



IN THIS EDITION:

Article 1: Celebrating Developmental Disabilities Awareness Month

Article 2: CHOICES Conference

Article 3: Ten Years of SSAN

Article 4: New Member: Maria Marquez

Article 5: Disability Pride

Article 6: Special Olympics

Article 7: How to Stay Safe in the Community

Article 8: Kudos Corner

Article 9: Community Resources

Article 10: Save the Dates

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Contributors:

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

Celebrating 35th Developmental Disability Awareness Month

By SSAN Members



During the month of March, the National Association of Councils on Developmental Disabilities (NACDD) partners with the Association for University Centers on Disabilities (AUCD) and National Disability Rights Network (NDRN) to create a social media campaign that highlights the many ways in which people with and without disabilities come together to form strong, diverse communities.

You can participate in NACDD's efforts by sharing your stories and helpful resources using the hashtag #DDAM2022 to tag their content on social media.

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

"I am grateful that 35 years ago, President Ronald Regan proclaimed March as 'Developmental Disabilities Awareness Month'. This means that people with developmental disabilities are recognized in the month of March." – Desiree Boykin, SSAN Chairperson, ARCA SSAN Representative.

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

(Continue on page 2: "DD 2022: 35 Years")



VOICES of SSAN

March 2022

Volume 28

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

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

– Robert Balderama, North Valley Hills Regional SSAN Representative

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

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

"Celebrating Developmental Disabilities Awareness Month is important. People with developmental disabilities are always making and enforcing changes to promote independence and a better quality of life." – Julie Gaona, Los Angeles Regional Representative



CHOICES Institute

Conference Update- questions 473-6950

SAVE THE DATE!

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

Theme for CHOICES 2022:

Everyday HEROES, Everyday CHOICES

(same as our 2020 cancelled conference)

This will be a FREE event, but you MUST REGISTER

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

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

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

New mailing address: CHOICES Institute

2529 W. March Lane Suite 105 Stockton, CA 95207



VOICES of SSAN

March 2022

Volume 28

Celebrating Ten Years of SSAN: Members Reflect

“I’m grateful for the SSAN members and their willingness make their voices heard in the community. SSAN members are friendly and warm towards everyone.”

– Desiree Boykin, ARCA SSAN Representative

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

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

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

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

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

– Lisa Cooley, Sacramento Regional SSAN Representative

“Over the last 10 years the Statewide Self-Advocacy (SSAN) has been an asset to the state of California because it has allowed a body of advocates from entities that deal with people with disabilities to come together as one voice. It has been an instrument for people to share information and get information to better the services and supports for people with disabilities in California. The evidence has shown over the last two years during the pandemic that SSAN has taken an important role to make sure that the word was getting out about vaccinations, CDC regulations, ways to get food and supplies that were needed, distributing personal protective equipment in their local areas, and being a support network for each other.

– Nicole Patterson, DDS SSAN Representative



New Member Spotlight: Maria Marquez

By Maria Marquez, SCDD SSAN Representative



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

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

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

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

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

SSAN Members

- Nathaniel Florez – North Coast
- Charles Nutt – North State
- Lisa Cooley – Sacramento
- Ellen Sweigert – North Bay
- Regina Woodliff – Bay Area
- Robert Balderama – North Valley Hills
- David Forderer – Central Coast
- Rebecca Donabed – Sequoia
- Julie Gaona – Los Angeles
- Sean Sullivan – Orange County
- Daniel Fouste – San Bernardino
- Paul Mansell – San Diego Imperial
- Desiree Boykin – ARCA
- Russell Rawlings – CFILC
- Nicole Patterson – DDS
- Scott Barron – DRC
- Robert Levy – UC Davis Mind Institute
- Kecia Weller – UCLA Tarjan Center
- Wesley Witherspoon – SCDD and USC Children’s Hospital
- Maria Marquez – SCDD



Disability Pride

By Paul Mansell, San Diego Regional SSAN Representative

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

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

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

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

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

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

(Continue on page 6: "Disability Pride")



VOICES of SSAN

March 2022

Volume 28

(Continued from page 5: “Disability Pride”)

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

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

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



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

Safety in the Community

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

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

SSAN Mission Statement

The Statewide Self-Advocacy Network (SSAN) promotes leadership and builds bridges that strengthen advocacy among disability communities by focusing on policy change.

[SSAN past Newsletters, Annual Reports, and Meeting info](#), can be found at www.scdd.ca.gov under the “self-advocacy” tab

Let us know if you want to see anything specific in future newsletters!

How do you contact the SSAN Newsletter Editor Robert Levy? Leave a message for him by contacting the SCDD Self-Advocacy Coordinator **Riana Hardin at (916) 263-8196**

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



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

Self-Advocates For Emergency Education

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



Interested in keeping your community safe?

Please join us for one of our meetings:

Every 1st & 2nd Friday of the month

from 8:30-10:00am

We welcome you to learn and participate:

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



For more information about the next Zoom meetings

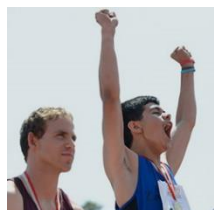
Please contact:

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

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



Special Olympics: Promoting Inclusion through Sports



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

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

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

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

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

Learn About SSAN Member Organizations

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

Self-Determination Update

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



VOICES of SSAN

March 2022

Volume 28

Kudos Corner

By Wesley Witherspoon

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

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

Community Resources

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

SAVE THE DATES

Disability Rights California



Events and Trainings:

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

CalABLE



News and Trainings:

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

CHOICES Conference

“Every Day Heroes”

Contact [Dena Hernandez](#) to learn more



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

Plain Language COVID—19 Resources Available on:

[SCDD Website](#)

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

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

[Office of Self-Determination Ombudsperson](#)