



VOICES of SSAN

June 2020

Volume 21

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Contributors:

- Desiree Boykin
- Robert Levy
- Wesley Witherspoon
- Sean Sullivan
- Paul Mansell
- David Forderer
- Nicole Patterson

Message from the Editors

By Robert Levy, UC Davis MIND Institute Representative and Desiree Boykin, ARCA SSAN Representative

We hope that everyone is safe during these uncertain times. The number of people that are infected with COVID—19 and the number of people who die from COVID—19 continues to increase. This disease is affecting every part of our daily lives. Over 40 million people in the U.S. have lost their jobs because of COVID—19 and the Stay at Home orders that have been issued across the country. It is sad to have our normal routines changed because of COVID—19. We have had to stop going to work, going grocery shopping, traveling or hanging out with friends at restaurants and the movies.

It is important to remember to practice social distancing by keeping 6 feet or more apart at when you must leave your house. Remember to wash your hands for at least 20 seconds or more too. Stay home if you are feeling sick. Find things to do around your home to keep yourself busy during this lockdown period.

Because of the current situation of with COVID—19, this Edition of the SSAN Newsletter “Voices of SSAN” is shorter than usual and focuses on information about COVID—19 and includes tips and resources to help you stay healthy and connected.



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Reflections on Sheltering in Place

By Paul Mansell, San Diego Regional Representative

I woke up this morning to a dreary day with clouds, wind, and rain—yuck! I hate gloomy weather and it sums up my feelings about sheltering in place. Practicing social distancing or wearing personal protective equipment (PPE) feels so unnatural and contrived—something out of a horror movie. I want to get up and be free to do my typical morning routine, commute to work, and start another day at the office. It is frustrating that human contact is limited to a phone, computer, or some handheld device.

I have been sheltering in place since early March and sometimes it feels like I am a prisoner in my own home. Going into the office to work seems like a distant memory. My underlying health conditions, have me cautious about returning to work at the office. I am thankful that I can work from home, when I know that so many people have lost their jobs. I am thankful for that security.

Creating and refining a routine has helped me to adapt in these uncertain times. My days consist of working, checking in with coworkers and friends, and limiting the amount of news I watch; the count of actual and expected deaths is overwhelming. My dining room table has become my virtual office. I use an iPad to connect to my agency's software platform, but my office phone is not linked to my personal phone, so technology continues to be a weak spot for me. I am grateful for the technology that I do have, as it helps me to be productive while working.

I have enrolled in Meals on Wheels to reduce my need to go to the store, since hoarding and crowds create a challenge. Most of my shopping is limited to going to Rite Aid to pick up my prescriptions.

This whole experience has taught me that relationships and connections are important and key to mental health, and they need to be maintained on an ongoing basis. Sheltering in place is terribly lonely and leads to anxiety. As much as I want to go outside, go to a nice restaurant or shopping, I realize staying home is the only weapon we have against this virus.

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I try my best to stay connected with my community while sheltering in place. I Skype, Zoom, call, text, and email family, friends and colleagues. It is not the same as face-to-face, but it goes a long way to build and maintain relationships.

We are going through historic times that no doubt will shape this country for years to come in ways I can't even begin to imagine. I need a break from the enormity of it all. Watching movies helps me travel to a land far away where there are no viruses, quarantines, or shelters in place—only stardust. I need the getaway even if it is for only an hour or two.

Thoughts on COVID—19 from SSAN Members

“COVID—19 does not discriminate, it affects everyone no matter what you do. Be safe out there.” – Wesley Witherspoon, USC Children’s Hospital UCEDD SSAN Representative

“I am thankful for the number of South-Central Los Angeles Regional Center staff and vendors that have gone the extra mile in supporting all individuals served that SCLARC during these difficult times.” – Desiree Boykin, ARCA SSAN Representative

“I have been incredibly productive and proactive during these turbulent times. I started my very own podcast radio show where I talk about autism, ABA, and mental health and so on!! I understand that this pandemic is very serious, but I am doing my best to have a glass half full attitude!! ” – Sean Sullivan, Orange County SSAN Representative

SSAN Members

- Nathaniel Florez – North Coast
- Teresa Moshier – North State
- Lisa Cooley – Sacramento
- Chen Curtiss – 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 Fousté – 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



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Tips to Stay Healthy from COVID—19



1. Wash your hands for at least 20 seconds. If it helps, this is the same amount of time that it takes to hum “Happy Birthday” twice.



2. Cover your mouth with a tissue or sleeve when coughing or sneezing



3. Avoid touching your face



4. Clean items around you like doorknobs, tables and phones

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**



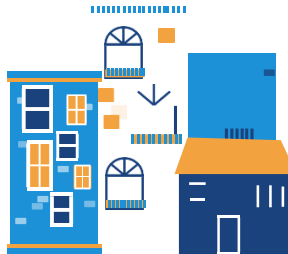
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More Tips to Stay Healthy from COVID—19

5. Stay home if you feel sick



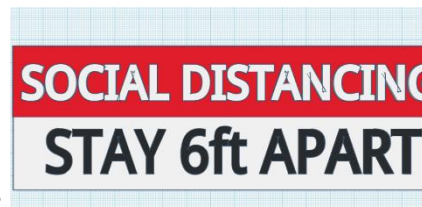
6. Call before visiting your doctor



7. Wear a face covering when you go out to a public place



8. When possible stay 6 feet away from people who do not live with you



Learn About SSAN

Partners

- [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.



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Remembering Cheryl Hewitt

By David Forderer, Central Coast Regional Representative

David Grady, SCDD Regional Manager
Central Cost Office



It is with a heavy heart that SSAN says goodbye to Former Chair Cheryl Hewitt, who recently passed away. Cheryl served in all three leadership roles in SSAN (Chair, Vice—Chair and Secretary) from 2013 to 2017. As Chair of SSAN, Cheryl played an important role in laying the foundation for many important parts of the groups' structure. Cheryl worked closely with many different staff at the State Council on Developmental Disabilities to advocate for the increase of inclusion, independence and autonomy for people with disabilities throughout California. In addition to working with SCDD in various capacities, Cheryl served as an advisor to the staff of the Stanford Medical Center, as well as to a member of City Council and other local politicians. Cheryl was Chair of the Local Self—Determination Advisory Committee and the local IHSS Advisory Committee. At the time of her passing, Cheryl Hewitt was the Chair of the Central Coast Regional Advisory Committee (RAC), continuing her advocacy to the end and will be missed by those who had the opportunity to know her.

David Forderer remembers: "I met Cheryl Hewitt a year or so before I joined the Council, while waiting for a meeting at the San Andreas Regional Center (SARC). At the time I was on the Board of Directors of SARC. When I was appointed to serve on the Council in 2012, I recommended Cheryl to be my replacement on the board at SARC. This led to the development of a good working relationship. At the time of her passing, Cheryl was on the Board of the Silicon Valley Independent Living Center (SVILC). Cheryl Hewitt was a powerful voice in the Disability Rights Movement and was very vocal about her belief in the importance of people with disabilities being able to live Self—Determined lives.

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Even though our approach to advocacy was different, we worked well together, and I appreciated Cheryl’s passion and determination to create a world where people with disabilities could have their voices heard.”

David Grady, Regional Manager of the Central Coast Office of the State Council on Developmental Disabilities reflected on the fact that Cheryl had the ability to help both parents and community members understand what self—advocacy truly means. “Cheryl provided family and community members with a visual representation of someone with an intellectual and developmental disability having the ability to speak to power and have her voice be heard. Cheryl helped family members and community members to understand the importance of their roles in empowering their sons and daughters develop their own powerful voices.”





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Community Resources

[Aunt Bertha](#) is a nationwide social care network that connects people seeking help to programs and verified social care providers that serve them.

Thousands of nonprofits and social care providers serve their communities. But for most people, navigating the system to get help can be difficult, frustrating and take a lot of time. Aunt Bertha aims to make navigating the service delivery system easier for you.

The State Council on Developmental Disabilities is on YouTube!

Check out their [Series of Informational Videos on COVID—19](#) featuring people with disabilities.

SAVE THE DATES

ADA for the Next Generation



What: Virtual Public Policy Forum and Celebration

Date: July 29, 2020

Registration:

<https://bit.ly/2U31Q6e>

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.