

Posted on: www.scdd.ca.gov

### STATEWIDE SELF ADVOCACY NETWORK MEETING INFORMATION

DATE: Wednesday, December 4 and Thursday, December 5, 2019

**TIME:** Wednesday, December 4, 2019 10:00am – 5:00pm

Thursday, December 5, 2019 9:30am – 3:00pm

WHERE: Crowne Plaza Sacramento Northeast

5321 Date Avenue Sacramento, CA 95841

(916) 338-5800

**TELECONFERENCE SITE: See Last Page** 

Toll-Free Call-in Number: 1-800-839-9416 Participant Code 8703085

<u>Sites NOT listed as a Teleconference Site: The Public May Listen In ONLY</u>

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 the meeting, should contact Riana Hardin at State Council on Developmental Disabilities 3831 N. Freeway Blvd, Suite 125, Sacramento, CA 95834 or by phone:916-263-8196 or

Email: <u>riana.hardin@scdd.ca.gov</u>
Requests must be received by 5 pm, on
Monday, November 25, 2019

### **AGENDA FOR DAY 1**



December 4, 2019 10:00 am - 5:00 pm

1. Call to Order, Welcome and Introductions
Presented by: Nicole Patterson, Chairperson, Desiree Boykin,
Vice-Chairperson, and Lisa Cooley, Secretary



2. Review and Approval of Agenda
Presented by: Desiree Boykin, Vice-Chairperson
ACTION



3. Review and Approval of Minutes September 4 & 5, 2019
Presented by: Nicole Patterson, Chairperson
ACTION



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



5. Active Shooter Guidance Training Overview
Presented by: Rihana Ahmad, SCDD Manager –
State Plan and Self–Advocacy
Information



6. Updates from the SSAN Chair Presented by: Nicole Patterson, Chairperson Information



**Lunch** – 90 minutes. On your own –



**SSAN Workgroup Discussion**Presented by: Nicole Patterson, Chairperson



ACTION

7.

### 8. My Educational Journey

Presented by: Lisa Cooley, SSAN Sacramento Regional Representative Information



### **BREAK**

### 9. Voters Choice Act Explained

Presented by: Scott Barron, Disability Rights California SSAN Representative and Gabriel Taylor, Voting Rights Advocate, Disability Rights California

Information



### monnation

### 10. Member Action Reports and Networking

Presented by: ALL **Information** 



### 11. 5:00pm Adjourn



### **AGENDA FOR DAY 2**



December 5, 2019 9:30 am - 3:00 pm

### 1. Call to Order

Presented by: Nicole Patterson, Chairperson, Desiree Boykin, Vice-Chairperson, and Lisa Cooley, Secretary



### 2. Public Comment

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



### 3. SCDD Update and MOU

Presented by: SSAN Officers and SCDD Executive Director, Aaron Carruthers



### **ACTION**

### 4. People with Disabilities and the Census

Presented by: Allie Cannington, Statewide Community Organizer, California Foundations for Independent Living Centers



### Information

**Lunch** – 90 minutes. On Your Own



### 5. December Newsletter Approval & Ideas for next edition Presented by: Robert Levy – Newsletter Chair

Presented by: Robert Levy – Newsletter Chair **ACTION** 



### 6. SSAN Annual Report

Presented by: SCDD Self–Advocacy Coordinator, Riana Hardin **ACTION** 



### 7. Input for next SSAN Meeting & Complete Meeting

**Evaluations** ALL



8. Adjourn



### **TELECONFERENCE SITE(S):**

Office of Clients Rights Advocacy 17215 Studebaker Rd., Suite 195 Cerritos, California 90703

SCDD San Bernardino Regional Office 685 E Carnegie Drive, Suite 125 San Bernardino, CA 92408

SCDD Los Angeles Regional Office 411 N. Central Avenue, Suite 620 Glendale, CA 91203

\*\*\*All times indicated, and the order of business are approximate and subject to change.\*\*\*



### DAY ONE AGENDA ITEM 3 ACTION ITEM

### **Statewide Self-Advocacy Network**



### **APPROVAL OF SEPTEMBER 2019 MINUTES**

### **Attachments**

September 2019 Minutes

### **Recommended Action**

Approve the September 2019 SSAN Meeting Minutes.

### Statewide Self Advocacy Network Meeting Minutes September 4-5, 2019 Crowne Plaza, Sacramento

### **SCDD Regional Members Present**

Nathan Florez – North Coast
Teresa Moshier – North State
Lisa Cooley – Sacramento
Chen Curtis – North Bay
(teleconference)
Robert Balderama – North Valley Hills
David Forderer – Central Coast
Rebecca Donabed – Sequoia
Julie Gaona – Los Angeles
(teleconference)
Sean Sullivan – Orange County
Daniel Fouste – San Bernardino
Paul Mansell – San Diego–Imperial

### **Agency Members Present**

Desiree Boykin – ARCA
Robert Levy –UCD MIND Institute
Wesley Witherspoon – USC CHLA
(SCDD Representative)
Scott Barron – DRC
(teleconference)
Nicole Patterson – DDS
Renee Wooten – CFILC

### **Members not Present**

Regina Woodliff – Bay Area Kecia Weller – UCLA Tarjan Center

### SCDD Staff in attendance

Dena Hernandez – SCDD North Valley Hills Mary Agnes Nolan – SCDD North State Riana Hardin – SCDD HQ Aaron Carruthers – SCDD HQ

### Non-SCDD Facilitators

Angela Lewis Jana Chapman-Plon – DDS Briana Vigoa

### **Presentators**

Danielle Wilson – CDSS CalFresh Shaina Meiners – CDSS CalFresh

### **Others Present**

David Moshier Allie Cannington - CFILC

### **DAY 1**

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

SSAN Chairperson Nicole Patterson, Representative from DDS, called the meeting to order at 10:04 am.

SSAN Secretary, Lisa Cooley, Sacramento Regional Representative, did an attendance roll call for members present. Members introduced themselves, and the region or agency that they represented.

### 2. Review and Approval of Agenda

SSAN Chairperson Nicole Patterson, reviewed the agenda for the day. Members reviewed and approved the agenda.

ACTION: Motion #1 to approve the was made by Wesley Witherspoon /Second by Daniel Fouste. A roll call vote was taken. Motion passed. See vote log on page 7.

### 3. Review and Approval of Minutes June 5 – 6, 2019

The members reviewed the minutes from June 5 - 6, 2019.

ACTION: Motion #2 to approve the June 2019 minutes was made by David Forderer/ Seconded by Rebecca Donabed. A roll call vote was taken. Motion passed. See vote log on page 7.

### 4. Public Comment

Members discussed what the purpose of this item was and who qualified as a member of the public. The SSAN Chairperson, Nicole Patterson, stated that this item was for anything not on the agenda.

### 5. Update from the Chair

SSAN Chairperson Nicole Patterson talked about the importance of the MOU discussion scheduled next on the agenda. The Memorandom of Understanding is the contract with the State Council on Developmental Disabilities and it is due to be signed in January. The SSAN Chairperson requested members fill out the SSAN Annual Report handout to help in the drafting of the 2018 – 2019 SSAN Annual Report.

### 6. SSAN and SCDD MOU

SCDD Executive Director Aaron Carruthers reviewed the MOU between SCDD and SSAN that was signed in 2017 in an effort to clarify the roles and responsibilities of each party. The discussion started off by defining the review process for the MOU. Members provided input on both language and content of the MOU. The morning session covered sections 1, 2, and 3 of the MOU.

Members suggested that language be added stating that "SSAN members will share their knowledge and skills with communities and elected officials." Members felt that the goal of SSAN was to strengthen and further their skills instead of train them. Members requested that all shoulds and shalls be changed to "need to". Members discussed combining section 3.7, 3.8, and 3.9 and keeping 3.10. If additional input is needed, the SSAN Officers will be contacted. Materials for this item can be found starting on page 21 of the September 2019 SSAN Packet.

### 7. Break for Lunch

### 8. SSAN and SCDD MOU Continued

The afternoon review session covered sections 4, 5, 6, and 7 of the MOU. Members discussed ways to grow the network and if it was possible to have more than one SSAN Rep for each region. Section 4.2.5 will be changed from "one regional manager" to "one SCDD staff". 4.2.9 was shortened to read "SCDD will inform SSAN of the SSAN budget", taking out the section referring to marketing and budgeting skills. If additional input is needed, the SSAN Officers will be contacted. Materials for this item can be found starting on page 21 of the September 2019 SSAN Packet.

### 9. SCDD Update

Due to time constraints the SCDD Update was not given. This item will be addressed at the December SSAN meeting.

### 10. Break

### 11. Person Centered Planning

SSAN Member, Paul Mansell, San Diego Regional Representative provided members with a presentation on his experience during the person centered planning process.

### 12. Member Reports

Members reported on their self-advocacy and SSAN related activity since the June 2019 SSAN meeting.

### 13. Wrap-up:

SSAN Chair Nicole Patterson thanked members for their participation during the first day of the SSAN meeting and reminded members that day two of the September SSAN meeting would start at 9:00 AM.

Day 1 of the meeting was adjourned at 4:50 PM.

### **SSAN DAY 2 Minutes**

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

SSAN Chairperson, Nicole Patterson, Representative from DDS, called the meeting to order at 9:15 am.

SSAN Secretary, Lisa Cooley, Sacramento Regional Representative, did an attendance roll call for members present.

### 2. Public Comment

There was no public comment

### 3. Finalizing SSAN Priorities

SSAN Chairperson, Nicole Patterson, Representative from DDS facilitated a conversation with the members to finalize the SSAN priorities. Members discussed the importance of engaging youth in the self-advocacy movement and the idea of creating a SSAN Facebook page. SCDD will look into the process for creating a page. It was decided that the moderators of the page would be the SSAN Officers and the SCDD Self-Advocacy Coordinator. The second focus will be on Transportation. Members would like presentations on both topics for the December meeting.

### 4. Updates on CalFresh

Representatives from the Department of Social Services (DSS), Danielle Wilson and Shaina Meiners provided SSAN members with an overview of the policy and programmatic changes from the CalFresh program. For more information on the program, visit the <a href="CalFresh Website">CalFresh Website</a>. An accessible version of the powerpoint can be found at <a href="https://www.scdd.ca.gov/selfadvocacy">www.scdd.ca.gov/selfadvocacy</a>.

### 5. Approval of the September Newsletter

SSAN Newsletter Workgroup Chair, Robert Levy, presented members with a draft of the September edition of the SSAN newsletter. The following corrections were made: change 25<sup>th</sup> to 24<sup>th</sup> on the title for the Statewide Self-Advocacy Conference. Members discussed ideas for the December edition of the newsletter.

ACTION: Motion #3 to approve the 18<sup>th</sup> Volume of the Voices of SSAN Newsletter with the suggested changes, was made by Wesley Witherspoon/ seconded by Teresa Moshier. A roll call vote was taken. Motion passed. See the vote log on page 7.

ACTION: Motion #4 to postpone the SSAN workgroups until the December meeting, was made by Daniel Fouste/ seconded by Wesley Witherspoon. A roll call vote was taken. Motion passed. See the vote log on page 7.

### 6. Input for Next SSAN Meeting

SSAN members would like the following items to be discussed at the December meeting:

- Safety and Active Shooter
- Person Centered Training
- Affordable Housing
- Inclusion Films
- · Disability perception and insight videos
- · Law enforcement trainings
- YO! Disabled and Proud
- The Census
- · Touch of Understanding
- Transportation and Disability
- The March 2020 election

The Next SSAN meeting will be on December 4-5 at the Crowne Plaza in Sacramento.

Meeting Adjourned at 2:58 PM

### ROLL CALL VOTE RESULTS

Name	Region	Roll Call	Motion 1	Motion 2	Roll Call	Motion 3	Motion 4
Wesley Witherspoon	SCDD	Present	See Bellow	See Below	See Bellow	See Below	See Bellow
Nathaniel Florez	North Coast	Present	For	For	Present	For	For
Teresa Moshier	North State	Present	For	For	Present	For	For
Lisa Cooley	Sacramento	Present	For	For	Present	For	For
Chen Curtiss	North Bay	Conference Line	For	For	Conference Line	For	For
Robert Balderama	North Valley Hills	Present	For	For	Present	For	For
Regina Woodliff	Bay Area	Not Present	Not Present	Not Present	Not Present	Not Present	Not Present
David Forderer	Central Coast	Present	For	Abstain	Not Present	Not Present	Not Present
Rebecca Donabed	Sequoia	Present	For	For	Present	For	For
Julie Gaona	Los Angeles	Conference Line	For	For	Conference Line	For	For
Sean Sullivan	Orange County	Present	For	For	Present	For	For
Daniel Fouste	San Bernardino	Present	For	For	Present	For	For
Paul Mansell	San Diego	Present	For	For	Present	For	For
Desiree Boykin	ARCA	Present	For	For	Present	For	For
Nicole Patterson	DDS	Present	For	For	Present	For	For
Robert Levy	Mind Institute	Present	For	For	Present	For	For
Wesley Witherspoon	USC - CHLA	Present	For	For	Present	For	For
Kecia Weller	Trajan Center	Not Present	Not Present	Not Present	Not Present	Not Present	Not Present
Renee Wooten	CFILC	Present	For	For	Present	For	For
Scott Barron	DRC	Conference Line	For	For	Conference Line	For	For



### DAY ONE AGENDA ITEM 5 INFORMATION ITEM

### **Statewide Self-Advocacy Network**



### ACTIVE SHOOTER GUIDANCE TRAINING OVERVIEW

Following the December 2015 shooting at the Inland Regional Center, it was found that there was a gap in response and the procedure did not include people with Disabilities and Access and Functional Needs (DAFN). California Office of Emergency Services, Office of Access and Functional Needs published the Active Shooter Awareness Guidance in an effort to improve the accessibility of procedure for responding to future situations.

As a follow up to the publication of the Active Shooter Guidance the State Council on Developmental Disabilities collaborated with Cal OES, PrepItForward, Earthquake Country Alliance (Great Shakeout) and Southern CA Earthquake Center (Great Shakeout) to develop training curriculum designed to allow participants to learn how to prepare, sign-up for alerts, and practice what they learn. These trainings have been used to train representatives from state agencies, community members and self-advocates throughout the state.

Rihana Ahmad, SCDD Manager, State Plan and Self–Advocacy will provide members with an overview of SCDD's efforts to implement the training.

### **Attachments**

None

### DAY ONE AGENDA ITEM 6 INFORMATION ITEM

**Statewide Self-Advocacy Network** 

### Listen Learn Lead Building Bridges SSAN Immit Starpman

### **UPDATES FROM THE SSAN CHAIR**

The SSAN Chair will provide a verbal update to SSAN members.

### DAY ONE AGENDA ITEM 7 ACTION ITEM

**Statewide Self-Advocacy Network** 

### Listen Learn Lead Building Bridges SSAN Bankstarpac

### SSAN WORKGROUP DISCUSSION

At the September SSAN meeting members voted to suspend the SSAN workgroups until the December SSAN meeting. This agenda item provides SSAN with the opportunity to have a discussion on the future structure of the SSAN workgroups.

### DAY ONE AGENDA ITEM 8 INFORMATION ITEM

**Statewide Self-Advocacy Network** 



### **MY EDUCATIONAL JOURNEY**

SSAN Member Lisa Cooley, Sacramento Regional SSAN Representative will provide members with an impact statement about her educational journey.

### DAY ONE AGENDA ITEM 9 INFORMATION ITEM

**Statewide Self-Advocacy Network** 



### **VOTERS CHOICE ACT EXPLAINED**

SSAN Member Scott Barron, Peer Advocate at Disability Rights California and Gabriel Taylor, Voting Rights Advocate at Disability Rights California, will provide SSAN with an introduction to the Voters Choice Act, a law that was passed in 2016 that will modernize elections in California by allowing counties to conduct elections under a new model which provides greater flexibility and convenience to voters. People with Disabilities are an important voting block for the upcoming election in 2020. This presentation will allow members the opportunity to engage in a Question and Answer session over Skype.

### Additional Resources

California Voter's Choice

California's Voter's Edge

**Disability Rights California Voting Publications** 

League of Women's Easy Voter Guide

### Recommended Action

None

### DAY ONE AGENDA ITEM 10 INFORMATION ITEM

**Statewide Self-Advocacy Network** 



### MEMBER ACTION REPORTS AND NETWORKING

Members will have the opportunity to update SSAN on their activity related to SSAN and self-advocacy since the September meeting.

### **Attachments**

SSAN Member Action Reports

### **MEMBER REPORT**

# KEY: SA-Self Advocate FA- Family Advocate O- Other (not SA or FA)

Building Bridges	Name:		Month	_Year
RESENTEI	RESENTED (or spoke) at a Meeting. Conference or Training Event in your role a	Conference or Training Evo	ent in vour role as a SSAN member:	nember:

### DATE Title or Topic of Meeting, Conference or **Event and Relevance to SSAN Goals** held WHERE it was How many SA many FA How

How

Others

# ATTENDED a meeting, training or conference in your role as a SSAN member:

			DATE
		Event and Relevance to SSAN Goals	DATE Title or Topic of Meeting, Conference or
		held	WHERE it was
		many SA	How
		many FA	How
	Others	many	How

## **RESOURCES** you would like to share with SSAN

### DAY TWO AGENDA ITEM 3 ACTION ITEM

### **Statewide Self-Advocacy Network**

### SCDD UPDATE AND MOU



The MOU between SCDD and SSAN was signed in 2017 in an effort to define the roles and responsibilities of the State Council on Developmental Disabilities (SCDD) and the Statewide Self-Advocacy Network (SSAN). The MOU needs to be reviewed every three years.

SCDD Executive Director Aaron Carruthers will lead members in a review of the updates made to the MOU following the September SSAN meeting.

If time allows, SCDD Executive Director Aaron Carruthers will provide members with an agency update.

### **Attachments**

- MOU between SCDD and SSAN with updates from the September SSAN Meeting
- Summary of September and November Council meetings

### Recommended Action

Approve the REVISIONS to the MOU between SCDD and SSAN

### **Memorandum of Understanding**

### Between

### The Statewide Self Advocacy Network (SSAN)

and

### The State Council on Developmental Disabilities (SCDD).

This Memorandum of Understanding (MOU) defines the relationship between the Statewide Self Advocacy Network (SSAN) and the State Council on Developmental Disabilities (SCDD). The purpose of this MOU is to clarify the roles, responsibilities and expectations of both groups in order to facilitate a working relationship which benefits both parties.

### 1. MOU Background

- **1.1.** The following document is a reflection of efforts by both SSAN and SCDD to define their roles and responsibilities.
- 1.2. SSAN established an MOU workgroup at their March 2015 meeting to express their ideas during the MOU process. Members of SSAN were identified to participate in the MOU drafting process in order to ensure that the voices of self-advocates were reflected in the MOU. This resulted in a SSAN DRAFT MOU presented at the June 2016 SSAN meeting and was given to SCDD for consideration.

### 2. Mission of SCDD and SSAN

### **SCDD Mission**

**2.1.** The mission of SCDD is to advocate, promote, and implement policies and practices that achieve self-determination, independence, productivity and inclusion in

all aspects of community life for Californians with intellectual/developmental disabilities (I/DD) and their families.

2.1.1. To carry out its mission regarding self-advocacy, SCDD has adopted Goal 1 of its State Plan, which states Californians with I/DD and their families reflecting the diversity of the state will have increased information and supports to advocate for civil and service rights to achieve self-determination, integration and inclusion in all areas of community life.

### **SSAN Mission**

- **2.2.** The mission of SSAN, a project of SCDD, is to promote leadership and build bridges that strengthen advocacy among disability communities by focusing on policy change.
  - 2.2.1. SSAN exists to encourage people with disabilities to organize and create change for good. The goal is for SSAN members to further and strengthen their skills as advocates and to share their knowledge and skills with their communities\_and elected officials. As a cross-disability network, SSAN connects individual members with organizations and leaders across the state of California in order to advance the self-advocacy movement. It is the goal of SSAN to provide members with the resources, knowledge and tools that will empower them to become effective, informed leaders within their communities across the state, so that they may train others.
  - **2.2.2.** SSAN is dedicated to demonstrating that Californians with disabilities are strong, independent and make

enhanced contributions\_to society. Through collaborating with other advocacy organizations and disability communities, SSAN wants to support, develop and strengthen self-advocacy throughout California and local regions.

**2.2.3.** SSAN recognizes that in order to have the most impact in systems change advocacy, they will be a cross disability training network.

### 3. Guiding Principles

- 3.1. SCDD is committed to supporting policies and practices that achieve self-determination, independence, productivity and inclusion in all aspects of community life for Californians with I/DD, other disabilities, and their families. SCDD supports the effort of SSAN members, helping them to advocate, promote and implement SSAN's work, as it aligns with Goal 1 and Objective 2 of the SCDD State Plan and the mission of the State Council.
- 3.2. The SCDD supports the efforts of SSAN members and assists them in advocating, promoting and implementing their goals so long as they align with the SCDD State Plan (especially Goal 1) or the mission of the Council. SCDD and SSAN recognize the importance of the following principles:
- **3.3.** SCDD needs to have open communication with SSAN and its members.
- **3.4.** SCDD needs to respect all SSAN members as qualified individuals to consider all matters before the SSAN, including policy positions and discussions, decision making processes and SSAN actions.

- **3.5.** SSAN needs to respect the SCDD Self-Advocacy Coordinator and in return, the Self Advocacy Coordinator needs to respect SSAN members.
- **3.6.** Goal 1 of the SCDD State Plan affirms SCDD's commitment to supporting self-advocacy.
- **3.7.** SCDD needs to promote self-advocates in leadership roles in SSAN by providing them with the knowledge, skills, ad training necessary to train other self-advocates to become leaders in their communities and across the state.
- **3.8.** SSAN members will be leaders in their communities and advocate for people with disabilities.
- **3.9.** SSAN members need to conduct themselves a professional manner at all times, adhering to all laws and rules of the State of California.

### 4. ROLES AND RESPONSIBILITIES OF SCDD AND SSAN

### 4.1. SCDD Responsibility Regarding SSAN Membership:

- 4.1.1. SCDD will recognize that SSAN membership has been established by the SSAN Bylaws and consists of (1) SCDD Regional Representatives and (2) representatives from organizations that serve and advocate for those within the disability community. As a cross-disability training network, SSAN leadership and no less than 50% of its members will be individuals with I/DD.
- **4.1.2.** SCDD will assist SSAN in the recruitment process of the SSAN SCDD Regional Representative. An SCDD Regional Representative to SSAN is defined as a self-advocate within one of the 12 SCDD regional

offices' geographic areas. Each of the SCDD Regional Offices will facilitate the selection process of one (1) Regional Representative from their local I/DD community within the Regional Office's area. While each SCDD Regional Office tailors a set selection criterion to address the specific needs of their area, successful candidates for SSAN membership will possess leadership skills and be actively involved in their community. SCDD Regional Offices will review their Regional Representative choice every four years and make a recommendation to SSAN leadership.

#### 4.2. SCDD General Responsibilities:

- **4.2.1.** SCDD will work with SSAN in the following areas, but not limited to: to develop and give training to self-advocates and those who want to become trainers and/or leaders about: self-advocacy, self-determination, person-centered planning and/or leadership. SSAN members will train other self-advocates in California and report to SCDD on the number of trainings and presentations that were given and how many people attended. SCDD will work with SSAN on a pre/post-test and satisfaction survey for trainings.
- **4.2.2.** The SCDD Self-Advocacy Coordinator will act as the main contact person between SSAN and SCDD staff. The Self-Advocacy Coordinator will provide support and guidance in order to help SSAN achieve their goals.

<sup>&</sup>lt;sup>1</sup> Support refers to giving help or assistance to self-advocates of SSAN as they seek to become better advocates.

- **4.2.3.** The SCDD Self Advocacy Coordinator will maintain communication with all SSAN members and work with SSAN leadership to review communication materials, including meeting agendas, meeting minutes, Chair updates, newsletter publications and quarterly meeting packets.
- **4.2.4.** The SCDD Executive Director will give final approval prior to the distribution and online posting of quarterly meeting packets. The Executive Director will also review any other materials that may have potential impact on SCDD. The Executive Director will provide feedback in a timely manner, allowing time for any changes to be made, if any.
- **4.2.5.** SCDD Regional Managers (or regional office CPSIIs) will provide support<sup>2</sup> to their Region's SSAN Representative upon request as long as the request is reasonable. There will be one (1) SCDD Staff who provides direct support<sup>3</sup> during SSAN quarterly meetings and assists in SSAN operations.
- 4.2.6. At the request of SSAN, SCDD can provide training and support<sup>4</sup> to the SSAN as a whole and its individual members on topics relevant to the independent living movement, self-advocacy, and leadership skills; so long as it reflects the mission, vision and purpose of SCDD and the SSAN vision statement and financial support is available.

<sup>&</sup>lt;sup>2</sup> Support refers to providing SSAN members in their region with the tools and resources needed to be leaders in their community.

<sup>&</sup>lt;sup>3</sup> Refers to the regional manager who is assigned to assist the Self-Advocacy Coordinator with overseeing SSAN. Regional managers may provide logistical and technical support such as note taking and recording minutes during SSAN meetings.

<sup>&</sup>lt;sup>4</sup> Refers to resources and professional development.

- **4.2.7.** SCDD will approve each SSAN quarterly meeting based on an agenda approved by the SSAN leadership. If the projected cost for an agenda item is beyond the SCDD budget limits, SCDD will inform SSAN leadership at least 14 days before the next SSAN meeting.
  - **4.2.7.1.** The SSAN leadership and members must submit any requests or changes to the SSAN meeting that may require additional funding at least 30 days before the next SSAN meeting.
- **4.2.8.** SCDD will provide logistical support<sup>5</sup>, such as scheduling and teleconference lines for SSAN work groups and leadership meetings between SSAN's quarterly in person meetings.
- **4.2.9.** SCDD reserves the right to set the budget for training and meeting expenses for SSAN.
  - **4.2.9.1.** SCDD will inform SSAN leadership of the SSAN budget.
  - **4.2.9.2.** SCDD staff will meet with SSAN leadership once a year to review the SSAN budget.
- **4.2.10.** SCDD will provide logistical and technical assistance<sup>6</sup> at no more than four (4) in person, two (2) day meetings. SCDD will take responsibility for arranging and coordinating SSAN meetings. SCDD will undertake the responsibility of booking and

<sup>&</sup>lt;sup>5</sup> Refers to scheduling meetings, creating a calendar of all SSAN quarterly and workgroup meetings. Logistical support also includes opening and operating the conference line(s) for workgroup meetings.

<sup>&</sup>lt;sup>6</sup> Refers to booking the hotel meeting rooms and working with hotel staff to set up the audio and visual aspects of the meeting (projector for the PowerPoint and captions).

- funding hotel meeting rooms, lodging and transportation for meeting attendance. Facilitation and attendant services are available upon request.
- 4.2.11. SCDD will provide regular in person and written policy briefings and updates a) at quarterly SSAN in person meetings and b) between these meetings on legislation or issue positions taken by the SCDD council members or legislation and issues as requested by the SSAN leadership or its members, regardless of SCDD's position, as long as staff is allowed to work on the issue(s) under the State of California rules, such as the rules that apply to staff work on candidate or ballot measure matters. SCDD will endeavor to provide these policy briefings or updates, either in person or written, in plain language as requested by the SSAN and SCDD.
- **4.2.12.** SCDD will provide SSAN with the resources on advocacy and the legislative process. SCDD cannot advise SSAN in a way that is partisan.
- **4.2.13.** SCDD will work with SSAN to update a yearly work plan for Goal 1, Objective 2 in the State Plan.

#### 4.3. SSAN Responsibilities

- **4.3.1.** SSAN will develop trainings which relate back to Goal 1 of the SCDD State Plan and report back on the number of trainings and presentations that were conducted in between SSAN meetings.
  - **4.3.1.1.** SCDD shall approve any training materials SSAN develops prior to their use.

- **4.3.2.** SSAN members will report their activities and progress in the form of Member Action Reports.
- 4.3.3. As a project of SCDD, SSAN may advocate legislative and policy positions taken by the Council. SSAN may provide input to SCDD on legislation that is of interest to SSAN. SSAN may provide input on legislation the Council is considering, including after the bill introduction deadline in February and before the Council meeting in March.
- 4.3.4. Members of SSAN may not use SCDD resources to organize around a legislative issue that is not included in the SCDD Legislative Agenda. SSAN members may not support or oppose any candidate for office, political party, or ballot measure.
- **4.3.5.** SSAN members will distribute SCDD materials to their communities and inform their cross-disability networks about SCDD publications and handouts related to, but not limited to, self-determination and person-centered planning.
- **4.3.6.** SSAN will make sure that all member and community events associated with SSAN will relate to the missions of both SSAN and SCDD and be in accordance with Goal 1 of the SCDD State Plan and this Memorandum of Understanding.
- **4.3.7.** SSAN will collaborate with other organizations and train other members within their own communities and networks on how to advocate for the needs of people with disabilities.

- 4.3.8. SSAN is responsible for getting the word out regarding SSAN activities to the I/DD communities regarding upcoming self-advocacy trainings and information related to self-determination, person centered planning and changes that may affect the disability community in members' region(s) and across the state.
- **4.3.9.** SSAN will request technical assistance and logistical help from SCDD to plan the quarterly in person SSAN meetings within a reasonable amount of time, so that the SCDD staff can make arrangements in compliance with state regulations, policies and practices.
- **4.3.10.** SSAN Officers will develop a list of agenda goals or priorities at each quarterly in person SSAN meeting. SSAN leadership agrees to inform SCDD support staff<sup>7</sup> of these agenda goals and priorities immediately so that they may begin to plan to support the SSAN.
- **4.3.11.** The SSAN leadership will request that SCDD present any policy or issue briefing or updates either in writing or in person at least 30 days before any meeting. This will apply to either a quarterly in person meeting or workgroup meeting.
- **4.3.12.** SSAN will conduct all meetings according to California's open meeting laws, using Robert's Rules of Order.

<sup>&</sup>lt;sup>7</sup> Self-Advocacy Coordinator and Regional Managers.

- **4.3.13.** SSAN will receive training on the Bagley-Keene Act every two (2) years and is expected to follow the Bagley-Keene Act.
- 4.3.14. SSAN may create work groups to focus on issues of importance as they arise. SSAN work groups are expected to follow the rules set forth in this MOU and remain neutral and objective in their activities.

#### 5. Reporting

- 5.1. SSAN leadership agrees to report all of SSAN's activities and progress to the SCDD Self-Advocacy Coordinator and other concerned staff in a timely manner and respective of deadlines communicated by the SCDD staff. SCDD agrees to give SSAN three (3) months' notice of reports needed. SCDD will report on the SSAN's progress and activities to state and federal government agencies.
- **5.2.** SSAN is expected to produce a high quality, uniform quarterly newsletter, which highlights actions taken and issues of concern within the cross-disability community.
  - 5.2.1. SCDD will work with SSAN in developing a report to collect information about training. Each year, this information must be given to the Administration on Intellectual and Developmental Disabilities (AIDD), the federal agency that provides funding to SCDD for its work. AIDD needs to know how many people were trained, if they were satisfied with the activity, and how much they believe they learned from each presentation. AIDD also wants to know if the people who attended were self-advocates, family

- advocates or others who may be professionals or community members.
- **5.2.2.** Member action reports will be submitted at all SSAN meetings, in order to document the outcome of all community-based activities between meetings.
- **5.3.** Workgroups will also report progress at SSAN meetings, in the form of 5-minute updates.
- **5.4.** All of the above-mentioned items are to be included in the Annual Report, compiled by the Self-Advocacy Coordinator. The Self-Advocacy Coordinator will review the Annual Report with SSAN members at the end of each year.

#### 6. SCDD Support

6.1. SSAN is a project of SCDD, and SCDD recognizes the importance of supporting this project. However, this MOU does not guarantee that the SCDD will continue to fund SSAN. SSAN and its members should not expect funding from SCDD because of this document. The budget for SSAN is decided by SCDD. By agreeing to this MOU, SSAN and its members acknowledge this fact.

#### 7. Termination and Review

- **7.1.** This MOU can end when either SSAN or SCDD decides to end it by providing 30 days advance notice. SSAN must have a majority vote in order to terminate. Termination must also be approved by SCDD.
- **7.2.** If this MOU is not approved by both SSAN members and SCDD then this agreement will not become active.

- **7.3.** This agreement will be reviewed every three (3) years by both SSAN and SCDD. Every three years it must be approved by majority vote of SSAN members and SCDD Council members in order to stay in effect.
- 7.4. If SCDD Council members decide to offer a grant to a non-SCDD entity to carry out Goal 1 activities and a grant is awarded, this agreement will end. SSAN will receive at least a six month notice between SCDD's intention to award a grant and ending this agreement.
- **7.5.** If SSAN decides by majority vote of its members to establish itself as an entity separate from the State of California, SSAN must find its own funding, and this MOU will no longer be effective. If SCDD decides not fund SSAN anymore, this agreement will end and SSAN members may decide to form a new group.

#### 8. CHANGES TO THE MOU

**8.1.** Any proposed changes to the MOU must be submitted to both SCDD and SSAN for consideration. Any proposed changes must be approved by a majority of SSAN members and SCDD.

#### **Contact Information**

State Council on Developmental Disabilities
Executive Committee
Secretary
Address
Telephone
Fax
E-mail

Statewide Self Advocacy Network Leadership Secretary Address Telephone Fax E-mail

	Date:
(Partner signa	iture)
(Partner name	e, organization, position)
	Date:
(Partner signa	iture)
(Partner name	e, organization, position)



Californians with developmental disabilities are guaranteed the same full and equal opportunities for life, liberty, and the pursuit of happiness as all Americans.

# September 17, 2019 State Council Meeting Summary

#### SIGNIFICANT ITEMS

- New Councilmembers Julio Garnica and Karen Millender sworn in. Julio is a selfadvocate representing the San Bernardino/Inland Region. Karen is a family advocate representing the Orange County Region.
- The Council reviewed the Public Charge Rule. It is critical to have clear, accurate information:

<u>Disability Rights California's overview</u> <u>Governor Newsom's Guidance</u>

- The Governor's Office of Emergency Services and Pacific Gas and Electric talked about turning off electricity and gas during extreme weather to prevent fires <u>Find out how it will work</u> See what you can do
- The Council's <u>2019-2020 Policy Platform</u> includes:

Self Determination

Self-Advocacy

**Employment** 

Housing

Transportation

Health Care

Education

Community Participation

Transition to Adult Life

Safety

Quality/Rates for Service and Supports

 Council Chair Maria Marquez announced <u>SCDD Committee assignments</u> for Councilmembers

#### **OTHER ITEMS**

- During Public Comment, representatives from Disability Voices United offered comments regarding the Cycle 42 grants and concerns about the Statewide Self Determination Advisory Committee Goals
- Executive Director Aaron Carruthers gave a report including updates on the SCDD budget, DS Task Force progress, and the work of the State Plan. He also discussed employment and public safety, provided indepth descriptions of the Cycle 42 grant projects, and welcomed new SCDD Information Officer Lea Park-Kim.
- Read more about the projects funded by the Council: 1) California Transition Alliance "Let's Work, 2) California Supported Living Network "Quality Services Through Outcome-Based Measures"

#### **COUNCIL ACTIONS**

#### The Council:

- Approved the July 2019 minutes
- Approved the Sponsorship request from the FASD Network
- Approved the 2019 Executive Director Evaluation Tool and Timeline
- Approved the 2019-2020 draft legislative platform revisions with edits suggested by Councilmembers
- Approved the 2019 Nominating Committee

#### **FUTURE MEETING**

November 14, 2019 – Crowne Plaza
 Sacramento Northeast, 10:00 am - 4:00 pm



Ensure that Californians with developmental disabilities are guaranteed the same full and equal opportunities for life, liberty, and the pursuit of happiness as all Americans.

# November 14, 2019 State Council Meeting Summary

#### SIGNIFICANT ITEMS

- On November 14<sup>th</sup>, the Council hosted its last meeting of 2019 at the Crowne Plaza hotel in Sacramento. State Plan Committee Chair Kilolo Brodie and Executive Director Aaron Carruthers presented the Council a summary of work done during the 2019 federal fiscal year. SCDD provided 9,190 people direct technical assistance on their questions, trained 20,952 people, and overall reached 1.963.804 Californians. Learn more here:
  - o 2018-2019 PPR
- Councilmembers the recommended approach for the Cycle 43 community development grants. Cycle 43 would make available 12 \$20,000 grants (\$240,000 total) for the top priority need in each region. The Council also reviewed the timeline and draft request for proposals (RFP). Councilmembers had an active discussion about the recommended areas of emphasis before voting to approve the timeline and RFP for Cycle 43. More details are available about the process:
  - o Cvcle 43 Timeline
  - o Cycle 43 RFP
- The Council held elections for the offices of permanent Chair and Vice Chair. Candidates presented speeches to the Council on their vision for the Council. Councilmember Maria Marquez won the election for Chair and Councilmember Julie Austin won the election for Vice Chair. The Chair and Vice Chair terms run through December 2020.

- Following the elections, the Council went into a closed session to complete the 2019 Executive Director Evaluation. When open session reconvened, the Chair announced that the State Council unanimously approved the Executive Director evaluation.
- Council Chair Maria Marquez offered her congratulations and well wishes to outgoing Councilmembers Catherine Blakemore and Kris Kent.
- Executive Director Aaron Carruthers gave a report to the Council, including updates on the Self-Determination Program and information about the Statewide Self-Determination Advisory Committee (SSDAC). He also discussed several other issues including employment, public safety, disparities and national leadership.

#### **SUMMARY OF COUNCIL ACTIONS**

#### The Council:

- Elected a permanent Chair and Vice Chair to serve through December 2020
- Approved the 2019 Executive Director Evaluation and recommendations
- Approved the September 2019 Council meeting minutes
- Approved the Cycle 43 Grant timeline and Request for Proposals (RFP)
- Approved the 2018-2019 Program Performance Report (PPR)

#### **FUTURE MEETING DATE**

 January 28, 2020, Hilton Hotel, Sacramento Arden-West, 10:00 am - 4:00 pm

#### **DECEMBER 4-5, 2019**

### DAY TWO AGENDA ITEM 4 INFORMATION ITEM

**Statewide Self-Advocacy Network** 



#### PEOPLE WITH DISABILITIES AND THE CENSUS

Article 1 Section 2 of the US Constitution gives Congress the responsibility of conducting a count of people living in the United States every 10 years. This count is known as the Census. The outcome of the Census determines not only the number of US representatives each state will have. Allie Cannington, Statewide Community Organizer for the California Foundation for Independent Living and Renee Wooten, CFILC SSAN Representative, will provide members with an overview of the outreach efforts currently being done in an effort to include people with disabilities in the process because they are considered a "hard to count" population.

#### **Attachments**

- Census Factsheet in English
- Census Factsheet in Spanish

### THIS PAGE IS INTENTIONALLY BLANK



# **Disability Counts!**

### #DisabilityCounts2020

Census Day is April 1st, 2020!



#### WHAT IS THE CENSUS?

The United States Census counts the country's population every decade. The collection of data about who lives in the United States and where is important for electoral representation, health care, housing, and education.

The next Census is in 2020. For the first time in history, you will be able to take the survey online or on paper.



## WHY IS THE CENSUS IMPORTANT TO PEOPLE WITH DISABILITIES?

People with disabilities make up 26% of the US population (nearly 1 in 4), however barriers to participation in the Census have made it difficult to provide an accurate count.

When people with disabilities have not been able to participate in the Census, we are not counted accurately. This leads to a lack of funding of important services for disabled people.

Many social service programs such as special education and disability services that assist people in becoming or maintaining their independence rely on Census survey data.



### **GET COUNTED!**

#### WHY IS AN ACCURATE **CENSUS IMPORTANT?**

An accurate Census count provides the government with data needed to:





#### Make sure that the population is represented accurately

- To determine how the seats of the House of Representatives are divided among individual states
- And so that resources are given out equally for all Americans, including people with disabilities



**Identify and better meet emerging needs** for Medicaid, Special Education, low-income housing, food and income benefits, access to internet, and other community resources.









Join us in spreading the word

**#DisabilityCounts2020** 





### **ILA DISCAPACIDAD CUENTA!**

### #DisabilityCounts2020

¡El día del censo es el primero de abril del 2020!



### ¿QUÉ ES EL CENSO?

El censo de los Estados Unidos cuenta la población del país cada diez años. La recopilación de datos sobre quién vive en los Estados Unidos y dónde, es importante para la representación electoral, la atención médica, la vivienda y la educación.

El próximo Censo es en el año 2020. Y por primera vez en la historia, usted podrá realizar la encuesta en línea o en papel.

## ¿POR QUÉ EL CENSO ES IMPORTANTE PARA LAS PERSONAS CON DISCAPACIDAD?

Las personas con discapacidad representan el 26% de la población de los Estados Unidos (casi 1 de cada 4), sin embargo, las barreras para la participación en el Censo han dificultado proporcionar un recuento exacto.

Cuando las personas con discapacidad no han podido participar en el Censo, no se cuenta con precisión. Esto lleva a una falta de financiación de servicios importantes para personas con discapacidad.

Muchos programas de servicios sociales como la educación especial y servicios para discapacitados que ayudan a las personas a convertirse o mantener su independencia dependen de los datos de la encuesta del Censo.



¡HÁGASE CONTAR!

## ¿POR QUÉ ES IMPORTANTE UN CENSO EXACTO?

Un recuento exacto del censo proporciona al gobierno los datos necesarios para:



## Asegurarse de que la población esté representada con precisión.

• Para determinar cómo se dividen los escaños de la Cámara de Representantes entre los estados individuales

• Y para que los recursos se distribuyan por igual para todos los estadounidenses, incluidas las personas con discapacidad;

Abordar la discriminación (injusticia) y poner en práctica las leyes de derechos civiles que protegen los derechos de voto, la igualdad de oportunidades de empleo y más.

• Identificar y satisfacer mejor las necesidades emergentes de Medicaid, educación especial, viviendas de bajos ingresos, beneficios de alimentos e ingresos, acceso a internet y otros recursos de la comunidad.









Ayúdenos a correr la voz

**#DisabilityCounts2020** 

#### **DECEMBER 4-5, 2019**

### DAY TWO AGENDA ITEM 5 ACTION ITEM

#### **Statewide Self-Advocacy Network**



## DECEMBER NEWSLETTER APPROVAL AND IDEAS FOR NEXT EDITION

Robert Levy, Chair of the SSAN Newsletter Workgroup will present SSAN members with a DRAFT version of the December Newsletter and ask members for any changes or additions. Robert will then lead a discussion about ideas for the December Newsletter.

#### **Attachments**

DRAFT December Voices of SSAN Newsletter

#### **Handouts**

None

#### Recommended Action

Approve the DRAFT December Voices of SSAN Newsletter

### THIS PAGE IS INTENTIONALLY BLANK

#### In this Edition:

Article 1: My Perception of

Adversity

Article 2: Disability and

2020 Census

Article 3: Working and

**Receiving Benefits** 

Article 4: San Diego

**Jobtoberfest** 

Article 5: My Journey Update

Article 6: 2019 Summer

Institute Recap

Article 7: Supported Life

**Conference Recap** 

Article 8: Kudos Corner

**Editor:** Robert Levy, UC Davis MIND Institute

#### **Contributors:**

- Sean Sullivan,
   Orange County
- Renee Wooten, CFILC
- Lisa Cooley,
   Sacramento
- Paul Mansell, San Diego
- Robert Levy, UC Davis MIND Institute
- Wesley Wittherspoon, USC Childrens' Hospital

### **My Perception of Adversity**

By Sean Sullivan, Orange County SSAN Representative

What does it mean to face adversity?

On the off chance that you don't know what it means, here is what it means. Adversity means unfair obstacles and challenges such as being born into a poor family.

The majority of people tend to look at adversity as a bad thing, I prefer to consider adversity as a friend. What I mean by that is, adversity is an opportunity to learn from the challenges we experience in our lives. It is an opportunity to grow stronger with each and every obstacle we overcome and conquer. I would like to end my article by saying that when we face adversity and overcome them it means we were stronger than the challenges we were faced with and should celebrate.

As the year comes to a close, I like to think back on all of the challenges that I have faced. I take note of the ones that I was fortunate to have beaten and analyze all the challenges I failed to overcome and think about why I struggled to overcome them and what I can do differently in the coming year to overcome those obstacles.

# Disability and the 2020 Census

#### By Renee Wooten, CFILC SSAN Representative

I recently sat down with Allie Cannington, the Statewide Organizer for the California Foundation for Independent Living Centers to talk about the 2020 Census and the effort to conduct outreach to traditionally hard to reach populations like people with disabilities.

#### What is the Census?

The United States Constitution (Article 1 Section 2) requires that the everyone living in the US be counted every ten years. This process is called the Census.

#### Why is it important?

The outcome of the Census impacts funding for services and supports that people rely on, as well as the number of US Representatives each state gets. Services that are affected by the Census include:

- Long Term Services and Supports
  - The number of Section 8 vouchers available
  - Funding for CalFresh
  - MediCal/Medicaid
  - o Durable medical equipment
  - IHSS Funding
- Special Education Grants
- State Children's Health Insurance Program (S-Chip)
   (Continue on Page 3: "Disability and Census")

#### **SSAN Members**

- Nathaniel Florez North Coast
- Teresa Moshier –
   North State
- Lisa Cooley –
   Sacramento
- Chen Curtiss –
   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
- Daniel Fouste –
   San Bernardino
- Paul Mansell –
   San Diego Imperial
- Desiree Boykin ARCA
- Renee Wooten 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

#### (Continued from Page 2: "Disability and Census")

It is important to know/remember that your participation in the Census process will not impact the benefits you receive or be reported to immigration services.

#### Ways to participate?

There will be three main ways to participate in California's efforts to complete the Census. The first stage will be online. If you do not have access to the internet, you can check out your local Independent Living Center or your local library to participate in the Census process. The second will be through the mail, the third will be through in-person door-to-door interactions.

#### Ways to educate others on the Census?

Contact your local Complete Count Committee for ways to get involved. People can also <u>Apply to be a Census Taker</u>. Contact your local ILC and SCDD offices for more ways to get involved.

To find out more check out these resources:

- Video: What is the Census?
- Video: Disability and Inclusion: Census 2020
- <u>Disability Rights California 2020 Census Toolkit</u>

Each year, the Census Bureau budgets out how much it will cost to conduct the Census, this year there are several concerns about the costs associated with conducting the Census on a new web-based platform. As the number of people in the United States grows, the costs associated with conducting the Census grows as well.

Check out

**#DisabilityCensus2020** and **#DisabilityCounts2020** on social media to keep the conversation going around the Census.

### 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 past Newsletters, Annual Reports, and Meeting info, can be found at www.scdd.ca.gov under 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 (916) 263-8196

# 20<sup>th</sup> Annual Jobtoberfest was a HUGE SUCCESS!

**By Paul Mansell**, San Diego and Imperial SSAN Representative

The San Diego Committee on Employment of People with Disabilities sponsored the 20<sup>th</sup> Annual Jobtoberfest at the Pechanga Sports Arena from 10-2 on 10/22/19. 65 Employers and resource providers attended, and 900 jobseekers came. The committee gave out three scholarships for people with disabilities going to college, trade school, or any other school that will lead to employment.

The Committee works year-round in preparation for the event. During the year employers are invited to quarterly Lunch and Learn educational meetings where employers learn how to employ people with disabilities.

Below is a proclamation they received for all their hard work. The proclamation says the following: Be it proclaimed by the Chairwoman Dianne Jacob and all members of the San Diego County Board of Supervisors on the 27<sup>th</sup> Day of October 2019 that they commend the San Diego committee on the employment for people with disabilities for their commitment to providing those with disabilities employment and do hereby declare that this day to be "Jobtoberfest Day" throughout San Diego County.



### **November Journey Update**

By Paul Mansell, San Diego and Imperial SSAN Representative

Let me recap my amazing journey traveled since DDS drew my name in their Self-Determination lotto on October 1<sup>st</sup>, 2018—so much has happened! On May 10, I went through Orientation. On July 3, I had my Person Driven Plan meeting. On August 27, I had my Budget meeting, my personal budget was certified, and my PDP with spending plan was submitted. On September 19, I had my IPP/AR. On October 1, my plan went into effect, one year to the day from the day my name was drawn from the lotto. I was the first non-pilot participant to have their plan approved in the state. Wow! I wanted to be first—yeah doggie!

I have a simple IPP with 6 outcomes—maintain competitive integrated employment; maintain optimal health; broaden my social connections; follow a monthly budget; use a medical alert service; and manage my finances. My IPP calls for 5 funded services—12 hours/month of ILS, a Compass card (San Diego Regional Transit card), San Diego People First Conference registration, a medical alert service, and a FMS. As simple as my plan is, it took a lot of hard work to transfer my service payments from SDRC to my FMS. Sometimes the simplest things can be hard to do.

The hard part of my plan is not getting the services I want and need but making changes in my life style and I am the only one who can make those changes. This falls under the principles of responsibility and accountability.

The plan calls on me to make difficult changes—for example, following a Low-Cal diet and exercising. My doctors have been egging me to do this for years. It is hard to follow a Low-Cal diet with so many good food options, added to my tendency to be an emotional eater. I do go on 15-minute walks twice a week with my ILS worker, but I am going to add a third walk to my routine. I am considering do it Friday evening after work. Making this change will be hard, because I do not like being out when it is dark, but I look forward to the challenge of meeting the goals in my plan.

I am excited the plan calls on my professional development and growth. In particular my PDP calls on me to become a self-determination mentor to meet one-on-one with plan participants and to share my insights and experiences on how to be successful in self-determination. I want to share my belief that successful self-determination requires respect, open communication, fortitude, hard work, and trust. It takes a team.

### **2019 Summer Institute Recap**

**By Robert Levy,** UC Davis MIND Institute SSAN Representative and **Lisa Cooley,** Sacramento Regional SSAN Representative

The UCD MIND Institute just wrapped up their 17th annual Summer Institute Conference. The Conference was held on Friday August 2, 2019 It was held at the UC Davis Conference Center in Davis, California.

The annual MIND Summer Institute on Neurodevelopmental Disorders is a one-day conference intended for a wide range of professionals, including educators, psychologists, physicians, nurses, occupational therapists, physical therapists, and speech and language pathologists, as well as consumers, family, caregivers, and students. The focus of the Institute is to help participants keep pace with the latest advances in neurodevelopmental research and the most current standards for best practices in prevention, assessment, treatment, and support services, and increase their knowledge and skills in the areas of developmental disabilities, early identification, service provision, inclusion, transition to adulthood, and other medical, legal, social and policy issues related to disabilities.

Conference presentations are available in video format on <u>Summer Institute Videos page</u>, and most of them are also available on <u>UCTV</u>

The summer Institute planning committee included Steve Ruder, along with many others that worked together to organize this year's daylong event featuring several breakout sessions, along with a moving keynote panel presentation. The theme for this year was: "Inside Out: Personal Perspectives About the Challenges and Successes Shared by Self-Advocates with Autism". There were two keynote presentations. One of the keynotes was a panel presentation featured 3 moms and their sons who talked about the day to day challenges in life living with developmental disabilities like autism and working to achieve independent living goals like moving out of their parent's house and going to college, along with their interests. The second presentation was called: Parent and Youth Perspectives: How to Empower Students with DD to have Voice and Agency in Schools. This year's conference included Qualtrics self-evaluations, which is an online platform used to collect data. (Continue on Page 8: "Summer Institute")

**(Continued from Page 7: "Summer Institute")** The day of the conference, I, Robert Levy, helped with the registration process and assisted about 25-30 people. I also attended sessions and learned a lot.

If you want to learn more about the sessions at the 2019 UC Davis Summer Institute, check out the <u>Summer Institute Videos</u>

Lisa Cooley, attended this year's Summer Institute and learned about a program for Dignity Hospital patients that helps them during their hospital stay. This program has a nurse advocate that helps patients get their disability related needs met. The nurse advocate also works with other nurses to teach them about disabilities. The advocates that were a part of the keynote presentation are all a part of a local toastmasters group for people who have developmental disabilities.

Be on the lookout for information about the 18th annual UCD MIND Institute Summer Institute coming in 2020!

# **Supported Life Conference Recap**

I attended the Supportive Life Conference in Sacramento on October 10-11. There are several speakers who attended the conference. I saw Kecia speak about sexual abuse of people with intellectual/developmental disabilities. 1 out of 6 people with ID/DD males are sexually abused. Most crimes against people with ID/DD are not reported. I saw Nancy Bargmann of DDS speak about barriers for different groups. Leroy F. Moore Jr. spoke about cerebral palsy, African American issues with being disabled. Kristin Wright spoke about Education and people with disabilities. Laurie Rodriguez spoke about employment for people with ID/DD. At the conference, there was discussion on Diabetes, IEPs, diversity and disparities, inclusion, emergency preparedness, housing, etc. I even attended a safety class. The big takeaway from this conference is that people with disabilities, their families, and staff are becoming more empowered in the State of California.

### Learn About SSAN Partners

- Association of Regional Center Agencies
- <u>California Foundation</u>
   <u>for Independent</u>
   <u>Living Centers</u>
- <u>Department of</u><u>Developmental</u>Services
- <u>Disability Rights</u> <u>California</u>
- <u>University of</u>
   <u>California</u>, <u>Davis</u>
   MIND Institute
- University of California, Los Angeles, Tarjan Center
- <u>University of</u>
   <u>Southern California</u>,
   <u>Children's Hospital</u>

#### **Self-Determination Update**

Check out the latest

DDS Self-Determination

Newsletter for the latest on
California's SelfDetermination Program.

### **Kudos Corner**

**By Sean Sullivan,** Orange County SSAN Representative

This month we recognize Rebecca Donabed, who represents the Sequoia Regional Office of the State Council on Developmental Disabilities on SSAN. Rebecca has overcome a lot of adversity and is very dedicated to SSAN.

Rebecca has been an outstanding member of SSAN for many years, being a leader not only within her community, but also across the state. Rebecca is consistently dedicating herself to SSAN's mission and vision. When the position of Secretary became vacant, Rebecca stepped up to the task, taking on a leadership role, which requires courage and a strong work ethic. As a member of the previous leadership team, Rebecca worked collaboratively with the other members of the team to plan fun and informative meetings. So, Kudos to you Rebecca!

#### SAVE THE DATES

Deadline to Apply to be a delegate at the 2020 Youth Leadership Forum is December 31st!

Apply to Present at:
25<sup>th</sup> Annual Statewide
Self-Advocacy
Conference
May 8<sup>th</sup> and 9<sup>th</sup>, 2020
Speaker Applications due
on December 20<sup>th</sup>, 2019
contact
info@supportedlife.org
for speaker applications.

SCDD is currently in the process of developing the next Five Year State Plan

We need your input: http://bit.ly/stateplaninput.

Contact your regional office of the State Council on Developmental Disabilities for information on trainings happening in your area.



THIS PAGE	IS IN	TENTI	ΊΝΔΙΙ Υ	' I FFT	RI ANK
HIIOFAGL	IO III		JINALLI		DLAIN

#### **DECEMBER 4-5, 2019**

### DAY TWO AGENDA ITEM 6 ACTION ITEM

#### **Statewide Self-Advocacy Network**



#### SSAN ANNUAL REPORT

The SCDD Self–Advocacy Coordinator and SSAN Officers will present SSAN members with the 2018–2019 SSAN Annual Report that summarizes SSAN Activity for the past year.

#### **Attachments**

DRAFT 2018–2019 SSAN Annual Report

### THIS PAGE IS INTENTIONALLY BLANK



# **SSAN Annual Report**

The Statewide Self-Advocacy Network

# The 2018 – 2019 SSAN Annual Report was produced by the California State Council on Developmental Disabilities



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

# 2018-2019 SSAN Annual Report

### **Table of Contents**

TABLE OF CONTENTS	2
ABOUT SCDD	
ABOUT SSAN	
AGENCY MEMBERS	
SSAN MEMBERS	6
MESSAGE FROM THE CHAIR	7
2018 – 2019 SSAN MEETINGS	9
Words from SSAN Members	
2018 – 2019 Highlights	12

# **About SCDD**

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

SCDD has identified self-advocacy as their top goal in their current State Plan and is committed to supporting self-advocacy in California. To meet their commitment to establishing and strengthening a program led by individuals with intellectual and developmental disabilities, develop and promote leadership skills, and expand participation in a cross-disability coalition, SCDD created the Statewide Self-Advocacy Network (SSAN) in 2012. Through supporting SSAN, SCDD aims to help self-advocates in California increase knowledge and provide support to help them advocate for their civil and service rights and achieve integration and inclusion in all areas of community life. SCDD supports SSAN members' efforts to be leaders in their communities.

# **About 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 is a cross-disability network of self-advocates that was established in 2012 and works to do the following:

- Develop the knowledge and skills to make a difference in our region and state.
- Speak up for all people with disabilities.
- Learn about and advocate for issues important to all people with disabilities.
- Lead regional and statewide advocacy groups and networks.
- Train advocates in their communities in order to grow the Self-Advocacy movement in California.
- Share information about programs and supports for people with disabilities.

# **Agency Members**



California State Council on Developmental Disabilities



California Department of Developmental Services



California Foundation for Independent Living Centers



Association of Regional Center Agencies



Disability Rights California

### California UCEDDs



**UCLA Tarjan Center** 



USC Children's Hospital



UC Davis MIND Institute

### SSAN Members (Roster) 2018–2019



- North Coast Region Nathaniel Florez
- North State Region Teresa Moshier
- Sacramento Region Lisa Cooley
- North Bay Region Chen Curtiss
- Bay Area Region Regina Woodliff
- North Valley Hills Region Robert Balderama
- Central Coast Region David Forderer
- Sequoia Region Rebecca Donabed
- Los Angeles Region Julie Gaona
- Orange County Region Sean Sullivan
- San Bernardino Region Daniel Fouste
- San Diego Region Paul Mansell

Association of Regional Center Agencies – Desiree Boykin

California Foundation of Independent Living Centers –



Department of Developmental Services



UCDAVIS MIND INSTITUTE



Department of Developmental Services – Nicole Patterson
 Disability Rights California – Scott Baron

Renee Wooten

- State Council on Developmental Disabilities Wesley Witherspoon
- University Center on Excellence in Developmental Disabilities
  - UC Davis MIND Institute Robert Levy
  - UCLA Tarjan Center Kecia Weller
  - USC Children's' Hospital Wesley Witherspoon

### **Message from the Chair**

I am extremely proud of the Statewide Self-Advocacy Network (SSAN) members and my executive team for the past eight months as we worked together to carry out the mission of the SSAN, as well as the executive team vision for SSAN, to continue strengthening advocacy work across California by educating, being active members in our communities and agencies, and being a voice for people with disabilities. The SSAN will also keep working on encouraging more partners from the disability community to join the SSAN table. This will help make it possible for the SSAN to work more on system change issues that face all persons with disabilities in California. We have done this so far by filling all our vacancies. Currently, we have a goal to reach out to the youth to learn about the issues that are important to them and find creative ways to join the generations together to work on common issues.

I would like to share a little about the executive team. We were elected in December of 2018 and our first official meeting as SSAN's leadership was in March of 2019.

### **Desiree Boykin (Vice-Chairperson)**

Desiree has a B. A. degree in Health and Human Services. In 2011, South Central Los Angeles Regional Center hired her as their Consumer Advocate. She is passionate about the people they serve having the resources they need to reach their goals. Desiree also serves on the Association of Regional Center Agencies' Client Advisory Committee (ARCA CAC). The ARCA CAC elected her to serve as their representative for the SSAN.

### **Lisa Cooley (Secretary)**

Lisa started doing disability advocacy work over twenty years ago because our local transportation provider thought that she could walk to a bus stop because she could walk around her house. She became so good at advocating that she decided to become a member of the State Council on Developmental Disabilities. She also is a longtime member of her regional center's Client Advisory Committee. Her passion is to empower people with disabilities and move California forward.

#### **Nicole Patterson (Chairperson)**

I have been involved with the SSAN since the beginning in 2012 representing the California State Department of Developmental Services (DDS) as a partner. I have worked for DDS for fourteen years as the Coordinator of Advocacy Services. I provide a voice, on behalf of people we serve, to the Director and the Department, on issues and problems that people with disabilities may be facing in California. I also help to come up with solutions. I have worked in the field of empowering people with disabilities for the past 25+ years. I am passionate about working with people with all types of disabilities, providing assistance and advising them on their rights, helping to change the future view of people with disabilities. It's important to me to show California and other states that people with disabilities can be fully included in all aspects of life by helping to educate the people who provide services, and to enlighten the communities we live in.

I would like to thank the California State Council on Developmental Disabilities for their continued support of the SSAN project, the SSAN vision, and for empowering SSAN members as advocates on a state and local level.

Nicole Patterson SSAN Chairperson

# **2018 – 2019 SSAN Meetings**

SSAN held 4 meetings between October 1, 2018 and September 30, 2019 in Sacramento, California. Each SSAN meeting included member reports on issues and concerns in their regions, legislative updates, training for members, and resources to distribute to member's communities. Highlights from Meetings include:

- Established an ad hoc workgroup to review and revise the SSAN By-Laws
- Elected a new Chair, Vice-Chair and Secretary to serve a two-year term
- Participated in a training on the California legislative process
- Presentation on AUCD and the importance of Competitive Integrated Employment
- Presentation on healthy relationships
- > Identified priorities for the year
- Discussed the importance of Disability Sensitivity
- Disability Pride and Being a Better Advocate
- Impact of the Camp Fire on People with Disabilities
- Overview of the Disability Organizing Network
- Reviewed the MOU between SCDD and SSAN
- Person Centered Planning
- Reviewed and approved 4 editions of the SSAN Newsletter

### **Words from SSAN Members**



"I have attended conferences and trainings that lead me to meet advocates from across the US and the territories. This has given me the opportunity to advocate for SSAN at the national level." – Wesley Witherspoon, Los Angeles

"Transportation is a big issue in my area and across the state. I attend the San Joaquin Regional Transit District (RTD) as a way of interacting with the transportation agency and to try to improve access to transportation in my county."

— Robert Baldrama, Stockton





"As the Chair of San Diego People First, I enjoy the ability to share information from SSAN with my local community and bring ideas from my region to SSAN."

- Paul Mansell, San Diego

"I enjoy being able to connect and share my story with other self-advocates in Riverside and across the state."

- Daniel Fouste, San Bernardino





"I enjoy being able to mentor others and share my knowledge and experiences in advocacy."

- David Forderer, San Jose

"I am the first female President of Paradise People First. I enjoy sharing stories about my community and how they came together to respond to the Camp Fire."

- Teresa Moshier, Willows





"As a new member to SSAN, I am looking forward to continuing to strengthen the connection between SSAN, CFILC and the Disability Organizing Network." – Renee Wooten, Sacramento

"I've been a part of SSAN for 5 years now. I enjoy learning from all of my fellow self-advocates from California." – Desiree Boykin





"I enjoyed being able to learn from advocates from across California and attend the Statewide Self-Advocacy Conference in May. There were a lot of good sessions." – Lisa Cooley, Sacramento

# 2018 - 2019 Highlights

SSAN Members participate in Coalitions, Boards and Planning committees throughout California along with providing self-advocates, family advocates and others, trainings related to increasing self-advocacy and access to community supports. During the 2018 – 2019 reporting period, members reported reaching 4525 people throughout California and across the country. Highlights from members include:

- Participated at Regional Advisory Committees
- Participated at SCDD Meetings in Sacramento
- Participated on the SCDD Self Advocacy Advisory Committee
- Attended, presented at and organized the following conferences:
  - Statewide Self Advocacy Conference in Sacramento
  - o Supported Life Institute in Sacramento
  - PFCA Gatherings
  - o CHOICES 2019 conference in Stockton
  - o San Diego People First conference.
- Members are on their regional center boards, IHSS Public Authority, transportation boards, and People First groups.
- Wrote and sent their stories to their Legislators
- Collaborated with regional offices to give statewide trainings with GetSafe
- Participated in advocacy training "Leadership Academy"
- Presentations informing their community about SSAN
- · Collaborating with agencies to conduct interviews
- Presentation on the California Self-Determination Program
- Transition Fairs and presentations made across the state



### **DECEMBER 4-5, 2019**

## DAY TWO AGENDA ITEM 7 ACTION ITEM

### **Statewide Self-Advocacy Network**



#### INPUT FOR NEXT MEETING & COMPLETE MEETING EVALUATIONS

The SSAN Chair will lead the group in a discussion about ideas for the March 2020 meeting and members will have the opportunity to complete meting evaluations for the December 2019 meeting.

#### **Attachments**

None

### THIS PAGE IS INTENTIONALLY BLANK