Advocacy and Systems Change in Developmental Services

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The unfiltered voice of the community

SCDD's role in the system

Who we are

- Independent state agency
- Created in federal and state law
- Led by people with developmental disabilities and families, appointed by the Governor
- Sacramento HQ and 12 regional offices

1. **Listen**
   We go to people and families and bring what we hear to decision-makers.
2. **Build capacity**
   We train people to know their rights and speak up for themselves.
3. **Advocate for systems change**
   Across every system in a person's life, not just regional centers: school, health care, housing, work, and safety.

Our federal partners

- **Disability Rights California**
  Protects legal rights
- **University centers (UCEDDs)**
  Research, training, and services

Sources: Developmental Disabilities Assistance and Bill of Rights Act of 2000; Welf. & Inst. Code §4520 et seq.

A voice earned through trust

People trust SCDD with their stories.

105,900
Californians we reached directly

11,800
People we helped one-on-one

34,000
People we trained

2,600
Medicaid stories sent to Congress

What people tell us drives our State Plan and the Council's policy priorities:

- Civil rights
- Education
- Employment
- Community services
- Health care
- Safety and emergencies
- Housing
- Emerging issues

Sources: SCDD 2025 activity data; SCDD Policy Platform 2027–2031.

What we hear from people and families

4,200+

survey responses about what people need most

Conducted 2025 by paper, web, phone, and in person.

Self-Advocate top issues

1. Housing
2. Health and safety
3. Employment
4. Regional centers
5. Community and inclusion

Problems that persist

- Regional center experience depends on where you live
- Systems are hard to navigate; paperwork is “emotionally draining”
- Not enough workers: direct support, caregivers, school staff

Source: SCDD Community Priorities Survey, Aug.–Sept. 2025.

The community's ideas, unfiltered

Six years of There Should Be a Law: every submission is published. We bring them to you.

664
ideas from the community 2021–2026

92 → 184
ideas a year doubled

20%
from self-advocates

What six years show

"Does it work when a person needs it?"

- Getting services is the most consistent concern
- The problem now is making rights and programs work in practice
- Community living depends on systems working together

What we built

Regional Center Services webpage

Explains every regional center service in plain language. Starts with what a person needs. Built with our federal partners.

scdd.ca.gov/regionalcenterservices

Source: SCDD, Six Years of There Should Be a Law: What the Community Has Told SCDD, 2021–2026 (Nov. 2026).

Questions to carry into your work

Federal changes

How will federal Medicaid changes reach home and community-based services?

Consistency

Would a person with the same needs get the same answer and services at every regional center?

Housing

Where will adults live when aging parents can no longer provide care?

Employment

What keeps more people with developmental disabilities out of regular jobs?

Plain language

Can people understand the letters and notices they get?

Relationships

What is the impact when benefit rules keep people from marrying, aka “marriage penalty”?

Connect

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Information and Resources for Legislative Staff

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