

There Should Be a Law Report 2023

3rd Annual Contest Results



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Nothing About Us Without Us...

Executive Summary

This is the State Council on Developmental Disabilities (SCDD) 3rd annual There Should Be a Law contest. The contest provides persons with intellectual and developmental disabilities (I/DD) a unique forum to talk about the issues and challenges they are experiencing and an opportunity to provide their recommendations. Indeed, it is a report “by us for us.”

It has been 33 years since Americans with Disabilities Act was enacted and though there have been some strides towards creating equal access to opportunities, progress has been slow. There remains much work to be done to improve the lives of people with I/DD. It is our hope this direct feedback from the I/DD community encourages members of the California Legislature and their staff to investigate issues and champion solutions.

The issues have been categorized by policy areas that include employment, education, housing, transportation, safety, and services.

Terms Defined:

Family Advocate: Family member who advocates for a relative with an intellectual and/or developmental disability.

Self-Advocate: Person with an intellectual and/or developmental disability, advocates for oneself.

Service Provider: individuals or agencies who provide services to persons with I/DD.

Professional: experts in any matter relating to the needs of the I/DD community.

Mental Health (Human Services)

Submission 1. Self-Advocate

ISSUE: People with mental-health conditions, in particular children, who have aggressive behaviors as a symptom of their condition, have very little help and support. Parents are left with very little options. They feel they have no place to turn to for help. Psychologists and psychiatrists can offer some help, but if a child needs a step-up in care or more intensive treatment, there is no place to go as higher outpatient or inpatient. Inpatient places cater to older teenagers and not specifically children with aggressive behaviors. Most seem to cater to depression, anorexia or bulimia, or substance abuse. Aggressive behavior is not an area of focus. The outpatient facilities are the same way: older teens and those conditions listed above. In fact, aggressive children are most of the time turned away from these outpatient centers because they could be a threat to the other participants. There are not enough beds in hospitals. I have been told children and parents must wait for days in emergency

rooms for a bed somewhere and only in more serious cases. I have been told by the Orange County CAT (mental health emergency team) that they only come when parents feel either their life or the child's life is at risk. In other words, if they feel their child is suicidal or actually able to kill them. Other than that, they advise parents to call the police on their children!

So, if a child with mental health who is not improving with ABA at home or other forms of therapy, has a crisis involving aggressive behavior that is not egregious enough to qualify for CAT, then there is no alternative except to call the police, which is not most times trained to deal with mental health crisis.

RECOMMENDATION:

- create centers with wrap around care set up for all children with aggressive behaviors.
- insurance companies to fund those services in full or at very little cost to parents.
- for there to be a higher monetary reimbursement to mental care providers by insurance companies so there is an incentive to providers to accept insurance.
- these centers can offer both outpatient and inpatient care to younger children and pre-teens with aggressive behaviors as their most predominant issue.
- that they can receive intensive therapy at these centers with psychological and psychiatric care on a regular basis.
- that these kids are not shunned away by providers and centers and are dealt with more compassion, instead of having to resort to law enforcement.

Submission 2. Family Member

ISSUE: available resources, support, programs, and fund for services for children with mental/behavioral health issues.

RECOMMENDATION: consistent and open to public sources and information.

Human Services

Submission 1. Family advocate

ISSUE: Families have easier access to caregivers or agencies.

RECOMMENDATION: That state will pay competitive wages to care givers that have training in protective supervision.

Submission 2. Family Advocate

ISSUE: A shared database between all agencies that help children with disabilities so they can connect and help families efficiently.

RECOMMENDATION: A database that everyone can have access to.

Submission 3. Self-Advocate

ISSUE: Help all Social Workers/Service Coordinators/parents/professionals have background training on IEP's, Section 504 Plans, navigating the special education system and various services that parents must fight for.

RECOMMENDATION: Have a mandatory training to educate social workers from all agencies on what parents go through when a child has been diagnosed with a disability, train them on learning how to navigate the special education process, how to attain achievable services such as SSI, IHSS, conservatorship, and learn how to help the needs of families but the course must be a mandatory training.

Submission 4. Professional

ISSUE: employees who have disabilities are not eligible for regional center services

RECOMMENDATION: Make attendant care a paid benefit for employees who have disabilities who are not eligible for regional center services.

Submission 5. Family Advocate (from Spanish)

ISSUE: There are issues with the self-determination program (SDP), FMS (financial management services) and regional centers.

RECOMMENDATION: To impose sanctions on FMS providers and regional centers to keep them accountable for not providing services on time to clients. For clients to have the right to select the regional center they want if that regional center fails to provide services needed to client.

Background Note: SDP allows clients with I/DD to select who/where they want to seek services (as opposed to traditional services offered by regional centers). Clients are given a budget for the selection of services. FMS are vendored by regional centers to pay for the services the clients have selected to hire. Though clients like having freedom of choice to select services, the issue is paying for these services via FMS. A lot of times, client services are cancelled due to FMS not paying the service providers on time. For example, clients must stop going to college or going to work because they do not have the necessary support services to continue --because those providing their services are not being paid on time. FMS is reimbursed by the regional centers and claim they are not reimbursed on time for services, which then affects the client's ability to receive services.

See FMS: <https://www.altaregional.org/post/financial-management-service-fms>.

Submission 6. Self -Advocate

ISSUE: everybody with special needs a therapy dog, that's so important for us.

RECOMMENDATION: help get dogs for people with special needs.

Submission 7. Family Advocate

ISSUE: I would like to solve the problem of parents (caregivers) being forced to have respite hours completed at their home. Parents do not have to stay at home to have respite hours, so why can't hours be completed with someone that does not want to go to your home. For example, a person I

trust with my child should be able to supervise my child at their home or another location, if they do not want to watch my child at my house. If respite is supposed to be able to be beneficial to caregivers, why can't caregivers choose to have their special needs child watched at a family member's home or another person's home, who they trust with their child.

RECOMMENDATION: Caregivers should be able to choose to have respite hours completed in their home or at another person's home or location. Since the caregiver does not have to be at home during respite hours.

Submission 8. Professional

ISSUE: Not enough RNs and LVNs to care for the medically vulnerable population. I have signed up dozens of RNs and LVNs over the last 28 years to work as individual nurse providers and regional center has paid me as a consultant to do this, but I am getting ready to retire and there should be a clear-cut way for a nurse to be able to sign up on the DHCS web site. There are no clear instructions or clear outline of experience requirements on how a nurse can do this on their own. (For example: I have had providers write in their resume that they worked 30 hours a week for 3 years and been turned down due to not multiplying it out to show that it equals 3,120 hours.)

RECOMMENDATION: There should be a selection for RN and LVN on the DHCS web page naming all provider types. You should be able to click on the RN or LVN and find clear concise instruction on which forms to fill out and the experience required for the RN and LVN. There needs to be clear instruction on the next steps to take in signing up for electronic billing, etc.

Submission 9. Professional

ISSUE: I find that local regional centers are not doing enough to promote state-funded services, so many people with IDD miss out on the opportunity for day programs, therapeutic services, transportation, employment supports, etc., as funded by regional centers (RCs). Only 18% of people in CA receive services from agencies, and I believe that number would be much higher if more people knew about Lanterman and RCs.

RECOMMENDATION: Mandate that a regional center representative present available services for qualifying individuals at every student's first IEP and first transition planning meeting (~age 16).

Submission 10. Self-Advocate

ISSUE: Having to somehow prove that patients who have developmental or other disabilities need certain drugs to deal with disability complications.

RECOMMENDATION: Require prescription drug coverage for all medications without prior authorization if a patient has been prescribed a particular medication for than five years.

Submission 11. Self-Advocate

ISSUE: A lack of adult doctors who have more than adequate knowledge of developmental disabilities beyond pediatric healthcare.

RECOMMENDATION: The solution is to combine pediatric and adult medicine into a new specialty that is called adult developmental and behavioral medicine. It would combine the best of developmental disability and behavioral health care with adult medicine to provide more effective healthcare for adults who have developmental disabilities or dual diagnoses.

Submission 12. Self-Advocate

ISSUE: The complexities of getting durable medical equipment and assistive technology repaired.

RECOMMENDATION: Simplify the process of getting durable medical equipment and assistive technology repaired.

Submission 13. Self-Advocate

ISSUE: Oral Care

RECOMMENDATION: Overall support for oral care for people with disabilities.

Submission 14. Family Advocate

ISSUE/RECOMMENDATION: We should have a developmental checklist card similar to a vaccine card, so children can be identified early if they have any special needs and receive services as soon as possible.

Education

Submission 1. Family Member

ISSUE: Focusing on neutral communication, representation, and advocacy for children in the school system. Also, another idea is to have funding for workshops for special needs families.

RECOMMENDATION: To create an advocate position in the school system for each school with a special needs program that is not hired by or representing the school (3rd party). A neutral position that focuses on the needs of the students and communicates and implements ideas with the school.

For the workshops, I would fund the state council so that they can grant workshops to our local community, supporting families and giving them tools to succeed, especially in the area of special needs.

Submission 2. Family Advocate (from Spanish)

ISSUE: Students with nonverbal skills experience behavioral problems at school. Police do not know how to respond to I/DD students who are nonverbal.

RECOMMENDATION: Create a program to train police or school staff on how to respond to nonverbal students experiencing a crisis.

Submission 3. Professional

ISSUE: Increasingly, districts across the state are misinterpreting IDEA's provision for Alternate Achievement Standards as an endorsement of an "alternate curriculum" for students with developmental disabilities. The separate pre-packaged curricula used most widely in CA have been demonstrated to be poorly aligned to Common Core standards (Taub et al, 2019) and do not support high quality literacy instruction for students with extensive support needs. Further, the use of these curricula reinforces the "separateness" of special education settings and the idea that these students should learn something inherently different from students without IEPs on the "core curriculum." Thus, the problem I hope to address is the use of alternative curricula as a systemic barrier to inclusive education for students with intellectual and developmental disabilities.

RECOMMENDATION: All students are general education students first, and all students should have access to the core curriculum, with supports and services outlined in their IEP. I propose that special education programs be required to utilize the same core curricula adopted within a student's school/district and that any specialized curricula adopted for use in special education settings be subject to the same rigorous adoption process required for general education curricula adoptions. Curriculum adoption processes should include considerations for accessibility for all students, including those with extensive support needs, and committees should include members familiar with evidence based practices related to all populations to be served by the curricula. Holding state curriculum adoption committees accountable to all students and emphasizing access to the core curriculum for students with disabilities ensures that procedures already outlined in the California Education Code are applied equitably to all students in the state. In addition, adoption of more specialized curricula within districts should take place only when there has been a demonstration that the current general education curricula cannot be adequately adjusted to meet the unique needs of students served. This can be considered within a student's IEP rather than a global adoption based on student eligibility labels. Given the significant evidence base for general education curriculum access for students with extensive support needs, this should be a high bar.

Submission 4. Family Advocate

ISSUE: There is currently no generic resource for special education advocacy, which is leaving many people with the inability to pay for an advocate, have a knowledgeable person attend an IEP with them, have someone review an IEP without worrying about funds.

RECOMMENDATION: Either create a generic resource where special education advocacy can be a service offered to families through special education funds or replicate the FDLRC service (which is an extremely competitive program for law students with only 20 being accepted annually, and in extremely high demand) at other regional centers.

Submission 5. Self-Advocate

ISSUE: The need for more services for college students who have disabilities who do and do not live on campus, especially if they need help with their wheelchairs.

RECOMMENDATION: Have wheelchair repair and other services available for wheelchair and mobility aid using students on all college campuses. Doing this will help students by providing them with a more effective way of getting their wheelchair repaired without having to miss school unnecessarily.

Submission 6. Self-Advocate

ISSUE: A lack of adequate funding disabled students attending 4-year colleges who need to use attendant services.

RECOMMENDATION: Increase funding for the disabled students' programs to include more funding for 24-hour attendants for wheelchair using college students who need them.

Housing

Submission 1. Self-Advocate

ISSUE: Housing has been very difficult. Due to inflation going up. It is very hard to get the things that I need to survive after I pay all my bills. For example, I must pick what medication to pay for and what ones I can go without. Even though I need all my medication to live I must pick which ones to get.

RECOMMENDATION: I have a solution that could help with all my peers and myself. It is that all the regional centers that get grants to build or buy homes or apartments for the regional center clients to live in that are struggling to live. We would be in our communities and be able to support each other in our communities.

Submission 2. Family Advocate

ISSUE: Housing and safety vulnerability to our kids when they become adults.

RECOMMENDATION: There are very few supporting solutions for our kids once they become adults and enter in the system. I feel we can do much more for the disable young adults who are more at risk once they reach adulthood.

Submission 3. Family Advocate

ISSUE: Supportive Housing

RECOMMENDATION: Building tiny homes around a central service delivery hub. The service hub would include social, nutrition, and career planning centers and it would ideally be located within a public transit center.

Submission 4. Self-Advocate

ISSUE: Requiring people who have developmental, intellectual or any other disability to have a credit or employment history to qualify for renting an apartment or house.

RECOMMENDATION: Accept other forms of consistent income to rent apartments or homes.

Submission 5. Self-Advocate

ISSUE: A lack of housing for people who also need attendant care that isn't institutional.

RECOMMENDATION: Having housing available with many attendant care options provided.

Submission 6. Self-Advocate

ISSUE: Increased demand for independent living and supported living providers in and beyond Sacramento County.

RECOMMENDATION: Tell more people about the benefits of increased access to independent and supported living services for adults who have developmental and intellectual disabilities.

Submission 7. Self-Advocate

ISSUE: Accessible housing shortage.

RECOMMENDATION: Increase the amount of affordable housing available that is accessible for people with developmental disabilities and intellectual disabilities.

Civil Rights

Submission 1. Self-Advocate

ISSUE: The lack of disability specific exercise centers that are available and affordable for people who have disabilities in California. There is one in Sacramento with Bay Area locations, but it is for people who can afford to pay privately.

RECOMMENDATION: Encourage companies that are disability specific exercise centers to use and accept a variety payment method that don't involve medical insurance companies because they can (and will) limit the number of times that someone can visit the center or make rules regarding the progress of someone who visits the center.

Submission 2. Self-Advocate

ISSUE: The lack of wheelchair accessible hotel shuttles and limousines for business travelers and tourists who have disabilities and want to get around a town and not rely on public transportation services that require visitors to temporarily register to use Paratransit services for short travel period for example people who come to Sacramento for a day and a half for a meeting.

RECOMMENDATION: Require big chain hotels and limousine companies to retrofit their buses and limousine buses with lifts to accommodate mobility aids for passengers who have disabilities

Submission 3. Family Advocate

ISSUE: Future planning for disabled people. Right now, how I understand the process of getting Special Needs Trusts (SNT) and the financial planning with it set up, the parents/caregivers of the disabled person are totally "on the hook" for paying for this process. How things are being explained to me is that regional center/DDS (whichever government agency) will pay the difference beyond what an "abled" person would pay for the same thing. An Estate Trust and a Special Needs Trust are not nearly the same thing. They just coincidentally have the word "Trust" in their respective titles. An abled person would never need a Special Needs Trust. An Estate Trust would not be able to meet the needs of the Disabled Person after their caregivers are not able to take care of them. So, DDS/Regional Center should be able to cover the initial cost of the legal side of this process.

RECOMMENDATION: My solution to this problem is to require that all regional center persons served have the LEGAL side of the Special Needs Trust set up as a part of the initial intake process and the education/guidance/referral to the Financial Planner to get the funding started. I am NOT asking that the DDS/Regional Center FUND the SNT. If this process is started when the person served/client/participant is still supported, the money savings for DDS/state of California will be substantial on the "aged" end when the caregivers are no longer able to take care of the disabled person.

Submission 4. Family Advocate

ISSUE: Safety and death of our kids.

RECOMMENDATION: The solution will be to make all the cities certified in autism awareness and other disabilities, teach our kids since kindergarten that we are all different with the same value.

Submission 5. Professional

ISSUE: The inadequate attention given to Fetal Alcohol Spectrum Disorders, the largest preventable cause of developmental disabilities.

RECOMMENDATION: An annual report by all Regional Councils of the total number of parents and caretakers who presented children with indications of FASD and those enrolled in Regional Council and Early Start caseloads, including county-level data on children with FASD identified by Plans of Safe Care as required by federal legislation and special education identification in the new category of FASD added in 2022 legislation. With an estimated 300,000 students in California K-12 schools affected by FASD, schools should be supportive, as well as thousands of parents and caretakers of these children.

Submission 6. Family Advocate

ISSUE: Adults with disabilities who receive child support (CS) should be able to get their SSI as well as Adult Disabled Child Support. Currently they lose 1dollar SSI for every \$1 in CS they get. If there was a law that said Family Court Judges could order the CS per the SSA Special Needs Trust exception laws, the kids to get both. (CAL Able account only works if the CS is low)

RECOMMENDATION: Make a law that specifically says California Superior Court family court judges can order child support per SSA special needs. Trust exceptions. Some other states have these laws.

Submission 7. Self-Advocate

ISSUE: Having a lack of places for younger people who have developmental disabilities to go on the weekends besides self-advocacy meetings.

RECOMMENDATION: Create community centers for people with disabilities and without disabilities.

Submission 8. Self-Advocate

ISSUE: A lack of major hotel chains having almost no wheelchair accessible shuttles for travelers going to and from airports.

RECOMMENDATION: Encourage most hotel chains to offer wheelchair accessible airport shuttle services for travelers who use mobility devices or who have visible or non-visible disabilities.

Submission 9. Professional

ISSUE: Community activities, events, and programs are divided into age groups and people with disabilities.

RECOMMENDATION: Integrated community events, activities, and programs.

Employment

Submission 1. Self-Advocate

ISSUE: Decrease the 85% underemployment and unemployment rate of autistic adults.

RECOMMENDATION: Increase the funding available to a research group researching issues related to neurodiversity and employment by proposing a partnership involving the Stanford Neurodiversity Project and all the UC and CSU schools. The schools will receive funding from the state to sign up as corporate partners with the Stanford Neurodiversity Project through the SNP Corporate Partnership Program. Any interested employers at the schools wanting to hire neurodivergent students will receive training from the Stanford Neurodiversity Project to make their workplaces more inclusive of neurodivergent individuals. This partnership will allow neurodivergent individuals to gain work experience while enrolled as college students. The partnership costs vary depending on the level of corporate partnership that universities select. The partnership is renewable annually, and universities can decide whether they want to continue their participation.

Submission 2. Professional

ISSUE: How to support a person with disabilities to maintain and advance in their employment. Once a person is hired, the individual may struggle with performance due to needed accommodations. All companies assume the individual should know what kind of accommodation they will need. Advancement in a company for people with disabilities does not have any development support.

RECOMMENDATION: a person with disabilities should have full access to ADA support provided by the company which includes leadership development, environmental accessibility, and full access to information they can understand.

Submission 3. Professional

ISSUE: The "honorarium" requirement by statute limits all state board, committee, and council members to \$100/day for state business as a member of that board/committee/council. 1) this statute is 25+ years old and has never increased in amount. 2) The State Council self-advocates are uniquely situated that they perform other state council business state and nationwide with this very limited compensation for their time. I understand the need to make sure state members are not profiting from state business, but self-advocates usually are of limited income and seek only fair compensation for their time. The same statute covers doctors on the medical board and volunteers of many advocacy councils.

RECOMMENDATION: 1) update the \$100 a day to match inflation for all committees/boards/councils. 2) consider a self-advocate carve out or exception to allow additional compensation in certain circumstances.

Submission 4. Professional

ISSUE: Employment for people with or without disabilities is a challenge. This starts with the first step in seeking employment which is handing in or submitting your resume. People are judged and based on that information the seeker may or may not get a phone call to schedule an interview. Next is the interview of answering questions from their standard company interview questionnaire and then you may or may not get a callback. If you're hired for a position, you have experience in you get the universal and company standard process of training. After that, it's the standard probation period guidelines and company standards. Most of all, businesses will not hire you if you need a job coach but can't have one; the length of employment for that person is going to be short. The individualized employment choice is limited to a work program if you need a job coach. Businesses don't invest in people. They don't take the time to teach at their level how to thrive in the company or provide support for growth or develop a plan so a person can learn how to effectively do the job successfully.

RECOMMENDATION: Inclusive leadership and systematic change. Promote inclusive practices with a systemic change for person-centered hiring, training, and development of people so they can thrive in life.

Safety

Submission 1. Self-Advocate

ISSUE: A lack of disability access for temporary tiny home housing for use after a natural disaster.

RECOMMENDATION: Give people who have been evacuated from their homes vouchers that they can use for their own accessible housing instead of the FEMA tiny homes that are inaccessible.

Submission 2. Self-Advocate

ISSUE: A lack of accessibility for evacuation of hotels (especially small hotel chain type hotels.) during natural disasters or minor flooding.

RECOMMENDATION: Require all hotels regardless of type or price category to have wheelchairs that can accommodate people who have disabilities and can be used for efficient evacuation during an emergency.

Transportation

Submission 1. Self-Advocate

ISSUE: That of getting more Punch Passes, and bus passes to those who are regional center consumers, even those like me, who are in the Self-Determination Program (SDP).

RECOMMENDATION: We need to see that more Punch Passes, and bus passes be given monthly to those who are regional center consumers, even those like myself, who are in SDP, on their IPP.

Submission 2. Self-Advocate

ISSUE: A lack of wheelchair accessible back-up transportation.

RECOMMENDATION: Create a system of backup transportation providers.

Federal Policy: SSA

Submission 1. Family Advocate

ISSUE: Many issues regarding Social Security.

RECOMMENDATION: changing the current rules to allow disabled persons to better themselves without the fear of losing all their benefits. Which could potentially save the government millions of dollars. Alleviating the masses of paperwork required, hence alleviating the workload at the Social Security offices. Creating separate departments at Social Security so you can speak to someone knowledgeable in the area of your needs @ Social Security, SDI, SSDI, Etc.