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STATEWIDE SELF ADVOCACY NETWORK MEETING INFORMATION



DATE: Wednesday, March 9, 2022 and Thursday, March 10, 2022



TIME: Wednesday, March 9, 2022 10:00 AM – 3:00 PM
Thursday, March 10, 2022 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.

JOIN ZOOM MEETING: <https://bit.ly/SSANMar2022>

MEETING ID: **895 4087 8872**

MEETING PASSWORD: **340528**

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: **(669) 900 9128**

MEETING ID: **895 4087 8872**

MEETING PASSWORD: **340528**

Accessibility

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



AGENDA FOR DAY 1

March 9, 2022

10:00 AM – 3:00 PM

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

Presented by: Desiree Boykin, Chairperson, Paul Mansell, Vice-Chairperson, and Robert Levy, Secretary



2. Public Comment

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



3. Review and Approval of December 2021 Minutes

Presented by: Desiree Boykin, Chairperson

ACTION



4. Updates from the SSAN Chair

Presented by: Desiree Boykin, Chairperson

Information



5. Update SSAN Priorities

Presented by: Desiree Boykin, Chairperson

ACTION



6. SCDD Update

Presented by: Aaron Carruthers, SCDD Executive Director

Information



Break



7. SSAN Workgroups

Presented by: ALL

Discussion



8. SSAN Youth Representative

Presented by: Youth Workgroup Chair

ACTION



9. SCDD Legislative Update

Presented by: Bridget Kolakosky SCDD Deputy Director of Policy
and Public Affairs

Information



10. Input into Special Incident Reporting Categories

Presented by: Leslie Morrison, DDS Division Chief: Office of Quality
Assurance and Risk Management

Discussion



11. Recess Until Next Day

Presented by: Desiree Boykin, Chairperson

Information





AGENDA FOR DAY 2

March 10, 2022

10:00 AM – 2:00 PM

1. Call to Order, Welcome and Introductions

Presented by:

- Desiree Boykin, Chairperson
- Paul Mansell, Vice-Chairperson
- Robert Levy, Secretary



2. Public Comment

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



3. SCDD DAC Disability Video Project

Presented by: SCDD DAC
Discussion



4. I/DD Representation in Media

Presented by: Alice Kina Diehl, Actor
Information



Break

5. Approval of March 2022 SSAN Newsletter

Presented by: Robert Levy, Newsletter Workgroup Chair
ACTION



6. UC Davis MIND Institute Grant Project

Presented by: Aubyn Stahmer, UC Davis MIND Institute Director
of Community-based Treatment Research
Robert Levy, CCEDD Community Advocate



Information

7. Planning for June 2022 Meeting

ALL

Discussion



8. Adjournment

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MARCH 9, 2022
SSAN MEETING AGENDA ITEM 3
ACTION ITEM



Statewide Self-Advocacy Network
Approval of December 2021 Minutes

Attachments

- December 2021 Minutes

Recommended Action

Approve the December 2021 SSAN Meeting Minutes

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Statewide Self—Advocacy Network Meeting Minutes December 8 & 9, 2021 Zoom

SCDD Regional Members Present

Nathan Florez — North Coast
(Day 2)
Lisa Cooley — Sacramento
Ellen Sweigert — North Bay
(Day 2)
Regina Woodliff — Bay Area
(Day 1)
Robert Balderama — North Valley Hills
Rebecca Donabed — Sequoia
David Forderer — Central Coast
(Day 2)
Julie Gaona — Los Angeles
Daniel Foust — San Bernardino
(Day 2)
Paul Mansell — San Diego—Imperial

Agency Members Present

Maria Marquez — SCDD
Robert Levy —UCD MIND Institute
Wesley Witherspoon — USC CHLA
Kecia Weller — UCLA Tarjan Center
(Day 1)
Scott Barron — DRC
Nicole Patterson — DDS
Desiree Boykin — ARCA

Members Not Present

Sean Sullivan — Orange County
Russell Rawlings—CFILC

SCDD Staff in Attendance

Rihana Ahmad — SCDD HQ
Aaron Carruthers — SCDD HQ
Riana Hardin — SCDD HQ
Dena Hernandez – SCDD North
Valley Hills
Beth Hurn — SCDD HQ
Bridget Kolokosky – SCDD HQ
Debbie Marshall — SCDD San Diego
Sarah May – SCDD North State
Peter Mendoza – SCDD Sacramento
Chanel Murray —
SCDD North Valley Hills
Charles Nguyen — SCDD HQ
Mary Agnes Nolan —
SCDD North State
Tina Reszler – 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



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SSAN Minutes

1. Call to Order, Welcome and Introductions

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

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

2. Public Comment

There was no public comment.

3. Review and Approval of September 2021 Minutes

The members reviewed the minutes from the September 7 & 8, 2021 meeting. Materials for this agenda item can be found on pages 7–14 of the December 2021 SSAN Meeting Packet.

ACTION: Motion #1 to approve the September 2021 minutes was made by Kecia Weller/Seconded by Wesley Witherspoon. A roll call vote was taken. Motion passed. See vote log on page 8.

4. Updates from SSAN Chair

SSAN Chairperson Desiree Boykin announced that there are no updates at this time.

5. SCDD DAC Video Project

Peter Mendoza, CPS II Sacramento Regional Office and SCDD Disability Advisory Committee (DAC) Member asked for SSAN members' feedback and collaboration on a section of their video training project focused on different types of disabilities. Members expressed interest in contributing to this project and suggested that this item be brought back at the March 2022 meeting for further discussion.



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6. SCDD Update

SCDD Executive Director Aaron Carruthers provided SSAN members with an update on SCDD activity since the September SSAN meeting. Executive Director Carruthers talked about the challenges of responding to the ongoing public health crisis of COVID–19 and keeping everyone safe. SCDD continues to address vaccine hesitancy among Californians with I/DD and their communities by providing timely, up to date and easy to understand information about the different types of COVID—19 vaccines. SCDD sponsored [California Senate Bill 639](#) was signed by Governor Newsom and will go into full effect in January 2025. SCDD will be asking for input from people with I/DD who have experience working in sheltered workshops receiving subminimum wage in order to put together a report for the California Legislature.

7. SSAN Workgroup Discussion

SSAN Officers led an open conversation about the structure of the SSAN Workgroups and encouraged members to share their thoughts and ideas about how to improve SSAN workgroups. Officers expressed concern about low attendance and concerns that members may be participating in too many workgroups. Members had the following ideas on how to address these concerns: limit the number of workgroups people can participate in and send reminder emails/text messages to remind members of the meeting dates and times. SSAN Members discussed the following changes to workgroup names/functions:

- SSAN Operations will take the place of the Officers, Bylaws and Membership Workgroups
- Self-Determination Workgroup
- Employment Workgroup
- Newsletter and Communications Workgroup
- Youth Engagement Workgroup
- Legislative and Civic Engagement Workgroup



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8. 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 December 2021 SSAN Packet.

9. How the ADA Changed the Built World

SSAN Members viewed a short video about the impact that the landmark Americans with Disabilities Act (ADA) had on improving building standards and accessibility in the USA.

10. Getting Rid of the R Word

A representative from Special Olympics Southern California presented on the impact words have on the way the broader public thinks about people with disabilities and the different types of projects that Special Olympics does throughout the year to support athletes with disabilities, educate communities, and advocate for disability rights. This includes “Spread the Word to End the Word,” an ongoing Special Olympics campaign to encourage the public to stop using the “R” word in everyday language. You can take part in their effort by [Taking the Pledge](#) with Spread the Word today.

11. Recess Until Next Day

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



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SSAN DAY 2 Minutes

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

SSAN Chairperson, Desiree Boykin, ARCA Representative, called the meeting to order at 10:00 A.M.

An attendance roll call was taken.

2. Review of Agenda

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

3. Public Comment

Bridget Kolakosky, SCDD Deputy Director of Policy and Public Affairs, told SSAN members about an upcoming hearing on the Lanterman-Petris-Short Act to talk about expanding the act to include people who are in extreme crisis, but not necessarily at risk of harming themselves or others. The hearing is scheduled for next week and she asked that SSAN members consider submitting public comment about their thoughts, concerns and experiences.

Vireo Salgado, SCDD San Diego Regional Office Intern requested that SSAN include a flyer for Project Self-Advocates for Emergency Education (S.A.F.E.E.) in the December 2021 SSAN Newsletter.

4. Planning for the Future and 2022 Meeting Dates

Rihana Ahmad, SCDD Manager – State Plan and Self-Advocacy, provided SSAN members with an overview of the 2022–2026 SCDD State Plan and how the work SCDD staff will be engaging in presents opportunities for collaboration between SSAN and SCDD staff. Members shared ideas about the issues and focus areas SSAN should prioritize for 2022.



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5. Approval of the September 2021 SSAN Newsletter

SSAN Secretary and Newsletter and Communications Workgroup Chair, Robert Levy reviewed the DRAFT December 2021 Voices of SSAN Newsletter (with the addition of the Project SAFEE flyer that was presented during public comment) and called for a motion to approve the December 2021 Edition.

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

ACTION: Motion #2 to approve the December 2021 Newsletter with the inclusion of the Project SAFEE flyer was made by Ellen Sweigert/Seconded by David Forderer. A roll call vote was taken. Motion passed. See vote log on page 8.

6. Approval of the SSAN Annual Report

Riana Hardin, SCDD Self-Advocacy Coordinator reviewed the DRAFT 2020–2021 SSAN Annual Report with members. The 2020–2021 SSAN Annual Report highlights the work of SSAN members during SSAN meetings and in their communities throughout October 2020–September 2021. SSAN members discussed the possibility of taking a group photo over Zoom at a future meeting for next year's Annual Report.

ACTION: Motion #3 to approve the 2020–2021 SSAN Annual Report was made by Desiree Boykin/Seconded by Rebecca Donabed. A roll call vote was taken. Motion passed. See vote log on page 8.



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7. Planning for March 2022 Meeting

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

- SCDD DEAP projects
- DDS initiatives
- Safety and self-advocacy
- Housing
- Legislative update on SB 639 and LPS hearing
- Elections
- Social and recreational services
- Mental health
- Self-Determination

8. Adjournment

Meeting was adjourned at 1:43 P.M. The next SSAN meeting will be on March 9th and 10th 2022 using Zoom.



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DECEMBER 2021 SSAN VOTE TALLY

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

MARCH 9, 2022
SSAN MEETING AGENDA ITEM 4
INFORMATION ITEM

Statewide Self-Advocacy Network



Updates from the SSAN Chair

The SSAN Chair would like to welcome everyone to the March 2022 Meeting and will take a moment to provide a verbal update to SSAN members.

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MARCH 9, 2022
SSAN MEETING AGENDA ITEM 5
ACTION ITEM



Statewide Self-Advocacy Network

Update SSAN Priorities

In 2019 SSAN adopted priorities, or focus areas based off the 2016–2021 SCDD State Plan. On October 1, 2021, SCDD began a new State Plan Cycle with different Goals and objectives. At the December 2021 SSAN meeting members shared ideas on projects and issues that they would like to work on. The SSAN Operations workgroup reviewed the ideas from the December meeting and are suggesting a few updates to the SSAN Priorities.

Attachments

- 2019 SSAN Priorities
- DRAFT 2022 SSAN Priorities

Recommended Action

Approve the 2022 SSAN Priorities

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SSAN SCDD State Plan Focus

2019/2020



At the March 2019 SSAN meeting SSAN Members voted to focus their efforts in increasing advocacy, awareness and participation in 3 State Plan goal areas:

- **State Plan Goal 1: Self-Advocacy**

- **Focus:**

1. Self-Determination
2. Youth Engagement and Training
3. Modernizing approach to self-advocacy
4. Training job coaches on the principles of self-advocacy
5. Strengthening connection between Regional Centers and SSAN
6. Training and outreach in schools
7. Invite others to present at SSAN about Self-Advocacy
 - Resources for Independent Living DOGFITE
 - An organization in the field of aging
 - SAC 6
8. Share resources related to Self-Advocacy
9. Have a (2) At-Large Youth Representatives
 - North
 - South
10. Tell more stories about self-advocacy

- **State Plan Goal 6: Formal and Informal Community Supports**

○ **Focus:**

1. Access to transportation

- Collaborate with Uber/Lyft for Access
- Train organization on the needs of people with disabilities
- Public Transportation
- Get on boards
 - Recommend a policy with a specific % of people with disabilities on public transportation boards

2. Supported Decision Making

- Training on what it is
- For who, self-advocates & Professionals
- Make it a legalized process

3. Regional Centers

- Teaching people with disabilities other resources in community
- Teaching people with disabilities about what regional centers pay for and for whom
- Eligibility for regional center services
- Eligibility for generic services
- Transition to adulthood
- Expand to other departments
- Self-Advocates would be doing these trainings and reminding staff that people with disabilities are the customer and why they have jobs.

- **State Plan Goal 2: Employment**

○ **Focus:**

1. Talk to Employers

- let them know about the tax credit for hiring people with disabilities
- People with disabilities want to work

2. Ask people what they need help with

- Direct them to resources
- Help them if they have knowledge/info

3. Volunteering to build resume/skills

- Identify your skills & find a way to utilize skills
- Knowledge of how to fill out applications
- Knowledge on how to build a resume

4. Deciding if you want to work full-time or part time

5. Having knowledge on how to act and what the expectations are

6. Webinar about employment & Social Security

7. How to overcome fear

8. How to get a state job

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2022–2026 SSAN Priorities



The Purpose of the SSAN Priorities is to guide SSAN in choosing and prioritizing activities, projects and short-term/log-term goals. Based on feedback from members, the SSAN Operations Workgroup recommends the following Priorities:

❖ **Priority 1: Strengthen Self-Advocacy in California**

○ **Focus: Civic Engagement**

1. Connecting SSAN with Independent Living Centers
2. Educate self-advocates about the legislative process
3. Train self-advocates on how to engage with elected officials

○ **Focus: Youth Engagement**

1. Modernizing our approach to self—advocacy
2. Increase SSAN Presence on Social Media
 - SSAN Facebook page/group
 - LinkedIn
 - Twitter
3. Visiting schools to find out what is important to students.
4. Provide Disability History training in schools
5. Get involved with the Youth Leadership Forum (YLF)
6. Provide Anti-Bullying/Harassment Trainings

○ **Focus: Self-Determination**

1. Engagement and training
2. Strengthen connection between regional centers and SSAN
3. Educate self-advocates about Supported Decision Making

❖ **Priority 2: Improve Access to Services and Supports**

○ **Focus: Medical Care and Resources**

1. Advocate for more accessible medical offices
2. Advocate for timely, reliable information in Plain Language
3. Accountability and open communication

○ **Focus: Transportation Services**

1. Increase disability participation on Transportation Boards
2. Create trainings about the needs of people with disabilities
3. Future projects/collaborations with CalTrans
4. Increase access to Rideshare services
 - Collaborate with Uber/Lyft for better access

❖ **Priority 3: Improve Access to Competitive Integrated Employment**

○ **Focus: Training**

1. Training Job Coaches on Self-Advocacy
2. Train Employers
 - Tax Credit
 - People with Disabilities want to work
3. Find out what people need help with
 - Provide Resources
4. Finding/building Your Skills
5. How to Get a State Job
6. Building a Resume
7. Collaboration with UC Davis MIND Institute

○ **Focus: Building Awareness**

1. Legislative Efforts
2. Sharing Stories/Lived Experiences
3. Mentorship Programs
4. Ending Subminimum Wage (SB 639/other legislation)

MARCH 9, 2022
SSAN MEETING AGENDA ITEM 6
INFORMATION ITEM



Statewide Self-Advocacy Network

SCDD Update

Since the December 2021 SSAN meeting, the State of California, the United States of America, and countries around the world continue to face challenges in addressing the public health and safety challenges of COVID–19. SCDD continues to work with statewide and local partners to advocate for the inclusion of people with I/DD in the vaccination rollout. SCDD Executive Director Aaron Carruthers will update SSAN members on Council activity related to meeting the needs of Californians with I/DD during these challenging and unique times.

Possible Handouts

- January 2022 Council Meeting Summary

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MARCH 9, 2022
SSAN MEETING AGENDA ITEM 7
INFORMATION ITEM



Statewide Self-Advocacy Network

SSAN Workgroups

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

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

Handouts

- SSAN Workgroup Descriptions
- SSAN Workgroup Roster

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MARCH 9, 2022
SSAN MEETING AGENDA ITEM 8
ACTION ITEM



Statewide Self-Advocacy Network

SSAN Youth Representative

Engaging with youth with disabilities is an important part of growing and strengthening the self-advocacy movement in California. The SSAN Youth Engagement Workgroup developed a Youth Survey to find out what topics are important to youth with disabilities and to understand youth familiarity with the self-advocacy movement and disability history. The survey was presented at the March 2021 meeting and posted to the SSAN webpage and shared on social media in June 2021. The Youth Engagement Workgroup wrote an article about the findings in the December “Voices of SSAN Newsletter”.

The SSAN Youth Workgroup, along with the SSAN Operations team, believe strongly that there needs to be a designated Youth Representative on SSAN and would like to reach out to Youth Organizing (YO!) Disabled and Proud to find a qualified candidate to fill the seat.

Attachments

- Youth Survey Article

Recommended Action

Approve the Youth Engagement and SSAN Operations Workgroups recommendation of adding YO! Disabled and Proud as a member organization of SSAN and encourage members of YO! Disabled and Proud to apply to be a member of SSAN.

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SSAN Youth Survey Data

By **Kecia Weller**, UCLA Tarjan Center UCEDD SSAN Representative

Regina Woodliff, Bay Area SCDD Regional 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.

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MARCH 9, 2022

SSAN MEETING AGENDA ITEM 9
INFORMATIONAL ITEM



Statewide Self-Advocacy Network

SCDD Legislative Update

SCDD Deputy Director Bridget Kolakosky will provide SSAN members with an update on SCDD Legislative activities. Updates may include:

- SCDD Sponsored Legislation
- Results of “There Should be a Law” contest
- Other state and national legislative updates

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MARCH 9, 2022
SSAN MEETING AGENDA ITEM 10
INFORMATION ITEM



Statewide Self-Advocacy Network

Input into Special Incident Reporting Categories

The California Department of Developmental Services (DDS) would like input from self-advocates on possible changes to Title 17 regulations pertaining to special incident reporting.

Presenter

Leslie Morrison
Division Chief | Office of Quality Assurance and Risk Management

Attachment

- Changes to Special Incident Reporting Requirements

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Changes to Special Incident Reporting Requirements

What is a Special Incident?

Special incidents are critical and unexpected events that happen to an individual with an intellectual or developmental disability and that must be reported. All of them indicate a possible health or safety risk and maybe the need for additional services and supports.

Only certain events are considered special incidents. These events are listed in California regulations. The Department of Developmental Services (Department) wants your input about potential changes to the things that must be reported.

What is the current list of special incidents?

For all individuals served by a regional center:

1. The death of an individual.
2. When an individual is the victim of a crime.

For individuals receiving services and supports from a provider or vendor:

3. When an individual is missing and a missing persons' report has been filed with a law enforcement agency;
4. When someone suspects or knows that an individual is being abused, neglected, or exploited;
5. When an individual gets a serious injury or has an accident that injures them;
6. All medication errors; and
7. An unplanned or unscheduled hospitalization for certain illnesses or conditions.

How is a special incident reported?

When a provider learns about an incident, they make report to the individual's regional center. This information is recorded in a secure database at the regional center. The regional center then reports the incident to the Department.

What happens after someone files a special incident report?

Regional center staff probably will contact the individual or their provider to learn more. The regional center wants to make sure the individual is safe and has the supports and services that they need. Sometimes a special incident report may reveal that the individual needs more help, even just for a little bit of time.

Why consider changing what is reported?

The things that must be reported have not changed in many years. It is good to occasionally check whether we know the right things that can help us keep people safe.

Think about:

- What should regional center staff need to know about and why?
- How this will work from individuals living independently in the community?
- Are there privacy or infringement on independence considerations?
- How would you feel if someone let regional center staff to know about these events if they happened to you or one of your peers?

What next?

The Department is asking for input from a variety of people and organizations, including regional centers and providers. After that, the Department may start the official process to change the regulations, if enough people think changes would be helpful. We will reach out to you again for more input if proposed regulations have been released.

In the meantime, if you have any questions, please contact Josh Sudarma at Josh.Sudarma@DDS.CA.gov or call him at (916) 651-0454.

MARCH 10, 2022
SSAN MEETING AGENDA ITEM 3
INFORMATION ITEM

Statewide Self-Advocacy Network
SCDD DAC Disability Video Project



As a follow-up to the presentation at the December 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.

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MARCH 10, 2022
SSAN DAY 2 AGENDA ITEM 4
INFORMATION ITEM

Statewide Self-Advocacy Network

I/DD Representation in Media



In honor of the 35th National Developmental Disabilities Awareness Month, The SSAN Operations Workgroup has invited Alice Kina Diehl to talk to SSAN about I/DD Representation in Media.

Attachments

- Alicia Kina Diehl Bio

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Alice Kina Diehl was born in 1986 with Cerebral Palsy! Her namesake is her great aunt who was a well known stage actor. Alice wanted to be a professional baseball player. When that dream went as far as it could, she grew up to become the winner of the Media Access Office, first annual John Ritter Scholarship for young Actors with disabilities in 2003, at the age of 16. Around that same time, she also ran her very own cable access show pre social media days about film. She eventually moved to Southern California in 2005. Where she was given another a scholarship to study under Laura Gardner at the Howard Fine Acting Studio in Hollywood. She has been featured in many tv shows, such as...SPEECHLESS, FOR THE PEOPLE, SPECIAL and SORRY FOR YOUR LOSS. In 2018, she was given her first Co-star role as EMD Stephanie Gaskins on Fox's 911. A year later she was given her first National commercial spot LIVE MORE INDEPENDENTLY for UNTIED HEALTHCARE. She now currently runs an Instagram and website with her amazing wife called Rollinstoned in Southern California. The platform focuses on ending stigmas around LGBT, BIPOC, disability/illness and medical cannabis. Rollinstoned is now officially sponsored by several medical cannabis companies as well as being official Spokesmen for the Banana Bros. Otto grinder. In 2022 at the age of 35, she was selected as the face of the Permobil USA applewatch smartdrive! The sky is the limit. All Disabled lives are worthy!!!

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MARCH 10, 2022
SSAN MEETING AGENDA ITEM 5
ACTION ITEM



Statewide Self-Advocacy Network

Approval of March 2022 Newsletter

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

Attachments

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

Recommended Action

Approve the DRAFT March 2022 Voices of SSAN Newsletter

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IN THIS EDITION:

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Article 2: CHOICES Conference

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Article 4: New Member: Maria Marquez

Article 5: Disability Pride

Article 6: Special Olympics

Article 7: How to Stay Safe in the Community

Article 8: Kudos Corner

Article 9: Community Resources

Article 10: Save the Dates

Editor: Robert Levy

Contributors:

- Desiree Boykin
- Nicole Patterson
- Paul Mansell
- Robert Levy
- Robert Balderama
- Maria Marquez
- Ellen Sweigert
- Rebecca Donabed
- Wesley Witherspoon
- Robert Levy

Celebrating 35th Developmental Disability Awareness Month

By SSAN Members



In 1987 President Ronald Regan proclaimed March as ‘Developmental Disabilities Awareness Month’. In honor of the month, the National Association of Councils on Developmental Disabilities partners with the Association for University Centers on Disabilities and National Disability Rights Network to create a social media campaign that highlights the many ways in which people with and without disabilities come together to form strong, diverse communities.

NACDD is encouraging people to share stories, resources and raise awareness about the different barriers that people with I/DD face in all aspects of life by using the hashtag #DDAM2022 to tag their content on social media.

Here are a few thoughts from SSAN Members on the importance of DD Awareness and Acceptance:

“Having a whole month dedicated to celebrating developmental disabilities is one of the best things that has happened in the movement of disability awareness, as it raises awareness no matter how old someone is. I am proud to say those who started the movement are still active and continue to fight for our rights.” – Maria Marquez, SCDD SSAN Representative

(Continue on page 2: “DD 2022: 35 Years”)



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(Continued from page 1: "DD 2022: 35 Years")

"The fact that we are out there and representing people with developmental disabilities is a positive thing and I hope it is a national thing! I want everyone to know that I am very proud of their efforts to include people with developmental disabilities. Having a Developmental Disabilities Awareness month is a great thing".

– Robert Balderama, North Valley Hills Regional SSAN Representative

"The reason why I think that it is important to have developmental and intellectual disability month is because there are so many different types of disabilities that are classified as an intellectual or developmental disability. It gives us a moment to shed light on not only what people can learn about those disabilities, but they can join us in celebrating the milestones of how far we have come and how much work we still have to do as advocates and citizens of the state of California. "

– Nicole Patterson, DDS Representative

"35 years of Intellectual and Developmental Disability Awareness Month is important because we need to recognize people with disabilities because everyone will eventually join our club: the disability club!" – Rebecca Donabed, Sequoia Regional Representative



CHOICES Institute

Conference Update- questions 473-6950

SAVE THE DATE!

CHOICES Institute will be holding its **34th ANNUAL** Conference on **FRIDAY, May 20, 2022** on ZOOM 10:00am-12noon

Theme for CHOICES 2022:

Everyday HEROES, Everyday CHOICES

(same as our 2020 canceled conference)

This will be a FREE event, but you MUST REGISTER!

The cost for the conference is FREE and will include a free conference T-shirt ONLY with registration.

Registration information will be available and live at the end of February 2022

Questions? Call 209-473-6950 or Email Dena.Hernandez@scdd.ca.gov

New mailing address: CHOICES Institute

2529 W. March Lane Suite 105 Stockton, CA 95207



Celebrating Ten Years of SSAN: Members Reflect



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

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

“I have been a part of SSAN since it started 10 years ago. At first, I wasn’t sure if I was interested in being part of this group. My supervisor Steve Ruder thought it would be a great opportunity to be part of SSAN, so I did, decided to give it a try and was one of the founding members of SSAN. As we get to celebrate 10 years at SSAN it is nice to think about all of the new opportunities that I have had, like being the chair of the newsletter/ communication work group committee and now serving as an officer as SSAN Secretary. SSAN has helped me to practice public speaking by speaking at conferences and sharing my story and being a Self-Advocate. Happy 10th birthday and as we reach this milestone birthday, hopefully all of us at SSAN can keep on doing the Self-Advocacy work to make it a better place for people with I/DD to have a productive life in the community.”

– Robert Levy, SSAN Secretary UC Davis MIND Institute SSAN Representative

“I am just proud that it (SSAN) took off like it did. It was a seed that sprouted, like an experiment that went well! We keep doing good work for people with disabilities and can’t believe it has been ten years!”

– Robert Balderama, North Valley Hills Regional SSAN Representative

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

– Lisa Cooley, Sacramento Regional SSAN Representative



New Member Spotlight: Maria Marquez

By Maria Marquez, SCDD SSAN Representative



Hello Statewide Self-Advocacy Network community. My name is Maria Marquez and I am the new representative for SCDD on SSAN. I have over 25 years of experience advocating for myself and others with many different groups and

boards and look forward to using my past experiences to be a part of SSAN. I was appointed to serve on the State Council on Developmental Disabilities (SCDD) in 2017 by Governor Jerry Brown and was reappointed in 2020 by Governor Gavin Newsom. As a part of my role as an At Large member of the Council I sit on different committees and task forces, including the Executive Committee, Legislative and Public Policy Committee (LPPC), the Self-Advocates Advisory Committee and I represent SCDD on the Department of Developmental Services (DDS) Task Force. I have been a Self-Advocate Faculty member with [CA LEND](#) since 2019.

An important moment in my self-advocacy journey was when I was encouraged to attend and speak at Capitol Action Day, from there, I got involved with my regional center board, and later, the DDS CAC and the Family Resource Center of East Los Angeles Regional Center. I have been lucky to meet a lot of different people in my different advocacy roles, including Michael Long, who was the first person with a disability to work at DDS. I am passionate about self-determination and believe that everyone has a right to live their life the way they choose.

My advice to future self-advocates is to try to be what you want. Go to meetings, listen, learn how to ask for help, and help others. Self-advocacy is your adventure: enjoy what you are doing. The fight for our rights has not stopped and advocates need to encourage and mentor each other, so that we can see what is possible.

I look forward to working on SSAN to continue my advocacy journey.

SSAN Members

- Nathaniel Florez – North Coast
- Charles Nutt – North State
- Lisa Cooley – Sacramento
- Ellen Sweigert – North Bay
- Regina Woodliff – Bay Area
- Robert Balderama – North Valley Hills
- David Forderer – Central Coast
- Rebecca Donabed – Sequoia
- Julie Gaona – Los Angeles
- Sean Sullivan – Orange County
- 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
- Maria Marquez – SCDD



Disability Pride

By Paul Mansell, San Diego Regional SSAN Representative

Most people would agree that healthy self-esteem is a foundation for a happy life. That sounds simple. People with disabilities have had difficulties having positive self-esteem or self-image because of their disabilities. Society has looked at disability through different lenses: viewing disability as a punishment for something a person has done or viewing disability as a problem that needed to be fixed. These points of view resulted in institutionalization and marginalization of people with disabilities.

Society at long last is re-examining how it looks at us, with the passage of legislation such as the Americans with Disabilities Act (ADA) in 1990. It was a tremendous civil rights victory, one that all Americans should feel proud of. However, we still had dysfunctional bodies, minds, or behaviors. These can make life discouraging and frustrating, and it is easy to label them as bad.

Doctors gave me the diagnosis of Epilepsy at age 13. I thought the way my neurologist did it was over the top, fit for a soap opera. He did assure me that by the time I grew up, I would outgrow it and drive—having Epilepsy is all about driving and taking meds. My mother told me to hide my Epilepsy and never let anybody know I had it because people would discriminate against me. It is hard to hide having Epilepsy when the side effects of the anti-seizure meds noticeably drugged me out. Still, being a self-conscious teenager, I tried my best to hide something wrong about myself. I wasn't fooling anyone except myself. I may have had a diagnosis, but I didn't see myself as disabled.

That all changed when I had my major mental breakdown at 33. When the doctors diagnosed me, I was overwhelmed. I saw myself as disabled, which affected my identity and culture. I was now a member of the population called disabled, and this was a terrible thing, and my self-esteem tanked. It had never been strong, to begin with, but now it was worse than ever.

I should have considered myself lucky because meds controlled my disorders, leading to a reasonably manageable life. At the time, I was receiving SSI and living in a Section 8 apartment, and I had to contend with poverty. I regarded this as another obstacle in my life and suppressed my self-esteem even more. Even when I got a good job and got a place of my own in a good neighborhood, my self-esteem was still in the pit. I saw therapists, and they taught me CBT, and I got good at coming up with balanced thoughts, but my self-esteem wouldn't budge any.

I was stuck in this holding pattern for over 15 years with slight improvement.

(Continue on page 6: "Disability Pride")



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(Continued from page 5: “Disability Pride”)

Fortunately, I am prone to self-reflection, and I do a lot of it. Well, I was thinking one day. I wanted to have good self-esteem and be happy, but parts of me, my disabilities, were terrible. They were terrible because my neurology was defective. Then out of nowhere, the thought that came to me was why was a behavior terrible? Neurons don't have a norm to them, regardless of utility. This insight liberated me, and I could love all of me, not just my strengths, and with this new freedom, I discovered a new pride in myself. I call this disability pride.

My disabilities still affect my identity and culture, but not in the way they had before. I still have a bond and a relationship with others who share my label, but those relationships no longer focus only on negative disability experiences. Instead, it reflects our fraternity and solidarity as equals. This insight freed me from a crushing burden that I have carried all these years and gave me the impetus to expand my involvement in self-advocacy. I am no longer on just a mission all by myself fighting discrimination and injustice. I am striving to build a fraternity of people to get the support and resources we need. I have the purpose of empowering us to lead satisfying and successful lives to our highest potential in our communities. This new way of thinking was a complete mind-shift for me.

With this new way of thinking, I could look at myself in the mirror each morning and take pride in myself. I could love all of me and be free of guilt and shame. My self-esteem has soared, and so has my happiness. I try to tell others that they, too, can love their disabilities and take pride in themselves. It's all in loving the complete you with no regrets, hesitations, or reservations. You can be victorious by leading an integrated and inclusive life among your friends, family, neighbors, and co-workers.



[This Photo](#) by Unknown Author is licensed under [CC BY-NC-ND](#)

Safety in the Community

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

You want to be safe on the Internet, at home, on transportation, and in the community. To be in the community, travel with someone you trust. Talk to the police, fire department, and ambulance if an emergency comes up. To be safe on the Internet, you have cybersecurity and don't give anyone confidential information about yourself. Be careful about what you download and who you are friends with. Be careful with social media, don't tell too much information about yourself. Don't give people you don't trust any money. When you leave home, make sure you lock your doors, windows, and gates. If you can, buy a security system or cameras to watch your home. You can also buy a dog to protect your home. When you are travelling, make sure that you are away from other people. When you are out in the community, do not carry a lot of money and secure all of your valuables. Carry a whistle with you to make noise if something happens. Also carry a flashlight if you go out a night. When you are out, try to stick with people you trust, avoid any confrontations with other people. Tell someone you trust where are you going, what time that you expect to be back, and who that you are going with. Don't take things from strangers. Watch your things at all times when you are out. Call the police department if you take a vacation to check on your home while you are gone. Don't tell your staff your ATM number or give them your money. Be careful with work and romance scams as well.

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**

Check out the [SCDD YouTube Page](#) for stories from self-advocates, past meetings, and more!



Project **S.A.F.E.E.**

Self-Advocates For Emergency Education

Project SAFEE is organized by self-advocates committed and responsible to create positive change in the world of emergency education. We build social awareness for individuals who have developmental disabilities and make a difference in our community.



Interested in keeping your community safe?

Please join us for one of our meetings:

Every 1st & 2nd Friday of the month

from 8:30-10:00am

We welcome you to learn and participate:

- Promote safety awareness
- Commit to attend every meeting
- Show professionalism and good attitude
- Have a strong voice for leadership and education
- No experience necessary but dedication required



For more information about the next Zoom meetings

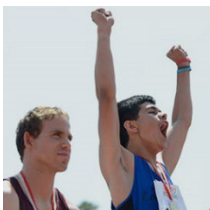
Please contact:

Debbie Marshall at (619) 913-8232 or email debbie.marshall@scdd.ca.gov

Sarah May at (530) 895-4027 or email sarah.may@scdd.ca.gov



Special Olympics: Promoting Inclusion through Sports



Special Olympics is an organization that has impacted the lives of people with disabilities, including many members of SSAN. The Special Olympics was founded in 1968 by Eunice Kennedy Shriver and held its first Western Regional Special

Olympics in Los Angeles with athletes from 7 different western states competing in track and field and swimming. The first International special Olympics was held in 1972 in Southern California with over 2500 athletes from 8 countries. Since then, Special Olympics has continued to change the lives of people with disabilities around the world.

Today, Special Olympics is the world's largest sports organization for people with intellectual and developmental disabilities. 4.4 million athletes in 170 different Countries, along with volunteers and supporters work to transform lives through the joy of sports.

Outside of sports, Special Olympics encourages healthy living, youth leadership development, education and advocacy. One of their ongoing projects is [Spread the Word: Inclusion](#) which works to stop the use of harmful terms for people with disabilities. The theme for 2022 is "Champions of Change". You can follow along on social media using @PledgeToInclude to join the campaign and look forward to future stories from SSAN members of how Special Olympics and other social programs have made a difference in their lives.

Special Olympics recognizes March 2nd as a global day of inclusion, so this March 2nd: how are you planning to be inclusive to others?

Learn About SSAN Member Organizations

- [Association of Regional Center Agencies](#)
- [California Foundation for Independent Living Centers](#)
- [Department of Developmental Services](#)
- [Disability Rights California](#)
- [University of California, Davis MIND Institute](#)
- [University of California, Los Angeles, Tarjan Center](#)
- [University of Southern California, Children's Hospital](#)

Self-Determination Update

Self-Determination is LIVE in California. Check out the [DDS Self-Determination Newsletter](#) for the latest on California's Self-Determination Program. Talk to your service coordinator to learn more.



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Kudos Corner

By Wesley Witherspoon

I would like to give Kudos to Maria Marquez, who is the new SCDD representative to SSAN. Maria has had a long career in self-advocacy and is a strong advocate for Self-Determination. Maria started her self-advocacy movement career when she was asked to attend and encouraged to speak at Capitol Action Day by Hilda Solis. She remembered practicing her speech on the plane ride up to the event. Her Service Coordinator at East Los Angeles Regional Center encouraged her to join their CAC, and later the DDS CAC.

Maria worked for Disability Rights California for 7-8 years as a Peer Self-Advocate but had to take some time off for health reasons. Maria was the first person in California to sign-on to Self-Determination during the pilot project and was the first to get her budget approved. Her involvement in Self-Determination and self-advocacy led to her being appointed to the State Council on Developmental Disabilities in 2017 by Governor Brown. Maria was recently recommended to attend the AUCD Academy where she looks forward to learning how to be a national advocate for disability rights. Kudos to you Maria Marquez and thank you for your contribution to self-advocacy in California!

Community Resources

- [SARTAC Advisory Committee Application](#)
- [ARCA Regional Center COVID-19 Resources](#)
- [COVID-19 Stimulus Checks Won't Affect Your Benefits](#)
- [DRC's Build Back Better Resources](#)
- [SSAN Youth Survey](#)
- [SSA Ticket to Work Tips to Open Your ABE Account](#)

SAVE THE DATES

Disability Rights California



Events and Trainings:

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

CalABLE



News and Trainings:

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

CHOICES Conference

"Every Day Heroes"

Contact [Dena Hernandez](#) to learn more



Arc of California
[2022 Public Policy Conference](#)

Plain Language COVID—19
Resources Available on:

[SCDD Website](#)

Register for the Monthly
[California Statewide Self-Advocacy Chats](#) on Zoom

The Arc of California
[Breakdown of Build Back Better](#)

[Office of Self-Determination Ombudsperson](#)

MARCH 10, 2022
SSAN MEETING AGENDA ITEM 6
INFORMATION ITEM



Statewide Self-Advocacy Network

UC Davis MIND Institute Grant Project

UC Davis MIND Institute was recently awarded a grant to fund a project looking at different ways to improve inclusion of people with developmental disabilities in research about people with developmental disabilities. The goal of the project to help researchers and people with developmental disabilities work together to decide what research to do in the areas of telehealth, equal access to healthcare and transition to adulthood. We hope that building partnerships between people with disabilities and researchers will help answer research questions important to the community.

UC Davis MIND Institute will be organizing focus groups for feedback and will be developing training materials to help researchers learn best practices for including people with developmental disabilities in research projects.

Presenters:

- Aubyn Stahmer, Director of Community-Based Treatment Research
- Robert Levy, CEDD Community Advocate

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MARCH 10, 2022
SSAN MEETING AGENDA ITEM 7
INFORMATION ITEM

Statewide Self-Advocacy Network



Planning for June 2022

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

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