



2020

April

Making Quality A Habit

Putting Person Centered Practices to Work

Vol. 1, Number 3

Special Edition

Supporting people, their families, and the people that support them through COVID-19

A Note

In this special edition, we're focusing on the pandemic and its effect on individuals, their families, and supporters. Scott and Lori Shepard are major contributors to this issue. Scott and Lori are exceptional service providers (Avenues SLS) in Southern California and long time practitioners of person centered practices.

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A Service Provider Perspective

Inside this edition, you'll find some of our thoughts about how we're going about supporting individuals, their families and our staff in navigating this pandemic. We realize that no one strategy fits all providers, but we hope you'll find something that will support your efforts as you continue to provide services to individuals through this crisis.

Congress has passed and President Trump is expected to sign the Families First Coronavirus Response Act which, among other benefits, provides many employees in the US with up to two weeks of paid sick leave and up to 12 weeks of protected and partially paid Family and Medical Leave Act leave for absences from work. The Act requires employers with fewer than 500 employees and government employers to provide employees with this additional paid sick leave. All our employees and yours desperately need this support.

You can help! We hope that all governors will provide us with increased rates or funding pass-throughs to accommodate these needed increased benefits for staff. Write your governor today in support of pass-through funding.

In the meantime, stay safe for yourself, your family and the individuals you support.

Scott and Lori Shepard

Situation: Fluid

As everyone has experienced, everything is fluid, with daily changes related to supporting people (with and without disabilities) to deal with COVID-19. Here are some thoughts from Scott and Lori:

We recommend that you develop 1-page descriptions and/or communication dictionaries (or plans) for each person you support, in the event that they become quarantined or hospitalized away from people that know them. Our efforts over the past (several) weeks have been to use Person-Centered Practices to (one person at a time) develop the following for each person we support:

- Education plans for each person we support and the team and family members that support them regarding COVID-19 (we like the one by Green Mountain Self-Advocates www.gmsavt.org).
- COVID-19 transition books (in writing, with pictures, etc., personalized to individual learning needs) to help explain the changes in routines people are experiencing in their lives, and letting them know that we are not the only ones impacted. **Note:** Remember to include pet care if applicable.
- Staffing/support plans to minimize the number of people folks are in contact with (no more than 3 staff per team weekly for 24/7 support).
- Plans to ensure people in community employment have coaches & safety procedures based on where they work (for those individuals working at essential jobs).

Some Concerns for Providers:

- We are accruing overtime due to Sheltering in Place (at home) while minimizing the number of team members/housemates each person is in contact with. We hope that there will be easy solutions by our state and local agencies to get reimbursed for what is needed.
- We also have staff who are losing hours due to people Sheltering in Place (limiting to 3 staff per team ideally). We are coordinating these staff work to purchase needed foods & supplies and drop them off at people's residences without going inside (especially for people who are the most vulnerable).
- Limit staff from working/supporting people in multiple settings (this includes staff who have multiple jobs and who spend time in multiple and/or crowded environments).
- We are identifying back-up support options for each team in the event of a sickness within the team and how to quarantine in home.

For California Providers:

Based on input from the DDS, here are some of the directives we have seen or expect to see:

- Day Programs have authority to provide programming in people's homes, and have been encouraged to offer their staff to residential/SLS agencies to support people who are sheltering at home.
- Check-ins and virtual support for people as well as "teleservice" and creative ways to assist people to maintain connections and support mental health during the day are encouraged. DDS has posted some guidelines (3/18/20) for flexibility and waiving some requirements in supports: https://www.dds.ca.gov/wp-content/uploads/2020/03/DDSDirective_AdditionalWaivedRequirements_03182020.pdf

Put Your One Page Descriptions and Communication Plans into Action

If people don't already have them (or even if they do), we recommend that you adapt a one page description for medical professionals, and for potential new staff in the event that staff or family members get sick. Remember to include: (1) What I want my Doctor or Health Care Professional to know about me; (2) How best to support me; (3) Medical basics; and (4) What's important to me. You can find some wonderful examples of One-Page Descriptions and blank templates at Helen Sanderson and Associates (<http://helensandersonassociates.co.uk>)

We also use what we call a Communication Dictionary to assist the individual and support team and to educate and train new staff and community members about the meaning of non-verbal communication and non-traditional ways a person may communicate. It's an effective communication "bridge" for people while they are getting to know new staff or when they are with people who don't know them (for example, medical professionals, community members at a new church/gym/job, etc.)

Bottomline, these two tools can assist people to be more comfortable with any of the new interactions in the community that will likely occur during these changing and stressful times.

Steve's Communication Dictionary (Rev. 9-17)

When Steve:

It may mean:

We should:

Takes your hand and pulls on you, or grabs your car keys

"I want to go"

Prompt Steve to touch the car keys then walk with him to the car

"I want something"

Say "show me", and follow him to see what he wants

**Sings "Ahh-ahh-ahh",
Or "eee, eee, eee", etc.**

"I'm happy", "I'm enjoying this",
"I'm saying 'Hi'"

Say "Hey Steve, you sure are happy" so that community members understand that Steve is happy.

If Steve's in a store or if he is around other people who don't know him, and startles people with his noises;

Steve is happy and wants to say "Hi"

Say "Steve, you sure are happy", or "Hey Steve, are you saying 'Hi'?"

**Stands up and begins to walk away or towards something
(He may get up and walk rapidly)**

He wants to use the bathroom, get a drink of water, or do something purposeful (he has a reason for standing up and moving!)
He may also be attempting to get a twig or branch to twirl in his hand

Follow him and see where he is going (his initiating getting up has a purpose!). Do not simply try to stop him or tell him to sit down, as he may have an accident or need a drink.

Winks or closes his eye (like he is winking)

The sun may be bothering Steve and/or he could possibly have a headache

Give Steve hat and sun glasses; offer tylenol if behavior continues

My Medical One Page Description

**AXXXX
XXXXX**

Age 44



Things to Know About me

How to support me

Medical Basics

- I use facial and physical cues to communicate.
- I sometimes use sounds.
- I carry a small output device to let my coaches now when I need help.
- I'm an active member of my community and enjoy volunteer work at different places in Santa Clarita.

- Don't use long sentences or bombard me with words.
- Verbal communication is still ok but don't talk non stop.
- Keep a neutral tone of voice it helps me remain calm.
- I don't like to be touched but when I'm visiting the doctor I understand it is for my well being.
- I want to be part of the conversation when you are talking about me or giving information about me.
- If I am feeling nervous or need some space, I often grimace, then I bite my tongue and if you still are in my space, I will probably pinch your arm. On very rare occasions, I may bite you if you are still close to me.
- I am very prompt dependent meaning I don't initiate very many things. I look for permission before I do typical things. For example: If you set a dinner plate next to me, I will wait for you to tell me to go ahead and eat. I try to give you the "right" answer by watching your actions and eyes for cues about what I should be doing or choosing.
- When relaxed I tend to sway my head and smile.

- Autism
- Intellectual and Developmental disabilities
- Possibly allergic to Tetanus-Diphtheria vaccine-Hives.
- Seizures linked to flu vaccine.
- Seizure disorder.
- I am sensitive to the sun so I have to wear a hat, and sun glasses since heat has been linked to be a seizure trigger.
- *I had LEFT half hip replacement surgery in approx. 2004.*
- *I was hospitalized in May 2015, due to a kidney failure. My kidneys are back to normal since then.*



Sample COVID-19 book for Ronda

Here is how the COVID-19 Pandemic is changing your routines, your life:

California has shut down eating in restaurants, including your favorite the California Chicken Cafe

Restaurants only offer Take-Out or Drive-Thru now

Your regional center has CANCELLED all face-to-face meetings due to COVID-19 for the next month

California has said that people over the age of 65 should Shelter In Place (or stay at home) to slow down the spread of this disease until it can be stopped

Schools have closed, so some of your staff who are parents need to stay home with their kids instead of go to work

Sheltering in Place means that FEWER people will be supporting people

Avenues is trying to have only 3 people with each person so that fewer people get sick with the virus!

Your roommate is going to continue to live with you. V will be there to support you when she is not with her mom, and G will also be supporting you.

J is going to stay with her roommate at their apartment so you won't see her for now

Your friends who are staying home in their apartments will be frustrated and lonely, so they want to see you on their computer when you and your roommate Facebook with them. X, Y, Z (other people you know) are your friends who are sheltering at home

Things to help **DO** to AVOID the virus:

- **WASH** your hands! (a lot!)
- **KEEP** social distance of **6 feet from others**
- **CLEAN** counters and door knobs
- **DRINK** lots of water (this helps to kill the virus)

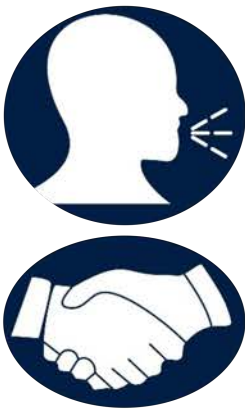
Provided by Avenues SLS; they are currently developing COVID-19 books for everyone they support. Books will be used by individuals, supporters and family members as well.

COVID-19 Information By and For People with Disabilities



What is COVID-19?

- It is a new illness spreading around the world.
- It's nickname is coronavirus.



How do you get it?

- Someone with COVID-19 gives you their germs.
- When they cough or sneeze, their germs get in the air, on you, and on things.
- Germs get into your body through your mouth, nose, and your eyes.

What happens if you have it?



A fever of 100.4°
or higher



Coughing



Hard time breathing

This page is excerpted from a booklet developed by Green Mountain Self-Advocates and is available at <http://www.gmsavt.org>.
Also translated to Spanish thanks to the California State Council.

COVID-19

social narratives



What it is
How to Stop Germs
School Closures

Breezy Special Ed

Available for download from *Breezy Special Education*
<http://www.breezyspecialed.com>

Sessions

Hosted by Support Development Associates

Virtual World Cafe - Session 2

April 8, 2020
2 Sessions
10:00 AM EDT
2:30 PM EDT

Session 1 - 10:00 AM

You are invited to a Zoom meeting.
When: Apr 8, 2020 10:00 AM Eastern Time (US and Canada)

Register in advance for this meeting:
<https://zoom.us/join/joiner/vpYqcuqtrJlqMFK1O4uKvhOTyILw4TVLLQ>

After registering, you will receive a confirmation email containing information about joining the meeting.

Session 2 - 2:30 PM

You are invited to a Zoom meeting.
When: Apr 8, 2020 02:30 PM Eastern Time (US and Canada)

Register in advance for this meeting:
<https://zoom.us/join/joiner/LJwicu6hrDkob2mLm3yT8B8dCjmRXcDz1w>

After registering, you will receive a confirmation email containing information about joining the meeting.

On March 23, 2020, Support Development Associates, LLC; Public Consulting Group; The National Leadership Consortium on Developmental Disabilities; Dr. Karyn Harvey and Julia Kenny hosted a World Cafe conversation in response to the pandemic and its current and future impact on supports and services. The questions that were answered by the more than 100 participants in 7 breakout rooms were:

- 1) What's been your major learning, insight, or discovery so far as you have helped people navigate the changes that have come about because of COVID-19?
- 2) What impact might the learning from this crisis have on the way services are offered in the future; is there something positive that may emerge?
- 3) How are we/how could we help people stay engaged and connected given that we are all more separated from one another now?
- 4) (asked of all participants) What should be the priorities for our attention going forward?

This next session will focus on routines (see the next page) and will explore:

- What is 1 approach that worked?
- What is 1 approach that didn't work?
- What advice would you give to people who are struggling with supporting routines?

Session 2 will be held on April 8th. For more information and to register, go to COVID-19 Information at www.sdaus.com/home.



Support Development Associates LLC

The continued importance of ritual and routines

Michael Smull

March 2020

As I wrote decades ago, rituals and routines are important. They “ease us through our days”. They provide predictability and when they are ours, a feeling of control. Having rituals that I choose, that are followed, is also comforting. For all of us, our rituals have been severely disrupted. New restrictions on where we can go, what we can safely do, add to our anxiety. To cope, we cling to those rituals that remain and establish new rituals within our new reality. We seek ways to comfort ourselves and they are a part of self-care.

We need to apply this to those we are supporting and those who provide the support. A few questions that may help are:

- What are the rituals and routines that are important to each person?
- Can they be maintained in the new environment?
- If yes, who needs to know and what do they need to do?
- If no, what can we do to replace them?
- Where “my” ritual conflicts with “yours” what is the best way resolve the conflict?
- How can we make sure that each person providing the support knows?
- Where and how can we adapt the new routines (reflecting the new restrictions) to reflect what matters to each person.
- Where we have 1 page descriptions can we adapt them to reflect the new reality?

In these difficult and traumatic times, we need to do what we can to address quality of life. This is an important part of that effort.

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404.626.2707
www.sdaus.com

Other Resources

National Down Syndrome Society - www.ndss.org/covid-19-fact-sheet/

Social Stories for Social Distancing (video) - www.youtube.com/watch?v=EMwsvsMmif4

Supporting Individuals with Autism Through Uncertain Times (UNC School of Education and UNC FOG Autism Team) https://afirm.fpg.unc.edu/sites/afirm.fpg.unc.edu/files/covid-resources/Supporting%20Individuals%20with%20Autism%20through%20Uncertain%20Times%20Full%20Packet_0.pdf

Tips For Social Distancing, Quarantine, And Isolation During An Infectious Disease Outbreak
https://8fd2f6f4-a084-4d1e-b3e6-db6ce5a2ce3c.filesusr.com/ugd/17ee81_30f0e0767d2a448a8eef88c14a4d1e89.pdf

Personal Emergency Plan for People with Access and Functional Needs - California Health & Human Services Agency <https://www.chhs.ca.gov/wp-content/uploads/2019/10/CHHS-Personal-Emergency-Plan.pdf> Also available in Spanish <https://www.chhs.ca.gov/wp-content/uploads/2019/10/Personal-Emergency-Plan-DAS-SPANISH-Reader.pdf>