

Beyond the Medical Diagnosis: Supporting the Person with a One Page Description

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The Learning Community
for person centered practices

The Learning Community for Person Centered Practices

envisions a world where all people have positive control over the lives they have chosen for themselves. Our efforts focus on people who have lost or may lose positive control because of society's response to the presence of a disability. We foster a global learning community that shares knowledge for that purpose.

The Core Concept

Important TO, Important FOR, and the Balance Between

Important TO	Important FOR
<p>What is Important TO a person includes those things in life that help us be satisfied, content, comforted, and happy. They include:</p> <ul style="list-style-type: none">• People to be with/relationships• Culture and identity• Purpose and meaning• Status and control• Things to do• Places to go• Rituals or routines• Rhythm or pace of life• Things to have <p>They include what matters most to the person — their own definition of quality of life.</p> <ul style="list-style-type: none">• What is Important TO a person includes only what the person says:• With their words• With their actions <p>When words and actions are in conflict, listen to action. Ask why?</p>	<p>What is Important FOR a person includes:</p> <p>Issues of health:</p> <ul style="list-style-type: none">• Prevention of illness• Treatment of illness/medical conditions• Promotion of wellness (e.g., diet, exercise) <p>Issues of safety:</p> <ul style="list-style-type: none">• Environment• Well-being — physical and emotional• Freedom from fear <p>What others see as necessary to help the person:</p> <ul style="list-style-type: none">• Be valued• Be a contributing member of their community• Build value as defined by the person

Key Point:

What is Important TO a person is based on what they say with their words and behaviors. When words and behaviors are in conflict, we need to pay attention to the behaviors and ask WHY.

Important TO and Important FOR Are Connected

- Important TO and Important FOR influence each other.
- No one does anything that is Important FOR them (willingly) unless a piece of it is Important TO them.
- It is not about being happy OR healthy, satisfied OR safe.
- It is about being happy AND healthy, satisfied AND safe.



Important TO and FOR Are Connected

- Important TO and Important FOR influence each other.
- It's not Important TO vs. Important FOR. Both are important.
- No one does anything that is “Important FOR” them (willingly) unless a piece of it is “Important TO” them.

The balance is dynamic (changing) and always involves trade-offs:

- Among the things that are “Important TO”
- Between Important TO and FOR



For me, a house or an apartment becomes a home when you add one set of four legs, a happy tail, and that indescribable measure of love that we call a dog.



Support the person
to be healthy and
safe within the
framework of what is
Important To them

Liam's One Page Introduction

For **Medical** Appointments

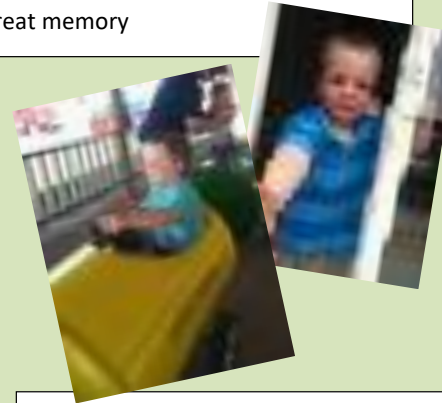


What people **love** and **admire** about Liam:

- Silly -Goes with the flow
- Eager to learn –A good hugger
- Bright, good, sweet, and loving boy
- Likes an adventure -Great memory

SUPPORT Liam needs to help him stay happy, healthy, and safe:

- Liam needs help knowing his surroundings to get around. Assist him in new environments so he does not get hurt. Ex: watch so he does not hit his head, get 'into stuff' he shouldn't, hold his hand.
- Liam uses his hands to communicate. It is important to be attentive to what he is saying or he will become frustrated. He uses tactile American Sign Language. (feels signs with his hands).
- Liam needs to know what is happening first before any procedure or task begins. For example: before you listen to his heart, let him feel the stethoscope and touch his chest where you are going to listen. Another example: if you want to weigh him, allow him to feel the scale.
- If he seems to be getting frustrated he may need a break. A break may include the following: walking in the hallway (assisted), checking out new toys/books, or introducing him to new friends.
- Liam is happiest and most cooperative, when he is not kept waiting long.



Things that are **IMPORTANT TO** Liam:

- Know where Mom and Dad are☐
- Meeting new friends
- It is important to Liam to know who you are by feeling your **identifier** (a watch, ring, necklace, bracelet, name tag, etc..) and also letting Mom or Dad introduce you.
- Liam likes going to medical appointments. He likes to say hi to the doctors/nurses and feel new things.
- Liam likes to be heard and responded to. For example: if he signs something, he will expect an answer back.
- He enjoys toys that are cause and effect (push a button and they do something), shape sorter toys, a random collection of toys that are placed in a bin, books that have Braille or parts you can touch...
- snacks/drinks: Liam likes drinks of water (Dixie cups work great) and all different kinds of snacks or treats (crackers, cookies, suckers, fruit snacks, fruit etc.)

I LOVE SOMEONE #RARE



What we LOVE and ADMIRE about SOPHIE:

- Big, bright smile
- Fun-loving and joyful
- Great sense of humor - loves sneezing, burping, & slapstick
- Loves people
- Takes pride in her health (e.g. brushing her teeth)
- Unconditionally loving

What Important to SOPHIE:

- Always having access to her treasured bag of photos of friends & family
- Watching favorite musicals- Annie (all 3 versions!) and Mama Mia
- Watching teen shows (with cute boys!) on Disney + (Hannah Montana) and Netflix (Liz and Maddie). She loves Mickey Mouse cartoons, too
- Knowing what to expect before it happens (using Social Stories are ideal)
- Not being forced to do anything – especially to comply with non-essential procedures (e.g. height/weight)
- Getting to sit on a chair vs. a hospital bed (before she is sedated)
- Patient, friendly staff

What YOU can do to BEST support Sophie:

- Provide a simple explanation of what will happen and what she should expect (using the “Stories About Me” app on her iPad is ideal)
- Give her ample “wait time” to respond (due to apraxia and developmental delays)
- Sophie almost always says “no” when asked a question. Say “Do you mean yes?” to try and see if she really means yes (See “How Sophie Communicates” document)
- Praise her for her cooperation
- Reassure her “it won’t hurt”
- Use her treasured photos and iPad to help distract and calm her
- Get her height/weight from Mom. Do not force Sophie to get on a scale
- BP and stethoscope may not be tolerable- be willing to let it go



Andrew: XXX-XXX-XXXX
Mom: XXX-XXX-XXXX
Dad: XXX-XXX-XXXX
Greg: XXX-XXX-XXXX

Great Things About David!

Medical appointments

- A loyal friend
- An incredibly hard worker
- A committed distance runner and athlete
- A good son & brother
- Persistent – will work for the things he wants
- An overcomer
- Sensitive to the feelings of others
- A role model
- A train expert
- Creative photographer
- A very careful driver

What's Important to David:

- My truck
- Distance running & competition
- His independence & freedom
- Music of all kinds – I really like classic rock
- My faith in God
- Wearing baseball caps, UT or Cross Country clothing
- Managing my health issues but not allowing them to control my life.
- Knowing what to expect. Feeling prepared.
- Having a choice.
- Being respected – he knows when others don't think he is competent.



DAVID



What it takes...

- Help me understand what you want me to do. You might have to show me.
- Ask my permission before looking at my facial or head tumors or asking questions about my disease.
- Don't push me or lecture me ("bricks on my head").
- Help me manage my medications and diet. Explain what they are doing and why I need them.
- Explain my medical issues in concrete terms. Analogies are also helpful.
- Tell me what you're going to do before you do it. Give me choices about how it's done when possible. I prefer a needle over bad-tasting medicine or the gas mask (in surgery)
- Use a fun sense of humor with me. It works a lot better than demanding.

Ask these questions:

WHERE?

Where will this be used? Context?

WHAT?

What do you want readers to learn?

HOW?

- How is support best provided?

If it's not read...not used...It's not helpful.



Context – Health Care Settings

- What do people like and/or admire about this person?
 - Avoid functioning levels
 - Focus on personality, gifts & abilities



- What's Important TO this person at medical appointments, health care settings?



How is this person best supported in this context?

- What eases anxiety? Discomfort? Fear? What helps the person feel safe?
- Describe communication – how does the person communicate, what supports are helpful?
- How can staff prepare the person for procedures, exams, care and/or services?
- How is pain expressed? Eased or alleviated?
- Medication: what works best?
- Are there any accommodations needed ahead of time or at time of appointment?
- Any other tips to help staff help you?

How is this person best supported in this context?

- How does the person manage his/her mobility? What supports are helpful?
- How does the person like to meet new people? Identifier? Other supports?
- What creates confusion, anxiety, or other discomfort? What helps?
- Does the person use any technology assistance? What technology, how does it help, and what do others need to know/do to support?

's One Page Description

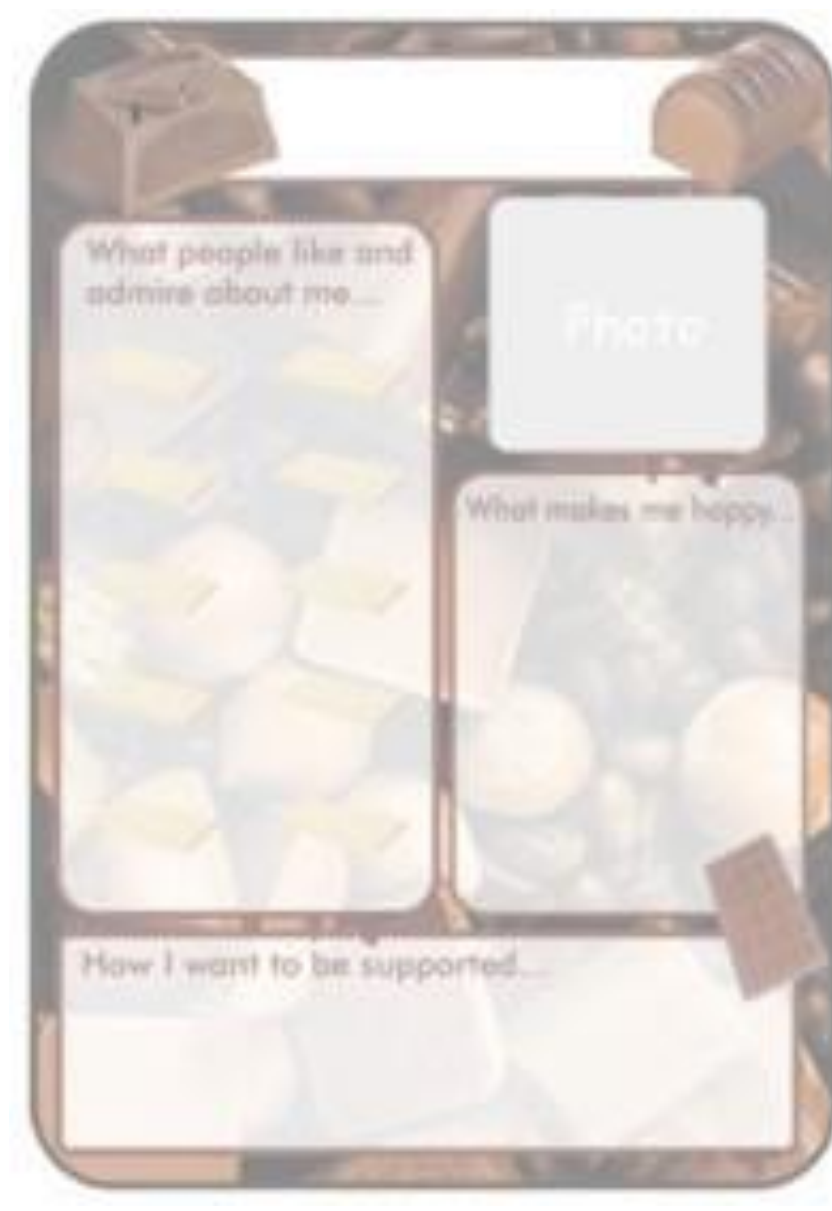
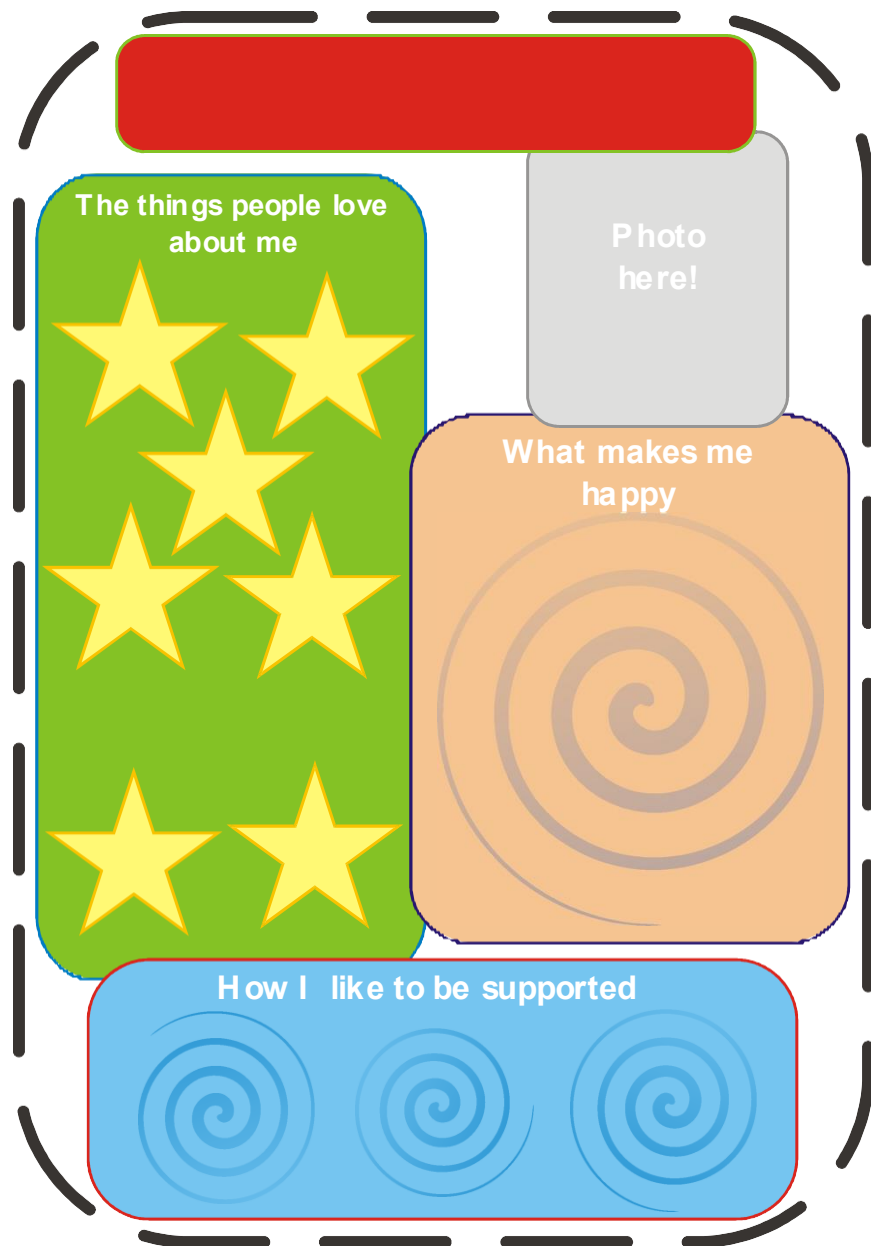
For Medical appointments

What People Like and Admire about _____

Insert
Photo
Here

What is Important to

How to best support _____



The Ins and Outs: One Page Profiles for Healthcare Settings



[Ins and Outs of One Page Profiles- Healthcare Settings](#)

MORE VIDEOS

Check here for a powtoons video review on
creating a one page description

[https://www.youtube.com/watch?v= dR6vAVxb18](https://www.youtube.com/watch?v=dR6vAVxb18)



TSC isn't easy.
The TSC Alliance is a great source of support.
Reach out.

