



NOTICE/AGENDA

CORRECTED

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES LEGISLATIVE AND PUBLIC POLICY COMMITTEE MEETING

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JOIN BY TELECONFERENCE: (VOICE ONLY)

CALL IN NUMBER:

1-888-475-4499

MEETING ID:

961 0387 0208

DATE: January 19, 2022

TIME: 10:00 AM – 2:00 PM

COMMITTEE CHAIR:

Julie Austin

Item 1. CALL TO ORDER

Item 2. ESTABLISH QUORUM

Item 3. WELCOME AND INTRODUCTIONS

Item 4. PUBLIC COMMENTS

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This item is for members of the public to provide comments and/or present information to this body on matters not listed on the agenda. There will be up to 20 minutes allocated to hear from the public with each person allotted up to 3 minutes to comment.

Additionally, there will be up to 10 minutes allocated to hear from the public on each Council agenda item, with each person allotted up to 1 minute to comment.

Item 5. APPROVAL OF SEPTEMBER 2021 MINUTES 

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Item 6. PURPOSE OF LPPC AND OVERVIEW OF LEGISLATIVE PROCESSES

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Bridget Kolakosky, Deputy Director

Item 7. FEDERAL LEGISLATIVE & REGULATORY UPDATES

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Item 8. 2022 LEGISLATIVE PROPOSALS

Page 11

Julie Austin, Committee Chair and Bridget Kolakosky, Deputy Director

a. Review Bill Idea Contest Submissions

Item 9. UPDATES AND STANDING AGENDA ITEMS

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- a. Council Meeting Summary
 - b. DDS Taskforce and Workgroups
 - c. Self-Determination Program
 - d. CalABLE
-

Item 10. MEMBER UPDATES

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All

Item 11. 2021 MEETINGS AND ADJOURNMENT

March 17th, June 7th, September 13th

Accessibility:

Pursuant to Government Code Sections 11123.1 and 11125(f), individuals with disabilities who require accessible alternative formats of the agenda and related meeting materials and/or auxiliary aids/services to participate in this meeting should contact (916) 263-7919. Requests must be received by 5 business days prior to the meeting.

All times indicated and the order of business are approximate and subject to change.

January 19, 2022

**AGENDA ITEM 4.
INFORMATIONAL ITEM**

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES – LPPC

Public Comment

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January 19, 2022

AGENDA ITEM 5.

ACTION ITEM

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES – LPPC

Approval of September 2021 Minutes

Members will review and approve the September meeting minutes.

Action Recommended

Approve the September 9, 2021 minutes.

Attachment(s)

September 2021 Meeting Minutes

Handout(s)

None.



DRAFT

**Legislative and Public Policy Committee Meeting Minutes
September 9, 2021**

Attending Members

Julie Austin (FA)
Jeana Eriksen (SA)
Andy Imperato (DRC)
Connie Lapin (FA)
Maria Marquez (SA)
Karen Millender (FA)
Rosie Ryan (SA)
Wesley Witherspoon (SA)
Julie Neward (FA)

Members Absent

Jonathan Nelson (FA)
Olivia Raynor (Tarjan)

Others Attending

Chris Arroyo
Aaron Carruthers
Kelly Headrick
Sabrina Kappe
Robin Maitino-Erben
Karen Mulvany
Mary Agnes Nolan
Pamela Perls
Matt Traverso

1. CALL TO ORDER

Committee Chair Julie Austin called the meeting to order at 10:02 a.m.

2. ESTABLISH QUORUM

A quorum was established.

3. WELCOME/INTRODUCTIONS

Members and others in attendance introduced themselves.

4. PUBLIC COMMENTS

None.

5. APPROVAL OF THE JUNE 2021 MEETING MINUTES

Members were presented with the draft meeting minutes.

It was moved/seconded (Marquez [SA]/ Eriksen [SA]) and carried to adopt the June 2021 meeting minutes as presented. Passed by acclamation. See page one for a record of members present.

6. **FEDERAL LEGISLATIVE AND REGULATORY UPDATES**

Members were provided the hyperlink to NACDD to obtain federal legislative and regulatory updates on items of interest.

7. **STATE LEGISLATIVE, BUDGET AND REGULATORY UPDATES**

Deputy Director, Bridget Kolakosky and Policy Analyst, Matt Traverso took members through each bill contained in the Legislative Bill Chart beginning on page 19 of the packet.

The updates began with the wonderful news that the Council's Co-Sponsored bill, SB 639, passed assembly with 45 final votes. A complete list of the bills that were discussed are as follows.

Sponsored/Co-Sponsored Bills:

Employment: [SB 639](#)

Community Supports: [AB 34](#), [AB 813](#), [AB 1007](#), [SB 672](#)

Public Safety: [AB 971](#),

Education: [AB 126](#), [SB 291](#), [SB 692](#)

Education & Safety: [AB 610](#),

Health and Safety: [AB 270](#), [AB 323](#), [AB 1400](#), [AB 1417](#), [AB 118](#), [SB 52](#)

Education & Employment: [AB 299](#), [AB 313](#)

During the updates, members asked questions, made suggestions and requested clarification on a variety of bills before asking for public comment. Below is a summary of the public comments that were made.

Ms. Pamela Perls provided public comment on AB 118 stating that she understands that a dozen pilot projects can be funded (nothing permanent). She went on to add her experience with Contra Costa County. They are struggling to put together a crisis response team due to lack of funding. She then went on to provide comment on AB 988, stating that she believes it is a federal mandate. Ms. Perls wonders if that plays into the status of AB 988.

Ms. Karen Mulvany provided public on AB 971, stating it would be helpful if the bill could be amended to allow certification by qualified individuals (e.g., conservators, etc.) for individuals who cannot communicate using typical methods.

Following the legislative bill updates, Deputy Director Bridget Kolakosky provided an update on the Governor's Budget. Currently there are ten (10) budget trailer bills that have been introduced. Deputy Director Kolakosky will be tracking each of those bills and keep the Council apprised to the outcomes.

Final comments on this agenda item included asking for more transparency and accountability for the system when making recommendations to bill authors.

8. 2022 LEGISLATIVE PLANNING

Deputy Director Kolakosky provided members with a brief overview of where the State is in the 2-year legislative process and presented the policy priorities identified in the new 2022-26 State Plan. Members then considered whether changes were needed to the policy priority document to better align it with the new State Plan. Changes recommended are as follows: revise the 2021 policy priorities to add a section on emerging issues and add subcategories including but limited to self-determination, disparities and barriers.

It was moved/seconded (Connie [FA]/ Eriksen [SA]) and carried to recommend that the Council adopt the changes proposed above.
Unanimous. See page one for a record of members present.

Deputy Director Kolakosky then introduced members to the bill idea form and the Council's first bill idea contest. The form is designed to capture legislative ideas year-round and everyone is invited to enter their ideas into the online form at any time. The Bill Idea Form can be found at <https://bit.ly/BillIdeas>.

The deadline for the contest is October 15, 2021. Following the deadline, staff will review the bill idea submissions and bring recommendations back to LPPC for consideration. If the winning bill idea becomes a bill in 2022, the winner will be included in the legislative process.

9. UPDATES AND STANDING AGENDA ITEMS

Members were provided a summary of the July Council meeting as well as updates on recent Council activities. Members were also provided hyperlinks to the state agency webpages in order to provide the most recent implementation updates on the DDS Taskforce and Workgroup, Self-Determination Program and CalABLE programs.

10. **MEMBER UPDATES**

Committee member Wesley Witherspoon reported that his Regional Advisory Committee is concerned about the success of the Self-Determination Program and access to affordable housing.

Committee member Julie Neward reported that California SIBS is hosting monthly meet ups. Judy Mark was the guest speaker at the last meeting. California SIBS is also working on The Time is Here kits and mental health resources.

Committee member Rosie Ryan reported that she has been participating in hearings related to SB 639.

Committee member Connie Lapin reported that DVU hosts an SDP connect meeting every week.

11. **FUTURE MEETING DATES**

To be determined. The Chair has proposed meeting in late October or early November.

12. **ADJOURNMENT**

Meeting adjourned at 2:40 p.m.

January 19, 2022

**AGENDA ITEM 6.
INFORMATIONAL ITEM**

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES – LPPC

Purpose of LPPC and Overview of Legislative Processes

Deputy Director Bridget Kolakosky will provide members with an overview of the Committee's purpose and go over the state legislative process.

Attachments

None.

Handout(s)

Committee Purpose and Legislative Process Presentation

January 19, 2022

**AGENDA ITEM 7.
INFORMATIONAL ITEM**

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES – LPPC

Federal Legislative and Regulatory Updates

The goal of this agenda item is to provide updates on the latest federal legislative and regulatory issues. For updates on policies affecting National Association of Councils on Developmental Disabilities (NACDD) please visit <https://www.nacdd.org/policy/>.

Attachments

None.

Handout(s)

Could be additional handout(s) day of meeting.

January 19, 2022

AGENDA ITEM 8.

POTENTIAL ACTION ITEM

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES – LPPC

2022 Legislative Proposals

The goal of this agenda item is for Committee members to continue activity planning for 2022. The Committee will begin this by reviewing an overview of the bill ideas submitted as part of the 2021 Bill Idea Contest. To assist in guiding this discussion, staff has included Policy Platform and Policy Priorities. Any actions should reflect these previously approved documents.

Attachment(s)

2021 Bill Contest Result Report
Policy Platform
Policy Priorities

Handout(s)

Bill Idea Contest Highlights



2021 SCDD BILL IDEA CONTEST

A comprehensive list of all submissions

Abstract

In October 2021, SCDD Launched its first ever “There Should Be a Law” contest. The outcome was nearly 100 bill ideas submitted by parent and self-advocates with the remainder submitted by community members and professionals in the intellectual and developmentally disabled field.

This comprehensive collection of submissions provides valuable insight into the community’s current concerns and their proposed solutions.

This document (as of 1/67/2022) do not necessarily reflect policy positions of the Council.

Bridget Kolakosky, Deputy Director of Policy and Public Affairs
State Council on Developmental Disabilities

Bridget.kolakosky@scdd.ca.gov

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2021 BILL IDEA CONTEST SUBMISSIONS

Education Bill Ideas

1. SPECIAL EDUCATION LAW FIRMS

*submitted by expert

Problem: School districts are currently employing expensive law firms to directly engage with and/or intimidate family advocates – using district funds to pay for adversarial actions.

Solution:?

2. IQ TESTS

*submitted by family member

PROBLEM: Due to the case Larry P. v. Wilson Riles, a California-based judicial decision (1972), there is a prohibition on the use of intelligence tests for African-American students.

BACKGROUND: The issue was centered around biased intelligence testing that led to overrepresentation of minority children in special education classes, particularly students with mild mental retardation. As a result of this 50-year old mandate, African-American children are not able to receive the same standardized intelligence tests as their peers. Parents will never be able to intellectually assess how their children are faring in comparison to other ethnic groups. It is racial segregation, specific to African-Americans.

SOLUTION: Choice is what is missing with this law. Parents of African-American students in the California k-12 system should be able to decide if they prefer the "alternative/equivalent" intelligence tests, or the IQ test(s) EVERY OTHER CHILD WHO IS NOT Black is given (i.e., the Wechsler Intelligence Scale for Children-Revised/WISC-R) to help determine what academic supports and resources are needed for student success.

3. SPECIAL EDUCATION STANDARDS

*submitted by family member

PROBLEM: Parents of children with disabilities report major issues with oversight, accountability, and parent access to rights and information in the Special Education system.

BACKGROUND: Special education standards are inconsistently executed across the state and vary between counties and districts. This leads to lower or higher quality education for special education students depending on their school. For instance, the same student may be offered inclusive class experiences in one district, but not the

other. As a result, students may lose services when transferring to another district, thus being denied what was determined a free appropriate public education (FAPE) in their previous district.

Of particular concern are immigrant families, who are further disadvantaged due to language barriers and lack of knowledge of the educational system. Interpretation and translation of information is not always available for these parents, creating an additional disparity in the provision of services and supports.

Precedent in the law states that school districts ought to provide all supports and services necessary to mainstream a student and help them bridge the achievement gap with their general education peers. However, special education students seldom leave the segregated classroom setting between kindergarten and post-secondary school.

California is legally required to uphold the federal Individuals with Disabilities Education Act (IDEA) and to do so for all students with disabilities. School/district adherence to Special Education standards need to be monitored on an ongoing basis by those internal as well as external to district administration. The lack of statewide consistency in Special Education points to a failure in oversight and accountability, resulting in education disparities and the denial of equal education as a basic right.

In addition, parents of children with special needs lack access to information, resources, and support when seeking Special Education services for their child. Most school districts do not provide information to parents beyond legal language on their basic rights. Parents often navigate the legal process of obtaining an Individualized Education Plan (IEP) on their own, without understanding the process or realizing resources exist. This lack of information and support prevents parents from fully and equally participating in the IEP process and subsequent IEP meetings. The gap in information creates a power imbalance between the parent and school system, which contributes to communication breakdowns and conflicts, and is a disservice to the IEP process, child, and all parties involved. Parents and districts need better tools to promote positive communication and collaboration. The Special Education system must bear responsibility for ensuring that parents have access to the information, resources, and support needed to equally participate in the IEP process and that the resulting IEP is truly inclusive of parent input.

SOLUTION: Parents for Change, a parent advocate group facilitated by Parents Helping Parents in San Jose, CA, proposes state legislation that requires the establishment of a Special Education Oversight Committee and Special Education Ombudsperson for each Special Education Local Plan Area (SELPA).

The purpose of the Special Education Oversight Committee is to monitor and enforce adherence of schools/districts to specified Special Education standards as set by the California Department of Education and derived from the federal IDEA. The committee is made up of representatives both internal and external to the Special Education system. At minimum, the committee includes parents of students with disabilities in the district representing all school levels (elementary, middle, high school), a range of district special education faculty (mild-mod, mod-severe, resource specialist, etc.), the SELPA Director, and a Board of Education Trustee serving that district. SELPAs that include more than one district, such as in Santa Clara County, may establish a greater number of parents, educators, and board representatives to encompass multiple districts. A Special Education Ombudsperson role is also established that serves and reports to this committee.

The role and responsibilities of the Special Education Ombudsperson is to ensure children with special needs receive all services and supports needed to benefit from public education by fostering an environment where collaboration and cooperation exist between parents, staff, and administration.

In addition to serving on the Special Education Oversight Committee, the Special Education Ombudsperson acts as a resource for parents of children with special needs and a liaison between parents and the IEP team or school/district administration. Each district requires at least one ombudsperson, along with additional ombudspersons as per the minimum standards of the Ombudsperson Association.

Some of the main duties of the ombudsperson include: providing plain language information and education to parents regarding Special Education laws, legal rights, the IEP process, and their child's IEP, via individual meetings, orientations, and/or trainings; providing training and professional development to educators and administration regarding the above; serving as a point of contact for parent, educator, and district questions and concerns; acting as a liaison between parent, district, and community organizations; attending or arranging parent support persons to attend IEP meetings; ensuring parents have language access at IEP meetings and receive IEP documents and other official documents in the parent's native/preferred language; investigating concerns and promoting compliance with Special Education laws by monitoring systemic issues and reporting to the Special Education Oversight Committee; all parents of students with IEPs, 504 accommodations, and potential disabilities are provided a basic plain-language guidebook on Special Education and the IEP process, as well as a list of Special Education resources – these resources will include the Special Education Ombudsperson and the regional Parent Training and Information Center.

4. TEACHER CREDENTIALING

*submitted by family member

PROBLEM: Students with disabilities are not getting included in regular education classrooms due to general ed teachers not having the tools to support them and their transition appropriately.

SOLUTION: Establish a class or credential on neurodevelopmental disabilities required for every teacher.

5. ADVOCACY

*submitted by family member

PROBLEM: Quiero aprender más para abogar por mi hijo con más seguridad
[in English] I want to learn more to advocate for my child with more confidence.

SOLUTION: Aprender, dedicacion, escuchar.

[in English] Learn, dedication, listen.

6. HIGHER LEARNING DISCLOSURE REQUIREMENTS

*submitted by family member

PROBLEM: Disclosure requirements and inclusive language at CSU and community colleges

BACKGROUND: The Disabled Student Programs and Services (DSPS) also known as Special Services, was enacted in 1976 through the passage of AB 77 (Lanterman). This bill funded support services and instructional programs for students with disabilities in the California Community Colleges. Currently the law does not allow students to access DSPS services without verifying their disability, this disclosure requirement functions as a barrier to accessing services, for those students who do not wish to disclose their disability. Perceived discrimination and the desire to protect students' ideal identity (not disabled) is a barrier in getting services.

The People First Respectful Language Modernization Act of 2006 was enacted by the Council of the District of Columbia on July 11, 2006 to require the use of respectful language when referring to people with disabilities in all new and revised District laws, regulations, rules, and publications and all internet publications.

Educational places like community colleges, State colleges, Universities across the country are experiencing diversity. Diversity, equity, and inclusion (DE&I) is a broad and

shifting landscape, and it is currently undergoing another much-needed evolution. With the rising importance of neurodiversity in DE&I initiatives, people are starting to recognize the existence of hidden disabilities.

SOLUTION: In keeping with the changing landscape related to neurodiversity, equity and inclusion, I propose the following in the form of law:

- A statewide study to understand if the current practices in both community colleges as well as State colleges are meeting the needs of the growing neurodiverse community.
- Study to determine if non-disclosure would promote increased enrollment of students to colleges. Will non-disclosure encourage students to take up additional supports and services? The current law requires them to disclose their disability to access supports. Is this a deterrent for students to access supports?
- Change the name of the program, Disabled Student Program and Services to a name that promotes neurodiversity, equity and inclusion. The name DSPS with the stress on individuals with disabilities is redundant and offensive. We have to keep in mind, that the name should reflect the best practices to promote inclusion. We are not coming up with a safe place for the students in the college campus, but rather making the entire campus a safe place for all students. Some suggestions are:
 - Supports and Services for Student Excellence (SSSE)
 - Student Support Services (SSS)
 - Student Excellence Program (SEP)
 - Student Accessibility Services (SAS)
 - Accessible Campus Community and Equitable Student Support (ACCESS)

7. SPECIAL EDUCATION SERVICES

*submitted by family member

PROBLEM: Principalmente que nos den la atención que requieren nuestros hijos para su defensa de educación y servicios ya que los abogados son pocos y seleccionan los casos y no dan mucha importancia a la mayor.

[in English] Mainly for you to give us the attention that our children require for the advocacy of their education and services since the lawyers are few and select the cases and do not give much importance to the majority

SOLUTION: Que se modifique las leyes en educación especial y que se capaciten al personal ya que casi nunca entienden las necesidades y servicios que necesitan nuestros hijos y siempre quieren quitar servicios en vez de mejorarlos.

[in English] That the laws on special education be modified and that the staff be trained more since they almost never understand the needs and services that our children need, and they always want to remove services instead of improving them.

8. DISABILITY SERVICES

*submitted by family member

PROBLEM: El Distrito Unificado de Oakland. No ofrece los servicios adecuados. Para los estudiantes con discapacidad.

[in English] Oakland Unified District. It does not offer adequate services. For students with disabilities

SOLUTION: He pedido asesoramiento legal.

[in English] I have asked for legal advice.

9. GENERAL CLASSROOM INCLUSION

*submitted by family member

PROBLEM: An existing belief that children with disabilities are best educated separately from their neurotypical peers.

BACKGROUND: "When inclusive [practice] is fully embraced, we abandon the idea that children have to become 'normal' in order to contribute to the world. Instead, we search for and nourish the gifts that are inherent in all people. We begin to look beyond typical ways of becoming valued members of the community, and in doing so, begin to realize the achievable goal of providing all children with an authentic sense of belonging." --

Norman Kunc (1992) broadreachtraining.com

There are better outcomes for employment and independence for adults when they have had opportunities of inclusion from the beginning. Special day class preschools should not exist, or only very rarely. The opportunities given to children at a young age- when they are all learning to be in the world will greatly influence their opportunities as adults.

SOLUTION: A system wide change that supports inclusive education as the norm beginning with preschool. Teacher training in Universal Design ideas.

10. HIGHER LEARNING OPPORTUNITIES FOR PEOPLE WITH DISABILITIES

*submitted by family member

PROBLEM: Currently most of the programs offered for young adults with intellectual and developmental disabilities in California are located in communities of great wealth and many have requirements that individuals attending these programs be a recipient of regional center services within their catchment area or be under a certain age.

BACKGROUND: Thinkcollege.net provides a list of college programs nationwide providing specialized educational programs, what they offer, as well as research being conducted on this population. Some of the research, like that coming out of the program offered at the University of Iowa, indicates that of the young adults that graduate from

these programs - 80% are employed vs. 20% that are not. Additionally, these programs increase independent living opportunities. There is a program at Taft Community College which has been in operation since 1995 and was initially funded by the Kern Regional Center. Its data also indicates their graduates are more likely to be employed. Finally, UC Davis recently started a new program with Federal grant monies, but it limits attendees to individuals under the age of 24.

SOLUTION: Increase higher educational opportunities and labor skill-based training for people with intellectual delays. Provide increased funding to community college programs located in less economically advantaged communities such as Riverside County, San Bernardino County, and Inyo County. Ensure individuals of any age can take part in these programs.

11. SERVICES FOR STUDENTS WITH DISABILITIES

*submitted by family member

PROBLEM: Families are moving to different states to receive better services and benefits. The services we receive for our children with disabilities in schools need to be improved in this state.

SOLUTION: Special Education requirements need to have equilateral mandates nationwide and not statewide. If services for special needs and disabled children were unilaterally equal nationwide, individuals would not feel compelled to move to a state with better services.

12. PARENT INFORMATION SYSTEM OF SUPPORT

*submitted by family member

PROBLEM: Misinformation is a big issue for parents who are trying to attain answers regarding their child's education. Parents are not provided enough information about their child's education.

SOLUTION: Create a system of support at every school district where parents can get questions. Each system of support should include a direct contact for parents where they can get their questions answered.

13. SERVICE OPTIONS FOR STUDENTS WITH DISABILITIES

*submitted by family member

PROBLEM: There is a lack of collaboration and transparency for the benefit of students with disabilities. Currently, when students have educational needs, the local educational agencies do not always offer all of the evidence-based tools and resources they have at

their disposal. Instead, the local educational agency expects parents to know what the child needs.

SOLUTION: A program should be created to build evidence-based options and ensure all schools are able to offer multiple evidenced-based options to students with individualized educational programs. Additionally, create statute that says school staff must discuss the service options available at the school and which services are appropriate for the student's educational benefit.

14. SPECIAL EDUCATION INSTRUCTIONAL AID TRAINING

*submitted by family member

PROBLEM: There is a lack of trained, licensed, and/or certificated support personnel and staff in special education classrooms.

BACKGROUND: Currently, there are no requirements for the need for Instructional Aids to have any type of licensure or certification. These are the same aids that are often in charge of supporting goals written in the IEPs. Additionally, the responsibilities of a special education aid can include changing, feeding, and assisting students while using the bathroom. This can be dangerous if support staff has not been trained on things like feeding tubes, wheelchairs, etc.

SOLUTION: Increase the minimum requirements necessary for an individual to become an instructional aid for students with disabilities.

15. CHARTER SCHOOL CO-LOCATION

*submitted by family member

PROBLEM: Under Proposition 39 charter schools are allowed to co-locate on public school campuses and use classrooms deemed unenrolled. This means that classrooms used for services that include speech therapy, physical therapy and occupational therapy that do not have official rosters are lost to the co-locating school. This has left students with disabilities who require special education and related services without a space dedicated to their needs.

BACKGROUND: Shirley Avenue Elementary school in the San Fernando Valley recently lost space used for special education services to a co-locating school.

SOLUTION: Create legislation that protects classrooms and other spaces used for special education purposes from co-locating schools. The legislation could say that all rooms used for individualized educational program compliance is be protected under the

Individuals with disabilities Education Act and the Free Appropriate Public Education statute are protected from Proposition 39.

16. COMMUNITY COLLEGE PROGRAMS

*submitted by self-advocate

PROBLEM: There is a lack of education, employment and community resources in the community.

SOLUTION: Create programs at every community college based on the North Orange County Continuing Education program for adults with intellectual and developmental disabilities and require that 50% of the administration and staff have disabilities.

17. GENERAL CLASSROOM INCLUSION RATE

*submitted by other individual

PROBLEM: Students with intellectual and developmental disabilities in public schools are not included in the general education classroom at a high enough rate.

SOLUTION: Ensure that more students with intellectual and developmental disabilities are included in the general education classroom.

18. IEP TRANSLATION

*submitted by other individual

PROBLEM: Those who don't speak English cannot access Individualized Education Programs.

SOLUTION: Require LEAs to translate Individualized Education Programs within 30 days of the IEP meetings being concluded.

19. OFFICE OF ADMINISTRATIVE HEARING EXPERT WITNESSES

*submitted by other individual

PROBLEM: Expert witness fees are not recoverable by families even if they win their due process appeal against Local Educational Agencies.

BACKGROUND: In the past, the law permitted families to be reimbursed expert witness fees if they won their due process case.

SOLUTION: Reinstitute the requirement that Local Educational Agencies reimburse the cost of expert witness fees if a family wins their due process case.

Employment Bill Ideas

1. RETIREMENT ACCOUNTS FOR INDIVIDUALS WITH DISABILITIES

*submitted by family member

PROBLEM: Balances in 401K count against the \$2000 max resource limit to receive Supplemental Support Income for an individual and \$3000 per couple.

BACKGROUND: When employer contributes to employees 401K - it is usually conditional on employee contribution (e.g. 50c for every \$1 contributed by employee to a maximum of \$1000/yr. etc.) This combination makes a person with a disability getting Supplemental Support Income and trying to get work experience ineligible for Supplemental Support Income. Since a 401K cannot be withdrawn before age 60 or so the problem does not go away but only gets worse month to month to avoid this, a Supplemental Support Income receiving employee must request to not participate in the 401K, which results in the employee foregoing the 401K matching from employer and is also not able to save for retirement. Loss of Supplemental Support Income can also mean loss of Medi-Cal/Medicaid which is a severe loss for a client with a disability.

SOLUTION: The ABLE account and the Cal-ABLE account have been established by law for the disabled to save for retirement and Qualified Disability Expenses. Withdrawals can be made any time for qualified reasons the balance does not count as a resource for Supplemental Support Income. The account grows tax free. Mandate that all employers (or employers exceeding a certain size - e.g., 100 employees) who offer 401K matching must offer the match to employees with disabilities who have ABLE accounts and deposit the money into the ABLE account as a match of their contributions to the ABLE account.

2. JOB DEVELOPER COORDINATION

*submitted by family member

PROBLEM: There is a lack of coordination between job developers for individuals with disability, which means that individuals with disabilities may work in a silo and not be connected with the right job developer for their skill set.

SOLUTION: Change the current job developer compensation program so that job developers split the compensation of placing an individual with disabilities in a job, like in real estate where there is a selling agent and a buying agent. This adjustment will provide incentive for job developers to work together to place individuals with disabilities correctly.

3. DISABILITY AWARENESS TRAINING

*submitted by self-advocate

PROBLEM: There is a lack of training focused on ensuring individuals with disabilities can be included in the workplace.

SOLUTION: Have a disability awareness/acceptance and perception training module for all employees to learn about the fact that people of all abilities have the right to work and how to make people of all abilities feel included.

4. STATEWIDE INTERNSHIP PROGRAM EXPANSION

*submitted by self-advocate

PROBLEM: People with developmental disabilities over transition age are underemployed.

SOLUTION: Expand the age limit for the statewide internship program.

5. HIRING DISCRIMINATION

*submitted by self-advocate

PROBLEM: Employers discriminate against potential candidates because the applicant has a verifiable disability.

SOLUTION: Ensure employers are not able to discriminate against an applicant due to the fact the potential candidate has a verifiable disability.

6. LEAP EXPANSION

*submitted by other individual

PROBLEM: The lack of individuals with disabilities being employed by the state through the Limited Examination and Appointment Program and the lack of awareness and understanding of the program within the state departments.

SOLUTION: Use CalHR along with the departments identified in the Assembly Bill 313 report to boost awareness of the Limited Examination and Appointment Program in different ways, also increase education of managers and others in positions to hire people with disabilities about the program.

Health Bill Ideas

1. EMERGENCY MENTAL HEALTH CARE

*submitted by expert

PROBLEM: Most behavioral health departments discharge patients without treatment if the individual has a developmental disability because hospitals state they are unable to provide treatment.

BACKGROUND: these departments are not able to provide long term or ongoing treatments like counseling, yet they should have an obligation to medically treat an emergency. Examples include a chemical imbalance; high toxicity levels, high lithium, risperidone levels, etc. At times, they don't even complete simple lab tests.

SOLUTION: Emergency mental health care should be available for individuals that require emergency support via 5150/5250 holds. Absent without official leave, 5150, 5250 holds can be successful if appropriate care is provided to individuals with intellectual disabilities.

2. SECONDARY HEALTHCARE DISPARITIES

*submitted by family member

Problem: there are disparities in access to secondary healthcare services.

Solution: increase access to ABA therapy, Speech and Language pathologist and outpatient Occupational Therapy. Require businesses to have a certain percentage of their clients be children and adults with ID/DD. Example: 100 clients at an ABA center. 15% of those kids would be with I/DD, which can help with long term outcomes in our community.

3. TAX FOR MEDI-CAL EXPANSION

*submitted by self-advocate

PROBLEM: Med-Cal and regional center programs added in the state's 2021-22 budget will not be sustainable over time due to a lack of funding.

SOLUTION: The state should levy a permanent tax on all managed care plans and use any available funds from Prop 56 to pay for Medi-Cal managed care plan services.

4. MANDATORY DENTAL COVERAGE

*submitted by self-advocate

PROBLEM: There is a lack of dental coverage for people with disabilities.

SOLUTION: Add dental services under the basic Medi-Cal coverage program.

5. MEDI-CAL MANAGED CARE EXPANSION

*submitted by self-advocate

PROBLEM: The state's general fund cannot fund the investments for ongoing purposes included in the 2021-22 state budget. Additionally, elderly individuals and individuals with disabilities eligible for Medicare are forced to enroll in a Medi-Cal managed care plan.

SOLUTION: Levy a tax on medical managed-care organizations and commercial insurance companies to ensure Medi-Cal expenses can continue to be covered. Additionally, make Medi-Cal managed care plans include services such as counseling and cognitive behavioral therapy, all non-cosmetic dental procedures, podiatric services, and low vision aids. Lastly, do not make individuals eligible for Medicare enroll in a Medi-Cal managed care plan.

6. REGULAR PSYCHIATRIC EVALUATIONS

*submitted by other individual

PROBLEM: Individuals diagnosed with mental illness; Schizophrenia Depression and Bi-polar have mental challenges that can go unaddressed.

SOLUTION: Mandate that every single person with mental disability has the option to have a psychiatric evaluation and counseling at a regular interval to ensure the proper treatment is being administered.

7. NEW AND EXPECTING PARENT EDUCATION

*submitted by other individual

PROBLEM: All children, whether neurodiverse, neurotypical, having a developmental disability or not, should be born to parents who know the importance of engaging their babies and how it supports their development. Parents should know that this helps their babies' brains develop, helps their babies' feel safe and secure, and is a real investment in their child's future.

SOLUTION: Mandate that hospitals need to provide new parents with pre-birthing classes about social emotional development and parenting, covered by medical insurance and Medicare, and that parents are able to leave their jobs to participate. Doctors should be informed and be required to refer new parents/patients to these programs.

Housing Bill Ideas

1. AFFORDABLE HOUSING

*submitted by expert

Problem: Landlords are now required to accept section 8 vouchers; however, some discovered a workaround by requiring a deposit that is 3-4 times the rent.

Solution:

- Lower the rental qualifications
- Establish a maximum deposit that landlords can require
- Increase the value of the vouchers (local, state and federal) to accommodate the regional cost of housing
- Licensed payee service providers should be exempt from the excessive deposit requirement landlords are asking for.

2. FINANCIAL HOUSING SUPPORT

*submitted by family member

Problem: An individual with an intellectual or developmental disability with a guardian who also has a disability.

Solution: Establish automatic, permanent financial housing support for families who have both an individual and guardian/parent who have been diagnosed with a developmental disability, an intellectual disability, or a psychiatric condition.

3. LACK OF AVAILABLE HOUSING

*submitted by family member

PROBLEM: Housing.

SOLUTION: Add both incentive and penalties to the requirement that cities provide very, very low-cost housing to accommodate those with developmental disabilities on Supplemental Support Income and Social Security Disability Insurance.

4. LACK OF AVAILABLE HOUSING

*submitted by family member

PROBLEM: The lack of life long, affordable housing for people living with intellectual and developmental disabilities.

BACKGROUND: Families have shown they are willing to come together to share both financial and other resources in order to increase the housing stock for our population. However, most families cannot afford to privately fund a lifetime housing option, and very few publicly funded units are developed annually, leaving a huge need that far outstrips supply.

SOLUTION: Remove the disincentives that exist currently for families who could invest limited private/personal capital to create affordable housing for people with intellectual and developmental disabilities in California. By reducing or eliminating property taxes on privately developed housing projects, California special needs families could be incentivized to collaborate in housing development, reducing their short- and longer-term costs and ensuring more people are able to participate. Also, similar to the state's recent efforts to incentivize construction of Accessory Dwelling Units by streamlining zoning and permitting requirements, streamlining permits for collaborative housing projects could be done for single or multi-family use dwellings targeting people living with intellectual and developmental disabilities as well.

5. GOVERNMENT: TRANSFER OF PROPERTY TAX BASIS

*submitted by family member

PROBLEM: Current Property Tax Law, Proposition 19, does not allow for the transfer of the primary property's tax basis, upon death, to a Special Needs Trust, which has a

separate employer identification number. For example, a parent of an adult with a developmental disability, a child who has lived his/her entire life at their home, cannot receive the transfer of the current property tax basis, upon death of the parent, if he/she depends on a Special Needs Trust.

BACKGROUND: A large number of individuals with developmental disabilities in California have Special Needs Trusts set up on their behalf for oversight and to ensure that they don't lose needed benefits and support to maintain some quality of life. Proposition 19 was promoted as a law to benefit the disabled population. However, it actually leaves out many of our most vulnerable citizens with disabilities that depend on Special Needs Trusts. This gap in the law which can result in property taxes rising significantly may force many individuals with developmental disabilities from their homes, homes which provide comfort, familiarity and may be set up to accommodate involvement and limitations.

SOLUTION: Create a law that allows for transferring the current property tax basis of a family private home to a Special Needs Trust that benefits an individual with a disability upon death of a family member and allows a Special Needs Trust to transfer the property tax basis when moving to another property that individual with a disability will occupy.

6. LACK OF AVAILABLE HOUSING

*submitted by self-advocate

PROBLEM: There is a lack of available housing for people with disabilities.

SOLUTION: Create housing opportunities specifically for people with disabilities.

7. HOUSING OPPORTUNITIES FOR PEOPLE WITH DISABILITIES

*submitted by self-advocate

PROBLEM: There is a lack of accessible housing for people with disabilities who are employed but make too much money to qualify for housing vouchers.

SOLUTION: Create housing programs for people with disabilities that do not qualify for housing vouchers due to the fact they make too much money.

8. LACK OF HOUSING AND THE SELF-DETERMINATION PROGRAM

*submitted by self-advocate

PROBLEM: There is a lack of affordable housing for people with physical disabilities, and the Self-Determination Program limits individuals to the thinking that they cannot live without parental supervision.

SOLUTION: Create a housing program for people with disabilities who can live alone with the appropriate support and ensure the Self-Determination Program does not stereotype and will individualize services for each client.

9. LIMITED HOUSING

*submitted by other individual

PROBLEM: there are limited resources for homeownership for families with a member with I/DD.

SOLUTION: Special financing and access to homeownership for families with a member with ID/DD. Empower families to have the ability to provide a safe haven and protection for family members by providing the opportunity to own their own home.

Human Services Bill Ideas

1. REGIONAL CENTERS: VENDOR PROGRAM PRICING

*submitted by expert

Problem: set cost of attendance is 1) not flexible; 2) not waivable; and 3) lacks equity in pricing

Background: a non-profit providing a Spanish speaking program discussing Autism is over \$100, they serve low-income, immigrant families with developmental disabilities. A similar English version by a different vendor is more affordable.

Solution: support those who need it most by making the prices more equitable. Do not personally charge families for educational workshops that non-profits provide. The organizations that serve these communities should have prices that reflect community needs without sinking the organization's staffing system.

2. REGIONAL CENTERS: DDS EARLY START BILLING

*submitted by expert

Problem: Department of Developmental Services' Early Start system pays for the hours/days of services provided (attendance), instead of the amount of hours contracted for on Regional Center purchase of services (POS). This is an operational billing/payment flaw. This practice harms the fiscal health of Early Start Providers by only allowing for reimbursement when a family actually shows up. It does not factor in that a provider has planned and staffed a slot for a child regardless of whether the child is in attendance or not. Additionally, hours indicated in the POS and on the IFSP are not flexible and do not "roll over" from month to month. This makes it impossible for a Provider to "catch up" by providing these "lost" hours of service and the determined IFSP hours remain unfilled.

Background: The amount of hours in a POS are based on the level of child's need as determined by the Individual Family Service Plan. Early Intervention providers cannot predict the actual hours that a child will be in attendance, and therefore cannot predict the reimbursement that will be generated for developmental or therapeutic services. These providers often experience fiscal difficulties when actual reimbursements are below the "value" of the POS, while fixed costs and personnel costs remain for the provider. The fiscal challenges and uncertainty faced by Providers in the current system result in inconsistent services for families, delays in timely services and inconsistent application of best practices in early intervention. Changes in California employment laws compel Providers to pay home visitors or therapists— regardless of whether they generate billable hours by seeing the client. Paperwork requirements and other miscellaneous parts of the service model are wrapped into the attendance reimbursement rate. But if attendance is low, reimbursement is low, yet all the other pieces of services are still required to be met. In the private sector, payment for a slot is paid in full regardless of usage. In the medical system there are typically payments for last minute cancellations or "no shows." This is not true for Early Start providers, causing a parity issue.

SOLUTION: Adjustments need to be made to the DDS reimbursement system – allowing providers to be reimbursed based on a family's maximum POS hours (enrollment) and not based on attendance. Alternatively, Providers need a mechanism for billing last minute cancellations and "no shows."

3. SUPPORT SERVICES: WORKFORCE STAFFING ISSUES

*submitted by expert

Problem: quality services cannot be provided without a skilled and committed workforce.

BACKGROUND: We can talk about outcomes all day long but it always comes down to the skills and integrity of the person providing the supports and services. With a focus on person centered services and supporting individuals with I/DD to lead meaningful and productive lives, more than ever, we need a workforce that is smart, skilled, educated, and committed.

When I first entered the field, most agencies required college degrees but as time has passed and as most agencies can't afford to pay much more than minimum wage, organizations are happy to hire people who basically just show up. The people we support deserve better. When they are in K-12, they work with a professionally educated workforce so why does this suddenly end at 18 or 22? Their disabilities don't disappear, and their challenges are lifelong. We need to come up with creative solutions to enhance our workforce.

SOLUTION: Reduce student college loans if they work for an organization that serves people with I/DD for at least two years. Further reduction of their loans could be granted

if they stay at the organization beyond the two-year period. Perhaps in CA, this could be for any student who attends a UC or Cal State institution.

4. REGIONAL CENTERS: SERVING THOSE WITH COMPLEX NEEDS

*submitted by expert

PROBLEM: we are seeing a growing population of adults who are rejected from Regional Center vendorized programs due to their high needs; their complex behaviors cannot be addressed safely in existing adult "behavior management" day programs.

BACKGROUND: at the age of 22, after the individuals transition from school programs, they have no access to adult services. They are often isolated to the home environment or, in some cases, the behavior escalates, and the individual then requires residential treatment or hospitalization. This is a growing crisis that is not getting enough visibility. Like the concept of Enhanced Behavior Support Homes (EBSH) that serve individuals whose needs exceed the minimum requirements of level 4i facilities, there is a need for developing Enhanced Adult Behavior Day Programs designed to serve clients whose needs exceed the resources available at existing adult behavior management day programs.

SOLUTION: Require a new type of service for adults with intellectual and developmental disabilities who have intensive behavioral needs. There needs to be a service code that specifically applies to this type of support with appropriate rates to match the levels of support these individuals require.

5. LANTERMAN ACT FAMILY COST PARTICIPATION AND PARENTAL FEE PROGRAMS

*submitted by expert

PROBLEM: The Lanterman Act's Family Cost Participation Program and Parental Fee Programs (implemented in 2005) create real barriers for families.

SOLUTION: Repeal the Family Cost Participation and the Parental Fee programs, this would restore the Lanterman Act's full protections and rights for families.

6. CONSERVATORSHIP ALTERNATIVES

*submitted by expert

PROBLEM: Many developmentally disabled children age into adult care without a legal decision maker for health, education, SSI, etc. Conservatorship is expensive, complicated, and there are few resources to support families, particularly if the parents are undocumented. It leaves a lot of individuals in limbo and causes delays and barriers to care and getting needs met.

SOLUTION: A law that would establish a process for individuals that need a legal decision maker to evaluate a family member or other available caregivers. The California Hospital Association has guidance for a similar policy for hospitals that has stood up in court. Also, codify the conservatorship alternatives that are being promoted by advocates.

7. REGIONAL CENTERS: CHILDCARE

*submitted by expert

PROBLEM: Childcare is not readily available to families with children with developmental disabilities.

SOLUTION: Regional Centers should pay the full cost of a 1:1 aide in preschool, afterschool, and day camps as needed by the family from birth until age 23 to enable organizations to provide the support a family needs for full inclusion. Regional Centers should also actively work with providers to develop after school and day camp programs for teens and young adults and pay the full cost of those programs including transportation from middle school, high school, and continuing education to these programs during the school year so that older students with developmental disabilities have care opportunities.

8. REGIONAL CENTERS: CENTRAL LIST OF AVAILABLE SERVICES, FEES AND AGE RANGE

*submitted by expert

PROBLEM: There is no central location to research services available to regional center clients nor the cost of those services. Many individuals with I/DD do not know they have access to.

BACKGROUND: Agencies, ranging from LEA's to regional centers, do not state what services are offered or what they might qualify for. They also do not know the age ranges served by different agencies. The system is based upon guesswork and the luck of knowing someone who is well informed, or worse, having to pay out of pocket for an attorney and/or an advocate.

SOLUTION: Require all agencies that work that contract with public support providers (e.g., LEAs, Regional Center, DOR, etc.) to publish all services they offer with public paid costs and qualifications so that service availability is clear and so people know how to go about qualifying for those services]. At a school, this would look like a menu presented to a family about a continuum of placements, including NPSs / NPAs, as well as the DIS services. You can't ask about what you don't know!

9. RECREATION AND THERAPIES

*submitted by expert

PROBLEM: there are no financial supports for access to therapies and recreational activities that parents believe will support their child's health, emotionally and physically. Examples include: swimming, horseback riding, camping, karate, etc.

SOLUTION: providing the funding and permitting the family to make the correct decisions as to how and with whom they enroll their child.

10. GROUP HOME STAFFING

*submitted by community member

PROBLEM: I love bike riding and my advocate won't let me ride because she thinks I would not be able to keep up with the group which I think I would. She won't let me try because she doesn't think I can ride 10-12 miles per hour which I think I can.

BACKGROUND: I might be able to attend a bike ride, but it depends on if there is enough staff available. If not, then I cannot go which makes me mad. It feels like my voice is not being heard. This bike ride is part of an XXX Bike Campaign which is a group that you can join where you can ride your bike all the time and feel good about it. I live at a group home. It is an ok place to live, but my advocate is really strict, and I don't think she thinks that I can do anything which I don't like at all. In Closing, I wish my home had more staff to support residents like me and maybe other residents to go out in the community 1 on 1 and do what we want.

SOLUTION: Require more staff at group homes to support the residents and provide more opportunities.

11. IN-HOME SUPPORT SERVICE NURSING

*submitted by family member

PROBLEM: Home Health Care Service needs more Licensed Vocational Nurses (LVN) to take care of patients.

SOLUTION:

-Allow a Certified Nursing Assistant (CNA) and In-Home Support Service (IHSS) care workers to be trained to do medical care such as suctioning, G-tube feeding, and administering medicines.

-The CNAs and IHSS care workers who can do medical care can be paid higher wages. (but not the level of LVN)

-A Home health agent will provide the training and assign them to work with the patients.

-Patients are allowed to use some percentage of their authorized hours for trained CNA or IHSS workers. For example, if the patient is authorized 580 hours of LVN services per month, he/she can use 10%-20% (58-116hours/month) of authorized hours for trained CNA or IHSS care workers.

-Nursing managing agent will assess the patient to determine if the patient qualifies for this kind of service. The patient has to be no ventilator dependent, stable and in relatively easy conditions.

12. REGIONAL CENTERS: ABA/RESPITE CARE PROVIDERS

*submitted by family member

PROBLEM: Minimum qualifications for in-home ABA or respite care providers under Regional Center contract.

BACKGROUND: Regional Center of the East Bay only vendorizes ONE company to provide supervisory services (aka; babysitting) for those clients with intense behaviors. The one company contracted, Maxim Healthcare Services, does NOT require experience working with people with intense behaviors including SIB and/or aggression with people or property. Furthermore, they do NOT mandate training or provide training at the most minimal level to assist their staff.

SOLUTION: Require 40 hours of training for RBT certification. Staff should also have to participate in ongoing training to further provide learning opportunities and experiences that might include role-playing so that they may better understand their client's needs as well as their own potential responses.

13. REGIONAL CENTERS: DUE PROCESS INEQUITY

*submitted by family member

PROBLEM: Inequity in Regional Center Due Process: In Office of Administrative Hearings (OAH) special education due process hearings with Local Education Agencies (LEA's), legal fees are reimbursed if students/parents prevail in hearings. However, legal fees are not reimbursed to prevailing clients/families in OAH Regional Center hearings. This creates disparity and financial hardship and prohibits many from accessing their due process rights, thus creating barriers and limiting access to necessary services and supports.

SOLUTION: create parity with OAH special education cases by requiring reimbursement of legal fees to clients/families through Regional Centers when clients/families prevail in Regional Center OAH due process hearings. This reimbursement could be accomplished through the POS process.

14. SUPPLEMENTAL SUPPORT INCOME BENEFITS LIMIT

*submitted by family member

PROBLEM: The \$2000.00 limit on personal assets for those that receive Supplemental Support Income benefits is too low.

SOLUTION: Raise the limit.

15. REGIONAL CENTERS: APPOINTMENT OF REGIONAL CENTERS AS CONSERVATORS

*submitted by family member

PROBLEM: It is a conflict of interest for regional centers to be appointed as conservators of consumers. This puts regional centers in the position of legally not providing any services to the consumer. There is no system of checks and balances in this situation and the potential for abuse and negligence is too great.

SOLUTION: Train the public guardian on how to act as conservator of adults with developmental disabilities and appoint this individual as such when there is no other family member to do this.

16. REGIONAL CENTERS: CONSUMER ADVOCATE SHORTAGE

*submitted by family member

PROBLEM: There is a shortage of consumer advocates to assist consumers and family members of consumers in advocating for services from regional centers.

BACKGROUND: Prior to the restructure a few years ago, area board directors were able to advocate for individual consumers in person; since area boards were changed to regional advisory committees, directors are no longer able to advocate for consumers.

SOLUTION: Make consumer advocates available to assist consumers and family members in getting services from regional centers and educating them on their rights.

17. REGIONAL CENTERS: FAIR HEARING PROCESS

*submitted by family member

PROBLEM: Consumer disagreements with regional centers regarding quality and availability of services and accessing services.

BACKGROUND: Regional centers have lawyers that represent them in fair hearings, and consumers are at an extreme disadvantage and the playing field is not level.

SOLUTION: Adding an attorney fee provision to the contracts the Department of Developmental Services has with regional centers or adding an attorney fee provision to the Lanterman Act. This would allow consumers access to legal counsel to assist them in getting services that a regional center denies.

18. REGIONAL CENTERS: ACCOUNTABILITY AND TRANSPARENCY

*submitted by family member

PROBLEM: -Threats of retaliation/expulsion by service providers against parents who seek quality services for their children/regional center consumers.

-Accountability of service providers as measured against the service plans, they submit to regional centers

-Lack of notice of and accessibility to regional center board meetings and other meetings.

SOLUTION: -Enact an amendment to the Lanterman Act to ban retaliation against parents/consumers as punishment for parental advocacy.

-Enact an amendment to the Lanterman Act to eliminate confidentiality of service plans provided to a regional center by service providers.

-Enact an amendment to the Lanterman Act to make regional center board meetings and other meetings subject to the Brown Act.

19. REGIONAL CENTERS: LIFE SUPPORT PLANNING

*submitted by family member

PROBLEM: Many parents and other caregivers of regional center clients are aging out of their oversight and problem-solving roles.

BACKGROUND: Although clients and family care providers such as aging parents know they need to plan, many experience sadness and fear when it comes to planning.

Future planning is much more than just financial or legal planning. Without someone noticing changes and coordinating across boundaries, the quality of life inevitably deteriorates for many Regional Center clients who do not have natural advocates, i.e., problem-solvers in their lives.

SOLUTION: Include life support planning as a mandatory Regional Center service for clients. Everyone being served by the Regional Center would get a Life Support Ally to work directly with the aging care provider(s) to develop the plan for their loved one and to serve as the advocate and overseer for the person with a disability when the surviving care provider dies or is unable to fulfill the role. This could be modeled off of the current provision in the Lanterman Act section 4541(a)(1) that allows the State Council to appoint an authorized representative for an RC consumer.

20. REGIONAL CENTERS: OVERSIGHT AND ACCOUNTABILITY

*submitted by family member

PROBLEM: There is a lack of accountability and transparency from regional centers.

SOLUTION: Resubmit and pass Assembly Bill 812 (Frazier), on the topic of having the California Health and Human Services Agency convene a working group to examine topics related to oversight and accountability of the developmental services system, from the 2019-20 legislative session.

21. REGIONAL CENTERS: HOME AND COMMUNITY CARE STAFFING ISSUES

*submitted by family member

PROBLEM: Neither regional centers nor IHSS provide sufficiently trained staff for their clients who cannot function independently at home nor in the community.

BACKGROUND: Home and Community Care Staffing are among the most difficult issues for families of adult children with severe autism and other disabilities. Clients of regional centers require specialized and individualized assistance in order to be able to access their community successfully and partake in recreational and/or vocational activities. Without individualized direct support, clients are usually isolated in homes with minimal engagement and a very bleak life. Most group day programs are not Person Centered in nature and not appropriate for individual needs. One size does not fit all, and adult day programs do not have the ratios of staff to clients that are required for success. Most often heavy sedation is used to manage these individuals.

SOLUTION: A mandate on regional centers to contract with applied behavioral analysis behavioral agencies to employ and train 1:1 support staff for clients with severe disabilities. Create incentives to direct care staff such as a housing stipend that would be adjusted to the cost of rents in their service area.

22. INSURANCE FOR SERVICE FEES

*submitted by family member

PROBLEM: People with disabilities having to use all their benefits, including their trust funds for services such as attorney consulting fees, certified public accountant fees, moving fees, fiduciary fees, aid fees and other fees that could be covered by an insurance plan.

SOLUTION: Creating an insurance plan which a family member(s) or other pay into like life insurance to cover any miscellaneous fees a person with a disability may incur over

the remainder of their lifetime which would not be managed for free after the death of the family member who cared for them.

23. REGIONAL CENTERS: EDUCATION OF AVAILABLE SERVICES

*submitted by family member

PROBLEM: Many people in low income, underserved communities are unaware that they can apply for services from their local regional center if their child just got diagnosed with a qualifying disability.

SOLUTION: Create a program where a family living in an underserved community on Medi-Cal has a child that receives a qualifying disability diagnosis must be provided information on how to apply for services from their local regional center during the medical appointment when the child is initially diagnosed.

24. SUPPLEMENTAL SUPPORT INCOME (SSI) AND SOCIAL SECURITY DISABILITY INSURANCE INCOME (SSDI) THRESHOLD

*submitted by family member

PROBLEM: Receipt of SSI/SSDI is contingent on ensuring an individual's income level remains lower than a specified threshold. This threshold is significantly lower than the poverty level, and the fear of losing these critical benefits can be a disincentive for finding employment. Additionally, programs like the Paid Internship Program will count towards this threshold when the individual is not officially employed.

SOLUTION: Raise the threshold regarding SSI/SSDI to, at least, the poverty level and do not count government programs such as the Paid Internship Program or Department of Rehabilitation's On-the-Job Training toward the threshold.

25. TELETYPEWRITER/TELECOMMUNICATIONS DEVICE FOR THE DEAF (TTY/TDD) SYSTEM IMPROVEMENT

*submitted by self-advocate

PROBLEM: There is a lack of understanding on how to use TTY/TDD and the TTY/TDD system does not work very well and is not user friendly.

SOLUTION: Make TTY/TDD training available to the public and improve the TTY/TDD system.

26. IN-HOME SUPPORT SERVICES AND MEDI-CAL REASSESSMENTS

*submitted by self-advocate

PROBLEM: Individuals with permanent disabilities, such as cerebral palsy or muscular dystrophy, are required to have yearly even though their disability does not change.

SOLUTION: Allow for In-Home Support Services and Medi-Cal eligibility reassessments to happen every three years rather than every year.

27. IN-HOME SUPPORT SERVICES: HOME-BASED SUPPORT

*submitted by other individual

PROBLEM: Families and caregivers are forced to make the decision to place their child in a facility or congregate care due to lack of resources.

BACKGROUND: Currently, once a client that is a dependent of the state reaches the age of 21, all funding with the exception of Supplemental Security Income and In-Home Support Services is no longer available. Placing an individual in a facility is much more expensive-to the state.

SOLUTION: Create a program that will continue to support clients with severe disabilities that require full care in a home-based setting where they can continue to receive quality care in the least restrictive environment.

28. REGIONAL CENTERS AND SELF DETERMINATION PROGRAM

*submitted by other individual

PROBLEM: Community is not informed on the process of the self-determination program.

SOLUTION: Mandate regional centers to report on the Self Determination Program process to the community similar to the annual POS reports. In a proactive way, create more accountability and clarity on the SDP program. Monitoring and sharing data is crucial for the community to be collaborative in the participation and support.

29. REGIONAL CENTERS: VENDOR REVIEW SYSTEM

*submitted by other individual

PROBLEM: The scarcity of available services and lack of available knowledge about the quality of the agencies and individuals providing services leave self-advocates and family members with a difficult time choosing between services.

SOLUTION: Regional centers should be required to create an online review system for vendors where families can rate the services they receive.

30. CHILDREN'S RESIDENTIAL CARE REMOVAL

*submitted by other individual

PROBLEM: The automatic removal of young people in children's residential care once they reach age 22.

SOLUTION: Amend Title 17 and Title 22 to authentically reflect Home and Community-Based Services and choice.

31. REGIONAL CENTERS: COMPENSATORY SERVICES

*submitted by other individual

PROBLEM: There is no way to combat or advocate against the frequent delays people have accessing regional center services. The only option is to file a fair hearing request to appeal the "apparent" denial of a service when an excess of time has passed since the request for the service.

BACKGROUND: In special education, there is a concept called compensatory education. If a service is requested, denied or not responded to, one can appeal that decision. In the appeal process (whether in an informal meeting, mediation, or the actual due process hearing), the student is frequently awarded compensatory education going all the way back to when the person first requested the services, even if many months or even over a year has passed. If someone should have received a special education service, they are awarded services commensurate to the loss of those services, for a time period going back as far as two years. No such provision exists in regional center cases.

SOLUTION: Replicate the special education compensatory education system for Regional Centers by requiring regional centers to fund compensatory services in situations where they should have provided a service but did not. Additionally, regional centers should be authorized to offer compensatory services as part of settlement agreements and the informal meeting and mediation in the fair hearing process.

32. SELF-DETERMINATION PROGRAM TRANSLATORS

*submitted by other individual

PROBLEM: There are few independent facilitators in the Self-Determination Program and even less that speak languages other than English. This makes access to support, a central principle of the Self-Determination Program, difficult or impossible for self-advocates and family advocates to access.

SOLUTION: Require the Department of Developmental Services to devote a specified percentage of their budget to reduce Regional Center disparities by funding interpreters and translators to work with independent facilitators.

33. REGIONAL CENTERS: DATA

*submitted by other individual

PROBLEM: The lack of available data concerning the Self-Determination Program and the pandemic services provided through Regional Centers.

SOLUTION: Require Regional Centers to disclose service dollar data with the disparity data concerning the Self-Determination Program and the pandemic services provided through Regional Centers.

34. REGIONAL CENTERS: APPEAL PROCESS

*submitted by other individual

PROBLEM: Regional Centers are hiring attorneys to aid them in appeal hearings with families.

BACKGROUND: The appeal process is intended to be a family friendly process. The use of attorneys demonstrates an attitude of refusing to work with families to resolve disagreements formally. Most families do not stand a chance when the Regional Centers use an attorney in fair hearings.

SOLUTION: Require that if the Regional Center hires an attorney to represent them, they fund an attorney to represent the self-advocate and/or the family. Note this is not a reimbursement, this is straight up funding. Families living in poverty cannot afford to lay out the expenditures and get reimbursed later.

35. REGIONAL CENTERS: BOARD MEETING TRANSPARENCY

*submitted by other individual

PROBLEM: The inability of the public to meaningfully participate in Regional Center board meetings and other public meetings.

BACKGROUND: The Lanterman Act requires Documents reviewed by Regional Center boards to be available. Some Regional Centers put one copy of the packet for the public to examine and share. Others put out copies. Others will charge. Additionally, public input is only taken on issues where action will be taken or issues not on the agenda. No public comment is taken on issues on the agenda where no action will be taken.

SOLUTION: Require regional centers to comply with the Bagley-Keene Open Meeting Act or the Brown Act.

36. REGIONAL CENTERS: DATA SHARING

*submitted by other individual

PROBLEM: Regional Centers do not make their data on the services they provide available to the public.

BACKGROUND: Regional Centers are contractees of California's Department of Developmental Services. In the past Regional Centers have claimed that they comply with Public Records Act requests in order to oppose legislation, but currently they state that they don't have to follow it.

SOLUTION: Require regional centers to comply with the Public Records Act.

37. CONSERVATORSHIP TIMEFRAMES

*submitted by other individual

PROBLEM: Under current law, conservatorships may last into perpetuity even if there is no evidence that the conservatorship is necessary or needs to continue.

SOLUTION: Conservatorships need to be limited to a specific timeframe, with a process that is based on evidence that the conservatorship is necessary prior to renewal.

Public Safety Bill Ideas

1. LAW ENFORCEMENT TRAINING

*submitted by community member

Problem: The systemic abuse of individuals on the autism spectrum by law enforcement.

Solution: Helping law enforcement officers become more capable of identifying and approaching persons appropriately on the Autism Spectrum. We are already engaged with law enforcement on the specifics of this idea, and they are very clear about the expectations. We have also introduced this idea to our Champions (the youth and adults living with autism), and they are excited about this important opportunity.

2. UPDATED EMERGENCY LAWS

*submitted by community member

PROBLEM: the public safety of children and adults on the autism spectrum

SOLUTION: Emergency laws

3. FIRST RESPONDER COMMUNICATION

*submitted by family member

PROBLEM: Communication failures between first responders and individuals with different communications styles.

SOLUTION: Much like organ donors have a visual identifier on their Driver's License/CA ID, allow residents to self-identify their special needs. California should establish a symbol/icon that identifies a person as requiring unique methods of communication. The icon would be a visual method to alert first responders to check a database to learn what the person is identified as their special circumstance and how best to interact with them. For example:

-Someone with Autism: 'avoid yelling instructions, no bright lights, avoid physical touch' and 'best method of communication is a low voice, speak slowly and wait 5-10 seconds for a response'.

-Someone with epilepsy: 'shouting and physical movements are involuntary and will subside over time' and 'best method of communication is help me to a seated position, encourage me to breathe slowly, if possible, play calming instrumental music/lullaby'.

4. ABUSE SETTLEMENT TRANSPARENCY

*submitted by family member

PROBLEM: People with IDD have the highest rates of abuse and a broad lack of understanding and systems, other than "Awareness Months". Training district attorneys and increasing penalties for conviction is being discussed. We need to uncover the abuse with an understanding of how secret settlements are keeping people quiet, to suffer in silence and live in fear as they don't even trust their loved one out of the home. This then burdens the family caregiver, as 80% of people with intellectual and developmental disabilities in the regional center system live with their families. Caregivers need to know where the safe places are and when abuse happens, how it is responded to.

SOLUTION: "Secret Settlement Transparency for Dependent Adults with Intellectual and Developmental Disabilities Who Are Victims of Sexual Assault." We need data on the cover-up of abuse via an annual report on secret settlements that is managed by the Attorney General's office. Without data, we cannot discuss solutions.

5. CAREGIVER ABUSE

*submitted by family member

PROBLEM: The problem of abusive caregivers moving from job to job where they can commit more abuse. Unless there is a criminal record, potential employers do not have a way of tracking an applicant's history of abuse.

SOLUTION: Establish a California Caregiver Abuse Registry. Registries like this already exist in 27 US states.

6. SEXUAL ASSAULT DATA

*submitted by family member

PROBLEM: There is a lack of quality data on the number of people with intellectual disabilities who have been sexually assaulted.

BACKGROUND: "If this were any other population, the world would be up in arms," Nancy Thaler, a Pennsylvania Department of Human Services deputy secretary in charge of the state's developmental disability programs, told NPR. "We would be irate, and it would be the No. 1 health crisis in this country." We cannot develop specialized treatment programs or apply for grant funding to combat or treat this problem without increased data and knowledge about the where, when, how, and by whom these crimes are being committed. Bureau of Justice found that people with any type of disability are more than two times more likely to be sexually assaulted than people without disabilities, but there were previously no government statistics on the subject concerning intellectual disabilities, specifically.

SOLUTION: Require law enforcement agencies to receive at least 8 hours of training annually on how to interview and assist someone with intellectual disabilities//developmental disabilities/Autism.

-Require law enforcement agencies, child protective and adult protective agencies to collect specific data regarding the number of people with intellectual disabilities//developmental disabilities/Autism in the State of California who have been assaulted.

-Hire social science researchers to collect and disseminate this data annually to all law enforcement, regional centers, and child and adult protective agencies working with this population.

7. LEGAL PROCESS DISABILITY ISSUES

*submitted by family member

PROBLEM: The legal system does not take into account the fact that an individual has a disability and should be dealt with differently from other individuals.

BACKGROUND: If a person has been identified as having an intellectual or developmental disability or has been a client who has received special services from a regional center or school during their lifetime, their court and sentencing process should be somewhat different than the norm. They deserve special consideration throughout the process and a special sentence with a distinct emphasis on services similar to an individualized program plan. The state of New Mexico has had such legislation for years.

SOLUTION: Create a special sub-unit in all prosecutor's offices with special training focused on dealing with individuals with intellectual and developmental disabilities.

8. ABUSE OF PEOPLE WITH DISABILITIES

*submitted by family member

PROBLEM: The abuse of individuals with disabilities is a significant problem in the community.

SOLUTION: While this bill idea did not provide concrete solutions, examples might include creating programs focused on identifying abuse and communicating it to authorities. Also consider expanding educational opportunities aimed at protecting individuals with disabilities from abuse.

9. POLICE TRAINING

*submitted by self-advocate

PROBLEM: There is a lack of proper training for police officers on how to interact with people with disabilities.

SOLUTION: Mandate that police must attend training on interacting with people with disabilities. That includes information about different disabilities, including Autism Spectrum Disorders, deafness, and physical disabilities.

10. LAW ENFORCEMENT

*submitted by other individual

PROBLEM: Law enforcement officers pose a high risk to I/DD individuals.

SOLUTION: Any law enforcement officer entering a home with an individual with a I/D disability not be armed, not be required to handcuff and that the officer(s) will not have implied immunity. Also, the community needs to be more involved.

Assorted Bill Ideas

1. **AMERICANS WITH DISABILITIES ACT: CHANGING STATIONS - PUBLIC ACCESS**

*submitted by expert

Problem: individuals with Cerebral Palsy (CP) and similar disabilities need access to bathroom changing stations. The “baby” changing station with a picture of the baby is demeaning and the changing stations are not big enough and cannot support an adult.

Solution: public places such as parks, stores, malls, etc. should be required to have a bathroom that accommodates individuals with CP and similar disabilities.

Accommodations might include removing the pictures of the baby, reinforcing the stations so that it's strong enough to support an adult. For businesses like malls, they should be required to provide these accommodations on every floor.

2. **AMERICANS WITH DISABILITIES ACT (ADA): WHEELCHAIR ACCESS**

*submitted by family member

PROBLEM: The inaccessibility of the park, beach, trail, lake to individuals who use wheelchairs

BACKGROUND: Please see: <https://curbfreewithcorylee.com/2014/11/20/most-wheelchair-accessible-beaches-in-the-world/>

SOLUTION: Options such as Mobi Mats can be put on the ground to create a smooth area for wheelchairs and those using rollator type devices. This is far less expensive than concrete or asphalt. For ocean/lake access, a movable ramp could be placed at the end of the mobi mat so a person can have direct access to the water. At the beach, a lifeguard could be asked to move the ramp as the water changes and monitor/advise on water conditions. Park rangers could do the same for lake access.

3. **AMERICANS WITH DISABILITIES ACT: PUBLIC ACCESSIBILITY**

*submitted by family member

PROBLEM: lack of access to outdoor areas, particularly state beaches, beaches in the national park system and beaches under municipal jurisdiction for individuals with disabilities.

SOLUTION: Mandate that simple wooden platforms/paths over the sand to the water, ramps down steep embankments to the beach, and walkways/paths over the sand to the water be built at all national, state, and municipal beaches.

4. AMERICANS WITH DISABILITIES ACT: BUILDING ACCESS

*submitted by other individual

PROBLEM: People with disabilities cannot effectively access buildings built before the Americans with Disabilities Act was put into place.

SOLUTION: All buildings should be retrofitted so they are accessible to people with disabilities.

5. GOVERNMENT: PUBLIC IN PERSON MEETINGS

*submitted by expert

PROBLEM: people with intellectual and physical disabilities often have difficulty participating in-person at public meetings. If public entities return to meeting in person only at some point, people who have been able to increase their participation through Zoom, should have the right to continue to participate in this manner.

SOLUTION: require public agencies to allow "virtual participation" in lieu of making physical appearances.

6. GOVERNMENT: PUBLIC MEETING GOVERNANCE: GREENE ACT

*submitted by community member

PROBLEM: participation in Community Advisory Committees for school districts. Currently, public participation is limited under the Brown Act to in the form of Public Comment. The Greene Act allows community members to participate more fully, including asking questions during presentations. However, the Greene Act is limited to SELAC meetings (Site English Learners Advisory Committee) and DELAC (District English Language Advisory Committee), but most districts even run those using the Brown Act limitations to community participation.

BACKGROUND: As a CACSE leader I want to be a participant in the discussions at DELAC meetings where I am refused participation due to not fitting the criteria for membership. My district limits DELAC membership to those that are a parent or guardian of a student who is an English Learner. I have attended the meetings for years and witness that a Special Education lens is missing from the presentations.

SOLUTION: amend the Greene Act to include all advisory committees that districts are mandated to have including DELAC, CACSE (Community Advisory Committee for Special Education) and advisory committees that are school district created.

7. GOVERNMENT: VIRTUAL ACCESS TO PUBLIC MEETINGS

*submitted by family member

PROBLEM: Voices of those with disabilities are not being heard by elected officials and lawmakers.

SOLUTION: Those with disabilities and their caregivers should be allowed to attend public meetings virtually. COVID-19 allowed unprecedented access for those representing these voices.

8. GOVERNMENT: BROWN ACT EXPANSION

*submitted by family member

PROBLEM: In-person participation at meetings of community advisory committees (CAC) to the special education local plan areas (SELPA) is a challenge for the families of students with disabilities.

BACKGROUND: CAC attendees are typically parents of children with disabilities, a population with little time and inclination to spend 30-60 minutes in traffic to attend a CAC meeting. CAC to the SELPA meetings are subject to the Brown Act and thus are required to be in-person or with disclosed addresses of committee members if via Zoom. During the COVID lockdown we were able to increase CAC participation dramatically because we could do it via Zoom under suspension of Brown Act requirements.

SOLUTION: Make CAC to the SELPA meetings permanently accessible via Zoom to increase community participation and willingness to serve on the CAC - carve out an exception to the Brown Act for the CAC.

9. GOVERNMENT: DATA COLLECTION

*submitted by family member

PROBLEM: Data collection by the government implies that there are different races, but there are not.

SOLUTION: remove race-based data in recognition that there is only one race - the human race. This will help people get over their fears of what is different and will unite us all.



Policy Priorities 2022

PROTECTING AND ENHANCING CIVIL RIGHTS

Every person with intellectual and developmental disabilities (I/DD) has the right to self-determination, equality of opportunity, full participation, independent living and economic self-sufficiency no matter their disability.

The Council will work to ensure civil rights, including identification and reduction of racial and ethnic inequalities and disparities, are protected and enhanced and full implementation of state/federal policies including but not limited to the Workforce Innovation and Opportunity Act, Home and Community-Based Services Settings Rule, Every Student Succeeds Act and Achieving Better Life Experience Act.

GUARANTEEING ACCESS TO EDUCATION AND EMPLOYMENT

Every student with I/DD has the right to a quality inclusive education with their peers that prepares them for post-secondary education and/or competitive integrated employment (CIE). Students in both secondary and postsecondary education with disabilities must be provided the same opportunities for learning, in the classroom and on-line, as students without disabilities.

Every person with I/DD should have the opportunity to be employed in CIE. Individuals must have access to information, benefits counseling, transition planning, job training, career exploration and information and support for inclusive post-secondary education. New or expanded pathways to CIE must be developed and supported, including apprenticeships and internships.

The Council will work to ensure the implementation of the Individuals with Disabilities Education Act, Every Student Succeeds Act and other federal and state policies to ensure that students with disabilities are provided the services and supports needed to receive quality inclusive education.

The Council will work to ensure the full and robust implementation of the Workforce Innovation and Opportunity Act and California's Employment First Law, that policies and practices improve opportunities for and incentivize CIE, to create hiring incentives and supports for all employers and contractors and make the state a model employer.

Identifying and Prioritizing Emerging Issues in the I/DD Community

Every person with a developmental disability should not have to deal with problems of that arise due to the emergence of inequality issues in the community. Events in our every day lives, both due to policy changes and unforeseen events, have the ability to cause unintended consequences for the I/DD community. These issues must be identified and acted upon swiftly to ensure as little harm as possible is inflicted.

The Council will work to ensure any and all emerging issues including but not limited to dealing with disparity across all I/DD issues, barriers to participating in a community setting, and roadblocks to access for people with I/DD are dealt with through policy changes. The Council will work to ensure the Self Determination Ombudsperson program at the Department of Developmental Services uses its authority to ensure people with I/DD become successful participants in the Self Determination Program.

PROMOTING ACCESS TO QUALITY SUPPORTS IN THE COMMUNITY

Every person with I/DD should have the ability to fully participate in their communities. Receiving quality, individualized services is the cornerstone for people with I/DD to be safe, healthy and to promote self-determination, interdependence and inclusion. Community-based services/supports require adequate wages for providers; therefore, the state must restore rates. Disparities in access, outcomes and quality for services and supports must be addressed. Complexities in the service delivery systems must be reduced.

The Council will work to continue to restore the Department of Developmental Services programs cut in 2009, to make meaningful improvements to the service delivery system to reduce disparities, increase transparency and accountability and increase quality outcomes, support efforts to provide adequate wages to providers for inclusive and quality supports, and work to ensure successful implementation of the Self-Determination Program.

ENSURING SAFETY IN THE COMMUNITY

Every person with I/DD has a right to be safe and must be provided emergency preparedness training and training in personal safety. Law enforcement personnel, first responders, emergency medical professionals and the judicial system must be trained in how to work with people with I/DD (including those who are suspects, victims or witnesses of crimes) during the course of their duties.

The Council will work to ensure people with I/DD are safe, free from abuse and neglect and have access to services and supports in their communities during all types of disasters or emergencies and an adequate safety net for people in crisis and access to adequate crisis intervention services.

IMPROVING HOUSING AND COMMUNITY LIVING

Every person with I/DD should have the opportunity to live in the community. Permanent, affordable, accessible, safe and sustained housing options must be continually developed. Statewide inclusive living options for individuals with I/DD must be increased and enhanced through access to housing and subsidies that are paired in a timely manner with needed services and supports.

The Council will work to implement the policy recommendations in the Statewide Strategic Framework for Housing and create a dedicated housing fund to support integrated community housing for people with I/DD.



CALIFORNIA STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

POLICY PLATFORM 2021

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Over 50 years ago, the State Councils on Developmental Disabilities were established in federal statute. The Councils are currently authorized in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) in each of the 56 states and territories to “promote self-determination, independence, productivity, integration and inclusion in all aspects of community life” for individuals with intellectual and developmental disabilities (I/DD) and their families through advocacy, capacity building, and systems change. The Lanterman Act established the California State Council on Developmental Disabilities (Council) to fulfill those rights.

The Council is comprised of 31 members appointed by the Governor including individuals with I/DD and their families, representatives from the DD Act partners (Disability Rights California and the three University Centers for Excellence in Developmental Disabilities), and mandated state agencies that provide services and supports to individuals with I/DD. To implement the rights in the DD Act, the Council develops and implements a five-year state plan that contains goals, objectives, strategies, and outcomes designed to improve and enhance the availability and quality of services and supports. In addition to the Council’s Sacramento headquarters, regional offices support individuals with I/DD and their families through activities such as advocacy, training, monitoring, and collecting and disseminating public information.

The Council works with policymakers and other stakeholders to ensure policies pertaining to the rights of individuals with I/DD are protected and enhanced by ensuring individuals with I/DD can experience equality of opportunity, full participation, independent living, and economic self-sufficiency. These four pillars are enshrined in the Americans with Disabilities Act of 1990 (ADA). The Council supports the full and robust implementation and enhancement of state and recent federal policies that enshrine the values of the ADA such as the Workforce Innovation and Opportunities Act (WIOA), Home and Community-Based Services Setting Rule (HCBS), Every Student Succeeds Act (ESSA), and Achieving Better Life Experience (ABLE) Act.

The Council believes that individuals with I/DD and their families must be included and consulted in all aspects of the policy making process to ensure their needs are adequately and appropriately addressed. The Council works to address disparities in access, outcomes, and quality for all services and supports. The Council believes in ensuring transparency and accountability for state and federal programs providing services and supports to individuals with I/DD. Furthermore, the Council believes that complexities in the service delivery system must be reduced and that assistance in navigating services

and supports should be provided to individuals with I/DD and their families. The State of California must ensure that funding is used to achieve positive outcomes for individuals with I/DD and their families.

Disparities in services and supports can result in severe health, economic, and quality of life consequences. Services and supports must be distributed equitably so that individual needs are met in a culturally appropriate and linguistically competent manner regardless of race, ethnicity, income, intellectual or physical ability, age, and geographic location. Information and materials must be provided in plain language and/or alternative formats as requested.

PROMISE OF THE LANTERMAN ACT

The Lanterman Act promises to honor the needs and choices of individuals with I/DD by establishing an array of quality services throughout the state. Services must support people to live inclusive lives in their communities. Access to needed services and supports must be inclusive and not be limited through service caps, means testing, median rates, family cost participation fees, or other financial barriers. California must not impose artificial limitations, delays, or reductions in community-based services and supports that would compromise the health and safety of people with I/DD.

SELF-DETERMINATION

Individuals with I/DD and their families must be given the option to select and direct their services and service dollars through Self-Determination. The person with I/DD is in charge. With the support of those they choose and trust, individuals with I/DD and their families are empowered to develop their own unique needs, develop their own life goals, and construct those services and supports most appropriate to reach their full potential. The process begins with a Person Centered Plan (PCP) which details their unique needs, competencies, and aspirations. Self-Determination gives individuals with I/DD the tools and the basic human right to pursue life, liberty and happiness in the ways that they choose.

SELF-ADVOCACY

Individuals with I/DD must be in charge of their lives and be respected for the choices made. They must be provided the opportunity and support to be heard and be leaders in the service system and society including voting and other civic responsibilities. Individuals with I/DD must be protected against voter suppression and provided the same access to vote independently as individuals without disabilities. Self-advocates must have access to training, assistive technology, information, and materials in plain language and opportunities to participate in the policy making process.

EMPLOYMENT AND ECONOMIC SELF-SUFFICIENCY

Every person with a developmental disability should have the opportunity to be employed in competitive integrated employment (CIE). CIE means full or part time work at minimum wage or above, with wages and benefits similar to those without disabilities, fully included

with co-workers without disabilities, and located in the community. California must invest in systems change efforts that will result in a measurable increase in CIE for people with I/DD. This priority is consistent with California's Employment First Law that states CIE is the priority outcome for working age individuals with I/DD regardless of the severity of their disability.

Policies, service delivery practices, and financing must set expectations for CIE, microenterprise training, and/or self-employment. Individuals with I/DD must have access to information, benefits counseling, transition planning, job training, and inclusive post-secondary education. Adequate provider rates must be established for the provision of services and to incentivize quality and inclusive employment outcomes.

Employers must be engaged, prepared, and supported to employ individuals with I/DD. New or expanded pathways to CIE, including apprenticeships and internships, must be developed and supported for all individuals with I/DD regardless of severity of disability. The Council supports the phasing out and elimination of subminimum wage and/or segregated employment for all individuals with I/DD.

TRANSPORTATION

Access to transportation is essential to education, employment, healthcare, and inclusion of individuals with disabilities. Timely accommodations must be available to people with I/DD that are available to people without disabilities. Mobility training must be a standard program among transportation providers to increase the use of available transportation and reduce reliance on costlier segregated transportation systems. Barriers between geographic areas and transportation systems must be addressed so people with I/DD can travel as safely and easily as people without disabilities. Emerging transportation options must be available and accessible to people with I/DD. Opportunities for car ownership must be increased.

HEALTH CARE

Every person must have access to comprehensive, timely, quality, and affordable health care, dental care, and wellness services as well as access to plain language information and supports to help in understanding health plans and making informed decisions about their health care. This requires informed consent, individualized and appropriate medication and treatments, and an adequate network of health professionals. Individuals with disabilities must have equal access to intensive medical services, testing, and vaccinations for communicable diseases as individuals without disabilities. Testing for communicable diseases must be provided in the same timeframe as it is provided to individuals without disabilities regardless of the person's living situation (live at home, live with family, or live in congregate living.)

All individuals with disabilities, including individuals with multiple health care needs, must have access to routine preventative care, mental and/or behavioral health treatment, dental care, durable medical equipment, and reproductive health needs. Service system complexities must not delay, reduce, or deny access to services. Individuals must be

reimbursed for insurance co-pays, co-insurance, and deductibles when their health insurance covers therapies that are on their Individual Program Plans (IPPs).

EDUCATION

Every student has the right to be safe in school and to receive a quality education with their peers that prepares them for post-secondary education and/or competitive integrated employment (CIE). Schools must ensure robust implementation of the Individuals with Disabilities Education Act (IDEA), Every Student Succeeds Act (ESSA), and other federal and state laws and regulations. Students with disabilities must be provided a free and appropriate public education and have access to the same opportunities for learning, in the classroom and online, as students without disabilities. School districts and other educational agencies must be held accountable for implementing all state and federal laws.

Students with disabilities must be educated alongside their peers without disabilities in the least restrictive environment (LRE). The needs of the student must not impact the child's placement in LRE. Parents must be provided information and training regarding how to access Free Appropriate Public Education (FAPE) and LRE. Students with disabilities must have access to the same virtual learning models as students without disabilities, and all related services must be provided for students with disabilities to access their education. Parents and students must have equal participation in the Individual Education Program (IEP) process including the ability to give informed consent. Comprehensive transition planning must be considered as part of the IEP process.

Teachers, school leaders, paraprofessionals, and other school-based professionals must be trained to use valid, positive, and proactive practices such as individualized school-wide positive behavior interventions and supports with fidelity. Schools must ensure that robust policies and practices are created and implemented to reduce bullying and harassment of students with disabilities. The Council opposes the use of all forms of seclusion and restraint. All school-based professionals and staff must be provided training on how to interact with students with disabilities.

HOUSING

Statewide inclusive living options for individuals with I/DD must be increased and enhanced through access to housing and subsidies that are paired in a timely manner with needed supports and services. Community education and integration must be provided to reduce discrimination. Permanent, affordable, accessible, safe and sustained housing options must be continually developed to meet both current and future needs.

COMMUNITY PARTICIPATION

Individuals with I/DD must have access to and be fully supported to fully participate in their communities with their peers without disabilities through opportunities in all areas of community life including but not limited to education, employment, recreation, organizational affiliations, spiritual development, and civic responsibilities that provide a life similar to individuals without disabilities.

TRANSITION TO ADULT LIFE

All services, including education, rehabilitation, independent or supported living, and regional center services, must support students and adults to transition to competitive integrated employment, post-secondary education, or other opportunities including volunteering that will lead to meaningful employment in the community. Transition services must be considered at the earliest possible opportunity and across the lifespan. Adults with I/DD must have access to meaningful activities of their choice with the appropriate services and supports including aging adults.

SAFETY

All people have a right to be safe. Every person must be provided emergency preparedness training for all types of emergencies or disasters. Individuals with I/DD experience a much greater rate of victimization and a far lower rate of prosecution for crimes against them. The same level of due process protections must be provided to all people. Individuals with I/DD should be trained on personal safety, how to recognize crimes, how to protect themselves against becoming victims of crime including on the internet, how to protect themselves from human trafficking, and how their participation in identification and prosecution can make a difference. In addition, too many interactions between law enforcement and individuals with I/DD end in avoidable tragedy. Law enforcement personnel, first responders, emergency medical professionals, and people in the judicial system must be trained in how to work with individuals with I/DD during the course of their duties including those who are suspects, victims, or witnesses of crimes. The Council opposes the use of all forms of seclusion and restraint.

QUALITY AND RATES FOR SERVICES AND SUPPORTS

Having access to and receiving quality individualized services and supports is the cornerstone for individuals with I/DD to be safe, healthy, and to promote self-determination, interdependence, and inclusion. An adequate safety net must be in place to immediately and timely address medical, mental health, behavioral, residential, staffing, equipment, or other needs when those services or supports fail, are interrupted, are not available, or additional services and supports are necessary for urgent or immediate need.

The state must streamline burdensome and duplicative regulations and processes that do not lead to positive, inclusive outcomes for individuals with I/DD and their families. Quality and timely assessment and oversight must be provided. The state must measure what matters, and the results must be administered in a culturally competent manner. The results must also be made public and be used to improve the system of services and supports. The state must restore and provide ongoing monitoring of rates to adequately support the availability of quality services for individuals with I/DD. A planned and systematic approach to rate adjustments must prioritize and incentivize quality services and supports.

For more information, contact: scdd@scdd.ca.gov | 916-263-7919

January 19, 2022

**AGENDA ITEM 9.
INFORMATIONAL ITEM**

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES – LPPC

Updates and Standing Agenda Items

The goal of this agenda item is for Committee members to provide updates on the following items and be updated on the actions of the Council.

Official agency updates on the DDS Taskforce and Workgroup, Self-Determination Program and CalABLE can be found by clicking the hyperlinks below.

- a. November Council Meeting Summary
- b. DDS Taskforce and Workgroup ([Updates](#))
- c. Self-Determination Program ([Implementation Updates](#))
- d. CalABLE ([Updates](#))

Attachment(s)

None.

Handout(s)

Could be additional handout(s) day of meeting.

January 19, 2022

**AGENDA ITEM 10.
INFORMATIONAL ITEM**

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES – LPPC

Member Updates

The goal of this agenda item is to allow Committee members time to provide local updates from their community on policy related issues not included in the agenda.

Attachment(s)

None.

Handout(s)

Could be additional handout(s) day of meeting.