

December 2023

IN THIS EDITION:

This issue of the Voices of SSAN Celebrates the lives, voices, and accomplishments of people with disabilities.

Front Page: International Day of Persons with Disabilities

- Page 3: Employment Webinar Recap
- Page 4: Recapping the NACDD Conference in Florida
- Page 5: The RISE of Giants
- Page 6: Turning Concern into Action
- Page 7: Recapping the UC Davis MIND Summer Institute
- Page 8: FNRC SDP Film Premiere
- Page 9: 2023 Supported Life Conference Recap
- Page 10: My Experience with YLF
- Page 11: Kudos Corner
- Page 12: Good News Corner and Self-Advocacy Reads
- Page 13: Holiday Tips and Save the Dates

Page 13: Community Resources Page 14: DDS CAC is Recruiting Editor: Robert Levy

Contributors:

- David Forderer
- Nicole Patterson
- Rebecca Donabed
- Wesley Witherspoon
- Robert Levy
- Ellen Sweigert
- Lisa Cooley
- Sony Force
- Charles Nutt

International Day of Persons with Disabilities



INTERNATIONAL DAY OF PEOPLE WITH DISABILITIES

What Is It:

Since 1992, the United Nations (UN) has recognized December 3rd as International Day of Persons with Disabilities (sometimes shortened to IDPD). IDPD encourages people from around the world to be more compassionate to the challenges people with disabilities face in their everyday lives. The day doesn't discriminate between mental and physical disabilities. The spirit of the day is to ensure that all people in the world have equal opportunities for work, play, for healthcare, and for success. People with disabilities are very often contributing and valued members of society. This disability day is all about appreciating them.

When a day is dedicated to a specific population or identity group it is an opportunity to recognize their humanity and the value that they bring to their communities. Every year, the UN announces the theme for the year. The 2023 theme is "United in Action," and you can learn more about it at <u>https://idpwd.org/</u>.

Every year SSAN uses the December edition of the newsletter to celebrate the organizations that support improving the lives of people with disabilities and the accomplishments of people with disabilities in California, America, and around the world.

Continue reading on Page 2 of the December 2023 Edition of Voices of SSAN: "IDPD"



December 2023

VOICES of SSAN

Continued from Page 1 of the December 2023 Edition of Voices of SSAN: "IDPD"

Here are a few ideas on how to observe International Day of Persons with Disabilities:

- Become an advocate: if you notice access barriers in shops or places that you frequent, encourage the shop owner, manager and/or elected officials to work to address those barriers.
- 2. Lend a hand by volunteering your time at a disability nonprofit, senior center, nursing home, or outpatient clinic. Something as simple as delivering needed supplies can make a big difference to someone who is struggling.
- 3. Show compassion by putting in effort to understand the perspective and challenges others are going through.

Here are a few social media hashtags to use to bring awareness about the day:

- #IDPD
- #IDPD2023
- #InclusionMatters
- #DisabilityRights
- #EqualOpportunity
- #AccessibleWorld
- #CelebrateAbilities

This issue is full of stories of advocates working together to create positive change in their communities. At the end of this issue is list of ways you can turn your concern into action. Hopefully our list will spark your own ideas of thing you can do to make positive change in your community and raise awareness of disability issues.

Resources and Information to Learn More about International Issues and Positions on Persons with Disabilities:

- United Nations (UN) Disability Strategy
- <u>World Health Organizations: Importance of the Convention on the Rights of People with</u> <u>Disabilities</u>
- YouTube Video: What is the UN Convention on Rights of Persons with Disabilities (CRPD)



December 2023

Recapping the SSAN Employment is Possible for Everybody Webinar

By SSAN Employment Webinar Workgroup

The Statewide Self-Advocacy Network (SSAN) hosted their first webinar event on October 30, 2023, in honor of National Disability Employment Awareness Month (NDEAM). The webinar highlighted some examples of paths taken by advocates on their employment journey in pursuing their passions.

The webinar was made-up of a panel of 5 individuals who shared stories about how they successfully entered and maintained employment, either through an organization or starting their own business. The panelists who participated are as follows:

- Rebecca Donabed Community Organizer, Resource for Independence Central Valley (RICV)
- Robert Levy UCEDD Self-Advocacy Specialist, UC Davis MIND Institute
- Nicole Patterson Advocacy and Self-Advocate Liaison Specialist, California Department of Developmental Services
- Sean Sullivan Motivational Speaker, IKnowAutism
- Nicole Adler Equal Rights Advocate, Producer, Creative Director, and Host of "The No No Show", and Motivational Speaker
- Lisa Cooley moderated and facilitated the event

Along with participating in the panel discussion, Nicole Adler talked about her experience as a host of the YouTube channel "The No No Show" and her dreams for the future. Check out her channel at <u>https://www.youtube.com/@TheNoNoShow</u>

The event was well received. Over 265 people registered for the event and nearly 150 people were in attendance.

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

The feedback from those who attended the event was overwhelmingly positive and we received ideas for future events, including an annual SSAN NDEAM event. Stay tuned for our next event!!



December 2023

Wesley at the NACDD Conference in July 2023

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



The theme for this year's National Association of Council on Developmental Disabilities (NACDD) Conference was "Beyond the Conversation: It's About Action". The Conference was held July 22-26 in Orlando, FL. As the Chair of the California State Council on Developmental Disabilities (SCDD), I was able to attend the conference along with SCDD Executive Director Aaron Carruthers. I enjoyed connecting with advocates from across all 50 States in the continental USA and 6 territories.

I had the chance to train other Council Chairs in different states on how to run a meeting. Along with learning and connecting with others, I had the chance to go to Disney Springs. It was hot and humid there, the temperature sometimes reached 95 degrees, but it felt like it was 115 degrees. It was so hot that it was even hard to walk one block without breaking a sweat. I saw a lot of lizards, and I even saw an alligator as well. Overall, Florida has a nice climate. It is warm throughout the year.

Volume 35

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



December 2023

The RISE of Giants in the North Coast Region RISE: Our Voice, Our Power, Our Community

Sonya Force, North Coast Regional SSAN Representative

My name is Sonya Force. I joined SSAN as the North Coast Regional SSAN Representative in July. Along with SSAN, I am a part of the SCDD North Coast Regional Advisory Committee (RAC) and am a member of Realizing Independent Success and Empowerment (RISE). I started my advocacy and leadership journeys when I joined RISE. The North Coast Region of California is famous for their majestic Redwoods and the storied trails of Bigfoot that can be found in the area. As part of the Redwood Coast Regional Center, we, a group of folks with disabilities, are working hard in Del Norte, Humboldt, Lake, and Mendocino Counties to make a difference. We're not just a committee; we're advocates for our own lives. With the guidance of a couple of RCRC staff and a community mentor, we're diving into the HCBS Final Rule, making sure our friends and neighbors understand their rights and the services available to them.

RISE is excited to have just passed our first year of success. Our work is as diverse as the ecosystem around us. We've had our hands in everything from helping with professional training to creating job opportunities through a theater program. We've pushed for better health education and stronger medical advocacy because we believe knowledge and support are key to thriving.

Every month, we meet to tackle the latest challenges and plan for the future. We've been a driving force behind People First chapters, where we champion the idea that everyone should have the chance to stand up for themselves. And we know how to bring people together—whether it's sharing a meal at a holiday dance or spreading the word through flyers, we're all about building our community.

What's truly special about RISE is that it's ours. We lead it, we decide where the money goes, and we see the impact of our decisions. Whether it's setting aside funds for snacks to boost meeting attendance or fighting for an accessible vehicle to broaden our horizons, we're making moves that matter.

Continue reading on Page 6 of the December 2023 Edition of Voices of SSAN: "RISE"



December 2023

VOICES of SSAN

Continued from Page 5 of the December 2023 Edition of Voices of SSAN : "RISE"

From providing translators to make sure no one is left out of the conversation to nurturing new self-advocates within our ranks, we're all about inclusion and growth.

We are RISE: a group of friends, a team of leaders, and a family of advocates. Together, we're working to ensure that our community is one where every person, no matter their abilities, has the opportunity to live their best life. Join us, support us, and watch us as we grow—not just as a group, but as a beacon of hope and empowerment on the North Coast. I would like to thank RISE, our special mentors and RCRC for helping me realize, I still have a purpose and an opportunity to make a difference in the lives of others.

Tips for Turning Concern into Action

It can be hard to know what you can do to help advocate for change. Here are some ideas for how to turn your concerns and worries into action:

- Share your thoughts with family members and friends
- Consider mentoring another advocate
- Write a social media or blog post, host or be a guest on a podcast, or speak in front of groups of people
- Write a letter to the editor or opinion piece for your local newspaper or organization newsletter
- Contact to your local representatives about important issues
- Get involved with your community by joining a club, board, or attending a city council meeting to share your concerns
- Donate your time by volunteering for an organization
- Join a board or commission like the <u>Department of Developmental Services Consumer</u> <u>Advisory Committee (DDS CAC)</u>
- Learn about the issues important to candidates and vote



December 2023

Recapping the 2023 UC Davis Summer Institute

By Robert Levy, UC Davis MIND Institute UCEDD SSAN Representative

This year marks the 18th annual Summer Institute. This year also was the first time in 4 years to have it in person. This year's Institute was also on Zoom, making it the first hybrid UC Davis Summer Institute. This year's Summer Institute was held at Hiram Johnson High School in the Sacramento area.

The theme for the event was about Inclusion for all, and the last presentation of the event was a panel discussion. The panel discussion was about personal stories about the impact of inclusion across lifespan and contexts. There were 6 different breakout sessions for the Institute. The first session focused on inclusion in education and was for both the English-speaking and Spanish speaking communities. The second session was focused on inclusion in medical settings. The third session focused on inclusion in K-12 Education. The fourth session focused on inclusion in employment. The fifth session focused on inclusion in post-secondary education. The sixth session focused on inclusion in the transition planning process.

The participants also did a survey to see what changes they want to see next year in 2024 for the 19th annual Summer Institute. There were a total of 258 attendees. Here was the break down: about 160 attendees in-person and 98 were on Zoom. All the attendees were from the US only. All of the presenters did a great job and the Summer Institute planning committee members did a great job planning another successful Summer Institute. You can watch recordings of the event, now available on UCTV and it will also be available on the UCD MIND Institute website at a later date. Check out the UCD MIND Institute 2023 Summer Institute Conference Recap newsletter article when you get the chance. You can also check out the Inclusion: Always and for All YouTube video link

Upcoming Event: Winter Advocacy Symposium 2024



Hosted by: Resources for Independence Central Valley (RICV) Symposium Theme: Climb Strong and Reach the Peak Dates: January 22–26 Location: Online <u>Register Today!</u>

Session Topics: Housing and Safety, Homeless Advocacy, Emergency Preparedness, Voting, Disability History and Advocacy, Legislative News, Environmental Advocacy, and Youth Advocacy!



December 2023

Far Northern Regional Center Self-Determination Advisory Committee SDP Film Premiere

By Charles Nutt, North State Regional SSAN Representative

Far Northern Regional Center's (FNRC) Local Self-Determination Advisory Committee (SDAC), of which I serve as Chairperson, hired a local filmmaker named Doug Churchill (<u>www.DougChurchill.com</u>), to produce a short documentary film on the Self-Determination Program (SDP). When the film was completed, the Local SDAC coordinated a Film Premier, in partnership with the State Council on Developmental Disabilities (SCDD), North State Regional Office, and Disability Rights California/Office of Clients' Rights Advocacy (DRC/OCRA), to showcase the documentary and to educate the community about the Self-Determination Program. The film follows 3 families who are enrolled in the program and how they navigate through the program. They share how the SDP has improved the lives of their loved ones and their families.

The SDP Film Premier occurred on October 19, 2023, and had 2 showings: 10am-12noon and 6pm-8pm at the Gaia Hotel in Anderson, California. The families featured in the film presented as panelists and shared their experiences in the Self-Determination Program and answered many questions from the audience. It was attended by approximately 100 people between the 2 film showings and was very successful. People seemed to learn a lot about the program and asked good questions.

The Local SDAC will be coordinating future film showings to continue outreach and education for individuals and families served by FNRC. For those who can't attend an in-person showing, the <u>Self-Determination Program Video</u> is now available to watch online.

Volume 35

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 <u>SCDD YouTube Page</u> for stories from selfadvocates, past meetings, and more!



December 2023

2023 Supported Life Conference Recap

By Nicole Patterson, Department of Developmental Services SSAN Representative

On October 26th and 27th the Supported Life Institute held the 37th Annual Supported Life Conference at the Windham Hotel in Sacramento. There were well over 300 attendees from advocates, professionals, and parents.

On October 26th the conference was kicked off with a keynote By Joey Travolta, Founder of Inclusion Films. Joey has directed & produced over 20 films. Joey Travolta founded Inclusion Films to help train people with all abilities in the art of filmmaking, passionately creating & finding jobs for people, plus building skills transferrable to other job opportunities.

Tony Anderson, Executive Director of Valley Mountain Regional Center, and Eric Ciampa, a Service Provider from Alta California Regional Center, did a keynote during lunchtime about how two neighboring Regional Centers Valley Mountain & Alta California team up in cutting-edge efforts to professionalize work of direct support staff, service providers, and regional center staff in promoting the value of the work of creating community inclusion.

As always, the sessions did not disappoint, covering topics like employment, social recreation, selfdetermination, health and wellness, and communication through technology.

October 27th was another day filled with useful information starting with a kickoff keynote by Harry Bruell, CEO of PathPoint, a large service provider in Central & Southern CA that works to support people with disabilities to live the life they choose. PathPoint provides employment support, life skills, and relationship building. He is also father of a daughter with a mental health disability. His keynote focused on the need to boost employment rates and addressing the problems with obtainable solutions.

Don Perata finished off the keynotes during lunch as he shared his knowledge and experience of being a successful CA political leader. His experience includes 4 years as Leader of the State Senate. He is often described as an advocate for people with disabilities, individuals with mental illness, & the elderly. Sen. Perata continues to further policy advocacy in the field and uses his experiences to find effective ways to create political change.

The conference ended with sessions on housing, CalABLE, Home and Community Based Services Final Rule, Social Security and Employment, Building Friendships, and End of Life Support.



December 2023

Measuring the Impact of the Youth Leadership Forum (YLF)

By Ellen Sweigert, North Bay Regional Representative Lisa Cooley, Sacramento Regional Representative

The first ever California Youth Leadership Forum (YLF) happened over 30 years ago as a statewide self-advocacy and leadership development program to help high school Juniors and Seniors (transition-age) connect with pre-employment, post-secondary educational options and independent living skills like financial literacy. YLF is a meaningful program for both the attendees (or delegates), but also for those that volunteer their time to support and guide. There are a number of SSAN members who have attended YLF in the past and two that would like to share their experiences with you in this edition.

Ellen Sweigert was just a high school student who had a dream of living a life dedicated to making the world a better place for people with disabilities. The Principal of Pacific Grove High School nominated her to attend in 2006, after seeing her leadership potential. When she heard she was selected to attend she was overjoyed at being a part of something worthwhile. Ellen really had a good time during YLF. YLF helped her in many ways. She gained advocacy skills to help her speak up for herself. She was able to meet legislative members and learned from them. After the YLF Ellen was asked to sit on a panel providing feedback and share her experiences attending the YLF. Ellen definitely recommends this to anyone who wants to "go the distance" for people with disabilities. Attending YLF helped her to know for certain that she wanted to be a self-advocate and help others with disabilities find their dream.

Lisa Cooley attended the YLF Mentor Luncheon in 2007, and really enjoyed meeting with the next generation of leaders in the disability community. YLF was not something that was around when she was younger and in high school. Lisa appreciated that YLF includes disability history in their programing since it is often not included in history books or materials covered in high school. By attending the luncheon, Lisa learned that the activities that happened during the week of the Youth Leadership Forum help students who have disabilities have pride in themselves as people who have disabilities. The YLF Luncheon is great because it gives delegates the opportunity to get to know successful adults who have careers.



December 2023 Kudos Corner



Charles Nutt has a lot of advocacy experience, that started back when he joined the Statewide Self-Advocacy Network (SSAN) in 2013, representing the North State Region. After being on SSAN for a year, he applied to represent the North State on the State Council on Developmental Disabilities (SCDD). After Charles was appointment by the Governor's Office to serve on the Council in 2014, he decided to resign from SSAN to focus on his work as a Councilmember and give another advocate the opportunity to be a SSAN member. During his time on the Council, Charles was elected to serve as Vice-Chair.

After his time on the Council ended in 2019, Charles continued his advocacy work within his region by serving on the North State Regional Advisory Committee (RAC), where he was appointed Chairperson of the North State RAC since 2021. Charles is also involved in the Far Northern Regional Center (FNRC) Self-Determination Advisory Committee, in an effort to support the Self-Determination Program at both the local and statewide level.

Some of Charles' other advocacy work has included serving as a member of the Department of Developmental Services (DDS) Consumer Advisory Committee (CAC), participating in SCDD's Project SAFEE (Self-Advocates for Emergency Education), and Leaders Empowering Self-Advocates (LESA) a group out of San Diego. Charles rejoined SSAN in 2022, to fill the North State Regional Representative vacancy. Charles was elected Chairperson of SSAN in 2022 and looks forward to working with other members of the Leadership Team to support the work of SSAN.

Through his advocacy experiences, Charles has had the opportunity to travel to other states for conferences and trainings, developed relationships with self-advocates, and remains a dedicated advocate for policy and system change to make it a better world and service system for people with disabilities. Charles feels that in order to make things happen or change the system, one needs to be involved in the process, and always be positive, productive, and professional. He believes in "walking the talk", "practicing what you preach", and "living your values".

When Charles is not busy with his advocacy work, he enjoys spending time with his wife (Alissa), son (Evan), their 6 dogs, 3 cats, in their home in the woods of Northern California. As a family, they enjoy traveling, trying new restaurants, walks in nature, and playing console games. SSAN is happy to have you as a part of our network. Let's give a big kudos to Charles!



December 2023

Good News Corner

Here are some websites that you can find uplifting news to brighten your day:

- The Good News Network: California for up-to-date information ٠ about interesting positive things that are happening
- <u>Positive News</u> is a site that you can check out to see what is happening around the world that is positive
- Good Good shares really good news, not just feel-good news
- Happy News celebrates all that is good in the world
- Optimist Daily is a site that shares solutions and good news from around the world

Disability-Related Reads and Podcasts

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

Disability Scoop is an online resource with disability-related news





respect

World Institute on Disability News has updates on what is happening around the world

<u>RespectAbility News</u> has updates on national efforts to ability engage people with disabilities in the political process







Learn About SSAN **Member Organizations**

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

Self-Determination Update

Self-Determination is LIVE in California. Check out the

DDS Self-Determination Newsletter for the latest on California's Self-**Determination Program.** Talk to your service coordinator to learn more.



December 2023

Tips for Coping with the Holidays

The Holiday Season is a fun time of year. There are so many parties and celebrations. However, it can be a hard season if someone does not have family, have problems with family, or relationships problems or alone and don't want to be. Here are some tips:

- 1. Do not spend too much money, there is life after the holidays.
- 2. Do not eat too much food, you could end up feeling sick, and it is also hard to lose weight.
- 3. Do not be too hard of yourself. There are high expectations. Sometimes your expectations can't be met.
- 4. Do not drink too many alcoholic beverages. Even though it is a happy time of year, bad things can occur during this time.
- 5. Take pictures and make memories, this time of year might be the only time for those memories.
- 6. Be kind to others, you don't know what other people are going through. Volunteer, give to people who need things, etc.
- 7. Take time for yourself, remember self-care is important.
- 8. Talk to your support staff, neighbors, co-workers, and/or people who live with you.
- 9. Get plenty of sleep
- 10. Take care of your pets and plants.
- 11. Be thankful for what you have it, it could be worse.

Community Resources



Volume 35





DDS' CAC is RECRUITING!

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

About the CAC:

December 2023

- Fifteen (15) self-advocate members from all over California
- Meets at least four (4) times a year in Sacramento, or online with Zoom
- * Members share information with their local self-advocacy organizations
- Brings input from those groups back to the CAC
- * Transportation, hotel, meal, and facilitator costs (if needed) will be paid by DDS

If you would like to apply to be a CAC member, here is what you need to do:

- * Check the link below to see if we are recruiting from your regional center.
- You must have an intellectual or developmental disability and receive regional center services to apply.
- * You must be a member of a local self-advocacy group or other organization that serves or empowers people with developmental disabilities.
- * You **MUST** be nominated for membership by your local self-advocacy group or developmental disability organization.

DDS is currently recruiting CAC members served by the following regional centers:

- Regional Center of Orange County (RCOC)
- * Regional Center East Bay (RCEB)
- Inland Regional Center (IRC)

- North Bay Regional Center (NBRC)
- Redwood Coast Regional Center (RCRC)
- * San Andreas Regional Center (SARC)
- * Tri Counties Regional Center (TCRC)

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

BAS

Interested advocates should fill out the online <u>DDS Consumer Advisory Committee Application</u> and submit it with their nomination letter.