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STATEWIDE SELF-ADVOCACY NETWORK (SSAN) **MEETING INFORMATION**



DATE: Thursday, June 6, 2024



TIME: 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

MEETING DETAILS:

Physical Location:

Holiday Inn Sacramento Downtown

300 J Street

Sacramento, CA 95814

ZOOM LINK:

<https://bit.ly/SSAN2024June>

Call-in Information:

CALL IN NUMBER: (669) 900 9128

MEETING ID: 891 3374 0369

PASSCODE: 164616

Accessibility

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MEETING AGENDA

June 6, 2024

10:00 AM – 3:00 PM

1. Call to Order, Welcome and Introductions

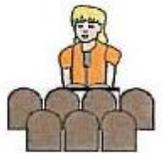
Presented by:

- Charles Nutt, Chairperson
- Nicole Patterson, Vice-Chairperson
- Rebecca Donabed, Secretary



2. Public Comment

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



3. Review and Approval of February 2024 Minutes

Presented by: Charles Nutt, Chairperson

ACTION



3. SCDD Update

Presented by: SCDD Headquarters Staff

Information



4. Updates Master Plan on Developmental Services

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

Information



5. Lunch Break



6. June 2024 Edition of Voices of SSAN Newsletter

Presented by: Robert Levy, Newsletter Workgroup Chair

Information



7. SSAN Tipsheets

Presented by: SSAN Tipsheet Workgroup

Information

8. Adjournment



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JUNE 6, 2024

SSAN MEETING AGENDA ITEM 3

ACTION ITEM

Statewide Self-Advocacy Network

Approval of February 2024 Minutes



Attachments

- February 2024 Minutes

Recommended Action

Approve the February 2024 SSAN meeting minutes

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Statewide Self-Advocacy Network Meeting Minutes

February 28-29, 2024 (Zoom)

SCDD Regional Members Present

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

Agency Members Present

Scott Barron – DRC
Desiree Boykin – ARCA
Jason Cook-Harvey – YO Disabled and Proud
Russell Dawson - Rawlings – CFILC
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
Alex Reyes – SCDD
Ellen Sweigert – North Bay

SCDD Staff in Attendance

Rihana Ahmad – SCDD HQ
Veronica Bravo – SCDD HQ
Aaron Carruthers – 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

Susan Crow – Department of Developmental Services
Gabe Taylor – Disability Rights California



DRAFT

Day 1: 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, and an important issue facing their communities. Members mentioned improving Self-Determination, disability organization and coalition-building, creating healthy relationships, climate change, accessible public transportation, and affordable housing as significant issues.

2. Public Comment

There was no public comment.

3. Review and Approval of December 2023 Minutes

The members reviewed the minutes from the meeting on December 12th, 2023. Materials for this agenda item can be found on pages 5-12 of the February 2024 SSAN meeting packet.

ACTION: Motion #1, to approve the December 2023 minutes, was made by Kecia Weller and seconded by Sonya Force. A roll call vote was taken. Motion passed. See Vote Log on page 5.

4. SCDD Update

The State Council on Developmental Disabilities (SCDD) Executive Director, Aaron Carruthers, provided updates on SCDD activities held since the September 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. 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.



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5. Energizing the Disability Vote

Representatives from Disability Vote California provided SSAN members with an overview of the types of issues and decisions voters will be asked to make during the March 5th primary election. This presentation covered the history of Disability Vote California, the different voting options available to voters, an overview of the Voters' Choice Act, and ideas for how people with disabilities can engage in the voting process. Members were encouraged to report any voting access issues to the Disability Rights California Voter Hotline at (888) 569-7955. Members shared concerns about ensuring that their votes are secure, regardless of party preference. Members also asked about the possibility of voting by email.

6. HCBS Final Rule

Susie Crow, the Department of Developmental Services' (DDS) Chief of the Home and Community Based Services (HCBS) Division, provided members with an overview of recent updates to the HCBS Final Rule. Members shared concerns that the HCBS Final Rule is not being followed the same way through every regional center and/or provider. For more information on this topic, visit the [DDS HCBS Hub](#). DDS also has [HCBS Training Information](#) that members were encouraged to review.

7. Reflections on the Day

SSAN members shared their reflections from Day 1 of the February SSAN meeting.

8. Recess

At 2:18 PM, SSAN Chair, Charles Nutt, declared the meeting in recess until 10:00 AM the next day.



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DAY 2: SSAN Minutes

1. Call to Order, Welcome and Introductions

SSAN Chair Charles Nutt called the meeting to order at 10:05 AM.

2. Public Comment

There was no public comment.

3. Accessible Transportation Planning

Mark Barry, Branch Chief of the Division of Rail and Mass Transportation (at CalTrans), within the Federal Transit Administration's (FTA) §5310 Program, and Kathy Pongratz, Chief of the FTA §5311 and Intercity Bus Branch (also at CalTrans) provided a presentation from the Department of Transportation on their Federal Transit Administration (FTA) 5310 Program that provides funding to private nonprofit groups and qualifying public agencies to meet the transportation needs of older adults and people with disabilities. SSAN members were encouraged to work with their local transportation agency to improve accessibility and to let them know about the California Department of Transportation's (DOT) funding opportunities.

4. SCDD Legislative Update

SCDD Policy Analyst, Veronica Bravo, provided SSAN members with an overview of the legislative process and the SCDD policy priorities for 2024, which focus on work, home, and health. SCDD's Legislative and Public Policy Committee (LPPC) will be meeting on March 14th to recommend a slate of bills for the Council to support in 2024. Materials for this agenda item can be found on pages 25-28 of the February SSAN meeting packet.

5. Approval of the February 2024 Voices of SSAN Newsletter

As the SSAN Newsletter Project Lead, Robert Levy reviewed the DRAFT February 2024 Voices of SSAN Newsletter. Project Lead Levy called for a motion to approve the February 2024 Edition. Materials for this agenda item can be found on pages 29-48 of the February 2024 SSAN meeting packet.

ACTION: Motion #2 to approve the February 2024 Newsletter, as presented, was made by Charles Nutt and seconded by Kecia Weller. Motion passed. See Vote Log on page 5.



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6. Update on SSAN Workgroups and Projects

The SSAN Webinar Workgroup, SSAN Employment Tip Sheet Workgroup, SSAN Success Stories Workgroup, and the Disability Training Workgroup provided updates on the work that they have done since December's SSAN meeting.

Members were encouraged to register for, spread the word about, and attend the March Developmental Disabilities Awareness Month Webinar, scheduled for March 27th.

7. Meeting Takeaways and Planning for June 2024

Members shared their reflections on the two-day meeting, reporting that they enjoyed learning about the HCBS Final Rule, updates on what members have been up to since the last meeting, and the voting presentation.

8. Adjournment

The February 2024 SSAN meeting was adjourned at 2:30 PM.



DRAFT

SSAN VOTE LOG: FEBRUARY 2024

Name	Region	Roll Call	Motion 1	Roll Call	Motion 2
Alex Reyes	SCDD	Virtual	For	Absent	No Vote Recorded
Sonya Force	North Coast	Virtual	For	Virtual	For
Charles Nutt	North State	Virtual	For	Virtual	For
Lisa Cooley	Sacramento	In Person	For	Virtual	For
Ellen Sweigert	North Bay	Absent	No Vote Recorded	Absent	No Vote Recorded
Sara Desumala	Bay Area	Virtual	For	Virtual	For
Robert Balderama	North Valley Hills	Absent	No Vote Recorded	Absent	No Vote Recorded
David Forderer	Central Coast	Absent	No Vote Recorded	Absent	For
Rebecca Donabed	Sequoia	Absent	For	Virtual	For
Julie Gaona	Los Angeles	Virtual	For	Virtual	For
Sean Sullivan	Orange County	Absent	No Vote Recorded	Virtual	For
Eric Aguilar	San Bernardino	Virtual	For	Virtual	For
Viri Salgado	San Diego	Virtual	For	Virtual	Vacant
Desiree Boykin	ARCA	Virtual	For	Virtual	For
Russell Rawlings	CFILC	Virtual	For	Absent	No Vote Recorded
Jason Cook-Harvey	YO! Disabled & Proud	Virtual	For	Absent	No Vote Recorded
Nicole Patterson	DDS	In Person	For	In Person	For
Scott Barron	DRC	Virtual	For	Virtual	For
Wesley Witherspoon	USC – CHLA	Virtual	For	Virtual	No Vote Recorded
Kecia Weller	UCLA Tarjan Center	Virtual	For	Virtual	For
Robert Levy	UCD MIND Institute	Virtual	For	Virtual	For

JUNE 6, 2024

**SSAN MEETING AGENDA ITEM 4
INFORMATION ITEM**

Statewide Self-Advocacy Network

SCDD Update



A staff member from SCDD Headquarters will update SSAN members on what SCDD has been doing to meet the needs of Californians with I/DD.

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**SSAN MEETING AGENDA ITEM 5
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.

Questions? We want to hear from you!

One of the workgroup priorities is the development of person-centered regional center services.

- What person-centered services have worked for you?
- How can your experience impact the Master Plan?

Do you have ideas about priorities that the Committee should consider?

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JUNE 6, 2024

SSAN MEETING AGENDA ITEM 6

Information ITEM

Statewide Self-Advocacy Network



June 2024 Newsletter

Robert Levy, Project Lead for the Voices of SSAN newsletter, will present the June 2024 newsletter edition and ask SSAN members for feedback. Members are encouraged to consider writing an article for the September edition and identify a topic about which they would like to write. The September newsletter will focus on the topic of employment.

Attachments

- June 2024 edition of Voices of SSAN newsletter
- Voices of SSAN newsletter article tips

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IN THIS EDITION:

The Americans with Disabilities Act (ADA) was signed into Law in 1990. This issue is full of information about the impact of policy and laws on the lives of people with disabilities.

[Front Page:](#) Celebrate the ADA

[Page 2:](#) Looking Back Moving Forward Recap

[Page 3:](#) Disability Policy Forum

[Page 4:](#) Travel Tips

[Page 5:](#) History of Regional Centers

[Page 7:](#) Earthquake Safety Tips

[Page 9:](#) Grassroots Day

[Page 10:](#) Community Resources

[Page 11:](#) Turning Concern into Action

[Page 12:](#) 2024 DRC Gala Recap

[Page 12:](#) SCDD Storytellers

[Page 13:](#) 2024 Choices Conference

[Page 14:](#) Kudos Corner

[Page 15:](#) Disability Reads and Listens

[Page 16:](#) DDS CAC is Recruiting

Editor: Robert Levy

Contributors:

- SSAN Webinar Workgroup
- Wesley Witherspoon
- Charles Nutt
- Eric Aguilar
- Robert Levy
- Robert Balderama

Celebrating the Americans with Disability Act (ADA)



July 26, 2024 will mark the 34th anniversary of the signing of the [Americans with Disabilities Act \(ADA\)](#). The ADA was signed into law on Thursday July 26, 1990, by the late 41st US President George Herbert Walker Bush.

The ADA has opened doors and opportunities for people with disabilities because we are able to have better access to employment, transportation services, public spaces, and communication systems. People with disabilities are now able to go more places with the help of more accessible transportation services, that were not options for them before. This means that people with access and functional needs (AFN) are able to go to work and travel throughout their communities more freely, leading to their own independence thanks to adaptations on public transportation and the existence of curb cuts, ramps and accessible bathrooms.

The need for advocacy is never done, but it is important to celebrate advocacy and legislative achievements, so we know that we are making an impact. Thank you, all past or present self-advocates, for working on getting the ADA bill signed into law. Today people with disabilities are glad that we have ADA for community use. So, for ADA happy 34th anniversary. For next year on to the 35th anniversary of ADA by continuing the self-advocacy work as a nation to keep on having a productive life for all people with disabilities throughout the nation.

Check out the section on “Turning Concern into Action” for ideas on how to celebrate and advocate for accessibility.



Looking Back and Moving Forward

By: The Webinar Work Group

The Statewide Self-Advocacy Network (SSAN) hosted its second webinar event on March 27th, 2024, in honor of celebrating the national Developmental Disabilities Awareness Month. The webinar highlighted two perspectives from advocates and their family members.

The panel was made-up of 4 individuals, who shared stories as self-advocates living with a developmental disability and navigating the world around them, and as a parent who helped raise and support them and is now joining their self-advocate in advocating with them in living and reaching their dreams.

The four panelists who participated are as follows:

- ✪ Renee Perls – Self-Advocate and college student, from the Bay Area
- ✪ Pamela Perls – Parent of Renee, from the Bay Area
- ✪ Ryan Fitch – Self-Advocate and college student, from the Central Coast Area. Check out Ryan's YouTube channel at <https://www.youtube.com/@ryanfitch21>
- ✪ Melissa Fitch – Parent of Ryan, from Central Coast Area. Check out Melissa's website at www.raisingryan.org
- ✪ Robert Levy was the moderator for the event; he facilitated the panelists, answering 7 slightly different questions geared toward the advocates and their parents.

The event was well received, with over 200 people registered. Nearly 100 people were in attendance.

The Statewide Self-Advocacy Network (SSAN) would like to give a special thank-you to the State Council on Developmental Disabilities (SCDD) for their continued support of us and in promoting leadership and building bridges that strengthen advocacy among disability communities.

The feedback from those who attended the event was positive. Stay tuned for our next event!!



Wesley at the Disability Policy Forum

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



On April 8-10 2024, I attended the Disability Policy Seminar. There were several organizations in attendance:

1. American Association of Intellectual and Developmental Disabilities AAIDD
2. Association of University Centers on Disabilities AUCD
3. Autism Society
4. National Association of Council on Developmental Disabilities
5. Self-Advocates Becoming Empowered
6. TASH
7. The ARC
8. United Cerebral Palsy UCP

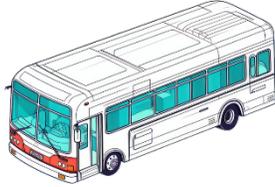
I meet with national leaders such as Tia Nellis with TASH, Liz Weintraub with AUCD, and many others from across the country. We have an opportunity to attend Hill Day meetings with our elected officials to share what we learned at the seminar and help build more support for disability issues in Congress. We worked to change disability policy for the country. The Disability Policy Seminar was held at the Westin Hotel Downtown in Washington DC. There were over 600 people in attendance from the 50 states and 6 territories. The next Disability Policy Seminar will be held on April 7-9, 2025 in Washington DC at the Westin Hotel Downtown.

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

Tips for Packing for a Trip

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



What you decide to pack when going on a trip, will depend on where you are going and how many days you will be on your trip. I find it helpful to make a list of all the things that I will need for a trip to help me pack. Here are some examples of the things you should pack for long trips:

1. Clothes; you may be able to wash your clothes at your destination
2. Medication (It is important to pack enough medication for your whole trip and even some extra)
3. Money
4. Shoes
5. Toiletries (e.g. soap, deodorant, shampoo, body wash, conditioner, etc.)
6. Cellphone, tablets, chargers, computer
7. Identification (State ID/Driver's License, and/or passport)
8. Your bus/train/plane ticket(s)
9. Glasses or any other access equipment you feel you need
10. Books, magazines, or reading materials
11. Communication tools
12. Activities to pass the time (e.g. fidget spinners, small puzzles, notebook, etc.)

Important Reminders:

1. If you are traveling by plane, don't carry more than 3.4 ounces of liquids in your carry-on luggage/bag.
2. Don't carry anything fragile on the trip, as going through security can damage items.



Regional Centers & the Lanterman Act

By Charles Nutt, SCDD North State Regional SSAN Representative

For the first half of the 20th century (1900-1950) in California, like other states, people with intellectual and developmental disabilities lived in large institutions. Community services were limited, and out-of-home care in large public and private institutions was typically the only service option available.

Social, political, and economic views and policies between the 1920's and 1940's led to the growth of the Eugenics movement. Eugenecists promoted the idea that the world's social problems could be eliminated by selectively limiting people's ability to have children if they were seen as having "undesirable genes." Eugenecists recommended that people who had "weaker genes," including those with mental, intellectual, and developmental disabilities, be sterilized or segregated from others.

The Eugenics movement lost some credibility following World War II but continued to impact public policies and the lives of people with disabilities for another twenty years through the ongoing practice of involuntary sterilization and the use of institutionalization as a means of isolating people with disabilities.

In the 1950's, families of children with intellectual and developmental disabilities began to organize and create their own community support and service systems as an alternative to institutional care. Parent-run organizations, such as Aid for Retarded Citizens (ARC) in San Francisco and Exceptional Children's Foundation in Los Angeles, established private schools, activity centers and sheltered workshops for their sons and daughters with disabilities who were denied access to public education and vocational services.

In the early 1960's, the civil rights movement and the election of President John F. Kennedy (who had a sister with a severe mental disability) helped to speed the change process. As mental disability became a big part of the national agenda, federal dollars were directed toward ways to provide community services for people with mental retardation (now known as 'intellectual disability').

In 1964, there were over 13,000 people with developmental disabilities residing in four overcrowded institutions in California (called state hospitals), and another 3,000 on waiting lists. At the urging of parents, a subcommittee was created to investigate concerns about the care provider in state hospitals and the need to build additional institutions.

Continued on page 6 of the June edition of Voices of SSAN newsletter ('Regional Centers')



Continued from page 5 of the June edition of Voices of SSAN newsletter ('Regional Centers')

The investigation revealed serious problems with the existing state hospitals and that building more institutions would cost a lot of money. This prompted the Legislature to seek an alternative. In 1966, funds were given to establish two pilot regional centers, one in northern and one in southern California. The centers would provide community-based services to support individuals who were in danger of being placed in state hospitals. Assemblymember Frank D. Lanterman co-authored the legislation for the pilot project. During their first year of operation, the pilot centers served 559 people.

These first two regional centers were so successful that the Legislature set out to design a statewide system. In 1969, the Lanterman Mental Retardation Act established the regional center system, which today includes twenty-one regional centers throughout California.

In 1973, the Lanterman Mental Retardation Act was expanded to include people with cerebral palsy, epilepsy, autism, and other conditions closely related to mental retardation. In 1976, the legislation was renamed the Lanterman Developmental Disabilities Services Act (a.k.a the Lanterman Act) and amended to establish the right to treatment, habilitation services and individualized program planning. In 2014, the law changed the term of 'mental retardation' to 'intellectual disability.'

By the mid-1980's, the availability of community-based services was not only helping people to successfully live in their home communities, but also assisting hundreds of individuals to move out of state hospitals (renamed state developmental centers in 1978). In 1985, there were only 7,100 people living in state developmental centers, while over 78,000 individuals were receiving community-based services through the regional center system.

In 1992, Senate Bill 1383 updated the philosophy of the Lanterman Act and expanded the range of available services and supports. The new philosophy embraced the concept of 'empowerment,' establishing person-centered planning and giving individuals and their families more choice and authority to make decisions about their own lives.

By the turn of the century, a major shift in California's developmental services system was evident. In 2001, only 3,800 people were still living in state developmental centers, while more than 163,000 individuals and families were receiving community-based services.

Today, the service system continues to focus on providing services and supports through community-based providers and continuing the goal of reducing the number of people living in state developmental centers. As of February 2015, only 1,147 people were still living in state developmental centers and about 287,000 individuals and families were receiving community-based services coordinated through the regional center system envisioned by Assemblyman Frank Lanterman.



Earthquake Preparedness Tips for Seniors, People with Disabilities, and Others with Access and Functional Needs (AFN)

By Eric Aguilar, SCDD San Bernardino Regional SSAN Representative

Disasters can strike quickly and without warning, which can force you to evacuate your neighborhood, school or workplace, or confine you wherever you are.

Emergency preparedness is crucial for people with disabilities because they may face unique challenges during emergencies. These challenges could include mobility issues, sensory impairments, communication barriers, or reliance on medical devices. Being prepared helps ensure they have necessary supplies, support systems, and evacuation plans tailored to their specific needs and enhancing their safety and ability to effectively respond to emergencies.

Ensuring earthquake preparedness for people with disabilities involves some additional considerations to ensure their safety and well-being.

Here are some tips:

Create a personal support network with family, friends, neighbors, caregivers, or others who can assist during an emergency. Discuss your needs and make sure they know how to help you.

Develop a communication plan with your support network. Make sure you have a way to stay in touch during and after an earthquake. This could include phone calls, text messages, or social media.

Plan an evacuation route with multiple evacuation routes from your home or workplace, considering accessibility needs. Practice using these routes regularly.

Prepare an emergency kit and customize it with essential supplies tailored to your needs, such as medications, medical equipment, mobility aids, personal hygiene items, communication devices, and important documents (like medical records and emergency contacts).

Keep emergency information accessible by maintaining a list of important contacts, medical information, and any specific instructions or accommodations you may need during an emergency. Store this information in a readily accessible location, both digitally and in hard copy.

Secure your environment and assess your living or working space for potential hazards and make necessary modifications to enhance safety. This may include securing heavy furniture, installing grab bars, and ensuring clear pathways.

Continued on page 9 of the June edition of Voices of SSAN newsletter ('Earthquake Preparedness')



Continued from page 7 of the June edition of Voices of SSAN newsletter ('Earthquake Preparedness')

Stay Informed about earthquake risks and updates through local news, weather alerts, or emergency management agencies. Sign up for alerts and notifications if available.

Practice Preparedness Drills regularly with your support network to ensure that everyone knows their roles and responsibilities. Consider different scenarios and how you would respond.

Educate others, including those in your support network - caregivers, and neighbors about your specific needs and how they can assist you during an earthquake or other emergencies.

Consider alternate transportation if you rely on public transportation. Consider other options in case regular services are disrupted. Arrange for transportation with your support network or local authorities if needed.

Stay calm and patient: During an earthquake or its aftermath, remain as calm as possible. Follow your emergency plan and instructions from authorities. Be patient and cooperative with rescue personnel.

Remember, individual needs vary, so it's essential to customize your preparedness plans according to your specific abilities and requirements. Additionally, involving others in your planning process can greatly enhance your safety and preparedness.



2024 ARCA Grassroots Day

By **Desiree Boykin**, ARCA SSAN Representative

The ARCA Grassroots Day happened on April 2, 2024 and was in person this year after being held for the past 3 years on Zoom. ARCA has been hosting Grassroots Day since 1998. On Grassroots Day, each regional center brings a parent, a board member, regional center staff, and individuals served by the regional center to Sacramento to advocate for bills and issues that are important to the regional center system.

The South Central Los Angeles Regional Center (SCLARC) delegation was able to speak to Assemblymember Issac Bryan, from the 55th District, Assemblymember Blanca Pacheco, from the 64th District, Assemblymember Josh Lowenthal from the 69th District, and staff for Assemblymember Anthony Rendon, Assemblymember Tina McKinnor, as well as state Senator Lola Smallwood.

We shared key talking points that were provided by the Association of Regional Center Agencies (ARCA):

- Don't delay the provider rate increase, which was approved during the last Legislative session. The rate increases are important in making sure that people who support people with disabilities receive a fare wage for their hard work.
- Recent minimum wage hikes for workers at fast food restaurants and big health care facilities have made it harder to recruit and retain direct support professionals (DSP), who make community life possible.
- The Master Plan for Developmental Services will be an historic opportunity to plan for the future success of our service system. It is important that the Master Plan center around the Lanterman Act's entitlement to services and should explore equitable service availability, ways to build on Employment First, and lifespan planning that recognizes the roles and needs of family caregivers as they age.

Continued on page 10 of the June edition of Voices of SSAN newsletter ('Grassroots Day')



Continued from page 9 of the June edition of Voices of SSAN newsletter ('Grassroots Day')

Legislation for Support and/or Co-Authoring:

AB 2002 (Sanchez) – This bill would create a free, optional 'Blue Envelope' program for drivers with disabilities (or drivers of passengers with disabilities), with documents to provide to a law enforcement officer, let them know whether the driver or a passenger has disability-related needs that should be considered during interactions. It is based on similar programs from San Diego and Riverside counties.

ARCA strongly supports the Governor’s proposed repeal of two fees that are charged to families receiving regional center services. These fees – sometimes called ‘disability taxes,’ – impact Early Start families the most. Getting young children services quickly is very important. The fees function as barriers to receiving needed services and can create problems between service coordinators and the families they are supporting.

Advocating for these key points will hopefully be considered as Governor Newsom does the May revise. We look forward to going forward for the next Grassroots Day in 2025.

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](#)



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’s 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!

Tips for Turning Concern into Action

It can be hard to know how 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; think about and make a list of your ideas about making the situation better. Is there anything on that list that you can do?
- 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 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 local, state, and national elections. Let your voice and your choice be heard by voting.



Recapping the 2nd Annual DRC Gala

By Robert Levy, UCD MIND Institute UCEDD SSAN Representative

On Wednesday, February 28, 2004, the 2nd annual Disability Gala took place at the Sacramento Central Library (828 J Street, Sacramento, Ca 95814), with about 200 people. I was the only SSAN member and attended with my sister, Kim Rothschild. Others who attended included my co-workers at the UCD MIND Institute (UCEDD) - my supervisor Steve Ruder, along with Cindy Ruder, UCEDD Director Aubyn Stahmer and her friend, Olivia Viola Zertuche Wrisley, and my co-worker at PEC, Jackie Armstrong. The Disability 2024 Gala schedule agenda link is at <https://www.disabilityrightsca.org/gala-2024-program>, which will give you the event breakdown. Last year (2023) was the 1st annual, inaugural event. It started because they wanted to see if it was a success and if the community wanted to come back each year. Since it was a success, they decided to come back each year with the community. Numerous businesses decided to be sponsors. I met with actor Troy Kotsur, who was a cast member in a 2021 movie called 'Coda.' He is non-verbal, deaf and uses sign language. I heard from all of the presenters, and I learned a lot. There was an award ceremony. Let's thank all the Disability Gala Planning Committee members for their hard work in putting this 2nd annual event together in 2024. I am looking forward to a successful 3rd annual Disability Gala next year in 2025 - for the 3rd year in a row.

Share Your Story on the SCDD Storytellers Blog



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

You can find the Storytellers' blog under the 'News and Events' tab at the top of the SCDD website – 'SCDD Blog.' We look forward to reading the next story; it might be yours!



Recapping the 2024 Choices Conference

By **Robert Balderama**, SCDD North Valley Hills Regional Representative

Our yearly Choices Conference was sold out, as over 500 people attended. At the San Joaquin County Office of Education in Stockton. Choices provided training and education for people with developmental disabilities and their families.

The Choices Committee is a group of individuals with developmental disabilities and people who don't have disabilities.

The emcees were Chuck Struthers and P.J. Swan. Like always, they were great.

The keynote speakers this year were Chrissy Franzoni, Minette Oliver, P.J. Swan, and Cheyenne Anderson.

Also, there was a micro-business fair held, too, where you could buy shirts, jewelry, postcards, art, paintings and more.

The PCS advocates were the best. They were entertaining and kept the crowd dancing on their feet. Looking out into the room felt great - looking at everybody getting along and having a great time. They performed some songs I haven't heard in a long time.

I had an amazing time you should plan to go next year. See you there.



Kudos Corner



When someone does a good job or achieves a goal, people sometimes say “Kudos to you.” Since June of 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 June 2024 issue, I would like to give kudos to Sean Sullivan, who has represented the SCDD Orange County regional office on SSAN since December 2017. Here are a few highlights of Sean’s accomplishments:

Sean started his own business, called I Know Autism, to share resource advice with others. He helps businesses like airports improve their knowledge of disability awareness and accessibility. He has also shared his story on radio shows, podcasts, TEDTalks, and other forums. This past October, Sean participated in the first SSAN webinar, sharing his employment journey with others. The great thing about Sean is that he is a good listener, always has a positive attitude, and is ready to highlight the good in any person or situation. Sean is a great storyteller and is always ready to share his experiences with others so that they do not feel alone.

I asked Sean to share what his hopes and dreams were for SSAN and Self-Advocacy, his response was that he did not have any specific hopes and dreams for SSAN because he know how hard members work to be a part of SSAN. He would like to see more collaboration with other self-advocacy groups around the state and even nationally. Sean hopes that the hard work that he puts into his business will help it to grow. Kudos to you, Sean!



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.



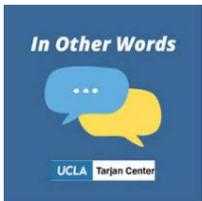
[RespectAbility News](#) has updates on national efforts to engage people with disabilities in the political process.

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.



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.

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.



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

JUNE 6, 2024

**SSAN MEETING AGENDA ITEM 7
INFORMATION ITEM**



Statewide Self-Advocacy Network

SSAN Tipsheet Workgroup

At the September 2023 SSAN meeting, members created new workgroups, one of which is the Employment Tipsheet Workgroup. This workgroup will create tipsheets to help guide advocates in their employment journeys. Members of the workgroup chose to shorten the name of the group to the SSAN Tipsheet Workgroup to allow flexibility on the types of tipsheets that the group creates.

So far, the Tipsheet Workgroup has created 4 employment-related tipsheets and would like to know if there are any other tipsheets 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 Dressing for Success Tipsheet
- SSAN Reasonable Accommodations Tipsheet
- SSAN Preparing for an Interview 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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