



NOTICE/AGENDA

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES COUNCIL MEETING

This meeting is being held in person. Members of the public may participate in person and listen by telephone. Accessible formats of all agenda and materials can be found online at www.scdd.ca.gov.

MEETING DETAILS:

PHYSICAL LOCATION: Holiday Inn, 300 J St, Sacramento, CA 95814

TELECONFERENCE (CALL-IN NUMBER): (888)-475-4499 or (877)-853-5257

MEETING ID: 821 2009 4881 **PASSCODE:** 011256

DATE: September 29, 2026

INFORMAL SOCIALIZING: 10:00 AM – 10:30 AM

MEETING TIME: 10:30 AM – 4:00 PM

COUNCIL CHAIR:

Julie Gaona

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.

Separately, 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.

Members of the public must be in person to provide a public comment.

**Item 5. APPROVAL OF JULY 2026 MINUTES **

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All

Item 6. CHAIR REPORT AND COMMITTEE REPORTS

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Julie Gaona, Council Chair

- A. Statewide Self-Determination Advisory Committee (SSDAC)
- B. Executive Committee
- C. Legislative and Public Policy Committee (LPPC)
- D. Self-Advocates Advisory Committee (SAAC)

Item 7. STATEWIDE SELF-ADVOCACY NETWORK REPORT

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SCDD SSAN Representative Eric Aguilar

Item 8. EXECUTIVE DIRECTOR REPORT & STAFF REPORTS

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Aaron Carruthers, Executive Director

- A. Chief Deputy Director Report
- B. Deputy Director of Policy and Public Affairs Report
- C. Deputy Director of Regional Office Operations Report
- D. RAP Report
- E. QA Project Update Report

Item 9. NOMINATIONS FOR CHAIR & VICE CHAIR

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Aaron Carruthers, Executive Director

Item 10. 2027 LEGISLATIVE PLANNING

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Harold Fujita, Chair of the Legislative and Public Policy Committee (LPPC) and Chris Arroyo, Deputy Director of Policy and Public Affairs

- A. Adopt Policy Projects 
- B. 2026 Bill Idea Contest

Item 11. CLOSED SESSION: PERSONNEL

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Pursuant to Government Code Section 11126(a)(1), the Council will have a closed session to determine the evaluation of a public employee.

Item 12. RECONVENE OPEN SESSION

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Pursuant to Government Code Section 11126.3 (f), there will be an announcement of any publicly reportable actions taken during closed session.

Item 13. NEXT MEETING DATE AND ADJOURNMENT

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The next Council meeting will be held on Zoom on November 17, 2026.

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 Yaritza Sanchez at (916)-207-2856 or yaritza.sanchez@scdd.ca.gov. Please provide at least 3 business days prior to the meeting to allow adequate time to respond to all requests.

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

SEPTEMBER 29, 2026

**AGENDA ITEM 4.
INFORMATION ITEM**

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Public Comments

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SEPTEMBER 29, 2026

AGENDA ITEM 5.

ACTION ITEM

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Approval of July 2026 Minutes

The draft minutes from the July 21, 2026 Council meeting have been included in the packet for review. Councilmembers will vote on whether to approve the minutes.

Attachment

July Council Meeting Minutes

Action Recommended

Approve the July Council meeting minutes.



DRAFT
Council Meeting Minutes
July 21, 2026

Members Attending

Andy Imparato (DRC)
Ana Acton (CDA)
Azucena Garcia-Ferro (S.A.)
Bob Twomey (F.A.)
Brianna Heath (UCEDD)
Cathay Liu (F.A.)
Debra Cooper (CHHS)
Eric Aguilar (S.A.)
Harold Ashe (F.A.)
Harold Fujita (F.A.)
Irene Valdez (F.A.)
Jessica Brown (F.A.)
Joseph Billingsley (DHCS)
Julie Gaona (S.A.)
Kara Ponton (S.A.)
Kim Rothschild (F.A.)
Larry Yin (UCEDD)
Liz Laugeson (UCEDD)
Lupe Rodriguez (F.A.)
Melissa Fitch (F.A.)
Michi Gates (DDS)
Michelle Padilla (S.A.)
Nestor Nieves (S.A.)
Sascha Bittner (S.A.)
Sherry Johnson Alvarez (F.A.)
Sonia Jones (S.A.)

Members Absent

Maria Aliferis-Gjerde (DOR)
Noelia Hernandez (CDE)
Rosanna Ryan (S.A.)

Others Attending

Aaron Carruthers
Austin Murphy
Barbara Imle
Chanel Murray
Chris Arroyo
Veronica Bravo
Christine Tolbert
Darlene Hanson
Lisa Hooks
David Delgado
Debbie Marshall
Dena Hernandez
Francisco Sudiactal
Greg Gonzalez
Heather Kroencke
Judi Muirhead
Judy Mark
Kevin Rowell
Maureen Fitzgerald
Michael
Michelle Cave

Others Attending (cont.)

Nick Lutton
Nina Spiegelman
Patricia Jackson
Rachel Kripke-Ludwig
Renee Bauer
Riana Hardin
Robin Maitino-Erben
Sam Wijesiriwardane
Scarlett VonThenen
Sheraden Nicholau
Yaritza Sanchez
Yolanda Cruz

Legend:

SA = Self-Advocate
FA = Family Advocate

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1. CALL TO ORDER

Chair Julie Gaona called the meeting to order at 10:31 A.M.

2. ESTABLISH QUORUM

A quorum was established.

3. WELCOME AND INTRODUCTIONS

Members and others in attendance introduced themselves.

4. PUBLIC COMMENTS

Dr. Clarissa Kripke, Clinical Professor of Family and Community Medicine at the University of California, San Francisco, provided a public comment in support of communication access, including facilitated communication, spelling to communicate, and rapid prompting.

5. APPROVAL OF MAY 2026 MINUTES

Action 1

It was moved/seconded (Bittner [S.A.]/ Padilla [S.A.]) and carried to approve the May 2026 Council meeting minutes as presented. (See last page for a voting record of members present)

6. CHAIR REPORT AND COMMITTEE REPORTS

Chair Julie Gaona recognized Disability Pride Month and the anniversary of the Americans with Disabilities Act. She highlighted SCDD's latest Storytellers blogs featuring Councilmembers Eric Aguilar, Sascha Bittner, Azucena Garcia-Ferro, herself, and her husband Rigo. She reflected on her experiences with independence and the continued need for self-advocacy and disability education. She encouraged people with disabilities to continue advocating for themselves and others. She noted that ending the marriage penalty remained one of her personal goals.

7. DISABILITY RIGHTS MOVEMENT IN CALIFORNIA: THEN & NOW

Self-Advocates Advisory Committee Chair Sascha Bittner presented on the history and impact of California's disability rights movement. She discussed the Independent Living Movement, the 1977 occupation of federal offices to secure enforcement of Section 504, passage of the Americans with Disabilities Act, creation of California's regional center system, efforts to move people out of institutions, and the growth of the People First movement.

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Ms. Bittner explained that these efforts helped advance the rights of people with disabilities to live in the community, make decisions about their lives, choose their supports, and participate fully in society. Members discussed the importance of protecting the progress made through disability advocacy and opposing efforts that could move people back toward institutional settings. Ms. Bittner emphasized that the work must continue and that future advocacy must be led by self-advocates, guided by the principle of “Nothing About Us Without Us.”

8. SCDD UPDATES & STAFF REPORTS

Executive Director Aaron Carruthers provided updates on the federal, state, and SCDD budgets. He reported that the House Appropriations proposal maintained level federal funding for Developmental Disabilities Councils. Although the proposal avoided a funding reduction, federal funding for Councils has not increased since 2021, while costs have increased by approximately 16%.

Mr. Carruthers reported that the Governor signed the 2026–27 State Budget on June 29, 2026. The budget rejected proposed cuts to In-Home Supportive Services (IHSS) and Adult Protective Services, delayed Medi-Cal cuts for people with unsatisfactory immigration status until July 1, 2027, and included a \$2.4 billion investment in special education. It also set the Medi-Cal asset limit at \$23,000 and included a version of the Medi-Cal Fair Share Contribution, which the Council supported in May to provide additional funding for health care.

Additionally, SCDD received \$2.4 million in one-time funding to create a Special Education Parent Action Network. SCDD also received \$730,000 to help pay for administrative services provided by the Department of Social Services, including personnel, information technology, accounting, contracting, and legal support.

Members discussed proposed regional center assessments, local Self-Determination Program funding, Medi-Cal work requirement exemptions, federal deferrals of Medi-Cal payments, and new federal language related to Olmstead and center-based employment. The Department of Developmental Services clarified that the proposed standardized assessment would apply when determining regional center eligibility and would not require people currently served to be reassessed for eligibility. A separate annual comprehensive needs assessment for people already

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receiving services would replace the Client Development Evaluation Report and support the Individual Program Plan process.

9. **POLICY PLATFORM: REVIEW & APPROVAL**

Deputy Director of Policy and Public Affairs Chris Arroyo presented proposed revisions to the Council's Policy Platform. He explained that the revised platform combines three existing policy resources into one document and aligns SCDD's policy and legislative activities with the 2027–2031 State Plan. The platform states the Council's positions and guiding principles and provides staff with a consistent framework for evaluating policy issues and developing positions, advocacy, public comments, communications, and partnerships. It is organized into eight priority areas: civil rights, education, employment, community services and supports, health care, public safety and emergency preparedness, housing and community living, and emerging issues.

Action 3

It was moved/seconded (Bittner [S.A.]/ Padilla [S.A.]) and carried to approve the Legislative and Public Policy Committee's (LPPC) recommendation to adopt the proposed revisions to the Policy Platform to take effect on October 1, 2026. (See last page for a voting record of members present)

10. **POLICY POSITION: FACILITATED COMMUNICATIONS AS AN INCLUSIVE PRACTICE**

Deputy Director of Policy and Public Affairs Chris Arroyo and Executive Director Aaron Carruthers presented a proposed policy position on individualized communication systems and supports as inclusive practices. They shared that SCDD had received reports of services being denied and communications being rejected because a person used assistance to spell or type. The proposed position supports access to communication systems and supports that reflect each person's needs, preferences, and chosen method of communicating. Under the policy, communication and services should not be automatically rejected solely because assistance is used or the communication method is disputed. Decisions should be individualized and consider the person, communication method, support, and context while centering the person's choices, authorship, and control.

Judy Mark, President of Disability Voices United, provided a public comment in support of the proposed policy. She shared that DVU had

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worked on communication access through its programs and advocacy for at least six or seven years. She reported that DVU had heard from the community that regional centers were denying communication supports and that administrative law judges had ruled against individuals seeking access to those services. She expressed deep appreciation to the Council for considering the proposed policy.

Dr. Clarissa Kripke voiced a public comment from her daughter, Rachel Kripke Ludwig, leader of the Other Option self-advocacy organization for Bay Area AAC users. Ms. Kripke Ludwig expressed support for the proposed policy.

Darlene Hansen, a speech-language pathologist, provided a public comment in support of the proposed policy. She shared that she had used various modes of augmentative communication in her practice for over 35 years, helping people learn different communication strategies and gain access to communication. She stated that the responsibility was not to decide whether a person's communication was real, but to ensure that each person had access to a communication method that allowed them to express their thoughts, choices, and ideas. She emphasized that communication is a human right.

Action 3

It was moved/seconded (Gaona [S.A.]/ Bittner [S.A.]) and carried to adopt the policy position recognizing facilitated communication as an inclusive practice. (See last page for a voting record of members present)

11. CLOSED SESSION: PERSONNEL

The Council went into closed session.

12. RECONVENE OPEN SESSION

The Council reconvened from closed session with no actions to report.

13. NEXT MEETING DATE AND ADJOURNMENT

The next Council meeting will be held on Zoom on July 21, 2026. Chair Gaona adjourned the meeting at 2:54 P.M.

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Name	Vote 1	Vote 2	Vote 3
Acton, Ana	NP	Abstain	Abstain
Aguilar, Eric	NP	Aye	Aye
Ashe, Harold	Aye	Aye	Aye
Billingsley, Joseph	Aye	NP	NP
Bittner, Sascha	Aye	Aye	Aye
Brown, Jessica	Aye	Aye	Aye
Cooper, Debra	NP	Abstain	Abstain
Fitch, Melissa	Aye	Aye	Aye
Fujita, Harold	Aye	Aye	Aye
Gaona, Julie	Aye	Aye	Aye
Garcia-Ferro, Azucena	Aye	Aye	Aye
Gates, Michi	Abstain	Abstain	Abstain
Heath, Brianna	Aye	Aye	Aye
Imparato, Andy	Aye	Aye	Aye
Johnson Alvarez, Sherry	Aye	Aye	Aye
Jones, Sonia	Aye	Aye	Aye
Laugeson, Liz	Aye	Aye	Aye
Liu, Cathay	Aye	NP	NP
Nieves, Nestor	Aye	Aye	Aye
Padilla, Michelle	Aye	Aye	Aye
Ponton, Kara	Aye	Aye	Aye
Rodriguez, Lupe	Aye	Aye	Aye
Rothschild, Kim	Aye	Aye	Aye
Twomey, Bob	Aye	Aye	Aye
Valdez, Irene	Aye	Aye	Aye
Yin, Larry	Aye	Aye	Aye

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SEPTEMBER 29, 2026

**AGENDA ITEM 6.
INFORMATION ITEM**

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Chair Report and Committee Reports

Council Chair Julie Gaona will provide Councilmembers with an oral report about her recent activities and current priorities for the Council.

SCDD committee summaries have been provided for informational purposes.

Attachments

Statewide Self-Determination Advisory Committee (SSDAC) Summary 8/10

Executive Committee Summary 8/25

Legislative and Public Policy Committee Summary 9/10

Handout

Self-Advocates Advisory Committee (SAAC) Summary 9/21

AGENDA ITEM 6A.

STATEWIDE SELF-DETERMINATION ADVISORY COMMITTEE (SSDAC) SUMMARY

Date of Meeting

August 10, 2026

Meeting's Focus

The Statewide Self-Determination Advisory Committee (SSDAC) met via Zoom on August 10, 2026, to receive updates from the Co-Chairs, the State Council on Developmental Disabilities (SCDD), and the Department of Developmental Services (DDS) on Self-Determination Program (SDP) implementation, funding, and statewide standardization, and to hold the Co-Chair election.

Co-Chairs Rick Wood and Nestor Nieves provided updates on Committee priorities, the SSDAC Workgroup, and their July 22 meeting with DDS on local volunteer advisory committee (LVAC) implementation funds. SCDD Executive Director Aaron Carruthers reported on the redesigned two-part SDP orientation, now delivered solely by SCDD, and on state and federal updates. DDS staff shared updates on enrollment, the cost-effective definition, and standardization work.

The meeting included extensive discussion regarding Senate Bill 163, which changes how implementation funding may be used and directs it to local resource fairs and standardized statewide trainings. DDS asked the Committee for input on how that training should be designed and delivered. Members and public participants raised concerns about the loss of local flexibility, whether a standardized statewide approach can meet the needs of rural and underserved communities, and how the funds will be distributed.

Members and public participants also raised broader concerns regarding inconsistent practice across regional centers, delays in access to services, and the responsiveness of the Office of the Developmental Services Ombudsperson.

Chris Miller of the Redwood Coast Regional Center LVAC was elected Co-Chair, running unopposed after the two other candidates withdrew. The Committee recognized outgoing Co-Chair Rick Wood for his service.

Item's Acted Upon

- Approval of the May 5, 2026 meeting minutes.
- Election of Chris Miller as SSDAC Co-Chair.

Future Meeting Dates

December 3, 2026.

AGENDA ITEM 6B.**EXECUTIVE COMMITTEE SUMMARY**

Date of Meeting

August 25, 2026

Meeting's Focus

The Executive Committee met on August 25, 2026. The meeting included one sponsorship request, nine conflict resolution plans, an SCDD budget update, a report from the Executive Director, and a closed session.

Executive Director Carruthers reported that both Council-sponsored bills, SB 1052 (Gonzalez) on authorized representation and AB 2360 (Arambula) on plain language, were held in the Senate Appropriations Committee. He discussed SCDD's work on budget trailer bill proposals related to a Special Education Parent Action Network, Regional Center assessments, and civil commitments at Porterville Developmental Center. He also reported that SCDD had met or exceeded all measurable objectives in its current five-year State Plan and submitted its 2027–2031 State Plan by the federal deadline. SCDD's annual "There Should Be a Law" contest received 184 ideas, which will help inform future legislative priorities. Mr. Carruthers also announced upcoming community conversations across the state.

Items Acted Upon

- Approved the June 2026 meeting minutes.
- Approved a sponsorship request from Community Interface Services.
- Approved conflict resolution plans for Regional Center Board Members Elizabeth Rodriguez, Pam Gruber, Rebekah Wilson, Diana Larson, Mike Sawyer, William Lewis, Nilo Choudhry, Terry Magady, and Jacquie Colton.

Future Meeting Date

October 20, 2026

AGENDA ITEM 6C.

LEGISLATIVE AND PUBLIC POLICY COMMITTEE SUMMARY

Date of Meeting

September 10, 2026

Meeting's Focus

On September 10, 2026, the Legislative and Public Policy Committee (LPPC) met to receive updates on the bills that Council took positions on and to select and recommend 2027 policy projects for the Council's consideration.

Deputy Director Christopher Arroyo presented seven policy project ideas for 2027 and asked the Committee to recommend four to pursue actively and two to hold in reserve.

Deputy Director Arroyo provided members with an overview of the sixth annual "There Should Be a Law" contest. This year SCDD received 184 ideas. Human services and education accounted for 42 percent of submissions, and three themes emerged: addressing barriers, participating fully and safely in community life, and economic security. He noted that staff will look at all six years of contest data together to see how these concerns have changed over time.

Executive Director Aaron Carruthers provided federal updates, including the U.S. Department of Justice slip opinion on the integration mandate associated with *Olmstead v. L.C.* and its recent citation in litigation, related activity concerning intentional communities and HCBS services, and a federal continuing resolution funding the government at current levels through early December.

Items to be Acted Upon

- The Committee approved the June 2026 Meeting Minutes, as amended.
- The Committee acted to recommend policy project ideas for 2027, identifying the first four ideas as primary, keeping ideas 5 and 6 in the mix, and eliminating idea 7.

Future Meeting Dates

If needed, October 13, 2026

SEPTEMBER 29, 2026

**AGENDA ITEM 7.
INFORMATION ITEM**

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Statewide Self-Advocacy Network (SSAN) Report

The Statewide Self-Advocacy Network (SSAN) is a project of the Council. Members will hear updates from SCDD SSAN Representative Eric Aguilar on recent activities.

Handout

May be additional handout(s) on the day of the meeting

SEPTEMBER 29, 2026

**AGENDA ITEM 8.
INFORMATION ITEM**

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Executive Director Report & Staff Reports

SCDD Executive Director Aaron Carruthers will provide Councilmembers with an oral report regarding recent Council activities. Additionally, SCDD staff reports have been included in the packet for informational purposes.

Attachments

Chief Deputy Director Report
Deputy Director of Regional Office Operations Report
RAP Report
QA Project Report

Handouts

Executive Director Report
Deputy Director of Policy and Public Affairs Report



Chief Deputy Director Report

September 2026

Rihana Ahmad

Overview:

The Chief Deputy Director (CDD) continues to oversee operational functions in collaboration with staff, while identifying tools and strategies to strengthen organizational effectiveness. Recent efforts have focused on engaging with staff, leadership, and external partners to support program development, policy implementation, and operational alignment.

Key initiatives include implementation and oversight of the Supported Decision-Making Technical Assistance Program (SDM-TAP), along with collaborative discussions with the Department of Developmental Services (DDS) on the Quality Assurance (QA) program, Self-Determination Program (SDP) Orientations and Statewide Self-Determination Advisory Committee (SSDAC) projects.

Core administrative responsibilities are being prioritized, including executive oversight of the agency's budget development and monitoring processes, contract and procurement oversight, personnel management, interagency coordination, and day-to-day operational support across the organization.

The following sections highlight recent activities and accomplishments from some of the operational and program support units under the Chief Deputy Director's oversight.

Personnel:

- ✓ Conducting 4 recruitments in FY 2027 (July 1, 2026 – present)
- ✓ SCDD completed part one of the Dymally -Alatorre Bilingual Service Act Language Survey. Data from the survey is being compiled for CalHR reporting.

Budget:

- ✓ Reconciled the State Controller's Office (SCO) Schedule 8 and submitted the Schedule of Salaries and Wages (7A) to Department of Finance (DOF)
- ✓ Conducted and submitted past year expenditure reporting to DOF for General Fund and Reimbursements

- ✓ Completed the June to July Payroll Deferral Drill for DOF
- ✓ Finalized the contract with approved budget documents for SDM-TAP
- ✓ Created new budget allocation templates for regional offices
- ✓ Provided operational support for Chief Deputy Director payroll projection and Basic State Grant (BSG) cashflow analysis

Information Technology:

- ✓ SCDD IT Staff completed and submitted SCDD's annual compliance and risk reports to CDT on July 31st in addition to their ongoing support and maintenance of agency technology and hardware.
- ✓ SCDD IT staff facilitated agency migration from landline-based telephones to Microsoft Teams virtual calling software. Staff held several office hours and staff training to ensure a smooth transition.

Business Operations and Committee Supports (BOCS):

- ✓ Since the July Council meeting BOCS unit continues to refine and finalize Standard Operating Procedures (SOPs) that will ensure alignment on committee, council planning, invoicing and other key business operations:
 - Most recently they completed the Agency's *Small Business and Disabled Veteran Business Enterprise First Procurement Policy* and submitted it to the Department of General Services (DGS) for review ahead of agencywide implementation.
- ✓ BOCS staff have begun preparing end-of-fiscal year reports to its various control agencies to ensure compliance with AB 2019 mandated procurement goals.
- ✓ BOCS staff also processed invoices, purchase orders, travel claims, and reimbursements for Councilmembers and staff, to ensure timely payments and compliance.
- ✓ BOCS, in partnership with other key staff, have begun 2027 Council and Committee planning.

State Plan:

- ✓ SCDD staff submitted the 2027-2031 State Plan and supporting documentation to the Administration on Community Living (ACL) on August 15th. The materials included the Council Staff's annual work plan, performance metrics, and updated Evaluation Plan, and comprehensive review and analysis of available disability Services across the state. After review, the ACL will provide a determination on whether the Council's plan will be fully approved.
- ✓ To date, the SPT has received more than 1,600 activity reports for this FFY, all of which have currently been reviewed. The FFY will end on September 30th, with the new 5-year State Plan, with its goals and objectives, taking effect on October 1st.

- ✓ In anticipation of the end-of-year (and end of 5-year State Plan cycle) Program Performance Review (PPR), the State Plan Team has been working with regional office staff to collect anecdotal outcome and impact data, emerging issues, new initiatives, etc.
- ✓ On behalf of ACL, our federal technical assistance agency (ITACC) has been collecting and posting Council impact stories to its website. California has submitted and had 6 impact stories posted to ITACC's national website <https://itacchelp.org/council-work-and-results/>:
 - **Service Connections**
 - Professional Training ([CA: Service Connections – Professional Training - ITACC](#))
 - Technical Assistance Clinics ([CA: Technical Assistance Clinics - ITACC](#))
 - Expanding Access to Self-Determination ([CA: Expanding Access to Self-Determination - ITACC](#))
 - **Caregiving**
 - California CARE Registry for First Responders, Vulnerable Populations, Caregivers, & Disasters ([CA: California CARE Registry for First Responders, Vulnerable Populations, Caregivers, and Disasters...](#))
 - **Well-Being, Individual Rights, & Safety**
 - Sensory-Friendly Health Care ([CA Sensory-Friendly Health Care - ITACC](#))
 - Life Care Portfolio ([CA Life Care Portfolio - ITACC](#))

Self-Advocacy:

- ✓ The Statewide Self-Advocacy Network (SSAN) held its second meeting of the year on Wednesday September 2nd. SSAN members also provided feedback on the Department of Developmental Services' (DDS) updated grievance process. Additionally, SSAN Members heard updates from SCDD Executive Director Aaron Carruthers on recent State and Federal Disability policy issues and discussed how recent changes to Medicaid funded programs have been affecting them and their communities.

Statewide Self Determination Advisory Committee (SSDAC):

- ✓ Negotiations with DDS to renew the SSDAC contract are continuing. In the meantime, SCDD is working with DDS on a six-month no-cost extension to the current contract so that the contract period aligns with the State fiscal year. A new five-year contract period is expected to begin July 1, 2027.
- ✓ SSDAC leadership also participated in the DDS Roundtable on September 10. The discussion focused on making sure the community and stakeholders receive consistent information and identifying ways to improve the Self-Determination Program overall.

- ✓ SSDAC Co-Chair elections were held on August 10. Chris Miller was elected and began serving his two-year term as Co-Chair on September 1.

Supported Decision-Making Technical Assistance Program (SDM-TAP):

- ✓ The internal implementation phase of the SDM-TAP at SCDD has begun, with the team finalizing its workplan for the first year of the five-year contract.
- ✓ To inform the workplan and development of program performance metrics, the SDM-TAP team is conducting a landscape analysis of available resources and a needs assessment of internal and external stakeholders.
- ✓ As part of the needs assessment, the team has met with five Regional Centers and plans to meet with 10 more over the next several weeks. The team is also surveying SCDD staff to identify the training and resources they need to effectively provide technical assistance and education on Supported Decision-Making (SDM) to community members.

Self-Determination Program Orientation Project

The SCDD Statewide Self-Determination Program (SDP) Orientation Project is a long-term Interagency Agreement with the California Department of Developmental Services (DDS) to deliver the required first step of the Self-Determination Program. Since July 2022, SCDD has run these sessions statewide in multiple languages, led by SCDD staff alongside co-trainers with lived SDP experience.

As of April 1, 2026, SCDD and DDS launched a redesigned two-part orientation (Part A and Part B), each two hours long; both are required before starting the SDP transition process. The new curriculum improves consistency and aligns with updated statute and policy. The SCDD webpage offers registration, resources, and recordings for both parts in English/ASL and Spanish. Full live Zoom attendance is required for a certificate.

Participation remains strong with 2,040 attendees in July (Part A 1,046 | Part B 994) and 1,675 attendees in August (Part A 831 | Part B 844).

In addition to regular monthly English and Spanish sessions, SCDD offers live AI translation for English-language sessions. In July and August 2026, this tool was used by attendees in Arabic, Chinese, Korean, Lao, Persian (Farsi), Portuguese, Russian, Spanish, Uighur, and Vietnamese. SCDD plans to expand the updated curriculum into all contracted languages, pending completion of translations.

Attendee feedback:

Thank you for such a comprehensive and informative class last night. You really cared about the people who needed the information. Appreciated. - Y.R.

Great vibes. You connect and work well together! Not boring. You make it fun! Thanks! - W.K.

Thank you for being so informative and clear with this training! - S.J.

Thank you ladies for choosing to be here to help out people the way you do.....and thanks for having [co-trainer] share her experience. She is very inspiring!!!! - A.H.

Her testimonial is really giving me the confirmation this is the path for our family please thank her for speaking today really encouraging - J.M.



Deputy Director, Regional Office Operations (DDR00)

Report, September 2026

Sheraden Nicholau

Overview:

The Deputy Director of Regional Office Operations is the lead position fulfilling the department's federal and state mission for systems change and capacity building. This position leads the 12 regional teams to carry out the work of the State Plan, including systemic identification and removal of barriers that keep people with IDD from living integrated lives in the community.

Additionally, this position:

- Represents SCDD externally to build partnerships and advance the work of the SCDD.
- Leverages change management to maximize SCDD's impact.
- Provides leadership and oversight of the programmatic, administrative, and strategic work of the SCDD regional teams.
- Supervises SCDD Regional Managers.

Recent Regional Office Highlights:

- ✓ SCDD Regional Offices, in partnership with SCDD Communications and IT, have wrapped up a successful SCDD themed-month in August, for Back to School 2026, featuring Education Basics and Q&A trainings, and Promoting Inclusion in Education trainings, in English and Spanish. This month's content also included an updated 2026-2027 Back-to-School Guide in English and Spanish. In September, the team kicked-off SCDD themed-month content for Emergency Preparedness Month. This includes trainings in English and Spanish, in partnership with Project

SAFE, and a 2026 -2027 Safe Together Resource Guide, available in English and Spanish.

- ✓ Starting in August 2026, SCDD Regional Offices have begun hosting and co-hosting a series of 12 Community Conversations across CA. These Community Conversations are an opportunity for community members to meet in-person with SCDD Director Carruthers, to hear updates on the Council's work and policy developments, to have a chance to connect with other advocates, and to share perspectives on the issues that matter most to the community.

Recent External Partnership Highlights:

- ✓ SCDD DDROO was a keynote speaker, moderator, or presenter at recent conferences, trainings, and events:
 - Crisis Intervention Training (CIT) sessions, for law enforcement and first responders across counties
- ✓ SCDD, in partnership and contract with UC Davis, has begun finalizing planning for the 2027 calendar year of CA Department of Social Services' Community Care Licensing statewide trainings. This work will involve nine full-day training sessions, training hundreds of Community Care Licensing Analysts, and providing paid panel work for community leaders with IDD / lived experience.
- ✓ This fall, SCDD will be providing statewide training for approximately 500 CA Department of Rehabilitation (DOR) staff members, through their Student Services Learning Sessions. This training will benefit DOR staff members working directly with youth and young adults with disabilities pursuing employment through higher education, technical training, and workforce preparation programs.



Recent Administrative Highlights:

- ✓ SCDD regional teams and HQ teams continue to collaborate on updating in-house procedures and best-practices, for effective and efficient regional operations.
- ✓ Eight SCDD teams are in process of renewing their office lease or evaluating new lease options.
- ✓ Three SCDD Regional Offices are in the process of recruiting and hiring team members.

State Plan Activities Year-to-Date from the Regional Offices & HQ Team Members:

SCDD team members continue to lead and contribute to a variety of statewide and regional activities in this final year of the current State Plan.

Activities conducted and reported on to-date this fiscal year include:

- ✓ 302 self-advocacy activities (Goal 1), impacting 4,725 individuals
- ✓ 1,135 systems change activities (Goal 2), impacting 24,484 individuals
- ✓ 627 capacity-building activities (Goal 3), impacting 25,559 individuals
- ✓ Delivering a total of 529 trainings / events, and 1,535 meetings, chats, and clinics
- ✓ Preparing 525 self-advocates and 31 family advocates to be trainers, facilitators, and presenters across 350 prep sessions
- ✓ Developing 101 curricula and resources, updating 56 curricula and resources, and translating 16 curricula and resources
- ✓ Reaching 15,058 **new** individuals with SCDD's work

A Few Recent State Plan Activities Highlights:



(L) Attendees attend a presentation from SCDD at the 3rd Annual Government & Disability Summit, in Ventura. (R) Director Carruthers joins SCDD Regional Managers, Jennifer Lucas and Nick Lutton, for a photo op at the summit.



(L) For the first time, the City of Stockton declared a proclamation for Disability Pride Month / Disability Rights Month, in celebration of the ADA. This milestone comes after the Mayor's Disability Roundtable Committee made a formal recommendation. (R) A photo of the proclamation.



The Roxie Theatre hosted a special double-feature, *Sign 504 Now!* and *Vivien's Wild Ride*, with a live panel discussion. The Roxie Theatre and Dr. Kevin Mintz were proud to partner with SCDD, the GLBT Historical Society, and the Center for Independent Living for the event. SCDD Councilmember Bittner, SCDD Regional Advisory Committee Member Dr. Mintz, and SCDD team members smile in front of the venue.

Goal 1: Self-Advocacy

- ✓ The SCDD San Diego Imperial Regional Office supported four trainers with lived experience and I/DD from the Leaders Empowering Self-Advocates (LESA) group. These trainers provided a boardmanship training at the SCDD Statewide Self-Advocacy Chat. With support, the trainers updated and presented the first of a two-part boardmanship training, designed to increase participants' knowledge of board membership, roles and responsibilities, and the application process. Twelve advocates interested in leadership participated. Participants learned about boards of



directors, board member responsibilities, advisory boards, and facilitation tools and tactics. Participants engaged by asking questions and discussing their experiences and interest in serving on boards. As a result, participants increased their knowledge of boardmanship, leadership responsibilities, and gained a better understanding of how to pursue board opportunities. Additionally, this session strengthened peer leadership, and peer support for growing new leaders throughout California.

- ✓ The SCDD North Valley Hills Regional Office provided support, resources, and served as co-trainer in partnership with a trainer and leader with lived experience from Self Advocacy Council 6 (SAC6). This trainer and leader served previously as a Regional Advisory Committee (RAC) member. Trainings were provided to a group in Jackson and a group in Valley Springs, through Central Valley Training Center. These trainings aimed to educate and motivate participants, and to provide tools for participants to start developing new self-advocacy groups in the region. The hope is for new groups to form, and for those groups to collaborate with SAC6 for leveraged networking, opportunities, and visibility. The lead trainer and SCDD staff provided these presentations and resources with 30 self-advocates and staff in attendance in both locations. Several advocates reported having received self-advocacy group formation resources for the first time. The lead trainer and SCDD staff will follow up with these participants in the quarter ahead to offer additional supports and input into their newly formed groups.

Goal 2: Systems Change

- ✓ The SCDD Sequoia Regional Office and SCDD Central Coast Regional Office presented 'Advancing Disability-Inclusive Healthcare: Systemic Considerations and Practical Tools' at the third annual California Government & Disability Summit in Ventura. The three-day summit brought together approximately 300 attendees from government agencies, disability organizations, independent living centers, public health and behavioral health systems, utilities, and other community partners to advance

disability inclusion and accessibility. The 2026 theme, ‘Access that Moves Us: Quality Care, Mobility, and Safety’, addressed health, accessibility, transportation, emergency preparedness, employment, technology, and other areas affecting people with disabilities. SCDD provided a breakout session focused on healthcare access and equity for people with disabilities, particularly people with I/DD. The presentation examined systemic barriers, gaps and disparities in healthcare, disability rights, and the challenges people with IDD experience navigating multiple systems, including Medi-Cal, regional centers, and behavioral health. Participants received practical strategies for improving communication and accessibility, strengthening person-centered supports, and promoting informed decision-making and equitable access to quality healthcare. Approximately 50 people attended the session; engagement continued well beyond the scheduled hour, with several participants remaining for approximately an additional hour of questions, technical assistance, discussion, and exploration of potential partnerships. The presentation generated interest in additional training and collaboration, from state departments, healthcare facilities, and paramedicine. Participant feedback included:

- *‘Thanks to you and your colleague for a great presentation’*
 - *‘Interested in having you both as a guest speaker’*
 - *‘Excellent presentation would love to connect further’*
 - *‘Thank you so much, the information was so important’*
 - *‘We are working on connecting with medical facilities to provide trainings, we would love to work with you on this’*
- ✓ The SCDD North Coast Regional Office, in partnership with DREDF, have provided training and technical support over the last seven months to two special education advocates hired by Hoopa Tribal Education Association. Both advocates are members of the Hoopa Valley Tribe and are parents themselves. The intent of this has been to invest in building their knowledge and capacity and, thus, provide Hoopa families



with competent, culturally relevant information and support from within their community. At a recent back to school event, SCDD staff shared a resource table with the two family advocates from the Hoopa Tribal Education Association. They reported that more than 60 families recently have asked for assistance. During that single event, another six families approached and signed up for advocacy assistance with their children's IEPs. This approach's responses from the community indicate that this is an effective approach to serve Hoopa Valley families in education. This approach is producing stronger outcomes for this community, compared to more traditional training and IEP clinics provided by external partners.

- ✓ The SCDD Bay Area Regional Office participated in and provided support for Congreso Familiar, an annual conference for Spanish language families with children and family members with disabilities. This conference provided families with leadership skills and resources to access services and supports in their community. This year, approximately 175 family advocates, self-advocates, and professionals participated. The conference featured several informational workshops, social activities, and a resource fair – all in an inclusive, supportive, and festive atmosphere. SCDD provided a variety of resources and materials to attendees at the resource fair, and served approximately 48 family advocates, self-advocates, and professionals with technical assistance or recommended resources based on their interests and needs. Attendees engaged in valuable workshops in their primary / preferred language, met key support and advocacy partners, networked with other families and agency providers, as well as accessed resources and tools to better access services in their community.
- ✓ The SCDD Orange County Regional Office serves on the Southern California Association of Governments (SCAG), a governing body that includes the agencies and cities within the 6 counties of Imperial, L.A., Orange, Riverside, San Bernardino and Ventura to manage the long-term growth of infrastructure for the transportation, housing, air quality and land use needs of the Southern California region. This

monthly meeting of community based organizations sought input on issues that impact the quality of life for all individuals in the region. This included ways to improve safety for individuals with disabilities using pedestrian walkways while e-scooter and e-bike users increasingly utilize these same sidewalks. When the discussion of the 'Go Human' public education campaign to improve driver awareness of pedestrian safety began, SCDD offered to connect the 'Go Human' team with individuals with lived experience who are willing to provide input about how to improve access for all on these shared sidewalks in the region. The SCAG 'Go Human' team scheduled follow-up discussion with SCDD regarding traffic safety messaging surrounding usage by individuals with disabilities. Other items discussed included four "Complete Street" demonstration projects. These demonstrations aim to improve streets' integration of commercial, retail, recreation, and residential uses - whether users access streets on public transit, in vehicles, on-foot and on bicycles.

- ✓ The SCDD North State Regional Office visited the Siskiyou County Opportunity Center, toured, and presented during the organization's all-staff monthly meeting. Topics included an overview of SCDD, navigation of the SCDD website and training schedule, and available resources. Hard-copy resources were provided for continued community access. Following the presentation, a self-advocate expressed interest in participating in SCDD's Storyteller Blog to share her employment journey. The interview will be a part of SCDD's October 2026 National Disability Employment Awareness Month (NDEAM) themed content. Additionally, SCDD met one-on-one with the Siskiyou County SELPA Executive Director, to discuss SCDD training opportunities and resources, ongoing Community Advisory Committee (CAC) meetings, potential partnership in developing a Siskiyou County resource fair for students and families with I/DD, and opportunities for SCDD consultation as needed. The SELPA Director provided context regarding significant historical and current changes within Siskiyou County special education, navigating staffing changes and community concerns as the 2026–27 school year approaches.

Goal 3: Capacity-Building

- ✓ The SCDD Sacramento Regional Office provided training to 40 families, focused on understanding and applying Person-Centered Planning (PCP). The training covered practical ways families can use a PCP approach when participating in IPP and IEP processes. Families learned how PCP centers the child's unique voice, strengths, preferences, hopes, and dreams - rather than their diagnosis. Families also learned how active listening can support children in expressing their ideas, needs, and goals. The training emphasized identifying what helps each child thrive, feel safe, and succeed in both school and community environments. Participants gained tools for incorporating person-centered strategies into individual plans, supporting greater self-determination, independent problem solving, and meaningful engagement for school age children. As an outcome of this training, families reported feeling more confident in advocating for their child's needs through a person-centered lens. Post-training, participants will receive follow up support from SCDD, with staff scheduled to return and provide additional training for families and self-advocates on using a person-centered approach to emergency planning.

- ✓ The SCDD San Bernardino Regional Office convened the 'Entrepreneurship & Empowerment Summit', in partnership with The Defeating Epilepsy Foundation and Caravanserai: Alliance for Entrepreneurs. This event brought together neurodivergent individuals, families, self-advocates, support networks, entrepreneurs, and small-business experts to promote entrepreneurship, self-employment, and economic empowerment. The event provided practical business information, shared lived experiences, highlighted available resources, and created connections for continued support. Thirty-nine attendees met with entrepreneur exhibitors and speakers who shared their businesses, experiences, and pathways to entrepreneurship. Self-Determination Program Independent Facilitators, the Inland Empire Health Plan, and the CA Department of Rehabilitation contributed. The summit strengthened an inclusive entrepreneurship network and helped advance



self-determination, economic empowerment, and greater access to small-business opportunities for neurodivergent individuals and their families. It also created a foundation for continued collaboration, resource sharing, and entrepreneurial support beyond the event.

- ✓ The SCDD North Bay Regional Office hosted a 'Relationships Decoded' webinar, presented by Dr. Katie Pedgrift, creator of the curriculum. More than 60 participants attended to learn about sexual safety, healthy relationships, boundaries, consent, and recognizing potentially unsafe situations. The training provided accessible information designed to strengthen knowledge and promote greater personal safety, self-advocacy, and informed decision-making. Attendees with I/DD, family members, and other community members gained information to support personal choice, communication, self-determination, and the ability to recognize and communicate personal boundaries. The event created an inclusive educational space where people with disabilities, families, professionals, and community partners could learn together, delving into issues often overlooked in services. This training strengthened community capacity while promoting the right of people with I/DD to develop safe, healthy relationships and to participate fully in their communities.
- ✓ The SCDD Los Angeles Regional Office developed a statewide directory of Spanish-language support groups for individuals with developmental disabilities and their families, with promotional support from Colaboración Latina de California (CLC). Colaboración Latina de California (CLC) includes our federal partner, the UC Davis MIND Institute, and other collaborative community partners. The directory currently includes 40 Spanish-language support groups across the state and is expected to grow as a live resource. It will be reviewed and updated regularly. Groups listed on the directory are organized by virtual, in-person, and hybrid options, with contact and location information provided, as applicable. [A registration link](#) invites new Spanish-language support groups to submit their information for inclusion in future versions of



this directory. The directory can be accessed through a link and/or QR code, which will always link to the most current version as the directory is updated. SCDD created a flyer which includes this link and QR code for wide distribution to promote the directory and increase awareness of this resource throughout Spanish-speaking communities. Thus far, over 300 family advocates have reviewed the directory. Californians may view the flyers with directory [here](#).

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Rights and Advocacy Program Working inside DDS state operated facilities Council Report for September 2026

Holly Bins, RAP Manager

Julie Hillstead, Canyon Springs VAS Coordinator
Springs Rights Advocate

Robbin Puccio, Canyon

Judi Muirhead, PDC VAS Coordinator
Advocate

Maria Arredondo: PDC Rights

191 Individuals served (census, Sept. 1)	163 Individual-centered meetings attended	83 Committee sessions & rights reviews	3 Individuals placed into the community
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Program Highlight: Independent Rights Review at PDC

Admission, housing, treatment, and accommodation of transgender and gender non-conforming individuals

The RAP Team conducted an independent, rights-focused review of how Porterville Developmental Center admits, houses, treats, and accommodates transgender and gender non-conforming individuals in its care. Maria Arredondo, Rights Advocate for PDC, conducted the investigation; Judi Muirhead, VAS Coordinator, assisted throughout and accompanied her for interviews; the Rights Advocate, VAS Coordinator, and RAP Manager jointly met with the Clinical Director.

- **Scope:** admission packets, admission strategies, and risk-management practices.
- **Interviews:** individuals served at the facility, direct-care staff, Unit Supervisors, and Program Management.
- **Leadership:** a direct meeting with the PDC Clinical Director on admission procedures.

Individuals in a secured treatment setting depend on admission and housing decisions made largely outside their control, with direct consequences for their safety, privacy, and dignity. Reviewing those decisions independently of the facility — drawing on the individuals' own accounts alongside those of staff and management — tests whether current safeguards work in practice, not only on paper.

Findings

The review is complete and produced a thorough assessment of current practices and the safeguards supporting the rights, safety, and needs of transgender and gender non-conforming individuals at PDC. RAP recommended a standardized individualized pre-admission assessment, clearer documentation and early reassessment of placement decisions, consistent name/pronoun records, and practical staff training and oversight.

Activity detail by program

Measure	PDC RA	PDC VAS	CS VAS	CS RA	Total
Census (September 1, 2026)	155	*	*	36	191
IPP and special meetings	19	8	28	19	74
Transition and placement meetings	1	51	22	n/r	74
Court hearings attended	0	2	5	8	15
Incident Action Team meetings	16	2	0	0	18
HRC / behavior & medication reviews	25	0	0	9	34
Denial-of-Rights reviews / active DORs	11	2	0	1	14
Escort review committee	8	0	0	0	8
Quality assurance / administrative review	0	0	0	9	9
Individuals placed into the community	—	2	1	—	3
Transferred PDC → Canyon Springs	—	2	—	—	2
Returned to PDC (county jail / community)	—	1 / 0	—	—	1
Staff reached through rights training	55	—	—	13	68

* The PDC and Canyon Springs censuses are each reported by two teams covering the same population; the total counts each facility once. “n/r” = not separately reported.

Advocacy in Action

- **PDC Rights Advocate:** Two General Event Reports were filed on behalf of individuals reporting physical and psychological abuse by staff; both received emotional support and a well-being evaluation, one with 1:1 staffing, and Protective Services Branch investigated. An individual facing phone restrictions instead received a voluntary plan, which he has followed successfully.
- **PDC VAS:** Quality Assurance referred two individuals with escalating behaviors tied to absent or negative family contact; both accepted services. At a TRM special on restrictive interventions, the VAS Coordinator identified antecedents including a delayed transfer and rising unit census, and the individual's transfer to Canyon Springs will proceed as planned.

At an emergency IBST, an individual retained tablet access in common areas with 2:1 staff, pending court review.

- **Canyon Springs Rights Advocate:** The Rights Advocate has paired with the facility BCBA to deliver monthly training that combines rights education with practical self-regulation tools, so individuals both understand their rights and have the means to exercise them. Four Individual Council meetings were facilitated on the units.
- **Canyon Springs VAS:** An individual who had waited more than a year for EBSH approval, through repeated cancelled placement dates, was placed into the community in July 2026. Advocates supported a family through conservatorship proceedings and are preparing a WIC § 4731 complaint to the regional center. Advocates continue to press for employment planning in IPP meetings.

Systemic Issues

- **Identification and benefits.** Individuals are placed into the community from PDC without valid California ID cards and without original birth certificates, delaying SSI establishment and making a Real ID difficult to obtain. Those found non-restorable face added difficulty qualifying for SSI. Personal and incidental funds are returned to Social Security on placement and re-routed through the regional center, leaving some individuals waiting six months or longer for their own money.
- **Placement delays.** Individuals recommended for transition receive non-specific timeframes and can wait months for building, licensing, or residential reasons; several have developed emotional and anxiety issues as a result. Staffing shortages in community homes and employment programs continue to delay placements, and provider-to-regional-center communication is frequently slow.
- **Communication and access.** Community homes rely on internet phone systems with frequent outages or on staff personal cell phones, leaving supported-living residents with no reliable point of contact. Providers neglect to submit Special Incident Reports despite monthly reminders. Provider trainings held over Zoom on unit cell phones drop out, and advocate access to individuals is limited between 3:00 and 4:00 p.m. by programming and shift changes.
- **Service capacity.** Services for the aging population in the community are increasingly needed and increasingly difficult to find.
- **Resolved this period.** Multiple payphone failures across PDC units degraded phone access. Work orders were submitted, alternative phones provided, and the issues resolved. The facility is now phasing out payphones for two IT-issued phones per unit, with hardware already on order.



Quality Assessment Project (QAP) Report

September 2026

Recent Past Cycle: Family Surveys

Family Surveys collect demographic information on both the individual receiving services ('family member') as well as the person who fills out the survey (the 'respondent') and information on services and supports received.

Child Family Survey (CFS): Mailed to families who have a child family member (ages 17 and under) who lives with the respondent and receives at least one regional center funded service in addition to case management.

Adult Family Surveys (AFS): Mailed to families who have an adult family member (ages 18+) who lives with the respondent and receives at least one regional center funded service in addition to case management.

Family Guardian Survey (FGS): Mailed to families who have an adult family member (ages 18+) who lives in the community (outside the family home) and receives at least one regional center funded service in addition to case management.

Surveys were offered in a total of 19 languages: Arabic, Armenian (Eastern), Chinese (Simplified and Traditional), English, Farsi, Hindi, Hmong, Japanese, Khmer, Lao, Mien, Punjabi, Russian, Spanish, Tagalog, Thai, Ukrainian, and Vietnamese.

The NCI Family Survey Cycle collection has now been completed with a total of 17,219 submitted surveys.

Current Cycle: In-Person Survey (IPS)

The upcoming IPS cycle is scheduled to begin January 2027. During this cycle, a random sample of individuals 18 years or older, receiving at least one regional center funded service in addition to case management, will be surveyed.

Respondents will be given the option to have their face-to-face survey conducted in-person at their preferred location or virtually using Zoom Healthcare.

The target for all 21 regional centers remains 400 each for a statewide goal of 8400 surveys.

To conduct these surveys, SCDD plans to contract with 150-200 surveyors statewide covering languages such as Spanish, Mandarin, Cantonese, and Vietnamese.

Trainings for all surveyors and Quality Assessment Coordinators (QACs) are being conducted in November/December 2026, implemented through live webinars and self-paced online training modules.

About National Core Indicators

National Core Indicators {NCI} strives to provide states with valid and reliable tools to help improve system performance and better serve people with intellectual and developmental disabilities and their families.

Through a contract with Department of Developmental Services {DDS}, State Council on Developmental Disabilities {SCDD}, using the NCI Survey tools, collects quantitative data on consumer satisfaction, provision of services, and personal outcomes. Data collection is completed through face-to-face interviews with consumers as well as mail-in surveys from families.

This data collection effort will enable DDS to evaluate the quality and performance of California's developmental disability service delivery system and among all 21 regional centers over time.

For RC results of past surveys go to: <https://www.dds.ca.gov/rc/nci/>

For more information about the NCI go to: <https://www.nationalcoreindicators.org/>

Scan QR code below to go to QA Project Webpage
scdd.ca.gov/qap



QAC Regional Center Assignments

QAC: Sarah Wirrig
Support Staff: Jennifer Rosenfeld
**Far Northern
Redwood Coast
North Bay**

QAC: Ron Usac
Support Staff: Valerie Buell
**East Bay
Golden Gate**

QAC: George Lewis
Support Staff: Valerie Telles
**Alta California
Central Valley
Valley Mountain**

QAC: Esteban Ortiz
Support Staff: Vacant
**Inland
Kern
San Diego**

QAC: Jenny Villanueva
**San Gabriel Pomona
Frank D. Lanterman
Westside**

QAC: Lia Cervantes-Lerma
**Eastern Los Angeles
South Central Los Angeles
Harbor**

QAC: Patricia Jackson
North Los Angeles

*Support Staff: Michele Wagner
and Marina Bchtkian*

QAC: Nancy Carlson-Zapata
Support Staff: Vacant
**San Andreas
Orange County
Tri-Counties**

Table 1: AFS Total Completed Surveys by Race/Ethnicity 2025-26

	Goal	Complete	% Goal
Alta California	400	663	
Asian	46	77	167%
Black	46	47	102%
Hispanic	83	102	123%
Other	38	36	95%
White	187	401	214%
Central Valley	400	481	
Asian	31	30	97%
Black	20	28	140%
Hispanic	250	244	98%
Other	15	23	153%
White	84	156	186%
East Bay	400	487	
Asian	94	114	121%
Black	73	63	86%
Hispanic	103	107	104%
Other	26	172	662%
White	104	31	30%
Eastern LA	400	355	
Asian	56	70	125%
Black	4	7	175%
Hispanic	299	237	79%
Other	10	4	40%
White	31	37	119%
Far Northern	400	236	
Asian	14	4	29%
Black	10	4	40%
Hispanic	67	30	45%
Other	19	12	63%
White	290	186	64%
Frank D. Lanterman	400	299	
Asian	57	60	105%
Black	27	19	70%
Hispanic	201	137	68%
Other	7	4	57%
White	108	79	73%
Golden Gate	400	240	
Asian	147	94	64%
Black	26	12	46%
Hispanic	107	52	49%
Other	26	8	31%
White	94	74	79%
Harbor	400	390	
Asian	60	85	142%
Black	40	27	68%
Hispanic	186	127	68%
Other	38	41	108%
White	76	110	145%

Table 1 continued: AFS Total Completed Surveys by Race/Ethnicity 2025-26

	Goal	Complete	% Goal
Inland	400	970	
Asian	20	64	320%
Black	47	100	213%
Hispanic	219	448	205%
Other	25	54	216%
White	89	304	342%
Kern	400	261	
Asian	13	13	100%
Black	31	14	45%
Hispanic	231	133	58%
Other	19	18	95%
White	106	83	78%
North Bay	400	351	
Asian	35	38	109%
Black	44	25	57%
Hispanic	118	93	79%
Other	42	30	71%
White	161	165	102%
North LA County	400	523	
Asian	30	59	197%
Black	42	43	102%
Hispanic	201	217	108%
Other	11	12	109%
White	116	192	166%
Orange County	400	750	
Asian	81	197	243%
Black	9	12	133%
Hispanic	147	185	126%
Other	45	76	169%
White	118	280	237%
Redwood Coast	400	147	
Asian	10	4	40%
Black	12	2	17%
Hispanic	76	14	18%
Other	28	5	18%
White	274	122	45%
San Andreas	400	542	
Asian	109	137	126%
Black	9	14	156%
Hispanic	165	167	101%
Other	28	185	661%
White	89	39	44%
San Diego	400	783	
Asian	38	96	253%
Black	25	37	148%
Hispanic	189	281	149%
Other	32	65	203%
White	116	304	262%

Table 1 continued: AFS Total Completed Surveys by Race/Ethnicity 2025-26

	Goal	Complete	% Goal
San Gabriel/Pomona	400	353	
Asian	63	74	117%
Black	18	19	106%
Hispanic	249	186	75%
Other	20	15	75%
White	50	59	118%
South Central LA	400	391	
Asian	4	8	200%
Black	81	76	94%
Hispanic	302	291	96%
Other	8	7	88%
White	5	9	180%
Tri-Counties	400	466	
Asian	20	30	150%
Black	7	7	100%
Hispanic	187	202	108%
Other	19	18	95%
White	167	209	125%
Valley Mountain	400	271	
Asian	42	33	79%
Black	33	21	64%
Hispanic	174	89	51%
Other	27	17	63%
White	124	111	90%
Westside	400	263	
Asian	20	21	105%
Black	105	67	64%
Hispanic	156	90	58%
Other	37	21	57%
White	82	64	78%

Table 1 continued: AFS Total Completed Surveys by Race/Ethnicity 2025-26

	Goal	Complete	% Goal
Report Totals	8400	9222	110%
Asian	990	1308	132%
Black	709	644	91%
Hispanic	3710	3432	93%
Other	520	823	158%
White	2471	3015	122%

Table 2: CFS Total Completed Surveys by Race/Ethnicity 2025-26

	Goal	Complete	%Goal
Alta California	400	463	
Asian	57	70	123%
Black	45	35	78%
Hispanic	89	101	113%
Other	81	88	109%
White	128	169	132%
Central Valley	400	395	
Asian	24	24	100%
Black	15	12	80%
Hispanic	264	255	97%
Other	43	37	86%
White	54	67	124%
East Bay	400	364	
Asian	98	107	109%
Black	50	26	52%
Hispanic	135	113	84%
Other	55	41	75%
White	62	77	124%
Eastern LA	400	224	
Asian	54	57	106%
Black	5	2	40%
Hispanic	287	130	45%
Other	30	22	73%
White	24	13	54%
Far Northern	400	161	
Asian	11	3	27%
Black	8	2	25%
Hispanic	81	36	44%
Other	45	16	36%
White	255	104	41%
Frank D. Lanterman	400	222	
Asian	48	38	79%
Black	30	13	43%
Hispanic	207	101	49%
Other	10	6	60%
White	105	64	61%
Golden Gate	400	194	
Asian	118	84	71%
Black	21	6	29%
Hispanic	144	42	29%
Other	45	20	44%
White	72	42	58%
Harbor	400	262	
Asian	49	44	90%
Black	40	21	53%
Hispanic	198	118	60%
Other	71	49	69%
White	42	30	71%

Table 2 continued: CFS Total Completed Surveys by Race/Ethnicity 2025-26

	Goal	Complete	% Goal
Inland	400	563	
Asian	19	42	221%
Black	28	37	132%
Hispanic	173	237	137%
Other	127	159	125%
White	53	88	166%
Kern	400	235	
Asian	15	15	100%
Black	28	15	54%
Hispanic	265	141	53%
Other	26	15	58%
White	66	49	74%
North Bay	400	193	
Asian	30	16	53%
Black	29	6	21%
Hispanic	159	63	40%
Other	82	42	51%
White	100	66	66%
North LA County	400	400	
Asian	28	35	125%
Black	39	39	100%
Hispanic	226	206	91%
Other	16	15	94%
White	91	105	115%
Orange County	400	352	
Asian	91	89	98%
Black	9	7	78%
Hispanic	142	92	65%
Other	83	80	96%
White	75	84	112%
Redwood Coast	400	108	
Asian	6	2	33%
Black	10	1	10%
Hispanic	109	34	31%
Other	56	11	20%
White	219	60	27%
San Andreas	400	325	
Asian	104	91	88%
Black	5	1	20%
Hispanic	192	140	73%
Other	50	40	80%
White	49	53	108%
San Diego	400	543	
Asian	36	61	169%
Black	16	21	131%
Hispanic	185	203	110%
Other	88	122	139%
White	75	136	181%

Table 2 continued: CFS Total Completed Surveys by Race/Ethnicity 2025-26

	Goal	Complete	% Goal
San Gabriel/Pomona	400	242	
Asian	71	80	113%
Black	14	8	57%
Hispanic	273	131	48%
Other	16	7	44%
White	26	16	62%
South Central LA	400	282	
Asian	2	5	250%
Black	55	46	84%
Hispanic	323	220	68%
Other	17	6	35%
White	3	5	167%
Tri-Counties	400	301	
Asian	10	11	110%
Black	3	2	67%
Hispanic	224	148	66%
Other	36	31	86%
White	127	109	86%
Valley Mountain	400	299	
Asian	46	38	83%
Black	31	11	35%
Hispanic	199	148	74%
Other	54	35	65%
White	70	67	96%
Westside	400	163	
Asian	19	12	63%
Black	96	34	35%
Hispanic	172	64	37%
Other	43	13	30%
White	70	40	57%

Table 2 continued: CFS Total Completed Surveys by Race/Ethnicity 2025-26

	Goal	Complete	% Goal
Report Totals	8400	6291	75%
Asian	936	924	99%
Black	577	345	60%
Hispanic	4047	2723	67%
Other	1074	855	80%
White	1766	1444	82%

Table 3: FGS Total Completed Surveys by Race/Ethnicity 2025-26

Race/Ethnicity	Goal	Complete	% Goal
Asian	93	65	70%
Black	103	30	29%
Hispanic	223	91	41%
White	747	622	83%
Other	58	41	71%
Total Statewide Sample	1224	849	69%

SEPTEMBER 29, 2026

**AGENDA ITEM 9.
INFORMATION ITEM**

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Nominations for Chair & Vice Chair

The State Council on Developmental Disabilities (SCDD) has two officers: Chair and Vice-Chair. The Council holds elections for these officers every two years during the last Council meeting of the appropriate calendar year.

The Council begins the election process by accepting nominations from Councilmembers at the second-to-last Council meeting of an election year.

Councilmembers will nominate candidates for the Chair and Vice-Chair positions for the November 2026 Council election.

Attachment

Detail Sheet on 2026 Officer Elections

COUNCIL MEETING DETAIL SHEET

ISSUE: 2026 Officer Elections

SUMMARY: The State Council on Developmental Disabilities (Council) has two officers, Chair and Vice-Chair. The Council holds elections for these officers every two years during the last Council meeting of the appropriate calendar year. The Council begins the election process by taking nominations from all members at the second to last meeting of meeting of an election year.

BACKGROUND/DISCUSSION: On September 29, 2026, the Council will begin the process of electing a new Chair and Vice-Chair by asking members for nominations for both Chair and Vice-Chair.

WHO CAN BE AN OFFICER?

Only self and family advocate members are eligible to hold these positions. See [Welfare and Institutions Code Section 4521\(b\)\(1\)](#) for information on membership.

The Chair and Vice-Chair will be held by one self-advocates and one family advocates. See page 9 Article VII, Section 2 of the Council [Bylaws](#).

WHO CANNOT SERVE?

A self or family advocate member with less than one year left on their second term.

An agency representative.

WHO IS ELIGIBLE UNDER THESE RULES?

Eric Aguilar
Jessica Brown
Azucena Garcia-Ferro
Sascha Bittner
Julie Gaona
Sherry Johnson Alvarez
Sonia Jones
Nestor Nieves
Michelle Padilla
Lupe Rodriguez

Bob Twomey
Irene Valdez
Melissa Fitch

WHO CAN MAKE A NOMINATION?

- An eligible Councilmember may nominate themselves.
- Any Councilmember can nominate an eligible Councilmember.

WHAT ARE THE DUTIES OF THE CHAIR?

Along with the typical duties of all Councilmembers, the Chair

- Leads all Council meetings.
- Sets the agenda for Council meetings.
- Appoints committee chairpersons and members to all Council committees.
- Appoints Council representatives in relation to other agencies and consumer groups.
- Represents the Council as needed.

WHAT ARE THE DUTIES OF THE VICE-CHAIR?

Along with the typical duties of all Councilmembers, the Vice-Chair

- Performs all the duties of the Chair if the Chair is absent or upon request of the Chair.
- Serves as Chair of the Executive Committee.
- Serves as the Council's Parliamentarian.
- Serve as the Chair of the Executive Committee.

WHAT WILL HAPPEN NEXT?

Before the next meeting, nominated members will be sent a candidate statement form that explains why they wish to serve as an officer. The completed form will be included in the November 19th Council meeting packet.

At the November 17th Council meeting, members will vote for their next Chair and Vice-Chair.

On January 1, 2027, the new officers will begin serving.

PREPARED: September 15, 2026, by Yaritza Sanchez, Assistant to the Executive Director

SEPTEMBER 29, 2026

AGENDA ITEM 10.

ACTION ITEM

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

2027 Legislative Planning

On September 10, 2026, the Legislative and Public Policy Committee (LPPC) heard an overview of the submissions for the 6th Annual “There Should Be a Law” contest. The LPPC also discussed ideas for 2027 policy projects and voted on which projects should move forward to the full Council for consideration.

Chair of the Legislative and Public Policy Committee (LPPC) Harold Fujita and Deputy Director of Policy and Public Affairs Chris Arroyo will provide Councilmembers with an overview of the 2026 “There Should Be a Law” contest submissions, discuss the LPPC’s recommended policy projects, and request the Council to consider and approve the LPPC’s recommendations.

The following six ideas are being considered:

- Continue strengthening plain language
- Fingerprinting and background checks of personnel at off-campus school worksites
- Disability-related chronic absenteeism in schools
- Eliminate SSI marriage penalty and raise asset limits
- Eliminate regional center internal review committees
- Allow IHSS meetings to be recorded

Attachment

2026 6th Annual “There Should Be A Law” Full Report

Handout(s)

PowerPoint Presentation

May be additional handout(s) on the day of the meeting

Action Recommended

Approve the LPPC’s recommended policy projects for 2027.



There Should Be a Law Report

CALIFORNIA STATE COUNCIL
ON DEVELOPMENTAL DISABILITIES

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THERE SHOULD BE A LAW REPORT – 2026 CONTEST

INTRODUCTION

“Instead, we began to think about the world as we believed it should be.” — Judy Heumann

This year marks the State Council on Developmental Disabilities’ (SCDD) 6th Annual There Should Be a Law Contest. The contest provides Californians with intellectual and developmental disabilities (I/DD), their families, and others in the community with an opportunity to identify challenges experienced, describe how those challenges affect their lives, and propose solutions. By bringing these experiences and ideas together, the contest provides a direct way for the community to help inform public policy and systems change.

This report serves several important purposes. For legislators, policymakers, and state agencies, it provides direct insight into the issues affecting people with I/DD and their families and the solutions the community believes should be considered. For the public and those who participated in the contest, it reports back what SCDD heard and provides a statewide picture of the ideas submitted. For the Council, the report helps identify issues for further exploration and potential action, including legislation, administrative solutions, policy work, and other systems change efforts.

At the heart of this report is the voice of the community. The experiences and recommendations of people with I/DD and their families provide valuable insight into how systems, programs, and policies work in everyday life. The ideas that follow are intended to preserve the substance and perspective of those who submitted them and ensure that lived experience is part of the conversations where policy and systems change are considered.

“Getting the laws and regulations passed was, of course, only the beginning. Even today, we must persist in ensuring that people continue to learn about the laws, use the laws, and fight for effective implementation.” — Judy Heumann

In 2026, Californians with I/DD and their families continued to navigate systems built on important rights, services, and commitments to inclusion, independence, and choice. Yet barriers such as complicated processes, inconsistent practices, limited information, and workforce and provider shortages can still separate what laws and programs promise from what people experience. Much of the work ahead is therefore not simply about creating new rights or programs but making existing commitments meaningful. Rights matter when people can exercise them, services when people can access them, choice when people have real options, and inclusion when people can participate fully in their communities.

The ideas in this report are starting points for further examination, discussion, and action. A personal experience can reveal a broader systems issue, and a proposed solution can lead to legislation, administrative change, policy development, education, or other systems change. SCDD invites policymakers, state agencies, community organizations, advocates, and other partners to listen closely to these experiences, engage with people with I/DD and their families, and use these ideas to build on what works, address remaining barriers, and make systems more effective, responsive, and accountable.

PURPOSE AND PREPARATION OF THIS REPORT

This report is designed to faithfully present the ideas submitted through the There Should Be a Law Contest while organizing them clearly and usefully for the public, policymakers, and the Council. SCDD sought to include submissions that identified a recognizable issue and proposed a recommendation or solution, including ideas that may differ from SCDD policy or perspectives held by others in the I/DD community.

To make the report clear and accessible, SCDD summarized, condensed, translated, or lightly edited submissions for clarity and readability while seeking to preserve the substance, perspective, and proposed solution of each submitter. Entries are grouped by policy category and include a descriptive title, the type of person who submitted the idea, an issue, and a recommendation. SCDD assigned titles and categories for organizational purposes.

Inclusion of an idea does not mean that SCDD endorses the proposal or every statement contained in it. Facts, statistics, legal interpretations, personal experiences, and other information presented within an entry reflect information provided through the submission and have not necessarily been independently verified by SCDD. When additional information may help readers understand an entry, SCDD may include a clearly identified SCDD note providing relevant background, such as information about current law or existing programs. These notes are separate from the submitter's idea and represent information provided by SCDD.

The submissions should be understood as ideas for consideration, not findings or conclusions reached by SCDD. Publication does not mean that SCDD has independently verified every factual statement or determined that a proposal is legally, administratively, or fiscally feasible. Ideas selected for further consideration may require additional research, analysis, and development before action is taken.

2026 CONTEST AT A GLANCE

The 2026 There Should Be a Law Contest received 184 entries across 11 policy categories. The largest number of submissions concerned Human Services and Education, together accounting for 78 entries. The breadth of the submissions reflects how many different systems affect the everyday lives of people with I/DD and their families, while the concentration of ideas in particular areas also helps identify where people are experiencing recurring barriers or see opportunities for change.

- Total entries: 184
 - Human Services: 48
 - Education: 30
 - Civil Rights: 20
 - Public Safety and Emergency Preparedness: 18
 - Health: 14
 - Federal Policy: 13
 - Housing: 13
 - Employment: 11
 - Mental Health: 6
 - Transportation: 6
 - Miscellaneous: 5

Across the submissions, several themes appeared repeatedly. People described difficulty navigating systems, finding accurate information, accessing services consistently, and understanding available supports. Many ideas called for clearer information, greater transparency and accountability, better coordination, less paperwork, and more consistent implementation of existing rights and programs. Education submissions also emphasized inclusion, staff training, access to appropriate services, and earlier preparation for employment, postsecondary education, independent living, and adulthood. Together, these concerns suggest that the challenge is often not whether a right or program exists, but whether people can actually understand, access, and benefit from it.

Other submissions focused on what people with I/DD need to participate fully and safely in community life, including accessible public spaces, healthcare, housing, transportation, emergency response, behavioral health, employment, abuse prevention, and support for families and caregivers. Economic security also emerged across categories, with concerns about affordable housing, employment, benefit and asset limits, marriage penalties, caregiving costs, and repeated eligibility requirements for permanent disabilities. When similar concerns appeared in multiple submissions, that repetition was meaningful because it showed that

different community members were identifying the same or related barriers. Taken together, the 2026 entries provide both individual ideas for consideration and a broader picture of where systems are working, where they are falling short, and where further action may be needed.

TERMS DEFINED

For purposes of this report, the following terms are used to describe the relationship of the person submitting an idea to the I/DD community:

Self-Advocate: A person with an intellectual and/or developmental disability who advocates for oneself and may also advocate for others.

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

Service Provider: A person or organization that provides services or supports to people with I/DD.

Professional: A person with professional knowledge, expertise, or experience related to the needs, services, supports, or rights of people with I/DD.

CONTEST ENTRIES BY CATEGORY

CIVIL RIGHTS

CR-01. Accountability in Conservatorship and Probate Investigations – Professional

ISSUE: Families who lovingly care for their loved ones with disabilities should not face extra workloads, have accurate information they provide ignored, or have their rights and boundaries disrespected during the conservatorship process. Families should know their rights and have protection under the law from being taken advantage of or treated disrespectfully by probate investigators and other staff involved in conservatorship interviews, reviews, and reports.

RECOMMENDATION: Create a separate oversight office, not linked to or paid by the same office being reviewed, to oversee probate investigators and others responsible for conservatorship interviews, reviews, and reports. The office should address inaccurate reporting, failure to consider accurate information provided by families, unethical behavior, and poor work performance, and should be able to take corrective or disciplinary action. Families should be able to have concerns addressed in a timely and efficient manner without creating additional work for those caring for their loved ones with disabilities.

CR-02. Education Authorization as an Alternative to Conservatorship – Professional

ISSUE: According to the Judicial Council's Court Statistics Report, California courts handle more than 18,000 conservatorship and guardianship cases each year, and filings continue to increase. The Judicial Council is also conducting a comprehensive conservatorship study required by AB 1194 (Probate Code Section 1458), due to the Legislature by January 1, 2027. Limited probate conservatorships, specifically for adults with developmental disabilities, may be sought so families can continue helping with educational decisions even though a less restrictive option, an Education Authorization, may be available. One power commonly granted through limited conservatorship is authority over educational decisions,

which may instead be addressed voluntarily through an Education Authorization.

AB 1663 (2022) increased awareness of alternatives to conservatorship, but there is currently no standardized statutory Education Authorization form. An accessible form could increase awareness and use of this alternative, help adult students retain autonomy while choosing who supports them in educational decision-making, reduce unnecessary reliance on conservatorship, and make the authorization easier to distribute and explain through schools.

RECOMMENDATION: The Legislature should adopt a statutory Education Authorization form under California Education Code Section 56041.5. A standardized form would make this underused tool more accessible and help adults with disabilities retain their decision-making rights while voluntarily choosing support for educational decisions.

CR-03. Caregiver Access to Public Restrooms – Family Advocate

ISSUE: My son is being excluded from all outings because his caregiver of the opposite sex cannot go into all bathrooms with him. My 29-year-old son cannot use the bathroom unattended, and he also cannot be left alone.

RECOMMENDATION: We need public restrooms that allow a mother or other caregiver to accompany an adult with a disability who needs assistance, especially when the caregiver and the person with a disability are of opposite sexes.

CR-04. California Community Living Guarantee – Family Advocate

ISSUE: People should be guaranteed the support to live in their community before they are guaranteed a place in an institution. Under Medicaid (Medi-Cal), home- and community-based services for people with I/DD are treated differently from institutional services. People should not be denied the support they need to live safely and with dignity in their own homes and communities because of waiting lists or inadequate funding.

RECOMMENDATION: California should guarantee home- and community-based services as a state entitlement for every eligible person with I/DD. Every person should have the right to receive the services needed to live

safely and with dignity in their own home and community. This would correct a fundamental inequity: today, institutional care is effectively guaranteed, while community living often depends on optional programs with limited funding. People should be guaranteed the support to live in their community before they are guaranteed a place in an institution.

CR-05. California's Surveillance Footage Retention Laws and Abuse of Persons with I/DD – Professional

ISSUE: People with I/DD are far more likely than people without disabilities to experience physical abuse, neglect, and civil rights violations. When something happens, especially to someone who is nonverbal or has high support needs, it often takes months for caregivers or advocates to detect changes in behavior or behavioral health, conduct their own investigation, or work through administrative reporting backlogs. According to national policy and legal advocacy frameworks from organizations such as Justice in Aging, a policy that affects everyone equally can still have a disparate or discriminatory effect on people with disabilities. Thirty- to 90-day video deletion policies are a textbook example because it inherently takes longer than 90 days to report abuse when there are communication barriers. Extended retention and administrative holds would provide a systemic reasonable accommodation and help ensure that surveillance systems protect civil rights.

RECOMMENDATION: California should require government and public agencies, public universities, special districts including transit agencies, FHA-governed housing such as assisted living facilities and nursing homes, and regional center vendor systems to retain surveillance video for at least one year, or two years when vulnerable populations such as people with I/DD live at the facility. The law should also require an automatic “Administrative Hold” when a parent, advocate, or ombudsman reports an incident involving a person with I/DD to the appropriate enforcement agency, preventing the recording from being overwritten until a subpoena duces tecum is received or the investigation concludes.

CR-06. Information is Difficult to Retain – Self-Advocate

ISSUE: I believe there should be audio, video, and AI technology used to give people the opportunity to listen to and watch any and all documents and information given to them. Unfortunately, it is difficult for some people

to retain what they read, which can make it difficult to understand what they sign or remember information.

RECOMMENDATION: Give people the opportunity to use audio, video, and AI technology to listen to and watch documents and information. This may help people feel more comfortable signing documents and be more involved in their education and self-advocacy.

CR-07. Accessible Public Restrooms – Family Advocate

ISSUE: People who require universal changing tables often only travel by automobile to get around California. AB 662 (2015) provides those tables in places of entertainment, but if you are driving across our state, there is often nowhere for those individuals to be toileted with dignity. This can mean going for hours without being changed. Besides general dignity, this is also a safety issue because going long distances without being changed can cause skin breakdown and infection.

RECOMMENDATION: Require family-style restroom areas to include a secure space where a person can be toileted with dignity, consistent with the parameters of AB 662 (2015), including a height-adjustable changing table and hoist. This would allow people with disabilities who need these accommodations to travel across California more safely and with dignity.

CR-08. People with Disabilities Have The Right to Be in Community – Self-Advocate

ISSUE: I think people with disabilities should be allowed to be in the community and have the same rights as everybody.

RECOMMENDATION: The law that needs to change is the law that is trying to remove people with disabilities out of the community. Removing the bill to confine people to institutions would allow people with disabilities to remain in their homes and with their families.

CR-09. Accommodation of Sensory Rooms – Self-Advocate

ISSUE: People with I/DD need to have a quiet and sensory room because sometimes things can get too noisy and overwhelming.

RECOMMENDATION: I would like to see more sensory rooms and quiet rooms at places where people with disabilities congregate.

CR-10. Accessibility of Public Restrooms – Professional

ISSUE: I have had to pick up disabled clients who have wet or soiled themselves because they are out and about and no one will let them use their restroom. This has been an issue over the years. People with I/DD can be out in the community and be refused use of bathrooms.

RECOMMENDATION: If someone has an I/DD, they should be exempt from “you have to buy something” or “employees only” restroom restrictions.

CR-11. Chair Lift Maintenance and Training – Self-Advocate

ISSUE: Tens of thousands of dollars are spent putting these lifts in; however, they are not tested frequently to make sure they are in working condition. As a family with a wheelchair user, our general experience has been that the teams are always scrambling to figure out how the lifts work, even though they function in a very specific way.

RECOMMENDATION: The lifts need to be tested monthly to make sure they work, and staff in public spaces, such as restaurants and stadiums, need to be provided training annually to make sure they know how to operate the lifts.

CR-12. Disability Competency of Family Courts – Professional

ISSUE: Families of children with developmental disabilities are often misunderstood in family court systems. Parents who provide most of the disability-related caregiving and advocacy are not always recognized for that labor. Behaviors related to autism, trauma, communication disabilities, or sensory dysregulation are sometimes misinterpreted by court professionals who lack specialized training. This can lead to unsafe custody decisions, disruption of medical and therapeutic supports, re-traumatization of children with disabilities, increased family conflict, and poor long-term outcomes for children with I/DD.

RECOMMENDATION: California family courts need standardized disability competency requirements. Require annual training on I/DD, autism, trauma-informed practices, communication differences, sensory needs, elopement risks, and behavioral supports. Require courts to recognize caregiving labor and require disability-informed custody recommendations when children have documented developmental disabilities. Improve access to interpreters and culturally responsive disability advocacy for bilingual families.

CR-13. Inclusive Playgrounds – Professional

ISSUE: Currently, kids who use wheelchairs or have other mobility needs are often unable to play on a playground with their peers of the same age because of the ground material, such as bark, or playground equipment that does not allow them to access it.

RECOMMENDATION: I would like to see all playgrounds, especially new playgrounds, be ADA compliant.

CR-14. Make Voting Ballots Accessible – Family Advocate

ISSUE: People with I/DD may be easily overwhelmed by the current ballot, which is printed small with tight spacing between letters and lines. The lack of images can make it hard to focus on the many names listed and easy to confuse candidates. A more accessible ballot could make it easier for people with I/DD to vote.

RECOMMENDATION: There should be a specialized ballot available for people with I/DD. This ballot would be printed larger, with more accessible and less wordy descriptive text wherever possible. Phrases such as “Vote for ONE” would be highlighted. It could use colored shading to separate the choices in each race and make clear which choices belong to which race. It might also include headshot images of people running for office and more spacing between letters and lines. A committee of people with disabilities could weigh in on the creation of the ballot.

CR-15. Ensure Families with Disabilities are Treated with Respect and Compassion – Family Advocate (Translated from Spanish)

ISSUE: People can be extremely offensive, insensitive, and rude when speaking to parents of children with disabilities, especially when excluding or rejecting their children from activities.

RECOMMENDATION: There should be a law that ensures parents seeking resources, services, and support for their children are treated with respect, compassion, and dignity by those in positions of authority.

**CR-16. Change Statute of Limitation for Disability Civil Lawsuits
– Family Advocate**

ISSUE: Disability civil rights are violated with impunity, daily and on a massive scale. Why? Because there is virtually no possibility of civil rights violations ever getting redressed. California's Civil Rights Department admits it can only handle 4% of the cases it receives. Independent of the near impossibility of finding a disability lawyer, it is far beyond most people with I/DD and their conservators to sue independently to recover from violations of their disability rights. To enforce disability rights through California's Civil Rights Department, people with I/DD have only an absurdly, nearly unattainable one-year statute of limitations.

RECOMMENDATION: Change the statute of limitations for both Civil Rights Department complaints and disability civil lawsuits to a minimum of five years, with additional time allowed for good reason.

CR-17. Increase Accessibility for Writing – Family Advocate

ISSUE: Increases accessibility for people who have trouble writing and/or mobility to a mailbox.

RECOMMENDATION: The right to send/receive mail and access to letter writing materials should be updated to include a right to send/receive e-mail and access to internet/email.

CR-18. Electric Carts at Supermarkets – Professional

ISSUE: Two electric carts in supermarkets are not enough, especially as more of us are becoming included in the community.

RECOMMENDATION: Require grocery stores to have at least four working electric carts.

CR-19. Stop Restrictive Paybacks – Professional

ISSUE: California’s current rules for court-supervised settlement trusts often harm the very people they are meant to protect. Under Probate Code §§3600-3613, people with disabilities who are minors or lack legal capacity may be required to use self-settled special needs trusts with Medicaid payback for court-approved settlements. Adults with capacity, however, can use Medi-Cal-compliant trusts without Medicaid payback. This unequal treatment can leave minors and adults without capacity with fewer choices and reduce the value of modest settlements.

Beginning January 2026, Medi-Cal will impose a \$130,000 resource limit. For settlements below this amount, payback trusts are unnecessary to preserve eligibility. Requiring them can reduce the value of settlements, discourage families from pursuing claims, and reduce accountability for wrongdoers. For example, a minor with a \$75,000 settlement or an adult who lacks capacity with a \$100,000 settlement may still be required to use a payback trust even though the settlement is below the Medi-Cal resource limit.

RECOMMENDATION: Amend Probate Code §§3600-3613 to allow court-approved settlements under \$130,000 to be placed in irrevocable trusts that comply with Medi-Cal rules. Permit trustees who are not household members and eliminate Medicaid payback requirements when eligibility is otherwise preserved.

Give people with disabilities who are minors or lack capacity the same settlement trust options available to adults with capacity, especially for recoveries below \$130,000. This would preserve more of the settlement for the beneficiary, maintain incentives to pursue claims, and help hold wrongdoers accountable.

CR-20. Stop Draining Modest Settlements and Deter Professional Trustees – Professional

ISSUE: Rule of Court 7.903 requires court supervision of settlement trusts exceeding \$20,000 for persons with disabilities and minors. This outdated

threshold can drain modest trusts through legal costs and discourage professional trustees, leaving vulnerable individuals worse off instead of protected. A \$25,000 settlement, for example, may lose nearly half its value to petitions, accountings, and fees. Private fiduciaries may also avoid these cases because the costs outweigh the economics.

The \$20,000 threshold is no longer realistic in today's economy and can trap small cases in a costly court process. Shrinking the real value of small settlements can also discourage persons with disabilities or their families from pursuing claims, limiting accountability for wrongdoers.

RECOMMENDATION: Reform Rule of Court 7.903 by raising the court-supervision threshold to \$50,000 when a care plan is approved by the civil court and to \$100,000 when the settlement is managed by a licensed private fiduciary or pooled trust. Private fiduciaries would remain regulated by the Professional Fiduciaries Bureau, and pooled trusts would remain overseen by nonprofit boards.

Trustees should be protected from liability for expenditures made within an approved care plan, with court approval required only for expenses outside the plan. These changes would protect small settlements from being consumed by court costs, expand access to professional trustees and pooled trusts, maintain safeguards, and ensure more of the settlement directly serves the beneficiary.

EDUCATION

ED-01. Create Home-Based Special Education – Family Advocate

ISSUE: California’s only statewide option for students with disabilities who cannot attend school is Home and Hospital Instruction (HHI), which provides minimal instructional hours, general education instruction only, and inadequate IEP implementation. HHI is designed for temporary illness, not long-term disability, leaving families without access to special education services, structured literacy instruction, curriculum, or differentiated supports at home.

RECOMMENDATION: Create a statewide home-based special education support program that provides structured literacy instruction, curriculum access, special education services, and differentiated supports for students with disabilities who cannot safely or meaningfully attend traditional school environments.

ED-02. Equitable Pay for Special Education Teachers – Family Advocate

ISSUE: The budget for valuable public servants should pay teachers equal to police and firefighters. We need to invest as much in our public educators as we do in other vital public servants. We would have more qualified public-school teachers and special education teachers because they would be able to afford living in the areas where we need teachers. They need to earn a living wage and be valued as much as other government employees.

RECOMMENDATION: I want to see special education teachers and all teachers at public schools entitled to equal pay to other public servants, such as police and firefighters. These other public servants make decent wages, and teachers are no less valuable than police and firefighters. Perhaps private schools could pay extra taxes to help pay for public schools.

ED-03. Improving Special Education Access and Quality – Family Advocate

ISSUE: Right now, too many families face delayed evaluations, denied services, untrained staff, unsafe classrooms, unfair discipline, and IEP plans that do not meet the real needs of the child. Parents often have to fight for basic rights that should already be guaranteed.

RECOMMENDATION: I want to change special education law in California by reforming how schools identify, support, and protect students with disabilities. The system needs faster services, better-trained staff, stronger parent rights, and real accountability.

ED-04. Safety in Classrooms – Family Advocate

ISSUE: Currently, there is no true way to know what happened when a child comes home injured or when parents do not believe a teacher who is relaying information about an outburst in the classroom.

RECOMMENDATION: I want to add cameras in self-contained classrooms for children who are nonverbal and/or have communication issues.

ED-05. Strengthen Accountability in School Services – Family Advocate

ISSUE: Students with disabilities can be placed in California nonpublic schools (NPSs) after families are told that in-district options are limited, without a thorough evaluation of the least restrictive environment or meaningful parental participation. Heavy reliance on nonpublic schools can also discourage districts from developing inclusive programs in students' home schools and communities. Once students are placed, families may face limited communication and oversight, including failure to disclose significant incidents involving restraint, seclusion, law enforcement, or other unsafe and emotionally harmful conditions.

There are also concerns about weak accountability for academic and behavioral progress, staff qualifications, instructional quality, and whether specialized services are consistently provided. Students may remain in restrictive placements longer than necessary because of inadequate transition planning, while families already managing complex medical, behavioral, and caregiving responsibilities are left with limited advocacy and effective ways to ensure their child receives a free appropriate public education (FAPE).

RECOMMENDATION: Amend California Education Code §56366 to strengthen accountability and ensure that placement in a certified Nonpublic School or Nonpublic Agency remains a true placement of last resort. Before placement, districts should document the in-district options, supplementary aids, services, and behavioral interventions considered; explain why less restrictive options are insufficient; provide families with written information about alternatives and procedural rights; and obtain informed written parental consent except where otherwise allowed by law. Placements should be based on current evaluations and individual need, not district convenience, staffing shortages, funding limitations, or program availability. Every placement should also include a transition plan and be formally reconsidered at least every six months to determine whether the student can return to a less restrictive public school setting.

Districts should remain responsible for students placed in NPSs through ongoing monitoring of IEP services, educational and behavioral progress, staff qualifications, and safety practices. Parents should be notified within one business day of significant incidents such as restraint, seclusion, elopement, injury requiring medical treatment, law enforcement involvement, abuse or neglect allegations, or emergency behavioral interventions. Require annual district capacity assessments, stronger staff training and qualifications, public reporting and audits by the California Department of Education, accountability for student outcomes and expenditures, corrective action for districts with consistently high NPS placement rates, and stronger family rights and expedited due process when placement is disputed.

ED-06. California Alternate Assessments (CAA) Reporting Requirement – Professional

ISSUE: If money is allocated to CAA-designated students, we need data to track whether that money is being used effectively. More importantly, since the passage of ESSA in 2015, California has not once met its obligation to limit CAA designation to 1% of the student population. The U.S. Department of Education has previously written to the State Board of Education requesting a plan to address this, but the percentage continues to grow. California has also introduced two excellent initiatives that may inadvertently incentivize districts to place students on CAA: the Alternative Pathway to a Diploma, which is restricted to students on CAA, and AB 2526

(2026), which provides additional funding for students with this designation. CAA is a great thing for some students, but it can be very restrictive for students who it is not appropriate for. It should be restricted to the 1% of students with the most significant disabilities.

As an advocate, I see young children being placed on CAA in kindergarten to justify placement in classrooms using an alternative curriculum, even though state assessment does not begin until third grade. Students may also be told that the only path to a diploma is an alternative curriculum in a separate classroom. I have personally met students whose CAA eligibility was challenged and who were found capable of taking a full course of study, working toward a diploma on a regular pathway, and pursuing degree programs in college. About 1.5% of all students are on CAA, compared with 2.2% of Black students, more than double the cap, indicating that the designation may be being used for resegregation purposes.

RECOMMENDATION: Existing law requires LEAs to report data to the California Department of Education on alternative assessments, disability eligibility categories, educational environments, and diploma outcomes. Add a requirement that LEAs report the percentage of students designated for CAA by eligibility category, educational environment, and whether they graduate with a diploma in 12th grade or by age 22.

ED-07. California Inclusive Early Pathways to Employment & Postsecondary Planning Act – Family Advocate

ISSUE: Students with disabilities have the same dreams as their peers: to attend college, build careers, live independently, and contribute to their communities. Yet many families report that conversations about these possibilities begin too late or never happen at all. Although transition planning is required under existing law, it often begins after critical academic decisions have already been made. By middle school, students are selecting courses, discovering interests, and forming expectations about their futures. Students with disabilities deserve the same early opportunities to explore what is possible. California has more than 800,000 students receiving special education services, making it the largest special education system in the nation.

Early transition planning, high expectations, work-based learning, self-advocacy instruction, exposure to college and career options, and family engagement can lead to better adult outcomes. Yet many students still graduate without visiting a college campus, participating in meaningful career exploration, or understanding the full range of postsecondary opportunities available to them. Students with disabilities deserve futures built on opportunity, not assumptions. Equal opportunity includes equal exposure to college, career, employment, and independent living planning, not merely access to special education services.

RECOMMENDATION: Beginning in 6th grade, every student with an IEP should receive age-appropriate postsecondary planning as part of the annual IEP process, based on the student's strengths, interests, goals, and aspirations rather than disability category or assumptions about future capability. Students should receive opportunities comparable to those available to nondisabled students to explore college, Career Technical Education, vocational and certificate programs, competitive integrated employment, independent living, self-advocacy, and self-determination. They should also have access to college and career fairs, campus visits, work-based learning, job shadowing, internships and apprenticeships when available, dual enrollment when appropriate, career counseling, leadership opportunities, financial literacy, and other real-world experiences.

Beginning in 6th grade, families should also receive annual information about postsecondary education, employment, transition requirements, financial aid, adult services, and other resources early enough to make educational decisions that maximize future opportunities. Schools should provide ongoing professional development to educators involved in transition planning and develop partnerships with colleges, employers, Regional Centers, workforce agencies, and community organizations. The California Department of Education should annually report outcomes such as postsecondary enrollment, Career Technical Education participation, competitive integrated employment, wages, and independent living so California measures success not only by diplomas earned, but by lives launched.

ED-08. Limited Post-Secondary Opportunities for I/DD Students
Limits Employment – Family Advocate

ISSUE: Resources for neurodiverse individuals at the college level in California are very limited. Programs like the College Living Experience are available to a limited number of students from high-income families or those who qualify through Regional Centers. Other more limited programs through organizations like Special Kids Connect and Parents Helping Parents struggle to maintain consistent funding. AB 447 (2023) lays the foundation for some of this work, but it is more focused on creating non-degree programs. There is a growing subset of individuals who, with adequate supports, would be better served by pursuing traditional degree programs with support for executive functioning, social, and communication skills that would increase their ability to participate more fully in the workforce.

RECOMMENDATION: Public colleges and universities offer a place for students with I/DD to integrate more fully into their communities. Provide legislation and state funding for services on college campuses that support these students to succeed academically and socially while building vital life skills. This would create a foundation for more productive and engaged citizens and, in the long term, ease the burden on families and our health and social services systems.

ED-09. Safety Training in Schools via IEP – Family Advocate
(Translated from Spanish)

ISSUE: Help prevent situations in which people with autism or other I/DD, including nonverbal adults, experience a crisis at school or in the community and are not properly understood by law enforcement officers or other first responders. Currently, law enforcement officers often do not have sufficient training to effectively respond to these situations, which can cause the crisis to escalate or become dangerous and, in some cases, result in serious or even fatal outcomes.

There is also a need to better prepare students and adults with I/DD to recognize law enforcement officers, understand their role as authority figures, and know how to communicate or express their needs during an emergency, especially when they rely on nonverbal communication or assistive communication devices.

RECOMMENDATION: Create and implement a mandatory program within schools, especially in high school and transition-to-adulthood programs, as

part of the IEP for students and adults with I/DD, including nonverbal individuals. The program would provide opportunities for positive interactions with law enforcement in a safe and controlled environment and teach students and adults how to recognize police officers, ask for help during an emergency, and communicate using nonverbal communication or augmentative and alternative communication (AAC) devices.

Law enforcement officers would receive training on autism, I/DD, and effective communication with nonverbal individuals, along with de-escalation techniques, crisis intervention strategies, and sensory awareness. The program would also include guided simulations or practice exercises to improve mutual understanding and emergency response.

ED-10. Lack of Inclusion in Schools – Family Advocate

ISSUE: I have a severely autistic child who is being barred from school. It has been over a year. No consequences for violations of federal law incentivize bad actors. Based on personal experience and local news, students with disabilities are strongly discriminated against here in Southern California.

RECOMMENDATION: Impose aggressive penalties and discrediting for institutions or organizations that violate the law in regard to admissions.

ED-11. Educating Middle/High School Students on Autism Needed to Stop Ridicule – Self-Advocate

ISSUE: As a 15-year-old teenage girl with diagnosed autism and ADHD, I know how powerful the culture of social media can be, including the dangerous amount of influence it has on younger people. Social media has played a major role in further stigmatizing disabilities by perpetuating and normalizing stereotypes, especially about autism, to the point where it has become socially acceptable in most settings, including schools, to mock, ridicule, and laugh at it. As a result, many autistic kids, including myself, choose not to speak up about our disabilities or ask for help because it is so common for teens to treat autism as something to be ashamed of.

Many adults are not aware that there has been a social media trend where teens use the term “acoustic” to refer to autistic people in a derogatory way. In a way, “acoustic” has become the new “r” word, leading to more

commonly accepted mockery and stereotypes surrounding autism and other disabilities. These toxic narratives have created an uncomfortable, isolating, and even unsafe environment for students with disabilities and discourage us from seeking the support we need and deserve.

RECOMMENDATION: I propose that middle schools and high schools be required to hold assemblies educating students about autism, ADHD, and other I/DD. The assemblies should provide accurate information, challenge harmful stereotypes, and clearly convey that students with disabilities have a support system at school and are encouraged to speak up. Disabilities should not be treated as something to be ashamed of or frowned upon.

Ideally, more education about these issues would occur throughout the school year. Taking time to address and de-stigmatize disabilities and challenge the unhealthy stereotypes constantly being spread across social media can help foster a more open and safe environment for everyone. It would allow kids with disabilities, specifically people such as myself with autism spectrum disorder, to feel safer and more secure at school without the pressure to remain silent for fear of being mocked or judged by other students.

ED-12. Sensory Equity in Education – Family Advocate

ISSUE: Currently, 10% to 20% of all students, and 60% to 100% of students with an active IEP or 504 plan, present with objective, learning-related visual efficiency deficits that cause text to double, shimmer, or blur. Sustained near work under these conditions triggers an involuntary Autonomic Nervous System (ANS) survival response of fight, flight, or freeze. Due to systemic implicit bias, schools misidentify these reflexive safety mechanisms, including restlessness, task avoidance, or visual meltdowns, as “willful defiance” or misconduct, a penalty that falls disproportionately on Black students, low-income families, and students with pre-existing labels. By catching these sensory barriers upstream, schools can replace punitive containment with targeted, evidence-based remediation, lower district legal liabilities, and keep children stabilized in the least restrictive environment (LRE).

RECOMMENDATION: We propose enacting “The Sensory Equity in Education Act,” adding Section 49455.5 to the California Education Code and creating a mandatory, legally enforceable safety gate called “Evaluate

Before Escalate.” No public school or charter school could execute an involuntary disciplinary removal, scale up a Tier 2/3 behavioral compliance plan, or initiate a Functional Behavioral Assessment (FBA) for a student demonstrating persistent academic failure or behavioral dysregulation without first conducting a comprehensive sensory and neuro-optometric screening to rule out underlying functional visual efficiency disorders.

The law would define diagnostic authority, standardize the clinical assessment battery to measure oculomotor, vergence, and accommodative facility rather than only distance sight, and require Vision Therapy to be fully recognized and funded as an approved IDEA related service when an adverse educational impact is proven. This change eradicates a systemic, hidden driver of California’s school-to-prison pipeline and resolves widespread denials of a free appropriate public education (FAPE).

ED-13. Paraeducators Need Training in Crisis Management – Family Advocate

ISSUE: California currently employs over 100,000 paraeducators who provide most of the direct, face-to-face support to students with intensive disabilities. Under Education Code § 45330, an individual can be hired as a special education aide based on a high school diploma and basic math and reading requirements. Aides routinely step into classrooms on Day 1 with zero training in crisis management or disability laws. Because Education Code § 56070 only vaguely requires staff to be “appropriately trained” without defining timelines, untrained aides are forced to learn crisis de-escalation through dangerous trial and error, directly resulting in preventable student and staff injuries.

California has banned dangerous prone restraints through “Max Benson’s Law” (SB 483), but the state does not proactively train staff on what to do instead. Telling an untrained, panicking aide what they cannot do without teaching them what they should do creates an unsafe classroom environment. Specialized aide training is currently only legally required if a parent knows how to fight for it in an IEP meeting, creating a severe equity gap for low-income or non-English-speaking families who cannot access intensive legal advocacy.

RECOMMENDATION: Amend California Education Code §§ 45330, 49006, and 56070 to create a proactive statewide safety standard. Require a

minimum 15-hour pre-placement orientation before an employee is left unsupervised or assigned to students with known Behavior Intervention Plans (BIPs). Standardize training across California's 1,000+ school districts to include crisis de-escalation and nonviolent intervention, the legal limits of restraint and seclusion under AB 2657, basic IEP implementation, data collection and Child Find obligations, and Positive Behavior Interventions and Supports (PBIS).

Direct the California Department of Education to design and host a free, asynchronous online training platform, eliminating curriculum creation costs for local districts. The state should also provide dedicated funding to reimburse school districts for the wages of new paraeducators completing the required modules so the requirement does not become an unfunded mandate.

ED-14. Accountability of High School Transition Quality – Self-Advocate

ISSUE: Check what schools are doing in transition and see how many of our students are working or trying to work after they leave public school at age 22, even if they apply for regional center or the Department of Rehabilitation (DOR).

RECOMMENDATION: Transition programs, especially for students ages 18–22, should provide real job-site training, not just classroom worksheets, and weekly community-based instruction. Schools should partner with adult agencies such as DOR and local regional centers and give students exposure to real employment in the community and within the school district. Some of our students can do jobs such as recreation aide, kitchen work, or janitorial work that do not require a diploma.

ED-15. Improve Accountability and Oversight to Build Public Trust – Professional

ISSUE: Current policies do not adequately prevent an entity from applying for or operating a Nonpublic School (NPS) certification despite a history of serious regulatory violations. In some cases, organizations with repeated substantiated deficiencies, enforcement actions, or documented incidents of abuse and other serious violations may close, reorganize, or rebrand under a different name or service model, such as a school, group home, or

other program, while continuing operations with limited accountability. Existing policies may not sufficiently consider an organization's compliance history across related entities when reviewing new NPS applications.

RECOMMENDATION: Require state agencies to consider an applicant's compliance and enforcement history, including substantiated violations, license revocations, and other serious regulatory actions, when evaluating NPS applications. After a defined threshold of serious or repeated violations, agencies should have the authority to deny approval or require enhanced review for new applications submitted by the same owners, operators, or affiliated entities, even if they operate under a different name or organizational structure. These safeguards would help prevent entities with documented patterns of serious noncompliance from avoiding oversight through rebranding while ensuring due process and fair review of each application.

ED-16. High School Transition and Falling through the Cracks – Professional

ISSUE: Many students with mild/moderate support needs earn a diploma but are not yet prepared for independent adult life, employment, postsecondary education, or community participation. Disability does not end at graduation. Right now, students with extensive support needs can receive services beyond an alternate diploma, but students with mild/moderate support needs are slipping through the cracks. This creates an equity issue during the critical transition from school to adulthood.

RECOMMENDATION: California law should be amended to allow all students with disabilities who have an Individualized Education Program (IEP) to continue receiving services and transition services through age 22, regardless of whether they have earned a high school diploma or equivalent. Students with mild/moderate support needs would have the option to continue participating in transition programs, vocational training, employment preparation, independent living instruction, and related services if the IEP team determines those services are still necessary.

ED-17. Barriers in Competitive Sports – Family Advocate

ISSUE: Currently, the California Interscholastic Federation (CIF) only acknowledges barriers related to physical disabilities at its competitions

and does not provide a para-division for swimmers who qualify for CIF and have I/DD. Students with ASD or I/DD and a mild physical disability must therefore compete against students who have only a mild physical disability. This is not fair. CIF also limits para-events to the 50- and 100-yard freestyle, uses reduced scoring points of 20 versus 2, allows 40 typical swimmers to advance in an event compared with nine Para III swimmers, has no qualifying times, and inserts para-events during convenient breaks in the typical swimmers' event schedule rather than when the best performance would be given. CIF also provides little representation on its social media accounts, celebrating a student who helps with Challenger on Instagram while providing no actual celebration or discussion of Challenger or Para-Division swimmers.

CIF needs to stop othering swimmers with disabilities. Layering in a para-division does not automatically create equal access or an integrated system. CIF assumes that students with I/DD participate at the Challenger level, creating a restrictive environment and equal access issue. The basic rules for participation should be equal for all swimmers. A first-place win, regardless of physical ability, should be scored the same and given the same championship status.

RECOMMENDATION: There should be a law requiring equal access for student athletes with I/DD participating in CIF para-divisions in swimming and track and field. Student athletes with disabilities should have a real competitive environment against similar peers. As it now stands, a student with a documented mild physical disability who has been accepted into UCSB and onto its swim team can compete against a student in a special day class who has a mild physical disability along with Down syndrome and dyspraxia. That is not a fair competitive environment.

Students with I/DD are not being given equitable access to CIF championships. For many special day class students who participate on swim or track and field teams, CIF championships are their final competitive opportunity because they do not progress to national competitions, college participation, or competitive team competitions. Swimming is a great lifelong exercise for many people with disabilities and should be encouraged.

ED-18. Restrictive Environments and Teachers – Professional

ISSUE: Too often, educators recommend more restrictive environments without any first-hand knowledge of the program structure, organization, or curriculum being recommended. Recommendations are being made that are not informed. Educators typically have not been in the more restrictive classroom and are basing these critical placement decisions on assumptions.

RECOMMENDATION: All IEP team members making a recommendation for a student's placement should be required to observe the proposed placement before adding their agreement to the recommendation.

ED-19. Double Silo Causes Twice-Exceptional Students to be Underserved – Self-Advocate

ISSUE: The “double silo” effect currently causes twice-exceptional (2E) students, meaning students who are gifted and also qualify for special education, to be underserved. Gifted students can be misidentified or penalized because standardized test scores are masked by their disabilities.

RECOMMENDATION: The state should implement a mandatory “intersectional” data-coding system to identify and separately track 2E students. All magnet and gifted programs should be required to provide integrated RSP services or equivalent supports to accommodate disability-related needs. The state should also create a streamlined inter-district transfer process specifically for 2E students when their home district cannot provide a free appropriate public education (FAPE) that addresses both their gifted status and their disability.

ED-20. Increase Work-Based Learning – Professional

ISSUE: Increase access for all students to work-based learning, WorkAbility I (WAI), career technical education (CTE), regional occupational programs (ROP), and other work-based learning opportunities.

RECOMMENDATION: In lieu of background checks, allow a parent, guardian, or student who is 18 years or older to sign a consent form before the student interacts with a person employed by a contractor. The form would state that the parent, guardian, or student understands that the

contractor's employee has not completed a valid criminal records summary as described in Education Code §44237.

ED-21. Meaningful Parent Participation and IEP Consent – Family Advocate

ISSUE: To be able to participate and consent, parents need to understand the IEP and have adequate time to process the information. Without that time, parents may feel they cannot provide meaningful input and may later disagree with an IEP they already signed.

RECOMMENDATION: Districts should be required to ensure that parents have time not only to understand the IEP, but also to process the information before consenting. This could include preparation meetings or questionnaires and giving parents adequate time to review, sign, and consent to the IEP.

ED-22. Require Disability Training for General Education Staff – Professional

ISSUE: Students with disabilities spend most of their school day in general education classrooms, yet many general education teachers receive little or no practical training on disability characteristics, accommodations, behavior supports, executive functioning deficits, sensory regulation, dyslexia and reading disabilities, autism, ADHD, trauma-informed practices, IEP implementation, and legal responsibilities under IDEA and Section 504. As a result, accommodations are inconsistently implemented, behaviors are escalated instead of supported, students are disciplined for disability-related needs, students fall behind academically, and families experience constant conflict with schools.

RECOMMENDATION: Require all California general education teachers and administrators to complete annual training in disability awareness, IEP implementation, accommodations and modifications, inclusive instructional practices, behavior de-escalation, executive functioning supports, evidence-based reading interventions, and disability law requirements. The law should also require practical classroom strategies, training created with input from disability advocates and parents, and accountability measures for districts.

ED-23. Schools Must Consider Supports Outside of School When Planning In-School Supports – Professional

ISSUE: If a child requires constant supervision for safety outside of school, schools should not be allowed to ignore that information when determining educational supports at school. Children who qualify for IHSS Protective Supervision have already been determined to require continuous supervision because of impaired judgment, safety risks, impulsivity, elopement, aggression, self-injurious behavior, or an inability to recognize danger. Despite this documented level of need, schools often deny additional adult support, place students in unsafe environments, rely on repeated suspensions, or expect general education staff to manage significant behaviors without adequate support. This leads to unsafe situations, loss of instructional time, repeated behavioral escalation, trauma, and denial of meaningful access to education.

RECOMMENDATION: Require school districts to consider IHSS Protective Supervision eligibility as relevant evidence of supervision and safety needs during IEP development. Districts should conduct an individualized analysis of the need for 1:1 or shared aide support, additional behavioral staffing, safety plans, supervision accommodations, or specialized placement, and document in writing the reasons for approving or denying additional adult support. Districts should not be allowed to deny additional adult support solely because of cost, staffing shortages, district policy, or assumptions that the support would create “dependence.”

ED-24. Enforce IDEA by Creating Penalties – Professional

ISSUE: School districts repeatedly violate the Individuals with Disabilities Education Act (IDEA) because there are few meaningful consequences when they fail to assess students, fail to implement IEPs, miss required timelines, deny services, or fail to provide records.

RECOMMENDATION: Create escalating state penalties for school districts that repeatedly violate IDEA. Remedies could include mandatory corrective action, public reporting, increased state monitoring, financial penalties, and required compensatory education funds for parents.

ED-25. Districts Should Allow More/Better Placement Options
– Family Advocate

ISSUE: Districts need to give parents options and the possibility of new placements when a child's current school and services cannot meet their needs. Parents should have access to schools and programs that are equipped to support children with autism or other disabilities when their current placement is not meeting their academic or other needs.

RECOMMENDATION: Allow our children to explore other placements that truly know how to support kids with disabilities. These could include other facilities or third-party programs outside the district, as well as online schooling and programs that provide appropriate supports for students with disabilities.

ED-26. Provide Continued Education Until 22 Years of Age
– Professional

ISSUE: Many students with mild/moderate support need to earn a diploma but are not yet prepared for independent adult life, employment, post-secondary education, or community participation. This policy would eliminate that barrier and ensure that students receive support during the critical transition from school to adulthood. Disability does not end at graduation. This will promote equity because right now we have a diploma for students with extensive support needs that allows them to receive services beyond this alternate diploma. It is already in ed. Code but our students with mild/moderate support needs are slipping through the cracks.

RECOMMENDATION: California law should be amended to allow all students with disabilities who have an Individualized Education program to continue receiving services and transition services through age 22, regardless of whether they have earned a high school diploma or equivalent. Students with mild/moderate support needs would have the option to continue participating in transition programs, vocational training, employment prep, independent living instruction, and related services if the IEP team determines those services are still necessary.

ED-27. Statewide Advanced Learning Plans for Gifted Students – Family Advocate

ISSUE: Gifted education services vary widely across California by district, school, teacher, and available funding, leaving many students without meaningful academic challenge or support. Unequal access often depends on ZIP code rather than student need, many gifted and twice-exceptional students do not receive instruction tailored to their strengths, pace, or social-emotional needs, and neurodivergent and underserved students with disabilities, autism, ADHD, language differences, or low-income backgrounds are often overlooked in traditional gifted programs. Districts are not currently required to document goals, monitor progress, or ensure gifted students are making academic growth, and families often have limited visibility into the services actually being provided. When advanced learners are unchallenged, they may experience boredom, masking, anxiety, school avoidance, behavioral issues, or underachievement.

RECOMMENDATION: Require a statewide Advanced Learning Plan (ALP) as a legally mandated document for every identified gifted student, similar to the system used in Colorado. An ALP would provide a consistent statewide framework for documenting and addressing each student's individualized academic and social-emotional needs, goals, services, and progress while increasing accountability and parent partnership. The requirement should apply to identified gifted students from early childhood through grade 12 and be modeled on Colorado's ECEA Rule 22-20-R-12.00.

ED-28. Real-Time Access to IEP Service Logs – Family Advocate

ISSUE: Families of students with disabilities often do not know whether required IEP services are actually happening consistently. Speech therapy, occupational therapy, counseling, reading intervention, or aide support can be missed for weeks or months before anyone realizes. By the time records are requested and received, a child may already have lost critical learning time or regressed. Schools have the data in real time, but families frequently do not, and parents must submit formal record requests, follow up repeatedly, and wait long periods just to understand what services were delivered. Without shared visibility, disagreements can become “your word against ours,” and parents cannot easily identify recurring cancellations, staffing shortages, substitute gaps, or systemic service-delivery problems.

RECOMMENDATION: Require schools to give parents real-time online access to IEP service logs through a secure portal. Families should be able to see when required services were provided, missed, canceled, or rescheduled, similar to how parents can already view grades and attendance online. This would help parents support their child's education, identify problems earlier, and hold schools accountable. Students with disabilities deserve accountability, and parents deserve timely access to information that directly affects their child's education and progress.

ED-29. Include Developmental, Relationship-Based Interventions as an Option – Professional

ISSUE: Children with I/DD have been subjected to applied behavior analysis (ABA) at home and at school, while Developmental, Relationship-Based Interventions (DRBI) approaches have been found to have equally meaningful, scientifically measured outcomes. Staff who interact with students must also have training in child development and relational health in order to provide supportive relationships.

RECOMMENDATION: California law should specify that evidence-based behavioral intervention "includes as an option developmental, relationship-based interventions (DRBI)."

ED-30. Family Caregiver Student Loan Forgiveness Act – Family Advocate

ISSUE: Current federal student loan discharge programs provide relief when borrowers themselves become totally and permanently disabled, but there is no comparable protection for parents and family members who are unable to pursue their careers because they provide around-the-clock care for a loved one with significant disabilities. As a single parent caregiver, I have dedicated my life to supporting an individual who requires protective supervision and continuous care through regional center services. This work is essential and saves the state substantial costs by preventing institutional placement, but it comes at a significant personal and financial sacrifice. Many caregivers earned college degrees and incurred student loan debt expecting to work in their chosen professions, but the demands of 24-hour caregiving make it impossible to maintain full-time employment or earn the income necessary to repay these loans. Caregivers are often

forced to leave careers, reduce work hours, or decline advancement opportunities to meet the needs of their family member with disabilities.

Family caregivers are an invisible workforce. We provide critical care, supervision, advocacy, transportation, medical coordination, and daily support that allows people with disabilities to live safely and with dignity in their communities. Family caregivers frequently live on limited incomes while performing work that would otherwise cost government agencies tens of thousands of dollars annually if provided through institutional or residential care. Our contributions should be recognized through meaningful financial relief. Student loan forgiveness would acknowledge the sacrifices we make and help ensure that families can continue providing care without overwhelming financial hardship.

RECOMMENDATION: Create a student loan forgiveness program for parents and legal guardians who provide full-time care for individuals receiving regional center services and requiring protective supervision. Allow partial or full discharge of federal and state student loan debt after a specified number of years of documented caregiving, recognize family caregiving as a public service equivalent to other professions that qualify for loan forgiveness programs, and provide additional protections for caregivers who are unable to maintain traditional employment because of caregiving responsibilities.

EMPLOYMENT

EMP-01. Employment Training – Family Advocate

ISSUE: Many employees with I/DD are hired but are not given training methods that match how they learn. Standard onboarding is often too fast-paced, not adapted to different learning styles, and focused on compliance rather than skill development. This leads to high job turnover, underemployment or job loss despite willingness and ability to work, reliance on external job coaching services that may not be available or consistent, and employers missing out on capable long-term employees because of preventable training gaps.

RECOMMENDATION: Require large employers with 200 or more employees to provide structured, individualized, on-the-job training and workplace support for employees with I/DD. This should include assigned or designated workplace support personnel, such as job coaches or trained staff; individualized training plans focused on skill learning rather than discipline; training methods adapted to different learning needs; time-adjusted onboarding based on demonstrated learning progress; and protections against using training documentation primarily as a punishment tool while an employee is participating in good-faith training.

EMP-02. Accessible Employment Records – Professional

ISSUE: California law needs to be updated so that when employers provide personnel records under Labor Code § 1198.5 and payroll records under Labor Code § 226, the records are not only available but also organized, complete, and accessible in a way employees, including people with I/DD, can meaningfully understand and use. Employees may receive records that are out of order, split apart from related pages, incomplete, cut off in scans, or provided in large batches without an index or page numbers. Electronic records may also be image-based PDFs that cannot be searched, navigated, or read by assistive technology, while employees who request paper copies may instead receive electronic files that are not usable for them. These barriers can make it extremely difficult for people with I/DD to understand their employment history, verify pay or disciplinary actions, or exercise their legal rights. The core problem is the gap between “records

were provided” and “records can actually be understood, navigated, and used.”

RECOMMENDATION: Change California law to require personnel and payroll records to be organized in a clear and logical order, such as chronological order; kept intact so multi-page documents are not split or separated; complete, legible, and not cut off or partially scanned; and accompanied by a basic index or summary when large volumes of records are produced. Records should also be provided in the employee’s requested format, such as paper copies by mail or accessible electronic files, when reasonably feasible. If provided electronically, records should be in a truly accessible format rather than image-only files that cannot be read, searched, navigated, or used with assistive technology. The goal is to ensure that the right to obtain employment and payroll records is meaningful in practice, especially for people with I/DD.

EMP-03. Caregivers Protected Class in Employment – Family Advocate

ISSUE: Children with disabilities often require specialized therapies, medical appointments, evaluations, and emergency care during normal business hours. Without workplace flexibility, many parents are forced to reduce their hours, leave the workforce, or lose their jobs altogether, creating financial instability for families already facing significant medical expenses and increasing reliance on public assistance. Parents and family caregivers of dependents with disabilities represent an experienced, resilient, and highly skilled segment of the workforce, yet current employment laws can force them to choose between earning a living and ensuring their loved ones receive medically necessary care.

RECOMMENDATION: Establish family caregiver status as a legally protected class. Employers should be required to provide reasonable accommodations for employees who are primary caregivers of dependents with disabilities unless doing so would create an undue hardship for the employer. Accommodations could include flexible scheduling, remote or hybrid work when feasible, modified work hours to attend medical appointments, and protection from discrimination, retaliation, demotion, or termination based solely on caregiving responsibilities.

EMP-04. Remove CARF Barrier for More Vendor Services for I/DD – Professional

ISSUE: Requirements made by the Commission on Accreditation of Rehabilitation Facilities (CARF) for employment services create a barrier to having more vendors available to provide employment services.

RECOMMENDATION: Remove CARF accreditation as a requirement for employment services. This would open the door to more vendors, broadening opportunities for people with I/DD to receive employment services.

SCDD Note: Chaptered trailer bill language (SB 163, 2026) amended Welfare and Institutions Code §4851 and removed the requirement for a work activity programs or supported employment programs to comply with the requirements of CARF.

EMP-05. More Work Incentives Planning and Assistance for Successful Transition to Employment – Family Advocate

ISSUE: DOR should not be used for regional center clients so that one organization can track and assist the consumer from beginning to end. More Work Incentives Planning and Assistance (WIPA) services are needed and should be assigned to each consumer as soon as they start looking for employment, not after they get a job. The WIPA should work side by side with the service coordinator to help the consumer apply for the right programs and protect their rights.

RECOMMENDATION: When a regional center client finds gainful employment, they should not lose the supports that helped them get there. They should receive help identifying and applying for the right programs, such as Ticket to Work or working disabled programs, retain needed supports such as a job coach, and maintain the right insurance coverage. For example, if they had Medicare, they should be able to keep it so they do not lose access to the medical coverage they need.

EMP-06. AI Risk Screening Out Neurodistinct Candidates – Family Advocate

ISSUE: AI-powered hiring tools, performance management systems, and skills assessments are being deployed at scale without adequate testing for

neurotype bias. These systems risk screening out neurodistinct candidates not because they lack capability, but because they have different patterns of communication, response timing, or task sequencing that algorithms may flag as deficient. Without intervention, neurodistinct workers will be disproportionately displaced from the jobs they currently hold and disproportionately screened out of the jobs that replace them. The AI transition amplifies existing disadvantage rather than reducing it.

RECOMMENDATION: Any workforce policy developed to address employment shifts resulting from the rise of artificial intelligence should include people with I/DD and address their inclusion in the changing workforce.

EMP-07. Employment Opportunities and Wages – Family Advocate

ISSUE: Individuals with Down Syndrome can have a job and feel good about themselves. My son cannot compete for work with a typical person.

RECOMMENDATION: I would make a law allowing a person to accept lower wages if they are not able to perform at the same level as a typical person. If this cannot be done, the government should be required to have 15% of its workforce be individuals with Down Syndrome.

SCDD Note: This recommendation does not align with SCDD's work to eliminate subminimum wage employment. SCDD led the stakeholder process required by SB 639 (Durazo, 2021) to develop California's multiyear plan to phase out subminimum wages for workers with disabilities and has continued working to support the transition to competitive integrated employment at minimum wage or higher. For more information about SCDD's work on the elimination of subminimum wage, visit SCDD's SB 639 webpage, <https://scdd.ca.gov/sb639-home>.

EMP-08. Employment Access Needed – Professional

ISSUE: Many adults with I/DD leave high school without real work experience, resumes, transportation training, or pathways into employment. As a result, many become isolated at home, dependent on family members, or stuck on waiting lists for services. Families are often told employment is unrealistic, even when individuals can work with the right supports. Increasing employment access would increase independence, improve mental health and confidence, reduce long-term reliance on public systems, and create more meaningful community inclusion. Research and

advocacy organizations consistently identify employment access as a major unmet need within the I/DD community.

RECOMMENDATION: Require paid internship opportunities for adults with I/DD in every regional center area, partnerships between schools, regional centers, employers, and employment providers, transportation support for employment activities, and person-centered employment planning before a student exits special education. The law should also prioritize competitive integrated employment instead of lifelong segregation or isolation after graduation.

EMP-09. Make DOR Forms Accessible – Professional

ISSUE: I cannot download the necessary DOR forms to help high school students transition from school into adulthood. After several emails, I was able to get the forms emailed to me. The forms are difficult to read, do not provide enough space to write answers, especially for people with occupational therapy or mobility needs, and must be printed, completed, and then scanned or faxed.

RECOMMENDATION: Make DOR forms downloadable, legible according to individual needs, and electronically fillable using options such as talk-to-text. Make the DOR application easier to access and complete, especially for people in rural areas who may lack access to copy machines, printers, or broadband.

EMP-10. Help People with Disabilities Become Employed – Professional

ISSUE: Help people with disabilities become employed.

RECOMMENDATION: Strengthen the employment tax incentive for private and nonprofit employers that train and hire people with disabilities.

EMP-11. TEMP 109 – Angel Martinez Jr. Worker Heat Protection and Accountability Act – Family Advocate

ISSUE: Workers can suffer serious and preventable injuries when signs of heat illness, dehydration, or other medical distress are ignored and they are allowed or required to continue working. Warning signs may include

vomiting, dizziness, confusion, disorientation, weakness, loss of balance, or altered mental status. When supervisors or managers know that an employee is experiencing these symptoms but do not remove the employee from hazardous duties or allow the employee to seek medical attention, the employee may be placed at risk of catastrophic injury, permanent disability, or death.

Angel Martinez Jr. showed warning signs, including vomiting and disorientation, before suffering an injury that left him permanently disabled. Workers should not be required to continue working, including mandatory overtime or weekend work, when serious warning signs indicate that they may be experiencing heat illness or another medical emergency.

RECOMMENDATION: Enact the Angel Martinez Jr. Worker Heat Protection and Accountability Act (TEMP 109) to require employers, supervisors, and managers to act when an employee displays signs of heat-related illness or serious medical distress. An employee experiencing symptoms such as vomiting, dizziness, confusion, disorientation, weakness, loss of balance, or altered mental status should be immediately relieved from duty and referred for medical evaluation. Employers should be required to remove the employee from hazardous duties, allow the employee to return home or seek immediate medical care without penalty, document the incident and actions taken, and prohibit mandatory overtime or weekend work until the employee is medically cleared to return.

If an employer, supervisor, or manager knowingly disregards documented signs of heat illness or medical distress and the employee suffers catastrophic injury, permanent disability, or death as a result, the injured worker and their family should be able to seek lifetime medical care related to the injury, long-term disability support, compensation for ongoing care needs, recovery of expenses incurred by family caregivers, and additional penalties against employers that knowingly failed to act. The goal is to ensure warning signs are acted upon before they result in life-changing injuries while creating accountability and support for workers and families when those warning signs are knowingly ignored.

HUMAN SERVICES

HS-01. Create Elected Regional Center Boards Through a Membership Model – Family Advocate

ISSUE: Regional center boards are currently appointed, not elected. Welfare & Institutions Code § 4622 requires boards to meet certain composition requirements, including geographic and ethnic representation, disability-related knowledge, and that at least 50% of members be people with developmental disabilities or their parents or guardians, with at least 25% being people with developmental disabilities themselves. But nothing in current law makes the board answerable to the people it serves. There is no election, no term structure tied to accountability, and no mechanism for the population served to remove or replace someone who is not representing them well. The state is now moving toward a “professionalization” model that pushes boards to add members with governance, legal, and fiscal expertise. That is not unreasonable on its own, but as currently framed it risks trading community accountability for credentialing without adding a mechanism for members to hold the board accountable.

Regional centers should instead operate as membership organizations, structurally similar to a cooperative or credit union, where people receiving services are the actual constituent members with electoral power rather than simply a customer base. The Lanterman Act was designed around nonprofit corporations rather than direct government delivery of services, but people with disabilities should not have to depend on charities to live an enviable life. People with disabilities should ultimately be in charge of making sure their regional center works for them and not for service providers.

RECOMMENDATION: Create a membership-organization model and establish membership rights, election procedures, and bylaws requirements as a condition of the state contract. Every person eligible for regional center services would be a member. Adult members would cast one vote in their own right, while one parent or guardian would vote for a minor member. Boards would be elected by the membership rather than appointed. Seventeen seats would be filled by candidates meeting professional, board, or service-provider-experience requirements, with remaining seats open to

any member regardless of credentials. Members would serve staggered three-year terms, with roughly one-third of the board elected each year, and the board would elect its own president and officers. A member-elected nomination committee would recruit and screen candidates using a DDS-standardized qualifications form, with professional-track and general candidates placed on separate lists.

Use single transferable vote (STV), the multi-winner form of ranked-choice voting, for board elections, with separate elections for professional-track and general seats. Mail voting should be available by default, and ballots should be available in accessible and plain-language formats. DDS should administer and certify elections using a standardized statewide process for ballot design, mail-ballot handling, STV counting, and dispute resolution rather than allowing each regional center to run its own election.

Accountability should also include annual elections, a recall process for off-cycle removal of individual board members, routine publication of board votes, minutes, and financial information to members, and continuation of existing conflict-of-interest rules, including prohibiting a board member from voting on a rate that pays their own business.

HS-02. Access to Information About Services – Family Advocate

ISSUE: I believe every family should automatically receive a clear, easy-to-understand resource guide or handbook as soon as a child is diagnosed or enters the system. The guide should include available services, benefits, rights, programs, and support options, with explanations of eligibility and how to apply. Currently, many service coordinators or social workers only provide resources when families specifically ask for them, but families may not know what questions to ask. Parents cannot ask for something they do not know is available.

RECOMMENDATION: Create a Parent Resource Transparency policy across public benefit systems serving children and adults with disabilities, including regional centers, services under the Lanterman Act, Medi-Cal, and special education. Families should receive a comprehensive resource guide from the beginning rather than being expected to discover available services and supports on their own. This would reduce stress, improve access, and help people obtain needed services earlier.

HS-03. Continuity and Training for Service Coordinators – Self-Advocate

ISSUE: When people served by a regional center lose their service coordinator during program transitions, trust is disrupted, they must repeatedly re-explain their needs and goals, and progress is delayed. Maintaining continuity supports person-centered planning, reduces stress, improves follow-through, and strengthens advocacy, especially for those with complex or evolving needs.

RECOMMENDATION: Persons served should be allowed to keep the same service coordinator unless there is a clear, specific reason for reassignment. Program transitions should not automatically cause a service-coordinator change. Service coordinators should also receive cross-training across multiple service models, with stronger training on supporting people who are blind or have low vision, including accessible communication and disability-specific awareness.

HS-04. Automatic Medi-Cal Waiver Enrollment for Eligible Regional Center Clients – Family Advocate

ISSUE: Currently, the Medi-Cal waiver through a regional center cannot be applied for until a denial letter is received from Medi-Cal. During annual IPPs, people may have needs listed that qualify them for the Medi-Cal waiver, but this does not automatically give them the waiver. There is a lengthy application process and wait time that can cause lapses in Medi-Cal-funded services, including medical treatment, ABA services, and IHSS. When the waiver is finally approved, families may have to reapply for IHSS or return to waiting lists for other services. This can be especially harmful for people receiving protective supervision who need IHSS to remain safely at home and for families who depend on that support while providing 24-hour supervision.

I have personally met families affected by this, including mothers who choose to remain single or avoid moving in with partners because they fear losing SSI or Medicaid and know how long the waiver process can take. They cannot afford to lose healthcare or IHSS during the wait. Families have had to make difficult choices to avoid a lapse in medical services or IHSS because they know their child or relative qualifies for the Medi-Cal waiver but may still wait several months and then have to reapply for

services such as ABA and other necessary therapies. These gaps can make a family's housing situation financially unsustainable and create pressure toward institutionalization.

RECOMMENDATION: Regional center clients who are determined during their annual IPP to meet Medi-Cal waiver eligibility criteria should automatically be placed on the Medi-Cal waiver regardless of their current benefit status. This would prevent lapses in services if they later lose SSI, Medicaid, or other eligibility. People who qualify for coverage through another source could continue to use that funding while maintaining waiver eligibility so they do not have to begin a lengthy application process after losing other coverage.

HS-05. Regional Center Board Accountability – Professional

ISSUE: Regional centers must be accountable to their communities. Communities must be able to see the materials presented to regional center boards and committees for their meetings. Holding meetings on Zoom also increases transparency and accessibility.

RECOMMENDATION: Require regional centers to post board and committee meeting packets and require all board and committee meetings to be available on Zoom. Harbor Regional Center told me in an email that it follows the law and that neither posting board-of-directors meeting packets nor holding meetings on Zoom is required by law.

HS-06. Service Integration Needed for Aging and I/DD – Professional

ISSUE: The problem is predictable, growing, and the system is not ready. California serves approximately 527,000 people through its regional center system, and more than 59,000 are projected to be age 45 or older by 2030. More than 75% of adults with I/DD live at home with family caregivers, many of whom are now in their 70s and 80s and managing their own health changes while continuing to provide complex, lifelong support. In Los Angeles County alone, an estimated 26,891 adults with I/DD may be living at home with aging caregivers by 2030. Without aging preparedness, families face caregiver collapse and emergency placements, undetected dementia, fragmented services, and preventable institutionalization. Adults with Down syndrome face a high lifetime risk of dementia, often developing symptoms before age 65, while families may be forced to navigate an

entirely new aging-services system at the same time their own ability to do so is declining.

California has major planning frameworks for both developmental services and aging, but the operational infrastructure needed to routinely connect these systems around the same person and family has not been established. Shared planning tools, navigator roles, workforce training, referral systems, and coordination protocols are needed. An aging parent who has spent decades navigating the regional center system may suddenly have to manage their own declining health while addressing their adult child's age-related health needs, Medi-Cal, Medicare, the Individual Program Plan (IPP), housing, services, and the question of who will provide support when the parent no longer can. Although the Lanterman Act promises lifelong services, California does not have a dedicated case-management model for aging within developmental services, a later-life planning instrument specifically designed to supplement the IPP, a Futures Planning vendor code, or a formal statewide framework connecting regional centers with the aging-services network. Families are therefore left to carry much of the coordination and future-planning burden themselves.

RECOMMENDATION: Require the Department of Developmental Services (DDS) to establish a statewide Aging Preparedness Pilot for adults with I/DD that anticipates later-life needs before individuals and families reach a crisis. Create specialized Older Adult Case Management Units within regional centers for adults age 45 and older, staffed by people trained in gerontology, dementia recognition, caregiver dynamics, Futures Planning, and aging with lifelong developmental disabilities. DDS should also develop an Individual and Family Aging Plan (IFAP) to supplement the IPP beginning around age 45 and address the future needs of both the person with I/DD and their aging caregiver, including advocacy, housing, succession of family and other supports, healthcare, dementia-related needs, and continuity of the person's support network. DDS and regional centers should establish formal coordination with Aging and Disability Resource Centers and Area Agencies on Aging through coordinated referrals, warm handoffs, and Memoranda of Understanding. Family Resource Centers should also expand to include aging supports such as Cross-System Navigators, a shared digital resource hub, healthcare access training, caregiver support groups, and dementia education.

Create a Futures Planning vendor code so regional centers can fund specialized planning for what will happen when an aging caregiver can no longer provide support. DDS should develop workforce training for service coordinators and direct support professionals on aging, dementia recognition, caregiver dynamics, later-life planning, and coordination with aging services, using existing training infrastructure when possible. The pilot should operate in two to three regional center areas for approximately three to five years before statewide implementation, with independent evaluation, annual reports to the Legislature, and measurable Core Indicators examining emergency placements, preventable hospitalizations, caregiver crises, unnecessary institutionalization, service fragmentation, costs, and workforce needs. Aging Preparedness should ultimately become a named strategic priority within DDS and regional center planning, with measurable goals, accountability structures, dedicated funding, and Core Indicators. The goal is to move California from reacting to aging-related crises to anticipatory planning and make the Lanterman Act's commitment to lifelong services meaningful throughout the lifespan of people with I/DD.

HS-07. Regional Center Clients – Family Advocate

ISSUE: New regional center clients may not know what services, programs, and supports are available to them, and service coordinators do not always offer what the person needs.

RECOMMENDATION: Require regional centers to provide a mandatory orientation for new clients.

HS-08. Service Coordinators' Authority – Family Advocacy Organization

ISSUE: Decisions are not being made at the IPP meeting. As reported in the Master Plan for Developmental Services, service coordinators are presently acting as "messengers," sending information from IPP meetings to managers, clinical teams, and committees. Decisions are being made outside of the IPP meeting rather than with the person served, or their representative, in the room. This goes against a person-centered approach and leads to devastating delays and gaps in service delivery.

RECOMMENDATION: Clarify in law that service coordinators have the authority to approve services that meet a person's needs. Require an

authorized decision-maker to be present at every IPP meeting so decisions are made at the program plan meeting. Eliminate internal decision-making meetings or committees that make decisions about a person's services without involving the person served or their representative.

HS-09. Align State and Federal Standards for Diagnosis of I/DD
– Family Advocate

ISSUE: Research has clearly shown that the brains of young adults are not yet fully formed before age 22, and some years beyond that. Adolescents and young adults are therefore prone to risk-taking behaviors that can result in lifelong injuries and reduce their ability to provide for their own food, clothing, or shelter or make other independent living choices involving employment, financial management, and other areas. California's current age standard for I/DD also differs from the federal standard, creating confusion and inconsistency with federally funded programs.

RECOMMENDATION: Bring California's eligibility standard for I/DD into alignment with the federal standard by changing the age from birth to 18 to birth to 22. Because the regional center system receives substantial federal funding through Medicaid waiver dollars, California should use the federal age standard. The current four-year difference between state and federal standards denies appropriate supports to people who acquire significant disabilities between ages 18 and 22, a particularly at-risk period for injuries.

HS-10. Conflict of Interest for SSA Representative Payees and
Vendors – Professional

ISSUE: Currently, there is no restriction preventing a regional center vendor from also being an SSA-approved representative payee for a client the vendor is funded to serve. This means a service provider, such as an SLS, ILS, or other direct service provider, can serve as the representative payee while also being funded to provide regional center services to the same person. Current Welfare & Institutions Code conflict-of-interest provisions address regional center boards and employees, but not vendored service providers.

RECOMMENDATION: Prohibit a regional center vendor that serves as a person's representative payee from also providing regional center-funded

services to that same person. Separating these roles would prevent potential fiduciary abuse and undue financial influence.

HS-11. Accommodation in Camps and Reimbursement – Family Advocate

ISSUE: Camps are accepting regional center clients and saying they are willing to provide accommodations, receiving payment for an entire summer that can total around \$10,000, and then after the first week saying the child has too many issues and they do not want the child there, while keeping the nonrefundable payment. This has happened to us three years in a row, and I see a pattern with camps in the West Valley area of Los Angeles. During tours and conversations before camp starts, they seem willing and accommodating. Once camp begins, they make the child seem like the issue and say they do not have staff to handle the child. When I ask for a refund, I am told their terms do not allow refunds after the first day.

When I tell the regional center that my child is not doing well according to the camp and I want to choose a different social recreational activity, I am told it was my fault that I selected the camp and that there is nothing I can do and no other activity can be funded during those hours. It is unfair to have the child in the middle of all this feeling horrible. I think camps have found a loophole that allows them to make the child feel unwelcome so the child leaves while they keep the regional center funding for the entire summer. When I asked the regional center for a list of camps it recommends, it did not have one, meaning families must choose their own camp and can then be told they were responsible for that choice.

RECOMMENDATION: Regional centers should advocate when camps impose discriminatory rules or fail to provide promised accommodations for autistic children. Even when a camp has a no-refund policy after the first day, the regional center should help the parent seek reimbursement when the camp is the one saying it does not want the child to remain. Autistic children should have extended refund periods because it can take several days for them to become accustomed to changes associated with attending camp.

Camps should not be able to accept regional center funding for an entire summer, fail to provide the accommodations they said they would provide, encourage an autistic child to leave, and then keep all of the funding

because their contract says there are no refunds after the first day. Families should either receive reimbursement or be able to use the funding for another social recreational activity.

HS-12. People with I/DD and Families Must Navigate Complex Systems – Self-Advocate

ISSUE: Many people with I/DD must navigate complex administrative systems largely on their own. This difficulty is compounded when they lack a natural circle of support. Existing advocacy mechanisms are often fragmented, reactive, or available only after harm has already occurred. People without trusted support networks are especially vulnerable to service disruptions, procedural confusion, retaliation, housing instability, and preventable crises. The Uncommon Council is designed to provide continuous advocacy, preserve trust, reduce preventable harm through early intervention, strengthen person-centered practice, improve community integration, and help conserve public resources by preventing costly crises before they occur.

RECOMMENDATION: California should create a permanent, relationship-centered advocacy framework that provides continuous, trusted advocacy before crises occur. The Uncommon Council would complement, not replace, existing regional centers, service coordinators, legal services, and other public systems by filling the structural gap experienced by people who must navigate complex systems without family or other trusted support. The framework would emphasize prevention, continuity, transparency, collaboration, and sustainable community integration while generating governance intelligence to improve public systems over time.

HS-13. Self-Determination Program Barriers – Family Advocate

ISSUE: My son has been a participant with SCLARC for over 15 years and in the Self-Determination Program (SDP) for over four years. Every renewal brings barriers that cause delays, including caseload changes and new team members who do not have the skill set needed to complete tasks, creating a risk that deadlines will not be met. I have attended meetings at other regional centers where families have expressed the same frustrations.

RECOMMENDATION: Require the Department of Developmental Services (DDS) to establish a statewide policy requiring assistance to families participating in SDP to be provided by regional center service coordinators who have completed DDS-approved, program-specific training. Any service coordinator assigned to review or approve a participant's Person-Centered Plan or Spending Plan should maintain a current DDS training certificate and complete continuing education. Each regional center should maintain designated SDP units or teams with trained personnel, no more than four case workers per team, and service coordinator caseloads that include a minimum of 20 SDP claims or are otherwise based on statewide data regarding participation and service needs. Each team should also include a service coordinator assistant to support documentation, paperwork, and other administrative functions.

DDS should audit regional centers to ensure compliance with established policies and make audit results publicly available. These requirements should promote consistent implementation across regional centers, equitable access for participants and families, and reduce discretionary or unclear restrictions when comparable plans have been approved elsewhere.

HS-14. Adult Day Programs for Specific Needs – Family Advocate

ISSUE: Regional centers only have adult day program options in three areas: behavioral, medical, or community-based. We are falling between what is available. Being at home every day is not good and is not addressing the issues we need help with.

RECOMMENDATION: Create adult day programs that can be designed to meet a person's specific needs rather than limiting options to behavioral, medical, or community-based programs.

HS-15. Pay Parents to Stay Home as Caregivers – Family Advocate

ISSUE: Children and other family members with disabilities can remain protected in their homes under the care of family members who love them and want to continue caring for them. I come from the 1960s and 1970s, when children who were neurodivergent or had fewer or extra chromosomes were treated horribly because families were not given the proper support from state agencies to keep them at home and provide their

care. Parents should not have to send a family member somewhere else simply because they cannot afford to stay home and provide the daily care the person needs.

For family members who are nonverbal, there is an additional concern about placing them somewhere they may not be able to communicate what is happening to them or whether they are receiving proper care. Families know their loved ones and want to ensure they are cared for by someone who has their best interests at heart.

RECOMMENDATION: Allow parents to stay home with a decent salary to care for their children or family members with disabilities. Paying parents to provide this care would save the state and federal government thousands upon thousands of dollars each month compared with paying foster parents or agencies as much as \$10,000 per month. Families should be supported to keep their loved ones safely at home rather than being forced to choose outside placement because the parent cannot afford to provide full-time care.

HS-16. People with I/DD Should Not Have to Be Re-Diagnosed to Receive Benefits – Family Advocate

ISSUE: My daughter is going to be 30 this year. She was born with ataxia cerebral palsy. Every year since her diagnosis, the same questions are asked about her disability to determine whether she is still disabled. She will never get better. She will never meet society's expectations of what is considered normal for her age. The pain and suffering parents and caregivers are put through to repeatedly defend their family member's disability, either annually or initially to obtain disability benefits, is heartbreaking, especially when benefits are denied. There is no dignity in repeatedly requiring proof of a permanent disability.

RECOMMENDATION: When a person is determined to have a permanent disability at birth or soon afterward, services and benefits based on that disability should continue for life without repeatedly requiring the person or family to prove the diagnosis again. Once the permanent nature of the disability has been established, there should be no further questions about whether the underlying diagnosis still exists.

HS-17. Medical Record Barriers to Regional Center Eligibility – Family Advocate/Professional

ISSUE: Under the Lanterman Act, adult applicants must establish a qualifying developmental disability that began before age 18, is expected to continue indefinitely, and constitutes a substantial disability. However, public schools routinely purge special education files after five years and medical providers may no longer have childhood records after seven years, making physical childhood records extremely difficult to locate for adults in their 30s and 40s. Families may arrive at regional center intake as adult life demands increase and aging caregivers become less able to provide care, only to encounter an insurmountable documentation barrier. The xFusion project's current "Modernization Blind Spot" further worsens this problem by prioritizing more recent health records while leaving historical childhood data behind. Families may be forced to fax forms and wait 30 to 90 days for static, non-searchable records, even though regional centers are expected to assess eligibility using medical, psychological, and developmental information.

Historical Medi-Cal and IHSS records could provide objective evidence of childhood functional needs even when the records contain outdated diagnoses or historical bias. Providers and county social workers had to document services and program eligibility for services such as specialized transportation, 1:1 behavioral support, clinical therapy, or IHSS care. Years of documented services and supports could therefore help establish that significant functional needs existed during childhood. Giving families direct access to these historical records would allow them to use the state's own records to demonstrate childhood onset and overcome a documentation barrier before aging caregivers reach burnout.

RECOMMENDATION: Require the Department of Health Care Services (DHCS) to integrate an on-demand, consumer-facing historical data retrieval function into the xFusion project. The law should direct DHCS to modify or extend its existing xFusion contract and Enterprise Data Warehouse work so an individual-initiated digital Subject Access Request can trigger an automated point query of legacy records. The system should securely extract the individual's complete historical Medi-Cal and In-Home Supportive Services (IHSS) records dating back to 1980. The same legacy data layers currently available to state auditors and academic researchers

should be made directly accessible to the individuals whose records they contain.

Historical records should be delivered directly to the individual or their designated advocate within 72 hours in a text-searchable digital format, such as a downloadable spreadsheet or data file. The system should not require long-term storage of the extracted information on the portal. This would give adults seeking regional center eligibility and their families usable historical evidence of childhood services and functional needs when original medical, school, or other records are no longer available.

HS-18. Create More Communication Support Services – Family Advocate (Translated from Spanish)

ISSUE: People with disabilities who have speech and communication challenges often do not have enough resources to make progress in their communication skills. Support through schools and regional centers leaves much to be desired. As the mother of a young man with Down syndrome, autism, an intellectual disability, and who is nonverbal, I feel that not enough is being done to help him achieve his communication goals.

RECOMMENDATION: Strengthen communication services within regional centers and make providing effective and appropriate communication tools for every person who needs them a priority. There is also a need for training programs, ongoing support, and better sharing of information about available communication resources. When communication services are inadequate or poor quality, people cannot make meaningful progress. If you do not know how to communicate, you are at a significant disadvantage. It is almost as if you do not exist.

HS-19. Regional Centers Need Accounting and Quality Assurance – Professional

ISSUE: Regional centers need to regularly perform billing audits of providers, especially their largest provider organizations, which are increasingly made up of private, for-profit organizations owned by private equity. Regional centers have never had sufficient operations funding to properly staff their accounting and quality assurance departments and perform billing audits of providers. Current quality assurance funding focuses on licensed residential providers and internal audits of vendor files,

while annual independent audits or reviews required of providers examine financials rather than billing integrity.

RECOMMENDATION: Create a dedicated external Purchase of Services (POS) Auditor position at each regional center, reporting directly to the executive director to reduce potential conflicts of interest with other departments. The position would audit large POS providers, improve accountability for state and federal purchase-of-services funding, and help identify and rein in potential fraud by provider organizations, including organizations acquired by private equity and accountable to shareholders.

HS-20. Mandate Caseload Management in Regional Centers – Professional

ISSUE: Regional center service coordinators can have caseloads so high that they cannot provide people with the support they need. Case management begins with the service coordinator, and unmanageable caseloads are a direct barrier to regional center clients receiving the supports they need and have a right to receive.

RECOMMENDATION: Establish enforceable regulations limiting regional center caseload sizes to manageable levels and require regional centers to comply with those limits.

HS-21. IHSS Protective Supervision Determinations for People with Lifelong Disabilities – Family Advocate

ISSUE: Families who depend on IHSS Protective Supervision for a loved one with a lifelong disability such as autism or cerebral palsy experience fear and PTSD knowing that the service could be reversed each year by a new person visiting their home. Although remedies exist to appeal a decision, the system is set up to “inspect” the person instead of supporting the person.

RECOMMENDATION: Do not put self-advocates and their families through a yearly judgment process in which a social worker who does not know the person or family makes a decision about whether Protective Supervision is still needed to remain safely at home. Lifelong disabilities do not resolve themselves, making repeated annual determinations an unnecessary state

expense. Regional centers could provide IHSS offices with reliable updates about these individuals as an additional check and balance.

HS-22. Parent Navigator Program to Help Families Access Services – Professional

ISSUE: Families are often expected to navigate multiple complex systems immediately after receiving a diagnosis. Many parents report confusing eligibility requirements, long wait times, inconsistent information, language barriers, transportation challenges, and a lack of coordinated support. Families who cannot afford attorneys, advocates, or private consultants are often left to navigate these systems alone. As a result, services may be delayed, benefits can go unused, educational supports can be missed, caregiver stress increases, and children may not receive needed interventions.

RECOMMENDATION: Create a standardized, free, peer-led Parent Navigator Program to help families understand and access regional center services, early intervention, Individualized Education Programs (IEPs), Medi-Cal and private insurance, IHSS, behavioral health services, transition-age youth services, employment and independent living resources, disability-related benefits, and community-based supports. Navigators would not provide legal advice but would help families understand systems, complete applications, gather documentation, attend meetings for support, and connect with appropriate resources. Priority should be given to low-income families, culturally diverse communities, rural communities, and families with limited English proficiency.

HS-23. Disability Life Navigators to Help Access Services – Professional

ISSUE: Many people with I/DD qualify for valuable services but never receive them because the system is complicated and difficult to navigate. Families often become full-time case managers trying to understand multiple agencies with different rules, applications, and deadlines. When students leave high school, many families experience a significant gap in services and do not know where to turn. A Disability Life Navigator would increase access to existing services, improve employment outcomes, reduce missed opportunities and benefit losses, reduce caregiver stress,

promote independence and self-determination, and improve coordination without requiring families to navigate the system alone.

RECOMMENDATION: Require regional centers to provide each person served aged 14 and older with a certified Disability Life Navigator. The navigator would develop a long-term transition plan; coordinate communication among regional centers, school districts, the Department of Rehabilitation, Medi-Cal, Social Security, IHSS, housing agencies, and community providers; help families complete applications and meet deadlines; connect individuals to employment and post-secondary opportunities; assist with housing and transportation planning; explain supported decision-making and self-advocacy options; and continue providing support after high school rather than ending assistance at graduation. The goal is not to create more bureaucracy but to make existing services easier to access and more effective.

HS-24. Regional Center Vendor Accountability – Professional/Family Advocate

ISSUE: California requires many people with developmental disabilities to obtain services through DDS-funded intermediaries. When those entities ignore communications, misrepresent legal requirements, deny payments without justification, refuse accommodations, or otherwise obstruct services, consumers can have fewer practical remedies than other Californians. Public duties have been outsourced, but public accountability has not followed. Entities entrusted with taxpayer funds should be directly answerable to the consumers they serve.

RECOMMENDATION: Require any regional center, financial management services (FMS) provider, contractor, or vendor receiving DDS funds to publish its business practices, consumer-rights policies, anti-discrimination policies, accessibility and ADA procedures, complaint procedures, and fiduciary obligations as a condition of receiving public funds. Establish that individuals receiving DDS-funded services retain the same consumer protections available in the private marketplace and may seek legal remedies when DDS-funded entities engage in discrimination, denial of accommodation, unfair business practices, misrepresentation, retaliation, breach of fiduciary duty, or failure to perform their obligations.

HS-25. Funding for DSP Training – Self-Advocate

ISSUE: Direct Support Professionals (DSPs) are chronically under-trained because vendors do not have a consistent way to be reimbursed for staff time spent participating in important training, especially training designed and led or co-designed and co-led by people with I/DD. Right now, vendors cannot be reimbursed unless a regional center decides to dedicate special funding for training, which means training does not happen nearly as often as it should.

RECOMMENDATION: Allow vendors to bill or receive reimbursement for DSP staff time committed to important training, especially training designed and presented by people with I/DD. Increased training could decrease burnout and turnover, potentially reduce overall training costs, increase client satisfaction and healthy activity, improve HCBS compliance, create workforce-development opportunities for DSPs, provide a professional advocacy and workforce-training pathway for people with I/DD who want their ideas brought forward, and create greater diversity in the training environment.

HS-26. Friend Registry to Combat Isolation and Loneliness – Self-Advocate

ISSUE: People with disabilities want to have friends too.

RECOMMENDATION: Create a friend registry for people with disabilities that connects people in California with others in different states and countries and helps them find pen pals and good people to talk to rather than being used for certain things.

HS-27. Eliminate Annual IHSS Reassessments for Adults – Family Advocate

ISSUE: My son is 18 years old. His disability is profound. It will not magically go away next year or the year after that.

RECOMMENDATION: Change the IHSS yearly reassessment policy and eliminate annual reassessments for people over age 18.

HS-28. Require Regional Centers to Inform Families About Available Services and Benefits – Family Advocate

ISSUE: We paid thousands of dollars for social recreation, hearing aids, therapy, medications, activities, equipment, and other needs. No one ever told us that some of these things could have been paid for. We have also had several service coordinators, and they never offered us respite or other services.

RECOMMENDATION: Require parents of children with disabilities to be informed about Medi-Cal, IHSS, CCS, and other services and financial supports that may be available. Regional centers should be required to ensure that people receive all of the services and benefits they qualify for instead of waiting until the person or a family member learns about a service and requests it.

HS-29. More Flexibility in Personal Assistance – Self-Advocate

ISSUE: Our ability to function inside and outside our homes depends on having the support we need. We may have one Personal Assistant (PA) at home and then need a PA so we can leave our home, be out in the community, and complete tasks we would not be able to complete on our own. Participants continuously face changes in how we are allowed, or not allowed, to have security and maintain PA hours in the way we want and need them in our homes while accommodating our needs and Self-Determination Program budget.

RECOMMENDATION: Allow greater flexibility in how Personal Assistance (PA) hours are used so participants can arrange support based on when and where we need it, including having support in the home and separate support to leave the home, participate in the community, and complete tasks they cannot do independently. Participants in the Self-Determination Program should be able to maintain and adjust PA hours within our individual budget without unnecessary restrictions that interfere with our ability to function safely and independently.

HS-30. Communication Training and Access – Family Advocate

ISSUE: Communication access is limited for people who use augmentative and alternative communication (AAC), and services to implement

communication supports need to be highly individualized. Vendors may not be experienced, trained, or available to provide these services.

RECOMMENDATION: Add a service code for participant-directed communication support and training so clients can select the people who provide this service.

HS-31. People Are Not Aware of Regional Center Services – Family Advocate

ISSUE: People with I/DD can slip through the cracks because no one told them the Lanterman Act or regional center services exist. Many people who may qualify have already been involved in publicly funded systems for years. A student may attend IEP or 504 meetings. A person may receive county services, be unhoused, be in foster care, be in a hospital or correctional setting, or age into senior services, yet no one may be required to document that regional center information was discussed. This creates a civil rights and equity problem. Families with more knowledge, money, language access, internet access, or advocacy support may find regional center services earlier, while BIPOC, low-income, rural, immigrant, non-English-speaking, unhoused, justice-involved, and otherwise underserved communities are more likely to be missed. A right people are never told about is a right they may never use.

RECOMMENDATION: Require publicly funded systems to provide written and verbal information about the Lanterman Act and regional center services at key meetings, intakes, case reviews, discharge planning, reentry planning, and other relevant encounters. This would help ensure that children, adults, and seniors do not miss regional center services simply because nobody was legally required to tell them the door existed.

HS-32. Unreliable and Inconsistent Guidance for Early Start Services – Family Advocate

ISSUE: I surveyed 13 different organizations that provide Early Start services in the area, and the results were overwhelmingly similar: families are being denied access. Families report being told to “wait and see,” denied access to specialist consultation, and receiving inconsistent information depending on which service coordinator they are assigned. These practices delay intervention during the most critical period of child

development and create unequal access to services across California. Families should receive written documentation whenever a service or assessment is denied.

RECOMMENDATION: Ensure that infants and toddlers with developmental delays receive timely access to specialist expertise, consistent information across regional centers, and individualized services based on family need rather than administrative barriers. Protect consultation services, require timely review of specialist requests, require written explanations for denials, establish statewide consistency standards, and improve family access to information and rights.

HS-33. Eliminate Annual IHSS Reassessments for Non-Progressive Disabilities – Self-Advocate

ISSUE: Current law requires IHSS reassessments every year even when a person's disability is not progressive.

RECOMMENDATION: Have the IHSS reassessment done once instead of every year for people with non-progressive disabilities.

HS-34. Use a Strengths-Based Model for Planning – Self-Advocate

ISSUE: Disability systems need to transition to a strengths-based model with no limits on a person's potential and with supports based on individual needs. Current systems can keep people with disabilities in poverty, restrict career advancement, separate functional skills from academics, steer people toward limited career pathways, treat group homes as the norm, and create financial penalties for earning more, building assets, marrying, having relationships, or having children. People should be able to use their unique strengths, interests, talents, gifts, abilities, and passions to choose their own path in work, education, housing, relationships, and community life without losing the supports they need to function.

RECOMMENDATION: Eliminate the \$2,000 asset cap and other financial barriers that prevent people with disabilities from building wealth, qualifying for market-rate housing, or advancing in careers without losing needed supports. Medicaid waiver and disability services, including IHSS and regional center supports that traditional health insurance does not provide, should continue regardless of income. SSI should supplement income until

a person's combined SSI and other monthly income exceeds 4.5 times the median rent where they live, allowing people to meet typical landlord income requirements. Marriage, relationships, and having children should not terminate supports or reduce benefits.

Require person-centered planning and Self-Determination for all new regional center clients and phase out the traditional regional center model by transitioning everyone to Self-Determination. Education and workforce systems should offer a broad range of inclusive career pathways, including vocational education, career technical education, community college, college degrees, and graduate school based on the person's chosen career. K-12 education should provide both academics and functional and independent-living skills without denying a diploma. Students graduating at 18 should be able to use their remaining transition funding for college, careers, and other supports, and 18-to-22 transition programs should move from high school campuses into age-appropriate settings such as workplaces, ROP programs, community colleges, and universities. Schools should promote supported decision-making rather than guardianship as the norm. Disability systems should prioritize community life over group homes, restore DEI practices in employment and higher education, and use person-centered planning so people choose the services and providers that best support the life they want.

HS-35. Clearer Guidelines for Protective Supervision – Family Advocate

ISSUE: Families caring for loved ones with I/DD need clearer guidelines and a better understanding of IHSS Protective Supervision so they do not have to live in fear of losing a vital service. For many families, Protective Supervision is essential to ensuring their loved one's safety and well-being. Losing this support can have a significant negative impact on both the person with disabilities and family members providing daily care.

RECOMMENDATION: Reform the definition and interpretation of self-direction within the Protective Supervision program to provide greater clarity and consistency. There should be a shared understanding throughout the system, from social workers to administrative law judges, of what self-direction means so eligibility decisions accurately assess a person's ability to recognize danger, exercise judgment, and maintain their own safety.

HS-36. Standardize Future Planning – Family Advocate

ISSUE: Many families spend years focused on day-to-day caregiving and do not receive structured support to plan for the future. When a parent becomes ill, becomes disabled, or dies, people with developmental disabilities can face housing instability, loss of supports, emergency placements, and unnecessary crises. Too often, families are left to navigate these complex decisions on their own. As a single parent of an adult son with developmental disabilities, I have spent years navigating housing, financial planning, emergency preparedness, and future caregiving. In my work supporting families, future planning is one of the most common concerns raised by parents, particularly aging parents and single parents without other family members available to provide future support.

RECOMMENDATION: Establish a standardized future-planning process so people with developmental disabilities and their families have access to information, resources, and structured support before a crisis occurs. Future planning should address areas such as housing, financial planning, emergency preparedness, future caregiving, and continuity of supports.

SCDD Note: Welfare and Institutions Code §4646.5 (a)(9) addresses caregiver succession planning, which includes some elements of this recommendation. Other elements of this recommendation would expand, strengthen, or add to those existing requirements.

HS-37. Parents Forced to Give Up Employment if No Protective Supervision – Family Advocate

ISSUE: There is a gap in services for families with autistic or disabled children and dependent adults with disabilities. IHSS approves only the most severe cases for Protective Supervision, and many parents have been forced to give up employment because their child cannot attend school full time or at all. A child may be intellectually and socially capable but becomes completely dysregulated at school and unable to participate in education or have a positive social interaction. Although schools are required to offer a free appropriate public education (FAPE), some parents are forced to homeschool their child for the child's well-being. During COVID, IHSS made exceptions to strict rules, but these children are now being denied reassessment.

RECOMMENDATION: Create waivers to compensate families who have lost employment because their child cannot attend school full time or part time due to disability. IHSS live-in paid providers caring for dependent family members should also be eligible for unemployment benefits even when their IHSS income is tax-free.

HS-38. Freedom to Travel Without Loss of Benefits – Family Advocate

ISSUE: My adult son with disabilities cannot leave the country for more than 30 days without losing benefits, so he cannot take a long summer vacation or extended road or airline trips to visit family in Germany, Sweden, or the United Kingdom like other adults can. We are told that benefits such as IHSS may have to be paid back if the person is gone for more than 30 days. Why should our adult children with disabilities lose benefits because they travel for two or three months when other adults can travel?

RECOMMENDATION: Allow adults with disabilities to travel as they wish without automatically losing needed benefits because they are temporarily away from home.

HS-39. Mothers as Caregivers Regardless of Legal Status – Family Advocate (Translated from Spanish)

ISSUE: Mothers may be unable to serve as paid caregivers for their own children with autism or other disabilities when they do not have a valid Social Security number for employment because they are immigrants. This can prevent families from providing care as the ones who know the child's individual needs and can provide stability and a sense of safety.

RECOMMENDATION: Allow and recognize mothers as the first choice or primary IHSS provider for their own children, even when the mother does not have a valid Social Security number for employment because of immigration status.

HS-40. Offer Better Support to Parents in Regional Centers – Family Advocate

ISSUE: I am a mother who had a terrible experience with a regional center and felt that I was not respected.

RECOMMENDATION: Increase monitoring and provide training so regional center staff respect client rights and provide parents with better support.

HS-41. Data Collection for Regional Center Staffing – Professional

ISSUE: The existing regional center core staffing formula may not reflect the true cost of staffing or differences in costs among regional center catchment areas. Without regularly comparing the formula with actual staffing costs, the state cannot clearly identify the gap between available funding and what regional centers actually need.

RECOMMENDATION: Require California to conduct a study every other year comparing the true cost of regional center staffing with the existing core staffing formula. The analysis should be conducted by regional center catchment area and account for differences in cost of living.

HS-42. Allow IHSS Meetings to Be Recorded – Professional

ISSUE: Many IHSS administrative hearings result from disagreements about what was discussed during the initial in-home assessment. This is particularly difficult for applicants with disabilities affecting memory, verbal expression, or cognitive function. These “he said, she said” disputes create an adversarial environment and may require an Administrative Law Judge to resolve factual disagreements. Because California is a two-party consent state, IHSS departments and social workers almost universally decline requests to record assessments.

RECOMMENDATION: Allow parents and applicants to record IHSS assessment meetings. Clear recordings would allow either party to correct mistakes, reduce disputes and formal hearings, and allow the applicant and social worker to focus on the assessment knowing statements can later be reviewed for accuracy. To address labor concerns, recordings could be prohibited from use in employment reviews or performance evaluations of social workers, and social workers could make their own recordings to guard against misleading editing.

HS-43. Update Service Standards to Address System Barriers – Professional

ISSUE: Current definitions, quality standards, cost-effectiveness rules, vendor structures, and IPP processes can create barriers to preventive, wellness-based, culturally grounded, and community-defined supports.

RECOMMENDATION: Require AB 143 (2026) to explicitly include preventive, wellness-based, and culturally grounded supports rather than only billable clinical hours. Require the AB 1208 (2025) quality framework to include community-defined outcomes such as mobility, belonging, and well-being. Define Lanterman Act cost-effectiveness in terms of system-level savings, including reduced crises, emergency room visits, and caregiver burnout, rather than only per-unit service cost. Regulations should also authorize and fund pre-IPP navigation services as a distinct vendor category.

HS-44. Title 17 Accommodation Requirements – Self-Advocate

ISSUE: People can face additional costs when staff assistance is needed as an accommodation.

RECOMMENDATION: Change Title 17 so staff assistance is treated as a standard accommodation and does not cost the person extra. Providing needed support should reduce barriers and costs for the person receiving services.

HS-45. Regional Centers Should Add Attorney Fee Provision for Fair Hearings – Family Advocate

ISSUE: The regional center fair-hearing process is stacked against consumers and family members. Most families cannot afford attorneys' fees and therefore may not even file for a hearing. Without access to legal representation, consumers and families are at a significant disadvantage when challenging regional center decisions.

RECOMMENDATION: Add an attorney-fee provision to the regional center fair-hearing process that allows consumers who prevail to have their attorneys' fees paid, similar to attorney-fee provisions in special education

due process matters. This would help level the playing field and make the hearing process fairer.

HS-46. Adults with I/DD Experience Loneliness – Self-Advocate

ISSUE: Adults with I/DD experience loneliness, which can be made worse by difficulty understanding and following neurotypical social cues. Children have schools that provide regular opportunities for interaction, but older youth and adults with I/DD need greater attention to socialization and opportunities to build relationships.

RECOMMENDATION: Include funding in the California state budget for well-managed socialization programs that give young adults with I/DD opportunities to meet people, build relationships, and participate socially.

HS-47. Independent Living Services and Supported Living Services Quality Assurance – Self-Advocate

ISSUE: There are disparities in the quality of services and supports that clients receive through Independent Living Services and Supported Living Services. Disrespect and lack of accountability can undermine trust between people receiving services and the staff who support them, making people less comfortable communicating problems.

RECOMMENDATION: Require Independent Living Services and Supported Living Services agencies and companies to hire only staff members who have a certificate or degree related to the work they perform. Having appropriately trained and qualified staff would build a stronger foundation of trust and accountability and could make clients more comfortable communicating concerns with staff who understand their needs.

HS-48. Lanterman Act Information, Referral, and No Wrong Door Access – Professional

ISSUE: People who may qualify for regional center services can spend years interacting with publicly funded systems without ever being told about the Lanterman Act or how to request regional center intake. This can occur in schools, healthcare systems, county programs, foster care, homeless services, correctional and reentry systems, senior services, and other

public programs. People and families with less access to information, language assistance, advocacy, or other resources may be particularly likely to miss services because no public agency is responsible for making sure they know those services exist.

RECOMMENDATION: Establish a statewide “No Wrong Door” requirement so publicly funded systems provide plain-language, accessible, and multilingual information about the Lanterman Act and regional center services when a person may qualify. Agencies should document that the information was provided, give the person the correct regional center contact information, explain how to request intake and appeal a denial, and provide referral assistance or a warm handoff when requested.

DDS should develop statewide materials, training, documentation standards, and referral procedures; require public posting of regional center information; and track whether people are being reached across communities and systems. The law should establish oversight and accountability when agencies repeatedly fail to provide required information or referral assistance, while ensuring that enforcement does not reduce services or supports available to people with I/DD.

HEALTH

HLTH-01. Mobility Chairs and Insurance Barriers – Self-Advocate/Professional

ISSUE: Mobility chairs may be covered by insurance only for use inside the home. Many people at SCDD Regional Advisory Committee meetings have expressed frustration with this limitation. How can we be mobile only inside our homes but not outside them? People can still be excluded from public life if they cannot use the equipment they need in the community.

RECOMMENDATION: Remove the in-home-use-only limitation from insurance coverage for mobility chairs so people can use covered mobility equipment both inside and outside their homes.

HLTH-02. GLP-1 Medications Should Be Covered by Medi-Cal for People with I/DD – Professional

ISSUE: GLP-1 receptor agonists such as Wegovy and Zepbound offer therapeutic value for some people with I/DD and autism spectrum disorder (ASD), who experience higher rates of metabolic complications, heart disease, and obesity. Some people with I/DD and Autism Spectrum Disorder (ASD) are prescribed atypical antipsychotic medications such as risperidone or aripiprazole, which can cause rapid weight gain and metabolic problems. People with ASD may also experience sensory aversions to healthy foods, limited physical mobility, metabolic vulnerabilities, “food noise,” or compulsive behaviors that make weight management more difficult. Excluding obesity treatments from Medi-Cal coverage creates systemic health inequities for low-income Californians with disabilities.

RECOMMENDATION: Reverse the trailer bill language excluding GLP-1 medications such as Wegovy, Zepbound, and Ozempic from Medi-Cal coverage beginning January 1, 2026, and restore coverage for adults age 21 and older. Ideally, these medications should be covered for all Medi-Cal beneficiaries when medically appropriate. If broader coverage is not restored because of budget constraints, Medi-Cal should at minimum cover GLP-1 medications for people with I/DD and ASD who are at increased risk of heart disease, diabetes, high cholesterol, metabolic complications, or

excessive weight gain associated with antipsychotic medications. Cutting coverage may save money in the short term but result in greater long-term costs from preventable chronic disease.

HLTH-03. Health Insurance Options Past Age 26 – Family Advocate

ISSUE: People with disabilities and their families need clearer information about their rights and options when dependent health insurance coverage changes after age 26, including when continued group coverage may be available following medical review. Sudden changes can disrupt an entire medical plan of care, including scheduled appointments, durable medical equipment (DME), assessments, established specialists, and relationships with providers who know the person's needs.

RECOMMENDATION: Require timely notice and clear information before health insurance coverage changes for a dependent with a disability after age 26. The person with a disability should have a voice in choosing among available options and enough time to consider continued coverage, COBRA, new insurance plans, and changes to doctors or specialists without unnecessary interruption of medical care.

HLTH-04. Expand Disability Eligibility Criteria for Continued Health Coverage – Family Advocate

ISSUE: Health insurance is extremely unaffordable. Our son can work part time but cannot manage a full-time position, and the amount he earns would go almost entirely toward health insurance. He is already unable to support himself on part-time income.

RECOMMENDATION: Expand disability eligibility criteria for adult children who cannot obtain or sustain full-time employment or other employment that provides health benefits but are able to work part time. Documented disabilities from medical providers, regional centers, schools, or similar sources should be considered when determining continued eligibility. These individuals may still be chiefly dependent on the primary subscriber for support and maintenance and should be able to remain on the family health plan when appropriate.

HLTH-05. Require Insurance Companies to Provide Occupational Therapy Coverage – Professional

ISSUE: Occupational Therapy coverage is highly inconsistent and often inadequate. Insurance reimbursement rates can be so low that Occupational Therapy providers in the Bay Area cannot sustainably remain in network and instead operate out of network, reducing access for children with autism and other neurodevelopmental disabilities.

RECOMMENDATION: Require insurance companies to provide adequate Occupational Therapy coverage that meaningfully meets the needs of children with autism and other neurodevelopmental disabilities.

HLTH-06. Creation and Expansion of Specialized Child Development and Rehabilitation Centers – Family Advocate (Translated from Spanish)

ISSUE: I am not aware of any law that guarantees that all children with developmental disabilities can attend a comprehensive rehabilitation center regardless of the type of health insurance they have. Families rely on different insurance plans and programs, and access to therapy can vary depending on insurance coverage, waiting lists, or where they live. This can create inequality among children who need the same types of support.

RECOMMENDATION: Invest more resources in creating and expanding specialized child development and rehabilitation centers that provide frequent and accessible therapy services for children with developmental disabilities. Expanding these centers could reduce long waiting lists, help families receive earlier support, improve children's development, and strengthen the well-being of families.

HLTH-07. Delayed Access to Early Intervention and Developmental Evaluations – Family Advocate

ISSUE: Many children with developmental disabilities wait too long for neurological evaluations, diagnoses, therapies, and intervention services. Delayed access can cause children to miss critical developmental windows, worsen delays, and increase safety risks for children with motor, neurological, or communication impairments. Earlier evaluations and intervention would help children receive medical care, therapies,

educational support, and safety services sooner while reducing stress on families.

RECOMMENDATION: Provide children with developmental disabilities and neurological red flags faster access to pediatric neurology and developmental evaluations in California. High-risk children should not be forced to wait months for referrals and testing during critical developmental years. Earlier identification and intervention should be prioritized, including for children with autism who experience early regression.

HLTH-08. Plain Language Documents at Hospitals – Self-Advocate

ISSUE: People with mental health conditions or developmental disabilities can feel afraid or confused when they are asked to sign lengthy documents they do not fully understand during admission to or discharge from a hospital or institution. People should not be placed at a disadvantage or taken advantage of when they are ill, confused, or otherwise vulnerable.

RECOMMENDATION: Require hospitals and institutions to provide admission and discharge documents in plain language so people can understand what they are being asked to sign and make informed decisions about their care and rights.

HLTH-09. Require Physicians to Complete I/DD Competency and Bias Training – Family Advocate

ISSUE: California has one of the largest populations of people with I/DD in the United States, yet physicians receive almost no required training in how to care for them. More than 400,000 Californians receive I/DD services, and adults with I/DD are living longer than ever, but the medical workforce has not kept pace. Many physicians complete residency without learning how to examine, communicate with, or treat adults with I/DD. This mismatch creates predictable and preventable harm.

RECOMMENDATION: Establish statewide competency requirements for physicians who treat patients with I/DD. California already requires continuing medical education (CME) addressing areas such as cultural and linguistic competency and implicit bias, but does not require I/DD-specific competencies. Physician education should include the skills needed to communicate with, examine, and provide appropriate healthcare to people

with I/DD rather than relying only on individual residency or fellowship programs that choose to provide this training.

HLTH-10. Dental Care Gap Is a Public Health Crisis – Family Advocate

ISSUE: My husband and I have a 44-year-old daughter with Ataxic Cerebral Palsy and multiple disabilities who lives at home with us. She is nonverbal, has significant support needs, cannot be left alone, and needs help with feeding, dressing, toileting, and hygiene. Because of her disabilities, regular dentists would not treat her. After our family dentist referred us to Highland Hospital Dental Clinic for the Disabled in Oakland, it took two years to get through the process and finally receive dental surgery on April 23, 2026. While we waited, one of her molars fell out, creating a choking risk. Highland ultimately pulled six additional loose teeth because of bone loss, filled three cavities, and performed a deep cleaning. The bill was \$35,000.

Highland did a great job, but no follow-up is required now that her dental care is up to date. If another problem develops, we may have to go through the same process and lengthy wait again. Highland is one of very few facilities equipped to provide this type of dental care, meaning people with significant disabilities may wait years while experiencing pain, infections, tooth loss, or choking risks and may have to travel long distances for treatment. We are fortunate to live only 4.5 miles from Highland. People who need special accommodations should not have to wait up to two years or travel great distances to receive basic dental care.

RECOMMENDATION: Expand access to timely, affordable dental care for people with disabilities who need specialized accommodations by increasing the number and capacity of dental providers and facilities able to serve them. People should have a clear and timely pathway to treatment without having to repeatedly navigate lengthy administrative barriers while dental problems become more serious.

Specialized dental care should also include an ongoing path for follow-up and future treatment so people do not have to start the entire process over each time a new dental problem develops. Faster access to appropriate dental treatment would reduce pain, infections, tooth loss, choking risks, and other health complications associated with untreated dental problems.

HLTH-11. Don't Cut Medi-Cal Benefits – Self-Advocate

ISSUE: People should have a fair chance to live their best life without having to worry about whether they can go to the doctor or get the care they need. Access to healthcare is necessary for people to live in the community and have the same opportunities as everyone else.

RECOMMENDATION: Stop cutting Medi-Cal benefits. People need Medi-Cal to live in the community and should not have to keep jumping through hoops to get their basic healthcare needs met. If the Lanterman Act says we are entitled to have a life like everyone else, then the system should act like it.

HLTH-12. Remove Annual Health Insurance Reassessment Requirement for Permanent Disabilities – Family Advocate

ISSUE: Families are repeatedly required to complete disability paperwork for conditions that are lifelong and have no cure. This takes time from doctors and parents simply to keep children with permanent disabilities on an employer-sponsored health insurance policy. Having to repeatedly state that nothing has changed is stressful and heartbreaking. One time should be enough when the disability has already been established as permanent.

RECOMMENDATION: When a doctor certifies that a disability is lifelong or an illness is incurable, an employer-sponsored health plan should not be allowed to require the same disability certification every year. If the person changes to a different health plan, the new carrier should be allowed to request certification only once. Ideally, the certification should be maintained by the employer and shared through Human Resources when the employee selects a different health plan so the family does not have to repeatedly ask the doctor to complete the same form.

HLTH-13. Medi-Cal Renewal Each Year for Permanent Disabilities Is a Burden – Family Advocate

ISSUE: My son has a lifelong disability, significant cerebral palsy, and has access to Medi-Cal without family income being counted. Even so, I am required to complete a quarter-inch-thick renewal packet every year. The renewal process is time-consuming, confusing, and frequent, and it creates

a risk of gaps in healthcare coverage even though his disability is permanent.

RECOMMENDATION: Allow people with lifelong disabilities who are not subject to income requirements to maintain Medi-Cal eligibility for life or for an extended period such as 10 years. If an annual renewal is still required, provide a simple one-page form allowing the person or family to indicate that nothing has changed since the last renewal, sign it, and continue coverage.

HLTH-14. Remove Annual Recertification for Medicaid Eligibility
– Family Advocate

ISSUE: Having a disability is difficult, expensive, and requires a great deal of paperwork. Even with advocates and wraparound services such as Enhanced Care Management, people should not have to constantly prove a disability that is not going to go away. Annual recertification creates burdens for people with disabilities and the family members supporting them and puts people, especially those with I/DD, at risk of losing benefits or experiencing gaps in coverage. It also creates unnecessary paperwork and workload for government staff.

RECOMMENDATION: Remove the annual Medicaid eligibility recertification requirement for people with I/DD or require recertification only once every five years.

MENTAL HEALTH

MH-01. Rescind ECT Treatment Regulations – Family Advocate

ISSUE: California has highly restrictive requirements governing electroconvulsive therapy (ECT), with additional restrictions for people with I/DD. As a result, people with I/DD may have to travel outside California to receive treatment, creating significant cost, delay, and inconvenience for people and families seeking medical care. Regional center clients are subject to requirements that people who are not regional center clients do not face and are not subject to this oppressive, expensive and time-consuming regulation.

RECOMMENDATION: Rescind the additional ECT regulation that applies to people with developmental disabilities. Patients with developmental disabilities should have equal access to treatment and should not have to go through wholly unnecessary hurdles solely because they receive regional center services.

MH-02. Incentives to Recruit Quality Behavioral Health Professionals for I/DD – Professional

ISSUE: California faces a significant shortage of behavioral health professionals trained to work with people who have both I/DD and mental health conditions. People experience long waitlists or cannot find qualified providers, behavioral health needs may go untreated until they become crises, and families struggle to locate appropriate services. Emergency departments, law enforcement, and psychiatric hospitals can become the default response to preventable behavioral health crises. Existing providers may also lack specialized training in communication differences, trauma-informed care, positive behavioral supports, and diagnostic considerations for people with I/DD.

RECOMMENDATION: Establish a workforce development program with financial and educational incentives to recruit, train, and retain behavioral health professionals specializing in people with I/DD and co-occurring mental health conditions. Strategies could include student loan repayment or forgiveness, graduate and postgraduate stipends, paid internships and clinical fellowships, university partnerships creating I/DD behavioral health

specialty tracks, continuing education and certification programs, incentives for providers serving rural and underserved communities, and funding for culturally and linguistically responsive training. The goal should be a sustainable pipeline of clinicians with expertise in dual diagnosis.

MH-03. Services and Supports for Chemical Dependency and Sexual Issues – Professional

ISSUE: Regional center clients with substance use disorders or inappropriate sexual behavior can become involved in the criminal justice system without the underlying behavioral health issue being adequately addressed. Substance use may be connected to the behavior that resulted in arrest, while unaddressed sexual behavior can lead to criminal charges, incarceration, or state hospitalization. When these needs are not identified and treated early, people may spend years in inappropriate settings without receiving adequate treatment.

RECOMMENDATION: Require funding for substance use treatment and services addressing inappropriate sexual behavior for regional center clients involved in or at risk of involvement with the criminal justice system. Substance use treatment, including inpatient treatment when appropriate, should be available before a criminal matter is resolved so the relationship between the person's substance use and the alleged conduct can be considered. Services addressing inappropriate sexual behavior should also be available early enough to prevent escalation and reduce the likelihood of incarceration or hospitalization.

MH-04. Crisis Receiving Centers for People with I/DD and Co-Occurring Behavioral Health Needs – Professional

ISSUE: When a person with I/DD experiences a behavioral health crisis, the available response may be hospitalization in a mental health facility, an emergency room, or law enforcement. These settings and responders are often not equipped to address the person's communication, sensory, behavioral, and disability-specific support needs, which can prevent the person from receiving appropriate crisis services.

RECOMMENDATION: Require the Department of Developmental Services (DDS) and county behavioral health departments to jointly develop and expand specialized crisis receiving centers for people with I/DD

experiencing behavioral health emergencies. The state should provide dedicated funding for planning, staffing, training, and ongoing operation of these centers throughout California.

MH-05. Mobile Crisis Team – Family Advocate

ISSUE: I called 911 during a mental health crisis involving my adult daughter, who has a cognitive impairment and learning disability. Although I told officers she was having a mental breakdown, I was not offered the option of a “5150” psychiatric hold. She was taken to county jail, remained there for 30 days, received a suspended sentence, and now has a criminal record. The court later ordered her into a group home for two years. The group home cost approximately \$4,747 per month, including about \$855 from her SSI and \$3,892 from the regional center. I believe that if her crisis had resulted in appropriate psychiatric intervention rather than jail, it could have prevented the criminal justice consequences and avoided substantial public expense. Had she been placed for the 72-hour hold, that would have saved the regional center and the taxpayers \$47,559/year and for the two years a total of \$94,263!

RECOMMENDATION: When someone calls 911 about a person experiencing a serious behavioral or mental health crisis, responders should determine whether the person has a cognitive, learning, or other disability that may be contributing to the crisis. When appropriate under the law, the person should be connected with a mobile crisis or behavioral health response and evaluated for a 72-hour psychiatric hold rather than being automatically taken to jail. The person who called 911 should be asked for relevant information about the individual’s disability and crisis needs so responders can make an informed decision.

MH-06. Behavioral Health Not Accessible – Family Advocate

ISSUE: My son needs care from the Stanford Neurodevelopmental Psychiatric Clinic, where providers have expertise with more complex patients. We have been unable to find a psychiatrist in Alameda County with the expertise he needs. Alameda County Behavioral Health will only refer him to psychiatrists on its provider list within the county and has refused to refer him outside the county. People with I/DD and mental health conditions should be able to receive appropriate specialized care when the needed expertise is not available locally. Currently, each county is

responsible for mental health care of Medi-Cal patients with mental health conditions, many of whom also have ID/D. If there is no appropriate care within the county, Medi-Cal does not require them to refer to an appropriate provider outside of their county. This violates the mental health parity law for health care!

RECOMMENDATION: Allow county behavioral health systems to refer people outside the county when the county does not have a provider capable of delivering the specialized behavioral health services the person needs.

HOUSING

HOU-01. Affordable Housing – Family Advocate (Translated from Spanish)

ISSUE: Stable, affordable housing for adults with developmental disabilities continues to be one of the most significant barriers to achieving independence and long-term stability. Programs such as the Section 8 Housing Choice Voucher Program, subsidized housing, and other public housing assistance programs often have years-long waiting lists and limited application periods, making timely access to housing difficult.

RECOMMENDATION: Create a Housing Equity and Priority Access Program to ensure meaningful and equitable housing opportunities for adults with developmental disabilities. The program should establish priority status for people with developmental disabilities in public and subsidized housing programs, including Section 8 Housing Choice Vouchers and other affordable housing waiting lists; actively monitor waiting-list openings and help people and families apply; and ensure that living with family members is not treated as evidence that a person does not have a legitimate need for housing supports or resources.

The program should also establish clear guidelines defining the extent of parental responsibility once a person with a developmental disability reaches adulthood, recognizing that family members should not be considered a permanent substitute for the formal support system. Long-term housing planning should begin in early adulthood, and housing transition assistance should be available for security deposits, accessibility modifications, essential furnishings, and other initial moving and transition expenses.

HOU-02. Affordable Housing Specific to I/DD – Professional

ISSUE: Supported Living Services (SLS) is supposed to allow adults with I/DD to live in their own home or apartment in the community, with individualized supports funded by the regional center and rent paid from the person's own income, typically Supplemental Security Income/State Supplementary Payment (SSI/SSP). In California today, that structure has broken down. Average SSI/SSP income available for all living expenses,

including rent, is approximately \$1,183 per month, while HUD Fair Market Rent for a one-bedroom unit in major California counties is \$2,300 to \$3,000. Federal Housing Choice Vouchers cannot close this gap: more than 180,000 California households are on HUD waiting lists, some major jurisdictions have closed their waiting lists, and other housing authorities face funding shortages that threaten existing assistance. These are not temporary disruptions. They reflect a structural shortage that leaves extremely low-income households without practical access to rental assistance.

For adults with I/DD, this creates a largely invisible housing failure because regional centers, family homes, and group placements often absorb the crisis before a person becomes unhoused. Without a dedicated and reliable operating subsidy, Supported Living arrangements remain financially viable mainly for families who can purchase housing or privately subsidize rent, disproportionately excluding lower-income families and families of color. California has promoted social inclusion for more than 25 years, but DDS, regional centers, and local housing authorities continue to operate in separate systems that rarely connect developmental services with mainstream affordable housing. Even when affordable housing is built, extremely low-income households often cannot afford the rent without deep, ongoing rental assistance.

RECOMMENDATION: Establish State-Funded Common Use Housing Vouchers (CUV), a California-controlled, tenant-based rental subsidy administered through the California Housing and Homelessness Agency (CHHA) that complements rather than replaces federal Housing Choice Vouchers. The CUV should be a single cross-system program serving extremely low-income households across aging, I/DD, behavioral health, and homelessness systems rather than an I/DD-only benefit. It should use income-based tenant contributions and local payment standards, be insulated from federal voucher waitlist closures and funding volatility, and enable extremely low-income households to afford newly built and existing affordable housing. New York's state-funded Housing Access Voucher Program provides a model for a cross-population structure, while San Diego's Navajo Family Apartments demonstrates that a voucher can close the affordability gap for people with I/DD within a mainstream affordable housing development.

The program should target the more than 480,000 extremely low-income renter households in California that cannot access the private market without deep rental assistance and phase implementation toward approximately 500,000 households by the late 2030s. Each recipient should receive an Individual & Family Independence Plan (IFIP) addressing voucher terms, support configuration, renewal expectations, and community participation so housing and service systems do not operate in parallel. CHHA should maintain a statewide accountability and equity dashboard tracking voucher utilization, tenancy retention, and disparities by age, disability, race and ethnicity, and geography. The program should help ensure that extremely low-income households can actually occupy housing created through Low-Income Housing Tax Credits, bonds, Homekey, and other affordable-housing investments by closing the gap between what those units charge and what households can afford.

HOU-03. Shift from Reactive to Proactive Model to Prevent Homelessness for People with I/DD – Professional

ISSUE: Current housing programs can require people to experience homelessness or reach a severe housing crisis before they qualify for assistance. For people with significant disabilities and aging caregivers, waiting until homelessness occurs creates unnecessary trauma, instability, and greater costs. The target population should include people who are at imminent risk of homelessness so vulnerable aging adults and people with disabilities can receive assistance before their housing situation collapses.

RECOMMENDATION: Expand the “Target Population” under Chapter 6.7 of the Multifamily Housing Program to include people who are “At Imminent Risk of Homelessness.” This would shift the program from a purely reactive model, which requires systemic failure and trauma before intervention, to a proactive and preventative model. For a person with a severe disability, preventing homelessness is significantly more cost-effective, medically stable, and humane than trying to resolve homelessness after it occurs.

HOU-04. Housing Discrimination – Family Advocate

ISSUE: My family experienced disability housing discrimination even though we were not doing anything wrong. The landlord had no basis for the discrimination other than the fact that he did not like people with disabilities. When a civil rights complaint is filed, complainants should be

able to know whether the complaint was actually investigated and what evidence was reviewed.

RECOMMENDATION: Require greater oversight and transparency in investigations of housing discrimination complaints. Investigators should document that an investigation occurred and provide complainants with information about what was reviewed and how the decision was reached. When I ask what was done during the investigation, I have a right to know. I have a right to know whether they actually looked at the video and why the video was not enough proof.

HOU-05. Training for Landlords and Property Management – Family Advocate

ISSUE: My son is five years old, has severe autism, and cannot speak. He has been discriminated against by property management companies and landlords countless times since his diagnosis at age two. Families may need landlords and property managers to safely accommodate routine home maintenance when a person is at risk of elopement, receives medical or therapeutic services in the home, or has other disability-related needs.

RECOMMENDATION: Require landlords and property management staff to receive training about common disability-related needs and how to safely provide accommodations without discriminating against or putting tenants at risk. Training should address elopement, self-injurious behavior, situations where two or more people may need to be present to protect the tenant or others, scheduling maintenance around in-home therapy, timely repair of hazards for people with PICA or other health risks, dangers such as black mold, and respectful communication with family members. Training must be provided in a language staff understand, with interpretation available when necessary.

HOU-06. More Affordable Housing – Professional

ISSUE: Many people have been on Section 8 waiting lists for 15 years or more. People with disabilities and low-income households need more housing options, including opportunities for affordable rental housing, homeownership, and economic independence.

RECOMMENDATION: Provide housing grants, rental assistance, and assistance with starting microbusinesses so people have more options for stable housing and opportunities to increase their economic independence.

HOU-07. Limited Affordable Housing – Family Advocate

ISSUE: We need to take housing seriously. After the Eaton Fire, it was a challenge to find housing because my daughter uses a wheelchair. Housing is one of the most important needs as people transition into adulthood, and accessible housing is itself a health and safety issue.

RECOMMENDATION: At age 14, all regional center clients should be screened for Section 8 housing so planning can begin before they transition into adulthood. Housing should be treated as a central part of transition planning because, after health and safety, it is one of the most important needs, and housing itself is a health and safety matter.

HOU-08. Give Priority to People with Disabilities for Section 8 – Family Advocate

ISSUE: Section 8 housing should be more accessible for people with disabilities and regional center clients. Many people with disabilities cannot work, their financial situation will not change, and they may continue to need affordable housing.

RECOMMENDATION: Give people with disabilities priority access to Section 8 housing. They should have a shortcut through the waiting process and be put at the front of the line when their disability and financial circumstances establish an ongoing need for affordable housing.

HOU-09. Exempt Heirs with Permanent and Substantial Disabilities from Property Taxes – Family Advocate

ISSUE: People with permanent and substantial disabilities often have little income beyond SSI or SSDI and could be displaced from the only home they know if property taxes exceed their income after their parents die. If an adult child with a disability cannot afford the property taxes and must leave the family home, California may instead face the substantial cost of finding and supporting other housing in a market where housing is already scarce and expensive.

RECOMMENDATION: Exempt heirs with permanent and substantial disabilities, as recognized by the Social Security Administration (SSA), a California regional center, or another state agency, from full property tax assessment when they inherit and continue living in the family home after their parents die. The additional tax assessment could instead be suspended and collected in arrears when the person dies or moves to other housing.

HOU-10. Change Criteria for Affordable Housing – Self-Advocate

ISSUE: Affordable housing would help people with disabilities live healthier and happier lives because they would have a stable place to live and enough money left for food, bills, and other needs. Having a safe home can also help people feel independent, confident, and like they belong in their community instead of constantly worrying about how they will make it through the month.

RECOMMENDATION: Change the criteria for affordable housing so more people with disabilities can qualify and afford to live independently. People should not have to choose between housing, healthy food, medication, and other basic needs.

HOU-11. More Inclusive Housing – Self-Advocate

ISSUE: We need to respect every person and the diversity that makes each of us different.

RECOMMENDATION: I would like to build a group home for women like me in my neighborhood.

HOU-12. Aging Caregivers and Adult Children with I/DD Planning – Family Advocate

ISSUE: Adults with I/DD may face homelessness as their parents age and their health declines. Subsidized housing is already in short supply, and many adults with developmental disabilities are living with aging parents long after those parents are able to provide the same level of care. This is a housing and care crisis that no one is paying attention to, and these

residents will be the new homeless as baby boomer parents die without safe housing and future supports in place.

RECOMMENDATION: Give adults with I/DD whose parents are over age 70 the highest priority for HUD Section 8 Housing Choice Vouchers so they can obtain housing before their aging caregiver can no longer support them. Housing planning and access should occur before the family reaches a crisis.

HOU-13. People with I/DD Should Automatically Qualify for a Section 8 Voucher – Professional

ISSUE: People with regional center-qualifying I/DD should automatically have access to a Section 8 voucher when requested, along with SSI and Medi-Cal, once disability and income qualifications are established. Without reliable affordable housing, people with I/DD face threats of homelessness, families struggle to establish permanent housing for their adult children, and agencies providing 24-hour supports may have difficulty supporting people in their own homes. Greater housing access would reduce pressure on residential settings, increase neighborhood diversity, and improve quality of life.

RECOMMENDATION: Restructure the Section 8 qualification system so regional center clients who meet applicable income requirements automatically qualify for a voucher when requested. Eligibility should be non-negotiable and unconditional once the person's disability and financial qualifications are established.

PUBLIC SAFETY AND EMERGENCY PREPAREDNESS

PSEP-01. Safety and Access to Land Telephone Lines – Family Advocate

ISSUE: People with disabilities, people with medical needs, and older adults need access to a simple telephone line that does not depend on electrical power, battery power, or an internet connection. Plain old telephone service (POTS) copper landlines can continue working during power or internet outages, allowing people to reach family members and call 911. When a call is made from a traditional landline, 911 can also immediately identify the address, while alternatives may not provide the same reliability.

RECOMMENDATION: Prohibit the removal of POTS copper telephone landlines so people who need reliable emergency communication, including older adults and people with medical or intellectual disabilities, continue to have access to them.

PSEP-02. 911 No Wheelchair Left Behind – Professional

ISSUE: People who use specialized or motorized wheelchairs can become separated from their equipment when transported by ambulance. Wheelchairs can be heavy and difficult to secure in an ambulance, expensive to replace if lost or damaged, and essential to a person's mobility, healing, continuity of care, dignity, freedom, access, and independence.

RECOMMENDATION: Require or encourage Emergency Medical Services agencies to establish a "911 No Wheelchair Left Behind" process so people transported by ambulance are reunited with their wheelchairs at the hospital. When the wheelchair cannot travel in the ambulance, the patient or first responders should be able to request a wheelchair-accessible EMS vehicle to collect the equipment and deliver it to the same hospital. San Mateo County already uses this approach, developed with input from its Emergency Medical Care Committee and the Stanford Medicine Alliance for Disability Inclusion and Equity, and it can serve as a model for other counties.

PSEP-03. Battery Backup for Community Water Systems – Professional

ISSUE: The fire in Paradise, California, was much worse because the community water system did not have battery backup. When wildfire or another emergency interrupts electrical power, community water systems must still be able to keep water flowing to fire hydrants.

RECOMMENDATION: Require every community water system in California to install battery backup capable of keeping water flowing during a wildfire or power failure so firefighters continue to have the water they need to fight fires.

PSEP-04. Train Law Enforcement to Recognize Disability-Related Needs – Family Advocate

ISSUE: I am the mother of a son with autism, and sometimes he becomes overwhelmed and loses control when he gets upset. Young people with disabilities may not understand directions and may become more distressed when people yell at them, pressure them, or ask too many questions. I have seen cases where young people have died after not responding to police commands. On one occasion, a young man with special needs went into the street without clothes and did not respond when police called to him. I do not even want to say what happened because it is too painful. This worries me very much.

RECOMMENDATION: Create a bracelet, necklace, or other visible identifier that law enforcement and other people would recognize as indicating that a person has a disability or special support need. The identifier should help police understand that the person may communicate or respond differently so they can interact appropriately and avoid unnecessary use of force.

PSEP-05. Regional Center Contact When a Person Is Taken Into Custody or Placed on a Hold – Family Advocate

ISSUE: When a person with a developmental disability is taken into custody or placed on a psychiatric hold, responders may not know that the person is a regional center client or have the background information needed to understand the person and locate appropriate services.

RECOMMENDATION: Require the regional center to be contacted when a person with developmental disabilities is taken into custody or placed on any type of hold so the person can be identified as a regional center client, relevant background information can be provided, and needed services can be located.

PSEP-06. Background Check Consistency Across All Regional Centers – Professional

ISSUE: Different fingerprinting and background-check requirements across regional centers and programs create confusion for companies, vendors, self-advocates, and workers. Inconsistent rules can interrupt continuity of services, make it difficult for providers to know how staff should be fingerprinted, and allow people to “work the system” by changing counties. Individuals and families should know that people providing support have gone through a clear and consistent vetting process.

RECOMMENDATION: Establish one uniform statewide fingerprinting and background-check process for everyone providing support to people with I/DD through DDS-funded services, including regional centers and the Self-Determination Program (SDP). Requirements should be the same across regional centers and programs, clearly communicated in advance, and should apply to all SDP providers rather than only those providing personal care. Vendors and self-advocates should not have to determine different requirements from agency to agency or depend on each agency obtaining its own Originating Agency Identifier (ORI) number.

PSEP-07. Cameras to Protect Nonverbal Residents – Family Advocate

ISSUE: Residents who cannot communicate may be particularly vulnerable to abuse and mistreatment and may not be able to report what happened to them.

RECOMMENDATION: Require a camera monitoring system whenever a nonverbal resident lives in a residential home and require a minimum of two staff members to be present.

PSEP-08. Use of Cameras to Monitor Safety – Family Advocate

ISSUE: More must be done to stop hidden abuse of people with developmental and physical disabilities in care homes, nursing homes, and family homes receiving public funding for their care. I wrote a book called *Untangle* describing abuse and received recognition from the California State Legislature for rescuing my brother with developmental disabilities from abuse.

RECOMMENDATION: Require cameras in care homes, nursing homes, and family homes that receive funding to provide care, with security video monitored only by designated auditors. I do not want to hear that “privacy” is more important than the safety of people who are vulnerable to hidden abuse.

PSEP-09. Timely Licensing Investigations and Corrective Action – Family Advocate

ISSUE: Licensing investigations of serious injuries and deaths can take too long or fail to fully address what happened. In one case involving a burn that required hospitalization, the timeframe for addressing the abuse was two years. In another case involving a death report, a death certificate was requested but the follow-up was never completed.

RECOMMENDATION: Require serious injury investigations to be completed within no more than two months and require a Plan of Action explaining how the facility will prevent the same type of injury from happening again. For example, after a burn on hot asphalt, the corrective plan could require staff to lift the person or place a blanket or mat underneath the person until they can be fully moved.

PSEP-10. Shatterproof Glass – Self-Advocate

ISSUE: Broken glass can cut the hands of people using manual wheelchairs when it becomes caught in their wheels, puncture mobility-device tires, and cut the feet of people who have low vision or are legally blind.

RECOMMENDATION: Require alcohol bottles, including liquor, wine, and beer bottles, to be made from shatterproof glass like the glass used in modern windows.

**PSEP-11. Residential Care: Require Two Staff Members for Safety
– Professional**

ISSUE: Many individuals in licensed residential care have only one staff member on shift at least once each day, frequently at night. This can leave people vulnerable to abuse they may be unable or afraid to report. When only one staff member is present overnight, staff may also fall asleep, and I have been told of situations where individuals had not received needed repositioning to prevent pressure injuries, medication, incontinence care, or other supports. A single staff member may also have difficulty safely completing transfers, position changes, hygiene, and other physically demanding tasks.

RECOMMENDATION: Require at least two staff members on every shift in licensed residential care. A second direct support professional would increase accountability, help protect clients from abuse or unmet needs, assist with physically demanding care, reduce injury risks for both staff and clients, and protect staff from false accusations or aggression by clients.

PSEP-12. Voluntary Emergency Registry – Family Advocate

ISSUE: Families of people with I/DD often worry about wandering, elopement, communication barriers, and emergencies. If someone becomes lost, separated from a caregiver, or experiences a crisis, first responders may have little information about how to communicate effectively or provide appropriate support. A voluntary registry could help responders act more quickly and safely, reduce misunderstandings, improve communication, reunite families faster, and prevent injuries or traumatic interactions.

RECOMMENDATION: Create a secure, voluntary statewide registry where people with I/DD, or their caregivers when appropriate, can provide information that may assist emergency responders. Information could include communication preferences, sensory sensitivities, medical needs, emergency contacts, known triggers, calming techniques, and recent

photographs. Access should be limited to authorized first responders and emergency personnel responding to an emergency.

PSEP-13. Communication Training for Law Enforcement and First Responders – Family Advocate

ISSUE: People with autism and developmental disabilities may communicate, behave, or respond differently during emergencies. Without proper training, first responders can misinterpret disability-related behavior as noncompliance, aggression, or suspicious activity. This can lead to unnecessary escalation, trauma, injury, or poor outcomes and can undermine trust between first responders and the disability community.

RECOMMENDATION: Require all first responders in California to receive initial and ongoing training on autism and I/DD. Training should include communication techniques, sensory sensitivities, de-escalation strategies, recognition of disability-related behaviors, wandering and elopement awareness, and best practices for interacting with people who are minimally verbal or nonverbal.

PSEP-14. Prohibit Use of Cage Cribs in Pediatric Subacute Nursing Homes – Family Advocate

ISSUE: I think disabled children should not have to live in cages. Putting children in cages is objectively very bad and I should not have to argue that it is bad. Children in pediatric subacute facilities who are restrained in totally enclosed cribs can spend 16 or more hours a day in them. Children learn to crawl and walk by moving freely, and children who spend most of their lives confined in these cribs cannot move freely and are extremely delayed in developing gross motor skills. Facilities argue that enclosed cribs are necessary because children with tracheostomies, ventilators, or medical tubes may pull on their equipment, but grabbing and pulling are normal developmental behaviors for toddlers and young children.

Spending hours in a totally enclosed crib does not prevent a child from pulling out a tracheostomy tube. On the contrary, it encourages children to pull out the tube because doing so causes staff to enter the room and interact with them. Pediatric nursing homes should keep floors clean rather than restraining children because they might fall or touch the floor. Adults in

nursing homes have a right to fall. We cannot restrain adults simply because they might fall, so why are we restraining children?

RECOMMENDATION: Explicitly prohibit totally enclosed cribs and barred enclosures in pediatric subacute nursing homes. These terms should include the various enclosed crib designs used for toddlers who are old enough to climb out when not directly supervised. The same types of cribs are already prohibited in licensed childcare settings and Intermediate Care Facilities (ICFs), yet they are commonly used in hospitals and pediatric subacute nursing homes.

PSEP-15. Nationwide Alert for People with Disabilities – Family Advocate

ISSUE: We have Megan’s Law, Silver Alerts, and other alert systems, but what about autistic children and adults with disabilities who go missing and may be at risk of drowning or other danger? Why is there not a nationwide alert for our children and adult children with disabilities?

RECOMMENDATION: Create a nationwide alert similar to a Silver Alert when a child or adult with a disability is reported missing or in danger so more can be done immediately to locate the person.

PSEP-16. Mandatory Training for Law Enforcement – Family Advocate (Translated from Spanish)

ISSUE: Although protocols such as Stop and Identify exist, law enforcement officers are not required to complete this training.

RECOMMENDATION: Require mandatory training for police officers, firefighters, and other public servants who interact with members of the public.

PSEP-17. Reduce Road Rage – Self-Advocate

ISSUE: Road rage and aggressive driving can cause accidents. I have seen drivers aggressively cut people off, which in turn caused other drivers to tailgate to avoid being cut off and made otherwise more passive drivers become aggressive.

RECOMMENDATION: Require drivers to use turn signals when changing lanes or making turns as a way to reduce aggressive driving, road rage, and accidents.

PSEP-18. Protect People from Sexual Abuse – Anonymous

ISSUE: Sexual abuse occurs in residential homes and this must be fought.

RECOMMENDATION: Require two staff members to be in the room whenever personal care is being provided to a person with I/DD. Staff should also document each time they enter a person's room through a log or report.

TRANSPORTATION

TR-01. Lack of Parking Spaces for Accessible Vehicles – Family Advocate

ISSUE: The number of active disabled parking placards has increased substantially over the past decade. From 2013 to 2016, the DMV issued approximately 1.1 million placards, while in 2023 it issued 2.3 million and has averaged between 2.3 and 2.5 million placards per year since. Vehicles that are not modified for wheelchair access often park in van-accessible spaces even when standard accessible spaces are available, leaving vehicles equipped with wheelchair ramps with nowhere to park.

RECOMMENDATION: Designate a percentage of van-accessible parking spaces specifically for vehicles used by people who rely exclusively on wheelchairs for mobility. These spaces would be identified by a yellow strip added to the van-accessible parking sign, and the DMV would issue a corresponding yellow endorsement sticker to qualifying placard holders. Other placard holders would not be permitted to park in the yellow-designated van-accessible spaces.

TR-02. Accessible Parking Near Businesses – Self-Advocate

ISSUE: There needs to be accessible parking within 30 yards of accessible storefronts or rear entrances. Cities such as Ventura closed several blocks of the downtown Main Street shopping area to vehicles to create outdoor dining during COVID, and the City has not reopened those blocks or provided accessible parking close enough to the businesses. Some people who are able to walk want those blocks off Main Street to remain closed.

RECOMMENDATION: Require accessible parking to be available within 30 yards of accessible storefronts or rear entrances so people with disabilities can reach businesses when streets are closed to vehicle traffic or parking is otherwise removed.

TR-03. Accessibility at Bus Stops – Professional

ISSUE: California law states that people may not park in designated bus zones, but the curb must be painted red or white to indicate that it is a

designated bus zone. In my Zip code, none of the curbs are painted to indicate bus zones, including areas directly in front of bus stops, so cars are routinely parked there. This creates significant accessibility and safety problems. Public buses often have to stop in the middle of the street and deploy their ramps into the roadway, requiring us to help students using wheelchairs or with other mobility needs leave the sidewalk and enter the street to board the bus.

RECOMMENDATION: Require all public bus stops to be clearly designated as bus zones and paint the curb red so vehicles cannot park in the area needed for buses to safely pull to the curb. This would allow riders using wheelchairs and other mobility devices to board from the sidewalk instead of entering the street to reach the bus ramp.

TR-04. More Bus Routes Needed for Public Transportation
– Self-Advocate

ISSUE: I live in Fairfield, California. I use FAST Connect ADA paratransit on Saturdays when I go to the mall, and I use Route 3 to travel from the mall toward Fairfield Walmart and Carl's Jr. The closest Route 3 stop to my home is at Heath Drive and Breton Drive, and the walk from my house to that stop takes about an hour. This is wrong for people in my area who need Route 3.

RECOMMENDATION: Bring Route 3 back to the Safeway on Waterman Boulevard. People who live in this area need Route 3 to get to doctors' and dentists' appointments, work, the mall, Raley's, Fairfield Walmart, and the Transportation Center, where they can connect to Route 7 to attend Solano Community College. Transit staff should meet and work with the City Council on the budget and other issues needed to restore this route.

TR-05. Not Enough Rideshare Options and Transportation
Accessibility – Self-Advocate

ISSUE: People with disabilities in Sacramento, and throughout California, who depend on transportation services do not have enough rideshare options that meet their accessibility needs.

RECOMMENDATION: Require or expand transportation network company services that provide wheelchair- and mobility-aid-accessible vehicles and make those services available to all riders with disabilities.

TR-06. Access to Public Transportation in San Diego – Self-Advocate

ISSUE: I need access to public transportation in Scripps Ranch.

RECOMMENDATION: Add public transportation service to Scripps Ranch.

MISCELLANEOUS

MISC-01. Plain-Language Process to Receive Support Services – Family Advocate

ISSUE: Many people with I/DD are expected to navigate school, work, transportation, healthcare, community programs, and emergencies without tools that match how they process information. Families and support teams often have to figure out what to do during a crisis instead of having clear steps available ahead of time.

RECOMMENDATION: Require statewide plain-language readiness tools for people with I/DD across daily-life settings, including school, work, regional center services, transportation, and community programs. Tools should include emergency contacts, trusted pickup and release instructions, communication supports, job-site support needs, transportation safety steps, verification before releasing a person to an unfamiliar adult, caregiver backup plans, and simple “what to do next” instructions.

The plan should be reviewed and practiced regularly so it is not just paperwork. It should help the person with I/DD understand their rights, ask for help, participate in their own safety, and self-advocate.

MISC-02. Change the Name of the Lanterman Act – Professional

ISSUE: The name of the Lanterman Act should be changed to better reflect the people the law supports. The current name constantly reminds people of the racist and unsavory past of Frank Lanterman rather than reflecting the disability rights embodied in the law.

RECOMMENDATION: Rename the Lanterman Act so its name reflects the people who benefit from it and the spirit of the legislation. A new name would reflect real change in how California views disability rights and allow everyone to embrace the law under a name that represents the people it serves.

MISC-03. Use Public Awareness to Support Inclusion – Professional

ISSUE: There has never been an ongoing public effort to educate communities about including people with disabilities as part of the mainstream community. Greater awareness is needed so people understand that people with disabilities are members of their communities and should be included.

RECOMMENDATION: Create ongoing public-awareness efforts about people with disabilities and community inclusion, including brochures, billboards, and information in public places. Communities should also provide safe living environments with appropriate caregiving services and appropriate education that helps people self-advocate, express themselves, and communicate their feelings.

MISC-04. Telephone Wait Lines – Professional

ISSUE: Many government services reached by telephone are vital to everyone and particularly important to people with disabilities. People can become disenfranchised, angry, and eventually give up when they cannot reach someone who can help them. Even if a caller is number 1,000 in line, knowing later that they are number 975 lets them know they are moving toward eventually speaking with someone.

RECOMMENDATION: Require every government hotline that places callers on hold to tell the caller at least every 10 minutes where they are in the queue.

MISC-05. Make Exclusion from Jury Duty Permanent – Family Advocate

ISSUE: Requiring people with permanent disabilities or their caregivers to repeatedly “certify” conditions that will never change forces them to jump through unnecessary hoops, often within a short timeframe. A Request for Hardship Excusal may require a physical letter with a physician’s signature on medical-center letterhead. Even when the letter can be uploaded electronically, the physician may still have to prepare and physically sign the document and send it to the patient before it can be submitted. How many people with disabilities or caregivers can reliably jump through these hoops, even if they have a regular physician?

My son just received a jury summons. He was “permanently excused” in 2012 based on autism and cognitive deficits, with documentation from his doctor and the San Andreas Regional Center. It turns out that “permanently excused” is not permanent, and now I am jumping through hoops to renew his excusal.

RECOMMENDATION: For permanent disability conditions such as autism and cognitive deficits that will never change or be “cured,” Jury Commissioners should not require updated certification from a current physician. Permanent conditions should mean permanent excusal from jury duty.

FEDERAL POLICY

FED-01. Social Security Limits – Family Advocate

ISSUE: People with developmental disabilities receiving Social Security benefits are limited in how much money they can keep in their bank accounts. The current limit is \$2,000. My son had his benefits cut off because his balance went above that amount. He should be able to maintain savings to pay bills or rent or save for housing and other needs. The current policy is discriminatory. He contributes to household expenses, cannot work, has no other income, and it makes no sense that he cannot accumulate more than \$2,000.

RECOMMENDATION: Raise the maximum amount of money a person with a developmental disability receiving Social Security benefits can keep in a bank account without losing benefits.

FED-02. SSI Income Limits Should Be Updated to Reflect the Economy – Family Advocate (Translated from Spanish)

ISSUE: Family income limits for people with disabilities under Supplemental Security Income (SSI) have not changed in more than 20 years. Everything else has become more expensive, but the income limits have not increased, meaning fewer people are able to qualify for assistance. Two-parent households should also be allowed two vehicles because one parent may need a vehicle for work while the other is needed to take a child to medical appointments and school.

RECOMMENDATION: Require SSI income eligibility thresholds to be automatically updated every five years so families can continue to qualify as economic conditions and the cost of living change. Allow two vehicles for two-parent households when one vehicle is needed for employment and another is needed to transport the child to medical appointments, school, and other necessary activities.

FED-03. Burden of Paperwork Hurdles to Remain Qualified for Services – Family Advocate

ISSUE: I recently received another packet requiring us to prove my daughter's developmental disability, with only about 10 days to respond. The envelope referenced the North Carolina Department of Health and Human Services, while the letter itself had California Department of Social Services letterhead, adding to the confusion. The form had tiny print, and my daughter has selective mutism, refuses Zoom-like appointments because she does not want to see or show her face, and can experience months of intense perseveration when her disability is discussed if it is not handled carefully. I called to explain these difficulties but received no response.

RECOMMENDATION: Reduce the enormous, unnecessarily harmful, and duplicative burden of repeatedly requiring people with permanent developmental disabilities and their families to prove that they remain eligible for services. The process should provide reasonable time to respond, accessible paperwork, and ways to complete required reviews without unnecessarily re-traumatizing the person with a disability.

FED-04. Federal Rules Penalize Families Who Use Home Care
– Family Advocate

ISSUE: Current federal rules create a bureaucratic Catch-22 for families of medically fragile children. A state Medicaid agency may determine that a child meets an institutional level of care and qualifies for a Home and Community-Based Services (HCBS) waiver, yet SSI parental deeming can still prevent the child from receiving cash benefits because the family brought the child home instead of applying while the child was physically hospitalized. This creates a “hospitalization penalty” that financially penalizes families for providing care at home.

Families also bear substantial hidden costs of home care. Parents may reduce work hours, leave employment, or pay higher utility costs to operate medical equipment. Medicaid waivers may cover medical services and therapies without addressing these broader economic effects, while parental deeming can prevent families from receiving SSI cash benefits that would help maintain a stable home environment.

RECOMMENDATION: Amend federal law so any child who qualifies for a state HCBS Medicaid Waiver is automatically exempt from parental deeming for SSI cash benefits, regardless of whether the family applied

while the child was physically in a hospital. If the state determines that the child meets an institutional level of care, the federal government should accept that determination and waive the parental income barrier.

FED-05. Stop Separation of Families – Family Advocate

ISSUE: Protecting the safety, well-being, development, and care of people with disabilities through family unity is essential. Families are being separated because of immigration policies. Parents with no criminal record are being separated from their families simply because they are undocumented, leaving a painful void in their children's lives. These are parents who work, provide for their families, pay rent, and care for their children. They should not be targeted or persecuted. This is now our family's situation.

RECOMMENDATION: Create a law that protects family unity and provides forgiveness for immigration violations, particularly for people who have no federal criminal record. Children with disabilities should be able to remain with the family members who provide their care and the financial support needed for rent, food, and other necessities.

FED-06. Increase SSI Asset Limit – Self-Advocate

ISSUE: The SSI asset limit needs to be increased proportionately to a living wage. Many people with disabilities, including regional center clients, depend on SSI, and being able to have only \$2,000 in countable resources at one time is limiting and unrealistic. Other people have the right to hold more assets. People with disabilities may need savings for an emergency, travel, an investment, or other expenses. Why should it be different for people with disabilities who rely on SSI and simply need additional support and accommodations?

RECOMMENDATION: Increase the SSI asset limit so people with disabilities, including regional center clients, can have greater financial security and freedom and live fully integrated and independent lives on their own terms.

FED-07. Update Durable Medical Equipment in Medicare Policy – Self-Advocate

ISSUE: Medicare policy limits coverage of Durable Medical Equipment (DME), especially power wheelchairs, based on use in the home. This creates barriers for people who need equipment to function outside their homes and for people living in rental housing where some equipment cannot be used without remodeling.

RECOMMENDATION: Change Medicare policy so it covers all types of medically necessary Durable Medical Equipment and allows people with disabilities to replace equipment that is more than five years old when replacement parts for older equipment are difficult to obtain.

FED-08. Incentive to Work – Self-Advocate

ISSUE: State and federal limits on how much money a person can have in checking and savings accounts and how much they can earn are far too low. Costs keep increasing while the limits do not. As a result, many people with I/DD must live in poverty and unsafe locations because rents are high and there are not enough Section 8 vouchers available.

RECOMMENDATION: Allow people with I/DD to have income and savings of up to \$5,000 per person without being penalized. This would help people avoid poverty and keep basic services such as SSI, Medi-Cal, and IHSS while increasing the incentive to work and save without fear of losing benefits.

FED-09. Fear of Losing CalFresh Benefits – Family Advocate

ISSUE: Beginning June 1, 2026, “able-bodied” CalFresh recipients are required to volunteer 80 hours per month to continue receiving benefits. Some regional center service recipients have disabilities that make finding or performing volunteer work difficult or impossible. My son is nonverbal, autistic, and has two Harrington rods in his back following scoliosis.

RECOMMENDATION: Regional center service recipients whose disabilities affect their ability to find or perform volunteer work should not be subject to the 80-hour-per-month requirement for CalFresh benefits.

FED-10. Marriage Penalty Is Not Fair – Family Advocate

ISSUE: When two people receiving SSI or SSDI marry, their benefits are reduced than if they were unmarried individuals. This creates a marriage penalty that encourages people to live together without being able to marry.

RECOMMENDATION: Allow people receiving SSI or SSDI to marry without losing or having their benefits reduced because of the marriage. They need to be able to keep their benefits.

FED-11. Remove Asset Limit for SSI – Family Advocate

ISSUE: It is ridiculous that a person with a disability is limited in how much they can save or how much value they can have in life insurance for death and funeral planning. People should be able to save for their own funeral or prepare financially in case the family member who provides care and support dies. Otherwise, they may be left without adequate resources.

RECOMMENDATION: Remove dollar limits on savings and life-insurance value for people receiving SSI. This would allow people with disabilities to build financial resources in case a caregiver dies and to pay for their own funeral arrangements.

FED-12. Insurance Policy Limits Mobile Devices to In-Home Use Only – Self-Advocate

ISSUE: People who depend on power wheelchairs face inadequate access to wheelchair repairs and insurance policies that restrict mobility-device coverage to in-home use.

RECOMMENDATION: Change Medicare coverage policy for power mobility devices so people who depend on power wheelchairs can use the equipment they need to safely and effectively participate in their communities. The current “in-home use only” language limits independence and can prevent people with disabilities from accessing the community.

FED-13. End Marriage Penalties for People with Disabilities – Professional

ISSUE: People with disabilities should not have to choose between their right to marry and maintaining essential benefits. Income-based programs such as SSI and Medicaid count spousal income, which can push couples

over eligibility thresholds and destabilize their financial security. This not only deprives people of love and commitment but forces them to choose between marriage and the supports they need.

RECOMMENDATION: Create a policy that separates marriage from financial penalties so people with disabilities can marry without losing essential benefits. The right to marry is a fundamental human right, and no person with a disability should have to sacrifice financial stability to exercise it.

ACKNOWLEDGEMENTS

The State Council on Developmental Disabilities extends its sincere appreciation to everyone who participated in the 2026 There Should Be a Law Contest. People with I/DD, family advocates, professionals, and community organizations shared ideas drawn from their experiences with schools, regional centers, healthcare, housing, transportation, employment, public safety, and many other systems. Their willingness to identify problems and propose solutions made this report possible.

Many submissions reflect deeply personal experiences. Participants described barriers they have faced, services they struggled to obtain, systems that did not work as expected, and changes they believe would improve the lives of people with I/DD and their families. SCDD is grateful to everyone who trusted us with these experiences. Lived experience provides insight that cannot always be found in statutes, regulations, reports, or data, and it can reveal both where systems are working and where change is still needed.

We also thank the family members, supporters, advocates, service providers, community organizations, and others who helped people participate in the contest. Some helped individuals develop or submit their ideas, while others shared information about the contest, provided communication assistance, or helped make participation more accessible. Their efforts helped ensure that more voices and perspectives could be included.

SCDD also appreciates the legislators, legislative staff, state agencies, policymakers, advocates, and community partners who take the time to read and consider the ideas contained in this report. Not every proposal will become legislation, but an idea may lead to further research, administrative change, policy development, education, collaboration, or another form of systems change. We hope these submissions encourage continued discussion about how California can make its systems more effective, responsive, and accountable to the people they are intended to serve.

Most importantly, the ideas in this report belong to the Californians who submitted them. The There Should Be a Law Contest is built on a simple principle: the people who experience our systems should help shape how

those systems change. SCDD thanks everyone who shared an experience, identified a problem, proposed a solution, or helped another person participate. Your ideas help turn lived experience into opportunities for systems change.



Access this report online: <https://scdd.ca.gov/policyandlegislation/>

California State Council on Developmental
Disabilities Headquarters
3831 North Freeway Blvd. #125
Sacramento, CA 95834

Phone: (916) 263-7919
Toll Free: (833) 818-9886
Email: Policy@scdd.ca.gov
www.scdd.ca.gov

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SEPTEMBER 29, 2026

AGENDA ITEM 11.

ACTION ITEM

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Closed Session: Personnel

Pursuant to Government Code Section 11126(a)(1), the Council will have a closed session to determine the evaluation of a public employee.

SEPTEMBER 29, 2026

**AGENDA ITEM 12.
INFORMATION ITEM**

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Reconvene Open Session

Pursuant to Government Code Section 11126.3 (f), there will be an announcement of any publicly reportable actions taken during closed session.

SEPTEMBER 29, 2026

**AGENDA ITEM 13.
INFORMATION ITEM**

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Next Meeting Date and Adjournment

The next Council meeting will be held on Zoom on November 17, 2026.