

# Tools for Supporting People when Familiar Supports aren't available

(Due to Quarantine, Hospitalization, Isolation, etc.)

Lori Shepard



AVENUES  
SUPPORTED LIVING SERVICES

[www.AvenuesSLS.org](http://www.AvenuesSLS.org)

**2 Critical Tools to have in the event that  
People we support may need to be  
supported by people who don't know them**

- **One-Page-Profiles**
- **Communication Dictionaries**

# 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
- Is 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 (ex: how to support me AT WORK, What I want my Doctor or Health Care Professional to know about me, etc.)

What are my favorite .... (for students meeting new classmates and teachers)

# 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.

## 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.



## 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

## 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

## 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.

## Some of My Labels:

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

# My One Page profile



Axxxx

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

AXXXX  
XXXXX

Age 44

## 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.

## How to support me



## 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.***

# Pam



## What is important to know about Me:

My name is XXXXXX XXX XXXXX but I like to be called Pam. I am 61 years old and unmarried. First, I would like you to know about my disabilities so you can know best how to treat me. I am normally in a wheelchair all of the time. This is due to my Cerebral Palsy. I am unable to walk. I will need assistance with all transfers from gurney to bed, bed to wheelchair, etc. I have Epilepsy and take medication for seizures that do not happen often, but I think it is important for you to know about that. I have Dystonia on my left side, in particular my left hand, which is spastic so I use my right hand for just about everything. This is why I need someone to cut my food, and why I transfer from my right side. I am stronger on the right. I wear a leg brace on my left lower leg. I need it on for all standing transfers. I also wear wrap around knee pads on both knees (2 pads on the left, one on the Right) for standing transfers. I can only stand up for a few seconds with the help of 2 people.

I have dementia and I am diabetic, but I do not take medication for either. My diabetes is controlled through my diet so I avoid sugar and carbs. I have a current medication list folded and put in a ziplock baggie in my purse. This will tell you exactly what medications I take, the dosages, and what they are for. I have to be on a liquid restriction of 36 oz per day. It is very important that I stick to that. If I have more fluid my sodium level drops and I start vomiting. Dr.XXXXXXXXXX is treating me for that.

These are my doctors. If you need to consult with any of them, you have my permission.

**Dr. X (Internist/Diabetic Specialist) 867-5309 Dr. Y (Neurologist) 867-5309  
Dr. Z (Nephrologist) 867-5309**

I also go weekly to the **Wound Care Center** at Valley Presbyterian Hospital for a reoccurring wound on the top of my right foot.

## How Best To Work With Me:

I get confused when a lot of information is given to me at once. Please speak slowly, and give me time to process what you have said. If I am unsure of something and feel pressured to answer I might say yes, when in fact I may not know the answer. So please give me time. Sometimes I do not answer right away. I have trouble with my memory, so having something written I can read and reread will help the information to sink in and is less likely to be forgotten. I enjoy watching TV and like game shows. I need to be able to be in touch with my roommate, who also works with me. Her name is XXXX XXXXXX. She works with me through Avenues Supported Living Services. XXXX's phone # is 818-867-5309. You have my permission to speak with any of the 3 people listed regarding my condition. Ms X or Mr Y at 867-5309 may also be contacted. But please do call Ms.Z, or Ms. A so I can include them in any and all discussions regarding information or treatment needed. Thank you!

# 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, at the gym, 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

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)*

[illegible]

## Steve's Communication Dictionary

### When Steve:

**Takes your hand and pulls on you**

### It may mean:

"I want to go"

### We should:

Prompt Steve to touch the picture of the car/car keys then walk with him to the car. Then, use picture album to see if Steve points to a picture of a specific place.

"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;

Then you should:

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

**Stands up and begins to walk away or towards something**

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 a toileting accident or need a drink.

**These two tools can assist people (and the doctors and other professionals who may be treating them) to be more comfortable with necessary interactions in these changing times**

**Lori Shepard**



**AVENUES**  
SUPPORTED LIVING SERVICES

**[www.AvenuesSLS.org](http://www.AvenuesSLS.org)**