



# VOICES of SSAN

September 2021

Volume 26

## IN THIS EDITION:

**Article 1:** Connecting Community

**Article 2:** California Statewide

Self-Advocacy Conference Recap

**Article 3:** SCDD Self-Advocacy Role

**Article 4:** Public Transportation Tips

**Article 5:** FNRC Service Coordinator

**Article 6:** 10 Years Working at UC

Davis MIND Institute

**Article 7:** Role of Support

**Article 8:** Social Justice and

Disability

**Article 9:** Interview: Far

Northern Regional Center

**Article 10:** Kudos Corner

**Article 11:** Community Resources

**Article 12:** Save the Dates

**Editor:** Robert Levy

## Contributors:

- Ellen Sweigert
- Desiree Boykin
- Wesley Witherspoon
- Matthew Lagrand
- Teresa Moshier
- Robert Levy
- Julie Gaona
- Paul Mansell

## Connecting Community to SSAN

**By Ellen Sweigert,** North Bay Regional SSAN Representative

As Self Advocates, it's our responsibility to connect our communities to SSAN. How you ask? Starts with the self-advocates, by developing your relationship with your communities. Getting involved with networking is another good way to connect your community to SSAN. It is important to make a good impression when networking. Connecting to the right people in the field of disability advocacy could really improve peoples' awareness of SSAN. Once we connect with other disability advocates and agencies, it is important to have a tool for keeping a portfolio of the agencies and advocates that we meet. It is also good to have an idea about the information that you want to share with others. Keeping each other informed and updated From SSAN to your community.

Many agencies in our communities probably have not even heard of SSAN. It's up to us to get those agencies to lean on us to lend a voice for them. To feel comfortable connecting with SSAN through their own statewide organizations. By providing leadership for people with disabilities, we can always use more self advocates that are passionate about disability advocacy just like us.

## SSAN Youth Survey

SSAN has created a [SSAN Youth Survey](#) to get information about what interests youth with disabilities. SSAN encourages people with disabilities ages 17 to 30 to provide their feedback; but welcomes anyone who is interested in participating to fill out the survey.



## California Statewide Self-Advocacy Conference

By SSAN Chairperson Desiree Boykin, ARCA SSAN Representative

May 7, 2021 the Supported Life Institute celebrated its 25<sup>th</sup> year of hosting the Statewide Self-Advocacy Conference. Over 200 self-advocates and support staff attended this conference virtually over Zoom. The Conference started with a popcorn style getting to know each other in the breakrooms. Jackie Armstrong, an advocate from Sacramento, had led a discussion about the value of going from a shelter workshop to employment alongside people in your community. She inspired many self-advocates to keep on striving.

The second speaker, Chris Benedict talked about overcoming fear and pain. Chris gave examples of how fear can stop adults with disabilities from moving forward. Self-advocates need to push from the negative images and create their own vision for a wonderful future. Chris ended this speech by saying that he wants all self-advocates to have a positive life. There was a break in the speakers for returning favorite: Zumba fitness instructor Yulissa, who gave us Zumba class.

Keynote speaker, Russell Lehman, a motivational speaker and poet from Las Vegas, Nevada shared his experience with depression and finding his voice. With the support of his family and therapy, he was able to overcome his sad times. He has written books and consults with self-advocates in all 50 states. Russell's message was to in your time accept your disability and get the supports to move forward with your life.

The third session focused on Emergency Preparedness. The presenter, Catherina Nelson talked about how being prepared for a fire or an earthquake can help in the long run. Having food water for a week personal necessities and extra batteries and an extra charger for your phone. All this item need to include in your emergency bag. Contact to a family member or friend outside of the state of California. Extra battery for your wheelchair if you need too.

Paul Mansell, SSAN Vice-Chairperson and Client Advocate from San Diego Regional Center, along with SCDD Self-Advocacy Coordinator Riana Hardin explained the ABC's of Self-Determination program. The presentation covered: who can be a part of the program, the role of a fiscal manager and an independent facilitator. The Self-Determination Program went to effect this summer and is an alternative to traditional services at the 21 Regional Centers. Paul gave his personal story of how the Self-Determination program changed his life and living a life that puts his hopes and dreams first. **(Continue on Page 3: "Statewide Self-Advocacy Conference")**



**(Continued from Page 2: “Statewide Self-Advocacy Conference”)**

The last session was “Relationships...Happy and Loving One is the Best to have” by Herb Hastings, Client Advocate at the Regional Center of the East Bay. In this final session he talked about the social cues to know if someone is interested in a relationship or friendship. Rejection happens but keep on moving forward. Some helpful tips included: don’t ever going to someone’s house on the first date, and meet them in public setting like the beach, movies, mall, and parks. It is a good idea to make sure you have enough cash to get home. Always tell 5 people where you’re going and what time your returning. After the first date or meeting keep on communicating, it takes 10 to 15 dates to know if the person is serious about you. In time you will meet family members. If they have social media accounts look to see what they might be going for that day. But don’t judge anyone based on posts. Self-Advocates felt confident this information as they seek healthy friendships and relationships. Self-Advocates look forward to meeting in May 2022.

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## **Role of the SCDD Self-Advocacy Coordinator**

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

I had the chance to talk with SCDD Self-Advocacy Coordinator, Riana Hardin on her role at SCDD recently and wanted to share what we talked about with you.

As the SCDD Self-Advocacy Coordinator, Ms. Hardin has a lot of different responsibilities. A big part of Ms. Hardin’s job is providing technical support (scheduling/hosting Zoom meetings, preparing meeting materials, and distributing information and resources) to self-advocates across California through supporting the Self-Advocates Advisory Committee (SAAC) and the Statewide Self-Advocacy Network (SSAN). Ms. Hardin is also a part of SCDD’s State Plan and Self-Advocacy Unit and reviews SCDD materials to make sure that they are in plain language and are also digitally accessible to people who uses screen readers.

Ms. Hardin enjoys the fact that there is a lot of variety in the different projects that she works on and that there are always opportunities to contribute to the work of SCDD. Ms. Hardin enjoys talking to advocates and learning about the different issues that are important to them. Ms. Hardin hopes that by working with self-advocates to create presentations, papers, articles and events, that she can give them the tools and resources to advocate for themselves and others.

Ms. Hardin is amazed that there is a council on developmental disabilities in each state and territory in the United States. **(Continue on Page 4: “SCDD Self-Advocacy Role”)**



**(Continued from Page 3: “SCDD Self-Advocacy Role”)**

It is neat to learn from other state councils on developmental disabilities to figure out if there are any best practices that would work in California.

An example of this is the National Association of Councils on Developmental Disabilities (NACDD) started hosting monthly national self-advocacy chats focused on topics that are important to people with I/DD near the end of last year. After attending one of them, Ms. Hardin put together a project proposal for the California Statewide Self-Advocacy Chats, which has increased the number of self-advocates and community members that know about SCDD.

Ms. Hardin thinks that one of the awesome things about SCDD is that when a problem or an issue comes up (like wildfires, mass shootings, COVID–19) SCDD staff work together to figure out what the needs of a community is and work collaboratively with each other and other agencies/organizations to help address those needs (like distributing PPE and Go Kits or putting together trainings/conferences).

It is important for self-advocates to know that you have a voice, you matter, and you can make a difference in your life and for others. An important step in having your voice heard is by connecting with your local Regional Office of SCDD for upcoming events, resources and information. You can also sign-up to be on our mailing list for up-to-date information about what is happening in California and nationally.

The future of self-advocacy in California is promising. There has been a lot of positive changes in the recent years with adoption of the Employment First Policy, the start of the Self-Determination Program, efforts to transition people from developmental centers to community living settings, and the recent mainstreaming of tools like Zoom. Ms. Hardin is confident that self-advocates in California (and across the country and even the world) can meet the challenges and work together to find solutions to problems and barriers.



## Public Transportation Tips

By **Matthew Lagrand**, SCDD SSAN Representative

Family has been important in developing self advocacy skills. I have learned a lot about self-advocacy from my dad. My dad taught me to use public transportation when I need to go places in town. He and I would go places using public transportation.

Since I do not drive, public transportation is an important tool that helps me to get to places on my own, independently. Before I learned how to use public transportation, someone would have to drive me there.

### Tips:

- Sit near the driver
- Let the driver know what stop you are getting off at
- Look both ways when crossing the street to get to a bus stop
- Wear bright colors when traveling at night
- When taking the train, you can sit anywhere you want to
- Wear a face covering when appropriate
- Practice social distancing when appropriate
- No food or drink on the bus

Public transportation helps me to travel different parts of California and even to other states to visit family and friends.

### SSAN Members

- Nathaniel Florez – North Coast
- Teresa Moshier – 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
- Matthew Lagrand – SCDD



## An Interview with Morag Longmire, my Service Coordinator!

By Teresa Moshier, North State Regional SSAN Representative



I appreciate all the work that my Service Coordinator does to help me be successful and wanted to ask her about her job. Morag Longmire has worked for Far Northern Regional Center for over 21 years and has had quite a journey!

Ms. Longmire graduated from Chico State in 1995. After traveling around Europe for a few months, she returned to Chico and started working for the Arc of Butte County in 1996. As an Independent Living Services (ILS) worker,

Ms. Longmire provided ILS to adults with developmental disabilities and was my ILS worker for about 1 ½ years. While at the Arc of Butte County, Ms. Longmire worked in the day program and was the Parenting and ILS Coordinator before she was hired at Far Northern Regional Center.

Ms. Longmire's favorite part about being a Service Coordinator is working with people and supporting them in developing goals and working towards accomplishing them. She enjoys the learning about the different life experiences of the people she works with and supports and the fact that every day is a little different. Ms. Longmire has a caseload of 81 people.

The pandemic has been a bit of an adventure for regional centers and staff has had to learn and adapt to manage their jobs and continue to support people and families. FNRC staff has learned to work remotely, but without the support of the Office Assistants, it would have been much harder. Ms. Longmire appreciates the dedication of FNRC IT department and the fact that all of the employees have supported each other during these times. The good news is Far Northern Regional Center staff have returned to the office on June 21, 2021 and the "normalcy" is a great feeling. Although they have lots of COVID-19 protocols in the office.

I feel Morag Longmire is very helpful. I remember how helpful she was as my ILS Worker and appreciated working closely with her. I even remember a pasta salad she taught me to make. She is very reliable and has always been there for me. Morag is important to me and we go way back!



## **My Work Experience from the Last 10 Years at UCD MIND Institute**

**By Robert Levy, UC Davis MIND Institute UCEDD SSAN Representative**

When I first started out back on Wednesday April 27, 2011, I was an unpaid CEDD staff intern as a volunteer now I am currently a paid staff. When I first started out at the UCD MIND Institute UCEDD I did not know how to do my job duties. My supervisor Steve Ruder has shown me how to do my job duties and showed me how to do presentations and become part of SSAN and other self-advocacy groups. He even showed how to present and became a self-advocate and helped me develop my leadership skills. I have presented at the state Capitol for Capitol Action Day, I even presented for our nation's capital at the Association University's Center on Disabilities conference. I also testified and met with my national and state legislatures and their staff members to support the bills by explaining to them why those bills should become law for other people with disabilities to have a productive life. Some of the bills I have supported were Employment First and Self Determination services that both became law in 2013. I have been advocating for eliminating subminimum wage since 2017 and I am supporting the current bill SB639.

Now I have developed some leadership skills. I became the chair for the Newsletter/ Commutation work group committee in 2015. I just became an officer for SSAN as a Secretary. Next year when the SSAN group members have elections I would like to run again for either Vice Chair or Chair for SSAN. Being on the Leadership role for has helped me to build on leadership skills to have my work resume.

When COVID hit I learned how to use the new technology like how to use zoom to attend meetings and how to use the otter recording system by getting information from upcoming conferences or webinars that I will need in the future for my personal use.

The other thing I learned is how to use Qualtrics self evals forms to get online data from either the UCD Davis MIND Institute UCEDD for their training workshops and their conference trainings workshops and for the SSAN meetings being our new way to get the work done more efficiently by the support of either Steve Ruder or Riana Hardin.

Since I have been working from home over a year now, I have been learning a lot of new ways to my job. It will be interesting to see how my job changes as more work comes once we all meet back in person once the COVID pandemic ends.

As I work on my next decade of employment at the UCD MIND Institute UCEDD I like to continue working on my self-advocacy work for the UCD MIND Institute UCEDD and for the community too.



## The Role of Support in Independence

By Julie Gaona, Los Angeles Regional SSAN Representative

Independence is important for all people in general.

Unfortunately, sometimes the people who have developmental disabilities are not raised or looked at that way. Self-advocates and people that support them to be independent should advocate for their independence. Parents play a big part of their child being independent. Unfortunately, fear, lack of knowledge and resources to help their child with developmental disabilities can keep children with intellectual and/or developmental disabilities (I/DD) from being independent.

There needs to be more advocacy promoting independence for people with I/DD to have independence. An example of this would be presentations in schools, day programs, etc. My husband and I give presentations every year to parent groups that have children with developmental disabilities. We talk about our life story and how we became independent. The parents learn a lot from our presentation. We open their eyes about how their child can be independent. I feel if the self-advocates do more presentations like this from different disabilities and points of view that we can change people's lives in a positive way. Sometimes, self-advocates are so focused on advocating for their own needs that they forget the importance of educating others. We need to focus on the youth to help us be better advocates as well.

The parents that support their child with I/DD in a positive way must be advocating to the other parents the importance of their child being independent. My mother, husband, and I did a presentation for a group called Tiger.

**(Continue on Page 9: "Role of Support")**

### 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](http://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**





# VOICES of SSAN

September 2021

Volume 26

## (Continued from Page 8: “Role of Support”)

Tiger supports parents that have children with I/DD. My mother told the parent it’s important to have meetings with each other. The reason why is to discuss different techniques they use when advocating to make their child’s life more independent. Another benefit of parent groups and sharing stories is that it allows for the parents to support each other. By working together, parents can to change policies that are there to stop children in being independent. This collaboration really helps change the barriers their children face to be independent.

The caregivers need to understand they are also part of developing independence in people with I/DD. People with I/DD who are raised to be independent, can still get ignored by the caregivers. This is a problem. Caregivers that are taking care of the people who need them, need to respect their wants and wishes to be independent. People with I/DD must believe in themselves so, they don’t get left behind and are able to be independent. Today, there is more opportunity for children to be mainstreamed in public schools. People with I/DD must be educated to know that it is possible if, they are able to be mainstreamed. Today’s world we live in there is a lot of technology that can help a person with I/DD be independent without being judged.

## 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.



## Social Justice and the Disability Experience

By Paul Mansell, San Diego Regional SSAN Representative

“Each time a man stands up for an ideal or acts to improve the lot of others or strikes out against injustice, he sends forth a tiny ripple of hope.”

–Bobby Kennedy

When I think about what self-advocacy means, I am struck by many different definitions and ideas, but a common theme is the call for social justice for people with disabilities. Many different topics fall within social justice. All having the common theme that everyone deserves to be treated fairly and have access to the services and supports needed to live. Social justice is the view that everyone deserves equal economic, political and social rights and opportunities. Social justice issues include tolerance and acceptance, equality, voting rights, climate/environmental justice, affordable, accessible and integrated housing, access to adequate healthcare, racial/ethnic injustice, income/wealth gap, gun violence, education and economic opportunity, hunger, and food insecurity.

There are four interrelated principles of social justice: equity, access, participation and rights. Recent media attention around interactions between police officers and people of color (some of which resulted in death) Breonna Taylor, Trayvon Martin, and George Floyd to name a few, has meant that social justice relates to calls for reform within the criminal justice system.

It is not enough to talk about Social Justice, it is time to act through thought, word, and deed. We need to study the issues and identify the problems. Come together, join up with open minded people, develop allies and partners, and organize. We need to brainstorm, formulate solutions, set goals, develop action plans, and take responsibility. We need to take bold steps--write articles for newsletters and newspapers, contact governmental officials, attend meetings and rallies, testify, make in person visits, working in campaigns, and vote.

Advancing Social Justice is at the heart of Self-Advocacy and working together, the disabled community can make it happen.

Check out my new [Blog on Self-Advocacy](#)



## Interview: Far Northern Regional Center

By Teresa Moshier, North State Regional SSAN Representative



Far Northern  
Regional Center



In order to learn more about what Regional Center staff do, I reached out to Melissa Gruhler, the Executive Director at Far Northern Regional Center. Melissa has been the Executive Director at Far Northern Regional Center (FNRC). Ms. Gruhler has worked in many different roles at FNRC from Service Coordinator, Supervising Service Coordinator, Case Management Supervisor and Associate Director of Client Services, before becoming the Executive Director in July of 2019.

### Where did You Work Before FNRC?

Prior to starting at Far Northern Regional Center, I worked at a SMART Center – at the time it was called Private Industry Council, for a couple years and prior to that provided Independent Living Services (ILS) for adults with developmental disabilities in the State of Washington. In the early 90's I worked in a residential facility for emotionally disturbed children between the age of 6-13. Other positions in my early adulthood including cashiering, waitressing, and office work.

### What is Your Favorite Part of Being the Executive Director of Far Northern Regional Center?

Everyday is a new day! My favorite part is being involved in upcoming programs and services. I enjoy launching new services and being involved in seeing them grow. Since I've been working at Far Northern Regional Center for almost 26 years and through all my positions, I've watched progress and have watched people blossom. I enjoy watching people reach their goals. I am appreciative of the work that FNRC staff does to support 8,300 people with developmental disabilities and their families (as of May 31, 2021).

### How has Covid-19 changed the way FNRC operates?

As of March 2020, most of the employees at Far Northern Regional Center were working remotely out of their homes. Recently our staff have returned to the office. We have learned that remote working can work and has many benefits, however, relationships have changed. Without face-to-face connection, there is an inability to make in-depth relationships. On June 11, 2021 Far Northern Regional Center opened the lobby doors in their Chico Office and on June 21, 2021, they opened the lobby in their Redding Office. Appointments are being requested for scheduling meeting with staff and safety protocols are in place in all common areas, including mask requirements.

### Where would you like to go for a vacation?

It's not where I want to go, it's who I want to spend it with! Whether it's at home, in Redding or anywhere in the state, I want to spend it with my family!



# VOICES of SSAN

September 2021

Volume 26

SAVE THE DATES

## Kudos Corner

By Wesley Witherspoon

I would like to give kudos to Daniel Fouste, who represents San Bernardino on SSAN. Daniel has been a member of SSAN for 5 years.

The thing I like about Daniel is that he is honest, persistent in his efforts to reach his goals, and always has a positive attitude. Daniel is committed to being an active participant of SSAN and has worked closely with the SCDD San Bernardino Regional Office to do outreach and trainings in the community. No matter how busy Daniel may be, he always makes time for his family and friends.

Daniel brings a valuable insight and perspective to SSAN and how to advocate for and include people with disabilities into activities. Daniel is not just great at advocating for himself: he advocates for other people with disabilities as well. Kudos to you Daniel!

## Community Resources

- Check out the State Council on Developmental Disabilities' [Series of Informational Videos on COVID—19](#) featuring people with disabilities on Youtube.
- [SCDD Plain Language Vaccine FAQ](#)
- Association of Regional Center Agencies (ARCA) [Regional Center COVID-19 Resources](#)
- [My Turn CA](#) is can help you find a vaccine clinic near you
- [Vaccine Finder](#) helps you find a vaccine site across the USA
- The Social Security Administration (SSA) says [COVID—19 Stimulus Checks Won't Affect Your Benefits.](#)
- Talk to your doctor to figure out which vaccine is best for you
- Need a ride to an appointment? Ride share companies can help

Disability Rights California



Events and Trainings:

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

**Check with your Local Regional Center for Local Self-Advocacy Trainings/Events.**

CalABLE



News and Trainings:

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

**Contact your SCDD Regional Office for:**

- upcoming trainings
- local self-advocacy meetings
- emergency preparedness resources for you and your family.

**Plain Language COVID—19 Resources Available on:**  
[SCDD Website](#)

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