

# Navigating Regional Centers

## 3<sup>rd</sup> Annual Stanford Down Syndrome Conference

November 1, 2024

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# Our Time Today...

- About Your Partners
- History & Advocacy: This is YOUR System to Protect
- Examples of IDD Services & Your Rights Under the Lanterman Act
- Tips & Tools for Your IDD Services
- Additional Resources & Examples



# Your California State Council

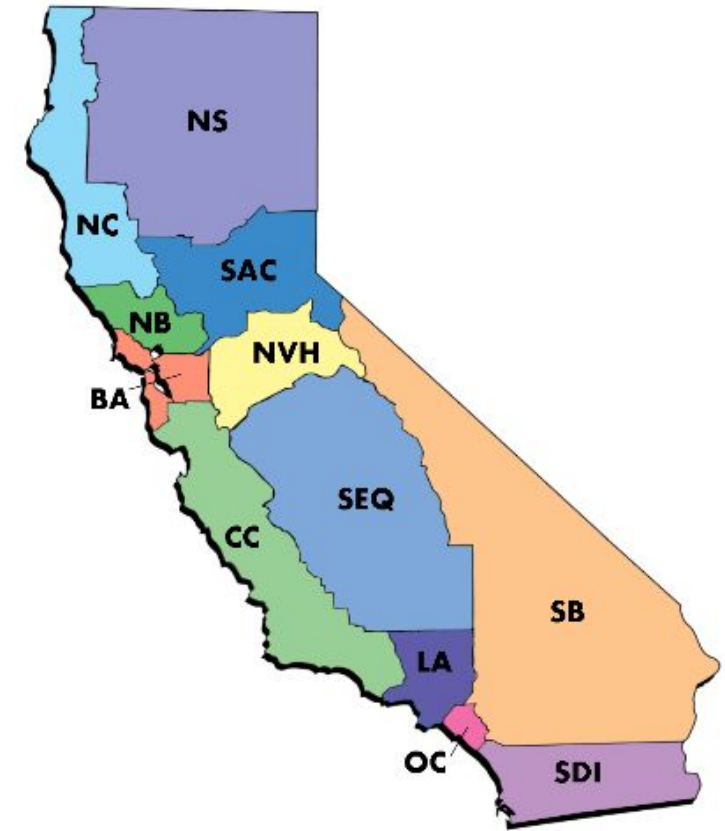
**The State Council on Developmental Disabilities (SCDD / State Council)** is established by state and federal law as an independent state department.

## Our Vision

Californians with developmental disabilities are guaranteed the same full and equal opportunities for life, liberty, and the pursuit of happiness as all Americans.

## Our Mission

The Council advocates, promotes and implements policies and practices that achieve self-determination, independence, productivity, and inclusion in all aspects of community life for Californians with developmental disabilities and their families.

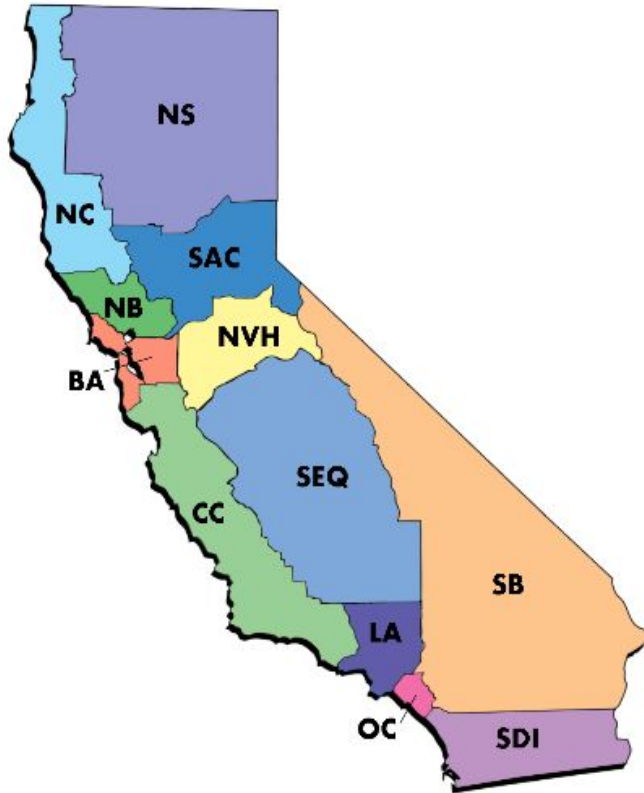


# Your CA State Council: Authority through Fed & State

- Led by people with IDD and their families
- 31 Governor's Appointees
- Authority to
  - Advocate, capacity build, change systems
- Work statewide and locally, lifespan needs
- [The Developmental Disabilities Assistance and Bill of Rights Act of 2000](#)
- [Lanterman Developmental Disabilities Services Act](#)



# State Council's Regional Offices



- **Connect people to needed services and supports**
  - Systems navigation, inform about rights & resources, etc.
- **Strive to improve services and supports**
  - Review policies and practices, identify services needed but not available, monitor legislation. Help build capacity.
- **Help people become part of their communities**
  - Encourage and assist various advocacy organizations, educate the public, help the community engage in systems change work and leadership development.



# Stanford Developmental-Behavioral Pediatrics



- **Vision:** All children reach their optimal developmental, behavioral, and emotional health and are fully included in a supportive, loving community.
- **Mission:** Improving the health and well-being of children at risk for or with developmental delays, behavioral differences, and developmental disabilities and their families through exceptional clinical care, professional education, clinical and translational research, community service, and advocacy.
- **Values:** All individuals should be included and welcomed in our community, regardless of the age, sex, gender, race, ethnicity, or ability. We believe that families, schools, communities, and societies thrive when they embrace diversity and inclusion.



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# History and Advocacy for the Developmental Disability Community in California (1 of 2)

**Before** the Lanterman Act was advocated for, developed, and signed (1969):

- Over 13,000 people with IDD were incarcerated in state hospitals with thousands more on the waitlist.
- Parents of newborns with genetic conditions were told: “Don’t bring your child home”; “Tell your friends your child died.”
- “I saw a patient in Fairview who has been in seclusion for two years in a tiny cell that I wouldn’t keep a mongrel dog in. There was no toilet there, no bed, and he was stark naked on the cement floor without even a blanket – the only thing in the cell was a bedpan.”

Theodore Braun. (2000). We’re Here to Speak for Justice: Founding of California’s Regional Centers.

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# History and Advocacy for the Developmental Disability Community in California (2 of 2)

- California is the **only state** that has legislation which entitles services to individuals with intellectual and developmental disabilities (IDD).
- The signing of the Lanterman Act was driven by family advocates.
- The Lanterman Act clearly defines the **rights** of the people with IDD to be provided with services and the corresponding **obligation** of the state to provide them. These are rights that we cannot take for granted.
- Continued advocacy is critical to uphold the Lanterman Act today and into the future.





The Lanterman Act, **like all other civil rights**, will only survive into the future if our community is vigilant, active, and engaged in protecting and upholding it.



Now let's get a high-level overview of  
the **IDD Services Systems** through the  
Lanterman Act...



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# Examples of How Lanterman Act Protects the Rights of People with IDD

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- Services that protect liberty, provided in the least restrictive (most integrated) way;
- Dignity, privacy and humane care;
- Treatment, services and supports in natural community settings, to the greatest extent possible;
- Choices in one's own life, including where and with whom one chooses to live, relationships with people in the community, how to spend time (including education, employment and leisure), the pursuit of one's chosen personal future;
- The opportunity to make decisions and to have information understand to help make informed choices.

See W&I Code §§ 4502 for more info



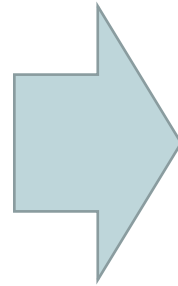
# Structure of the IDD Service System (1 of 2)

## Department of Developmental Services (DDS)

DDS oversees the delivery of services on behalf of the Regional Centers to people with developmental disabilities.

DDS has performance contracts with each Regional Center.

DDS provides directives to Regional Centers.



## Regional Centers (RCs)

RCs are non-profit agencies.

Governed by a board of directors & in contract with DDS.

Responsible for determining eligibility, per the law.

Responsible for the coordination of services.

Responsible for development of Individual Program Plan (IPP), with you.



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# Structure of the IDD Service System (2 of 2)

## Regional Centers (RCs)

- Regional Centers are non-profit agencies.
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## Service Providers / Vendors

- May be for-profit or non-profit.
- Are vendored, or otherwise are approved to provide services.
- Provided to persons eligible for Regional Center services, as written in their IPP.
- Service providers are responsible for delivering services.



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# IDD Services Systems: Traditional Services v Self-Determination

## Traditional IDD Services

- You and your RC are responsible for the development of Individual Program Plan (IPP).
- Your RC is responsible for the coordination of services to people with developmental disabilities.
- Your RC pays your service providers. Service providers must be vendored.
- Services must be HCBS and CMS compliant.

## Self-Determination Services

- You and your RC are responsible for the development of Individual Program Plan (IPP).
- You and your circle of support are responsible for the coordination of your services.
- Your Financial Management Services (FMS) works with you to pay your service providers. Your service providers may or may not be vendored. You develop the contracts.
- You may choose to work with an Independent Facilitator.
- Services must be HCBS and CMS compliant.

<https://scdd.ca.gov/sdp-orientation/> To learn more...



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# A Few Terms to Know about the IDD Services System



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# A Few Terms to Know (1 of 2)

**Person-Centered Planning (PCP):** Person-centered planning (PCP) is a planning process for identifying a person's strengths, challenges, preferences, needs, desires, short- and long-term goals, and more. It helps map out what is important **TO** a person, and what is important **FOR** a person.

PCP helps a person and their circle of support determine what kinds of supports and services (natural and formal) will best support them.



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# A Few Terms to Know (2 of 2)

- **Individual Family Services Plan (IFSP):** A formal written plan that outlines the early intervention services that a child will receive when they are eligible for Early Start.
- **Individual Program Plan (IPP):** A formal written plan that is the legal agreement between a person with IPP and the state. It is a plan that results from planning efforts which may include discussions, meetings, and/or person-centered planning efforts. Thinks of an IPP as an 'action plan' that talks about goals and the support a person needs to live the way they want.



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# **So, What Are Examples of Services & Supports?**

# WIC Section 4512(b)

“Services and supports for persons with developmental disabilities” means specialized services and supports or special adaptations of generic services and supports directed toward the **alleviation of a developmental disability** or toward the **social, personal, physical, or economic habilitation or rehabilitation** of an individual with a developmental disability, or toward the **achievement and maintenance of an independent, productive, and normal life**. The determination of which services and supports are necessary for each consumer shall be made through the individual program plan process...

# WIC Section 4512(b) (cont.)

...The determination shall be made on the basis of **the needs and preferences of the consumer** or, when appropriate, the consumer's family, and shall include consideration of a range of service options proposed by individual program plan participants, the effectiveness of each option in meeting the goals stated in the **individual program plan**, and the **cost-effectiveness** of each option...



## **Services and supports listed in the individual program plan may include, but are not limited to:**

...diagnosis, evaluation, treatment, personal care, daycare, domiciliary care, special living arrangements, physical, occupational, and speech therapy, training, education, supported and sheltered employment, mental health services, recreation, counseling of the individual with a developmental disability and of the individual's family, protective and other social and sociolegal services, information and referral services, follow-along services, adaptive equipment and supplies, advocacy assistance, including self-advocacy training, facilitation and peer advocates, assessment, assistance in locating a home, childcare, behavior training and behavior modification programs, camping, community integration services, community support, daily living skills training, emergency and crisis intervention, facilitating circles of support, habilitation, homemaker services, infant stimulation programs, paid roommates, paid neighbors, respite, short-term out-of-home care, social skills training, specialized medical and dental care...

## **Services and supports listed in the individual program plan may include, but are not limited to (cont.):**

telehealth services and supports, as described in Section 2290.5 of the Business and Professions Code, supported living arrangements, technical and financial assistance, travel training, training for parents of children with developmental disabilities, training for parents with developmental disabilities, vouchers, and transportation services necessary to ensure delivery of services to persons with developmental disabilities. This subdivision does not expand or authorize a new or different service or support for any consumer unless that service or support is contained in the consumer's individual program plan.”

## WIC Sections 4646.4 & 4659(a)

When purchasing services and supports, shall ensure all of the following:

- Utilization of **generic services** and supports when appropriate.
- Consideration of the family's responsibility for providing similar services and supports for a minor child without disabilities.

...Shall identify and pursue all possible sources of funding for consumers receiving regional center services. These sources shall include, but not be limited to:

- Government programs, including Medi-Cal, school districts, federal supplemental security income, etc.
- Private entities, to the maximum extent they are liable for the cost of services, aid, insurance, or medical assistance to the consumer.

# Generic Services, in Other Words...

- Services and supports that other agencies (not DDS or regional centers) that have a legal responsibility to fund. (i.e. School District, IHSS through the county, etc.).
- The regional center cannot provide services that you are eligible for through generic services but **CAN** while coverage is being pursued but before a denial is made.
- The regional center can help you advocate for generic services, when requested at the IPP.
- The regional center is the 'Payer of Last Resort'.



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# Tips & Tools



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# The Individualized Program Plan (IPP) – The Foundation (1 of 2)

- The IPP is a contract: a formal and enforceable agreement.
- Know what should be included in your IPP.
- Know your right to sign all, or only parts you agree with.

W&I Code §§ 4646, 4646.5, 4648(a)(1)



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# The Individualized Program Plan (IPP) – The Foundation (2 of 2)

- Review your current IPP (if applicable).
- Know when you can request another IPP meeting or make a change to your IPP.
- Make a list of goals and a list of services and supports to reach your goals.
- Know your IPP planning team.
- Ask for an interpreter (if applicable).

W&I Code §§ 4646, 4646.5, 4648(a)(1)



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# Best Practices in Working with Your Regional Center & Service Providers

- Know your regional center contacts, their best method of contact, who their supervisor and unit manager are. Get to know your regional center's website and DDS' website.
- Save all documentation (paper trail) with the regional center and service providers.
- Keep on top of what goals and needs are relevant to you / your person. Communicate early and plan ahead whenever possible.
- Know your rights and the timelines for action.



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# **Overview of IDD Services Dispute Resolution & Other Complaints Processes**



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# Dispute Resolution

- **Notice of Action (NOA):** If the regional center denies a service request, a NOA must be issued. The NOA will have important timelines and appeal information.
- **Appeal:** After receiving a Notice of Action (NOA), you have **60 days** to appeal. This process is asking for a decision to be reviewed when you believe the decision was incorrect. Fill out a Fair Hearing Request Form in writing or online:  
<https://www.dds.ca.gov/general/appeals-complaints-comments/fair-hearings-complaint-process/>.
- **Aid Paid Pending:** The right for your existing service to continue unchanged, if appealed within **30 days**.

# Dispute Resolution (cont.)

- **Informal Meeting** (optional): A meeting with decision makers from the regional center to discuss the services you need and the dispute. The informal meeting must take place within **10 days of receipt** of your appeal. The regional center then has **5 working/business days** to send you a letter with their decision.
- **Mediation** (optional): A meeting with you, a regional center representative, and a mediator (a neutral third party trained to serve as a mediator) to be held within **30 days** of your appeal. A written resolution (agreement) goes into effect **10 days** after both parties agree.
- **Fair Hearing**: The administrative decision-making process through the Office of Administrative Hearings (OAH). This is the procedure to appeal a decision of the regional center. The hearing should be held within **50 days** of your appeal.

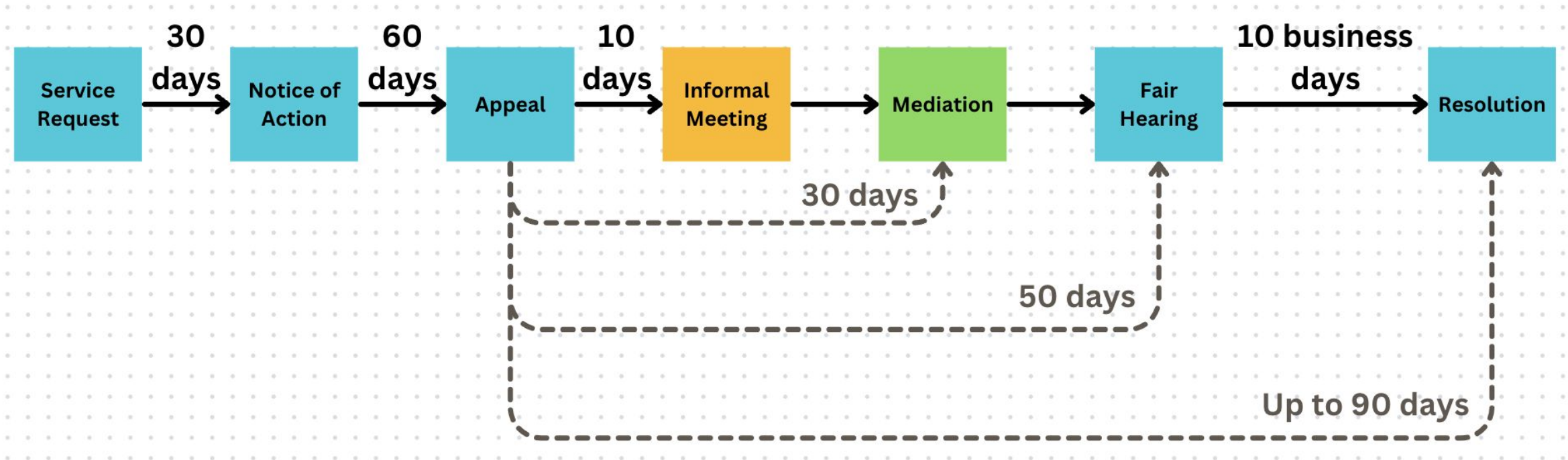


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# Service Request Denials & Timelines for Appeal





# Fair Hearing

- A hearing before an Administrative Law Judge (ALJ) from the Office of Administrative Hearings (OAH).
- The hearing takes place within **50 days** of the hearing request (unless one of the parties asks for a delay for a good reason).
- Right to interpreters.
- There are new limits on when a regional center attorney can attend an informal meeting, mediation, and a fair hearing.
- All parties can ask for reconsideration within **15 days** of the judge's decision.
- Decisions given within **90 days** of appeal. You can appeal the fair hearing decision within **180 days**. This appeal is to Superior Court.

# Section 4731 Complaint (1 of 2)

- The right to make a complaint if you believe your rights have been violated. Under this process, you are asking that the regional center, developmental center, or provider, change its procedures in the future.
- Send a completed DS 255 form or letter that is dated and signed to the regional center or developmental center director.
  - They have **20 working days** to send a letter with their response.

## Section 4731 Complaint (2 of 2)

- If you do not agree with the regional center or developmental center directors' response, you have **15 working days** to send a letter to the director of the Department of Developmental Services (DDS).
  - When the director of DDS receives your complaint, they will have 45 days to send you a letter with their decision.

# Whistleblower Complaints & Language Access Complaints

- **Whistleblower Complaints:** Reporting improper regional center or vendor activity. This includes submitting a clear statement of the improper activity and any evidence to support it. Confidentiality is key.
- **Language Complaints:** When not satisfied with the bilingual services received, utilize the DDS Language Access Complaint Process Form DS 6022 from the DDS website.

Dymally-Alatorre Bilingual Services Act; Title VI of Civil Rights Act of 1964

<https://www.dds.ca.gov/general/appeals-complaints-comments/>



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# Thoughts Around Advocacy



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***SPEAK YOUR MIND,  
EVEN IF YOUR VOICE SHAKES***

-Maggie Kuhn

***Never doubt that a small  
group of thoughtful, committed  
citizens can change the world.  
Indeed, it is the only thing that ever  
has.***

-Margaret Mead, U.S. Anthropologist

An illustration showing several hands of different skin tones (teal, orange, brown, purple) stacked on top of each other in a circular arrangement, symbolizing unity and collective action.

## Ways to Advocate in Your Community



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# IDD Services System Advocacy (1 of 2)

Meetings to consider attending:

- **Regional Center Board of Directors** meetings – Regional Centers policies and final decisions are reviewed and voted on *at these meetings by the Board of Directors*.
- **POS** meetings – Regional Center must compile data of the Purchase of Service (POS) that they provide to the people they serve and *hold a public meeting on this/report it to the community*.



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# IDD Services System Advocacy (2 of 2)

Meetings to consider attending:

- **Performance meetings** – Regional Centers must work with the community they serve to develop goals and yearly objectives in their performance standard areas *through public meetings/by holding a meeting*.
- **Public Meetings, Info Sessions, or Hearings** involving Department of Developmental Services.
- **State Council** meetings, or State Council Regional Advisory Committee Meetings.



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# Examples of Legislative Advocacy

- Join Coalitions, Committees, or Advisory Bodies.
- Letters / Email / Phone calls (support/oppose, informative).
- Visit Offices.
- Testify at Hearings.
- Rallies, Lobby Days, Protests.
- Social Media Actions.



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# Opportunity at Public Meetings!

- Be present and a part of the process.
- Providing public comment.
- Providing testimony on an issue.
- Reporting back to other community members in your network.
- Review the agenda and mode of meeting ahead of time and share with your network.



# Additional Resources and References (1 of 2)

- State Council on Developmental Disabilities (SCDD):  
<https://scdd.ca.gov/resources/>
- Department of Developmental Services' (DDS) appeals and complaints information: <https://www.dds.ca.gov/general/appeals-complaints-comments/>
  - [https://www.dds.ca.gov/wp-content/uploads/2024/07/July\\_2024\\_Lanterman\\_Appeals\\_Process\\_Updates.pdf](https://www.dds.ca.gov/wp-content/uploads/2024/07/July_2024_Lanterman_Appeals_Process_Updates.pdf)
  - <https://www.dds.ca.gov/general/appeals-complaints-comments/fair-hearings-complaint-process/fact-sheets/>
- Disability Rights California's (DRC) Rights Under the Lanterman Act Manual:  
<https://rula.disabilityrightscalifornia.org/>
- DDS' Self-Determination Program (SDP) Homepage:  
<https://www.dds.ca.gov/initiatives/sdp/>



# Additional Resources and References (2 of 2)

- About Home and Community-Based Services (HCBS):  
<https://www.dds.ca.gov/initiatives/cms-hcbs-regulations/assessment-information/> & <https://www.dds.ca.gov/initiatives/cms-hcbs-regulations/faq-hcbs-rules/>
- Project AFECT Homepage:  
<https://dbpeds.stanford.edu/community-service/project-afect.html>
- Family Resource Centers of CA: [home - Family Resource Centers Network of California](#)
- Parent Training and Info Centers: [California - Center for Parent Information and Resources](#)



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# State Council on Developmental Disabilities' Regional Offices

North Coast (Del Norte, Humboldt, Lake, Mendocino) [northcoast@scdd.ca.gov](mailto:northcoast@scdd.ca.gov) (707) 463-4700

North State (Butte, Tehama, Plumas, Lassen, Glenn, Modoc, Shasta, Siskiyou, Trinity) [northstate@scdd.ca.gov](mailto:northstate@scdd.ca.gov) (530) 895-4027

Sacramento (Alpine, Colusa, Sierra, El Dorado, Nevada, Placer, Sacramento, Sutter, Yolo, Yuba) [sacramento@scdd.ca.gov](mailto:sacramento@scdd.ca.gov) (916) 263-8134

North Bay (Napa, Solano, Sonoma) [northbay@scdd.ca.gov](mailto:northbay@scdd.ca.gov) (707) 648-4073

Bay Area (Alameda, Contra Costa, Marin, San Francisco, San Mateo) [bayarea@scdd.ca.gov](mailto:bayarea@scdd.ca.gov) (510) 286-0439

North Valley Hills (Amador, Calaveras, San Joaquin, Stanislaus, Tuolumne) [northvalleyhills@scdd.ca.gov](mailto:northvalleyhills@scdd.ca.gov) (209) 473-6930

Central Coast (Santa Clara, Monterey, Santa Barbara, Ventura, San Benito, San Luis Obispo, Santa Cruz) [centralcoast@scdd.ca.gov](mailto:centralcoast@scdd.ca.gov) (408) 324-2106

Sequoia (Fresno, Kern, Mariposa, Madera, Kings, Tulare, Merced) [sequoia@scdd.ca.gov](mailto:sequoia@scdd.ca.gov) (559) 222-2496

Los Angeles (Los Angeles) [losangeles@scdd.ca.gov](mailto:losangeles@scdd.ca.gov) (818) 543-4631

Orange County (Orange) [orangecounty@scdd.ca.gov](mailto:orangecounty@scdd.ca.gov) (714) 558-4404

San Bernardino (San Bernardino, Riverside, Inyo, Mono) [sanbernardino@scdd.ca.gov](mailto:sanbernardino@scdd.ca.gov) (909) 890-1259

San Diego Imperial (San Diego, Imperial) [sandiego@scdd.ca.gov](mailto:sandiego@scdd.ca.gov) (619) 688-3323



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## Let's Connect

### Websites:

<https://scdd.ca.gov/>

<https://dbpedst.stanford.edu/>

### On Social:

<https://www.facebook.com/CalSCDD>

<https://x.com/CalSCDD>

<https://www.instagram.com/calscdd/>