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- Ellen Sweigert
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- Lisa Cooley

## Family and Friends During the Holidays

**By Paul Mansell, San Diego Regional SSAN Representative**

Short days, long nights, and the chill in the air mark the return of winter. Starting with Halloween and stretching through Martin Luther King’s Birthday, we celebrate countless holidays. During this festive time, we think of our relationships, both friends and family and how they bring such joy and meaning to our lives. We think of home. We are mindful of how busy the holidays are, full of parties, special food, and obligations. The holidays can be the best and also the most stressful time of year.

We have so many traditions with family and friends. Although with the COVID–19 Pandemic, we have been forced to change our plans. Luckily, this year’s travel restrictions do not look to be as bad as last year’s. Hopefully we can use this holiday season to get together with friends and family. We tell long stories, reminisce, sing songs and eat, boy do we eat. We also exchange gifts, some modest, and others lavish.

The holiday can be a hectic and stressful time of year, busy with parties and celebrations, travel, and all that eating. The days are short, and the nights are long, and the weather is miserable. Barren trees signal that nature has gone to sleep, and it is time to hibernate. This gets some people down.

To have a happy holiday season, let moderation be your guide. Have fun, but don’t overdo it, especially with the eggnog. Find time to rest and stay centered but do enjoy this special time of year.



## SSAN Youth Survey Data

By **Kecia Weller**, UCLA Tarjan Center UCEDD SSAN Representative  
**Regina Woodliff**, Bay Area SCDD Regional Representative

In July 2021, the SSAN Youth Engagement Workgroup created and shared a Youth Engagement Survey to find out what the youth/young adults are thinking about now. SCDD sent this youth survey to Yo! Disabled and Proud and some other places where youth hang out. Regina and I want to share some of the results from this survey and the information we learned with you.

So far, there have been a total of 136 respondents answered the survey. Out of those respondents – only 15% were 16 years old to 22 years old and 25% were 23 years old to 30 years old (The youth survey's target audience).

***Here are some responses from the question: What do you think is keeping youth with disabilities from being involved with Self-Advocacy?***

- ✓ I would like to see more Youth driven people first groups
- ✓ Feeling safe going to in person activities without parental supervision
- ✓ Not sure how to speak up for themselves due to lack of social skills
- ✓ Judgement and preconceived ideals about disabilities. They are all different not all people are the same.

Since 2007, both Regina and I had the idea to bring young adults into the Self-Advocacy movement. Now the SSAN Youth Engagement Workgroup wants to bring the young adults into SSAN, so young adults can learn from SSAN members and SSAN members can learn from the young adults. In the future, SSAN will have a youth/young adult seat on SSAN. Both Regina and I are extremely excited to have a young adult on SSAN with us.

### SSAN Youth Survey

There is still time to participate in the [SSAN Youth Survey](#). SSAN wants to hear from youth with disabilities about their interests. 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.



## Addressing Vaccine Hesitancy

By **Robert Balderama**, North Valley Hills Regional SSAN Representative

Vaccine hesitancy continues to be an ongoing issue for people with disabilities, especially concerning the COVID–19 vaccines. The fact is that people with disabilities are vulnerable due to our complex medical needs and are at a higher risk of developing serious illness if we get sick from COVID–19. Another vulnerable population is the elderly and it is important for them to get vaccinated in order to protect themselves. COVID–19 is a serious public health issue and it is important to follow rules and public health guidance as we have a civic/social responsibility to protect others by being up to date on our vaccinations.

Being vaccinated not only protects yourself, it is also a way to protect first responders and healthcare workers. I know that there is concern about how fast the COVID–19 vaccines came out, but medical experts have been working on developing mRNA vaccine technology for many years and a lot of time and energy has gone into developing and learning about this new method of delivering vaccines.

If you have any questions or concerns about how vaccines will affect you, it is important to talk to your doctors about your concerns. It is unfortunate, but understandable that the history of medical mistreatment of people with disabilities is resulting in some people being hesitant to get vaccinated. Actions you can take:

- Bring your concerns up with your doctor and or public health officials
- Encourage hospitals and medical groups to do more outreach and have conversations with people with disabilities on vaccines
- Create spaces where people can ask questions and feel heard
- Help develop and review materials to make sure they are in plain language (easy to understand)

There is a lot of misinformation out there about the vaccines and it is important to ask questions and make sure that you are getting your information from a reliable source. I understand that mistrust of officials who aren't honest can lead to resistance of information or rules, so it is important to bring up your concerns and the reasons why you are concerned with the individual/official responsible. Please consider getting vaccinated against COVID–19 or at least being respectful of other peoples' health needs.



## Notes from SSAN Employment Panel

By **Rebecca Donabed**, Sequoia Regional SSAN Representative

During the September SSAN meeting, the Employment Workgroup organized a panel of people with disabilities to talk about their different jobs. Having a job or being employed is important since jobs are a tool to gain independence. It is important for people with disabilities to show other people with disabilities that it is possible to be independent and have a job and of course, working allows you to earn money to buy things.

During the workgroup meetings leading up to the September meeting, members of the workgroup talked about the types of questions that should be asked and the types of jobs that we wanted to include on the panel. We ended up including a regional center staff, a retail worker, a university worker, a state worker and an independent living center worker. Once the workgroup decided on the types of jobs to highlight, we went to work looking through our contacts to figure out who would be available to be a part of this panel.

### These are the questions that were asked:

- What is your job?
- How did you find your job?
- Do you work on your own or with help (job coach/assistant)?
- What are some tasks/responsibilities of your job?
- What is your favorite part of job?

### Advice from panelists:

- Not give up in looking for a job
- Use job sites like Indeed to look for open jobs
- Volunteering
- Don't be afraid to get help from a job coach

Members of the panel mentioned the following resources to help people with disabilities find a job:

- [DOR](#)
- [LEAP](#)

If you are interested in getting involved or attending a workgroup meeting, we meet over Zoom on the 3<sup>rd</sup> Friday of the month at 12:00 P.M. Please email [Riana.Hardin@scdd.ca.gov](mailto:Riana.Hardin@scdd.ca.gov) if you are interested in attending the next Employment Workgroup meeting.



## Being Active in the Community as a Self- Advocate

By Ellen Sweigert, North Bay Regional SSAN Representative

As a Self-Advocate that has the passion to represent people with disabilities, it's really important for us to become active in our communities. We all have our own ways of becoming active in our communities. There are 10 steps of being an effective Self Advocate:

1. Believe in yourself
2. Know your rights
3. Decide what you want
4. Get the facts
5. Planning strategy
6. Gather support
7. Target efforts
8. Express yourself clearly
9. Assert yourself clearly
10. Be firm and persistent

I have always had the drive to believe in myself being a self-advocate from the disability community of Monterey and Pacific Grove. When I moved up to Napa, I worked to get to know about the disability community here in Napa. By working to get to know about the disability community in Napa, I also learned about my rights. I attended a lot of trainings and presentations through the North Bay Regional Office of SCDD. I decided I wanted to get more involved with them as they had connections and facts of the local disability community. By connecting with the North Bay Regional Office of SCDD, I was able to build a community where I could be an active member. After I created the foundation of my disability community in Napa, I started to create strategies as a self-advocate.

**(Continue on Page 6: "Being Active")**

### SSAN Members

- Nathaniel Florez – North Coast
- Vacant – 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
- Vacant – SCDD



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Building relationships within disability networks is key to any successful community and advocacy effort. Building relationships with other advocates and advocacy groups allows you to collaborate, share resources, and support each other as you focus your energy on a common goal or target together, this collaboration leads to becoming active in the disability community. I often think about how effective I can become as a self-advocate.

Through my volunteer work at the Napa Historical Society, I have met somebody who was on the Napa city council. Because I was able to express my thoughts clearly, the Napa city councilmember was willing to listen to me and suggest that I should go meet Tiffany Carranza, who is the city clerk in the city of Napa. So I took responsibility, went down to meet her there and I asserted myself clearly. Now, I am becoming an effective self-advocate with the disability community of Napa and getting myself active with the city of Napa. This experience has taught me a lot and I continue to maintain a good working relationship with the Napa city clerk and ensuring that the disability community is represented within our community of Napa.



## Emergencies in California

By Wesley Witherspoon, USC Children's Hospital UCEDD SSAN Representative



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Emergencies can occur anywhere in California. Emergencies are earthquakes, fires, floods, pandemics, landslides, drought, volcanoes, extreme heat, severe storms, extreme cold and winter storms, tornadoes, tsunamis, power outages, avalanches, shootings, violent crime, car accidents, and medical; those are the emergencies that are most common. We can't prevent emergencies, but we can prepare for emergencies. You can take CERT classes, learn First Aid and CPR. Unfortunately, first responders can't be everywhere. If you listen to the news and what people are advising, it could help you. You should also role play about possible emergencies. Learn how to prepare with your family, friends, co-workers, etc. You can save a life by knowing what to do in an emergency. Buy First Aid kits and/or Go Bags with food and water and place them in an area easy to get to. Learn to how evacuate an area because it will be important in an emergency. People with disabilities can survive an emergency. Know how to contact the Fire Department, paramedics, Animal Control, and Law Enforcement.

### 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**

**Check out the [SCDD YouTube Page](#) for stories from self-advocates, past meetings, and more!**



# Project **S.A.F.E.E.**

## **Self-Advocates For Emergency Education**

Project SAFEE is organized by self-advocates committed and responsible to create positive change in the world of emergency education. We build social awareness for individuals who have developmental disabilities and make a difference in our community.



**Interested in keeping your community safe?**

**Please join us for one of our meetings:**

**Every 1<sup>st</sup> & 2<sup>nd</sup> Friday of the month**

**from 8:30-10:00am**

We welcome you to learn and participate:

- Promote safety awareness
- Commit to attend every meeting
- Show professionalism and good attitude
- Have a strong voice for leadership and education
- No experience necessary but dedication required



**For more information about the next Zoom meetings**

Please contact:

Debbie Marshall at (619) 913-8232 or email [debbie.marshall@scdd.ca.gov](mailto:debbie.marshall@scdd.ca.gov)

Sarah May at (530) 895-4027 or email [sarah.may@scdd.ca.gov](mailto:sarah.may@scdd.ca.gov)





## Sacramento United People's First Self-Determination Presentation

By Robert Levy, UC Davis MIND Institute UCEDD SSAN Representative

On Wednesday September 8, 2021, the Sacramento United People First chapter meeting had a presentation on the Self-Determination Program (SDP). Staff from [Progressive Employment Concepts/Community Employment Services](#) and [Supported Life Institute](#) shared how the program works, and how to get enrolled in SDP. Both presenters talked about how to budget your money account in the SDP, how to figure out the staff members that you want to hire and much more.

The first step to SDP is to contact your service coordinator at your regional center, or check out resources like DDS and SCDD or Regional Center Self-Determination webpages to learn more. The next step is to go through an orientation, followed by finding your own financial management service. Next you will need to get a list of available PCP providers. work on budget, work on spending plan, organize your PCP team. Then you will have to think about hiring your own staff. Once you have hired your staff, you will work to set up your goals. The presenter from the Supported Life Institute shared how SDP has helped him out in different ways in both his job and gaining independent living skills.

I am proud to have been a part of the effort to get this Self-Determination signed into law in 2013 by Former Governor Jerry Brown. I am excited that finally in 2021, thanks to current Governor Gavin Newsom, all regional center clients have the option of deciding to participate in Self-Determination.

Before SDP started, people with disabilities weren't able to set their own goals to work on in their daily lives. With the SDP this is another new tool to help people with disabilities to have a productive life with their employment and their independent living skills.

I thought that this presentation by PEC/CES and Supported Life Institute was great and gave us information to pass on to the community.

Before the Self-Determination Program became law in California, self-advocates had limited amount of freedom and choice in their services. Now people who receive regional center services can use this new tool to help them out to build their future goals. One of the potential benefits to Self-Determination is that people with disabilities can improve their choices and options for employment development and independent living skills to build a brighter future for themselves.



## Coordinated Future Planning Task Force

By Lisa Cooley, Sacramento Regional SSAN Representative

The Association of Regional Center Agencies (ARCA) recently started a new initiative (collaborative project) and is encouraging regional centers across California to participate. I was asked to participate in Alta Regional Center's Coordinated Future Planning Task Force that is made up of Alta California regional center staff, service providers, family members and clients. The purpose of the task force is to help create training materials to help our service coordinators discuss caregiver succession planning with families and aging adult clients.

Our meetings have recently started focusing on the creation of learning objectives for our service coordinators to help them understand coordinated future planning because it will be helpful for them when they are doing caregiver succession planning.

To learn more about Alta's Task Force visit the [Coordinated Future Planning](#) page on Alta California's website. To learn more, check out Alta California's [Coordinated Future Planning PowerPoint](#). Talk to your regional center to learn more about their participation in this initiative and find out how you can get involved.

### 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.



## Kudos Corner

By Kecia Weller

Regina Woodliff has many Self-Advocacy accomplishments. Regina is on the SCDD Bay Area Regional Advisory Committee, Treasurer for the Bay Area People First Chapter, and she's a Co-Founding Member of California Statewide Self-Advocacy Network. Regina likes helping others learn emergency preparedness and preventing Sexual Harassment in middle and high schools with her facilitator, Ron Usac. Regina has a very open mind with all types of things that she learns about and teaches other Self-Advocates about. Regina wants young adults to become involved with SSAN as young adult leaders.

When Kecia Weller and Regina first met at a Self-Advocacy meeting in 2007, Regina was very shy and didn't talk much at the Self-Advocacy meetings. After Kecia mentored Regina for a little bit, Regina found her "self-advocacy voice". Regina ended up being a member-at-large and the Treasurer of the Self-Advocacy Board of Directors. Regina is so much of an inspiration to Kecia and other people. "I really admire Regina because she's the voice for other people with disabilities who can't share their own voices in public forums" said Regina's long-time mentor, Kecia. Kudos to Regina for her long record of advocating for other people with disabilities!

## Community Resources

- [SARTAC Advisory Committee Application](#)
- [ARCA Regional Center COVID-19 Resources](#)
- [COVID-19 Stimulus Checks Won't Affect Your Benefits](#)
- [UC Davis 2021 Neurodiversity Summit](#)
- [DRC NDEAM Videos](#)
- [DRC's Build Back Better Resources](#)
- [UC Davis 2021 Summer Institute Youtube Playlist](#)
- [SSA Ticket to Work Tips to Open Your ABL Account](#)

## SAVE THE DATES

### Disability Rights California



#### Events and Trainings:

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

### CalABLE



#### News and Trainings:

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

### Connect with your SCDD Regional Office for:

- Training Opportunities
- Self-Advocacy Meetings
- Resources

### Coming Soon:

#### Arc of California

[2022 Public Policy Conference](#)

### Plain Language COVID-19 Resources Available on:

[SCDD Website](#)

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

The Arc of California [Breakdown of Build Back Better Office of Self-Determination Ombudsperson](#)