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STATEWIDE SELF ADVOCACY NETWORK MEETING INFORMATION

DATES: Wednesday, September 3, 2025, and Thursday, September 4, 2025

DAY 1 TIME: 11:00 AM – 3:00 PM DAY 2 TIME: 11:00 AM – 2:30 PM

MEETING DETAILS:

This meeting is being held using the Zoom meeting platform.

ZOOM LINK:

https://bit.ly/SSAN-September-2025

Call-in Information:

CALL IN NUMBER: (669) 900 9128

MEETING ID: 885 0048 5686

PASSCODE: 416890

Accessibility

SSAN is a project of SCDD and values people's access needs. If you would like SSAN materials in different formats and/or languages, please contact Riana Hardin at (916) 263-8196 or Riana.Hardin@scdd.ca.gov. We ask that you give at least 5 business days notice before the meeting to allow enough time to respond to all requests.



<u>DAY 1</u> <u>AGENDA</u> September 3, 2025 11:00 AM – 3:00 PM

1. Welcome and Introductions

Presented by:

- Rebecca Donabed, Chairperson
- Eric Aguilar, Vice-Chairperson
- Ellen Sweigert, Secretary



2. Review and Approval of June 2025 Minutes
Presented by: Rebecca Donabed, Chairperson
ACTION



3. SCDD Update

Presented by: Aaron Carruthers, SCDD Executive Director **Information**



Lunch Break (45 minutes 12:00 pm – 12:45 pm)



4. Systemic Advocacy Leadership Academy (SALA)

Presented by: Chris Arroyo, SCDD Deputy Director, Policy and Public Affairs

Information

5. Medical Advocacy

Presented by: Wesley Witherspoon, USC Children's Hospital UCEDD SSAN Representative

Information

6. Recap and Reflections

Presented by: SSAN Leadership Team





<u>DAY 2</u> <u>AGENDA</u> September 4, 2025 11:00 AM – 2:30 PM

1. Welcome and Introductions

Presented by:

- Rebecca Donabed, Chairperson
- Eric Aguilar, Vice-Chairperson
- Ellen Sweigert, Secretary



2. SSAN Newsletter

Presented by: Robert Levy



3. Networking Needs

Presented by: SSAN Officers

Information



Lunch Break (45 minutes 12:15 pm – 1:00 pm)



4. Updates on the Master Plan

Nicole Patterson, DDS SSAN Representative

5. Emergency Planning: Wildfires and Floods

Presented by: Eric Aguilar, San Bernardino Regional SSAN
Representative
Wesley Witherspoon, USC Children's Hospital
UCEDD SSAN Representative



6. Reflections and Closing Remarks

Presented by: SSAN Leadership Team



SEPTEMBER 3, 2025

SSAN MEETING DAY 1 AGENDA ITEM 2

ACTION ITEM

Statewide Self-Advocacy Network Approval of June 2025 Minutes



Attachments

• June 2025 Minutes

Recommended Action

Approve the June 2025 SSAN Meeting Minutes



Statewide Self-Advocacy Network Meeting Minutes

June 4 and 5 (Virtual)

SCDD Regional Members Present

Sonya Force - North Coast

Lisa Cooley - Sacramento

Ellen Sweigert – North Bay

Sara Desumala – Bay Area

Crystal Enyeart – North Valley Hills

Daniel Stickney - Central Coast

Rebecca Donabed - Sequoia

Julie Gaona - Los Angeles

Sean Sullivan - Orange County

Eric Aguilar - San Bernardino

Viri Salgado – San Diego

Agency Members Present

Rosie Ryan – SCDD

Scott Barron - DRC

Desiree Boykin – ARCA

Robert Levy – UCD MIND Institute

Nicole Patterson - DDS

Kecia Weller – UCLA Tarjan Center

Wesley Witherspoon – USC CHLA

Members Not Present

North State

Russell Dawsons-Rawlings - CFILC

YO Disabled and Proud

SCDD Staff in Attendance

Chris Arroyo - SCDD HQ

Veronica Bravo - SCDD HQ

Aaron Carruthers – SCDD HQ

Albert Feliciano – SCDD Los Angeles

Riana Hardin - SCDD HQ

Dena Hernandez - SCDD N. Valley Hills

Brian Hoang - SCDD HQ

Barbara Imle - SCDD HQ

Debi Marshall - SCDD San Diego

Austin Murphy – SCDD HQ

Ibrahim Muttaqi – SCDD HQ

Gabriela Solval - SCDD Bay Area

Others Present

Greg Alcantra

David Forderer

Valley CAPS Plus

Amelia Ott

Maor Douek



June 2025 SSAN Minutes

Day 1

1. Call to Order, Welcome, and Introductions

SSAN Chairperson and Sequoia Regional Representative, Rebecca Donabed, called the meeting to order at 10:03 AM. SSAN Vice-Chair, Eric Aguilar, then reviewed the SSAN Meeting Agreements with members, reminding members to be respectful to others in the meeting and try to listen to others with the intent to understand. Members were asked to introduce themselves by sharing their name and the region and/or agency they represent. They were also asked to share an advocacy activity they had participated in since the last meeting, and any coping strategies they find helpful during stressful times. Members mentioned attending meeting with elected officials, speaking at conferences, and participating in planning meetings and trainings.

2. Public Comment

There were no public comments.

3. Review and Approval of March 2025 Minutes

The members reviewed the minutes from the March 2025 meeting. Materials for this agenda item can be found on pages 5-12 of the June 2025 SSAN meeting packet.

ACTION: Motion #1, to approve the March 2025 minutes, was made by Lisa
Cooley and seconded by Daniel Stickney. A roll call vote was taken.
Motion passed. See Vote Log.



4. SCDD Update

State Council on Developmental Disabilities (SCDD) Executive Director, Aaron Carruthers, provided updates on SCDD activities since the March 2025 SSAN meeting. This agenda item focused on providing updates on proposed federal changes to Medicaid/Medi-Cal program. Proposals include establishing work requirements, changes to provider taxes, and more frequent eligibility reviews. Members were encouraged to participate in the SCDD's "Tell Your Story" campaign and motivate others to do so as well.

5. Service Delivery Codes Website Project

Albert Feliciano, SCDD staff from the Los Angeles Regional Office, gave a presentation about the Service Delivery Codes project. This project is a collaborative effort between SCDD and DDS to create a user-friendly, comprehensive tool that outlines the services offered through the Regional Center. The primary goal of the project is to provide advocates and their families a tool they can use to identify services they may need, that may be available through the Regional Center, and how to request them. Suggestions from participants included adding location-based filtering, and providing links to specific programs and vendors listed. Members would like to be kept informed about any beta testing opportunities and the project's launch timeline.

6. What's Your Platform

SSAN Secretary and North Bay Regional Office Representative, Ellen Sweigert, gave a presentation on creating a personal platform based on life-changing experiences. There are three parts to creating a personal platform. First, you need to know your own story and what you want to tell others about your experience. Next, you need to know what helped you during your experience or journey. The last part is thinking about how you can help others going through the same or similar experience.



7. History of Self-Advocacy

SSAN San Diego Regional Representative, Viri Salgado, and UC Davis MIND Institute UCEDD Representative, Robert Levy, gave a presentation on the history of self-advocacy. They traced the modern self-advocacy movement from Sweden in the 1960s, to its growth in North America during the 1970s and 1980s highlighting the rise of People First groups and the passage of the Americans with Disabilities Act (ADA) in 1990. Self-advocacy is about speaking up for their rights, making your own choices, and being fully included in your communities.

8. Systemic Advocacy Leadership Academy (SALA)

Chris Arroyo, SCDD Deputy Director of Policy and Public Affairs, provided members with another training from the Systemic Advocacy Leadership Academy (SALA). This agenda item focused on the importance of critical thinking concepts. There were several videos shared during this agenda item and covered 5-step process to making decisions. The first step is to develop your question. Next, you should gather information to help you answer your question. Next, apply the information. Then you should consider the implications. The last step is to explore and understand other points of view.

9. Recap and Reflections

Members reflected on the day's events and what they plan on sharing with their communities.



1. Welcome and Introduction

Chair Rebecca Donabed, called the meeting to order at 10:01 AM. Vice-Chair Eric Aguilar reviewed the SSAN meeting guidelines. Members introduced themselves and shared their summer plans.

2. SSAN Newsletter

Robert Levy, SSAN Newsletter Project Lead, reviewed the June 2025 Voices of SSAN Newsletter with members. This edition of the newsletter focused on celebrating disability pride. Robert asked for volunteers to write articles for the September edition of the newsletter, which will focus on the topic of employment for people with disabilities.

3. Future of SSAN

The discussion on the Future of SSAN opened with members sharing some accomplishments of SSAN over the years included presenting at conferences and schools, sharing information with local advocacy groups, writing articles in a quarterly newsletter, participating in the development of the Master Plan on Developmental Services, and planning outreach events.

Members shared their ideas about what the future of SSAN could look like. Ideas shared included encouraging members to host local advocacy activities in their communities, giving more presentations at schools, learning more about self-advocacy groups in other states, hosting more public facing activities, using social media, and technology in their advocacy efforts, and working on statewide/regional projects between meetings. Members would like to see SSAN grow by including People First of California, CalTASH, and other cross-disability groups in SSAN. Members will be receiving a survey link to share more ideas in the coming weeks.



4. Updates on the DD System

Nicole Patterson, the Department of Developmental Services (DDS) SSAN Representative shared that DDS is looking for 40 self-advocates from across California to be a part of their Lived Experience Advisory Committee (formally known as the consumer advisory committee). Ms. Patterson looks forward to updating SSAN on the implementation of the Master Plan on Developmental Services in September.

5. Heatwave Safety

Eric Aguilar, SSAN Vice-Chair and San Bernardino SSAN Representative, provided members with tips and resources to help plan and prepare heat waves.

6. Reflections and Closing Remarks

Members reflected on important information that they would like to share with their communities.



SSAN VOTE LOG: JUNE 2025

Name	Region	Day 1 Attendence	Motion 1	Day 2 Attendance
Rosie Ryan	SCDD	Present	Abstain	Present
Sonya Force	North Coast	Not Present	Not Present	Not Present
VACANT	North State	Not Present	Not Present	Not Present
Lisa Cooley	Sacramento	Present	For	Present
Ellen Sweigert	North Bay	Present	For	Present
Sara Desumala	Bay Area	Present	Abstain	Present
Crystal Enyeart	North Valley Hills	Present	Abstain	Present
Daniel Stickney	Central Coast	Present	For	Present
Rebecca Donabed	Sequoia	Present	For	Present
Julie Gaona	Los Angeles	Present	Abstain	Present
Sean Sullivan	Orange County	Present	For	Present
Eric Aguilar	San Bernardino	Present	For	Present
Viri Salgado	San Diego	Present	Not Present	Present
Desiree Boykin	ARCA	Present	Abstain	Present
Russell Dawson– Rawlings	CFILC	Not Present	Not Present	Not Present
VACANT	YO! Disabled & Proud	Vacant	Vacant	Vacant
Nicole Patterson	DDS	Present	For	Present
Scott Barron	DRC	Present	For	Present
Wesley Witherspoon	USC - CHLA	Present	Abstain	Present
Kecia Weller	UCLA Tarjan Center	Present	Abstain	Present
Robert Levy	UCD MIND Institute	Present	For	Present

SEPTEMBER 3, 2025

SSAN MEETING DAY 1 AGENDA ITEM 3 Information Item

Statewide Self-Advocacy Network

SCDD Update



SCDD Executive Director Aaron Carruthers will update SSAN members on the Council's activities related to meeting the needs of Californians with I/DD during these challenging times.

SEPTEMBER 3, 2025

SSAN MEETING DAY 1 AGENDA ITEM 4 INFORMATION ITEM

Statewide Self-Advocacy Network



Systemic Advocacy Leadership Academy (SALA)

Systemic Advocacy & Leadership Academy (SALA for short) is a statewide training program developed by the Los Angeles Regional Office. SALA introduced its first statewide cohort in 2024. The SSAN Leadership Team has asked to include parts of the SALA trainings into each SSAN meeting in 2025.

SCDD Deputy Director of Policy and Public Affairs, Chris Arroyo, will build on the information shared at the March and June SSAN meetings.

Attachments

Systemic Advocacy Strategies Menu



SYSTEMIC ADVOCACY STRATEGIES MENU

GATHER INFORMATION

- Research existing laws, regulations, court cases, policies, and practices
- Surveys! Gather historical information, statistics
- Create focus groups to gather data
- Find the issues that are common to as many people as possible
- Identify barriers to create better targeted solutions
- Collect information from relevant service agencies

GET LARGE GROUPS OF PEOPLE TOGETHER

- Be well organized
- Spend energy wisely and pick your battles
- Identify & recruit advocacy organizations & allies! (SCDD, DRC, DREDF, ILCs, self-advocacy groups, parent support groups etc.)
- Seek to understand the priorities of others, such as self-advocates and family members
- Organize parent leaders and organizations by area or each regional center
- o Protest in large numbers or hold rallies
- Use social media to educate and recruit people
- Create coalitions (get people and organizations together who think like you)
- o Join forces with other groups and share the advocacy objective

SPREAD AWARENESS TO RECRUIT PEOPLE

- o Educate others (use social media, videos, etc.)
- Send targeted e-blasts
- o Get the press involved, write an op-ed, or write an editorial
- Guide the media on relevant issues
- Train professionals and others who can help amplify the message
- Develop information flyers and share them with others
- Train two individuals in each area (such as by regional center) so they can share information in their areas
- Find convenient ways to communicate and use plain language (text messages, information flyers, FB, etc.)
- Exercise consistency, discipline, focus, and follow up on the project regularly to ensure that people stay in the movement
- Effectively write a story! Amplify the story through the above!
- Write petitions (historically not terribly effective, but they can help with awareness)



GET LAWS PASSED OR POLICIES/PRACTICES CHANGED

- Talk to your legislators get bills/laws passed!
- O Visit legislators and other people just to get to know them!
- o Educate local officials on current bills and ask them to support or oppose them
- Give public testimony at CA State budget hearings to get policies passed that you want
- Advocate and/or work with mayors, city councils, county board of supervisors, board members of organizations, and/or other local officials to get the changes you want
- Join an advisory committee or board of directors! Join the group that you want to see changes in (neighborhood councils, advisory committees, boards, etc.)
- o Write letters and get meetings with department heads (IHSS, DOR, etc.)
- Apply for grants and do the work yourself (may need an agency to handle the money)
- Consider systemic complaints, such as special education state compliance complaints, regional center 4731 complaints, whistleblower complaints, and more



MENÚ DE ESTRATEGIAS DE ABOGACÍA SISTÉMICA

RECOPILAR INFORMACIÓN

- Investigar las leyes, regulaciones, casos judiciales, políticas y prácticas existentes
- o ¡Encuestas! Recopilar información histórica, estadísticas
- o Crear grupos de enfoque para recopilar datos
- Encuentre los problemas que son comunes a la mayor cantidad de personas posible
- o Identifique las barreras para poder crear soluciones mejor orientadas
- o Recopilar información de agencias de servicios relevantes

REUNIR GRANDES GRUPOS DE PERSONAS

- Estar bien organizado
- Use su energía sabiamente y elija sus batallas
- ¡Identifique y reclute organizaciones y aliados de defensa! (SCDD, DRC, DREDF, ILC, grupos de autodefensa, grupos de apoyo para padres, etc.)
- Trate de comprender las prioridades de los demás, como los autodefensores y los miembros de la familia
- o Organizar a los padres líderes y organizaciones por área o cada centro regional
- o Protestar en gran número o realizar eventos o reuniones de promoción
- o Utilice las redes sociales para educar y reclutar personas
- o Crear coaliciones (reunir a personas y organizaciones que piensen como usted)
- Unir fuerzas con otros grupos y compartir el objetivo de la abogacía

CONCIENCIAR PARA RECLUTAR PERSONAS

- o Educar a otros (usar redes sociales, videos, foros, ferias informativas, etc.)
- o Enviar mensajes electrónicos dirigidos
- o Involucrar a la prensa, escribir un artículo de opinión o escribir un editorial
- o Orientar mejor a los medios de comunicación sobre los temas relevantes
- Capacitar a profesionales y otras personas que puedan ayudar a amplificar el mensaje
- o Desarrollar volantes informativos y compartirlos con otros
- Capacitar a dos personas en cada área (por ejemplo, por centro regional) para que puedan compartir información en sus áreas
- Encuentre formas convenientes de comunicarse y utilizar un lenguaje sencillo (mensajes de texto, folletos informativos, Facebook, etc.)
- o Ejercer coherencia, disciplina, concentración y realizar un seguimiento regular del proyecto para garantizar que las personas permanezcan en el movimiento.



- ¡Escribe una historia de manera efectiva! ¡Amplifica la historia a través de lo anterior!
- Escribir peticiones (históricamente no muy efectivas, pero pueden ayudar con la conciencia)

CAMBIAR LEYES Y POLÍTICAS Y PRACTICAS

- o Hable con sus legisladores: ¡haga que se aprueben proyectos de ley!
- o Visite a legisladores y otras personas, ¡sólo para conocerlos!
- Presentar propuestas de ley a legisladores que tengan seres queridos con discapacidades
- Educar a los funcionarios locales sobre los proyectos de ley actuales y pedirles que los apoyen o se opongan
- Brinde testimonio público en audiencias del presupuesto estatal de California para aprobar las políticas que desea
- Abogar y/o trabajar con alcaldes, concejos municipales, juntas de supervisores del condado, miembros de juntas directivas de organizaciones y/u otros funcionarios locales para lograr los cambios que desea
- o ¡Únase a un comité asesor o mesa directiva! Únase al grupo en el que desea ver cambios (juntas vecinales, comités asesores, juntas, etc.)
- Escribir cartas y conseguir reuniones con jefes de departamento (IHSS, DOR, etc.)
- Solicite becas y haga el trabajo usted mismo (es posible que necesite una agencia para manejar el dinero)
- Considere quejas sistémicas, como quejas de cumplimiento estatal de educación especial, quejas de 4731 del centro regional, quejas de denunciantes y más

SEPTEMBER 3, 2025

SSAN MEETING DAY 1 AGENDA ITEM 5 INFORMATION ITEM

Listen Learn Leard

Statewide Self-Advocacy Network

Medical Advocacy

Wesley Witherspoon, Project Coordinator at USC Children's Hospital UCEDD, will provide members with training on how to advocate for yourself in a doctor's office.

SEPTEMBER 3, 2025

SSAN MEETING DAY 1 AGENDA ITEM 6 INFORMATION ITEM

Listen Loarn Load

Statewide Self-Advocacy Network

Recap and Reflections

This agenda item is meant to give members a chance to reflect on the day's discussions.

SEPTEMBER 4, 2025

SSAN MEETING DAY 2 AGENDA ITEM 2 INFORMATION ITEM





September 2025 Edition of Voices of SSAN Newsletter

Robert Levy, Project Lead for the Voices of SSAN Newsletter, will share the September 2025 Newsletter with members. Robert will lead a discussion about the December 2025 Newsletter, so please come prepared with ideas for the types of articles you would like to see in the next edition.

Attachment

Voices of SSAN Newsletter Article Tips

Handout

September 2025 Voices of SSAN Newsletter



Voices of SSAN Newsletter Article Tips

Audience: Keep in mind that "Voices of SSAN" is shared with people across California. Try to write articles that would interest the statewide disability community.

Purpose: What is the point of the article? Why do you want to write it? If it is a human-interest story (about a personal journey), you should tie it back to a regional, statewide, national, or international issue so that other people can relate to or want to read the article.

Helpful Tips:

- Connect your article back to the Mission/Vision/Purpose of SSAN
- Articles should be about systemic (city/county/regional/statewide) problems
- Limit individual advocacy articles
- · Stay away from writing about personal details of an individual

Types of Articles: Articles in "Voices of SSAN" should be related to the SCDD State Plan. The SCDD State covers topics of self-advocacy and Self-Determination, Systems Change efforts, and Capacity Building (trainings). Article types can include:

- Information and Resource Sharing (the reader learns something)
- Call-to-Action (you want the reader to do something)
- Event Recaps
- Bios and interviews to help SSAN and learn about people
- "Kudos Corner" articles are recognize the advocacy efforts of others
- Announcements and Save the Dates

Key Parts of Articles:

- Title
- Author (Your Name)
- Introduction: Tie the article back to SSAN
- Evidence or Support: 1-3 paragraphs
- Closing: Tie it back to SSAN



Voices of SSAN Interview Article Tips

Audience: Keep in mind that "Voices of SSAN" is shared with people across California.

Choosing a Person to Interview:

- Is the person a regional/statewide/national/international leader?
- Does the person have the ability to affect change?
- Does the person have a story or experience people with disabilities from across California can relate to?
- Is the person making positive impact/or change that can be shared with other regions/organizations to improve their practices?

Choosing a Message

- What do you want the reader to learn from reading the article? Make sure you have a clear purpose in mind when writing
- Do you want to inspire others to do something like get involved in a project or campaign?

Choosing Your Interview Questions

- Ask questions that relate to SSAN, self-advocacy or the focus areas in SCDD's State Plan
- Choose questions that relate to your message
- Ask open ended questions that will allow the person to respond in detail.
- Avoid questions that can be answered with a simple "yes" or "no"

Writing Your Interview Article

- Add your own thoughts in response to what the interviewee has said
- Use the interview's responses to shape your article instead of having a question/answer format
- Remember your audience and purpose when writing your interview article



Voices of SSAN Kudos Corner Article Tips

When some does a good job or achieves a goal, people sometimes say "Kudos to you". SSAN started the Kudos Corner in June 2019 as a way to recognize SSAN members for their local and statewide advocacy work.

This tip sheet is designed to help members write future Kudos Corner Articles. Here are some important things to include in articles of recognition:

- 1. Name of person receiving kudos
- 2. Region/Organization they are with
- 3. How long they have been on SSAN
- 4. Their Advocacy/SSAN Achievements
- 5. Examples of how they have helped other SSAN members and/or other advocates (mentorship)
- 6. Their hopes and dreams for SSAN and the Self-Advocacy Movement in CA, US, and Globally



Voices of SSAN Member Highlight Article Tips

A member highlight or sometimes called a "bio" is a way for SSAN and readers of the Voices of SSAN Newsletter to learn more about a new member of SSAN. Here are some tips for what kind of information should be included in a Member Highlight Article.

- 1. Name
- 2. Region/Organization
- 3. How long they have been on SSAN
- 4. How did you learn about SSAN
- 5. What made you want to join SSAN
- 6. Any advocacy accomplishments
- 7. Why the joined SSAN
- 8. What they hope to learn or gain from being a member of SSAN

SEPTEMBER 4, 2025

SSAN MEETING DAY 2 ITEM 3 INFORMATION ITEM

Statewide Self-Advocacy Network



Network Needs

Members will have a chance to share more about their ongoing projects and talk about issues that will require collaborative efforts.

SEPTEMBER 4, 2025

SSAN MEETING DAY 2 ITEM 4 INFORMATION ITEM

Statewide Self-Advocacy Network

Update on the DD System



Nicole Patterson, SSAN Representative for Department of Developmental Services, will give an update on changes to the developmental disabilities service delivery system.

SEPTEMBER 4, 2025

SSAN MEETING DAY 2 ITEM 5 INFORMATION ITEM

Statewide Self-Advocacy Network

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Emergency Planning

Eric Aguilar, SSAN Vice Chair and San Bernardino Regional Representative, and Wesley Witherspoon, SSAN Representative for USC UCEDD, will share tools and strategies that will help you stay safe during wildfires and floods.

SEPTEMBER 4, 2025

SSAN MEETING DAY 2 AGENDA ITEM 6 INFORMATION ITEM

Listen Loarn Load

Statewide Self-Advocacy Network

Meeting Reflections and Closing

This agenda item is meant to give members a chance to reflect on the day's discussions and topics. Members will have a chance to share ideas for items to include in December's meeting.