Disability Rights California
California's protection & advocacy system

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Legislative/Public Policy Platform for 2017

Budget Advocacy:

We will provide budget advocacy to protect needed benefits and services. We will monitor the state budget, work to avoid future cuts and restore prior service reductions. This could include advocating for proposals to repeal service limitations adopted as part of the state fiscal crisis.

We will advocate for maintaining and increasing funding for our Office of Clients' Rights Advocacy and California Office of Patients' Rights.

Legislation Introduced by Others:

We will continue to work with stakeholder groups and on legislation proposed by others consistent with our legislative principles. Possible 2017 issues include: community-based services for competency restoration; enforcement of disability access laws so attempts to change the law enhances and does not erode rights; supporting a "Permanent Source" bill, and similar affordable housing funding legislation; and advocating to expand exemptions and exceptions related to In-Home Supportive Services (IHSS) Overtime Implementation.

Legislative or Policy Proposals by Impact Area:

1. Stop discrimination, end institutionalization and increase community living choices

Fix Problems Created by the DDS Median Rate and Expedite Health and Safety Exceptions

Reimbursement rates for certain categories of residential and non-residential services provided by regional center vendors have been frozen at 2008 levels for existing providers and capped at the statewide median for new providers. The median rate system does not allow regional centers or vendors to negotiate higher rates in regions with higher costs of living and doing business or in circumstances in which an individual requires more intensive services to live in the least restrictive environment.

The system leads to situations where individuals at risk of institutionalization or living in institutions must remain in institutions at a far higher cost and in a far more restrictive environment. California Department of Developmental Services (DDS) has a health and safety waiver exemption process to allow regional centers to deviate from the 2008 rate freeze. The approval process for health and safety waiver requests on average takes 6 to 9 months thereby significantly delaying community services.

Proposal: Through budget or policy advocacy, we will advocate to:

1. Increase the median rate or allow for an automatic health and safety exception rate for people moving out of institutions or at risk of institutionalization as a way of taking into consideration the cost and restrictive nature of institutional care.
2. Streamline and expedite the health and safety waiver process. Recognizing that people for whom health and safety waivers are requested are likely to need urgent relief and services, we recommend setting clear and timely deadlines for DDS to respond to waiver requests, and a mechanism to have the request that is not responded to within the timelines deemed provisionally approved, pending a final response from DDS with associated fair hearing and aid paid pending rights upon a final response from DDS.
3. Make the health and safety waiver process more transparent. For example, DDS could track and publicize data regarding the number, type, and dates of submission of health and safety waivers submitted by regional centers, the timeline of DDS's responses, and whether the waiver was granted or not.

Strengthen protections for people placed in Institutions for Mental Disease (IMD)

The law restricts the placement of regional center clients in an IMD by a regional center when there is an emergency. There's no clear statutory guidance about what constitutes an emergency. The statute further restricts these placements to no more than 180 days total. Unfortunately, many regional center clients remain at IMDs well beyond the 180 days.

Proposal: Through budget or policy advocacy, we will advocate to:

1. Strengthen the language in the IMD statute so circumstances that constitute an "emergency" are similar to standards to admit people into a short term Developmental Center (DC) crisis unit.
2. Amend the law to explicitly prohibit a court from extending IMD placement for over 90 days, unless the emergency or crisis continues to exist similar to what occurs with the placements in the short-term crisis units in developmental centers.
3. Implement restrictions on the number of individuals that any one regional center can place within a fiscal year.

2. Eliminate abuse and neglect and improve quality of care

Add an Additional Department of Public Health Citation Level

The Department of Public Health (DPH) issues citations for regulatory violations with various penalty amounts based on the level of harm to the resident. The maximum citation (Class AA) and monetary penalty is issued when staff misconduct is a direct proximate result of a resident's death, i.e., the immediate reason which caused the death of the resident. Often, a lower level of citation (Class A) and monetary penalty is issued when a resident dies but DPH finds there is a substantial probability the resident's death was caused by staff misconduct, but believes there is insufficient evidence of direct proximate cause. These are very fact-intensive decisions, and DPH is very conservative in making a finding of direct proximate cause.

DRC investigated 11 cases, including consulting with medical experts, and reviewed hundreds of other citations issued in the past 15 years. We determined that DPH often issued a low level citation and a correspondingly low penalty amount, even when a nursing resident died because of the facility staff's negligent care.

Proposal: Through budget or policy advocacy, we will advocate to add an additional level of citation (with a corresponding penalty) for a resident's death while in a long term health care facility when the death is related to or involves care staff abuse or neglect but there is insufficient evidence of direct proximate cause.

Limit Seclusion and Restraint in Schools

Numerous DRC investigations have found schools continue to use behavioral restraint and seclusion excessively and that there are inadequate statutory limitations on their use in schools. In 2013, the legislature eliminated state requirements for data collection, public reporting and proactive development of positive behavior support plans. California is lagging behind other states and is non-complaint with US Department of Education recommendations limiting the use of behavioral restraint and seclusion.

Proposal: Through budget or policy advocacy, we will advocate to place appropriate limitations and safeguards on the use of behavioral restraint and seclusion. Specifically, the proposal would ban particularly dangerous practices, including mechanical and chemical restraint and physical restraint that limits an individual's ability to breath, define restraint and seclusion, limit the use of restraint to emergencies involving immediate risk of physical harm or serious physical injury, prohibit or time-limit the use of seclusion, prohibit the use of seclusion or restraint to discipline or punish, and require public data reporting.

Increase Out-of-Cell Time for Jail Inmates with Mental Health Disabilities

State law and regulations provide that jail inmates can be out of their cells a minimum of 3 hours per week. Many jails use this minimum as the basis for their "out-of-cell" schedules. Many inmates spend 5 to 6 days a week in their cells 24 hours a day.

Research indicates physical and mental health is comprised by prolonged solitary confinement and thus result in inhumane and arguably unconstitutional conditions of confinement.

Individuals with mental health disabilities account for approximately 20% of individuals in jails or about 15,000 people. Solitary confinement is emotionally destructive especially for inmates with mental health

disabilities. These inmates lack access to outside advocacy and have limited ability to advocate for themselves because of their circumstances.

Proposal: Change the law to allow inmates with mental health disabilities more time out of their cells.

3. Increase access to benefits, services and health care

Restore the In-Home Supportive Services Share of Cost Buyout

Until 2009, there was a share of cost buyout, which meant that the state was paying the share of cost for some IHSS recipients who had income above SSI level, enabling them to keep their income to live on. The repeal of the IHSS share of cost in 2009 left some IHSS consumers with income way below the inadequate SSI amount – the $600 medically needy amount. This has left these consumers – who should be at less risk for institutionalization – at more risk and penalized for having income for which they may have worked and should be able to keep. It impedes the chances for people to leave institutions if they have only $600 a month to live on.

Proposal: Through budget or policy advocacy, work to restore the IHSS Share of Cost Buyout Program.

Fix the “wobbler” issue which affects individuals who alternate (wobble) between eligibility and ineligibility for the Aged Blind Disabled Federal Poverty Level (ABD FPL) Medi-Cal Program

The “wobblers” are people who have Medicare and Medi-Cal and get bounced every couple of months between one Medi-Cal program which requires a high share of cost and another Medi-Cal program which does not require a share of cost. (Share of cost means the monthly amount the individual has to pay out of pocket for Medi-Cal services to meet Medi-Cal income rules.)

They are people under the age of 65 who receive Social Security Disability Insurance (SSDI), or people over the age of 65 who receive Social Security retirement benefits. For example, Ms. Doe receives $1,300 in SSDI and pays $104 for Part B Medicare. With her net income at $1,196, she can qualify for Medi-Cal through the ABD FPL program that allows income up to $1,221, pays her Medicare Part B premium, and does NOT require a share of cost. When she gets on the ABD FPL Medi-Cal program and Medi-Cal pays her Medicare Part B premium, her net income goes back up to $1,300 – above the $1,221 limit for the program. To stay on Medi-Cal, she is

forced to be on the Medi-Cal Medically Needy (MNIL) program, which allows her to keep only $600 per month. With income of $1,300 per month, she must pay share of cost of $700 per month before Medi-Cal will begin paying for her Medi-Cal covered services. Now that she is on the MNIL Medi-Cal program, she begins paying her own Medicare Part B premium again bringing her monthly countable income back down to $1,196, qualifying her again for the ABD FPL Medi-Cal program at no share of cost. Medi-Cal starts paying her Medicare Part B premium again and the cycle repeats. The only current way to fix this is for Ms. Doe to purchase a supplemental medical insurance policy, which she does not need, because this is the only way under Medi-Cal rules to bring her income low enough so that when her Medicare Part B premium is added to her SSDI income, she is still below the $1,221 threshold for the ABD FPL program.

Proposal: Through budget or policy advocacy, we will advocate to work on a solution to assist individuals who “wobble” between eligibility and ineligibility for the ABD FPL Medi-Cal Program.

4. Increase access to education, housing, transportation and employment

<u>Data sharing legislation related to Employment Outcomes for People with Intellectual and Developmental Disabilities</u>

Current DDS data does not allow it to assess employment outcomes by geography, disability type, severity of disability, ethnicity, or age. There is a lack of data on the quality of employment for the people served and regional center clients who do not receive day or employment services. Without better data, California cannot know how well it is implementing Employment First, where it is succeeding, or where it needs to improve.

The State Council on Developmental Disabilities (SCDD) committed at its July 2014 meeting to sponsor legislation requiring: (1) Franchise Tax Board or Employment Development Department (EDD) to release to DDS income data for regional center clients; (2) DDS to collect data from regional center service providers on all working-age regional center clients on hours worked, income earned, type of job, and other relevant employment data; and (3) DDS to maintain confidentiality of individual income data.

Proposal: Through budget or policy advocacy, we will work with the SCDD on legislation to obtain data and improve data sharing to implement the Employment First Policy and advance Completive Integrated Employment.

Require the California Department of Education (CDE) to publicly report Individuals with Disabilities Education Act (IDEA) state compliance complaint decisions

Federal law does not require State Educational Agencies (SEAs) to publicly report state compliance complaint decisions. Federal guidance states that SEAs may do so, but must "ensure that the confidentiality of any personally identifiable information in the complaint decision is protected from unauthorized disclosure."[1] At this time, 12 states publish state compliance complaint decisions online: Colorado, Delaware, Florida, Indiana, Maine, Maryland, Montana, Nevada, Ohio, Oregon, Wisconsin, and Wyoming.[2] The CDE does not publicly report state compliance complaint decisions. This prevents the public from accessing information about complaints.

Proposal: Through policy advocacy, we will advocate for CDE to publically report state compliance complaint decisions.

Improve Accessibility in State and Local Government Funded Housing

There is an enormous shortage of affordable housing that is accessible to people with mobility, hearing, and vision disabilities. In 2013, DRC introduced SB 550 (Jackson), which would require housing subsidized with state and local government funding to meet the same or similar standards for accessibility as federally funded housing. This includes a requirement that at least 5% of multifamily subsidized housing units be fully accessible to people who use wheelchairs, and that 2% be accessible to people with vision and hearing disabilities.

While the bill was defeated that year, it was one of the catalysts for changes to one major subsidy program (Tax Credits). Programs funded with tax credits in California now have to meet a 10%/4% accessibility standard.

Proposal: Through legislative or policy advocacy expand federal accessibility standards to other affordable housing fund sources.

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[1] OSERS (Jul. 2013), *Questions and Answers on IDEA Part B Dispute Resolution Procedures* 32, available at: https://www2.ed.gov/policy/speced/guid/idea/memosdcltrs/acccombinedosersdisputeresolutionqafinalmemo-7-23-13.pdf. "Return to Main Document"

[2] Links for each state database is available at: http://www.advocacyinstitute.org/iscrc/sample.shtml. "Return to Main Document"

5. Make sure the autonomy, preferences and choices of people with disabilities are respected

Provide Protections to Parents with Disabilities in Dependency Proceedings

California law currently provides specific protections for parents with physical disabilities in dependency proceedings but does not cover parents with mental, psychiatric, or developmental disabilities.

California courts have long rejected the proposition that parental rights may be curtailed on the basis of a parent's physical disability. (*In re Marriage of Carney* (1979) 24 Cal.3d 725, 736.)

In 2011, the California legislature codified the Carney decision. (See Senate Bill 1188 (2010) modifying Cal. Family Code § 3049 to state: "It is the intent of the Legislature in enacting this section to codify the decision of the California Supreme Court in *In re Marriage of Carney* (1979) 24 Cal.3d 725, with respect to custody and visitation determinations by the court involving a disabled parent.")

Neither the California courts nor the legislature have sufficiently addressed the issue of a court's (or a child welfare agency's) reliance on a parent's mental, psychiatric, or developmental disability in the context of proceedings impacting parental rights. State law in fact provides that a court may find a child to be a dependent of the court based on a parent's "inability…to provide regular care for the child due to mental illness, developmental disability, or substance abuse." Cal. Welf. & Inst. Code § 300(b).

Proposal: Through policy advocacy, we will amend the law to provide statutory guidance making clear that courts must avoid discrimination on the basis of mental, psychiatric or developmental disability, by considering whether the provision of accommodations or services can ensure parents have equal access to parenting opportunities while ensuring children's safety and well-being.

Ensure Accessible Voting Systems are Offered to all Voters

Currently, a polling place is required to have an accessible voting system, but there are no standardized protocols to ensure voters are aware of the option to use an accessible voting system. Voter awareness often hinges

on whether a poll worker can spot a disability and offer the accessible system.

Proposal: Through policy advocacy, we will ensure poll workers offer the use of an accessible voting system to all voters.

Ensure a Statewide Standard Emergency Ballot Form is Created and Available Online

The emergency ballot form process is time intensive and can be challenging for hospitalized voters. Further, the lack of state-wide uniformity of the ballot form prevents effective voter education and hinders voter participation. County election websites and the Secretary of State website should provide standardized downloadable forms for printing and easy use.

Proposal: Through policy advocacy, we will advocate to ensure a standard statewide emergency ballot is created and available on line.

Require County Election Officials to Provide Accessible Voting Information on their Websites

Many counties provide little to no information on accessible voting on their websites. The websites are the primary source of local voting information. Most do not contain sufficient information about accessible voting options in the county.

Proposal: Through policy advocacy, we will advocate to require that counties post information on accessible voting on their websites.

6. Increase culturally competent and geographically accessible services

Increase access to critical documents in a consumer and family's primary language.

DRC has made good progress over the last several years ensuring that families and consumers have access to key documents such as the Individual Program Plan (IPP) in the consumer and/or families' native language and ensuring timely receipt of these documents in threshold languages. However, some critical documents such as Individualized Education Plans (IEPs) developed by local educational agencies, are not always translated or timely translated, even though educational agencies are required to provide language access under State law.

Proposal: Through budget or policy advocacy, work with other stakeholders to ensure that students receive copies of their IEP in their native language and that timely translations are provided in threshold languages; work continue to improve language access to documents in other service systems.