STATEWIDE SELF ADVOCACY NETWORK MEETING INFORMATION

DATE: Wednesday, December 8, 2021 and Thursday, December 9, 2021

TIME: Wednesday, December 8, 2021 10:00 AM – 3:00 PM
      Thursday, December 9, 2021 10:00 AM – 2:00 PM

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

MEETING ID: 962 1640 5690
MEETING PASSWORD: 8703085

Check out Zoom Download Instructions and Tips on how to use Zoom to learn the basics about the Zoom platform.

OR

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CALL IN NUMBER: (888) 475-4499
MEETING ID: 962 1640 5690
MEETING PASSWORD: 8703085

Accessibility

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All times indicated and the order of business are approximate and subject to change.
1. **Call to Order, Welcome, and Introductions/Member Report**  
   Presented by: Desiree Boykin, Chairperson, Paul Mansell, Vice-Chairperson, and Robert Levy, Secretary

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

3. **Review and Approval of September 2021 Minutes**  
   Presented by: Desiree Boykin, Chairperson  
   **ACTION**

4. **Updates from the SSAN Chair**  
   Presented by: Desiree Boykin, Chairperson  
   **Information**

5. **SCDD DAC Disability Video Project**  
   Presented by: SCDD DAC  
   **Information**

6. **SCDD Update**  
   Presented by: Aaron Carruthers, SCDD Executive Director  
   **Information**
7. SSAN Workgroup Discussion
   Presented by: SSAN Officers
   Discussion

   Break

8. SSAN Workgroups
   Presented by: ALL
   Discussion

9. How the ADA Changed the Built World
   Presented by: ALL
   Discussion

10. Getting Rid of the R Word
    Presented by: Special Olympics Southern California
    Information

11. Recess Until Next Day
    Presented by: Desiree Boykin, Chairperson
    Information
1. Call to Order, Welcome and Introductions
   Presented by: Desiree Boykin, Chairperson, Paul Mansell, Vice-Chairperson, and Robert Levy, Secretary

2. Review of Agenda
   Presented by: Desiree Boykin, Chairperson

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

4. Planning for the Future and 2022 Dates
   Presented by: SCDD Staff and SSAN Officers

5. Approval of December 2021 SSAN Newsletter
   Presented by: Robert Levy, Newsletter Workgroup Chair
   ACTION

6. Approval of 2020–2021 SSAN Annual Report
   Presented by: SSAN Officers
   ACTION

7. Planning for March 2022 Meeting
   ALL
   Discussion

8. Adjournment
DECEMBER 8, 2021
SSAN MEETING AGENDA ITEM 3
ACTION ITEM

Statewide Self-Advocacy Network

Approval of September 2021 Minutes

Attachments

September 2021 Minutes

Recommended Action

Approve the September 2021 SSAN Meeting Minutes.
Statewide Self—Advocacy Network Meeting Minutes
September 7 & 8, 2021
Zoom

SCDD Regional Members Present
Teresa Moshier — North State
Lisa Cooley — Sacramento
Ellen Sweigert — North Bay
Regina Woodliff — Bay Area
(Day 2)
Robert Balderama — North Valley Hills
David Forderer — Central Coast
Rebecca Donabed — Sequoia
Julie Gaona — Los Angeles
Daniel Fouste — San Bernardino
(Day 1)
Paul Mansell — San Diego–Imperial

Agency Members Present
Matthew Lagrand — SCDD
Robert Levy — UCD MIND Institute
Wesley Witherspoon — USC CHLA
Kecia Weller — UCLA Tarjan Center
(Day 2)
Scott Barron — DRC
Nicole Patterson — DDS
Desiree Boykin — ARCA
Russell Rawlings—CFILC

Members Not Present
Nathan Florez — North Coast
Sean Sullivan — Orange County

SCDD Staff in Attendance
Rihana Ahmad — SCDD HQ
Aaron Carruthers — SCDD HQ
Riana Hardin — SCDD HQ
Beth Hurn — SCDD HQ
Robin Maitino–Erben — SCDD HQ
Debbie Marshall — SCDD San Diego
Sarah May – SCDD North State
Chanel Murray —
SCDD North Valley Hills
Charles Nguyen — SCDD HQ
Mary Agnes Nolan —
SCDD North State
Tobias Weare — SCDD North Bay

Presenters
Teresa Anderson
Ally Cannington
Isaac Haney-Owens
Gabriel Taylor

Others Present
Ryan Duncanwood
Michael Esquibel
Chynna Glasson (NeuroNav)
Kimberly Laymon
James Stolarek
SSAN Minutes

1. Call to Order, Welcome and Introductions

SSAN Chairperson Desiree Boykin, ARCA Representative, called the meeting to order at 10:09 AM.

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

2. Public Comment

There was no public comment.

3. Review and Approval of June 2021 Minutes

The members reviewed the minutes from the June 9 & 10, 2021 Meeting. Materials for this agenda item can be found on pages 5–14 of the September 2021 SSAN Meeting Packet.

ACTION: Motion #1 to approve the June 2021 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. Updates from SSAN Chair

SSAN Chairperson Desiree Boykin, ARCA Representative, expressed the hope that SSAN continues to thrive and that SSAN can inspire the next generation of self-advocates to get involved in the Self-Advocacy Movement. Chairperson Boykin reminded members about the importance of wearing your face masks and following local guidelines for addressing COVID–19.
5. Conversation on Civility

Members had an open conversation about the importance of civility in conversation and how to actively listen to those who you have disagreements with.

6. SCDD Update

SCDD Executive Director Aaron Carruthers provided SSAN members with an update on SCDD activity since the June SSAN meeting. SCDD continues to educate communities about the safety of the different COVID–19 vaccines and collaborate with community partners in an effort to organize accessible vaccine clinics for people with I/DD.

Executive Director Carruthers talked about the challenges of responding to the ongoing public health crisis of COVID–19 and keeping everyone safe. SCDD continues to address vaccine hesitancy among Californians with I/DD and their communities by providing timely, up to date and easy to understand information about the different types of COVID—19 vaccines.

Executive Director Carruthers provided SSAN with an update on California Senate Bill 639 and SCDD’s efforts to advocate for competitive integrated employment (CIE) and end the practice of paying people with I/DD subminimum wage.

7. SSAN Workgroups

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

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

Materials for this agenda item can be found on pages 27—30 of the June 2021 SSAN Packet.
8. Accessible, Affordable Housing Options and Resources

Allie Cannington, Manager, Advocacy and Organizing and Isaac Haney-Owens, Analyst at The Kelsey provided SSAN Members with information about disability-forward housing solutions and building knowledge and power.

The presentation covered California’s history of racist and ableist housing policies and practices. Members were encouraged to use the information and resources to become advocates for accessible, affordable housing solutions. The presentation explored the connection between building communities, changing systems, and promoting affordable, accessible and disability inclusive housing models. Materials for this item can be found on pages 31 to 42 of the September 2021 SSAN Packet.

9. Recess Until Next Day

SSAN Chairperson Desiree Boykin declared the meeting in recess at 3:17 PM. The September 2021 SSAN meeting will return from recess at 10:00 AM Wednesday, September 9th, 2021.
SSAN DAY 2 Minutes

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

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

An attendance roll call was taken.

2. Review of Agenda

Members reviewed the agenda for day two of the SSAN meeting.

3. Public Comment

There was no Public Comment.

4. Voting Discussion

Representatives from Disability Rights California (DRC) and California Foundation for Independent Living (CFILC) provided members with important information about the upcoming California Recall election planned for September 14th and the importance of the disability vote in the election process.

5. Employment Panel

The SSAN Employment Workgroup organized an employment panel of people with different types of jobs and disabilities to share their experiences working.

6. Approval of the September 2021 SSAN Newsletter

SSAN Secretary and Newsletter and Communications Workgroup Chair, Robert Levy reviewed the DRAFT September 2021 Voices of SSAN Newsletter with members and called for a motion to approve the September 2021 Edition.

Materials for this agenda item can be found on pages 49–64 of the September 2021 SSAN Meeting Packet.

ACTION: Motion #2 to approve the September 2021 Newsletter was made by Ellen Sweigert/Seconded by Regina Woodliff. A roll call vote was taken. Motion passed. See vote log on page 7.
7. Social Justice and Disability

The Arc of California Public Policy Director, Teresa Anderson provided SSAN members with an introductory presentation on Social Justice and Disability.

8. Planning for December 2021 Meeting

SSAN members brainstormed topics/presentations for the December 2021 meeting. Suggested presentation topics included:

- The Blame Game
- Update/training on Self-Determination
- Getting Rid of the R word
- Disability Laws (Possible SSAN Training)
- SSA N Annual Report
- Invite Arc of California back
- Housing (The Kelsey)

Additionally, members requested that each day of a SSAN meeting be limited to 4 hours long.

9. Adjournment

Meeting was adjourned at 2:04 P.M. The next SSAN meeting will be on December 7th and 8th 2021 using Zoom.
# JUNE 2021 SSAN VOTE TALLY

<table>
<thead>
<tr>
<th>Name</th>
<th>Region</th>
<th>Roll Call</th>
<th>Motion 1</th>
<th>Day 2 Roll Call</th>
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<td>SCDD</td>
<td>Present</td>
<td>For</td>
<td>Present</td>
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<td>Robert Levy</td>
<td>Mind Institute</td>
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Statewide Self-Advocacy Network

Updates from the SSAN Chair

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

Attachments

SSAN 2021 Revised Member Report
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<th>DATE</th>
<th>Title or Topic of Meeting/Event</th>
<th>Where it was held (Regional or Statewide)</th>
<th>Organization or Group Connected or Statedwide (Regional)</th>
<th>How did you learn?</th>
<th>How it relates to SSAN/Self-Advocacy?</th>
<th>How many SA?</th>
<th>How many FA?</th>
<th>How many Others?</th>
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MEMBER REPORT

Tell us if you...

Name: _______________________

Month ____________________ Year ____________________

Key: SA-Self Advocate; FA-Family Advocate; O-Other (not SA or FA)
### SCDD State Plan Goals
- Self Advocacy
- Employment
- Housing
- Health & Safety
- Education
- Community Supports

### Resources

<table>
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<th>Title or Topic of Resource</th>
<th>Internet Link/Address</th>
<th>Will bring a copy</th>
<th>Resources you would like to share with SSAN</th>
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### Additional Questions

**Are there any BARRIERS that have kept you from participating in advocacy related activities?**

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<tr>
<th>Barrier</th>
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**Is there anything that your local self-advocacy group would like SSAN to work on?**

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<tr>
<th>Topic</th>
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**Anything else you would like to REPORT or any questions or Training/Project ideas you would like to share with SSAN?**

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<tr>
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Statewide Self-Advocacy Network

SCDD DAC Disability Video Project

As a follow-up to the presentation at the June SSAN meeting, SCDD DAC members would like to get SSAN members’ feedback on what it means to have a disability. SCDD DAC would appreciate SSAN’s input on how to put together a short video on this topic and is looking for volunteers to work with us on this part of our project.

Background Information:

California State Agencies have internal committees to address different issues and/or needs within state departments. The SCDD Disability Advisory Committee (DAC) is a committee of SCDD employees who identify as having a disability and/or are interested in fostering a disability inclusive environment at SCDD. DACs exist in state agencies to make recommendations to agency Executive Directors and Human Resources (HR) about best practices in hiring and supporting employees with disabilities.
Since the September 2021 SSAN meeting, the State of California, the United States of America, and many countries around the world continue to face challenges in addressing the public health and public safety challenges of COVID–19. SCDD continues to work with statewide and local partners to advocate for the inclusion of people with I/DD in the vaccination rollout. SCDD Executive Director Aaron Carruthers will update SSAN members on Council activity related to meeting the needs of Californians with I/DD during these challenging and unique times.

Possible Handouts

- September 2021 Council Meeting Summary
- November 2021 Council Meeting Summary
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SSAN MEETING AGENDA ITEM 7
INFORMATION ITEM

Statewide Self-Advocacy Network

**SSAN Workgroup Discussion**

SSAN Officers will lead an open conversation about the structure of the SSAN Workgroups and encourage members to share their thoughts and ideas on how to improve SSAN workgroups.

**Attachments**

- SSAN Workgroup Descriptions
SSAN Workgroup Purpose, Goals, and Measurable Objectives

SSAN OFFICERS WORKGROUP

**Purpose:** The SSAN Officers are responsible for planning and setting the agenda for each Full SSAN Meeting, Review and Approve recommendations relating to SSAN Membership, and Review recommendations relating to changes to the SSAN Bylaws.

**Goal:** To increase participation and awareness of SSAN meetings and resolve issues relating to membership.

**Measurable Objective:** SSAN Officers will work together to plan up to four Full SSAN Meetings a year. Full SSAN meetings will include presentations/trainings suggested by SSAN members, and “standing” agenda items.

SSAN MEMBERSHIP WORKGROUP

**Purpose:** The SSAN Membership Workgroup will review and make recommendations to SSAN Officers relating to SSAN Membership and the SSAN Membership Process.

**Goal:** To increase representation of self-advocates across California.

**Measurable Objective:** SSAN workgroup members review the SSAN Membership process for open positions on SSAN.

- Review SSAN Marketing Materials
- Review SSAN Application Process Materials
- Review Applications for SSAN
- Make Recommendations to the SSAN Officers about SSAN Membership
SSAN EMPLOYMENT WORKGROUP

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

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

**Measurable Objective:** Members of the SSAN Employment Workgroup will:

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

SSAN SELF-DETERMINATION WORKGROUP

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

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

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

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

**Purpose:** The SSAN Bylaws Workgroup will review and make recommendations to the SSAN Officers about updates to the SSAN Bylaws.

**Goal:** Ensure that the SSAN Bylaws are in plain language and easily understood by all members of SSAN.

**Measurable Objective:** Review the SSAN Bylaws at least once a year and make recommendations to the SSAN Officers on suggested updates in language and/or meaning.

SSAN YOUTH ENGAGEMENT WORKGROUP

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

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

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

**Purpose:** The Legislative and Civic Engagement workgroup will inform and educate our partners and communities on statewide legislation that SCDD has taken a position on.

**Goal:** Increase the community’s awareness on the State Council on Developmental Disabilities’ legislative platform and priorities.

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

SSAN NEWSLETTER/COMMUNICATION WORKGROUP

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

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

**Measurable Objective:** The Newsletter/ Communication workgroup will produce 4 newsletters highlighting SSAN’s advocacy work throughout California. The Newsletter/Communications workgroup will try to ensure that future editions are in accessible formats.
SSAN workgroups will meet to discuss current and ongoing projects. Workgroups are encouraged to review and discuss their workgroup Goals and Priorities, suggesting updates as needed. The following SSAN workgroups will meet using Zoom Breakout Sessions:

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

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How the ADA Changed the Built World

The impact that laws have on our lives often extends beyond the original intent or goal of the law. The SSAN Officers invite members to view the video “How the ADA Changed the Built World,” about the impact that the ADA has had on society as a whole, followed by an open discussion where members can share their thoughts.

The SSAN Officers request that both SSAN members and members of the public approach this conversation with an open mind and a willingness to listen to others.

Resources

- YouTube: How the ADA Changed the Built World
- YouTube: Crip Camp
- Patient No More Exhibit
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Getting Rid of the R Word

Words are a powerful tool to express your thoughts and feelings, and can have strong impact on others. The words that we use to talk about people based on their identities can be particularly harmful. Since 2009, Special Olympics has been campaigning to “Spread the Word to End the Word” in an effort to reframe the words used to label people with developmental disabilities.

Representative(s) from Special Olympics Southern California will provide SSAN members information about the ongoing campaign to stop the use of the R word in everyday language. Read up on the 2021 Theme: Connection.

The SSAN Officers request that both SSAN members and members of the public approach this conversation with an open mind and a willingness to listen to others.

Resources

Cross Streets Vol 1 on Soundcloud
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SSAN DAY 2 AGENDA ITEM 4
INFORMATION ITEM

Statewide Self-Advocacy Network

Planning for the Future and 2022 Dates

As a project of the California State Council on Developmental Disabilities (SCDD) the California Statewide Self-Advocacy Network (SSAN), is a cross-disability training network. The work of SCDD is guided by the State Plan, which is updated every 5 years. October 2021 marked the beginning of the new State Plan.

SCDD Staff will provide a presentation on how SSAN activities and projects fit in with the new State Plan and how it impacts the work of SCDD and projects like SSAN.

Resources

- 2022–2026 SCDD State Plan
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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 March 2022 Newsletter.

**Attachments**

- DRAFT December 2021 Voices of SSAN Newsletter
- Voices of SSAN Newsletter Article Tips Newsletter Article Tips

**Recommended Action**

Approve the DRAFT December 2021 Voices of SSAN Newsletter
Family and Friends During the Holidays
By Paul Mansell, San Diego Regional SSAN Representative

Short days, long nights, and the chill in the air mark the return of winter. Starting with Halloween and stretching through Martin Luther King’s Birthday, we celebrate countless holidays. During this festive time, we think of our relationships, both friends and family and how they bring such joy and meaning to our lives. We think of home. We are mindful of how busy the holidays are, full of parties, special food, and obligations. The holidays can be the best and also the most stressful time of year.

We have so many traditions with family and friends. Although with the COVID–19 Pandemic, we have been forced to change our plans. Luckily, this year’s travel restrictions do not look to be as bad as last year’s. Hopefully we can use this holiday season to get together with friends and family. We tell long stories, reminisce, sing songs and eat, boy do we eat. We also exchange gifts, some modest, and others lavish.

The holiday can be a hectic and stressful time of year, busy with parties and celebrations, travel, and all that eating. The days are short, and the nights are long, and the weather is miserable. Barren trees signal that nature has gone to sleep, and it is time to hibernate. This gets some people down.

To have a happy holiday season, let moderation be your guide. Have fun, but don’t overdo it, especially with the eggnog. Find time to rest and stay centered but do enjoy this special time of year.
SSAN Youth Survey Data
By Kecia Weller, UCLA Tarjan Center UCEDD SSAN Representative

In July 2021, the SSAN Youth Engagement Workgroup created and shared a Youth Engagement Survey to find out what the youth/young adults are thinking about now. SCDD sent this youth survey to Yo! Disabled and Proud and some other places where youth hang out. Regina and I want to share some of the results from this survey and the information we learned with you.

So far, there have been a total of 136 respondents answered the survey. Out of those respondents – only 15% were 16 years old to 22 years old and 25% were 23 years old to 30 years old (The youth survey’s target audience).

Here are some responses from the question: What do you think is keeping youth with disabilities from being involved with Self-Advocacy?

- I would like to see more Youth driven people first groups
- Feeling safe going to in person activities without parental supervision
- Not sure how to speak up for themselves due to lack of social skills
- Judgement and preconceived ideals about disabilities. They are all different not all people are the same.

Since 2007, both Regina and I had the idea to bring young adults into the Self-Advocacy movement. Now the SSAN Youth Engagement Workgroup wants to bring the young adults into SSAN, so young adults can learn from SSAN members and SSAN members can learn from the young adults. In the future, SSAN will have a youth/young adult seat on SSAN. Both Regina and I are extremely excited to have a young adult on SSAN with us.

SSAN Youth Survey

There is still time to participate in the SSAN Youth Survey. SSAN wants to hear from youth with disabilities about their interests. SSAN encourages people with disabilities ages 17 to 30 to provide their feedback; but welcomes anyone who is interested in participating to fill out the survey.
Addressing Vaccine Hesitancy

By Robert Balderama, North Valley Hills Regional SSAN Representative

Vaccine hesitancy continues to be an ongoing issue for people with disabilities, especially concerning the COVID–19 vaccines. The fact is that people with disabilities are vulnerable due to our complex medical needs and are at a higher risk of developing serious illness if we get sick from COVID–19. Another vulnerable population is the elderly and it is important for them to get vaccinated in order to protect themselves. COVID–19 is a serious public health issue and it is important to follow rules and public health guidance as we have a civic/social responsibility to protect others by being up to date on our vaccinations.

Being vaccinated not only protects yourself, it is also a way to protect first responders and healthcare workers. I know that there is concern about how fast the COVID–19 vaccines came out, but medical experts have been working on developing mRNA vaccine technology for many years and a lot of time and energy has gone into developing and learning about this new method of delivering vaccines.

If you have any questions or concerns about how vaccines will affect you, it is important to talk to your doctors about your concerns. It is unfortunate, but understandable that the history of medical mistreatment of people with disabilities is resulting in some people being hesitant to get vaccinated. Actions you can take:

- Bring your concerns up with your doctor and or public health officials
- Encourage hospitals and medical groups to do more outreach and have conversations with people with disabilities on vaccines
- Create spaces where people can ask questions and feel heard
- Help develop and review materials to make sure they are in plain language (easy to understand)

There is a lot of misinformation out there about the vaccines and it is important to ask questions and make sure that you are getting your information from a reliable source. I understand that mistrust of officials who aren’t honest can lead to resistance of information or rules, so it is important to bring up your concerns and the reasons why you are concerned with the individual/official responsible. Please consider getting vaccinated against COVID–19 or at least being respectful of other peoples’ health needs.
Notes from SSAN Employment Panel

By Rebecca Donabed, Sequoia Regional SSAN Representative

During the September SSAN meeting, the Employment Workgroup organized a panel of people with disabilities to talk about their different jobs. Having a job or being employed is important since jobs are a tool to gain independence. It is important for people with disabilities to show other people with disabilities that it is possible to be independent and have a job and of course, working allows you to earn money to buy things.

During the workgroup meetings leading up to the September meeting, members of the workgroup talked about the types of questions that should be asked and the types of jobs that we wanted to include on the panel. We ended up including a regional center staff, a retail worker, a university worker, a state worker and an independent living center worker. Once the workgroup decided on the types of jobs to highlight, we went to work looking through our contacts to figure out who would be available to be a part of this panel.

These are the questions that were asked:

- What is your job?
- How did you find your job?
- Do you work on your own or with help (job coach/assistant)?
- What are some tasks/responsibilities of your job?
- What is your favorite part of job?

Advice from panelists:

- Not give up in looking for a job
- Use job sites like Indeed to look for open jobs
- Volunteering
- Don’t be afraid to get help from a job coach

Members of the panel mentioned the following resources to help people with disabilities find a job:

- DOR
- LEAP

If you are interested in getting involved or attending a workgroup meeting, we meet over Zoom on the 3rd Friday of the month at 12:00 P.M. Please email Riana.Hardin@scdd.ca.gov if you are interested in attending the next Employment Workgroup meeting.
Being Active in the Community as a Self-Advocate

By Ellen Sweigert, North Bay Regional SSAN Representative

As a Self-Advocate that has the passion to represent people with disabilities, it’s really important for us to become active in our communities. We all have our own ways of becoming active in our communities. There are 10 steps of being an effective Self-Advocate:

1. Believe in yourself
2. Know your rights
3. Decide what you want
4. Get the facts
5. Planning strategy
6. Gather support
7. Target efforts
8. Express yourself clearly
9. Assert yourself clearly
10. Be firm and persistent

I have always had the drive to believe in myself being a self-advocate from the disability community of Monterey and Pacific Grove. When I moved up to Napa, I worked to get to know about the disability community here in Napa. By working to get to know about the disability community in Napa, I also learned about my rights. I attended a lot of trainings and presentations through the North Bay Regional Office of SCDD. I decided I wanted to get more involved with them as they had connections and facts of the local disability community. By connecting with the North Bay Regional Office of SCDD, I was able to build a community where I could be an active member. After I created the foundation of my disability community in Napa, I started to create strategies as a self-advocate.

(Continue on Page 6: “Being Active”)

SSAN Members

- Nathaniel Florez – North Coast
- Vacant – 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
- Daniel Fouste – San Bernardino
- Paul Mansell – San Diego Imperial
- Desiree Boykin – ARCA
- Russell Rawlings – 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
- Vacant – SCDD
Building relationships within disability networks is key to any successful community and advocacy effort. Building relationships with other advocates and advocacy groups allows you to collaborate, share resources, and support each other as you focus your energy on a common goal or target together, this collaboration leads to becoming active in the disability community. I often think about how effective I can become as a self-advocate.

Through my volunteer work at the Napa Historical Society, I have met somebody who was on the Napa city council. Because I was able to express my thoughts clearly, the Napa city councilmember was willing to listen to me and suggest that I should go meet Tiffany Carranza, who is the city clerk in the city of Napa. So I took responsibility, went down to meet her there and I asserted myself clearly. Now, I am becoming an effective self-advocate with the disability community of Napa and getting myself active with the city of Napa. This experience has taught me a lot and I continue to maintain a good working relationship with the Napa city clerk and ensuring that the disability community is represented within our community of Napa.
Emergencies in California

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

Emergencies can occur anywhere in California. Emergencies are earthquakes, fires, floods, pandemics, landslides, drought, volcanoes, extreme heat, severe storms, extreme cold and winter storms, tornadoes, tsunamis, power outages, avalanches, shootings, violent crime, car accidents, and medical; those are the emergencies that are most common. We can’t prevent emergencies, but we can prepare for emergencies. You can take CERT classes, learn First Aid and CPR. Unfortunately, first responders can’t be everywhere. If you listen to the news and what people are advising, it could help you. You should also role play about possible emergencies. Learn how to prepare with your family, friends, co-workers, etc. You can save a life by knowing what to do in an emergency. Buy First Aid kits and/or Go Bags with food and water and place them in an area easy to get to. Learn to how evacuate an area because it will be important in an emergency. People with disabilities can survive an emergency. Know how to contact the Fire Department, paramedics, Animal Control, and Law Enforcement.

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 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
Sacramento United People’s First Self-Determination Presentation

By Robert Levy, UC Davis MIND Institute UCEDD SSAN Representative

On Wednesday September 8, 2021, the Sacramento United People First chapter meeting had a presentation on the Self-Determination Program (SDP). Staff members from Progressive Employment Concepts/Community Employment Services and Supported Life Institute shared how the program works, and how to get enrolled in SDP. Both presenters talked about how to budget your money account in the SDP, how to figure out the staff members that you want to hire and much more.

The first step to SDP is to contact your service Coordinator at your Regional Center. The next step is to go through an orientation, followed by finding your own financial management service. Then you will have to think about hiring your own staff. Once you have hired your staff, you will work to set up your goals. The presenter from the Supported Life Institute shared how SDP has helped him out in different ways in both his job and gaining independent living skills.

I was one of the self-advocates who helped to get this Self-Determination signed into law in 2013 by Former Governor Jerry Brown. I am excited that finally in 2021, thanks to current Governor Gavin Newsom, all regional center clients have the option of deciding to participate in Self-Determination.

Before SDP started, people with disabilities weren’t able to set their own goals to work on in their daily lives. With the SDP this is another new tool to help people with disabilities to have a productive life with their employment and their independent living skills.

I thought that this presentation by staff of PEC/CES and Supported Life Institute was great and gave us information to pass on to the community.

Before the Self-Determination Program became law in California, self-advocates had limited amount of freedom and choice in their services. Now people who receive regional center services can use this new tool to help them out to build their future goals. Self-Determination can help people with disabilities improve their employment and their independent living skills to build a brighter future for themselves.
Coordinated Future Planning Task Force

By Lisa Cooley, Sacramento Regional SSAN Representative

The Association of Regional Center Agencies (ARCA) recently started a new initiative (collaborative project) and is encouraging regional centers across California to participate. I was asked to participate in Alta Regional Center’s Coordinated Future Planning Task Force that is made up of Alta California regional center staff, service providers, family members and clients. The purpose of the task force is to help create training materials to help our service coordinators discuss caregiver succession planning with families and aging adult clients.

Our meetings have recently started focusing on the creation of learning objectives for our service coordinators to help them understand coordinated future planning because it will be helpful for them when they are doing caregiver succession planning.

To learn more about Alta’s Task Force visit the Coordinated Future Planning page on Alta California’s website. To learn more, check out Alta California’s Coordinated Future Planning PowerPoint. Talk to your regional center to learn more about their participation in this initiative and find out how you can get involved.

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.
Kudos Corner
By Kecia Weller

Regina Woodliff has many Self-Advocacy accomplishments. Regina is on the SCDD Bay Area Regional Advisory Committee, Treasurer for the Bay Area People First Chapter, and she’s a Co-Founding Member of California Statewide Self-Advocacy Network. Regina likes helping others learn emergency preparedness and preventing Sexual Harassment in middle and high schools with her facilitator, Ron Usac. Regina has a very open mind with all types of things that she learns about and teaches other Self-Advocates about. Regina wants young adults to become involved with SSAN as young adult leaders.

When Kecia Weller and Regina first met at a Self-Advocacy meeting in 2007, Regina was very shy and didn’t talk much at the Self-Advocacy meetings. After Kecia mentored Regina for a little bit, Regina found her “self-advocacy voice”. Regina ended up being a member-at-large and the Treasurer of the Self-Advocacy Board of Directors. Regina is so much of an inspiration to Kecia and other people. “I really admire Regina because she’s the voice for other people with disabilities who can’t share their own voices in public forums” said Regina’s long-time mentor, Kecia. Kudos to Regina for her long record of advocating for other people with disabilities!

Community Resources
- SARTAC Advisory Committee Application
- ARCA Regional Center COVID-19 Resources
- COVID–19 Stimulus Checks Won’t Affect Your Benefits
- UC Davis 2021 Neurodiversity Summit
- DRC NDEAM Videos
- DRC’s Build Back Better Resources
- UC Davis 2021 Summer Institute Youtube Playlist
- SSA Ticket to Work Tips to Open Your ABLE Account
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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DECEMBER 9, 2021
SSAN MEETING AGENDA ITEM 6
ACTION ITEM

Statewide Self-Advocacy Network

Approval of 2020–2021 SSAN Annual Report Newsletter

The SCDD Self–Advocacy Coordinator and SSAN Officers will present SSAN members with the 2020–2021 SSAN Annual Report that summarizes SSAN Activity for the past year.

Handout

- DRAFT 2020–2021 SSAN Annual Report

Recommended Action

Approve the DRAFT 2020–2021 SSAN Annual Report
Statewide Self-Advocacy Network

Planning for March 2022

The SSAN Chair will lead the group in a discussion about ideas for the March 2022 meeting and members will have the opportunity to complete meeting evaluations for the September 2021 meeting.