

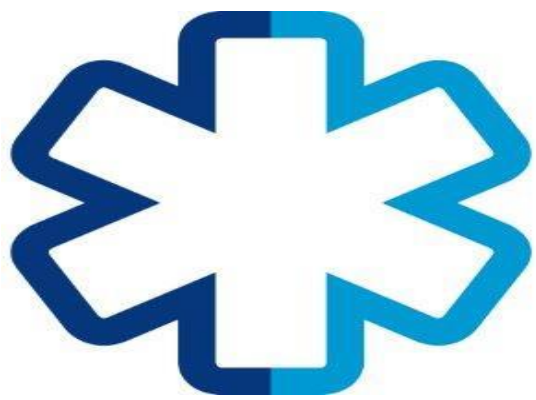
LEARNING TO USE THE EYE-GAZE TECHNOLOGY IN AIDED COMMUNICATION: HABILITATION PROCESS WITH THREE PARTICIPANTS WITH RETT-SYNDROME

Lotta Lintula, MA, Tampere University Hospital, Tampere University



**UNIVERSITY
OF TAMPERE**





Pirkanmaa Hospital District



TAMPERE UNIVERSITY HOSPITAL

- 500 000 habitants
- Outpatient Clinic for Intellectual Disability has about 10 patients diagnosed with RETT.
- Mobility Aid Unit assesses and lends suitable communication devices

THE AIM OF STUDY

- Find out which areas of function are most often used to describe habilitation process to gain eye-gaze technology as a communication aid by professionals.
- How professionals and parents describe the participants' ability to learn to use eye-gaze technology, its influence on the participants' communication skills and their possibilities to take part in social situations as an active partner.

Background: piloting habilitation process

PHASE I:

Rehearsing periods with Tobii-I[®] device

- **GOAL:** To learn the use of eye-gaze as a conscious tool of navigation at computer screen.
- 3-month rehearsing periods twice a year
- Phase I lasts two years or less if subject reaches the criteria to use a device as a communication aid earlier.

PHASE II:

- **Access to the eye-gaze computer permanently.**
- **GOAL:** Communication using the device

Method: Natural habilitation process

- As the goals were set individually and several persons took part both to decision making and carrying out the habilitation, the processes between subjects were different.
- Occupational therapy or/and speech therapy going on through the habilitation process
- School and family committed to rehearse with the subject
- Regular team meetings: goals and how to reach them.
- Clinical reports of speech and occupational therapists

Method

Three year follow up: subjects

- 12 years
- MECP2, c.401C>G
- Epilepsy in remission
- Walks with light support



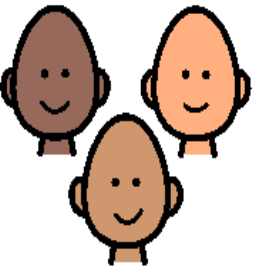
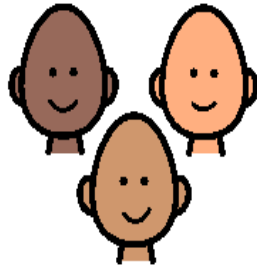
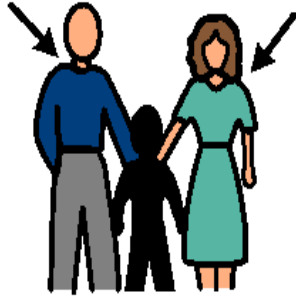
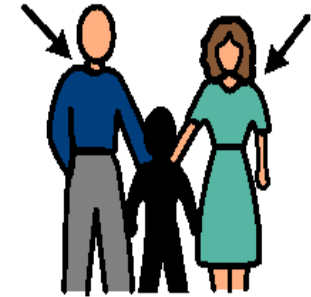
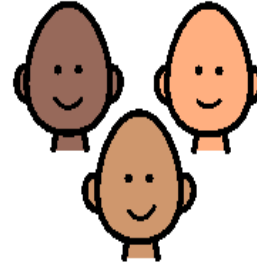
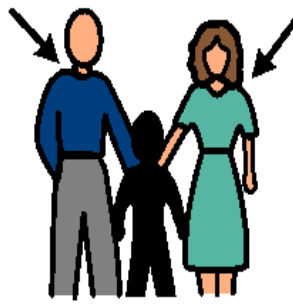
- 13 years
- MECP2
- Epilepsy: monthly seizures
- Does not walk



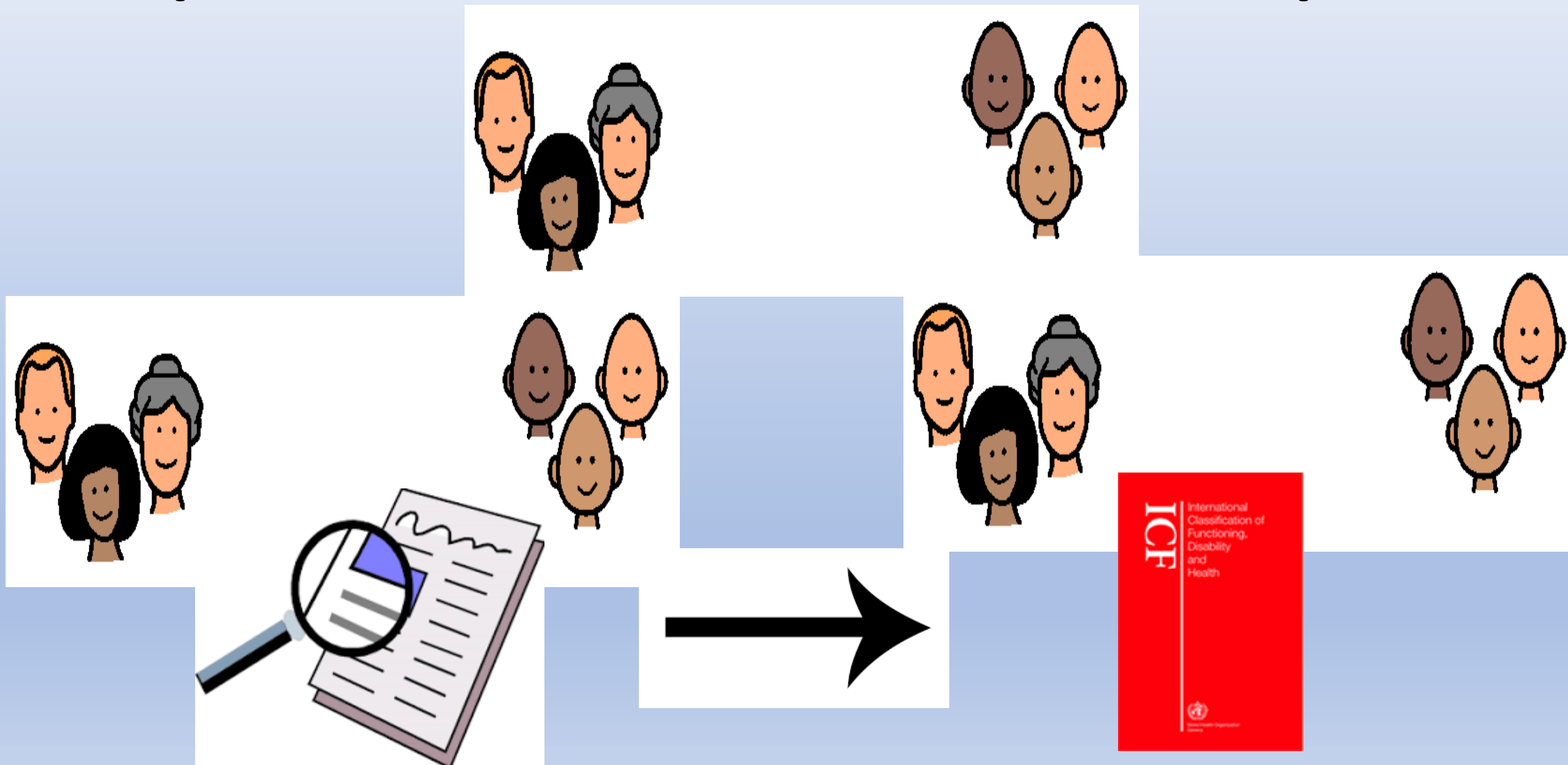
- 15 years
- MECP2, 1163_1197 del
- Epilepsy in remission
- Walks with strong support



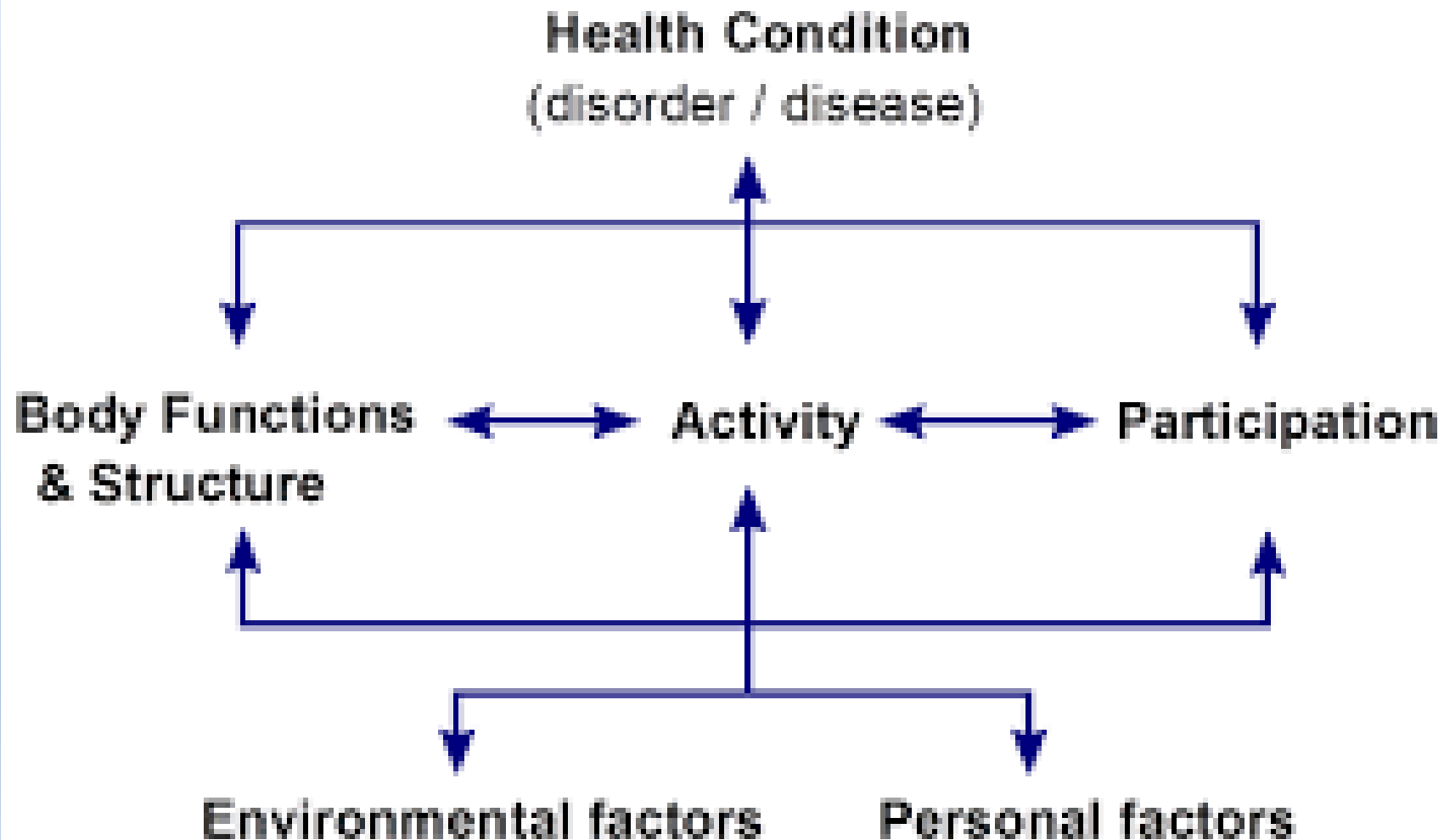
Teamwork



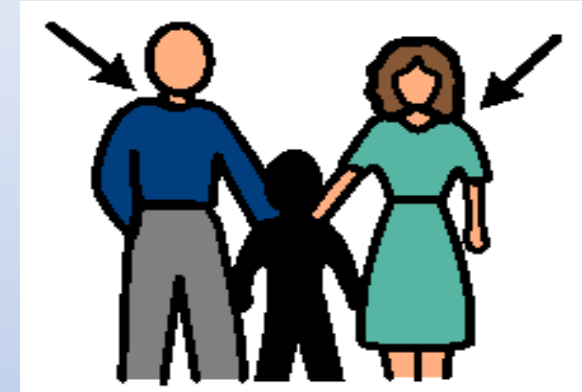
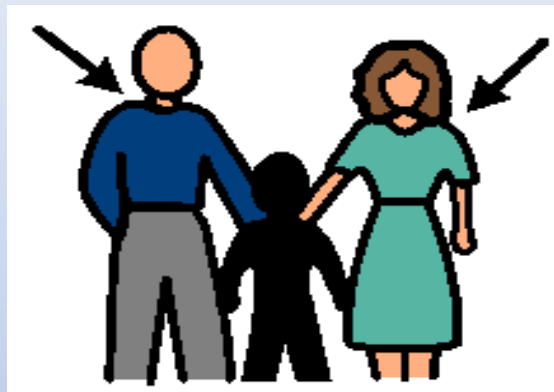
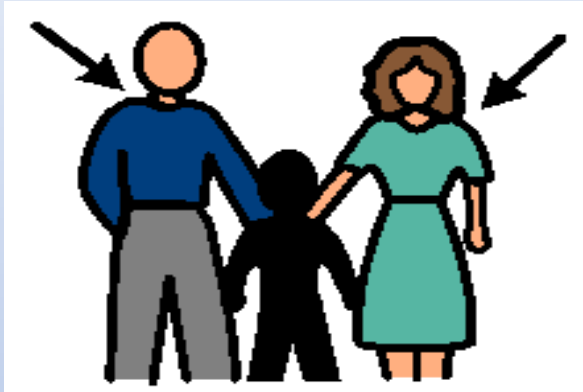
We studied the documents made by professionals about this habilitation process.



ICF/ICF-CY, International Classification of Functioning, Disability and Health



Parents were interviewed about their experiences of the process.



- parents' description of the habilitation process
- comments to the habilitation (i.e. what therapies and when, intensity)
- comments to the device and the qualities of the computer
- participants' and families' experiences during the follow-up
- participants ability to function and participate and factors that influences to it during the follow-up
- How to do this properly in the future

Results

- All subjects learned to use eye-gaze technology as a communication aid.
- All subjects were reported to have some dyspraxia in eye-gaze-use, though it eased during the habilitation process
- All subjects' ability to communicate with the device varies a lot depending on e.g. their alertness and motivation.

RESULTS: HABILITATION GOALS

-the most used ICF-categories

ICF-code		% (total)/ of phrases)	EXAMPLE
d110	Watching	13%/30%	In this period the goal is to strengthen eye-gaze use as a conscious tool.
d360	Using communication devices and techniques	7%/17%	To learn to express feelings and needs using 1-2 symbols from her communication device.
b215	Functions of structures adjoining the eye	6%/15%	To improve ability to fix the eye-gaze intentionally.
d135	Rehearsing	6%/14%	She needs a lot of repetition and rehearsing to learn the choosing technique.
d210	Undertaking a single task	5%/13%	To learn to change the communication table independently
d177	making decisions	5%/12%	The parents hope that she could choose what to eat for breakfast

RESULTS: PROFESSIONAL OBSERVATIONS: The most common used ICF-categories

ICF-code		%/total	%/n(phrases)	
b215	Functions of structures adjoining the eye	9 %	20 %	"Fixing the gaze to the one point for a long time is hard to her"
d210	Undertaking a single task	8 %	19 %	"She plays the easy games once and quickly and is not willing to repeat"
b130	Energy and drive functions	7 %	17 %	"If she is not motivated, it's impossible to make her try"
d335	Producing nonverbal messages	6 %	14,62 %	"Expresses 'yes' for an answer using a gesture with her tongue."
d177	making decisions	5 %	12,31 %	"She is able to choose of several choices"
d110	Watching	5 %	11,73 %	"She is now able to make choices independently by using intentional eye gaze."
d360	Using communication devices and techniques	4 %	9,04 %	"She can change the communication table and combine two symbols in a row."

Results: Improvement

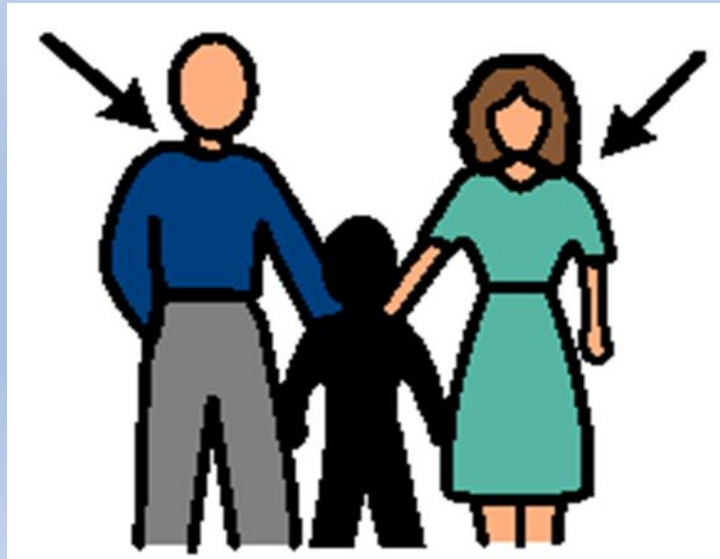
An area of function was mentioned to have improved during the follow-up time (using expressions like *do more/better than before, xx has improved/developed, she has learned to xx*).

ICF-code		%(total)/ of phrases)	EXAMPLE
b215	Functions of structures adjoining the eye	25%/11%	"She has learned to move her gaze throughout the whole screen"
d210	Undertaking a single task	20%/9%	"Compared to last year she needs less guidance and support from an adult to use the computer"
b147	Psychomotor functions	11%/5%	"Her hands stay calm now while working and she doesn't slap the screen anymore"
d160	Focusing attention	11%/5%	"She is able to focus longer than before and she is now able to get back to rehearsing after distractions"

Results: Parents

- Parents believed that the device had a positive impact on their daughters' participation possibilities, but found the repeated evaluations stressful.

“She can now express her feelings, interests for the first time. People have always been important to her and now she can talk us about her friends.”



How to do this properly

The intensity of rehearsing and access to the device:

“The daily rehearsing with lots of repetitions” “often, but in small sessions”

“You can’t learn, if the device is taken away for a while. You have to start all over, when you get it back”

Software modification

“Content of the communication material should be modified constantly” “There should be tables that enables the participation to the conversation”

How to do this properly:

Education and support

The therapists guiding the near working personnel i.e. personal assistants, school staff

“The speech therapist should have time enough to guide the school staff and develop the content of the communication material with them”

Education to the parents

“There should be education to the parents how to create communication tables, because the professional don't have enough time to do up-date the material”

Knowhow of the assisting personnel

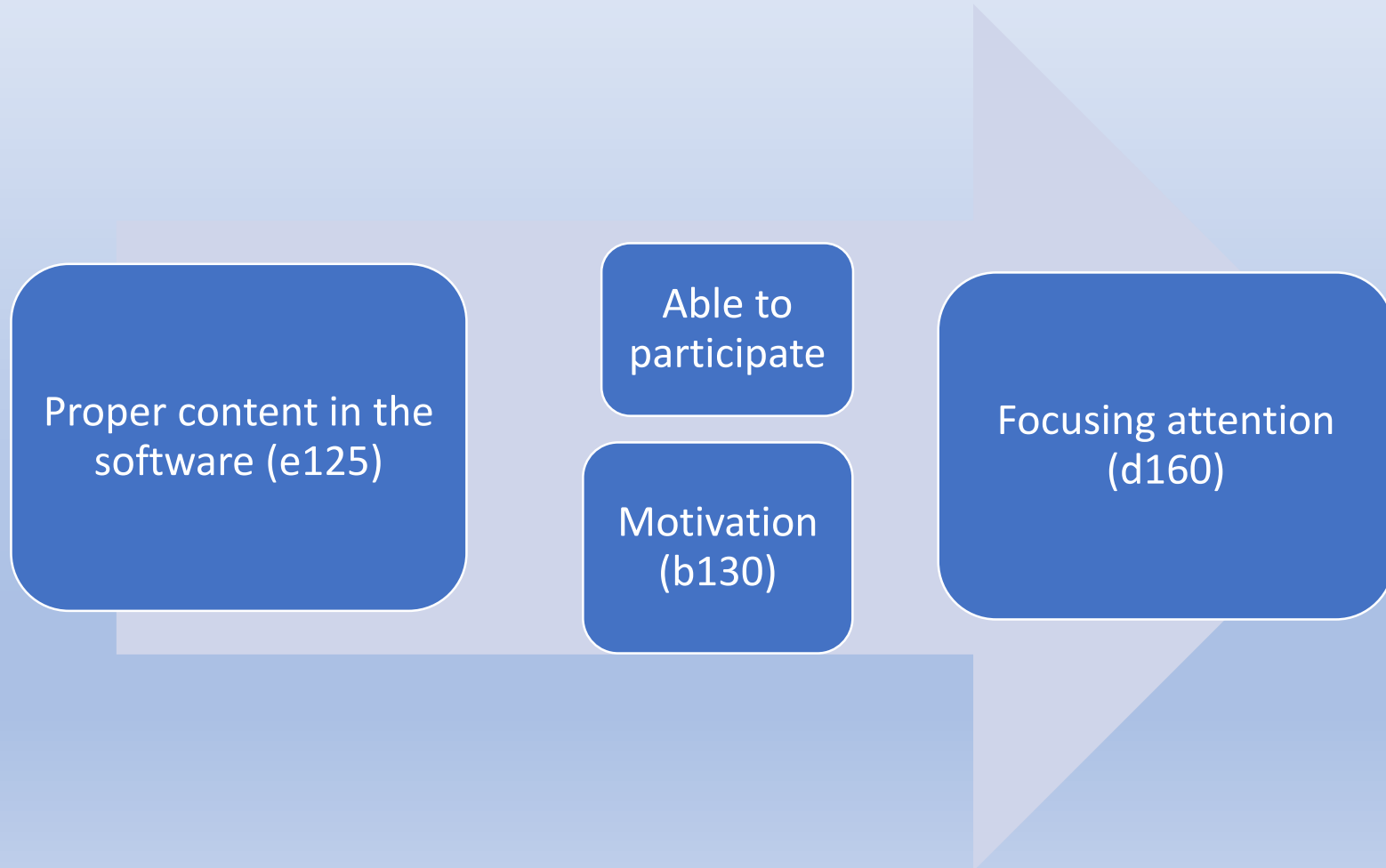
“At school there should be at least two adults in the class who are familiar with the device and the software modification”

How to do this properly:

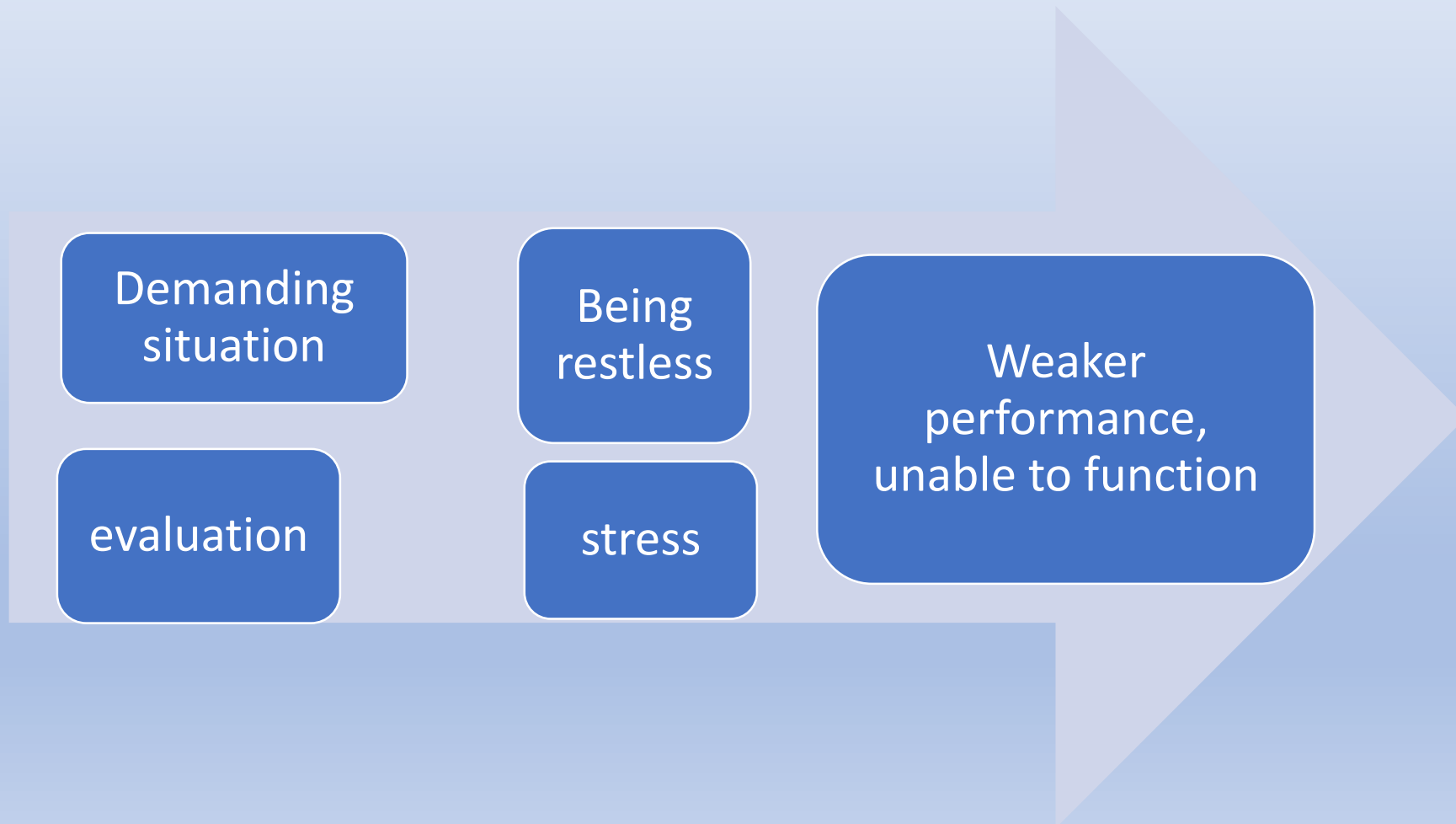
Focus to the communication from the beginning

- “That’s the main thing anyways. You can play games and everything, but the most important thing is that one can express herself and participate for real from the very beginning”.

Parental Interviews: What influences to the function

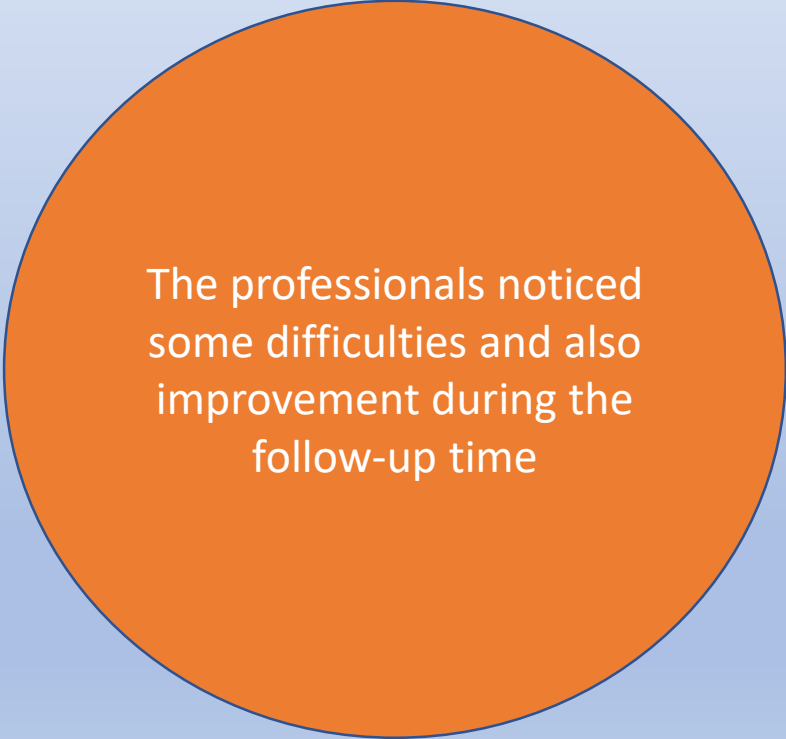


Parental Interviews: What influences to the function

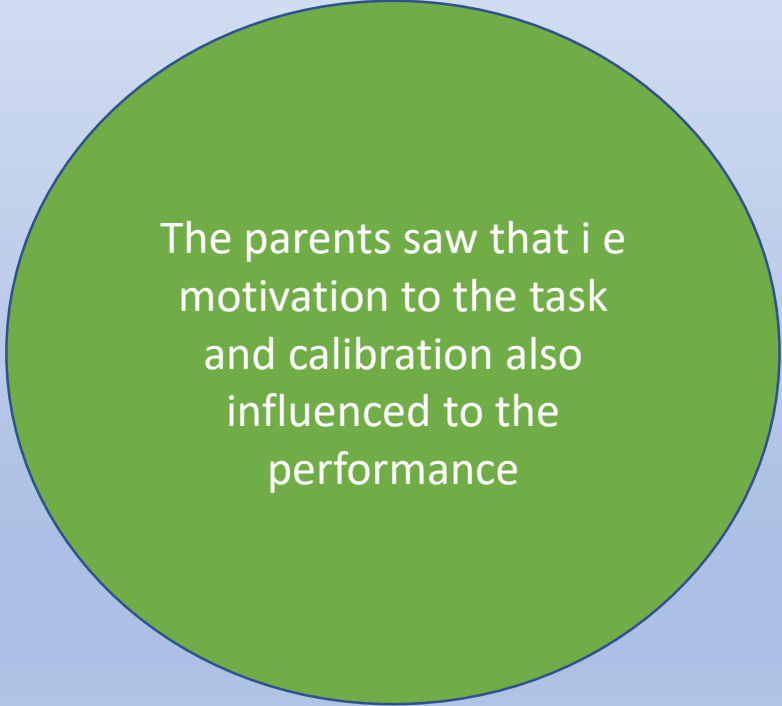


B215 Functions of structures adjoining the eye

including voluntary and tracking movements and fixation of the eye



The professionals noticed some difficulties and also improvement during the follow-up time



The parents saw that i e motivation to the task and calibration also influenced to the performance

B130: energy and drive functions

including energy level and motivation

- Motivation was seen as a important factor explaining the ability to function

D3: Communication

new functions were mentioned in categories communication – producing; conversation and use of communication devices and techniques

But not so much in categories i.e. communication-receiving or mental functions of language

Conclusion

- Professionals different views on subjects' abilities influenced how the habilitation was carried out.
- ICF is a useful tool for defining meaningful concepts when analyzing natural habilitation process.
- It is important to use eye-gaze computer to the every day communication early on, while simultaneously training the movements and fixation of the eye.

Thanks to the subjects, their families and schools;
PhD Auli Sirén, Mobility Aid Unit in Tampere University
Hospital and Neuropsychologist Marjatta Musikka-Siirtola

