STATEWIDE SELF ADVOCACY NETWORK MEETING INFORMATION

DATE: Wednesday, June 9, 2021 and Thursday, June 10, 2021
TIME: Wednesday, June 9, 2021 10:00 AM – 4:00 PM
Thursday, June 10, 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 EXECUTIVE ORDER N-29-20, teleconferencing restrictions are waived during the COVID-19 pandemic. 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: 948 7123 5577
MEETING PASSWORD: 8703085

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

OR

JOIN BY TELECONFERENCE: (VOICE ONLY)
CALL IN NUMBER: (888) 475-4499
MEETING ID: 948 7123 5577
MEETING PASSWORD: 8703085

Accessibility

Pursuant to Government Code Sections 11123.1 and 11125(f) and Executive Order N-29-20 (This Executive Order can be found by clicking the link on page one of the agenda, or by typing https://www.gov.ca.gov/wp-content/uploads/2020/03/3.17.20-N-29-20-EO.pdf into your web browser), individuals with disabilities who require accessible alternative formats of the agenda and related meeting materials and/or auxiliary aids/services to participate in this meeting should contact Riana Hardin at (916) 263-8196 or Riana.Hardin@scdd.ca.gov. Please provide at least 3 business days prior to the meeting to allow adequate time to respond to all requests.

All times indicated and the order of business are approximate and subject to change.
1. **Call to Order, Welcome, and Introductions**
   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 of Agenda**
   Presented by: Desiree Boykin, Chairperson
   *Information*

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

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

6. **Social Justice Conversation**
   Presented by: SSAN Officers
   *Discussion*

7. **SCDD Update**
   Presented by: Aaron Carruthers, SCDD Executive Director
   *Information*

**Break**
8. SCDD DAC Project
   Presented by: Sarah May, SCDD DAC Chair

9. SSAN Workgroups
   Presented by: ALL
   Discussion

10. Self—Determination Rollout Update
    Presented by: Statewide Self-Determination Advisory Committee (SSDAC) Co-Chairs: SCDD Council member Maria Marquez, and Rick Wood
    Information

11. Member Reports
    Presented by: ALL
    Information

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

2. **Review of Agenda**  
   Presented by: Desiree Boykin, Vice-Chairperson  
   Information

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

4. **Hopes and Dreams Conversation**  
   Presented by: SSAN Officers  
   Information

5. **Vaccine Hesitancy Discussion**  
   Presented by: Project SAFE  
   Information

   Break

6. **Approval of June 2021 SSAN Newsletter**  
   Presented by: Robert Levy, Newsletter Workgroup Chair  
   ACTION

7. **SCDD 2021 Legislative Update**  
   Presented by: Bridget Kolakosky, SCDD Deputy Director of Policy and Public Affairs  
   Information

8. **Planning for September 2021 Meeting**  
   ALL  
   Discussion

9. **Adjournment**
JUNE 9, 2021

SSAN MEETING AGENDA ITEM 4
ACTION ITEM

Statewide Self-Advocacy Network

APPROVAL OF MARCH 2021 MINUTES

Attachments

March 2021 Minutes

Recommended Action

Approve the March 2021 SSAN Meeting Minutes.
SCDD Regional Members Present
Teresa Moshier — North State
Lisa Cooley — Sacramento
Robert Balderama — North Valley Hills
David Forderer — Central Coast
Rebecca Donabed — Sequoia
Julie Gaona — Los Angeles
Daniel Fouste — San Bernardino
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
Scott Barron — DRC
Nicole Patterson — DDS

Members Not Present
Nathan Florez — North Coast
Regina Woodliff — Bay Area
Sean Sullivan — Orange County
Desiree Boykin — ARCA
Russell Rawlings — CFILC

SCDD Staff in Attendance
Rihana Ahmad — SCDD HQ
Aaron Carruthers — SCDD HQ
Riana Hardin — SCDD HQ
Dena Hernández —
SCDD North Valley Hills
Lisa Hooks — SCDD North Bay
Beth Hurn — SCDD HQ
George Lewis —
SCDD North Valley Hills
Sarah May — SCDD North State
Tania Morawiec — SCDD HQ
Mary Agnes Nolan —
SCDD North State
Sarah Wasiak — SCDD HQ
Tobias Weare — SCDD North Bay

Non-SCDD Facilitators
Jana Chapman—Plon
Wayne Glusker

Presenters
Julia Lowe — DDS
Maricris Acon — DDS

Others Present
Maria Cafirma
Ryan Duncan Wood
Alicia Garispe
Alissa Norman
SSAN Minutes

1. Call to Order, Welcome and Introductions

   In the absence of the SSAN Chair, SSAN Vice-Chairperson Paul Mansell, San Diego Regional Representative, called the meeting to order at 10:05 AM.

   SSAN Vice-Chairperson Paul Mansell requested that Riana Hardin, SCDD Self—Advocacy Coordinator assist in the attendance roll call. Members introduced themselves and the region or agency that they represented.

2. Public Comment

   There was no public comment.

3. Review of Agenda

   SSAN Vice-Chairperson Paul Mansell reviewed the agenda for the day with the members.

4. Review and Approval of Minutes December 10 & 11, 2020

   The members reviewed the minutes from December 8 & 10, 2020 Meeting. Materials for this agenda item can be found on pages 7–16 of the March 2021 SSAN Meeting Packet.

   **ACTION:** Motion #1 to approve the December 2020 minutes was made by Lisa Cooley/ Seconded by Julie Gaona. A roll call vote was taken. Motion passed. See vote log on page 8.

5. Updates from SSAN Chair

   SSAN Vice-Chairperson Paul Mansell informed members that SSAN Chair Desiree Boykin was unable to attend the March 2021 meeting, and that he would be facilitating the meeting in her absence.

6. Developmental Disabilities Awareness Month Conversation

   SSAN Vice-Chairperson lead members in a discussion about March being recognized as Developmental Disabilities Awareness Month. Members talked about the different types of developmental disabilities and why it is important to raise awareness about intellectual and developmental disabilities. Materials for this agenda item can be found on pages 19—22 of the March 2021 SSAN Packet.
7. SCDD Update

SCDD Executive Director Aaron Carruthers provided SSAN members with an update on SCDD activity since the December SSAN meeting. This focused on the agency’s efforts to advocate for people with I/DD to be considered a vaccine priority. Starting March 15th people with disabilities and certain health conditions will be eligible to receive the vaccine. DDS and other agencies are developing guidance on how to notify clients about their eligibility, including the documentation needed to verify eligibility.

Members shared their experiences with COVID—19 vaccines and the different places you can go to get vaccinated. SCDD Executive Director Carruthers talked about putting together a media campaign about the vaccines and asked if any SSAN members would be interested in sharing their experiences as a part of the campaign.

Members asked for clarification on if the COVID—19 Vaccine would be mandatory. Right now, the focus is on educating the public about vaccine eligibility and availability. There are still a lot of unknowns about how to show proof of vaccination.

Materials for this agenda item can be found on pages 23—28 of the March 2021 SSAN Packet.

8. Emergency Preparedness Training

Scott Barron, Disability Rights California (DRC) Peer Advocate and DRC SSAN Representative, along with Julie Ebi-McKenzie, SCDD Manager—North Coast Regional Office provided SSAN Members with a training on how to prepare for different types of emergencies.

This training covered different types of emergencies, how to plan for emergencies and what to do when you are in an emergency. This training incorporated materials from the Department of Developmental Services (DDS) and Prep It Forward.

Members shared their personal experiences responding to different types of emergencies.
9. SSAN Workgroups

The SSAN Workgroups met using Zoom Breakout Rooms to talk about current projects 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 31—36 of the March 2021 SSAN Packet.

10. Youth Survey

Members of the SSAN Youth Workgroup presented SSAN with the DRAFT SSAN Youth Survey the workgroup created in an effort to get feedback from youth with disabilities on their experiences with self-advocacy, their interests, and how to get youth more involved in self-advocacy activities.

Nicole Patterson, DDS SSAN Representative and Chair of the SSAN Youth Workgroup, reviewed the questions included in the survey with SSAN members. The following suggested changes were made:

Under question 6 about current living arrangements, members would like to add “partner/significant other/married” in between roommates and in apartment/home.

Materials for this agenda item can be found on pages 37—40 of the March 2021 SSAN Packet.

**ACTION:** Motion #2 to approve SSAN DRAFT Youth Survey with suggested changes, was made by Kecia Weller/ seconded by Wesley Witherspoon. A roll call vote was taken. Motion passed. See the vote log on page 8.
11. **Member Reports**

SSAN Members reported on their self-advocacy related activities since the December 2020 SSAN meeting.

Members talked about a wide range of concerns including: the harassment that people with disabilities are experiencing on public transportation, DDS is looking for new members to participate in their stakeholder groups, ongoing anxiety due to COVID—19, the need for increased awareness about mental health concerns, and the importance of employment for people with I/DD.

Several members reported collaborating with their local SCDD office on projects related to emergency preparedness.

Materials for this agenda item can be found on pages 41—46 of the March 2021 SSAN Packet.

12. **Recess Until Next Day**

SSAN Vice-Chair Paul Mansell declared the meeting in recess at 3:52 PM. The March 2021 SSAN meeting will return from Recess at 10:00 AM Thursday, March 11th, 2021.
SSAN DAY 2 Minutes

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

SSAN Vice-Chairperson, Paul Mansell, San Diego Regional Representative, called the meeting to order at 10:03 A.M. SSAN Secretary, Robert Levy, UC Davis MIND Institute UCEDD Representative, did an attendance roll call for members present.

2. Review of Agenda

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

3. Public Comment

There was no Public Comment.

4. Self-Determination Update: Paul Mansell

SSAN Vice-Chair Paul Mansell provided SSAN members with an overview of his experience with the Self-Determination process. This agenda item included information on the orientation process, figuring out service needs, the process for developing a budget, and writing/implementing and updating a Person-Centered Plan.

SSAN members were given the opportunity to ask questions at the end of the presentation.

5. Conflict Resolution Training

Tania Mowawiec, SCDD Deputy Director—Regional Office Operations and Yolanda Cruz, SCDD Regional Office Manager—Sequoia Office, provided SSAN members with an introductory training on conflict resolution. This training covered the following information: what is conflict, what conflict feels like, what conflict does to our bodies, different styles of managing conflict and steps to conflict resolution.

Members expressed an interest in having additional trainings related to conflict resolution.
6. Approval of the March 2021 SSAN Newsletter

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

**ACTION:** Motion #3 to approve the December 2020 minutes was made by Lisa Cooley/ Seconded by Julie Gaona. A roll call vote was taken. Motion passed. See vote log on page 7.

7. SCDD 2021 Legislative Update

Bridget Kolakosky, SCDD Deputy Director of Policy and Public Affairs provided SSAN Members with an SCDD Legislative Update. This presentation covered: SCDD priorities for the 2021 California State Legislative Cycle, as well as a preliminary list of bills that the Legislative and Public Policy Committee (LPPC) recommended the Council take a position on.

For more Information relating to bills under consideration by LPPC, visit the [SCDD Legislative and Public Policy Committee Page](#). The LPPC Presentation from the meeting will be posted on the SSAN Page.

8. Planning for June 2021 Meeting

SSAN members brainstormed topics/presentations for the June 2021 meeting. Presentation topics mentioned included:

- Ticket to Work Panel
- Self-Determination Panel/Update
- Harassment Presentation
- How to Prep for Brush Fires
- Follow-up Conflict Resolution Training
- Mental Health During the Pandemic
- Disability Pride Presentation with YO! Disabled and Proud

9. Adjournment

Meeting was adjourned at 2:00 P.M. The next SSAN meeting will be on June 9th and 10th 2021 using Zoom.
# MARCH 2021 SSAN VOTE TALLY

<table>
<thead>
<tr>
<th>Name</th>
<th>Region</th>
<th>Roll Call</th>
<th>Motion 1</th>
<th>Motion 2</th>
<th>Day 2 Roll Call</th>
<th>Motion 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Matthew Lagrand</td>
<td>SCDD</td>
<td>Present</td>
<td>For</td>
<td>For</td>
<td>Present</td>
<td>For</td>
</tr>
<tr>
<td>Nathaniel Florez</td>
<td>North Coast</td>
<td>Not Present</td>
<td>Not Present</td>
<td>Not Present</td>
<td>Not Present</td>
<td>Not Present</td>
</tr>
<tr>
<td>Teresa Moshier</td>
<td>North State</td>
<td>Present</td>
<td>For</td>
<td>For</td>
<td>Present</td>
<td>For</td>
</tr>
<tr>
<td>Lisa Cooley</td>
<td>Sacramento</td>
<td>Present</td>
<td>For</td>
<td>Did Not Participate</td>
<td>Present</td>
<td>For</td>
</tr>
<tr>
<td>Ellen Sweigert</td>
<td>North Bay</td>
<td>Present</td>
<td>For</td>
<td>For</td>
<td>Present</td>
<td>For</td>
</tr>
<tr>
<td>Regina Woodliff</td>
<td>Bay Area</td>
<td>Not Present</td>
<td>Not Present</td>
<td>Not Present</td>
<td>Not Present</td>
<td>Not Present</td>
</tr>
<tr>
<td>Robert Balderama</td>
<td>North Valley</td>
<td>Present</td>
<td>For</td>
<td>For</td>
<td>Present</td>
<td>For</td>
</tr>
<tr>
<td>David Forderer</td>
<td>Central Coast</td>
<td>Present</td>
<td>Did Not Participate</td>
<td>For</td>
<td>Present</td>
<td>For</td>
</tr>
<tr>
<td>Rebecca Donabed</td>
<td>Sequoia</td>
<td>Present</td>
<td>Did Not Participate</td>
<td>Abstain</td>
<td>Present</td>
<td>For</td>
</tr>
<tr>
<td>Julie Gaona</td>
<td>Los Angeles</td>
<td>Present</td>
<td>For</td>
<td>For</td>
<td>Present</td>
<td>For</td>
</tr>
<tr>
<td>Sean Sullivan</td>
<td>Orange County</td>
<td>Not Present</td>
<td>Not Present</td>
<td>Not Present</td>
<td>Present</td>
<td>Not Present</td>
</tr>
<tr>
<td>Daniel Fouste</td>
<td>San Bernardino</td>
<td>Not Present</td>
<td>Not Present</td>
<td>Not Present</td>
<td>Present</td>
<td>For</td>
</tr>
<tr>
<td>Paul Mansell</td>
<td>San Diego</td>
<td>Present</td>
<td>For</td>
<td>For</td>
<td>Present</td>
<td>For</td>
</tr>
<tr>
<td>Desiree Boykin</td>
<td>ARCA</td>
<td>Not Present</td>
<td>Not Present</td>
<td>Not Present</td>
<td>Not Present</td>
<td>Not Present</td>
</tr>
<tr>
<td>Russell Rawlings</td>
<td>CFILC</td>
<td>Not Present</td>
<td>Not Present</td>
<td>Not Present</td>
<td>Present</td>
<td>For</td>
</tr>
<tr>
<td>Nicole Patterson</td>
<td>DDS</td>
<td>Present</td>
<td>For</td>
<td>For</td>
<td>Present</td>
<td>For</td>
</tr>
<tr>
<td>Scott Barron</td>
<td>DRC</td>
<td>Present</td>
<td>For</td>
<td>For</td>
<td>Present</td>
<td>For</td>
</tr>
<tr>
<td>Wesley Witherspoon</td>
<td>USC – CHLA</td>
<td>Present</td>
<td>For</td>
<td>For</td>
<td>Present</td>
<td>For</td>
</tr>
<tr>
<td>Kecia Weller</td>
<td>Trajan Center</td>
<td>Present</td>
<td>For</td>
<td>For</td>
<td>Present</td>
<td>For</td>
</tr>
<tr>
<td>Robert Levy</td>
<td>Mind Institute</td>
<td>Present</td>
<td>For</td>
<td>For</td>
<td>Present</td>
<td>For</td>
</tr>
</tbody>
</table>
The SSAN Chair will provide a verbal update to SSAN members.
SOCIAL JUSTICE DISCUSSION

The rise in hate crimes against minority groups, along with ongoing civil unrest from interactions between law enforcement and black, Indigenous and people of color (BIPOC) and/or people with disabilities, has left many feeling uneasy. The SSAN Officers would like to provide a safe space for SSAN members to talk about social justice issues and current events. The SSAN Officers will lead members in a conversation about issues and events happening in their communities, the state, and at the national level that have impacted them.

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.
THIS PAGE IS INTENTIONALLY BLANK
Since the March 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.

**Attachments**

- March 2021 Council Meeting Summary

**Handout**

- May 2021 Council Meeting Summary
March 23, 2021
State Council Meeting Summary

SIGNIFICANT ITEMS

• On March 23rd, 2021, the State Council on Developmental Disabilities (SCDD) held its second Council meeting of the year. The meeting’s focus included a discussion of the SCDD 2021 Legislative bill package and a review of the current status of COVID-19 vaccine eligibility for people with developmental and other disabilities in the state of California.

• This month’s Member Spotlight series recognized Councilmember Julie Neward. Julie is a Family Advocate who shared the story of her sister Natalie and emphasized the importance of raising awareness of sexual abuse of people with disabilities in care homes. For more details, check out SCDD’s “About The Councilmembers” web page and Julie’s action organization, the California Sibling Leadership Network.

• Councilmembers heard reports from Executive Director Aaron Carruthers and Council Chair Wesley Witherspoon. Chair Witherspoon highlighted March as Developmental Disabilities Awareness Month and reminded the Council that as of March 15th, the I/DD community now has priority access to the COVID-19 vaccine. Executive Director Carruthers noted that this is largely due to advocacy efforts that the Council and the I/DD community have been participating in over the last few months. Carruthers’ report also included a question and answer discussion with the latest vaccine updates, underscoring the theme of Eligibility versus Availability.

• LPPC Chair Julie Austin and Deputy Director of Policy and Public Affairs Bridget Kolakosky presented the 2021 Legislative bill package for Council approval. Members discussed the merits and flaws of the bills presented and determined that there were four bills to request amendments to. The Council approved a partial bill package and voted separately to support the following bills if amended: AB 126, AB 971, AB 610 and AB 313. For more detailed information, a complete description of these bills is available in the hyperlinks above.

• Executive Director Aaron Carruthers presented the draft 2021-2022 SCDD budget. More information about the finalized budget will be available at the May 2021 Council meeting and Councilmembers will take a vote on whether to approve it for fiscal year 2021-2022.

SUMMARY OF COUNCIL ACTIONS

The Council:

• Approved the January 2021 Council meeting minutes
• Approved the 2021 Legislative Package with conditions to support several bills if amended

FUTURE MEETING DATE

• The next Council meeting will be held on May 25th, 2021.
Statewide Self-Advocacy Network

SCDD DAC Project

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.

SCDD DAC Chair, Sarah May, Manager—North State Regional Office, would like to talk to SSAN about collaborating on video project SCDD DAC is working on. The project is to create a series of training videos about best practices for interacting with people with all types of disabilities in a work environment.
SSAN WORKGROUPS

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

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

Attachments

- SSAN Workgroup Descriptions
THIS PAGE IS INTENTIONALLY BLANK
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 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 continue to 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 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.
SELF-DETERMINATION ROLLOUT UPDATE

In October of 2013, Governor Jerry Brown signed a law that created the Self-Determination Program in California. Self-Determination is built on the principals of freedom, authority, support, responsibility and confirmation and is meant to give Regional Center clients more choices in the types of services they receive.

In October of 2018, 2,500 Regional Center clients were chosen to participate in the soft roll-out of California’s Self-Determination Program, with the understanding that Self-Determination would be available as a choice for all Regional Center clients in 3 years.

SSAN members will get a chance to hear from the Co-Chairs of the Statewide Self-Determination Advisory Committee (SSDAC) Maria Marquez and Rick Wood about how preparation for the statewide roll-out of Self-Determination is going and how SSAN can help to educate their communities about the Self-Determination Program in California.
THIS PAGE IS INTENTIONALLY BLANK
SSAN MEETING AGENDA ITEM 11
INFORMATION ITEM

Statewide Self-Advocacy Network

**MEMBER ACTION REPORTS**

Members will have the opportunity to update SSAN on their activities related to SSAN and self-advocacy

*Attachments*

- 2021 SSAN Member Action Report
- 2021 How to fill-out SSAN Member Action Report
NEW MEMBER REPORT

Explanation

The new report format is attached. This new form will help SCDD staff to put the annual SSAN report together.

How to complete the form:
1) Write your name on the line, put the month and year of the report on the lines.
2) The Key at the top of the page explains what SA, FA and O means when reporting how many people were there. If you ATTENDED a meeting, conference or training event fill out each box as best you can.
3) Write your name on the line, put the month and year of the report on the lines.

<table>
<thead>
<tr>
<th>DATE</th>
<th>CHOICES CONFERENCE HELD</th>
<th>WHERE IT WAS HELD</th>
<th>TITLE OR TOPIC OF MEETING</th>
<th>How many FA</th>
<th>How many SA</th>
<th>How many Others</th>
</tr>
</thead>
<tbody>
<tr>
<td>4/6</td>
<td>Stockton</td>
<td></td>
<td></td>
<td>0-30</td>
<td>0-10</td>
<td>0-460</td>
</tr>
</tbody>
</table>

Example:

DATE

4/6

Title or Topic of Meeting

CHOICES CONFERENCE HELD

WHERE IT WAS HELD

How many FA

How many SA

How many Others

SA - 460

FA - 10

0-30

0-10

0-460

Example:

If you ATTENDED a meeting, conference or training event fill out each box as best you can.

3) Write your name on the line, put the month and year of the report on the lines.

1) Write your name on the line, put the month and year of the report on the lines.

2) The Key at the top of the page explains what SA, FA and O means when reporting how many people were there.
4) If you **PRESENTED** (or spoke) at a Meeting, Conference or Training event - fill out each box as best you can.

<table>
<thead>
<tr>
<th>DATE</th>
<th>Title or Topic of Meeting, Conference or Event</th>
<th>WHERE it was held</th>
<th>How many SA</th>
<th>How many FA</th>
<th>How many Others</th>
</tr>
</thead>
<tbody>
<tr>
<td>5/4</td>
<td>SCDD North Valley Hills RAC mtg</td>
<td>Modesto</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

5/4 | SCDD North Valley Hills RAC mtg | Modesto |             |             |                |

5) **TALKED** to Self Advocates about SSAN, Self Advocacy or other topic - fill out each box as best you can.

<table>
<thead>
<tr>
<th>DATE</th>
<th>Title or Topic of Resource</th>
<th>Internet Link/address</th>
<th>Will bring a copy of Resource</th>
<th>CHOLS Conference Registration Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>6/1</td>
<td>Employment: How to get a job</td>
<td>They wanted to know how to start</td>
<td>In person</td>
<td>3</td>
</tr>
</tbody>
</table>

6) **RESOURCES** you would like to share with SSAN - fill out each box as best you can.

<table>
<thead>
<tr>
<th>DATE</th>
<th>Title or Topic of Resource</th>
<th>Internet Link/address</th>
<th>Will bring a copy of Resource</th>
<th>CHOICES Conference Registration Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>6/1</td>
<td>Employment: How to get a job</td>
<td>They wanted to know how to start</td>
<td>In person</td>
<td>3</td>
</tr>
</tbody>
</table>

7) Anything else you would like to REPORT or any questions or Training ideas you would like to share with SSAN?

**EXAMPLE:** I received a Self Advocacy Leadership Award for my advocacy work!

I would like to see SSAN have its own conference, maybe move to different parts of the state each year.

**EXAMPLE:**

<table>
<thead>
<tr>
<th>DATE</th>
<th>Title or Topic of Resource</th>
<th>Internet Link/address</th>
<th>Will bring a copy of Resource</th>
<th>CHOICES Conference Registration Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>6/1</td>
<td>Employment: How to get a job</td>
<td>They wanted to know how to start</td>
<td>In person</td>
<td>3</td>
</tr>
</tbody>
</table>

**EXAMPLE:**

<table>
<thead>
<tr>
<th>DATE</th>
<th>Title or Topic of Resource</th>
<th>Internet Link/address</th>
<th>Will bring a copy of Resource</th>
<th>CHOICES Conference Registration Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>6/1</td>
<td>Employment: How to get a job</td>
<td>They wanted to know how to start</td>
<td>In person</td>
<td>3</td>
</tr>
</tbody>
</table>
MEMBER REPORT

Tell us if you...

Presented (or spoke) at a meeting, conference or training event in your role as a SSAN member:

<table>
<thead>
<tr>
<th>Date</th>
<th>Title or Topic of Meeting, Conference or Training Event and How it Relates to SSAN Goals</th>
<th>Where it was held</th>
<th>How many SA</th>
<th>How many FA</th>
<th>How many Others</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Date</th>
<th>Title or Topic of Meeting, Conference or Training Event and How it Relates to SSAN Goals</th>
<th>Where it was held</th>
<th>How many SA</th>
<th>How many FA</th>
<th>How many Others</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Prepared (or spoke) at a meeting, conference or training event in your role as a SSAN member:

Name:

Year: ___________________________  Month: ___________________________

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 you would like to share with SSAN

<table>
<thead>
<tr>
<th>Title or Topic of Resource</th>
<th>Internet Link/Address</th>
<th>Will bring a copy of resource</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Anything else you would like to share with SSAN?

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

Is there anything that your local self-advocacy group would like SSAN to work on?
JUNE 10, 2021

SSAN DAY 2 AGENDA ITEM 4
INFORMATION ITEM

Statewide Self-Advocacy Network

HOPES AND DREAMS CONVERSATION

The SSAN Officers will lead members in an open discussion about their hopes and dreams for the future. The SSAN Officers encourage members to share their hopes and dreams for themselves as a SSAN member, for their communities, and the future of SSAN.

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.
SSAN DAY 2 AGENDA ITEM 5
INFORMATION ITEM
Statewide Self-Advocacy Network
VACCINE HESITANCY DISCUSSION

Self-Advocates for Emergency Education, or Project SAFE is a group of self-advocates from different parts of California who are interested in educating other self-advocates about emergency response through peer advocacy.

Project SAFE will be joining the June SSAN meeting to provide members with information about how to address hesitancy from some members of the community in getting the COVID—19 vaccine.

In preparation for this presentation and discussion item, you may want to think about sharing:

- Concerns that you might have about the COVID—19 Vaccines
- Concerns you have heard from advocates in your communities
- Concerns you have heard from outside of your community

The SSAN Officers understand that some may be uncomfortable with this topic and that people may have strong feelings about the COVID—19 vaccines. Participation comes in many forms and the SSAN Officers understand if you choose not to participate in the discussion but ask that you be open and respectful with the presenters and each other.
Robert Levy, Chair of the SSAN Newsletter Workgroup will present SSAN members with a DRAFT version of the June Newsletter and ask members for any changes or additions. Robert will then lead a discussion about ideas for the September Newsletter.

**Attachments**
- DRAFT June 2021 Voices of SSAN Newsletter

**Recommended Action**
Approve the DRAFT June 2021 Voices of SSAN Newsletter
**My Battle with COVID—19**

**By David Forderer,** Central Coast Regional SSAN Representative

I have been watching TV, as many others have, and have been surrounded with coverage of the ongoing COVID—19 virus. Like many other self-advocates, I stayed home for weeks on end, only going out when it was absolutely necessary. I heard many stories of people’s battles with the virus. Most of the stories did not have a happy ending. I certainly thought that if I stayed home and protected myself well when I did go out by wearing both a mask and a face shield: I would be fine. All last year I had no issues at all and then one of my part time caregivers came down with COVID in February of this year.

Upon hearing the news about her infection, I decided to get tested to see if I had become infected. When I first talked with someone after I was tested, I was told that my test was negative, but they wanted me to check back with them in a few days to see if I had developed a “late stage forming case”. Well as life would have it, 4 days later when I contacted them; I was informed that I was indeed infected.

I was told to immediately go into quarantine, along with my full-time roommate and caregiver Raymond. Thankfully Raymond had recently received his COVID vaccine and he was willing and able to take care of me full-time as my part-time caregivers were asked to quarantine for 2 weeks at their individual homes.

In the early stages, after being notified that I had become infected, I didn’t have any symptoms right away, but within 5 days after being infected I began to lose energy slowly day after day. Less than 10 days later I had almost no energy and all I wanted to do was sleep. I didn’t even have energy to sit up and eat.

*(Continue on Page 2: “COVID—19”)*
(Continued from Page 1: “COVID—19”)

I then developed a very bad cough and could not talk at all without constantly coughing. I then realized I had no appetite either. During the next 2 weeks of my quarantine, I slept constantly while watching television throughout the day and evening. During this time, I lost a total of 14 pounds.

As the days went by, I coughed less and less and slowly began to regain my appetite. Approximately 6-7 weeks later I began to feel as though I was returning to normal. As each day passed, I felt better and stronger as well. Finally, 10 weeks after being infected I back to my old self eating 3 meals a day feeling normal.

I felt very blessed that I had a mild case of the virus as I know so many others who had horrible issues with the virus and still have lingering health issues months later.

**COVID—19 Vaccination Resources**

<table>
<thead>
<tr>
<th>Statewide</th>
<th>Doses Administered by County of Residence</th>
</tr>
</thead>
<tbody>
<tr>
<td>16,833,703 (49.0%) People fully vaccinated</td>
<td>Los Angeles: 8,154,000</td>
</tr>
<tr>
<td>4,648,478 (13.2%) People partially vaccinated</td>
<td>San Diego: 3,280,620</td>
</tr>
<tr>
<td>36,265,229 (80.4%) Doses administered</td>
<td>Orange: 3,040,779</td>
</tr>
<tr>
<td>248,638 Average doses per day</td>
<td>Santa Clara: 2,45,216</td>
</tr>
<tr>
<td>7,370,929 Doses on hand</td>
<td>Alameda: 1,356,178</td>
</tr>
<tr>
<td>(30 days of inventory)</td>
<td>Riverside: 1,711,316</td>
</tr>
<tr>
<td>45,119,680 Doses Delivered</td>
<td>San Bernardino: 1,466,765</td>
</tr>
<tr>
<td>10,651,850 CDC Pharmacy Doses Delivered</td>
<td>Sacramento: 1,277,602</td>
</tr>
</tbody>
</table>

![Map of California showing the number of vaccinations given in each county](image)

Many of California’s 21 Regional Centers have partnered with local pharmacies and grocery stores to improve vaccine access to regional center clients, some have even organized their own clinics. Consider checking with your regional center for clinics near you.

**Resources**

- SCDD Plain Language Vaccine FAQ
- Association of Regional Center Agencies (ARCA) Regional Center COVID-19 Resources
- My Turn CA is can help you find a vaccine clinic near you
- Vaccine Finder helps you find a vaccine site across the USA
- Talk to your doctor to figure out which vaccine is best for you
- Need a ride to an appointment? Ride share companies can help
Interview with SCDD Executive Director
Aaron Carruthers

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

Since SSAN is a project of the State Council on Developmental Disabilities (SCDD) I wanted to take the opportunity to ask SCDD Executive Director Aaron Carruthers a few questions and share his answers with you.

Q: What is the Vision for the California State Council?
A: SCDD is an independent, federally funded state agency charged with overseeing the developmental disabilities delivery system. Our vision is to continue to be a guiding force for positive, life-altering changes for people with I/DD and their families. We are the state’s leader in advocacy and in training future advocates. We will keep changing the world together!

Q: Why is the State Council important to California?
A: The State Council is the only entity in law that has the role of being a watchdog over the system. We look at the person, not the program. We fight for how education, public safety, health care, regional centers, housing, jobs, and recreation are all serving people. We look at how the whole system is serving the whole person.

Q: What do you enjoy about your job?
A: I enjoy everyone I get to work with! I enjoy SSAN! I enjoy that we are all a part of this civil rights movement together. We have the great privilege to have positions of influence to make the lives of people better. You and I take that seriously. There are many needs, many challenges, and many opportunities to advocate and make a difference. Let's change the world together!

(Continue on Page 4: “SCDD Interview”)

SSAN Members
- Nathaniel Florez – North Coast
- Teresa Moshier – 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
- Matthew Lagrand – SCDD
Q: What should self-advocates across California know about?

A: This is a time of great change. COVID and the pandemic changed how we live, work, and play. Many are struggling to get what they need to live each day. And, when it is over, how we live may not look like it did before. This is an opportunity for you. What do you want the world to look like tomorrow? How do you want it to be different? And better? Advocates get to dream of a better world and work to make that happen. What do you want to be better in the future?

Q: What is the Future of Self-Advocacy in California?

A: You tell me. What do you want the future to be?

SSAN Turns 9!

By Robert Levy, UC Davis MIND Institute UCEDD Representative

In 2012 the Statewide Self-Advocacy Network (SSAN) was born with the help of the State Council on Developmental Disabilities (SCDD). SSAN is cross-disability training network with 22 self-advocates from across the state of California with intellectual/developmental and other disabilities. SSAN members collaborate with each other to advocate for protecting the rights and services for people with disabilities that allow them to participate in their communities. There have been a lot of changes to SSAN over the last 9 years. In this past year, SSAN has welcomed 3 new members to the team. Members have come and gone, but SSAN continues to educate our communities on issues and programs that impact our lives. With laws and programs like the Cal ABLE Act, Employment First Policy and Self-Determination, people with intellectual and developmental disabilities can have more independence and say in how they live their lives. Despite challenges like wildfires, earthquakes and the ongoing COVID—19 pandemic: SSAN continues to do good work. Over the last year, SSAN members have been advocating for access to COVID—19 vaccines and volunteering in their communities to handout personal protective equipment (PPE) and even participate in vaccine clinics. Hopefully 2022 SSAN will be able to meet in-person again and we will go back to normal.
Self-Determination Offers the Developmental Disability Provider System Unique Benefits and Challenges

By Paul Mansell, San Diego Regional SSAN Representative

For too many people with developmental disabilities, their families, and their advocates they find the Developmental Disabilities (DD) system calcified and unresponsive to meet their unique needs and desires to live meaningful and fulfilling lives in their community. Self-Determination offers an opportunity to empower people with developmental disabilities and their families and tailor services to their needs, hopes, culture, and values.

People with developmental disabilities and their families taking charge of their lives needn’t threaten either the system or the status quo, but rather supplement and augment the DD system. It does represent change, and many find themselves groping in the dark, uncertain on what to do next. They are more comfortable with the ways it has been even with all its imperfections and limitations.

Members in the DD system need to educate themselves on the many facets of Self-Determination. People with developmental disabilities, parents, and advocates are frustrated when their Service Coordinators don’t know what to do—e.g., calculating a certified budget. What is a simple procedure becomes a major roadblock. Regional Centers need to own their responsibility and train their staff in Self-Determination and implement priorities, policies, and procedures that embrace Self-Determination.

Proponents of Self-Determination may have little experience in taking charge of their services and their lives. They may well benefit from support to fully take advantage of the freedoms offered to them through Self-Determination. They are used to the system doing everything for them although they find the system inadequate to meet their needs.

Many, people with developmental disabilities, their families, and service providers, find stepping out into the unknown and untested scary and intimidating. They find differences in opinion frustrating and a cause for enmity. We need to remember; members of the DD community are united in their caring and have a strong desire to support people with developmental disabilities and their families—working together we are a team. Some may have doubts about the efficacy of Self-Determination, but that does not negate their compassion.

Persons with Developmental Disabilities, their families, and their advocates, may find themselves ill prepared for the demands of accountability and responsibility that comes with Self-Determination. They may lack the entrepreneur spirit to take advantage of their new freedoms. (Continue on Page 6: “Self-Determination”)
They may find the role as employer overwhelming and reading the paperwork and reports burdensome. This is when supports from the DD system can be most helpful.

The pre-enrollment steps of the Self-Determination process are needlessly complicated and need to be streamlined. People with Developmental Disabilities, their families, and their advocates would benefit from trained supports to navigate their way through this crucial stage of the Self-Determination process. Getting to know your histories, your wants and needs, your hopes, your goals, and your north star is hard work and should not be discounted. Those unaccustomed with numbers may find the certified budget and spending plan steps bewildering. The role of and funding for the Independent Facilitator needs to be clarified and expanded to include the pre-enrollment steps.

Above all else Self-Determination requires communication, respect, and confidence that the program will work and that people with Developmental Disabilities and their families can succeed with their plans and lead meaningful and satisfying lives in their community.

SSAN Youth Survey

The SSAN Youth Workgroup has created a SSAN Youth Survey to get information about what interests youth with disabilities. The SSAN Youth Workgroup 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.
New Member Spotlight

By Matthew Lagrand, SCDD SSAN Representative

I have been in leadership for a long time, starting in high school. I was co-president of a club in high school called Shasta High School Disability Outreach. When I was co-president, I had to make a lot of important decisions like looking for funding for activities like camping trips and Special Olympics and make sure everyone was doing their jobs.

Sometimes when someone wasn’t doing their job, it was up to me to decide on whether to let that person go or not.

In 2001 I served as a member of Student Council at Taft College. This experience helped me to develop my leadership skills.

2001—2009 I was on the Bakersfield Arc (BARC) Board of Directors, where I represented the Supported Living Services Department.

In 2009—2018, I was on the Kern Regional Center Board of Directors before applying to serve on the State Council on Developmental Disabilities. One of the responsibilities of Regional Center Board of Directors was to evaluate the Executive Director’s performance.

(Continue on Page 8: “New Member”)
The Board of Directors of Regional Centers is also responsible for conducting an interview process for candidates for the position of Regional Center Executive Directors. This is a very important job because an Executive Director is responsible for making sure that a regional center meets the needs of their clients and community. Decisions made by an Executive Director can impact the services that Regional Center clients receive. Regional Center Board of Directors are also responsible for reviewing/approving vendor contracts for the regional center.

As the new SCDD representative to the Statewide Self-Advocacy Network, I hope to help SSAN grow and advocate for people with disabilities to have access to the services and supports that help them live in their communities. I am proud to be living in California, that has so many great opportunities and services for people with disabilities.

One of my hopes is to work to improve communications between SSAN, Council members and SCDD staff. Better communication will help raise awareness of issues happening in the community. I care about Public Safety issues and want to make sure that nobody gets badly injured and is able to live their best lives.

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.
SSAN Employment Webinar: Social Security Benefits

By Rebecca Donabed, Sequoia Regional SSAN Representative

On March 26th, 2021 the SSAN Employment Workgroup hosted a Webinar Training on managing Social Security Benefits when you work or go back to work. The SSAN Employment Workgroup partnered with Work Incentives Planners (WIPs) from the Department of Rehabilitation (DOR) to put together the webinar.

This webinar covered topics such as:

- Why someone receiving benefits should consider working
- What happens to your benefits (like SSI, SSDI, MediCal, MediCare) when you get a job
- Different DOR Services to Help You
- What a DOR Work Incentive Planner is and how they can help you

Other disability related benefits offered through SSA include the Childhood Disability Benefits (CDB) and the Disabled Adult Child (DAC) credit. These are basically two different names for the same benefit. People with disabilities can receive this credit once they turn 18 when their parent is either: 1) disabled, 2) retired, or 3) deceased.

When/If you decide to get a job there are some Work Incentives to think about. The Trial Work Period (TWP) is a 9-month period after you get a job and continue to receive your full SSDI/CDB Checks, no matter how much money you are receiving from your job.

It is important to know that your Medicare coverage will last at least six or seven years when you start working. Remember: if your work hours or situation changes for the worst: your benefits can be adjusted based on your new situation.

If you want to find out more about work incentives planners and how to manage working while receiving benefits: contact your local DOR office in your area. You can also consider opening a CalABLE Account to save the money you earn and not impact your Social Security Benefits! CalABLE Accounts are a good option to help you save money whether you are working or not. Check out CalABLE to learn more about that program.

Be on the lookout for more webinars by the SSAN Employment Workgroup.
Ticket to Work Program Information

By Robert Levy, UC Davis MIND Institute UCEDD SSAN Representative

On Thursday February 18th I attended a panel presentation and training on the Ticket to Work Program offered by the Social Security Administration. The event was hosted by the Sacramento Regional Office of SCDD and took place over Zoom. Pam, from Progressive Employment Concepts (PEC) was the lead presenter, other panelists included two PEC clients with different employment experiences and backgrounds, and the owner of a local dog grooming company called Lucky Penny Dog Groomer, who hired a PEC client.

During her portion of the panel talk training, Pam talked about what customized employment does for people with disabilities: helping clients to have productive lives. The two PEC clients shared their experiences and the owner of Lucky Penny Dog Groomer talked about what it was like hiring a PEC client. Watch the full SCDD Ticket to Work Program Informational Training on YouTube.

Swimming

By Wesley Witherspoon, USC Children’s Hospital UCEDD Representative

It is summertime and many people will head to a pool, river, lake, ocean, or any body of water to escape the heat. It is very important to know how to swim the right way. If you decide to swim, make sure you know how to swim. You need to understand your limits and ability when you swim. Unfortunately, many people who do not know their limits while swimming drown. Many people with Developmental/Intellectual Disabilities have drowned in the water. Make sure that you put on safety items such as floatation device or a life jacket. Be careful if you go to the deep water. You need to be near a lifeguard or someone who can help you if you are in the water. Be careful if you go in the water, others might make waves in the water, if you are not prepared how to deal with the water, you could drown. Also, if you go to the beach, the waves could be high. Stay a distance from the water if you want to lay down or sit somewhere. If you decide to swim, you will enjoy benefits such as exercise, staying cooler, and having fun. Once again, if you decide to go swimming, please be careful.
Interview: Far Northern Regional Center

By Teresa Moshier, North State Regional SSAN Representative

In order to learn more about what Regional Center staff do, I reached out to Larry Withers, the Associate Director of Client Services – South at Far Northern Regional Center. Larry has been working at Far Northern Regional Center (FNRC) since April Fools’ Day 1993, so he knows quite a lot about Regional Center Services.

Where did You Work Before FNRC?
Before I started working for Far Northern, I had many different jobs that all taught me important lessons about the type of job I wanted. My first job out of high school was working at the Redding Taco Bell. This job was a lot of hard work, in a hot environment. By the time I left Redding to attend college, I vowed I would find a more rewarding job with air conditioning.

I moved to Arcata to attend Humboldt State University when I was 20. At the advice of a friend, I applied to work at different day programs and care homes. I was hired to work at HCAR, a work and day program in Eureka. While working at HCAR, I found a second job at Butler Valley, a care home in Arcata that worked with clients with significant disabilities.

My two and a half years at Butler Valley taught me that no matter what you hear from others, always give people a chance because they will surprise you. Many of the consumers we had at that home were considered too disabled to participate in most programs. Yet I found that if you had expectations and patience amazing things could happen. By the time I left that job I was the house manager supervising 10-12 staff while studying full time at Humboldt State.

I left Butler Valley to take a break from college and travel. I went to Europe alone, visiting seven countries and met amazing people. This experience gave me the energy to return to Arcata and complete my degree. When I returned to Arcata, I was hired at a care home for children. We served six boys, most diagnosed with Autism and Downs Syndrome. Of all jobs I ever had, this job was probably the most active and demanding, while also being the most fun job. Everything was new and exciting to the children and the staff was amazing.

I graduated from Humboldt State and then returned to Redding to be near family. While living in Redding, I obtained a part-time job as an ILS instructor for Retirement Housing Foundation (RHF) in Redding. Several months afterward, a Service Coordinator (SC) at FNRC told me that they were leaving their job and encouraged me to apply. I have been with FNRC ever since.

(Continue on Page 12: “Interview: FNRC”)

55
Did you work in the Redding Office as a service coordinator? How did you move to the Chico Office and when?

In 1997, my wife Julie, finished her AA degree from Shasta College and we decided to move to Chico rather than having her commute from Redding. I applied for a transfer to FNRC’s Chico Office and was approved for that in May of ‘97. We moved within a month to Chico and Julie started Chico State that fall. I also planned to obtain my master’s degree at Chico State, so the move was had both educational and employment advantages. Julie and I both finished our master’s degrees while living in Chico.

It was a hard transition, because I had to leave my clients in Redding and all the resources, I knew about to help the clients on my caseload. I had to establish new relationships with vendors, staff, and the community. It can take a while to build those relationships again.

I was promoted four years later to a Case Management Supervisor, supervising 10-15 Service Coordinators a position I held until about four years ago when I accepted the position of Associate Director of Client Services.

What is your favorite part about being an Associate Director of Client Services?

The best part of being an Associate Director is the ability to make changes that improve the lives of our clients and their families on a larger scale. Everyone at FNRC makes a difference by showing up to work with our clients, but this position gives me the ability to make changes, create new plans, or services that affect large numbers of people.

For example, I coordinated our Diversity Project several years ago and was able to complete extensive research and met with scores of people throughout FNRC’s catchment area to determine client and family needs and ways we can serve non-white communities better. Based on these efforts, I wrote a grant for a Promotoras Program at FNRC.

The Promotoras program uses people from the local communities that speak the same language and share the same culture to encourage families to use FNRC services. Promotoras workers may also help people obtain needed services and support through advocacy and assistance. There are now two Promotoras programs at FNRC and each program has worked with hundreds of clients to improve our outreach to the Hmong and Latinx communities.

(Continue on Page 13: “Interview: FNRC”
How has Covid-19 changed the way FNRC operates?

While the way we interact with clients has changed, FNRC staff continue to prioritize the needs of our clients. Most of our client and family meetings happen over Zoom or telephone instead of in-person. Internally, most of our staff meetings happen over zoom too.

Until recently, only about 12-15 people were working in the Chico office, down from 60-70 before the pandemic. With so few people working in the office, it felt too quiet and a bit lonely. I missed hearing people laughing and talking in the halls and being around familiar people.

COVID also dramatically increased everyone’s workload, including mine. Meetings to discuss clients with COVID or ones we feared were exposed went from ten minutes each day to almost 2 hours during the peak in January. Managing PPEs, making sure they were given to clients along with our own staff, took a lot of time. With 80% of my staff working from home, work processes have had to adapt.

FNRC remains focused on meeting the needs of our clients, COVID did not change that. We remain committed to making sure both our clients and our staff are safe and able to live their best possible life. We continued to improve our person-centered planning and training for the community and staff. Furthermore, FNRC has worked hard to implement one of the more effective self-determination programs in California.

Where would you like to go for a vacation?

Before the pandemic, I was planning a long vacation to Alaska and I’d love to drive the Alcan Highway someday. I am still interested in going there but will probably wait a year or two given the pandemic and huge travel rush I am expecting in the next year. Until then, I plan to visit the coast a lot and enjoy the salt air.
Kudos Corner
By Teresa Moshier

I want to give Kudos to Wesley Witherspoon. Wesley is an outstanding advocate for people with disabilities statewide in California and at the national level. Over the last year, during the COVID—19 Pandemic, Wesley has been doing a great job of educating Californians with intellectual and developmental disabilities about resources available and how to safely protect yourself from getting sick.

Wesley regularly write articles for the SSAN Newsletter and give trainings at quarterly SSAN meetings. Wesley’s commitment to educating others helps him stand out from others.

In addition to being a great advocate and awesome SSAN member, Wesley is also a supportive friend and mentor to other self-advocates and is always willing to offer help to his friends in need. Wesley represents the University of Southern California (USC) Children’s Hospital UCEDD on SSAN, on top of that, Wesley is currently serving as the Chair of the State Council and Chair of the Employment First Committee. Kudos to you Wesley Witherspoon!

Community Resources
Check out the State Council on Developmental Disabilities’ Series of Informational Videos on COVID—19 featuring people with disabilities on Youtube.

Governor Newsome just released the May Revise Budget, which details the states budget for the next fiscal year that starts on July 1, 2021.

The DDS 2021 May Revision Highlights has information from the Governor’s May Revise that impacts people with developmental disabilities and the regional center system.
SCDD 2021 LEGISLATIVE UPDATE

SCDD Deputy Director of Policy and Public Affairs, Bridgette Kolakosky will provide SSAN members with an update on legislation that SCDD has taken a position on and discuss the role SSAN members can have in supporting SCDD’s legislative agenda.
The SSAN Chair will lead the group in a discussion about ideas for the September 2021 meeting and members will have the opportunity to complete meeting evaluations for the June 2021 meeting.