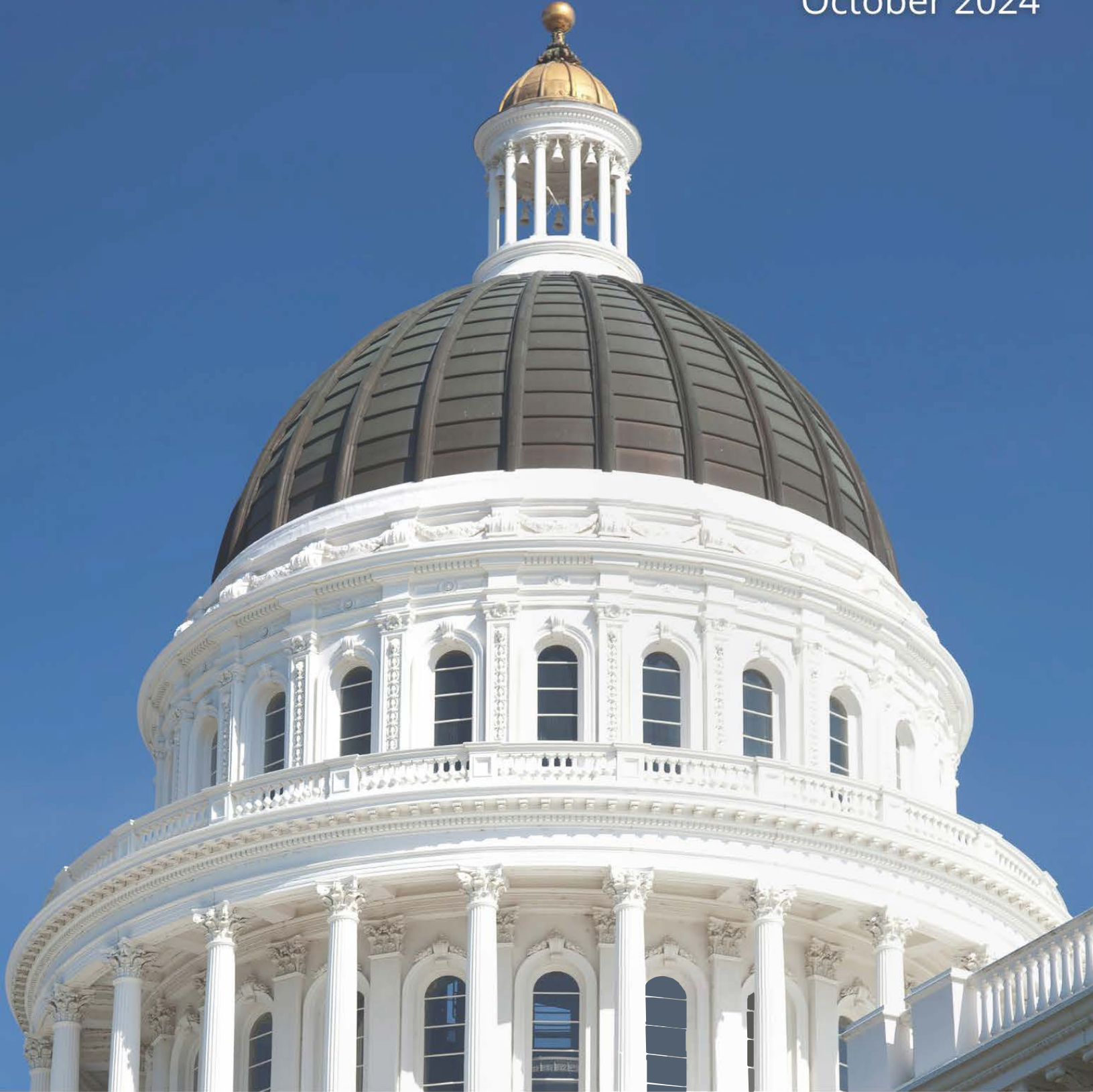


# 4th Annual There Should Be a Law Contest Report

October 2024



Prepared by:

**The California State Council on  
Developmental Disabilities**



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# There Should Be a Law Contest, Report 2024

## Voices from the Community

This is the State Council on Developmental Disabilities (SCDD) 4th annual *There Should Be a Law* contest report. The contest is a unique platform that provides persons with intellectual and developmental disabilities (I/DD) an opportunity to have a conversation with the public and law makers—to talk about their experiences, share their frustrations and challenges-- but also empowers them with a role to actively seek solutions to improve the quality level of their lives. SCDD is honored to advocate for the I/DD community and to provide a vehicle where persons with I/DD can use their voices to advocate for themselves.

The issues and recommendations are presented in the voice of the person who submitted it. Submissions have been categorized by policy areas that include public safety (12 ideas), health (14 ideas), human services (24 ideas), education (16 ideas), employment (6 ideas), housing (5 ideas), transportation (5 ideas), civil rights (3 ideas), and federal matters (4 ideas). SCDD presents the ideas without endorsement.

## Equity/Justice in Inclusion

Asked in September 2024, we received close to 100 bill idea submissions on topics in nine different areas. One thing is clear-- much work remains to be done to improve the quality of lives of persons with I/DD and their families. For those with lived experience or others that are caring for a loved one with I/DD, progress has not come fast enough. We have learned to become warriors because every day we must fight for what we and our loved ones need. But to truly have a meaningful life, we cannot lack essential supports and services nor lack the same opportunities that others without I/DD have. This means we have the appropriate level of supports at exactly the time we need them. It means, we have the same quality education and the same opportunities for education. It also means we have the same opportunities for competitive integrated employment. For there to be equity/justice, there must be inclusion. For there to be progress, there must be inclusion for the I/DD community in *all* things. That is why this year our policy priorities will focus on *Equity/Justice in Inclusion*.

## Calling on Champions

Meaningful change does not happen overnight nor without the help from others. The I/DD community cannot see progress towards inclusion without partners willing to advocate. We will need partners and champions with a willingness to join in the advocacy and help tackle challenges the community asks for. We share their experiences and encourage people with I/DD, family members, lawmakers, and partners to work together to identify solutions.

## 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 who 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.

## Public Safety

### **Public Safety Submission 1. Arrest Pedophiles (Self-Advocate)**

**ISSUE:** Protection of people with I/DD against pedophiles we need to do more in this area.

**RECOMMENDATION:** arrest all pedophiles keep them locked up for life.

### **Public Safety Submission 2. Train on Police Interactions (Family Advocate)**

**ISSUE:** (translated from Spanish) Our community has seen many accidents and tragedies in the television news in recent years. Parents, families, and colleagues have all experienced this. People with intellectual disabilities, who have non-verbal behavioral crises, have lost their lives at the hands of the police. This situation is alarming and urgent, we must take action. We as parents are very concerned and are asking for a solution to this problem. PLEASE.

**RECOMMENDATION:** All Special Education students who have training with the police, should have their transition plan to adulthood ready before they leave High School. This training would be essential, and everything should be implemented as a goal in each student's Individualized Education Program (IEP). Include a mandatory section in the IEP such as their Rights IN A POLICY

### **Public Safety Submission 3. Train Police (Professional)**

**ISSUE:** Law Enforcement negative interactions with persons with developmental and intellectual disabilities.

**RECOMMENDATION:** All levels of Law Enforcement, including Police, Sheriff, CHP, Correctional and Detention Officers, etc. should be required to take classes on interacting with persons with disabilities. This should not be a "one and done" class, but should be a reoccurring program (quarterly, every 6 months, etc.) that includes persons with I/DD, their family members and other people with disabilities presenting what their experience with law enforcement has been and how any negative interaction with law enforcement could have been less devastating had the officers recognized they were working with someone with a disability...and changed their procedures to accommodate the person with a disability.

### **Public Safety Submission 4. Better Disaster Planning (Family Advocate)**

**ISSUE:** At the moment, disaster planning is done by those with limited experience working with people with disabilities or who are touched by the Access and Functional Needs (AFN) community. Training often leaves out our demographics or it's an "add-on" after the fact but not embedded into the initial strategies. Most importantly, community members do not get to give input on shortfalls, scarcity of resources, or even the planning of how they will be helped. My goal would be for the Office of Emergency Services (OES), from the state down to each county and city, to hold community forums to share and hear from their communities.

**RECOMMENDATION:** The California State OES would oversee guidelines that mandate that all OES hold community forums—in public and virtually—they must involve community participation. These events must work with stakeholder organizations from all communities that would be impacted by a disaster to engage community members in attending and letting their voices be heard. These events could be about sharing plans and getting feedback. They can be about new rollouts, possible programs, or purely educational - but there must always be room for input from the community, and it must be meaningful.

### **Public Safety Submission 5. Jail Diversion (Self-Advocate)**

**ISSUE:** People with developmental disabilities/mental health issues going to jail/prison. This can be very frightening to them and as scary as if someone was going to physically harm them.

**RECOMMENDATION:** If someone with a developmental disability or mental health issue is really struggling emotionally send them to a mental hospital/ hospital when they start acting out and won't calm down, not jail.

### **Public Safety Submission 6. Scam Alerts (Family Member)**

**ISSUE:** Special Banking designation for all accounts of special needs people. A safety alert “of some kind” to prevent SCAM-artists from preying on and taking advantage of the accounts of special people.

**RECOMMENDATION:** I think a type of CODE associated with the account that transferred the call (scammer) / fraudulent c ‘banker’ to a REAL banker.

### **Public Safety Submission 7. Fingerprint Registry (Family Advocate)**

**ISSUE:** When you need to do anything requiring to have a law-abiding person be fingerprinted for employment or for volunteering to serve those who are disabled (or not). I am a law-abiding citizen and have been fingerprinted so many times I have lost count. Why can’t “good” fingerprints be stored and shared like they do for “the bad” guys?

**RECOMMENDATION:** An adult who is fingerprinted should be able to have their prints stored and shared. It is unnecessary for one to pay repeatedly to be fingerprinted once you have done it. Maybe it could be good for a certain amount of time.

### **Public Safety Submission 8. Train Police (Family Advocate)**

**ISSUE:** Volatile DUI arrests for autistic adults. Training and new laws for not understanding commands as opposed to punishment. There are no special accommodations for disabled adults that do not understand laws or Miranda rights.

**RECOMMENDATION:** More training for police officers. Classes from regional to help clients how to behave while dealing with police.

### **Public Safety Submission 9. Registry for Officers (Family Advocate)**

**ISSUE:** When police officers are called to a situation involving someone with a developmental disorder, a lack of understanding or information about the individual’s condition can lead to tragic outcomes. For instance, officers may misinterpret the person’s behavior or communication style, which can result in unintended harm or fatal incidents.

**RECOMMENDATION:** Implementing a state-level registry system for law enforcement could provide officers with advance information about locations and individuals with developmental disorders. This would allow officers to be better prepared and informed before arriving at the scene. Additionally, offering training on developmental disorders can further enhance their understanding and lead to safer, more effective interactions.

### **Public Safety Submission 10. Disability Identification (Family Advocate)**

**ISSUE:** A better way to identify special needs in professional situations. i.e. at the hospital, with interactions with police. Our any place where it would bring a more understanding interaction.

**RECOMMENDATION:** My solution. Have a (optional) note on California identification cards that there is a disability so when they're in contact with hospitals or police officers they can see that the person is disabled. It may help professionals better help the disabled persons.

### **Public Safety Submission 11. Online Safety Training (Family Advocate)**

**ISSUE:** There should be a law to help protect and educate persons with developmental disabilities from online predators and scammers. Predators purposely target neurodiverse individuals because they know they don't have the "filter" to weed out scams and others trying to gather their trust and information. They also know that the developmentally disabled person wants relations and friends.

**RECOMMENDATION:** Makes laws to enable developmentally disabled and neurodiverse community with workshops, online tutorials and mandatory classes in middle and high school and other programs geared to them about online safety. Have resources readily available for our community. Hold companies accountable for putting in safety features to help protect the user.

### **Public Safety Submission 12. Stop Fiduciary Abuse (Professional)**

**ISSUE:** I want to solve the problem of fiduciary abuse crimes against the DD and ID population, not being prosecuted and there being no consequence or deterrent from ongoing abuse.

**RECOMMENDATION:** Fiduciary Abuse is often perpetrated by someone close to the victim, such as a family member or caregiver, whom they depend on. Because of this, when criminal reports and/or APS reports are filed, and when the investigation takes place, the victim is afraid of getting their abuser in trouble, and thus will often resort to, "its ok, it was a misunderstanding; they didn't mean to; etc..." and they are afraid of how it may affect their living arrangement, care, and other family supports. I envision the approach would be much like the domestic violence laws and victim supports are in place now.

## Health

### **Health Submission 1. EMUP Designation for Persons with I/DD (Professional)**

**ISSUE:** Persons with IDD are a population that is underserved and found to have health disparities.

In 2023, the National Institutes of Health (NIH) designated people with disabilities as a population with health disparities. NIH released notice of funding opportunities calling for research applications focused on novel and innovative approaches and interventions that address the intersecting impact of disability, race and ethnicity, and socioeconomic status on healthcare access and health outcomes. By California designating IDD as an EMUP, it has the ability to incentivize clinicians/physicians to specialize in the healthcare needs of those with IDD and increase overall access to providers.

**RECOMMENDATION:** Designate persons with IDD to be as an “Exceptional Medically Underserved Population” (EMUP) in California.

What California designation of IDD as an EMUP would do:

- Expansion of physician and dentist training in the care of persons with IDD, funding for expanded prevention and screening;
- Scholarship or loan repayment incentives for clinicians to serve this population;
- Community health center grants to provide care;
- Prioritization in research of issues affecting people with IDD; and
- Inclusion of people with IDD in clinical trials—particularly in later-stage therapeutic research.

### **Health Submission 2. Health Insurance Advocacy (Self-Advocate)**

**ISSUE:** Families struggle navigating health insurance processes. Each family has to become an insurance expert while trying to manage caretaking.

**RECOMMENDATION:** If DDS is the payer of the last resort, they must help exhaust those resources.

Create a Health Insurance Advocacy unit within each regional center, which helps send insurance requests/appeals/tracks denial letters on behalf of consumers/families. This covers young families who are in the early years of adjusting to their child's disability and seeking intervention services. Coordinates with service coordinators. DDS must adequately fund these experts, and reimburse \$100,000 per position, and written in law measure for reimbursement to keep pace with inflation.



Each Health Insurance Company (including Medi-Cal) operating within the state must set up a direct lines and specialized representatives for the Regional Centers to call.

Having experts who understand the routine would streamline the process, and really improve the quality of life for families.

### **Health Submission 3. Respite Worker Give Lifesaving Help (Family Advocate)**

**ISSUE:** Respite Workers and other direct support staff being told they are not allowed to give clients lifesaving emergency medications, such as Epi-pens. Respite workers are not being informed they have the right to volunteer to give lifesaving pre-dosed medication and may be told information which makes their job feel at jeopardy if they chose to save the client's life.

**RECOMMENDATION:** Coordinate with the California Emergency Medical Services Authority and any other departments necessary to make the law CLEAR that respite workers (and all-over direct support workers employed to be) in a supervision role of a person with an ID/DD can volunteer to administer pre-dosed time sensitive layperson designed lifesaving medications such as Epi-Pens.

Workers must be informed of their rights to provide such medications, without risk to their jobs. "Save the client's life, over liability concerns" must be the creed. Form with signature for all workers informing them of their right to volunteer.

Change the insurance law to prevent Liability Insurance Companies from penalizing service agencies who have workers who volunteer to give lifesaving medications.

Look to following the legal path that the school took in the Education code to be exempt from California Code, Health, and Safety Code - HSC § 1797.197a.

### **Health Submission 4. Medical System Navigation (Family Advocate)**

**ISSUE:** Support navigating the medical system for adult regional center clients and their caregivers. Medical systems like Kaiser Permanente don't seem to be designed to assist members with developmental disability who can't advocate for themselves. Especially if they are non-verbal and have fear entering the medical office in person. It has been challenging to understand or know the polices to get IHSS forms signed for example. Or to even know if one's medical referral to a third party has been denied and get denial letter/email.

**RECOMMENDATION:** My solutions to get support in navigating the medical system is to be offered a "medical social worker" to help assist which steps to take for the regional center client / caregiver to have access to medical care and forms to be fill out. Also, to help solve challenges.

### **Health Submission 5. Stop Recertification (Family Advocate)**

**ISSUE:** County social services requires a re-certification for Medi-Cal benefits. Every year we have to request a DDS waiver to qualify. Our son was born with a genetic condition that will last his entire life Trisomy 21 Down Syndrome.

**RECOMMENDATION:** The solution to end yearly recertification to qualify for Medi-Cal services is to mark my son's condition T21 Down Syndrome as a lifelong condition that does not require recertification on a yearly basis for Medi-Cal and to have this as a federal recognition too.

This way we do not have to spend time filling out forms and waiver and speaking to many different people at social services to have a waiver provided. It is time consuming and wastes resources.

### **Health Submission 6. Need Life Insurance Options (Family Advocate)**

**ISSUE:** The lack of life insurance options to our disabled population. Trying to find life insurance is like finding a needle in the haystack!

**RECOMMENDATION:** Make insurance companies give options for life insurance to then disabled population.

### **Health Submission 7. Need Dental Providers (Family Advocate)**

**ISSUE:** Disabled people also need good dental services and coverage in special settings if they need to go under sedation for treatment do to the disability because the lack of service individuals end up having more severe dental problems.

**RECOMMENDATION:** We need better dental pay for services for disabled patients, so Doctors are willing to work with them and training to work with special needs.

### **Health Submission 8. Expand CalFresh Options (Professional)**

**ISSUE:** I would like to expand on the California Bill (SB 628) to allow the disabled, elderly, and those with medical conditions to be offered healthy meals by food delivery services such as Hello Fresh, Mom's Meals, factor, Home Chef, etc. As a vendor professional, I discovered that many disabled clients do not cook due to food insecurity, cost, or education on dietary needs. I believe that SB 628 could be expanded to include such services for individuals who have food insecurities. Hence, they would be able to have nutritious meals delivered daily to their homes, which would improve the obesity pandemic and chronic illnesses that relate to poor eating habits. Food is medicine; therefore, providing healthy sources directly to the client will serve to reduce other medical-related illnesses.

**RECOMMENDATION:** I believe in expanding on California Bill SB 628 to allow individuals who have food insecurities access to third-party health meal services under the Department of Social Services (DDS). This would enable Alta Regional Center Clients (ACRC) clients to gain more access to healthy prepared meals daily that can be covered by medical. Vulnerable populations such as people with disabilities need nutritional education as to how food is medicine. The client can quickly get a referral from durable medical equipment (DME) vendors who can be certified to provide a referral under a health and safety code (356-399). This would solve the client's need to have a caregiver who may not be fully aware of the client's dietary needs along with diet restrictions. Expanding on this bill, SB 628 would improve the delivery systems for food access. The third-party healthy meal services provider could have a tax break incentive by using ACRC DME-vented small businesses, which would be cost-effective for medical food programs such as Snap and CalAIMs, which currently have limited resources.

### **Health Submission 9. Dental School Training (Family Advocate)**

**ISSUE:** The total lack of dental care for ID/DD individuals of all ages.

**RECOMMENDATION:** Require Dental Schools to train dental students to work with this community. Require dental students with student loans to offer services to this community as part of their repayment plan. Require the California Dental licensing board to make a certain percentage of all licenses available ONLY if the certifications to work with our community are met. Make it a law that the IDD/DD community MUST be able to receive treatment by licensed/accredited/certificated dentist and hospitals. And that TREATMENT is always the goal.

### **Health Submission 10. Life-Supporting Equipment (Family Advocate)**

**ISSUE:** Individuals who rely on life-supporting equipment, like oxygen concentrators or suction machines, need uninterrupted access to these devices.

Currently, if the equipment breaks and was already purchased item, the provider doesn't replace it immediately. The patient's doctor must submit a new prescription and justification, which can take days to weeks to get insurance approval. During this time, the patient may need to be hospitalized, putting their health at risk.

**RECOMMENDATION:** A law should require service providers to offer temporary equipment immediately when life-supporting devices break. Insurance companies must fund this temporary equipment to ensure patients receive the necessary support without delay.

### **Health Submission 11. Specialized Waiting Rooms (Family Advocate)**

**ISSUE:** I am certain I can speak for the majority of the individuals that reside in this our lovey state of California when I say that the public health care system does not meet our expectations of reasonable wait time limits when it comes to attending appointments at our local clinics. Parents often attend appointments that they have been waiting for months and on top of that we have to wait in a waiting room for at times more than an hour. If you ever encounter an autistic child at a waiting room, you will see how their behavior is much different from a neurotypical child. You will also notice the behavior of a parent to an autistic child is also different. Waiting, excessive talking, lights, noise and expected to be seated can all be overstimulating and overwhelming for an autistic brain. There is also a concern for autistic individuals who elope. Eloping children can easily access automatic doors causing a safety concern. If you see an eloping child, you will most likely also see a parent running after them. As a parent to a special needs child, I am continuously worried about my child's safety not to mention how exhausting it can be to be in a waiting room running after my child for an hour while also supervising another child. Having no waiting rooms specifically for special needs individuals is a big problem for them and their families. While other parents discipline their child with words of 'stay seated' expecting that in return, other parents do not have that option. We both deserve to be in a space waiting for health care where we have a bit of tranquility and feel our children safe. Why should receiving health care have to be twice as hard for special needs families?

**RECOMMENDATION:** Specialized waiting rooms for special needs individuals. Every clinic should be responsible for providing a safe, low sensory, enclosed, quiet waiting area for special needs individuals and their families.

### **Health Submission 12. Follow Medi-Cal Policy (Professional)**

**ISSUE:** Medi-Cal Managed Care Organizations are not mandated by the State of California to follow the same Process and Payment Allowable outlined in the Medi-Cal Formulary for the members prescribed medical supplies as it is with Medi-Cal. All Managed Care Organizations have been established to manage the Medi-Cal Benefit but are not following Medi-Cal Policy as they are permitted to make up their own Process and Allowable per product. One example is Anthem Blue Cross that modified their payment allowable(s) to a Commercial Plan allowable in 2018 and does not allow for State required Sales Tax. Their allowable(s) and lack of Sales Tax payment has remained unchanged since 2018.

**RECOMMENDATION:** All Managed Care Organizations must be mandated to follow all Medi-Cal Policy, Procedure and Allowable(s) as outline in the Medi-Cal Formulary.

### **Health Submission 13. Free Art Sessions (Family Advocate)**

**ISSUE:** Frustration and low self esteem

**RECOMMENDATION:** I would love to see free, weekly art sessions just for the autistic/disabled community. Our children (and adults) have so many frustrations and structured but free-lance style art sessions could provide a creative outlet without peer pressure from being with typical kids who can generally follow instructional art at a much faster pace.

I've considered approaching our local Park and Rec dept. It could be so beneficial for them to have the opportunity to spend time with peers just doing fun, creative, enriching activities. Thank you for your consideration of this possibility.

### **Health Submission 14. Expand DME Beyond Home Use (Self-Advocate)**

**ISSUE:** The idea that to get durable medical equipment for people who have a disability they must use it only in the home. Most common homes are not always wheelchair accessible for wheelchairs to be used in homes.

**RECOMMENDATION:** Get rid of the idea that durable medical equipment is only for home use.

### **Health Submission 15. No Denial of Therapy (Family Advocate)**

**ISSUE:** Health insurance companies can deny coverage for residential therapy from mental health patients and youths of California

**RECOMMENDATION:** All forms of health insurance should not be allowed to deny therapy of any kind.

## **Human Services**

### **Human Services Submission 1. Service Coordinator Reimbursement (Family Advocate)**

**ISSUE:** DDS only reimburses regional centers \$34,000 per service coordinator. Leading to regional centers not being able to offer competitive salaries for qualified employees.

The Service Coordinator case ratio is too high, and turnover is too high, leaving many clients cycling through workers, and sometimes without a service coordinator at all.

**RECOMMENDATION:** DDS must reimburse regional centers \$100,000 per service coordinator, and a percentage formula must be put in place to account for future inflation. High turnover is wasting training time and causing redundancy. Service Coordinators must be an investment.

Penalize DDS Executive level salaries every year this is not corrected.

### **Human Services Submission 2.                      Respite Worker Pay (Family Advocate)**

**ISSUE:** Many respite workers only make \$0.81 above minimum wage. There is a hiring crisis, families are going without services. Many families must tip employees out of pocket to keep them from leaving for better paying jobs (Per 2021 State Audit Report- DDS & Respite). This means wealthier families have more access to services. Services should be available to all, especially those in poverty.

**RECOMMENDATION:** Ref- INITIAL STATEMENT OF REASON, TITLE 17 DIV 2. DDS, CHPT 3 COMMUNITY SERVICES (Google "DDS Initial reason Respite"). Per the initial statement of reason "Maintaining a wage for respite workers above the minimum wage is essential to recruit and retain individuals who are willing to assume the degree of responsibility required, have the ability to provide optimal level and quality of service, and accept the sporadic/intermittent work schedule inherent in the delivery of respite service."

Per statement, in 1989 Respite workers were given \$0.81 above the \$4.25 minimum wage. That is 19% over minimum wage! Reform respite worker and other direct support worker positions, to be a percentage over the fast-food worker minimum wage. The law needs the percentage in writing, not an amount!

For the love of all that is good, do NOT ban tipping either, as DDS declined to state whether it was allowed in the state auditor's report. That's the worst solution here. Pay a fair wage, this concern will be resolved.

### **Human Services Submission 3.                      Regional Center Board Meetings (Community Member)**

**ISSUE:** There should be a uniform set of state law requirements applicable to the public meetings of the regional center board of directors and its committees. This would apply to how meeting notices and meeting materials are made available to the public. It should also cover requiring all such meetings to be public. There should be a wide range of practices covering how regional centers publicize meetings and make materials available.

**RECOMMENDATION:** Using Bagley Keene as a foundation, there should a legislation adapted for the regional center board and committee meetings. All meetings should be

noticed and at the regional center website. All materials should be put up on the website. All materials introduced during the meeting should be posted at the start of the meeting - similar to how the State Council posts new material for the full Council meeting. It should be prohibited to have closed committee meetings. All board meeting packets should be posted and retained at the regional center website. Some regional centers have years of board packets posted. Alta has not a single posted board packet, only the minutes.

#### **Human Services Submission 4. Family Court Services (Self-Advocate)**

**ISSUE:** Family Court System delaying services for our families due to the ongoing parental disputes with services being affected.

**RECOMMENDATION:** Bill Proposal: Family Services Continuity Act

##### Section 1: Purpose

To ensure that beneficiaries of county and/or regional services, involved in Family Court matters, can continue to receive the necessary support from established professionals and community resources, regardless of their residence within the county their case is being heard.

##### Section 2: Definitions

**Beneficiary:** Any minor or adult receiving services under Family Court jurisdiction.

**Recipient:** The individual designated to receive services as per diagnosis.

**Service Providers:** Includes teachers, doctors, therapists, and providers/educators of any extracurricular activities.

##### Section 3: Continuity of Services

Beneficiaries residing in counties where Family Court matters are being heard must follow the recipient services, to which they receive such services, to ensure continuity and effectiveness of their care.

Service providers must maintain their involvement with the beneficiary, regardless of any changes in the beneficiary's caregiver/parent resolution/mandates with Family Court Services.

##### Section 4: Judicial Responsibilities

Courts are required to familiarize themselves with each case individually and the recipient's service individualized program plan.

The judicial system must expedite the county transfer of any cases using concise, clear, and timely information to minimize delays in their service provision.

## Section 5: Community Resources

Community resources should adapt to follow the beneficiary within 60 days of any relocation or change in service requirements, where feasible.

Timely transition is critical to ensure uninterrupted access to services and support for the recipient's well-being.

## Section 6: Documentation and Monitoring

Discussions regarding caregiver planning during Individualized Program Plan (IPP) meetings must be documented.

Any regression or denial of any or all services by caregivers or parents should also be recorded to monitor compliance and service delivery.

## Section 7: Implementation

This Act shall take effect immediately upon passage to ensure that beneficiaries receive timely and consistent services throughout the Family Court process.

Effective advocacy for those with disabilities necessitates addressing discrimination in all its manifestations, including the particular difficulties encountered by those who find themselves at the junction of many discriminatory systems.

### **Human Services Submission 5.**

### **Conservatorship Alternatives (Family Advocate)**

#### **ISSUE: (Translated from Spanish) There should be alternatives to**

**Conservatorship:** mechanisms for assisted decision making rather than a full or complete power of attorney-to permit parents of children with severe disabilities that are not able to make decisions for themselves.

**RECOMMENDATION:** Parents' Rights Act for Persons with Disabilities to Manage Alternative Decisions to Conservatorship. Provide parents with legal tools to manage decisions on behalf of their children. Protect the autonomy and rights of people with severe disabilities who cannot express their will. Allow parents to act as legal representatives in making specific decisions (health, education, and finances.)

There is a law on alternatives to conservatorship for people with disabilities who have the ability to express their will, but people who cannot express their will have been left out of this project or rather this law.



## **Human Services Submission 6. No Payee in SDP (Self-Advocate)**

**ISSUE:** Regional Center clients who use self-determination should not have use a payee.

**RECOMMENDATION:** I think that the money should go directly to the client if they express a desire to pay for their services directly. As a Regional Center client who lives independently and manages his own money it's a disappointment that I have to use a payee if I want to be in the self-determination program. The companies that manage my money can charge over a hundred dollars a month to pay each service provider. I am fully capable of keeping track of my money and ensuring that my two service providers get paid on time. Additionally, I am willing to learn the necessary information about how to prepare payroll for my employees. While I understand that California may be looking out for our best interest by having us use financial service providers, I believe that people who want should be able to get a check from the state to pay their providers directly. This will ensure that we will have access to the services we need and can change services without having to wait for someone to write the checks. While I understand that some clients might blow their budget, I believe people should be given the opportunity to manage their own money with the knowledge that they could run out of money and learn from the consequences of their actions.

## **Human Services Submission 7. Data on Unmet Needs (Family Advocate)**

**ISSUE:** Data on unmet needs is critical to developing adequate service provider networks and reducing disparities but is not collected.

I am a member of the DDS Regional Center Performance Measurement workgroup which created the new statewide IPP template that will be required starting January 2025. I and other workgroup members advocated that the IPP template should include a section to identify unmet needs, meaning vendored services that are desired but not available to the individual due to a lack of providers. However, an unmet needs section was not included in the IPP template. This vital data is needed to identify disparities experienced by racial and ethnic groups, and high needs individuals, who are often underserved or excluded in the entrance criteria of vendored providers (see title 17 section 56714), and to provide regional centers with the information they need to develop an adequate service provider network.

**RECOMMENDATION:** Amend the IPP section of the Lanterman Act to include a provision that the IPP template shall include a section that identifies the unmet needs of the individual, and if possible, measures the needed hours of service and location of service delivery.

This data, compiled across a given region, would form the foundation of market research, which in the private sector motivates entrepreneurs to start new businesses.

Note that the IPP Agreement and Signature Form, Under “Acknowledgements” requires the individual to acknowledge that they have “discussed and shared information about any needs [they] have right now or in the future with [the] service coordinator,” but does not at present memorialize or quantify that data. See [https://www.dds.ca.gov/wp-content/uploads/2024/07/Enclosure B Individual Program Plan Agreement and Signature Form.pdf](https://www.dds.ca.gov/wp-content/uploads/2024/07/Enclosure_B_Individual_Program_Plan_Agreement_and_Signature_Form.pdf).

**Human Services Submission 8. SDP Regional Center Flexibility  
(Family Advocate)**

**ISSUE:** (Translated from Spanish) Empowering Self-Determination consumers to choose the regional center they feel best fits their needs. This bill should also include awareness raising, DDS will develop regulations or directives or policies to empower consumers to choose regional centers.

**RECOMMENDATION:** Though there is no law on this, individual circumstances may warrant an exception to the geographic boundaries that regional centers have. There is no provision in the law that specifically prohibits a consumer from obtaining service coordination from one regional center while living within the catchment area of another regional center.

**Human Services Submission 9. Regional Centers Provide DDS Services  
(Family Advocate)**

**ISSUE:** Inequality in regional center service delivery system.

**RECOMMENDATION:** This law would require that all of California’s regional centers provide all the services listed in the DDS service codes, at a minimum. Additional services could still be provided by region.

**Human Services Submission 10. Include Regional Center Employees as  
Mandated Reporters (Professional)**

**ISSUE:** Mandated Reporting Requirements

**RECOMMENDATION:** Include specific reference to Regional Center Employees in the Penal Code 11165.7 definition of "mandated reporters."

### **Human Services Submission 11. Training for Caregivers (Family Advocate)**

**ISSUE:** I would like to see all caregivers to be required to take a course with certification before being allowed to care for our developmentally disabled or any disabled person in need of daily or long term care.

As far as I know, there is no specific training available for caregivers to determine if their personality is even suitable for such an important job. Needless to say, their background needs to be checked first.

**RECOMMENDATION:** More oversight and stricter selection. More pay to attract qualified people.

### **Human Services Submission 12. Make ABLE Account Contributions Tax Deductible (Family Advocate)**

**ISSUE:** That contributing to an Able account is not tax deductible at the state level. These accounts are specific for disability related expenses. In California you can have up to \$100,000 in a CalABLE account without it impacting your public benefits (e.g. medical or SSI). However, the state does not have a tax benefit for contributing to those accounts although they are fundamental to the long-term wellbeing of people with disabilities. I am funding one for my 6-year-old son to help me have peace of mind for his care when I can no longer care for him. I have read that other state's have this provision and it seems like a win-win to me to help incentivize families to save.

**RECOMMENDATION:** That contributing to an CalABLE account is not tax deductible at the state level. These accounts are specific for disability related expenses. In California you can have up to \$100,000 in a CalABLE account without it impacting your public benefits (e.g. medical or SSI). However, the state does not have a tax benefit for contributing to those accounts although they are fundamental to the long-term wellbeing of people with disabilities. I am funding one for my 6-year-old son to help me have peace of mind for his care when I can no longer care for him. I have read that other state's have this provision and it seems like a win-win to me to help incentivize families to save.

### **Human Services Submission 13. Independent Review of SDP Spending Plans (Family Advocate)**

**ISSUE:** (translated from Spanish) Equity in Self Determination Services

**RECOMMENDATION:** That DDS hire an agency to review spending plans. That the agency that accepts control be knowledgeable about the 5 principles of self-determination. That the issue of self-determination be subject to specific laws that clients are free to hire their own supervisors and providers and that the Regional Center

and the people who approve spending plans not be employees of regional centers. To avoid retaliation against clients for their parents' advocacy.

**Human Services Submission 14. Lived Experience in Board Representation (Self-Advocate)**

**ISSUE:** Manipulation of Boards and Committees to advance status quo agendas that do not represent the interest I/DD Populations and their families at large.

**RECOMMENDATION:** Board Composition will be updated to reflect background, culture and ethnicity to ensure that boards are composed of a diverse community of individuals with similar education and experience to support equitable progress and change. When the board or committee is comprised mainly of educated white professionals. Persons of color from the I/DD or parents that do not have the acumen to interpret the information, or actions presented the effort becomes unbalanced. While individuals may be well meaning, lived experience trumps expressed concern.

**Human Services Submission 15. Programs for People Who Use Wheelchairs (Family Advocate)**

**ISSUE:** For day programs they want a better pay because it's a very exhausting daily job to care for clients with wheelchair with all the need of transportation and transfers some are diaper changing and just more need to care for. With a better pay they will open door for wheelchair bound clients.

**RECOMMENDATION:** We need better Day programs that include every disability like clients in wheelchairs not just ambulatory day programs should get some kind of help to purchase wheelchair accessible vans to help the special needs population.

**Human Services Submission 16. Better Ways to SCDD, DRC, RC Info (Self-Advocate)**

**ISSUE:** There are too many decisions about our lives that are made without us. Government agencies, non-profits, and individuals get laws passed, report their data, and change our benefits and regional center rights without any notice to us. We do not get information about regional center services when we apply. We are not told about the SCDD, Disability Rights California, or the regional center system.

**RECOMMENDATION:** At the very least, all regional centers and protection and advocacy offices must provide online newsletters or listservs to anyone who is affected by the laws they propose and the services they provide. Whenever someone applies for Special Education or Regional Center services, they should be given the choice to

receive newsletters or emails from the SCDD, regional centers, and any agency or non-profit that receives state and federal funding and lobbies in our name.

### **Human Services Submission 17.      Use Unspent Dollars for Relocation (Family Advocate)**

**ISSUE:** As a parent of a young adult with a developmental disability who lives in a rural region of California, I know how difficult it is obtaining appropriate services for my loved one. Families in rural communities throughout California face disproportionate financial and geographical hurdles in helping their loved ones to actualize their most fulfilled, purpose-driven lives through appropriate person-centered plans as part of the Self-Determination Program (SDP).

Rural families are disproportionately financially taxed, because they strive for years to find anything that will help their loved ones, often when they are able, resorting to paying out-of-pocket expenses to secure anything that may help, often times for items or services that are disallowed by the Regional Centers. For families who have no resources, often the more likely scenario in poorer counties, like Plumas and Sierra Counties, children and adults with disabilities are just frankly unserved. Given that last Regional Center returned millions of dollars in unused plan monies, this is a betrayal of those citizens who are most vulnerable.

**RECOMMENDATION:** I wish for these underserved families living in rural areas, who face unique geographic, cultural, and financial impediments, to be able to set aside multiple years of prior unused, approved SDP spending plans for participant relocation to geographic areas known to be centers of excellence for services delivery.

Often, we as families hear from Regional Centers that we just need to find people who can provide a proxy of what is needed, someone who can be trained, etc. This is not an appropriate response. We either need to be free to move to areas where there are robust services, often in areas where housing is not financially tenable otherwise, or have the State spend considerable resources to bring these providers to us. The alternative is continued years spent by individuals and their families in rural California, treading water, at considerable cost of time and the family's resources, trying to fit into the State's version of their service delivery model, when it really should be the other way around.

**Human Services Submission 18.      Age-Appropriate Conservator Language  
(Family Advocate)**

**ISSUE:** When I filled out paperwork for Conservatorship for my son who is a young adult many of the questions, we're referring to a senior citizen and it was hard to filter out what questions that were relevant and which weren't. When it was all done, my proof of Conservatorship was two typed 8 1/2 x11 sheets of paper.

**RECOMMENDATION:** There should be separate forms for young people and seniors getting Conservatorship papers drawn up. Once you have Conservatorship you should receive a wallet size card (like a credit card) stating the person's name and that they are a conserved adult. This would be so much easier to show when needed like at doctor's offices, for adult programs, etc.

**Human Services Submission 19.      3-Minute Wait Times on Phones  
(Professional)**

**ISSUE:** Phone call wait times and holds take a very long time and no human is available.

**RECOMMENDATION:** Ensure availability of human person within 3 minutes of phone hold time in any government office. This will keep the faith of the people in reaching out to any state or federal office for getting help or assistance with their concerns.

**Human Services Submission 20.      Comply with Timeframes  
(Family Advocate)**

**ISSUE:** Vendorization process is 45 days and it's been a year no response I have been paying out my pocket for insurance most of the time and I don't understand.

**RECOMMENDATION:** Vendorization number approval.

**Human Services Submission 21.      Transitioning to Adult Independence  
(Family Advocate)**

**ISSUE:** It should be automatic that each individual remains safe and have a seamless transition to self-sufficiency as they become an adult. There is a disconnect when it comes to transitioning from a parental household and a death of a parent.

**RECOMMENDATION:** More programs.

**Human Services Submission 22. Evaluate RC Providers for Efficacy (Family Advocate)**

**ISSUE:** Abuse, neglect, incompetency, and unsafe conditions describe the problem for individuals in the state of California who are or should be receiving services from DDS and the \$14.1 billion budget.

**RECOMMENDATION:** Require all DDS programs and Regional Center Services to be evaluated for efficacy by outside evaluation companies that can demonstrate no conflict of interest and who are qualified to conduct evaluation using methodologies that hold up to peer review.

**Human Services Submission 23. Discount Sports Activities (Family Advocacy)**

**ISSUE:** Funding for recreational sports for children with disabilities.

**RECOMMENDATION:** There should be discounts for recreational sports packages so children with disabilities can participate without having the financial hardship.

**Human Services Submission 24. Supported Living Services for Adults Living with Aging Family (Family Advocate)**

**ISSUE:** Adult disabled children (sometimes referred to as child, below) who are in need of SLS Services, cannot be living at home when receiving these services. (I'm assuming the premise is that parents who reside with their disabled children are expected to care for them and therefore the SLS Service is not "yet" needed.)

This creates many problems as now, an aging caregiver who may be on the brink of being physically unable to care for the adult disabled child - Age 22+, now needs to find a separate housing location for their child before SLS services can begin. Housing is extremely hard to find. Yes, group homes exist, but for a child who is unable to care for themselves, often times, choice is taken from them in terms of who they live with, where they live, and who their caregivers are, (in other words, not person centered). Otherwise, if one is seeking to live in an apartment, short supply housing vouchers have to be applied for. Apartments aren't readily available with ADA considerations such as needing accessible ramps, larger doorways, larger bathrooms, and wider hallways. ADU's can be built in some cases, or a 2nd home can be purchased, but both scenarios require most people to dip into much needed retirement or caregiving savings. Finding housing and caregiving is a huge task that aging parents face in their later fragile years, all while their child still needs to be cared for.

**RECOMMENDATION:** Allow SLS services to be provided to adult disabled children living with parents age 65+ who live in owned homes. This allows parents to slowly back

away from the day-to-day responsibilities of caring for adult disabled children and gets the child used to being cared for by someone else, while remaining in a familiar environment. In addition, it alleviates the need to find other housing which can be difficult to find. Additionally, if the house is one that has been used as a primary residence for both the parent and the child, upon the parents passing, the child (or representatives of the child) can apply for a parent/child exclusion of property tax reassessment under Prop 19, passed by voters in 2020. This may keep the costs of staying in the home lower for a child who may be relying on social security income as their primary source of income.

No longer can children (disabled or typical) inherit real property from a parent without reassessments unless the exclusion is applied for.

(Succession plans must be documented and legal advice may be sought for passing down housing.)

## Education

### **Education Submission 1.                      Exceptions from Special Ed Permit for Substitute Teachers (Family Advocate)**

**ISSUE:** The current rule requiring substitute teachers to have a Special Education Permit after 20 days in a special education classroom is hindering the quality of education for students with special needs. In a time of teacher shortages, this rule is particularly problematic. My daughter's class provides a perfect example: their beloved teacher is on maternity leave, and they've found an exceptional substitute who has invested time and energy into learning each student's individual needs and routines. However, due to the 20-day limit, this valuable substitute must leave the class, forcing students to adjust to yet another new teacher, disrupting their learning and emotional well-being. This rule should be amended to allow qualified substitute teachers to continue supporting students with special needs, ensuring greater consistency and continuity in their education.

**RECOMMENDATION:** To address the issue of frequent substitute teacher turnover in special education classrooms, the current policy should be revised. Either the 20-day limit for substitute teachers without a Special Education Permit should be extended, or exceptions should be made to the certification requirement for substitutes who have demonstrated a high level of competence and experience in supporting students with special needs. Additionally, the state could invest in a truncated professional development program that substitute teachers can complete to enhance their knowledge and skills in special education, providing an alternative pathway to qualifying for extended classroom time.



## **Education Submission 2. Addressing Gaps in Services (Family Advocate)**

**ISSUE:** The state needs to provide clear guidance on IEP implementation when there are gaps in services. As we saw during covid, there were many who were unable to get the services their IEPs clearly outlined. Years later, the schools are still struggling with provider shortages, and many are not able to implement IEP services. And parents and guardians of these students are being left in the dark as to what services they are (or are not) receiving that are listed in IEPs.

**RECOMMENDATION:** The state should have clear expectations for school districts of what reasonable gaps in services are, and when and how families should be informed about team changes, and what rights families have when services are unable to be provided due to lack of staffing. I suggest schools must send a notice to families within 5 business days if there is going to be a prolonged pause in services, for instance due to the speech therapist quitting, an estimate of when services will begin again, and a plan on how to make up the missing session times.

## **Education Submission 3. Protect Non-Verbal Autistic Students (Family Advocate)**

**ISSUE:** (Translated from Spanish) The problem this bill would address is the vulnerability of nonverbal children with autism to abuse in schools. Unable to verbally express situations of abuse, these children are at greater risk of suffering abuse that goes unnoticed. Currently, there is a lack of specific preventative measures, adequate training of school staff, and a legal structure that clearly defines responsibilities in cases of neglect or abuse. In addition, there are no effective oversight mechanisms to ensure compliance with protection protocols.

**RECOMMENDATION:** Proposed Bill: Create a Preventive Protocol and Responsibility for the Protection of Non-Verbal Children with Autism in Schools. According to my brief research on the topic, there is no specific law in California that exclusively addresses the abuse of non-verbal autistic children in schools and the liability for such acts. However, laws such as the Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act guarantee protections for students with disabilities, including appropriate educational interventions and prevention of discrimination.

## **Education Submission 4. Triggers for Dyslexia Screening (Family Advocate)**

**ISSUE:** Dyslexia diagnosis and supports

**RECOMMENDATION:** When testing is done for an IEP or any other educational assessment and there is any data showing that there is a problem, the schools should

have to notify the parents of the findings and encourage them to seek professional help with a diagnosis for dyslexia. Many parents are not made aware of this issue and the children suffer because the parents think the learning disability is due to other diagnosis like Autism etc. They do not want to spend the resources for the children and blame it on the child.

**Education Submission 5.            Let IEP Students Participate in Graduation (Professional)**

**ISSUE:** Bill idea regarding education and the ability to walk in a graduation ceremony.

In 2019, I had a student named Pedro who was on an IEP since the 3rd grade and was refused the right to walk in his high school graduation ceremony. Despite my efforts, he was deemed a "non-grad" by my district due to credits and grades, and he was too embarrassed to continue services ~ especially because he wouldn't be permitted to walk with his class anyway. I hugged his Mom as she cried when she heard the news and I stood by his side on graduation day. 4 years later, he died due to complications with surgery on Christmas Day. I have been looking for a means to propose this as an idea and dedicate it with his namesake.

**RECOMMENDATION:** Allow students in IEP to walk in high school graduation.

**Education Submission 6.            Schools Disclose What They Spend on Legal Services (Family Advocate)**

**ISSUE:** Transparency about the money that schools spend on defending themselves from special education lawsuits and avoiding providing appropriate education to students with disabilities by requiring all budgets and expenditures related to legal compliance be posted in their website in a regular basis.

**RECOMMENDATION:** Open Checkbook: require all Local Education Agencies, including dependent and independent charter schools, county offices of education, and SELPAs, to post on their website an itemized and annotated ledger showing all contracts, budgets, and expenditures of payments related to legal consultation, representation, defense, litigation and compliance of special education policies, programs or individual matters. Includes but not limited to payments to attorneys, families and their attorneys via settlement, insurance payments, or otherwise, third party experts and service providers, alternative dispute, mediators, and professional development. Such open checkbook shall be updated in real time and no less frequently than monthly. It shall be accessible, searchable, and able to be exported for use in spreadsheet applications.

**Education Submission 7. Allow IEPs During School Hours (Family Advocate)**

**ISSUE:** School IEP meeting scheduling. Parents and guardians of kids who have an IEP, especially parents who both want to attend the IEP but find it hard to meet before or after school hours - since meeting before or after school hours causes challenges with dropping off kids, picking up kids, and finding childcare for during the IEP meeting.

**RECOMMENDATION:** If parents request than an IEP meeting be held during school hours, the school should be required to get substitute teachers to cover for all teachers who need to be at the IEP meeting.

**Education Submission 8. Create “Forever Schools” of Learning (Family Advocate)**

**ISSUE:** Upon graduation from transition programs, many severely intellectually delayed and disabled young adults find themselves with limited options for continued education or meaningful engagement. While some day programs exist, they are often not suited for individuals with more severe disabilities, leaving families struggling to find adequate support.

**RECOMMENDATION:** The transition from school to adulthood is a critical period for intellectually delayed and disabled individuals. Unfortunately, current day programs in California often do not meet the educational and social needs of severely intellectually delayed individuals once they age out of the education system. To address this gap, we propose the creation of “Forever School,” a lifelong educational institution designed to provide continued learning, development, and engagement for young adults with severe intellectual delays.

Our mission is to ensure that these individuals have access to a structured, nurturing environment where they can continue to grow intellectually, socially, and emotionally-creating a true “forever” school environment that supports them throughout their lives.

Without ongoing educational and social engagement, these individuals can experience stagnation in their development, isolation, and a decline in their overall quality of life. It is crucial that we create a lifelong learning environment where these individuals can continue to develop and thrive.

1. Create a comprehensive educational program designed specifically for the needs of severely intellectually delayed individuals who have graduated from traditional transition programs.
2. Develop individualized education plans (IEPs) that focus on lifelong learning, communication skills, social development, life skills, and cognitive stimulation.

3. Provide a safe and structured environment that fosters personal growth, social interaction, and meaningful engagement for students.

4. Offer additional services, such as physical therapy, occupational therapy, and vocational training, to support the holistic development of each student.

5. Engage families and caregivers by offering them respite and support services to help them navigate the challenges of caring for individuals with severe intellectual delays.

### **Education Submission 9. Group Students in Smaller Groups by Age (Family Advocate)**

**ISSUE:** There are two problems that need/must be solved. My daughter is in a day class through the county for children with multiple disabilities. The first issue, currently, there are only two classes for children between the ages of 3-21 years old. The first classroom is for children between the ages of 3-12 and the second classroom is for children and adults between the ages of 12-21 years old. The issue is that we have a large age range mixed in one classroom. These children/adults aren't participating with children/adults within their age range. Additionally, it is incomprehensible how a teacher teaches a 12-year-old and a 21 year old the same "subjects".

The second issue, the classroom that is aged 12-21 years old is excluded from their neurotypical peers. Currently, that classroom is located in an old high school that is no longer used by children. Therefore, this classroom is isolated, marginalized and excluded from society and other peers.

**RECOMMENDATION:** For Problem #1 - Instead of having two classes (3-12 and 12-21) there should be at minimum 4 classrooms. They can be split up into ages 3-6, 6-12, 13-17, and 18-21.

For Problem #2 - The county and or school district should be responsible and accountable for providing proper education, facility, and inclusion for children and adult with multiple disabilities. There should be a classroom in all the schools for children with such need. I am not thinking these kids should be in the regular curriculum with the neurotypical children/adult because most if not all are medically fragile and having intellectual disabilities. However, in this day and age we should be offering something much better.

**Education Submission 10. Adjust Attendance Requirements (Family Advocate)**

**ISSUE:** Students with intellectual and developmental disabilities often have more medicine needs than students with non-existent intellectual and developmental disabilities. Why are they expecting to have the same attendance required when these students often times have more medical services and appointments to attend to thrive?

**RECOMMENDATION:** As a parent, I believe it's unfair to have this same attendance required for the neediest of students. This not only impacts education funding related to average daily attendance but divides schools and caregivers who prioritize medical needs as without medical needs being addressed academics will not be as successful.

**Education Submission 11. Faster Safety Solutions (Family Advocate)**

**ISSUE:** Safety for children in schools that have an IEP especially for eloping (running away off campus endangering themselves) be able to go above chain of command and immediately get this handled like gates being fixed and 1 on 1 aids immediately.

**RECOMMENDATION:** That the district of the school approved this type of issue right then in the moment presented for the safety of these children and others.

**Education Submission 12. Cameras on Busses and In Classrooms (Family Advocate)**

**ISSUE:** I'd like to know my child is 100% safe in his bus and Special day Classroom for special needs along with a lot of other parents.

**RECOMMENDATION:** We need to put cameras in the classrooms and busses of individuals with delays.

**Education Submission 13. Inform about Rights and Access to Evaluations (Family Advocate)**

**ISSUE:** Navigating the educational system can be challenging for parents, especially if they're unaware of their rights or the support available for their children. If a school is taking a dismissive approach to behaviors or academic support needs, it's important for parents to understand their options and advocate effectively. Schools often do not inform parents about their rights for evaluations, unless they are having an Initial IEP meeting, it is taking too long for a student to improve academically, or behaviors worsen with time. Often times they just provide an evaluation for speech to place student under those criteria to make them eligible for special education services instead of providing a comprehensive and psycho-educational evaluation, unless parents request for such.

Charters as state funded should follow the same special education laws as Public Schools

**RECOMMENDATION:** It should be mandatory for schools to provide families with special education rights during enrollment or have a point of contact on the student handbook on the disciplinary section since many of the behaviors might occur due to a condition not diagnosed or identified.

Another solution could be connecting Regional Centers to schools in order provide workshops or consultation services to support families who are interested to get evaluations, IEP process information. (It should be mandatory for Charter Schools)

**Education Submission 14.            Train on Inclusive and Least Restrictive Environments (Professional)**

**ISSUE:** Lack of appropriate supports and education for school leaders in creating environments for inclusion. While CA has indicators for improving least restrictive environment, school leaders are not equipped to support this work. They receive very little or no training in their credential programs on special education and inclusive environments. So much of creating inclusive environments ends up supporting all students so this should be a key element to their training.

**RECOMMENDATION:** Require credential programs to incorporate robust knowledge in inclusive environments and supporting all students in general education including those with disabilities.

**Education Submission 15.            Cameras in Classrooms and Nurses' Offices (Professional)**

**ISSUE:** Ensuring that our non-verbal clients, consumers, students, etc are not abused in anyway or taken advantage of.

**RECOMMENDATION:** Cameras in special education classrooms and in nurses' offices where diapers are changed. even on playgrounds.

**Education Submission 16.            Require Proof of School Board Approval for Litigation (Family Advocate)**

**ISSUE:** Lack of representation of people with disabilities by school district boards. Lack of accountability in the initiation of litigation against students with disabilities for denial of services by school districts.

**RECOMMENDATION:** Require that the Office of Administrative Hearings obtain proof from school administrators that the school board has approved litigation against children with disabilities when a hearing request is before the Office of Administrative Hearings.

## Employment

### **Employment Submission 1. Disability Etiquette Training (Family Member)**

**ISSUE:** Many people in society are unaware of how to interact with individuals with disabilities.

**RECOMMENDATION:** I envision a future where all new employees are required to complete disability etiquette training as part of their onboarding process.

### **Employment Submission 2. Employment Trial Periods (Self-Advocate)**

**ISSUE:** There are very few disability-to-disability mentor, and peer career opportunities!! That give people with disabilities the opportunity to help other people with disabilities in any capacities!! Often a lot of "neurotypical" people's perceptions of people with disabilities are that our abilities & IQ is that of an infant simply because of certain behaviors/stimuli!!

**RECOMMENDATION:** My solution is this: Pass a bill in favor of people with disabilities getting between 15- and 30-day trial in disability related professions!!

### **Employment Submission 3. Accept Proof of Disability (Self-Advocate)**

**ISSUE:** Some jobs require a person to pass a board exam prior to employment and they say they offer testing accommodations for their exam, but when it came to accepting the documents, they deny them. They did not even look at the documents from school psychologists or disability specialists. They said school disability professionals cannot diagnose, so you may have a disability, but you don't know.

**RECOMMENDATION:** The solution is to make a law that forces entities to accept documentation from school disability AND that people do not have to disclose great details about their disabilities. The agency I encountered wanted great details and was making a judgement themselves if I had a disability.

#### **Employment Submission 4. Allow Subminimum Wage (Family Advocate)**

**ISSUE:** To allow sub-minimum wage employment once again for persons with disabilities.

**RECOMMENDATION:** For politicians who changed the law to see that they took away the opportunity to have a job-no matter how small- to those who want to work but can't meet the normal standards for employment. Change the law. Allow sub minimal wage work for those who want it.

#### **Employment Submission 5. Create an Autistic Idea Journal (Self-Advocate)**

**ISSUE:** Autistic unemployment

**RECOMMENDATION:** Solution: Research Proposal: Autistic Idea Journal

Elaboration: "Traditionally, influential erudition has emerged outside of traditional institutions. In risk analysis, some autistics inadvertently break the law, out of repetition. Some autistics, without malicious intent, harass others out of extreme emotional distress, repetition and mental breakdown. The common good and negative utilitarianism both call for society to give autistics an outlet for their abnormally high creativity. Experiments need skin in the game."

([https://www.researchgate.net/publication/382795247\\_Research\\_Proposal\\_Autistic\\_Idea\\_Journal](https://www.researchgate.net/publication/382795247_Research_Proposal_Autistic_Idea_Journal) ).

#### **Employment Submission 6. Allow Subminimum Wage (Family Advocate)**

**ISSUE:** Since the state law changed in 2021 to no longer allow disabled people to receive less than minimum wage, my daughter has worked 12 hours total. Not 12 hours per week, not 12 hours per month, 12 hours TOTAL in 3 years. And it's not just my daughter, it's the majority of the adults in her Goodwill support group. Goodwill actively works to try to find jobs for them. The 12 hours they did find in 2023 was a convention willing to use disabled adults to screen name tags as people went into their convention. My daughter used to work at a restaurant 2 hours per day, rolling silverware into napkins. The pay was about \$3/hr, but she was proud of getting a paycheck and proud of doing work to support her community. She was proud of teaching new adults who came into the group the process of their work. The 3-4 disabled adults in her group now have to figure out how they are going to kill time every day. Some days they do attend classes that are supposed to give them "job skills", but the state is just wasting it's money for kids like my daughter. My daughter has cerebral palsy and ADHD, so she has to be in an environment that stays basically the same every day in order to get any work done, which basically means some sort of manual labor, but because of her CP, she can go only go about 1/4 the speed of a typical person. The adults in her group are



about the same. With the current laws, any chance of her every working again is a pipe dream.

**RECOMMENDATION:** It's possible that "job training" might be helpful to a few of the adults at Goodwill and similar programs, but for a larger percentage, it's a waste of money. The money would be much better spent either subsidizing actual work, for example the rolling of silverware that my daughter used to do, have the restaurant pay her minimum wage, but have the state reimburse the business for the delta between what she earned, and her "actual value", as measured by what she could do in one hour vs what a typical person can do, or go back to the former program, where disabled individuals are paid less. If the state wants to continue to waste money, how about a survey to find out if the change in law actually did any good. I'm sure you find in the majority of the cases, all that happened is a source of pride and dignity was taken away from these adults.

## Housing

### **Housing Submission 1. Housing After Hospitalizations (Family Advocate)**

**ISSUE:** Housing for people with developmental disabilities after hospitalizations.

**RECOMMENDATION:** For San Diego Regional Centers and Housing Authorities to work together with all hospitals to ensure adequate post-discharge housing.

### **Housing Submission 2. Housing is a Right (Self-Advocate)**

**ISSUE:** Homelessness.

**RECOMMENDATION:** It should be a law that people with intellectual and developmental disabilities deserve to have some kind of roof over their heads for safety reasons.

### **Housing Submission 3. Expand Low Income Housing Lottery Eligibility (Family Advocate)**

**ISSUE:** Housing for disabled adults and elderly

**RECOMMENDATION:** There should be a law that the housing for low income doesn't ALL go to the farm workers. Cabrillo economic held a lottery for low-income housing and after my disabled son was picked for it, we were told the lowest income housing was only for the farm workers. They never specified this before the lottery and the second level of low income was more than his SSI monthly amount. This should not

happen! There is no low-income housing available to those with SSI as their only income. This should be illegal!

#### **Housing Submission 4. Vouchers for Seniors with I/DD (Self-Advocate)**

**ISSUE:** The lack of affordable housing for seniors who have disabilities and don't have income for traditional retirement housing.

**RECOMMENDATION:** Create vouchers for retirement communities so that seniors who have developmental disabilities can have access to more senior living options.

#### **Housing Submission 5. Create a Pilot Independent Living Community (Self-Advocate)**

**ISSUE:** Individuals with Disabilities: Persons who have a physical or mental impairment that substantially limits one or more major life activities.

Independent Living Community: A designated area within California where participants will live, equipped with necessary facilities and support services.

Support Services: Services that include but are not limited to healthcare, counseling, job training, and financial management education.

Section 4: Establishment of the Pilot Program: Program Creation: The State of California shall establish the Independent Living Community Pilot Program (hereafter referred to as "the Program") to run for one year.

Location: The Program will be located in a designated area within California, chosen for its accessibility, resources, and suitability for the community's needs.

Participants: Up to 100 individuals with disabilities will be selected to participate in the Program. Selection criteria and procedures will be determined by the Department of Social Services.

#### **Section 5: Community Living**

Housing: Participants will be provided with housing in a tiny home community designed to meet accessibility standards.

Basic Necessities: The Program will ensure that participants have access to food, clothing, healthcare, and other essential services.

Support Staff: Trained support staff will be available to assist participants with daily living activities and provide guidance as needed.

**RECOMMENDATION:** The purpose of this Act is to establish a one-year pilot program in the State of California that provides individuals with disabilities the opportunity to live

independently in a supportive community. This program aims to foster autonomy, enhance life skills, and improve quality of life through structured roles, job opportunities, and money management education.

## Transportation

### **Transportation Submission 1. Improve Accessible Transportation (Self-Advocate)**

**ISSUE:** I would like to see my local paratransit be on time. They need to get better at getting customers to destinations and appointments on time. This is an ongoing problem and many customers either customer's cancel or complain that they are late to work or to the doctor. The issue is ride windows keep on getting changed by an auto on phones letting them know and this is a problem. I am referring to Access a ride in my area of Santa Clara County. It has been getting really bad. It affects many customers that use the services.

**RECOMMENDATION:** I would like to see that there is a way to make this system with the paratransit more organized and not have it be such a mess. My solution is maybe there is a way that a grant bill can go in affect for more accessible vehicles for Access a ride that can be donated and get more drivers trained and hired. More cut away vans, more mini vans. More big vehicles that are accessible. This will help many customers to get to destinations on time also the windows will stay the same and not change. Also, instead of computers scheduling the rides to bring back live people to schedule them so they are not going to the other side of town instead of where people drop off happens first. I would love to see this help all the counties all over California.

### **Transportation Submission 2. Improve Accessible Transportation (Family Advocate)**

**ISSUE:** Transportation for disabled like ACCESS they take like two hours to take a client to a destination when it should only take like 30 minutes ride, it's extremely exhausting for clients.

**RECOMMENDATION:** Better pay for ACCESS employees because there is a lack and because the pay is no good, they need to organize their routes better too.

### **Transportation Submission 3. Renew ID Cards Online (Family Advocate)**

**ISSUE:** Ca ID not renewable online. If CA driver's licenses are renewable on line CA IDs are not a majority of people who do not have driver's licenses are disabled, not to even mention seniors. This results in people who are able to drive not having to drive to renew their licenses. However, people who do not drive need to find some sort of transportation to renew their ID. I believe this is discrimination against the disabled.

**RECOMMENDATION:** The solution is for the state to mandate that CA IDs be available to renew online. (Note: The Department of Motor Vehicles allows online renewal for ID cards if there was no change of address and it is not the first time applying for the ID.)

### **Transportation Submission 4. Allow More Forms of Proof for ID (Family Advocate)**

**ISSUE:** Getting a California Identification

**RECOMMENDATION:** Have a form and picture from Alta Regional Center to present at DMV and to social security. My daughter didn't have a student identification. Her school was Guiding Hands. I list her social security card. I do have her social security number. It's been difficult. And I still don't have a valid California identification.

### **Transportation Submission 5. Create Blue Curbs at Homes (Family Advocate)**

**ISSUE:** I hope to solve parking issues for those who have access to disabled parking, especially in front of their homes/ apartment building.

**RECOMMENDATION:** I would like for those who are given a blue placard/ disabled parking access, be given a blue curb in front of their homes/ apartment building.

## **Civil Rights**

### **Civil Rights Submission 1. Allow Conserved Right to Vote (Family Advocate)**

**ISSUE:** Denial of right to vote if conserved

**RECOMMENDATION:** Revise the conservatorship laws to permit people who are conserved to have the right to vote.

### **Civil Rights Submission 2. Annual Review of the Need for Conservatorship Professional**

**ISSUE:** I understand why conservatorship was created, parents, case manager, family members and care providers were concerned about health and safety. My challenge to all is, can there be a time limit? With deciding someone's life decisions, it should not be permanent. Can it be perhaps a probation period and maybe every year it's reviewed? In my opinion, service providers should ask themselves these questions: Would I be ok with having a conservatorship? Can I speak up for myself? Who would help me? Why do I have a conservatorship?

**RECOMMENDATION:** A yearly probation period would benefit all. During the Annual meeting discuss is conservatorship needed? And if so why. I'm concerned that fawning happens a lot of the time and the ones we serve feel trapped. It's time to evolve. Like the closing of state hospital, it's time for a new change with our fellow human beings and give back the ownership of their lives.

### **Civil Rights 3.      Respect Medical Privacy (Self-Advocate)**

**ISSUE:** Ageism and Alzheimer's/Dementia and Terminal illness under the age 65 and HIPPA Rights being Violated along with Disrespect and Disregard! On almost a daily basis my HIPPA Rights are violated by doctors, nurses, staff, first responders, police, firefighters and the general public because of the lack of education about so many diseases under the age of 65! One example is Early On-Set Alzheimer's, I was diagnosed with Early On-Set Alzheimer's at 42 and Died of a Cardiac Arrest for 18 minutes at 43. Every day, people say to me, I'm too young to have "Alzheimer's" I'm not doing this for me. I'm doing this for everyone like me who is either too scared or can't share their story anymore!

**RECOMMENDATION:** Sharing my story along with the factual medical records will help others know they are not alone and will also help Educate All Medical professionals and First responder's!

## **Federal Policy**

### **Federal Submission 1.      Enforce SSA Guidelines (Professional)**

**ISSUE:** SSA beneficiaries harmed by Social Security. Harm may be both medical, such stress exacerbating a pre-existing medical condition and/or financial, such as individuals that are unable to meet their basic needs as a direct result of actions and/or a lack of timely action by SSA, and/or by SSA Staff not following procedures set by the SSA.

**RECOMMENDATION:** The Social Security Administration needs a separate agency to ensure they follow their own policy guidelines. This agency should be empowered to administer sanctions and/or disciplinary action when violations to policy have been

egregious. This agency could also be responsible for making sure new policy is administered in a uniform and timely fashion among the various local offices. Also, to implement a uniform understanding of policy which is currently open to interpretation by each individual office.

I see this as being similar to an audit that spot checks quality of service. But may also be triggered by a report filed by a beneficiary. Similar to how someone may file a complaint with the labor board.

### **Federal Submission 2. Enforce Volume Limits on TV Ads (Council Member/Family Advocate)**

**ISSUE:** "Structure," including an environment that is reasonably predictable and consistent, is vital to the wellbeing of most people on the autism spectrum and other people with I/DD. Despite the CALM Act (Commercial Advertising Loudness Mitigation Act), which was enacted over a decade ago, virtually nothing has changed in the perceived volume of commercial advertising. The volume of commercials today is still far louder than the program. The jumps back and forth in broadcast volume that occurs between advertising and program content is a source of needless anxiety for many people on the autism spectrum, particularly those with acute hearing sensitivity. Additionally, a recent study suggests millions of teens and young adults are at risk of early hearing loss. They stand to benefit from addressing this problem as well.

**RECOMMENDATION:** The Audio Engineering Society (AES) proposed in 2018 (and revised in 2023) loudness guidelines in the form of "AES71 -- Recommended Practice Loudness Guidelines for Over-the-Top Television and Online Video Distribution." Binding legislation requiring adherence and compliance with AES71 for all audiovisual programming in California would address the problem.

### **Federal Submission 3. Amend ADA for Employment (Self-Advocate)**

**ISSUE:** It is so hard to be hired with a position that you qualified for and meet all requirements listed on the job posts. As soon as you go into your interview and your disability is visible the employer finds a way and excuses to not hire the candidate. This is a true disadvantage for people with disabilities. We are the largest minority group with the employment statistics. We need to change this!

**RECOMMENDATION:** Top priority! We need an employment national rally day to come and make a stance. Ask for change in the interview process that it is an open process with employers. The required ADA Coordinator of 50 or employees, should be designated to a person with a qualified disability, education, and experience. ADA Amendment that all direct disability related agencies require 50% staff with disabilities at all levels.

**Federal Submission 4. Add Families to HUD Risk of Homelessness Scoring (Professional)**

**ISSUE:** Housing for our families with disabled children.

**RECOMMENDATION:** Currently the scoring used for risk of homelessness for various housing agencies does not include a higher score for a parent caring for a disabled child. We currently have families struggling to find housing with children that are dependent and have multiple pieces of equipment. Expand the sec 811 HUD to include not only people with disabilities but the caregivers of children under 18 with disabilities.

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