



IN THIS EDITION:

Article 1: Letter from SSAN Officers

Article 2: COVID—19 Update

Article 3: SCDD Chair

Article 4: Self-Determination

Article 5: New Member

Spotlight: North Bay

Article 6: Raise the Roof Program

Article 7: NDEAM 2020

Article 8: Employment During COVID—19

Article 9: UC Davis SEEDS Program

Article 10: Kudos Corner

Article 11: Community Resources

Article 12: Save the Dates

Article 13: Community Announcements

Editor: Robert Levy

Contributors:

- Desiree Boykin
- Paul Mansell
- Robert Levy
- Wesley Witherspoon
- Lisa Cooley
- Ellen Sweigert
- Scott Barron
- Teresa Moshier

Letter from SSAN Officers

By Desiree Boykin, Association of Regional Center Agencies
Paul Mansell, San Diego Regional Center
Robert Levy, UC Davis MIND Institute UCEDD

Happy New Year! I hope everyone is having a wonderful 2021. As we approach this amazing New Year, we are all fighting as hard as we want to make sure that adults with disabilities are a part of the conversation for vaccines. SSAN will continue to learn about and educate our communities on the issues that impact the lives of people with intellectual and developmental disabilities such as: finding meaningful work or volunteering their time in the community and the importance of self-determination where advocates are in control of the services to improve the quality of life they live every day.

We continue to inspire the next generation by using social media and understanding how they want to find their voice. I look forward to working with all of the SSAN officers and SSAN members as we change the world. One day at a time.

– **Desiree Boykin, SSAN Chair 2020—2022**

“I am grateful for the opportunity to serve as your Vice-Chair from December 2020—December 2022. I have a vision for SSAN that sees beyond the pall of the pandemic to promote self-advocacy, capacity building, and systems change. I see SSAN advancing the cause of self-advocacy educating state officials to our needs, experiences, and dreams. Also, I see us educating fellow self-advocates on issues of vital importance to them and their well-being—especially employment, transportation, and Self-Determination. Lastly, I see SSAN collaborating with other disability groups to make a common voice advancing our well-being, social justice, and equity.”

– **Paul Mansell, SSAN Vice—Chair 2020—2022**

(Continue on Page 2: “Letter”)



VOICES of SSAN

March 2021

Volume 24

(Continued from Page 1: “Letter”)

“Thank you for the opportunity to serve as the SSAN Secretary for 2020—2022. I am excited about my new role within SSAN. I look forward to working with the SSAN Chair and Vice-Chair to support SSAN members for the next two years. I hope to be able to provide SSAN members with important information about services and supports for Californians with intellectual and developmental disabilities. I hope to draw from leadership skills that I have developed through chairing the SSAN Newsletter/Communication Workgroup, as well as my experience as Treasurer for the ASAN group for the Sacramento chapter. I will do the best job as I can for this group as your Secretary for the next 2 years. Thank you for giving me the opportunity to serve, it’s a huge role to build more leadership skills.”

– Robert Levy, SSAN Secretary 2020—2022

Our Vision for the Next 2 Years

As the new leadership team of SSAN, we look forward to continuing the important self-advocacy work of SSAN in order to make sure that people with disabilities are included in society and able to live a meaningful life. We are here to help and support both new and long-time members. We hope to contribute to building a solid SSAN identity through building cross disability partnerships and working collaboratively with the workgroups to support SSAN projects.

We plan on working together address and respond to concerns related to ongoing COVID—19 and other social issues. It is our hope that we will build off of the work of previous SSAN Officers to build community and strengthen relationships during these trying times. Thank you for your support as your new SSAN Officers.



COVID—19 Update

By Robert Balderama, North Valley Hills Regional Representative



With COVID-19 numbers still growing around the world we must continue to emphasize the importance of following the guidelines like maintaining our distance from others especially those of us that are more vulnerable. We follow the guidelines to protect ourselves, our loved ones, those that support us and their families too. The guidelines will help us all to do our part in preventing the spread of the COVID-19 virus.

Take these precautions to do your part:

Wear your mask



Continue to Wash your hands with soap and warm water **often** for at least 20 seconds or to make it fun sing happy birthday. Use Hand Sanitizer as a back-up too.

Cover your cough or sneeze with your sleeve, or tissue. Dispose of tissue and wash your hands afterward.



DON'T TOUCH your face, avoid touching eyes, nose or mouth, especially with unwashed hands.

KEEP YOUR DISTANCE Avoid close contact with people who are sick.



STAY HOME If you experience respiratory symptoms like a cough or fever, stay home.

GET HELP If you experience symptoms of COVID-19 (cough, fever, shortness of breath), call your health care provider or local health department before seeking care.

Doing these things will also help us get our children back into the schools and protect those teaching them. Let's do our part.

For up-to-date information about the COVID—19 visit [COVID-19.CA.GOV](https://www.covid-19.ca.gov).

(Continue on Page 4: "COVID—19 Update")



VOICES of SSAN

March 2021

Volume 24

(Continued from Page 3: “COVID—19 Update”)

COVID—Vaccine Update: People with Disabilities are a Vaccine Priority

Your voice has been heard! Thank you to all the fierce self-advocates, family advocates, and community members who urged making people with developmental and other disabilities a vaccine priority. Thanks to your effort, beginning March 15, healthcare providers may use their clinical judgement to vaccinate individuals age 16-64 who are deemed to be at the very highest risk for morbidity and mortality from COVID-19 as a direct result of one or more of the following severe health conditions:

- **Cancer**, current with debilitated or immunocompromised state
- **Chronic kidney disease**, stage 4 or above
- **Chronic pulmonary disease**, oxygen dependent
- **Down syndrome**
- **Immunocompromised state** (weakened immune system) from **solid organ transplant**
- **Pregnancy**
- **Sickle cell disease**
- **Heart conditions**, such as heart failure, coronary artery disease, or cardiomyopathies (excludes hypertension)
- **Severe obesity** (Body Mass Index 2 is greater or equal to 40 kg/m²)
- **Type 2 diabetes mellitus** with hemoglobin A1c level greater than 7.5%

OR

If as a result of a **developmental or other severe high-risk disability**, one or more of the following applies:

- The individual is likely to develop severe life-threatening illness or death from COVID-19 infection
- Acquiring COVID-19 will limit the individual's ability to receive ongoing care or services vital to their well-being and survival
- Providing adequate and timely COVID care will be particularly challenging as a result of the individual's disability.

Since November, SCDD has urged that people with disabilities be a priority for the COVID vaccine along with professional and family caregivers.

See [SCDD Full Statement](#) on this big announcement.



Message from the Chair of SCDD

By Wesley Witherspoon, USC Children's Hospital UCEDD Representative



I became the SCDD Chair on January 1, 2021. As SCDD Chair, I got a lot of responsibility to handle. As a leader, I make some important decisions. If you want to be a good leader, you need to understand how to work with other people. I attend a lot of meetings. You must know how to run a meeting, negotiate, delegate, compromise, organize, etc. I must motivate people to get the results that we want. I am working to make California a national leader for people with intellectual and developmental disabilities. I am reading books on how to be an effective leader. I also need to have hands on experience to become a good leader. I am committed to working many different hours. I decide what is important. I am on-call throughout the week. As a leader, you learn to bring out the best in everyone. You must put out an agenda and make sure it is organized. California has over 600,000 people with Intellectual and Developmental Disabilities. People with disabilities have the right to vote, work, have relationships, live where they want to live, and have social lives. Self-Determination will be available to everyone who receives services from a Regional Center in June. It is a privilege to serve as the SCDD Chair. Thank you.

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



My Experience in Self-Determination

By Paul Mansell, San Diego Regional Representative

I have had a positive experience in Self-Determination receiving individualized supports and services that better meet my hopes, dreams, and goals. Through Self-Determination, my plan better meets my needs, my quality of life has improved, and I have grown personally and professionally as a result.

My involvement with Self-Determination began over 20 years when I helped oversee the design and development of the original Self-Determination Pilot Project at San Diego Regional Center (SDRC). I subsequently attended a conference on Self-Determination and have read materials by leaders in the field on Person Centered Planning.

I was overjoyed when I was selected to be in the original rollout of Self-Determination. I went through Orientation and felt overwhelmed with all the information. I immediately set out to work on developing my new plan. I learned who my new service coordinator was. Based on my prior experience, I knew who I wanted to be my FMS, who my Person Centered Plan (PCP) writer would be, and because I had such a tiny budget, I decided to go with my Service Coordinator as my Independent Facilitator. I also knew what type of PCP I wanted: a MAP. All this knowledge helped me simplify the pre-enrollment process. Even so I felt like the pre-enrollment process was ballroom dancing with three partners. It was at times very confusing. It took me a year to get enrolled in Self-Determination. It took a lot time and hard work.

My individualized budget was tiny, so I had to be very economical with my spending plan. I played it conservative and basically transferred my traditional services over to my Self-Determination Plan. This worked out fine but then the pandemic hit: everything went out the window, especially my Independent Life Skills (ILS) support services. The number of hours were cut back significantly; consequently, my spending on ILS dropped dramatically. I wanted to use my whole budget, so with the assistance of my SC and my FMS, I creatively revised my spending plan. This took a lot of work and I am glad I did it. Year two may promise to bring the same. It is hard to plan with the pandemic in our midst.

It might be helpful to view your Self-Determination Plan as a project with the final outcome being your north star. All the steps, timelines, procedures, and milestones are focused with one purpose, reaching that north star. I am very happy with Self-Determination, and I encourage everyone who is dissatisfied with traditional service to give it a consideration.



New Member Spotlight

By Ellen Sweigert, North Bay Regional Representative



My Name is Ellen Sweigert. I was recently accepted to join SSAN. I have always been passionate about disability advocacy. I come from a family of lawyers. My dad is a lawyer and my grandfather, two of my great grandfathers, and several uncles were also lawyers. I knew that I would not become a lawyer myself, but my dream has always been to become active in disability advocacy. Chasing this dream has given me a background of being active advocating for disabled people.

I was born in 1988 with Down Syndrome. I attended Pacific Grove School District as a fully included student in regular classrooms from pre-kindergarten through 12th grade. I was elected Student Body Vice President as a seventh grader at Pacific Grove Middle School in 2001 and gave a stirring commencement speech at my high school graduation in 2007. I served for several years as an ambassador for Easter Seals of Central California and was selected to attend the Governor's Youth Leadership Forum for Students with Disabilities at California State University, Sacramento in the summer of July 2006.

(Continue on Page 8: "New Member")

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**



VOICES of SSAN

March 2021

Volume 24

(Continued from Page 7: “New Member”)

In October 2006, I was selected to serve on a disabled youth panel for Monterey County Committee for Employment of People with Disabilities. In 2009, the mayor of Pacific Grove appointed me to the City’s Americans with Disabilities Advisory Committee. I have lived independently in Napa, California since 2013, with the support of Moving Forward Towards Independence, a nonprofit independent living program. I worked for Parents Can, a nonprofit agency providing support services to parents of people with disabilities and I volunteer for the Napa County Historical Society. In addition to serving on the Statewide Self Advocacy Network, I also currently serve as the Napa co-chair of the North Bay Regional Advisory Committee.

I feel disability advocacy in my heart, and I look forward to continuing my work in this area as a member of the Statewide Self Advocacy Network and I am excited about getting to know the other members personally and learning what drives them.

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.



Raise the Roof: An Affordable Housing Leadership Training

By Paul Mansell, San Diego Regional Representative

Last fall I had the good fortune of participating in Raise the Roof—a virtual training series for self-advocates on affordable housing. Advocates from all over the country attended the trainings. It was sponsored by the Kelsey Group, an organization that advocates for affordable housing for people with disabilities. This training was a free-of-cost program for leaders with disabilities to increase knowledge and their network of the housing industry, advocacy and development, which will include 6 modules over a 12-week period and offer peer learning cohorts and office hours with mentors.

I became interested in affordable housing when I was on SSI. I was living at home with my mother, but I wanted to live independently. On SSI I couldn't afford rent, so I applied for Section #8 housing. I was put on the waiting list, and I waited. Years went by, but eventually I got my voucher, and I moved into my own place with ILS supports. It was demanding but I made a go of it.

Getting back to the training, it consisted of US-based adult advocates with disabilities who wanted to increase knowledge and effectiveness in changing housing policy, early career professionals that would like to build credentials in housing, and others that were curious about how housing gets built.

Here is some information on housing in San Diego: rent and utilities in an apartment or the monthly mortgage payment and housing expenses for a homeowner should be less than 30 percent of a household's monthly income to be considered affordable. Currently, the median income for a family of four in San Diego is \$63,400. This means \$19,020.

A key takeaway from the class was that shelter is not only a basic need but a fundamental right. America simply doesn't have enough affordable housing for the poor, low income, seniors, and the people with disabilities.

Where people with disabilities live affects our health, our career opportunities, our children's education, and our safety. Practices such as zoning locks us out of good housing and neighborhoods and crams us into run down, impoverished, crime infested communities, isolated from public transportation, grocery stores, and other supports, services and living conveniences. **(Continue on Page 10: "Raise the Roof")**



VOICES of SSAN

March 2021

Volume 24

(Continued from Page 9: “Raise the Roof”)

The scarcity of affordable housing compels us to compete against each other; instead of standing together united in solidarity. Inconsistent response to the pandemic and inconsistent access to services like testing, transportation, PPE and vaccinations have shown the inequities of income, wealth, and housing distribution in this nation.

To those who say we should be responsible and self-reliant in life, give us a foundation to base our life and opportunities to strive for more. To those who tell us to be content with what we have, we say open the doors of opportunity to us, so we may become empowered and strive to fulfill our potential and reach the American dream for ourselves and our families.

We are not asking for handouts, but opportunities to reach our potential. How can we achieve when narrow doorways, stairs, and curbs block our access? How can we integrate into the broader community when regular and reliable mass transit doesn't come to our homes? How can we prepare wholesome and nutrition meals when there are no grocery stores in our neighborhoods? How can our children succeed in school unless our schools are fully funded and have committed and caring teachers? Affordable housing is more than just a rent or mortgage that fits within our monthly budget, it is about hope, dignity, and respect.

Email raisetherooft@thekelsey.org to learn more about affordable housing.



National Disability Employment Awareness Month Turns 75!

By **Scott Barron**, Disability Rights California's Representative

CALIFORNIA CELEBRATES

**NATIONAL
DISABILITY
EMPLOYMENT
AWARENESS
MONTH**

#NDEAM19 #WorkItCA



The disability rights movement has worked hard to improve the lives of people with disabilities. With the passage Americans With Disabilities Act in 1990 and other state and federal antidiscrimination laws, individuals with disabilities have fewer physical barriers and greater access to services and supports in the community. But finding a job, let alone a job that pays at least minimum wage, can be difficult for people with disabilities. Without a good paying job, it is hard for many people with disabilities to live a productive and independent life community.

Unfortunately, this is not a new issue for the disability community. In 1945, Congress originally named the first week in October “National Employ the Physically Handicapped Week” in response to the large number of service members with disabilities returning home from World War II. Since then, the event evolved into a month-long observance and was renamed “National Disability Employment Awareness Month (NDEAM)” in 1998. The 75th anniversary celebrated with the theme “Increasing Access and Opportunity.”

Even with landmark legislation recognizing the civil rights of people with disabilities, data consistently shows that individuals with disabilities are underemployed compared to individuals without disabilities. According to the Centers for Disease Control, approximately 25% of Californians have a disability. However, only about 50% of individuals with disabilities across the nation have a job. This information shows that there is more work to be done. Advocates must still take the time to better explain how hiring people with disabilities can help the employee and the employer. **(Continue on Page 12: “NDEAM”)**



(Continued from page 11: “NDEAM”)

The new self-determination program and the recent changes to the services offered through the Department of Rehabilitation are more examples of how concrete steps are being taken to encourage people with disabilities to explore potential career opportunities and honor the legacy of the NDEAM.

As an individual with a developmental disability who has been competitively employed for the last 12 years, I have a unique perspective on the importance of the NDEAM. As I grew up, I always knew that I would be competitively employed. As a Peer Advocate with Disability Rights California (DRC), I have helped many consumers develop their self-advocacy skills and understand their individual rights. Because of my work, clients become more confident in believing they can get a job they enjoy in the community.

I recognize that my success is due in large part to the trailblazing individuals with disabilities that came before me. Through my work a DRC and participation in SSAN, I plan to carry on the tradition behind why the NDEAM was started so many years ago.

Resources

- [University of Oregon Division of Equity and Inclusion NDEAM information](#)
- [NDEAM: Increasing Access and Opportunity 2020 Event](#)
- [DRC: Increasing Access and Opportunities Resources and Information](#)
- [NDEAM Employment Experience Robert Levy](#)
- [NDEAM Career Advice from SCDD Councilmembers](#)



Adapting Employment During COVID—19

By Teresa Moshier, North State Regional Representative

I work for [the Call Connection](#), a call center that is operated by [AMJAMB Supported Living Services](#). Because of the COVID—19 Public Health Crisis, Call Connections employees are currently working from home doing our calls at home and we also do zoom every day. We have to be careful that we limit how many people are in the office at a time. Here are some things we do on zoom:

- Monday, we play bingo and we win prizes
- Tuesday, we do exercises and chat
- Wednesday, we do sign language
- Thursday, we exercise and chat
- Friday, we do arts and crafts

AMJAMB has had to make changes to how they do business due to crisis outside of their control. The first time was due to the Paradise Campfire, where workers were off work for 98 days. We wanted to go back to work; but could not go into the office because of smoke damage from the fire. Because of the damage the Camp Fire had on the City of Paradise, the AMJAMB office is now in Chico, CA, instead of Paradise, CA. The second time AMJAMB has had to make changes was in response to COVID—19. It has been a challenge to adapt the way we deliver our services, but the employees at AMJAMB are here to help. If you ever need a med reminder, or just a friendly chat, you can call AMJAMB at 530-872-3627.

UC Davis SEEDS Program



By **Lisa Cooley**, Sacramento Regional Representative
Robert Levy, UC Davis Mind Institute Representative

UC Davis is starting a new scholars program designed for students with intellectual and developmental disabilities (I/DD). The program is called Supported Education to Elevate Diversity or S.E.E.D. for short scheduled to start in the fall this year (Fall 2021).

The purpose of the [SEED Program](#) is to give students with I/DD between the ages of 18—26 an opportunity to participate in a four—year college program. The program is designed to provide students with the opportunity for:

- Personal Growth
- Interconnectedness
- Reaching and stretching toward independence
- Hard work
- Developing skills within context
- Learning to live in a community
- Working toward employment
- Leaning into areas of interest and study

The SEED program is funded through a five-year grant that doesn't have to be renewed every year. Support services for students are individualized the same way IPPs are and students are encouraged to use natural supports and use their self-advocacy skills when necessary.

If this program sounds interesting to you, consider [Applying for the UC Davis SEED Program](#). We look forward to seeing how the UC Davis SEED program benefits students with I/DD in their career paths.



VOICES of SSAN

March 2021

Volume 24

Kudos Corner

By Desiree Boykin

I've admired Paul for his leadership skills and ability to work with other Self- Advocates across the State of California. In 2019 Paul ask me to co-present with him at the San Diego People First Conference in San Diego. Paul was the chair at that time and made sure that 500 attendees knew where to go for each session for the weekend. Paul has worked as a Client Advocate for San Diego Regional Center for over 20 years. He works out daily and lives independently. He has been a part of the SSAN since 2016.

Paul has written articles for the Newsletter work group on Who inspires you, Self-Determination, voting, finding your voice, and techniques to cope with mental health issues during COVID—19. Paul is active member of the People First of San Diego group. He also calls in twice a week at the Advocates Advisory Committee Fun Chat. Paul wants to inspire the next generation of Self-Advocates to understand their rights accomplish their hopes and dreams.

Paul is extremely excited to be a part of the Self- Determination program. Paul represents the San Diego Imperial office. He is now Vice Chair of the SSAN. Kudos to you Paul Mansell!

Community Resources

Check out the State Council on Developmental Disabilities' [Series of Informational Videos on COVID—19](#) featuring people with disabilities on Youtube.

[Northern California Business Advisory Council \(BAC\)](#) was established to promote partnerships between local businesses and employment training programs.

SAVE THE DATES

Disability Rights California



Events and Trainings:

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



**California's 14th Annual
Developmental Disabilities
Public Policy Conference**

Monday March 15th—
Thursday, March 18th, 2021

[REGISTER TODAY](#)

**Contact your SCDD Regional
Office for:**

- **information on upcoming trainings**
- **local self-advocacy meetings**
- **find out how to get Personal Protective Equipment (PPE) for you and your family.**

**Plain Language COVID—19
Resources Available on:**

[SCDD Website](#)



DDS Symposium

DDS is proud to present a web series brought to you by partners throughout the state to showcase real-world examples of innovative services in action to meet individual consumer needs during the COVID-19 pandemic.

[Session 1: October 21, 2020](#)

[Session 2: October 28, 2020](#)

[Session 3: November 4, 2020](#)

[Session 4: November 12, 2020](#)

SAVE THE DATE

Registration coming soon:

The Statewide Self-Advocacy Conference

Date: Friday, May 7, 2021

Time: 10 AM to 4 PM

Where: Zoom

Contact:

info@supportedlife.org

Community Announcements

On February 17, 2021 Governor Newsom announced an agreement had been reached to provide low income Californians with a one-time \$600 payment. This relief effort would give low-income Californians, including those receiving the California Earned Income Tax Credit for 2020, those participating in CalWORKS, SSI/SSP, and receiving CAPI grants much needed economic relief. In addition, the agreement would provide a stimulus check to taxpayers with individual tax identification numbers who did not receive federal stimulus payments.

Undocumented immigrants would also be eligible to receive the one-time payments if they filed tax forms. ITIN taxpayers who also qualify for the California earned income tax credit would receive a total of \$1,200, state leaders said.

In all, the state would provide \$5.7 million payments to low-income Californians.

California residents could be eligible for the earned income tax credit if they have annual incomes of \$30,000 or less, which last year included 3.9 million taxpayers.