

# **Building A System For Tomorrow**

## **Supporting People With Developmental Disabilities To Lead Inclusive Lives**



**Prepared by the  
Association of Regional Center Agencies  
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## LIST OF ABBREVIATIONS AND ACRONYMS

<i>ACRC</i>	Alta California Regional Center
<i>CART</i>	Clinical Services, Advocacy, Research and Technical Assistance and Training
<i>CBO</i>	Community–Based Organization
<i>CIE</i>	Competitive Integrated Employment
<i>CLAS</i>	Culturally and Linguistically Appropriate Services
<i>CMS</i>	Centers for Medicare and Medicaid Services (Federal)
<i>CSF</i>	Core Staffing Formula
<i>CSH</i>	Corporation for Supportive Housing
<i>CVRC</i>	Central Valley Regional Center
<i>DDS</i>	Department of Developmental Services
<i>DOR</i>	Department of Rehabilitation
<i>DSP</i>	Direct Support Professional
<i>ELARC</i>	Eastern Los Angeles Regional Center
<i>ESC</i>	Enhanced Service Coordinator
<i>FDLRC</i>	Frank D. Lanterman Regional Center
<i>FQHC</i>	Federally Qualified Health Center
<i>GGRC</i>	Golden Gate Regional Center
<i>HCBS</i>	Home and Community Based Services
<i>HCD</i>	Department of Housing and Community Development
<i>HCV</i>	Housing Choice Voucher
<i>HHS</i>	U.S. Department of Health and Human Services
<i>HIPAA</i>	Health Insurance Portability and Accountability Act
<i>HUD</i>	U.S. Department of Housing and Urban Development
<i>IDD</i>	Intellectual Developmental Disability
<i>IPP</i>	Individual Program Plan
<i>LHA</i>	Lanterman Housing Alliance
<i>ODEP</i>	The Office of Disability Employment Policy
<i>OMH</i>	Office of Minority Health

<i>OPS</i>	Operations (Budget)
<i>PCP</i>	Person–Centered Planning
<i>PCT</i>	Person–Centered Thinking
<i>PIP</i>	Paid Internship Program
<i>POS</i>	Purchase of Service (Regional Center funds)
<i>SC</i>	Service Coordinator
<i>SCC</i>	Special Care Centers
<i>SDC</i>	Sonoma Developmental Center
<i>SDRC</i>	San Diego Regional Center
<i>SDP</i>	Self–Determination Program
<i>SLS</i>	Supported Living Services
<i>SMUD</i>	Sacramento Municipal Utilities District
<i>SP</i>	Service Provider
<i>SRCH</i>	Santa Rosa Community Health
<i>SSI</i>	Supplemental Security Income
<i>SSP</i>	State Supplementary Payment
<i>TLCPCP</i>	The Learning Community for Person–Centered Practices
<i>TCRC</i>	Tri–Counties Regional Center
<i>UOP</i>	University of The Pacific
<i>VMRC</i>	Valley Mountain Regional Center
<i>WIOA</i>	Workforce Innovation and Opportunity Act

# **Building A System For Tomorrow**

## **EXECUTIVE SUMMARY**

The Association of Regional Center Agencies represents the network of 21 non-profit regional centers that coordinate services for, and advocate on behalf of, over 320,000 Californians with developmental disabilities. The regional center system began in 1969 with the passage of the Lanterman Developmental Disabilities Services Act. Half a century later, while the goal is the same – providing services and supports to help people with developmental disabilities lead healthy, productive lives in their community – the vision for what is possible has evolved to include full community membership.

Beginning with intake, assessment, and eligibility determination, regional centers provide lifelong services and supports to help those served lead the most independent and productive lives in their chosen communities. Service coordinators are the backbone of the regional center service system. Supporting community participation, serving diverse communities, meeting complex needs, and implementing new programs – these are substantial responsibilities for service coordinators to shoulder. This paper focuses on the essential resources the developmental services system needs to build a system for the future in full compliance with evolving federal and state expectations. It offers practical and creative solutions to meet today's challenges with an eye towards tomorrow's goals.

### **Part 1. Supporting Community Participation**

Living and working in one's own community is essential to leading a meaningful and fully included life. Additionally, the federal government expects services and supports to be individualized and community-based. This helps individuals with developmental disabilities achieve goals such as independent living and competitive integrated employment.

Moving into your own home means achieving independence and personal autonomy. People with developmental disabilities choose community life but lack affordable

housing options, as even affordable housing may be out of reach. Improvements will require:

- Expanding rental assistance programs;
- Increasing supportive housing opportunities, and
- Changing policies to both increase housing and better support the many families who care for loved ones at home.

Work is more than a paycheck – it enhances dignity, self-worth, and a sense of belonging. The most successful job opportunities are created by:

- Partnering with community-based businesses;
- Providing individualized job development; and,
- Supplying quality job training and job coaching services.

Ensuring programs and services are community-based and comply with federal rules requires service providers be paid for the actual services they are providing. With the expectation that services are more individualized, skilled, and training-oriented, direct support professionals must be compensated for their complex work. After decades of outdated rate structures, service providers cannot recruit or retain enough experienced staff. The ongoing rate study is California's best hope for a sustainable rate structure that will make possible the integrated life people dream of.

## Part 2. Service To Diverse Communities

California boasts one of the most ethnically and linguistically diverse populations in the world. In the last ten years, the number of people supported by regional centers in the Hispanic community has risen well over 70%, and those in the Asian community have increased 67%. Over 24% of all individuals served by regional centers speak a primary language other than English.<sup>i</sup>

Successful service delivery to diverse communities goes beyond language access, and must also include understanding diverse value systems, recognizing cultural practices, and offering preferred services, which lead to the identification of effective solutions.

Many systems fall short of the goal of service equity in part due to socio-economic status, immigration pressures, and cultural preferences. Supporting equitable service delivery requires:

- Sustained funding for diversity projects;
- Expanding traditional services to match cultural values; and,
- Reducing caseload ratios to allow for time to nurture a positive and trusting relationship with individuals and families from diverse communities.

### Part 3. Supporting People With Complex Service Needs

Some people supported by regional centers have complex needs that must be met through involved service coordination to ensure they can live safely in the community with appropriate services. Success depends on creative solutions paired with inter-agency collaboration.

People with developmental disabilities face multiple barriers to accessing health care, including adequately trained clinicians, accessible clinics, and an appropriate support system. Modernizing the health care system must include:

- Updating reimbursement rates;
- Payment for time spent; and,
- Creative non-traditional service delivery that is responsive to individual needs.

As California relies less on institutional care for those with complex behavioral and psychiatric support needs, it must identify and support effective strategies to meet these needs in community settings. Forensic, behavioral, and psychiatric support needs require a tremendous amount of expertise. Services and supports can only be created through:

- Cross-collaboration with community-based agencies;
- Development of specialized resources; and,
- Robust, specialized training.

## Part 4. Supporting Dynamic Service Coordination

Service coordination is the core of the regional center system – the direct link to individuals with developmental disabilities and their families. Service coordinators are primarily responsible for ensuring people with developmental disabilities have the opportunity to lead the fully included lives they dream of. With new requirements and legal mandates, additional support is needed to allow the support system crafted many years ago to evolve.

State law requires the service system help the individual live their preferred future. Person-centered thinking accepts each individual as the expert in their own life, and guides the planning team in supporting the individual's choices. Successful person-centered planning takes time. Lowering caseloads provides that, letting service coordinators partner in the creation of enduring person-centered plans.

The new Self-Determination Program will provide participants more flexible choice in services, providers, and budgeting. Regional centers will need support to:

- Carry out accounting changes;
- Provide comprehensive training; and,
- Prepare service coordinators for a dual system of service delivery.

Service coordinators are crafting more individualized plans for an increasingly complex, diverse community, which requires cultural competence and expertise in fields such as forensics, behavior, psychiatry, and medicine. New mandates threaten to overshadow the essence of service coordination – fostering the relationship between the individual and the regional center. Effectively meeting those mandates requires lowering caseloads to allow them time – time to meet the demands of the job, time to learn and develop expertise in specialized programs, and time to nurture a positive relationship with the individuals supported by the regional centers and their families. There must be adequate resources to build the system of tomorrow – to support individuals with developmental disabilities to live the meaningful lives they choose for themselves in their own communities.



## **PART 1: SUPPORTING COMMUNITY PARTICIPATION**

Today, more people with developmental disabilities are seeking to lead fully-included lives by living, working, and engaging in communities of their choosing. Fulfilling this goal requires a vision for the future and attention to current policy needs. Those needs include meeting federal expectations, providing access to affordable housing, developing integrated employment opportunities, and ensuring sustainable funding for community service providers to employ well-qualified direct support professionals.

### **Supporting Community Participation In Housing**

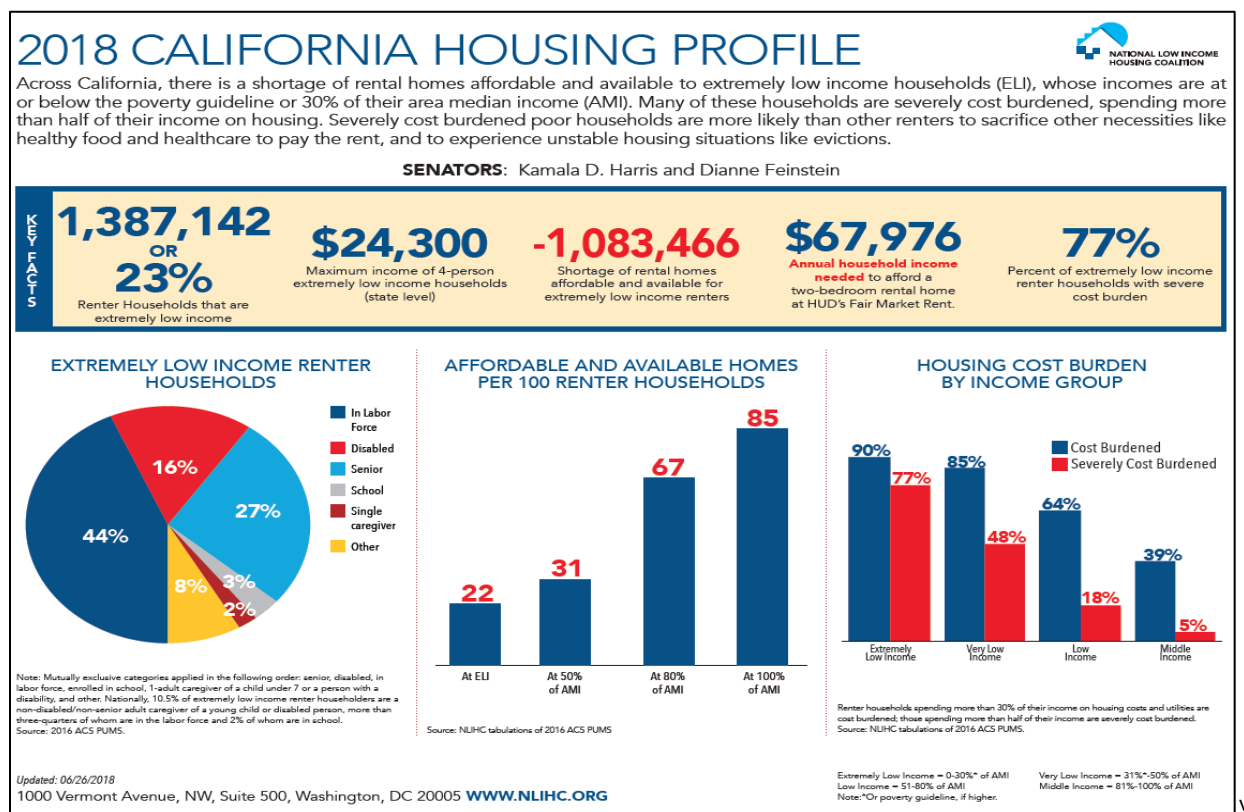
Housing is a fundamental ingredient to living an independent, self-directed and gratifying life. People with developmental disabilities often rely solely on public benefits which dwindles their already limited housing options. They are being priced out of many neighborhoods as rental prices skyrocket and affordable housing inventories shrink. Although the housing crisis impacts all low-income families, the brunt force of the crisis is devastating to people with disabilities who depend on Supplemental Security Income (SSI), which is less than the federal poverty level. Dreams of independent living in the community are often dashed by the reality of the lack of affordable housing.

Housing prices across the country are far outpacing the monthly SSI benefits and many people with disabilities are forced to remain living in the family home, group living arrangements, or in extreme circumstances, driven to homelessness. With the massive housing crisis in California, the community-based developmental services system is hard pressed to keep the promises outlined in the Lanterman Act,<sup>ii</sup> or to comply with the legal requirements to support people with developmental disabilities to live in the least restrictive settings in the community.

For over 1 million Californians with disabilities and seniors, the monthly SSI/State Supplementary Payment (SSP) grants are their sole source of income. For individuals living in their own home in 2018, the total SSI/SSP monthly payment for a single person with a disability who lives in their own home is \$910.72. Renting even a modest unit in an individual's own community requires spending most of their income, leaving little for

food or basic necessities. Housing is considered affordable if it consumes less than 30% of total monthly income. In California, “a studio apartment rent exceeds one-half of the SSI/SSP Grant in all 58 counties and is higher than the entire Grant in 17 counties.”<sup>iii</sup> The most significant impact is seen in metropolitan areas.

Rural communities are also adversely affected by the housing crisis. In the Redwood Coast Regional Center area, for instance, the community has suffered severe wildfire damage in recent years intensifying the local housing crisis with reduced inventory and increased rental costs of more than 200%, affecting both families and service providers. Partnering with local and state government, and housing development organizations, is also necessary in rural communities to confront these serious housing challenges.<sup>iv</sup>



The National Low-Income Housing Coalition reports housing costs are totally unaffordable for SSI recipients and people working for minimum wage.<sup>vi</sup> The stark reality is people with developmental disabilities cannot afford to live independently without housing assistance. The *2018 California Housing Profile* illustrates that even with rent subsidies, there is a significant shortage of affordable rental homes. Many low-income

households are severely cost burdened, spending more than half of their income on rent and are more likely to sacrifice necessities like food and health care to pay the rent. Regional centers are often ready and willing to provide services to help individuals live independently to achieve their Individual Program Plan (IPP) goals but this is often beyond reach due to the cost of housing. The majority of adults with developmental disabilities live at home with their families but this is not always the intended goal.<sup>vii</sup> Without sufficient resources to afford a shared apartment, living options are restricted to staying in the family home or moving to a more restrictive setting. The lack of affordable housing is impeding progress towards more independent lives.

Choosing where you live is a vital part of independent living. Federal and state law supports this choice.<sup>viii</sup> The Lanterman Act provides opportunities for adults with developmental disabilities, regardless of the degree of disability, to receive the supports necessary to live in homes that they own or lease. Regional centers offer supported living services (SLS)<sup>ix</sup> to help individuals exercise meaningful choices and control their daily lives, but the housing crisis impacts any decisions to live independently, as in order to be eligible for SLS, the individual is required to live in his or her own home. Unfortunately, an individual reliant upon SSI cannot bear the hefty weight of housing costs and as a result, living independently may not be a realistic option.<sup>x</sup>

*There is only so much you can afford when you are on SSI. I have had to choose between food and housing before.*  
– Chris Miller

## **Solutions To Lessen The Effects Of The Housing Crisis:**

### **1. Expand rental assistance programs**

Federal and state rental assistance programs are invaluable to maintaining housing stability for individuals with developmental disabilities. The U.S. Department of Housing and Urban Development (HUD) administers federal aid to local housing agencies that manage housing for low-income residents. Rental assistance<sup>xi</sup> may include: Housing Choice Vouchers, Public Housing, Project-Based Section 8, Section 811, Section 202,

and rental assistance programs funded by the U.S. Department of Agriculture.<sup>xii</sup> In California, the Department of Housing and Community Development (HCD)<sup>xiii</sup> administers programs to provide grants and loans to create rental and homeownership opportunities for veterans, seniors, people with disabilities, and homeless. While HCD has provided more than \$3 billion in funding for the development of affordable housing in the last three decades,<sup>xiv</sup> the severity of the housing crisis demands an infusion of rental assistance funding to meet the extraordinary housing needs of people with developmental disabilities.

One shortcoming of the housing voucher program is that there are long wait lists. It was reported in January 2018 that “as many as 50,000 people who cannot afford to pay the going rate for a rental home or apartment in Sacramento County will start rolling the dice in a lottery for subsidized housing. The odds are long: Only 7,000 spots on the housing authority’s waiting list are available.”<sup>xv</sup> Increasing federal and state rental subsidies will improve the housing outlook for people with developmental disabilities who may have a goal of living independently avoid waiting years to achieve that dream.

## **2. Increase supportive housing opportunities**

Permanent supportive housing combines lease-based, affordable housing with tenancy supports to help individuals live safely in the community. A leading advocate of supportive housing, the Corporation for Supportive Housing, noted the importance of “the central mandate of *Olmstead* – to provide people with disabilities the housing and support they need to live in the most integrated setting possible in a community of their choice.”<sup>xvi</sup> One successful integrated joint housing project between Regional Center of Orange County and the Department of Developmental Services (DDS) is Harbor Village which offers a safe, clean, affordable subsidized housing option for people with developmental disabilities and to the general public at fair market rent on land that was once part of Fairview Developmental Center.<sup>xvii</sup>

- **Section 811** subsidizes rental housing opportunities with supportive services in two ways: by providing interest-free capital advances and operating subsidies to

nonprofit developers of affordable housing for persons with disabilities; and by providing project rental assistance to state housing agencies.<sup>xviii</sup>

- **DDS Rental Unit** is a program created through the 1994 *Coffelt* Agreement. Although funding has been exhausted, the program design reflects concepts from both affordable housing and supported living arrangements with rent at 30% of income and long-term affordable housing for those who chose to live in an independent environment.<sup>xix</sup>
- **DDS Affordable Housing** projects increase capacity building and housing production of affordable housing through the purchase, rehabilitation, or construction of real property.<sup>xx</sup>

### **3. Support families caring for individuals in the family home**

Many individuals with developmental disabilities reside with aging caregivers and when the caregiver is no longer able to provide necessary supports, the person may be faced with moving to a group living situation. This life change disrupts personal relationships, community integration, and even access to familiar service providers and supports. It is important for planning teams to address current caregiver support needs when planning for the future as well. The California Legacy Homes Program allows families to gift real property to non-profit housing coalitions to provide an option for the person with a disability to remain in their home – all within the framework of maximum choice, independence, and meeting the needs and aspirations of the individual.<sup>xxi</sup> Ultimately, the planning team will ensure the individual's choice of living goal is person-centered and that all options are considered.

### **4. Appreciate the value of living in a community of your own choosing**

Compounding the housing crisis is the fact that housing disparities and housing discrimination continue to exist. Federal and state law prohibit disability-based discrimination which cover a broad range of housing providers such as landlords, realtors, lenders, owners, independent living homes, and homeless shelters.<sup>xxii</sup> Unfortunately, NIMBYism, an acronym for "Not In My Backyard," describes when

neighborhood residents believe a new development (e.g., affordable housing or group home) as inappropriate for their local area. Some argue the “biggest impediment to building more housing is resistance within local governments that control land use.”<sup>xxiii</sup> Housing advocacy is necessary to prevent housing discrimination and dispel unfair assumptions about people living in an affordable housing development.<sup>xxiv</sup>

*Housing Choice Vouchers* (HCV) offer another way to lessen disparities and increase potential. HCV’s allow more flexibility for families to choose affordable and safe housing, and they also enable children to grow up in better neighborhoods with chances of long-term health and success. “...[V]ouchers could do much more to help these and other children grow up in safer, low-poverty neighborhoods with good schools.”<sup>xxv</sup> All people should have an equal opportunity to pursue life in a decent and safe neighborhood, regardless of the neighborhood they are born into.

## **5. Advance housing advocacy efforts to improve housing opportunities**

Organizations throughout California that serve the housing needs of people with developmental disabilities have formed the Lanterman Housing Alliance (LHA).<sup>xxvi</sup> In an effort to create a roadmap for sustainable and supportive housing for people with developmental disabilities, LHA launched an initiative in October of 2017 to create a Strategic Framework to provide a roadmap to increasing affordable housing for Californians with developmental disabilities.<sup>xxvii</sup> The Lanterman Coalition,<sup>xxviii</sup> consisting of the major stakeholders in the California developmental services system, proposed the dedication of funding generated from the closure of the remaining developmental centers be preserved for housing for people with developmental disabilities to increase the development of affordable housing to improve overall housing choices.<sup>xxix</sup> While the exact value of the developmental center properties is unknown, it is estimated their closure will generate \$100 million annually in savings to the state. Kristin Martin, Executive Director of HOPE, which has partnered with Harbor Regional Center for years to increase housing opportunities, opined “As the affordable housing industry continues to face rising property values, funding source instability, and growing need, it has become increasingly essential to bring together the right partners.”<sup>xxx</sup>

Tackling the housing crisis for people with developmental disabilities will require long-term solutions with collaboration from stakeholders and policy makers working in tandem to address the unmet housing needs of this population. The struggle for the developmental disability service system is to find creative and operational solutions to a broad nationwide housing problem that adversely affects Californians with developmental disabilities in a more profound way than other sectors of the population.

### **Supporting Community Participation In Employment**

Employment opens a door to endless possibilities for individuals with developmental disabilities. Earning a paycheck is an essential part of independence and personal development. Nurturing workplace relationships and being part of the greater community is also valuable. But achieving employment goals can involve overcoming barriers to obtaining *competitive integrated employment*.

The challenges of discrimination, misconceptions, and lack of workplace accommodations lead to lower wages and less labor market participation. “About 9 of 10 adults of working age with autism or other forms of intellectual or developmental disabilities are unemployed... many of these adults want to be a part of the workforce, but employers are often hesitant to hire employees with IDD.”<sup>xxxi</sup> Despite these obstacles, people with disabilities seek meaningful work to achieve their goals and improve their lives.

Living, working, and socializing with people in your community is essential to independence. Working alongside people without disabilities for a living wage and benefitting from career advancements alongside co-workers is an inextricable part of that independence. “Social capital” describes a person’s connectedness or engagement with individuals or communities associated with labor

*Work is about more than making a living,  
as vital as that is, it's fundamental to  
human dignity, to our sense of self-worth  
as useful, independent, free people. –  
William J. Clinton*



force participation. “Maximizing inclusion of persons with disabilities within society, requires that policy makers and service agencies must not lose sight of *social capital* as a construct as equally important human, and economic capital. Innovative programs and services that are offered throughout the lifespan should incorporate strategies to address each of these types of resources.”<sup>xxxii</sup> For people with disabilities, employment provides an invaluable opportunity for engagement that fosters greater independence.

### **The Employment First Policy**

The Lanterman Act<sup>xxxiii</sup> mandates services and supports to enable people to live “more independent, productive, and normal lives.”<sup>xxxiv</sup> California’s Employment First Policy provides “... *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.*”<sup>xxxv</sup> After decades of segregated worksites, subminimum wages, and little advancement to competitive employment, people now have tools to help them achieve this.

### **The Competitive Integrated Employment Blueprint**

In May of 2015, DDS, California Department of Rehabilitation (DOR) and California Department of Education collectively agreed to the California Competitive Integrated Employment Blueprint.<sup>xxxvi</sup> It outlines ways to help youth and adults with developmental disabilities achieve competitive integrated employment (CIE), which means earning at least minimum wage working alongside people without disabilities.<sup>xxxvii</sup> The Workforce Innovation and Opportunity Act (WIOA) is a federal law signed in 2015 designed to help job seekers access employment, education, training, and other services to succeed in the labor market.<sup>xxxviii</sup> WIOA also improves access to education and workforce services for people with significant barriers to employment such as veterans and individuals with disabilities, and at-risk youth to help ensure all have an opportunity for a good job.<sup>xxxix</sup>

### **Achieving CIE Requires Collaboration, Innovation, And Increased Support**

Regional centers actively promote and provide opportunities for working-age individuals to receive services and supports in the areas of vocational training, job preparedness,



and higher education. Increasing employment requires centers “identify strategies and resources necessary to help people with disabilities to acquire paid employment as the first step toward increasing the participation of this population in the workforce.”<sup>xi</sup>

Attaining CIE requires an overhaul of how systems address vocational goals.

Historically, when someone wanted employment, the regional center’s role was a referral to DOR. Although schools must provide employment-related services, this doesn’t bridge cleanly to the adult world. As noted below, regional centers administer the Paid Internship Program, CIE Incentive Payments, and coordinate vocational supports including:

- *Job development;*
- *Vocational training and skills development;*
- *Job placement and job coaching services; and,*
- *Mobility training and postsecondary education.*

*I was on SSI for a long time, but I am happy to pay taxes now. The day when I got my business card with my name on it was a very happy day for me. – Desiree Boykin, South Central Los Angeles Regional Center*

### **Paid Internship Program (PIP)**

To encourage CIE opportunities, California established PIP to let the individual and employer assess if the internship is a good job match without financial risk. PIP funding is statutorily limited to a maximum of \$10,400 per year for each individual in an eligible setting.<sup>xli</sup> Some regional centers partner with local schools to implement PIP to transition school-aged individuals into the workplace as young adults. One limitation of PIP can be providing school-funded job supports beyond the school day. While PIP can provide valuable employment opportunities for individuals with developmental disabilities, no funding is available to compensate service providers for helping people to find and secure internship opportunities.

### **Competitive Integrated Employment (CIE) Incentive Payments**

CIE incentive payments only apply to a full or part-time work at minimum wage or higher.<sup>xlii</sup> Eligible programs (supported employment or day programs) receive

incremental payments of \$1,000 for 30 days of CIE, an additional \$1,250 for the next 6 consecutive months, and the final \$1,500 if the person remains with the employer for 12 consecutive months.<sup>xliii</sup> Offering a monetary incentive to a business is a positive way of promoting CIE in the community while also incentivizing future CIE employment opportunities by offsetting some of the costs of job development tasks.

## **Solutions To Improve Appropriate Employment Opportunities:**

### **1. Provide comprehensive and creative job development**

PIP and CIE payments have helped employment development. But there are still barriers to wider implementation. Successful individual placement begins with a quality vocational assessment that includes: discovering interests, preferences, experiences, academic level, skill level, aptitudes for new areas, and possible adaptations that may be needed to be successful in a job placement. The job developer then works with the employer to assess the job skills, needed experience, and workplace adaptations. Building relationships is both essential and time-intensive. While DOR provides some funding based on an Individual Plan of Employment, it is not enough for the development of jobs for people with complex needs.

### **2. Consider non-traditional employment opportunities**

Non-traditional jobs for people with developmental disabilities can be supported by the regional center, DOR, school, and natural supports, but each requires highly individualized job development, and significant time and resources.

- Microenterprises are small businesses owned by individuals who make the decisions and oversee the business. This offers “the opportunity to schedule their work day to accommodate their productivity levels and schedule.”<sup>xliv</sup>
- Self-employment is an individual working in his or her own small business, with control and responsibility for decisions affecting the conduct of the business.<sup>xlv</sup>
- Customized employment is “a flexible process designed to personalize the employment relationship between a job candidate and the identified business needs of an employer.”<sup>xlvi</sup>

### **3. Expand community partnerships and create inclusive work environments**

Regional centers promote CIE by partnering with local businesses. Sacramento Municipal Utilities District (SMUD)<sup>xlvii</sup> has provided many CIE opportunities for individuals served by Alta California Regional Center (ACRC) within information, technology, security, power generation, and customer service. SMUD noted hiring a person with a developmental disability brings value to the company beyond the employee's work efforts; the benefits also include an inclusive and diverse work environment that positively infuses the company. While CIE requires businesses to venture into a new territory, partnering with regional centers improves the likelihood of success. Valley Mountain Regional Center worked with Cintas to provide job

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*SMUD has a commitment to hiring people with disabilities and it is now part of the fabric of the organization. --Mysti Champion-Freyenberger, Sacramento Municipal Utilities District*

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opportunities and employment training. Cintas adapted its interview process to accommodate interviewee needs.<sup>xlviii</sup> While there may be challenges in developing CIE opportunities in an area with a high unemployment rate of 30%,<sup>xlix</sup> agency collaboration between San Diego Regional Center and DOR led to Arc Imperial Valley hiring multiple people at StrikeZone.<sup>l</sup> Achieving CIE means partnering with community businesses that value a diverse integrated workforce.

Project SEARCH programs match businesses with capable adults with developmental disabilities who are eager to intern and learn new skills with the goal of being hired full-time. The Project SEARCH South Bay is one example of a successful collaboration between Kaiser Permanente, Best Buddies Jobs, Harbor Regional Center, and Los Angeles Unified School District that has improved CIE opportunities for many people with developmental disabilities.<sup>liii</sup>

### **4. Ensure CIE progress is measured by individual employment goals**

The societal value of employment is undeniable. Earning a living wage in one's broader community lays the foundation for an independent, dignified, and more productive life.

The question is not whether employment is a suitable goal but whether it is a person's *chosen* goal. To monitor statewide progress in achieving CIE, DDS posts employment data that compares employment rates for working-age people without disabilities to those with *any* disability to those with a developmental disability. DDS concludes the “general population has a significantly higher employment rate than people with developmental disabilities.”<sup>liii</sup> While the Bureau of Labor Statistics June 2018 Jobs Report revealed people without disabilities are twice as likely to be employed than people with any disability,<sup>liv</sup> it does not show the various reasons why some individuals are not in the workforce. Measuring CIE progress requires a closer look at reliable data regarding individual goals and outcomes.

## **5. Encourage teaching early vocational skills to improve workforce readiness**

Like others, people with developmental disabilities are not always prepared to enter the workforce immediately after exiting school. Regional centers encourage families to self-teach early vocational skills such as good hygiene and chore completion.<sup>lv</sup> The Office of Disability Employment Policy (ODEP) developed *Skills to Pay The Bills*, a curriculum to teach “soft” or workforce readiness skills to youth ages 14 to 21 to develop workplace interpersonal and professional skills.<sup>lvi</sup> Entering the work force begins with the individual believing early on that he or she has the potential to be employed one day.

Achieving CIE for people with developmental disabilities depends on multiple factors: agency collaboration, increasing successful community partnerships, accurate data analysis, and the recognition that permanent job placements require quality job development and vocational support. In recognizing the importance of employment, California budgets \$29 million annually in PIP and CIE payments<sup>lvii</sup> but these dollars must work in unison with strong job development services to be implemented successfully. Building a network of individualized vocational services and community-based supports for people with developmental disabilities also requires a commitment to provide the requisite resources to achieve this goal.

## **Supporting Community Participation With The Home And Community-Based Services Final Rule**

California's regional center system provides lifelong services to over 320,000 people with developmental disabilities. Most services are funded in large part by federal money from the Centers for Medicare and Medicaid Services (CMS), with federal funding accounting for 40% of the community-based developmental services budget.<sup>lviii</sup> Federal dollars require compliance with the Home and Community-Based Services (HCBS) *Final Rule*, which requires that settings where people live or receive services provide opportunities for community access and integration. Nationally, compliance is required by March 2022. Service providers (SPs) will need, in some cases, to reconfigure programs and hire more experienced staff to achieve this outcome.<sup>lix</sup> The problem is HCBS compliance is not automatically tied to new rates or improved funding sources.

CMS defines HCBS as “types of person-centered care delivered in the home and community. A variety of health and human services can be provided...and are often designed to enable people to stay in their homes, rather than moving to a facility.”<sup>lx</sup> State HCBS Waiver programs must:

- Demonstrate waiver services will not cost more than services in an institution;
- Ensure the protection of people's health and welfare;
- Provide reasonable standards to meet the needs of the target population; and,
- Ensure services follow an individualized and person-centered plan of care.<sup>lxi</sup>

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*Now, with HCBS requirements like exploring integrated community opportunities, service providers will need sufficient resources to hire more experienced staff. While the movement to individualized instead of group settings is consistent with community integration, the cost is greater to the service provider but unfortunately, the resources remain the same.*

*-- Mark Klaus, President & CEO, Home of Guiding Hands*

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HCBS settings must be integrated and support full access to the community. SPs may need to modify policies and operations, or train staff to comply with new expectations.<sup>lxii</sup> Creating a more individualized, community-integrated system means moving away from

rigid group structures. While the movement to smaller group service delivery is well underway (e.g., homes serving only four people), the rules require that even settings with less people provide more individualized opportunities. But these mandates mean SPs need sufficient resources to hire:

- More staff to accommodate smaller service delivery model in the community;
- Staff with more experience in the system to maintain quality;
- Staff who have the teaching skills and training to manage complex behavior; and,
- Staff who are trained to monitor and manage medical needs<sup>lxiii</sup>

### **Direct service provision requires renovation**

A vibrant, *HCBS-compliant* community service system can fulfill the expectations of the HCBS Final Rule while meeting the needs of a more complex population. This begins with renovating the system at the base – the direct support professional (DSP) level. At

*We must begin the process by overhauling the rate system to ensure the amount we pay people to support individuals with developmental disabilities accurately reflects the work that is actually being done.*

*– Steve Miller, Disability Planning and Consultation*

the same time that SPs have fought in recent years for enough money to pay DSPs even minimum wage, DSP work is becoming ever more complex. DSPs are no longer just care providers, monitors, or helpers. Instead, this area of service

delivery requires a higher level of skills, including teaching people vocational skills, providing positive behavior intervention, training in social and independent living skills, and managing complex health conditions.<sup>lxiv</sup> SPs struggle to find and retain qualified DSPs capable of teaching and training individuals the skills to achieve their unique goals in the community.

Recruiting DSPs with the experience, training, and skills matched to the specialized needs of individuals with developmental disabilities is almost impossible at the low wages most rates allow. Quality service provision requires ensuring SPs can recruit and maintain staff to provide services with dignity and humanity. Low unemployment and

obsolete pay rates make the pool of available candidates for DSP jobs shallow at best. As statewide and local minimum wages have increased, SPs are faced with paying minimum wage for DSP jobs, which have skillset and work demands above typical minimum wage jobs. Managing complex behaviors, teaching independent living skills, and providing vocational training in the system is not the same as serving coffee or stocking shelves – but the pay rates are. SPs cannot recruit and retain reliable, experienced, and trained DSPs for minimum wage. Ultimately, rates of pay must reflect the actual services provided in the modern developmental disability service system.

Evolving job responsibilities now require teaching and training individuals, not just caretaking and maintenance. Individuals who are living and participating in community life today require a much higher level of service and supports than years ago. In March 2018, major characteristics of people supported in the community include severe behavior problems (19.3%), property destruction (17.9%), and self-injuriousness (20.8%).<sup>lxv</sup> With mandates under *Olmstead* and HCBS, society's notion of who can live safely and successfully in a community setting has moved far beyond what was imagined when the Lanterman Act was enacted over fifty years ago. As complex support needs increase, so do the DSP skillset and training needs.

While Title 17 regulations set a floor for DSP qualifications and program operation, longtime SP Steve Miller warns the regulations lack specificity and leave personnel requirements for specific job duties to the individual providers, who may have diverse requirements for DSPs, with some unmatched to new federal and individual expectations.<sup>lxvi</sup> This can lead to a failure to fully incorporate services to meet complex needs. Previously, DSPs maintained health and safety, provided care and comfort, and ensured protection and shelter. Now, expanded demands and requirements include:

- HCBS compliant individualized services in community-based integrated settings;
- Specialized and 1:1 level of services to be provided;
- Teaching independent living and social skills;
- Providing positive behavioral support;
- Providing vocational training and support;



- Managing medical conditions; and,
- Providing health care interventions.

HCBS is about supporting people to live in communities and providing all necessary services in the community setting. For example, job coaching requires DSPs coordinate with employers to integrate and support individuals in the workplace, which requires more experience and judgment than a staff person may have directly after high school. SPs used to have employees who would train and mentor young less experienced staff. Over time, recruitment of more qualified staff deteriorated because pay rates could not compete with agencies such as school districts or other government entities.<sup>lxvii</sup> In the past, when minimum wage was at \$5/hour, SPs could pay a higher rate of \$10/hour, which led to more qualified staff. Without the ability to offer greater than minimum wages today, it is challenging for SPs to recruit experienced staff to fill vacant positions.

## **Solutions To Revitalizing Direct Service Provision:**

### **1. Evolving direct support professional (DSP) standards**

DSP quality has suffered primarily because low wages attract a limited pool of less-qualified candidates. Formal requirements include being 18 years old with a high school diploma, but individual SP requirements have declined. If SPs are lucky enough to recruit good DSPs, turn-over is high because wages do not match the job responsibilities. Some long-time DSP staff have left for other jobs because “people have to be able to live and support their families.”<sup>lxviii</sup> Serving individuals with multiple, unique support needs requires qualified and experienced staff. Part of the commitment to quality service delivery to people with developmental disabilities requires enabling SPs to pay DSPs for the quality, experience, and longevity individuals deserve.

### **2. Institute comprehensive rate reform**

To ensure long-term, consistent, quality service provision, rates are just the first step in revitalizing the service system. Antiquated rates do not reflect the modern delivery models in settings such as day services, licensed residential care, or supported employment. As with the private sector, the human services field must offer career



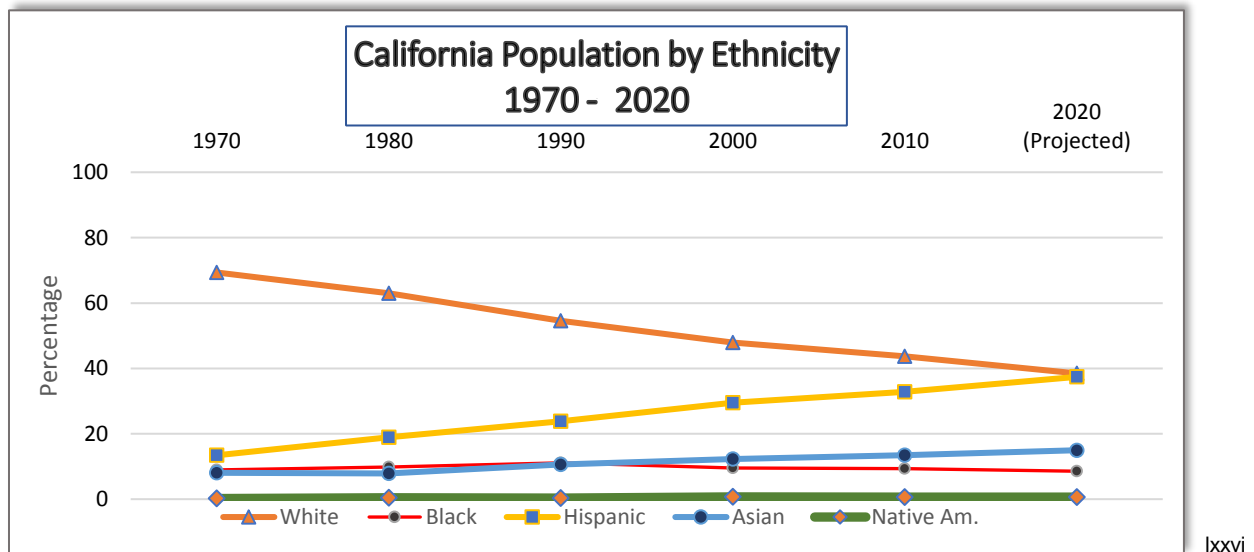
opportunities to DSPs (e.g., opportunities to receive continuing education, regular training, and certifications) who should be treated and valued as professionals.

- California is in the midst of a rate study to address the sustainability, quality, and transparency of community-based services for individuals with developmental disabilities. DDS contracted with Burns and Associates, a health-policy consulting firm, to conduct the rate study. The final recommendations will be submitted to the Legislature by March 1, 2019.<sup>lxi</sup>
- Median rate freezes damage the service system. For instance, there is sometimes more than a 40% difference in pay rate between two SPs who are providing the same service in the same geographic area. The system suffers from that disparity. Study recommendations should ensure rates are no longer based on a median, but reflect the actual local service delivery cost, taking into account differences in costs (e.g., labor and lease rates) as well as the lower billable service hours in rural areas due to travel time between communities.
- Local minimum wages and statewide minimum wage increases significantly impact SPs and must be incorporated into rate reform. Although statute lays out a process for requesting a rate adjustment if an employee is paid less than the statewide minimum wage for certain services, salaried employees with more experience and responsibilities are not funded by the minimum wage increases and SPs paying higher minimum wages cannot access these funds.<sup>lxx</sup>
- Additionally, DDS and regional centers are prohibited from increasing existing rates without following either the unanticipated rate adjustment or health and safety waiver processes.<sup>lxxi</sup> Regional centers must apply to DDS via the Health and Safety Waiver process based on an individual's unique needs, or risks to health and safety.<sup>lxxii</sup> Community-based day programs and in-home respite providers may seek unanticipated rate adjustments directly from DDS but both can be complex and lengthy processes that were not designed to address systemic challenges.

While rate reform is the study's goal, the analysis must include the recognition that the modern-day DSP is more than just a caretaker. DSPs are also trainers, teachers, educators, caregivers, mentors, and medication administrators, which are job duties that considered in isolation would result in higher wages. Market conditions and inaccurate, antiquated job descriptions will provide inadequate information. Instead, the rate study should tease out exactly what services DSPs provide on a day-to-day basis and evaluate the work by considering the expectations and requirements of a fully HCBS-compliant service system. Service delivery expectations have expanded with every new regulation and legal requirement without the rates being adequately adjusted to meet those expectations. Now is the time to correct those wrongs.

## **PART 2: SERVICE TO DIVERSE COMMUNITIES**

California is home to one of the most ethnically diverse populations in the world<sup>lxxiii</sup>. The Lanterman Act provides an entitlement to services and supports for individuals diagnosed with developmental disabilities, regardless of age, race, ethnicity, spoken language, or economic status.<sup>lxxiv</sup> Regional centers provide a multitude of services and supports to hundreds of thousands of individuals with developmental disabilities and families from a variety of ethnic, cultural, and linguistic backgrounds in their local communities. “The regional center population is extremely diverse, comprising at least 23 ethnicities and 45 spoken languages.”<sup>lxxv</sup> Successful service delivery to diverse communities depends on sustained and consistent funding to support creative programs, targeted outreach, and continuing education and training in cultural competence. These help staff and service providers understand the nuances of cultural values and beliefs to let them build a long-term cultural connection in the community.



California is a majority-minority state with the Hispanic population as the predominant demographic. As the most populous state in the country, it is also one of the most racially diverse, with the largest number of Native Americans, the fifth largest population of African Americans and one-third of the nation's total Asian American population.<sup>lxxvii</sup> As the state's population has grown and evolved in the last 10 years, so too has the population of individuals supported by regional centers. Overall growth in the

developmental disability service system is significant at 40%. However, Hispanic and multiethnic individuals served in the system rose well over 70% in the same time frame and Asian individuals with developmental disabilities rose in excess of 67%. Hispanics are the fastest growing segment of the system's population as it continues to serve a rapidly changing and diverse demographic.<sup>lxxviii</sup>

For the last several years, regional centers have undergone extensive analysis of their purchase of service (POS) spending for individuals from ethnically and racially diverse communities. DDS collects data from each regional center related to POS authorization, utilization, and expenditures. Regional centers meet with their communities to review the data, discuss proposed strategies to ensure equitable access to services, and then submit their proposals to DDS to review.<sup>lxxix</sup> This approach, however, does not capture the complete narrative of how people with developmental disabilities are served by regional centers. Systemic barriers beyond regional center control impact diverse communities, such as state Budgets that fail to reinstate culturally responsive services such as social recreation and camp after nine years of suspension. If the overall goal is to address issues of equity, it is essential to begin by recognizing that the regional center system is one piece of the puzzle of services that help support individuals from diverse communities and their families.

### **Solutions to address equity issues in the system:**

#### **1. Measure diversity progress over time and the impact of external factors**

When measuring progress in serving diverse populations, it is imperative to recognize that some families, regardless of an array of available services, are detached from the broad social service system due to other factors such as socioeconomic, national immigration policies, and illiteracy. A successful diversity-focused program must be evaluated not simply by the narrow measure of a single fiscal year or dollars spent. Instead, the accomplishments should be reviewed across a longer period of time with a scale that measures variables such as engagement, purpose, development of trusting relationships, and feeling comfortable in self-advocacy. Although economic measures such as POS data provide one aspect of regional center service delivery, it is one-

dimensional and is incapable of revealing the root causes of differences or explain the underlying reasons why authorized POS services are not utilized.

Community Navigator Programs are developed in many systems of care and structured to help targeted communities gain access to the services and support they need.

Community navigators are trained volunteers who may also specialize in areas such as cancer treatment, mental health services, criminal justice, or domestic violence support. For example, the Community Navigator Program at Silberman School guides domestic violence victims and young people at risk of criminal justice involvement, who have unmet service needs in the community, linking them to vital, quality services that they want or need but may not currently accessing.<sup>lxxx</sup> Community navigator programs are utilized in traditionally underserved communities to access a variety of programs. This model provides the preliminary infrastructure necessary to implement a localized system of care that is responsive to the individual needs of targeted communities, the people who receive services, and their families.<sup>lxxxi</sup>

The Pew Research Center noted little difference between men and women in the likelihood of self-reporting a disability but significant differences by race and ethnicity. Asians were least likely to say they had a disability (6.9%), followed by Hispanics (8.8%) with Whites at 13.9%.<sup>lxxxii</sup> If equity is determined by the amount of POS dollars spent on members of a certain ethnic group, there must also be recognition of other barriers to

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*A mí me ha parecido una excelente vía de comunicación, por fin me siento integrada y tomada en cuenta, sin importar el idioma, me hace sentir con más ánimos y confianza de acercarme a VMRC así como buscar y aprender sobre los servicios de los que mis hijos se pueden beneficiar. Es increíble pedir ayuda y tener quien responda sin tanta burocracia. – Patricia Flores, August 10, 2018*

*I found it an excellent way of communication, I finally feel integrated and taken into account, regardless of the language, it makes me feel more encouraged and confident to approach VMRC as well as find and learn about the services of my children can benefit. It's amazing to ask for help and have someone to respond without so much bureaucracy.*

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service delivery such as stigmatization and misconception of disability within a culture. Thus, assumptions based predominantly on how regional centers spent dollars lack key insights to guide broad policy decisions.<sup>lxxxiii</sup>

Connecting with some communities means obtaining “cultural knowledge” about their cultural characteristics, history, values, beliefs, and behaviors. Acquiring this knowledge leads to “cultural sensitivity” and recognizing differences exist between cultures. Simply recognizing those differences Without assigning values to them is extremely valuable to becoming a culturally competent system.<sup>lxxxiv</sup> Many factors influence family acceptance of disability-related services. It is important to recognize some beliefs about disability are deeply engrained in culture and despite education and the supports offered, may take significant time to evolve.

## **2. Provide systemic support and sustained funding for diversity projects**

Funding that first became available in 2016 has been instrumental in providing regional centers resources to be creative and innovative in their efforts to serve individuals from diverse communities and improve equitable access in the developmental disability service system. Through an allocation of \$11 million annually, DDS through its Disparity Funds Program has helped seed efforts to reduce disparities in the developmental disability service system, but ongoing funding is critical to sustain the dynamic programs that have been developed.

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*I like that we are being heard about the needs we have in our communities.*

*It is still a work in progress but I feel I have been given a lot more information that does not make me feel limited.*

*-- Maria Chavez, Spanish speaking family served by  
Valley Mountain Regional Center*

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DDS largely uses POS data to determine if Disparity Funds Programs increased service utilization. Remaining focused on POS spending as the barometer of a successful diversity program is myopic and fails to recognize that a long-lasting and impactful diversity program takes time to develop, requires establishing trusting relationships, and involves training and education that may not translate into immediate changes in service

utilization in one fiscal year. Instead, progress begins with increased family contacts and positive communication lines with the assigned service coordinator, greater attendance at family support meetings, and newly acquired confidence to speak up in educational or program planning meetings.

A successful diversity program is dependent upon enduring resources to consistently nurture and develop the program over an extended period of time. Serving diverse communities also requires regional centers with already limited resources to go beyond the traditional service delivery model and train staff to utilize culturally sensitive models of service delivery. Serving a diverse population significantly increases staff time to educate practitioners, service providers, and community-based agencies. These comprehensive changes to improve cultural awareness and service delivery to diverse communities should be part of the calculation when measuring progress.

Frank D. Lanterman Regional Center (FDLRC) built its flourishing *Promotora* program by partnering with a community-based organization (CBO) that provided well-trained, bilingual staff who had established relationships within Spanish-speaking communities. With the DDS Disparity Funds Program, FDLRC was able to expand the program from 52 families to 104 families. The *Promotoras* were highly-trained community leaders, tenacious in their outreach efforts and highly skilled in building positive relationships of trust with the monolingual families they served.<sup>lxxxv</sup> FDLRC continues its contract with the CBO. With these Disparity Funds, FDLRC was able to contract with the same CBO to train Korean Community Health Workers to conduct similar services within the Korean community. Similar to community navigators, the *Promotoras* and Community Health Workers, were trained in the regional center system and learned to not only translate specific terms, but also to educate families on the function of regional center services. While the program is extremely cost-effective, its true value is the ability to foster an enduring and positive relationship of trust and understanding between the regional center and the family. Increasing awareness and understanding of the service system is a critical step in program planning and service utilization. It is essential for California to value and provide ongoing fiscal support to diversity programs that have longevity and the opportunity to evolve and prosper.

### 3. Recognize issues of equity are not unique to this service system

As regional center programs work to build bridges to culturally diverse communities, it is important to recognize that families served are often found to be isolated from other government agencies such as Social Security, In-Home Support Services, and Medi-Cal.<sup>lxxxvi</sup> Challenges accessing services are not limited to the regional center system. Far Northern Regional Center Diversity staff found that families served by its *Promotora* program were underutilizing services in all county health and human services programs, not just in the regional center system.<sup>lxxxvii</sup> Some counties have available *promotoras* who assist with accessing only county services; by contrast, regional center-funded *promotoras* assist with accessing a broad range of community resources that include but are not limited to the regional center.<sup>lxxxviii</sup> Unfortunately, when considering POS expenditures in the regional center system, DDS data does not include costs for

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*Me gustó que la promotora viniera a mi casa para ayudarme con la situación de mi hijo. Me enseno hacer llamadas y buscar recursos en la comunidad que yo no tenía conocimiento y gracias a ella pude entender un poco más de los servicios que beneficia a mi hijo y también a la familia completa. -- Celia Lopez, Spanish speaking family served by Frank D. Lanterman Regional Center*

*I like that the promotora was coming to my house to help me with my son. She taught me how to make phone calls and look for resources in the community that I did not know about and thanks to her I was able to understand more about the services that are available to benefit my son and the entire family.*

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services received or funded outside the regional center system (e.g., education-funded services, In-Home Support Services, etc.).<sup>lxxxix</sup> As regional centers must ensure other public resources are used first,<sup>xc</sup> this deficiency in data analysis prevents the regional center or DDS from knowing in the aggregate whether individual needs are being met by other public agencies and if so, if there are existing unmet service needs or not.

There are many factors that influence how diverse communities access healthcare services. Research shows individuals with limited English proficiency are less likely to seek health care, including preventive services, even when they are insured.<sup>xcj</sup> They are also more likely to report negative health care experiences, perhaps reflecting language



barriers in communicating with health care providers. The cumulative effects of factors such as limited English proficiency, citizenship status, low education, and poverty result in additional barriers to diverse communities that impact all social service systems.<sup>xcii</sup>

The California Statewide Plan to Promote Health and Mental Health Equity considered the root causes and consequences of health inequities in California. The plan recognized disparities result from a broad range of socioeconomic forces, including income security, education and child development, housing, transportation, health care access, environmental quality, and other factors that shape the health of entire communities – especially vulnerable communities.

A study being conducted by Children’s Hospital Los Angeles is underway to examine underlying factors that contribute to differences in service utilization in the regional center system. Recognizing the underlying barriers will help the system address them.<sup>xciii</sup> If families are struggling to pay the rent or buy groceries, scheduling occupational therapy may not be a priority. Policies developed to improve the regional center system’s response to diverse communities must also account for all of the other factors impacting how services are delivered to individuals with developmental disabilities who are from diverse ethnic and racial backgrounds.

#### **4. Reduce caseload ratios to help improve issues of equity**

Eastern Los Angeles Regional Center’s (ELARC) model of improving service delivery to diverse communities is with specialized caseloads of a 1:40 ratio instead of the statewide average of 1:74 or more<sup>xciv</sup>. Enhanced Service Coordinators (ESC) are assigned to monolingual Spanish or Cantonese speakers or to individuals who utilize less than \$2,000 POS dollars per year. With smaller caseloads, ESCs have more time to provide multiple face-to-face contacts with their families to develop trust, accommodate a dynamic meeting schedule beyond regular work hours, and slowly introduce the family to new concepts in - and the complexities of - the regional center system.<sup>xcv</sup> Teaching families about the system is not as simple as translating words but also taking additional time to help monolingual families understand the function and benefits of available community services, whether funded by the regional center or not.

The ESC model is reminiscent of a time when service coordinators had smaller caseloads that were in line with statutory expectations and thus the opportunity to build rapport through frequent communication with their families. The regional center system has endured decades of funding cuts and inflationary pressures that have driven up caseload ratios and directly impact how service coordinators can provide services to families. Increased regional center staffing resources are critical to reversing this trend and enhancing service delivery to diverse communities.

Achieving equitable access to culturally responsive services and ensuring cultural competence within an agency is a time-intensive endeavor and should never be treated as a one-time initiative.<sup>xvii</sup> In the Disparity Funds Program Guidelines for 2017-18, DDS states it is “committed to learning more about the challenges consumers and families face in accessing services, and using existing resources to make measurable progress in reducing disparities in POS expenditures and improving access to needed services for diverse communities....” Unfortunately, many regional centers that submitted proposals to continue funding progressive and innovative projects commenced the year prior were denied, in part because the total volume of proposals from regional centers and community-based organizations far exceeded available funds.

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*I think this year is better than last year because it's more helpful and ELARC will check on me, check on my job records. It's helpful.*  
-- Maggie Cheung, Cantonese speaking family served by  
Eastern Los Angeles Regional Center

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## **5. Implementing best practices throughout the system will require agency resources and comprehensive training**

In 2000, Office of Minority Health within the U.S. Department of Health and Human Services (HHS) developed national standards for Culturally and Linguistically Appropriate Services (CLAS) to ensure people receive culturally and linguistically appropriate care. The National CLAS standards establish a framework for organizations to serve increasingly diverse communities through the provision of quality care and services that are responsive to diverse cultural health beliefs and practices, preferred

languages, health literacy, and other communication needs.<sup>xcvii</sup> This is done to achieve a vision of “a nation free of disparities in health and health care.” In updated CLAS standards in 2013, the definition of culture was expanded to include not only racial, ethnic, and linguistic groups but also geographical, religious and spiritual, biological, and sociological characteristics.<sup>xcviii</sup> In 2014, the California Department of Public Health’s Office of Health Equity drafted its Statewide Plan to Promote Health and Mental Health Equity, which outlined priorities and goals targeted for implementation through 2019.<sup>xcix</sup>

Implementing CLAS standards requires application in an agency’s policies, recruitment, training, services, and supports at all levels. As the developmental services system seeks to improve access for a culturally diverse population, CLAS standards offer an examined method by which to improve equity in the system. However, long-term implementation and training of CLAS to service providers and staff, while ideal, would also require ongoing funding.

## **6. Recognize improving equity in the system also requires expanding services consistent with cultural values**

Serving a diverse community mandates more than just improving programs and outreach. It also means providing an array of services that meet the unique needs of the particular community based on their traditions, attitudes, values and ideas. With most adults with developmental disabilities residing in the home of a parent, guardian, or conservator at 61.1%,<sup>c</sup> the system must broaden service options to support these families. A Polynesian family shared that personally caring for a family member with a disability in the family home is part of their cultural value system; social and recreation programs enrich that personal choice while respecting their cultural beliefs.<sup>ci</sup> Data reflects individuals from culturally diverse communities utilized social and recreational services and camp at high levels when those services were available. The failure to restore these services perpetuates barriers in the system.<sup>cii</sup> The effectiveness of language access and outreach is limited without services and family supports consistent with the unique needs and values of diverse communities.

Regional centers strive to provide needed high-quality services in an equitable manner that is consistent with an individual's cultural values and beliefs. Measuring the success of this mission should be based on the degree to which needs are met, which requires a broader examination than just POS expenditures. Cultural values impact decision making, perceptions, and ultimately, whether an individual or his or her family utilizes a service offered. Achieving equity in the developmental disability service system will require a long-term commitment to equal access, an appreciation of the complex lives of individuals from diverse communities, understanding the root causes of differences in service utilization, and the recognition that evolution in policy will take time to succeed.

## **PART 3: SUPPORTING PEOPLE WITH COMPLEX NEEDS**

People with complex needs (e.g., medical, forensic, psychiatric, and behavioral) require significant supports and services to help them live safely in the community. Service coordination for this population is similarly complex. It requires learning intricate systems, locating and creating specialized services, and implementing a matrix of services and supports to meet each individual's unique needs. Expanding services for this population requires innovation, collaboration, and an infusion of resources to meet those extraordinary responsibilities.

### **Supporting People With Complex Health Care Needs**

The responsibility of providing services for people with developmental disabilities with complex medical needs is shared by regional centers and healthcare delivery systems. Healthcare for the average insured patient is typically reasonably available and accessible. However, the system strains to respond to patients with complicated medical needs due to their disability or a serious health condition. Individuals with developmental disabilities are often more complex to treat and care for, not only because of the underlying medical issue, but also, as one doctor noted, because of “difficulty waiting, behaviors that limit cooperation, special medical problems, multiple caregivers or complex interdisciplinary teams, people with multiple specialists, mental health problems, challenges getting them undressed and safely on an exam table, communication challenges, those who require diagnosis based on direct observation, and those who require increased time to take history.”<sup>ciii</sup> As the population of individuals with developmental disabilities rises in the community, the system must be equipped to meet their specialized health care needs to enable them to live safe and healthy lives.

Improving healthcare for individuals with developmental disabilities requires identifying the issues and creative problem solving. Dr. Ingrid Lin, Director, Clinical Services at Golden Gate Regional Center (GGRC) identified some of the obstacles to flexibility meeting the complex medical needs of individuals served.<sup>civ</sup> Valley Mountain Regional Center (VMRC) recently identified similar barriers in the dental care system.<sup>cv</sup> The most

salient barriers to accessing quality health care for individuals with developmental disabilities are as follows:

### **1. Low reimbursement rates and unpaid service time**

Over 200,000 individuals served in the regional center system are covered by Medi-Cal. <sup>cvi</sup> Medi-Cal rates are inadequate given the extra time and skill needed to properly serve this vulnerable population. This results in a severe shortage of clinical providers available to meet the need. Making matters worse, most clinicians are paid by procedure, not by time spent. A typical well-care exam may take an hour for a patient with a developmental disability and a complex medical history, instead of the typical 20-30 minutes allotted. This extra time is not reimbursable in the current system. One clinician noted “If you can fill your chair with someone who can pay private fees and sit still, versus someone where you get 30¢ on the dollar from Medi-Cal and who takes longer and who you don’t feel comfortable dealing with, it’s obvious who most doctors will choose.”<sup>cvi</sup> Unreimbursed costs and low reimbursement rates degrade the system, and the pool of available clinical providers becomes unsustainably shallow.

### **2. Time-consuming coordination between clinicians and care providers**

Patients with developmental disabilities may need substantial support to facilitate healthcare access and treatment. Help from a family member or a service provider may be needed to coordinate medical appointments, follow medical recommendations and act as the point-of-contact to report medical concerns due to an individual’s communication abilities. For an individual with a developmental disability, a routine dental cleaning may also involve sedation. Unfortunately, for some clinicians a barrier is uncompensated time it takes to coordinate care for a patient with special needs. Clinicians and direct support professionals must work in unison to adequately support the complex health and dental care needs of individuals with developmental disabilities.

### **3. Lack of clinical training for health care providers**

A fundamental flaw in the healthcare system is the lack of clinical training in caring for people with developmental disabilities, which may lead a clinician to offer less specialized care than they would for other patients. In one case, a doctor suspected a

patient was having seizures but refused to order an electroencephalogram because he erroneously assumed the patient could not endure the procedure.<sup>cviii</sup> “Without appropriate training and awareness, healthcare providers may hold incorrect assumptions and stereotypes about people with disabilities, which can result in inadequate and inappropriate care.”<sup>cix</sup> The University of California San Francisco Office of Developmental Primary Care noted “there are not sufficient, trained clinicians, ...and there are no community-based, training programs in California for health professionals to learn to serve adolescents and adults with developmental disabilities.” In a Kaiser Permanente survey of 922 physicians, most felt they had “poor” or “fair” knowledge of providing care for individuals with autism. Lack of clinical training in medical school or in residency programs was the noted cause of such deficiencies.<sup>cx</sup> Understanding developmental disabilities is vital to providing complete access to quality health care.

#### **4. Lack of accessible clinics and effective communication**

Medical offices need to be equipped structurally and have the ability to communicate effectively with all patients. Unfortunately, many health clinics and dental offices do not have accessibility features such as specialized exam tables for people who use wheelchairs. “People with developmental disabilities also report difficulty communicating with some health care providers, because too little time is available during standard office visits for discussion of complex health issues or the appropriate, understandable presentation of information so that people with developmental disabilities can participate in their health care decisions and become informed about wellness and prevention activities.”<sup>cxii</sup> These shortcomings lead to deficient medical care and may deter people from seeking future health care services.

#### **5. Inflexible service delivery**

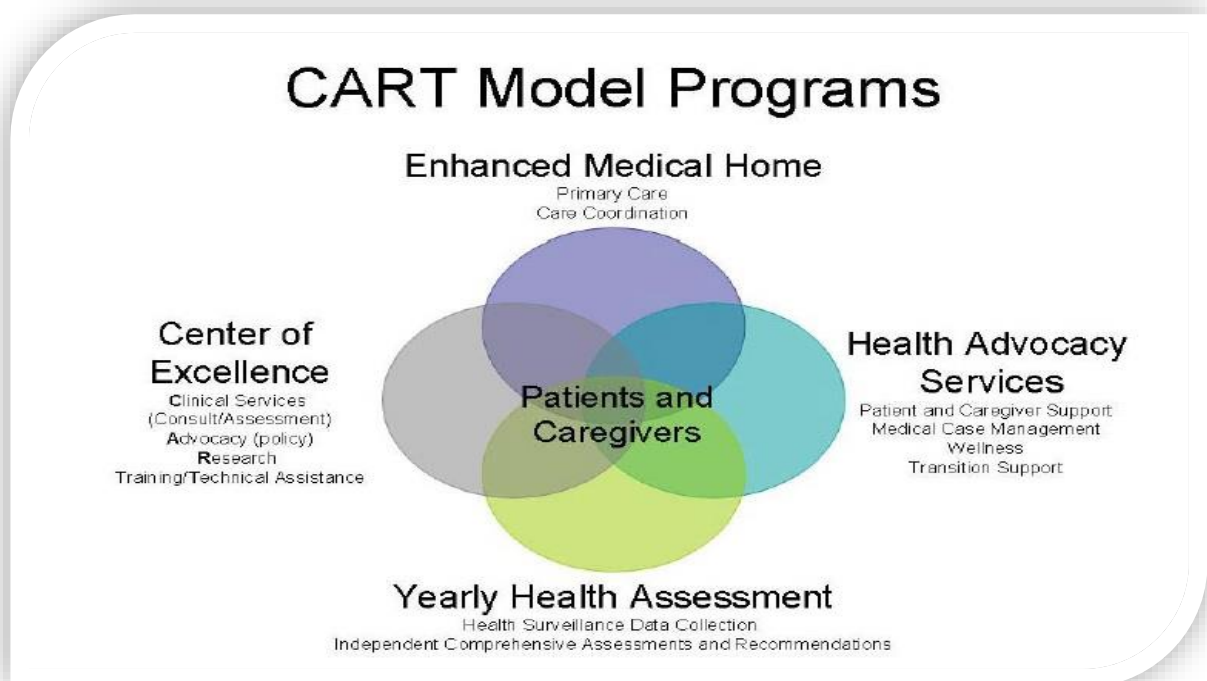
The medical service system is challenged to find all of the solutions to close the gap in health care access for patients with developmental disabilities. Doctors and nurses usually cannot make home visits. Some clinicians report that the patient’s refusal to go into a doctor’s office often results in not receiving medical care at all.

## Solutions To Improve Health Care Access:

- **Federally Qualified Health Centers (FQHCs)** provide primary care for people who are primarily low-income and have better reimbursement rates than Medi-Cal to enhance sustainability.<sup>cxii</sup> The Achievable Health Center is an example of an FQHC created by the Achievable Foundation with support from Westside Regional Center to “provide high quality, integrated health care to individuals with intellectual and developmental disabilities, their families, and other vulnerable populations.”<sup>cxiii</sup> Achievable offers highly experienced and well-trained clinicians willing to take extra time to make individuals feel comfortable and safe in the clinic environment.<sup>cxiv</sup> In Northern California, Santa Rosa Community Health (SRCH) Dutton campus is an FQHC that provides patient-centered care and serves a variety of populations, including people transitioning from Sonoma Developmental Center (SDC) and other patients with developmental disabilities.<sup>cxv</sup> Resulting from a successful partnership between North Bay Regional Center, SRCH, DDS, SDC Parent Hospital Association, and Senator Mike McGuire, Dutton’s focus on supporting patients with developmental disabilities exemplifies an integrative care model that incorporates wide doors to accommodate wheelchairs, a low-stimulation calm room for those not comfortable in the waiting room, and specialty medical and dental services.<sup>cxvi</sup> FQHCs are also beneficial as they offer medical providers experienced in the treatment and communication needs of people with developmental disabilities alongside training opportunities for new clinicians with less experience working with this population.
- **Special Care Centers (SCC)** provide comprehensive, coordinated care to patients served by California Children's Services with specific medical conditions. SCCs are organized around a specific condition or system, and have multi-disciplinary, multi-specialty providers who evaluate the patient’s needs and develop a family-centered health care plan for timely, coordinated treatment.<sup>cxvii</sup> SCCs also provide technical assistance and accommodations for patients with complex medical conditions (e.g., spina bifida).



- **Dual-Agency Clinics** close the service gap for patients with both a mental health and developmental disability. The Puente “Bridge” Clinic offers services by bridging agency resources from San Mateo County Behavioral Health & Recovery Services, GGRC, and Health Plan of San Mateo.<sup>cxviii</sup> Agency collaboration ensures patients receive appropriate health care.
- **CART Services** is a multidisciplinary mobile health care team with the goal of ensuring transition-age youth and adults with developmental disabilities have access to health care services.<sup>cxix</sup> CART has been successful with medically fragile and behaviorally complex individuals as they offer centralized, comprehensive care for individuals served by participating regional centers. The model provides flexibility and consolidated clinical expertise, but is available to a small number of individuals. As it focuses on clinical education rather than direct service, sustainable funding has been difficult to identify. **CART** includes: **C**linical services, **A**dvocacy, **R**esearch, and **T**echnical Assistance and **T**raining for clinicians to create a sustainable workforce.



- **Mobile Clinics** provide medical care in the community. Through the Health Plan of San Mateo, registered nurses travel to the patient's home to complete an exam or administer medication which provides immediate access for patients who need urgent care, primary care, health screenings, vaccinations, school/work physicals, family planning, and other referrals.<sup>cxx</sup> For individuals with behavioral issues, mobile clinics are a cost-effective way to provide faster access to appropriate care in the comfort of the home, reducing injury and behavioral risks. For individuals moving from developmental centers, Regional Center of the East Bay has identified Registered Dental Hygienists in Alternative Practice and dentists who have mobile capability to complete dental work in a home setting more frequently than what is covered by state plans.<sup>cxxi</sup>
- **Virtual Dental Home** is a program created by University of the Pacific (UOP) School of Dentistry to provide community-based dental care to underserved communities to ensure access to dental care, oral health education, oral health training for caregivers, and preventative care.<sup>cxxii</sup> VMRC is working with UOP to ensure individuals served by VMRC receive quality dental care.

Comprehensive health care access for people with developmental disabilities calls for creative solutions through collaboration between agencies, policy makers, clinicians, insurers, service providers, and patients. "Since the life expectancy of people with developmental disabilities has steadily increased and institutional care is no longer the norm, the community will need ongoing support to implement best practices in caring for transition age youth and adults with developmental disabilities."<sup>cxxiii</sup> To ensure people with developmental disabilities have access to quality health care, we must transform the health care system to meet their complex medical and dental care needs.

## **Supporting People With Complex Behavioral, Psychiatric, And Forensic Service Needs**

Today, regional centers and their community partners support an array of individuals with developmental disabilities who require specialized supports in light of their complex behavioral and psychiatric support needs. As the state's developmental centers reduce capacity and close while there is simultaneously a commitment to decrease reliance on other locked settings, the community-based developmental services system is charged with developing and implementing effective strategies to support increasingly significant needs in these areas.

### **The Overlap Between Developmental And Psychiatric Disabilities**

Individuals with developmental disabilities are more likely than the general population to be diagnosed with a psychiatric condition as well.<sup>cxxiv</sup> People who are “dually diagnosed,” which refers in this context to those with both a developmental and psychiatric disability, do not fit cleanly into the psychiatric treatment world, as it is not sensitive to their developmental needs. Similarly, services designed to support people with developmental disabilities have not historically been infused with expertise in managing complex psychiatric conditions.

### **Systemic Responses To Behavioral Challenges**

An additional challenge is the meaning that each system attaches to behavioral challenges, which may arise from the developmental disability, the comorbid psychiatric condition, or the interplay between the two. The developmental disabilities services system often views behavior as having communicative intent.<sup>cxxv</sup> In other words, unwanted behaviors are the person's way of most effectively communicating the desire for attention, escape, access to tangible things, or stimulation.<sup>cxxvi</sup> The theory is that behavior is maintained because it serves a function and can be decreased by providing a better path to obtaining the desired outcome. Mental health systems, however, may perceive that unwanted behaviors are indicative of a need for more effective medication management or talk therapy. The disconnect between the two systems can leave both trying to address the same challenges in different, and sometimes contrary ways.

## Specialized Supports For Behavioral And Psychiatric Needs

The goal of behavioral and psychiatric support services is to help people maintain the least restrictive community placement possible. Day and residential service providers have long used consultants to enhance service delivery to this population. Recently, new services have been established to meet these needs, including:

- **Enhanced Behavioral Supports Homes** provide enhanced behavioral supports, staffing, and supervision in a homelike setting.<sup>cxxvii</sup> Some homes feature delayed egress and secure perimeters to address the specific challenge of individuals who endanger themselves by leaving the home. One challenge Administrators note is the constant struggle to hire and maintain experienced, well-trained DSPs who meet specific behavioral training requirements and are willing to work with residents with sometimes assaultive behaviors.
- **Community Crisis Homes** provide a high-level of behavioral support in a temporary setting to address significant behavioral challenges and to return to the previous or a more appropriate permanent home.<sup>cxxviii</sup>
- **Mobile Crisis Services** provide on-demand coaching and support as needed when behavioral challenges arise with the goal of de-escalating the situation and achieving stability to allow the person to remain in the current residential setting.

## Needs Of Multi-Agency Juveniles

The array of service systems that juveniles may come into contact with is broader than that for adults and additionally includes the juvenile justice system, child welfare services, and the school system. Again, challenges arise from the need to coordinate appropriate services while adhering to the individual processes and funding requirements of each system. As in the adult system, the ultimate goal is the provision of services and supports to nurture growth and overall stability for each child.

## **Safety Net Services**

In 2012, a moratorium was placed on most new developmental center admissions that were not tied to involvement with the criminal justice system.<sup>cxxix</sup> In 2015, the state announced the planned closures of Sonoma and Fairview Developmental Centers along with the General Treatment Area of Porterville Developmental Center.<sup>cxxx</sup> These moves prompted the system to identify services that need to be developed when developmental centers can no longer serve as a backstop for those struggling to maintain community living. In addition to the specialized services noted earlier, in 2017 the state made a commitment to establish two state-operated mobile crisis teams, mental health and forensic wrap-around services, state-run acute crisis homes, and mental health and forensic step-down homes for those leaving secure settings.<sup>cxxxi</sup> This is with the recognition that the system must slow the flow of individuals into secure settings and provide them with robust supports as they leave them.

## **Supporting Individuals With Forensic Involvement**

Involvement in the criminal justice system, which may occur due to impairments in functioning, mental health conditions, or co-occurring substance abuse problems, complicates regional centers' provision of services to people with developmental disabilities. It requires significant forensic resource development internally and within the community, inter-agency collaboration, court compliance, law enforcement communication, and an overall commitment to educating and training people in the community about developmental disabilities. Compounding these challenges is the lack of service providers with expertise in this area who are willing and able to support this high-risk group at rates unmatched to the high-level service need.<sup>cxxxii</sup>

Manager of Forensic & Behavioral Health Services of San Diego Regional Center, Peggie Webb, noted “many individuals we serve have poor coping strategies, minimal ability to regulate their emotions, may self-medicate with alcohol and drugs, or become easy targets for victimization.”<sup>cxxxiii</sup> Assisting an individual with a diversion plan, competency training, or facilitating developmental center admissions or transitions can be difficult and require complex service coordination that includes:

## **1. Diversion plan support**

Diversion is a criminal court process for individuals with developmental disabilities charged with less serious offenses that includes services to help remedy behaviors leading to the original arrest, and avoids conviction and a criminal record.<sup>cxxxiv</sup> When diversion is ordered, service coordinators consult with staff with clinical, resource, and forensic expertise to craft the diversion plan, which may require referrals to day programs, clinical treatment, vocational training, or a substance abuse program. According to John Decker, CPP/Forensics Manager at Alta California Regional Center, non-compliance with a diversion plan causes more frequent court reports and additional court appearances, which due to court scheduling practices can each take a significant part of a work day. These cases require a tremendous amount of work including writing court reports, coordinating services, and appearing in court.

## **2. Competency training**

Defendants must understand the charges faced and be able to assist in their own defense. Defense attorneys may call into question the competence of defendants with developmental disabilities in these areas. If following assessment, the court finds the individual competent, the case proceeds, but if found incompetent, competency restoration training may be ordered. For charges other than serious felonies, the court will often order regional centers to provide competency training in the community. Service coordinators synchronize and monitor the training and services required for success. Those who achieve competency return to the criminal justice system. For those who do not, regional centers work with the court to assess next steps.

## **3. Developmental center admissions and transitions**

Individuals charged with serious felonies and found incompetent to stand trial receive competency training in secure settings, usually Porterville Developmental Center. Some individuals achieve competence and return to the justice system. Some have a prompt resolution to their criminal court case and are sentenced time served, at which point the regional center works to locate appropriate community services.<sup>cxxxv</sup> Others are convicted and sentenced to jail or prison terms. Those who do not achieve competence may stay longer in a developmental center.

Transition planning for leaving a developmental center can require multiple individual program planning meetings in distant locations over an extended period of time. Re-entry into the community requires developing and identifying resources, securing public benefits, and careful planning. Matching the individual with services that provide the appropriate level of supervision and clinical support upon exiting the developmental center reduces the likelihood that the person will return to the criminal justice system. Service coordinators often patch together services to support the needs of the individual moving from a secured setting back into the community – this type of case management requires a higher skill level and knowledge base.

#### **4. Internal resources developed by regional centers**

Service coordination with forensic cases is specialized and time-consuming. To aid staff, although not included in the Core Staffing Formula, several regional centers have developed a comprehensive forensic program with forensic staff who provide technical support for court reports and serve as the liaison to the criminal court, Public Defender's office, District Attorney's office, and law enforcement agencies.<sup>cxxxvi</sup> Oftentimes, this involves the creation of a forensic review team that reviews criminal court cases and provides service coordinators with support around criminal court issues, civil commitments, specialized residential placements, probation, and victim advocacy.<sup>cxxxvii</sup>

#### **5. Community training and collaboration with other agencies**

Regional centers also liaise with community-based programs to establish and maintain effective resources for individuals with developmental disabilities who present with behavioral, psychiatric, and forensic challenges. Community trainings provide good opportunities for regional centers to establish valuable relationships and also educate county agencies, law enforcement, court personnel, and other organizations that interact with individuals with developmental disabilities. Presenting regional center information in the community ultimately helps to “dispel myths about [the existence of] ‘Regional Center Island’ where everyone is taken care of.”<sup>cxxxviii</sup> Regional center community training improves access to community-based services and opens the door to future forensic resources as noted here:

- **County resource teams** may include the regional center, county task force, public defender, mental health, and law enforcement coming together regularly to share resources, cross-train, and coordinate services for dually-served individuals.
- **Vendored agencies** may provide specialized anger management training, day and vocational training, substance abuse treatment, and coping skills training for individuals with developmental disabilities and families.
- **Law enforcement outreach** includes information about developmental disabilities, regional centers, and tips on how to safely meet this vulnerable population's needs.
- **Jail Liaison** coordination helps to initiate regional center contact if jail personnel suspect an inmate is a regional center client, allowing discharge planning and court responsibilities to begin in a more-timely manner.

## 6. Developing residential placement options

The lack of safe and appropriate housing can be a blockade to effectively serve individuals with complex behavioral or forensic needs in the community setting.<sup>cxxxix</sup>

There are a limited number of residential placements for this population because the rates currently do not reflect the high-level service demands, or the increased risks and potential liability of a crime against other residents, staff, or neighbors. Developing sex offender treatment homes, for example, is further complicated by statutory restrictions that limit the placement of individuals previously convicted of a sexual offense in licensed care."<sup>cxli</sup> Regional centers may be forced to consider less than adequate placement options and patch services together to make them as successful as possible. As a last resort, regional centers are forced to consider options such as sober living homes, mental health board and care homes, and single room occupancy homes that do not offer specialized supports for people with developmental disabilities. Unfortunately, these options do not resolve the overall capacity problem and individuals may be more vulnerable to victimization by other non-disabled residents.<sup>cxli</sup>



## **Solutions To Improve Access To Forensic, Psychiatric, And Behavioral Services:**

1. Increase comprehensive trainings and technical support for regional center staff to ensure the appropriate education and skillset necessary to meet the demands of coordinating forensic services.
2. Establish more cross systems care coordination and resource development, which includes inter-agency resource sharing, consultation, training, and collaboration on joint projects. Removing roadblocks to this would allow each system to offer its expertise in supporting people with multi-system involvement.
3. Increasing the inventory of appropriate residential placements will help to alleviate inappropriate placements that result in instability, but also meet the unique needs of this population. DSPs in these environments are providing a high-risk service that mandates specialized training and experience to carry out their job responsibilities as they adequately provide for the most complex persons in our society. They need robust training and adequate compensation to encourage longevity. Ultimately, developing sustainable adult and juvenile placement options with qualified and well-trained staff is the only way to achieve optimum health and safety for the individual and the community.

To meet increasingly complex needs of individuals served, regional centers have created elaborate networks of clinical and criminal justice resources and services. Despite the operational toll and regulatory limitations in the service system, centers have managed to stretch modest resources to train, educate, and collaborate with agencies involved with the mental health and court systems, law enforcement agencies, and community partners to serve some of the most complex people in society. But the infrastructure required to meet the needs of individuals with developmental disabilities has far outpaced the available resources to preserve health and safety demands. Policies and necessary funding supports must reflect this transformation.

## **PART 4: SUPPORTING DYNAMIC SERVICE COORDINATION**

Service coordination is the heart of the regional center system. Service coordinators are the first point of contact for individuals with developmental disabilities and their families for support, services, and guidance. This role is instrumental to an individual achieving his or her unique goals. The responsibilities placed on service coordinators continue to grow with person-centered planning, the new Self-Determination Program, and increased mandates in the system. The system must provide structural support, training, and resources so service coordinators can ensure the choices, needs and goals of individuals with developmental disabilities can be realized.

### **Person-Centered Planning**

Person-centered planning (PCP) is the process of discovering an individual's preferred goals, choices, strengths, abilities, and needs within the framework of their lifestyle and cultural background.<sup>cxlii</sup> In essence, PCP is realizing the person is the expert in his or her own life. Applying person-centered practices means supporting individuals with developmental disabilities in creating a life they choose for themselves. PCP is rooted in the individual's personal preference rather than expert opinions and clinical recommendations. PCP is focused on the individual with members of the planning team adopting the role of consultants or advisors who help the individual and family achieve their preferred future.<sup>cxliii</sup> While PCP has been implemented in some form throughout the country for decades, new mandates such as the HCBS Final Rule are revitalizing the practice system-wide.

### **Legal Mandates For PCP**

Federal law requires PCP be built into a state's home and community-based service system. PCP approaches to service delivery and system design continue to emerge with various Medicaid regulations, including changes to the 1915(c) HCBS Waiver regulations and the 1915(i) State Plan Amendment.<sup>cxliv</sup> "The person-centered approach is at the heart of the current state and federal developmental services policy... although California has been using a person-centered approach since the 1990s, DDS must

implement recently enacted federal and state regulations and policies that further advance person-centered policies.”<sup>cxlv</sup>



<sup>cxlvi</sup> The Centers for Medicare and Medicaid Services (CMS) distinguishes between “*Person-centered thinking (PCT)*, which helps to establish the means for a person to live a life that they ... have good reasons to value, and *person-centered planning*, which is a way to assist people needing HCBS services and supports to construct and describe what they want and need to bring purpose and meaning to their life. Further, *person-centered practice* is the alignment of service resources that give people access to the full benefits of community living and ensure they receive services in a way that may help them achieve individual goals.”<sup>cxlvii</sup>

The Lanterman Act includes elements of PCP as the individual program plan (IPP) requires the gathering of information to determine the life goals, capabilities and strengths, preferences, barriers, and concerns or problems of the person with developmental disabilities.<sup>cxlviii</sup> The Department of Developmental Services (DDS) describes PCP as “assisting persons with developmental disabilities and their families to build their capacities and capabilities. This planning effort is not a single event or

meeting, but a series of discussions or interactions amongst a team...”<sup>cxlix</sup> Part of the planning process includes the team assisting the individual in choosing a living option, identifying people to socialize with, and preferred types of daily activities, including desired jobs. This is called a *preferred future*, and is based on the individual's strengths, capabilities, preferences, lifestyle, and cultural background. The IPP records the decisions made by the team which includes what needs to be done, by whom, when, and how, to support the individual to begin working toward the preferred future.<sup>cl</sup>

### **Person-Centered Thinking (PCT) Lays The Foundation For PCP**

PCT is the philosophical foundation of person-centered planning. PCT is a long-term process whereby broad implementation and practice is created with specialized training. PCT is a philosophy that requires the team to “put individuals first, listen carefully and learn who they are and what they want from life, then work together to set goals, create personalized plans, and put them into practice.”<sup>cli</sup> Successful implementation of PCT requires extensive agency commitment to the philosophy and significant training. Regional centers may dedicate much effort to successfully implementing PCT throughout its agency, but PCT and its practice is always evolving. If individuals who use services are to have positive control over their lives, and be self-directed in their own communities, then those who are supporting the individual need to have PCT skills.

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*All people have positive control over the lives they have chosen for themselves. – The Learning Community for Person-Centered Practices*

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The Learning Community for Person-Centered Practicing (TLCPCP) provides an educational forum, supports, facilitation, and ongoing training opportunities to help participants develop PCT skills.<sup>clii</sup> Some regional centers have also utilized TLCPCP trainers and strategies to successfully implement PCT in their local communities. Tri-Counties Regional Center (TCRC) has embraced the PCT philosophy and practices by integrating it throughout the agency -- from hiring processes, to service coordination, to partnering with service providers, to management styles. Satisfaction surveys and data analysis after a decade of implementing person-centered practices at TCRC indicate improvement across all metrics.<sup>cliii</sup> TCRC’s person-centered practice is based on

creative problem solving, meaningful goal setting, and innovative action planning. The importance of the to/for dichotomy is consistent with federal law and also ties to federal funding. To implement PCT, TCRC made organizational changes that included:

- Assume the positive and possible of a person rather than focusing on challenges;
- Support the many different ways people choose to live, without judging choices;
- Use People First Language to always put people before disabilities;
- Confirm understanding before acting or responding;
- Seek input from those affected by each decision; and,
- Be well-informed about the services available to include in your plan.<sup>cliv</sup>

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*Person-Centered Thinking ensures that the focus of our work and planning stays on the perspectives of the individuals affected by the planning. PCT can do this by helping us learn what is important TO and important FOR the people we serve. Things that are important TO individuals are what matters most to them and makes them happy. Things that are important FOR individuals are what they need to be healthy and safe and valued as members of their community. You and your Planning Team will work together to find the best ways to support you to achieve things that are both important TO and FOR you.*

*- Tri-Counties Regional Center.*

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### **PCP Helps To Ensure Services And Supports Are Person-Centered**

PCP views the entire person; not just the portion of the person that has identified needs. PCP is an approach to forming life plans that are centered on the individual for whom they are built.<sup>clv</sup> PCP includes the individual, the service coordinator, service providers, support staff, and any family members or friends the person chooses to include. Service coordinators guide the PCP process to discover how someone wants to live, work, or recreate in the community.<sup>clvi</sup> Events like the *California Gathering*,<sup>clvii</sup> hosted in partnership by TCRC and Eastern Los Angeles Regional Center (ELARC), offer opportunities to learn and share resources about how to put PCT into practice. Rachel Hagans, Director of Client Services at Central Valley Regional Center (CVRC), notes that “PCT is really about how you think and approach your work, how you explore with families and get to know them. It affords you the tools to better access and understand

what people want for their lives.”<sup>clviii</sup> While IPP goals are not entirely different from PCT practices being implemented, how service coordinators *explore* the wants and needs of people they serve has changed and vastly improved with PCP.<sup>clix</sup>

*One-page profiles* provide an “at-a-glance way of knowing what really matters to people, that can be taken with them as they move through services and come into contact with people. It captures the most important information about a person on a single sheet of paper under three simple headings: *what people appreciate about me, what’s important to me, and how best to support me.*”<sup>clx</sup> One-page profiles are another valuable tool for exploring what is important *to*, and what’s important *for*, an individual.<sup>clxi</sup>

### **Implementing PCP Requires System-Wide Support And Training**

PCP can be a paradigm shift for many regional centers due to the time constraints and funding requirements. Similarly, the Early Start program is also about outcomes -- what do you want to achieve, not what services you already receive. Like Early Start, PCT requires the identification of resources needed to successfully implement the plan. Changing agency practices requires funding and the time allotted to conduct extensive training and technical assistance to implement PCT. CVRC used grant funding to provide PCP training. Unfortunately, once grant funding is exhausted, sustainability is difficult. Systemic implementation of PCP will require:

- Trainings that include coaching and technical assistance offered to staff, families, community partners, and service providers;<sup>clxii</sup>
- Organizational and system support for sustained funding for implementation and maintenance;
- Reduced caseload ratios to allow more time to implement;<sup>clxiii</sup> and,
- Consistent sharing of PCT and PCP resources throughout the regional center system.

Implementing PCT throughout a regional center requires a commitment to person-centered practices, support for comprehensive agency-wide trainings, technical assistance for connecting PCT resources, and policy changes that support the incorporation of PCT and person-centered practices throughout the system.<sup>clxiv</sup> PCT

training and education can be invaluable to service coordination but this process takes time and the requisite funding resources to be successful.

PCT provides a quality foundation to meet the unique needs of individuals with developmental disabilities. It offers a positive pathway to learning about and appreciating what an individual chooses for themselves. It helps the planning team to listen better to the individual, and also develop person-centered plans that reflect not only what is important for the person but also what is important to the person. “Moving toward a person-centered system requires considerable thought and planning to be effective.”<sup>clxv</sup> To transform the developmental disability service system into a person-centered service system, as required to maintain federal funding, a commitment to implementation is necessary and it must be paired with the requisite funding and structural support to succeed.

### **The Self-Determination Program**

The Self-Determination Program (SDP) offers a dynamic and innovative way of serving Californians with developmental disabilities. SDP allows participants the freedom, control, and responsibility in choosing services and supports they need to achieve their individualized goals. Participants will have the flexibility to purchase services not traditionally available that may be more culturally aligned with their values. They will have the opportunity to negotiate and create agreements with their chosen service providers (SPs) who are not required to be regional center vendors. SDP provides an alternative way for regional centers to offer services. Instead of service coordinators *authorizing* services, they will work in partnership with the participant as a guide in planning. While the regional center will maintain responsibility to *certify* the individual budget amount, the team will work together to develop the individual budget plan to purchase the services and supports needed. SDP is an exciting opportunity for participants to create plans they may have imagined previously but until now, not had the opportunity to fully realize.



Self-Determination Pilot projects have been successfully implemented in some regional centers for 20 years. In 2013, the current SDP was signed into law with a requirement for matching federal funding to be implemented. After a lengthy approval process, the Centers for Medicare and Medicaid Services (CMS) approved the federal waiver application on June 6, 2018.<sup>clxvi</sup> With the support of its Self-Determination Advisory Workgroup, the Department of Developmental Services (DDS) has several SDP components nearing completion in order for the program to become operational in late fall of 2018.<sup>clxvii</sup> SDP will be available statewide for three years to 2,500 individuals. The lottery selection process is intended to also reflect the diverse population of the state. State law provides in part: *“The Self-Determination Program...shall be available to individuals who reflect the disability, ethnic, and geographic diversity of the state.”*<sup>clxviii</sup>



For many individuals, the most positive aspect of SDP is that it is centered around the person with greater opportunity for flexible service delivery.<sup>clxix</sup> The IPP process is also person-centered, but in SDP, the responsibility for identifying or developing resources to carry out the plan lies with the team, rather than the regional center. This process affords flexibility and creativity in a system that has been bogged down with rate restrictions for years. Although total dollars will be capped, participants will be free to explore new services and pay competitive rates for them.

Pilot SDP participants have also consistently expressed satisfaction with having the freedom and authority to manage their own person-centered SDP even if the services were from traditionally vendored providers. Elizabeth Harrell, Manager of Training and Information at Eastern Los Angeles Regional Center (ELARC) explains that “good planning is essential to self-determination, and this process takes time.” A well-developed person-centered plan requires outlining needed services that are incorporated in the IPP. As the new SDP begins, it is important to be mindful that implementation statewide will be a methodical and time intensive process that will hopefully incorporate lessons learned from the long-standing pilot programs.<sup>clxx</sup>



Traditional service planning may be done for 1 (up to 3) years with the flexibility to add services as necessary.<sup>clxxi</sup> However, while changing the IPP may be easier in SDP, the law states the individual budget “shall be calculated no more than once in a 12-month period unless revised to reflect a change in circumstances, needs, or resources of the participant using a process specified...”<sup>clxxii</sup>

## **SDP Increases Flexibility And Supports The Regional Center-Family Relationship**

By its design, SDP offers opportunities to strengthen the regional center-family relationship. In the pilot program, planning teams found that being more creative in supporting participant needs in new and flexible ways changed the nature of the conversations and collaboration between planning team members.<sup>clxxiii</sup> The SDP affords participants the freedom and authority to make their own decisions, which some pilot regional centers report resulted in greater satisfaction even when services did not work out as planned. Also beneficial to SDP is the ability for participants to purchase services in their own neighborhoods that are culturally consistent with their values and choices, including social recreation services and camp if desired. Moreover, regional centers report SDP participants in the pilot programs were excellent stewards of state funds and accepted their responsibilities well.

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*All individuals, regardless of ability, have the right to access the basic elements that make-up a good life, beginning with: family, independence, personal responsibility, and freedom of choice. The Lanterman Developmental Disabilities Services Act builds upon these basic fundamentals so that all individuals have the right to live their lives as they choose.*

*– Santi Rogers, Former Director of DDS*

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## **Solutions To Support Successful Implementation Of SDP:**

### **1. Provide comprehensive training in all facets of SDP**

Regional centers will have to provide comprehensive orientations, on-going training, and technical assistance to implement SDP. With the significant change in service planning and delivery, training will not only be necessary for service coordinators, but also, regional center fiscal departments, purchase of services, community services and

training departments. Regional centers will provide all of these trainings in addition to supporting the necessary SDP orientations and on-going training required for participants and their families. Comprehensive SDP training is a prerequisite to its successful implementation, which will require additional resources to complete.

## **2. Reduce caseload ratios in response to the increased service coordinator job responsibilities in SDP**

With the new SDP, regional centers are tasked with essentially running dual service systems. The traditional service system and SDP will function simultaneously and require regional centers to make infrastructure changes. For example, budget certification is a new requirement for regional centers. This process will mandate new accounting methodologies to calculate an individual budget based on the previous 12 months of POS dollars with adjustments for unmet needs or changing circumstances. Developing complex individual budgets is likely to require cooperation between various regional center staff as this is a skillset not typically within the realm of service coordination but must be influenced by person-centered considerations.<sup>clxxiv</sup> For this reason, staff will need the time and on-going training and technical support to carry out their new job responsibilities.

Smaller caseloads would be an effective remedy for service coordinators to address issues such as increased orientation and training, specialized skill development, and an increased workload. A reduced caseload offers SCs and participants more time develop a person-centered plan with a corresponding individual budget that will be enduring and successful. Smaller and more specialized caseloads reduce time constraints and also increase case management resources necessary to successfully implement SDP.

## **3. Educate participants about SDP approved services that may offer flexibility while other services may not be approved**

In SDP, participants will be able to access services with flexible rates. Rate restrictions serve as a barrier to the traditional service system and are often the root cause of resource challenges. According to Mike Keeley, Director of Consumer Services at San

Andreas Regional Center, SDP “opens the door to services families would like but regional centers cannot usually provide” due to statutorily imposed rate restrictions.<sup>clxxv</sup> For example, SDP participants may choose to prioritize certain services in their individual budget and pay a higher rate than what would be permitted in the traditional system even though this choice may reduce other services in the individual’s budget. In addition, SDP will also allow participants access to suspended services such as social recreation, camp, and non-medical therapies such as equestrian, art and music therapy.

SCs will need to be equipped with sufficient information to consider non-traditional services. For example, some of the definitions of billable services in SDP are so broad, their boundaries are not intuitive.<sup>clxxvi</sup> While some may look to SDP to access particular services they believe are invaluable, they will need help understanding federal funding restrictions as these restrictions were not present in the SDP pilot. When conflicts arise in SDP, additional resources must be allotted to ensure disputes are adequately resolved in a judicious and timely manner. Typically reserved for community services, SCs will also need specialized training in the new SDP service codes and definitions to fully comply with SDP requirements.

#### **4. Recognize the infrastructure changes necessary to implement SDP**

While service coordination is a critical aspect of SDP, implementation requires multiple components working in tandem to be successful. For example, to accommodate payroll requirements for non-vendored service providers, regional centers may need to make more frequent payments in their accounting departments. Regional center fiscal departments regularly comply with audit requirements to document how purchase of service (POS) funds are spent, but SDP budget certification will require regional centers to consider a way to document funds that would have been spent in the traditional service system.

Regional centers will also need to have designated staff to serve as liaisons to Local Advisory Committees, FMS agencies, DDS, and other statewide groups. The Core Staffing Formula,<sup>clxxvii</sup> which provides most of regional center operations funding, did not

envision most of the SDP tasks that will be required of the regional center system to implement SDP.

With SDP on the horizon, regional centers will endeavor to carry out a number of critical functions to implement SDP in a timely and successful manner. All of these tasks are essential to fully accomplishing a statewide SDP, but they also require resources to hire, coordinate, and train the necessary staff to discharge the responsibilities of the Self-Determination Program. Service coordinators are once again expected to be the force behind launching a new statewide program, and must have the opportunity to succeed through training and lower caseloads for their new job responsibilities.

### **Increasing Mandates**

At the inception of the developmental disabilities service system fifty years ago, the Lanterman Act was a mere 11 pages. Today, it runs over 346 pages and has dramatically changed service coordinator (SC) job responsibilities. In years past, SCs could build enduring relationships with families they served by spending quality time in their homes exploring what services matched the unique needs of their loved one. SCs had the flexibility and resources to be creative and offer unhurried guidance and personal assistance in obtaining suitable services. They are now obligated to conduct the individual program plan (IPP) meeting in a manner that feels *government-like* - confirming information about the Family Cost Participation Program<sup>clxxviii</sup>, Medicaid Waiver compliance, managed care enrollment, and voter registration, etc. The umbrella of regulatory requirements in the system threatens to overshadow the service coordinator-family relationship.<sup>clxxix</sup> With increased mandates layered into case management, coupled with high caseload ratios, and outdated budgeted salaries, regional centers have difficulty recruiting qualified, dedicated, and experienced people to work as SCs long-term.

Administratively, in addition to case management, SCs must now go through a myriad of required trainings that are beyond the traditional service coordination role. Typically reserved for county employees, voter registration is now also part of the training

schedule. Privacy laws require Health Insurance Portability and Accountability Act of 1996 (HIPAA) training to protect the privacy and security of certain health information.<sup>clxxx</sup> Employment First<sup>clxxxi</sup> policies expanded vocational services in the system to help individuals achieve competitive integrated employment. Individuals with criminal justice needs, complex behavioral, or health care needs are difficult to serve in the community safely, but regional centers continue to be committed to serving this population by vastly increasing forensic services and clinical resources to meet these unrelenting demands. In short, SCs must be equipped with the resources to meet increasingly complex expectations, including navigating other systems that may have a role to play in supporting different aspects of the same person. To prevent new mandates from overshadowing the core work of service coordination, SCs must have the capacity to do both, which is only possible through specialized training paired with manageable caseloads.

## **Solutions to address the increasing mandates in the system:**

### **1. Lower caseloads**

Many of the increased mandates as well as the pending changes to the developmental services system boil down to SCs needing the time, resources and flexibility to do their job. With high caseload ratios, today, SCs do not have adequate time to develop a rapport with a family and focus on individual program plan (IPP) implementation. Under State law and a state commitment to the federal government, regional centers will maintain an average service coordinator-to-consumer ratio of 1-to-62 for consumers receiving services through the HCBS waiver. State law further requires RCs to maintain an average ratio of 1-to-45 for consumers who have moved from a DC within the previous 12 months, 1-to-62 for consumers age three and younger, and 1-to-66 for all other consumers. In reality, regional centers have been underfunded for decades, resulting in high caseload ratios year after year, which in March 2018 meant that 624 additional service coordinators statewide were needed to meet legal requirements.<sup>clxxxii</sup>

Lower caseloads would enable service coordinators more time to support complex cases involving the criminal justice system, intense behavior management services, or

medically involved cases. Most children served in the early days of the Lanterman Act had a diagnosis of Down syndrome. Behaviorally complex developmental disabilities such as autism were not as prevalent. Serving people with varied developmental disabilities today requires services to be more individualized and diverse. For those individuals choosing SDP, this will absorb more time to learn the new program rules and requirements. Lower caseloads would improve the ability of the SC to navigate specialized programs, explore complex service needs and afford more time to nurture the family-service coordinator relationship.

## **2. Resolve funding challenges**

One barrier to reducing caseloads is the outdated “Core Staffing Formula” (CSF) which was developed in 1978 to create a more equitable budgeting methodology. Regional center salaries were established based on comparable State of California classifications and wages with the intent of progressing simultaneously. Over the years, the regional center has grown more complex and expansive far beyond the benefits of CSF. For example, many budgeted salaries have not changed since 1991.<sup>clxxxiii</sup> The fringe benefit rate (23.7%) has been unchanged since 1989. The allotment for operating expenses (e.g., office supplies, travel, etc.) per position has been the same since 1985, even though technology is an indispensable part of service coordination. The IRS mileage rate has increased 165% since that time.<sup>clxxxiv</sup> Additionally, in excess of \$60 million is withheld annually from regional center OPS as salary savings (which the state stopped implementing for state departments in 2012) and various historical reductions that were never restored.<sup>clxxxv</sup>

Compounding the problem regional centers must compete with county and state agencies to recruit and retain service coordinators. When regional center salaries are not competitive, it is difficult to maintain consistency and enduring relationships between service coordinators and individuals and families served. Regional centers have been forced to reduce staff educational and qualification levels to recruit. They may also use funds allocated in the CSF to meet other staff needs such as technology not addressed in the formula. Maintaining caseload ratios aligns with a key federal mandate to help ensure continued federal funding to the State through the HCBS Waiver. This mandate

can be challenging to meet for rapidly growing centers such as Inland Regional Center, which has experienced an increase of approximately 2,000 new individuals served in the last year.<sup>clxxxvi</sup> The inability to recruit and retain staff has resulted in regional centers experiencing difficulty meeting the mandated caseload ratios, which, in turn, negatively impacts the quality of case management services provided to consumers and families and could have a negative impact on federal compliance with the HCBS Waiver.<sup>clxxxvii</sup>

### **3. Consider innovative ideas such as:**

- Reconfiguring the system to offer various levels of service coordination based on the service level the person needs.
- Appreciating the fact that regional centers struggle to recruit people with the right skillset because the job has expanded and requires specialized skills in accounting, forensics, employment, education, behavioral services, and the medical field.
- Incorporating new technology to improve resources available to support service coordination and other regional center functions, such as case management and accounting software systems that are less vulnerable to errors that arise from duplicative data entry.
- Exploring ways technology can improve service delivery to individuals and their families, such as video conferencing when travel to the regional center office is not possible.

### **Building On The Past, Looking Towards The Future**

Effective plan development and implementation is the core of the developmental disability service system. Plan development requires SCs with sufficient time to build rapport and explore resources to help individuals with developmental disabilities and their families chart a course towards their preferred future. Plan implementation requires having the resources at hand to put the plan into practice. The following programmatic evolutions will serve as opportunities to carry out this work if approached thoughtfully:

- The HCBS Final Rule<sup>clxxxviii</sup> mandates services be provided in the community – in natural environments. As a result, many traditional programs will require program conversions to comply with federal law. If not, SCs will assume the responsibility of finding an appropriate HCBS-compliant program that will cause minimal disruption to the individual’s daily routine. Although the goal of creating a system that offers greater levels of community integration is a noble one, it cannot be achieved without the appropriate case management resources, requisite service provider rates, and the qualified staff to meet high-level service needs.
- Sustainable rates support service coordination as its success is directly affected by the availability of service providers. Originally, service provider (SP) rates were predicated on competitive rates tied to the cost of providing services. Regional center services were intended to compliment generic resources. Presently, median rates limit resource development. In order to be competitive and maintain high standards of quality care, SP rates need to be based on the actual services being provided, recognize the skill level needed, and account for the geographic area in the rate calculation. Rate reform is one way to lessen the damage of the median rate restrictions and encourage resource development and innovation.
- Meeting the complex medical, behavioral, psychiatric and forensic needs of individuals in community-based settings requires creative strategies must be implemented and include cross-agency collaboration, expanding available specialized resources, and increasing the inventory of appropriate living options.
- Serving a diverse community requires systemic support for creative community-based projects, reducing case load ratios, accessible resources and offering services that are consistent with cultural values.
- Person Centered Planning (PCP)<sup>clxxxix</sup> is focused on the choices, needs, and dreams of the individual with a disability. It takes time to create and successfully implement a good person-centered plan. Ultimately, the goal in PCP is for the



individual to exercise informed choices. SCs will need sufficient time and the resource tools to aid in this process. Developing IPPs utilizing the PCP methodology takes much longer than using the traditional approach. Regional centers need additional resources to accommodate the necessary training, education, and increased workload related to PCP.

- The Self-Determination Program (SDP)<sup>CXC</sup> will be an opportunity for participants to exercise greater control in their own service planning, selection, and delivery. For some, SDP will allow maximum flexibility within established budgets and the chance to hire staff they choose for themselves. As noted earlier, implementing SDP will require extensive training, but it will also require regional centers to accommodate necessary administrative changes in accounting, community services, and case management departments. SDP will require sufficient time and the requisite resources to implement.

Today, increasing mandates burden a system already encumbered with low service provider rates, high caseload ratios and the lack of resources necessary to serve a diverse, more complex and fast-growing population of individuals with developmental disabilities. The developmental disability services system needs support to build the system for tomorrow – to help all individuals with developmental disabilities live productive, meaningful lives in their own communities.

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