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STATEWIDE SELF ADVOCACY NETWORK MEETING INFORMATION



DATE: Wednesday, September 4, 2024 and Thursday, September 5, 2024



TIME: Wednesday, September 4, 2024 10:00 AM – 3:00 PM
Thursday, September 5, 2024 10:00 AM – 3:00 PM

Members of the public may participate in person, telephonically, or by Zoom. Accessible formats of all agenda and materials can be found online at www.scdd.ca.gov

UPDATED MEETING DETAILS:

Physical Location:

SCDD Headquarters
3831 N. Freeway Blvd Ste 125
Sacramento, CA 95834

ZOOM LINK:

<https://bit.ly/SSAN2024September>

Call-in Information:

CALL IN NUMBER: (669) 900 9128
MEETING ID: 859 9271 7060
PASSCODE: 280999

Accessibility

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AGENDA FOR DAY 1

**September 4, 2024
10:00 AM – 3:00 PM**

1. Call to Order, Welcome and Introductions

Presented by: SSAN Officers



2. Public Comment

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



3. Review and Approval of June 2024 Minutes

Presented by: Charles Nutt, Chairperson
ACTION



4. SSAN Tip Sheets

Presented by: SSAN Tip Sheet Workgroup
Information



5. SCDD Update

Presented by: Aaron Carruthers, SCDD Executive Director
Information



Break



6. Voting is Your Voice and Your Choice

Presented by: Disability Vote California



7. Disability History

Presented by: Rebecca Donabed, SSAN Secretary
Information

8. Reflections for the Day





AGENDA FOR DAY 2

September 5, 2024

10:00 AM – 3:00 PM

1. Call to Order, Welcome and Introductions

Presented by: SSAN Officers



2. Public Comment

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



3. Understanding DOR Services

Presented by: Spencer Hoke, Regional Business Specialist
Information



4. Updates on the Master Plan on Developmental Services

Presented by: Nicole Patterson, Kecia Weller, and Lisa Cooley
Information



Break



5. Planning for the SSAN Annual Report

Presented by: ALL
Information



6. September 2024 Edition of Voices of SSAN Newsletter

Presented by: Robert Levy, Newsletter Workgroup Chair
Information



7. Meeting Takeaways and Planning for December 2024



8. Adjournment



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SEPTEMBER 4, 2024

SSAN MEETING DAY 1 AGENDA ITEM 3

ACTION ITEM

Statewide Self-Advocacy Network

Approval of June 2024 Minutes



Attachments

- June 2024 Minutes

Recommended Action

Approve the June 2024 SSAN Meeting Minutes

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DRAFT

Statewide Self-Advocacy Network Meeting Minutes

June 8, 2024 (Hybrid)

SCDD Regional Members Present

Sonya Force – North Coast
Charles Nutt – North State
Lisa Cooley – Sacramento
Ellen Sweigert – North Bay
Sara Desumala – Bay Area
Rebecca Donabed – Sequoia
Julie Gaona – Los Angeles
Sean Sullivan – Orange County
Eric Aguilar – San Bernardino
Viri Salgado – San Diego

Agency Members Present

Alex Reyes – SCDD
Scott Barron – DRC
Desiree Boykin – ARCA
Robert Levy – UCD MIND Institute
Nicole Patterson – DDS
Kecia Weller – UCLA Tarjan Center
Wesley Witherspoon – USC CHLA

Members Not Present

Robert Balderama – North Valley Hills
Russell Dawson - Rawlings – CFILC

SCDD Staff in Attendance

Rihana Ahmad – SCDD HQ
Ken DaRosa – SCDD HQ
Riana Hardin – SCDD HQ
Dena Hernandez – SCDD North Valley Hills
Ibrahim Muttaqi – SCDD HQ
Charles Nguyen – SCDD HQ
Gabriela Solval – SCDD Bay Area
Yaritza Sanchez – SCDD HQ

Others Present

Dana Cooley
Sarah May
'Bird,' Bay Area Autism Collective



DRAFT

June 2024 SSAN Minutes

1. Call to Order, Welcome, and Introductions

SSAN Chairperson and North State Representative, Charles Nutt, called the meeting to order at 10:15 AM. Members were asked to introduce themselves by sharing their name, the region and/or agency they represent, an advocacy activity they have done since the last meeting, and what they do to prepare for emergencies. Members mentioned emergency preparedness strategies like having go kits, providing support staff with information, and drinking lots of water. Members brought up the need to increase access and participation in the Self-Determination Program (SDP), disability organizing, coalition-building, creating healthy relationships, climate change, accessible public transportation, and affordable housing as significant issues that need attention.

2. Public Comment

There were no public comments.

3. Review and Approval of February 2024 Minutes

The members reviewed the minutes from the meeting on February 28-29, 2024. Materials for this agenda item can be found on pages 5-12 of the June 2024 SSAN meeting packet.

ACTION: Motion #1, to approve the June 2024 minutes, was made by David Forderer and seconded by Wesley Witherspoon. A roll call vote was taken. Motion passed. See Vote Log on page 4.

4. SCDD Update

The State Council on Developmental Disabilities (SCDD) Chief Deputy Director, Ken DaRosa, provided updates on SCDD activities held since the February 2024 SSAN meeting and information on how California's projected budget deficit may impact SCDD and services and supports for people with intellectual and/or developmental disabilities (I/DD). The State is planning to address the budget deficit by drawing money from its 'rainy day' fund. Members shared concerns about a proposed delay in raising pay rates for providers, as they may not be able to provide services to people with I/DD, as a result.



DRAFT

This agenda item also included status updates on Self-Determination Program (SDP) enrollment, and the legislation that SCDD is supporting. As of March 31, 2024, there were 4,242 regional center clients are enrolled in SDP. Unfortunately, there continues to be an under-representation (less people enrolled) of minorities within the program. Members expressed concern about the decline of in-person self-advocacy participation in many regions and that the high level of effort needed to participate in self-determination was making it hard for regional center clients to participate and understand the program.

The last update included in this item was about sheltered workshops. Since last year, the number of people in sheltered workshops has been cut in half and SCDD looks forward to helping lower that number to 0 (zero) by 2025.

5. Updates on the Master Plan for Developmental Services

SSAN members Nicole Patterson, Kecia Weller, and Lisa Cooley provided an update on the development of the Master Plan on Developmental Services. Development of the Master Plan on Developmental Services is still in the early stages and is a collaborative effort between representatives from different agencies, organizations, and advocates. The goal is to have a comprehensive plan drafted by March 2025. The committee developing the Master Plan is using input from focus groups, round table discussions, and comments from meetings and submitted to <mailto:DSMasterPlan@chhs.ca.gov> to guide the development process. Please visit <http://www.chhs.ca.gov/home/master-plan-for-developmental-services/> to learn more about the development process.

Members shared that access to grief counseling, resources on how to cope with loneliness, accessing affordable and accessible housing, and training on how to interact with people with I/DD for medical and mental health professionals, emergency responders, and law enforcement should be addressed and included in the master plan. The committee developing the master plan is looking for people to participate in future working groups. Members interested in joining the master plan workgroup were encouraged to let Nicole Patterson know.



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6. June 2024 Voices of SSAN Newsletter

This item was tabled for time. The June Edition of the Voices of SSAN Newsletter was included in the June meeting packet on pages 19-34. An email will go out to members about the September Newsletter focused on Employment next week. Tip sheets on how to write an article for the SSAN newsletter can be found on pages 35-38 of the June Packet.

7. SSAN Tip Sheets

This item was tabled for time. Material related to this agenda item can be found on pages 39-47 of the June Meeting Packet.

8. Adjournment

The June 2024 SSAN meeting was adjourned at 2:42 PM.



DRAFT

SSAN VOTE LOG: JUNE 2024

Name	Region	Roll Call	Motion 1
Alex Reyes	SCDD	In-Person	For
Sonya Force	North Coast	Virtual	For
Charles Nutt	North State	In-Person	For
Lisa Cooley	Sacramento	In Person	For
Ellen Sweigert	North Bay	Virtual	For
Sara Desumala	Bay Area	In-Person	For
Robert Balderama	North Valley Hills	Absent	Absent
David Forderer	Central Coast	Virtual	For
Rebecca Donabed	Sequoia	In-Person	For
Julie Gaona	Los Angeles	Virtual	For
Sean Sullivan	Orange County	In-Person	For
Eric Aguilar	San Bernardino	Virtual	For
Viri Salgado	San Diego	Virtual	For
Desiree Boykin	ARCA	In-Person	For
Russell Dawson-Rawlings	CFILC	Absent	Absent
Vacant	YO! Disabled & Proud	Absent	Vacant
Nicole Patterson	DDS	In Person	For
Scott Barron	DRC	Virtual	For
Wesley Witherspoon	USC – CHLA	In-Person	For
Kecia Weller	UCLA Tarjan Center	In-Person	For
Robert Levy	UCD MIND Institute	Virtual	For

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SEPTEMBER 4, 2024

**SSAN MEETING DAY 1 AGENDA ITEM 4
INFORMATION ITEM**

Statewide Self-Advocacy Network

SSAN Tip Sheets

The SSAN Tipsheet Workgroup will take a moment to share with members the 4 employment-related tipsheets they have created as a SSAN Resource and would like to know if there are any other tipsheets that they should create on the topic of employment. Please come prepared to share your ideas!

The Success Stories Workgroup has also created a tipsheet to share with members about how to tell your story.

Attachments

- SSAN How to Write a Resume Tipsheet
- SSAN Reasonable Accommodations Tipsheet
- SSAN Dressing for Success Tipsheet
- SSAN Sample Interview Questions Tipsheet
- SSAN Tell Your Story Tipsheet

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SSAN Tipsheet: Résumé



The goal of writing a résumé is to quickly show employers that you are a great fit for the job. Résumés are tools that help employers get an idea about your paid and volunteer work experience.

Name and Contact Information

- ✓ Your phone number
- ✓ Remember to use a professional email address (no nicknames)
- ✓ Links to a professional profile, like LinkedIn
- ✓ Your mailing address is optional

Experience

- ✓ Employment history
- ✓ Volunteer work (e.g. boards, commissions, hiring teams &/or similar work)
- ✓ Include keywords from the job description
- ✓ Talk about your impact at each organization, when possible

Education

- ✓ List your most recently completed educational level or degree
- ✓ Provide important certificates or awards that showcase your skills
- ✓ If you don't have completed educational experience, include related coursework

Additional Key Skills

- ✓ Volunteer work - connect your volunteer work with your skills (only if you didn't already include it in your work history section)
- ✓ Awards
- ✓ Achievements
- ✓ Interests and hobbies

References

- ✓ Use the phrase "References available upon request" on your résumé
- ✓ Prepare a list of references for people who can speak to your experience

**** Note:** There are different résumé formats; choose one that fits you and your professional background. Here is a link to some free sample résumé examples: <https://novoresume.com/resume-templates> **



SSAN Tipsheet: Dressing for Interviews



Why what you wear is IMPORTANT

Even though we think that our skills and abilities get us the job, appearance does count. First impressions are made within five minutes of meeting someone, so it is important to dress professionally when meeting potential employers.

Interview Clothing

- Clothes must be clean and not wrinkled
- Slacks, dress, or skirt in neutral colors - charcoal, black, or navy
- Collared, button-up shirt or blouse in white, black, or a soft, solid color
- Suit (pants and jacket in the same neutral colors - charcoal, black, or navy)
- Make sure the clothing you choose to wear works for your body type and fits well (not too tight or loose) and you can comfortably move without your clothes pulling too much

Footwear

- Wear closed-toe dress shoes that match your outfit and avoid wearing sneakers, sandals, or flip-flops
- Shoes should be polished and in good condition
- Be sure to wear socks that cover your calves

Grooming

Practicing good personal care is very important

- Shower or bathe
- Brush your teeth
- Wear deodorant

Hair

- ✓ When selecting a hairstyle, the simpler the look, the better
- ✓ Ensure that your hair is well-kept and will remain out of your face to avoid distractions
- ✓ If you have facial hair, ensure it is neat and trimmed.

Nails

- ✓ Nails should always be kept clean
- ✓ Use a neutral color, if wearing nail polish

Makeup

- ✓ If you wear makeup, a natural look is better
- ✓ Avoid makeup products that glitter or shimmer

Jewelry

- ✓ Any necklaces, earrings, or rings (accessories) that you choose to complement your outfit should be simple



SSAN Tipsheet: Reasonable Accommodations



Reasonable accommodations are the ways to make changes to the job or environment that allow a qualified individual with a disability to have an equal opportunity to employment.

Why?

You should request a reasonable accommodation if:

- ★ There is a barrier that makes it difficult for you to participate in the hiring process
- ★ There is a barrier that makes it difficult for you to perform your job
- ★ There is a barrier that makes it difficult to meet the job requirements
- ★ There is a barrier that makes it hard to access other benefits of employment

When?

- ★ You can request an accommodation when applying for a job
- ★ Request any accommodations necessary for an interview at least 2 days before your interview
- ★ After receiving a job offer
- ★ After gaining a temporary/permanent disability
- ★ When your disability or job changes

** Keep in mind that you are not required to request a reasonable accommodation until after an employer has made a job offer or after you discover that you need an accommodation to perform the job. **

How?

- ★ You can request a reasonable accommodation from your employer either verbally or in writing. It may be wise to request the accommodation in writing, so you have a record of your request. Here is a link to some samples of plain language letters you can use:

<https://askjan.org/articles/Sample-Language-for-Accommodation-Request-Letters.cfm>

Additional Tips:

- ★ Read the job description first to understand what will be expected of you
- ★ Some reasonable accommodation may need more time to prepare or use
- ★ It may require a personal conversation between an employer and employee (or potential employee, if they are interviewing for a job)
 - **Example:** needing to schedule an in-person interview at least two days ahead of time to help an interviewee who is dependent on transportation.
 - **Example:** Asking for the list of interview questions ahead of time
 - **Example:** Asking to use adaptive software for any writing samples during an interview
- ★ You don't need to be overly specific about your disability or disabilities to ask for or to get an accommodation
- ★ Accommodations don't have to be complicated or expensive
 - **Example:** An employee that can take notes during a meeting for another employee or job candidate who has difficulty with writing and listening at the same time



SSAN Tipsheet: Preparing for an Interview



There are many different questions that employers can ask during an interview. Some questions may be specific to the position, so be sure to read the job description carefully and think of examples of how your experience relates to the job.

Examples of questions that you should be prepared to answer in an interview:

1. Why should we hire you?
2. What are your strengths/weaknesses?
3. What is your greatest accomplishment?
4. How do you handle stress?
5. How do you work in a team setting?
6. Where do you see yourself in 5 years?
7. How would you describe yourself?
8. How do you deal with conflict?

**** Be mindful of how long your interview is scheduled for when answering interview questions. ****

Questions to think about when considering a job opportunity:

1. What are your salary expectations/needs?
2. If you receive SSI, how will it be affected by this job?
3. Is the position full-time or part-time?
4. What are the hours/schedule for the job?

It is also a good idea to think about questions that you may want to ask at the end of the interview:

**** Don't feel like you have to ask all of these questions. Choose one or two that you want to know the answers to the most. ****

1. What is your process for requesting for reasonable accommodations?
2. What is the team like that I would be working with?
3. What are some character traits that you are looking for in a successful candidate for this position?
4. What are the next steps in the hiring process?
5. Are there opportunities for training/growth/advancement within the department/organization/company?
6. What does a typical day at the job look like?
7. What is your management style?

General Interview Preparation Tips:

1. Plan your transportation route (e.g. bus, light rail/metro/trolley, taxi/rideshare, etc.)
2. Arrive at least 15 minutes before your interview start time
3. Remember to greet the people checking you in for your interview
4. Make sure your technology tools are working properly (e.g. computer, assistive technology, etc.)
5. Prep your clothes the day before (See the 'SSAN Dress for Success Tipsheet' for ideas)
6. Being nervous is normal and means that you care and want to do a good job. Remember to breathe - you have made it this far and they chose to interview you for a reason.



SSAN Tipsheet: Telling your Story



There are many ways for people to tell their story. The [SCDD Storyteller's Blog](#) was created by SCDD as a way for self-advocates, family advocates and professionals to share their experiences with others. Here are some tips to keep in mind when developing stories to share with others:

1. Introduce yourself and describe who you are

- ✓ Tell us your name and where you're from
- ✓ Why have you decided to tell your story (introduce your topic)?
- ✓ Who is your story meant for and why (e.g. people served, family, or providers)?

2. Include information related to the topic - good or bad

- ✓ It is important to give the reader or listener an example of any barriers you have experienced and what made you successful

3. Add personal details

- ✓ How have other people helped you in your life
- ✓ Who or what inspired you

4. Reflect on your past and how it shaped you

- ✓ Make sure when you're telling your story - you are balancing it between good and bad experiences
- ✓ Don't be afraid to show your personality

5. Stay organized

- ✓ **Beginning:** Talk about who you are and where you came from; introduce the topic and who you hope will get something out of your story.
- ✓ **Middle:** This is where you share personal details on what you're writing about, explain how it began, give an example of a time where it may not have gone so well, and end on a positive note that will be encouraging.
- ✓ **End:** Tie everything together and reflect on the past and how it shaped you today (this is another place where you can be encouraging to the reader).

6. Before submitting your story in writing, have someone else read it

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SEPTEMBER 4, 2024

**SSAN MEETING DAY 1 AGENDA ITEM 5
INFORMATION ITEM**

Statewide Self-Advocacy Network



SCDD Update

SCDD Executive Director Aaron Carruthers will update SSAN members on Council activities related to meeting the needs of Californians with I/DD during these challenging and unique times.

Possible Handouts

- Council Meeting Summary

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SEPTEMBER 4, 2024

**SSAN MEETING DAY 1 AGENDA ITEM 6
INFORMATION ITEM**



Statewide Self-Advocacy Network

Voting is Your Voice and Your Choice

Disability Vote California is a nonpartisan, collaborative project between the Arc of California, State Council on Developmental Disabilities (SCDD), Disability Rights California (DRC) and California Foundation for Independent Living (CFILC) that started in 2018. Disability Vote California works to educate Californians with disabilities on the voting process and build leaders throughout California who can educate their communities and encourage people with disabilities to participate in the voting process.

Representatives from #DisabilityVoteCA will provide an overview of the upcoming 2024 election cycle.

Presenters

Gabe Taylor, Disability Rights California, Senior Advocate,
Voting Rights Practice Group

Russell Rawlings, California Foundation for Independent
Living Centers, Community Organizing Manager

Wesley Witherspoon, USC Children’s Hospital,
Consumer Advocate

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SEPTEMBER 4, 2024

**SSAN MEETING DAY 1 AGENDA ITEM 7
INFORMATION ITEM**

Statewide Self-Advocacy Network



Disability History

Rebecca Donabed will share her presentation on disability history with members.

Presenters

Rebecca Donabed, SSAN Secretary, SCDD Sequoia Regional SSAN Representative

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SEPTEMBER 4, 2024

**SSAN MEETING DAY 1 AGENDA ITEM 8
INFORMATION ITEM**

Statewide Self-Advocacy Network



Reflections for the Day

This agenda item is meant to give members a chance to reflect on the day's discussions and agenda items.

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SEPTEMBER 5, 2024

**SSAN MEETING DAY 2 AGENDA ITEM 3
INFORMATION ITEM**



Statewide Self-Advocacy Network

Understanding DOR Services

A representative from the Department of Rehabilitation (DOR) will provide members with an overview of DOR services. This agenda item will give members the chance to provide feedback on how to support people with I/DD who are looking for support in their employment journey.

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SEPTEMBER 5, 2024

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

Statewide Self-Advocacy Network



Updates on the Master Plan on Developmental Services

What the Master Plan Committee for the Developmental Services System wants to achieve by March 2025:

- A plan for the future of developmental services to effectively provide equitable, consistent, and accessible services to all Californians with developmental disabilities.
- A plan for the entire lifespan of people with developmental disabilities, created with and by our partners across the state, and centering on the diverse voices of people with lived experience.
- A goal to modernize the system, in which the state pays for services based on quality services for the whole person - across all stages of life and across all diverse communities.

This agenda item will give members with the chance to hear from SSAN members who are involved in the development of the Master Plan on Developmental Services.

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SEPTEMBER 5, 2024

**SSAN MEETING DAY 2 AGENDA ITEM 5
INFORMATION ITEM**

Statewide Self-Advocacy Network

Planning for the SSAN Annual Report



SSAN Members will have a chance to reflect on the year's activities and talk about what should be included in the SSAN Annual Report.

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SEPTEMBER 5, 2024

**SSAN MEETING DAY 2 AGENDA ITEM 6
INFORMATION ITEM**

Statewide Self-Advocacy Network



September 2024 Edition of Voices of SSAN Newsletter

Robert Levy, Chair of the SSAN Newsletter Workgroup, will present SSAN members with a DRAFT version of the September 2024 Newsletter and ask members for any changes or additions. Robert will lead a discussion about ideas for the December 2024 Newsletter, so please come prepared with your ideas of the types of articles you would like to write for the next edition.

Attachments

- September 2024 Voices of SSAN Newsletter
- Voices of SSAN Newsletter Article Tips Newsletter Article Tips

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IN THIS EDITION:

This Edition of the Voices of SSAN Newsletter focuses on the topic of employment since October is celebrated as National Disability Employment Awareness Month (NDEAM).

Front Page: Celebrate NDEAM

Page 2: Peer Advocacy Connection

Page 3: 2024 NACDD Conference

Page 4: Mains' I Community Employment Program

Page 5: San Diego People First

Page 6: Community Resources

Page 7: Steps for Self-Advocates

Page 9: UCD MIND Institute

Page 10: Turning Concern into Action

Page 11: Disaster Preparedness for Pets

Page 11: SCDD Storytellers

Page 12: History of PEC & CES

Page 13: Kudos Corner

Page 14: Disability Reads and Listens

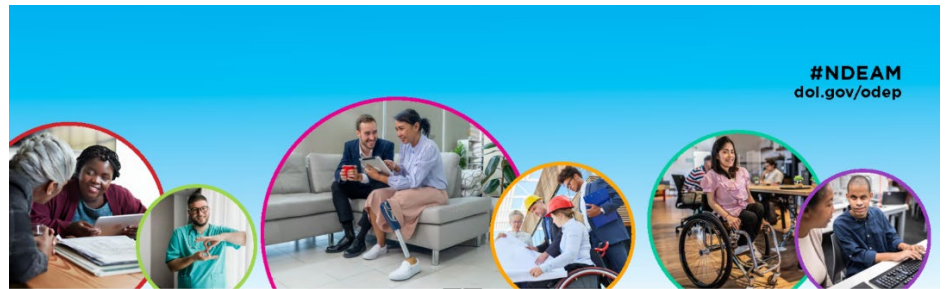
Page 15: DDS CAC is Recruiting

Editor: Robert Levy

Contributors:

- Lisa Cooley
- Wesley Witherspoon
- Charles Nutt
- Viri Salgado
- Robert Levy

More about this Edition's Theme



America has celebrated the important role people with disabilities play in our workforce since 1945. The month of October was officially recognized as National Disability Employment Awareness Month (NDEAM) by Congress in 1988. In honor of this SSAN uses the September issue of Voices of SSAN to highlight the issue of employment. The theme for this year is “Access to good jobs, every month of the year.” You can read more about how to participate in NDEAM by checking out the US Department of Labor’s [NDEAM landing page](#).

This edition highlights regional self-advocacy events, coalitions, shares some promising practices of regional employment agencies, advocacy tips, and resources. The SSAN Leadership team would like to thank members who wrote articles and shared information for this issue of Voices of SSAN.



Peer Advocates Connection Meeting

By: Lisa Cooley, Sacramento Regional SSAN Representative

The Peer Advocacy Connection, sometimes shortened to PAC is a self-advocacy group within the Sacramento region that has members from Colusa, Sutter, Yuba, Sierra, Nevada, Placer, El Dorado, Alpine, Sacramento, and Yolo Counties. PAC is supported by the Supported Life institute. PAC held their first meeting of the year on April 6th, 2024, at the Wyndham Hotel in Sacramento. The agenda for the day featured different advocates sharing their advocacy and employment journeys. Advocates shared their life journeys with Cerebral Palsy, vision impairment, and their struggles to find employment.

Two speakers shared their employment journeys. The first presenter, Thomas Hopkins shared his frustrations of working in a sheltered workshop. A sheltered workshop is a day program where people with intellectual and developmental disabilities do simple work activities for sub-minimum wages. Tom didn't like how he would do the same thing every day. Tom joined Capital People First to learn how to speak up for himself. Because of advocacy, Tom now works with the Supported Life Institute, providing support and mentorship to the PAC and other self-advocates in the region. Another presenter talked about their fun job working at a doggy daycare, watching animals whose parents were at work. Work looks different for everyone, and it was cool hearing about different examples of work.

A common theme at the meeting was the need for a steady support system. Attendees and presenters shared stories about their struggles to find support and having to rely on family members to be a vital part of their support system. Attending regional self-advocacy meetings, events, and conferences is a great way to connect with the community and learn from other advocates. I encourage you to ask your local Regional Center, SCDD Office and/or independent living center (ILC) for information about upcoming regional meetings near you.



2024 NACDD Conference

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



On July 22-26, 2024, the National Association of Council on Developmental Disabilities (NACDD) conference took place in Washington D.C. at Capitol Hilton. This year, the theme was “A World of Opportunities”.

The annual NACDD conference is a great way to network with other Chairs and Executive Directors. I met with Council Chairs and Executive Directors from 50 states and 6 territories. I led a session about healthy relationships to over 20 people. My panel was Tia Nelis from TASH and Presidential Council of Developmental Disabilities, Max Barrows Outreach Director Green Mountain Self-Advocates, and Frank Vaca, sexuality educator and peer mentor from Michigan.

I had the chance to tour a few the Smithsonian Museums including the African American museum, United States Holocaust Museum, and Air and Space Museum. I took the subway (called the metro in D.C.) by myself. I had a chance to meet up with Rebecca Donabed as she attended the National Council of Independent Living (NICL) conference in Washington DC from July 22-25. Together we visited the Museum of Illusions in Washington DC. I enjoyed DC and can’t wait to come back to Washington DC.

SSAN Members

- Sonya Force – North Coast
- Charles Nutt – North State
- Lisa Cooley – Sacramento
- Ellen Sweigert – North Bay
- Sara Desumala – Bay Area
- Robert Balderama – North Valley Hills
- David Forderer – Central Coast
- Rebecca Donabed – Sequoia
- Julie Gaona – Los Angeles
- Sean Sullivan – Orange County
- Eric Aguilar – San Bernardino
- Viri Salgado – 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
- Alex Reyes – SCDD

Mains'I Community Employment Program

By Charles Nutt, SCDD North State Regional SSAN Representative



On June 28, 2024, I interviewed Joseph Klobas, Job Developer Supervisor from Mains'I. I learned their Community Employment Program offers 2 employment opportunities.

Mains'I Community Employment Program incorporates the philosophy of Employment First and serves as the foundation to how they engage with the community, believing all people, including people with the most significant disabilities, can work, with or without support.

One of the services is the **Paid Internship Program** and the other is called **Direct Hire**, which means individual job development services to be hired directly by an employer. All people who are referred to the Community Employment Program are required to participate and complete the **Prep Academy**, which is a pre-employment training course that is 2x/week for 2 months (40-hour curriculum). This required course includes all skills and aspects that one needs to acquire a job in the community. Examples of topics covered in this course include: communication skills, interpersonal skills, developing a resume, good hygiene skills, being responsibility on the job and job environment.



The **Paid Internship Program** helps people identify the type of work/internship they want to experience, and the type of skills and requirements needed for the job. Then, the program's job developers build relationships with community employers that match the type of work or position the person is interested in experiencing. Each internship lasts up to one year with the goal that it will lead to a "direct hire" which means the employer hires the intern. The Paid Internship Program also assists in developing a resume and covers the person's salary and workers' compensation.

To receive employment services from Mains'I Community Employment Program, a referral is needed from Far Northern Regional Center. However, the Paid Internship Program is statewide through all the regional centers who contract with local vendors who provide employment services. If you want employment, talk to your service coordinator to learn more about Paid Internship Programs that are available in your region.



Celebrating the 30th Anniversary of San Diego Annual People First Advocacy Conference

By Viri Salgado, San Diego Regional SSAN Representative

It is with great pride and joy that we celebrated the 30th anniversary of San Diego People First Annual Advocacy Conference, which was held on June 7th & 8th, 2024.

This year marked another incredible milestone in our journey towards promoting inclusivity, advocating for disability rights, and celebrating the abilities of our diverse community. Through the dedication and support of our volunteers, sponsors, and attendees, we continue to break down barriers and foster a more inclusive event. This self-advocacy conference is run by self-advocates for self-advocates coming together and learning about strategies to live a full and productive life. This year's theme "Self-Advocates Take Charge and be the Change", highlighted the opportunity to connect and learn with our community. After so much planning and hard work, it was very rewarding to see everything come together for a successful celebration. We had over 300 attendees which included self-advocates, support staff, parents and community partners.

The SDPF Conference featured:

- **Inspirational Speakers:** This year, Wesley Witherspoon, Chair of the California State Council on Developmental Disabilities was our keynote speaker and did a great job at sharing what advocacy is all about. We also had a speaker panel of Self-Advocates who have been members of San Diego People First for more than 20 years and shared their life experience through advocacy.
- **Street Fair:** People with disabilities including bakers, artists, crafts people and small business owners showcased their creativity and talent.
- **Resource Fair:** Our resource fair provided information and support for individuals with disabilities and their families as well as highlighting the work of our sponsors.
- **Inclusive Activities:** Interactive workshops and games encouraged participation and education about various disabilities such as, the Voter's Experience, Self-Determination Experience, Vision Board Activity and Adaptive Martial Arts.

The 2024 San Diego People First Conference welcomed approximately 300 attendees from diverse backgrounds and abilities. We provide an opportunity for disability communities from a variety of places to convene and celebrate together annually.

Continued on page 6 of September Voices of SSAN Newsletter "San Diego PFC"



Continued from page 5 of September Voices of SSAN Newsletter "San Diego PFC"

The conference had a significant impact on our community because self-advocates came and shared their stories, their wisdom, and their joy together. It also Fostered a sense of belonging and pride within the disability community; people came to count on this annual event, and we believe this pride lifts people up throughout the year.

As we reflect on the success of the 2024 San Diego People First Conference, we are energized and inspired to continue our work in promoting disability pride and advocating for a more inclusive society. We look forward to having our next conference through collaboration, strengthening partnerships with local disability organizations and provide a platform for individuals with disabilities to showcase their talents.

I feel so grateful to be a part of the San Diego People First team! I have learned so much since I joined the group and met wonderful people. I would like to express my deepest appreciation to all the volunteers, speakers, artists, performers, and attendees who made the 2024 San Diego People First 30th Anniversary Conference a memorable and impactful event. We are PeopleFirst!

Community Resources



[SARTAC Zoom Meetings](#)



[ARCA Public Policy Resources Library](#)



[DRC's Resource Library](#)



[CalABLE](#)



[National Council on Disability](#)

An independent federal agency committed to disability policy leadership since 1978

[National Council on Disability](#)

[Social Security Administration's Ticket to Work Program](#)





Helpful Steps for Being an Effective Self-Advocate

By Ellen Sweigert, North Bay SCDD Regional SSAN Representative

Here are some helpful tips on how to be a self-advocate and get involved in an issue that matters to you:

1. Believe in Yourself

You are a unique and valuable person. You are worth the effort it takes to advocate for yourself and protect your rights. You can do it! You may need to work on raising your self-esteem to really believe in yourself and become your own best advocate.

2. Know Your Rights

You are entitled to equality under the law. Some of us who have had mental health challenges erroneously believe that we do not have the same rights as others. I did for a while. I allowed people I did not know well and did not trust to make decisions for me and take control of my life. I now have systems in place so if I am not able to make good decisions for myself, others of my choice will make them for me.

3. Decide What You Need and Want

Clarify for yourself exactly what you need. This will help you set your own goals and help you be clear to others about what it is that you want and need for yourself.

4. Get the Facts

When you advocate for yourself, you need to know what you are talking about or asking for. The internet is an excellent source of information. However, you will need to check its accuracy by looking at several different references to see if they agree. Check with people who have expertise in what you are considering. Ask others who have issues similar to yours. Check references in the library. Contact mental health agencies and organizations for information and support.

5. Planning Strategy

Using the information you have gathered, plan a strategy that you feel will work to get what you need and want for yourself. Think of several ways to address the problem. Ask supporters for suggestions. Get feedback on your ideas. Then choose to take action using the one that you feel has the most chance of being successful.

Continued on page 8 of September Voices of SSAN Newsletter “Self-Advocacy Tips”



Continued from page 7 of September Voices of SSAN Newsletter “Self-Advocacy Tips”

6. Gather Support

In advocating for what you need and want for yourself, it is helpful to have support from family members, friends and other people who have similar issues.

7. Target Efforts

Who is the person, persons, or organization you need to deal with to get action on this matter? Talk directly with the person who can best assist you. It may take a few phone calls to discover which organization or person can help, or who is in charge, but it is worth the effort. Keep trying until you find the right person. Maybe the right person is your spouse or another family member. Perhaps it is the head of the local housing agency, your doctor, a case manager, a vocational rehabilitation counselor, or a state legislator.

8. Express Yourself Clearly

When you are asking for what you need and want for yourself, be brief. Stick to the point. Don't allow yourself to be diverted or to ramble on with unimportant details. State your concern and how you want things changed. If the other person tries to tell you reasons why you cannot achieve what it is you want for yourself, repeat again what it is you want and expect until they either give it to you, help you get it, or refer you to someone else who may be able to give you what you need. If you feel this may be difficult for you, you may want to role-play different scenarios with a supporter or a counselor.

9. Assert Yourself Clearly

Don't lose your temper and lash out at the other person, their character or the organization. Speak out, asking for what you need and want, and then listen. Respect the rights of others, but don't let them “put you down” or “walk all over you.”

10. Be Firm and Persistent

Don't give up! Keep after what you want. Always follow through on what you say. Dedicate yourself to getting whatever it is you need for yourself.



History of Employment at UCD MIND Institute

By Robert Levy, UC Davis MIND Institute UCEDD SSAN Representative

This year marks 26 years since the UC Davis Medical Investigation of Neurodevelopmental Disorders (UCD MIND) Institute opened its doors. Several families with children with different disabilities came together to advocate for the creation of a permanent research center to understand autism and other developmental disabilities and the latest technologies and treatment approaches at a permanent location. 8 years later, in 2006 the UCD MIND Insitute started a program called Center of Excellence for Developmental Disabilities or CEDD to help other people with disabilities to have a productive life.

UCD MIND has a few ongoing programs and projects that I want you to know about:

- The Summer Institute was started in 2006. The Summer Institute is a day-long conference program with different training sessions.
- The MIND Institute shares a lot of information, programs, and trainings on YouTube. One good thing about having an online presence is that we are able to expand our reach. People can now learn about our work, no matter where they are in the world.
- UC Davis MIND Institute has a few different social media like YouTube, Facebook, Twitter, and Instagram.
- In the fall of 2021 UCD MIND collaborated with the UCD Office of Diversity, Equity, and Inclusion to start a new program called Redwood Seed Program to provide students with I/DD the opportunity to access a college education.
- In 2021, UCD MIND received funding to research best practices on how to include people with disabilities in medical studies.
- UCD MIND supports the Northern California Business Council and LEND trainings during the period from September through May each year.

I do regular presentations at the Northern California Business Council, as well as module trainings for the UC Davis Medical Students each year for the UCD MIND Institute.

Dr. Aubyn Stahmer is the new Director of the UCD MIND Institute. Kudos to Dr. Aubyn Stahmer as she had already taken over for Dr Leonard Abbeduto who retired in April of 2024.

This work will never be done; there is always something to do by helping out people with disabilities have a productive life. If it wasn't for several families who had decided to develop this idea there wouldn't be the UCD MIND Insitute and I wouldn't have job over there and I wouldn't be representative for SSAN.



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.

Visit the [SSAN Page](#) on the SCDD website to check out past newsletters, annual reports, and meeting info. You can also navigate to the SSAN page by clicking on the “Self-Advocacy” tab at www.scdd.ca.gov.

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!

Tips for Turning Concern into Action

It can be hard to know what you can do to help advocate for change. SSAN members have shared some ideas on how you can turn your concerns and worries into action:



- Share your thoughts with family members and friends.
- Consider mentoring another advocate.
- Write down the issue or problem that you are having, then think about and make a list of your ideas about what would make the situation better. Is there anything on that list that you can do to make the situation better?
- Write a social media or blog post.
- Listen to, host, and/or be a guest on a podcast.
- Write a letter to the editor or an opinion piece for your local newspaper or organization’s newsletter.
- Contact to your local representatives about important issues.
- Get involved in your community by joining a club or board.
- Attend a city council meeting to share your concerns.
- Connect with your local regional center, independent living center, and/or State Council on Developmental Disabilities regional office and ask about their self-advocacy groups and trainings.
- Donate your time by volunteering for an organization.
- Join a board or commission like the [Department of Developmental Services Consumer Advisory Committee \(DDS CAC\)](#).
- Learn about the issues important to candidates running in upcoming local, state, and national elections. Let your voice and your choice be heard by voting.

Disaster Preparedness for Pets



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

Do you know that pets need to prepare for a disaster just like people? Your pet is an extended part of your family that you do not want to leave behind or unprepared in an emergency situation.

When planning for an evacuation, have emergency supplies and traveling kits on hand. Have supplies that you use for your pet (leash, litter box, toys, pet bed) available. Your pets also need food and water and other supplies that they use (like medicine). Have lift boxes so that they can travel with you. Prepare for fires, earthquakes, and power outages. It is a good idea to have enough supplies to last several days. Before an emergency happens, make sure that your pets are microchipped so you can track them in case you get separated during a disaster. If you have to leave your pets behind, make sure your neighbors and emergency responders know that you have pets, so that they can check on them.

Some cities and counties have emergency shelters just for animals, so it is a good idea to look that information up ahead of time. Have an plan in place for something happens to you so they can take care of your pets, leave the contact information of someone who can help your animals.



The State Council on Developmental Disabilities (SCDD) has a tool for advocates to share their story and wants to hear your’s. [Storytellers](#), a [blog](#) where people with disabilities, their family members, professionals who work in the field disability services can share their stories of successes and

struggles. Check-out [Cole’s Story](#) that was published recently.

You can find the Storytellers blog under the “News and Events” tab on the top of the [SCDD website](#) as “SCDD Blog”. We look forward to reading the next story, it might be yours!



History of Employment at PEC and CES

By Robert Levy, UC Davis MIND Institute UCEDD SSAN Representative

This year marks 29 years since since PEC/CES first opened its doors for business to serve and support people with disabilities in finding and keeping jobs. During the last 29 years there have been a lot of clients and staff that came and gone. There have been a lot of changes on how PEC / CES works today from when it first started. Here are some highlight:

- Staff are able to work from home
- We are supporting weekly Talk O Tuesday's with a CES client.
- In the fall of 2022, PEC/CES started quarterly newsletter issues written by both staff and clients
- The team has done a lot of fundraisers like bingo, hosting a trivia night, Inclusion celebration, and scavenger hunt.
- Every year before covid hit even Christmas holiday staff/ client parties too. Now PEC/CES split up into teams based on the office location or project to have celebrations.
- PEC/CES supports a program for Micro Enterprises called Lending Works INC that helps the clients at PEC/CES by providing them with business loans to get started. Lending Works also gets support from Alta Regional Center. You can learn more about Lending Works INC at: [Lending Works INC Website](#).
- PEC/CES supports clients who want to start micro enterprises in June of 2007 and the will continue as long as there are clients who find meaning and passion in their businesses.

The great thing about PEC/CES is their investment in the discovery process, helping clients find out what they are passionate about and supporting their needs and efforts. So happy 29th anniversary PEC and on the 30th anniversary next year when it will be a great celebration by reaching a milestone a 3rd decade of business then. So Kudos to, Carole Watilo for helping out all of us clients with disabilities to have a productive life and become successful over the years.



Kudos Corner



When someone does a good job or achieves a goal, people sometimes say “Kudos to you”. Since June 2019 SSAN has used the Kudos Corner as a way to recognize SSAN members for their local and statewide advocacy work. Each quarterly newsletter has highlighted the accomplishments of a different SSAN member. For the September 2024 Issue we are celebrating and giving kudos to Ellen Sweigert, who has represented the North Bay region on SSAN since September 2020.

Here are a few highlights of what Ellen’s accomplishments. Ellen is passionate about advocacy and has been a regular contributor to Voices of SSAN. Before joining SSAN, Ellen was involved with Easterseals and the North Bay Regional Advisory Committee (RAC). Ellen participated in the California Youth Leadership Forum (YLF) where she learned how to advocate for herself. In 2008, she had to put her advocacy skills to the test when she was diagnosed with cancer. Advocacy helped her to find hope. Ever since, she has worked on finding ways to help others find hope too. Since March 2022, Ellen has worked as the Consumer Advocate at the North Bay Regional Center, where she serves as a resource and mentor for other self-advocates.

Ellen is currently working on putting together a workshop to help advocates find their advocacy platform. Ellen hopes to help grow SSAN membership, awareness, and participation in SSAN activities. Kudos to you Ellen!



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Disability-Related Reads

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



[Disability Scoop](#) is an online resource with disability-related news.



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



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



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

Learn About SSAN Member Organizations

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

Disability-Related Listens

Click on the logos to check out some creative content on disability related topics.



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 (SDP). Talk to your regional center service coordinator to learn more.



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DDS' CAC is RECRUITING!

The Department of Developmental Services (DDS) Consumer Advisory Committee (CAC) needs your voice to advise DDS on policies, programs, legislation, and regulations that affect the lives of Californians with intellectual and developmental disabilities.

Please note: Regional Center employees are not eligible for CAC membership.



Interested advocates should fill out the online [DDS Consumer Advisory Committee Application](#) and submit it with their nomination letter.

Registration is now open for the [38th Supported Life Institute Conference](#), which is a place for professionals, family members, and self-advocates to come together to learn about supports for people with disabilities to be fully included in their communities. Take a look at their [Digital Program](#) to learn more about the sessions being offered at the conference.

Check out the [Competitive Integrated Employment \(CIE\) Blueprint Landing Page](#) on the California Health and Human Services website.

Learn about how the [California Department of Rehabilitation \(DOR\)](#) can help you on your employment journey.

SAVE THE DATES

Disability Rights California



[Events and Trainings](#)

CalABLE



[News and Trainings](#)



[DO Network Training Library](#)

Plain Language Resources

Available on:

[SCDD Website](#)

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



[Current Issues and Resources](#)

[Voting Resources](#)

DRC Hotline: 888-569-7955

[Disability Vote California](#)

Questions about the Self-Determination Program? [The Self-Determination Advocates Leadership Group](#) meets monthly on Zoom.

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Voices of SSAN Newsletter Article Tips

Audience: Keep in mind that “Voices of SSAN” is shared with people across California. Try to write articles that would interest the statewide disability community.

Purpose: Is the article a human-interest story or an issues story? If it is a human-interest story, can you tie it back to an issue or larger regional or statewide problem?

Helpful Tips:

- Tie your article back to the Mission/Vision/Purpose of SSAN
- Articles should be about systemic (city/county/regional/statewide) problems
- Limit individual advocacy articles
- Stay away from writing about personal details of an individual

Types of Articles: Articles in “Voices of SSAN” should be related to the SCDD State Plan. The SCDD State covers topics of Self-Determination, Employment, Housing, Health and Safety, Transportation and other Long-Term Services and Supports (LTSS). Article types can include:

- Informational and Resource Sharing (you want the reader to learn something)
- Call-to-Action (you want the reader to do something)
- Event Recaps
- Bios and interviews help SSAN and learn about people
- “Kudos Corner” articles are recognize the advocacy efforts of others
- Announcements and Save the Dates

Key Parts of Articles:

- Title
- Author (Your Name)
- Introduction: Tie the article back to SSAN
- Evidence or Support: 1-3 paragraphs
- Closing: Tie it back to SSAN



Voices of SSAN Interview Article Tips

Audience: Keep in mind that “Voices of SSAN” is shared with people across California.

Choosing a Person to Interview:

- Is the person a regional/statewide/national/international leader?
- Does the person have the ability to affect change?
- Does the person have a story or experience people with disabilities from across California can relate to?
- Is the person making positive impact/or change that can be shared with other regions/organizations to improve their practices?

Choosing a Message

- What do you want the reader to learn from reading the article? Make sure you have a clear purpose in mind when writing
- Do you want to inspire others to do something like get involved in a project or campaign?

Choosing Your Interview Questions

- Ask questions that relate to SSAN, self-advocacy or the focus areas in SCDD’s State Plan
- Choose questions that relate to your message
- Ask open ended questions that will allow the person to respond in detail.
- Avoid questions that can be answered with a simple “yes” or “no”

Writing Your Interview Article

- Add your own thoughts in response to what the interviewee has said
- Use the interview’s responses to shape your article instead of having a question/answer format
- Remember your audience and purpose when writing your interview article



Voices of SSAN Kudos Corner Article Tips

When someone does a good job or achieves a goal, people sometimes say “Kudos to you”. SSAN started the Kudos Corner in June 2019 as a way to recognize SSAN members for their local and statewide advocacy work.

This tip sheet is designed to help members write future Kudos Corner Articles. Here are some important things to include in articles of recognition:

1. Name of person receiving kudos
2. Region/Organization they are with
3. How long they have been on SSAN
4. Their Advocacy/SSAN Achievements
5. Examples of how they have helped other SSAN members and/or other advocates (mentorship)
6. Their hopes and dreams for SSAN and the Self-Advocacy Movement in CA, US, and Globally



Voices of SSAN Member Highlight Article Tips

A member highlight or sometimes called a “bio” is a way for SSAN and readers of the Voices of SSAN Newsletter to learn more about a new member of SSAN. Here are some tips for what kind of information should be included in a Member Highlight Article.

1. Name
2. Region/Organization
3. How long they have been on SSAN
4. How did you learn about SSAN
5. What made you want to join SSAN
6. Any advocacy accomplishments
7. Why the joined SSAN
8. What they hope to learn or gain from being a member of SSAN

SEPTEMBER 5, 2024

**SSAN MEETING DAY 2 AGENDA ITEM 7
INFORMATION ITEM**

Statewide Self-Advocacy Network



Meeting Takeaways and Planning for December 2024

The SSAN Chair will lead the group in a discussion about potential agenda items for the December 2024 meeting. Members will also have the chance to share their thoughts on how the September meeting went.

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