

California: Spotlight on Augmentative and Alternative Communication (AAC) in Supported Decision-Making Advocacy

Background

Communication access is foundational to self-determination, especially for people who rely on augmentative and alternative communication (AAC). Without access to AAC, a person can experience profound barriers to expressing their choices, preferences, and decisions. Too often, people with communication access needs are denied the supports and accommodations that are critical for making their own decisions and directing their own lives.

As part of the Center on Youth Voice, Youth Choice (CYVYC), State Teams created action plans that identified youth-led strategies to advance alternatives to guardianship. [The California State Team \(CST\)](#), a member of the third cohort of State Teams, made communication access a central pillar of their action plan.

This effort has been driven by the strong advocacy of three Youth Ambassadors, Otto Lana, [William Del Rosario](#), and [Bella Santoyo](#), who are AAC users and formed the advocacy group [Mod Squad 4 Access](#). As part of the CST, co-led by [Disability Rights California \(DRC\)](#), they have prioritized supported decision-making (SDM) and communication access policy and practice changes. Their work has resulted in meaningful reform and education within the intellectual and developmental disabilities (IDD) service delivery system, the courts, and the education system.

Implementation

[CommunicationFIRST](#), a CYVYC National Coalition member, [defines AAC](#) as “all forms of communication other than speech, like gestures, eye gaze, vocalizations, facial expressions, and body positioning. *“Language-based AAC,” in turn, is defined as “any form of AAC that allows the person to communicate using words, such as alphabet boards, speech-generating devices, keyboards, and human revoicers.”*

AAC users are regularly left out of decisions about their own lives. As Otto Lana stated:

“There is a false assumption that individuals without oral fluency are incapable of decision - making, or having opinions, or critical thinking in any way shape or form. We are taught from a very young age to comply with the adult in the room. We are taught to never complain because complaining is not complying. We are punished for wanting something else, wanting more. So, it is no surprise that by 18 we have become an empty shell, incapable of decision - making or expressing anything at all because our thoughts were left unexpressed for years...Society is shocked to learn we are so much more under the surface.”



Otto, Bella, and William met with Speech-Language Pathology graduate students at Cal State San Marcos to discuss augmentative and alternative communication (AAC).

Systems serving AAC users often fail to respect or meet their communication needs. Courts may presume AAC users cannot communicate at all and impose guardianships (known in California as “conservatorships”), schools may hold low expectations and channel students into segregated programs, and IDD service systems may neglect to provide needed accommodations. Recognizing these barriers, and propelled by the MOD Squad 4 Access’ advocacy, the CST integrated communication access into SDM systemic reforms.

In 2022, California passed the “Probate Conservatorship Reform and Supported Decision-Making Act.” The law recognized SDM as a less-restrictive alternative to conservatorship, required courts to consider SDM before imposing conservatorships, and created a technical assistance program with grants and training to expand the use of SDM. Guided by its statewide action plan, the CST achieved coordinated reforms linking communication access and SDM across IDD services, courts, and education systems.



Otto, Bella, and William traveled to Sacramento to speak with lawmakers about improving access and support for communication, and to advocate for increased funding for support staff who assist individuals with communication needs.

Advocacy within the IDD Service Delivery System

Recognizing California’s plans to reform its IDD service delivery system, the CST seized two key opportunities to embed communication access and SDM into policy.

First, in 2024, the California Health and Human Services Agency began developing a [“Master Plan for Developmental Services”](#) to improve supports for people with IDD and their families, aiming to make services more person-centered, equitable, and data-driven. CST members from DRC and Disability Voices United were appointed to the Master Plan Committee. With their advocacy and feedback from Youth Ambassadors like William del Rosario, the plan—finalized in March 2025—recognized that: (1) regional centers, which provide assessments and case management services and determine eligibility for Department of Disability (DDS) services, must provide AAC and other accommodations to ensure access, (2) AAC devices must be supported in public and government spaces, and (3) AAC users must receive support they need to report abuse and neglect within the IDD system.

Second, the CST pushed to include communication access and decision-making supports in the DDS person-centered planning template. The [revised template](#) now asks how a person communicates, what others should know about communicating with them, and who they want as supporters. [DDS’s Person-Centered Planning Guide](#) also outlines strategies to ensure AAC users receive needed communication supports.

Advocacy in the Court System

In California, court investigators meet with individuals who may be subject to conservatorship and recommend to the judge whether one is needed. The CST recognized that educating those investigators about communication access and SDM is critical for preventing unnecessary conservatorships. In May 2025, the CST presented “Supported Decision-Making and Communication Access” at the California Association of Superior Court Investigators. The training was well attended, with participants noting they gained a deeper understanding of SDM and its real-life impact.

Advocacy within the Education System

Another component of the CST's work was incorporating SDM and communication access into special education transition planning and educating teachers and school professionals. The team partnered with the Center for Applied Special Technology (CAST) to develop guidelines for K-12 schools on creating inclusive environments, including for AAC users. These guidelines aim to reduce barriers to inclusion and ensure students' chosen communication systems are fully honored and valued. Youth Ambassadors played a key role in shaping the guidelines, emphasizing access to AAC. As a result, CAST released its updated [Universal Design for Learning Guidelines 3.0](#) in summer 2024, addressing biases related to expression and communication, including AAC.

Youth Ambassadors also engaged in direct outreach to educators about communication access and SDM. William Del Rosario and Bella Santoyo educated the Whittier School District's transition team on the importance of AAC and SDM for transition-aged youth. Otto Lana and Bella Santoyo also presented to Los Angeles-area educators and therapists, sharing personal experiences to help improve educational supports for AAC users.

Impact

Through advocacy, the CST ensured IDD person-centered planning documents affirm the right to communication access and decision-making. CST prompted courts and investigators to ask not just "can this person communicate?" but "what supports have they been offered?" and "is conservatorship appropriate?" Their work also led schools to incorporate SDM into transition planning and curricula. The next generation of policy leaders—youth AAC users—had a direct impact on systems change.

Suggestions for Replication

- » **Center people with lived experience.** AAC users must drive the change they want to see, and projects should compensate them for their expertise and vision.
- » **Take advantage of policy opportunities.** In California, passage of an SDM law created momentum for broader reform and input from the CST.

» **Build alliances.** The CST worked with state staff, self-advocates, family members, and legal advocates. This diverse coalition helped policymakers see the bigger picture through many perspectives.

» **Think systems, not just services.** SDM and AAC are not one-time interventions but principles and frameworks that must be embedded across courts, service systems, schools, and beyond.

» **Develop strategies to overcome resistance to change.** People can mistake not being able to speak for incompetence. Youth Ambassadors can shift mindsets and hearts. As Otto Lana said:

"We are attempting to make a seismic shift in institutions that believe disabled people need to be cured or cared for... Change is hard. But you know what else is hard? Diamonds. I choose hard. I choose to shine bright like a diamond. No bloated bureaucratic system will dull my shine. My shine will illuminate a path for others to follow."

» **It's a marathon, not a sprint.** As Otto Lana added:

"AAC and SDM are not easy... You will fall down ... But you must get back up. Human rights are at stake. Disabled people are people first and foremost and we have the right of freedom of choice to live our authentic lives."

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www.disabilityrightsca.org



The Kimmel Family Foundation Annual Neurodiversity Conference was held at the Sanford Consortium for Regenerative Medicine on UC San Diego's campus. Sponsored by the Autism Tree Project Foundation, a local San Diego nonprofit, the event featured Otto, Bella, and William presenting on authentic representation of disability in media. Their goal: to help change perceptions of disability.



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What is the Center on Youth Voice, Youth Choice?

At the Center on Youth Voice, Youth Choice, we work with youth with IDD, families, and supporters. We share information about alternatives to guardianship. Youth with IDD lead projects about alternatives to guardianship. We believe that you have the right to make your own decisions about your life!

[Visit the Center on Youth Voice, Youth Choice website](#) to learn more about *alternatives to guardianship* and what these words mean.

[Visit the Center for Public Representation's website](#) to learn more about *supported decision-making*.

Do you have more questions about this fact sheet and guardianship?

Please email the Center on Youth Voice, Youth Choice team at **youthvoice@umb.edu**