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STATEWIDE SELF ADVOCACY NETWORK MEETING INFORMATION



DATE: Wednesday, September 7, 2022 and Thursday, September 8, 2022



TIME: Wednesday, September 7, 2022 10:00 AM – 3:00 PM
Thursday, September 8, 2022 10:00 AM – 3:00 PM

This is a teleconference and zoom meeting only. There is no physical location being made available to the public per Government Code Section 11133. Therefore, Committee members are not required to list their remote locations and members of the public may participate telephonically or by Zoom from any location. Accessible formats of all agenda and materials can be found online at www.scdd.ca.gov.

MEETING DETAILS:

ZOOM LINK:

<https://bit.ly/SSANSept2022>

MEETING ID: 819 5717 0023

PASSCODE: 231561

TELECONFERENCE:

CALL IN NUMBER: (888)-475-4499

MEETING ID: 819 5717 0023

PASSCODE: 231561

Accessibility

Pursuant to Government Code Sections 11123.1 and 11125(f), individuals with disabilities who require accessible alternative formats of the agenda and related meeting materials and/or auxiliary aids/services to participate in this meeting should contact Riana Hardin at (916) 263-8196 or Riana.Hardin@scdd.ca.gov or Beth Hurn at (916) 263-8194 or Beth.Hurn@scdd.ca.gov. Please provide at least 3 business days prior to the meeting to allow adequate time to respond to all requests.

There are members of the public body who are participating in today's meeting that were granted a reasonable modification per the Americans with Disabilities Act (ADA). In order to protect their health and/or safety, they are participating remotely for this proceeding without providing their physical location. A physical location is being made available for the public, as well as a Zoom link for public participation. All times indicated and the order of business are approximate and subject to change.

Per the guidance by the Centers for Disease Control and Prevention, and the California Department of Public Health, wearing a mask and social distancing at least six (6) feet while indoors with others is strongly recommended. The Committee asks all participants who choose to attend the meeting at SCDD's HQ office to wear a mask and social distance whenever possible for the duration of the Committee meeting.



AGENDA FOR DAY 1

**September 7, 2022
10:00 AM – 3:00 PM**

1. Call to Order, Welcome, and Introductions/Member Report

Presented by: Desiree Boykin, Chairperson, Paul Mansell, Vice-Chairperson, and Robert Levy, Secretary



2. Public Comment

Public comment is welcome. Comment on agenda items is taken as they are discussed.



3. Review and Approval of June 2022 Minutes

Presented by: Desiree Boykin, Chairperson
ACTION



4. Updates from the SSAN Chair

Presented by: Desiree Boykin, Chairperson
Information

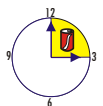


5. SCDD Update

Presented by: Aaron Carruthers, SCDD Executive Director
Information



Break



6. SCDD Website Feedback

Presented by: Rihana Ahmad, SCDD Manager
Information



7. SSAN Workgroup Updates

Presented by: ALL
Discussion



8. Introduction to Self-Determination Program Ombudsperson

Presented by: Office of the Self-Determination Program Ombudsperson
Discussion

9. CalABLE: Saving for your Future

Presented by: Dante Allen, Executive Director, CalABLE
Information



10. Reflecting on the Day and Recess

Presented by: Desiree Boykin, Chairperson
Information





AGENDA FOR DAY 2

September 8, 2022

10:00 AM –3:00 PM

1. Call to Order, Welcome and Introductions

Presented by:

- Desiree Boykin, Chairperson
- Paul Mansell, Vice-Chairperson
- Robert Levy, Secretary



2. Public Comment

Public comment is welcome. Comment on agenda items is taken as they are discussed.



3. UC Davis MIND Institute Grant Project

Presented by: Robert Levy, CCEDD Community Advocate,
UC Davis MIND Institute
Steve Ruder, Coordinator Transition Projects,
UC Davis MIND Institute

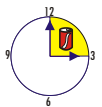


4. Choosing Your Style of Advocacy

Presented by: Jessica Riestra, Youth Organizer,
California Foundation for Independent Living
Information



Break



5. Your Vote: Your Voice

Presented by: Wesley Witherspoon, Consumer Advocate, USC Children's Hospital UCEDD
Information

6. Approval of September 2022 SSAN Newsletter

Presented by: Robert Levy, Newsletter Workgroup Chair
ACTION



7. The Importance of Individual Stories in the Disability Movement

Presented by: Scott Barron, Peer Advocate, Disability Rights California

Ibrahim "Bebo" Saab, Esq., Supervising Attorney for Outreach, Disability Rights California

Information



8. Planning for December 2022 Meeting

ALL



9. Adjournment

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SEPTEMBER 7, 2022
SSAN MEETING AGENDA ITEM 3
ACTION ITEM



Statewide Self-Advocacy Network
Approval of June 2022 Minutes

Attachments

- June 2022 Minutes

Recommended Action

Approve the June 2022 SSAN Meeting Minutes

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Statewide Self-Advocacy Network Meeting Minutes June 29 & 30, 2022 Zoom

SCDD Regional Members Present

Nathan Florez – North Coast
Charles Nutt – North State
Lisa Cooley – Sacramento (Day 1)
Ellen Sweigert – North Bay
Robert Balderama – North Valley Hills
Rebecca Donabed – Sequoia
Julie Gaona – Los Angeles
Paul Mansell – San Diego–Imperial

Agency Members Present

Scott Barron – DRC
Nicole Patterson – DDS
Desiree Boykin – ARCA
Kecia Weller – UCLA Tarjan Center
Robert Levy – UCD MIND Institute
Wesley Witherspoon – USC CHLA

Members Not Present

Regina Woodliff – Bay Area
David Forderer – Central Coast
Sean Sullivan – Orange County
Vacant – San Bernardino
Maria Marquez – SCDD
Vacant – CFILC

SCDD Staff in Attendance

Rihana Ahmad – SCDD HQ
Aaron Carruthers – SCDD HQ
Anne De Medeiros –
SCDD Sacramento
Julie Eby-McKenzie –
SCDD North Coast
Dena Hernandez –
SCDD North Valley Hills
Beth Hurn – SCDD HQ
Charles Nguyen – SCDD HQ
Mary Agnes Nolan –
SCDD North State
Tina Reszler – SCDD North State
Yaritza Sanchez – SCDD HQ
Victoria Schlusser – SCDD HQ
Gabriele Solval – SCDD Bay Area
Esteban Ortiz –
SCDD San Bernardino
Tobias Weare – SCDD North Bay

Presenters

Sherlyn Porter
April Dawson

Others Present

Sarah Davenport
Eric Aguilar
Alex Phuong



DRAFT

SSAN Minutes

1. Call to Order, Welcome and Introductions

SSAN Chairperson Desiree Boykin, ARCA Representative, called the meeting to order at 10:05 AM.

SSAN Chairperson Desiree Boykin requested that Beth Hurn, SCDD staff assist in the attendance roll call. Members introduced themselves and the region or agency that they represent and shared how the ADA has impacted their lives.

2. Public Comment

Eric Aguilar introduced himself and stated that he is interested in Joining SSAN.

Robert Balderama expressed that the ADA has made the world a safer place for people with disabilities.

3. Review and Approval of March 2022 Minutes

The members reviewed the minutes from the March 9 & 10, 2022 meeting. Materials for this agenda item can be found on pages 9-16 of the June 2022 SSAN Meeting Packet.

ACTION: Motion #1 to approve the March 2022 minutes was made by Charles Nutt/Seconded by Rebecca Donabed. A roll call vote was taken. Motion passed. See vote log on page 7.

4. Updates from SSAN Chair

SSAN Chairperson Desiree Boykin thanked SSAN members for their support over the past year as she worked through her grief after the loss of her parents and encouraged members to keep advocating for themselves and encouraging the next generation to engage in self-advocacy activities.



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5. SCDD Update

SCDD Executive Director Aaron Carruthers provided SSAN members with an update on SCDD activity since the March SSAN meeting. Executive Director Carruthers updated members on the Council's legislative work and continued efforts to increase access to vaccines, test-kits and COVID-19 related information. Executive Director Carruthers informed members that SCDD staff has undergone training in preparation to facilitate the statewide Self-Determination Program Orientation, and answered SSAN members' questions about how to ensure that Supported Decision Making is made available to those who would benefit from it.

6. SCDD Project Feedback: Expanding Access to COVID-19 Vaccines to the I/DD Community in California

SCDD Vaccine Project Manager Tamica Foots-Rachal provided an overview of the work that SCDD is doing to expand access to COVID-19 vaccines and information in the I/DD community and requested feedback from SSAN members on the accessibility of California's COVID-19 Parent Information Webpage and attached informational resources.

7. SSAN Workgroups

The SSAN Workgroups met using Zoom Breakout Rooms to talk about current and future projects. The following workgroups met:

- Legislative and Civic Engagement
- Employment
- Newsletter and Communications
- Self—Determination and Youth Engagement

8. Self-Advocacy: Living the Good Happy Life

Paul Mansell, SSAN representative from the San Diego–Imperial Region gave a presentation about happiness, providing strategies for living a happy and fulfilling life.



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9. Basics of Self-Care

Sherlyn Porter, Licensed Clinical Social Worker with the Tulare County Health and Human Services Agency provided a presentation on the impact of stress on our wellbeing and the importance of including self-care practices in your life. Members were given tips and strategies on how to relax and help people who are struggling, along with resources.

10. Recess Until Next Day

SSAN Chairperson Desiree Boykin declared the meeting in recess at 3:08 PM. The June 2022 SSAN meeting will return from recess at 10:00 AM Thursday, June 30, 2022.



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SSAN DAY 2 Minutes

1. Call to Order, Welcome, Roll Call and Introductions

SSAN Chairperson, Desiree Boykin, ARCA Representative, called the meeting to order at 10:07 A.M.

An attendance roll call was taken.

2. Public Comment

There was no public comment.

3. SCDD Legislative Update

Bridget Kolakosky, SCDD Deputy Director – Policy and Public Affairs, provided members with an overview of SCDD legislative activities, including an update on the status of the four bills that the State Council is sponsoring during the current legislative session.

4. From Awareness to Justice

April Dawson, Executive Director of Resources for Independent Living talked to members about embracing disability justice. Members shared their thoughts and experiences in relation to their identities as people with disabilities, person first language, and the medical model vs. the social model of disability.

5. Update from SCDD Self-Advocacy DEAP

Peter Mendoza, SCDD Sacramento Community Program Specialist provided information about current Self-Advocacy DEAP projects and asked for committee members' thoughts about Self-Advocacy related training topics for SCDD's Learning Management System, which is currently under development. Members expressed interest in the following topics:

- Emergency preparedness
- Medical accessibility
- Getting rid of disability stigma
- Self-Determination
- Respect from others
- How to be assertive
- Recognizing toxic relationships



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6. Approval of June 2022 SSAN Newsletter

SSAN Secretary and Newsletter and Communications Workgroup Chair, Robert Levy reviewed the DRAFT June 2022 Voices of SSAN Newsletter. Members asked to add the registration link for the UC Davis Summer Institute to the newsletter, along with an advertisement for Project SAFEE and the Red Cross' collaborative emergency preparedness training. Secretary Levy called for a motion to approve the June 2022 Edition.

Materials for this agenda item can be found on pages 39-51 of the June 2022 SSAN Meeting Packet.

ACTION: Motion #2 to approve the June 2022 Newsletter with the suggested edits was made by Charles Nutt/Seconded by Paul Mansell. Motion passed. See vote log on page 7.

7. Planning for September 2022 Meeting

SSAN members brainstormed topics/presentations for the September 2022 meeting. Suggested presentation topics included:

- SCDD Self-Advocacy DEAP
- Social Justice
- Citrus Heights Police Department Presentation
- Introduce the new Self-Determination Ombudsperson
- How Regional Center Consumer Advocates can assist Self-Advocates

8. Adjournment

Meeting was adjourned at 2:00 P.M. The next SSAN meeting will be on September 7-8, 2022 using Zoom.



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JUNE2022 SSAN VOTE TALLY

Name	Region	Roll Call	Motion 1	Day 2 Roll Call	Motion 2
Maria Marquez	SCDD	Not Present	Not Present	Not Present	Not Present
Nathaniel Florez	North Coast	Not Present	Not Present	Present	For
Charles Nutt	North State	Present	For	Present	For
Lisa Cooley	Sacramento	Present	For	Not Present	Not Present
Ellen Sweigert	North Bay	Present	For	Present	For
Regina Woodliff	Bay Area	Not Present	Not Present	Not Present	Not Present
Robert Balderama	North Valley Hills	Present	For	Present	For
David Forderer	Central Coast	Not Present	Not Present	Not Present	Not Present
Rebecca Donabed	Sequoia	Present	For	Present	For
Julie Gaona	Los Angeles	Present	For	Present	For
Sean Sullivan	Orange County	Not Present	Not Present	Not Present	Not Present
Vacant	San Bernardino	Vacant	Vacant	Vacant	Vacant
Paul Mansell	San Diego	Present	For	Present	For
Desiree Boykin	ARCA	Present	For	Present	For
Vacant	CFILC	Vacant	Vacant	Vacant	Vacant
Nicole Patterson	DDS	Present	For	Present	For
Scott Barron	DRC	Present	For	Present	For
Wesley Witherspoon	USC – CHLA	Present	For	Present	For
Kecia Weller	Trajan Center	Present	For	Present	For
Robert Levy	Mind Institute	Present	For	Present	For

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SEPTEMBER 7, 2022
SSAN MEETING AGENDA ITEM 4
INFORMATION ITEM

Statewide Self-Advocacy Network



Updates from the SSAN Chair

The SSAN Chair would like to welcome everyone to the September 2022 Meeting and will take a moment to provide a verbal update to SSAN members.

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SEPTEMBER 7, 2022
SSAN MEETING AGENDA ITEM 5
INFORMATION ITEM



Statewide Self-Advocacy Network

SCDD Update

Since the June 2022 SSAN meeting, the State of California, the United States of America, and countries around the world continue to face challenges in addressing the public health and safety challenges of COVID–19. SCDD continues to work with statewide and local partners to advocate for the inclusion of people with I/DD in the vaccination rollout. SCDD Executive Director Aaron Carruthers will update SSAN members on Council activity related to meeting the needs of Californians with I/DD during these challenging and unique times.

Handouts

- SCDD Sponsored Legislation Update
- Monkey Pox One Pager

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SEPTEMBER 7, 2022
SSAN MEETING AGENDA ITEM 6
INFORMATION ITEM



Statewide Self-Advocacy Network

SCDD Website Feedback

State Council on Developmental Disabilities staff would like feedback from SSAN members on the accessibility of the SCDD website, including the layout, design, type of information (content), and resources that should be hosted on the self-advocacy related pages.

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SEPTEMBER 7, 2022
SSAN MEETING AGENDA ITEM 7
INFORMATION ITEM



Statewide Self-Advocacy Network

SSAN Workgroup Updates

Since the June SSAN meeting, the SSAN workgroups discussed current, ongoing, and future projects over Zoom. The following SSAN workgroups will provide brief updates to the full SSAN:

- Employment
 - Chair: Rebecca Donabed
- Legislative and Civic Engagement
 - Chair: Paul Mansell
- Self-Determination
 - Chair: Nicole Patterson
- Newsletter
 - Chair: Robert Levy
- Youth Engagement
 - Chair: Nicole Patterson

Attachments

- SSAN Workgroup Descriptions
- SSAN Workgroup Roster and Meeting Times

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SSAN Workgroup Purpose, Goals, and Measurable Objectives



SSAN OPERATIONS WORKGROUP

Purpose: The SSAN Operations Workgroup includes the SSAN Officers, along with the Chairs of the Employment, Self-Determination and Youth Workgroup Chairs. The Operations Workgroup is responsible for planning and setting the agenda for each Full SSAN meeting, review and approve recommendations relating to SSAN membership, and recommendations relating to changes to the SSAN Bylaws.

Goal: To increase participation and awareness of SSAN meetings, general operations concerns and resolve issues relating to membership.

Measurable Objective: SSAN Operation Workgroup will work together to review SSAN Operating processes which include the responsibilities previously held by the Officers, Bylaws and Membership Workgroups:

- Plan SSAN Meetings
- Review Membership
- Review Marketing Materials
- Review Membership Process
- Review SSAN By-laws



SSAN EMPLOYMENT WORKGROUP

Purpose: The Employment workgroup will educate the community about the rights of people with disabilities and their ability to become contributing members of society by having competitive integrated employment.

Goal: To increase opportunities for people with disabilities to participate in competitive integrated employment. Increase access to resources available to support people with disabilities in the workforce.

Measurable Objective: Members of the SSAN Employment Workgroup will:

- Work with the SCDD Employment First Committee (EFC) and other groups/organizations advocating for access to competitive integrated employment (CIE) to provide feedback on the Employment First materials.
- Members of the workgroup will conduct outreach to individuals and groups to inform them about achieving gainful employment of the cross-disability community, (outreach includes passing out fliers, doing presentations, hosting informational webinars).

SSAN SELF-DETERMINATION WORKGROUP

Purpose: The SSAN Self-Determination Workgroup works to increase the number of people in all catchment areas that know about self-determination.

Goal: To increase self-advocates and their families, and the community's awareness of self-determination.

Measurable Objective: SSAN members will reach out in their communities to at least 3 individual groups per quarter to inform them about the new self-determination law.

- By providing individual information about self-determination
- By providing information by Power Point to different groups
- To identify groups that may benefit from a self-determination presentation
- Develop a tool to monitor how well the information is getting out to the community.



SSAN YOUTH ENGAGEMENT WORKGROUP

Purpose: The SSAN Youth Engagement Workgroup will work to increase awareness of youth with disabilities in California of the Self-Advocacy Movement and work to engage youth with disabilities in California in SSAN activities.

Goal: Create opportunities for cross generational interactions and include youth in the Self-Advocacy Movement.

Measurable Objective: Create a survey to distribute to youth groups on best practices for engaging, interacting with, and including youth in self-advocacy related activities.



SSAN LEGISLATION and CIVIC ENGAGEMENT WORKGROUP

Purpose: The Legislative and Civic Engagement workgroup is committed to informing and educating our partners and communities on statewide legislation that SCDD has taken a position on and matches SSAN priorities.

Goal: Increase the community's awareness of and engagement with SSAN supported parts of the State Council on Developmental Disabilities' legislative platform and priorities.

Measurable Objective: Develop materials that will increase the community's awareness and knowledge about bills and the California State Legislative Calendar. Examples include:

- How to Engage with the Legislative Process Training
- Draft Letters of Support
- Understanding the Legislative Calendar
- Submitting "There Should be a Law" Recommendation to SCDD.

SSAN NEWSLETTER/COMMUNICATION WORKGROUP

Purpose: The Newsletter/Communication workgroup will highlight SSAN activities and upcoming conferences/events to communicate what SSAN is doing and how they are connected in the community.

Goal: Increase the community's awareness of how SSAN is promoting the self-advocacy movement within the state of California.

Measurable Objective: The Newsletter/ Communication workgroup will produce 4 newsletters highlighting SSAN's advocacy work throughout California. The Newsletter/Communications workgroup will try to ensure that future editions are in accessible formats.

2022 Workgroup Assignments and Zoom Meeting Info

Operations	
Desiree Boykin*	
Paul Mansell	
Robert Levy	
Nicole Patterson	
Rebecca Donabed	

Employment	
Rebecca Donabed*	
Lisa Cooley	
Wesley Witherspoon	
Nicole Patterson	
Ellen Sweigert	

Legislative and Civic Engagement	
Paul Mansell*	
Robert Balderama	
David Forderer	
Julie Gaona	
Maria Marquez	

Newsletter	
Robert Levy*	
Desiree Boykin	
Kecia Weller	
Regina Woodliff	
Sean Sullivan	

Self-Determination	
Nicole Patterson*	
Julie Goana	
Paul Mansell	
Maria Marquez	
Robert Balderama	

Youth Engagement	
Nicole Patterson*	
Desiree Boykin	
Nathaniel Florez	
Kecia Weller	
Regina Woodliff	
Ellen Sweigert	

2022 Workgroup Assignments and Zoom Meeting Info

Workgroup	Meeting Date	Meeting Time	Zoom Info
Operations	Every Other Thursday	11:00 AM or 1:30 PM	https://bit.ly/SSAN_Operations
Employment	Third Friday of the Month	12:00 PM	https://bit.ly/SSAN_Employment
Legislative and Civic Engagement	Second Friday of the Month	11:00 AM	http://bit.ly/SSAN_Legislative
Newsletter and Communications	As Needed	As Needed	None
Self-Determination	Third Friday of the Month	10:00 AM	https://bit.ly/SSAN_SelfDetermination
Youth Engagement	Second Tuesday of the Month	10:00 AM	https://bit.ly/SSAN_YouthEngagement

SEPTEMBER 7, 2022
SSAN MEETING AGENDA ITEM 8
INFORMATION ITEM



Statewide Self-Advocacy Network

Introduction to Self-Determination Program Ombudsperson

The Office of the Self-Determination Program Ombudsperson exists to help regional center clients and Self-Determination Program participants and their families navigate through the program.

Representatives from the Office of the Self-Determination Program Ombudsperson will come to introduce SSAN members to the new Self-Determination Program Ombudsperson, Suzy Requarth.

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SEPTEMBER 7, 2022
SSAN MEETING AGENDA ITEM 9
INFORMATIONAL ITEM



Statewide Self-Advocacy Network

CalABLE: Saving for Your Future

CalABLE Executive Director Dante Allen will provide SSAN members with an overview of the recent updates to the CalABLE program and what potential role SSAN members can play on increasing awareness of the CalABLE program in their communities.

Presenter

Dante Allen, Executive Director, CalABLE

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SEPTEMBER 8, 2022
SSAN MEETING AGENDA ITEM 3
INFORMATION ITEM



Statewide Self-Advocacy Network
UC Davis Mind Institute Grant Project

UC Davis MIND Institute is currently working on a grant funded research project to learn about and develop best practices to help researchers to partner with people with disabilities to improve access to telehealth, access to healthcare services and transitioning to adulthood.

Steve Ruder, Transition Through Adulthood Projects Coordinator, UC Davis MIND Institute, Center for Excellence in Developmental Disabilities (CEDD) along with Robert Levy, CEDD Community Advocate, will provide SSAN with an update on the project and how you can get more involved with the project.

Presenter

Steve Ruder, Transition Through Adulthood Projects Coordinator,
UC Davis MIND Institute, CEDD

Attachments

- UC Davis MIND Institute CAP Invitation for SSAN

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Would you like to help the MIND Institute know what kinds of studies would help people with developmental disabilities get better services?

We are looking for people with developmental disabilities, family members, caregivers, clinicians, policy makers, funders, and researchers to work with us to improve research in healthcare.

A developmental disability is a difference in thinking or physical ability that starts during childhood and last a person's whole life. Some developmental disabilities affect the way people move, like cerebral palsy. Others affect how people learn or interact like Down syndrome or autism.

You can be a part of a new Partnership for Inclusive Research (PAIR) Team. You will be able to share your ideas about how to study healthcare. You can help decide what kind of studies will make healthcare better for people with developmental disabilities. You will help share that information back to people in your community.

We are looking people over 18 to join the team. No experience is needed. Your expertise is your experience with healthcare and services.

Please apply to join our project if you can join for one year.

You can apply if you are a member of at least one of these groups:

- Person with developmental disability
- Family member or caregiver of someone with a developmental disability
- Health care professional working with individuals with developmental disability
- Researcher with an interest in developmental disability
- Policymaker
- Person who works at an agency that funds services for people with developmental disabilities

Tasks will include:

- About 2 hours of training in how to be a good partner in a group with different types of people
- Monthly meetings (which you can do in person or by video conference) that last about 1 and ½ hours
- Some tasks between meetings that last about an hour

PAIR Team members will be paid \$25 per hour for their work. There may be funding available to help with childcare and transportation if you need it.

How to Apply:

Please email the following information to the project coordinator, Kris Wallman, at ktownsendwallman@ucdavis.edu. If you have any questions, call us at 916-703-0336.

Name: _____

Pronouns (optional) _____

Your contact information:

Email _____

Phone _____

Other, optional (for example, phone, text) _____

Which of these contact methods do you prefer we use? _____

SEPTEMBER 8, 2022
SSAN DAY 2 AGENDA ITEM 4
INFORMATION ITEM



Statewide Self-Advocacy Network

Choosing Your Advocacy Style

The world of advocacy is constantly changing. There are different tools to help you be an advocate today than were available to advocates who formed the modern disability rights movement. Jessica Riestra, Youth Organizer for the California Foundation for Independent Living Centers (CFILC) will present on how to choose your advocacy style.

Presenter

Jessica Riestra, Youth Organizer, California Foundation for Independent Living Centers (CFILC)

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SEPTEMBER 8, 2022
SSAN DAY 2 AGENDA ITEM 5
INFORMATION ITEM

Statewide Self-Advocacy Network

Your Vote: Your Voice



Wesley Witherspoon, Consumer Advocate at the USC UCEDD Children's Hospital in Los Angeles and USC SSAN Representative will provide a presentation on the importance of voting.

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SEPTEMBER 8, 2022
SSAN MEETING AGENDA ITEM 6
ACTION ITEM



Statewide Self-Advocacy Network

Approval of September 2022 Newsletter

Robert Levy, Chair of the SSAN Newsletter Workgroup will present SSAN members with a DRAFT version of the September 2022 Newsletter and ask members for any changes or additions. Robert will then lead a discussion about ideas for the December 2022 Newsletter, so please come prepared with your ideas for the December 2022 edition.

Attachments

- DRAFT September 2022 Voices of SSAN Newsletter
- Voices of SSAN Newsletter Article Tips Newsletter Article Tips

Recommended Action

Approve the DRAFT September 2022 Voices of SSAN Newsletter

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VOICES of SSAN

September 2022

Volume 30

IN THIS EDITION:

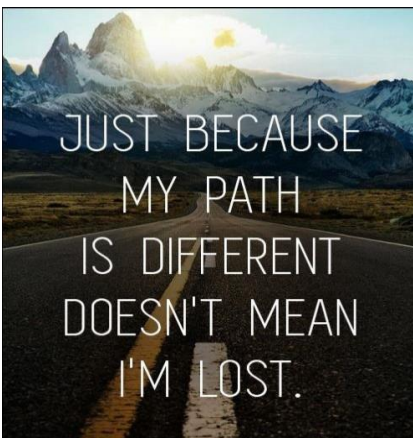
- Article 1:** SSAN Employment Stories
- Article 2:** Project SAFEE Trainings
- Article 3:** Recapping 2022 Statewide Self-Advocacy Conference
- Article 4:** PAIR Project Update
- Article 5:** Upcoming USC Trainings
- Article 6:** Best Times of Our Life
- Article 7:** Working Relationships with Providers
- Article 8:** What is Citizenship?
- Article 9:** Choices Conference
- Article 10:** Good News Corner
- Article 11:** Kudos Corner
- Article 12:** Tips for Staying Positive
- Article 13:** Community Resources
- Article 14:** Save the Dates

Editor: Robert Levy

Contributors:

- Lisa Cooley
- Rebecca Donabed
- Ellen Sweigert
- Project SAFEE
- Robert Levy
- Wesley Witherspoon
- Julie Gaona
- Robert Balderama
- Paul Mansell

SSAN Employment Stories



Having a job, being employed, looks different to everyone and the paths that they take to get their jobs is unique to them. Some people work part-time, others full-time, and others own their own business. Here are just a few stories from SSAN members about how they got where they are today.

Lisa Cooley, the Sacramento Regional SSAN Representative started her job by learning how to advocate for herself. Her local transportation provider mistakenly thought that she could use fixed route transportation services because she was able to walk around her house. But walking around a house is very different than walking to a fixed route bus stop which may be far away from someone's home. To learn how to advocate effectively for herself she got help from a disability rights organization called Protection and Advocacy Incorporated (now Disability Rights California). One of their advocates had a disability, taught her how to advocate her needs and how to tell her story to the hearing judge so that she could get access to the accessible public transportation. Lisa ended up advocating for herself so well that she started to participate on hiring teams with Disability Rights California whenever they have needed help hiring people to work for them and almost 31 years later, she is still participating on hiring teams with their organization when she has time to do it.

Rebecca Donabed, the Sequoia Regional SSAN Representative has been looking for a job for so long that she almost gave up on the idea that employment was an option for her.



Rebecca started out as a consumer of a regional center client and was told that having a job was not for her. Rebecca decided to go to college, where she did a lot of volunteer work with different groups, she even was able to help organize a symposium. Rebecca has had a part-time job at Denny's and served on the board of the Central Valley Regional Center (CVRC). She has been able to meet a lot of people through volunteering and make meaningful connections. Her case manager at the CVRC told her about the State Council on Developmental Disabilities (SCDD) and she was able to get appointed to represent the Sequoia Office at the state level. Rebecca's position on the board of SCDD, helped her to build up her confidence and continue to look for opportunities to get involved in her community after her term expired. Rebecca is now the Systems Change Advocate at Resources for Independence Central Valley and looks forward to encouraging other self-advocates to follow their dreams to find meaningful employment.

Employment Resources

[Job Accommodation Network \(JAN\)](#): Information about Reasonable Accommodations

[SCDD SB 639 Planning and Implementation Page](#): Get the latest updates on phasing out subminimum wage.

[Department of Rehabilitation Employment Services](#): The California Department of Rehabilitation has a lot of helpful tools for people with disabilities interested in looking for work.



VOICES of SSAN

September 2022

Volume 30



Project SAFEE stands for Self-Advocates For Emergency Education and is a committee of self-advocates that is supported by SCDD staff. Project SAFEE has partnered with the Red Cross and are doing a series of disaster preparedness workshops. So far our Emergency Preparedness Training series has included topics of General Preparedness and Wildfires, both workshops have been well attended with almost 200 participants! Check out our future training times and topics. We hope to see you soon!

Join us for a FREE virtual Emergency Preparedness Training Series

Mark your calendars for these upcoming sessions:

Date	Time	Topic
September 9 th	9 a.m. – 10:30 a.m.	Earthquakes & Tsunamis
October 14 th	9 a.m. – 10:30 a.m.	Floods & Landslides
November 4 th	9 a.m. – 10:30 a.m.	Home Fires

Get prepared before disaster strikes!

Registration Zoom Link:

https://bit.ly/ProjectSAFEE_ARCTRAININGS

For more information, or if you need an accommodation to participate in these trainings contact:

Jennifer Lucas: jennifer.lucas@scdd.ca.gov

Debbie Marshall: debbie.marshall@scdd.ca.gov

In collaboration with:



**American
Red Cross**





Recapping the 2022 Statewide Self-Advocacy Conference

By Lisa Cooley, Sacramento Regional SSAN Representative



This year's Statewide Self-Advocacy Conference took place on May 27th and 28th. The theme for the conference was "Looking Forward to Seeing you Soon". What made this year's conference different from conferences in the past? This was the first time I have attended this conference (and I have attended or presented at a lot of supported life conferences) as a hybrid conference. This meant that conference participants could either attend the conference in person or from the comfort of their homes.

The conference had excellent presentations from three regional center client advocates, David Lopez, from Alta California regional center who talked about what it's like being a client advocate for the regional center and taking responsibility for your services and life in general even though you have a disability, Herb Hastings, a client advocate and public speaker, who talked about what a healthy relationship is and how to be happy, and finally, SSAN Chair Desiree Boykin, a client advocate from south central Los Angeles regional center, who did a presentation talking about what her life has been like since losing her mother and dealing with grief. She shared memories of her mother and said that her parents support has made her the self-advocate that she is today.

Peter Mendoza, who works for the State Council on Developmental Disabilities did a presentation on knowing your rights and his life in disability advocacy. He started his professional life working in the Independent Living Center (ILC) side of our disability services system for several years. I learned a lot more about disability advocacy and his life that I didn't know before. The best part of the conference in addition to the presentations was getting to catch up with friends I haven't seen in person for a while. Here is a copy of the full [Conference Program](#) if you want to find out more about the sessions from this year's conference.

SAVE THE DATE

36th Annual Supported Life Conference

Re-Emergence: Community, Work, Arts, Play

Date: Thursday-Friday Oct. 13-14, 2022

Location: DoubleTree by Hilton Hotel – Sacramento, CA

See details at www.supportedlife.org



Update on the PCORI PAIR Grant Project

By Robert Levy, UC Davis MIND Institute UCEDD SSAN Representative

UC Davis MIND Institute was awarded a grant to fund a project looking at different ways to carry out inclusive research on people with intellectual and developmental disabilities. Since starting the project back in November 2021, we have started holding monthly community committee meetings for self-advocates. In the future we plan on holding sessions for advocates who are non-verbal and use communication devices. The idea to include advocates who are non-verbal came out of a presentation talk my supervisor Steve Ruder gave at a meeting with the researchers about the importance of including non-verbal advocates in the project. We are starting the project small, but plan on reaching out to different communities like people who are clients at Progressive Employment Concepts in Citrus Heights and at Community Employment Services in Davis after that.

Self-advocates who are part of the grant will be doing a training with me and receive materials of information for the researchers to use first following going out in the community after that. We are in the process of working on phase 2 of the PCORI PAIR grant project. I will be interviewed along with 2 other self-advocates on the project. In the past I have presented with my co-worker Dr. Aubyn Stahmer on the purpose of this PCORI PAIR grant project and how it is going to help people with disabilities participate in future research projects by using the tools developed through this project, these tools may even help the wider community too. For all of us that are involved with this project we have done a lot of work, however there is still a lot more work to be done. If it wasn't for this grant project, we may not have had the tools for the researchers to connect with people with disabilities and the wider community. Stay tuned for more updates.

Register for Upcoming USC Trainings

By Wesley Witherspoon, USC Children's Hospital UCEDD SSAN Representative



Please join USC Children's Hospital for a series of online trainings for adults and youth self-advocates and their families. The training sessions are hosted by me, Wesley Witherspoon, the Consumer Advocate at the University of Southern California (USC) University Center for Excellence on Developmental Disabilities (UCEDD) at Children's Hospital Los Angeles. Trainings are scheduled for Tuesdays or Thursdays depending on the month. Trainings are always scheduled between 11 AM to 12 PM. Upcoming training topics include: emergency preparedness, healthcare self-advocacy, voting, staying healthy, and much more! Please contact me for more information about upcoming training topics, dates, and times. [Register](#) for the next training today!



Best Times in Your Life

By Wesley Witherspoon, USC Children's Hospital SSAN Representative

Life is full of so many moments worth remembering, sometimes we lose track of the fun accomplishments. Do you remember times in your life that were fun? Your first date, graduating from high school, going on vacation, finding your first job. Those are memories that you will have for the rest of your life.

Finding a job that you feel works with your skill set, is meaningful to you and that you enjoy is quite a big accomplishment. Meeting a significant other, that is someone who understands you and is supportive of you, who you can laugh and cry with is a major accomplishment.

Sometimes we celebrate our accomplishments and hard work by going on a vacation to relax, which is a wonderful experience. How do you relax and celebrate your hard work? Do you take a vacation to paradise? That is a great experience. Do you enjoy dancing or going to a sport game?

After all the hard work that you do in school or work: you deserve fun breaks and vacations to create memories. Enjoying your memories with your loved ones is important for the future when things can happen. We have pictures of our memories. Knowing how to celebrate is important.

SSAN Members

- Nathaniel Florez – North Coast
- Charles Nutt – North State
- Lisa Cooley – Sacramento
- Ellen Sweigert – North Bay
- Regina Woodliff – Bay Area
- Robert Balderama – North Valley Hills
- David Forderer – Central Coast
- Rebecca Donabed – Sequoia
- Julie Gaona – Los Angeles
- Sean Sullivan – Orange County
- Eric Agular – San Bernardino
- Paul Mansell – San Diego Imperial
- Desiree Boykin – ARCA
- Recruiting – CFILC
- Nicole Patterson – DDS
- Scott Barron – DRC
- Robert Levy – UC Davis Mind Institute
- Kecia Weller – UCLA Tarjan Center
- Wesley Witherspoon – SCDD and USC Children's Hospital
- Maria Marquez – SCDD



Working Relationships with Providers

By Julie Gaona, Los Angeles Regional SSAN Representative

Self-advocates that need providers to independently be able to do daily tasks, must know what they need from a provider. Self-advocates must do an interview with providers before they hire them. They must tell the providers they are interviewing everything they need assistance with.

Communication is very important as well. An example of this would be someone being nonverbal, deaf, or speaking another language. There may also be different forms of communication. The provider and self-advocate need to know how to work with each other. The provider and self-advocate must respect each other's time. Providers must realize that they need be respectful to self-advocates by being on time, reliable, and always remember it's what the self-advocates want in their lives. Providers must not treat a self-advocate like a child or disrespect their family and friends.

Self-advocates must not take advantage of their providers. An example of this would be asking them to stay late when you know they're not able to. Self-advocates should not treat their providers like slaves. An example of this would be asking them to do several things at once. They must have patience with the providers to complete their tasks that they need to do.

When problems arise, there has to be communication between providers and self-advocates. Without communication, it can lead to unnecessary arguments. Two of the most important factors in a successful working relationship are patience and respect for each other while working.

SSAN Mission Statement

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

SSAN's past Newsletters, Annual Reports, and Meeting info, can be found at www.scdd.ca.gov under the "self-advocacy" tab

Let us know if you want to see anything specific in future newsletters!

How do you contact the SSAN Newsletter Editor Robert Levy? Leave a message for him by contacting the SCDD Self-Advocacy Coordinator **Riana Hardin at (916) 263-8196**

Check out the [SCDD YouTube Page](#) for stories from self-advocates, past meetings, and more!



DDS' CAC is RECRUITING!

The Department of Developmental Services (DDS) Consumer Advisory Committee (CAC) provides advice to DDS on policies, programs, legislation, and regulations that affect the lives of Californians with intellectual and developmental disabilities.

About the CAC:

- ☀ Fifteen (15) self-advocate members from all over California
- ☀ Meets at least four (4) times a year in Sacramento, or online with Zoom
- ☀ Members share information with their local self-advocacy organizations
- ☀ Brings input from those groups back to the CAC
- ☀ Transportation, hotel, meal, and facilitator costs (if needed) will be paid by DDS

If you would like to apply to be a CAC member, here is what you need to do:

- * Check the link below to see if we are recruiting from your regional center.
- * You must have an intellectual or developmental disability and received regional center services to apply.
- * You must be a member of a local self-advocacy group or other organization that serves or empowers people with developmental disabilities.
- * You **MUST** be nominated for membership by your local self-advocacy group or developmental disability organization.



Please note: Regional Center employees are not eligible for CAC membership.

Interested advocates should fill out the online [DDS Consumer Advisory Committee Application](#) and submit it with their nomination letter.



What is Citizenship?

By Paul Mansell, San Diego Regional SSAN Representative

Human beings are a beautiful species (group). The most important gift we have as humans is the freedom of choice and the will power to decide our own destinies. With our decision-making power we can make decisions that focus only on our self-interest, or we can live our life in a way that helps others in addition to ourselves.

Each person is an individual and unique, varying in personality, ability, opportunity, race, ethnicity, language, and creed. We celebrate the wonder of our individuality through sport every four years in the winter and summer Special Olympics, where athletes push the limits of excellence, beauty, and achievement. Beethoven expresses the brilliance of individuality in the "Ode to Joy" chorus in his 9th Symphony. As individuals, we have the right of freedom of expression and individuality. There is a dignity that comes with being able to make our own decisions and share our creativity with the world. Our ability to express ourselves freely brings about a dignity to our existence as humans.

According to the US Declaration of Independence, human rights include: the right to life, liberty, and the pursuit of happiness and no person or government should be allowed to take away your rights. A society cannot be free and safe if a portion of its people are denied their human rights. A person does not lose human rights simply because of one of their identities (race, ethnicity, religion, sexual orientation and identity, disability, or whether they live in a rural or an urban setting). While our freedom is inherent: it is not without limits. The idea of rugged individualism with limited interaction from the government fails to meet our needs as social beings. We live in societies and have social agreements on how we should treat others. In return for living by these agreements, we get benefits society has to offer: access to employment, the ability to buy items that we need and participate in the economy, exposure to cultural activities, access to healthcare and education.

Even though we have inalienable (can't be taken away) rights, simply for being human, people with disabilities (and other minority groups) have had to defend our right to access supports and services, as the way that society has viewed disability has changed over time, including the amount that people with disabilities should be included in their communities. As a Self-Advocate, I challenge people in positions of power to make decisions (elected leaders, governments, non-profit and for-profit leaders, and service providers) to remember that people with disabilities are deserving of human dignity and respect. We have human rights, abilities, hopes, and dreams too. I remind all that self-advocacy is the civil rights movement advancing the cause of people with developmental disabilities to live with the supports they need in order to follow their dreams and share their abilities with their community. People with disabilities have given much to society and will continue to contribute to positive change as long as we are offered the opportunity. The disabled are not a burden to society but complement the others in the community. We ask our community to give us justice, fairness, and our due.



Good News Corner

Here are some examples of websites that you can find uplifting news:

- [The Good News Network: California](#) for up to date information of interesting positive things happening.
- [Positive News](#) is a site that you can check out about what is happening around the world that is positive.
- [Good Good Good](#) shares really good news, not just feel good news.
- [Happy News](#) celebrates all that is good in the world.
- [Optimist Daily](#) is a site that shares solutions and good news from around the world.

Kudos Corner

By Paul Mansell, San Diego Regional SSAN Rep

Kudos to Scott Barron! Scott has been a great representative for Disability Rights California (DRC) on SSAN since 2017. He has an associate degree in Liberal Arts from Fullerton College and a bachelor's degree in Communications, specializing in Entertainment and Tourism from CSU Fullerton in 2006.

Scott is from Whittier, CA and works as a Peer Advocate for DRC and is a part of the Outreach team to connect community members to DRC resources, while helping staff to find opportunities to outreach to communities. He sits on many DRC and outside committees, giving feedback on projects. If that wasn't enough, Scott also helps with individual advocacy, working with clients 1 on 1.

Scott has always been interested in politics and believes that people should have a voice, so he figured why not start with his own. Scott was encouraged to join SSAN after learning about the group from the former DRC SSAN Representative. He was excited about the opportunity to represent DRC on such a passionate group. He hopes that one day other states can see the hard work that SSAN does and start collaborating with us because they want to create a similar organization. SSAN sets a high standard for how people with disabilities should be viewed in California, the United States, and on a global scale. What a dream: Kudos to you Scott!

Learn About SSAN

Member Organizations

- [Association of Regional Center Agencies](#)
- [California Foundation for Independent Living Centers](#)
- [Department of Developmental Services](#)
- [Disability Rights California](#)
- [University of California, Davis MIND Institute](#)
- [University of California, Los Angeles, Tarjan Center](#)
- [University of Southern California, Children's Hospital](#)

Self-Determination Update

Self-Determination is LIVE in California. Check out the [DDS Self-Determination Newsletter](#) for the latest on California's Self-Determination Program. Talk to your service coordinator to learn more.



VOICES of SSAN

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Tips for Staying Positive in Trying Times

There is so much happening in our communities right now and at times it can feel over whelming. Here are some tips for keeping calm that we want to share with you:

- Remember your ABC's: Always Be Caring
- Listen to music: your favorite artist, or type of music
- Have a dance party and move around
- Try boxing or Thai Chi
- Talk to a friend or family member
- Mentor another advocate
- Write about how you are feeling or thinking
- Read and learn something new
- Take a break outside: fresh air is good for you
- Check out a coffee/tea shop and people watch
- Volunteer for an issue that you care about
- Share your story/experiences with others
- Get plenty of rest to feel energized for the next day
- Try to eat healthy
- Practice Yoga/stretching or mindful meditation
- Know that you are not alone

Community Resources

- [SARTAC Zoom Meetings](#)
- [ARCA Regional Center COVID-19 Resources](#)
- [COVID-19 Stimulus Checks Won't Affect Your Benefits](#)
- [DRC's Build Back Better Resources](#)
- [Social Security Administration Blog](#)
- [SSA Ticket to Work Tips to Open Your ABLE Account](#)
- [Office of Self-Determination Ombudsperson](#)
- [How to Talk About Disability Sensitively](#)
- [World Institute on Disability News](#)

SAVE THE DATES

Disability Rights California



[Events and Trainings](#)

CalABLE



[News and Trainings](#)



[DO Network Training Library](#)

Plain Language COVID-19
Resources Available on:

[SCDD Website](#)

Register for the Monthly
[California Statewide Self-
Advocacy Chats](#) on Zoom



[Current Issues and Resources](#)

2022 Voting Resources

DRC Voting Hotline:
888-569-7955

[Disability Vote California](#)

[DVCA Nov 2022 Series](#)

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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: Is the article a human-interest story or an issues story? If it is a human-interest story, can you tie it back to an issue or larger regional or statewide problem?

Helpful Tips:

- Tie your article back to the Mission/Vision/Purpose of SSAN
- Tie your article back to the newsletter theme if there is one
- Write articles about systems change (city/county/regional/statewide) problems
- Limit individual advocacy articles
- When Interviewing people, ask questions related to systems change advocacy, SCDD State Plan and SSAN
- When possible, turn an interview into an article and stay away from question and answer format.
- 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. Here are some topic areas covered under the SCDD State Plan:

- Self-Determination
- Employment
- Housing
- Health and Safety
- Transportation and other Long-Term Services and Supports (LTSS)

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

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SEPTEMBER 8, 2022
SSAN MEETING AGENDA ITEM 7
INFORMATION ITEM

Statewide Self-Advocacy Network



Disability Voice in Society

Individual stories provide meaningful connection and help law makers, community leaders, and the general public to understand the impact of the laws and their role in creating accessible communities. Scott Barron, Peer Advocate, for Disability Rights California (DRC) and Ibrahim “Bebo” Saab, Supervising Attorney for Outreach, at Disability Rights California (DRC) will talk about the importance of individual stories within the disability movement. Affective Storytelling can help to:

- Pass major legislation
- Inspire others to advocate for change and share their story

This training will help you to learn how to use your own story to effectively advocate for the services you need.

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SEPTEMBER 8, 2022
SSAN MEETING AGENDA ITEM 8
INFORMATION ITEM

Statewide Self-Advocacy Network



Planning for December 2022

The SSAN Chair will lead the group in a discussion about ideas for the December 2022 meeting and members will have the opportunity to complete meeting evaluations for the September 2022 meeting.

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