

2021 – 2022 |



SSAN Annual Report

The Statewide Self-Advocacy Network (SSAN)



The 2021 – 2022 SSAN Annual Report was produced by the California State Council on Developmental Disabilities



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About SCDD

The California State Council on Developmental Disabilities (SCDD) is established by state (Lanterman Developmental Disabilities Services Act or Lanterman Act) and federal (Developmental Disabilities Assistance and Bill of Rights Act of 2000 or DD Act) law and is one of 56 State Councils on Developmental Disabilities within the U.S. and its territories. SCDD belongs to the National Association for Councils on Developmental Disabilities (NACDD), which provides guidance and support to all 56 Councils. Growing and supporting self-advocacy is a core principle for every State Council, as identified by the DD Act.

SCDD designated 'Self-Advocacy' as the focus for its first goal in the new 2022 – 2026 5-year state plan and is committed to supporting self-advocacy in California. To meet its commitment to establish and strengthen a program led by individuals with intellectual and developmental disabilities, develop and promote leadership skills, and expand participation in a cross-disability coalition, SCDD created the Statewide Self-Advocacy Network (SSAN) in 2012. Through supporting SSAN, SCDD aims to help self-advocates throughout California advocate for their civil and service rights and be integrated and included in all areas of community life. SCDD supports the efforts of SSAN members to be leaders in their communities.

About SSAN

The Statewide Self Advocacy Network (SSAN) promotes leadership and builds bridges that strengthen advocacy among disability communities by focusing on policy change.

Vision Statement

SSAN is a cross-disability network of self-advocates that was established in 2012 and works to do the following:

- Develop the knowledge and skills to make a difference in our region and state
- Speak up for all people with disabilities.
- Learn about and advocate for issues important to all people with disabilities
- Lead regional and statewide advocacy groups and networks
- Train advocates in their communities to grow the Self-Advocacy movement in California
- Share information about programs and supports for people with disabilities

Agency Connections



[California State Council on Developmental Disabilities](#)



[California Department of Developmental Services](#)



[California Foundation for Independent Living Centers](#)



[Association of Regional Center Agencies](#)



[Disability Rights California](#)

California UCEDDs



[UCLA Tarjan Center](#)

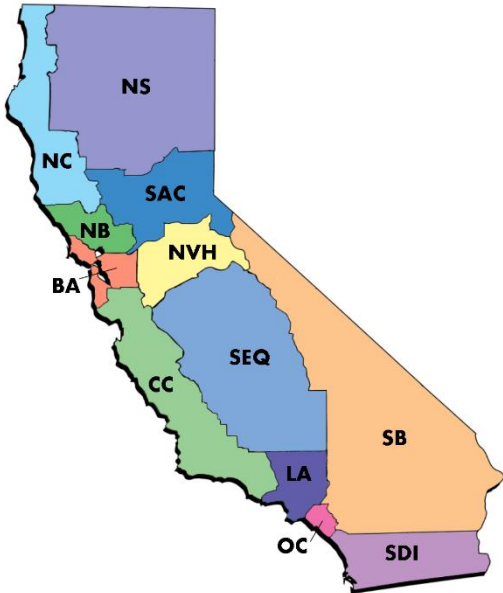


[USC Children's Hospital](#)



[UC Davis MIND Institute](#)

SSAN Members (Roster) 2021–2022



- North Coast Region – Nathaniel Florez
- North State Region – Charles Nutt
- Sacramento Region – Lisa Cooley
- North Bay Region – Ellen Sweigert
- Bay Area Region – Regina Woodliff
- North Valley Hills Region – Robert Balderama
- Central Coast Region – David Forderer
- Sequoia Region – Rebecca Donabed
- Los Angeles Region – Julie Gaona
- Orange County Region – Sean Sullivan
- San Bernardino Region – Daniel Fouste/
Eric Aguilar
- San Diego Imperial Region – Paul Mansell



- Association of Regional Center Agencies – Desiree Boykin
- California Foundation of Independent Living Centers – Russell Rawlings
- Department of Developmental Services – Nicole Patterson
- Disability Rights California – Scott Baron
- State Council on Developmental Disabilities –
 - Matthew Lagrand
 - Maria Marquez
- University Center on Excellence in Developmental Disabilities
 - UC Davis MIND Institute – Robert Levy
 - UCLA Tarjan Center – Kecia Weller
 - USC Children’s Hospital – Wesley Witherspoon

Message from the Officers

Thank you for electing us to serve as your SSAN Officers for 2020-2022. As your SSAN Officers, we were committed to continuing the important self-advocacy work of SSAN to make sure that people with disabilities are included in society and able to live meaningful lives. The great part about SSAN is that it connects advocates from across the state and opens doors to opportunities of collaboration. During the past 2 years, the SSAN Officers and Workgroup Chairs have helped to support SSAN members stay connected through these difficult times. We hope to continue supporting the vision of building a solid SSAN identity by supporting the next officers in building cross-disability partnerships and working collaboratively with the workgroups to support SSAN projects.

The need for self-advocacy, leadership and social engagement continues to be clear as new variants of COVID-19 and different health concerns come about, and as we continue to face both climate-related and social justice concerns. As the outgoing leadership team of SSAN, we hope to help the next SSAN Officers to support members during these uncertain times. We want to thank both SSAN members and our supporters for their hard work in and commitment to supporting self-advocacy. During these challenging times, it is important to support each other by showing compassion and appreciation.

Over the past year, SSAN members have worked together to advocate for access to COVID-19 vaccines, provide plain language public health and safety information, and end the practice of paying subminimum wage to people with I/DD in California. We, as the outgoing SSAN Officers, plan to continue to work together with the next leadership team to support members during ongoing public health challenges and other social issues. Thank you for your continued advocacy and participation in SSAN.

Desiree Boykin (Chairperson)



Desiree has been the Consumer Advocate at South Central Los Angeles Regional Center since 2011. She has a BA in Health and Human Services and is passionate about helping people access the resources they need to reach their goals. Desiree also serves on the Association of Regional Center Agencies' Client Advisory Committee (ARCA CAC). The ARCA CAC elected her to serve as their representative to the SSAN.

Desiree would like to take a moment to thank members for electing her to serve as the SSAN Chair from 2020 – 2022. The experience has been a very humbling experience. I thought that I would have had a chance to chair at least one meeting in person, like former SSAN chairs. COVID-19 changed that possibility, as the option to have an in-person meeting wasn't going to happen, so Zoom became the only way to have our meetings. All of us did our absolute best to participate and be patient with each other, as we learned the importance of having a good Wi-Fi connection to have a clear Zoom meeting. As much as we could while trying to keep outside distractions and noise at bay, we had to create Zoom guidelines. The speakers that presented did a wonderful job on various topics. I'm glad to have good fellow Officers, with Vice-Chair Paul Mansell, the San Diego Regional Representative, and Secretary Robert Levy, the UC MIND Institute Representative. I would like to thank all of you for your dedication to being a part of the SSAN during the pandemic. Thank you everyone and have a wonderful holiday season.

Paul Mansell (Vice-Chairperson)

Paul graduated with both a BA in Political Science and an MA in Educational Technology from San Diego State University (SDSU). Paul has worked as the Client Information Specialist at the San Diego Regional Center (SDRC) for 20 years, supporting self-advocacy in San Diego and Imperial Counties. He has been pleased to serve SSAN as Vice-Chairperson this past year. This role has built on his leadership experience with San Diego People First. Paul enjoys writing about the importance of self-advocacy and now has a blog at <https://self-advocacy.blog>.



Paul is excited that SSAN is getting increasingly involved in social justice issues like affordable housing and criminal justice reform. He feels that fighting for social justice is at the heart of what SSAN is all about. There are so many issues that fall under the umbrella of social justice. Paul hopes that next year SSAN will address the issue of environmental justice. Paul is proud of all SSAN has achieved this year, while working as a team. SSAN continues to navigate the pandemic and looks forward to the day when things can return to normal.

Robert Levy (Secretary)



Robert has worked at the UC Davis MIND Institute UCEDD since 2011 and has been a part of SSAN since it began in 2012. Robert has enjoyed being a part of the 2020–2022 Officers team, as it has allowed him to increase his leadership role within SSAN. Robert enjoys mentoring other SSAN members and helping self-advocates speak up for themselves. Robert enjoys educating others about employment issues for people with disabilities, the importance of competitive integrated employment (CIE), and ending subminimum wage practices for people with disabilities.

Robert has advocated at both state and federal levels for disability-related topics like self-determination, supported decision-making and employment-related legislation. Robert is grateful for the opportunity to be a part of the SSAN Leadership team and hopes to continue to support people with disabilities in leadership roles.

2021–2022 SSAN Meetings

SSAN held 4 meetings between October 1, 2021 and September 30, 2022. Meetings were held virtually, using Zoom due to the ongoing COVID–19 Pandemic. At meetings, members raised concerns about issues and concerns in their regions, were updated on legislative activity, participated in trainings on resources, systems, and strategies, and were encouraged to share what they learned in their communities. Some highlights include:

- Training:
 - Special Olympics “Spread the Word to End the Word”
 - Authentic Disability Representation in the Media
 - Understanding Disability Justice
 - Self-Care Strategies
 - The Role of Stories in the Disability Rights Movement
 - CalABLE
 - Choosing Your Advocacy Style
 - Importance of the Disability Vote in Elections
- Provided feedback on:
 - SCDD DAC training on Disability acceptance in the workplace
 - DDS special incident reporting categories
 - California Department of Public Health COVID-19 information
 - SCDD Webpages
- Informed on issues:
 - SCDD-supported legislation and agency updates
 - COVID-19 and other public health concerns
 - Efforts to end subminimum wage in California
- Discussions/Conversations:
 - Impact of the ADA on people with disabilities
 - Race, Disability, Equity, Inclusion, and Social Justice
 - Self-Determination Program

2021–2022 SSAN Approved Materials and Member Projects

- Reviewed and Approved
 - Minutes from 4 full SSAN meetings
 - Minutes from workgroup meetings
 - 2020-2021 SSAN Annual Report
 - Reviewed and approved 4 editions of the SSAN newsletter
- Projects and Collaborations
 - Department of Developmental Services (DDS) projects
 - Updated SSAN presentations
 - UC Davis MIND Institute PAIR Projects
 - Created a SSAN Youth Seat
 - Participated on SCDD Disability Expert Advisory Panels (DEAPs)
 - Developed the [SSAN Transition Employment Survey](#)

SSAN Members are regularly asked to participate in events and present at conferences because they are strong leaders in their communities across the state and throughout the nation.

- Members' Presentations and Project Topics:
 - Grieve the Loss of a Loved One
 - Diversity, Equity, and Inclusion
 - Self-Advocacy
 - Self-Determination
 - Healthy Relationships
 - Conversations with Medical Students

Reflections from SSAN Members



“I appreciate all the training and guidance SSAN members provide during each meeting and the respect that is given to each member when sharing their ideas. I would like to see SSAN include the younger generation in the self-advocacy movement. My wish for SSAN is that the group continues our hard work while maintaining flexibility and understanding. The way we provide self-advocacy may not be what the future generation is interested in.”

– Scott Barron, Disability Rights California Representative

“SSAN is important to me because it is a network of individuals who have a similar goal to teach self-advocacy and to become stronger leaders for individuals with disabilities in their communities throughout California and even nationally.”

– Charles Nutt, North State Regional Representative



“SSAN is important because it provides members a chance to share their thoughts and concerns for the developmental disability community in California. I am excited about expanding SSAN and the Self-Advocacy Movement to help the next generation of people who have developmental disabilities”

– Lisa Cooley, Sacramento Regional Representative



“Technology has been a game-changer for people with disabilities during this pandemic. Zoom and other platforms have allowed self-advocacy groups like SSAN to meet and advocate for change. I feel that SSAN has provided a safe space for self-advocates to be themselves and learn about topics that affect their lives. SSAN is a community of people who have unique talents and want to support each other to live their best lives.”

– Julie Gaona, Los Angeles Regional Representative



SSAN Reflections: Collaborating with Regional Offices to Respond to Community Needs

The COVID—19 pandemic continues to impact the way SSAN members are able to work in their communities and advocate for issues that are important to them. During 2021 and 2022, SSAN members worked with SCDD Regional Offices to put on virtual trainings and distribute personal protective equipment (PPE) to Californians with intellectual and developmental disabilities and their families. Key takeaways included:

“Being active in your community is an important part of self-advocacy and connecting with the North Bay Regional Office has helped me to work with communities and other self-advocates to grow the self-advocacy community in the North Bay. Through working with the regional office, I am able to grow a self-advocacy community that includes families, professionals AND self-advocates. The inclusion of all is highly important for the communities that we live in.”

❖ Ellen Sweigert, North Bay Regional SSAN Representative



“I have been working with the Regional Office to conduct outreach to the younger generation and am excited that the SSAN is interested in engaging youth with disabilities in 2022.”

❖ Kecia Weller, UCLA TARJAN Center UCEDD SSAN Representative



2021–2022 Member Highlights

SSAN Members participate in Coalitions, Boards and Planning committees throughout California along with providing self-advocates, family advocates and others with trainings related to increasing self-advocacy and access to community supports. Highlights from members during the 2021 – 2022 reporting period include:

- Participating on SCDD Regional Advisory Committees (RACs)
- Participating actively in virtual governance meetings
- Organizing, attending and presenting at the following conferences:
 - People First (PF) gatherings (Virtual)
 - Disability Rights California’s “Black & African-American Conference” (Virtual)
 - CHOICES Conference (Virtual)
 - California Statewide Self-Advocacy Conference (Hybrid)
 - Disability Vote California trainings and chats (Virtual)
 - Regional Self-Advocacy chats (Virtual)
- Collaborating on the UC Davis MIND Institute PAIR Project
- Serving on regional center Boards of Directors, IHSS Public Authority, transportation Boards, and in People First groups
- Sharing their stories with Legislators in support of SB 639 and the importance of ending subminimum wage in California
- Working with regional centers on Coordinated Future Planning Taskforces
- Collaborating with SCDD Regional Offices to give regional and statewide trainings
- Collaborating with SCDD Regional Offices to distribute personal protective equipment (PPE)
- Giving presentations and informing their communities about SSAN
- Giving presentations on the Self-Determination Program



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