

"There Should Be A Law":



Stakeholder Perspectives & Priorities on State Policies Related to Autism & Other Developmental Disabilities

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BACKGROUND

The Developmental
Disabilities Assistance & Bill
of Rights Act of 2000 (DD
Act), ensures individuals
with developmental
disabilities (IWDD) and their
families participate in the
design of and have access to
needed services and
supports.

The California State Council on Developmental Disabilities (SCDD) launched a Bill Idea Contest ("There Should Be A Law") in 2021 for self-advocates, families, and providers to share ideas and needs of the community.

OBJECTIVES

Summarize stakeholder priorities for state policies related to autism and other developmental disabilities.

CONTEST QUESTION

What problem do you hope to solve?

METHODS

Participants (n = 99) completed a survey created by SCDD.

Responses were tabulated and coded under problem domains and subdomains.

Frequencies were run to determine top priorities.

RESULTS

#1 Health & Human Services

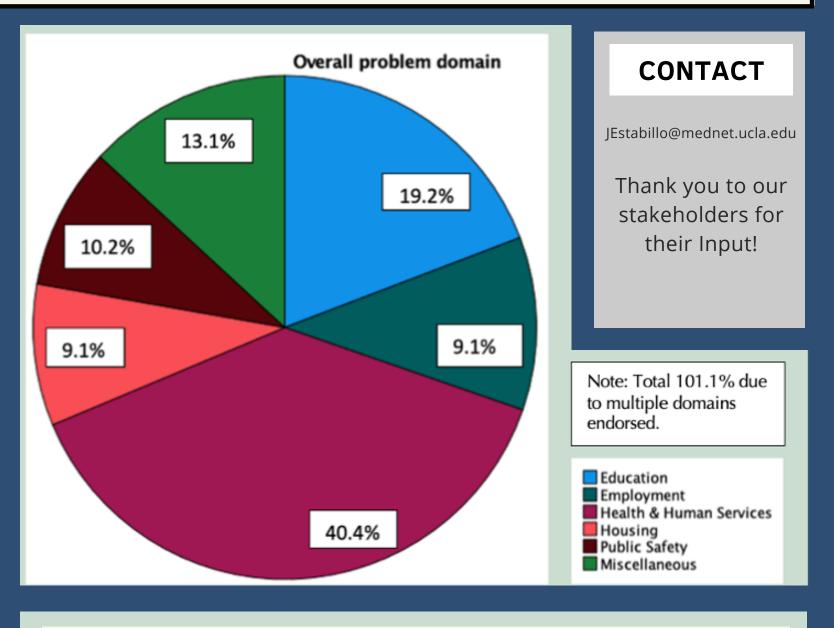
#2 Education

SUBMISSION EXAMPLE: HEALTH & HUMAN SERVICES

PROBLEM: "Consumer disagreements with Regional Center (RC) regarding quality and availability of services and accessing services."

SOLUTION: Add attorney fee shift to DDS contract with RC or to the Lanterman Act. All consumers to access legal counsel to assist with services that RC denies.

Problem Domains and Subdomains	n	%
Health and Human Services	40	40.4
Legal issues	6	6.06
Inconsistent provider standards & training	3	3.03
Lack of culturally responsive services	1	1.01
Parent issues	3	3.03
Lack of adult services & supports	6	6.06
Service access issues	16	16.16
Billing & insurance issues	8	8.08
Lack of transparency with Regional Center	5	5.05
Medical issues	1	1.01
Education	19	19.2
Legal issues	6	6.06
Inconsistent Special Education standards &	3	3.03
training		
Lack of culturally responsive services	2	2.02
Parent issues	5	5.05
Higher Education issues	2	2.02
Lack of adequate Special Education services	3	3.03
Inclusion issues	4	4.04



SUBMISSION EXAMPLE: EDUCATION

PROBLEM: "...major Issues with oversight, accountability, and parent access to rights and information in the Special Education system."

SOLUTION: Establish an Oversight Committee and Ombudsperson for each Special Education Local Plan Area (SELPA).

CONCLUSIONS

Top priorities are Health & Human Services and Education.

Access issues, systems barriers, and legal issues must be addressed.

To advance change, researchers, policymakers, and care systems must align priorities, policies, and practice with the needs of IWDD and their families.