



A Matter of Race and Place

**Recommendations for building
equitable policies for Californians with
intellectual & developmental disabilities**

Developed at a statewide conference of
people with I/DD, families, and professionals

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EXECUTIVE SUMMARY

Shaping California's Master Plan

In 2022, Disability Voices United (DVU) released an equity-focused report called “**A Matter of Race and Place**.” It documented severe inequities — by race and ethnicity, by region, by language, and along other lines — in California’s provision of services to those with intellectual and developmental disabilities (I/DD).

In 2023, the **Little Hoover Commission**, an independent state oversight agency, held a **series of hearings** responding to public concerns about the developmental disabilities service system. The Commission’s report, “**A System in Distress**,” urged California’s policymakers to address ongoing disparities in the availability and quality of services for people with I/DD. The hearings, combined with a series of critical news articles, eventually led Dr. Mark Ghaly, then-Secretary of California’s Health and Human Services Agency, to announce the creation of a **Master Plan for Developmental Services**.

The Master Plan is charged to provide recommendations that ensure equitable and culturally responsive services while improving accountability, standardization, and accessibility across the system. A draft of the plan is scheduled for release in Spring 2025. DVU strongly supports the Master Plan’s goal of exploring improvements, not just in the regional center system that provides direct services, but in areas of overlap and mutual dependence between disability services and housing, health care, education, immigration, and employment.



The Master Plan’s importance and urgency increased with the re-election of Donald Trump as President of the United States. With his new administration already following in the footsteps of his last, we expect him to continue his attacks on federal support for health care and services funded by Medicaid. The administration may also impose new limits on immigration and restrictions on disability rights and accessibility accommodations, threatening key legal provisions such as Section 504 of the Rehabilitation Act and the Affordable Care Act.

In preparation for these challenges, on November 8, 2024, DVU convened a conference in Los Angeles to gather input and feedback from over 300 self-advocates, family members, and professionals in the I/DD space.

The after-conference report that follows represents part of DVU’s contribution to public comment on the Master Plan. It delivers a set of concise, actionable recommendations for our state’s systems that support people with I/DD. In addition to collating and distilling input from conference attendees, we asked self-advocates and professionals to review the recommendations detailed below for clarity, substance, and relevance to ongoing discussions.

EVENT RECAP:

How We Found Our Answers

DVU convened the 2024 **Race and Place Conference** to gather, refine, and stress-test our community's shared understanding of what needs to change in California's developmental services system.

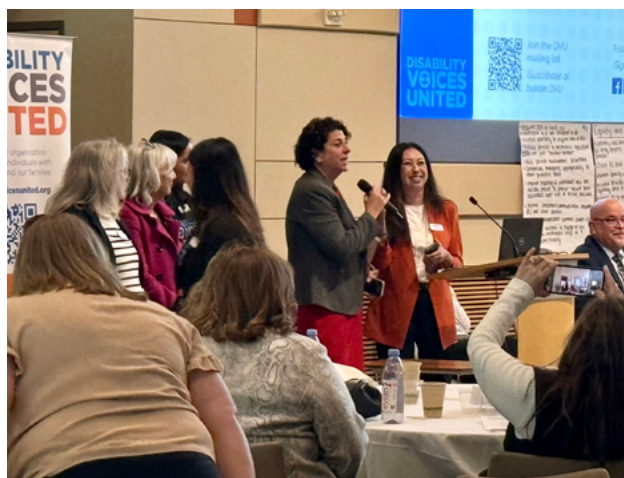
Sergio Aguilar-Gaxiola, MD, PhD, Director of the Center for Reducing Health Disparities at UC Davis, kicked off the event with an insightful keynote address detailing his experiences as a parent, provider, and scholar, and highlighting the potential impact of evidence-based systemic change. Two panel sessions, "We Know What We Know," and "We Know We Don't Know Everything," then discussed pressing issues people with I/DD and their families face and heard expert insights on the most promising paths forward — both within the **Master Plan** and alongside it.

The conference then split into parallel discussions on six equity-related focus areas:

- Diagnosis and Early Intervention
- Education
- The Regional Center System
- Primary and Preventative Health and Dental Care
- Mental Health/Crisis Intervention and Support
- Immigration and Language Access

Each discussion — led by self-advocates, family members, and professionals with subject-matter knowledge — focused on identifying challenges and proposing concrete, productive policy solutions.

The event concluded with a final equity solutions reality check. Discussion group leaders shared the top priorities identified in the breakout sessions, and audience members with lived experiences provided short-form, direct feedback, answering the vital question: "Will it work?"



This report collects their answers. It identifies the most pressing problems — the most urgent sources of disparities and harm to Californians with developmental disabilities — and lays out clear, common-sense steps toward their resolution.

FOCUS AREA:

Diagnosis and Early Intervention

Discussion Leaders & Expert Contributors

- **Marcos Aguilar, Jr.**, Director, Clinical and Intervention Services, Special Needs Network
- **Kathleen Barajas**, President, Project AIR, Chair, Metro Accessibility Advisory Committee, Self-Advocate
- **Silvia Hernandez-Cuellar, OTD, OTR/L**, Pediatric Occupational Therapist, Nurture Collective

Kathleen's Story

Diagnosed with cerebral palsy before her first birthday, Kathleen Barajas said, "I was fortunate that my parents realized I was not developing as I should have been." Still, her school offered no mainstreaming opportunities and her family made do without any financial help.

Like many Latino children, Kathleen managed through much of her formal education without access to support for her disability. "I struggled quite a bit throughout my life," she reflected. "I wish I had realized I could access services from a regional center much earlier. It would have made my life much less stressful."

"Access to early intervention is almost like pulling a raffle."

Marcos Aguilar



Barriers to Early Intervention

Kathleen's story reflects an underlying disparity: non-white children with I/DD are diagnosed significantly later.^{1,2} They face consistent barriers to assessment, Kathleen explains, "whether it's the parent not realizing certain signs" or the pediatrician dismissing the family's concerns. Between refusal to diagnose, language barriers, and lack of resources, pursuing care often falls to the family.

One diversity specialist at a regional center noted a widespread failure to diagnose among Latino children. "It comes down to luck of the draw with pediatricians — how much they care, how invested they are, how attentive they are, how well they speak your language, whether they have biases around Asian or Latino kids," she explained. Disinterested pediatricians treat too many minority children as "let's see if they grow out of it" cases.

"We need to see that [regional centers] are actually providing the services when we need them the most, when our children are small and they can make the biggest difference. Those are their most important years of development."

Session Participant

Self-advocates argued that it is far better to over-diagnose and refer than to avoid diagnosis and leave people struggling. The choice isn't between diagnosis and fitting in, they said, it's between a diagnostic label like "autism" or a social label like "disruptive." In both cases the child will be seen as different — but the formal diagnosis gives them access to support.

Services for children with I/DD are more effective when they are provided at younger ages,^{3,4,5} leading to long-term improvements in communication and life skills compared to children who start the same services just a year later.

While families with means can seek timely diagnoses from private providers, those without must endure long wait times at regional centers and for ABA assessments (90 days at Kaiser Permanente, 30-90 days at Easter Seals).

Discussion Highlights

Parents require more education. It's common for physicians to write parent concerns down but take no further action to educate the parents about typical development, and in some communities, parents may be initially unwilling to label behaviors as developmental delays.

Language prevents families from finding support. Lack of interpreters and the complexity of processes remain barriers to care. Support groups can share resources to improve understanding while gaining a community.

Early intervention has a time limit — and service delays run out the clock for disadvantaged families.

Basic information channels not utilized. Early detection starts with parents noticing symptoms and developmental delays. Simple measures, such as informational handouts in every language at pediatricians' offices, can help.

Pediatricians lack cultural understanding. "Physicians are less likely to listen to parents of color or to take their concerns seriously," said one participant. Many parents describe being dismissed in this way.

Recommendations from Conference Participants

Build trust in your communities. With culturally relevant information, regional centers can reach more individuals with peer-to-peer, family-to-family networks.

Educate parents. Empower families to advocate for their children by providing resources that simplify the complex process of seeking support. Participants suggested community events and educational pamphlets in hospitals to spread awareness of symptoms and expand early detection.

Train pediatricians to make more referrals. Engage pediatricians in training on I/DD symptoms and support. One participant suggested a continuing medical education (CME) program for physicians to improve awareness of the importance of early intervention.

Support advocates for families. Parents face overwhelming challenges just caring for their children. To navigate the regional center, health care, and educational systems, they need a knowledgeable advocate in their corner, starting very early on.

FOCUS AREA:

Education

Discussion Leaders & Expert Contributors

- **Lisa Mosko Barros**, Founder and CEO, SpEducational, Parent
- **Diana Pastora Carson**, Educator, San Diego State University, Author, Podcaster, DVU Board Member, Sibling
- **Vivian Haun**, Senior Policy Attorney, I/DD Practice Group, Disability Rights California
- **Oscar Mercado**, Self-Advocate and Communications and Outreach Manager, Integrated Community Collaborative
- **Nicole Voisard**, Self-Advocate



Oscar's Story

Diagnosed with autism in the second grade, Oscar Mercado stayed up late doing homework, only to see mediocre grades. No amount of determination could prevent overstimulation or allow him to process information the way his teachers presented it. Oscar's school offered no direct support or accommodations for his IEP (Individualized Education Plan), and school staff sometimes intentionally concealed information from his parents. They provided only one referral, to the nearby regional center, which sent Oscar home after a single screening.

"Not until high school did anyone make appropriate accommodations," Oscar said. "And that's because I asked for what I needed." Teachers more alert to his needs also began encouraging him, providing essential motivation. Once armed with the basic support required by law, Oscar earned straight A's for the first time.

A Free and Appropriate Public Education Is a Legal Right

Education is one area where the law is very clear on disability rights. The **Individuals with Disabilities Education Act (IDEA)** requires schools to provide disabled students with a "free appropriate public education," delivered through an IEP and specialized instruction, related services, and accommodations. The law requires more than tweaks to existing educational practices—it stipulates that the educational program itself be tailored to each student's unique needs.

With those supports, “the vast majority of special education students (80-85%) can meet the same achievement standards as other students,” [according to the National Center on Education Outcomes](#). That finding makes it even more troubling that administrators routinely flout IDEA requirements, failing to provide specially designed instruction, adequate interpretation, and reasonable accommodations.

Discussion Highlights

Lack of information for families. Among the most frequently raised concerns was a lack of information about legal rights, services, and accommodation options, as well as confusing informational resources (on school websites, on the [DRC website](#), and elsewhere). Vital documents like IEPs and the procedural safeguards that guarantee students and parents their rights are full of technical jargon and lack language translations.

Inadequate access to communication. Contrary to [the formal recommendation of the American Speech and Hearing Association](#), school districts often require students seeking augmentative and alternative communication (AAC) systems to display “readiness.” This counterproductive requirement effectively blocks access to communication for many students. Some schools provide AAC devices without the trained staff that make those devices effective for classroom communication.

Inconsistent approaches to educational support. Teachers shared that every school has different blind spots and varies in the use of special education classrooms, their approach to inclusion, access to segregated campuses, availability of 1-to-1 support, and whether they have additional support staff.

Disengaged school boards and missing data. School board members often neglect special education. While some are willing to act, they lack data to guide them. Vivian Haun explained, “Data is the official story that policymakers rely on to make decisions about funding for programs that affect your lives every day.”

Inadequate funding. Funding allocated for special education is insufficient due to state and district-level variation and inadequate federal contributions. President Trump’s goal to eliminate the U.S. Department of Education will likely lead to significant new cuts in funding.

According to Lisa Mosko Barros, “Individualized education is underfunded, meaning the federal government doesn’t give states enough money to carry it out,” with upcoming changes to the U.S. Department of Education impacting federal funding even further. She lists four additional systemic failures:

- “Professional development and support for teachers and providers;
- Qualitative data coming directly from students with disabilities and their families;
- Disability awareness, and the 1-2-3 punch of ableism, racism, and language barriers; and
- Accountability for the constant violations of students’ rights.”

Inequitable funding. The state distributes special education funding based on the total number of students — not the number of students with special education needs — in each Special Education Local Planning Area (SELPA). Additionally, funding allocation does not differentiate lower- and higher-needs students; districts receive no additional funds to support students who need intensive or complex accommodations. Additional funds are allocated for students who are foster youth, homeless, come from a low-income family, or for whom English is not a first language, but not for students with disabilities.

Misuse of special education funding. Instead of resolving disputes about special education support at the school site, many districts tend to push families to file for due process, costing districts millions of dollars in legal fees.

Ableism, bias, and policing of behaviors. Very often, children with I/DD are treated as classroom disruptions rather than as learners with different needs. This bias is significantly more common for children of color and stems from a combination of four critical factors:

- Lack of awareness about developmental disabilities
- Slow, missing, or inaccurate diagnoses
- Bias against children who need accommodations
- Poor understanding of cultural and linguistic differences

Recommendations from Conference Participants

Targeted student population. Session participants felt strongly that California state law should designate students with IEPs as a “targeted student population (TSP).” The

designation would include students with disabilities in the district’s Local Control and Accountability Plans (LCAPs), thereby requiring each school to support a special education committee feeding into their local Community Advisory Committee (CAC). These channels for advocacy and input would empower families of students with disabilities to organize across the district and demand action and new, more effective forms of oversight.

Accountability and parental involvement. Conference participants strongly recommended creating special education committees of parents/legal guardians of children with disabilities to actively engage with existing CACs, English Language Advisory Committees, and Parent Advisory Committees. We also call for more robust accountability to ensure that parents are not denied full participation in the development of their children’s IEPs or access to classroom observations.

Educator training. To combat widespread ableism and create more successful, welcoming classrooms, educators need greater awareness, stronger skill sets, and a better understanding of students’ rights. We strongly recommend that the state incorporate special education training focused on best practices and students’ rights under IDEA into:

- Statewide teacher credentialing
- Teacher education at the college level
- Teacher Continuing Education Units (CEUs) that focus on the needs of children with I/DD — including children from different cultural backgrounds
- Training for administrators and school district leaders, including board members



Noah's Story

Chris LyBurtus' son, Noah, needed significant psychiatric and behavioral support from well-trained staff. **What help he received was inconsistent or absent**, with ineffective interventions and medications and years of uncertainty. "I can't even count the number of 72-hour holds," Chris said, "with no real support from the regional center." Instead, regional center staff would reach out to the same facility, send her the same rejection, and tell her to call 911 — a particularly dangerous and alarming prospect for an African-American family.

Chris found help outside the regional center (RC) system, but the cost of private care — and long-term placement in a crisis intervention home — has been steep both financially and emotionally. Just after our conference ended, she was due in court to defend her right to bring Noah home again...still without the support they urgently need.

FOCUS AREA

Regional Centers

Discussion Leaders & Expert Contributors

- **William Del Rosario**, DVU Intern, Self-Advocate
- **Fernando Gomez**, Co-Founder, Integrated Community Collaborative & Board Member, DVU, Parent
- **Chris LyBurtus**, Parent
- **Jesse Weller**, Executive Director, San Gabriel/Pomona Regional Center
- **Amy Westling**, Executive Director, Association of Regional Center Agencies

Bureaucracy As Barrier

Some participants feel helpless. Others, desperate. Many have turned to sources outside the regional center system, often at significant personal expense.

The heart of these problems lies with the system's rigid administrative structure, a legacy of its 1969 creation. California's developmental services system is by far the largest in the country, with a projected 2025-2026 budget of over \$19 billion. The system's 21 regional centers collectively serve more than 500,000 people, but fixed catchment areas create regional inequities, and over the last decade, Latinos received just half the services provided to white counterparts.⁶ Investment in equity programs has achieved only modest

improvement. The most effective solution for many families, particularly in communities of color, is the flexibility to select preferred staff and services through the Self-Determination Program (SDP).

The SDP, however, is under-used, under-promoted, and clogged with bureaucratic barriers.

Discussion Highlights

Systemic racial bias and discrimination.

Participants described sharply varying treatment for different racial and ethnic groups, and for those from varied cultural backgrounds. "Voice has no color...until it does," said one participant. Another noted, "trust is lost because there is discrimination from [RC] staff at all levels and the communication is bad."

Inconsistencies and inequities. The 21 RCs often behave very differently despite the requirements set out in law. There are wide disparities in services between regional centers and among racial groups.

Lack of accountability. The regional centers have historically lacked accountability, which has led to

"You say the regional center is doing a lot of great things... I beg to differ. They're not doing great things. They are intimidating clients, families of clients, and even the Department of Developmental Service employees. Not acceptable."

African-American
Session Participant

poor service coordination, slow processing of eligibility determinations and requests for services, insufficient oversight from the Department of Developmental Services, and counterproductive incentives.

Compliance over outcomes. RCs are too often evaluated based on compliance measures (e.g., filling out paperwork), rather than impact on clients' lives. Similarly, service providers are rewarded for hours worked rather than for outcomes achieved.

Poor communication. Participants talked about frequent breakdowns in communication from RCs and their lack of collaboration with other systems, such as school districts. Many families had trouble finding basic information, such as which services an RC offers.

Compensation and turnover.

All other problems are exacerbated by low wages for frontline RC staff, causing many to eventually leave the system due to poor compensation.

"It's extremely hard for my brothers who are here with me today, and hundreds of other clients, to get the services that they need in our area — especially the more rural parts."

Latino Session Participant



Recommendations from Conference Participants

Accountability for person-centered outcomes.

Assessments of regional centers must shift from measuring compliance — i.e., whether services were provided — to measuring individual outcomes. The current patchwork of assessments, including performance contracts and National Core Indicators Surveys, should be replaced or repurposed to track whether the RC helps clients choose and achieve individualized goals.

"At this point, we can measure spending and people's satisfaction with their services. But those don't equate to outcomes, and they don't tell us whether the service performed its intended function."

Amy Westling

Remove bias and systemic racism. Conference attendees from communities of color stated that the bias they feel is both personal and structural. Multi-step administrative processes disproportionately exclude people of color and those with cultural norms that discourage challenging authority. There was very strong, widespread agreement that the path to receiving services must be simpler and more direct.

Remove the conflict of interest with service coordination. "The first priority is service coordinators," said one participant, "because if they don't do their job well, it's a breakdown for everybody." Participants from communities of color pointed to a specific conflict of interest: service coordinators are, in

theory, both advocates for families and gatekeepers who deny services. Clients want advocates who are 100% on their side — "outside the regional centers and outside the schools."

Make the Self-Determination Program the Core of the Developmental Services System. In addition to dramatically reducing administrative and bureaucratic barriers to participation in the SDP, and making every RC client aware of the program in an unbiased manner, participants advocated for a series of pilot programs expanding the SDP. Suggested expansions included:

- Placing all new RC enrollees directly into the SDP at a few target RCs
- Robust outreach and SDP enrollment among underrepresented groups at selected RCs
- Creating a new RC, one "without walls" (i.e., not limited to a specified catchment area), to exclusively serve participants in the SDP

"I can't tell you the number of times families tell me they don't qualify for regional center services, and meanwhile I'm looking at a clearly autistic 6-year-old who had early intervention and now is trying to get services from their school district."

Session Participant,
Regional Center Employee



Aaron's Story

Panelist Elizabeth Gomez shared the story of Aaron, a boy whose underlying health issue — a severe vitamin A deficiency causing problems with his vision — went untreated because doctors, teachers, and RC staff dismissed his complaints as behavioral symptoms. In the end, Aaron suffered the permanent loss of his sight.

Other participants had more positive stories about health care. Like the local dentist's office where staff played Disney movies and even spoke in character voices to help a young patient with I/DD feel comfortable undergoing treatment. These stories are all too rare, with accessibility limited by a widespread lack of basic training and baseline awareness.

Basic Accommodations Remain Unavailable to Many

Patients with disabilities need more face-to-face time with healthcare providers, but rarely receive it. They are also typically offered fewer options for follow-up care. Fundamentals of accessible health care — such as gradual desensitization for dental procedures — are widely ignored in medical training and licensing. For hospitals, clinics, and doctors' offices, "the licensing requirements around accessible equipment are virtually non-existent," according to session participants, even when the buildings themselves were accessible. Just getting in the door is a challenge for many families, thanks to unnecessarily complex paperwork, referrals, and applications.

The result is a healthcare system with the capacity — but not the inclination — to meet basic health needs for disabled patients.

FOCUS AREA:

Primary and Preventative Health and Dental Care

Discussion Leaders & Expert Contributors

- **Sergio Aguilar-Gaxiola, MD, PhD**, Director, UC Davis Center for Reducing Health Disparities, Parent
- **Dr. Michelle Catanzarite**, Chief Medical Officer, Achievable Clinic
- **Elizabeth Gomez**, Director, Integrated Community Collaborative, Self-Determination Advisory Committee Member, Parent
- **Miguel Lugo**, Outreach Specialist, Disability Voices United, Self-Advocate
- **Nicole D. Vick**, Staff Analyst, Center for Health Equity, Los Angeles County Department of Public Health

Discussion Highlights

Direct discrimination among providers. Session participants described their own experiences being refused routine preventive care and dental care. They referred to research attesting that half of all doctors prefer not to treat patients with disabilities — an already serious problem compounded by the limited number of providers who accept Medi-Cal.

Lack of basic data. Although both official and anecdotal sources confirm severe disparities in healthcare services and outcomes for people with I/DD,^{7,8} poor data quality makes it hard to determine the size of those disparities — or map out appropriate responses. Session facilitator Dr. Michelle Catanzarite said, "If you Google the health disparity in cancer screening rates, you'll see a very wide range of answers to that question. Sometimes it's a 10% difference, other times 45% or 50%."

Appropriate dental care is rare and costly. Some people with I/DD need full anesthesia for routine dental procedures such as exams and cleanings — anesthesia that requires advance clearance from multiple specialist visits. Families often find



themselves "waiting months because they have to go to their Medi-Cal funded cardiologist appointment, [then the] neurologist and pulmonologist," just to get their teeth cleaned. These delays are so long that they cause secondary health problems for some patients.

"People with DD are not seen. And we need whomever is involved in the services to be trained to see people. To treat us with dignity and respect."

Dr. Sergio Aguilar-Gaxiola

Recommendations from Conference Participants

Improved Access to Baseline Healthcare Services.

Conference attendees strongly endorsed organizational and administrative changes to improve accessibility. These included:

- Creating accountability when RCs and service providers fail to meet their obligation to visit and support adults with I/DD living outside their families' homes, particularly those in congregate settings. More broadly, strengthen mandates that regional centers and service providers must coordinate healthcare visits for clients
- Requiring regional centers to hire dental care coordinators
- Increasing Medi-Cal reimbursement rates for treating patients with I/DD and encouraging more specialist providers to accept Medi-Cal payments
- Supporting mobile healthcare providers for preventative and routine care

Training. Another cluster of urgent recommendations focused on training and licensing for medical providers, including:

- Training for healthcare providers by people with disabilities themselves
- Adding desensitization to dental school curriculums
- Instructional training videos on treating patients who have disabilities
- Updating state licensing requirements to include working with disabled patients
- Requiring doctors, dentists, and other healthcare providers to complete continuing education credits focused on caring for people with I/DD

Data Collection. Regional centers and service providers need to track healthcare outcomes for their clients, including avoidable deaths and surgeries, preventable cancer rates, obesity rates, use of psychotropic medications, preventable injuries, abuse, and neglect. This data should be made publicly available.

Participants also agreed that Federally Qualified Health Centers should be required to collect data on whether patients are also regional center clients, providing a more accurate measure of health disparities for people with I/DD.

FOCUS AREA:

Mental Health/Crisis Intervention and Supports

Discussion Leaders & Expert Contributors

- **Aminah Abdul-Hakim**, SDP Independent Facilitator/IRC Local
- **Gwen Jordan**, Clinical Director, Frank D. Lanterman Regional Center
- **Will Leiner**, Managing Attorney, I/DD Practice Group, Disability Rights California, Sibling



Ryan's Story

In 2024, Ryan Gainer, a 15-year-old African American boy with autism, was shot and **killed by San Bernardino County sheriffs** during a behavioral and mental health crisis. His parents had frequently sought help in the past — police had been called to the house five times — but the family never received comprehensive support to prevent future emergencies.



Conference speaker Aminah Abdul-Hakim laid out the ways that Ryan's story served as an example of systemic failure. His school missed opportunities to mobilize resources. Service providers fell short in providing adequate care. And the police failed to de-escalate what should have been a nonviolent situation.

"The crisis support system, be it police, mental health, or regional centers, is reactive when it should be proactive."

Gwen Jordan

Multiple Systems Fail in Mental Health Crises

As many as 10% of police calls involve people with mental health disabilities, but the same group accounts for 20-25% of those killed by law enforcement.^{9, 10, 11, 12}

Black men with behavioral health disabilities face disproportionate risk,¹³ as session discussion leader Will Leiner explained. "They are hurt or killed by law enforcement at a much greater rate than white men who show similar types of disabilities."

Discussion Highlights

Crises are easier to prevent than to resolve. "The way we do that is by training families and self-advocates to develop a circle of support that you call instead of calling 911," explained DVU President Judy Mark. "You are calling people who can actually help you and know you or know your child, know what triggers can be and have a toolkit to improve the situation in the long term."

Police are a bad option — and often the only one available.

RCs contract outside agencies to provide mobile and crisis support, but many participants said they received no help from those agencies when family members were in crisis, leaving the police as their only option.

Police training is not a solution. Sensitivity training for officers is not an effective means

"My friend, Vanessa Marquez, was shot 19 times after a wellness call in 2018. Before, when I tried to call [for services], what I got was 27 questions and reasons why she didn't qualify. So, it's not that nobody calls. Lots of us called. As soon as a family or friend says something, there needs to be an immediate response."

Session Participant

of preventing police violence against people with I/DD. The cautionary messages relayed during training sessions have minimal impact in the context of police departments' internal cultures of aggression and dehumanization, according to self-advocates.

Communities are fearful of the police. Disability looks different in everyone. Family members worry that the police will misunderstand the issue, leading to terrible consequences, particularly for people of color. One participant summarized by saying, "There has to be a way to, at least, let the people that work for law enforcement know that we're not feeling heard and we're not feeling protected by those that claim to be, you know, protection."

Break down silos. Siloes between professionals in mental health, housing, crisis response, and community services negatively impact treatment, care, and quality of life. They also complicate insurance funding, as well as which medical conditions are recognized.

"Thirty to forty percent of people with I/DD also have a mental health disability. And this is greater than the general population, where the rate of mental health disabilities is around 25%. Ten to twenty percent of people with I/DD also have high behavioral support needs."

Will Leiner

Recommendations from Conference Participants

Preventative services. The current siloed systems — mental health care provided by the counties and other services provided by regional centers, with Medi-Cal/insurance paying for psychiatrists — makes it too easy to fall through the cracks. We need to break down the silos to provide wraparound services for people who experience mental health crises.

Build a circle of support. Families need training and proactive support to help them avoid situations where they need to call the police. They need to build a circle of professionals and familiar people to be "on call." Participants also suggested that parents and families dial 988 rather than 911, and that families develop a plan that includes:

- Tools to use when a crisis occurs, such as breathing techniques, proprioceptive input, or calming words
- Medication to give in a crisis
- A psychiatrist and/or behaviorist to call
- Alternatives to restraint that allow individuals in crisis to be safe while retaining their dignity
- Supporters who can help

FOCUS AREA:

Immigration and Language Access

Discussion Leaders & Expert Contributors

- **Aida Amare**, President/Founder, Hope for Special Education, Parent
- **Katherine Perez, JD/PhD**, Director, The Coehlo Center for Disability Law, Policy, and Innovation, Sibling
- **Diana Ugalde-Lara**, Self-Advocate

Luis' Story

As the parent of a child with disabilities, Luis fights to stay in the country so that he can care for his daughter. He was enmeshed in legal proceedings when his immigration lawyer made an error, and the first Trump administration leveraged that mistake to list Luis for deportation. Fighting to stay in the United States and care for his disabled child became far more demanding and dangerous, ultimately costing tens of thousands of dollars.

Like so many of the self-advocates and family members who attended our conference, Luis worries that Trump 2.0 will target anyone who has a record with immigration enforcement for punitive action. Speaking for many in the room, Luis asked, "How can we defend ourselves?" His answer: "We can't get anxious. We can't get frightened. We need to unite with each other."



The Public Charge Rule Threatens Disability Rights

While people have a right to regional center and special education services regardless of immigration status, that right is threatened by the **"public charge rule,"** a policy stating that immigrants must be self-sufficient. Disabled people can potentially be denied a green card if the government makes a presumption that they will be dependent on government benefits. The Biden Administration limited the rule, mandating that a person cannot be prevented from immigrating based on disability alone, but that guidance could change at any moment.

At the conference, we heard from self-advocates waiting to get their green cards. They fear not only for the loss of their dreams of life here in California, but also for their safety if they are deported to countries without disability services and where they often have no one to help them.

Everyone in attendance agreed: we must work together to prepare for what is coming.

Language Access Is a Right, Not an Option

Immigrant participants also highlighted issues around language access. Families have a right to read and sign documents in their preferred language, and to have qualified interpreters present for meetings at RCs and schools.

Those rights are widely ignored, they said, pointing to delays in receiving translated materials that exceed required timelines. They also expressed concerns about the poor quality of interpretation at meetings and hearings — in one case, the translator for a remote hearing was audibly engaged in picking their child up from school while the hearing took place.

Discussion Highlights

Fears of deportation. “Vulnerable populations are fearful,” said one participant. Many spoke out in favor of community-based outreach through trusted individuals or groups such as faith leaders, youth advocates, or community centers.

Legal help is hard to find — and impossibly expensive. Participants reported a lack of attorneys who understand both immigration law and disability rights. Families asked for help finding low- and no-cost immigration attorneys, as well as tools and information to report unscrupulous and predatory legal practices.

Ineffective interpreters block access to services. Many of the interpreters currently working with schools and regional centers lack the technical vocabulary to relay important information about disability rights, education, or regional center services. Many also lack familiarity with specific language dialects.

Cultural competence is missing or inadequate. Staff in both education and disability services must understand the communities they serve. Quality care and effective communication demand a greater degree of cultural knowledge and awareness.

Delays in translated documents lead to delays in services. Participants expressed concerns about long wait times for translated legal documents from schools and RCs. Until those documents are received and signed, their children go without services.

Recommendations from Conference Participants

Ensure confidentiality about immigration status. Regional centers, service providers, and schools must guarantee confidentiality of immigration status of both the individuals and their family members.

Cultural humility with immigrant communities. RCs, school districts, and county social workers must build trust with diverse immigrant communities by providing culturally humble communication and accurate interpretation/translation.

Safety and security. Participants strongly agreed that disability services and immigration officials need formal structures for collaboration and knowledge-sharing. Other important protections include extending the program of humanitarian parole for undocumented parents of children with disabilities, financial support so that families can hire immigration attorneys, and reminders to renew DACA status.

Education and training. Families must be made aware of their fundamental rights and how to take legal action to protect themselves. This information must be:

- Widely accessible
- Written in multiple languages
- Employing plain language and visual aids
- Disseminated through print, digital, and community channels

At the same time, disability services providers need education on public charge concerns, while immigration attorneys need access to training on disability rights.



Notes

- 1 Aylward, B. S., Gal-Szabo, D. E., & Taraman, S. (2021). Racial, ethnic, and sociodemographic disparities in diagnosis of children with autism spectrum disorder. *Journal of Developmental & Behavioral Pediatrics, 42*(8), 682-689.
- 2 Gallegos, A., Dudovitz, R., Biely, C., Chung, P. J., Coker, T. R., Barnert, E., ... & Nelson, B. B. (2021). Racial disparities in developmental delay diagnosis and services received in early childhood. *Academic Pediatrics, 21*(7), 1230-1238.
- 3 Fuller, E. A., & Kaiser, A. P. (2020). The effects of early intervention on social communication outcomes for children with autism spectrum disorder: A meta-analysis. *Journal of Autism and Developmental Disorders, 50*(5), 1683-1700.
- 4 Daniolou, S., Pandis, N., & Znoj, H. (2022). The efficacy of early interventions for children with autism spectrum disorders: A systematic review and meta-analysis. *Journal of Clinical Medicine, 11*(17), 5100.
- 5 Maksimović, S., Marisavljević, M., Stanojević, N., Čirović, M., Punisić, S., Adamović, T., Đorđević, J., Krgović, I., & Subotić, M. (2023). Importance of Early Intervention in Reducing Autistic Symptoms and Speech-Language Deficits in Children with Autism Spectrum Disorder. *Children, 10*(1), 122.
- 6 Disability Voices United. (2022, Oct 26). **A Matter of Race and Place: Racial and Geographic Disparities Within California's Regional Centers Serving Adults with Developmental Disabilities.**
- 7 Videlefsky, A. S., Reznik, J. M., Nodvin, J. T., & Heiman, H. J. (2019). Addressing health disparities in adults with developmental disabilities. *Ethnicity & Disease, 29*(Suppl 2), 355.
- 8 Pham, H. H., Benevides, T. W., Andresen, M. L., Bahr, M., Nicholson, J., Corey, T., Jaremski, J., Faughnan, K., Edelman, M., Hernandez-Hons, A., Langer, C., Shore, S., Ausderau, K., Burstin, H., Hingle, S., Kirk, A., Johnson, K., Siasoco, V., Budway, E., Kit-Wells, M., et al. (2024). **Advancing health policy and outcomes for people with intellectual or developmental disabilities: a community-led agenda.** In *JAMA Health Forum* (Vol. 5, No. 8, pp. e242201-e242201). American Medical Association.
- 9 Fuller, D., Lamb, H., Biasotti, M., & Snook, J., (2015). Overlooked in the Undercounted: **The Role of Mental Illness in Fatal Law Enforcement Encounters.** *Treatment Advocacy Center.*
- 10 Lanionu, A., & Goff, P. A. (2021). Measuring disparities in police use of force and injury among persons with serious mental illness. *BMC Psychiatry, 21*, 1-8.
- 11 Saleh, A. Z., Appelbaum, P. S., Liu, X., Stroup, T. S., & Wall, M. (2018). Deaths of people with mental illness during interactions with law enforcement. *International Journal of Law and Psychiatry, 58*, 110-116.
- 12 Lineberry, S., Bogenschutz, M., Broda, M., Dinora, P., Prohn, S., & West, A. (2023). Co-Occurring Mental Illness and Behavioral Support Needs in Adults with Intellectual and Developmental Disabilities. *Community Mental Health Journal, 59*(6), 1119-1128.
- 13 Ross, C. T., Winterhalder, B., & McElreath, R. (2021). Racial disparities in police use of deadly force against unarmed individuals persist after appropriately benchmarking shooting data on violent crime rates. *Social Psychological and Personality Science, 12*(3), 323-332.

- 8:00-8:30 am **Registration**
- 8:30-8:45 am **Welcome**
- 8:45-9:15 am **Keynote**
What You Have to Know About Equity for People with Intellectual and Developmental Disabilities
 Sergio Aguilar-Gaxiola, MD, PhD, Director, UC Davis Center for Reducing Health Disparities, Parent
- 9:15-10:00 am **Panel**
We Know What We Know
 Individuals with I/DD and families who face disparity speak about their experiences and the barriers they face.
- Aminah Abdul-Hakim, SDP Independent Facilitator/IRC Local
 - Kyungshil Choi, Founder, Korean SDP Network, Parent
 - Julie Diep, Founder and President, OC Autism Foundation, Self-Advocate and Parent
 - Elizabeth Gomez, Director, Integrated Community Collaborative, Self-Determination Advisory Committee Member, Parent
 - Chris LyBurtus, Parent
 - Oscar Mercado, Communications and Outreach Manager, Integrated Community Collaborative, Self-Advocate
- 10:10-11:10 am **Panel**
We Know We Don't Know Everything
 Advocates and researchers on the lack of data, transparency and information needed to develop meaningful solutions.
- Victor Duron, Director, Master Plan on Developmental Services
 - Vivian Haun, Senior Policy Attorney, I/DD Practice Group, Disability Rights California, Sibling
 - Alison Morantz, Director, Stanford I/DD Law and Policy Project, Parent
 - Amy Westling, Executive Director, Association of Regional Center Agencies

- 11:15 am-12:15 pm **Breakout Sessions**
Ideas Exchange: Creating Solutions for Equity Together
 The breakout sessions provide an opportunity for the attendees to work together to develop policy solutions to longstanding inequities in the systems that are supposed to support people with I/DD.
- Primary and Preventative Health and Dental Care**
- Dr. Michelle Catanzarite, Chief Medical Officer, Achievable Clinic
 - Miguel Lugo, Outreach Specialist, Disability Voices United, Self-Advocate
 - Nicole D. Vick, Staff Analyst, Center for Health Equity, Los Angeles County Department of Public Health
- Regional Centers**
- William Del Rosario, DVU Intern, Self-Advocate
 - Fernando Gomez, Co-Founder, Integrated Community Collaborative & Board Member, DVU, Parent
 - Jesse Weller, Executive Director, San Gabriel/Pomona Regional Center
- Education**
- Lisa Mosko, Founder and CEO, SpEducational, Parent
 - Diana Pastora Carson, Educator, San Diego State University, Author, Podcaster, DVU Board Member, Sibling
 - Nicole Voisard, Self-Advocate
- Mental Health/Crisis Intervention and Supports**
- Gwen Jordan, Clinical Director, Frank D. Lanterman Regional Center
 - Will Leiner, Managing Attorney, I/DD Practice Group, Disability Rights California, Sibling
 - Hector Manuel Ramirez, Councilmember, Intertribal Disability Advocacy Council, Member, California Department of Health Care Service Behavioral Stakeholder Advisory Committee, Self-Advocate

- 11:15 am-12:15 pm **Breakout Sessions (continued)**
Immigration and Language Access
- Aida Amare, President/Founder, Hope for Special Education, Parent
 - Katherine Perez, JD/PhD, Director, The Coehlo Center for Disability Law, Policy, and Innovation, Sibling
 - Diana Ugalde-Lara, Self-Advocate
- Diagnosis and Early Intervention**
- Marcos Aguilar, Jr., Director, Clinical and Intervention Services, Special Needs Network
 - Kathleen Barajas, President, Project AIR, Chair, Metro Accessibility Advisory Committee, Self-Advocate
 - Silvia Hernandez-Cuellar, OTD, OTR/L, Pediatric Occupational Therapist, Nurture Collective
- 12:15-1:15 pm **Lunch and Award Ceremony**
Disability Equity Award Presented to Dr. Mark Ghaly
 Former Secretary, California Health and Human Services Agency
- 1:20-2:20 pm **Breakouts**
Ideas Exchange: Creating Solutions for Equity Together
- Breakout sessions repeat from the morning
- 2:30-3:30 pm **Final session**
Equity Solutions Reality Check
- Presentation of top recommendations for policy solutions to disparities with “reality check respondents,” people with lived and living experience



Acknowledgments

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Sponsors

This conference would not have been possible without the generous support of our sponsors. Your commitment to equity and inclusion has helped bring together advocates, policymakers, and community leaders to advance policies that support all Californians with intellectual and developmental disabilities.

- **Association of Regional Center Agencies**
- **Easterseals**
- **Aveanna Support Services**
- **Public Partnerships/PPL**
- **Tierra Del Sol Foundation**
- **WAYMO**
- **WITH Foundation**
- **Korean SDP Network**
- **Mains'l**
- **Path-Now**
- **Ritz FMS**
- **State Council on Developmental Disabilities**



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