Disability Rights California
California's protection & advocacy system

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Joint Hearing
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A Defining Moment: Considering the Closure of Developmental Centers and Its Impact on Residents, Families, and the Regional Center System

Testimony Regarding Maintaining a Safety Net: What Should Be the State's Ongoing Role in Providing Unique Services, Addressing Unmet Needs, and Ensuring the Well-Being of Those with Challenging Medical and Behavioral Needs

Testimony of Catherine Blakemore, Executive Director

Disability Rights California is the federally mandated protection and advocacy system and works to advance dignity, equality, independence, and freedom of Californians with disabilities. In addition to our federally required services, we provide the clients' rights advocacy assistance for consumers and their families at the 21 regional centers. Last year, we provided advocacy assistance to 25,736 individuals with disabilities including individuals with intellectual or developmental disabilities. In addition, through more than 800 trainings we provided more than 40,000 individuals with disabilities and their families with information about their rights. Our systemic and policy advocacy positively impacted more than 500,000 individuals.

The developmental disabilities system is in transition driven by a number of factors including the proposed closure of state developmental centers; service complexities which contribute to unmet need; and new federal

Medicaid and overtime requirements. We welcome this opportunity to provide our perspective on the critical steps the state must take to strengthen the service system and meet the unique and unmet service needs of each regional center consumer.

Creating a Strong Community Safety Net

With the closure of Sonoma, Fairview, and the non-forensic units at Porterville Developmental Centers, the community will be the safety net for the nearly 290,000 regional center consumers. We know first-hand the importance of adequate crisis and new service models for regional center consumers.

Last year we assisted Tyler. When Tyler's family could no longer provide the care she needed because she was having seizures, she was placed in a nursing facility and then a hospital. While her physical health improved, the extended hospital stay was stressful, and she experienced significant behavioral challenges. The regional center was not able to locate an appropriate living arrangement, and the community hospital didn't know how to handle her behavioral challenges so they restrained her in an enclosed bed. Being confined affected her speech and mobility, and her physical and mental health. Because there was not adequate community crisis capacity to address her behavioral challenges, our clients' rights advocate worked with the regional center and department to place her temporarily in the State's short-term acute crisis unit at a developmental center, and our Investigations Unit educated the hospital about their inappropriate use of seclusion and restraint. After a few short months Tyler's behavior, ability to express herself and her social skills greatly improved. She is now deciding where she wants to live in the community.

To ensure a strong community safety net, we encourage the State to do the following:

1. Work with the regional centers to expeditiously develop the quality enhanced behavioral health support homes required by statute. We are pleased that last month the Department submitted regulations that will allow these homes to become operational, but note that the Department of Social Services companion regulations, which address critical elements such as emergency behavior plans, the use of restraint and monitoring of behavioral services, have not been developed.

2. Promptly develop increased crisis capacity. The Department has yet to complete the development of regulations for crisis homes services or to expand access to crisis services provided in an individual's current home. Without this increased crisis capacity, we are concerned that inappropriate and expensive models such as locked institutions for mental disease (IMDs) will remain a common way of providing short and long-term crisis services. We have concerns about the cost of these services, since, for many individuals, the service is ineligible for Medi-Cal funding due to an exclusion in federal law; and more importantly, about the quality of service.

3. Develop "placements of last resort" as called for in the DC Task Force Report and work with stakeholders to determine the most effective means of providing these services including the State's on-going role in providing these services.

   Currently, the State operates small, short-term acute crisis units at Sonoma and Fairview. These programs have been successful due to clear statutory requirements requiring immediate and ongoing assessment of the individuals need and one year time-limited placements as well as the involvement of clients' rights advocates in the process, and the department's willingness to intervene with licensing and other agencies to ensure new living arrangement can timely open. WIC 4418.7(e)

   The community will not be able to be the safety net without similar capacity and requirements regarding the use of such facilities. At a minimum, the Department must have dedicated staff to ensure ongoing state involvement in these placements. Because private providers can also decline to serve individuals, we believe that State should have a role in providing residential services to those whom the private sector cannot serve; either with small state owned and operated facilities, or state supports in privately operated facilities.

4. Modify Health and Safety Exception Process. Exceptions to rate freezes and median rates are available for people whose service needs necessitate a higher rate. This is possible on an individual basis only by applying for a Health and Safety Waiver. In practice this is a lengthy process, requiring approval from both the regional center executive director and DDS. This process must move faster. Consideration should also be given to allowing regional enters to approve rate exceptions when exceptional circumstances exist.

5. Ensure adequate oversight of facilities providing short and long-term services to individuals in crisis including increased access to information and records by Disability Rights California, the federally mandated protection and advocacy agency.

   One of Disability Rights California's most important responsibilities is the investigation of abuse and neglect including the use of restraints in facilities providing care and treatment. DRC's Investigation Unit has been investigating cases of alleged abuse and/or neglect of residents at one IMD where regional center consumers are placed. Because of the gravity of our concerns, we filed complaints with the federal and state agencies. The Center for Medicaid and Medicare (CMS) made an unannounced site visit and due to flagrant health and safety violations, including failure to investigate two sexual assault complaints, made a finding of "Immediate Jeopardy." While the facility remedied the immediate concerns, our monitor continues to document problems with ongoing abuse, injury, inappropriate use of restraints and the death of a resident.

   Several years ago when there were concerns about the quality of care at state developmental centers, state law was changed to require increased reporting to DRC about specific types of injuries suggestive of abuse or neglect. With the transition to a community safety net, we propose that state law is amended to require that the protection and advocacy agency receive similar reports of injuries from IMDs, community crisis facilities and enhanced behavioral support homes. (See attached)

   Also, we encourage reduced caseloads for individuals who are receiving crisis services and are placed in community institutions such as locked IMDs. These individuals are likely to be the same individuals who would have been placed at developmental centers. Current law requires a reduced case load for individuals who are moving from developmental centers to the community this have been an important element for their successful transition, and we encourage a similar approach for individuals who are in crisis or locked facilities in the community.

Reduce Service Complexities

Beginning in 2009, due to the economic crisis, the State made more than a billion dollars in cuts to the developmental disabilities system. We are grateful for the efforts to restore funding for providers and regional centers through the Managed Care Organization (MCO) tax proposals, and the

efforts to improve outcomes in the employment area. However, an unintended consequence of the reductions is the increased complexity of the service system, which makes it difficult for consumers and families to access the services they need, and in the end, does not result in real savings to the State as the services are Medicaid funded, regardless of which state agency provides them.

In addition, the recent changes in federal law require the payment of overtime to workers providing personal care services. As a result, some service providers, have eliminated all overtime expenditures, others have required parents and conservators to sign agreements obligating the parent and consumer to assume full responsibility for managing the IHSS services even when a consumer is placed in a home operated by the provider. At least one regional center has sent a letter to all clients and families instructing them not to ask workers or caregivers to work extra hours as the rates paid to service providers do not allow for overtime pay, even though the Legislature approved a 5.82% rate increase expressly for this purpose. For consumers with the most significant needs, they often need continuity of support and support provided by a more highly trained worker. This often is not possible with IHSS due to high turnover.

Similar problems arise when individuals need to access medical or dental services provided through Medi-Cal. During the economic crisis, the law was changed to prohibit a regional center from purchasing medical or dental services for a consumer three years of age or older unless the regional center is provided with documentation of a Medi–Cal, private insurance, or a health care service plan denial, and the regional center determines that an appeal by the consumer or family of the denial does not have merit. Regional centers may pay for medical or dental services pending a final administrative decision on the administrative appeal if the family provides verification that an appeal is being pursued. The result is that families are required to appeal any decisions denying their child access to critical occupational or physical therapy, speech and language services, or dental services before regional centers will agree to pay for the service. This happens even though the State will should not save any money since the services are Medicaid eligible regardless which agency provides the services. The unintended consequence is that low-income families that use Medi-Cal do not have the time, resources or skills to appeal an adverse Medi-Cal decision and thus forego the service—which results in savings to the State.

As a way of reducing some of this complexity, we encourage you to do the following:

1. Change §WIC 4689 (f) to allow consumers' IPP teams to determine if using IHSS is an appropriate generic service. In making this determination, the IPP Team would consider the following: the nature or extent of the consumer's disability, the need for staff continuity and the need for supportive services staff with a higher level of skill, training or expertise. If the planning team determines that IHSS services are not appropriate, the consumer would not be required to utilize those services. (See attached WIC §4689(f) revision)

2. Make statutory changes clarifying that regional center funded home care services (Supported Living Services (SLS), In-Home Respite and Personal Assistance Centers) are not joint employers with IHSS or Waiver Personal Care Services.

3. Provide funding for pilot programs that provide access to temporary workers who can provide services when either the IHSS worker has exceeded the state-imposed overtime limits or the provider will not authorize overtime.

4. Ensure that the current state overtime provisions that allow a worker to work up to 66 or 70.5 hours apply to the regional center system including a funding allocation to specifically target this overtime. For example, when an SLS worker working for one SLS agency is paid through both IHSS and regional center funds, that worker should be eligible to work up to 66 or 70.5 hours per week regardless of the funding source. In addition, the statute should allow the same additional exceptions to these limits as is allowed in the IHSS program.

5. Amend WIC Section 4659 to no longer require families to pursue Medi-Cal administrative hearings before regional centers can pay for medical and dental services available through the Medi-Cal program. (See attached)

6. Provide additional Service Coordinators who can help families navigate generic services.

Improve Access to Mental Health and Dental Services

Dental Services

Children and adults with disabilities experience significant barriers to obtaining needed dental services as a result of low Denti-Cal reimbursement rates; this is related to the shortage of qualified providers, and the lack of adequate reimbursement for disability-related appropriate procedures and methods.

Denti-Cal rates are generally far lower than rates for private insurance. See page 32 of the State Auditor's report on Denti-Cal for children, available at https://www.auditor.ca.gov/pdfs/reports/2013-125.pdf. Likewise, anesthesia rates for Denti-Cal are significantly lower than rates for private insurance. For example, a typical private insurance rate is $275 for the first 30 minutes of anesthesia and $100 for each additional 15 minutes. On the other hand, a typical Medi-Cal rate is $42.14 for the first 30 minutes and $21.07 for each subsequent 15 minutes.

For people with disabilities, such as those with autism who may have difficulty communicating symptoms associated with dental problems or have behavioral challenges that make routine dental care more difficult to provide, the access problems are compounded particularly when specialized services are not available or the rates for those services are too low. When treatment is not available, individuals too often develop serious infections or horrendous pain and have no choice but to go to hospital emergency rooms, where they receive very expensive symptomatic care. For individuals with developmental disabilities, regional centers are "payers of last resort" for the disability-related services that their clients need. This means that regional center consumers must access generic services, such as Denti-Cal, before the regional centers can pay for the service. The requirement of requesting generic Denti-Cal services exists even when it is known that the service rate or type of service is inadequate given the disability-related needs and as a result, many months will have elapsed between the initial request for the service and when the service is provided.

As part of the Agnews Developmental Center closure plan, some regional centers received funding for Dental Coordinators to help ensure that consumers leaving Agnews could continue to access appropriate dental care. The use of Dental Coordinators proves to be an effective means of ensuring access to dental services. Some regional centers continue to have Dental Coordinators, and it appears that access to dental services is

enhanced at those regional centers. The Agnews and Lanterman closure plans continued the availability of dental services at those developmental centers.

We recommend the following solutions:

1. Funding for Regional Center Dental Coordinators at each regional center, as this is a proven way to increase access to dental services either by assisting consumers and families in accessing Denti-Cal or by quickly determining that Denti-Cal cannot provide appropriate specialized dental services and use purchase of service funds to obtain the needed services.

2. Increase the rates for anesthesia dental care and the rates for common preventive dental care. Consistent with the State Audit and other available information, California's Denti-Cal rates are extremely low compared to other states, inhibiting access to care and permit Denti-Cal reimbursement for services such as scaling and root cleaning, and periodic comprehensive evaluations. Increase the dental anesthesia rate to provide rate parity between anesthesia for other services and anesthesia for dental services.

3. Some developmental center dentists and staff have specialized expertise regarding the unique dental needs of regional center clients. Through the closure process, it is important to ensure that dental services and staff expertise regarding provisions of dental services continues to be available in the community.

Mental Health Services

As noted in the DC Task Force Report, an overarching issue is access to mental health services including care coordination and appropriate and continuous medication management. The Task Force Report notes that 22% of individuals living in Developmental Centers have prevailing psychiatric/mental health issues, and 51% are prescribed at least one psychiatric medication targeting behavioral challenges. From our work with individuals dually diagnosed with mental health and developmental disabilities who live in the community, we also know that these individuals are often served in emergency rooms and local hospitals, and have great difficulty accessing community mental health services.

We recommend that the Department convene stakeholders to look at current effective models of providing access to mental health services and new and

innovative options that can be attached to the yet to be developed community crisis services.

Obtain Federal Approval and Implement the Self-Determination Program

In 2013, the Legislature unanimously approved, and the Governor signed into law, SB 468 which created a statewide Self-Determination Program; a voluntary, alternative to the traditional way of providing regional center services. It provides consumers and their family with more control over the services and supports they need. Self-determination provides consumers, and their families, with an individual budget, which they can use to purchase the services and supports they need to implement their Individual Program Plan (IPP). Consumers and families may for example, purchase existing services from services providers or local businesses, hire support workers, or negotiate unique arrangements with local community resources. Family members of individuals residing at State Developmental Centers have indicated that this is one of their preferred ways to provide services as their loved one transitions from the developmental center to the community.

While the Department and regional centers have taken important steps to implement the program, we have yet to receive federal CMS approval due in large part to the inter-relationship between this waiver and the required Home and Community Based Services regulations required Transition Plan. The Transition Plan and the Self-Determination Waiver must both demonstrate how the State will ensure that as of March 2019, all waiver services, including self-determination services, meet the federal integration and choice requirements.

We encourage the Department to continue, and expedite, its work with Stakeholders to develop a strategy that provides sufficient assurances to CMS that the Self-Determination Waiver meets the HCBS requirements and if necessary, obtain a conditional time-limited approval. The experience of the Self-Determination Pilot Program is that consumers and families experience a high level of satisfaction with this program and that the cost to the state is often less than the costs associated with the traditional regional center service system.

Statutory Changes

Monitoring of Facilities and Living Arrangements Serving Individuals with Developmental Disabilities

Amend Welfare and Institutions Code 4659.2

(b) All regional center vendors that provide crisis or residential services or supported living services, long-term health care facilities, and acute psychiatric hospitals shall report the following to the agency designated pursuant to subdivision (i) of Section 4900 the following:
(1) Each death or serious injury of a person occurring during, or related to, the use of seclusion, physical restraint, or chemical restraint, or any combination thereof
(2) Any unexpected or suspicious death, regardless of whether the cause is immediately known.
(3) Any allegation of sexual assault, as defined in Section 15610.63, in which the alleged perpetrator is a staff member, service provider or facility employee or contractor.
(4) Any report made to the local law enforcement agency in the jurisdiction in which the facility is located that involves physical abuse, as defined in Section 15610.63, in which a staff member, service provider or facility employee or contractor is implicated.
(start delete) ~~to the agency designated pursuant to subdivision (i) of Section 4900~~ (end delete)
(5) The reports required in Sections (1)-(4) shall be made no later than the close of the business day following the following the death or serious injury. The report shall include the encrypted identifier of the person involved, and the name, street address, and telephone number of the facility.
(c) On a monthly basis all regional center vendors that provide residential services or supported living services, long-term health care facilities, and acute psychiatric hospitals shall report the following to the agency designated pursuant to subdivision (i) of Section 4900 the following:
(1) The number of incidents of seclusion and the duration of time spent per incident in seclusion;
(2) The number of incidents of the use of behavioral restraints and the duration of time spent per incident of restraint; and
(3) The number of times an involuntary emergency medication is used to control behavior.
(4) The reports required in sections (1)-(3) shall include the name, street address and telephone number of the facility.

Amendments to Ensure Access to Personal Care Services for Individuals Living in Supported Living Arrangements.

Amend WIC 4689

(f) The planning team, established pursuant to subdivision (j) of Section 4512, for a consumer receiving supported living services shall confirm that all appropriate and available sources of natural and generic supports have been utilized to the fullest extent possible for that consumer. The consumer's individual program planning team shall review and determine if the supportive services provided by the IHSS program are appropriate to meet the consumer's needs. In making that determination the individual program planning team shall consider the nature or extent of the consumer's disability, the need for staff continuity and the need for supportive services staff with a higher level of skill, training or expertise. If the planning team determines that IHSS services are not appropriate, the consumer shall not be required to utilize those services notwithstanding the requirements of sections 4659 and 4689.05.

Amendments to Ensure Access to Appropriate Medical or Dental Care without the Necessity of Pursuing a Medi-Cal Appeal

Amend to WIC Section 4659(d)

(d) (1) Effective July 1, 2009, notwithstanding any other law or regulation, a regional center shall not purchase medical or dental services for a consumer three years of age or older unless the regional center is provided with documentation of a Medi–Cal, private insurance, or a health care service plan denial (start delete) ~~and the regional center determines that an appeal by the consumer or family of the denial does not have merit. If, on July 1, 2009, a regional center is purchasing the service as part of a consumer's IPP, this provision shall take effect on August 1, 2009~~ (end delete). Regional centers may pay for medical or dental services during the following periods:

(A) While coverage is being pursued, but before a denial is made.

(Start delete) ~~(B) Pending a final administrative decision on the administrative appeal if the family has provided to the regional center a verification that an administrative appeal is being pursued.~~ (end delete)

(C) Until the commencement of services by Medi–Cal, private insurance, or a health care service plan.

(2) When necessary, the consumer or family may receive assistance from the regional center, the Clients' Rights Advocate funded by the department, or the state council in pursuing these (start delete) ~~appeals~~ (end delete) denials.