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## **STATEWIDE SELF ADVOCACY NETWORK MEETING INFORMATION**



**DATE:** Wednesday, June 7, 2023 and Thursday, June 8, 2023



**TIME:** Wednesday, June 7, 2023 10:00 AM – 3:00 PM  
Thursday, June 8, 2023 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](http://www.scdd.ca.gov)

### **MEETING DETAILS:**

#### **ZOOM LINK:**

<https://bit.ly/SSAN2023June>

**MEETING ID:** 831 4639 7808

**PASSCODE:** 156436

#### **TELECONFERENCE:**

**CALL IN NUMBER:** (669) 900 9128

**MEETING ID:** 831 4639 7808

**PASSCODE:** 156436

### **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](mailto:Riana.Hardin@scdd.ca.gov) or Beth Hurn at (916) 263-8194 or [Beth.Hurn@scdd.ca.gov](mailto:Beth.Hurn@scdd.ca.gov). Please provide at least 5 business days prior to the meeting to allow adequate time to respond to all requests



## **AGENDA FOR DAY 1**

**June 7, 2023**

**10:00 AM – 3:00 PM**

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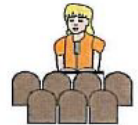
**1. Call to Order, Welcome, and Introductions/Member Report**

Presented by: Charles Nutt, Chairperson, Nicole Patterson, Vice-Chairperson, and Rebecca Donabed, Secretary



**2. Public Comment**

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



**3. Review and Approval of March 2023 Minutes**

Presented by: Charles Nutt, Chairperson

**ACTION**



**4. Review of SSAN Purpose and Workgroup Structure**

Presented by: SSAN Operations Workgroup



Break



**5. SSAN Medical Leave Policy**

Presented by: SSAN Operations Workgroup

**ACTION ITEM**



**6. Coordinated Family Services**

Presented by: DDS  
**Information Item**



**7. SCDD Update**

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



**8. Recess**

Presented by: Charles Nutt, Chairperson  
**Information**





## **AGENDA FOR DAY 2**

**June 8, 2023**

**10:00 AM – 3:00 PM**

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### **1. Call to Order, Welcome and Introductions**

Presented by:

- Charles Nutt, Chairperson
- Nicole Patterson, Vice-Chairperson
- Rebecca Donabed, Secretary



### **2. Public Comment**

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



### **3. Travel Policy Training**

Presented by: Beth Hurn, SCDD State Plan Analyst  
**Information**



### **4. SCDD Legislative Update**

Presented by: Veronica Bravo, SCDD Policy Analyst  
**Information**



**Break**



- 5. How to Plan and Prepare a Survival Kit**  
Presented by: Eric Agular, San Bernardino Regional SSAN Representative  
**Information**

- 6. Approval of June 2023 SSAN Newsletter**  
Presented by: Robert Levy, Newsletter Workgroup Chair  
**ACTION**



- 7. Youth Organizing**  
Presented by: Jessica Reistra, CFILC Youth Organizer



- 8. Meeting Takeaways and Planning for September 2023 Meeting**  
**ALL**

- 9. Adjournment**

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**JUNE 7, 2023**

**SSAN MEETING AGENDA ITEM 3**

**ACTION ITEM**

**Statewide Self-Advocacy Network**

***Approval of March 2023 Minutes***

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***Attachments***

- March 2023 Minutes

***Recommended Action***

Approve the March 2023 SSAN Meeting Minutes

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# DRAFT

## Statewide Self-Advocacy Network Meeting Minutes March 8 & 9, 2023 Zoom

### **SCDD Regional Members Present**

Charles Nutt – North State  
Lisa Cooley – Sacramento (Day 2)  
Robert Balderama – North Valley Hills  
David Forderer – Central Coast  
Rebecca Donabed – Sequoia  
Eric Aguilar – San Bernardino  
Julie Gaona – Los Angeles  
Paul Mansell – San Diego–Imperial

### **Agency Members Present**

Desiree Boykin – ARCA  
Talmadge House – CFILC  
Nicole Patterson – DDS  
Scott Barron – DRC  
Maria Marquez – SCDD  
Robert Levy – UCD MIND Institute  
Kecia Weller – UCLA Tarjan Center  
Wesley Witherspoon – USC CHLA  
Jessica Riestra – YO Disabled and Proud

### **Members Not Present**

North Coast Rep  
Ellen Sweigert – North Bay  
Sean Sullivan – Orange County  
Regina Woodliff – Bay Area

### **SCDD Staff in Attendance**

Rihana Ahmad – SCDD HQ  
Janet Fernandez – SCDD HQ  
Dena Hernandez –  
SCDD North Valley Hills  
Debbie Marshall – SCDD San Diego  
Veronica Magallanes – SCDD Sequoia  
Robin Maitino – SCDD HQ  
Tina Reszler – SCDD North State  
Yaritza Sanchez – SCDD HQ  
Victoria Schlusser – SCDD HQ  
Gabriela Solval – SCDD Bay Area  
Brian Weisel – SCDD HQ

### **Presenters**

Rihana Ahmad – SCDD HQ

### **Others Present**

Justin Hole  
Alexa McBride  
Holly O  
Alex Phuong  
Alec Pare  
Eunice Taylor  
Renee Wooten



# DRAFT

## **SSAN Minutes**

### **1. Call to Order, Welcome and Introductions**

SSAN Chairperson Charles Nutt, North State Representative, called the meeting to order at 10:06 AM. Chair Nutt began the meeting by calling for a moment of silence to remember Disability Rights Activist Judith Heumann who passed away on March 4, 2023. Following the moment of silence, members were asked to introduce themselves and share their thoughts on the impact Judith Heumann has had on the disability rights movement.

### **2. Public Comment**

Renee Wooten Introduced herself and said she appreciated hearing people's thoughts about Judith Heumann.

### **3. Review and Approval of December 2022 Minutes**

The members reviewed the minutes from the December 13 & 15, 2022 meeting. Materials for this agenda item can be found on pages 9-16 of the March 2023 SSAN Meeting Packet.

**ACTION: Motion #1 to approve the December 2022 minutes was made by Robert Levy/Seconded by Wesley Witherspoon. A roll call vote was taken. Motion passed. See vote log on page 7.**

### **4. Updates from SSAN Chair**

SSAN Chairperson Charles Nutt talked about the importance of SSAN and how SSAN representation and participation is needed by many different organizations and projects.



# DRAFT

## 5. SCDD Update

SCDD Manager of State Plan and Self-Advocacy, Rihana Ahmad provided SSAN members with an update on SCDD activities since the December SSAN meeting. SCDD is working with Senator Durazo to implement recommendations from the SB 639 Report to end subminimum wage practices in California for people with I/DD. SCDD Cycle 46 Grant applications open March 27<sup>th</sup> and SCDD will be providing a demonstration of the new online grant application platform at the March Self-Advocates Advisory Committee meeting. SSAN members are welcome to attend. The Statewide Self-Determination Advisory Committee has a new co-chair in Viviana Barnwell. 105 Self-Determination trainings have been conducted in English, Spanish, and Vietnamese, reaching 1528 people. There continues to be a 6-8 month waitlist for Financial Management Systems (FMS) and DDS continues to work to address this, as well as other emerging issues.

## 6. SSAN Workgroups

The SSAN Workgroup chairs provided updates on current and future projects. The following workgroups provided updates:

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

## 7. SCDD Facilitation Guide Input

SCDD North Valley Hills Regional Office Manager presented the SCDD Facilitation Guide and collected feedback from SSAN Members to ensure that the guide is accurate and complete.

Feedback from members included the need to include tips on how to manage relationships with facilitators who you have personal relationships with, clarify the difference between personal care and facilitation, and consider changing the design on the cover page.



# DRAFT

## **8. SCDD Quality Incentive Employment Survey Review**

Item was tabled for another meeting.

## **9. SSAN Impact Roundtable Discussion**

Day one ended with a discussion about how SSAN can make more of an impact throughout the state. Members discussed engaging in more issue-based work, holding trainings and townhalls throughout the state, increasing youth participation in SSAN and its activities, and conducting outreach and expanding membership to make SSAN more inclusive. Members also discussed the possibility of entering a group submission to SCDD's "There Should Be a Law" contest and the need to shift the workgroup structure. The operations workgroup will meet to review feedback from members and discuss possible changes.

## **10. Recess Until Next Day**

SSAN Chairperson Charles Nutt declared the meeting in recess at 2:25 P.M. The March 2023 SSAN meeting will return from recess at 10:00 AM Thursday, March 9, 2023.



# DRAFT

## **SSAN DAY 2 Minutes**

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

SSAN Chairperson Charles Nutt, North State Regional Representative, called the meeting to order at 10:05 A.M.

Members introduced themselves and described how SSAN has impacted their lives.

### **2. Public Comment**

SSAN member Robert Levy asked for the link to the Self-Advocacy DEAP meeting.

### **3. Approval of SSAN and SCDD MOU**

SCDD Manager of State Plan and Self-Advocacy, Rihana Ahmad reviewed the proposed updates to the MOU between SSAN and SCDD with members. Since the December 2022 SSAN meeting, the proposed updates to the MOU were presented to the SCDD Executive Committee, which voted to adopt the updates as presented. SCDD Manager Ahmad asked for a motion for approval of the updates to the MOU.

**ACTION: Motion #2 to adopt the proposed changes to the MOU between SSAN and SCDD by Nicole Patterson/Seconded by Lisa Cooley. Motion passed. See vote log on page 7.**

### **4. HCBS Update**

Representatives from the Department of Developmental Services (DDS) provided members with an update on California's implementation of the Home and Community Based Services (HCBS) Final Rule. DDS gathered input from SSAN members about training and implementation activities. SSAN members provided recommendations on resources that can be used to help Regional Center consumers understand their rights.



# DRAFT

## 5. SCDD Legislative Update

SCDD Deputy Director of Policy and Public Affairs Bridget Kolakosky provided an update on SCDD's legislative activities, including SCDD's policy priorities, current legislative efforts, and SCDD's efforts toward the implementation of SB 639. Deputy Director Kolakosky informed members about the impact that the current state of the economy is likely to have on the California Legislature's activities in 2023.

## 6. Approval of March 2023 SSAN Newsletter

SSAN Secretary and Newsletter and Communications Workgroup Chair, Robert Levy reviewed the DRAFT March 2023 Voices of SSAN Newsletter. Secretary Levy called for a motion to approve the March 2023 Edition. Materials for this agenda item can be found on pages 73-76 of the March 2023 SSAN Meeting Packet and additional handouts.

**ACTION:** Motion #3 to approve the March 2023 Newsletter as presented was made by Rebecca Donabed/Seconded by Wesley Witherspoon. Motion passed. See vote log on page 7.

## 7. Youth Leadership Forum

Representatives from the Youth Leadership Forum Planning team provided a presentation on the 2023 program and discussed how SSAN can help to encourage youth with disabilities to apply for the program.

## 8. Planning for June 2023 Meeting

SSAN members brainstormed topics/presentations for the June 2023 meeting. Suggested presentation topics included:

- Follow-up on accessible hotels project
- UCEDD Panel: Project Updates
- Youth Based Organizing
- Emergency Prep and Go Bags
- Youth Leadership Forum (YLF) Experience
- Making the most of your supports
- Coordinated Family Planning (DDS)
- SSAN Purpose



**DRAFT**

## **9. Adjournment**

Meeting was adjourned at 3:00 P.M. The next SSAN meeting is scheduled for June 7-8, 2023 over Zoom.



# DRAFT

## MARCH 2023 SSAN VOTE TALLY

Name	Region	Roll Call	Motion 1	Day 2 Roll Call	Motion 2	Motion 3
Maria Marquez	SCDD	Not Present	Not Present	Not Present	Not Present	Not Present
Vacant	North Coast	Vacant	Vacant	Vacant	Vacant	Vacant
Charles Nutt	North State	Present	For	Present	For	For
Lisa Cooley	Sacramento	Present	Not Present	Present	For	For
Ellen Sweigert	North Bay	Not Present	Not Present	Present	For	For
Regina Woodliff	Bay Area	Not Present	Not Present	Not Present	Not Present	Not Present
Robert Balderama	North Valley Hills	Present	For	Present	For	For
David Forderer	Central Coast	Present	For	Present	For	For
Rebecca Donabed	Sequoia	Present	For	Present	For	For
Julie Gaona	Los Angeles	Present	For	Present	For	For
Sean Sullivan	Orange County	Not Present	Not Present	Not Present	Not Present	Not Present
Eric Aguilar	San Bernardino	Present	For	Present	For	For
Paul Mansell	San Diego	Present	For	Present	For	For
Desiree Boykin	ARCA	Present	For	Present	For	For
Goldie House	CFILC	Present	Not Present	Present	For	For
Jessica Riestra	YO Disabled & Proud	Present	For	Present	For	For
Nicole Patterson	DDS	Present	For	Present	For	For
Scott Barron	DRC	Present	For	Present	For	For
Wesley Witherspoon	USC – CHLA	Present	For	Present	For	For
Kecia Weller	UCLA Trajan Center	Present	For	Not Present	Not Present	Not Present
Robert Levy	UC Davis Mind Institute	Present	For	Present	For	For



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**JUNE 7, 2023**

**SSAN MEETING AGENDA ITEM 4  
INFORMATION ITEM**

**Statewide Self-Advocacy Network**



***Review of SSAN Purpose and Workgroup Structure***

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The SSAN Vice-Chair, Nicole Patterson and SSAN Secretary Rebecca Donabed will review the purpose of SSAN and Workgroup Structure with members. This presentation will give members an opportunity to start a discussion about strengthening the structure of the SSAN so that we can continue improving our work as a network to promote advocacy and system change.

In preparation for this agenda item, think about the following questions and be ready to share your ideas with the group:

- What does SSAN mean to you?
- What do you think SSAN can do better?
- What do you see as your role in strengthening SSAN?
- Do you have any ideas on how to encourage workgroup participation?
- What would you like to see the SSAN work on in the next 2 years?
- What could you do to help make this happen?
- How can the SSAN or SCDD help you be a better SSAN member?
- What trainings should SSAN create?

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**JUNE 7, 2023**

**SSAN MEETING AGENDA ITEM 5**  
**ACTION ITEM**



**Statewide Self-Advocacy Network**

***SSAN Medical Leave Policy***

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The SSAN Operations Workgroup is considering the creation of a formal SSAN Policy for members who need to go on extended medical leave from SSAN. This policy will help to SSAN operate and share information with the community in the event that a member needs to go on leave. Please think about what should be included in the SSAN Leave Policy and come prepared to share your ideas.

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**JUNE 7, 2023**

**SSAN MEETING AGENDA ITEM 6  
INFORMATION ITEM**

**Statewide Self-Advocacy Network**



***Coordinated Family Services***

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Representatives from the Department of Developmental Services will provide information about the DDS Coordinated Family Services program.

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**JUNE 7, 2023**

**SSAN MEETING AGENDA ITEM 7  
INFORMATION ITEM**



**Statewide Self-Advocacy Network**

***SCDD Update***

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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.

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**JUNE 8, 2023**

**SSAN MEETING AGENDA ITEM 3  
INFORMATION ITEM**



**Statewide Self-Advocacy Network**

***SCDD Travel Training Policy***

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In preparation for the September in-person SSAN meeting, SCDD staff will provide members with a training on SCDD policies related to the process of arranging travel and filing travel expense claims.

***Attachment***

- SCDD SSAN Travel Training PowerPoint

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# **State Council on Developmental Disabilities**

## **Travel Policy and Procedure**



# **Current Travel Policy**

**Policy training is intended to clarify standards and expectations for travel arrangements and reimbursements.**

# Travel Requests

- Travel requests are to be submitted at least 30 days prior to the date of the meeting.
- All travel request must be sent to [travelclaims@scdd.ca.gov](mailto:travelclaims@scdd.ca.gov)
- Travel arrangements must be processed through the state system. Third party vendors like Expedia and Travelocity shall not be used.

# **Wanna Get Away Fares & Flight Change Requests**

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- SCDD is required to use Southwest Airlines “Wanna Get Away” fares whenever possible, which are non-refundable and costly to change.
- Flight change requests are limited to emergency situations only.
  - Possible Emergencies: illness, injury, or other serious and urgent personal matters
- Travel requests must include your preferred flight times, along with 2 back-up options in case your first choice isn't available.

# Hotel Reservations

- Travelers residing outside a 50 mile radius of Sacramento may request hotel accommodations.
- SCDD reserves a room block for SSAN meetings
- If you require reasonable accommodations, please include details in your request.

# Room Cancellations

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- Traveler must notify the Travel Coordinator at least 24 hours in advance if a cancellation is needed.
- Cancellations after business hours:
  - Traveler must contact the hotel directly to cancel and get a confirmation number for the cancellation.
  - Traveler must also email the Travel Coordinator to inform them of the cancellation.





# Room Cancellations (cont.)

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Failure to do so, will result in the following actions:

- 1<sup>st</sup> Occurrence – Traveler will receive a written warning via email.
- 2<sup>nd</sup> Occurrence – Traveler will receive a formal warning letter from SCDD and will be responsible for any charges incurred.
- 3<sup>rd</sup> Occurrence – Traveler will lose SCDD travel booking privileges for 6 months and will be responsible for reserving their own hotel rooms and seeking reimbursement after. In addition, the traveler will be responsible for any charges incurred due to the cancellation.



# Transportation

Reimbursement for transportation expenses will be for the method of transportation that is in the best interest of the state considering both cost and the traveler's time.

# Airport Parking

Parking will be  
reimbursed at the  
Economy rate



# Meals & Incidentals

Meal	Trip Begins	Trip Ends	Reimbursement Rate
Breakfast	At or before 6am	At or after 9am	\$7.00
Lunch	At or before 11am	At or after 2pm	\$11.00
Dinner	At or before 5pm	At or after 7pm	\$23.00

Incidentals: travelers receive \$5.00 reimbursement for incidentals for each 24-hours of travel

# Mileage Reimbursement

- Travelers may seek reimbursement for mileage when using their personal vehicle to attend meetings.
- Effective January 2023, mileage reimbursement rates are \$0.655 per mile.



# Submitting Reimbursements

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- All travelers shall submit their Travel Expense Claim (TEC) forms and supporting documents no later than 30 days after travel.
- TECs that are incomplete will be returned so be sure to complete all information on your form
  - Receipts (digital or original) must be submitted with your TEC.
    - Parking
    - Ground transportation (taxis, Uber, Lyft, etc.)

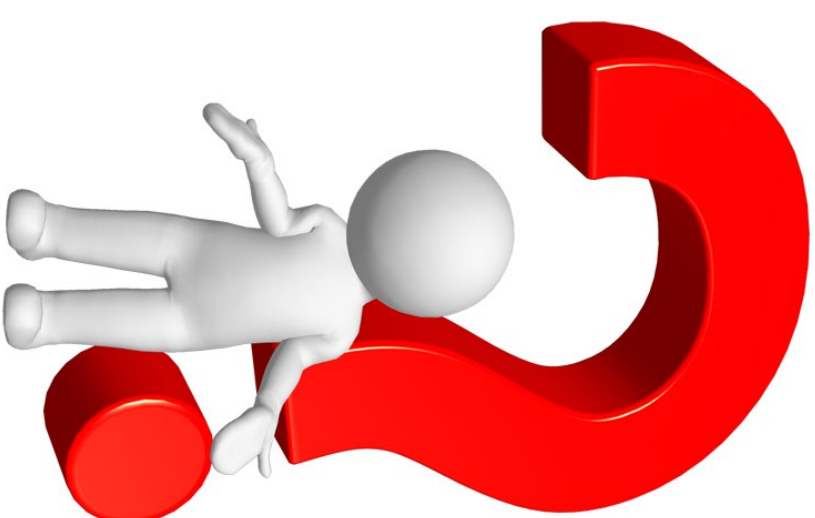


# Important Reminders

- Submit travel requests 30 days prior to meeting date.
- Wanna Get Away fares are non-refundable.
- Traveler is responsible for cancelling hotel reservation.
- Submit receipts with Travel Expense Claim no later than 30 days after travel.

# Questions about the Travel Policy?

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# How to Complete a TEC Form

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- Members are required to complete a TEC (Travel Expense Claim) Form following every trip.
- Submit forms with all original receipts via mail to SCDD HQ at 3831 North Freeway Blvd #125, Sacramento, CA 95834 or email to [travelclaims@scdd.ca.gov](mailto:travelclaims@scdd.ca.gov)
- It is important to keep receipts over \$10 (except meals). Lost receipts can only be reimbursed for up to \$10.





# Fill out the TEC Cover Sheet

- 1. Fill in personal contact information
- 2. Fill in meeting date(s) and details
- 3. Fill in travel details: cost, miles, etc.
- 4. Add any notes of extra details
- 5. Attach all receipts and itineraries

	Name	
	Email Address	
	Address:	
	City, State, Zip	
	Meeting Date(s)	
	Time Left/Time Return	
	Meeting Name	
	Meeting Location	
	Hotel	
	Plane	
	Rental Car	
	Parking	
	<i>If personal vehicle used:</i>	
	Mileage	
	Vehicle License Number	
	Shuttle/Taxi/Bus	
	Trip Name	
	Details:	
<b>Notes:</b>		
		

# What's Next...

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- TEC's are entered and submitted into the CalATERS system within 7 to 10 business days from receipt.
- Once submitted, the TEC goes through two levels of approval before being sent to the State Controllers Office for processing and check release. The approval process takes 2 to 4 business days.
- Once received, the State Controllers Office takes 5 to 7 business days to issue the check to the address on file.
- The average time to receive a check once your TEC is received is 4 to 6 weeks.

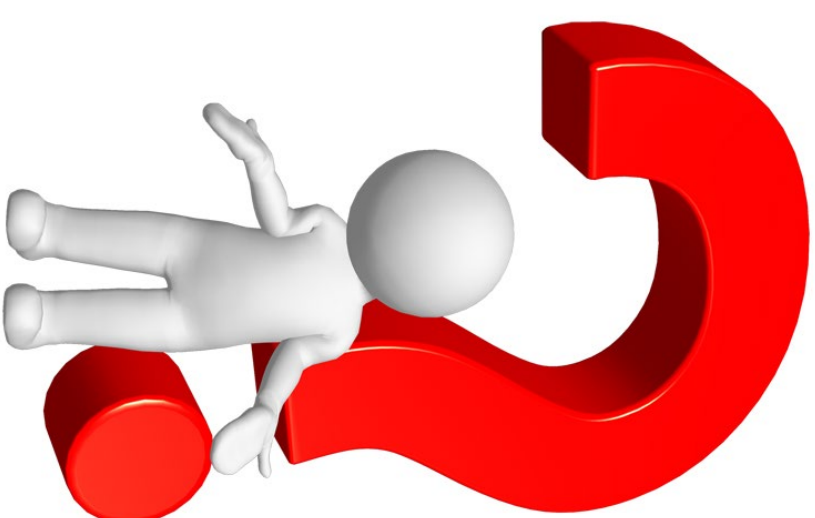
# First Time Requestors

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- First time travelers are required to complete a Payee Data Record (STD 204) in order to register them into the CalATERS system.
- Once received, a registration request is submitted to the State Controller's Office within 3 business days.

# Questions about Travel Expense Claims?

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**JUNE 8, 2023**

**SSAN DAY 2 AGENDA ITEM 4  
INFORMATION ITEM**

**Statewide Self-Advocacy Network**

***SCDD Legislative Update***

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SCDD Policy Analyst Veronica Bravo will provide SSAN members with an update on SCDD Legislative Activities.

**Presenters**

Veronica Bravo, SCDD Policy Analyst

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**JUNE 8, 2023**

**SSAN MEETING AGENDA ITEM 5  
INFORMATION ITEM**

**Statewide Self-Advocacy Network**



***How to Plan and Prepare a Survival Kit***

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SSAN San Bernardino Regional Representative Eric Aguilar will provide a training on how to plan and prepare a survival kit.

**Presenters**

Eric Aguilar, SSAN San Bernardino Regional Representative

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**JUNE 8, 2023**

**SSAN MEETING AGENDA ITEM 6**  
**ACTION ITEM**



**Statewide Self-Advocacy Network**

***Approval of June 2023 Newsletter***

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Robert Levy, Chair of the SSAN Newsletter Workgroup, will present SSAN members with a DRAFT version of the June 2023 Newsletter and ask members for any changes or additions. Robert will lead a discussion about ideas for the September 2023 Newsletter, so please come prepared with your ideas for the September 2023 edition.

***Attachments***

- DRAFT June 2023 Voices of SSAN Newsletter
- Voices of SSAN Newsletter Article Tips Newsletter Article Tips

***Recommended Action***

Approve the DRAFT June 2023 Voices of SSAN Newsletter

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## IN THIS EDITION:

**Article 1:** Remembering Judith Heumann

**Article 2:** Resiliency

**Article 3:** Recapping the California Statewide Self-Advocacy Conference

**Article 4:** Celebrating the 33<sup>rd</sup> Anniversary of the ADA

**Article 5:** Healthy Relationships

**Article 6:** Happy 11<sup>th</sup> Birthday SSAN

**Article 7:** Kudos Corner

**Article 8:** Good News Corner

**Article 9:** Self-Advocacy Reads

**Article 10:** Positive Tips

**Article 11:** Community Resources

**Article 12:** Save the Dates

**Editor:** Robert Levy

### Contributors:

- Robert Levy
- Paul Mansell
- Wesley Witherspoon
- Lisa Cooley
- Goldie House

## Remembering the Life and Legacy of Judith Ellen Heumann 1947-2023

**By Robert Levy, UC Davis MIND Institute UCEDD SSAN Representative**

The late Self-Advocate Judith Ellen Heumann was born on Thursday December 18, 1947, in Philadelphia, Pennsylvania. She was an American disability rights activist, known as the "Mother of the Disability Rights Movement." She was recognized internationally as a leader in the disability community. Heumann was a lifelong civil rights advocate for people with disabilities. Her work with governments and non-governmental organizations (NGOs), non-profits, and various other disability interest groups, produced significant contributions since the 1970s to the development of human rights legislation and policies benefiting children and adults with disabilities.

In June of 1949 Judy was diagnosed with Polio, which impacted her mobility and presented a number of access issues for the rest of her life. Judy grew up in Brooklyn, New York and had a determination not to give up on life. She made the best of it by being a self-advocate for the remainder of her life. She rejected cliches about disability as a tragic experience, saying, "Disability only becomes a tragedy for me when society fails to provide the things, we need to lead our lives – job opportunities or barrier-free buildings, for example. It is not a tragedy to me that I'm living in a wheelchair".

**Continue to page 2 of March 2023 Voices of SSAN.**



## Continued from page 1 of March 2023 Edition of Voices of SSAN

Judith Heumann and her parents had to fight repeatedly for her to be included in the educational system. The local public school refused to allow her to attend, calling her a fire hazard because of her wheelchair, which wasn't right.

In 2020 Judith Heumann appeared in a documentary called *Crip Camp* which it was about [Camp Jened](#), a summer camp in New York described as a "loose, free-spirited camp designed for teens with disabilities." The film features Larry Allison, [Judith Heumann](#), James LeBrecht, Denise Sherer Jacobson, and Stephen Hofmann, and focuses on campers who turned themselves into activists for the [disability rights movement](#) and follows their fight for accessibility legislation.

In 1992 she got married to Jorge Pineda, and last year they celebrated their 30<sup>th</sup> wedding anniversary. In 1993 they moved to Washington DC where she lived for remainder of her life. Judith was an international self-advocate too and has given numerous speeches, talks, and interviews.

On Saturday, March 4, 2023, in the afternoon Judith Ellen Heumann passed away at the age of 75 years and 76 days. The following Monday, March 6, news stations like NPR reported about her passing and impact on the Disability Rights Movement. A funeral was held for her on March 8<sup>th</sup> over Zoom. There were a lot of people throughout the world who attended and celebrated her life over Zoom. She left our world, and she will always be remembered for all the work that she has done, and she will be missed.

There is always going to be a need for self-advocacy. We still need to make even more improvements for our society in order for all people to have a productive life, just like anyone else who doesn't have a disability. People with disabilities should be treated equally and should never be segregated in our society again. Here are a few helpful links to articles remembering Judith Heumann and resources about her impact on the disability community:

- Here are a few videos about Judith Heumann:
  - [Our fight for disability rights -- and why we're not done yet | Judith Heumann TedTalk](#)
  - [Daily Show Interview March 2020](#)
  - [MSNBC Remembers Judy Heumann](#)
- Here are a few websites about Judith Heumann:
  - <https://judithheumann.com/>
  - [Disability Scoop Remembers Judith Heumann](#)
  - [Mobility International USA Remembers Judith Heumann](#)



## Resiliency

By Paul Mansell, San Diego Regional SSAN Representative

A number of failures, setbacks, and frustrations stand out when I reflect on my life. I have failed academics, romance, career, home ownership, and credit card management. The list goes on and on. So, what enabled me to pull myself together and carry on and persist after I encountered these adversities? I can answer that in one word, resiliency.

What is resiliency? It is a character trait fundamental to one's well-being. It allows us to pick ourselves up after adversity has knocked us cold, flat onto the mat. It hurts when adversity punches us in the face, and we get confused and disoriented as we fall to the ground. Everything seems to be spinning and then fading to black. We hardly know what to do as we stagger with all our effort to pull ourselves up on our own two feet. Once we are on our two feet, the world stops spinning and gradually comes into focus.

That is what resiliency is like for me. To ease my pain, I tell myself it is better to try and fail than never try. That helps a little; it is a baby step in moving again. Each step is tentative and unsteady. As I take more steps, my footing becomes steadier, surer, and more confident. I wish that change happened overnight, but it may take days, weeks, and sometimes years to get back up to speed.

What sustains us during this time of transition? For some, it is faith in a higher power; for others, it's the support of family, friends, and peers. For some, it is pride or a cause. For many, it is necessary; I must do so because my family depends on me; whatever you use, bite your teeth, clench your fists, get up, and go.

Life is too precious and wonderful to stay sprawled out on the ground. Sure, it hurts, and hurts badly. You tell yourself you tried, gave it your all, and came up short. That is even more reason to pull yourself up and get up. Remember this; you are a unique individual. There will never be a person like you with your exact talents, abilities, sensibilities, and preferences. You also have a particular purpose in life that you alone can fill. So, suck it up, carry on, and walk on the pathway we call life and the journey to your destiny.

## Recapping the California Statewide Self-Advocacy Conference

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



This year's [California Statewide Self-Advocacy Conference](#) was held on Friday, May 12 and Saturday, May 13, 2023. The theme for this year's conference was "Leaping Forward" and was the first time the conference was held in-person since the start of the pandemic. This year's conference was held at the Wyndham Sacramento (formerly the Crowne Plaza).

Daniel Meadows was the keynote speaker for day one of the conference and kicked things off by speaking about the importance of self-advocacy. He encouraged the crowd to speak up for themselves, and don't let others get in their way. This year's conference featured a number of sessions about self-determination, relationships, CalABLE, building friendships, Zumba, Regional Center services, self-advocacy, IHSS, and how to prepare for the end of your life.

I gave the keynote for the second day of the conference. My address focused on the importance of self-care and taking care of yourself when you are all alone. I shared my life story and my work to advocate for people with disabilities both in California and nationally.

Advocates from across California and Nevada attended the conference. There were over 200 people in attendance at this conference. Many people were happy to see each other after 3 years of COVID. Riana Hardin, Maria Marquez, Charles Nutt, and Lisa Cooley spoke about Self-Determination. Lisa Cooley spoke about In-Home Support Services. Lisa Cooley was also a part of the exhibit for Self-Determination. Kecia, Robert, and I also presented on COVID and our perspective UCEDDs.

I look forward seeing what sessions, information, and resources are shared at the 2024 California Statewide Self-Advocacy Conference. Keep a look out for information about the 2024 conference and consider applying to be a session presenter.





## Celebrating the 33<sup>rd</sup> Anniversary of the Americans with Disabilities Act (ADA)

By Robert Levy, UC Davis MIND Institute UCEDD SSAN Representative



July 26, 2023 will mark the 33<sup>rd</sup> anniversary of the signing of the [Americans with Disabilities Act \(ADA\)](#). The 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 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. Today people with disabilities are glad that we have ADA for community use. So, for ADA happy 33<sup>rd</sup> anniversary. For next year on to the 34<sup>th</sup> anniversary of ADA by continuing the self-advocacy work as a nation to keep on having a productive life for all people with disabilities throughout the nation.

### SSAN Members

- Vacant – 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 Aguilar – San Bernardino
- Paul Mansell – San Diego Imperial
- Desiree Boykin – ARCA
- Goldie House – 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
- Alex Reyes – SCDD



## Healthy Relationships

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



Relationships are important to us. It is good to have a healthy relationship with our friends, family, significant other, etc. However, there are relationships that are abusive. If you find yourself in an abusive relationship, it is ok to ask for help and remember that another person's treatment of you is not your fault.

Here are some signs to help you to know if you are in an abusive or unhealthy relationship:

1. Your partner communicates harshly to you
2. You feel mistreated by your partner
3. Your partner makes untrue accusations to you
4. Your partner tries to control what you do or how you spend your money
5. Your partner isolates you from your friends and family
6. Your partner forces sexual activities on you or controls your reproductive choices
7. Manipulates children or dependents
8. You or your partner are non-communicative with each other
9. You and your partner don't trust each other
10. There is a fight for control in the relationship
11. Your partner ignores your boundaries

These are just a few things to look out for if you are unsure of if your relationship is unhealthy.

**Continues to page 7 of June 2023 Voices of SSAN Newsletter.**

## 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.

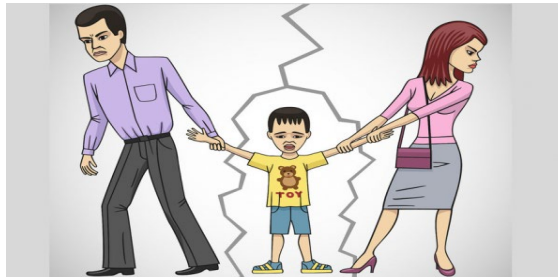
[SSAN's past Newsletters, Annual Reports, and Meeting info](#), can be found at [www.scdd.ca.gov](http://www.scdd.ca.gov) under the "Self-Advocacy" tab

**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!

Continued from page 6 of June 2023 Voices of SSAN Newsletter.



Here are some signs of a Healthy Relationship:

1. You and your partner communicate openly with each other
2. You and your partner respect each other
3. You trust each other
4. You are honest with each other
5. You see each other as equals
6. You set and understand each other's boundaries
7. You ask each other for consent
8. You support each other while parenting (children and pets)





## SSAN Celebrates 11 Years of Advocacy

By Robert Levy, UC Davis MIND Institute UCEDD SSAN Representative



It is hard to believe that the Statewide Self-Advocacy Network (SSAN) has just turned 11 this year. Over the years SSAN has seen a lot of changes in who has been a member, and there have also been changes in the staff who support us.

We are lucky that some founding members are still a part of this awesome group and able to help guide newer members. SSAN meetings have given us a lot of information on programs, resources, and legislation being considered both in California and nationally. We have participated in calls for action and rallies.

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.

Now that SSAN is heading for its 12th 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. Over the last year, we added a seat on SSAN for the Youth Organizing (YO!) Disabled and Proud to connect with and include youth with disabilities into our activities. Hopefully we will be able to continue to grow SSAN in the future, and develop more trainings to share with our communities. So, happy 11th birthday to SSAN! As we head into our 12<sup>th</sup> year: we will continue to advocate for ourselves and to make society better for people like us with disabilities to have a productive life.

### **Apply to be a Council Member for the California Behavioral Health Planning Council!**

The California Behavioral Health Planning Council (CBHPC) has two (2) open positions for direct consumers to sit on their board and advise the agency on policies, programs and practices. The agency is looking for people with lived experiences of mental illness who are receiving or have received mental/behavioral health services in California. If you are interested, consider filling out the

[Online California Behavioral Health Planning Council Member Application](#)



## Kudos Corner

**By Goldie House,** California Department of Developmental Services SSAN Representative

Let's give Eric Aguilar Kudos this month. He has been an advocate since 2019 by connecting with the State Council on Developmental Disabilities San Bernardino Regional Office Regional Advisory Committee (RAC) and other advocacy activities. When the opportunity opened up to represent San Bernardino as a member of SSAN last year, Eric saw the chance to continue his advocacy journey.

Eric puts together the skills, strategies, as well as other empowering tools, to educate individuals to be empowered and implement strategies to increase their self-advocacy.

Eric is so proud of the changes that have been accomplished for people with disabilities through advocacy. Advances in technology have opened-up a lot of opportunities for Eric since the start of COVID-19. The ability to take access and functional needs (AFN) trainings and certification courses online has allowed Eric to expand his leadership skills and knowledge of emergency management. Eric is passionate about ensuring that people with disabilities receive emergency preparedness and making sure that first responders and crisis management teams consider accessibility in the planning process. Eric is currently a member of the CAL OES planning and preparedness working group and serving as vice chair of the San Bernardino Regional Advisory Committee. Eric joined Statewide Self-Advocacy Network (SSAN) in 2022 and set to work sharing his knowledge of emergency preparedness by sharing tips in the March 2023 newsletter. Eric will also be working on emergency preparedness lectures for SSAN.

**Continue to page 10 of June 2023 Voices of SSAN Newsletter.**

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**Continued from page 9 of June 2023 Voices of SSAN Newsletter.**

At the beginning of COVID-19 Eric successfully completed 3 days of the Disability and Access and Functional Needs, (DAFN) Toolboxes Train the Trainer Academy. Eric had just finished completing the (DAFN) workshop. Eric has been on a journey to transform advocacy and has had a great start. Eric is grateful to be a member of a supportive group like the Statewide Self-Advocacy Network (SSAN) that has helped to him be proactive with learned skills and strategies of self-advocacy. Eric has made great impact at the San Bernardino Regional Office of State Council Developmental (SCDD) for being a positive team player and is participating in the Inland Empire Autism Society (IEAS). “Through my Mentorship of State Council Developmental Disabilities (SCDD), I have Found a passion for teaching and was selected to join the CAL OES planning and preparedness working group”.

As an individual with a disability, Eric has conquered numerous obstacles. He is grateful that nobody gave up on him growing up, even though he has a disability. This encouraged him to not give up on himself and got him interested in helping others through teaching and advocating. He wanted to give back to people with disabilities.

Eric enjoys inspiring people through his advocacy and giving back to disability communities. He likes the camaraderie he has with other people or groups with disabilities, and says we’re like the Marvel Avengers or the Justice League, or the X-men from all over the world.

For the dedication and resilience of strengthening advocacy, we give kudos to Eric Aguilar and we look forward to seeing his continued personal growth.

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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 about interesting positive things that are happening
- [Positive News](#) is a site that you can check out to see 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

## Disability-Related Reads and Podcasts

Here are a few Self-Advocacy and Disability-related publications to check out:



[Lawmakers Work to Improve Air Travel on Disability Scoop](#) through SB 1459 and other bills. [Disability Scoop](#) is an online resource with disability-related news



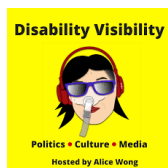
[Social Security Administration Blog](#) has SSI information



[World Institute on Disability News](#) has updates on what is happening around the world



[RespectAbility News](#) has updates on national efforts to engage people with disabilities in the political process



### 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.



## 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
- 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
- Stay involved in your community by joining a board

### Community Resources

[SARTAC Zoom Meetings](#)

[ARCA Regional Center COVID-19 Resources](#)

[DRC's Build Back Better Resources](#)

[SSA Ticket to Work Tips to Open Your ABLÉ Account](#)

[Office of Self-Determination Ombudsperson](#)

[US Dept Of Education Office of Civil Rights Digital Access Series](#)

[How to Talk about Disability Sensitivity](#)

[20 Ways to Boost Your Mood from Tips for Success](#)

## 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](#)

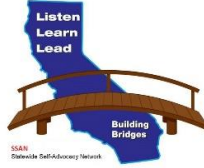
[Voting Resources](#)

DRC Voting Hotline:  
888-569-7955

[Disability Vote California](#)

Have questions about the Self-Determination Program? [The Self-Determination Advocates Leadership Group](#) meets monthly 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
- 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 8, 2023**

**SSAN MEETING AGENDA ITEM 7  
INFORMATION ITEM**

**Statewide Self-Advocacy Network**



***Youth Organizing***

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Jessica Riestra, Youth Organizer for the California Foundation for Independent Living Centers (CFILC) will provide SSAN members with an overview on the exciting projects being done by the Youth Organizing Disabled and Proud advocates and the importance of including youth in organizing efforts.

**Presenters**

- Jessica Riestra, CFILC Youth Organizer

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**JUNE 8, 2023**

**SSAN MEETING AGENDA ITEM 8  
INFORMATION ITEM**

**Statewide Self-Advocacy Network**



***Meeting Takeaways and Planning for September 2023***

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The SSAN Chair will lead the group in a discussion about potential agenda items for the September 2023 meeting. Members will also have the opportunity to complete meeting evaluations for the June 2023 meeting.

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