VOICES of SSAN

September 2020

IN THIS EDITION:

Article 1: Neighbor to Neighbor Project
Article 2: Advocacy and the Pandemic
Article 3: The Importance of Voting
Article 4: My New Podcast
Article 5: SSAN Turns 8!
Article 6: Camp Fire: Remembering Almost 2 Years Later
Article 7: New Member Bio
Article 8: SAC 6
Article 9: Member Interview
Article 10: Community Resources
Article 11: Save the Dates

Editor: Robert Levy

Contributors:
- Wesley Witherspoon
- Paul Mansell
- Daniel Fouste
- Teresa Moshier
- Sean Sullivan
- Russell Rawlings
- Robert Balderama
- Robert Levy
- Nicole Patterson

Neighbor to Neighbor Project

By Wesley Witherspoon, USC Children’s Hospital UCEDD Representative

COVID—19 has changed a lot about the day to day lives of people in California and across the country. Prior to COVID—19, people were giving handshakes and hugs. But because of the need to practice social distancing to fight this pandemic, some people with disabilities are feeling isolated from others. At one day program I attended prior to COVID—19 some of the participants did not have any friends. Having someone to talk to is important to our well-being. The State Council on Developmental Disabilities partnered with the Governor’s Office and California Volunteers to put together The Neighbor to Neighbor project as a part of Listos California, a resource hub for COVID—19 materials and community planning response tool for natural disasters.

The Neighbor to Neighbor Project focuses on checking in with your neighbors with disabilities in all kinds of ways, using different communication tools like the phone, computer, or smart-phone. Many people do not talk to their neighbors regularly, so you can also talk to your staff. You can also talk to your family. If you are fortunate enough to talk to your neighbors, you can. It is normal to feel isolated from time to time. You have the right to have a person to talk to you, however some people will not let you talk to them, just move on to the next person. We can have people talking to us if we want it. Check out this Neighbor to Neighbor YouTube video to learn more about the project.
Advocacy and the Pandemic

By Paul Mansell, San Diego Regional Representative

March seems so long ago, as we continue to shelter in place because of COVID—19. In some ways sheltering-in-place is nothing new for me. I don’t drive because I have epilepsy and getting out of my apartment has always been a real pain. I have to take the bus which takes forever or Uber which I can’t afford.

The hardest thing to deal with is the isolation, loneliness, and change in my routine. My ILS worker no longer comes to my place, instead we meet remotely. I have to be very proactive about reaching out to friends and family to fill the emptiness. I go out of my way to phone, text, and email people. I have found complimenting others is an excellent way to stay connected and helps build closer relationships.

I went to Burger Lounge with a friend and had dinner outside. I felt like I was in heaven. We take for granted our human contacts until they are taken away from us, then it becomes a major issue. I can’t recall the last time I gave someone a hug. I have a friend take me to Rite Aid to pick up my prescriptions, which I have a lot and have to go frequently.

Taking this extra effort to reach out to family, friends, peers, and co-workers has made a huge difference in my life. Instead of feeling sad and depressed I feel upbeat with a strong desire to connect with others—my mood is bright and colorful. Starting to exercise also helps. I advocated to my Service Coordinator for the Self-Determination Plan to purchase a treadmill. When I get it, I will be able to bike and walk while sheltering-in-place.

During the pandemic simple things like going to the supermarket have become a hassle. To reduce my need to grocery shop, I subscribed to Meal-on-Wheels, a meal delivery service for seniors. I also go online to Shipt.com and have my groceries delivered to my door. Also, I enrolled in On Trak, to improve my health and stay active. So even in a pandemic, we have power if we self-advocate.
The Importance of Voting

By Daniel Fouste, San Bernardino Regional Representative
Paul Mansell, San Diego Regional Representative
Wesley Witherspoon, USC Children’s Hospital Representative

Voting gives us the opportunity to have our voices heard through the choices we make in the people and ballot measures we support and vote for in an election. Voting gives people the chance to have a voice in deciding the direction of our communities, state and country. Voting also gives you the chance to support the issues that are important to you by voting for candidates that care about those issues. There is a certain sense of pride that one feels, when you turn 18 and go through the process of registering to vote, walking into your local polling location and casting your first ballot to participating in your first election.

With the challenges presented to the voting process because of COVID—19, voting in this election cycle looks different. Many polling places are having to adapt to follow social distancing requirements and there is an uncertainty about how many polling places are going to be able to meet the new requirements. Voting by mail is a good option because you can vote in the safety of your own home, and mail in your ballot with a limited risk to your health. Participating in the voting process is one way to participate in this system and in democracy.

People with disabilities have had to struggle to have their voices heard in the voting process and it is important that we continue to exercise our right to vote. There are many resources related to voting that help make the process of voting easier. The Easy Voter Guide put together by the League of Women Voters (Continue on Page 4: “Vote”)

SSAN Members
• Nathaniel Florez – North Coast
• Teresa Moshier – North State
• Lisa Cooley – Sacramento
• Vacant – 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
(Continued from Page 3: “Vote”)

is a good resource that provides easy to understand descriptions of the impact of proposed ballot measures and where candidates stand on issues like access to public transportation and long-term services and supports for people with disabilities and aging adults. America is a democratic republic and important decisions are made at the ballot box. Casting our votes and electing leaders who value our concerns and needs is clearly in our self-interests. Another way of saying it, our leaders will only act on our behalf if they hear our message and see that they are beholden to our votes for their electoral victory.

The last day to register to vote in November’s election is October 16th. We hope that you will make sure that you are registered and join us in voting in this, and future election cycles, because it is an important way to have your voice be heard.

**My New Podcast**

**By Sean Sullivan**, Orange County Regional Representative

I have been contemplating starting my own podcast for months. It took me a while to decide what I would talk about on my podcast. I kept wondering what content I would make that listeners would be interested in, who I would interview and how I would find people to interview. After I tackled those problems I started right away. Some examples of topics I talk about are:

- Autism
- Down’s Syndrome
- ADHA
- ODD and more

**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 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
SSAN Celebrates 8 Years of Advocacy

By Robert Levy, UC Davis MIND Institute UCEDD Representative

In 2012 the Statewide Self-Advocacy Network (SSAN) was born with the help of the State Council on Developmental Disabilities (SCDD). There have been a lot of changes to SSAN over the last 8 years. In 2015, Area Boards became Regional Offices of the State Council on Developmental Disabilities (SCDD) and Partners became members. In 2016, SSAN members decided to be a cross disability training network working to further the self-advocacy movement in California. Members have come and gone, but SSAN continues to educate our communities on things like CalABLE, Self-Determination, Employment First, and legislation. SSAN has continued to work in the face of challenges like wildfires, earthquakes and now COVID—19. While it has been difficult to adapt to meetings on Zoom, SSAN members continue to attend self—advocacy meetings, and be leaders in their communities during hard times. Hopefully for SSAN’s 9th birthday and beyond we will be done having coronavirus and the world will go back to normal.

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

Check out the latest DDS Self-Determination Newsletter for the latest on California’s Self-Determination Program.
Camp Fire: What Paradise Looks Like Almost 2 Years Later

By Teresa Moshier, North State Regional Representative

On November 8, 2018, the Camp Fire nearly destroyed the town of Paradise, California. The Camp Fire was the deadliest fire in the Nation since 1918 and destroyed 18,000 structures and it took 17 days to put out the fire and caused the worst air quality ever recorded. The fire displaced 16,000 people, including 700 Far Northern Regional Center clients. All Far Northern Regional Center clients got out.

Now it’s almost 2 years later and the town of Paradise is still recovering from the Camp Fire. So many buildings still are in the same state that they were when the fire hit. The only progress has been that their lots are cleared and cleaned up. The town of Paradise nearly lost their only hospital and they continue to rebuild their emergency room services, hoping to open again one day. They also lost Canyon View Clinic which was the original hospital and where I used to go for medical services. Through the PG&E class action lawsuit, insurance issues and lots of red tape, it’s taking much longer for progress and rebuilding to happen.

Before the Camp Fire, the population in Paradise was over 26,000 people and now the population after the Camp Fire is about 5,000 people, which is a decline of over 82% of the people. Many people had to move away from Paradise to other parts of California and other states too. According to Laura Larson, the former Far Northern Regional Center Executive Director, 25 clients moved out of state to live somewhere else.

(Continue on Page 7: “Camp Fire: 2 Years Later”)
(Continued from Page 6: “Camp Fire: 2 Years Later”)

My best friend, Taya Cooper, moved to Colorado to live near her family because there was no affordable housing left in Chico at that time. Now, my contact with Taya is through Facebook, Facetime and phone calls.

Although I’m glad she’s my best friend, I miss her a lot and I miss our “girls’ day” time together. We used to go shopping, do arts and crafts together and worked at AMJaMB’s The Call Connection together. I still have my job at The Call Connection and continue to make calls from my home, as the current pandemic put another curve ball in my path.

People First of Paradise was impacted by the Camp Fire. I was the President of People First of Paradise and my best friend, Taya, was the Vice President. We haven’t been able to meet since the Camp Fire, some people moved away and the restaurant, Cozy Diner, where we used to hold our meetings, still hasn’t opened because of the damage from the fire in November 2018. I keep in touch with some of the members through Facebook and phone calls. I hope that they can get another chapter started in Paradise. I like many others have had to move because of the Camp Fire. I hope to help start a People First Chapter in Glenn County, soon.

On the positive side, many people are rebuilding homes and working hard to move from RV’s and Camp Trailers to their newly built homes on their properties. That is good to see and good for the community. If I could sum up my article, I would say, Paradise is rebuilding slowly.
New Member Bio: Russell Rawlings

By Russell Rawlings, CFILC Representative

Hello SSAN Members and Allies!

My name is Russell Rawlings, and I am the Statewide Community Organizer for California Foundation for Independent Living Centers (CFILC). I am responsible for leading the Disability Organizing Network (DO Network).

I am proud to join this group of experienced self-advocates. Some of your names are familiar, and I do hope to connect with all of you. I hope to bring your voices and experience into the DO Network, a statewide network of cross-disability advocates.

I want to introduce myself to all of you. Before becoming Statewide Community Organizer at CFILC, I was Director of Advocacy at Resources for Independent Living (RIL) in Sacramento. RIL is the Independent Living Center serving Sacramento County and Yolo County.

I began my journey toward “independent living” here in Sacramento. Growing up in Texas as a significantly disabled, powerchair user with cerebral palsy, I struggled with access to transportation. My parents’ van with a wheelchair lift was my only transportation. The nearest bus to my parents’ home was over 3 miles away, and there were no sidewalks along the roads.

I feel very lucky to have found RIL in Sacramento. It was there that I found my identity as a disabled person. I learned about the Independent Living Movement. I was given the opportunity to serve as President of Disability Organizing Group for Initiating Total Equality (DOGFITE), an advocacy group held at RIL. This experience gave me the opportunity and confidence to learn about community organizing.

From my experiences serving as President of DOGFITE for more than 10 years and learning about community organizing, I became confident advocating not just for myself, but for the entire disability community. This gave me the confidence to apply for my first job at RIL in 2017.

(Continue on Page 9: “New Member”)

(End of Document)
RIL and California’s 28 Independent Living Centers all have staff working on “systems change,” or in plain language, helping their communities become more accessible by organizing people with disabilities to work on issue areas like: accessible, affordable housing, transportation, voting access and more.

It is my job as Statewide Community Organizer to help build the DO Network by bringing people with disabilities across California together to work on statewide systems change projects. Right now, our main project is advocating for a universal Long-Term Supports and Services benefit for Californians, to help Californians with disabilities have access to services that will help them live independently in their communities.

I look forward to connecting with each of you and learning more about the SSAN’s projects and priorities. I believe that the DO Network and SSAN do have similar goals, and I am excited to be able to bring the voice of self-advocates to our statewide network of disability rights advocates, organizers and activists.

You can reach me at russell@cfilc.org or by phone at 916-606-5300. I would love to talk to you or anyone you know in your community who is passionate about disability rights. Through our diversity, we are strong!
The Self Advocacy Council 6 (SAC6) knew fellow self-advocates were feeling down, alone and worried as the Corona Virus took over in March 2020. The SAC6 leadership decided to start having a Friday Zoom CHAT each week to check in on each other! We have had anywhere from 48 to over 100 people on each CHAT. On September 11, 2020- SAC6 celebrated its 20th CHAT! SCDD North Valley Hills and Valley Mountain Regional Center were asked by SAC6 to work with them to make this happen- TEAM WORK! Its been a BIG success! SAC6 plans to continue the Friday Zoom CHATS! Here are the topics and speakers for the 20 CHATS.

- **April 24, 2020- Stimulus Checks**- speaker Dena Hernandez/ SCDD North Valley Hills
- **May 1, 2020- Health & Wellness**- speakers were SAC6 Members
- **May 8, 2020- Update on all things Coronavirus**- speaker was VMRC Clinical Director- Claire Lazaro
- **May 15, 2020- US Census** -speakers SAC6 members, Dena Hernandez SCDD & DRAIL
- **May 22, 2020- SCAM ALERT**- speakers SAC6 members & Dena Hernandez/SCDD
- **May 29, 2020- DANCE PARTY**- celebrating all graduating students with disabilities!

(Continue on Page 11: “SAC 6 Chats”)

---

**SAC6 Friday Zoom CHATS helped connect self-advocates since April 24, 2020**

**By SSAN Representative- Robert Balderama**
(Continued from Page 10: “SAC 6 Chats”)

- **June 5, 2020- State Budget & How to contact your legislators**- speakers SAC6 members and Tony Anderson- VMRC Executive Director
- **June 12, 2020- Latest Health Advisories**- Speaker- Claire Lazaro- Clinical Director of VMRC
- **June 19, 2020- What is the DDS CAC?**- speakers SAC6 chair- Lisa Utsey and Nicole Patterson- DDS CAC Coordinator
- **June 26, 2020- Mental Health Awareness**- speakers were the SAC6 members
- **July 3, 2020- NO CHAT** due to 4th of July Holiday
- **July 10, 2020- Mental Health Awareness Part 2**- SAC6 members & Dr. Dave Demetral
- **July 17, 2020- Social Media Training**- speaker was Doug Bonnet- VMRC Assistant to the Director
- **July 24, 2020- VMRC Strategic Plan**- speakers Tony Anderson- VMRC Executive Director & Ami Sullivan from Kinetic Flow
- **July 31, 2020- VOTING**- speakers Scott Baron- SSAN members & DRC advocate and Nubyaan Scott- DRC/OCRA
- **August 7, 2020- Self Determination Program** – speakers- Kerstin Williams- SCDD RAC, VMRC SDAC & SAC6 member and the VMRC Self Determination Team
- **August 14, 2020- Disability Resource Agency for Independent Living (DRAIL)** speakers Mohamed Rashid & Kholoud Rashid- Community Organizers
- **August 21, 2020- VMRC Purchase of Services (POS) Disparity Info**- speaker- Gabriela Lopez- VMRC Cultural Specialist
- **August 28, 2020- Feeling Safe/Being Safe**- speakers SAC6 chair- Lisa Utsey and Nicole Patterson- DDS CAC Coordinator
- **September 4, 2020- Coping with Grief & Loss**- speaker- Dr. Dave Demetral
- **September 11, 2020- Person Centered Planning**- SAC6 consultant- Dena #1 Pfeifer & Dena #2 Hernandez SCDD North Valley Hills

Last two SAC6 Friday ZOOM CHATS for September will be

- **September 18, 2020- Law Enforcement & YOU**- How to be safe in our communities together with SAC6 & Officer Jesus Zavala from Stockton Police Department
- **September 25, 2020- Disability Cultural**- speakers Robert Balderama- SSAN Representative, Christina Mills- Executive Director of the CA Foundation on Independent Living (CFILC) and Andrew Imparato- Executive Director from Disability Rights CA.
Member Interview: Wesley Witherspoon

By Robert Levy, UC Davis MIND Institute Representative

I had the opportunity to interview Wesley Witherspoon about what self-advocacy means to him and the different ways he uses self-advocacy in his life. Wesley Witherspoon is the USC Children’s Hospital UCEDD Representative to SSAN.

Why is self—advocacy important to you?

Self-advocacy is important because it lists what we like and don’t like. Prior to Regional Center being used, people with disabilities did not have any rights. People with disabilities had to fight for their lives in the 60s and 70s to achieve the rights we have now. Without self-advocacy, someone else would make decisions for us.

How many different self—advocacy organizations do you belong to?

I am a member of the Self-Advocates Advisory Committee of the State Council on Developmental Disabilities, the Westside Self—Advocacy Group, Strengthening Self—Advocacy Los Angeles County, and the Self—Advocacy Board of Los Angeles County.

How did you get involved with SSAN?

I worked with SSAN for several years. I learned leadership skills, and got leadership experience by playing role games on computers and exercising. Those decisions I made helped me become a leader with SSAN. You need to know what the issues are concerning people with disabilities. I worked with several self-advocacy groups in the Los Angeles Area. I became a leader in the self-advocacy movement. My former supervisor Barbara Wheeler recommended me for SSAN. I have been involved with SSAN for over 3 years now.

How has self—advocacy helped you?

Before I got involved with self-advocacy. I did not have a job to go to. I did not have a significant other. I learned how to advocate for myself when I was a teenager. I learned about what I want and don’t want. With self-advocacy, I learned how to set a goal and complete what I want to do. I found a mentor and learned from others how to do things for myself. Self-Advocacy means deciding about what you want and don’t want.

(Continue on Page 13: “Interview”)

Why is it important for the 3 California UCEDDs to hire people with disabilities?

It is important to hire people with disabilities because they are a part of our communities. People with disabilities want the same things that people without disabilities have. A person with a disability likes to make money, have recreational activities, a chance for a social life they want. Without people with disabilities on staff, UCEDDs would have difficulties understanding the needs of people with disabilities. People with disabilities are essential for the advancement of the UCEDDs.

Do you have any statewide or national Collaborations with the 3 California UCEDDs?

We collaborate on the Statewide Self-Advocacy Network and the Association of University Centers for Disabilities.

Do you have any advice for other self—advocates to get involved in their communities?

My advice for self-advocates is that we are constantly learning. We are human, we are going to make mistakes. Learn from your mistakes. Know about yourself, what you like and don’t like. Get involved with your self-advocacy group. Learn how to be independent, ask questions, have someone mentor you as you go through your life. Take an assessment of your abilities and skills. Volunteer your time in the community and learn how to be pro-social. Do something you want to do. Learn how to speak up for yourself and how to communicate what you want effectively to authority figures like the police, elected officials, or if you are in a conservatorship or under 18, the person who is responsible for making decisions on your behalf. Learn about the history and struggles of people with disabilities. Listen to people who been through similar situations.
Kudos Corner

Desiree Boykin takes her job as Vice Chairperson of the SSAN very seriously, so much, so I think she has only missed one or two meetings since she began serving in 2013 as ARCA representative. She is a type of member that is always willing to help in any way possible to make the SSAN run smoother. We appreciate the work she does with the SSAN Newsletter Workgroup. She has a strong passion for young people and understands that we have a role in helping them become the leaders of tomorrow. Desiree, thank you for being a voice for the SSAN. Kudos to you!!

Community Resources

Disability Vote California is a non-partisan campaign to eliminate barriers to voting, promote accessibility of voting technology and polling places; educate voters about issues and candidates; promote turnout of voters with disabilities across the state, and protect eligible voters’ right to participate in elections.

Check out the State Council on Developmental Disabilities’ Series of Informational Videos on COVID—19 featuring people with disabilities on Youtube.

California Disaster Strategies Coalition consists of a broad group of community service providers and advocates working on inclusive emergency planning, response, recovery, and mitigation.

SAVE THE DATES

Disability Rights California
Events and Trainings

Training Page:
https://bit.ly/3jmZV6N

Supported Life Institute

Conference Page:
https://bit.ly/3gAfMwO

More Plain Language Resources relating to COVID—19 can be found on the SCDD Website:
http://www.scdd.ca.gov

Contact your regional office of the State Council on Developmental Disabilities for information on trainings and local self-advocacy meetings happening in your area or to find out how to get Personal Protective Equipment (PPE) for you and your family.