Amsterdam UMC
Universitair Medische Centra

C-BiLLT: Computer-Based instrument for Low motor Language Testing

Technical innovations to overcome for neuropsychological assessments in children with motor & sensory impairments

Dr. Johanna Geytenbeek, PhD, SLP, Speech-Language & Hearing scientist, senior researcher

Overview

- Background C-BiLLT- Why?
- Different parts of the C-BiLLT- How?
- Background psychometry- Use & interpretation?
- Clinical practice- 2 examples
- Summary

Background of the C-BiLLT

Background

"In my experience, current assessments DO NOT accurately assess my son's comprehension. For a long time, I have been saying this, but without a tool to accurately show his level of understanding it is difficult to explain to others. People assume that because he is not vocal, he doesn't understand – but this is not the case. He knows many things and is very bright."

Danijela, parent of a child with CP, GMFCS Level V

What do we want to know/understand?

C-BiLLT validity and reliability

Data collection 2008- 2014		
Particpants	**Number**	**Age**
Typically developing children	**n = 1046**	1;8 – 8:0 years
Children with CP	**n = 120**	1;8 – 12 years
Validity	**Tests**	**Outcome**
Construct validity	C-BiLLT/age in TD/CP	*r*=.82/ *r*=.36
Convergent validity	C-BiLLT/RDLS C-BiLLT/PPVT	*r*=.93 *r*=.88
Discriminant validity	C-BiLLT/CPM	*r*=.43
Structural Validity	EFA	*Factor 76%*
Internal consistency	75 items Guttman's Lambda	*0.93-0.94*
Reliability		
Interobserver agreement	n= 137/35	ICC = 0.97(CI
Intraobserver agreement	n= 37/35	ICC = 0.97

Language tracts

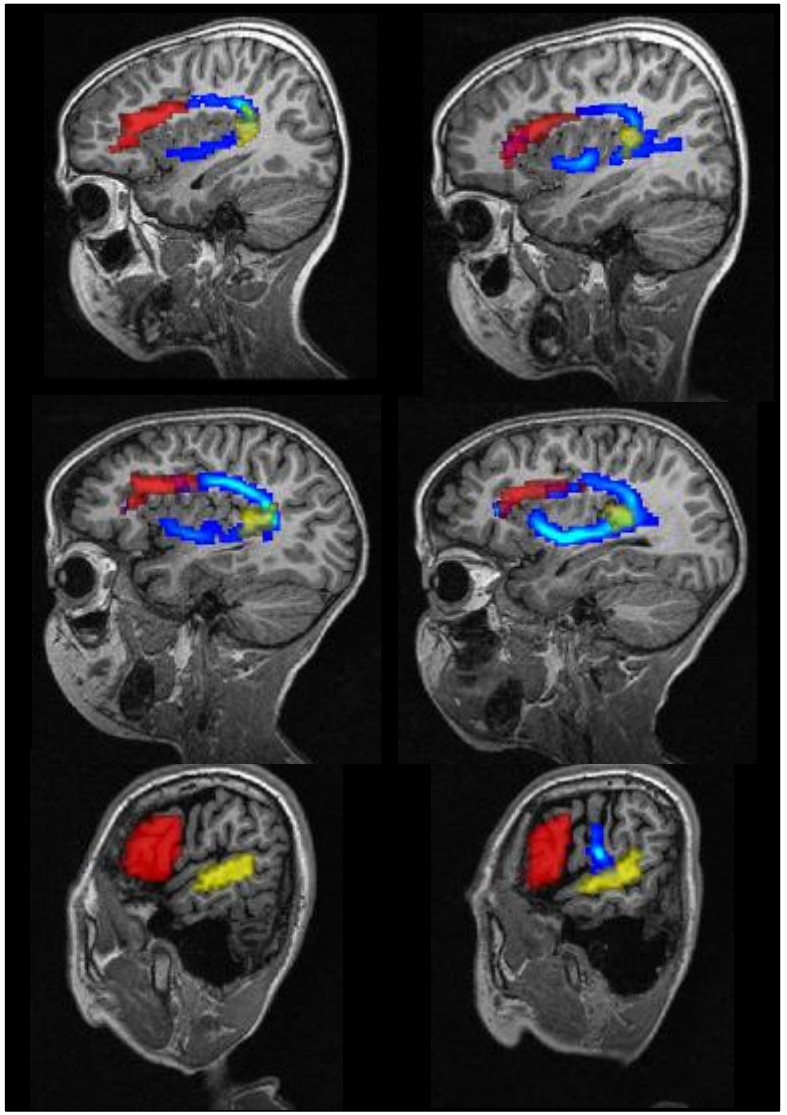
Participants

Controls: 4 M, 1 F Age : 12.5 +/- 3.8 years

CP children: 6 M 4 F, Age: 13.7 +/- 6.7 years
type: Spastic (n=1) Dyskinetic (n=4)
GMFCS level: Level IV (n=2), Level V (n=3)

Language comprehension: C-BiLLT

DTI: 12 directions, 1.5T Siemens



Control

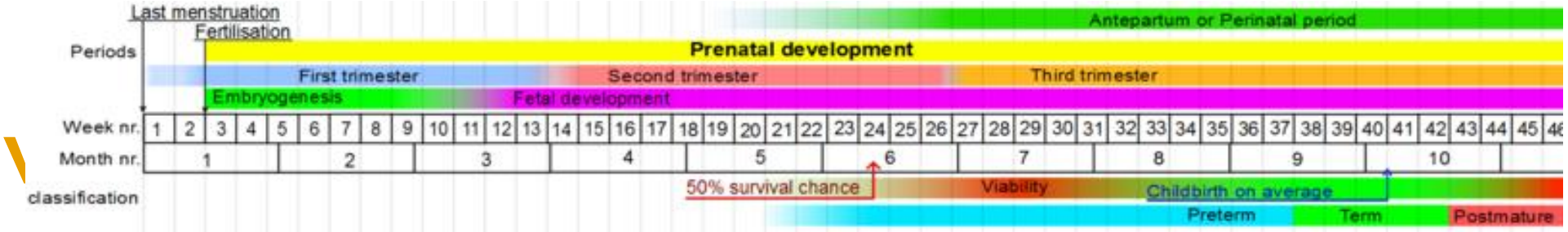
CP GMFCS IV

GMFCS V

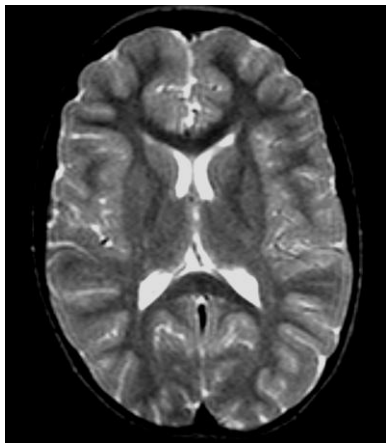
left right

Harlaar L, Pouwels PJ, Geytenbeek J, Oostrom K, Barkhof F, Vermeulen RJ. Neuropediatrics. 2013 Oct;44(5):286-90

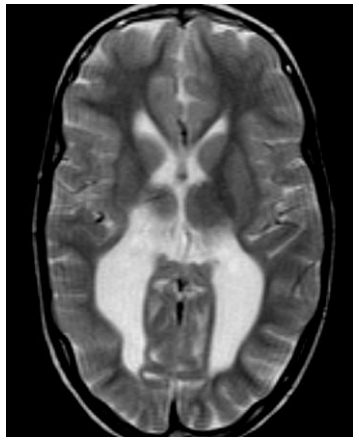
Bijv



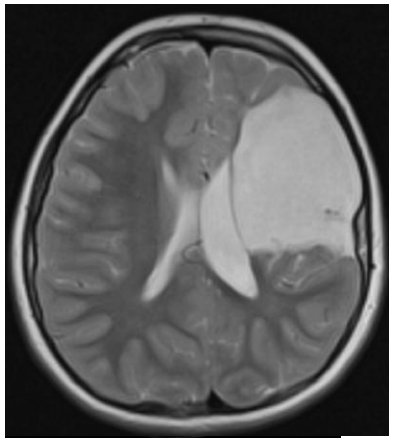
Localisation and severity of brain abnormalities



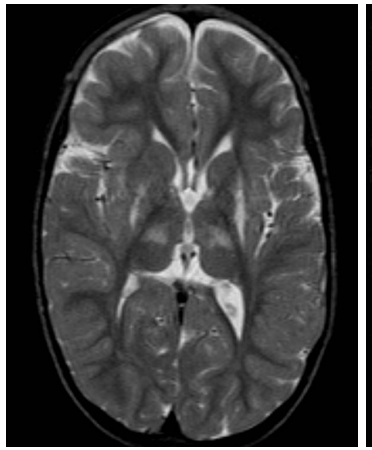
Normaal



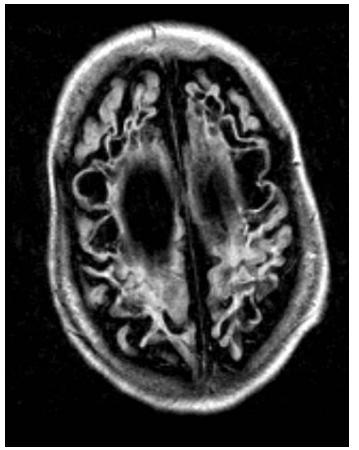
Rondom de ventrikels



Focaal

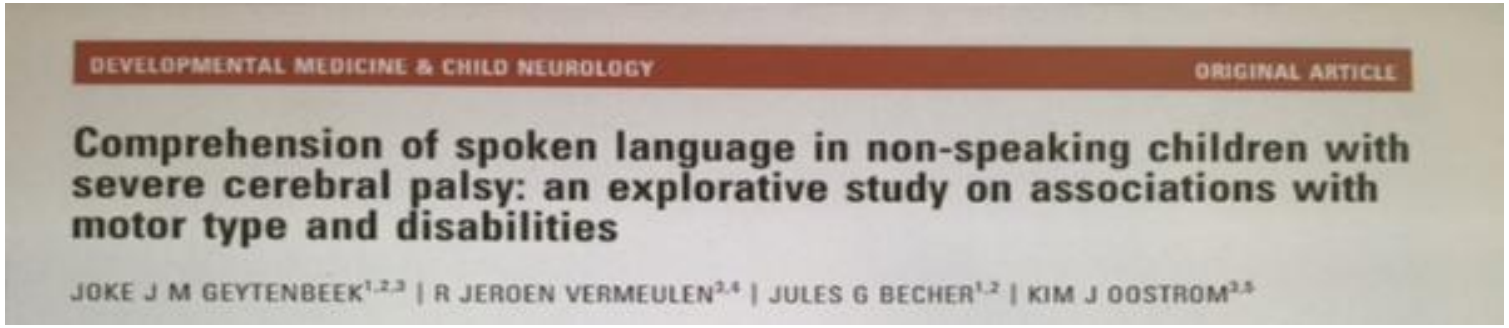


Basale kernen



Globaal

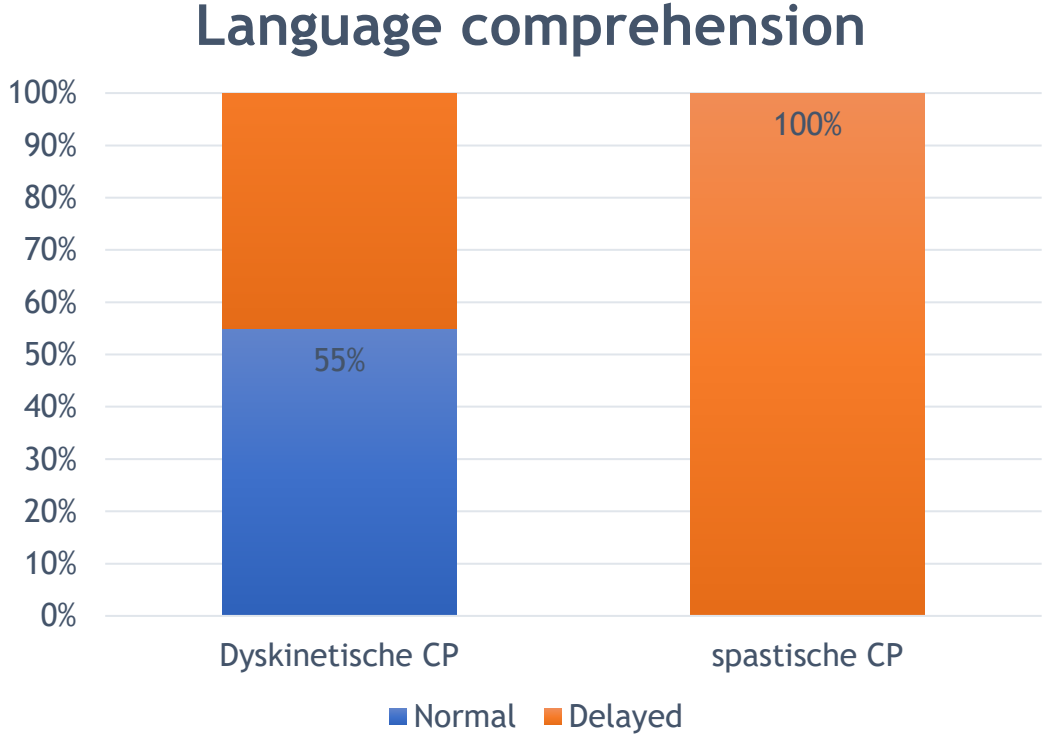
Krageloh-Mann & Horder 2007



87 not speaking children
Gem. lfd: 6;8 jaar (± 2;1 jaar)

GMFCS IV (39%)
GMFCS V (61%)

Spastic CP (54%)
Dyskinetic CP (46%)

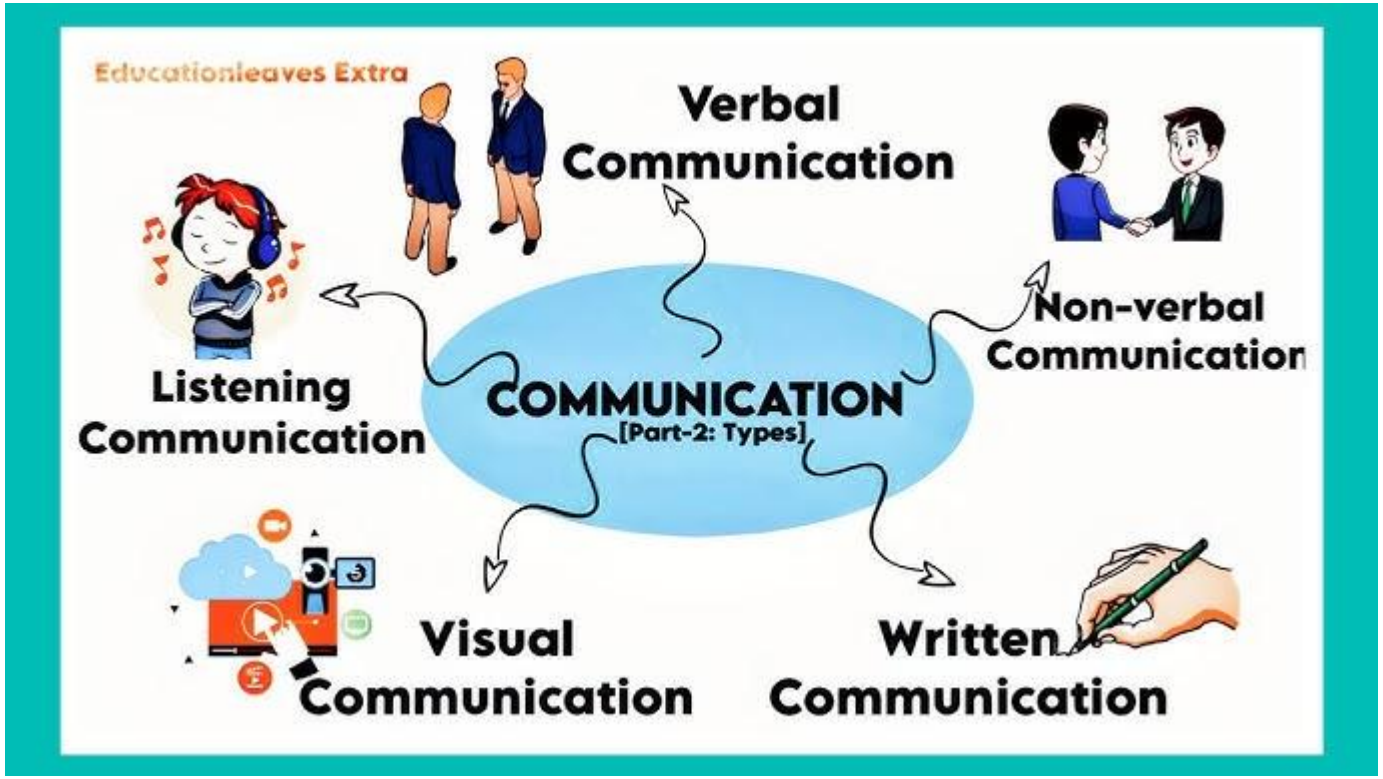


Multidisciplinary approach

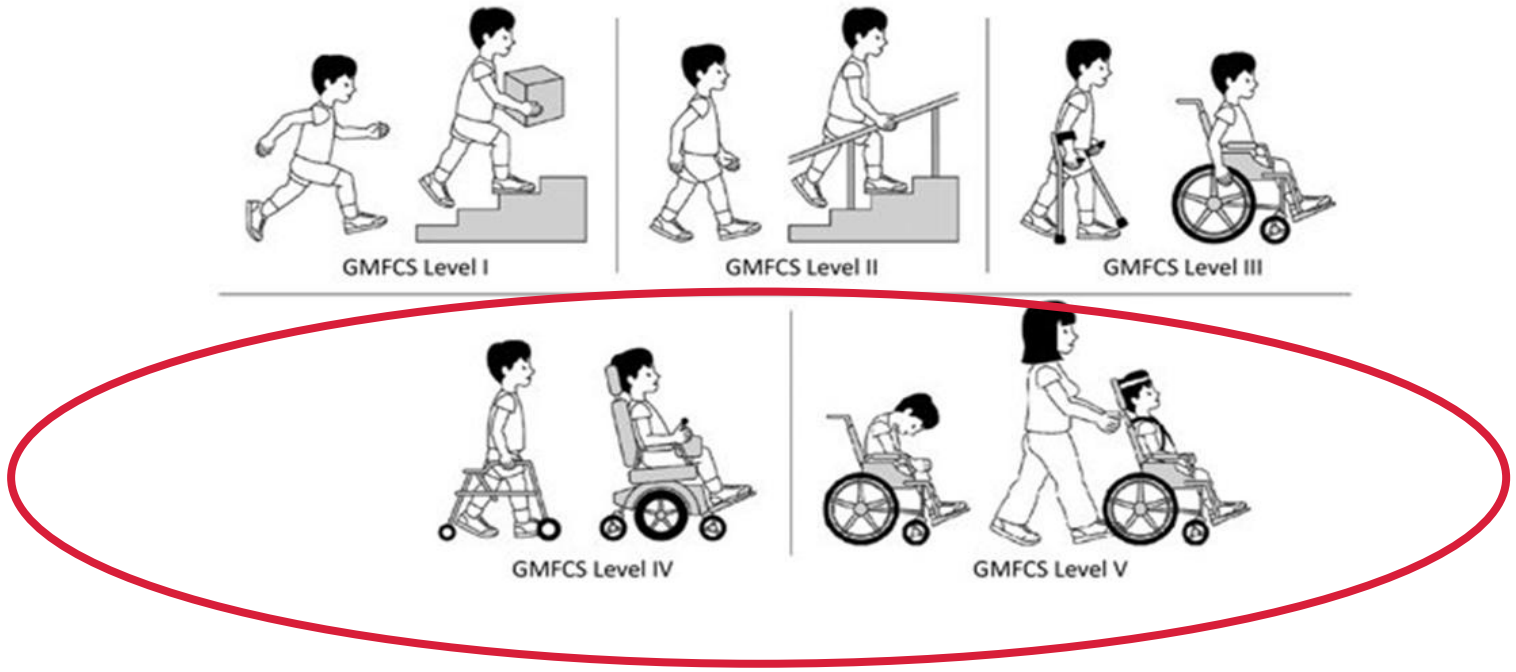
- Pediatric neurology
- Pediatric (neuro) psychology
- Pediatric rehabilitation medicine

Distinction between..

- Language
- Speech
- Communication



Psychometry



25-50%

85-100%

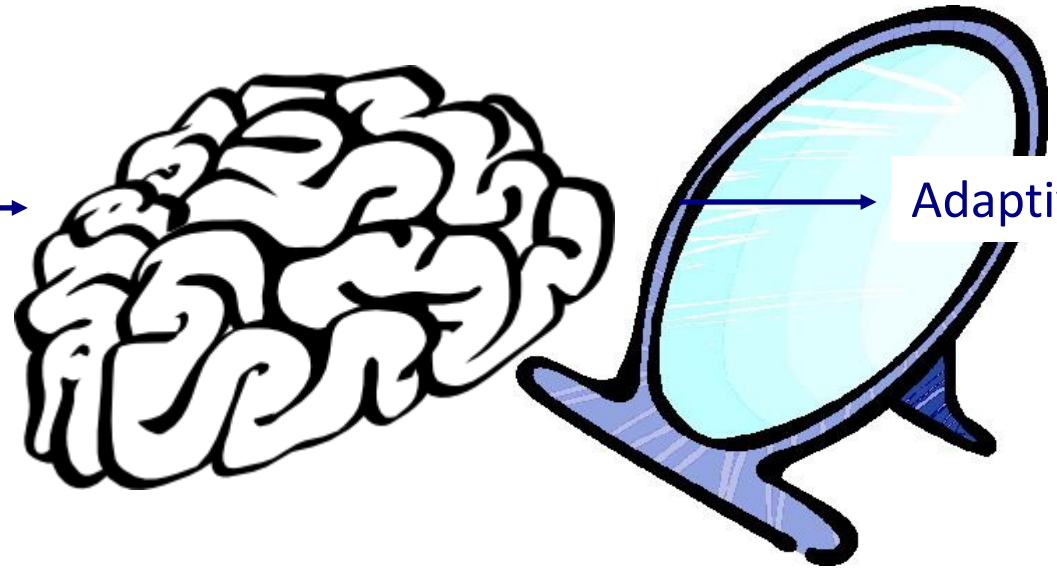
Main question

Communication: central function of our consciousness

feelings

observations

information



Adaptive response

Adaptive Skills = Life skills

Conceptuel skills:
concept of time, money, size etc.

Social skills:
understanding of social conventions

Practical life skills:
understanding of personal care (e.g. to shower, eating, dressing

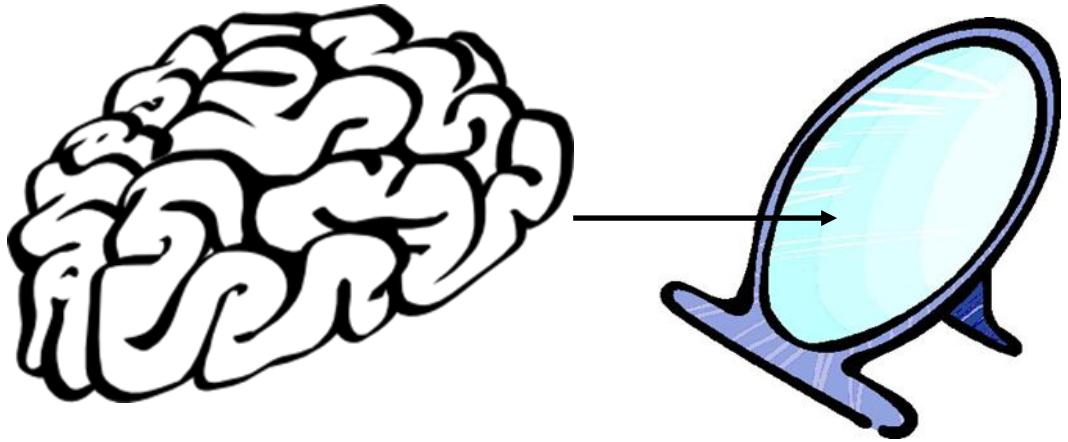
Adaptive capacity

- Two core symptoms of intellectual disability (DSM V):
  - Low IQ
  - Insufficient or low adaptive capacities

Feelings

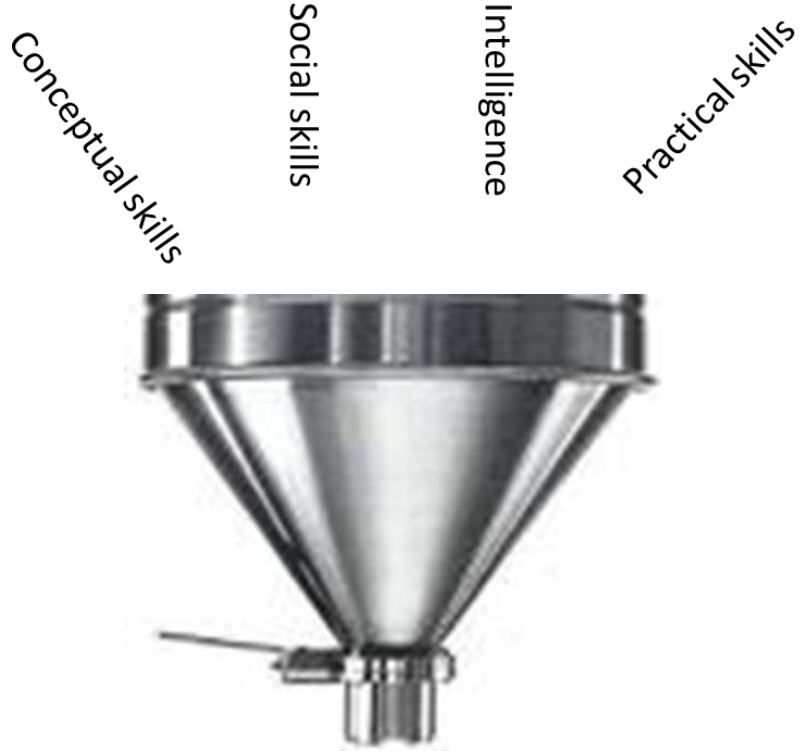
Sensations

Information



Adaptive respons

Diagnostic relevance



Language

Importance for Clinical practice

- *“I have my own method to figure out what a child understands of spoken language”*

- Overestimation
- Underestimation
- Frustration
- Behaviour issues
- Education plan
- Social isolement

How?

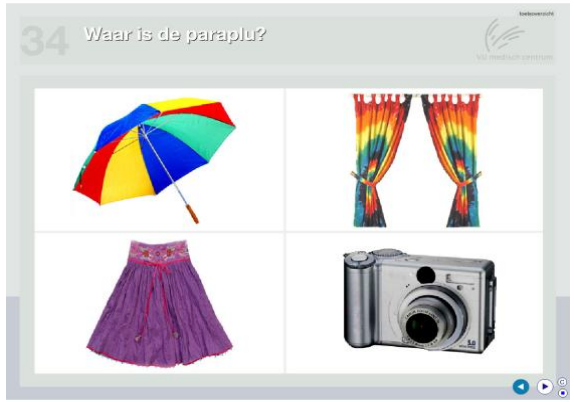
Different parts of the C-BiLLT

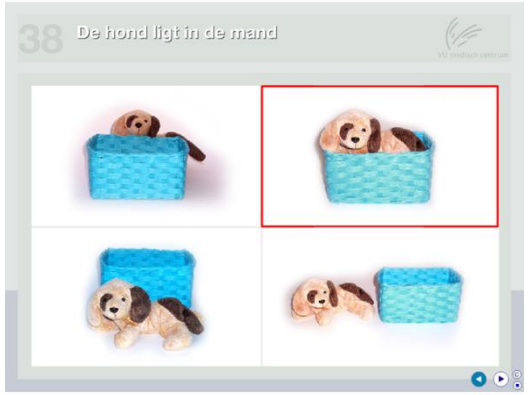
Background C-BiLLT

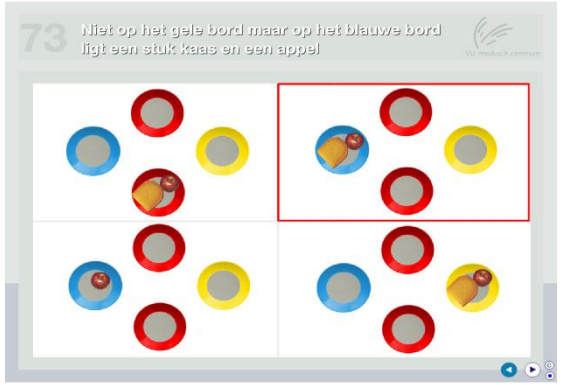
- Objective measure
- Eligible for children with the most severe limited mobility
- All body parts
- Autonomously response
- Images with clear contrast
- Items relevant
- Gradual construction in complexity

Test components C-BiLLT

- Pre-test
- Learning phase A.
- Computertest
- Learning phase B.
- Part 1
- Learning phase C.
- Part 2



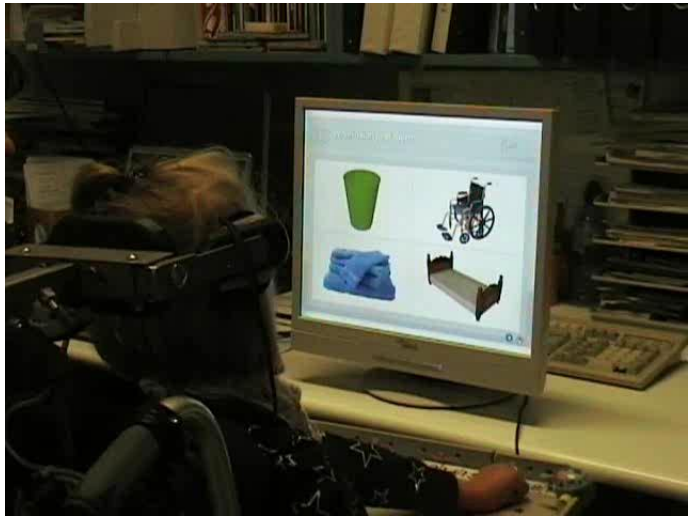




Geytenbeek et al. *Int J Lang Commun Disord*. 2015

Direct selection

Indirect selection



Use & interpretation

Validity and reliability C-BiLLT

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Reliability		
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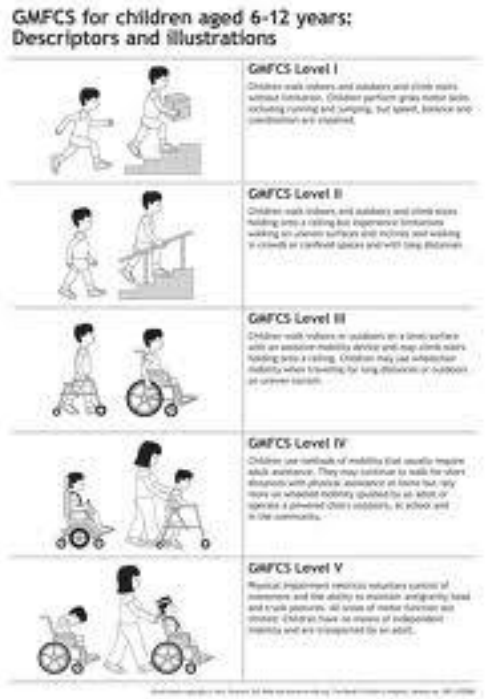
Geytenbeek et al. 2014 Reliability and validity of the C-BiLLT Augment Altern Commun. 2014

Results for many participants

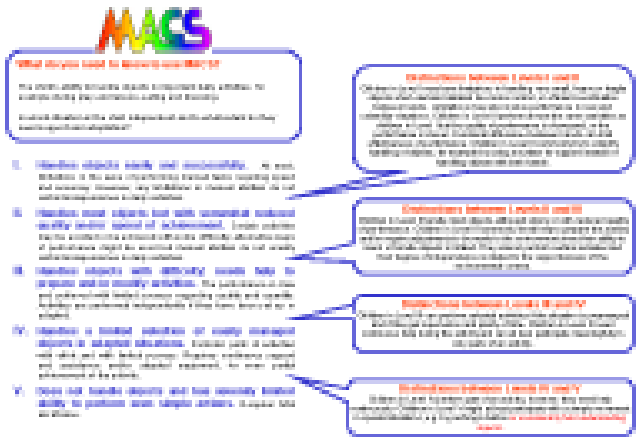
- No earlier test results
- Joint effort with psychology/cognitive assessment
- Pleasure in assessment
- Underestimation/ overestimation
- Confirmative for subjective impression
- Support for parents
- Implications for teachers, educational program

- Baseline assessment for intervention studies

Classification systems



GMFCS

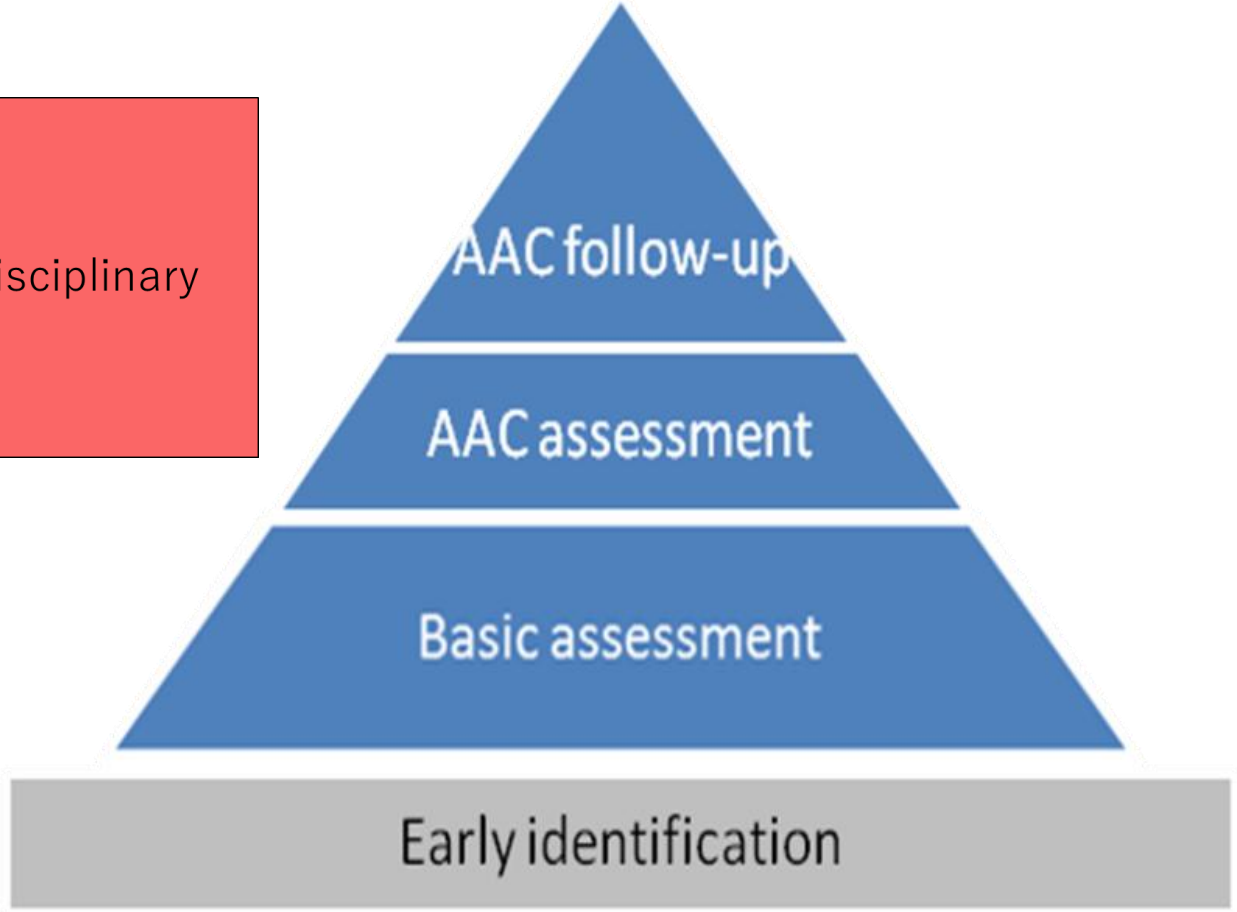


MACS

CFCS

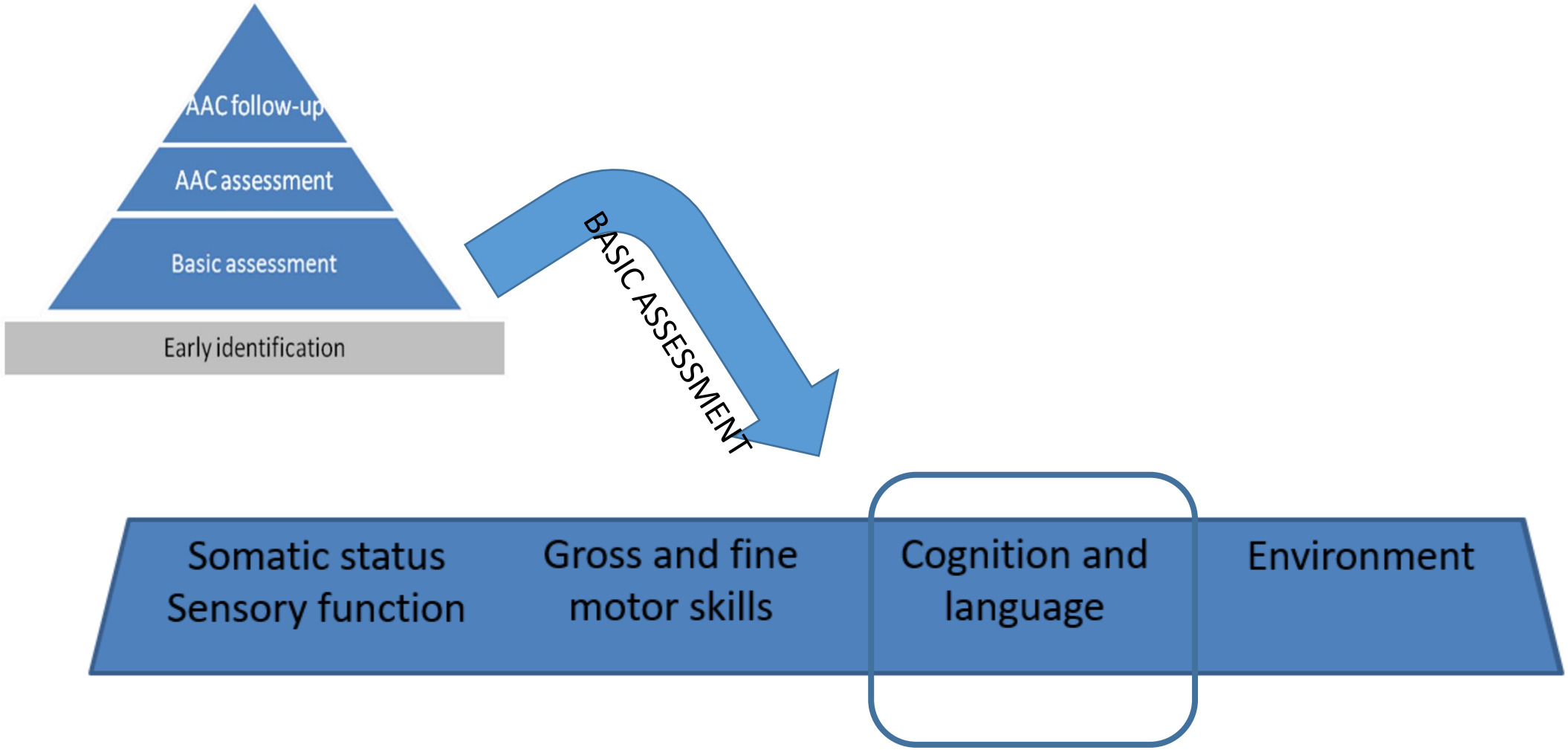
Comprehensive assessment for Augmentative and Alternative Communication

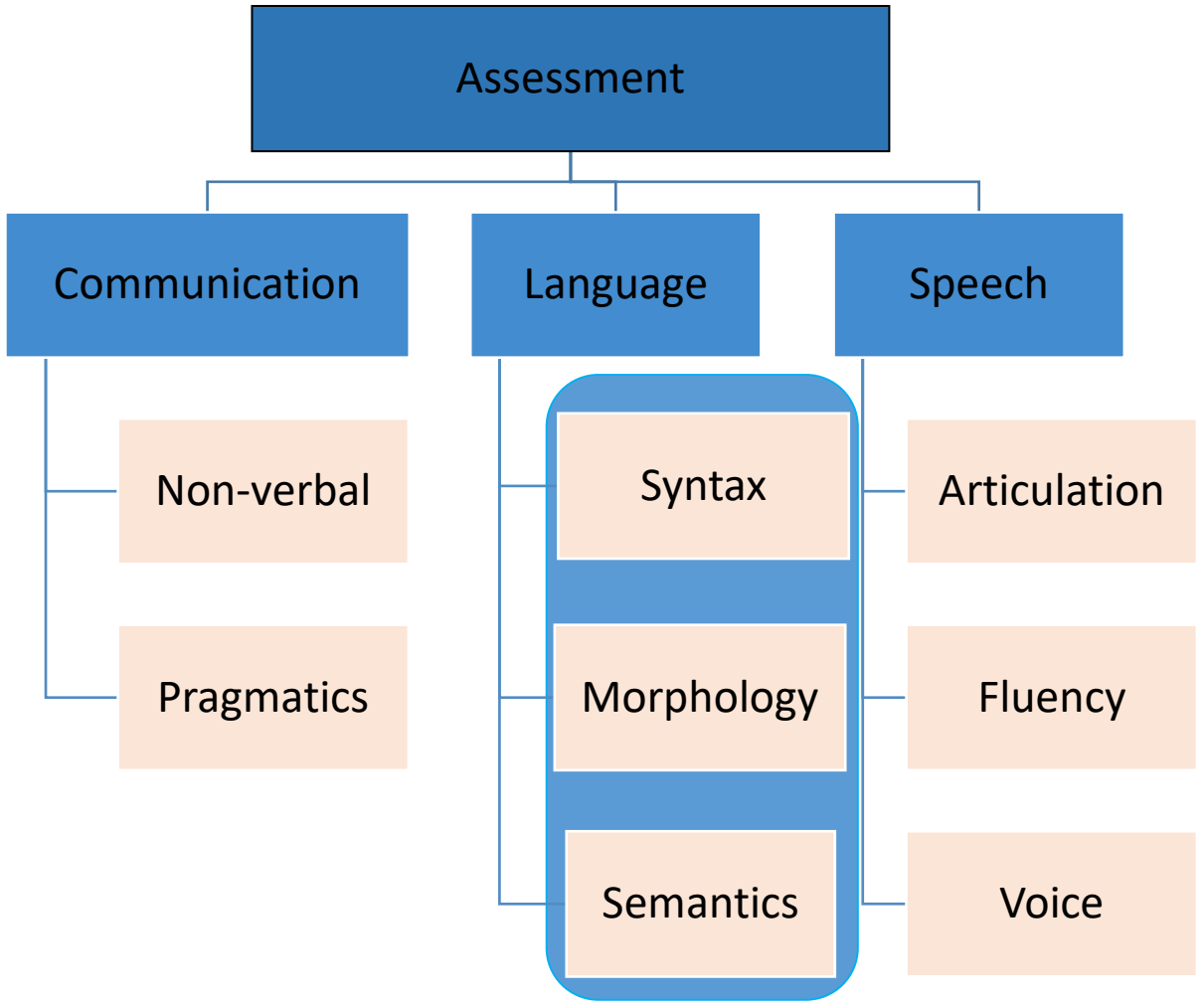
Multifaceted & multidisciplinary



Stadskleiv, 2015

Comprehensive assessment of aided communicators



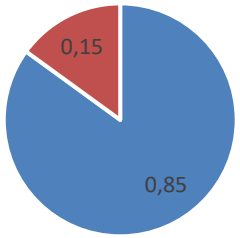


Thapar et al., 2015. Rutter's child and adolescent psychiatry, p. 685

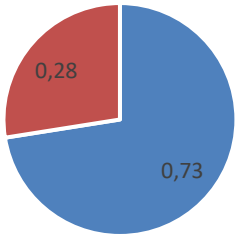
Spastic

GMFCS* level

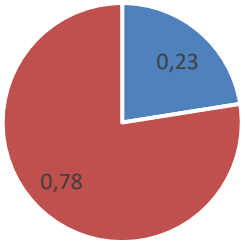
Unilateral



Bilateral;
Diplegia



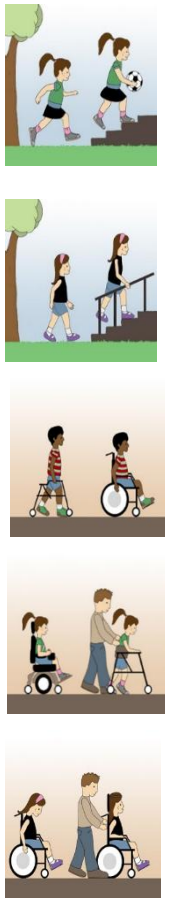
Bilateral;
Quadriplegia



Degree cognitive impairment

% IQ < 70

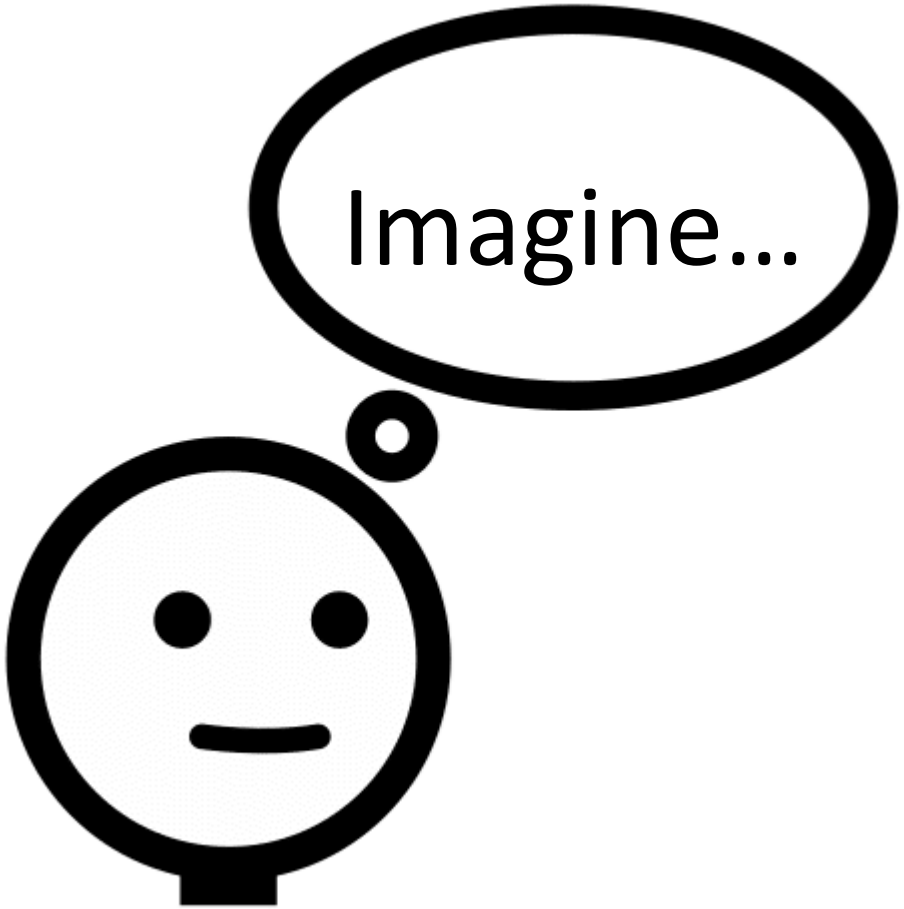
1 ≠ 1



Degree motor impairment

*Gross Motor Function Classification System
(GMFCS; Palisano et al., 1997)
(Stadskleiv, 2020)

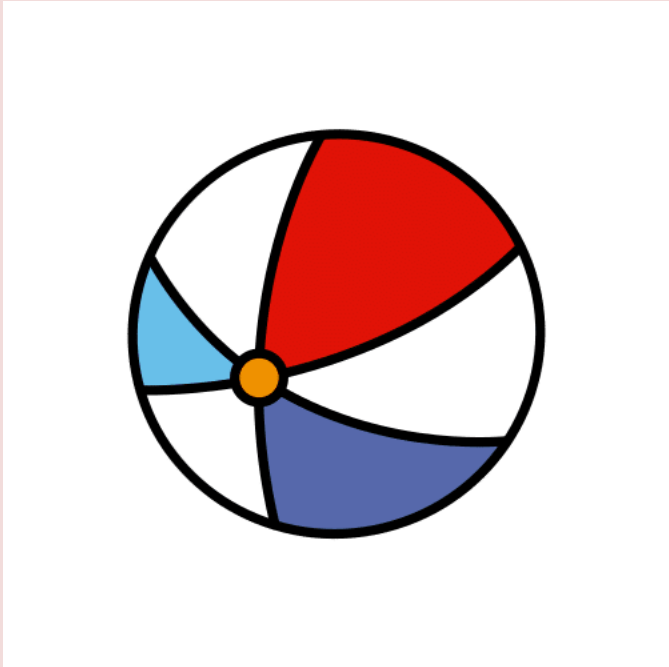
A true story

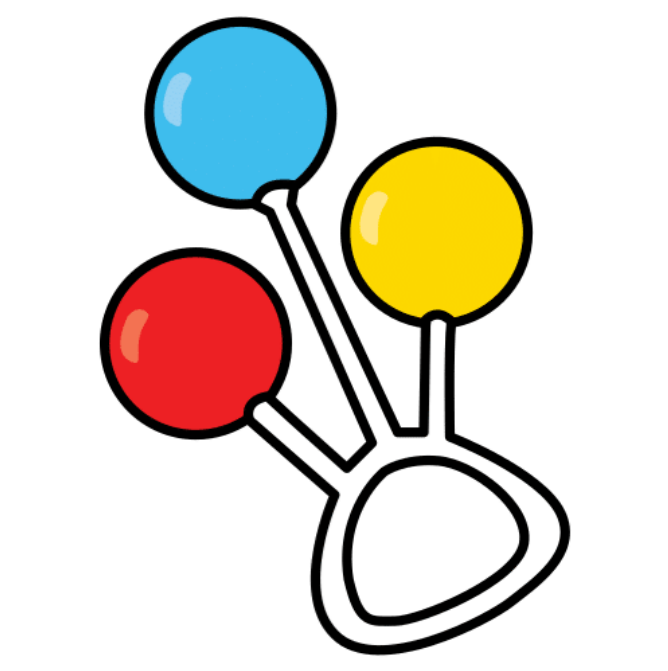


- You are a seventeen year old girl
- You cannot use your voice, nor voluntarily control your hands or legs
- You are able to express your thoughts, ideas and wishes in sentences when your communication device is mounted on your wheel chair
- You do this by controlling the device with your eye gaze

- You started at a new school a little over a year ago
- In the beginning you looked forward to entering secondary education – hoping that you would improve your reading skills, learn more math and learn about society and nature – things that interest you
- Your new teachers did not believe in reading the old reports about your cognition, believing it was better to give you a “fresh start”

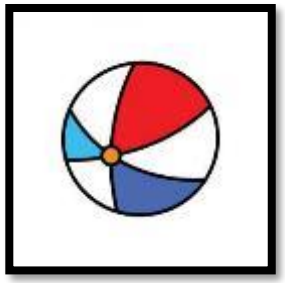
For the past year they have been offering you the choice of playing with

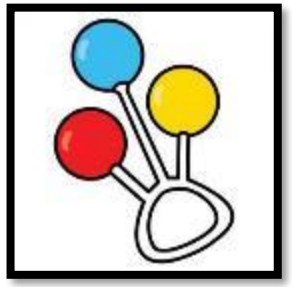




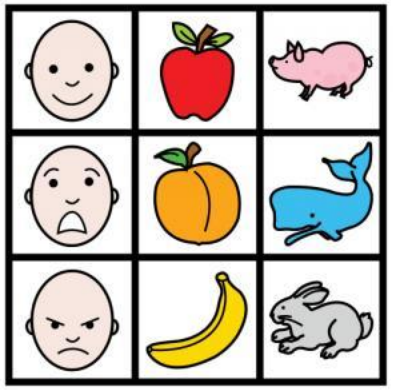
Aided communication

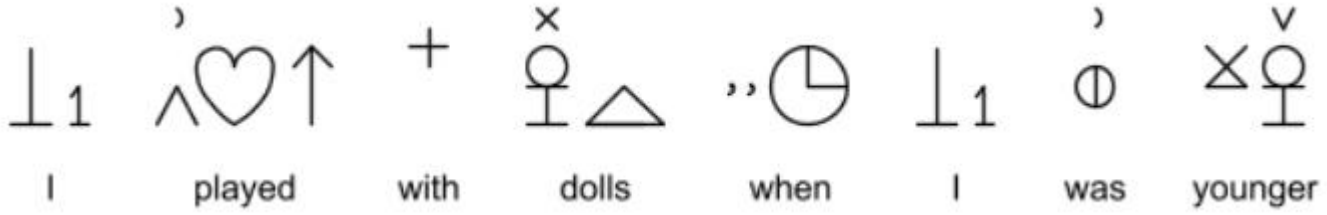
From single-word utterances => grammatically correct complex utterances

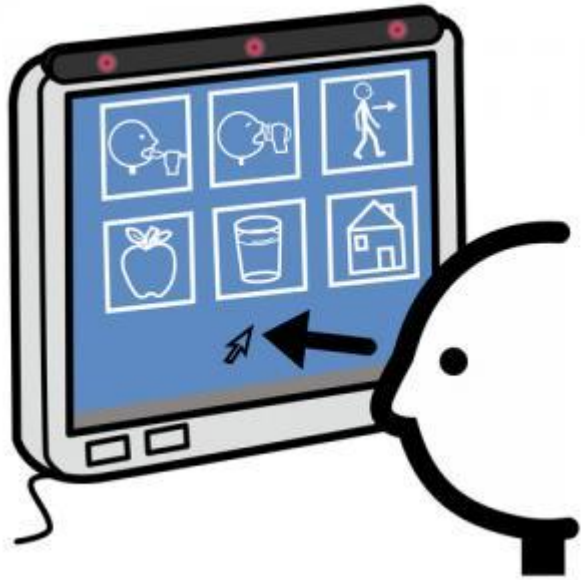




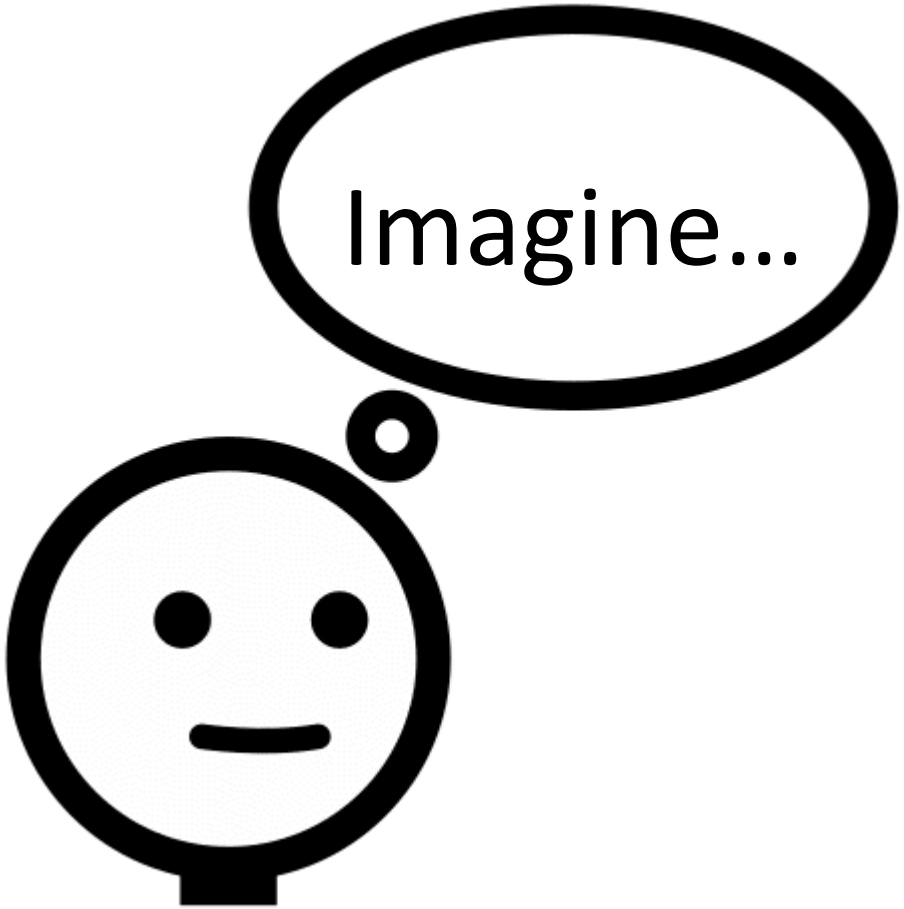
Paper-based & technological aids





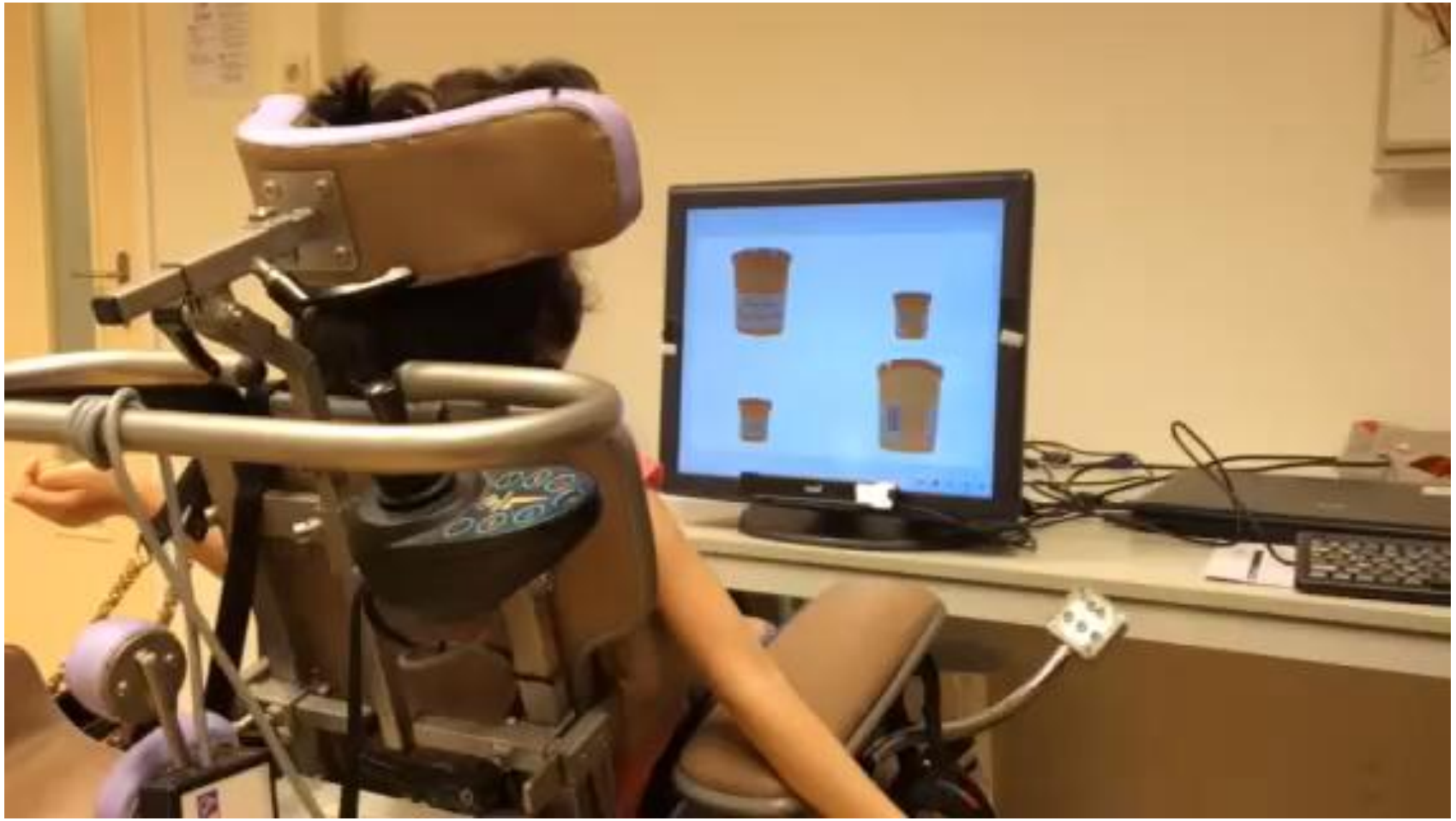


Another true story



- You are a six year old girl
- You cannot use your voice, nor voluntarily control your hands or legs
- You can understand everything what is being said or done
- You are looking a lot with your eyes, which only your mam notices, but doesn’t understand always
- You have a speech device you have to operate with your feet

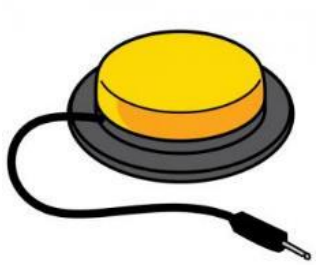
- Your parents are not happy with your speech device
- You have been assessed many times with psychological tests/language test acquiring fine motor skills
- You understood every question but couldn't figure out how to respond
- So, you did NOT respond, feeling frustrated and ANGRY
- Your mother has many doubts if she is over-or underestimating you



Assessment of language comprehension

Should at a minimum include

- Comprehension of spoken words (vocabulary)
- Comprehension of spoken sentences (grammar)



Need assessment tools (tests) which

- cover a wide area of functioning (from toddlerhood to adulthood)
- is normed for the spoken language
- can be answered regardless of degree of speech and motor impairments

Clinical practice

4. Acceptability, Appropriateness, and Feasibility (scale 0-5)

	Netherlands/Belgium (n=79)	Norway (n=9)
Acceptability	4.35 (.62)	4.39 (.24)
Appropriateness	4.08 (.71)	4.16 (.09)
Feasibility	4.07 (.64)	4.33 (.16)

Bootsma, Stadskleiv et al.

Survey users C-BiLLT

Diagnosis	n	(%)	Age	n	(%)	CFCS	n	(%)
Cerebral palsy	80	(26)	< 5 years	64	(35)	I	10	(5)
Down syndrome	32	(10)	6-12 years	66	(36)	II	23	(11)
Rett syndrome	28	(9)	13-17 years	28	(15)	III	50	(24)
Angelmann syndrome	19	(6)	> 18 years	27	(15)	IV	73	(34)
Language disorder	50	(16)				V	53	(25)
Syndrome other than listed	22	(7)						
Intellectual or developmental	17	(5)						
disability								
Autism spectrum disorder	16	(5)						
Other (*e.g., Acquired brain*	13	(4)						
injury, metabolic, muscle or								
mitochondrial diseases)								
Unknown	35	(11)						

Summary & questions

- C-BiLLT fills a gap in assessment needs for children & (young) adults with CCN
- C-BiLLT fulfills a need for other diagnosis groups
- Translation & cultural adaptations are easy to execute
- Reliability and validity for translated versions show excellent results
- Parents/caregivers/professionals have waited for this
- Scientifically sound

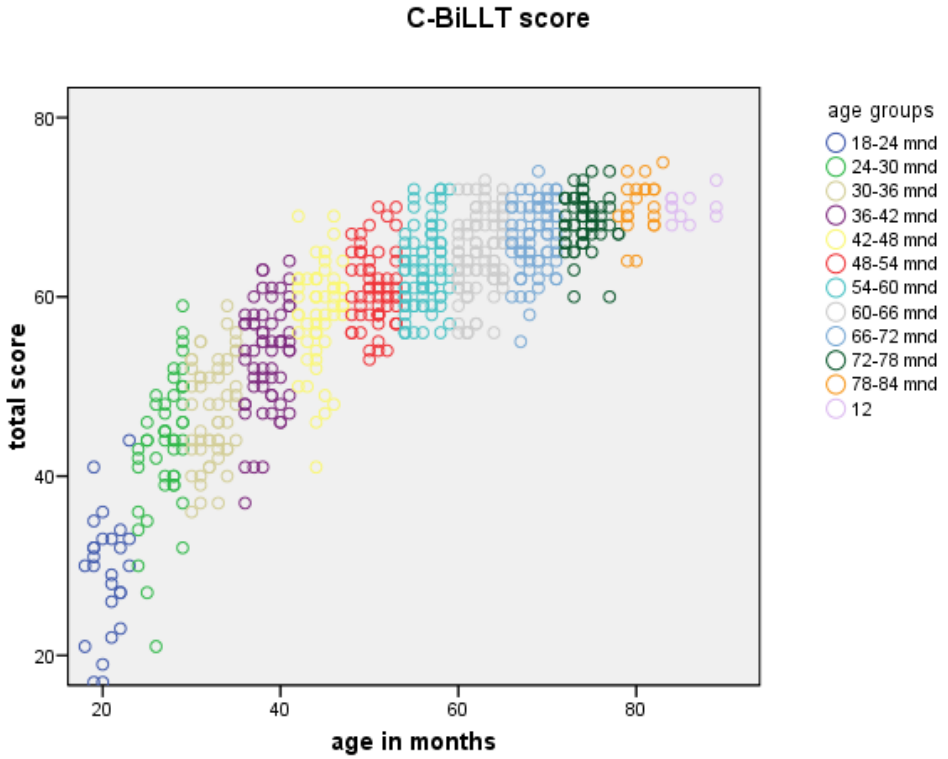
- Funding is necessary
- Implementation & maintenance ask for constant monitoring
- Data collection necessary
- Training is key to guarantee standardized assessment
- Technical equipment and use can be a challenge

C-BiLLT
Computer-Based instrument for Low Motor Language Testing

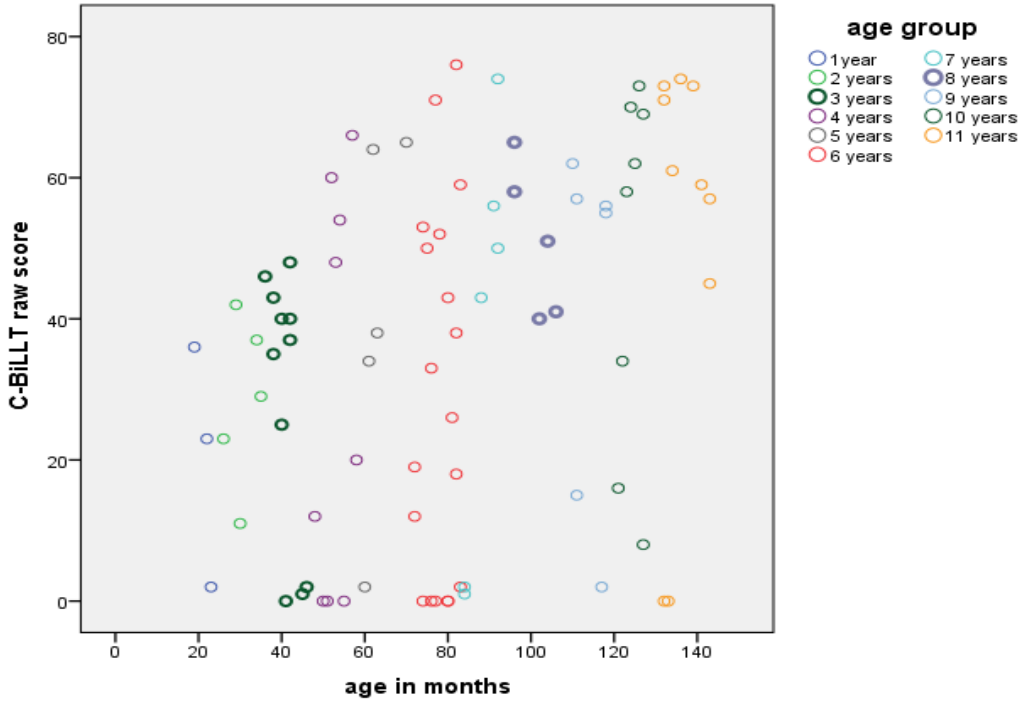
www.c-billt.com

C-BiLLT testresults

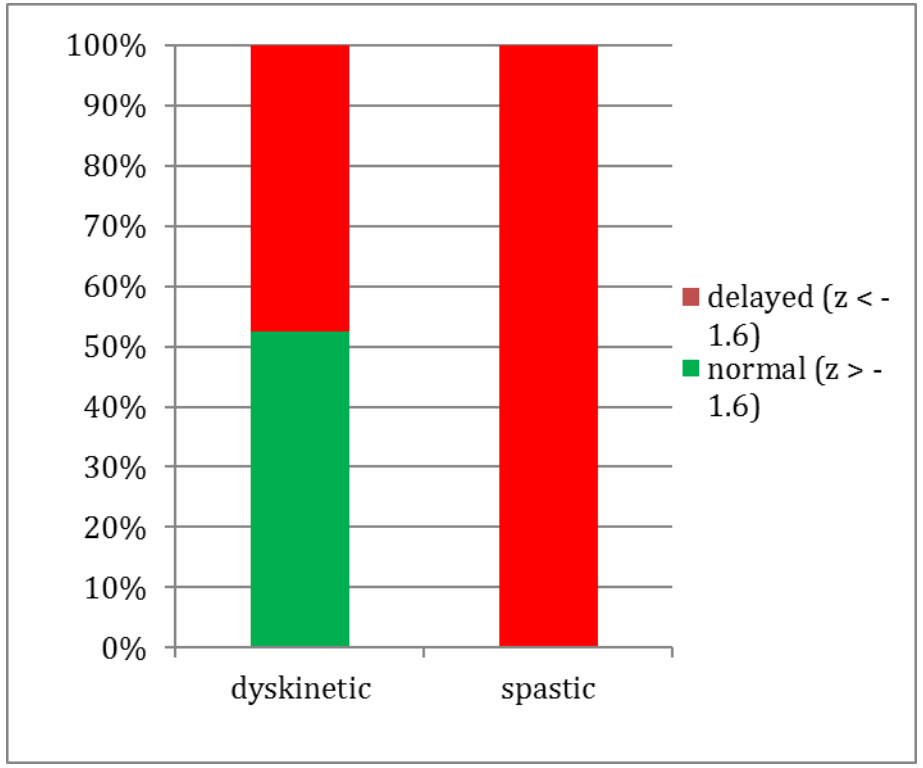
TD children



Children with CP



Interpretation testresults



- GMFCS IV: n=34
- GMFCS V: n=53

- Spastic: n=47
- Dyskinetic: n=40

p = < 0.001

p = 0.031

C-BiLLT in Europe and overseas

- Initial implementation efforts: journal publications, conference presentations, and professional training

- **The Netherlands and Belgium**
  - Released in 2015, now adopted in multiple contexts
  - 300+ clinicians trained
  - C-BiLLT now included in recent Dutch practice guidelines
- **Norway**
  - Released in 2019
  - 150+ clinicians trained (2019-22)
  - **Sweden**
  - Translation and adaptation complete, validation ongoing
- **Slovenia/Rumania**
  - Translation and adaptation complete, validation ongoing
- **Germany, UK/Ireland**
  - Validation almost completed
- **Italy/Spain/ France**
  - Translation and adaptation, seeking funding for validation

- **The United states of America**
  - Adapted the Canadian version
  - implementation traject
- **Canada**
  - Validation completed
  - Implementation throughout the provinces

- **Brasil**
  - Translation and adaptation, seeking funding for validation

- **Mexico**
  - Translation and adaptation, seeking funding for validation

Take home message

White matter damage has a major effect on language comprehension in children with severe CP

Nonspeaking or unintelligible children deserve objective and reliable assessments to reveal both under-or overestimation

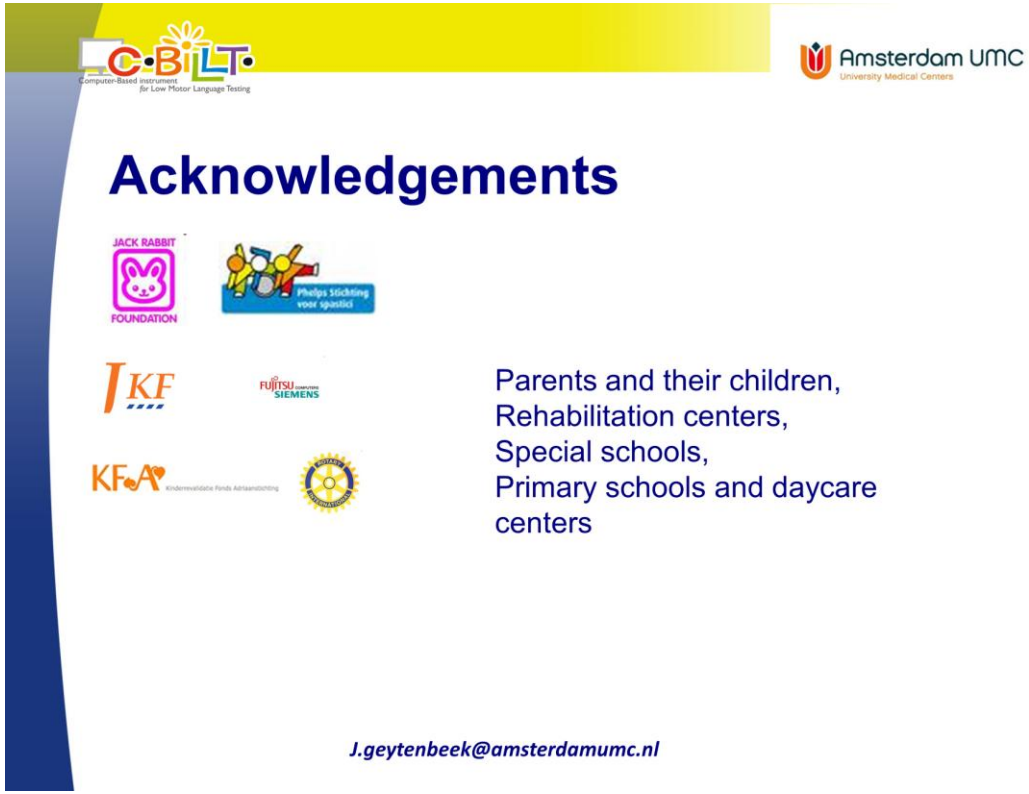
Not able to speak, does not mean ……not able to understand!

Functional mobility (GMFCS) is **not** associated with development of spoken language comprehension and functional communication

Language assessment may be a more reliable option in children with severe CP and representative for the child’s cognitive skills

Keep in mind the heterogeneity of the CP population

Questions?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