



People with different
abilities

...

Communication
Accessible information

...

Workshop

Elin Stark &
AnnaLisa Osvalder



Quotes from research study: Aphasia

Language disorder after brain injury

"I can take care of myself if I can stay at home"

"I can find information on my mobile/computer"

"I do not know how I can get help if my mobile doesn't work"

"I have never considered stocking up on food or medical supplies"

"I don't think society knows me and my needs in a crisis"



Quotes from research study: Bliss-symbolics

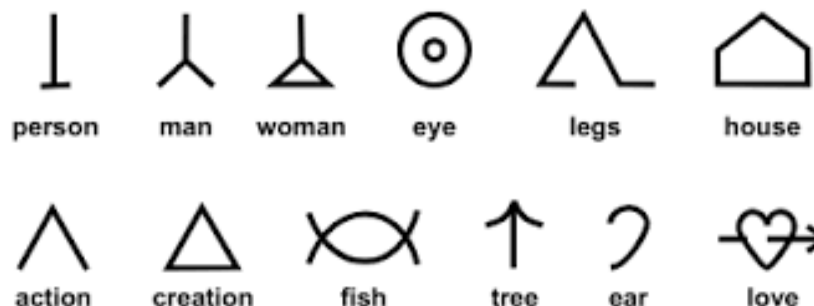
Used by persons with severe speech and physical impairments

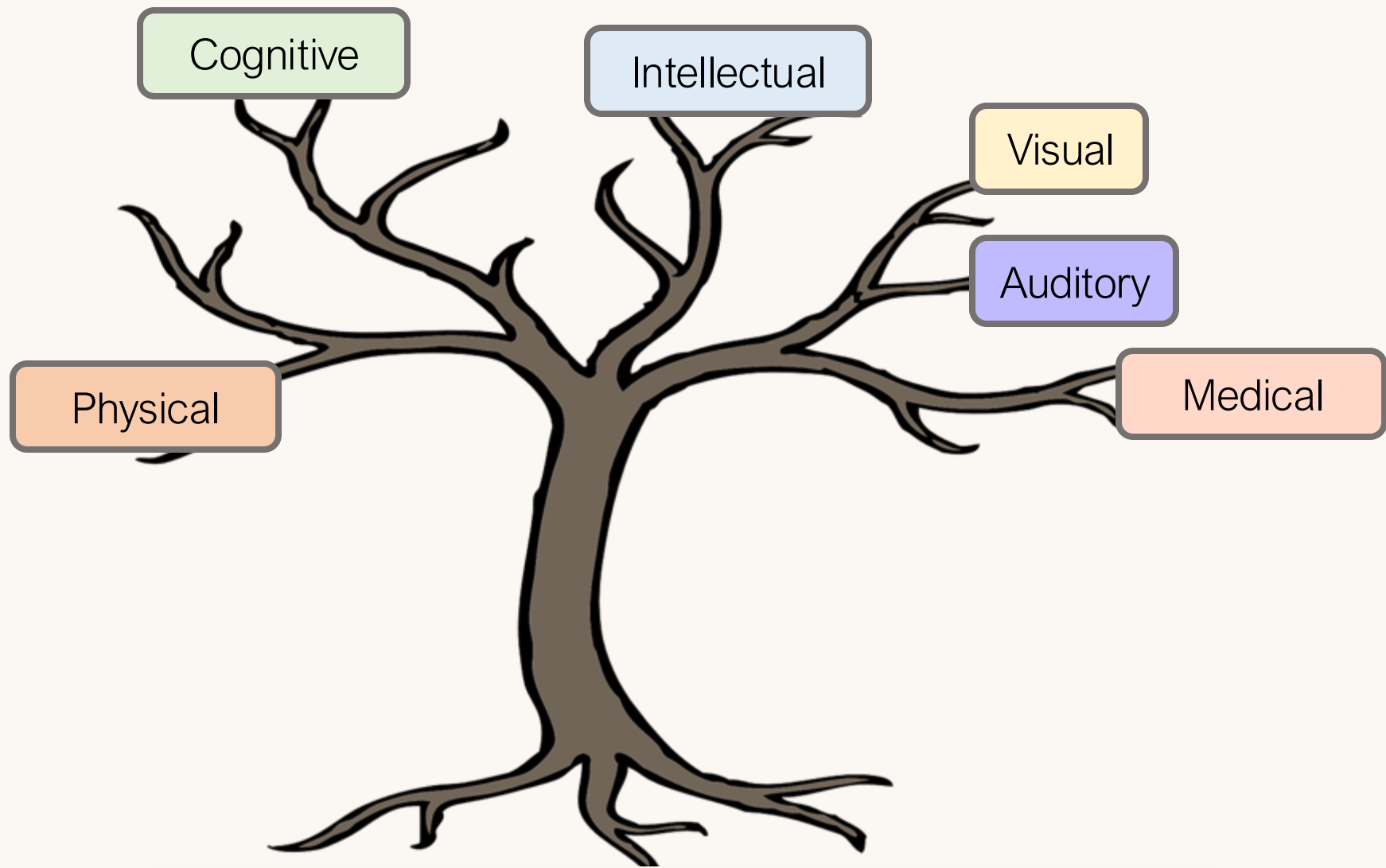
My whole life has been a crisis, so I am prepared

With them [the personal assistants] we can do anything. Without them we can do nothing

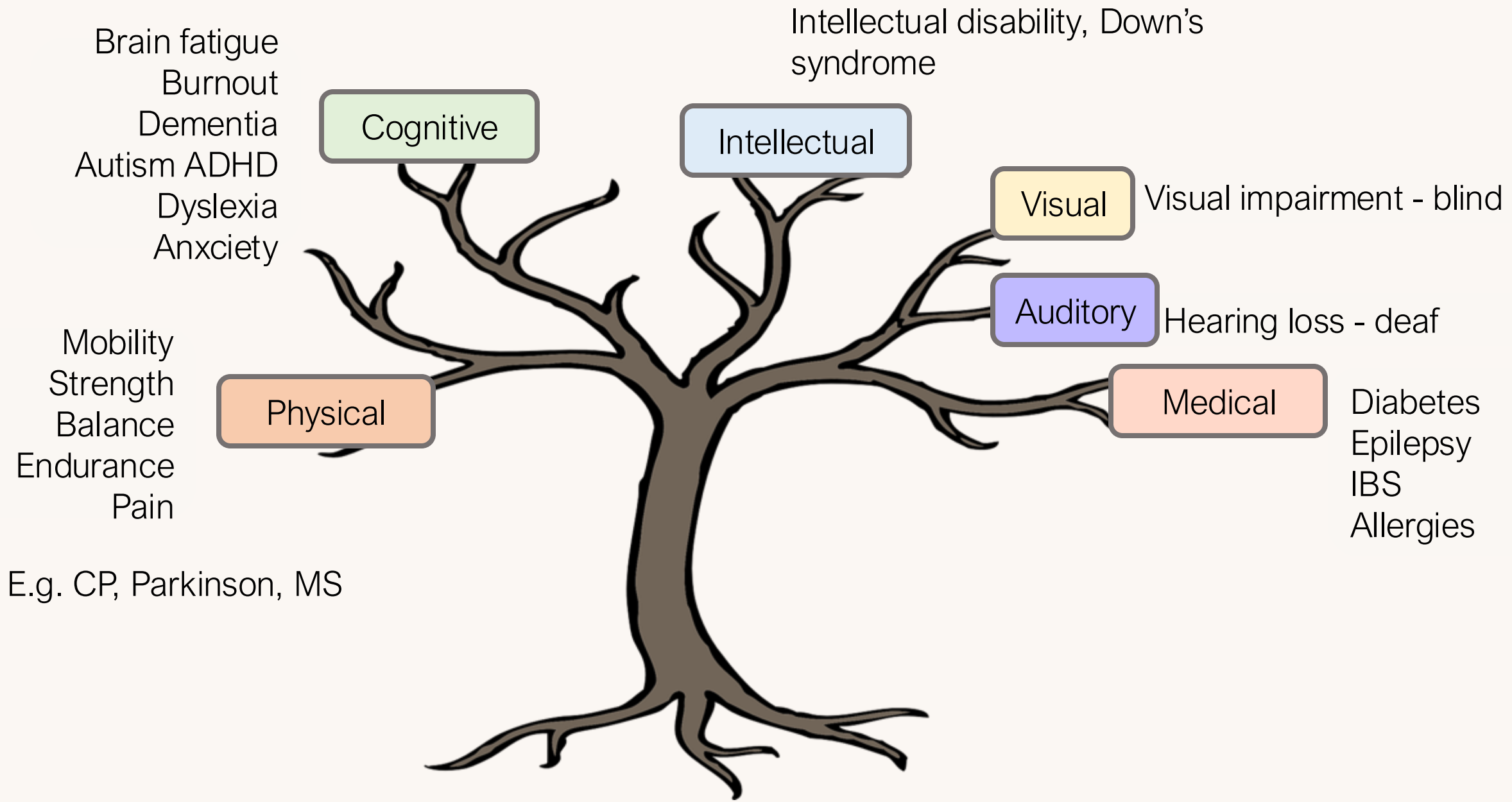
They are our family, we would never abandon them in an emergency

One becomes set on finding a solution.

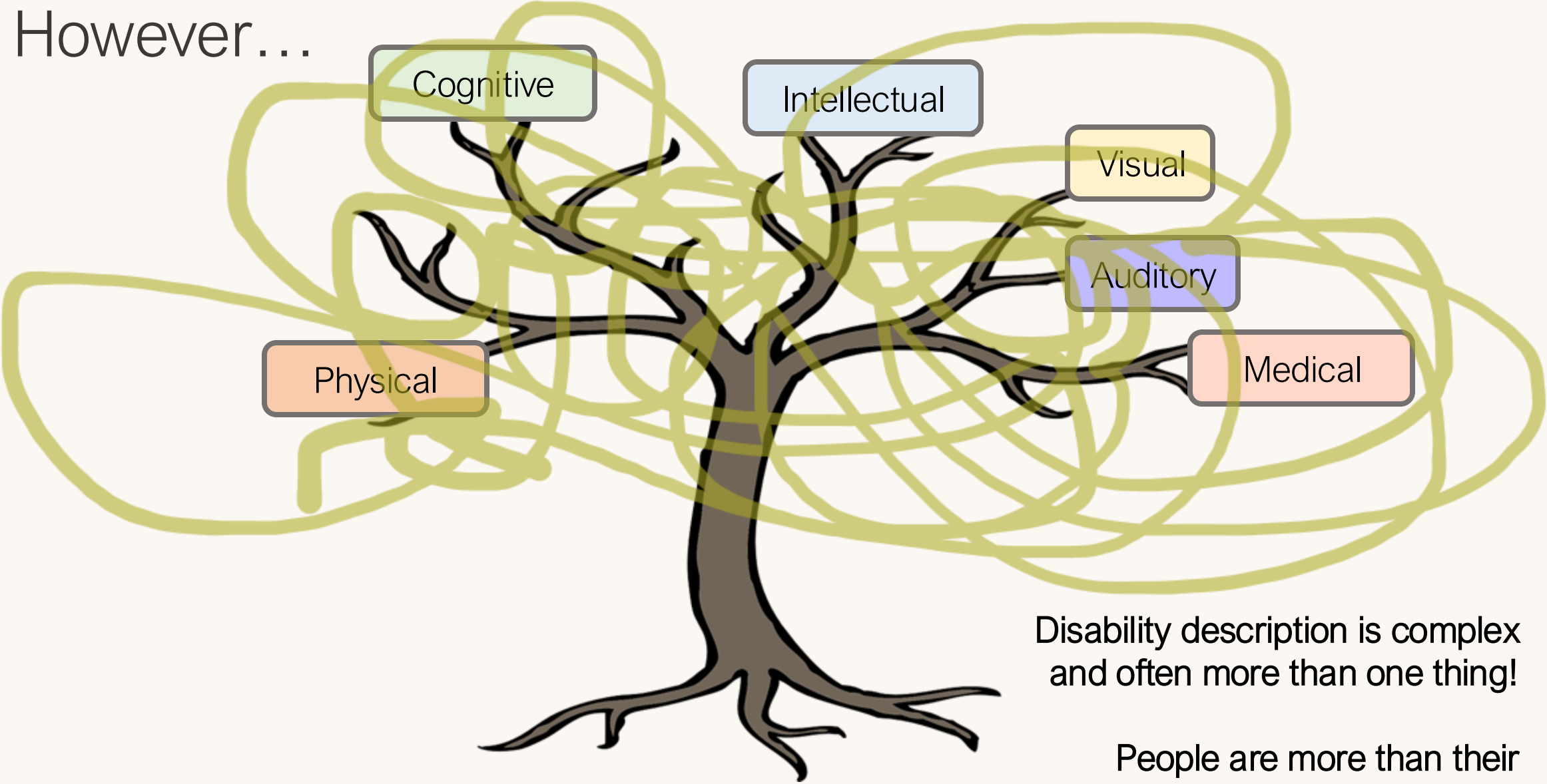




Different kinds of disabilities



However...



Disability description is complex and often more than one thing!

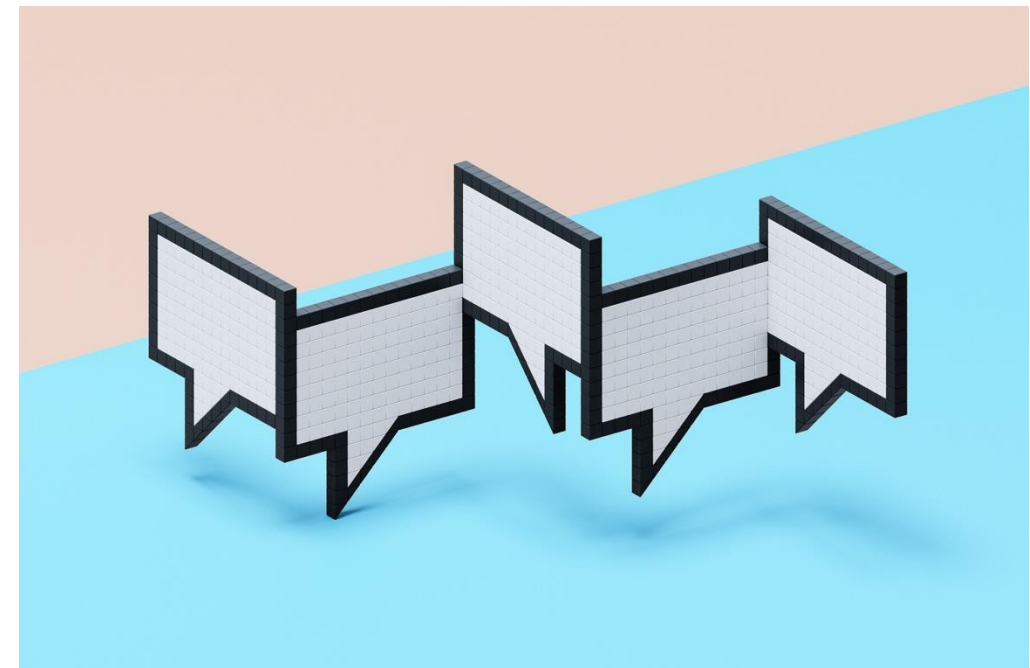
People are more than their disabilities



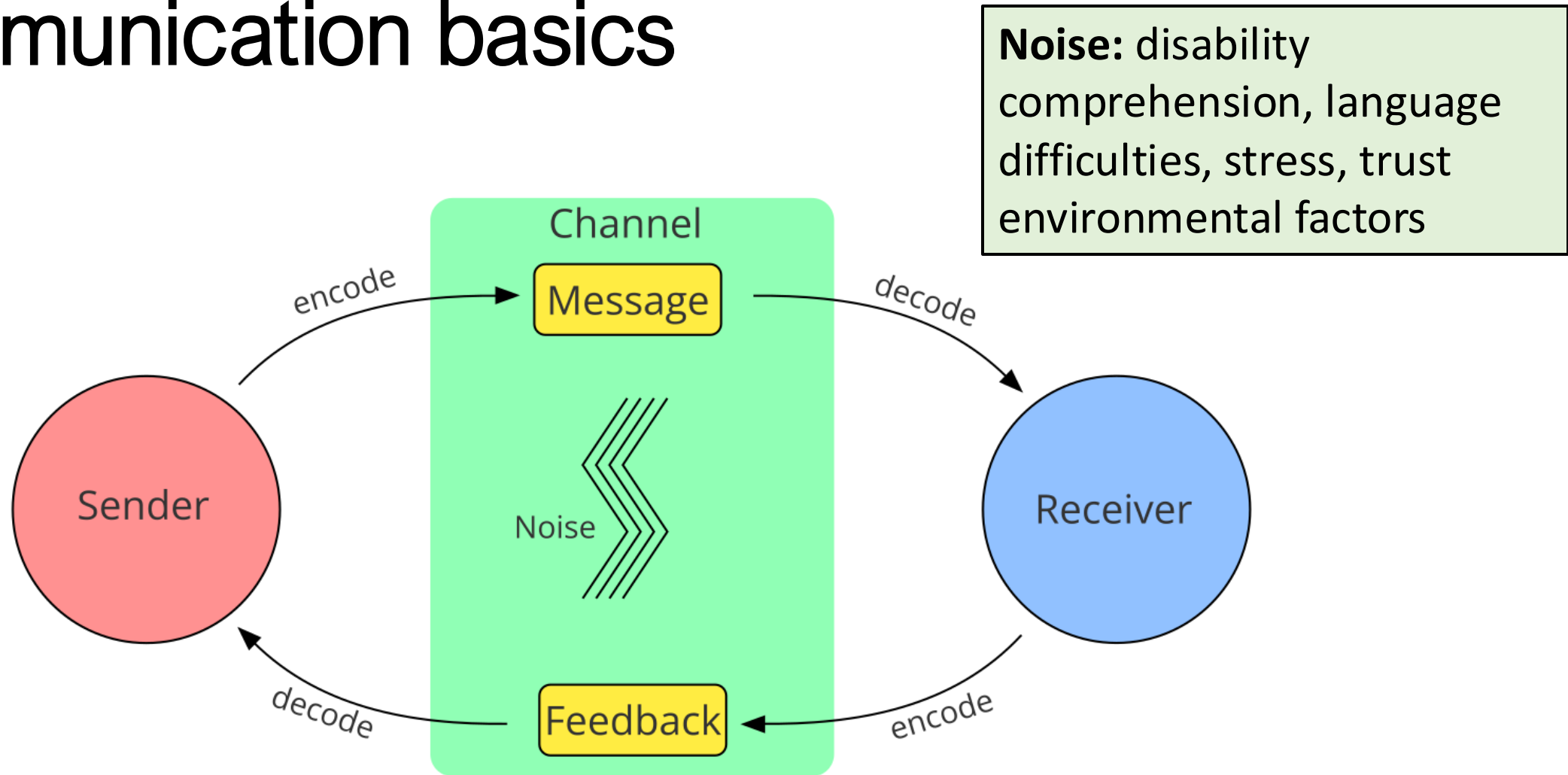
Many people with and without disabilities experience communication difficulties using language

Language: *knowing and understanding*

Knowing: *“owning” the language in the brain
Right vocabulary and grammar, finding words*



Communication basics



Adapting to accommodate communicative skills

- Language disorders, dyslexia, aphasia
- Intellectual, physical, or cognitive disabilities
- Hearing and visual impairments
- Different mother tongue



- Difficulties finding, understanding, and following crisis directives independently.
- Dependent on others to provide and augment information
- Message contamination!



Adapting to accommodate communicative skills

Some findings from the research project

- People with disabilities are more likely than others to acquire more disabilities during a crisis/catastrophe
- Many have the capacity to help themselves if they know what to do – thus freeing up resources for others
- Disproportionately many with intellectual disabilities died during the pandemic, without being extra sensitive to the virus.
- Non-Swedish speakers declined vaccines and mistrusted official information to a higher extent

Needs for people with communication difficulties

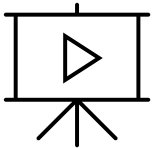
Findings from the research project re crisis information

- **Time** to process the information
 - **Shorter information messages**
 - **Simpler words**, easy to recognise and understand
 - **Clear facts**, avoid own interpretation
 - **Don't repeat** things
 - **Help in finding** relevant information
-
- **Keep basic communication material** at crisis centres and meeting points
 - **Disability organizations could function as hubs** of knowledge and contacts – but need to be invited to discussions
 - **Not all people with disabilities receive services** – they risk falling through the safety net

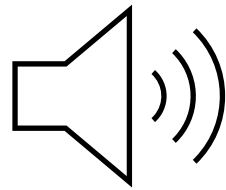


Examples of communication aids

- Alternative and augmentative communication (AAC) is:
 - Used to help produce speech
 - Used to help understand spoken speech
 - Used for both production and understanding of speech



Pictures or videos to complement text



Text-to-speech



Communication computers – symbols with sounds



Easy-to-read, short and simple

Emergency Communication 4 ALL Picture Communication Aid

Name: _____
 Address: _____
 Family Members/Caregiver: _____
 Emergency Contact: _____

Example: communication displays

- A layout of pictures representing words relevant for a certain situation.
- **Both** communication partners point to the pictures while they talk to help with both expression and comprehension
- Opens the mind: we can talk about all these topics!

WHO 	I, me, my 	I understand 	need 	food/drink 	walker 	battery 	emergency 911	service animal 	Allergy: <input type="checkbox"/> yes <input type="checkbox"/> no																																										
WHERE 	you, yours 	scared 	can't breathe 	bathroom 	wheelchair 	money 	broken 	I can't speak, but I can hear you.	I can spell my replies. Please be patient.	I will point to where I hurt. 																																									
WHAT 	she, her 	I don't understand 	help 	keys 	cane 	phone 	transportation 	<table border="1" style="width: 100%; border-collapse: collapse; text-align: center;"> <tr><td>0</td><td>1</td><td>2</td><td>3</td><td>4</td></tr> <tr><td>5</td><td>6</td><td>7</td><td>8</td><td>9</td></tr> <tr><td>A</td><td>B</td><td>C</td><td>D</td><td>E</td></tr> <tr><td>F</td><td>G</td><td>H</td><td>I</td><td>J</td></tr> <tr><td>K</td><td>L</td><td>M</td><td>N</td><td>O</td></tr> <tr><td>P</td><td>Q</td><td>R</td><td>S</td><td>T</td></tr> <tr><td>U</td><td>V</td><td>W</td><td>X</td><td>Y</td></tr> <tr><td>Z</td><td>?</td><td>.</td><td>!</td><td>SPACE</td></tr> </table>				0	1	2	3	4	5	6	7	8	9	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T	U	V	W	X	Y	Z	?	.	!	SPACE
0	1	2	3	4																																															
5	6	7	8	9																																															
A	B	C	D	E																																															
F	G	H	I	J																																															
K	L	M	N	O																																															
P	Q	R	S	T																																															
U	V	W	X	Y																																															
Z	?	.	!	SPACE																																															
WHEN 	he, him 	good 	hot 	bed 	hearing aid 	computer 	SNOW 																																												
WHY 	they, them, their 	quiet 	headache 	clothes 	oxygen 	home 	fire 																																												
YES 	we, ours 	sick 	cold 	medication 	glasses 	shelter 	rain/flood 																																												
information, ID 	family 	loud 	pain 	blanket 	communication device 	hospital 	wind 																																												
NO 	pet 	lost 	STOP 	follow 	charge 	leave, evacuate 	GO 																																												



Pain Scale










no

moderate

severe

The Picture Communication Symbols © 1981-2009 DynaVox Mayer-Johnson LLC. Used with permission. All rights reserved worldwide. Copyright © 2009 developed by Diane N. Bryen & Rachel Ravitch funded through the National Institute on Disability and Rehabilitation Research. Revised 2018 by Joanna L. King & Kim Singleton, MS, CCC-S funded through the Pennsylvania Department of Health.

Disaster Preparedness for People Who Have Limited Speech: Taking Responsibility for Your Safety

YES	NO	Check List for People with Limited Speech and Those Who Care About Them
		 <p>1. Do you have a support team? Does everyone know what to do?</p>
		 <p>2. Do you have an evacuation plan in case you need to leave home or work in an emergency situation? Do you know:</p>
		 <p>a. Where you will go?</p>
		 <p>b. How you will get there?</p>
		 <p>c. Who will transport you/come with you?</p>
		 <p>d. What you will take with you?</p>
		 <p>e. What your rights are in a shelter?</p>
		 <p>3. Is your “Go Bag” packed? (See “Go Bag” on page 3.)</p>
		 <p>4. Do you have paper (laminated) communication display(s) with you <u>at all times</u>? Do your displays include vocabulary for emergencies? Do you have written instructions about how to communicate with you <u>at all times</u>?</p>

Communication Passport Accident and Emergency

Things you must know about me



Name:

Like to be known as:



Phone:

Address:

Email:



Date of birth:



Next of Kin contact:

Address:

Relationship (e.g. Mum):

Phone:



How I communicate/what language I speak:



My support needs and who gives me the most support:



Who I live with:

These things are important to me



Seeing/Hearing (problems with sight or hearing):



How I eat food (food cut up, risk of choking, help with eating, etc):



How I drink (drink small amounts, thickened fluids, etc):



How I keep safe (bed rails, support with challenging behaviour, etc):



How I use the toilet (continence aids, help to get to toilet):



Sleeping (sleep pattern/routine):

Crisis communication, some guidelines

1. Communication should be in real time

access to the most up-to-date information, avoid stress(?)

2. Information should be accessible (anywhere):

mobile technology, radio, web-pages, written posters

3. Messages should be relevant to the (disabled) individual

- What has happened?
- Why?
- **What should I do?**
- When and how receive new information?
- Where to go for support/help?



Five recommendations for inclusive crisis communication



1. Accessible and inclusive (to all groups)
2. Actionable (what to do, positive actions)
3. Trusted and credible (initial trust, consistency)
4. Relevant and timely (from the beginning, regular updates)
5. Understandable and transparent (short, simple, clear and easy to recall)

Workshop: understanding and following information

- Work in groups of three
- Study the personas & the crisis message
- Discuss one persona at a time. Make sure to do at least two personas. Discuss their **strengths** and **challenges** in **understanding** and **carrying out** the instructions in the message
- **Fill in the template** for each persona – we will take a picture of it afterwards!



Persona 1: Anita

Anita is 24 years old and just started the architecture program at the University. She has always pushed herself very hard, and when she was 18, she became **paralyzed from the waist down** after running a marathon with pneumonia.

Apart from using a wheelchair, Anita is considered fully able to understand and participate in her daily life. Anita does, however, describes her living with **severe anxiety** which is triggered by being under stress and the feeling of not being in control (although studies are not a problem, since she can control her work schedule very well).



Persona 2: Fred

This is Fred. He is 27 years old and was born with **cerebral palsy (CP)** due to complications at birth. He uses an electric wheelchair and has **movement restrictions in all four limbs**. Since speech is very difficult, he communicates using a speech generating computer, which he controls through eye-movements. He is not able to read written words, and instead uses a language of symbols called Bliss. He reads emails and text messages on his computer.

Apart from the physical restraints, he also has a **mild intellectual disability and is completely deaf**. He understands others through their use of sign language or the Bliss symbols. He has help from assistants two hours every morning, two hours at lunch, and from early evening until midnight.



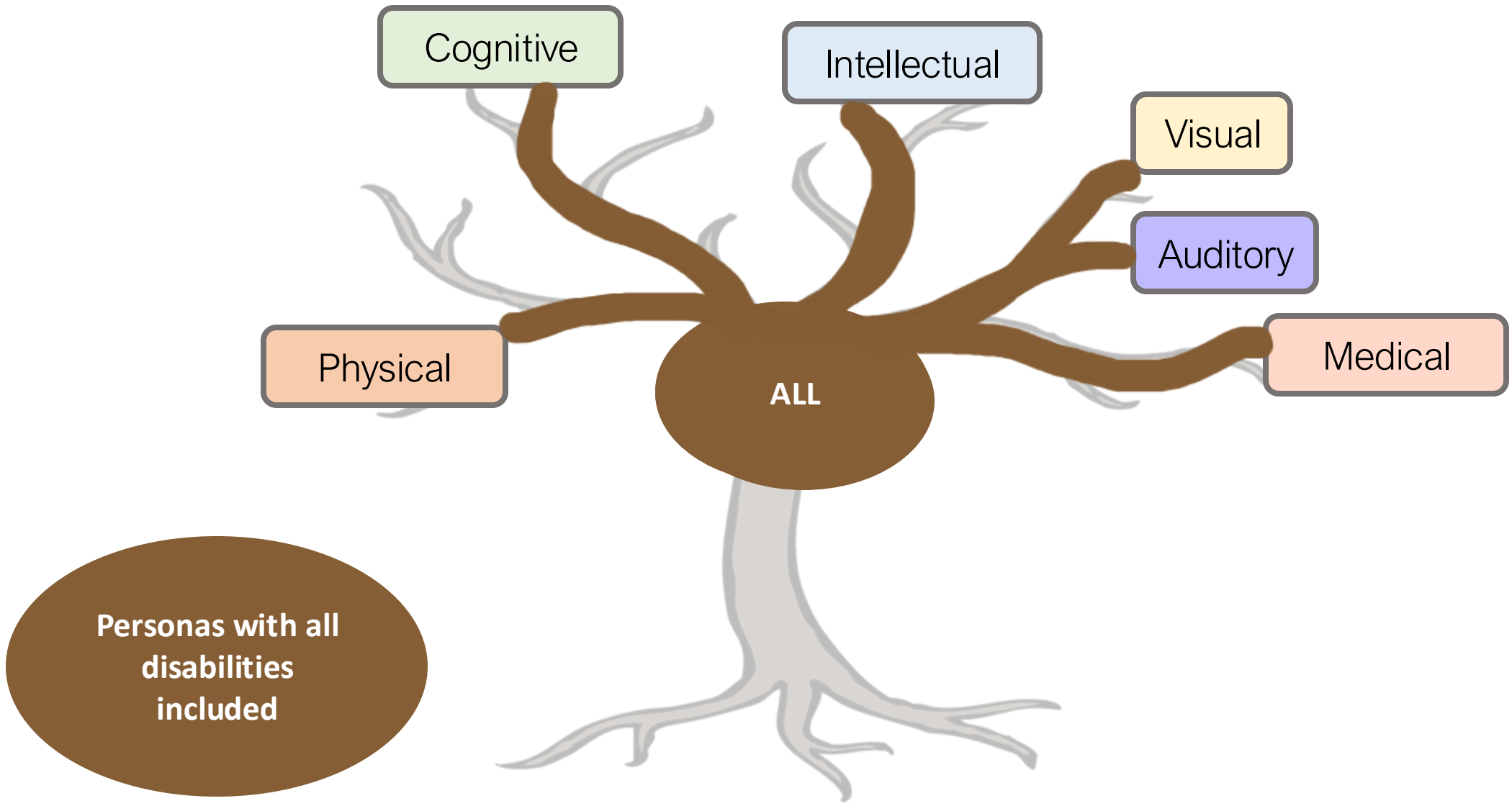
year	spring	summer	autumn	winter	Return to Main Board
☉	☉ ₁ ♀↑	☉ ₂ <>	☉ ₃ ♁↓	☉ ₄ ♁	←
Christmas	Easter	holiday	birthday	vacation	back a page
☉♁↑	☉↑↑	☉♥↑	☉♁	-♁♥↑	← 1 □
weather	rain	snow	air	wind	next page
♁	♁	♁	Z	Z	→ 1 □

Persona 3: Michaela (and Max)

This is Michaela. **She is 29 and has autism, ADHD, epilepsy, and is blind from birth.** She loves the drums and playing Rock Band, and she hates being forced to sit quietly. She is prone to anxiety attacks, which can be triggered by confusion or thinking she has performed badly. During an anxiety attack, she either shouts or acts out in self-harm.

She has no trouble understanding speech or speaking herself but is easily **overwhelmed by too much information** at once. She uses her service dog Max and a white cane to get around. Max is both a seeing eye dog, and an emotional support dog. He also brings her medicine in case of an epileptic seizure. Apart from Max, Michaela receives no other support on a daily basis.





Cognitive

Intellectual

Visual

Auditory

Physical

ALL

Medical

Personas with all
disabilities
included

Crisis scenario: Hurricane

- A large unpredictable storm has suddenly developed very quickly and entered the country, which is developing into a hurricane at a rapid pace. No warnings have had time to go out earlier about the storm and now the VMA sounds, and a text message goes out to all mobile phones that are connected to mobile towers in the area where the active VMA prevails.



Hurricane: *The crisis message reads:*

- Hurricane
- Stay indoors. Better protection than outside.
- Make sure windows and doors are properly closed.
- Prepare for power outages.
- Fill up water storage.
- Avoid the car.
- Do not go near power lines on the ground.
- Follow weather forecasts and warnings.
- Listen to national Radio to follow what is happening.
- Submit your own observations to crisisinformation.com, which uses crowdsourcing to collect information for a common map.

To take into account regarding crisis information: Discuss for the 3 personas

- Communicative needs?
- Ability to read?
- Ability to see and understand maps?
- Ability to act once information is understood?
- Use of bulky mobility devices?
- Presence of support animals?
(where the handler goes, the animal goes)
- Need for sign language interpretation? Other interpretation needs?
- Management of severe anxiety?
- Medical needs, e.g. epilepsy?





People with different
abilities

...

Communication
Accessible information

...

Workshop

Elin Stark &
AnnaLisa Osvalder
Chalmers University, Sweden

