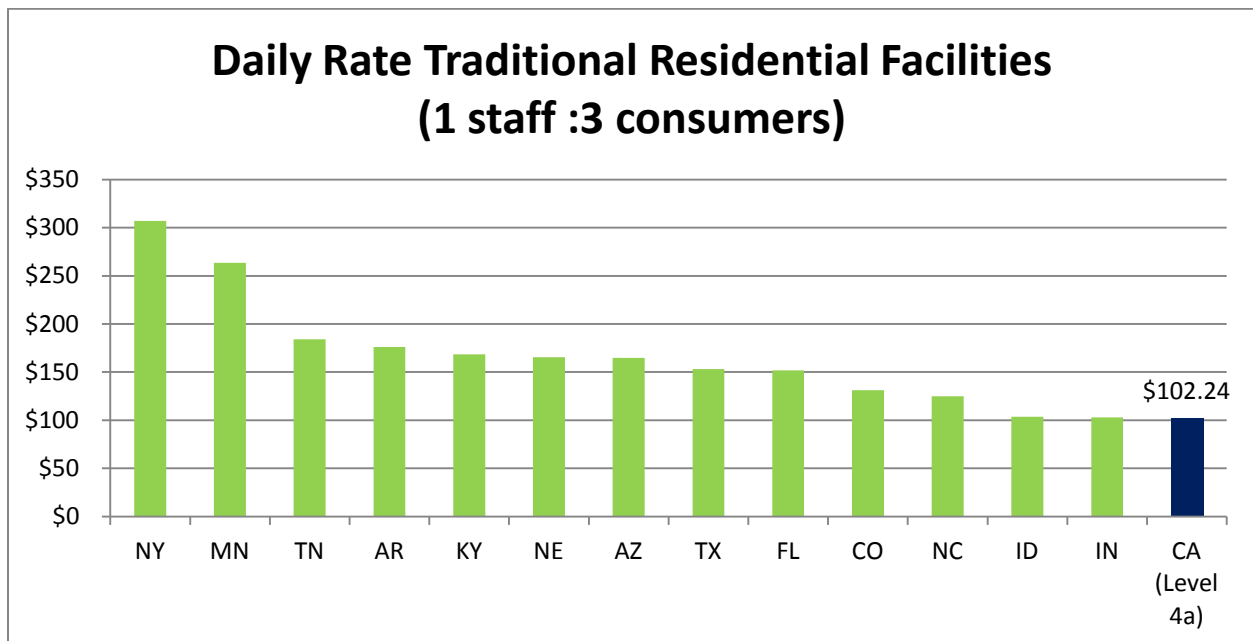
ARCA consulted with Norm Davis from Davis Deshaies, a national expert on rate-setting procedures in developmental services. Mr. Davis examined California's community developmental services rates and compared them to rates for similar services in other states taking into account the high cost of living 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. Detailed information regarding the specific service rates that Mr. Davis supplied appears on pages 21-24 and 27-28 of this report. In summary, the data shows:

- In spite of California's high cost of living, particularly in certain regions of the state, California's rates for core services lag behind other states, including large or western states that should be most similar to California.
- Calculating new rates based on historical median rates "perpetuates existing historical economic biases and creates a downward financial spiral for providers." This limits service quality and the number of individuals that can be served.
- California's rate setting methodologies are dated and not responsive to changing needs, costs, and economic conditions.
- The cost of living in various regions of California varies greatly, but most of California's service rates do not account for these geographic differences.^{xxxii}

For a similar comparison of California's commitment of resources to regional center operations, ARCA examined caseload ratios (the number of individuals served per service coordinator) from other states as well as salaries paid today for similar state and county positions in California. In short, California funds less case management services than most other states and funds these services at salaries that are far below those paid to state or county workers coordinating services in other service systems in the state.

Licensed Residential Homes

Homes licensed by the Community Care Licensing Division of the Department of Social Services provide food, shelter, care, supervision, and training to more than 26,000 individuals with developmental disabilities in California.^{xxxiii} The level of support provided is dependent on each individual's unique needs and can range from basic care and supervision (one staff person for six residents) to ratios of one staff per resident or greater. The majority of homes in operation are funded under the ARM rates, which classified and funded homes according to the level of support provided as level 1, 2, 3, 4a, 4b, 4c, 4d, 4e, 4f, or 4i. Other states offer homes that provide one staff person for every three individuals served, which is most consistent with facilities in California paid at the 4a ARM rate. 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.^{xxxii}



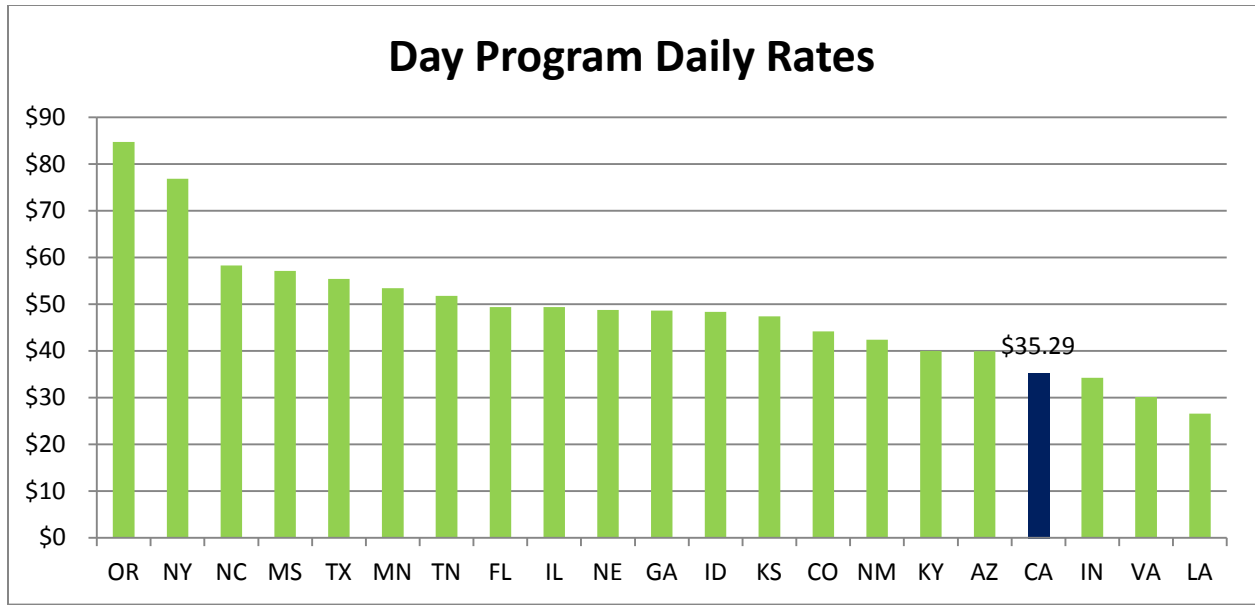
For specialized homes, California uses a negotiated rate system similar to other states, which establishes a customized rate for the home given the particular supports it will

provide. Until 2008, these rates were based on the projected cost of operations; since that time specialized home rates have been capped at the lower of either the statewide or regional median rate for that service, regardless of whether that rate is sufficient to cover the cost, leaving even specialized service providers making changes to their programs to contain costs. The information below provided by Mr. Davis illustrates that while rates for these homes are not as far out of step with other states as those for ARM rate homes, they are still approximately 10% lower than those for Arizona and 20% lower than those for Florida, both states with lower relative costs of living than California.^{xxxii}

Specialized Residential Home	
State	Average daily negotiated rate
New York	\$560 to \$1680 (\$1,120 mid-point)
Arizona	\$448
Florida	\$446 to \$577 (\$511 mid-point)
California (average of statewide FY 2014 per capita expenditures)	\$407
Texas	\$406

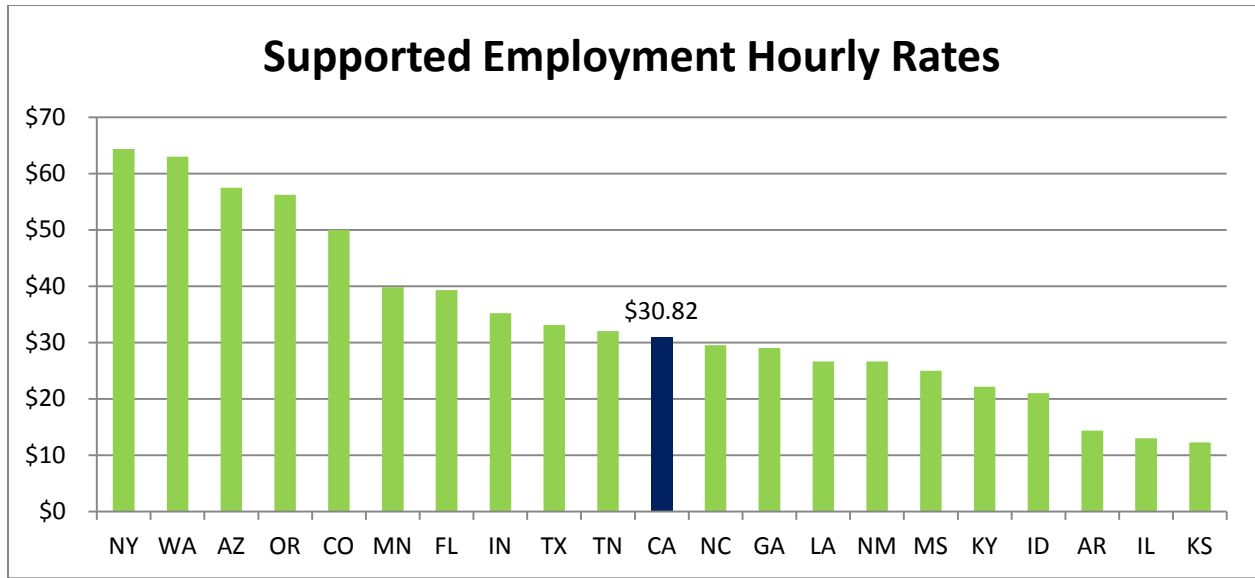
Day and Work Programs

States provide a variety of work and other activity supports to individuals with developmental disabilities to help them to access their communities on a daily basis. In Fiscal Year 2010-2011 (the most recent year with available data), California supported nearly 65,000 individuals in work activity, day, and “look-alike” day programs. Of that figure, over 53,000 individuals were supported in programs whose rates were set by DDS based on an Allowable Range of Rates that was last substantially updated in Fiscal Year 1998-1999.^{xxxiv} 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.^{xxxii}



Supported Employment

Supported employment provides the opportunity for individuals with developmental disabilities to work in integrated community settings alongside nondisabled peers. Some individuals are supported with a limited number of staff hours to work in individual community jobs with the same wages and benefits as their coworkers. For individuals requiring more intensive supports, group supported employment offers the opportunity for continuous job coaching on the same work site as other individuals with disabilities. California's supported employment rate is the same for each hour of on-the-job support whether a single individual or group is being supported. This rate was reduced by 10% in 2008 and has not yet been restored. Data supplied by Mr. Davis that is displayed graphically below demonstrates that while California's rate 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.^{xxxii}



California Cost-Drivers

When comparing service rates between California and other states, one must also take into account the cost of living and working in the state and the impact that has on the cost of service provision. Two distinct cost-drivers that make California unique are its cost of housing (and cost of property in general) and its workers compensation insurance rates.

A report titled *Out of Reach 2012: America's Forgotten Housing Crisis* examines the cost of a two bedroom apartment in different states in the country and goes on to discuss significant geographic differences within states. This study has been used to illustrate the lack of affordability of California's housing market for individuals with developmental disabilities, many of whom rely on \$889 per month in SSI benefits.^{xxxv} It is also a useful tool in examining the inaccessibility of the housing market for those that work to directly support individuals with developmental disabilities. At the time of that study, California's minimum wage was \$8.00 per hour. In order to afford a standard two bedroom apartment in California, a worker would need to work forty hours per week and earn \$26.02 per hour. This level of cost places California third nationally behind only Hawaii and the District of Columbia.^{xxxvi}

However, an even more dramatic story can be found by examining the regional differences within the state. While a worker in Modoc County would need to earn 1.4 times minimum wage (\$11.23 per hour) to afford a two bedroom apartment, a worker living in San Francisco or San Mateo Counties, would need to earn 4.6 times minimum wage (\$36.63 per hour) to afford the same size apartment. Just to pay the rent on a two bedroom apartment in San Francisco would have required a minimum wage worker to be paid for approximately 55 hours of work per week with no money withheld for income tax and no money left over for food, clothing, or transportation.^{xxxvii}

California's service rates do not take into account any geographic differences in the cost of service provision, despite recommendations for geographically-adjusted rates due to wage differentials in two separate reports in 1988 and 2001.^{xxxviii, xxxix}

As a practical matter, the cost of housing drives the cost of labor in a particular market. The current Federal minimum wage is \$7.25 per hour. California's state minimum wage is \$9.00 per hour and scheduled to increase to \$10.00 per hour in January 2016.^{xl} San Jose was the first California city to pass a higher citywide minimum wage, which rose to \$10.30 per hour January 1, 2015 and rises annually in response to increases in the cost of living.^{xli} The City and County of San Francisco has a minimum wage that will increase gradually until it hits \$15.00 per hour in January 2018.^{xlii} San Diego and Sacramento are scheduled to put the issue before voters in 2016.^{xliii, xliv} Service providers also face fiscal pressures from a number of other unfunded federal, state, and local employer mandates that are discussed in detail in Part 4 of this report.

Additionally, the affordability of real estate in a given area drives not only housing prices, but also the cost of securing commercial space needed to provide services. For instance, office space in Atlanta averages approximately \$32 per square foot per year. In Chicago the rate is \$49 and in Houston it is \$46. Rates in Philadelphia are \$32 and in Seattle it is \$41. In Los Angeles the rate is \$57 and in San Francisco it is \$70. This dynamic puts additional cost pressures on providers.

As a result of its size and complexity, California is often broken down into more manageable sections for study. For example, the Employment Development

Department considers the state to be broken up into the eight distinct economic regions below and tracks employment and prosperity data for those separately.^{xlv}



Other government programs make similar distinctions in an effort to better manage data and programs that cover 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. 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.^{xlvi} California's complexity requires that geographic differentials in costs be examined when developing equitable and sustainable rates.

Additionally, California's workers' compensation premiums are the highest of any state in the country. California's workers' compensation rates are 188% of the national

median and are 21% greater than the rates in Connecticut, which come in second. Overall, California's workers' compensation rates are approximately \$3.45 for every \$100 in wages paid to workers.^{xlvii} Rates paid in the human services field are substantially higher than rates paid for the state as a whole due to the actual and potential incidence of injury. Workers' compensation rates are volatile and can increase significantly in response to isolated incidents, particularly for providers serving individuals with the most complex needs.

The following two charts provided by Mr. Davis draw a comparison between the service rates paid to community providers and the cost of living and working in other states. For the sake of comparison, the first chart examines costs and rates in state capitals and the second looks at the cost of living and working in various states' largest city. Of the cities examined, the cost of living was cheaper everywhere outside of California with the exception of New York City. New York rates were significantly higher than those in California for supported employment and residential facilities, which more than makes up for the cost differential. Rates in other states examined here were all higher than California's rates for these services despite their lower cost of living.^{xxxii}

Comparison of Select State CAPITAL Cities to Sacramento California					
State	Cost of Living compared to Sacramento	Salary % needed to equal \$30,000 in California	State SE rate compared to California (\$30.82)	State CCF (1:3) rate compared to California (\$102.24)	Notes
New York (Albany)	7.3% lower	\$26,850 11.5% lower	109% higher (\$64.38)	200% higher (\$307.12)	Albany is less expensive to live and work; SE rates are 109% higher and CCF rates are 200% higher than California
Florida (Tallahassee)	30.7% lower	\$25,050 16.5% lower	27% higher (\$39.28)	49% higher (\$151.94)	Tallahassee is less expensive to live and work; SE rates are 27% higher and CCF rates are 49% higher than California
Arizona (Phoenix)	0.1% lower	\$27,000 10.0% lower	87% higher (\$57.51)	61% higher (\$164.88)	Phoenix is about the same to live but less expensive to work; SE rates are 87% higher and CCF rates are 61% higher than California
Texas (Austin)	23.2% lower	\$26,610 11.3% lower	7% higher (\$33.10)	50% higher (\$152.97)	Austin, Texas is less expensive to live and work; SE rates are 7% higher and CCF rates are 50% higher than California
Washington (Olympia)	13.0% lower	\$28,440 5.2% lower	104% higher (\$63.00)	-	Olympia, Washington is less expensive to live and work; SE rates are 104% higher than California

Comparison of Select State LARGEST Cities to Los Angeles California			
State	Cost of Living compared to Los Angeles	Salary % needed to equal \$30,000 in California	Notes
New York (NYC)	28.3% higher	\$32,250 7.5% higher	New York City, New York is more expensive to live and work
Florida (Jacksonville)	32.3% lower	\$25,560 14.8% lower	Jacksonville, Florida is less expensive to live and work
Florida (Miami)	19.6% lower	\$26,100 13.0% lower	Miami, Florida is less expensive to live and work
Arizona (Phoenix)	15.6% lower	\$26,700 10.8% lower	Phoenix, Arizona is less expensive to live and work
Texas (Houston)	40.7% lower	\$27,600 8.0% lower	Houston, Texas is less expensive to live and work
Washington (Seattle)	16.7% lower	\$29,250 2.5% lower	Seattle, Washington is less expensive to live and work

In all cases noted above, California service providers are seeking to do the same job with fewer resources and at a greater cost. After years of underfunding, many providers are beginning to reevaluate their ability to continue providing services to individuals with developmental disabilities in California. Guidance from the Centers for Medicare and Medicaid Services (CMS) indicates that “[w]aiver payment rates may be determined in a variety of ways and frequently the methods that are employed vary by the type of service.” It cautions, however, that whatever methodology is employed by states must ensure that “payments are consistent with efficiency, economy, and quality of care and are sufficient to enlist enough providers.”^{xlviii} Rates for some services are now so low that there are not enough providers to satisfy the demand for them. While in some cases substitute services are provided, in other instances, no appropriate alternative exists and individuals do without until appropriate services become available. This is the true cost of underfunding the community service system for individuals with developmental disabilities.

Compounding the lack of appropriate regional center funded community services is the simultaneous decline in services funded by other sources during the United States’ economic downturn that began in late 2007^{xlix}. For instance:

- Rates paid by the Department of Health Care Services for Intermediate Care Facilities for the Developmentally Disabled that serve individuals with significant medical needs were once based on the previous year’s costs for similar facilities statewide. This practice was stopped in 2007 and rates for some providers have

actually decreased by up to 10% in recent years.ⁱ Data from DDS reveals at least 76 Intermediate Care Facilities have closed since January 2010 in California, which resulted in a total loss of 458 beds.ⁱⁱ

- Medi-Cal rates for hospital-based dentistry do not cover the costs that facilities incur for use of their operating rooms. Recently, this led a large Sacramento hospital to decide to no longer offer operating room space to individuals needing dental care. Over 1,100 people, many with developmental disabilities, had been served at the facility in the previous year.ⁱⁱⁱ
- For Federal Fiscal Year 2015, the federal government reimburses California \$1 for every \$2 of spending in its Medi-Cal program. This puts the state at the bottom of the range with twelve other states. Mississippi is at the top of the range and receives almost \$3 in federal reimbursement for each \$4 the state spends on Medicaid services.ⁱⁱⁱⁱ

Funding limitations such as these put additional fiscal pressures on the resources of California's developmental services system. As these services become increasingly scarce, regional centers and community providers are left backfilling additional service needs, oftentimes without sufficient additional funding to account for new costs. This dynamic combined with California's low rate of federal reimbursement strains the service system further.

Case Management for Individuals and Families

California's budget for serving individuals with developmental disabilities in community-settings is divided into two sections. The great majority of the money is devoted to paying for individualized direct services through independent providers and is known as the "Purchase of Service" (POS) budget. The smaller portion supports regional centers to provide assessment, service coordination, resource development, service monitoring for effectiveness and compliance with federal requirements, and the like and is known as the Operations (OPS) budget. In the Governor's Proposed 2015-2016 Budget, POS makes up 88% of the funding devoted to the community-based developmental services system.^{liv} The two portions of the service system must work in tandem to support

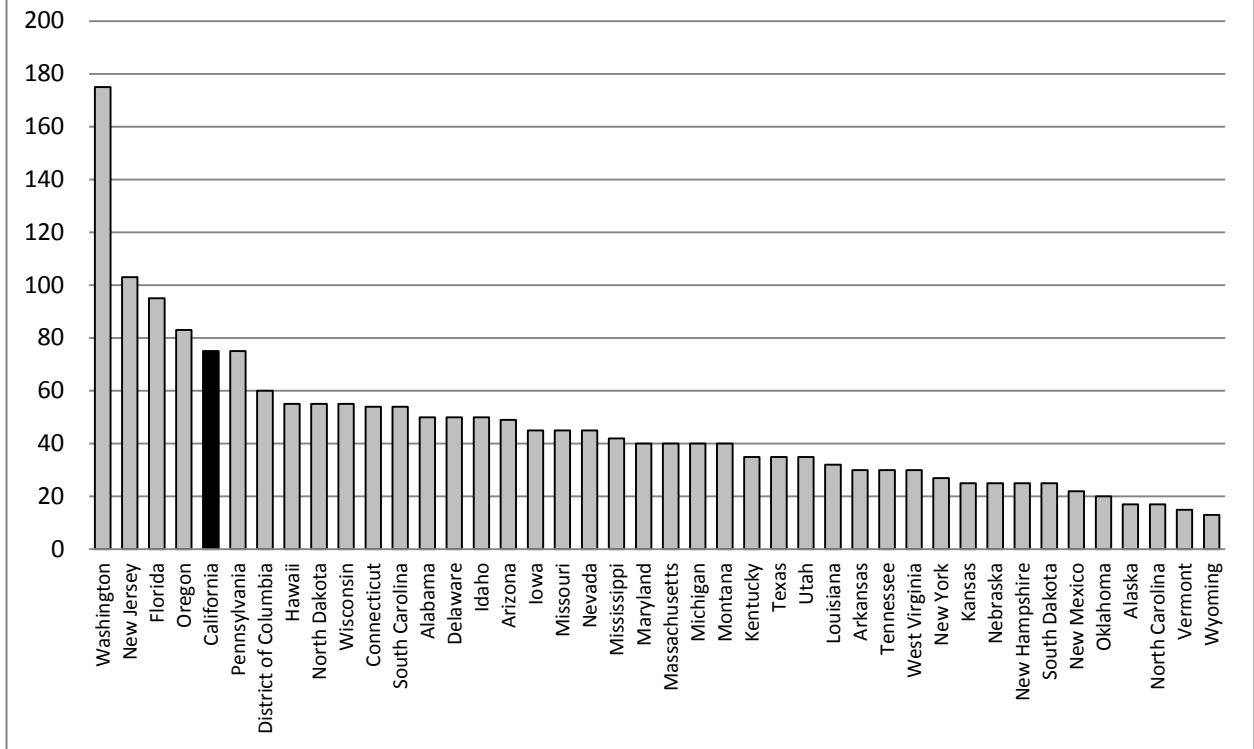
individuals and their families, a point emphasized by the federal requirement for “conflict-free case management,” which requires the separation of service planning and direct service provision.^{lv}

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. By way of comparison, the current state equivalent salary is \$50,340.^{lvi} 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.^{lvii} 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.

California mandates caseload ratios of one service coordinator for every sixty-two individuals (1 to 62) for those receiving federally funded community services and a caseload of 1 to 66 for others served by the regional center system.^{lix} Other states have much lower caseload ratio requirements which give the service coordinators more time to address the individual needs of the clients. The following are some of the caseload ratio requirements in other states:

- In 1996, NASDDDS surveyed 42 states regarding caseload ratios for their developmental services system. The highest caseload was Washington at 1:175 and the lowest was Wyoming at 1:13. The median was 1:40 and California came in at 1:75, the fifth highest.^{lx}

Developmental Disabilities Caseload ratios, FY 96 (1996 NASDDDS Survey)



- A survey conducted by NASDDDS 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).^{lxi}

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 state of Maine mandates a caseload ratio of 1:35 for its case managers in its Aging & Disability Services department.^{lxii}

- Minnesota Administrative Rules limit the caseload ratio for case managers for “services to adults with serious and persistent mental illness” to 1:30.^{lxiii}

In the 1999, the CityGate Associates study of the Core Staffing Formula noted:

The Core Staffing Formula has outlived its usefulness. The Lanterman Act (the primary mandate for DDS and RC services) has undergone major changes in the past seven years. The local catchment areas have all had varying levels of growth and change. When originally defined, each of the 21 RCs was intended to serve approximately the same number of consumers. In 1991-98, workload in RCs varied from 2,000 to 13,500 consumers, averaging 6,700. Information systems and automation were unknown in 1978. The Core Staffing Formula budgets for a different operating environment than exists today.

This study evaluated the caseload ratios and determined that caseload ratios should be computed taking into account the number of “Special Conditions” each client has. These Special Conditions were:

- Living Out-of-Home
- HCBS Waiver eligible
- Having a dual diagnosis (both a psychiatric and developmental disability)
- Early Start clients
- Having a Complex Preferred Program (medically needy, a diagnosis of autism, behavioral needs)

Based on expected client characteristics as for Fiscal Year 1999-2000, the overall caseload ratio needed was determined to be 1:53. Since then, the number of clients on the HCBS Waiver and the number of clients with a diagnosis of autism have risen dramatically.^{lxiv}

In 1997 the Health Care Financing Administration (now the Centers for Medicare and Medicaid Services or “CMS”) reviewed California’s developmental services system and found significant deficiencies. In response, it froze the number of individuals whose services qualified for offsets of federal financial participation. This sanction was not lifted for six years and ultimately cost the state \$933 million in lost federal funds. One of the deficiencies identified was an inability to ensure individuals’ health and safety. In response, a number of changes were made to the developmental services system, including the implementation of the 1 to 62 and 1 to 66 caseload ratios.^{xxx} In a 2007 report to the Legislature, DDS concluded of the federal sanctions, “This significant funding loss underscores the importance of meeting federal quality assurance standards in the developmental services system lest the savings achieved through cost-containment measures is dwarfed by subsequent losses in federal reimbursement.”^{lxv} Today, the stakes are higher as California’s developmental services system now relies on approximately \$2 billion annually in federal reimbursements.^{lxvi} California is incapable of reliably making assurances to the federal government that it is meeting the minimum standards required to continue receiving federal funding. In the near term, these failures put the system at risk of losing significant federal funding and failing to keep its promises to individuals with developmental disabilities and their families.

“This significant funding loss underscores the importance of meeting federal quality assurance standards in the developmental services system lest the savings achieved through cost-containment measures is dwarfed by subsequent losses in federal reimbursement.”^{lxv}

Part 3: No Easy Choices

Community service providers, many of which are nonprofit agencies or small businesses, have endured years of systemic underfunding as outlined in ARCA's report [*Inadequate Rates for Service Provision in California*](#). As noted in that report:

In 2003, many service rates were frozen at their already inadequate rates, and these rates remain frozen. Also in 2003, there was a restriction placed on regional centers preventing the use of POS funds to start up new programs. Service providers were subject to payment reductions from 1.25% to 4.25% from 2009 to 2013. Other factors affecting services were the implementation of an ongoing uniform holiday schedule (FY 2009-2010), a requirement for independent reviews and audits, and an administrative cap of 15% for providers (2011).^{lxvii}

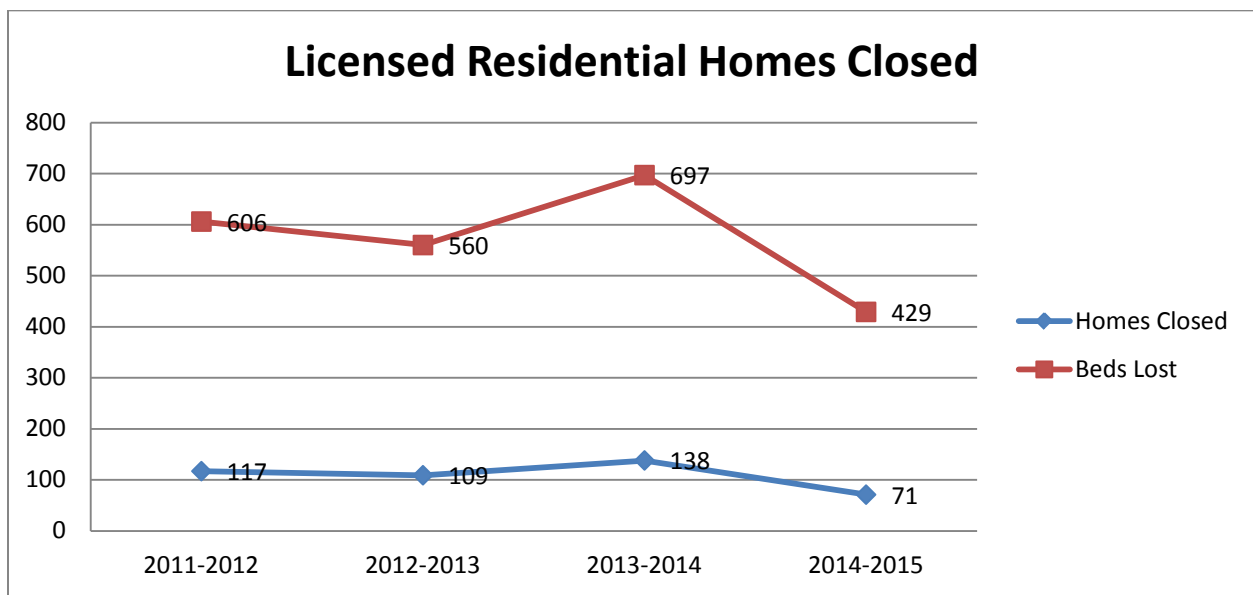
Many service providers have exhausted financial reserves and are now faced with the difficult choice of closing programs or trimming service offerings and expectations with the hope of remaining open. Steve Miller, former Executive Director of Tierra del Sol in Los Angeles recently wrote, “[We] will never willingly desert the individuals and families who are counting on us. But please do not mistake our unwillingness to quit as evidence that we are not failing, in fact we are. Not all at once – and not yet in headline grabbing numbers, but one agonizing person at a time and one agonizing decision at a time.”^{lxviii} In an effort to quantify these individual losses, ARCA conducted a survey of all of the regional centers regarding the trends they are seeing in their own communities around the state. There are no good choices, no easy choices, but still decisions must be and are being made.

“[We] will never willingly desert the individuals who are counting on us. But please do not mistake our unwillingness to quit as evidence that we are not failing. In fact we are. Not all at once – and not yet in headline grabbing numbers, but one agonizing person at a time and one agonizing decision at a time.”^{lxviii}

Licensed Residential Homes

Data from the Department of Social Services

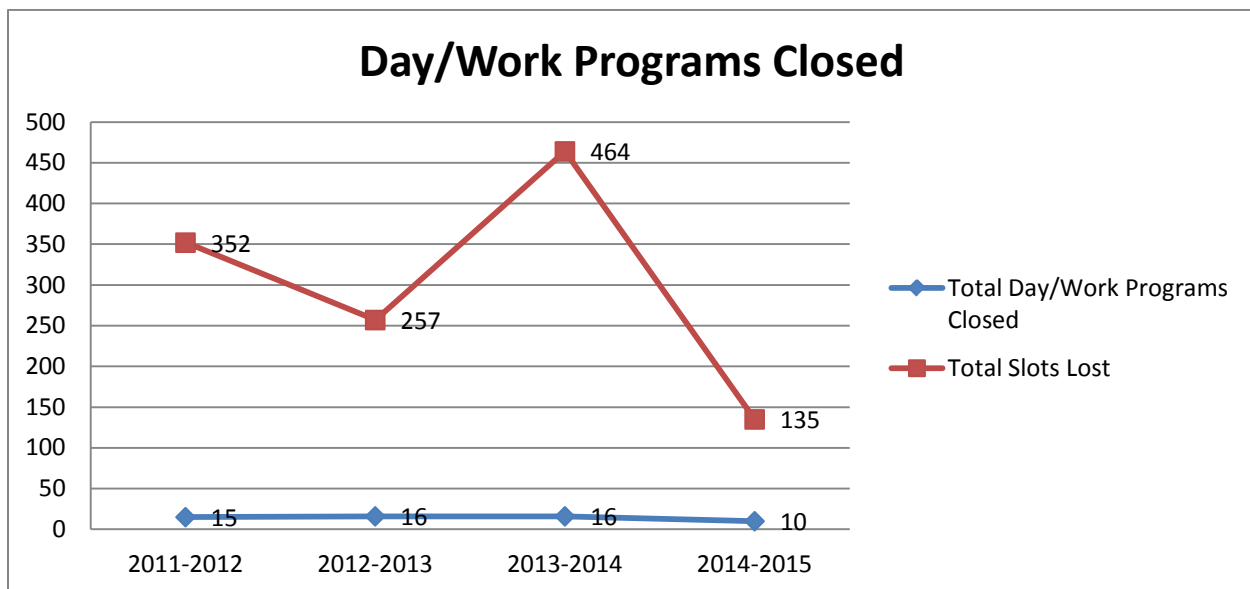
reveals that 172 homes that had been available to children with developmental disabilities closed in the five year period from November 2009 through November 2014. Of these closures, more than 90% were initiated by the provider deciding to discontinue providing the services. Similar services for adults with developmental disabilities have also declined in recent years. One regional center alone saw the loss of over 100 residential beds funded at ARM rates between July 2013 and September 2014, with the expectation that nearly 100 more will be lost in the short-term. All told, regional centers report the closure of 435 homes since the beginning of Fiscal Year 2011-2012, which represents a loss of almost 2,300 available beds. Less than 10% of the beds lost were in negotiated rate facilities. This is the type of loss that limits choice and opportunity for individuals in need of a safe and structured place to live.



A story recently appeared in the *Santa Cruz Sentinel* detailing one mother’s fears and struggles as the home serving her teenage son with autism headed for closure in response to inadequate service rates. Days before the home’s scheduled closure she said, “The rug has been pulled out from under us and we’re really scrambling.” She stated, “He’s got to stay here because he’s doing so well.” Difficult and unwanted change became necessary for this family because of the inability of the provider to continue offering quality services at the available rate.^{lxix}

Day and Work Programs

Data from DDS shows that a net of sixteen work activity programs that closed between Fiscal Year 2008-2009 and Fiscal Year 2013-2014.^{lxx} This statistic does not tell the full story, however. Work activity programs are a historic service model that in recent years has fallen out of favor with the federal government. The challenge with these closures arises when new programs are not developed and sustained at a rate that supports individuals to transition from one service model to another. Regional centers report that since the beginning of the 2011-2012 Fiscal Year 57 day and work programs have closed their doors, which is a loss of more than 1,200 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. Nearly 70% of the slots lost have been in traditional day and work services with the remaining losses occurring in “look-alike” day programs that oftentimes offer better negotiated service rates.



During Steve Miller's tenure as the Executive Director of Tierra del Sol, he was forced to close four programs that were consistently losing money and putting fiscal pressure on the rest of the organization. Three of these closures have taken place in the last five years. He notes of these decisions, "I will never forget the Friday night phone call from

the father yelling at me that he was going to sue me for destroying his family while in the background I could hear his wife sobbing, 'What are we going to do? What are we going to do?'...I will never forget the soft words from another couple 'He's done so well. I guess it was too good to last. Maybe someday you would think about taking our son back?'"

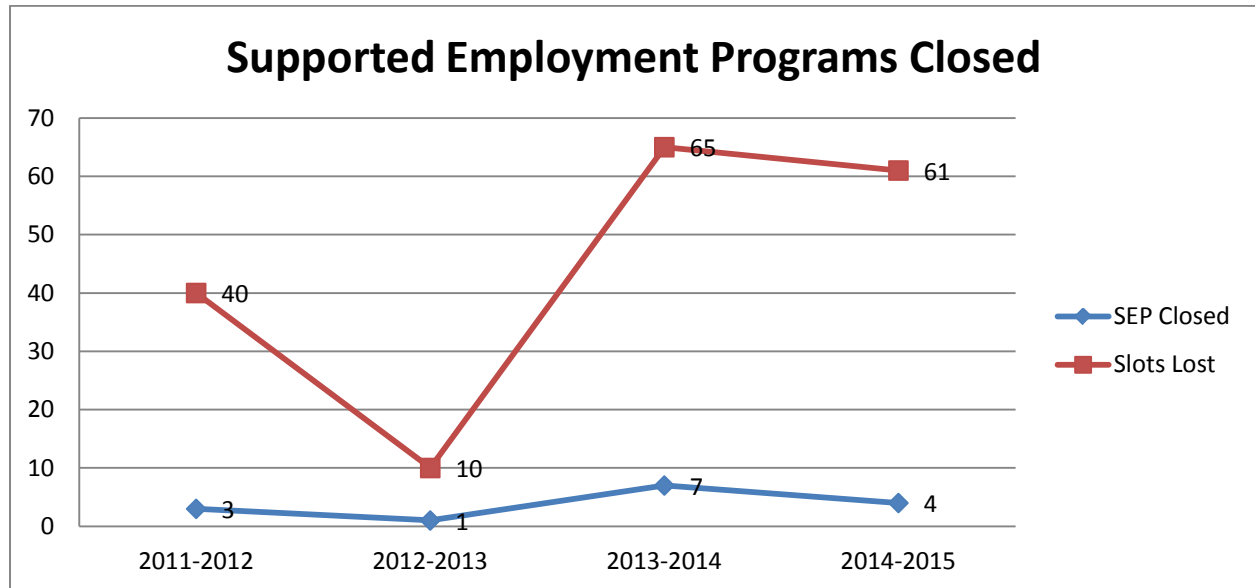
When one of these programs closed, another agency stepped in to provide alternative programming to the individuals that Tierra del Sol would no longer be serving. Mr. Miller remembers that the new provider had to change the program structure in order to offer the service at the available rate "but at least they would have a program. That became the standard for these clients." As these individuals still had a place to go during the day, they were not displaced, but the change in focus from the provision of the *right* service to the provision of *any* service had a significant negative impact on their quality of life.

"We no longer have the resources to offer enriched levels of staffing and close support for individuals who just need that little bit more help to make it through a major life transition like becoming employed or successfully moving into their own apartment. Each of these admissions is painful to make but tragic in consequence. Each translates into real people who are ready, willing and able to get on with their lives that will instead mark time because we can't give them the services we know how to provide."

Stagnation and reductions in funding levels change the nature of the services that can reasonably be provided to individuals. Mr. Miller notes that the system has changed and is no longer as responsive to individual needs as it once was. He says, "We no longer have the resources to offer enriched levels of staffing and close support for individuals who just need that little bit more help to make it through a major life transition like becoming employed or successfully moving into their own apartment. Each of these admissions is painful to make but tragic in consequence. Each translates into real people who are ready, willing and able to get on with their lives that will instead mark time because we can't give them the services we know how to provide."

Supported Employment

Regional centers report that 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.

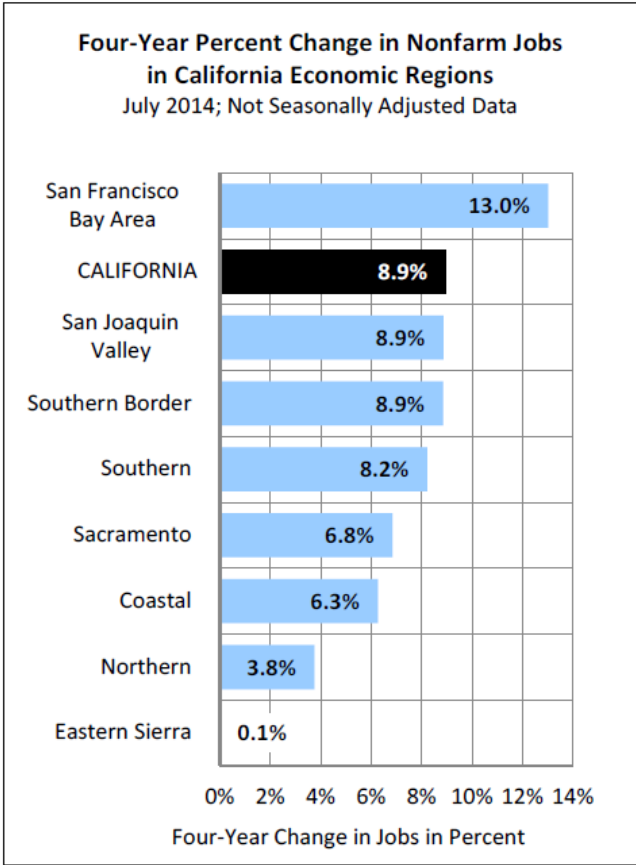
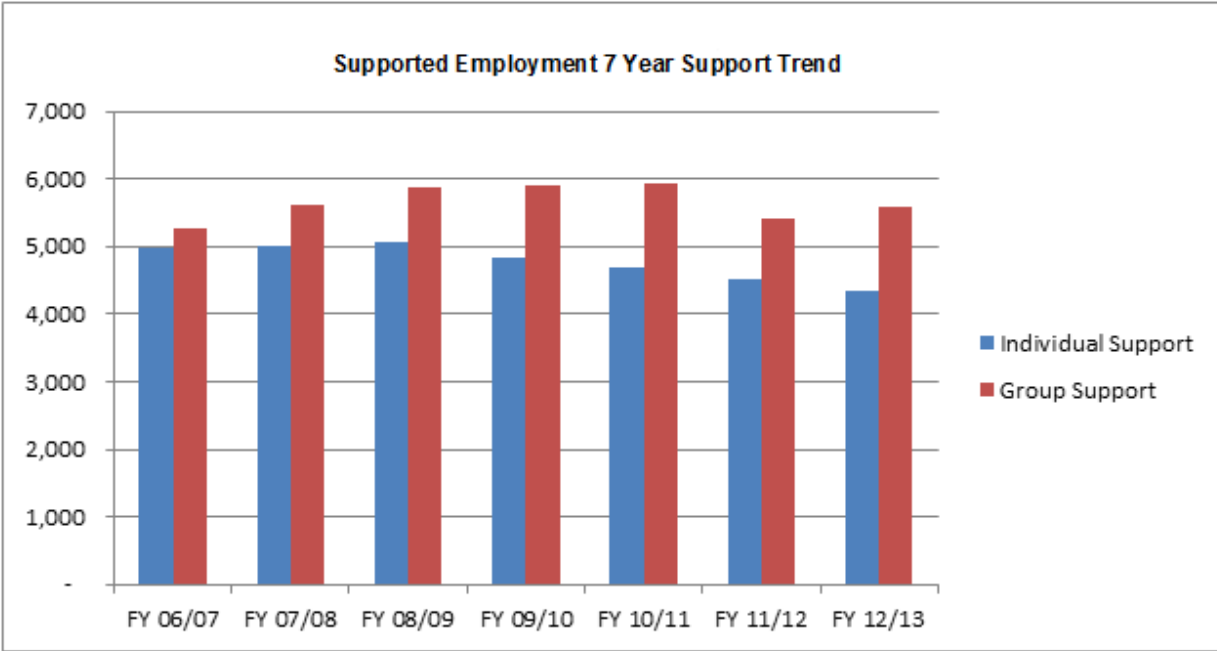


Recently Futures Explored, a day and work services provider in Northern California, stopped providing supported employment individual placement services. Ahead of the decision, their Executive Director Will Sanford wrote, “Futures Explored loses just under \$1,000 a year for each individual who receives Supported Employment services, creating an annual \$150,000 drain on agency resources. As we have created more community employment opportunities it has increased the drain on the agency...The current deficit level is unsustainable.”^{lxxi} He notes that because individuals working independent jobs do not require support at consistent times and in consistent amounts, only a maximum of 70-75% of job coaching hours are actually billable. Another source of loss is

“As we have created more community employment opportunities it has increased the drain on the agency...The current deficit level is unsustainable.”^{lxxi}

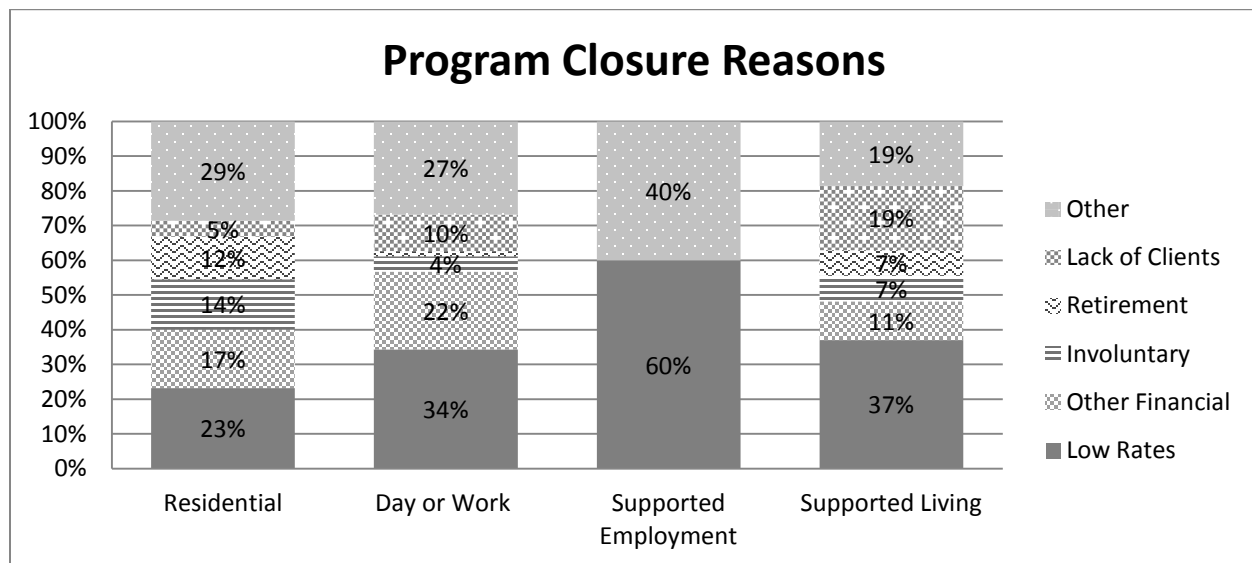
for hours helping an individual to find a job that will suit him and his particular talents and interests well, a process known as “job development.” In short, he notes, “They need the support when they need it.” Individuals may not require much support for a period of time but may need it suddenly in response to a new supervisor at work or a change in their living situation.

Futures Explored is not alone. While other agencies have not terminated existing service arrangements, they are limiting their losses by capping the number of individuals they serve or declining to accept new referrals. As the charts below illustrate, the number of individuals being served in individual supported employment arrangements has declined from over 5,000 in Fiscal Year 2008-2009 to approximately 4,300 in Fiscal Year 2012-2013, a decrease of almost 15%. Group supported employment has also seen a decline during this period as well. Regional centers report a loss of supported employment capacity that has left approximately 600 individuals ready and willing to work but unable to receive the appropriate supports they need to make this a reality. Much of that loss was in the period from July 2010-July 2014, which was a period that the general California job market saw tremendous growth. Approximately 9% more jobs added during that period, meaning that individuals with developmental disabilities lost ground while the rest of California’s population was gaining it.^{lxxii}



The Reasons Behind Program Closures

In its recent survey of regional centers, ARCA sought to capture the reasons that program operators ultimately decided to close their operations. While the number of programs closed varies significantly by program type from a high of 263 for community care facilities to 11 for supported employment agencies, the reasons given for program closure 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. Low rates lead to lower wages, higher turnover, and decreases in staff qualifications and ultimately service quality. A 2011 report by UCLA notes:

It has been shown that in response to increasing costs without corresponding rate increases, vendors offer lower pay to staff than do comparable employers. Given this competitive disadvantage, vendors struggle to recruit and retain direct-care staff, and newly hired staff often have less experience and lower levels of education than those whom they are replacing.^{lxxiii}

The California State Auditor noted in a 1999 report that service providers were experiencing approximately 50% turnover in staff with recruitment of replacement staff taking approximately three months, leading to “disruptions in services and impeding continuity for the consumers, who are continually experiencing the loss of familiar faces and establishing new routines and relationships with different staff.”^{lxxiv} Many studies have shown that high turnover has a negative impact on organizational effectiveness.^{lxxv} Some community providers opt to close when funding levels get too low, but others try to adapt and weather the storm, oftentimes compromising service quality in the process.

Individuals with developmental disabilities and their families oftentimes have a special relationship with the service providers that support them in their community. Providers have been carefully chosen and matched to meet the strengths and needs of individuals. When providers can no longer afford to continue offering services, the ripple effects of those decisions are significant. Staff members lose their jobs and individuals lose the support staff they have come to rely on. Family members lose the security of knowing that their loved one is in good, capable, familiar hands.

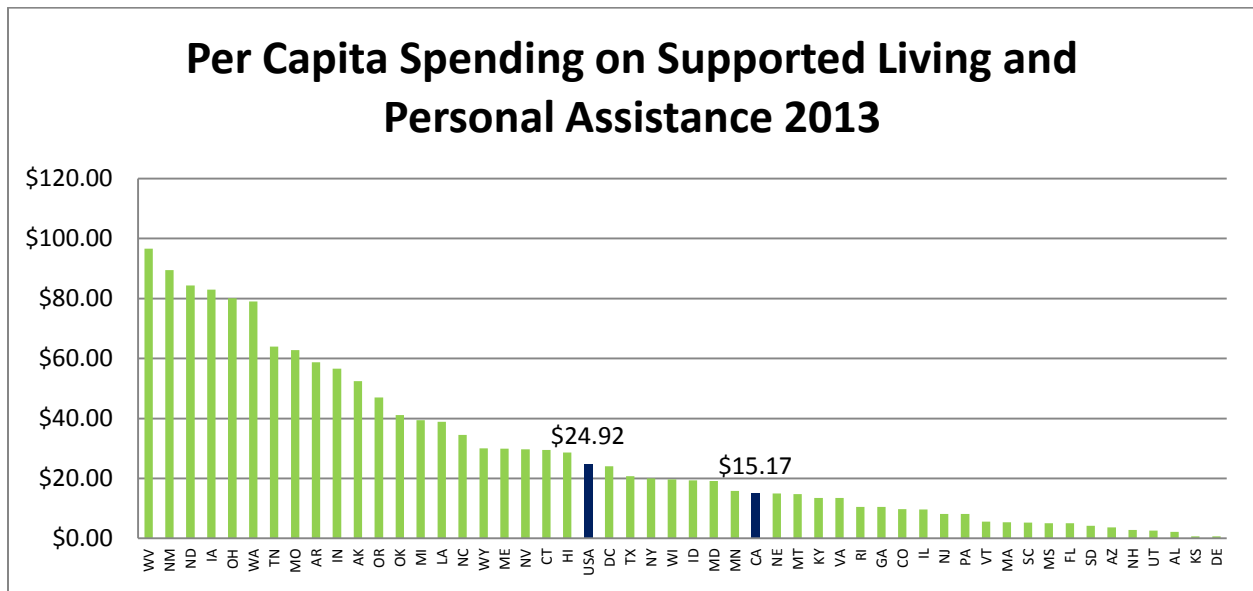
Resource Needs Arising from Service Scarcity

For the first time in many years, in the 2014-2015 Fiscal Year DDS has insufficient funds at its disposal to pay for all of the needed services promised to individuals with developmental disabilities by their regional centers. DDS is seeking over \$150 million more from the Legislature to cover this shortfall. In its justification for additional funding, the department cites a couple of reasons for the uptick in expenditures: 1) greater utilization of Supported Living Services (SLS); and, 2) greater utilization of negotiated rate care homes.^{lxxvi, lxxvii} Some of these increases may be in part a response to the decreased accessibility of other resource options.

As noted earlier, only 10% of the homes that have closed in recent years have been those with a negotiated rather than standard ARM rate. Utilization of such facilities is increasing, particularly for those with the most complex service needs. Of the individuals anticipated to leave institutional settings for the community this year, 66% are expected to require placement in negotiated rate residential settings, while only 14% are planning

to move to ARM rate facilities.^{lxxviii} Individuals' complex needs but also the economic realities of the residential funding model are driving this trend.

As illustrated below, nationwide, other states devote more resources to SLS and similar personal supports per resident of the state than California does.^{lxxix}



Greater utilization of SLS is typically considered a positive advancement for a service system. SLS allows individuals to live in their own homes in the community with support. In some instances, however, SLS is being chosen because other residential options that the individual's planning team believes are more appropriate are unavailable. ARCA's survey of regional centers found that in 67% of areas this dynamic has arisen to varying degrees.

This is particularly true for individuals with significant behavioral challenges who would otherwise require specialized residential facilities with enhanced staffing levels. These homes are particularly difficult to develop given the limitations of the median rate caps. Exceptions to the median rate for individuals whose service needs necessitate a higher rate are possible only on an individual basis by applying for a Health and Safety Waiver from DDS. As waivers are approved for one person at a time, residential care providers are uncertain whether the enhanced rate for each new resident will be approved or not,

making it difficult from a business perspective to develop these homes. In some cases, SLS becomes a more viable option because support levels are easier to customize based on each individual's specific needs.

Regional Center Operations Impacts

The reality of budgeted salaries 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 levels. This has also led to hiring service coordinators with less education and experience. At one time, many regional centers preferred to hire people with a Masters in Social Work to serve as service coordinators. Now, Masters-level case managers are the exception instead of the rule.

Consequently, those service coordinators who are hired must now carry a larger caseload. This is a problem that continues to grow, demonstrated by the fact that in 2011 regional centers employed only 88% of the service coordinators they were statutorily required to have; by 2014 the percentage dropped to 84%, with centers employing 661 fewer service coordinators statewide than they need to meet required caseload ratios.^{lvi} By 2014 no regional center was meeting all mandated caseload ratios, with one center reporting that their caseload ratio for those without federally funded services was 1 to 136 rather than the required 1 to 66.^{lxxx} And as other key regional center positions go unfilled in order to allow centers to pay service coordinators more than is budgeted by the state, service coordinators must also fulfill more functions, leaving them even less time to spend directly working with each individual and family.

Over the years, even though budgeted salaries have been frozen, the workload for the average case manager has increased. The developmental services system relies on increased federal funding and with it comes requirements for more rigorous monitoring of services and supports. Additional workload increases implemented since the Core Staffing Formula was introduced include:

- Health Reviews – During each individual's planning team meetings there must be

a review of their medical, dental, and mental health status and current medications.^{lxxxix}

- Transportation Plans – During planning team meetings, steps must be taken to ensure that individuals are as independent as possible in accessing transportation.^{lxxxii}
- Least Costly Provider – It falls on the service coordinator to ensure that the lowest cost provider that can meet a need is selected to provide a service.^{lxxxiii}

While not a new legal requirement, regional centers are serving increasing numbers of individuals who require a greater level of case management support. As mentioned earlier, the 1999 CityGate report suggested lower caseload ratios for individuals with a dual diagnosis, autism, and behavioral challenges. The incidence of autism in California has risen dramatically since that time.^{lxxxiv} Additionally, as California strives to serve those with complex needs in community rather than institutional settings, regional centers are supporting an increased number of individuals with dual diagnoses and behavioral challenges. For some individuals, particularly those with aged or deceased parents, the regional center case manager serves as the primary point of contact for a variety of decisions that must be made, ranging from medical services to residential options. Today, regional centers serve in excess of 10,000 individuals over the age of 62, many of whom require additional case management support due to a lack of active family involvement.^{lxxxv} Regional center case managers are skilled and effective, but they must be assigned caseloads that are small enough to allow them to be responsive to a variety of needs.

In the 2013-2014 Fiscal Year, approximately 20% of individuals served by California's developmental services system had no individualized supports purchased from service providers.^{lxxxvi} For this population, regional center case management support is the entirety of the developmental services they receive. Many times, these 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 regional center funded services. In direct response to short-sighted underfunding at the state level, it is this group that sees the highest caseload ratios.

California's developmental services system as a whole continues to lose ground. California serves nearly 15% more adults with developmental disabilities than it did at the beginning of the 2011-2012 fiscal year. Sixty percent of regional centers report that they have seen a decline in applicants to become community service providers in the last three years. The system is unable to recruit new providers at a rate that allows for both the replacement of lost services due to community service provider closure and the demand for new services stemming from caseload growth. The results of this struggle and its impact on individuals are becoming apparent. Today, almost 3.5% more adults with developmental disabilities are living at home with their families. Almost 2% fewer are living in community care facilities and a slightly smaller percentage are living independently.^{lxxxvii, lxxxviii} Progress is being interrupted and lives are on hold. What start out as economic decisions quickly become deeply personal ones.

Part 4: Changing Times and Expectations

In 1963 President Kennedy called on states to develop alternatives to institutional placement for individuals with developmental disabilities. Today, self-advocates, their families, and policy-makers again challenge state developmental services systems to do something more – something better – for individuals served in community settings. Recent changes to federal law are reminiscent of the ideals that drove the drafting of the Lanterman Act, such as inclusion and individualized quality services. In the last couple of years, changes to state and federal law have increased expectations on the developmental services system to strive to meet each individual's unique needs in more integrated community settings, to provide meaningful work opportunities, and to compensate service staff better. Also driving service change in California is its increased ethnic diversity and the number of individuals needing services in a language other than English. Responding to each of these changes will lead to better outcomes but only if sufficiently funded. If not, these new expectations will put additional stress on an already fragile service system.

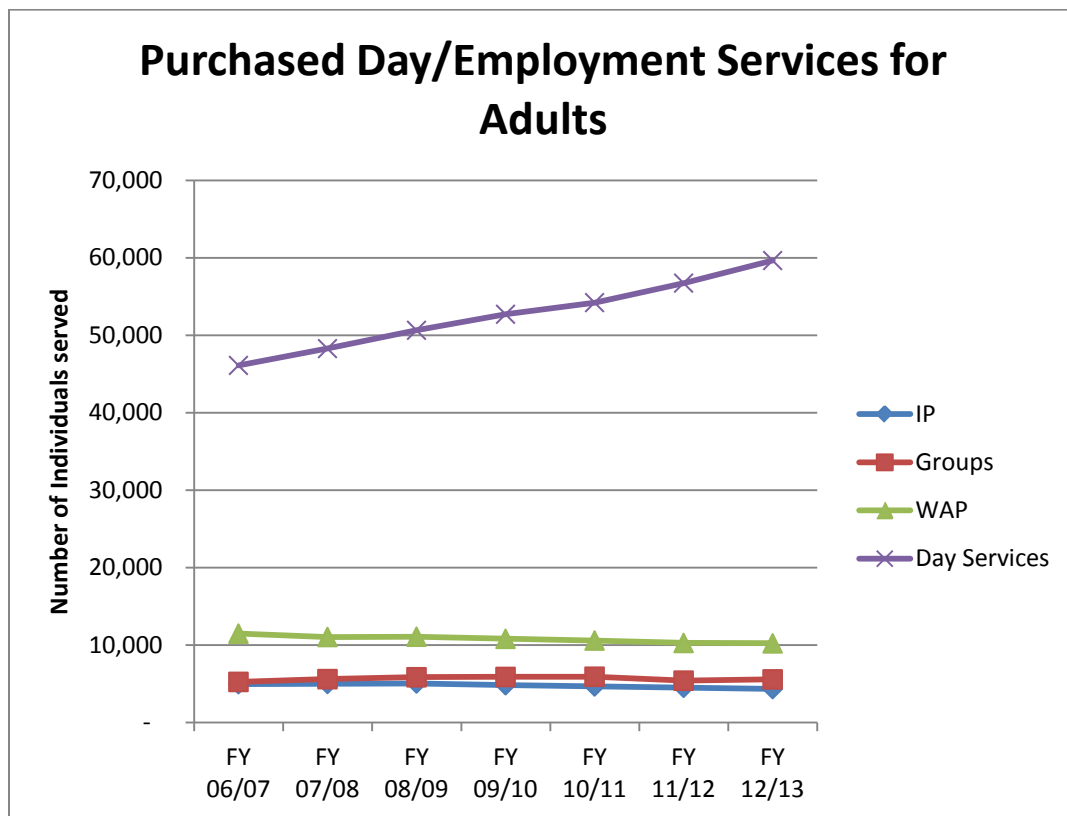
CMS Final Rule on Home and Community Based Services (HCBS)

In January 2014 CMS issued its Final Rule on HCBS, which outlined a significant number of changes to services and systems that must be made in order for states to continue receiving federal funding for services after March 2019. In essence, the Final Rule says:

- Individuals should be integrated into the community to the same degree that other community members are.
- All service settings must offer inclusion and community integration; previously this standard applied to only residential homes.
- Planning for services needs to be individually determined and focused on each person's unique goals and needs.

- States must submit transition plans that outline the steps they will take to ensure they meet these new expectations by March 2019 and continuously thereafter.^{lxxxix}

Changes resulting from these new expectations are likely to be significant, particularly for service providers that have endured years of cuts and rate freezes. As Sue North from the California Disability Services Association noted recently, “Providers are gunshy from years of absorbing losses. No program can afford the professionalism that used to exist in services. Serving the developmentally disabled in the community is now barely a paraprofessional career. This is not a growth industry because growth is not financed and the future at best is one of treading water.” She notes that providers understand that changes are needed and are now asking, “Where’s the roadmap – where are we going and what are the tools to get there?”



When looking at the way in which adults are spending their day, it is apparent that there will need to be changes in this sector in order for the state to continue receiving federal funds for these programs. As of Fiscal Year 2012-2013, nearly 60,000 individuals participated in day programs (either traditional or “look-alike” programs with negotiated rates). Some of these programs offer robust community integration while others do not. Of perhaps the greatest concern, however, is that in excess of 10,000 individuals are being served in work activity programs, which are also known as “sheltered workshops”. It is this type of program that has drawn federal criticism in Oregon and Rhode Island and resulted in those states planning to end their usage over time^{xc, xci}. These programs often have ratios of one staff to twenty or more consumers. If the expectation is that these services will be offered in a more individualized fashion in community settings, staffing ratios and funding levels will need to be adjusted accordingly. In both Vermont and Massachusetts, individuals were guaranteed no loss in overall service hours in the transition from sheltered to community work.^{xcii, xciii} Washington recently faced criticism for providing limited work opportunities without offering additional services to provide individuals with more full lives.^{xciv} As Ms. North notes, “Eliminating service models before having the alternatives in place is counter to the letter and spirit of the Lanterman Act.”^{xcv}

“Eliminating service models before having the alternatives in place is counter to the letter and spirit of the Lanterman Act.”

Residential facilities will also face significant changes in expectations. In order to comply with the new expectations, individuals must have the choice of single or shared rooms and a choice of roommates. Individual bedroom doors must be lockable. Meal times must be flexible with ready access to food around-the-clock. Visiting hours must have the same level of flexibility built in.^{xcvi} All of these changes are designed to allow individuals to live a more integrated, dignified life in the community, but all of these changes may also lead to increased service costs.

The CMS Final Rule requires that individual services be individually-determined through a robust person-centered planning process. This is a process that “addresses health

and long-term services and support needs in a manner that reflects individual preferences and goals.”^{xcvii} The Final Rule requires that the planning process be directed by the individual and result in a plan that strives for individualized outcomes through the use of services that the individual prefers and chooses. These concepts are consistent with the fundamental tenets of the Lanterman Act and the services that regional centers provided for individuals and families for decades. Legally mandated caseload ratios allow this level of attention to be paid to each individual served by the system. As the ability to meet these ratios has declined, so too has the ability to devote sufficient staff time to true person-centered planning.

Most services for individuals with developmental disabilities rely heavily on federal funding in California. As such, as the state works to come into compliance with the new CMS requirements, through the development of assessment tools, evaluation of service settings, necessary program modifications, and supporting individuals through service transitions, service provider and regional center staff alike will need to invest a tremendous amount of time and energy. The state must anticipate these costs and include them in future budget considerations in order to make the necessary transitions ahead of the 2019 federal deadline.

Employment Expectations

In July 2014 President Obama signed the Workforce Innovation Opportunity Act (WIOA). While it impacts workforce development services for all individuals, those with disabilities will see particularly profound impacts, including:

- Each state’s vocational rehabilitation agency (Department of Rehabilitation in California), will spend at least 15% of its budget on pre-employment transition services for individuals getting ready to leave the school system.
- Vocational Rehabilitation agencies can help people to pursue customized employment “based on an individualized determination of the strengths, needs, and interests of the individual.” This provides a great deal of flexibility.

- Group supported employment paying less than workers without disabilities receive will be available only on a short-term basis.
- As of July 22, 2016, the use of 14(c) subminimum wage certificates for individuals under the age of 24 will be limited.
- Community employment agencies known as “American Job Centers” must make sure that their sites and their programs are accessible for people with disabilities.^{xcviii}

Under the changes associated with WIOA, individuals with developmental disabilities become increasingly reliant on services beyond those focused specifically on that population. For instance, individuals under the age of twenty-four must access services through the California Department of Rehabilitation (DOR) before they become eligible to participate in a work program making wages less than the minimum wage. DOR must also prioritize services for individuals between ages 14 and 24. DOR received no additional funds to account for these changing expectations, so will invariably need to make service reductions in other areas in order to make these new priorities a reality.^{xcix}

Also, as noted earlier, California supports in excess of 5,000 individuals in group supported employment settings, largely because the fiscal losses for these individuals are less significant than the losses incurred for individual supported employment. WIOA makes clear that these group job supports will not be considered an acceptable long-term outcome if individuals are not paid the prevailing wage for the job. WIOA will require rethinking and reengineering the way that individuals are transitioned from school to jobs and ultimately careers.

In 2013 California passed its Employment First legislation. Thirty-two states now have similar laws, directives, or executive orders in place.^c California’s legislation requires that “opportunities for integrated, competitive employment shall be given the highest priority for working age individuals with developmental disabilities, regardless of the severity of their disabilities.”^{ci} The expectation is that individuals will be supported as necessary to work, earn money, and be part of community life. As noted earlier, regional centers know of approximately 600 additional individuals that would be candidates for

supported employment if sufficient provider capacity were available. Ideological values statements such as the Employment First Policy must be sufficiently funded in order to be fully realized.

Employee Compensation Requirements

Unlike government agencies, regional centers and their vendors do not receive automatic fiscal adjustments when mandates for employers increase. Recent changes related to health benefits, paid sick time, overtime pay, and minimum wage are examples that have surfaced in the last year alone. Specifically:

- “Small businesses with 50-99 full-time equivalent employees (FTE) will need to start insuring workers by 2016. Those with a 100 or more will need to start providing health benefits to at least 70% of their FTE by 2015 and 95% by 2016.”^{cii}
- Minimum wage was increased in California from \$8 to \$9 per hour effective July 1, 2014, and will increase to \$10 on January 1, 2016. Rates for some community service provider programs were increased to allow them to pay direct staff \$9.00 per hour. When the lowest paid employees in an organization receive a raise but other staff members do not, the gap between pay scales, which rewards longevity or taking on more challenging duties, shrinks. Service providers did not receive funding to address this dynamic.^{ciii}
- Beginning July 1, 2015, employers will be required to provide employees who work at least 720 hours per year with three paid sick days annually and a prorated share of these hours for employees who work less than that.^{civ}
- In September 2013 the United States Department of Labor announced new rules that as of January 1, 2015, would have required most employees supporting individuals in their homes to receive overtime if they work more than forty hours weekly. This issue is currently being appealed in federal court^{cv}, but if implemented will impact supported living, respite, and personal attendants that are contracted with the regional centers. Should this occur the budget adjustment

for this will be a 5.82% increase in the rates for those services to allow for the hiring of additional staff rather than the payment of overtime.^{cvi}

Service providers note that they want to pay their employees more for the tireless dedication they exhibit. Without adequate funding for these mandates, however, employees lose rather than gain ground. For instance:

- At a recent meeting to discuss steps needed to stabilize community-based services for individuals with developmental disabilities, a service provider shared his need to limit the number of individuals he supports in order to reduce his agency to less than fifty employees as he cannot afford the employer mandate under the Affordable Care Act.
- Supported living providers in some areas are not accepting referrals for individuals requiring overnight supervision in anticipation of potentially having to pay overtime to these employees. Many of these employees were previously being paid in excess of forty hours per week and know that depending on the federal court action that their hours and paychecks may be reduced.

In a recent letter to the Governor, Senator Beall and seven of his legislative colleagues proposed two common sense approaches to address these dynamics. First, provide regional centers and community service providers with Cost-of-Living Adjustments similar to what state employees receive, as the work done by the developmental services system is on behalf of the state. Second, fund regional centers and service providers for additional expenses arising from new expectations.^{cvii} For reference, this letter is attached to this report as Appendix A. In short, he recommends funding the system like any other state program.

Increasing Diversity

For the first time in July 2013 California's Latino population equaled its white population, with the expectation that it would surpass its white population in 2014.^{cviii} There is no question that over time, California's population has become increasingly diverse. Now, in excess of 24% of individuals with developmental disabilities served by California's

regional centers primarily speak a language other than English.^{cix} Regional centers and community service providers alike are striving to meet the increasing demands of greater cultural and linguistic diversity. Again, funding levels pose a challenge in this arena, particularly in securing services for adults with developmental disabilities.

ARCA asked regional centers in its previously mentioned survey about the services that are difficult to secure for non-English speaking children and adults and the primary reason why. For children, regional centers reported that many clinical services are difficult to secure such as behavioral services, speech therapy, and medical services. The primary barrier identified by 62% of the centers was the service providers' inability to identify qualified staff to provide services in the required languages. The picture was different for adult services, however, as for adults the services that were most difficult to secure were largely residential homes and day programs, which oftentimes employ lower-wage staff. Approximately 53% of regional centers reported that the primary challenge is service rates that do not allow providers to recruit bilingual staff, whereas only 33% reported that the primary barrier was the service providers' inability to identify bilingual staff. Again, service provider rates seem to be a significant challenge to serving a population that continues to grow. Couple this dynamic with the need to provide this population with increased case management time to communicate through interpreters and identify appropriate bilingual service options, and it is clear that underfunding of both case management and services for this population has a negative impact on service access.

California's community-based developmental services system is poised to do great things for the people that it serves, but it needs adequate resources to do so. Individuals with developmental disabilities, their families, and the staff that support them in the community have been promised and deserve so much. These promises are the very foundation of California's developmental services system. Over time, a lack of fiscal investment in the system has left it struggling to meet individual needs in a way that is responsive to and respectful of each person's unique preferences and choices. Providing services to individuals and families that allow more than a quarter of a million people to thrive in community settings is something that California knows how to do and

has historically done well. Erosion of funding for the system coupled with additional unfunded mandates have left it struggling to maintain many individuals rather than providing them with the robust supports they need in order to thrive. Fortunately, the community's commitment to the ideals of the Lanterman Act remains strong. The dedication remains to help the system to recover and again help individuals to achieve higher levels of integration, satisfaction, and independence.

Recognition of the funding shortfall and its impact on individuals with developmental disabilities is only the first step. The Lanterman Coalition, which represents the major advocacy, family, self-advocacy, and other stakeholder groups in California's developmental services system, has proposed an incremental, common sense approach to stabilize and propel the system forward. First, infuse the system with a one-time 10% funding increase in order to stabilize community service providers and regional centers and to prevent further decline. Second, reform funding for service rates and regional center operations to make them adequate, thoughtful, and designed to promote sustainability and quality outcomes. Third, in the interim years until such funding reform is implemented, provide the system with 5% annual increases in order to correct the course of the system and begin to set it on the path of again providing necessary supports to enhance each individual's independence and personal outcomes. ARCA and California's twenty-one regional centers embrace this strategy and encourage the Administration and the Legislature to begin the reinvestment in the state's developmental services system today.

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APPENDIX A

LETTER FROM SENATOR BEALL TO GOVERNOR BROWN

CALIFORNIA LEGISLATURE

STATE CAPITOL
SACRAMENTO, CALIFORNIA
95814

October 27, 2014

Governor Jerry Brown
Office of the Governor
State Capitol, Suite 1173
Sacramento, CA 95814

Dear Governor Brown:

Since the ratification of the Lanterman Act in 1977, California has recognized the right of people with developmental disabilities to live an independent and normal life. To facilitate the promise of the Lanterman Act, California created 21 regional centers to triage and direct more than 260,000 people with developmental disabilities to some 65,000 providers who furnish the appropriate support and services they need.

But the state's ability to meet our basic obligations to Californians with developmental disabilities is being severely hindered by a lack of employee cost of living increases for regional center employees and inadequate service provider rates.

Cost of living increases for employees and providers lag far behind inflation. The result has not only imperiled service providers who are struggling to remain open but has seriously undermined the ability of our regional centers to recruit and retain a qualified staff.

While state agencies generally build in cost increases such as health benefits, transportation cost increases and negotiated salary COLAs, regional centers and vendors within the California Department of Developmental Services (DDS) system do not have these accepted adjustments.

The California Department of Developmental Services (DDS) has seen some adjustments to their budget for policies such as federally mandated overtime changes and the state minimum wage adjustment. However, these increases went through an arduous legislative budget process instead of being built into the January base budget. Moreover, many other new federal and state mandates have not been included and these costs are absorbed by regional centers and providers. These include adjustments for transportation increases, health benefits, minimum wage mandates by local municipalities and other costs.

In the current budget year, funding for DDS is \$5.2 billion. Since 2009, the state has reduced costs to developmental services programs by more than \$1 billion (GF) instituting restrictions on payments for specific services, across-the-board reductions, mandated furlough days, suspension of services and other cuts. Prior to that, the state had frozen rates to providers in order to contain costs. These freezes and caps have fractured the infrastructure of the community services and support systems. Without building in adjustments for cost of living increases, it will not be sustainable. In 1999, even before the substantial reductions and freezes prompted by the Great Recession, the Bureau of State Audits released a report concluding that community services were "undermined by insufficient state funding and budget cuts."

Meanwhile, pending mandates from the Federal government will require California to restructure day programs, work programs and residential settings to reduce the number of consumers and require more community inclusion. State mandates that will be implemented include the Employment First model, self-determination pilot program, and others that require more intensive case management and development of new programs.


At a Senate Human Services hearing this month, many providers testified that they are unable to sustain innovative and inclusive programs, much less expand them or create new ones because of historic freezes and caps. I realize that the cost of total restoration is outside our reach today. However, we must take steps to address the gap -- 260,000 Californians who rely on the Lanterman Act need our help.

We urge you to apply fair budget policies that treat the regional centers and providers equal to other state agencies that build COLAs and fund new federal and state mandates in their base budget.

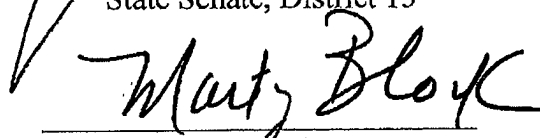
And, we respectfully request an end to the shifting of our financial responsibility for federal and state mandates onto our already fragile regional centers and providers. We strongly urge these costs -- as well as a COLA for regional center employees and providers -- be included in the January budget.

Thank you in advance for your consideration.

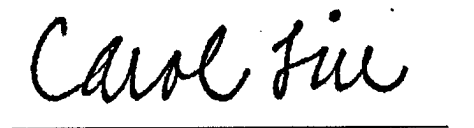
Sincerely,



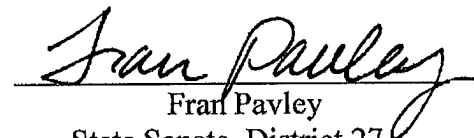
Jim Beall
State Senate, District 15



Marty Block
State Senate, District 39



Carol Liu
State Senate, District 25



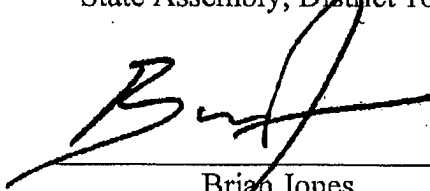
Fran Pavley
State Senate, District 27



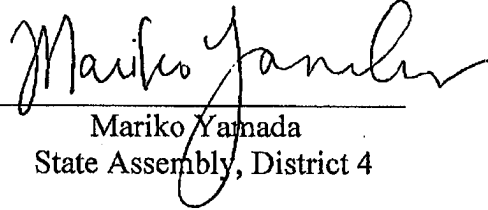
Joan Buchanan
State Assembly, District 16



Rich Gordon
State Assembly, District 24



Brian Jones
State Assembly, District 71



Mariko Yamada
State Assembly, District 4

Cc: Diana S. Dooley, Secretary, California Health and Human Services Agency
Santi Rogers, Director, Department of Developmental Services
California Senate Budget Committee Members
California Assembly Budget Committee Members