



VOICES of SSAN

March 2019 Volume 16

Meet the New SSAN Exec Team



Nicole Patterson (Chairperson)

My Name is Nicole Patterson and I am the new SSAN Chairperson. I have been involved with the SSAN since the beginning. I would like to tell you a little about myself. I have worked in the field of empowering people with disabilities for the past 25+ years.

My experiences include working with people with all types of disabilities providing assistance, advising people on their rights, and helping to educate people who provide services to people with disabilities. I have worked for the California State Department of Developmental Services for 13 years as the Coordinator of

Consumer Services. I provide a voice to the Director, and the Department, on issues and problems that people with disabilities may be facing in

(Continue on Page 2 – See Officers).

In this edition of the Voices of SSAN

- Meet the New SSAN Officers
- Meet New SSAN Member
- Thinking Ahead Materials
- Happy 7th Birthday SSAN
- 2018 AUCD Conference



Check out the Statewide Self Advocacy Network (SSAN) webpage at www.scdd.ca.gov/selfadvocacy



SSAN Newsletter Editor -Robert Levy

Contributors to this edition:

- Nicole Patterson
- Desiree Boykin
- Lisa Cooley
- Nate Florez
- Robert Levy
- Teresa Moshier
- Kecia Weller
- Wesley Witherspoon



(Officers – Continued from page 1).

California and help to come up with solutions.

I also assist with the coordination of the Department's Consumer Advisory Committee (CAC) in their work on self-advocacy projects. I also participate on consumer-driven projects across the state. I am married and I have a beautiful 10-year-old daughter. I enjoy going to the movies and traveling. I look forward to leading the SSAN for the next two years.

Desiree Boykin (Vice-Chairperson)

My Name is Desiree Boykin and I am the new SSAN Vice-Chairperson. I am a native of Los Angeles California, graduating from Dorsey High in 1997. After high school, I started El Camino College in Torrance California, later transferring to Cal State University Dominguez Hills in Carson California. I have a B. A. degree in Health and Human Services.

I learned about South Central Los Angeles Regional Center (SCLARC), applied for services, and started attending their local

self-advocacy group in 1998. In 1999, I ran and won the seat of President of the SCLARC Self-Advocacy group and served as President from 1999- 2003. I was recommended to the SCLARC board of Directors in 2000. I served on the board of directors for eleven years. I was a part of the Consumer Advisory Committee from 2008 until now. I served twice as the President of the CAC.

In December 2011, South Central Los Angeles Regional Center hired me as their Consumer Advocate. I like when the consumers reach their goals. I have also served on the USC UCEDD CAC starting in 2016 to the present. I now serve on the Association of Regional Center Agencies' Client Advisory Committee (ARCA CAC) as the representative for SCLARC. This board is made up of consumer advocates of the regional centers and consumers who serve on their local regional center boards of directors. The ARCA CAC elected me to serve as their representative for the Statewide Self- Advocacy Network in 2014. (Continue on page 3 – see Officers).



(Officers – continued from page 2).

I served one term as Secretary in 2015-2016.

Lisa Cooley (Secretary)

My name is Lisa Cooley. I am the new Secretary of the SSAN. I started doing disability advocacy work over twenty years ago because our local transportation provider thought that I could walk to a bus stop because I could walk around my house. I had to prove that despite walking around my house I needed Paratransit.

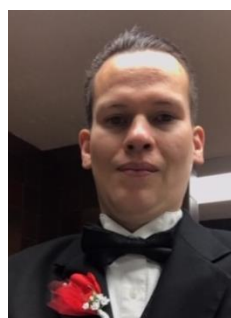
I learned how to advocate for myself with help from Disability Rights California and I became so good at advocating that I decided (with a little encouragement from a former State Council member) to become a member of the State Council on Developmental Disabilities. I am also a longtime member of my regional center's Client Advisory Committee and I have been a member of their board of directors. I am also a member of my University Center for Excellence on Developmental Disabilities Community Advisory Committee and United Cerebral Palsy grants committee.

Everything I've done professionally has been to empower people with disabilities and move California forward.

Our Vision for SSAN

The SSAN will continue strengthening advocacy work across California by educating, being active members in our communities and agencies, sharing information with SSAN and individuals in their communities, and being a voice for people with disabilities. The SSAN will also keep working on encouraging more partners from the disability community to join the SSAN table. This will help make it possible for the SSAN to work more with system change issues that face all persons with disabilities.

Meet New SSAN Member Nathaniel Florez, SCDD North Coast Region



Hi, I am Nate Florez and I have recently joined the Statewide Self Advocacy Network (SSAN). I live in Ukiah and I am an advocate helping with People First activities in Ukiah CA. I am currently the president of People First Ukiah (Continue on page 4 – see Nate).



(Nate – continued from page 3). and ran for a second term of office recently. I am the president again this year. I am a good communicator and reader, helping others to read the agenda at meetings. I am organized and keep meetings and timelines in order.

I am helping to increase the People First membership and getting training to the group on a variety of topics. I have brought in guest speakers for the People First meetings such as the County Sheriff to talk about bullying and staying safe. I have recruited new members to join People First and have increased their outside social activities, like barbeques at the park and having activities at meetings like an ice cream social to get people to come.

I helped the North Coast State Council office with their open house in Oct. and recruited other People First members to help with activities.

I have been a Regional Center Client of North Coast Regional Center since 1989.

To improve my leadership skills I speak at People First meetings, I chair the meetings and prepare the agenda. I also speak to students at the Ukiah High School Disability Resource Fair each year

encouraging them to come to people First meetings and activities and become self-advocates. I have increased my leadership skills by being on the People First Board and joining the SSAN with a hope to learn how to train others and be a better public speaker.

Some of the concerns I have for the North Coast area is that I would like to see more inclusive recreation activities. I have been advocating to keep the Bowling alley open as it was put up for sale and has been bought by a new owner who intends to close the bowling alley in a few months. Another bowling alley is hours away. Recreation opportunities are very scarce and not affordable.

I am looking forward to more training on being a self-advocate. I also feel People First and people with disabilities need training to help stop the bullying and helping people to be treated the same. I also want more disaster preparedness training.

I have a good attitude and I am determined to succeed. Being a member of SSAN will help me to develop those skills. I am really glad to have joined the SSAN.



Supported Life Institute

The YouTube videos and work booklets links resources information by Robert Levy SSAN representative of the UCD MIND Institute UCEDD

The Supported Life Institute wanted to do some interviews with people with disabilities on what they do out in their communities. So they came with an idea called “College Students and Professionals.” it was a grant by the State Council for Developmental Disabilities Sacramento Office. The narrator's are Cindy and Steve Ruder and they also did these interviews too. This project started back in April 2017 and it was completed in September 2018.

However everything wasn't finished until December 2018 when the 2 work booklets were posted on the Supported Life Institute website. Here are the links and resources to get into the College Students and Professionals YouTube video

library and the work booklets. Please check it out to see what you all think about those video interviews. There was one other YouTube video being the UCD MIND Institute 20th anniversary celebration that the CEDD staff member Patrick Hugunin did as a project. I'm in the video as well with many others who are part of the UCD MIND Institute staff and including the UCD MIND Institute Cafe staff member. So you can check all those 4 links and resources.

The College Students and Professionals YouTube videos library the link is at: <https://bit.ly/2TxLao7>

Work Booklet Successes in a workplace the link is at: <https://bit.ly/2NLo4oV>

Work booklet College Success the link is at: <https://bit.ly/2VFCKbK>

The UCD MIND Institute 20th anniversary Celebration the link is at: <https://bit.ly/2V81oly>



SAVE the DATES:

**24th Annual Calif.
Statewide Self-Advocacy Conference
Friday & Saturday
May 3rd & 4th, 2019**

Presented by: **Supported Life Institute**

“BUILD YOUR OWN TOOLBOX FOR SELF-ADVOCACY”



Statewide Sponsors

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Sacramento, CA




Supported Life Institute www.supportedlife.org 1010 Harley Way, Suite 180, Sacramento, CA 95825 916-567-1974

THINKING AHEAD My Way, My Choice, My Life at the End

Information Provided by
Nicole Patterson

Planning for end-of-life should be important to people with disabilities, better yet we should feel like it our responsibility to let people we love know what is important even during end-of-life planning as an advocate. This also allows you stay in control of your lives through the very end.

A day of unity and action for people with all types of disabilities and older adults. #DisabilityAgingUnited



**DISABILITY & AGING
CAPITOL ACTION DAY**


Unity Through Diversity

Featuring:

- Disability & Aging Community Resource Fair
- Educational Rally at Cesar Chavez Plaza
- March from Cesar Chavez Plaza to south steps of State Capitol
- Legislative Visits


May 23, 2019 • 10AM - 3PM
Cesar E. Chavez Plaza and the State Capitol
Sacramento, California

For more information, please visit: www.DisabilityActionCoalition.org
or scan the QR code to register.



THINKING AHEAD

My Way,
My Choice,
My Life at the End



"There is life, and there is death. You don't know what's going to happen today or tomorrow so you have to be prepared."
—Clemens (Pam Frank, 2008)

We should also want to know what our love one wishes are, because everyone needs help when thinking ahead and carrying out (Continue on page 7 – See Think).



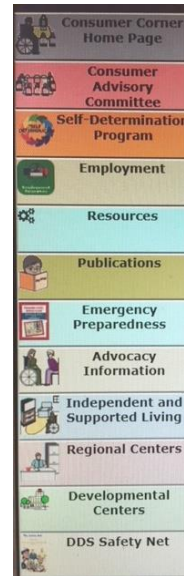
(Think – Continued from page 6), plans at the end of his or her life. You might need to be that person who advocates for someone wishes in your family at the end of their life.

Planning for end-of-life can be uncomfortable and overall stressful but remember, it can help protect your wishes and assist your loved ones during difficult situations. Proper planning for the end-of-life can be a gift to those you love. Below is a link to a workbook to assist people in making decisions about the end of their life.

[Thinking Ahead: My Way, My Choice, My Life at the End](#)



Check Out other resources from the Department of Developmental Services (DDS) - **Consumer Corner** – www.dds.ca.gov



SSAN 7th birthday

by Robert Levy SSAN representative of the UCD MIND Institute UCEDD

On April 11, 2012 there was a new self-advocacy network in State of California. SCDD helped to start the SSAN. There were also agencies throughout the state who were partners on SSAN. Right now there are currently 19 members out of 20 members.

SSAN members throughout the state are self-advocates that are doing the self-advocacy work to help the SCDD meet its self-advocacy goal. The network is a cross disability trained team.

During the last almost 7 years there have been a lot of (Continue on page 8 – see Birthday).



(Birthday – continued from page 7) members. Since SSAN began we worked on things like Self Determination, Employment First Policy, CalABLE ACT, staying informed on legislation, Housing, and Self-Advocacy events across the state.

Currently we have three new officers - Nicole Patterson is Chair, Desiree Boykin is Vice Chair and Lisa Cooley is our Secretary. There is still a lot more work that has to get done for all of us members at SSAN.

Happy 7th birthday SSAN!!!



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 Fouste – San Bernardino

- Paul Mansell – San Diego Imperial
- Desiree Boykin – ARCA
- Renee Wooten – 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

The Camp Fire Evacuation

By Teresa Moshier



On November 8, 2018 while I was at my physical therapy appointment I heard about the evacuation from my physical therapist while I was riding a stationary bicycle. This was about 8:15 am. The office is located on Clark Road, in Paradise, CA. I was really scared because my husband, David and I were separated, and I didn’t know where he was. I called my ILS worker who said she’d come and get me within 30 minutes, but then she called back because the (Continue on page 9 – see Fire).

(Fire – Continued from page 8). Skyway was closed and she couldn't come get me. I was really scared and I didn't know how I was going to get down the hill. I then called work and said I needed a way to go down the hill. My boss, Heidi, from AMJaMB came and got me and we evacuated to the K-Mart parking lot in Chico. She told me David had already gone down the hill with another staff at AMJaMB. When my boss picked me up, she had already picked up two of my co-workers and her daughter. I wanted to go get my medication but it happened so fast we couldn't get my "To Go Bag" or anything. It took us over an hour to get to Chico because of the back to back traffic. It usually takes about 15 minutes.

There was a lot of black clouds and a lot of traffic. We saw a lot of fire and it was really scary because you didn't know if it was going to get the car.



David and I stayed in a shelter for two days. We stayed at the East Avenue Church. There were a lot of evacuees.

After that, on the 10th, we went to my mom's. We've been staying there ever since.

The regional center was hit hard by the Camp fire. They had all the different agencies working to make sure that all the clients and staff were all safe. Laura Larson, the Executive Director of Far Northern Regional Center, lost one of her homes in the fire. A lot of clients in supported living lost their homes or apartments. 700 clients and about 100 staff were evacuated due to the Camp fire. 33 clients moved to different areas in our region and 25 clients moved out of state.

A lot of the programs affect by the Camp fire. 2 burned down – The Cove and ARC of Paradise. 2 had to move to Chico - Work Training Center CLC and Made in Paradise. Clients are now at programs in Chico and Oroville. All staff and clients were accounted for after the fire and Far Northern Regional Center did not lose any staff or clients in the fire. They are safe and with family & friends.

There are FEMA Trailers coming to Chico and Gridley.

Since I wrote my article on the Oroville Dam, (Continue on page 10 – see Fire).



(Fire – Continued from page 9). I have helped people be aware of what to do in an emergency.

What I have learned since the fire

- This was the deadliest fire in the Nation since 1918
- 18,000 structures were lost
- It took 17 days to put out and caused the worst air quality in the world
- 26,000 people were displaced and 700 were regional center clients



**Far Northern
Regional Center**

What worked for FNRC:

- Having emergency fairs
- Fire drills worked really well in Day Programs and Group Homes
- The emergency call that went out to all of the clients and staff in Paradise told us that there was a fire in the area and to pack your medicines and leave
- My regional center called in a prescription for my medication and paid for it

What didn't work was having too many programs in Paradise. When I interviewed Laura she said she was really impressed how people with disabilities were strong and didn't fall

apart during the fire when we were being evacuated. We all made it out alive.

State of California
Department of Developmental Services

Special Thanks to the Department of Developmental Services for letting our clients who are medically fragile stay at their hospital for a short time.

I want people to be aware that they should have a To Go Bag ready. And that you should have your medications in your bag.

Making friends and building closer friendships by Paul Mansell & Wesley Witherspoon

People need friends, we are social creatures. Friendships provide companionship, support, fun and recreation, advice, and opportunities. They enrich life and make it more fulfilling. Friendships can be our greatest asset.

In order to make friends, you have to learn how to be friendly to other people. You need to understand about personal boundaries. Personal boundaries are a limit on what a person feels comfortable with. For example, some people are only comfortable talking to a friend for 15 (Continue on page 11 – see Friends).



(Friends – continued from page 10). minutes a day. To make a friend, you have to consider someone else feelings. A friendship is about give and take. To be a true friend, you learn how to give to someone, and receive from someone as well. You learn how to support someone when they are going through good and bad times. A friendship should not be one-sided. One-sided means that one person receive all of the benefits from a friendship. A friendship is mutual, both parties receive a benefit. A true friend stays with you no matter what happens. To have a friend, you need to support someone unconditionally. A true friend checks up on you to see how are things going. Friends do things together: Go out, talk on the phone, socialize, and contact one another on social media. Sometimes your friends are long-distance, different cities, states, or even countries. Sometimes your friendships do not work out. Don't get discouraged if your friendships do not work out. Everyone is different.

In order to build closer friendships, you need to know to consider someone else feelings and life. For example, if you have a friend who is

sick, you might want to give them a break. People gain or lose family members, jobs, relationships, personal items, etc. You choose what to tell your friends. To have closer friendships, you have to learn to how to keep secrets. Your friends might disclose something that they don't want someone else to know. Friends are honest to one another. Honesty is telling the truth. Friends support one another. Friends learn how to compromise. Compromise means (Continued on Page 9-See Friends)

(Friends-Continued from Page 8)

that sometimes that you give in to some of your demands and do someone else demands. Friends trust one another. Friends learn how not to take advantage of one another. Friends learn how not to talk bad about one another. Friends allow others to be a part of their life. Friendships are steppingstones to a romantic relationship for some.

In an age of alienation and estrangement, we can take great satisfaction that with friends we are never truly alone. We have the power, as self-advocates, (Continue on page 12 – see Friends).



(Friends – Continued from page 11) to reach out to others, and to build new friendships. We have the power also to nurture our friendships to make them closer and more meaningful. So pick up the phone, and give your friend a call and tell them how much their friendship means to you. It will make their day.



Representative UCD MIND Institute / UCEDD.



Kecia, Wesley and Robert all attended the 2018 AUCD Conference in Washington D.C. The theme for this year’s conference was (Continued on Page 10- See AUCD)



(AUCD-Continued from Page 9) “We All Belong Here! Achieving Inclusive Communities”. The conference was held at the Renaissance Hotel in Washington D.C. from November 11-14, 2018.

Our experiences at the Association of University Centers on Disabilities (AUCD) Conference in Washington D.C.

By Kecia Weller SSAN Representative of the UCLA Tarjan Center / UCEDD, Wesley Witherspoon SSAN Representative of both USC Children's Hospital in Los Angeles / UCEDD / SCDD, and Robert Levy SSAN

In order to be able to present and attend the conference, we had to submit our proposal by Friday, June 15, 2018. It was a lot of work, but with the help of Steve Ruder, we were able to make that deadline. Our session was a panel discussion about our jobs at each of the three (Continue on page 13 – see AUCD)

(AUCD – Continued from page 12)
 California University Centers of Excellence in Developmental Disabilities (UCEDD) and the importance of employment for people with disabilities. The goal of the panel talk was to try to get other UCEDDs across the nation to hire people with disabilities.



Here is a summary of our experiences at the conference:

“I was excited to attend the conference for the first time in Washington D.C. I had the opportunity to meet with staff members of U.S. Senator Dianne Feinstein and U.S. Senator Kamala Harris and talk about the issues for people with disabilities to have productive lives including: healthcare, employment, inclusion, transportation, and much more. I also had the chance to see Senator Bob

Casey from Pennsylvania and Senator Orrin Hatch from Utah.” – Wesley Witherspoon, Consumer Advocate, USC Children's Hospital.



“I was excited to attend the 2018 AUCD Conference. This was my second year attending the conference. In addition to participating in the panel discussion with Kecia and Wesley, I had the opportunity to facilitate a session on supported decision making. During the session, I asked the self-advocates to break up into 3 groups and explained to them about the tools of Supported Decision Making. I also had the opportunity to meet with staff of U.S. Senator Dianne Feinstein. I also was able to meet with U.S. Congresswoman Doris Matsui and Congressman Ami Bera about the issues for people with disabilities to have a productive life.” – Robert Levy, UC Davis Mind Institute. (Continue on page 14)



(AUCD – continued from page 13).
“I was excited to attend the 2018 AUCD Conference for the first time in Washington D.C. One of the cool things that I got to do was attended a session about Council on Leadership in Advocacy (COLA). I learned a lot about the AUCD Leadership Academy. Dr. Olivia Raynor from UCLA Tarjan Center is a Guest Faculty for the Leadership Academy, which is neat. During the last part of the COLA session, we did a visioning activity, where we broke up into small groups and talked about our vision for the future of COLA.”



– Kecia Weller Consumer Advocate
UCLA Tarjan Center.

There were about 1,000 people who attended the conference. Conference attendees included professionals, support staff, self-advocates, family advocates, and legislators. We were able to meet people from all over the

U.S., including Puerto Rico, and even from other countries like Ghana, a country in West Africa. Hopefully we will be able to present or attend the November 17-20, 2019 AUCD Conference.

