Fifth Edition · 2025

CALIFORNIA STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

There Should Be a Law — Report

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THERE SHOULD BE A LAW – 2025 CONTEST

INTRODUCTION

This year marks the State Council on Developmental Disabilities' (SCDD) 5th Annual *There Should Be a Law* Contest. The contest provides a platform for the intellectual and developmental disabilities (IDD) community to speak out about their experiences, challenges, and what their vision is for ideal supports and services to live a meaningful life. For lawmakers and partnering agencies, this report provides first-hand insight into the lives of individuals with IDD and their families and the barriers they face. This is the unfiltered voice of the community. It is hoped that this report can assist in identifying administrative or statutory solutions to improve supports and services for the IDD community.

> *"Advocacy is not just a task for charismatic individuals or high-profile community organizers. Advocacy is for all of us; advocacy is a way of life. It is a natural response to the injustices and inequality in the world."* – Alice Wong, Disability Advocate

The year 2025 has been a difficult one for Californians with intellectual and developmental disabilities (IDD) and their families. Uncertainty over the state budget, reductions in federal funding, and the threat of deep cuts to Medicaid-funded programs have caused anxiety and hardship in communities across our state.

But in the face of these challenges, our community has shown what it means to be stronger together. Across counties, regions, and experiences, people united to speak up for the services and supports that make full lives possible. They shared personal stories, their worries, the impact of losing services, and their hopes for the future with courage.

That unity and determination were powerfully demonstrated when:

- More than 2,600 letters poured in from self-advocates, family members, and allies.

- Letters spoke about the irreplaceable value of Medicaid-funded services.

- They painted vivid pictures of what life would look like without these supports.

- They were sent directly to members of Congress, ensuring lawmakers heard from people whose lives are shaped by the policies they make.

This year's *There Should Be a Law Contest* continues that momentum, with over one hundred fifty entries received. The contest is more than a call for ideas; it reflects a community that refuses to be silent. Far from retreating, people are speaking up, joining forces, and showing what is possible when they act together. In fact, ***together*** is the **superpower** of the IDD community. It is what turns individual voices into a collective force capable of driving change.

This year also marks two milestones that remind us why this work matters:

- the 35th anniversary of the Americans with Disabilities Act (ADA) and

- the 60th anniversary of Medicaid.

These landmark laws have shaped opportunities, rights, and services for people with disabilities, reinforcing the belief that everyone deserves the chance to live, work, and participate fully in the life of our communities.

As we look ahead, we will continue down the path of advocacy and togetherness. Stronger momentum will be built by listening to individuals with IDD and their families and ensuring decision-making spaces and every venue where policy is shaped are built with people with IDD and their families. The voices we hear will guide us, the unity we share will strengthen us, and the hope we carry will drive us. We will keep moving forward together – toward a future where full inclusion, equity, and opportunity are a reality for all.

A NOTE ABOUT THIS REPORT

Being the unfiltered voice of the community, this report includes all submissions except for those that did not provide a clear problem and recommended solution. Some submissions were slightly edited for clarity and/or condensed to minimize reader time. Each submission bears a topic title and who submitted it.

A few ideas submitted do not represent the view, mission, or goals of SCDD and the IDD community as a whole, nor represent the vision of the Lanterman Act. Those ideas are still included here to represent the variety of views within a community with many perspectives.

TERMS DEFINED

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

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

Service Provider: Persons or agencies who provide services to individuals with IDD.

Professional: Experts in any matter relating to the needs of the IDD community.

CONTEST ENTRIES BY POLICY CATEGORY

CIVIL RIGHTS

1. Interaction with SSI and Child Support – Family Advocate

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

2. Family Court Reforms – Family Member

ISSUE: Fair treatment of caregiving parents: courts must stop treating full-time caregiving as "unemployment" and recognize unpaid care as real, essential work – equal in value to earned income in custody/support cases.

RECOMMENDATION: Mandatory disability training: require family court judges, lawyers, and mediators to receive training on developmental disabilities, caregiving systems (like IHSS), and long-term care realities. Recognition of Caregiving History ensures courts review which parents have historically provided hands-on care, advocacy, and service coordination – and give that caregiving work real weight in custody decisions. Accountability for non-compliant parents: deny primary custody to parents with a history of court order violations, abuse, or lack of involvement unless they prove they have changed and can meet the child’s needs. Prevent harmful custody transitions: stop custody transfers that remove a child from a stable, supportive home and cause developmental regression or loss of services – require courts to automatically review such cases. Center the child’s voice and well-being: give more legal importance to what the child shows or communicates through behavior, regression, or feedback from therapists and teachers, especially when distress is evident. Address legal inequality: ensure that a parent with money can't win custody just by hiring a better lawyer – prioritize the child's best interests and the caregiving reality over financial advantage.

3. Unaddressed Grievances, Crimes, and Civil Offenses – Self-Advocate

ISSUE: Unaddressed grievances, crimes, and civil offenses.

RECOMMENDATION: Statute of limitations: tolling needs to protect disabled from the statute of limitations.

4. LBGTQ Rights to Get Married – Self-Advocate

ISSUE: LBGTQ are not treated with the same respect and equal rights as others.

RECOMMENDATION: Treat the LBGTQ community with respect and allow them to get married and not tell them what they cannot do.

5. Conservatorships are Unfairly Expensive, Delay Access to Doctors and Medicine – Family Advocate

ISSUE: To get a conservatorship one must get a lawyer. I shouldn't have to get a lawyer to be able to speak for my son and a lot of parents struggle trying to get doctors' appointments or medications they need because they can't afford a lawyer. Right now, we have to hire a lawyer, and it could take 2 years and in the meantime you can't get medicine, doctor appointments, or speak for an adult child without the court papers, and I can't take my son to court for 2 years trying to get it and I can't afford an attorney.

RECOMMENDATION: So, we can speak for our own adult kids who can't speak for themselves without all the hassle we should be able to fill out the paperwork and have it approved once the court knows they can't speak for themselves.

6. People with Restraining Orders and Conservatorships – Family Advocate

ISSUE: When anyone, including those with a restraining order, can intervene and object and file for conservatorship.

RECOMMENDATION: Protecting disabled children and adults that are protected by a restraining order. If a disabled adult or child has a restraining order against another parent or adult, the restrained adult should not be able to file an objection to a guardianship/conservatorship or file for guardianship/conservatorship.

7. Protection Against Abuse of Conservatorships – Family Advocate

ISSUE: Give people under the conservatorship the right to not stay in it if the conservator abuses the conservatorship, to abuse them.

RECOMMENDATION: To hold the conservator accountable for his actions if he does extortion and physical abuse to the patient for his gain and not for the benefit of the self-advocate. There have been people in group homes who are ruled over unjustly because the conservators think they have the absolute right to do whatever they want to the self-advocate.

8. Current Truancy Procedures in Schools are Punitive – Family Advocate

ISSUE: As an unmedicated ADHD parent, I missed calling my child's school to excuse absences – not due to neglect, but because my disability impairs task initiation and memory. The district penalized my child with truancy flags. Schools only provide 5 days to excuse an absence. Look into absences in the school system – many forget to call. I know I do. This reflects a systemic failure: schools, healthcare, and social services lack mandatory supports for cognitive disabilities. Millions with ADHD, ID, or DD face similar punishments for 'missed steps' – losing benefits, housing, or custody**.** Current issue: ADA ignores time-blindness/executive dysfunction as an access barrier. Solution: mandate "cognitive accessibility accommodations" in schools, healthcare, and government services (e.g., flexible deadlines, multi-format reminders, task-amnesty clauses). Current issue: Medicaid HCBS covers ID/DD supports but rarely ADHD or executive function. Solution: expand HCBS waivers to fund cognitive navigators – trained advocates providing proactive, personalized support (e.g., reminder calls, form filing, school liaisons). Current issue: schools penalize parents for disability-related oversights. Solution: require districts to accept navigator outreach as valid absence documentation under ADA. Current issue: schools penalize parents for disability-related oversights.

RECOMMENDATION: Amend the Americans with Disabilities Act (ADA) and the Medicaid Home and Community-Based Services (HCBS) program to: 1) Recognize executive function support as a civil right under ADA Title II (public services) and Title III (public accommodations). 2) Fund cognitive accessibility navigators as a covered Medicaid HCBS waiver service for all states. Specific changes: ADA ignores time-blindness/executive dysfunction as an access barrier. Solution: mandate "cognitive accessibility accommodations" in schools, healthcare, and government services (e.g., flexible deadlines, multi-format reminders, task amnesty clauses). Current issue: Medicaid HCBS covers ID/DD supports but rarely ADHD or executive function. Solution: expand HCBS waivers to fund cognitive navigators – trained advocates providing proactive, personalized support (e.g., reminder calls, form filing, school liaisons). Solution: require districts to accept navigator outreach as valid absence documentation under ADA. Stops punitive actions (truancy charges, benefit cuts) against parents/individuals with cognitive disabilities. – Universal design: navigators use ID/DD-friendly methods (e.g., picture schedules for nonverbal individuals, voice reminders for ADHD). – Equity: low-literacy, low-tech, and sensory needs are centered – not an afterthought. Impact of the change – for families: my child’s absences would be excused via a navigator’s call. No more educational penalties for parental disability. – Systemic shift: schools/government must provide *proactive* support, not just reactive "accommodation." – Cost-saving: reduces crises (e.g. ER visits from missed meds, foster care placements from paperwork errors).

9. Establish a Communication Bill of Rights – Family Member

ISSUE: Communication is a basic human right; individuals with communication difficulties due to developmental disabilities are frequently denied appropriate training and support to effectively communicate in school and the community. There are many people who use alternative ways to communicate and their communication needs are frequently dismissed. Disability rights leader Elizabeth Bonker thoughts on the New York State bill: “…The bill is just the ADA for communication. We are the last to get our civil rights.”

RECOMMENDATION: We need to establish a Communication Bill of Rights for people with developmental disabilities in California. The New York assembly unanimously passed a Communication Bill of Rights on

June 13, 2025, with expectations that it will eventually pass the state senate and be signed into law. Here is the language of the passed bill:

> “In order to ensure that each person with a disability is able to lead a life of dignity, all persons with a disability shall have the right to communicate in their preferred manner and all staff and providers under this section, shall have the obligation to ensure and support such rights, which shall include, but not be limited to: (a) the right to utilize any communication method that meets their needs, including but not limited to: (1) augmentative and alternative communication (AAC) techniques and devices; (2) spelling boards, letterboards and typing-based communication; (3) sign language and non-verbal gestural systems; and (4) speech-generating devices or any other assistive technology; (b) the right to have such individual's communication method recognized and supported in schools, community residences, and public institutions; (c) the right to speech therapy and communication support by duly licensed professionals without arbitrary restrictions; (d) the right to have at least one trained staff member available in every facility or program to support individuals who require specialized communication assistance; (e) the right to receive appropriate communication supports from trained staff, including direct support professionals (DSPs), educators, and healthcare providers; and (f) the right to experience no restrictions or bans on an individual with disabilities' communication method.”

10. Universal Changing Stations in all Public Restrooms – Family Advocate

ISSUE: Public restrooms should be required to have Universal Changing Stations. Universal changing tables provide a clean, sturdy, and size-appropriate space for caregivers to assist a person with SMA or other disabilities with toileting, changing clothes, and other tasks. Due to a lack of these tables, many individuals with disabilities who require toileting support are forced to change on restroom floors or in vehicles. Others restrict food and water consumption or limit their time in public spaces to avoid needing to use the restroom.

RECOMMENDATION: AB 662 (Bonilla, 2015) requires universal changing stations in commercial places of public amusement. But this needs to be expanded upon to include all commercial businesses that have public restrooms, including gas stations and restaurants and schools.

11. Transfers Via Court Are Costly Process for Families – Family Advocate

ISSUE: Autistic kids/kids with special needs have to pay to be transferred through the court system. No one told us we had to do the transfer on top of the conservatorship and so we had to pay double. I have had to pay several thousands of dollars to get my husband's step-nephew transferred from No CA to SO CA! The process took over 2 years. It cost us money to get an attorney and get conservatorship and then the transfer process as well! It is a lot of time and money for the courts and the family!

RECOMMENDATION: Change the law so that autistic kids and kids with special needs do not need to pay to be transferred through the court system. Families should not have to pay if the person is going to a family member and transferring in-state too! It should be an instant transfer in state. Second, if a family member is doing a conservatorship, it should not cost the family any money!

EDUCATION

1. Accessible Dormitories – Self-Advocate

ISSUE: The policy at most colleges encourages college freshmen to live on campus.

RECOMMENDATION: Having wheelchair-accessible dorms with space for personal care attendants for students who have disabilities.

2. Students with Disabilities Estranged from Parents Are Falling through the Cracks – Professional

ISSUE: Disabled children fall between the cracks when they reach age 18 and their parents disown them. When a biological parent moves out of the state or country, the school district where the student with disability lives denies special education services by citing California Code, Education Code § 56041 and stating that the student should relocate to the state/country of the estranged parent to obtain education services. This is a denial of FAPE wherein disabled students are falling between the cracks and being denied services and access to completing their diploma requirements. As 99% of employers require a diploma for employment, this denial of FAPE results in students becoming unemployable and unable to become self-sufficient.

RECOMMENDATION: If a disabled student age 18+ is living in a residential facility and is estranged from his/her parent(s), the school of residence for the student to obtain special education until age 22 should be the school district wherein the residential facility is located. Once the student achieves age 18, they should be considered emancipated, and their education shouldn't be tied to the residence of the parent that they no longer reside with.

3. Interdistrict Permits – Family Advocate

ISSUE: Public School Choice for families seeking inclusive education School of Choice permits for students with disabilities local control funding formula (LCFF) and AB 602 funding for students with disabilities with a permit.

RECOMMENDATION: Add students with disabilities to CA Education Code §46600(b) pertaining to students who have been bullied – so that the district of choice must allow the school choice permit and the district of residence has to release the student if they are a student with a disability. This should also apply to intradistrict permits. This change could have unintended consequences because districts do not want to be destination districts for the most expensive students. Therefore, we add in a cost-bearing obligation so that the school of residence is obligated to reimburse the district of instruction for the full excess cost of whatever IEP services are provided as calculated by the SELPA (money follows the person). The district of instruction would receive the LCFF funding (including supplementary funding), the AB 602, but the district of residence would still need to fund any excess. This obligation is limited to students who are in a general education classroom for less than 80% of the day and want to move to a school that has a higher percentage of students with extensive support needs who are included for more than 40% of the day. This requires that schools have to publicly state the percentage (but not the number) of students with extensive support needs who are included for more than 40% of the day (or 80% or a new number, 60% – new numbers are costly). The financial obligation is also limited to students with extensive support needs – students on the California Alternative Assessment, students with Autism with a secondary eligibility, Multiple Disabilities, TBI, and ID. If these conditions don’t apply, or cease to apply, the students with disabilities should still have the right to get a permit without discrimination – the district must demonstrate that when they denied the permit, they did not provide a permit to a non-disabled family that applied at the same time. The District of Instruction receives the credit for test scores and graduation rates. Due process rights remain in place for families and for districts.

4. Modifications to State Board of Education Approved Instructional Materials – Family Advocate

ISSUE: Accessing general education for students with significant cognitive disabilities. The State Board of Education (SBE) approves instructional materials, including textbooks, for K-12 schools. The California Department of Education (CDE) plays a role in this process by developing curriculum frameworks and recommending instructional materials to the SBE. Local educational agencies then select textbooks from the approved list for their schools. (2005 California Education Code §§60040-60048: Article 3. Requirements, Materials)

RECOMMENDATION: Mandate that the SBE requires instructional material, including textbooks for high schools, to include sample modifications for students based on aligned alternative achievement standards as set out in the California Prioritized Connectors and Essential Understandings. CDE needs to monitor placement (LRE 5a, 5b, 5c) for students on the California Alternative Assessment to determine whether the Alternative pathway to a diploma is having the unintended consequence of excluding students from high school general education classes.

5. Evidenced-Based Literacy Instruction – Family Advocate

ISSUE: Reading for children with Down Syndrome and with intellectual disabilities. Assuming that AB 1454 (Rivas) is passed, we would like students with Down Syndrome (DS) and Intellectual Disability (ID) to have access to the same professional expertise, trained teachers, and reading specialists as other students who are learning foundational reading skills, regardless of what grade they are in. We need a law that mandates that children with ID and DS have access to evidence-based structured literacy instruction and teachers trained in these strategies, and evidence-based modifications to strategies for the DS Learning Profile, especially in middle and high school.

RECOMMENDATION: Utilizing language from AB 1454, the SELPA must ensure that students eligible for an IEP under Intellectual Disability or eligible for the California Alternative Assessment should have access to a teacher with the reading and literacy leadership specialist credential or the reading and literacy added authorization. The California Teacher's Credentialing Commission shall ensure that its standards of program quality and effectiveness for the preparation of candidates for the Extensive Support Needs (ESN) and Early Childhood Special Education (ECSE) specialist credential, and the teaching performance expectations for the preparation of candidates for the same credentials include preparation on how to deliver instruction and support teachers to deliver instruction through effective means for teaching literacy, to students with ID and Down Syndrome aligned to all of the following: (a) The English Language Arts/English Language Development (ELA/ELD) Framework. (b) Evidence-based means of teaching foundational reading skills, which shall include explicit and systematic instruction in print concepts, phonological awareness, phonics and word recognition, and fluency to all pupils, and attending to oral language development, vocabulary and background knowledge, and comprehension, including tiered supports for pupils with reading difficulties, English learners, and pupils with exceptional needs. c) This cannot be interpreted as restricting the placement of children with ID or DS in classrooms with teachers trained in specific reading strategies; rather, the provision of specially designed instruction must be expected to be portable and reach the child in the least restrictive environment. The California Department of Education should create a task force to collect and review evidence on the performance of children with Down Syndrome in California Public and Private schools, the best practices in Down Syndrome education, including reviewing the National Down Syndrome Society Guidelines on Inclusive Education for Students with Down Syndrome, and create A system for monitoring and reviewing the placement, progress, and outcome of students with Down syndrome – a CDE Guidelines for Educating Students with Down Syndrome document, similar to the CDE Guidelines for Dyslexia, to facilitate schools improving the provision of inclusive education for children with Down Syndrome. These strategies will also often support other students with ID.

6. Assessments and Student Inclusion – Family Advocate

ISSUE: Prioritizing Inclusive Placement: placement of students with IEPs under Intellectual Disability (ID), Multiple Disability (MD), or Autism, and students taking the California Alternate Assessment (CAA) Assessments for students with IEPs Teacher Credentialing Categories Non-Public Agency (NPA) registration.

RECOMMENDATION: Studies show that conducting an ecological study or assessment of a student's participation in the learning environment can be effective in providing inclusive practices and increasing accessibility in the least restrictive environment. However, in practice, schools are ill-equipped to conduct these studies since most schools or districts do not have inclusion specialists, and special education teachers do not have training in conducting these assessments. The term 'ecological assessment' is also used by ABA specialists to describe a type of behavior analysis. We are referring to an assessment of the learning environment to gauge the level of access the student has to participate in learning and identify inclusive practices that can increase access. We first need to set up a statewide work group to study how such ecological participation reports can be conducted effectively to assess how the students' participation can be improved. The work group could identify examples of assessments that are effective or could develop a proforma similar to the FBA form. This could be added to the statewide IEP form. It would be useful to have a clearer name for this kind of assessment. We need to identify criteria for professionals who are qualified to conduct an assessment. The work group could identify criteria for qualifications, such as inclusion specialist and inclusion facilitator, co-teacher, etc. Individual inclusion consultants also need to be able to register as individuals with the non-public agency (NPA) state list so that it is easy for school districts and SELPAs to contract with qualified professionals. Once we have established the criteria for the assessment and who can conduct it, the law could mandate situations in which the assessment is mandatory. For example, when the IEP team recommends that a child be moved to a self-contained classroom, or to increase the time spent outside general education for more than 20 minutes, the IEP team could be required to conduct an assessment to see how the LRE could be more accessible. Secondly, a child in a separate setting for more than 40% of the day should have an assessment annually, even if it means moving them to a general education classroom for some part of the day to assess. In a separate school, the assessment could be conducted based on observation of the child in the separate school and an observation of the classroom the child would attend if not disabled. If parents agree with the school, the opportunity to conduct the assessment can be waived. As with any other assessment, if the parents disagree with the results, parents can request an independent educational evaluation. https://www.tandfonline.com/doi/full/10.1080/13603116.2022.2136773#abstract.

7. Plain Language for Diploma Pathways – Professional

ISSUE: There aren't enough plain language materials concerning the different paths to a diploma, making it difficult for students and parents to make informed decisions.

RECOMMENDATION: Require CDE to develop plain language materials (in all threshold languages) that clearly describe all pathways to a high school diploma. These should be developed with input from stakeholders. The information provided should also include other resources for parents and students to learn more about diploma pathways. LEAs must review these pathways at IEP meetings starting at age 14 using CDE materials. The IEP team discusses and indicates on the IEP the diploma path the student will follow. This is reviewed at all subsequent IEPs.

8. Incentivizing Aspects of Teacher Credentialing – Professional

ISSUE: Teachers are often inadequately trained or lack key information about inclusive classrooms and teaching practices that fully include students with disabilities, thereby requiring unnecessary segregation or poor implementation of an individualized education program (IEP).

RECOMMENDATION: Develop an incentive program for teacher credentialing programs to require curricula and training on inclusive classroom and teaching practices including universal design for learning, differentiated instruction, and other related topics.

9. Data Collection on Inclusion of Students with IDD – Professional

ISSUE: In 2022-2023, the most current California statistics from the US Department of Education indicated California ranks the fourth worst performing state in the country for inclusion of students with disabilities. The past five years have similar outcomes.

RECOMMENDATION: Require LEAs to collect data on rates of inclusion for students with IDD. For example, collect data for the average number of hours per week students with IEPs are included in general education instruction, number of students who do not participate in general education, number of students who are fully included in general education, or other similar metrics. LEAs must then develop plans to increase these metrics including timelines and accountability.

10. Fingerprinting Staff at Off-Campus Workplaces – Professional

ISSUE: California Education Code §45125.1 indicates that any organization with which an LEA contracts must have criminal records checked for staff when the student is outside the immediate supervision of school personnel. Workplaces generally consider it too intrusive to require their staff to have their fingerprints checked and so therefore numerous LEAs have indicated that the unintended consequence of this provision is that schools are having great difficulty providing workplace placements or have ceased doing so. Though there are some exceptions by which placement can happen, such as getting parental consent to the placement or school personnel visit the site at least once every three weeks, LEAs are having difficulty implementing this provision and placements are reduced or eliminated. The programs impacted include workplace placements as part of a student's IEP, work-based learning, career preparatory programs, cooperative career technical courses with regional occupational centers, summer environmental internship programs, agricultural career technical programs, summer vocational programs, partnership academies, and the Strong Workforce Program. The Legislature recorded major declines in placements after the 2021 broadening of §45125.1 (AB 130). A 2022 CDE survey found **9,970 business partners declined** to accept work-based learning students; LAUSD reported about a **90% reduction** in qualifying worksites and drops from ~1,500 to ~100 special ed placements. Those data points led to SB 531's targeted work-based learning exemption noted above.

RECOMMENDATION: A number of changes can be considered and made to this provision to maintain student safety and still allow the provision of work-based learning. They include:

- No 1:1 or no closed-door rules, so there are requirements for line-of-sight supervision with designated cleared adults
- Standardized work-based learning MOUs that cover harassment/abuse reporting and incident reporting
- Training and vetting of the supervisor, training that includes mandated reporter training
- LEA site-risk screenings and safety plans
- And more.

11. Advocacy Resources for Families with a Student in Special Education – 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, or 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 Frank D. Lanterman Regional Center 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.

12. School Transportation Safety – Family Advocate (translated from Spanish)

ISSUE: School Bus Safety

Recommendation: Require 2 staff in school buses for safety to avoid cases of abuse. There have been cases of abuse that have not been reported or documented.

13. Police/School Safety Staff Training – Family Advocate (translated from Spanish)

ISSUE: Students with IDD can experience emotional crisis and sometimes demonstrate behavior that can be misinterpreted by police as violent. There are many documented incidents where persons with IDD have been hurt in interactions with police.

RECOMMENDATION: To prevent dangerous incidents between police and students with IDD disabilities, include police education/interaction training in the IEP.

14. Internet Safety – Professional

ISSUE: California's current education and disability laws do not require schools to teach internet safety, educate parents, or provide a reporting system for online exploitation – even though schools have provided students with Chromebooks, wifi hotspots, Google Meet, and other digital tools that increase access to online threats**.** Children with developmental disabilities are more likely to be targeted by online predators – and often less able to recognize unsafe behavior or speak up. Parents may also lack the knowledge to check devices or understand warning signs. Schools have provided technology, but not the tools to protect students.

RECOMMENDATION: Adopt a Student Online Safety Act (SOSA). This proposed law would require schools to: include internet safety education in all IEPs and 504 plans, provide mandatory training for educators, aides, and caregivers on online grooming, sextortion, and digital exploitation, and implement a confidential and accessible reporting system for students and their families to report concerns about online exploitation, inappropriate contact, or grooming behaviors. This law fills that gap by giving students, families, and educators prevention education and a way to report abuse when it occurs.

15. Communication Aids and Safety – Professional

ISSUE: PECS (Picture Exchange Communication System) is used by schools and clinics. PECS is a communication system. Those who created PECS claimed it is beneficial for children. Since the 1990's it has been widely used in classrooms and special day classes for children with autism. The problem with this system is that it relies on systematic hand over hand direction by a staff member who has been trained in it. The problem is that this communication method teaches it is ok to be touched and grooms for abuse.

RECOMMENDATION: There should be a law that prevents licensed and credentialed therapists and educators from using communication aids which require hand-over-hand control.

16. Equal Quality Classrooms – Professional

ISSUE: I've seen football stadiums and track fields being improved, but special education classrooms are still "temporary". It's very disheartening to see where our government places the priority in upkeeping these facilities. Every school that I have attended and worked at has bungalows/portable trailers for our special Education students.

RECOMMENDATION: When a new school is built, the special education buildings should be included in those plans. Analysts can predict that special education services are going to increase, so why not add them into the plan? When new construction is made on a school campus, it should also include upgrades and/or building permanent classrooms for special education students. So, if a football field is being redone, then the special education classrooms should be redone too.

17. Special Education Teacher Training – Family Advocate (translated from Spanish)

ISSUE: Many assistants and teachers are not trained in or have certification in special education.

RECOMMENDATION: The County of Education Office should plan training**.**

18. Lack of Inclusion and Equity in Education – Family Advocate

ISSUE: There is no inclusion in education. Need to make a systemic change in the community.

RECOMMENDATION: Systemic change starts with kids – teaching them at school about their peers with disabilities, how to advocate for them and how to create lifetime friendships, and modeling positive acceptance. Schools: every school must have inclusion standards. Districts: school districts must stop treating all kids the same, but to really create a plan for best support for students with disabilities. Most important, parents should have a say when they know the teacher is not fit to provide services protection and right to choose without difficulties to transfer a student If needed and when needed. The rule that a child has to fail twice before being granted the right for a better education in a private school is backwards. Transportation for students when school of choice is not in their neighborhood. Flexibility in arrival time at school due to how kids function, most parents have disabilities themselves that is hard to manage, and it is stressful for everybody to keep up with the time to start school at 8:15am. Teach independence. Access to advocate in schools, every school to have an advocate. Create centers for independence age 1 to 29 where everybody will learn independence and how to contribute.

19. Expulsion/Suspension Hearings and Students with Disabilities – Family Advocate

ISSUE: Caregivers and students with disabilities are not fully aware of their legal rights and protections, to adequately defend themselves when recommended for suspension or expulsion from school. This law can help to keep students with disabilities from the beginning stages of the school to prison pipeline, by keeping them in their schools when behavioral incidents are spurred by things outside of their control.

RECOMMENDATION: Legal advocacy (such as a lawyer with expertise in special education) should be legally required and provided at no expense to the caregivers – to represent the students with identified or suspected disabilities in any proceedings where a student is being recommended for expulsion or suspension by a school district.

20. Access to Public Education After Age 22 – Family Advocate

ISSUE: Once a developmentally disabled adult turns 22, they no longer have access to public school. Transition and postschool outcomes for Youth with Intellectual and Developmental Disabilities: (2017) American Journal on Intellectual and Developmental Disabilities examines postschool outcomes including employment, independent living, and community participation, finding many youths struggle to achieve independence after leaving school programs. No access to public school further isolates students once they age out of the school system. Being kicked out of school at 22 for this group causes mental anguish, it's heartbreaking for the individual experiencing it and the families that can't provide a solution to make the hurt go away. Most parents are aging, it is quite difficult to be a caretaker, their mental/physical health also declines. It adds stress to the family dynamic. I am getting older and at some point, won't be able to take him to football games, baseball games. He is my biggest concern in life, what happens to him when I'm gone?

RECOMMENDATION: Allow continued schooling. Adults who can’t attend junior college, vocational school, or get trained to have a part-time job should be assessed for continued education based on their abilities. A lot of the time their developmental age is much younger than 22 years old. When my son is 22 his developmental or functional age will probably be 10 years old. Adult day programs are a good fit for some but some of the population would benefit from continued schooling.

21. Modify Teacher Requirements to Alleviate Shortage of Teachers – Family Advocate

ISSUE: The law that says you have to go through a teacher preparation program to get a teacher credential after you already earned a bachelor's degree in education or liberal studies/many education related courses plus over 60 days of experience in the classroom as an aid or substitute.

RECOMMENDATION: The stiff requirements to become a teacher need to be modified so that the teacher shortage issue can be corrected.

22. Lack of Effective Implementation of IEP in Special Education – Family Advocate (translated from Spanish)

ISSUE: Even though the IEP is a legal document designed to provide supports to students with disabilities, many school districts do not implement them correctly or in full. This could be due to not having enough school staff.

RECOMMENDATION: Hire more trained special ed staff that include more therapists, psychologists, assistants, and teachers.

23. Disinformation, Lack of Supports and Inclusion in Special Ed – Family Advocate

ISSUE: Disinformation, lack of supports and inclusion, and denials of services in special ed.

RECOMMENDATION: Each IEP evaluation and 504 plans must be supported by information about the laws that protect it, as well as a list of resources including parent support groups in the area. Additionally, support from a special services social worker in the school district area should be offered, along with a list of evaluations and services with their acronyms in the language chosen by the parents.

24. Require Autism Spectrum Disorder Training for All Teachers – Community Member

ISSUE/RECOMMENDATION: All certified teachers (not just special education teachers) in the public school system should be required to receive autism spectrum disorder (ASD) training.

25. Recreation Therapy Access in Education – Family Advocate

ISSUE: Recreation therapy and social skills should be a part of the school services like occupational and speech therapies.

RECOMMENDATION: Districts need to provide recreation therapy and social skills for students on the spectrum.

26. Only Screening for Dyslexia Is Not Enough – Community Advocate

ISSUE: Current dyslexia screening without follow-up leaves families and students unsupported. Many students, like my daughter, are identified as at-risk but receive no services, leading to years of academic delay, bullying, and emotional trauma. Mandated intervention and communication will provide early help and reduce the long-term damage.

RECOMMENDATION: SB 114 must go beyond simply identifying risk factors for dyslexia. The law must be revised to mandate parent notification, choice of evaluator, clear timelines, and required school-based interventions based on screening results.

27. Transparency of SELPAs (Special Education) – Professional

ISSUE: Currently, there is very little accountability for special education spending. SELPAs in California have broad discretion in how to use funding for special education. Unfortunately, this has resulted in education dollars being used to litigate against families of students with disabilities when there is a dispute over the necessity of services requested by parents for their children with disabilities. Millions of dollars are spent each year to litigate against families of children with disabilities.

RECOMMENDATION: A requirement that Special Education Local Plan Areas (SELPAs) report how much of their budget is spent on direct services to students with disabilities. In the past, the Governor proposed an administrative cap on the percentage of special education funds that could be used by SELPAs on administrative services. Unfortunately, the language did not make it into the final budget.

28. Start Transition Planning at Age 13 – Family Advocate

ISSUE: Although current transition laws like IDEA and WIOA provide important guidelines, none of them mandate that transition planning or support services to begin at age 13.

RECOMMENDATION: Create a new law that specifically addresses this gap – one that ensures earlier preparation starting at age 13, especially for youth with developmental disabilities. Encourage gradual and individualized participation in community and societal life beginning at age 13. Self-determination: promote decision-making in all areas of one's life starting at age 13. Comprehensive intervention: ensure coordination across health, education, social assistance, legal, and employment sectors. Technological access and adaptations: facilitate the use of technology and personalized supports.

29. Change Funding for Special Education – Family Advocate

ISSUE: School districts are failing to implement critical IEP services, especially for students with severe autism and other developmental disabilities, due to budget limitations. These failures leave children without the supports they need to learn and grow, even when those supports are written into their IEPs. Currently, the prevalence of autism in males in California is 1 in 12.5 (US Department of Health and Human Services). This number is predicted to increase with time, so the issue of failing to implement IEP services will only become more apparent.

RECOMMENDATION: Right now, there is no law that requires districts to reserve specific funding for high-support services listed in students' IEPs (like one-on-one aides) even when those services are legally mandated. The state should require all school districts to reserve at least 10% of their special education and IDEA funds specifically to successfully implement high-support IEP services that are frequently delayed or denied due to staffing or budget excuses. According to my calculations, the reserved percentage could be up to 20-30% of the current $7.5 billion dollars needed for special needs services for the approximately 150,000 students with high-support needs. Alternatively, we could increase the total amount of funding allocated to special needs education. If the district cannot fulfill the service, it must offer a temporary contracted aide or compensate the family. Districts should also publish annual accountability reports and be subject to corrective action plans if they fail to meet IEP goals for high-needs students. This proposal would ensure that school districts prioritize funding to meet the needs of students with developmental disabilities, especially those with extensive support needs. The change will improve accountability and ensure that no student is denied essential services because of district funding issues**.**

30. Remove Barriers in WorkAbility – Professional

ISSUE: WAI recently conducted a CDE survey, which found that, based on WAI placement data, we are seeing a significant decline in employer participation and placement opportunities due to the increased compliance burdens of Education Code §45125.1. Employers, including those in rural areas, are struggling to meet fingerprinting requirements, and many are struggling to meet paid placement numbers. This disproportionately affects students with disabilities, who deserve a wide range of community placements that match with career assessments. The data suggests that students with disabilities who have exposure to work-based learning in high school experience greater success in post-secondary education. 'WorkAbility I: A California Transition Program National Technical Assistance Center on Transition (NTACT) – Predictors of Post-School Success evidence charts Engaging Youth in Work Experiences. Innovative Strategies Practice Brief. Issue 2.

RECOMMENDATION: I would like to see Education Code §45125.1 amended. Currently, there is a three-prong test in which all prongs must be completed for school districts to place students in work-based learning. We need students to return to work-based learning. Parents of students with disabilities should be afforded the same opportunities as students in independent study programs when they agree on the value of work-based learning in competitive integrated environments. The amend to EC §45125.1 would allow programs, CTE, WAI, DOR, TPP, WCW, to have students return to work-based learning (WBL) in the community setting. As the law stands, school districts are not placing students in WBL. The data is firm that the best indicator for post-secondary success for students with disabilities is exposure to work in the secondary setting. As the WAI CDE advisory chair, I have worked with legislators on this issue and have agreed that since this addition to the law was introduced during 2020, it has devastated a whole generation of WBL. There is currently a bill working its way through the legislature, SB 845 (2025, Perez). The first draft of this bill did include EC §45125.1 but was removed in the second writing.

31. More College Preparation, Opportunities for Gainful Employment – Family Advocate

ISSUE: School administrators and counselors need to be educated on all the possibilities that are out there for students with disabilities. They need to learn about and utilize ThinkCollege.org and help students strive for more, help them the same way typical students are helped with college searches. It will help with independence and hopefully lead to gainful employment.

RECOMMENDATION: School districts should be required to provide students with IEPs & 504's and their families with information about post-secondary education yearly starting when students transition out of elementary school if not sooner. Guidance counselors should be required to gain knowledge of college programs for students with disabilities to help students decide what all of the options available to them are. The current system doesn't push for students with disabilities to strive for college.

32. STEAM Curricula Needs to be Inclusive – Professional

ISSUE: Currently, no law mandates that STEAM curricula in California public high schools include autism-specific instructional methods or career-aligned arts training. This creates a critical gap for neurodivergent students, particularly those on the autism spectrum, who often struggle to access inclusive learning environments and future-ready career pathways.

California is home to over 91,000 K-12 students with autism, yet less than 10% receive meaningful post-secondary transition support. LA County accounts for one-third of these students. Despite a 12% projected job growth in music education and rising investment in creative economic jobs, most public-school music educators receive no training in neuroinclusive instruction. Without targeted and scalable interventions, neurodivergent students are excluded from STEAM learning and economic participation in California's $507B creative economy, deepening the stark disparities in education, employment, and representation in creative fields.

RECOMMENDATION: Amend California Education Code §§51210 and 51220 to include provisions for inclusive arts education and creative workforce development within K-12 STEAM instruction. These sections govern required courses of study in elementary and secondary education and currently do not address the unique needs of students with autism in arts instruction. Additionally, enhance the Education Code §56044, which outlines service provisions for students with exceptional needs. The proposed amendment would expand this section to fund and require specialized music educator training in evidence-based practices for teaching students with autism spectrum disorders. This would ensure that music educators are equipped to deliver inclusive, tech-enabled instruction that prepares neurodivergent students for careers in California's creative economy.

33. Education Policy on Chronic Absenteeism Disproportionately Affects Students with IDD – Family Advocate

ISSUE: Many students with disabilities – particularly those with chronic medical, neurological, or mental health conditions – miss school due to flare-ups or treatment but are punished under truancy laws instead of supported. Families face school attendance review board (SARB) threats, legal action, and even loss of educational placement. In our case, both of my children have complex disabilities, including epilepsy and autism. Despite medical documentation, we received truancy letters and threats from our district. Home hospital was denied because it wasn't appropriate for fluctuating, unpredictable absences. With no inclusive options, we were forced to exit public education entirely. I had to file a private school affidavit with the state, stay home, and educate them myself – even though I could be working and helping lift our family out of poverty. This change would stop the criminalization of disability and ensure students continue learning during periods of illness, instead of falling behind or being pushed out of school entirely.

RECOMMENDATION: Amend California Education Code related to chronic absenteeism and truancy (specifically Ed Code §§48260-48263) to protect students with disabilities – including those with IEPs and 504 Plans – from being labeled as habitual truants or chronically absent due to absences related to their disability. The law should clarify that disability-related absences supported by medical documentation, or an IEP/504 Plan cannot be treated as unexcused absences, truancy, or chronic absenteeism. Schools must provide students with access to curriculum during these absences – especially when home hospital instruction is not appropriate or is denied – through options like virtual instruction, independent study, or asynchronous access to assignments. The law should also prohibit schools from referring these families to SARB (School Attendance Review Boards) or Child Protective Services and instead require the IEP or 504 team to reconvene to address access to learning and disability-related support needs.

34. Substitutes Should Take Courses Prior to Working with Special Ed Students – Family Advocate

ISSUE: Requiring substitute teachers to have education/some credential to interact with special education students. Allowing schools to release some necessary IEP info to substitute to better serve the students.

RECOMMENDATION: Additional courses need to be required for substitutes to understand the students better. Confidentiality agreements should be signed. Creates a safer environment for students when a new person interacts with them. It would help with lowering incident rates. Students would feel safer, and continuity would be maintained in the classroom.

35. Lack of Inclusive College Planning for Students with IDD

ISSUE: More inclusive college planning and opportunities for students with IDD.

RECOMMENDATION: Amend AB 447 Inclusive College to provide students with a person-centered planning process and the opportunity to pursue an educational credential, including, but not limited to, a degree, certificate, or nondegree credential issued by the institution, and participation in formal commencement ceremonies upon satisfactory program completion. Provide individual supports and services for academic and social inclusion in academic courses, including but not limited to priority registration and the academic accommodation necessary for student success, extracurricular activities, housing, and other aspects of campus life, including formal commencement.

EMPLOYMENT

1. Extend Work Opportunity Tax Credit – Self-Advocate

ISSUE: Work Opportunities Tax Credit (WOTC)

RECOMMENDATION: Extend this law further than 2025, give business an incentive to hire people with disabilities.

2. Family Leave: Sibling Caregiver Bonding Leave – Family Advocate

ISSUE: When a sibling takes on the primary caregiver role for a sibling with IDD, there is a need for protected leave from work to transition the family roles and provide psychological support to their sibling with IDD. Neither the Federal nor California law specifically provides job-protected leave for siblings outside of direct care related to a serious health condition**.**

RECOMMENDATION: Amend both the California Family Rights Act (CFRA) and the California Paid Family Leave (PFL) program to create a new category of leave: *Sibling Caregiver Bonding Leave* (or Family Continuity of Caregiving Leave). Modeled after the bonding period available for parents through birth, adoption, or foster care, this new bonding leave would support adult siblings who assume caregiving responsibilities for a brother or sister with an intellectual or developmental disability (IDD), with or without conservatorship. Triggers for this bonding period could include: after a parent passes away, after a parent/conservator becomes incapacitated or otherwise unable to continue with primary caregiving, or the sibling takes on a conservator or primary circle of support role with a change in housing (e.g. sibling with IDD moves into sibling caregiver's home, sibling with IDD transitions from parent's home to another housing option, etc.).

3. Change Employment Practices to Hire Persons with Disabilities – Self-Advocate

ISSUE/RECOMMENDATION: For employers to hire employees with disabilities to work with their companies, employment programs to assist with community employment, safety while being employed, provide transportation.

4. Accessibility of DOR Services on CSU Campuses – Self-Advocate

ISSUE: I want to make it easier for CSU campuses and the California Department of Rehabilitation to form partnerships with one another, so that the DOR can host workshops on how to sign up for DOR services and for DOR counselors to provide drop-in hours to help students with disabilities access DOR services.

RECOMMENDATION: Making it easier for DOR to get connected to college students with disabilities, so that these students who have a disability diagnosis – but do not access DOR services – have an easier time to access services. It allows DOR counselors to work with students to get connected to these vital resources.

HEALTH

1. Require Medical Professionals to Listen to Patient or Patient Advocate – Professional

ISSUE: People with disabilities have different ways of communicating their needs than others without cognitive, speech or physical impairments.

RECOMMENDATION: If professionals in the health care field were required to participate in sensitivity training somewhere in their studies, that would help their thinking shift when working with someone with cognitive, physical or speech impairments. The professional must learn to talk to the patient directly about their health concerns. make a law that professionals in the medical field must listen to their patient or patient advocates when it comes to the person’s care. This could include something as small as what type of needle to use for a blood draw or to find out how a person may transfer to an exam table.

2. Expand CalFresh Options – Professional

ISSUE: I would like to expand on the California Bill (SB 628, Hurtado, 2023-2024) to allow individuals with disabilities, seniors, 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 (Hurtado, 2023-2024) 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 California Regional Center (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 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-vendored small businesses, which would be cost-effective for medical food programs such as SNAP and CalAIM, which currently have limited resources.

3. Explicitly 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."

4. Choice in Selection of Doctors – Self-Advocate

ISSUE: DDS and DHCS force adults with disabilities into managed MediCal and that means we cannot use our other health insurance. I have Tricare for example, and I lost all my doctors at UC Davis when DHCS forced me to switch to managed MediCal.

RECOMMENDATION: Allow people with disabilities with other healthcare to keep fee for service MediCal instead of managed MediCal.

Note: SCDD is supporting AB 974 (Patterson, 2025), which would set new rules to help beneficiaries enrolled in commercial health coverage and who use MediCal as a payer of last resort to maintain their providers as they transition from fee-for-service (FFS) MediCal to MediCal managed care. Currently, AB 974 is held in submission in Assembly Appropriations Committee since May 23, 2025.

5. Private Health Insurance Should Cover Nursing Services – Family Advocate

ISSUE: Private duty nursing is not covered by private insurance.

RECOMMENDATION: The ACA already mandates that insurance companies provide coverage for essential health benefits, which includes services for individuals with disabilities. However, the law could be amended to specifically include private duty nursing as part of the essential health benefits, ensuring coverage for those with specific needs. Medicaid and Medicare Policy Changes: Although Medicaid provides coverage for certain types of home nursing care for people with disabilities, private insurance companies often do not. Legislation could mandate that insurance companies align their policies with Medicaid and Medicare standards for home and private duty nursing, thus extending coverage for people with disabilities.

6. CalPERS Health Plan Unfairly Punishes Families with Disabled Adults – Family Advocate

ISSUE: The rule that permanently prohibits disabled adult dependents from being enrolled in a CalPERS health plan after age 26 if they were not already added before that age. This rule unfairly punishes families, even when the dependent has a lifelong disability and has had continuous health insurance coverage through another employer-sponsored plan.

RECOMMENDATION: Allow late enrollment of a disabled dependent over age 26, if: the disability began prior to age 26; the dependent has had continuous health insurance; the disability is certified by a medical provider (e.g., via the HBD-34 form); the CalPERS member is active or retired. This change would solve three problems: it protects disabled adult children – like my son, who is 31 and has had lifelong coverage through my spouse's employer – from being permanently barred from coverage due to a policy we were never adequately informed about. It supports workforce retention. I've worked at a courthouse for nearly 25 years and would like to continue. But caregivers like me are often forced to retire early and start a new career to obtain and preserve health coverage elsewhere for our disabled adult children. CalPERS and the state want to retain experienced workers – but this policy has the opposite effect. It ensures fairness for disabled Californians and their families who made responsible choices but are being penalized for which parent's coverage they used.

7. California Alzheimer's Disease Centers (CADC) – Family Advocate

ISSUE: Currently only one of the ten California Alzheimer's Disease Centers has the expertise to diagnose Alzheimer's disease in those with preexisting cognitive deficits. People with Down syndrome are turned away from the other nine centers! People with Down syndrome have a higher risk for developing Alzheimer's disease than any other population group, including any of the identified diversity populations. 70-90% of seniors with Down syndrome die of Alzheimer's disease, whereas only 33.3% of seniors in the general population die of Alzheimer's disease. Without access to the CADCs people with preexisting cognitive deficits are not included in the statistics gathered by the CADCs or any of the services supported by those statistics.

RECOMMENDATION: Require the California Alzheimer's Disease Centers CADCs to extend their dementia diagnostic services to specifically include people with preexisting cognitive deficits, such as those with Down syndrome.

8. Durable Medical Equipment – Family Advocate

ISSUE: Having to explain why someone who has a disability needs a particular type of durable medical equipment specifically a power chair.

RECOMMENDATION: Get rid of that policy so that people can get the equipment they need.

9. Fetal Alcohol Spectrum Disorders FASD Assessment and Diagnosing – Professional

ISSUE: Although children with Fetal Alcohol Syndrome (FAS) can be identified through physical characteristics at birth, most children with FASD (90%) have no visible physical abnormalities. Because diagnosis requires confirmation of prenatal alcohol exposure, a large proportion (as high as 80%) are undiagnosed or misdiagnosed with other conditions such as attention-deficit/hyperactivity disorder (ADHD), bipolar disorder, autism spectrum, and/or conduct disorder. There are more individuals living with FASD than with Down Syndrome, cerebral palsy, and autism spectrum disorder combined. The situation is especially acute for children in adoptive and foster care. FASD's costs have been reliably, conservatively estimated to total $2 million for each person affected by these disabilities – a fiscal and human cost with enormous long-term effects, including the costs in populations affected by homelessness, child welfare, and juvenile justice systems, and other state-funded services and supports. FASD affects more than 300,000 students in California's K-12 schools. Given its lifelong disabling impacts, FASD is nothing short of a silent epidemic. California's attention to FASD, with such sizable adverse human and economic consequences, needs to be remedied, especially for a state that claims to be a leader in health and human services, with a focus on early childhood issues.

RECOMMENDATION: A clarifying amendment to California Health and Safety Code §123605 to specify critical information that is necessary for diagnosing and treating FASD. We propose a new subsection (d) to read as follows: “Each needs assessment shall include data regarding prenatal alcohol exposure, including maternal and paternal drinking patterns before and during pregnancy, the approximate date of conception, and the date when the pregnant person found out about the pregnancy.”

10. Accountability in Dental Health Care Via MediCal – Self-Advocate

ISSUE: I want to see dentists and specialty dentists who accept MediCal for treatments not be allowed to find loopholes to charge a patient additional out-of-pocket funding. An example, if MediCal fully covers root canal treatments (including the cleaning agent used), dentists and endodontists should not be able to switch cleaning solutions to try to charge a patient hundreds of dollars.

RECOMMENDATION: MediCal laws need to be very strict, specific and enforced. There should be a complaint hotline and website to report on MediCal about fraud and abuse. An automatic complaint would also go to the Dental Board of California. Dentists will no longer be able to take advantage of people with disabilities and/or those less fortunate who are on MediCal.

11. Transparency to Avoid Surprise Healthcare Expenses – Community Advocate

ISSUE: Raising a child is expensive. Raising a child with special needs is super expensive. It’s difficult to find the right specialists and a child can wait months to get an appointment, which can have devastating consequences. What we don’t need are last-minute co-pay and deductible surprises. In my case, I had to take my daughter to a brain MRI for seizures several years ago. I was leaving work to get her to school when the medical office called to tell me to bring $600 for a deductible. I didn’t have $600, and they threatened to cancel the MRI.

RECOMMENDATION: I would like to see medical providers provide written cost estimates for any procedure or service expected to exceed $500 in total, with the amount of deductible and copay they expect to be paid at the time of service. This would need to be provided for the family or patient in advance. Doctors will say it’s the patient’s responsibility to know what their insurance covers, but that’s not always possible. Medical providers hire people experienced in insurance billing. Families overwhelmed with their child’s needs do not. Dentists routinely provide such written estimates. Its time all medical providers do so. It would allow families to budget for their child’s medical needs and not have the added stress of large surprise expenses.

12. Early Intervention Should Be Available to all Children at Birth – Professional

ISSUE: All parents with children from birth to age three should have the chance to get an early intervention check-up. Many parents don’t know where to start or who to ask when they’re worried about their child’s development. If there was a simple way to offer support, it could give parents peace of mind and give babies a better chance to grow, learn, and get off to a strong start in life.

RECOMMENDATION: Beginning with the hospitals, during adoptions, and when families enter the court system. These are moments when parents and caregivers are already reaching out for help. If we could offer early intervention evaluations at these points, we could support more families right from the start. Many parents don’t know what to look for or where to go. Giving them a clear path and support early on could make a big difference for their child’s future. 1. Kids get a strong start. When babies and toddlers get help early, they’re more likely to grow up healthy, learn faster, and do better in school. 2. Parents feel supported. Many parents feel unsure or overwhelmed. Early help gives them answers, tools, and peace of mind. It will improve mental health of parents 3. Fewer problems later. Catching delays early can prevent bigger challenges later. That means fewer kids needing special help in school or medical care. 4. Saves money for families and communities. Helping early costs less than fixing problems later. It’s a smart investment that helps schools, healthcare, and social services. 5. Builds stronger communities. When kids and families are supported from the start, everyone benefits. It leads to healthier, happier communities.

13. Durable Medical Equipment – Self-Advocate

ISSUE: Access to technical support for durable medical equipment malfunctions.

RECOMMENDATION: There needs to be 24/7 support available to rectify barriers pertaining to issues with durable medical equipment that individuals depend upon. If someone is using durable medical equipment and it malfunctions, they can get immediate necessary access to support no matter when it happens to regain and ensure safety and maintain quality of life.

14. HIPAA Privacy – Self-Advocate

ISSUE: Government sponsor medical clinics have a loophole, where they're not protecting the HIPAA rights of their patients and working with law enforcement against their patients. I was a victim over 18 months long operation, in which my therapist and doctors worked with law enforcement and lied to me to try and entrap me. I reported it to the State. They admitted that my therapists did work with them and gave them information. However, they said that it was not Illegal, because when I signed with that clinic, I signed away my rights to my privacy that they can share any information with law enforcement. She actively worked with them, and the state investigation admits that she did that, and there was no recourse for the torment she caused me.

RECOMMENDATIONS: Strict guidelines for HIPAA rights, which prohibit therapists and doctors from working with law enforcement that cause harm to their patients.

MENTAL HEALTH

1. Mental Health Barriers for IDD and Their Families – Family Advocate

ISSUE: Families of children with intellectual and developmental disabilities (IDD) often face serious challenges accessing consistent and reliable therapy services, such as Applied Behavior Analysis (ABA) and speech therapy, through regional centers and public schools. Services are frequently canceled without notice, staff turnover is high, and there is little accountability when authorized therapy hours go undelivered. This lack of consistency causes developmental regression, emotional distress, and places an unfair burden on families – especially those already navigating complex care needs with little support.

RECOMMENDATIONS: There should be a law that ensures consistency and accountability in the delivery of therapy services for children with IDD. The proposed law would require: 1. Minimum therapy delivery standards: regional centers and school districts must ensure at least 80% of authorized therapy hours are delivered each month. 2. Mandatory make-up policy: canceled sessions by providers must be made up within 14 calendar days unless the family declines. 3. Therapist continuity protections: limit how often a therapist or technician can be changed on a child's case – no more than once every 90 days unless requested by the family or due to emergencies. 4. Transparent reporting: parents should receive a monthly report of scheduled vs. delivered therapy hours**.**

2. Current Policy Puts Psychiatric Patients at Risk of Harm in Facilities – Family Advocate

ISSUE: I want to change the current policy that allows for mixed-risk psychiatric patients to be housed together in inpatient facilities. This includes both adults and children being placed in the same unit regardless of their mental health risk level (low, medium, high).

RECOMMENDATION: Facilities must be legally required to separate patients based on clinical assessment of risk and treatment needs during the intake process. This includes low-risk patients being housed only with other low-risk patients. Medium and high-risk patients being placed in secure and supportive environments suited to their needs. Consideration for age-appropriate separation (especially for minors). This change would protect vulnerable patients from being retraumatized or exposed to harmful behaviors. Reduce the formation of maladaptive relationships, such as sharing private information and unhealthy coping strategies. Increase the effectiveness of treatment, leading to better recovery outcomes. Reduce facility violence, conflict, and long-term mental health deterioration caused by inappropriate mixing of risk levels.

3. Mental Health and Addiction – Family Advocate (translated from Spanish)

ISSUE: I would like people with mental health issues caused by addictions to be rehabilitated.

RECOMMENDATION: That it be the addict's family members who decide to admit the patient into a rehabilitation center. Why do they ask the addict for permission, if it's known that they are no longer fit to make decisions – and they never admit that they have a problem?

HOUSING

1. Require Data Collection for Individuals with IDD in Biennial Homelessness Count – Professional

ISSUE: Data for persons with IDD are not being collected in the biennial homeless count. It is therefore difficult if not impossible to draw conclusions about the incidence of homelessness for individuals with IDD. This therefore leads to inadequate public policy development concerning individuals with IDD.

RECOMMENDATION: Include individuals with IDD in the data collection for homelessness, which to my understanding requires a statutory change.

2. Use of Cameras in Group Homes to Prevent Abuse – Family Advocate

ISSUE: There are restrictions on cameras being placed in group/crisis homes where nonverbal children are residents. Children cannot report or account for any occurrences themselves due to lack of speech or communication abilities. There is no way for a child who cannot speak to report any misconduct or abuse and no way to hold anyone accountable if abuse occurs.

RECOMMENDATION: Children who are nonverbal should have the option of having cameras in their room and common areas when placed in group/crisis homes unless parents are opposed to it.

3. Aging Caregivers and Their Adult Disabled Children – Family Advocate

ISSUE: Current supported living services (SLS) policy, according to the DDS website, will allow anyone as a roommate for the adult disabled SLS recipient, except a parent. There are many parents in California caring for their adult disabled children who are aging out. Once they are no longer able to care for their disabled child, the child may receive complete care services with the SLS model. However, if the adult child recipient is living with the parents, the parents or the child must move to a different dwelling. This policy is causing a financial and emotional hardship not only on my adult disabled child, but on numerous other families. My disabled daughter and I live together in the home that I own. It is cost prohibitive for either of us to move out, to build a tiny home (ADU) in our backyard, or to convert our home into a duplex. My daughter wants to remain living with me rather than in a separate dwelling. The current policy is unfair and discriminatory.

RECOMMENDATION: The policy needs to be changed to allow parents to remain living the same dwelling as their adult disabled children while the children receive SLS services. I have spoken to many families who are facing this financial and emotional dilemma. This policy change would solve the problem of them having to move apart into separate dwellings.

4. Tenant's Rights – Self-Advocate

ISSUE: Heat in California's Central Valley kills people. Rental places sometimes do not provide air conditioning. According to UCLA, approximately 29% of California rentals do not have air conditioning.

RECOMMENDATION: There should be a law requiring all rental units in the state of California to provide air conditioning for all tenants. This falls under 'California's Habitability Laws'. This will save many lives as heat, especially in California's Central Valley.

5. Homeless Resources for Homeless Prevention for IDD – Family Advocate

ISSUE: There should be more resources or a hotline with resources for adults and families with intellectual and developmental disabilities to address homelessness. A time of crisis is much harder to navigate when you have disabilities.

RECOMMENDATION: More resources, i.e. 24-hour hotline, shelters for families and adults with intellectual and developmental disabilities. Low-income housing communities dedicated to IDD and their families.

6. Build More Accessible Housing – Self-Advocate

ISSUE: A lack of accessible housing that is in the suburbs.

RECOMMENDATION: Increase the number of developers who build accessible housing. More accessible housing built everywhere and not in restricted areas.

HUMAN SERVICES

1. Explicitly Include Fetal Alcohol Syndrome as a Diagnosis to Establish Regional Center Eligibility – Family Advocate

ISSUE: Currently there are 4 named conditions for eligibility for the Regional Center under the Lanterman Act and a fifth category, having a disability similar to intellectual disability (ID) or requiring treatment similar to ID. The most common developmental disability in the United States is Fetal Alcohol Spectrum Disorder, at a prevalence of 5% of the general population. Yet for this disability there is not eligibility for the Regional Center, especially for those who have typical range IQ. In FASD adaptive functioning, the ability to live independently and to work are not tied to IQ, with adaptive functioning 1/2 to 1/3 of IQ. Without early diagnosis and intervention adapted to this disability, 75% of adults with FASD and typical range IQ will not live independently or be able to sustain work. Yet, Regional Centers across the state find children and adults with this disability to be ineligible for Regional Center services due to IQ, a spurious indicator of the ability to function in FASD. Instead, children and adults with FASD are seen in every system of care in California costing the state about $2 billion a year. Yet the one system which might support their needs finds them to be ineligible. The above leads to loss of productivity, a much-shortened life expectancy, families left on their own to help children, and teens and adults without support.

RECOMMENDATION: The FASD Network of Northern CA respectfully requests amending the Lanterman Developmental Services Act (California Welfare and Institutions Code §4521) to include a 6th eligibility category for Regional Center services: Fetal Alcohol Spectrum Disorder as a named condition (FASD). Understanding FASD: FASD is a spectrum, but most affected people show significant difficulty across at least 6 of the 7 life skills used by the regional centers to determine that an applicant has a substantial disability: communication, learning, self-care, self-direction, capacity for independent living, and economic self-sufficiency. Common deficits in FASD across the IQ range include poor abstract thinking, reasoning, memory, judgment, planning, organization, impulse control, self-regulation, understanding of time and money, recognition of risk or danger, communication, motor skills, social skills, and poor ability to sustain tasks across time, including activities of daily living. In fact, FASD, has been described in the literature as an ID equivalent disorder due to the severity of executive function deficits in affected persons. It is important to recognize that FASD is now a named condition for Early Start. However, staff with Early Start and the regional centers are not trained in this disability. Again, intervention and parenting are both based on understanding of the disability. Common interventions are contraindicated, like ABA, given the cognitive profile of FASD. FASD is also now a named condition under “other health impairment” for special education, with legislation passed in Sacramento.

2. Bar DDS and Regional Center from Being Named a Conservator – Professional

ISSUE: Appointment of DDS/regional center executive director as a conservator.

RECOMMENDATION: When a conservatorship is removed from a family member or a regional center client needs to be conserved for some reason, DDS/the regional center executive director should not be named, CA should establish a system similar to CASA (Court Appointed Special Advocates) for regional center service recipients.

3. Require Plain Language DDS Directives – Professional

ISSUE: Community members have shared the need for a policy change: plain language versions of all DDS Directives. DDS should be required to publish a plain language version of all directives at the time of directive release. The system is complex, many areas understaffed, and procedures and policy change evolve often. Community members need to review directives to understand what regional centers should be doing. This has become a part of self-advocacy and family-advocacy over the years. Additionally, many service providers have also mentioned that a plain language version of each directive would be helpful for them, for similar reasons.

RECOMMENDATION: Require DDS to publish a plain language version of all directives at the time of directive release.

4. Mandate Inter-Agency Data Sharing – Professional

ISSUE: To establish a mandatory statewide interagency data-sharing agreement between the Department of Developmental Services (DDS), the Department of Rehabilitation (DOR), and the California Department of Education (CDE) to track and evaluate the effectiveness of Local Partnership Agreements (LPAs) in increasing competitive integrated employment (CIE) for individuals with intellectual and developmental disabilities.

RECOMMENDATION: A legislative mandate that requires DDS, DOR, and CDE to enter into a formal interagency data-sharing agreement. This mandate should have a clear purpose, scope, required data sets, and privacy protections. In addition, a timeline for implementation. Special considerations would include IT upgrades aligning with interagency coordination.

5. Eliminate Income Maximums for IHSS – Self-Advocate

ISSUE: There is a requirement that says people who have IHSS must have a low-income level to qualify for IHSS.

RECOMMENDATION: Get rid of the income requirement so that more people can get the care they need.

6. Allow Regional Center Choice – Family Advocate

ISSUE: Disparity in regional centers: not all regional centers have the same vendors/services.

RECOMMENDATION: Allow families to select their regional center or have a choice in which regional center they prefer to use if the regional center assigned does not provide services needed for an IPP. An example is schools – if a school district does not offer services a child needs, the family is offered services outside of that school district. The same should be true of regional centers. Some regional centers do not offer certain services due to different policies.

7. Define Mechanism to Fund Overtime Pay for Individuals Who Require a Lot of Assistance – Family Advocate

ISSUE: Individuals who require a lot of assistance confront many structural barriers to accessing services that are discriminatory and which compromise entitlement to services. The current method of meeting high level needs, which centers on the Health and Safety (H&S) waiver, needs to be restructured. The decision to apply for a H&S Waiver should not be solely up to a vendor provider who can instead simply decline to serve the person at any time, before or after they accept a client.

RECOMMENDATION: We need a defined mechanism to fund overtime pay for individuals who require a lot of assistance. Overtime (OT) charges are routinely incurred by individuals who require a lot of assistance who require more than 40 hours a week of support, which creates a built-in discriminatory barrier to accessing services when that overtime is unfunded. The federal government first mandated overtime pay for direct support professionals (DSPs) in 2016, an act that created an unfunded mandate from which our system has never recovered. When DSP overtime became law, the state Department of Social Services (DSS) funded In Home Support Services (IHSS) overtime to some degree (up to 30.75 hours a week for providers working for only 1 client), but the Department of Developmental Services (DDS) did not follow suit, and OT has never been explicitly funded for high needs people in the regional center system.

Recommendations include the following:

1. Health and Safety Waiver Solution:
    a. Individuals who require a lot of assistance should be empowered to request a Health and Safety Waiver after they are rejected by a vendor provider who is accepting other clients but does not believe they can meet this client's needs.
        i. Vendors should be paid for their time to submit a Health and Safety waiver on a client's behalf, without which that client would be bereft of services.

b. Certain groups of individuals who clearly require a lot of assistance should be identified by a DDS stakeholder group in advance, for the purpose of automatic qualification for inclusion in a Health and Safety Waiver. These standing H&S Waivers should be publicly accessible and identified in a person's IPP. Such groups should include:
    i. Those who have been assessed by IHSS to require protective supervision (which in general means more than 40 hours a week of mandated support.)
    ii. Those who have a diagnosis that is associated with high authorized expenditures but low utilization of services. This combination is indicative of a barrier in accessing authorized services. For example, at Alta California Regional Center, this is clearly the case for adults over 22 who have a cerebral palsy diagnosis, where authorized service dollars are by far the highest ($77K), but utilization is by far the lowest (58%) of 5 major diagnostic groups (see p. 15 at ACRC Purchase of Service Data). ACRC Purchase of Service Expenditure and Demographic Data Fiscal Year Report 2020/21, p. 15. https://www.altaregional.org/sites/main/files/file-attachments/fy_20-21_pos_exp_data_-_english_1.pdf?1663108207

c. Overtime Solution:
    i. DDS should fund DSPs overtime to at least the same extent as DSS does for IHSS providers. The IHSS-funded overtime is up to 30.75 hours a week for a single IHSS provider working for only 1 client, or up to 26 hours a week for a single IHSS provider working for multiple clients.

d. Disability Related Absence Solution:
    i. People whose disabilities prevent them from meeting participation guidelines of a vendor provider should be empowered to apply for funding for disability-related absences, rather than be excluded from vital regional center funded programs.

8. Automatically Raise Staff Wages When Minimum Wage Increases – Family Advocate/Professional

ISSUE: There is no legal mechanism in CA to raise my staff wages (DSP, IHSS, and job coaches) whenever the state passes a new minimum wage mandate. This leads to wage compression and inability to hire and maintain staff.

RECOMMENDATION: Pass a law that would trigger an automatic rate increase (and/or DSP wage pass-through) every time the state passes a new minimum wage mandated increase. The increase must consider the additional increase needed for staff benefits, FICA, WC, etc. that is attached to any wage increase.

9. Include Individuals with IDD in Disaster Planning – Family Advocate

ISSUE: There is no place to go with my brother, and many others like him, during emergency evacuations. He requires a "durable environment," which he has in his personalized home. Reasonable accommodations are not only about being wheelchair accessible. During emergency evacuations people with high behavior support needs have no place to go.

RECOMMENDATION: Local and state agencies should include people with high behavior support needs in emergency preparations – that includes making spaces that are “durable environments” available during emergencies.

10. Allow In-Home Respite to Be Delivered Elsewhere – Family Advocate

ISSUE: Respite services are designed to give parents a break; however, respite services provided only in the home further isolate a person with disabilities. 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: Respite services should be allowed at any location where there is a respite provider available whether in the respite provider's home or out in the community.

11. Conservatorships – Family Member

ISSUE: Currently co-conservators who share 50/50 need to agree on all SDP activities.

RECOMMENDATION: Do not require co-conservators to agree on all activities. Many co-conservators are divorced mothers and fathers. A mother's choice of activities does not match a father's and vice versa, like an occupational therapists' activities will not match a physical therapists', and yet both are unique and important to the conservatee. The conservatee will get more varied, specific, and appropriate activities and will not have his/her activities halted because the conservators did not agree on the SDP activities.

12. Accountability of Regional Center Staff – Family Member

ISSUE: Accountability of Regional Center staff. Improve services through feedback from people that have received assistance.

RECOMMENDATION: Send Regional Center participants/family members annual surveys regarding the performance of their case manager.

13. IHSS Updates to Provider Log-In – Family Member

ISSUE: IHSS insists that the provider log in from inside the recipient's home, even when the recipient is better served by daily prompts on the phone. Some people with autism find face-to-face encounters to be exhausting. A prompt delivered over the phone does not make that the person with autism interpret facial and body expressions, which are well known deficits with this condition. The deficit is extreme enough that in-person help does not help at all. It creates confusion and anxiety. IHSS has no way to allow for services to be provided by a remote provider.

RECOMMENDATION: Allow for a waiver in IHSS services for clients with developmental disabilities who can respond to verbal prompts, but because of their disability, in-person help does not help. An ancillary change would be that in some cases a Notice of Action would be required when IHSS fires an IHSS provider for any reason. Currently, removing a provider is not considered a change in services which makes the action ineligible for appeal.

14. Aging Adults with IDD – Professional

ISSUE: I'm on the ONEGeneration Collaborative and there is general agreement that more needs to be done at the regional center (and DDS level) regarding older adult services in the IDD system. Generally, the IDD population is living much longer due to better healthcare and other factors. However, older family caregivers and older adults are not being provided with information and resources as the regional center system is not equipped for older adult specialization.

RECOMMENDATION: Legislation to add specialized care coordination and other support services at regional centers targeting older adults 45+ with intellectual disabilities

15. Access to IHSS Supports, Mental Health – Self-Advocate

ISSUE: I personally believe that Sacramento County having sole decisions over which disabled people qualify for services is detrimental to getting aid to those most vulnerable. Too much concern over fraud, but statistically mentally ill patients are the least likely to seek help out of fear, shame, and value of privacy. Our doctors, and providers with the most experience and knowledge of a patient’s disability, who are advocating for us should be heard, and recognized.

RECOMMENDATION: There needs to be changes made with the partnership between Medicaid and Sacramento County being in charge of approving IHSS services.

16. Autism Training IHSS – Self-Advocate

ISSUE: Current IHSS assessments vary significantly by county and individual worker. Many autistic applicants are denied or granted insufficient hours due to misunderstanding of their disability-related needs. Under-allocation of hours forces caregivers into economic hardship, burnout, or unsafe conditions.

RECOMMENDATION: Reduce assessment disparities by mandating autism-specific training for IHSS social workers. Require the development and use of standardized autism-specific assessment rubric to guide decision-making for both minors and adults. These changes would be implemented through CDSS's IHSS Training Academy (IHSSTA) and incorporated into assessment procedures and quality assurance protocols. Improves consistency and accuracy and decreases family crises. Increases predictability, transparency, and aligns with federal disability rights law requiring individualized, equitable assessments. Increases the autonomy, self-determination, and quality of life for people with disabilities and their families.

17. IHSS Staff Training – Self-Advocate

ISSUE/RECOMMENDATION: Staff in independent living support programs should be required to have an education in working with people with disabilities. Independent living programs should hire people who are well trained in working with people with disabilities.

18. Aging Adults with IDD Planning – Professional

ISSUE: Older adults with IDD and older family caregivers are being neglected and underserved by the system. The regional centers have expert knowledge and target case management for Early Start, but no such expertise for the consumers and families who are aging. The sheer numbers of adults and caregivers who are now living longer demand a specialized approach for this time in their life cycle.

RECOMMENDATION: The regional center system should implement specialized case management for adults 45+ and their older adult caregivers. They should institute Individual and Family Aging Plans (IFAPs). This structural change would mirror the Early Start approach to case management with a specialized unit that uses Individual and Family Service Plans (IFSPs) to serve the entire family unit. Additionally, the Family Resource Centers need to be outfitted with resources, trainings and support groups for older adults and older family caregivers; again, this would replicate the support that Early Start families receive.

19. IHSS Eligibility and Maintaining Benefits – Family Member

ISSUE: The process of remaining eligible for services is inefficient, unnecessary, and cumbersome**.**

RECOMMENDATION: At the beginning of each form/questionnaire there should be a short section that asks if the individual is a client of the regional center. If the disability is expected to be permanent. If there are any major changes to their living situation. If the answers to those questions are Yes, Yes, and No, then they shouldn't have to go through the whole form in order to keep their basic benefit.

20. Continue Care of Regional Center Services During Hospitalizations – Professional

ISSUE: When Regional Center consumers are hospitalized, they often lose access to their regular support providers due to funding restrictions, leaving them without advocacy or communication support during life-and-death medical decisions. This puts consumers at risk of being excluded from decisions about their own care, receiving treatment that does not align with their wishes, experiencing trauma and a loss of dignity at the end of life. This change would protect their rights, promote self-advocacy, and ensure person-centered care in their most vulnerable moments.

RECOMMENDATION: Amend the Lanterman Developmental Disabilities Services Act to guarantee uninterrupted access to regional center services and IDD-informed advocacy when consumers are hospitalized and facing end-of-life decisions. This would require an exception to current policies that typically pause regional center services during hospitalizations. There must be a funding exception that allows regional center services to remain active during these critical moments, even if hospital vendors are also billing for care. Regional centers must establish emergency response protocols to authorize these supports quickly.

21. IHSS Workers/Caregivers Should Be Able to Opt into FICA – Family Advocate

ISSUE: Parents often need to give up their careers to care for their children with developmental disabilities, often well into adulthood. Once a parent becomes too elderly or disabled to physically care for their adult child and be paid as a caregiver, they are left with no social safety net because they have worked for years but have not paid into Social Security. This is poor public policy, both for parent caregivers and for adults with disabilities, who may find their lives disrupted and their housing and basic supports jeopardized when their primary caregiver no longer has a source of income.

RECOMMENDATION: Parent caregivers/providers are currently prohibited from paying into FICA. I want parent IHSS providers to be able to opt into FICA, or if this is not possible, to be allowed to opt into the state retirement system for public employees, CalPERS.

22. Communication with Regional Centers: Should Include Zoom Meetings – Community Advocate

ISSUE: Regional centers have a moral obligation to communicate with their communities. Currently Harbor Regional Center informed that they are holding in-person meetings only.

RECOMMENDATION: Require board meeting agenda packets to be posted at the regional center website and require board meetings to be offered on Zoom. To expect people to attend in person is ridiculous when we have the technology of Zoom. And IPPs can be done remotely, why not regional center board meetings. A number of centers post packets and do Zoom meetings. That is a best practice.

23. CalWorks Process of Verification of Disability is Burdensome – Family Member

ISSUE: Stress and hardship in having to go to a physician to get a form signed each year. Policy with Health and Human Services for CalWorks program requires annual verification of disability (Form CW61) to waive participation in work, training, or educational activities be signed by a physician. Also, employer sponsored health insurance companies require a similar from be signed by a physician for adult children with a disability to be covered.

RECOMMENDATION: Persons with a permanent disability status should not need a physician to sign a form yearly to say they have a disability. Forms should have a check box for permanent disability.

24. Improve Service for Non-Verbal IDD Clients in Regional Centers – Family Advocate (translated from Spanish)

ISSUE: Service Coordinators do not explain what services are available to non-verbal clients.

RECOMMENDATION: Regional centers should both identify and inform families of the services available to help non-verbal IDD clients improve communication skills.

25. CA Children's Services (CCS) Program – Family Advocate (translated from Spanish)

ISSUE: Many clients and their families go without services because they do not know where to go to ask for supports.

RECOMMENDATION: For services to continue as children become adults, the same services provided by CCS, but with the focus on adults and to be named CAS for CA Adult Services.

26. IHSS Services Must Be More Person-Centered – Self-Advocate

ISSUE: The IHSS reassessment process must be more person centered.

RECOMMENDATION: Simplify the IHSS reassessment process so that it can focus more attention on what a recipient can or cannot do. It would put more emphasis on helping IHSS social workers know about their clients' physical capabilities if they have a specific physical disability rather than just giving them a mini mental health evaluation.

27. IHSS Respite Hours Are Not Enough – Family Advocate

ISSUE: My daughter needs to get in to a program but her worker from Alta California Regional Center told me and her teacher that she can't get in to a program at all period because she is in school until the age 22 year old but my daughter doesn't have anything to do at home, she is bored and needs to be around kids her age group not under me. She needs an activities program and needs a door-to-door pick up because we don't have a car to get to them to program. She needs to be in the group home for respite care that pays more hours. 120 hours is not enough; I need more breaks than that.

RECOMMENDATION: Provide more respite hours and additional assistance with activities for my daughter.

28. Delays in Self-Determination Programs – Family Advocate (translated from Spanish)

ISSUE: If services are approved in a regional center, they should not be removed without notice. They do not provide retroactive payments for SDP. Many administrative delays in SDP.

RECOMMENDATION: Provide strict deadlines, allow retroactive payments, automatic continuation without gaps, sanctions for delays.

29. Eliminate Racial Disparities in Regional Centers by Limiting Terms of Executives – Family Advocate

ISSUE: Racial disparities in services amongst minorities who are clients of the regional centers. Retaliatory actions by regional centers' executives against families who speak up for their rights and the rights of their children with developmental disabilities. Draconian style of misusing federal and state funds by regional center executives for retaliatory purposes. It allocates our tax dollars to the intended individuals with disabilities and not line the pockets of these authoritarian and corrupt executive staff at the regional centers. It eliminates DDS from having to reward the regional centers with more financial incentives. It eliminates the billions of dollars of federal and states funds that are still missing following audits into the regional centers and DDS. It eliminates the fraud and abuse by regional centers that deny their clients and the support that the family needs as promised in the Lanterman Act.

RECOMMENDATION: Individuals who hold the regional centers' executive positions, specifically the executive director, the director of support services, and any executive position in between, shall be terminated from holding these positions of no more than 5 years of service at all regional centers and shall not be permitted to continue employment with any regional center thereafter.

30. Regional Center Transparency – Family Advocate

ISSUE: Regional centers often give pamphlets to new families and offer support but aren't 100% transparent about the exact types of services and support RC consumers can get through regional centers. Right now, only people connected or who have the time to research information have the knowledge to ask for specific services. This is an equity issue for those underprivileged and/or lower socioeconomic status – and also for those who face language barriers.

RECOMMENDATION: Transparency – every regional center needs to make the list of possible services available on their website**.**

31. CPS and Regional Center Clients – Family Advocate

ISSUE: Child Protective Services (CPS) and Alta California Regional Center (ACRC) clients and how they deal with cases involving ACRC parents.

RECOMMENDATION: Change how ACRC clients are supported by CPS, ACRC has a duty to put resources in place to keep the family together, like mandatory placement with housing and an independent living services helper.

32. Oversight of Regional Center Vendor Agencies – Family Advocate

ISSUE: I am writing to you not only as a concerned citizen, but as a mother who lost her son while he was under 24-hour care through a vendor contracted by the regional center. His death, in part, resulted from a lack of proper oversight, regulation, and accountability in the care system. I am urging the State of California and the Department of Developmental Services to implement stronger requirements for vendor agencies and their staff.

RECOMMENDATION: Need improved oversight of vendored agencies at regional centers. I propose the following: mandatory training and counseling hours: all caregivers should be required to complete and document standardized training hours, including ongoing education. This training must include client-specific instruction based on each individual's diagnoses, capabilities, and restrictions. Client awareness and understanding: caregivers should be required to review and demonstrate understanding of each client's unique needs. This should be verified by supervisors and reviewed regularly. Activity documentation and oversight: while activity logs may currently be required, it appears enforcement is inconsistent. The regional centers and the State should establish a system to regularly audit caregiver notes and ensure compliance with documentation standards. Stricter hiring protocols for vendor agencies: agencies contracted by the State should be held to a uniform and enforceable standard of hiring that includes thorough background checks, mandatory drug testing, reference checks, and verification of qualifications. These steps are essential for the protection of vulnerable clients. I hope you will take this request seriously and consider adopting legislation or regulatory changes that could prevent future tragedies. No family should have to endure what mine has. The responsibility to care for our most vulnerable must come with clear expectations, accountability, and compassion.

33. Allow Parent Choice in Self-Determination Program – Family Advocate

ISSUE: The problem is that a child with IDD is forced into different circumstances and people that he is not familiar with and as we know, changes in routine and personnel are very difficult for autistic young adults.

RECOMMENDATION: Allow developmentally delayed adult children to be able to choose their parents to be their personal assistant.

34. Parent Caregiving Hardship – Family Advocate

ISSUE: As someone who is both disabled AND the parent of a disabled child, the amount of trauma I experienced raising her because I couldn’t work and couldn’t afford life has probably shortened my lifespan by 15+ years and caused significant damage to my brain, body, and mental health. I was dedicated to being there for my child, which STILL at 18 years old is nearly 24-7 care. That meant constant poverty and financial stress, but I didn’t have the choice to abandon her.

RECOMMENDATION: Parents of minors being unable to get paid by regional centers for the extraordinary caretaking that developmentally disabled children require.

35. Planning Death of Clients with No Family– Professional

ISSUE: Issue needs to be resolved as to who will take care of a client's passing if they have no family. When a client dies in a hospital and with no family, the body is taken to the county morgue and stays there for 5 years to be cremated with other bodies, unless regional center or provider will pay for it. No cremation allowed because of the 5-year limitation for any family member to claim the body.

RECOMMENDATION: Pre-needs should be provided and included as part of the regional center services during placement. Add as special services – for extra funding and should be done during placement.

36. Reduce/Prevent Caregiver Burnout – Family Advocate

ISSUE: Caregivers experience burnout and need support resources.

RECOMMENDATION: Create the Family Resilience & Caregiver Support Act (FRCSA). Purpose: to reduce caregiver burnout, increase access to trauma-informed resources, and prioritize the lived experience of families raising children with disabilities. This act places caregivers at the forefront by eliminating bureaucratic obstacles, providing monthly wellness stipends, and establishing parent-led community councils.

1. Paperwork streamlining & consumer-centered access caregivers of children with disabilities often face burnout before support ever reaches them — due to endless paperwork, re-qualifications, and redundant requests across agencies. This law ensures that families are not retraumatized by red tape:

   a. Existing legal documents will be honored: families who have already submitted proof of eligibility (e.g., SSI/SSDI approval, IEPs, guardianship orders, disability determinations) will not be required to complete additional eligibility forms.
   b. One-time verification form: a universal "One-Time Verification Form" will be used to link documentation across programs, making it valid for all relevant services statewide.
   c. Automatic cross-recognition: any agency receiving public funds must accept verified documentation from related services – removing the

need to “start over” with each new program. The goal: to put services in reach without exhausting the families who need them.

2. Monthly caregiver wellness stipend eligible primary caregivers of children receiving SSI/SSDI or with an active IEP will receive a $500 monthly stipend, delivered via a reloadable “Caregiver Resilience Card.” Approved uses include:

    a. Therapy or mental health support
    b. Somatic and holistic healing services
    c. Trauma-informed parenting workshops
    d. Home sensory tools and regulation equipment
    e. Short-term respite care with approved providers. Funds are non-taxable and renewed monthly. Caregivers are empowered to choose what supports their emotional and physical restoration.

3. Parent-Led Family Resilience Councils. Each region will form a Family Resilience Council (FRC) made up of parents and guardians of disabled children. Their role includes:

    a. Shaping and reviewing local disability and mental health services
    b. Approving trauma-informed training for respite providers and educators
    c. Hosting caregiver listening circles and resource-sharing events
    d. Serving as advocates and advisors to schools, clinics, and community programs Council members receive:
    e. A $250 monthly stipend for participation
    f. Priority access to new support programs and family grants
    g. Advocacy and trauma-informed leadership training. When caregivers are stable, resourced, and heard, children thrive. This act recognizes that healing begins with access, and access begins with removing barriers.

37. Inequality in Services: Self-Determination (SDP) v Traditional Program – Family Member

ISSUE: There's a widening inequality between what services and supports can be provided to those in the traditional model compared to those in SDP. Most alarming is the difference between what workers are allowed to be paid by state mandates in traditional services compared to what the same workers earn in SDP. For direct service providers (DSPs), for instance, the rate in San Diego is around $19/hour while the going rate here for those in SDP is $30-35. And many services – like communication partners, 1:1 supports, fitness coaches, and certain camps – are only available in SDP. The problems are: 1. The drain of DSPs from traditional service agencies to SDP clients. At my son's last day program, for instance, staffing issues kept him home at least twice a month, then for three months. Many of their workers were lured away by higher pay in SDP. 2. Some clients can't go into SDP because they're in or planning to go into group homes or they don't have a family member who can take on the rigorous tasks of managing SDP. They are being shut out. Also, regional centers don't seem to have a plan for taking over SDPs when parents die. 3. My sense from observing families is that SDP requires one parent or caregiver not to work to manage SDP (hiring, budgeting, payroll and more), transport loved ones and fill in for DSPs when they're sick. This raises income inequality issues.

RECOMMENDATION: I think the Council should research the potential inequality issues I've raised here, perhaps with a state university (like the UC Davis MIND Institute). Questions to ask include: what is the going rate for DSPs in traditional v. SDP? What services are available only to SDP clients that are not available to traditional model clients? What are the family incomes in the two groups? Can parents or guardians work full-time and manage SDP? How many clients in group homes are in SDP? What happens to SDP clients when their parent or guardian dies or is unable to manage the program?

38. IHSS Administrative Burden Creates Caregiving Barrier – Family Advocate

ISSUE: During the COVID-19 pandemic, the Public Authority was able to verify IDs and social security cards through email. However, this administrative process is done in person. Currently, when In-Home Supportive Services recipients find someone to employ as caregiver, they must wait for their hire to go through the verification process, which includes orientation, ID/social security check, and fingerprinting. This process takes up to 10 weeks. Currently in Santa Clara County, there is an over 10-week wait from the time of orientation until they can get their ID and social security card validated. Only then can the new hire get fingerprinted and then wait again to be told if they are cleared, then added to IHSS as a provider. This process should take a month, but it takes well over 3-4 months. Since there is a caregiver shortage, and we know that providers are undervalued and underpaid, this would help the entire state to address the backlog of providers entering the system and ensure that IHSS recipients can hire and get people paid in a reasonable amount of time. As a reminder, no private business can hold pay for multiple months due to onboarding requirements. Why is it okay for the IHSS program, which then loses provider opportunities for so many aging and disabled people it serves?

RECOMMENDATION: Modify the process for the Public Authority to verify IDs and social security cards from in-person to virtual, only for providers of the IHSS and WPCS programs. I would like there to be a virtual option, especially since your ID must be verified again when you get fingerprinted.

39. IHSS Protective Supervision Hours Should Be Eligible for Submission Because This Helps Clients that Cannot Communicate – Family Advocate

ISSUE: IHSS protective supervision hours do not apply when a recipient is hospitalized. When recipient is hospitalized and not under sedation or awake. When recipients are in clinics, i.e. cancer or repetitive treatments that require recipients to maintain hospital or clinic settings to ensure their health and prevent complication due to their inability to communicate symptoms, side effects or pain due to their cognitive global delay or impairment of speech.

RECOMMENDATION: IHSS protective supervision hours should be eligible for submission. This will facilitate process for hospital by 1) expanding ways to understand the needs and wants of patients that are not verbal and or have cognitive delay, and, 2) could increase the accuracy of diagnosis and treatment of patient by communicating new or known behavior, 3) reduce the risk for allergies to medication, 4) reduce the risk of over or under medicating patient due to not knowing how the patient communicates its wants or needs, 5) reduce the liability factor of eloping, escaping, falling, 6) reduce the risk of using excessive force by security personal when person is having a crisis, meltdown, or elopement, 7) reducing the risk of excessive medication when elopement, 8) reducing risk for patient/ recipient for self-injury or injury of nurses or staff.

40. Create Certification Programs to Encourage Quality Providers – Family Advocate

ISSUE: I want the California Online Community College (CalBright) to develop a certification program for providers of care for individuals with developmental disabilities. California is grappling with a crisis in access to care for individuals with developmental disabilities due to a substantial shortage of service providers dedicated to serving those with developmental disabilities. Staff providing direct care are paid at or just above the minimum wage and do not complete a robust prescribed course of training. As a result, the staff turnover rate is high. By developing a model curriculum that grants certification to individuals seeking to work with those with developmental disabilities, we can empower this essential workforce to demand higher wages because of their professional training

RECOMMENDATION: Amend the Education Code – the Legislature finds and declares both of the following: (A) There is a great need in the State for well-trained providers of care for individuals with developmental disabilities. (B) Providing care for California's population of individuals with developmental disabilities is a difficult job that requires a practitioner to possess unique and specific skills to provide the high-quality care that these individuals deserve. (2) It is, therefore, the intent of the Legislature to enable the California Online Community College to create a certification program to establish a pathway for people interested in these careers to obtain the necessary preparation. (b) The California Online Community College in collaboration with the Department of Developmental Services shall develop a model curriculum for a certification program for providers of care for individuals with developmental disabilities. This model curriculum shall be designed to be offered at the California Online Community College. In developing the model curriculum, the college shall consult with individuals and organizations with expertise in providing care to individuals with developmental disabilities and the training of practitioners for that task.

41. Service Provider Billing and Accountability – Community Advocate

ISSUE: With increased funding for service providers should come increased oversight, especially of the top 10 paid Purchase of Services providers. Some I have spoken to have been in the top 5 (as listed on their regional center 990s) for 10+ years and NEVER ever had anyone from the regional center or DDS step foot in their office door, let alone do a billing or staff training audit. And some are now being bought out by large private equity firms who demand profits and are not raising personnel wages of direct support professionals. Taxpayers and legislators deserve to know that DDS and regional center funding is being billed ethically, and that staff are given training the rate study included and regulations require.

RECOMMENDATION: Quality assurance and auditing regulations need to be expanded beyond just day programs and residential facilities, which are no longer the services being provided by the top paid POS service providers at most regional centers. Supported living services (SLS) agencies and personal assistance (PA) organizations are now the largest since the pandemic, and there is little to no oversight. Regional center caseload ratios need to be expanded to allow for one QA position and one external auditor position to work together on unlicensed programs such as SLS and PA and do audits of the top 5-10 POS service providers in each regional center every single year to do a sample billing audit and staff training compliance audit. When deficiencies or fraud are found, a deeper and expanded audit needs to be done. Any overpaid funds should be collected within three months of the audit, the provider be punished for at least a year and only given 90% QIP funding, and those collected funds should stay in the DDS system and not have to revert to the general fund. In a time of budget cuts, this could hold those providers who are making the most money to a reasonable standard of accountability to ethically manage public funds, and ensure they have systems in place to verify the State is paying for services provided. As another positive result, it may send a message to the predatory private equity organizations engaged in statewide merger and acquisition activities that the DDS/RC system is not a cash cow and there are standards and guardrails that exist.

42. Delay of Services in Regional Centers Is a Barrier to a Child's Progress – Family Advocate (translated from Spanish)

ISSUE: People with developmental disabilities face long waiting lists for general services such as therapies, psychological care, or psychiatry – especially when they rely on Medi-Cal. In my experience as a mother, I've seen that when there's an urgent need, families seek private services, but the regional center takes a long time to cover them because it is considered the "payer of last resort." This process can take months or even years, and in the meantime, the child misses out on important progress and loses valuable time that is crucial for early intervention and making meaningful developmental gains that could lead to a better quality of life in adulthood.

RECOMMENDATION: I propose the creation of a law that:
- Requires the regional center to respond within 30 days with options for accessing services when generic services have a waiting list and do not meet the need.
- Authorizes immediate coverage of private services if the generic provider has a wait time of more than 30 days.
- Prohibits the denial of urgent services solely because the regional center acts as the payer of last resort.
- Establishes automatic reimbursement for families who pay out of pocket due to a verified need.
- Impose administrative sanctions in cases of negligence or unjustified delays.

SAFETY

1. Emergency Safety – Professional

ISSUE: Persons with wheelchairs and evacuation safety.

RECOMMENDATION: Ensure that people with wheelchairs can evacuate safely during emergencies or disasters.

2. ADA Accommodations in Public Restrooms – Professional

ISSUE: Parents being able to move small children from diapers to using the toilet. For small-sized older people to have a safer way of using the toilet.

RECOMMENDATION: Include built-in small-sized toilet seat lids in public restrooms.

3. Training for Public Safety and Law Enforcement – Family Advocate (translated from Spanish)

ISSUE: People with autism should be treated with dignity and understanding when they experience a crisis or emergency.

RECOMMENDATION: Require sensitivity training for law enforcement and first responders.

4. Accessibility of Street Lights – Self-Advocate

ISSUE: Prevent crimes in dark alleyways and streets. Avoid astronomical fees in the City of San Francisco's electric bill when the people controlling the lights don't turn off the electric streetlamp.

RECOMMENDATION: Motion-sensitive streetlamps instead of electric ones to save electricity and to prevent crimes. Put motion-sensitive streetlamps in dark areas and alleys in the City of San Francisco to prevent crimes.

5. Require Public Safety Officer Trainings – Family Advocate

ISSUE: One in five people are neurodivergent, often with major sensory sensitivities. Public safety interventions can have bad outcomes when sensory conditions are triggered or not accommodated.

RECOMMENDATION: All police and public safety officers should be required to learn how to be sensory-friendly, recognize sensory overload, and know how to make sensory-sensitive people more comfortable.

6. Require Specialized Training for Public Safety Responders – Family Advocate

ISSUE: California currently lacks a statewide policy that ensures all emergency responders including police, firefighters, EMTs, and 911 dispatchers receive specialized training on how to safely and appropriately interact with individuals with intellectual and developmental disabilities (IDD). Additionally, there is no statewide system that allows people with disabilities to voluntarily share critical, non-medical support needs with 911 services in advance, which would help responders act appropriately and avoid unnecessary harm or escalation during emergencies.

RECOMMENDATION: Mandate all emergency responders in California: including police, firefighters, and EMTs to receive specialized, evidence-based training on how to appropriately interact with individuals with developmental and intellectual disabilities. It would also require 911 dispatch centers to implement voluntary disability alert systems that flag when a caller or resident has a disability, ensuring first responders are prepared. Instead of disclosing a specific disability label, the registry can simply state that the individual may require specific types of support or has unique communication or behavioral needs in emergencies.

7. Allow Cameras to Prevent Abuse – Family Advocate

ISSUE: It is not allowed to have video cameras in certain facilities that provide services. Cameras will provide transparency and will help staff, clients that cannot communicate and families.

RECOMMENDATION: Force video cameras in any service provided facility.

8. Create a Statewide Caregiver Abuse Registry – Family Advocate

ISSUE: I want to create a statewide Caregiver Abuse Registry that benefits individuals with disabilities that require caregivers.

RECOMMENDATION: A statewide registry can help individuals with disabilities and their families research any substantiated history of abuse by applicants seeking caregiving positions. It can decrease the risk of abuse by a caregiver by giving the individual doing the hiring more background information and discourages abusive caregivers from seeking more employment in the caregiving service sector because they know it has been logged into a public registry.

TRANSPORTATION

1. Hotel Lift-Equipped Shuttles – Self-Advocate

ISSUE: The policy that says that hotels don’t have to have lift-equipped shuttles for hotel guests who have disabilities**.**

RECOMMENDATION: Medium-to-large hotel chains need to have lift-equipped shuttle buses because many don’t**.**

2. Lack of Reliable Personal Transportation for IDD – Family Advocate

ISSUE: Prior to the pandemic, UBER WAV provided reliable door to door transportation for IDD Individuals at a reasonable price. Since the pandemic, UBER WAV no longer provides this service, leaving IDD individuals to rely on public transit. Public transit creates its own set of issues for the IDD community: it is not always a safe or time efficient mode of transportation. In addition, accessible transportation that is currently available is expensive. IDD individuals are on a fixed income and cannot afford to utilize this type of transportation.

RECOMMENDATION: Requiring UBER or another transportation agency to provide door-to-door transportation would allow the IDD community freedom to travel throughout the Bay Area to as their non-disabled peers to educational, recreational activities as well as medical appointments.

3. Improve Public Bus System – Self Advocate

ISSUE: Bus does not run on Saturdays and Sundays in El Dorado County. It would help me and give me something to do if I had transportation.

RECOMMENDATION: Have public transportation available on the weekends.

4. Transport Systems in CA Need Improvement – Family Advocate

ISSUE: People like my son could ride public transit without the fear of getting stuck or being defeated by ticketing or math (which is a permanent deficit for him). He could travel to work independently or to other locations on his own. We would be glad to pay.

RECOMMENDATION: California transport systems should have a system that would allow qualified individuals to have an annual pass to transport systems. Parents or conservators or other responsible entities could pay the annual fees, and the person wouldn't have to struggle with ticketing.

5. Lack of Access to Public Transportation Affects Employment – Self-Advocate

ISSUE: Remove public transportation barriers for Californians with disabilities – little to no access to public transportation causes barriers for employees who do not have transportation to get to jobs.

RECOMMENDATION: Change access laws for Californians with disabilities to remove public transportation barriers – to access our communities, our jobs, internships or applying for State government careers.

6. Improve Public Transportation, Remove Barriers for IDD – Self-Advocate

ISSUE: Barriers in public transportation limit us from accessing public transportation within our local, county, communities.

RECOMMENDATION: Removing transportation barriers to improve access.

MISCELLANEOUS

1. Eliminate Individuals with IDD from Serving Jury Duty – Family Advocate

ISSUE: I would like to propose a law that removes all IDD persons from being requested to serve on jury duty.

RECOMMENDATION: All names should be flagged and removed. The caregivers can have documentation that they are not required by law to show up.

> <u>SCDD Side Note:</u> This idea does not align with SCDD values and appears to reflect an individual perspective rather than a community view.

2. Bar Individuals with Unsatisfactory Immigration Status from Public Services – Family Advocate

ISSUE: Immigration Reform and Accountability Act

RECOMMENDATION: Services in education, employment, health, housing, safety, self-advocacy should go to citizens and legal residents. Everyone receiving these services should be required to show that they are here legally. Anyone caught using state or federal funds to provide these services or aiding/abetting individuals with unsatisfactory immigration status should be prosecuted.

> SCDD Side Note: This idea does not align with SCDD values and appears to reflect an individual perspective rather than a community view.

3. CA Social Work Title Protection – Professional

ISSUE: Giving title protection to all social workers in California will protect all consumers in California by ensuring that their social workers have met all the education requirements set by the Council on Social Work Education (CSWE), which includes time in the field conducting practicums (internships) to ensure they have the necessary experience. The idea would benefit people with intellectual and developmental disabilities by giving them the proper knowledge and confidence that their social worker has had both the academic and practicum experience required to obtain their degree and rightfully have the qualifications necessary to call themselves social workers.

RECOMMENDATION: Give title protection for all Social Workers in California by allowing only those with an academic degree accredited by the Council on Social Work Education (CSWE) to hold the title of Social Worker.

4. Undiagnosed Parents and their Children with IDD – Family Member

ISSUE: Children with special needs rely heavily on parents or guardians for consistent care, advocacy, and navigation of complex systems (medical, educational, social services). However, a significant but often overlooked population exists: parents who themselves have undiagnosed intellectual disabilities, cognitive impairments, or severe functional limitations, yet do not meet existing thresholds for state support. These parents are often not identified because they are outside the foster care or disability system, leaving children vulnerable to neglect – not from lack of love, but lack of parental capacity.

RECOMMENDATION: I want to introduce a new policy or law that ensures parents with undiagnosed cognitive, intellectual, or functional challenges – especially those raising children with special needs – are identified early and provided with structured support, rather than only being addressed through child welfare interventions after harm occurs. Create a statewide framework for parental capacity screening when a child is identified as having special needs. Establish Functional Support Plans (FSPs) for parents, similar to IEPs for children. Provide state-funded parent advocates or navigators to help parents manage educational, medical, and social service responsibilities. Mandate cross-agency communication between schools, healthcare providers, and child welfare agencies to identify at-risk families.

5. Universal Human Rights – Family Advocate

ISSUE: Lack of human rights, water should be a basic human right. Food should be a basic human right. Healthcare and mental healthcare, these things that are necessary for thriving together should be human rights. Belonging in community. Civic education, engagement, and participation should be a human right.

RECOMMENDATIONS: A declaration of universal human rights and the protection of said rights conferred upon all people with extra consideration for those unable to advocate toward such rights for themselves. I suggest a fundamental restructuring of how we make joint decisions to start following a hierarchy of values as a basis for the structuring of such rights and rationale of the inclusion of rights.

6. Amend Family Code to Allow Disabled Children to Receive SSI Benefits in Addition to Child Support – Family Advocate

ISSUE: Currently adult disabled children and their families are virtually being forced to choose between child support or SSI. The law should follow the intent of Congress, which is for this population to have the benefit of both.

RECOMMENDATION: Make it realistic for families of children/adult children with marked disabilities to get child support 1) without spending years and tons of money proving they are disabled 2) without losing (directly or via offset) their crucial title XVI SSI benefits.

7. Noise Pollution and Sensitivity to Loud Noise – Self-Advocate

ISSUE: I'm very sensitive to the loud noises that current leaf blowers create.

RECOMMENDATION: Making leaf blowers with quieter engines. I propose making a move from gas-powered engines to electric.

8. Educate Aging Caregivers on Estate to Protect Disabled Adult – Professional

ISSUE: Many disabled adults lose housing after their elder parents pass away or are relocated as a result. Disabled siblings are left out of trust monies and inheritance. Often siblings just push their disabled siblings out, they often must leave the family home because it is being sold, and once it is sold the disabled sibling must look for mediocre housing while the non-disabled siblings enjoy hundreds of thousands of dollars. There should be some oversight or at least education for the parents to plan. I do not see enough education for the parents when they establish their trust.

RECOMMENDATION: If the trust is equally shared it would provide for the disabled person, would take them off public funds, SSI at least for a while, they would have a greater say in their living situation. Their non-disabled siblings are not responsible and continue to watch them struggle. At least provide education to parents of the disabled community**.**

9. Pathway to Self Sufficiency – Professional

ISSUE: Thirty years of experience supporting people with disabilities and their families find and keep employment has taught me that the system is not designed to support people leaving public benefits. In fact, it perpetuates a dependance on public benefits through policies intended to control short term costs of state and federal government. Remove barriers to self-sufficiency that feeds the poverty mentality while promoting income generation that will lead to financial independence rather than further dependence on public benefits.

RECOMMENDATION: Pathway to financial independence for people who receive public benefits by coordinating Housing Authorities, and Health and Human Services Department policies that have asset tests or income restrictions aligned. The rules for public benefits should be the same, regarding asset tests, and the way programs treat income. This will likely require coordination with federal law makers to change federal policy as well. Change common definitions of income and assets. No asset limits for people who receive public benefits. Provide a reasonable time for someone to earn income with no penalties while still receiving public benefits. Such as 9-12 months. This gives the person time to replace the public benefit with other resources (i.e. private health insurance for MediCal, increased income for people receiving housing vouchers, or private funding for daycare and basic needs for Cash Aid/General Assistance/CalFresh).

FEDERAL POLICY

1. SSI/Medicaid Eligibility/Renewal Requirements – Professional

ISSUE: Elders and people with disabilities are required to 'prove' their ongoing age and/or disability. For those over the age of 65 and those with intellectual and developmental disabilities, this makes absolutely no sense. Neither category will change (for the better) on a year-to-year basis. Elders and individuals with IDD are typically limited in mobility, sufficient understanding, transportation, and/or timely access to medical providers, who are required to substantiate age/disability. Individuals with IDD have, by definition, a lifelong condition. It is unnecessary to duplicate efforts every 6-12 months and will simply cause for work, time, and money for all involved.

RECOMMENDATION: By permanently eliminating the requirement to 're-up' their eligibility, it will eliminate the risk of losing valuable supports and services. It will also eliminate the costs associated with scheduling unnecessary medical appointments for the purpose of simply providing documentation to the federal government.

2. Social Security Overpayments – Professional

ISSUE: People who need their SSI and comply with reporting procedures are punished for SSI's mistakes.

RECOMMENDATION: If income is reported properly to the Social Security Administration (SSA) and they continue to overpay for more than 3 months, they cannot request that it be returned or lower future payments. The government should properly staff SSA to avoid overpayments.