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**Editor:** Robert Levy

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- David Forderer
- Wesley Witherspoon
- Paul Mansell
- Matthew Lagrand
- Rebecca Donabed
- Robert Levy
- Teresa Moshier

## My Battle with COVID—19

**By David Forderer, Central Coast Regional SSAN Representative**

I have been watching TV, as many others have, and have been surrounded with coverage of the ongoing COVID—19 virus. Like many other self-advocates, I stayed home for weeks on end, only going out when it was absolutely necessary. I heard many stories of people’s battles with the virus. Most of the stories did not have a happy ending. I certainly thought that if I stayed home and protected myself well when I did go out by wearing both a mask and a face shield: I would be fine. All last year I had no issues at all and then one of my part time caregivers came down with COVID in February of this year.

Upon hearing the news about her infection, I decided to get tested to see if I had become infected. When I first talked with someone after I was tested, I was told that my test was negative, but they wanted me to check back with them in a few days to see if I had developed a “late stage forming case”. Well as life would have it, 4 days later when I contacted them; I was informed that I was indeed infected.

I was told to immediately go into quarantine, along with my full-time roommate and caregiver Raymond. Thankfully Raymond had recently received his COVID vaccine and he was willing and able to take care of me full-time as my part-time caregivers were asked to quarantine for 2 weeks at their individual homes.

In the early stages, after being notified that I had become infected, I didn’t have any symptoms right away, but within 5 days after being infected I began to lose energy slowly day after day. Less than 10 days later I had almost no energy and all I wanted to do was sleep. I didn’t even have energy to sit up and eat.

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I then developed a very bad cough and could not talk at all without constantly coughing. I then realized I had no appetite either. During the next 2 weeks of my quarantine, I slept constantly while watching television throughout the day and evening. During this time, I lost a total of 14 pounds.

As the days went by, I coughed less and less and slowly began to regain my appetite. Approximately 6-7 weeks later I began to feel as though I was returning to normal. As each day passed, I felt better and stronger as well. Finally, 10 weeks after being infected I back to my old self eating 3 meals a day feeling normal

I felt very blessed that I had a mild case of the virus as I know so many others who had horrible issues with the virus and still have lingering health issues months later.

## COVID—19 Vaccination Resources

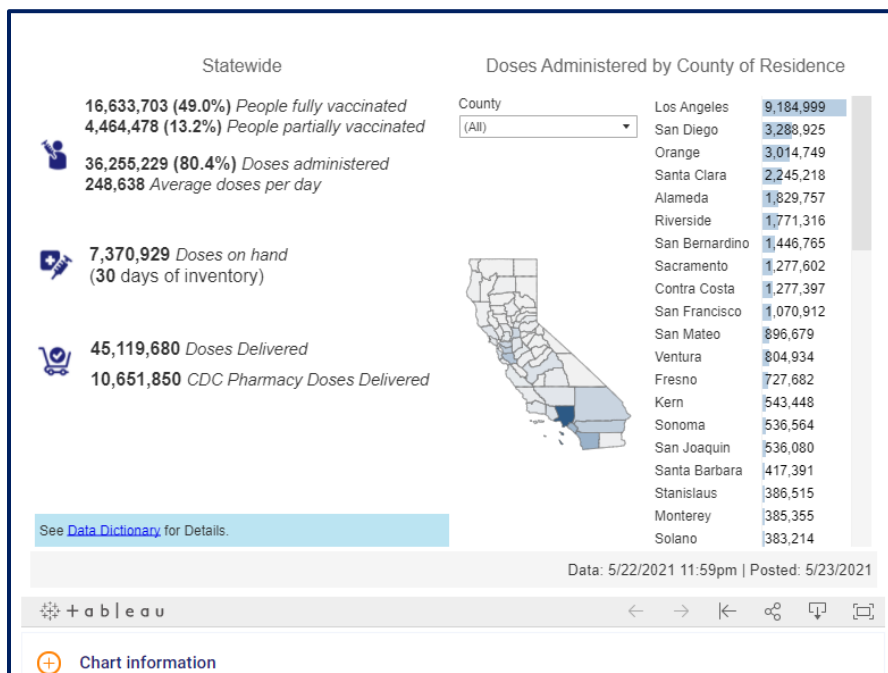


Figure 1 Map of California showing the number of vaccinations given in each county

Many of California’s 21 Regional Centers have partnered with local pharmacies and grocery stores to improve vaccine access to regional center clients, some have even organized their own clinics. Consider checking with your regional center for clinics near you.

### Resources

- [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
- Talk to your doctor to figure out which vaccine is best for you
- Need a ride to an appointment? Ride share companies can help



## Interview with SCDD Executive Director Aaron Carruthers

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

Since SSAN is a project of the State Council on Developmental Disabilities (SCDD) I wanted to take the opportunity to ask SCDD Executive Director Aaron Carruthers a few questions and share his answers with you.

### **Q: What is the Vision for the California State Council?**

**A:** SCDD is an independent, federally funded state agency charged with overseeing the developmental disabilities delivery system. Our vision is to continue to be a guiding force for positive, life-altering changes for people with I/DD and their families. We are the state’s leader in advocacy and in training future advocates. We will keep changing the world together!

### **Q: Why is the State Council important to California?**

**A:** The State Council is the only entity in law that has the role of being a watchdog over the system. We look at the person, not the program. We fight for how education, public safety, health care, regional centers, housing, jobs, and recreation are all serving people. We look at how the whole system is serving the whole person.

### **Q: What do you enjoy about your job?**

**A:** I enjoy everyone I get to work with! I enjoy SSAN! I enjoy that we are all a part of this civil rights movement together. We have the great privilege to have positions of influence to make the lives of people better. You and I take that seriously. There are many needs, many challenges, and many opportunities to advocate and make a difference. Let's change the world together!

**(Continue on Page 4: “SCDD Interview”)**

## 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



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**Q: What should self-advocates across California know about?**

**A:** This is a time of great change. COVID and the pandemic changed how we live, work, and play. Many are struggling to get what they need to live each day. And, when it is over, how we live may not look like it did before. This is an opportunity for you. What do you want the world to look like tomorrow? How do you want it to be different? And better? Advocates get to dream of a better world and work to make that happen. What do you want to be better in the future?

**Q: What is the Future of Self-Advocacy in California?**

**A:** You tell me. What do you want the future to be?

## SSAN Turns 9!

By Robert Levy, UC Davis MIND Institute UCEDD Representative



In 2012 the Statewide Self-Advocacy Network (SSAN) was born with the help of the State Council on Developmental Disabilities (SCDD). SSAN is cross-disability training network with 22 self-advocates from across the state of California with intellectual/developmental and other disabilities. SSAN members collaborate with each other to advocate for protecting the rights and services for people with disabilities that allow them to participate in their communities. There have been a lot of changes to SSAN over the last 9 years. In this past year, SSAN has welcomed 3 new members to the team. Members have come and gone, but SSAN continues to educate our communities on issues and programs that impact our lives. With laws and programs like the Cal ABLE Act, Employment First Policy and Self-Determination, people with intellectual and developmental disabilities can have more independence and say in how they live their lives. Despite challenges like wildfires, earthquakes and the ongoing COVID—19 pandemic: SSAN continues to do good work. Over the last year, SSAN members have been advocating for access to COVID—19 vaccines and volunteering in their communities to handout personal protective equipment (PPE) and even participate in vaccine clinics. Hopefully 2022 SSAN will be able to meet in-person again and we will go back to normal.



## Self-Determination Offers the Developmental Disability Provider System Unique Benefits and Challenges

By Paul Mansell, San Diego Regional SSAN Representative

For too many people with developmental disabilities, their families, and their advocates they find the Developmental Disabilities (DD) system calcified and unresponsive to meet their unique needs and desires to live meaningful and fulfilling lives in their community. Self-Determination offers an opportunity to empower people with developmental disabilities and their families and tailor services to their needs, hopes, culture, and values.

People with developmental disabilities and their families taking charge of their lives needn't threaten either the system or the status quo, but rather supplement and augment the DD system. It does represent change, and many find themselves groping in the dark, uncertain on what to do next. They are more comfortable with the ways it has been even with all its imperfections and limitations.

Members in the DD system need to educate themselves on the many facets of Self-Determination. People with developmental disabilities, parents, and advocates are frustrated when their Service Coordinators don't know what to do—e.g., calculating a certified budget. What is a simple procedure becomes a major roadblock. Regional Centers need to own their responsibility and train their staff in Self-Determination and implement priorities, policies, and procedures that embrace Self-Determination.

Proponents of Self-Determination may have little experience in taking charge of their services and their lives. They may well benefit from support to fully take advantage of the freedoms offered to them through Self-Determination. They are used to the system doing everything for them although they find the system inadequate to meet their needs.

Many, people with developmental disabilities, their families, and service providers, find stepping out into the unknown and untested scary and intimidating. They find differences in opinion frustrating and a cause for enmity. We need to remember; members of the DD community are united in their caring and have a strong desire to support people with developmental disabilities and their families—working together we are a team. Some may have doubts about the efficacy of Self-Determination, but that does not negate their compassion.

Persons with Developmental Disabilities, their families, and their advocates, may find themselves ill prepared for the demands of accountability and responsibility that comes with Self-Determination. They may lack the entrepreneur spirit to take advantage of their new freedoms.

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They may find the role as employer overwhelming and reading the paperwork and reports burdensome. This is when supports from the DD system can be most helpful.

The pre-enrollment steps of the Self-Determination process are needlessly complicated and need to be streamlined. People with Developmental Disabilities, their families, and their advocates would benefit from trained supports to navigate their way through this crucial stage of the Self-Determination process. Getting to know your histories, your wants and needs, your hopes, your goals, and your north star is hard work and should not be discounted. Those unaccustomed with numbers may find the certified budget and spending plan steps bewildering. The role of and funding for the Independent Facilitator needs to be clarified and expanded to include the pre-enrollment steps.

Above all else Self-Determination requires communication, respect, and confidence that the program will work and that people with Developmental Disabilities and their families can succeed with their plans and lead meaningful and satisfying lives in their community.

## **SSAN Youth Survey**

The SSAN Youth Workgroup has created a [SSAN Youth Survey](#) to get information about what interests youth with disabilities. The SSAN Youth Workgroup 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.



## New Member Spotlight

By Matthew Lagrand, SCDD SSAN Representative



I have been in leadership for a long time, starting in high school. I was co-president of a club in high school called Shasta High School Disability Outreach. When I was co-president, I had to make a lot of important decisions like looking for funding for activities like camping trips and Special Olympics and make sure everyone was doing their jobs.

Sometimes when someone wasn't doing their job, it was up to me to decide on whether to let that person go or not.

In 2001 I served as a member of Student Council at Taft College. This experience helped me to develop my leadership skills.

2001—2009 I was on the Bakersfield Arc (BARC) Board of Directors, where I represented the Supported Living Services Department.

In 2009—2018, I was on the Kern Regional Center Board of Directors before applying to serve on the State Council on Developmental Disabilities. One of the responsibilities of Regional Center Board of Directors was to evaluate the Executive Director's performance.

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### 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**



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The Board of Directors of Regional Centers is also responsible for conducting an interview process for candidates for the position of Regional Center Executive Directors. This is a very important job because an Executive Director is responsible for making sure that a regional center meets the needs of their clients and community. Decisions made by an Executive Director can impact the services that Regional Center clients receive. Regional Center Board of Directors are also responsible for reviewing/approving vendor contracts for the regional center.

As the new SCDD representative to the Statewide Self-Advocacy Network, I hope to help SSAN grow and advocate for people with disabilities to have access to the services and supports that help them live in their communities. I am proud to be living in California, that has so many great opportunities and services for people with disabilities.

One of my hopes is to work to improve communications between SSAN, Council members and SCDD staff. Better communication will help raise awareness of issues happening in the community. I care about Public Safety issues and want to make sure that nobody gets badly injured and is able to live their best lives.

## 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.





## SSAN Employment Webinar: Social Security Benefits

By Rebecca Donabed, Sequoia Regional SSAN Representative



On March 26th, 2021 the SSAN Employment Workgroup hosted a Webinar Training on managing Social Security Benefits when you work or go back to work. The SSAN Employment Workgroup partnered with [Work Incentives Planners \(WIPs\) from the Department of Rehabilitation \(DOR\)](#) to put together the webinar.

This webinar covered topics such as:

- Why someone receiving benefits should consider working
- What happens to your benefits (like SSI, SSDI, MediCal, Medicare) when you get a job
- Different DOR Services to Help You
- What a DOR Work Incentive Planner is and how they can help you

Other disability related benefits offered through SSA include the Childhood Disability Benefits (CDB) and the Disabled Adult Child (DAC) credit. These are basically two different names for the same benefit. People with disabilities can receive this credit once they turn 18 when their parent is either: 1) disabled, 2) retired, or 3) deceased.

When/If you decide to get a job there are some Work Incentives to think about. The Trial Work Period (TWP) is a 9-month period after you get a job and continue to receive your full SSDI/CDB Checks, no matter how much money you are receiving from your job.

It is important to know that your Medicare coverage will last at least six or seven years when you start working. Remember: if your work hours or situation changes for the worst: your benefits can be adjusted based on your new situation.

If you want to find out more about work incentives planners and how to manage working while receiving benefits: contact your local DOR office in your area. You can also consider opening a CalABLE Account to save the money you earn and not impact your Social Security Benefits! CalABLE Accounts are a good option to help you save money whether you are working or not. Check out [CalABLE](#) to learn more about that program.

**Be on the lookout for more webinars by the SSAN Employment Workgroup.**



## Ticket to Work Program Information

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

On Thursday February 18<sup>th</sup> I attended a panel presentation and training on the Ticket to Work Program offered by the Social Security Administration. The event was hosted by the Sacramento Regional Office of SCDD and took place over Zoom. Pam, from Progressive Employment Concepts (PEC) was the lead presenter, other panelists included two PEC clients with different employment experiences and backgrounds, and the owner of a local dog grooming company called Lucky Penny Dog Groomer, who hired a PEC client.

During her portion of the panel talk training, Pam talked about what customized employment does for people with disabilities: helping clients to have productive lives. The two PEC clients shared their experiences and the owner of Lucky Penny Dog Groomer talked about what it was like hiring a PEC client. Watch the full [SCDD Ticket to Work Program Informational Training on YouTube](#).

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## Swimming

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



It is summertime and many people will head to a pool, river, lake, ocean, or any body of water to escape the heat. It is very important to know how to swim the right way. If you decide to swim, make sure you know how to swim. You need to understand your limits and ability when you swim. Unfortunately, many people who do not know their limits while swimming drown. Many people with Developmental/Intellectual Disabilities have drowned in the water. Make sure that you put on safety items such as floatation device or a life jacket. Be careful if you go to the deep water. You need to be near a lifeguard or someone who can help you if you are in the water. Be careful if you go in the water, others might make waves in the water, if you are not prepared how to deal with the water, you could drown. Also, if you go to the beach, the waves could be high. Stay a distance from the water if you want to lay down or sit somewhere. If you decide to swim, you will enjoy benefits such as exercise, staying cooler, and having fun. Once again, if you decide to go swimming, please be careful.



## 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 Larry Withers, the Associate Director of Client Services – South at Far Northern Regional Center. Larry has been working at Far Northern Regional Center (FNRC) since April Fools’ Day 1993, so he knows quite a lot about Regional Center Services.

### Where did You Work Before FNRC?

Before I started working for Far Northern, I had many different jobs that all taught me important lessons about the type of job I wanted. My first job out of high school was working at the Redding Taco Bell. This job was a lot of hard work, in a hot environment. By the time I left Redding to attend college, I vowed I would find a more rewarding job with air conditioning.

I moved to Arcata to attend Humboldt State University when I was 20. At the advice of a friend, I applied to work at different day programs and care homes. I was hired to work at HCAR, a work and day program in Eureka. While working at HCAR, I found a second job at Butler Valley, a care home in Arcata that worked with clients with significant disabilities.

My two and a half years at Butler Valley taught me that no matter what you hear from others, always give people a chance because they will surprise you. Many of the consumers we had at that home were considered too disabled to participate in most programs. Yet I found that if you had expectations and patience amazing things could happen. By the time I left that job I was the house manager supervising 10-12 staff while studying full time at Humboldt State.

I left Butler Valley to take a break from college and travel. I went to Europe alone, visiting seven countries and met amazing people. This experience gave me the energy to return to Arcata and complete my degree. When I returned to Arcata, I was hired at a care home for children. We served six boys, most diagnosed with Autism and Downs Syndrome. Of all jobs I ever had, this job was probably the most active and demanding, while also being the most fun job. Everything was new and exciting to the children and the staff was amazing.

I graduated from Humboldt State and then returned to Redding to be near family. While living in Redding, I obtained a part-time job as an ILS instructor for Retirement Housing Foundation (RHF) in Redding. Several months afterward, a Service Coordinator (SC) at FNRC told me that they were leaving their job and encouraged me to apply. I have been with FNRC ever since.

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**Did you work in the Redding Office as a service coordinator? How did you move to the Chico Office and when?**

In 1997, my wife Julie, finished her AA degree from Shasta College and we decided to move to Chico rather than having her commute from Redding. I applied for a transfer to FNRC’s Chico Office and was approved for that in May of ’97. We moved within a month to Chico and Julie started Chico State that fall. I also planned to obtain my master’s degree at Chico State, so the move was had both educational and employment advantages. Julie and I both finished our master’s degrees while living in Chico.

It was a hard transition, because I had to leave my clients in Redding and all the resources, I knew about to help the clients on my caseload. I had to establish new relationships with vendors, staff, and the community. It can take a while to build those relationships again.

I was promoted four years later to a Case Management Supervisor, supervising 10-15 Service Coordinators a position I held until about four years ago when I accepted the position of Associate Director of Client Services.

**What is your favorite part about being an Associate Director of Client Services?**

The best part of being an Associate Director is the ability to make changes that improve the lives of our clients and their families on a larger scale. Everyone at FNRC makes a difference by showing up to work with our clients, but this position gives me the ability to make changes, create new plans, or services that affect large numbers of people.

For example, I coordinated our Diversity Project several years ago and was able to complete extensive research and met with scores of people throughout FNRC’s catchment area to determine client and family needs and ways we can serve non-white communities better. Based on these efforts, I wrote a grant for a Promotoras Program at FNRC.

The Promotoras program uses people from the local communities that speak the same language and share the same culture to encourage families to use FNRC services. Promotoras workers may also help people obtain needed services and support through advocacy and assistance. There are now two Promotoras programs at FNRC and each program has worked with hundreds of clients to improve our outreach to the Hmong and Latinx communities.

**(Continue on Page 13: “Interview: FNRC”)**



**(Continued from Page 12: “Interview: FNRC”)**

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

While the way we interact with clients has changed, FNRC staff continue to prioritize the needs of our clients. Most of our client and family meetings happen over Zoom or telephone instead of in-person. Internally, most of our staff meetings happen over zoom too.

Until recently, only about 12-15 people were working in the Chico office, down from 60-70 before the pandemic. With so few people working in the office, it felt too quiet and a bit lonely. I missed hearing people laughing and talking in the halls and being around familiar people.

COVID also dramatically increased everyone’s workload, including mine. Meetings to discuss clients with COVID or ones we feared were exposed went from ten minutes each day to almost 2 hours during the peak in January. Managing PPEs, making sure they were given to clients along with our own staff, took a lot of time. With 80% of my staff working from home, work processes have had to adapt.

FNRC remains focused on meeting the needs of our clients, COVID did not change that. We remain committed to making sure both our clients and our staff are safe and able to live their best possible life. We continued to improve our person-centered planning and training for the community and staff. Furthermore, FNRC has worked hard to implement one of the more effective self-determination programs in California.

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

Before the pandemic, I was planning a long vacation to Alaska and I’d love to drive the Alcan Highway someday. I am still interested in going there but will probably wait a year or two given the pandemic and huge travel rush I am expecting in the next year. Until then, I plan to visit the coast a lot and enjoy the salt air.



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## Kudos Corner

By Teresa Moshier

I want to give Kudos to Wesley Witherspoon. Wesley is an outstanding advocate for people with disabilities statewide in California and at the national level. Over the last year, during the COVID—19 Pandemic, Wesley has been doing a great job of educating Californians with intellectual and developmental disabilities about resources available and how to safely protect yourself from getting sick.

Wesley regularly write articles for the SSAN Newsletter and give trainings at quarterly SSAN meetings. Wesley’s commitment to educating others helps him stand out from others.

In addition to being a great advocate and awesome SSAN member, Wesley is also a supportive friend and mentor to other self-advocates and is always willing to offer help to his friends in need. Wesley represents the University of Southern California (USC) Children’s Hospital UCEDD on SSAN, on top of that, Wesley is currently serving as the Chair of the State Council and Chair of the Employment First Committee. Kudos to you Wesley Witherspoon!

## Community Resources

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

Governor Newsome just released the [May Revise Budget](#), which details the states budget for the next fiscal year that starts on July 1, 2021.

The [DDS 2021 May Revision Highlights](#) has information from the Governor’s May Revise that impacts people with developmental disabilities and the regional center system.

## SAVE THE DATES

Disability Rights California



Events and Trainings:

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

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



2021 People First of California Statewide Gathering on Zoom

Date: June 12<sup>th</sup>

[Register Here](#)

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 Zoom!