SSAN Annual Report

The Statewide Self-Advocacy Network
The 2020 – 2021 SSAN Annual Report was produced by the California State Council on Developmental Disabilities

California State Council on Developmental Disabilities
3831 North Freeway Blvd. Suite 125
Sacramento, CA 95834
916-263-7919
2020-2021 SSAN Annual Report

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The California State Council on Developmental Disabilities (SCDD) is established by State (Lanterman Act) and Federal (Developmental Disabilities Assistance and Bill of Rights Act of 2000) and is one of 56 State Councils on Developmental Disabilities within the US and its territories. SCDD belongs to a national association called the National Association for Councils on Developmental Disabilities (NACDD) that provides guidance and support to all 56 State Councils. Growing and supporting self-advocacy is a core principal for every State Council as identified by the Developmental Disabilities Act of 2000.

SCDD has designated self-advocacy as the first goal in its new State Plan and is committed to supporting self-advocacy in California. To meet their commitment to establishing and strengthening 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 in 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 in order to grow the Self-Advocacy movement in California.
• Share information about programs and supports for people with disabilities.
Agency Members

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) 2020–2021

- North Coast Region – Nathaniel Florez
- North State Region – Teresa Moshier
- 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
- San Diego 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 –
  - Wesley Witherspoon
  - Matthew Lagrand
- 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 during the December 2020 meeting. As your SSAN Officers, we are committed to continuing the important self-advocacy work of SSAN in order to make sure that people with disabilities are included in society and able to live a meaningful life. We are here to help and support both new and long-time members. We hope to contribute to building a solid SSAN identity through building cross-disability partnerships and working collaboratively with the workgroups to support SSAN projects.

The need for self-advocacy, leadership and social engagement is clear as the COVID-19 pandemic continues to present new challenges, and as we continue to face climate-related and social justice concerns. As the new leadership team of SSAN, we hope to learn from former SSAN Officers in order to support members during these uncertain times. We want to thank both SSAN members and our supporters for their hard work 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, plain language public health and safety information, and the ending of subminimum wage practices in California for people with I/DD. We, as the SSAN Officers plan to continue to work together address and respond to concerns related to ongoing COVID–19 and other social issues. Thank you for your support as your new SSAN Officers.
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 for the SSAN.

Desiree would like to thank SSAN members for the opportunity to serve as Chair from December 2020–December 2022. She served as the SSAN Vice-Chair from 2018-2020 and hopes to support SSAN in increasing conversations about social justice issues. She is grateful for the opportunity to work with all of you and looks forward to seeing SSAN continue to advocate for many young and older adults with developmental disabilities throughout California and encourage people with disabilities to get involved in creating positive change.

Paul Mansell (Vice-Chairperson)

Paul graduated with both a BA in Political Science and an MA in Educational Technology from 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 increasingly getting 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. This year, SSAN members wrote letters of support for SB 639, which will phase out the subminimum wage. There are so many of 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 look 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 is passionate about educating others about employment issues for people with disabilities and 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 Employment First Policy (California), Self-Determination, Supported Employment, and ending subminimum wage practices across the USA. Robert is grateful for the opportunity to be a part of the SSAN Leadership team and will be drawing from his experience as a leader with California Autistic Self-Advocacy (CASA), formerly Autistic Self-Advocacy Network (ASAN), to help grow SSAN.
2020 – 2021 SSAN Meetings

SSAN held 4 meetings between October 1, 2020 and September 30, 2021. The meetings were held virtually using Zoom. Each SSAN meeting included member reports on issues and concerns in their regions, legislative updates, training for members, and resources to distribute to member’s communities. Highlights from Meetings include:

➢ Trainings:
  o Alternative Delivery of Nonresidential Services
  o Emergency Preparedness
  o Conflict Resolution Training
  o COVID-19 Vaccine Hesitancy
  o Accessible, Affordable, Housing Options
  o Importance of Disability Vote and Governor Recall Election

➢ Informed on Issues:
  o SCDD Supported Legislation and agency updates

➢ Discussions/Conversations:
  o Race, Disability and Social Justice
  o Hopes and Dreams
  o Vaccine Equity and Hesitancy

➢ Workgroup Projects
  o Employment Panel of people with disabilities
  o Developed and Distributed the SSAN Youth Survey

➢ Reviewed and Approved
  o Meeting Minutes from 4 full SSAN Meetings and workgroup meetings
  o 2019-2020 SSAN Annual Report
  o Reviewed and approved 4 editions of the SSAN Newsletter
Reflections from SSAN Members

“SSAN is my passion and goes a long way to define my identity. It gives me opportunities to practice my leadership, communication, and social skills. I love to write articles for its newsletter. It gives me the opportunity to explore my understanding of self-advocacy, and helps me grow and appreciate acceptance, tolerance, diversity, inclusion, and interconnectedness. It has expanded my appreciation for social justice and activism.”
– Paul Mansell, San Diego

SSAN means being a part of a community that helps people with disabilities in California find their voice and share their experiences to effect change.”
– Wesley Witherspoon, USC Children’s Hospital UCEDD Representative

“The Statewide Self-Advocacy Network is important because it provides a voice 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 gamechanger for people with disabilities during this pandemic. Technology like Zoom has allowed self-advocacy groups like SSAN to meet and advocate for change. I feel that SSAN has provided a safe space and knowledge for all people with developmental disabilities to live and strive.”
– Julie Gaona, Los Angeles Regional Representative
Reflections on Subminimum Wage and Passage of CA Senate Bill 639

Members of SSAN participated in SCDD’s statewide efforts to end the practice of subminimum wage in California by writing letters, submitting stories, and sharing information on podcasts to educate lawmakers on the importance of passing SB 639. Here are a few members thoughts on why passage of SB 639 matters for Californians with I/DD:

“I used to work at Pride Industries where I worked for $.33/hour for about 2 years. When I got employee of the month, I asked them if I would be able to get a real job and was told no. So, I quit the workshop and was able get a part-time job making minimum wage. I now have 2 jobs!”
❖ Robert Levy, UC Davis MIND Institute, UCEDD SSAN Representative, to learn more about Robert’s employment story, check out his radio interview featured on the podcast Cross Streets Vol 8.

“Many years ago, I worked in a sheltered workshop. I don’t remember how much I was making, but I remember thinking that I should have been making more money. I left that job because it wasn’t right to be paid less than minimum wage for my work.”
❖ Regina Woodliff, Bay Area Regional SSAN Representative

“It’s a relief to know that California now recognizes the hard work of people with disabilities. People with disabilities are now able to make at least minimum wage, just like their able-bodied coworkers!”
❖ Rebecca Donabed, Sequoia Regional SSAN Representative
SSAN Reflections on 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 2020 and 2021 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 with youth with disabilities in 2022.”

❖ Kecia Weller, UCLA TARJAN Center UCEDD SSAN Representative
2020 – 2021 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 2020 – 2021 reporting period include:

- Participated on SCDD Regional Advisory Committees (RACs)
- Participated actively in virtual governance meetings
- Attended, presented at and organized the following conferences:
  - Supported Life Institute Conference (Virtual)
  - People First of California (PFCA) Gatherings (Virtual)
  - “I’m Empowered – It’s My Life” Conference (Virtual)
  - California Statewide Self-Advocacy Conference (Virtual)
  - Disability Vote California trainings and chats (Virtual)
  - Regional Self-Advocacy chats (Virtual)
- Members are on their regional center boards, IHSS Public Authority, transportation boards, and People First groups
- Shared their stories with their Legislators supporting SB 639 and the importance of ending subminimum wage in California
- Collaborated with SCDD Regional Offices to give regional and statewide trainings
- Collaborated with SCDD Regional Offices to distribute Personal Protective Equipment (PPE)
- Presentations informing their community about SSAN
- Presentation on the California Self-Determination Program