

Critical Tools for Supporting People When Familiar Supports aren't Available

Some things to do during the COVID-19 pandemic that will benefit you and your “team” that are sheltering in place

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As everyone has experienced, things are still pretty fluid, with ongoing changes related to supporting people to deal with COVID-19

- We recommend that you develop 1-page profiles and/or communication dictionaries for each person/family member you support, in the event that you or they become quarantined or hospitalized away from people that know them. Our efforts over the past month 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 & 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 each persons 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
 - 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 CIE have coaches & safety procedures based on where they work (for those individuals working at essential jobs)



Sample COVID-19 book - Ronda

How the COVID-19 Pandemic is impacting our routines, our lives:

California has shut down eat in restaurants, including California Chicken Cafe (restaurants only offer Take-Out or Drive-Thru now)

NLACRC has CANCELLED all face-to-face meetings due to COVID-19 for the next month

California has directed that people over the age of 65 should **Shelter In Place** (**stay at home**) to slow down the spread of this Pandemic until it can be cured

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

Sheltering in Place means that LESS people will be supporting people. Avenues is trying to have only 3 people with each person so that less people get sick with the virus!



Ronda's Book (continued)

Your roommate R is going to continue to live with you. **V** will be there too when she isn't 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.

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 them.

Things to help 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)*
- X, Y, Z (other people you know) are also sheltering at home to avoid catching the virus.

Some of the Tools We can Use

- One Page Profile
- Communication Dictionary
- Transition Book
- Assisting people to develop written expectations for their support staff to help direct and monitor them (Self-Advocacy)
- Calendar
- Routines
- Social Media
- Video Calling
- Mail/packages
- Social Stories & Songs
- AAC devices or other Communication tools/boards

One Page Profile – What is it?

A Person Centered Tool for Individuals, Staff, & Teams

Lori Shepard

Turn your Stumbling Blocks into Stepping Stones

How to Support Me at Work



- Call or text. Don't leave a voice message.
- I am a night owl, not a morning person.
- I don't like to be touched. I'm not a hugger.
- I like lists. I read everything.

Scott and I have 4 adult sons. We currently have two dogs and one bird. I am the oldest of 7 siblings. I moved to SCV when I was 3 - long before it was known as SCV.

Watch out for:

My ideas become your to-do list and projects... Assumptions (mine and yours)... Sarcasm... Last minute projects (including throwing things your way)... I can be loud..... and whistle... and talk really quickly...

"Either it gets done or it doesn't stressing about it doesn't do any good."



Before I Retire.....

I want to finish my to do list.....

I want to be confident about the sustainability of Avenues SLS.....

I want to have an AT successor at Avenues SLS.....

I want to help employees to have a career path with a matching pay scale.....

I want to develop a permanent product of our training materials....

I want to be in good health so I can enjoy many years to come...

1

FAVORITE STUFF

chocolate chip cookies, fireplaces, Nike shoes, books, classical music

2

FAVORITE PLACES

home, Alpine House, museums, libraries, church

3

FAVORITE ACTIVITIES

reading, sleeping, generating ideas, board/card games

What Is a One Page Profile

- Helen Sanderson and Associates
(<http://helensandersonassociates.co.uk>)
- Simple - easy to read and share - easy to adapt/update
- can be used across settings and for many purposes
- NOT just for people with disabilities, but a tool to help teams build strength
- Many samples online

What is the format

- Individualized pages with graphics or pictures that matter to the person
- Often key questions are asked:
 - What do people appreciate about me
 - What is important to me
 - How can you best support me

Other questions can also be asked based on the situation specific to the situation/place (how to support me AT SCHOOL/WORK)
What are my favorite (for students meeting new classmates and teachers)

We strongly recommend that you adapt one for medical professionals, and for potential new staff/supports in the event that staff or family members get sick.

Info to be sure to include:

- What I want my Doctor or Health Care Professional to know about me
- How best to support me
- Medical basics
- What's important to me

My One Page profile



Axxxxx

Age: 44

How to best support me :

Speech is not the best way I communicate, I use facial and physical cues to let you know when something is on my mind. Long sentences and bombarding me with words does not work for me, all it does its get me agitated and confused. If you model the activity or use visual cues like pointing and some verbal cues, I understand better, and tend to be more successful. If you also maintain a neutral low tone of voice when talking to me that helps me remain more calm. I do not like to be touched but a handshake or high-five are ok. 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 the dinner tray 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 Im relaxed I tend to sway my head and smile.

Things to know about me:

I live in my own place and I am an active member of my community. I volunteer at many different places within the Santa Clarita Valley. I enjoy places that are not super crowded. I like it when people keep their distance. I am always accompanied with different people who support me. I enjoy almost any type of movie genre and TV show. Crowded places usually make me steam .

What is important for me :

- My home
- My mother
- My independence
- My space

What people like about me:

- I am trusting
- I am patient
- I am caring for the people in my life/ people around me
- I am selfless
- Im engaged/present in group settings

My Medical OnePage Profile

AXXXXX
XXXXXX

Age 44

How to support me

Things to Know About me

- 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 wellbeing.
- 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 the dinner tray 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.



Medical Basics

- 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.*

Hello! My name is **Steve**.



How I prefer to Communicate:

When I am in a good mood, I'll let you know by singing loudly and laughing. Simply put - **the louder I am, the better!**

If I am pulling you then I want something. Typically, I might: need the bathroom, want to know when the next meal is, want to walk, need to know what is happening. Please talk to me calmly and ask what I want by giving me options so you can help!

Some things about me that I want you to know: I do NOT have fond memories of medical settings, and will be very anxious about being in a hospital and surrounded by people in lab coats. **It takes time to build up trust with new people**, so DON'T have a lot of DIFFERENT people trying to help me during my stay. **If you act nervous, I will be more nervous.** Smile and talk to me in an adult voice (not baby talk). Let me know what is happening.

People might be concerned about my **shakes and tremors**. These are unfortunate side effects of my medications, and I've been living with them for a long time. I am fine walking alone (even when I seem wobbly!). I might even reach for your arm just to say that I'm in a good mood, and serenade you. I also spill a lot when I eat. **Please cut my food.**

While I enjoy walking and exploring, I also understand that I might have to stay in my room. I love watching most **family friendly television**, and often watch shows from channels such as Cartoon Network,

Nickelodeon, and Disney. I also love rocking chairs, as the motion really soothes me.



In addition to watching TV, I think **mirrors are very interesting and would love to be able to have one next to me** as I'm relaxing. I find the reflections fascinating!

Healthcare specific: I am used to taking pills and capsules, and am often helped to take 2-3 at a time in a spoon, while I hold a water bottle to swallow them down. **I drink best with a water bottle or straw.** If I have a sore throat, I don't want to drink or eat anything. I will push your hand or the water away.

I will probably try to remove an IV, blood pressure cuff or anything that is uncomfortable. If I am not doing this, I am really sick!



Who is important to me in my Life:
I own my own house in Valencia, and live with **Trevor**
(818)554-0865.

Some of my oldest friends are **Scott and Lori**, who helped me to move into my own house and train the coaches who support me. HOUSE PHONE **(818)257-2100**

Boom's One Page Profile for Doctor Visits



GREAT THINGS ABOUT ME

- I am a great friend.
- I am a happy guy
- I am funny
- I am smart. MUCH smarter than you think I am
- I like to talk about the SF Giants. Baseball is a good way to make friends.
- I am resilient. I have been through a lot and I am still smiling
- I am brave. I will do things I don't understand if you help me.

WHAT'S IMPORTANT TO ME?

- Being understood when I talk. It's OK to make multiple guesses. I will work with you.
- Having control. I know I can't control everything, but let me control those things I can.
- Having my dad help me. He knows me better than you do. Listen to my dad.
- Knowing what is coming next. Visual schedules work great but I know they aren't always possible.
- Show me what you are doing by comparing to things I already know
- My preferred staff. I will do things for them I might not do for you.

WHAT YOU NEED TO KNOW TO SUPPORT ME:

- ❖ I don't understand your rules and they aren't important to me
- ❖ Know my rules. If you don't know 'em, ask my dad.
- ❖ Most of the time I don't understand why I have to do what you are asking. Give me time to process.
- ❖ If you are seeing me I am probably sick and my patience might be shorter than usual
- ❖ Give me control where I can have it
- ❖ Rewards are great but they have to be believable and happen soon.



XXXXXX XXX

Medical Basics:

- I have Cerebral Palsy (spastic/quadruplegic). I also have asthma and hypothyroid. *I am allergic to codeine and sulfa drugs.* Current medications are listed on my chart.
- I have a hard time coming out of anesthesia and some of that is because I am in a position that does not allow me to breathe. PLEASE ask my support team how to position me.
- I choke a lot when I am eating - I use my eyes to tell you if I need water, a pat on the back or just to let me get it down on my own. Just because I choke doesn't mean I need a liquid diet - I just need time to eat slowly and carefully.
- When I take pills, you need to throw them to the back of my mouth and quickly squirt water in for me to swallow. It often takes a few tries and they taste awful, so do it quickly.



What is Important to Me:

- | | |
|--------------------------------|-----------------|
| My family and friends | My dog |
| My relationship with God | My independence |
| My memories | My voice |
| People who take time to listen | People who care |
| People who are believers | People who try |

My Needs if I am Hospitalized:

- If at all possible, I need one of my support team with me.
- I need to be positioned on my left side in order to breathe. There is a very specific way so PLEASE ask my support people to show you how to move me.
- Feeding me and basically all my personal care needs are very specific to my body - PLEASE consult my support team.
- If you are nervous, I will be nervous - act confident even if you are not.
- Don't tell me to "relax" or "hold still" - that kind of pressure makes me more spastic.
- Listen to me. If I raise my voice it is important for you to stop and listen before we both get hurt or I die.

How Best to Support Me:

- The most important thing is for people to talk to ME and listen to my questions and responses.
- My support team can interpret for you, but please talk to me and look at me when I am talking.
- I know I am hard to understand and it takes a lot longer, but this is my life and my body and I need you to listen to ME.

What people like and admire about me:

- I speak my mind
- I am determined
- I listen to others, but make my own decisions
- I love learning new things
 - I try to help others whenever I can
 - I don't give up

Some of My Labels:

- *Author
- *Employee
- *Advocate
- *Home Owner
- *Board Member
- *Christian

Tracy Whitehorse



Tracy "Buddy" Whitehorse

I live in my own apartment by myself and shop for myself

I have worked in competitive integrated employment since High School and work is very important to me!

I work for Brite-works doing janitorial services. My job site is the Japanese Gardens, but they closed due to COVID-19

In the meantime I get paid to clean the Avenues Office once a week but would like more work as soon as we don't have to shelter in place



I want people to talk to me and slowly explain anything I need to do (like a new job) and what they will be doing, (like a dental procedure) so that I understand and am comfortable.



What works for Me:

-Show me what to do (don't talk too much because it confuses me)

-Notice when I do a good job

-Write things down so I can understand better

-Give me time to process

-It bothers me when people say my name too much

-I don't like places with too much noise

-I use a checklist to let my staff know when: I need to go to the bank, if something is broken at my apartment (so I don't trash it), if I have tooth pain, if I need to order eye drops or medications, if I need to go shopping



They only work if you share them

- Don't be afraid to create one page profiles specific to a time or place - we revise the "doctor" one for someone for every specialist she sees. We have a box for pressing issues that detail her needs for that doctor.
- Share with new team members and have them create one for themselves so you can all get to know them.
- Share with people at a new job, class, church or anywhere they will be building relationships. Share your own as well.
- Have the person give their one page profile to others as much as possible.
- Sometimes it is good to send it ahead so doctors or other professionals know what works before you get there.

How Can We Get Started?

- Start by creating your own. This will help you through the process and you can feel how it works.
- Ask others for ideas for your profile. It is amazing how much insight your co-workers, family and friends can give.
- Decide if it is for general purposes or a specific place/event/situation.
- Remember, this is a living document, so don't be afraid to hit "print". You can always change things.
- Share yours with other people and get them excited about creating one for themselves.
- Create one for "Team John" that includes what works for the team as a whole.

What Is a Communication Dictionary?

- A tool to assist the person & team to educate and train new staff and community members about the meaning of their non-verbal communication and non-traditional ways the person communicates
- A good way to teach the meaning and functions of behaviors
- A good communication “bridge” for people while they are working to develop improved communication systems through assistive technology and expressive language

Communication Dictionary

- What it is NOT:
 - A list of words we want the person to communicate
 - A list of ways / signs / articulation we want the person to work on (not a list of goals)
 - Something we can fill out once and forget about
 - Something one person can “make” and distribute

Name:

DOB:

Communication Dictionary

The intent of a communication dictionary is to document the various means and modes of communication used by a person who uses an alternate mode of communication. Communication partners are encouraged to provide a brief description of the person's communicative acts and what they mean to that person. The person may have multiple meanings. In these cases please include the various contexts and their meaning. Finally describe the suggested response to the communication. (Date your entries)

Communicative Act <i>Describe what the person uses as a display, symbol, gesture, etc.</i>	Definition <i>Provide the various meanings.</i>	Response <i>Suggested response.</i>

Steve's Communication Dictionary

When Steve:

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

It may mean:

“I want to go”

We should:

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

Sings “Ahh-ahh-ahh”, Or “eee, eee, eee”, etc.

“I want something”

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

“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

communication dictionary template

When PERSON



It might mean

he is processing your question
he fears he will be missing out on what he wants
he is thinking about something enjoyable
he is stressed about something
something is not as expected
a noise is bugging him
he knows he is trying to get away with something
he is not presently interested in the task at hand
he needs less stimuli right now
he is not feeling well
he is tired
he is hungry
he is anxious or needs help
he is confused
he is hot
he is cold
he is scared
something hurts
he is excited
he wants to tell you something, but he doesn't know how to say it
something is broken
he needs help
he needs to move around/pace/walk
he needs a break
he is concerned about something on his schedule
he is not sure what is expected of him
he wants some reassurance
He is bothered by something in the environment

We Should



When Dan	It Might Mean	We should
Clears his throat	He has a dry throat	Ask if he needs water
	He is trying to start a conversation	EITHER: ignore him until he "uses his words"
		OR: acknowledge his vocalization as communication and ask what he needs/wants
	He heard this noise and is imitating it	Say, "Yes, Dan, Scott just cleared his throat"
	He has a sore throat	Ask if his throat hurts

Transition Books

For known transitions as well as sudden transitions

Transition Books are personalized social stories related to an upcoming transition.

We typically use them for a new teacher, classroom, school or schedule.

We also use them for an upcoming family move, new baby, changing bedrooms or a planned vacation.

We create them for adults moving into their own place, when a sibling is going off to college, or other changes in family life.

They can also be made to describe changes in routines, a new job, or any other changes that will be taking place.

- ❖ A typical transition book will answer the following questions:

What is the current norm?

What change is going to happen & what will stay the same?

Who knows about this change & how everyone feels about this.

It's always good to share **why** a change is happening.

For example: Everyone graduates from Jr. High and goes to High School. It can be fun, but it is also a little bit scary. Last year, John moved to High School. Next year, I get to move to High School, too.

Create specific COVID-19 transition books (in writing, with pictures, etc., personalized to each persons learning needs) to help explain the changes in routines people are experiencing in their lives, and helping them understand that we are not the only ones impacted has been extremely helpful.

Here is a link to a sample:

[Dan COVID-19 Transition Book](#)

Now is a good time to look at AAC & Communication in General. Encourage Families to:

- Talk to SLP, OT, PT and other specialists about what can be done at home & through virtual supports
- As families to identify a word or set of words or activity that they can do regularly as a family, & make sure those words are available for the child to practice/learn
- Increased communication will decrease stress and “behaviors”
- Teach their child how to have Alexa, Siri or Hey Google play music or read a story.
- If the smart home device doesn’t understand them, program their voice output device to say the command.

Calendars

- Use a large desktop calendar, or a google calendar or whatever calendar you think will work for the child AND the family. It doesn't have to be a traditional calendar. It can be an under-bed shoe storage box if the child is better with tangible objects than words or photos
- Put changes and routines on the calendar
- “call Grandma” “laundry day” “McDonalds” “change the sheets”
- Not just the fun stuff and not just the chores
- Use pictures, words, icons/symbols, recordings, objects, whatever works
- You can cross things off when they are done or not

Routines

Stick to some known routines, but don't be afraid to create new ones

(Just put the new ones in the transition book and on the calendar)

Social Media

Facebook & Instagram

Email

Tic Tok

Ask students, families and teachers for more ideas

Video Calling

Chat with friends, relatives, teachers, etc. using video chats so students can see the person and vice-versa.

Kids can hold up their art work or a movie to show the other person.

Mail/Packages

Even though most of the mail WE get is bills and junk, kids really enjoy getting letters, packages and cards in the mail. Set students up with a pen-pal or relatives to send fun things to in the mail. Have students while at home to send letters, pictures and gifts to relatives and friends as well.

Social Stories & Songs

There are lots of social stories and songs about COVID19 all over the internet at this time. Take advantage of them.

We hope that these tools will assist you and the families/teams you support (and the doctors and other professionals who may be supporting them) to be more comfortable with necessary interactions in these changing times



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