Briefing Paper: Developmental Disabilities System Issues

About Disability Rights California

Disability Rights California is the agency mandated by federal law to protect and advocate for the rights of Californians with disabilities. In 2014, Disability Rights California provided legal and other advocacy assistance to 21,978 individuals, including 11,110 individuals with intellectual and other developmental disabilities.

Overview of the Developmental Disabilities System

California’s developmental disability system provides services to approximately 279,000 individuals with intellectual and developmental disabilities in the community. Under the Lanterman Act, Welfare and Institutions Code Sections 4400 et seq., the Department of Developmental Services (DDS) contracts with 21 non-profit regional centers that provide case management and contract with private agencies to provide the services identified in the individual’s individual program plan (IPP). A much smaller number of individuals, currently about 1,010 reside in state institutions called developmental centers. By the end of the 2015-2016 budget year, DDS estimates that the developmental center population will be 951 individuals.

Issues Affecting the Developmental Disabilities System

Continue Efforts to Reduce Reliance on Institutions and Minimize Loss of Federal Revenue

State and federal law require that individuals with disabilities receive their services in the most integrated setting possible. In 1965 there were over 13,000 individuals with intellectual and developmental disabilities living in state hospitals. As of the end of December 2014, the number of

developmental center residents was 1,147. At the end of budget year 2015-16 the state estimates 951 individuals will reside in the remaining institutions. The cost of providing services at developmental centers continues to rise as the population declines. This is due in part to high fixed costs. As of January 2014, this cost ranges between $283,900/per year to $363,291/per year. The budget figures reflect an average cost exceeding $500,000 when total DC costs are divided by the average population.

Significant concerns about the quality of care in state institutions have been raised by the Department of Public Health and federal Center for Medicaid and Medicare services. At Sonoma Developmental Center, in 2012 the federal government took action to decertify all Intermediate Care Facility-Developmental Disability (ICF-DD) units. In 2013, the state and federal government agreed to decertify four units provided that the state implemented a plan to correct the deficiencies. DDS reports that this resulted in an annual loss of more than $15 million in federal reimbursement. In July 2014, the California Department of Public Health (CDPH) notified DDS that the remaining ICF-DD units at Sonoma DC would be decertified due to a determination that Sonoma did not reach sufficient compliance. DDS has appealed. If DDS loses its appeal, the state will have to backfill approximately $34.5 million in lost federal funds in 2014-15, growing to $43 million in 2015-16. We anticipate another certification review at Sonoma in February 2015. Reviews at the other remaining state institutions are expected during the spring of 2015.

The Governor’s budget proposes $9.0 million in General Fund in the current year and $18.0 million in General Fund in the budget year, to increase the Secure Treatment Program (STP) at Porterville Developmental Center by 32 beds. This is to accommodate individuals who need to be restored to competency to stand trial. The Department of State Hospitals has other options for providing competency training which are less expensive including jails and other community facilities. These options should be explored by the DD system.

**DRC Recommendations:**

1. The Legislature should require the state to develop a plan to close the remaining state institutions within a specific timeframe. Individuals with intellectual and developmental disabilities can receive quality care in the community. Closure plans at Agnews and Lanterman Developmental Centers demonstrated it is possible to safely move individuals to the community and ensure their needs are met and the cost of serving individuals in the community is less than in state institutions.
2. Any plan to close a developmental center should ensure that at least a portion of the assets are used to benefit individuals with intellectual and developmental disabilities. For example, use land for mixed use community housing similar to Harbor Village at Fairview Developmental Center. Similar opportunities exist with the proposed transfer of Lanterman Developmental Center to Cal Poly Pomona and the development of Shannon’s Mountain at Fairview Developmental Center.

3. The Health and Human Services Agency and DDS should negotiate with the federal government to ensure that California receives federal matching funds for all current DC units while it is in the process of closing all state developmental centers. Receiving federal funds will ensure that the current state general fund back-fill can be used to develop needed new community living arrangements.

4. Rather than expanding the bed capacity at Porterville, Disability Rights California believes that alternative settings need to be developed for diversion and competency training.

**Strengthen the Community System**

As California moves away from institutional models of care, the community will be the safety net for hundreds of thousands of individuals with disabilities and it is critical that the community provide comprehensive services including safety net services.

**Reduce the Impact of the Budget Cuts and Invest in Innovative Services**

Beginning in 2009, the State made significant cuts to the developmental disabilities budget. The total cuts exceeded more than a billion dollars. The cuts affected nearly every aspect of the community system by reducing or eliminating services to consumers, cutting provider rates, and impacting regional center operation costs including case managers. Cuts included: cap on respite hours, prohibition on payments for day programs, work/employment supports and independent living services for most 18-22 year old consumers, elimination of funding for social recreation and camp services, and new requirements to use generic medical services.

In 2013 S.B. 468 (Emmerson) established a new self-determination service option. Regional Center consumers will be provided with an individual budget and increased flexibility to purchase services they find most useful to live and work in the community. DDS has recently submitted a waiver to authorize these services. For the first three years, 2,500 consumers and
their families will be eligible to participate in the program and thereafter, all regional center consumers on a voluntary basis.

**DRC Recommendations:**

1. Restore services cut during the budget crisis and invest in new and innovative service models, particularly the self-determination program authorized by SB 468.

**Implement the Federal Home and Community Based Services Regulations; and Federal Work Incentives Opportunity Act Which Require Access to Integrated Services**

The federal Centers for Medicare & Medicaid Services (CMS) adopted new regulations to maximize opportunities to receive services in the most integrated setting. Under the new rules, services that do not meet the new Medicaid standards will no longer be eligible for federal HCBS funding. California’s developmental disabilities service system is very dependent upon federal HCBS revenue.

All the services provided under the developmental disabilities waiver, and similar waiver programs, must meet these standards, including all community care licensed facilities and day services. Some settings such as institutions or facilities immediately adjacent to institutions are presumed to not meet these requirements. They require: full access to the greater community; individual choice; rights of privacy, dignity, and respect; freedom from coercion and restraint; and autonomy and independence in making life choices.

Both the HCBS regulations and Workforce Innovation and Opportunity Act strengthen the obligation to provide integrated day services and payment of minimum wage. Medicaid HCBS funding can no longer be used for segregated day programs and sheltered workshops. States must transition to community-based, integrated employment, and other integrated day services. The Workforce Innovation and Opportunity Act (WIOA) provides a significant opportunity to improve services for youth with disabilities. The law generally prohibits the payment of sub-minimum wage for individuals aged 24 or younger; requires the Vocational Rehabilitation State Plan to include strategies to address the needs of transition-aged youth including job exploration counseling, work-based learning opportunities, counseling on post-secondary educational opportunities; workplace readiness training; and instruction in self-advocacy.

DRC Recommendations:

1. Promptly develop the required Transition Plan which will ensure that residential services are provided in the most integrated setting possible including eliminating institutional models of care and specifically ensure implementation of consumer choice privacy provisions. Adjust provider rates as needed to implement the requirements.

2. Implement the new CMS and WIOA requirements, and in particular: a) eliminate the prohibition on regional centers providing transition and employment services and supports to 18-22 year old consumers; b) ensure that each regional center adopts and implements an Employment First Policy; c) eliminate subminimum wage; and d) assess the impact of provider rates particularly in the area of Supported Employment.

Ensure Equal Access to Regional Center Services Regardless of Ethnicity, Geographic Location or Primary Language

Beginning in 2012, regional centers were required to provide data regarding purchase of service expenditures based on a consumer’s ethnicity, disability, language, and age. That data continues to show disparities in the funds spent to provide services. In general, on a statewide basis, individuals who have limited English proficiency, individuals from communities of color and individuals from rural areas receive less Purchase of Service (POS) expenditures.

SB 555 (Correa) affirmed regional centers’ obligations to provide language access through means such as conducting the initial intake and assessments in the individual’s native language. It also required the development of the Individual Program Plan (IPP) and the IPP document to be provided in the individual’s native language. In our experience, this does not consistently occur.

DRC Recommendation:

1. Hold the Department and regional centers accountable for addressing the POS disparities and provide culturally and linguistically appropriate services that will help bridge the gap in purchase of service disparities.

Improve Access to Services By Carefully Reviewing Requirements To Access Generic Services

Recent changes in state law have made it more difficult to access the services and supports consumers and their families need and which may be more expensive for the state.
In-Home Nursing EPSDT Age-Out Problem

Children with the most significant medical needs can live at home with the support of home nursing. For Medi-Cal eligible children under age 21, Early and Periodic Screening Diagnosis and Treatment (EPSDT) funds this nursing. Home nursing hours are calculated based on the appropriate institutional level of care equivalent. Many young adults experience a devastating reduction of in-home nursing because adult rates are considerably lower than pediatric rates. For example, compare a nursing facility B rate of $110,000 per year for pediatrics to $56,000 adult rate; NF/AH waiver costs caps are even lower with a rate of $48,180 resulting in a loss of 57% of budget and nursing hours; and IHSS nursing costs are not deducted from EPSDT but are deducted from the NF/AH waiver budget.

As a result of 2009 amendments, WIC Section 4659 (c) requires regional centers to use “generic” health insurance resources including Medi-Cal. This means that consumers must apply for and utilize the DHCS NF/AH waiver as a generic service. The Lanterman Act provides an entitlement to services that may go beyond the NF/AH waiver cap. Because an individual can only be on one federal waiver, an unintended consequence of WIC Section 4659 (c) is that the State is using state-only funds for services where the cost could be split with the federal government.

Access to Behavioral Health Treatment (BHT) Coverage for Individuals with Autism

DRC applauds the efforts to expand behavior health treatment, including Applied Behavioral Analysis (ABA) services, to individuals with autism who are not regional center consumers by ensuring that these services are a Medicaid State Plan service. We caution, however, that a careful transition must occur to ensure that regional center consumers are not adversely affected. A similar transition requiring regional center consumers to access these services through their private health insurance plans had several unintended consequences including: lack of adequate provider networks, reductions in treatment services, and significant co-pays and deductibles.

In Home Support Services (IHSS)

Many consumers receive IHSS services which allow them to live at home with their families. All consumers who receive IHSS services continue to have a 7% reduction in the number of authorized IHSS hours. For the most part, this reduction has not been replaced by regional center services.

Effective January 1, 2015 all IHSS workers were to be eligible for overtime. The overtime provisions created complications for regional center
consumers because providers would not be able to work more than 61-66 hours per week. This posed unique challenges for some regional center consumers such as a parent who is the sole IHSS provider for two children will no longer be able to work in excess of 66 hours even if another qualified provider cannot be found. Some supported living providers whose workers also provide IHSS services have learned that they may be co-employers with the state and any additional support services or personal care hours they pay above 40 hours may be calculated as over-time hours. There are no automatic exceptions to the work week limits.

**DRC Recommendations:**

Reduce the impact and complexities of the current system so that families can more easily obtain the services they need from other service systems. This includes: a) ensuring that adult nursing waivers do not adversely impact consumers and creating a means by which additional nursing hours can be provided by regional centers while still maintaining the federal match; b) address barriers to regional center consumers who need BHT by allowing them to access their BHT through the regional center system or if a carve-out is not possible assign responsibility for determining eligibility for BHT and authorizing service type, frequency and duration to regional centers; hold regional center consumers harmless in the transition, and maintain current standards and rates; and c) if IHSS OT is restored, ensure an automatic exception process to IHSS hour limits for individuals who otherwise will be institutionalized or whose health and safety will be jeopardized.