Disability Rights California
California's protection & advocacy system

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Budget Advocacy:

We will provide budget advocacy to protect benefits and services needed by Californians with disabilities. We will monitor the state budget, work to avoid future cuts and restore prior service reductions to programs.

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

Ongoing Advocacy:

Sponsored Legislation:

If they become two-year bills, we will continue to work on our 2015 sponsored legislation. They include:

AB 918 (Stone): Health and Care Facilities: Seclusion Restraints: AB 918 will require the Department of Developmental Services (DDS) to publicly report data it currently collects about the use of physical or chemical restraint in regional center vendored facilities. The bill applies to vendored facilities that provide residential services and supported living services as well as long-term health care facilities and acute psychiatric hospitals. These facilities are currently required to report physical and chemical restraint, serious injuries and accidents, and consumer deaths. Additionally, AB 918 will require vendored community facilities, long-term health care facilities, and acute psychiatric hospitals to report to Disability Rights California (DRC) regional center consumer deaths or serious injuries occurring during or related to the use of restraint or seclusion.

AB 1518 (Assembly Aging and Long-Term Care Committee): Medi-Cal: Nursing Facilities: The Assembly Aging and Long-Term Care Committee

is the author of our AB 1518, which would make this Medi-Cal waiver a useful tool so Californians can receive long-term services and supports in their homes and avoid unwanted, unnecessary and expensive institutional care. For over a decade, DRC has represented consumers who want to avoid or leave facilities but who are stymied by the restrictions of the waiver. The consumers included young people with high nursing needs aging out of the state's Early Periodic Screening Diagnosis and Treatment (EPSDT) system, who lose half of their home nursing services when they turn 21.

AB 1235 (Gipson): Long-Term Care: Home Upkeep Allowance: The biggest barrier to people leaving nursing homes is the lack of affordable accessible housing. This bill would modernize California's Home Upkeep Allowance, a Medi-Cal provision that allows certain people in nursing homes to keep their home. This means they can leave the facility and have a home to return to. The bill includes a way for people who have already lost their homes to set aside funds, which would otherwise be used as share of cost, so they can obtain and, if necessary, modify a new home.

Legislation Introduced by Others:

We will work with stakeholder groups and otherwise work on legislation proposed by others consistent with our Legislative Principles and will advise the board of our activities on these issues. Possible issues in 2016 are: enforcement of access laws, to ensure attempts to change these laws enhance and do not erode rights (including possible introduction of a DRC sponsored bill to provide for example additional training for CASps, see below); assisted suicide legislation; and voting rights legislation.

Legislative or Policy Proposals by Impact Area

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

Ensure Compliance with Home and Community Based Regulations (HCBS)

New federal regulations governing settings, (such as where you live or where you work), that are funded with Medicaid Home and Community Based Services (HCBS) dollars went into effect on March 17, 2014. By March 17, 2019, the state must ensure that a setting allows for integration, choice, privacy, autonomy, and independence of people served there. Settings not meeting requirements will not be eligible for federal funding.

The regulations require significant changes to California's residential and non-residential settings that serve people with disabilities. While the new regulations affect all HCBS funded settings, by far the largest impact is on the developmental disabilities system, serving tens of thousands of people.

The Department of Developmental Services (DDS) and other state departments are working to develop a transition plan for the state to demonstrate how they will comply by 2019. The transition plan has not been approved by the federal government – California's plan falls short of demonstrating the state will comply by then.

Proposal: Through budget or policy advocacy ensure that funding and changes in the law provide for the development and expansion of residential and non-residential settings that comply with the HCBS federal regulations.

Ensure that Regional Center Consumers Can Use Regional Resource Development Projects to Remain in the Community

The Lanterman Act provides services and supports so individuals with developmental services can live in the community. The Regional Resource Development Projects (RRDP) are authorized by the Lanterman Act. The RRDPs are designed to:

- Assist consumers and their planning teams with planning for and transition from developmental centers to community living alternatives and provide post placement follow up.
- Assess consumers experiencing difficulty in their community environment and identify possible supports to preserve their community living arrangements.
- Arrange for and conduct assessments of people needing acute crisis services.
- Assist in the transition to, or preservation of, community living arrangements by providing focused training for consumers, families, service providers and regional center staff.

People who are at risk of losing their community placements and moving to development centers or other restricted setting have problems obtaining RRDP assessments and obtaining the services they need to remain at home or in their current community placement.

Proposal: Though budget or policy advocacy ensure services, supports and resources such as assistance from RRDPs are available, so regional center consumers stay in the community.

Ensure Regional Centers Comply with Timelines for Providing Community Services, Inform Consumers About Agreed upon Services, and Provide Information About Appeal Rights

The Lanterman Act allows regional centers to have an internal review process that makes final decisions about the provision of needed services or day programs. These internal processes ensure purchase of service policies are being followed, generic services are being utilized, and other legal mandates are followed. However, these staff-only committees often do not make decisions quickly. As a result, consumers can go a long time without needed services and supports.

Other problems encountered by regional center consumers include not being provided with an Individualized Program Plan (IPP) document at the end of the IPP meeting; and not being provided with information about their rights when there is a disagreement with the regional center about services and supports.

Proposal: Through legislative and policy advocacy, we will work to ensure: 1) timelines are followed so people get the services they need; 2) consumers and families receive a written IPP of agreed upon services

in their preferred language; and 3) consumers and families receive information about the complaint and appeal process at the beginning of the IPP meeting.

2. Increase the rights of people with disabilities to housing they can use and afford

Improve Accessibility in State and Local Government Funded Housing

There is a shortage of affordable accessible housing for people with mobility, hearing, and vision disabilities. In 2013, DRC introduced SB 550 (Jackson) that required housing subsidized with state and local government funding to meet the same or similar standards for accessibility as federally funded housing. Federal requirements include the following: 1) at least 5% of multifamily subsidized housing units be fully accessible to people who use wheelchairs; and 2) 2% be accessible to people with vision and hearing disabilities. While the bill did not move in 2013, it was one of the catalysts for change to one major subsidy program but not others. Specifically, 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.

Increase the Number of Certified Access Specialist (CASp) Program Inspectors Based on the Population of the Jurisdiction and Provide Funding for Additional Certification and Training

SB 1608 (Corbett, 2008) requires at least one building inspector in each local jurisdiction be CASp certified. We propose increasing the number of CASp certified building inspectors to a number based on the population of the jurisdiction served by the building department. For example, this would require more CASp certified building inspectors in Los Angeles than Sacramento because Los Angeles' population is greater.

Further, we propose the officials receive additional certification in housing access requirements. We know from our work that no CASp equivalent exists in the housing arena. In fact state and local governments are using existing CASps to confirm subsidized housing meets federal and state accessibility requirements. Current CASp

certification does not provide in-depth coverage of housing access requirements sufficient for a CASp to assess subsidized housing.

Proposal: Change the law to increase the number of CASps based on the population of the local jurisdiction and require certification or training on housing access requirements.

3. Eliminate abuse and neglect and improve quality of care

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

California law and regulations provide that jails can let inmates out of their cells a minimum of three hours per week. Many jails use this drastically low 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. This practice is inhumane and arguably unconstitutional. This is especially true for individuals with mental health disabilities, who account for approximately 20% of individuals in jails or about 15,000 people. Research indicates physical and mental health is comprised by prolonged solitary confinement.

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.

Department of Public Health (DPH) Citation Levels for Sexual Assaults

The citation level issued by the DPH as set out in law is based on the probability and severity of risk to the patient. The citation levels are listed below.

1. Class AA: a direct cause of death of a patient.
2. Class A: either (1) imminent danger that death or serious harm to the residents of the long-term health care facility would result, or (2) there is a substantial probability that death or serious physical harm would occur.

3. Class B: a direct or immediate relationship to the health, safety, or security of long-term health care facility patients. Sexual assaults are routinely cited at a “Class B” level with a $500 - $1,000 penalty fee.

Sexual assaults are traumatic and often pose lasting psychological trauma and serious physical health concerns. Sexual assaults are receiving enhanced scrutiny in other areas such as the military and on college campuses. DRC believes sexual assaults in licensed care facilities should receive comparable enhanced scrutiny.

Proposal: Require that sexual assaults be elevated, minimally, to a “Class A” level (penalty range $1,000 - $10,000).

State Corrections Mental Health Facilities Reporting to DRC

Three corrections facilities (Vacaville, Salinas, and Stockton) have mental health units operated by the Department of State Hospitals (DSH). As required by law, DSH reports to DRC the following incidents:

1. deaths and serious injuries related to the use of behavioral restraint and seclusion
2. unexpected or suspicious deaths
3. allegation of sexual assault involving a facility employee
4. physical abuse by a facility employee reported to local law enforcement

It is proposed that these units will no longer be operated by DSH rather they will be operated by California Department of Corrections and Rehabilitation (CDCR). This means DRC will not receive incident reports for people in these facilities because CDCR is not required to send reports to DRC. We are concerned there may be an increased use of restraint and seclusion when the programs are no longer operated by DSH. DSH has a treatment focus and CDCR has a punishment focus.

Proposal: If the units continue to be licensed as mental health treatment units, we propose legislative or policy advocacy to require CDCR to report the incidents listed above to DRC. This will ensure continuation of existing reporting requirements that will otherwise end due to a change in the department responsible for the programs.

Modify DRC's Access Authority to Cover "Copies" of Records

Current state and federal law entitle DRC "access" to records and information. Recently, DSH refused to provide DRC with copies of mortality review documentation but agreed to provide DRC on-site access to review certain documents contained within the facility's death review records. It is best practice to have an original copy of a document, rather than rely upon handwritten notes of a document reviewed on-site. New federal regulations permit allowable costs for copies of records, which would apply, in our view, to copies for DRC.

Proposal: Clarify the law to provide DRC "copies" of records and information pursuant to an abuse or neglect investigation, consistent with new federal regulations.

Timeliness of Department of Public Health (DPH) Investigations

For years, there have been significant delays in the DPH completing complaint investigations, most notably those involving grave and/or dangerous incidents resulting in death or serious injury.

In October 2014, the California State Auditor issued a report finding the DPH has 10,000 open complaints with investigations remaining open, on average, for a nearly one year, thereby "placing at risk the well-being of residents of long-term health care facilities." The Auditor recommended that the DPH establish time frames for completing complaint investigations.

In the last budget cycle, DRC worked on trailer bill language to require the DPH to complete investigations of incidents of abuse and neglect in a reasonable time frame. The Legislature and Administration supported the timelines. The proposal adopted by the Administration allows for new investigation timelines to be phased in over a few years, with the most egregious incidents being first to require timelines for completion. By July 1, 2018, all investigations into incidents of abuse and neglect must be completed in 60 days, with the possibility of an additional 60 days, if circumstances require it.

The requirements adopted by the Administration do not apply to incidents reported by the facilities (entity reported incidents or ERIs). They only apply to incidents reported by individuals. This year, we worked on a bill (AB 348 - Brown) that would require investigations of

ERIs to be completed in the same time frames as all other investigations. However, the bill failed to make it out of the Senate Appropriations Committee.

Proposal: Require the DPH to complete complaint investigations of ERIs and publish findings within the already established time frames for all other complaint investigations.

4. Increase access to benefits, services and health care

In-Home Supportive Services (IHSS) 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: Restore the IHSS Share of Cost Buyout Program either through budget advocacy or a policy bill.

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

Ensure that People with Disabilities in Sheltered Workshops are Protected Under the California Fair Employment and Housing Act (FEHA)

The FEHA prohibits harassment and discrimination by employers for a number of protected groups when the discrimination is based on race, color, religion, sex, gender, gender identity, gender expression, sexual orientation, marital status, national origin, ancestry, mental or physical disability, medical condition, age, pregnancy, denial of medical and family care leave, or pregnancy disability leave and retaliation for protesting illegal discrimination.

Under the Government Code, “employee” does not include anyone employed by his or her parents, spouse, or child, or any individual

employed under a special license in a nonprofit sheltered workshop or rehabilitation facility. This leaves people with disabilities employed in these settings no recourse for discrimination by their employer.

Proposal: Change that law so that individuals with disabilities who are in sheltered work are considered “employees” and are provided the same protections as other employees under California’s FEHA. Reform is needed to strengthen rights and protections for sheltered workshop employees who work in highly-restrictive environments and currently are not afforded the same protections against discrimination as other employees.