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STATEWIDE SELF ADVOCACY NETWORK MEETING INFORMATION



DATE: Wednesday, June 29, 2022 and Thursday, June 30, 2022



TIME: Wednesday, June 29, 2022 10:00 AM – 3:00 PM
Thursday, June 30, 2022 10:00 AM – 2:00 PM

Members of the public may participate in person, telephonically, or by Zoom. Accessible formats of all agenda and materials can be found online at www.scdd.ca.gov

MEETING DETAILS:

PHYSICAL LOCATION

SCDD HQ OFFICE
3831 North Freeway Blvd., #125
Sacramento, CA 95834

REMOTE LOCATION(S):

See last page

ZOOM LINK:

<https://bit.ly/SSANJune2022>

MEETING ID: 819 5717 0023

PASSCODE: 231561

TELECONFERENCE:

CALL IN NUMBER: (888)-475-4499

MEETING ID: 819 5717 0023

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

June 29, 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 March 2022 Minutes

Presented by: Desiree Boykin, Chairperson
ACTION



4. Updates from the SSAN Chair

Presented by: Desiree Boykin, Chairperson
Information

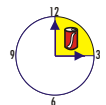


5. SCDD Update

Presented by: Aaron Carruthers, SCDD Executive Director
Information



Break



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

Presented by: Tamica Fouts-Rachel, SCDD Vaccine Program Manager
Information

7. SSAN Workgroups

Presented by: ALL
Discussion



8. Self-Advocacy: Living the Good Happy Life

Presented by: Paul Mansell SSAN Vice-Chair,
San Diego Regional Representative



Discussion

9. Basics of Self-Care

Presented by: Sherlyn Porter, Licensed Clinical Social Worker
Tulare County HHSA – Behavioral Health Branch

Information

10. Recess Until Next Day

Presented by: Desiree Boykin, Chairperson
Information





AGENDA FOR DAY 2

June 30, 2022

10:00 AM – 2:30 PM

1. Call to Order, Welcome and Introductions

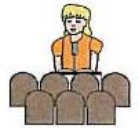
Presented by:

- 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. SCDD Legislative Update

Presented by: SCDD Staff
Information

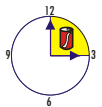


4. From Awareness to Justice

Presented by: April Dawson, Executive Director,
Resources for Independent Living
Information



Break



5. Update from SCDD Self-Advocacy DEAP

Presented by: Peter Mendoza, Community Program Specialist 2,
SCDD Sacramento Regional Office
Information



6. Approval of June 2022 SSAN Newsletter

Presented by: Robert Levy, SSAN Secretary, SSAN Newsletter
Workgroup Chair, and UC Davis MIND Institute SSAN
Representative



ACTION

7. SCDD DAC Project Update

Presented by: Julie Ebi-McKenzie, SCDD DAC Chair, Manager
North Coast Regional Manager



Information

8. Planning for September 2022 Meeting

ALL
Discussion



9. Adjournment

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JUNE 29, 2022
SSAN MEETING AGENDA ITEM 3
ACTION ITEM



Statewide Self-Advocacy Network
Approval of March 2022 Minutes

Attachments

- March 2022 Minutes

Recommended Action

Approve the March 2022 SSAN Meeting Minutes

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Statewide Self—Advocacy Network Meeting Minutes March 9 & 10, 2022 Zoom

SCDD Regional Members Present

Nathan Florez – North Coast
(Day 2)
Charles Nutt – North State
Lisa Cooley – Sacramento
Regina Woodliff – Bay Area
(Day 1)
Robert Balderama – North Valley Hills
Rebecca Donabed – Sequoia
David Forderer – Central Coast
Sean Sullivan – Orange County
Julie Gaona – Los Angeles
Paul Mansell – San Diego–Imperial

Agency Members Present

Maria Marquez – SCDD
Robert Levy – UCD MIND Institute
Wesley Witherspoon – USC CHLA
Scott Barron – DRC
Nicole Patterson – DDS
Desiree Boykin – ARCA

Members Not Present

Ellen Sweigert – North Bay
Vacant – San Bernardino
Russell Rawlings – CFILC
Kecia Weller – UCLA Tarjan Center

SCDD Staff in Attendance

Rihana Ahmad – SCDD HQ
Aaron Carruthers – SCDD HQ
Julie Eby-McKenzie – SCDD North Coast
Riana Hardin – SCDD HQ
Dena Hernandez – SCDD North Valley Hills
Beth Hurn – SCDD HQ
Bridget Kolakosky – SCDD HQ
Charles Nguyen – SCDD HQ
Mary Agnes Nolan –
SCDD North State
Tina Reszler – SCDD North State
Tobias Weare – SCDD North Bay

Presenters

Leslie Morison
Katie Hornberger
Aubyn Stahmer
Alice Kina Diehl

Others Present

Sarah Davenport
Gabriela Solval



DRAFT

SSAN Minutes

1. Call to Order, Welcome and Introductions

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

SSAN Chairperson Desiree Boykin requested that Riana Hardin, SCDD Self-Advocacy Coordinator assist in the attendance roll call. Members introduced themselves and the region or agency that they represent.

2. Public Comment

Dena Hernandez, SCDD Regional Manager – North Valley Hills, shared that the SCDD Self-Advocacy Disability Expert Advisory Panel (DEAP) would like SSAN members input on what work they should be focusing on and would like to know if a member of SSAN would be interested in attending the next Self-Advocacy DEAP meeting on March 30th.

3. Review and Approval of December 2021 Minutes

The members reviewed the minutes from the December 8 & 9, 2021 meeting. Materials for this agenda item can be found on pages 7–16 of the March 2022 SSAN Meeting Packet.

ACTION: Motion #1 to approve the December 2021 minutes was made by David Forderer/Seconded by Regina Woodliff. A roll call vote was taken. Motion passed. See vote log on page 8.

4. Updates from SSAN Chair

SSAN Chairperson Desiree Boykin reminded members that March is Developmental Disabilities Awareness Month and that it was important to celebrate and recognize the achievements and progress of the disability rights movement.

5. Update SSAN Priorities

In order to align SSAN activities with SCDD's new State Plan, The SSAN Operations Workgroup proposed making a few updates to the current SSAN Priorities. The proposed new priorities are: strengthening Self-Advocacy by focusing on civic engagement, youth engagement, and self-determination; improving access to services and supports by focusing on medical care and resources, and transportation services; and improving access to competitive integrated employment by focusing on trainings and building awareness.



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ACTION: Motion #2 to approve the Updated SSAN Priorities with the addition of the word “Accessible” before Medical Care and Resources and Transportation Services was made by Charles Nutt/Seconded by Paul Mansell. A roll call vote was taken. Motion passed. See vote log on page 8.

6. SCDD Update

SCDD Executive Director Aaron Carruthers provided SSAN members with an update on SCDD activity since the December SSAN meeting. Executive Director Carruthers talked about the challenges of responding to the ongoing public health crisis of COVID–19 and keeping everyone safe. SCDD continues to address vaccine hesitancy among Californians with I/DD and their communities by providing timely, up to date and easy to understand information and resources. Executive Director Carruthers addressed SCDD efforts to implement California Senate Bill 639 which will end subminimum wage in California by 2025. SCDD remains committed to supporting SSAN as an important part of the Self-Advocacy work under the new 5-year State Plan.

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
- Youth Engagement

8. SSAN Youth Representative

SSAN Youth Workgroup Chair, Nicole Patterson talked about the need to include the voices of youth with disabilities in on SSAN. The SSAN Youth Workgroup recommended to the SSAN Operations Workgroup that there be a dedicated member seat on SSAN connecting SSAN with an organization or group that advocates for youth with disabilities. Since Youth Organizing (YO!) Disabled and Proud is an existing statewide advocacy group, the Youth Workgroup would like to recommend YO! Disabled and Proud be a member of SSAN.



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ACTION: Motion #3 to approve the recommendation to invite YO! Disabled and Proud to be a part of SSAN was made by Regina Woodliff/Seconded by Rebecca Donabed. A roll call vote was taken. Motion passed. See vote log on page 8.

Due to a scheduling conflict the item “SCDD Legislative Update” was moved to day 2 of the meeting and “Approval of the March 2022 SSAN Newsletter” was moved to day 1 of the meeting.

9. Approval of the March 2022 SSAN Newsletter

SSAN Secretary and Newsletter and Communications Workgroup Chair, Robert Levy reviewed the DRAFT March 2022 Voices of SSAN Newsletter. Members asked that their quotes be added to the article on 10 years of SSAN and called for a motion to approve the March 2022 Edition.

Materials for this agenda item can be found on pages 41–54 of the December 2021 SSAN Meeting Packet.

ACTION: Motion #4 to approve the March 2022 Newsletter with the suggested edits was made by Regina Woodliff/Seconded by Paul Mansell. Motion passed. See vote log on page 8.

10. Input into Special Incident Reporting Categories

Katie Hornberger, Representatives from Department of Developmental Services asked SSAN members for input on Special Incident Reporting (SIR) categories and members shared their thoughts on regional center staff reporting pregnancies, relationship statuses, medication error, hospital visits and whether individuals should be told when a report has been filed. Members talked about the balance of reporting serious issues vs. being invasive and overbearing. Members expressed the importance of transparency and honesty about when and why a SIR is being filed.

11. Recess Until Next Day

SSAN Chairperson Desiree Boykin declared the meeting in recess at 3:02 PM. The December 2021 SSAN meeting will return from recess at 10:00 AM Thursday, December 9th, 2021.



DRAFT

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 10:00 A.M.

An attendance roll call was taken.

2. Public Comment

Charles Nutt, North State SSAN Member shared that surveys for the National Core Indicators are being sent out to families, and if you receive a survey, please fill them out. Regional Centers need to have 400 surveys completed. There are 3 different types of surveys, that can be completed online or mailed back to the SCDD North State Regional Office.

3. SCDD DAC Disability Video Project

As a follow-up to the presentation at the December SSAN meeting, SCDD DAC members asked for SSAN members' feedback on what it means to have a disability. SCDD DAC members asked for SSAN's input on how to put together a short training video on the topic of working with a disability.

Members of the SCDD Disability Advisory Committee (DAC) engaged in a conversation with SSAN members about what it means to have a disability, how disability impacts lives and what other people misunderstand about having a disability. Members shared how having a disability has changed their perspective on life.

4. I/DD Representation in the Media

Actress Alice Kina Diehl talked to members about the importance of authentic representation of people with disabilities in media. Members discussed the importance of groundbreaking films like *Coda* in mainstreaming disability culture and the importance of creating community with other actors with disabilities.



DRAFT

5. SCDD Legislative Update

Bridget Kolakosky, SCDD Deputy Director – Policy and Public Affairs, provided members with an overview of SCDD legislative activities. SCDD's inaugural "There Should Be a Law" contest was such a success that SCDD has considered sponsoring 3 pieces of legislation based on ideas from the contest. The three ideas SCDD is focusing on are reforming the fair hearing process for regional center clients ([SB 1092](#)), reforming conservatorship rules ([AB 1663](#)), and supporting housing options for older adults and people with disabilities ([AB 2547](#)). The SCDD Legislative and Public Policy Committee is also recommending that the Council support legislation to improve access to education for people with (I/DD) ([AB 2920](#)).

6. UC Davis MIND Institute Grant Project

Aubyn Stahmer, Director of Community-Based Treatment and Research, and Robert Levy, Center for Excellence in Developmental Disabilities (CEDD) Community Advocate talked to SSAN about a recent grant UC Davis MIND Institute was awarded to fund a project looking at different ways to improve inclusion of people with developmental disabilities in research about people with developmental disabilities. The goal of the Partnership for Inclusive Research (PAIR) project is to help researchers and people with developmental disabilities work together to decide what research to do in the areas of telehealth, equal access to healthcare and transition to adulthood. UC Davis MIND Institute hopes that building partnerships between people with disabilities and researchers will help in identifying research questions that are important to the community.

The first part of the project is to organize focus groups made up of self-advocates, community members and researchers to gather information. The second step will be to create community action partnership teams to research different strategies, and the last step will be to share the information nationally by giving presentations and putting together a toolkit.

Members suggested reaching out to Stanford Hospital and other hospitals specializing in I/DD and childhood illnesses.



DRAFT

7. Planning for June 2022 Meeting

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

- Disability Pride
- Citrus Heights PD Abuse Prevention
- Mental Health
- Internet Crime
- SCDD SA DEAP
- Voting/Disability Vote California/How the June Primary went
- SCDD DAC Project Update
- Coordinated Future Planning
- Legislation
- ADA Disability Sensitivity/Awareness
- Self-Determination Update

8. Adjournment

Meeting was adjourned at 2:01 P.M. The next SSAN meeting will be on June 15th and 16th 2022 using Zoom.



DRAFT

DECEMBER 2021 SSAN VOTE TALLY

Name	Region	Roll Call	Motion 1	Motion 2	Motion 3	Motion 4	Day 2 Roll Call
Maria Marquez	SCDD	Present	For	For	For	For	Present
Nathaniel Florez	North Coast	Not Present	Not Present	Not Present	Not Present	Not Present	Not Present
Charles Nutt	North State	Present	Abstain	For	For	For	Vacant
Lisa Cooley	Sacramento	Present	For	For	For	For	Present
Ellen Sweigert	North Bay	Not Present	Not Present	Not Present	Not Present	Not Present	Present
Regina Woodliff	Bay Area	Present	For	For	For	For	Not Present
Robert Balderama	North Valley Hills	Present	For	For	For	For	Present
David Forderer	Central Coast	Present	For	For	For	Not Present	Present
Rebecca Donabed	Sequoia	Present	For	For	For	For	Present
Julie Gaona	Los Angeles	Present	For	For	For	For	Present
Sean Sullivan	Orange County	Present	For	For	For	For	Not Present
Vacant	San Bernardino	Vacant	Vacant	Vacant	Vacant	Vacant	Vacant
Paul Mansell	San Diego	Present	For	For	For	For	Present
Desiree Boykin	ARCA	Present	For	For	For	For	Present
Russell Rawlings	CFILC	Not Present	Not Present	Not Present	Not Present	For	Not Present
Nicole Patterson	DDS	Present	For	For	For	For	Present
Scott Barron	DRC	Present	For	For	For	For	Present
Wesley Witherspoon	USC – CHLA	Present	For	For	For	For	Present
Kecia Weller	Trajan Center	Not Present	Not Present	Not Present	Not Present	Not Present	Not Present
Robert Levy	Mind Institute	Present	For	For	For	For	Present

JUNE 29, 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 June 2022 Meeting and will take a moment to provide a verbal update to SSAN members.

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JUNE 29, 2022

**SSAN MEETING AGENDA ITEM 5
INFORMATION ITEM**



Statewide Self-Advocacy Network

SCDD Update

Since the March 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.

Possible Handouts

- Council Meeting Summary

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JUNE 29, 2022
SSAN MEETING AGENDA ITEM 6
INFORMATION ITEM



Statewide Self-Advocacy Network

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

Advocating for early and equitable access to COVID–19 vaccines for people with I/DD continues to be a priority for SCDD. In response to the ongoing need for reliable information and resources, SCDD received funding from the federal government to continue outreach and education efforts.

The California State Council on Developmental Disabilities (SCDD) hired a Vaccine Program Manager to increase vaccine access and awareness for people with I/DD and develop best practices for addressing hesitancy related to COVID-19 and future public health emergencies.

Tamica Foots-Rachel, Vaccine Project Manager will review a short presentation on the project and would like your feedback and ideas on how to improve access to information about COVID-19 vaccines to people with I/DD.

Ahead of the June SSAN meeting, please take a look at the website: <https://schools.covid19.ca.gov/pages/parent-page> and make note of any changes that should be made or information that would be helpful to have on the page and be prepared to share your thoughts.

Handouts:

- Project Feedback PowerPoint

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JUNE 29, 2022
SSAN MEETING AGENDA ITEM 7
INFORMATION ITEM



Statewide Self-Advocacy Network

SSAN Workgroups

SSAN workgroups will meet to discuss current and ongoing projects. Workgroups are encouraged to review and discuss their workgroup Goals and Priorities, suggesting updates as needed. The following SSAN workgroups will meet using Zoom Breakout Sessions:

- 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

Handouts

- SSAN Workgroup Descriptions
- SSAN Workgroup Roster

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JUNE 29, 2022
SSAN MEETING AGENDA ITEM 8
INFORMATION ITEM



Statewide Self-Advocacy Network

Self-Advocacy: Living the Good Happy Life

Paul Mansell, SSAN Vice-Chair and San Diego Regional Representative will present on the importance of living the good happy life.

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JUNE 29, 2022

**SSAN MEETING AGENDA ITEM 9
INFORMATIONAL ITEM**



Statewide Self-Advocacy Network

Basics of Self-Care

Sherlyn Porter, Licensed Clinical Social Worker from the Tulare County Health and Human Services Agency, Mental Health Department, will be providing members with tips on how to relax and how to help someone who is struggling. She will provide information about the resources that are available to help and what you, as an advocate can do to help share information and work with local mental health agencies to educate others. She will also explain how the ongoing COVID–19 pandemic has changed the way people talk about mental health.

If you have any questions before the presentation, please feel free to send them to me in an email or text and I will forward them to the presenter.

Materials for this item will be shared after the SSAN meeting.

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JUNE 30, 2022
SSAN MEETING AGENDA ITEM 3
INFORMATION ITEM

Statewide Self-Advocacy Network

SCDD Legislative Update



SCDD staff will provide SSAN members with an update on SCDD Legislative activities. Updates may include:

- SCDD Sponsored Legislation
- A breakdown of this year's budget
- Other state and national legislative updates

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JUNE 30, 2022
SSAN DAY 2 AGENDA ITEM 4
INFORMATION ITEM



Statewide Self-Advocacy Network

From Awareness to Justice

April Dawson, Executive Director, Resources for Independent Living, the Sacramento Independent Living Center will be talking to members about moving beyond simple awareness of disability issues to working to promote disability justice in the workplace and beyond.

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JUNE 30, 2022
SSAN DAY 2 AGENDA ITEM 5
INFORMATION ITEM



Statewide Self-Advocacy Network

Update from SCDD Self-Advocacy DEAP

Peter Mendoza, Community Program Specialist 2, for the SCDD Sacramento Regional Office, and Co-Chair of the SCDD Self-Advocacy Disability Expert Advisory Panel (DEAP) will provide SSAN with an update.

Attachments

- Summary of SCDD Self-Advocacy DEAP Recent Activities

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**Self-Advocacy Disability Expert Advisory Panel (DEAP) Information
by Dena Hernandez-North Valley Hills & Peter Mendoza- Sacramento**

Self Advocates Advisory Committee (SAAC)

June 13, 2022

Reminder: What the DEAPs are and what the DEAPs do:

- State Council on Developmental Disabilities (SCDD) has started the new State Plan in October 2021.
- Self-Advocacy is one of the Goals of the SCDD State Plan. The other goal are focused on creating systems change and building capacity in education, employment, health & safety, housing, and self-determination
- To work on these goals statewide- SCDD has put together a **Disability Expert Advisory Panel (DEAP)** for each focus area. The DEAPs are made up of SCDD Headquarters staff, Manager's, and Community Program Specialists from our regional offices across the state.
- The main purpose of all the DEAP's is to focus on system change, advocacy and capacity building.
- We have been asked to put training modules (Learning Series) together for a SCDD Learning Management System- so people can access free trainings on different topics online.
- We wanted to hear from SAAC members as self-advocacy EXPERTS on what main things the SCDD Self Advocacy DEAP should focus on statewide.

UPDATE from the Self-Advocacy DEAP:

- The Self Advocacy DEAP thanks SSAN Chair Desiree Boykin, SAAC Chair Nicole Adler & Council Chair Wesley Witherspoon for volunteering to represent Self-Advocacy Leadership on this DEAP.
- Here are the important self-advocacy topics that the Self Advocacy DEAP came up with input from all the members from across the state and will be working on over the next 5 years:

- Speakers Bureau (could benefit all DEAPS- develop a policy for stipends for members)
- Youth Engagement
- Plain Language/ Easy Read/ ASL (Easy ACCESS)
- Representation on boards/committees (Nothing About Us without us)
- Legislative Advocacy/Educate Public officials
- Navigating regional center services & generic services
- Appeal Process (RC/Generic Services/Education)
- Promote self-advocacy to the youth
- Decision Making & Conflict resolution
- Interviewing skills (for a job, to volunteer, to be on a board etc)
- How to manage direct support staff (training/educate)
- How to educate/train IHSS employees
- Set up a 6 month/year-long statewide leadership academy
- How to Not Give Up/ Highlight of Leaders in our state- share the good and the bad
- Urban & Rural Areas- address these different needs
- Transportation Advocacy
- Equity & Disparities
- Success Stories from Self Advocate Leaders
- Healthy Relationships & sexuality
- SCDD Statewide Self Advocacy Conference- rotate North/South
- Provide info on any/ all self-advocacy conferences/seminars
- Collaborative trainings with staff and self-advocates and with topic experts
- Quarterly SA meetings and have certain themes: Transportation as an example
- Voter Summit
- Access to Independence

We are asking SSAN members to let us know any ideas or if we might have missed any topics. We will send a report/update for each SAAC meeting. You can email us anytime if you have questions, comments, or concerns! Thank you!

Dena.hernandez@scdd.ca.gov

Peter.mendoza@scdd.ca.gov

Riana.Hardin@scdd.ca.gov

JUNE 30, 2022

SSAN MEETING AGENDA ITEM 6

ACTION ITEM

Statewide Self-Advocacy Network

Approval of June 2022 Newsletter



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

Attachments

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

Recommended Action

Approve the DRAFT June 2022 Voices of SSAN Newsletter

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IN THIS EDITION:

Article 1: Preparing for Emergencies

Article 2: Project SAFEE Trainings

Article 3: Justice, Tragedy, and Disability

Article 4: Disability in the Park
Tips for Staying Positive

Article 5: Importance of Voting

Article 6: How a Bill Becomes a Law

Article 7: DDS CAC is Recruiting

Article 8: Celebrating 10 Years of SSAN

Article 9: Celebrating the ADA

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:

- Wesley Witherspoon
- Project SAFEE
- Paul Mansell
- Rebecca Donabed
- David Forderer
- Nicole Patterson

Preparing Emergencies

By Wesley Witherspoon, USC Children's Hospital SSAN Representative



We live in a culture of emergencies. There are many types of emergencies: fires, earthquakes, pandemics, floods, active crime scene, medical, heat wave, blizzard, drought, volcanoes, tornadoes, windstorms, brush fires, avalanche, tsunamis, and ice storms. It is important to prepare for an emergency. We don't know when an emergency will occur. Do you know what to do when you must leave your home? Preparing for an emergency can mean the difference between life and death. Do you have a First Aid kit? You can buy supplies for your First Aid Kit from discount stores. It is important to also include things like: your medication, clothes, food and water in your emergency kit, these are often things that people may not think about. Talk to your first responders such as fire fighters, police officers, and ambulance workers about how to survive in an emergency. Your local State Council on Developmental Disabilities office can be a good resource for education and training on emergency preparedness. I do a lot of trainings on emergency preparedness and other topics for my job, so you can always contact me if you want to learn more about emergency preparedness. Do you know where the shelters are located? What if the emergency occurs when you are working, shopping, or traveling? You can take a CERT (Community Emergency Response Team) class as well. You can also sign up for emergency alerts. You can turn to TV or radio if you are having an emergency.



VOICES of SSAN

June 2022

Volume 29



Join us for a FREE virtual
Emergency Preparedness Training Series

Mark your calendars for these upcoming sessions:

Date	Time	Topic
June 10 th	9 a.m. – 10:30 a.m.	General Preparedness
July 8 th	9 a.m. – 10:30 a.m.	Wildfires
August 12 th	9 a.m. – 10:30 a.m.	Power Outages/Heatwaves/Food Safety
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/ProjectSAFE_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**





Justice, Tragedy, and Self-Advocacy

By Paul Mansell, San Diego Regional SSAN Representative

Justice, ethics, morality, the good life, and self-advocacy are linked. Justice is a founding principle of society that guides and shapes our ethics or sense of right and wrong, as well as our morality. Justice is about more than laws or doing the greatest good for the majority of people. To have a sense of justice, you are not only committed to treating people fairly and giving them their due, but you are also committed to giving others mercy when they make mistakes and offering them the chance to change. Justice is not black or white but can see a broad spectrum of gray. Justice is embodied in a nation's constitution, laws, policies, regulations, and institutions in the just state.

Self-advocacy has both personal and social meanings. Personal self-advocacy is individually speaking up for your rights and sharing your needs, concerns, hopes, and dreams with the people in your life. Social self-advocacy is the collective civil rights movement of people with developmental disabilities voicing their concerns to leaders in society to make systemic changes in their lives so that they may achieve their potential and be integrated into their community.

Just governments or "states" give citizens or people the highest potential to lead a happy and good life. People have a voice in the way our government works and while sharing in the state's wealth, goods, and resources. Just governments promote the community's general welfare, protect and defend when a community is in danger, maintain the community's peaceful order, and divide and distribute goods, services, resources, wealth, and property. Citizens or "the people" are connected to each other and are an important part of promoting a just state in order to increase the well-being and happiness of the community.

Ideally, a just state treats all its citizens equitably, promotes fairness and holds people accountable for their actions because no one is above the law, regardless of status or wealth. A just state makes sure that the following services are accessible to its citizens: education, transportation, food, water, utilities, healthcare, law enforcement, and housing, leaving much to individual initiative and industry.

People vary in abilities, situations, opportunities, and fortunes. The just state has the responsibility to support the needs of people who are marginalized and vulnerable. We self-advocates benefit from this entitlement, but in return we have a responsibility to help create and maintain peace.

People have freedom of choice to decide how we live without worrying that others will take away our voice or choice. People generally act to promote their self-interest but may be inspired to work to promote the well-being of a group as a whole. We have the strength, with the right support, to reach our goals. When Self-advocates unite and voice our needs and concerns, we can make meeting our needs a priority and help make society more just for all its citizens.

(Continue on page 4: "Justice")



(Continued from page 3: “Justice”)

I firmly believe that Self-Advocacy is part of a much bigger whole of a just and fair society. Self-advocacy embodies many of our rights, including freedom of speech, fairness when we are on trial or in a hearing, and the right to choose who we hang out with. It is important not to dismiss peoples’ concerns as not a problem or as whining/complaining. The concerns of people with disabilities deserve to be heard and listened to. At the very least, we deserve respect, to be listened to, and not to be discounted. Self-Advocacy is the civil rights movement of persons with developmental disabilities speaking up for themselves, advancing their cause to further policies that will better empower them to reach their potential in their community with needed support. All we want is to be treated fairly, given our due, and afforded dignity just like every other person. Is that too much to ask for?

We feel strong as self-advocates, but the news is full of many troubling topics – hate crimes, mass shootings, foreign wars, and the national divide. This is heartbreaking, causing frustration, anger, resentment, and grief. Often, we feel overwhelmed and unsure of how to help in situations of civil unrest or tragedy. I, for one, have stopped watching the news because I don’t want to be overwhelmed or feel hopeless with all the negative things happening or experience negative emotions.

It is more than enough that we put up with harassment, stigma, and prejudice directed at us for having disabilities: but to also feel helpless when there is so much injustice in the world, is too much. We must work hard to unite to end those forms of abuse. The time has come for others to end these tragedies. Enough is enough.

Disability Pride in the Park

By **Rebecca Donabed**, Sequoia Regional SSAN Representative

Resources for Independence Central Valley (RICV) is planning the first ever Disability Pride event and is looking for partners to help support this first ever type of event celebrating the central valley disability community.

This event will have keynote speakers addressing important issues, cooking contests, food, music, arts and crafts, information booths and so much more. So, mark your calendars for October 22, 2022 and join us from 10 am to 4 pm in Fresno for a great time. If you can, or if you know of someone able to, consider becoming a sponsor of the event that is sure to be an empowering and inclusive event that celebrates everyone.

For more information, you can contact Susan Manuel at smanual@ricv.org.





Issue Spotlight: The Importance of the Disability Vote

By Wesley Witherspoon, USC Children's Hospital SSAN Representative



Voting is a very important issue as it is a way for people to tell law makers and elected officials about the issues that are important to them. There are a lot of different groups that meet to talk about voting issues. One of those groups is called

[Disability Vote California](#) or Disability Vote

CA. We met with Independent Living Centers (ILC) representatives to discuss voting. Voting is beneficial because it expresses what you want. I enjoy collaborating with people across California as they work to make voting accessible for all who choose to. Voting processes are organized by each county. There are 58 counties in California, so the voting experience is different depending on the county that you live in. In the past, people with disabilities were excluded from voting. The California Secretary of State has a whole page on options for [Voters with Disabilities](#) where you can learn about all the different ways that California is working to make the voting process more inclusive. California has over 39 million people, so voting can be very complicated. People have so many different opinions when it comes to voting. You vote the way you want to. Please vote in the election, if you choose to.

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
- Recruiting – 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



How a Bill Becomes a Law

By David Forderer, Central Coast Regional SSAN Representative

A bill starts with an idea that someone brings to a legislative body. Then that idea is put into language that would help to inform policy makers if the bill becomes a law. Once the language is completed, then it is discussed with the author's staff to adjust for any changes that need to be made. Once that is completed, it is presented to the members of the legislative body of which the bill's author belongs. The body then assigns the bill's idea to the appropriate sub-committee of the body, which has the responsibility of making any adjustments to the language of the bill. From there they could add additional language (broadening or narrowing the bill's focus) which would make it more appealing.

It is then voted on to either move it out of the committee, to shelve it (put into suspension or hold area), to keep working on it or to kill the bill entirely because of lack of support.

In California it is presented to both the senate and the assembly houses for approval. If both houses approve the bill it then moves on to the governor's office for approval. If it is approved, it becomes law. The governor can also veto the law (disapprove of the law) which stops the bill's movement. Then it repeats the legislative process all over again. It then can go to a conference committee where additional changes can be made to appease the governor or other legislators.

Once these changes are made, it moves into what is known as "final passage". From there it moves onto the governor's office again for approval. He can do one of the following: sign it, veto it or ignore it. If they don't sign the bill it will become law after a period of 10-12 days.

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 per year in Sacramento, or online with Zoom
- ☀ Members share information with their local self-advocacy organizations and bring
- ☀ 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 next page of the newsletter 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.





The DDS CAC is currently recruiting members from the following regional centers:

- ☀ Central Valley Regional Center (CVRC)
- ☀ East Los Angeles Regional Center (ELARC)
- ☀ Frank D Lanterman Regional Center (FDLRC)
- ☀ Harbor Regional Center (HRC)
- ☀ Inland Regional Center (RCRC)
- ☀ North Los Angeles Regional Center (NLARC)
- ☀ San Andreas Regional Center
- ☀ Tri Counties Regional Center (TCRC)
- ☀ Westside Regional Center (WRC)

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

Fill out the online application completely & submit it with your nomination letter at <https://www.dds.ca.gov/consumers/consumer-advisory-committee/>. If you're having trouble with the online form, use the contact information below to get help.



Celebrating Ten Years of SSAN: Members Reflect

"I'm grateful to the SSAN members for their willingness make your voices heard in the community. SSAN members are friendly and warm towards all members."

– Desiree Boykin, ARCA SSAN Representative

"SSAN is celebrating its 10th anniversary. I have been a SSAN member for 7 years. SSAN has gone a long way to defining my identity. It gives me opportunities to practice my leadership, communication, and social skills. I love to write articles for its newsletter. It allows me to explore my understanding of Self-Advocacy and helps me grow in my appreciation of acceptance, tolerance, diversity, inclusion, and interconnectedness. It has expanded my appreciation for social justice and activism."

– Paul Mansell, SSAN Vice-Chair, San Diego Regional SSAN Representative

"As we are in 2022 it hard to believe to that SSAN had just turned 10 this year. What a milestone year. As the 1st decade has closed for SSAN we have had a lot of staff and members. However, there are some founding members since it began 10 years ago. SSAN has helped to get a lot of bills signed into law. As self-advocate leaders we work hard to make sure that the work that we do makes things better for ourselves, as well as others who have I/DD and help them to have productive lives. So now that SSAN is heading for its 11th year, I look forward to working with staff and members of SSAN to keep doing the important work to improve the lives of people with I/DD, so they can feel included in their communities and have bright futures. So, happy 10th birthday SSAN." – Robert Levy, SSAN Secretary UC Davis MIND Institute UCEDD SSAN Representative

"I am just proud that it (SSAN) took off like it did. It was a seed that sprouted, like an experiment that went well! We keep doing good work for people with disabilities and can't believe it has been ten years!" – Robert Balderama, North Valley Hills Regional SSAN Representative

"Ten years of SSAN means that more people with disabilities are continuing to develop their leadership skills in substantial and meaningful ways."

– Lisa Cooley, Sacramento Regional SSAN Representative

"Over the last 10 years the Statewide Self-Advocacy (SSAN) has been an asset to the state of California because it has allowed a body of advocates from entities that deal with people with disabilities to come together as a voice. It has been an instrument for people to share information and get information to better the services and supports for people with disabilities in California. The evidence has shown over the last two years during the pandemic that SSAN has taken an important role to make sure that the word was getting out about vaccinations, CDC regulations, ways to get food and supplies that were needed, distributing personal protective equipment in their local areas, And being a support for each other. – Nicole Patterson, DDS SSAN Representative



Reflections on the Americans with Disabilities Act (ADA)

By Robert Levy, UC Davis MIND Institute UCEDD SSAN Representative



July 26th, 2022 will mark 32 years since the [Americans with Disabilities Act \(ADA\)](#) was signed into law on Thursday, July 26, 1990, by the late 41st US president George Herbert Walker Bush. The ADA has opened doors and opportunities for people with disabilities because we are able to have better access to employment, transportation services, public spaces and communication systems. People with disabilities are now able to go more places with the help of more accessible transportation services, that were not options for them before. This means that people with access and functional needs (AFN) are able to go to work and travel throughout their communities more freely, leading to their own independence thanks to adaptations on public transportation and the existence of curb cuts, ramps and accessible bathrooms. The need for advocacy is never done, but it is important to celebrate important advocacy and legislative achievements, so we know that we are making an impact. Thank you, all past or present self-advocates, for working on getting the ADA bill signed into law.



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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 Robert Levy, UC Davis MIND Institute UCEDD SSAN Rep Kudos to Lisa Cooley! She has been a great Self-Advocate for the Sacramento Regional Office of the SCDD and a longstanding SSAN member since 2015. She was the State Council on Developmental Disabilities board member and is currently a Coordinated Future Planning Task Force Member for Alta Regional Center and member for the Community Advisory Committee for the Alta Regional Center. She is a Community Advisory Committee member for the UCD MIND Institute UCEDD where I work. Lisa is also currently a member of SSAN for the Employment First work group. I think that Lisa Cooley is a great Self-Advocate because she doesn't want to let her disabilities keep her from being active in the Sacramento region and advocating for people with disabilities. She also has done numerous presentations for our community and has written numerous testimony letters to our local and national legislators to get federal and state bills signed into law. Keep on trucking Lisa Cooley, by doing all the Self-Advocacy work in our community. Kudos to you Lisa Cooley!

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.



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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:

- 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
- Go for a walk or jog 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](#)
- [SSAN Youth Survey](#)
- [SSA Ticket to Work Tips to Open Your ABLÉ Account](#)
- **FEEDBACK WANTED:** [Assistive Tech Engagement Survey](#)
- [Office of Self-Determination Ombudsperson](#)

SAVE THE DATES

Disability Rights California



Events and Trainings:

<https://bit.ly/3jmZV6N>

Registration coming soon for:



[UC Davis Summer Institute](#)

**"We Belong: Preparing for
Community Life and
Fulfillment After Highschool"**

Date: August 3, 2022

CalABLE



News and Trainings:

<https://bit.ly/3lGuo46>



Past 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**



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, tie questions back to systems change advocacy, SCDD State Plan and SSAN
- 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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JUNE 30, 2022
SSAN MEETING AGENDA ITEM 7
INFORMATION ITEM

Statewide Self-Advocacy Network

SCDD DAC Project Update



Members of the SCDD Disability Advisory Committee (DAC) will providing SSAN with an update on their Disability Video project.

Presenters:

- Julie Eby-McKenzie, SCDD DAC Chair and Manager–North Coast Regional Office
- Jennifer Lucas, SCDD DAC Secretary and Community Program Specialist–Central Coast Regional Office
- Peter Mendoza, DAC Member and Community Program Specialist–Sacramento Regional Office

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JUNE 30, 2022

**SSAN MEETING AGENDA ITEM 8
INFORMATION ITEM**

Statewide Self-Advocacy Network



Planning for September 2022

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

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