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.

Legislative or Policy Proposals by Impact Area

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

   a) **Improving the choices for young adults with significant medical needs by removing the EPSDT "Cliff"**

Many young adults with significant medical needs can live at home if they receive home nursing. For Medi-Cal eligible children and young adults under age 21, Early and Periodic Screening, Diagnosis and Treatment (EPSDT) funds home nursing. Home nursing hours are calculated based on the appropriate institutional level of care equivalent. Many young adults experience a devastating reduction in home nursing hours when they are no longer eligible for EPSDT and instead receive home nursing under the Nursing Facility/Acute Hospital Home and Community Based Services Waiver because adult waiver rates are almost 50% lower than pediatric waiver rates and Nursing Facility/Acute Hospital Home and Community

Based Services Waiver (NF/AH Waiver) cost caps are even lower with a rate of $48,180 resulting in a loss of 57% of budget and nursing hours.[1] Further, IHSS nursing costs are not deducted from EPSDT but are deducted from the NF/AH waiver budget. The Department of Health Care Services (DHCS) and the Department of Developmental Services (DDS) do not ensure that the "aging-out" individuals receive appropriate coordination between the two departments.

Proposals:

1) Ensure that individuals aging out of EPSDT and transitioning to the adult waiver, experience no reduction or interruption in nursing services, absent a reduction in need.
2) Require that DDS and DHCS jointly develop a care plan, at least 180 days before an affected individual reaches a 21st birthday.
3) If DHCS and DDS are unable to ensure neither reduction nor interruption in nursing services, they must issue a timely and adequate notice, informing the individual of a right to file for a Medi-Cal or regional center administrative hearing, and the availability of aid-paid-pending the hearing decision.

b) Equalizing funding for institutions and equivalent community-based services

The DHCS operates the NF/AH Waiver, which provides community services for individuals who would otherwise be placed in a nursing home or acute hospital. To be eligible for the waiver, the average per-person waiver cost cannot exceed the average cost of providing that care in an institutional setting. DHCS has set seven cost-caps, depending on its determination of each NF/AH Waiver participant's institutional level of care. These cost-caps are significantly below the actual cost of the equivalent institutions.[2] For certain individuals who require significant in-home care, the low cost cap may mean the difference between remaining at home with family or moving into a more costly institutional placement.

Footnote 1: For example, compare a nursing facility B rate of $110,000 per year for pediatrics to $56,000 adult rate.

Footnote 2: For example, the Medi-Cal program pays $271,697 per year to subacute facilities for adults over the age of 21 who are placed in those institutions. However, DHCS limits the equivalent waiver to $180,219 annually.

There are about 80,000 nursing home residents covered by Medi-Cal and thousands more living at home who qualify for nursing home care. About one quarter, approximately 20,000 people, of nursing home residents say they are interested in returning to the community. However, there are only 3,300 waiver slots to help those who want to get out of nursing homes or other institutions and those who want to stay out. There is no waiting list to enter a nursing home. However, there is a waiting list of approximately 700 people living at home who want to stay there and are eligible to go to a nursing home but cannot get waiver services.

Proposals:

1. Require DHCS to use NF/AH Waiver cost caps that are commensurate with the current institutional rate for equivalent level of care, increase cost caps when institutional rates increase, and require DHCS to offer exceptions to the cost cap when necessary to preserve a person's health, safety, or home placement.
2. Require DHCS to increase the number of slots on the NF/AH Waiver so there is no waiting list for people living at home and have a waiver slot available for anyone leaving a nursing home if waiver services are needed.

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

a) Preserve Housing for People Entering Nursing Homes

People who go into nursing homes, with Medi-Cal payment, have to turn over some of their income as a share of cost (SOC) if their income exceeds certain levels, and depending on whether there is a spouse living in the family home. Federal Medicaid law allows an alternative—people who intend to return home can use that SOC money to maintain their home.

Federal law allows the states to set their own standards for the amount of the allowance. California allows only $209 to maintain a home. Many other states have a more generous allowance and a more flexible policy.

To qualify for the California Home Upkeep Allowance program: 1) a person must intend to return home within six months of the date they began living in the nursing home; 2) get a written medical statement from a doctor certifying they "will be able to" return home within six months rather than

the federal standard of “may” go home; 3) a spouse or family is not living in the home; and 4) the home is being maintained for the person’s return.

Proposals:

1. Raise the Home Upkeep Allowance to the highest possible amount, such as the SSI standard.[3] This means that a person could retain up to the current SSI grant award for use in the Home Upkeep Allowance.
2. Conform to federal standards that allow for the likelihood and intention of returning home rather than requiring certainty that the individual will return home within six months.

b) School District Residence for Unconserved Adults

Current law requires that the school district responsible for providing special education services to an unconserved adult upon reaching age 18 remains the last district of residence. Often this is the parent’s district of residence. Exceptions are made when the last district of residence is the student’s placement at a group home, family home or foster home subject to placement by the court or a juvenile hall proceeding. Other exceptions are made with students under an interdistrict attendance agreement.

Unconserved adult students who reside in a different school district than their parents and live in a group home or other home arrangement and who are not placed by the courts face moving back to their parent’s district to continue to receive educational services; or file for due process to require the parent’s district of residence to fund the current placement.[4]

Proposal:

1. Work on a solution that would carve out an exception and permit an unconserved adult residing in a school district other than his or her parents to stay in the student’s current educational placement, or choose to move to another district of student’s choosing.

Footnote 3: **SSI amounts for 2015:** The monthly maximum Federal amounts for 2015 are $733 for an eligible individual, $1,100 for eligible couples.

Footnote 4: For example, those living in a supported living arrangement in a district different than their parent’s district

c) Notice of Action for Service Denial by the Department of Rehabilitation (DOR)

Current state and federal law require that the DOR shall send out a written notice when denying applicants initial eligibility for services or when it is determined that an eligible individual is no longer eligible for DOR services. The DOR does not typically provide written denial notices when denying a client's request for new or additional services not included in an Individualized Plan for Employment (IPE) and when the DOR decides to reduce or terminate a service. Without some documentation providing a date of denial, it is difficult for individuals to understand and exercise their appeal rights under current regulations.

Proposal:

1. We will work on an administrative or regulatory fix to address the problem so individuals can get the appropriate information, understand the issues, and exercise their appeal rights.

3. Increase access to benefits, services and health care

a) Fixing In Home Supportive Services (IHSS) overtime issues

Effective January 1, 2015, all IHSS workers are eligible for over-time pay for hours above 40 per week, because of new federal rules and state law. The state has budgeted a huge sum to pay overtime but is concerned that overtime costs may grow. To contain overtime costs, the legislature enacted controls on how many hours per week a provider can work (61-66), and imposed many new complex rules and responsibilities on consumers and providers. If a provider works for more than one consumer, it is the total hours worked which count towards overtime and the weekly limit. If the same provider performs the IHSS tasks and waiver personal care tasks, those hours are added together for overtime and the weekly limit. Beyond the burden of learning new timesheets, most IHSS consumers will not be harmed by the rules because they receive too few IHSS hours to trigger overtime. There are a few groups of people who are at risk of harm, including institutionalization, because they will not be able to find suitable providers to work the hours in excess of 61-66 and there are no exceptions to the work week limits.

The workweek limit creates problems for:

1) People on the NF/AH or IHO waiver, who use the same provider for their IHSS and waiver personal care, where that provider is working more than 66 hours a week (the new maximum). These people face another problem: the state is going to start enforcing a 12 hour a day cap, which is in the waiver but which the state has ignored for years.
2) Consumers whose provider works for more than one person (often two family members) on IHSS, where the provider is working a total of more than 61-66 hours a week (the new maximum). This can affect a parent who is taking care of two or more children who receive a lot of IHSS hours, a person taking care of a spouse and a child, an adult child taking care of two parents. The administration had been considering an exception allowing parents and grandparents to work more than 66 hours, but that exception is too narrow and their proposed daily limit of 12 hours does not work in every situation.
3) Some consumers who receive supported living services (SLS) because it appears that if an SLS worker also does IHSS work, the worker may be entitled to overtime based on the combined hours. While the DDS budget contained some money to pay overtime based only on SLS hours, no money was budgeted to pay for those additional aggregated hours. Because there is no guarantee of additional funds to pay that additional overtime, some SLS agencies are threatening to stop taking new clients, to discharge existing clients, and to limit their workers to 40 combined hours to avoid overtime. All of this can cause disruption to clients.

Proposal:

1. Find solutions to address the implementation issues noted above including an exception policy for the daily and workweek limits.

4. Eliminate abuse and neglect and improve quality of care

a) Law Enforcement Training and Mental Health Crisis

Law enforcement officers are often the first responders when people with mental health disabilities are in crisis. Without adequate training, officers may take inappropriate action resulting in death or serious injury to the person with the disability.

The Peace Officers Standards and Training Commission (POST) provides training to police officers. Officers are only required to receive 6 hours of

instructional time, covering all disabilities, out of 664 hours at basic training. They are not required to receive any additional or periodic refresher training in this area.

Proposal:

1. Work to increase and improve peace officer training. This could be done for example through a pilot program authorized by legislation or a taskforce force process engaging key stakeholders and law enforcement.

b) Timeliness of Department of Public Health Investigations

For years, there have been significant delays in the Department of Public Health (DPH) completing complaint investigations, most notably those involving grave and/or dangerous incidents resulting in death or serious injury. This fall, two reports by independent agencies support these findings.

- In August 2014, an external consulting group retained by DPH after coming under scrutiny in 2012 by the Senate issued a report finding DPH's failure to meet 12 of 18 CMS required performance indicators, including "untimely completion and low substantiation of complaint/incident investigations."

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

Proposal:

1. The proposal would require DPH to complete complaint investigations and publish findings within established timeframes, with more critical incidents (those involving death or serious injury) receiving priority and establishing timelines for Class A (120 days) and AA citations (90 days).[5]

5. Improve the quality of care and treatment in facilities and protect rights, while working towards the goal of returning to the community.

a. Restraint & Seclusion Use in Community Care Facilities

A 2003 DRC sponsored bill [SB 130, Chesbro] established minimal uniform standards for the use of behavioral restraint and seclusion in health care and residential settings in Health and Safety Code §1180. Data collection and critical incident reporting to the P&A was limited to state facilities, due to funding concerns.

Current regulations pertaining to use of restraint and seclusion in community care facilities are outdated. In 2008-2009, the Department of Social Services convened a stakeholder group to bring applicable regulations into compliance with Health and Safety Code §1180. The final revisions recommended by the stakeholder group have never been published for comment or implemented. One recent article identifies concerns about behavioral restraint in community settings including one story involving the death of a young man in a California group home. http://100r.org/2014/10/terminal-restraint-disabled-adults-killed-when-caretakers-pile-on/.

DDS has created new models of service for individuals moving from state institutions to the community, which include enhanced behavior homes. Some of which have delayed egress or secure perimeter. There are no restrictions on the use of seclusion and restraint in these.

Footnote 5: **Class AA** citations involve incidents with a direct proximate cause of death of a patient or resident. **Class A** citations involve incidents either presenting (1) imminent danger that death or serious harm would result to a patient or resident; or (2) substantial probability that death or serious physical hard would result to a patient or resident.

Proposal:

1. This proposal would require community care facilities to collect and publish data on the use of behavioral restraint or seclusion. It would also require these facilities to report to DRC serious injuries and deaths related to the use of restraint or seclusion. To prevent abuse and neglect, the proposal could also include other restrictions on the use of seclusion and restraint consistent with current best practices, including prohibiting prone restraint, limiting the use of restraint and seclusion to circumstances when an individual's behavior poses an imminent risk of serious physical harm, and requiring staff training.

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 2015 are: mental health commitment statutes and enforcement of access laws, to ensure attempts to change these laws do not erode rights.