The communicative development of children and young adults with severe multiple disabilities

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The project

- Context: longitudinal study, children and young adults with severe multiple disabilities

- Goal: describing communicative development, broad perspective, focus on language

- Today: communicative development based on assessments October 2012, May 2013 and March 2014
Severe multiple disabilities

- Problems with:
  - speech and communication
  - cognition
  - motor function
  - sensory awareness
  - behavior

Nakken & Vlaskamp, 2002
Severe multiple disabilities (SMD)

- Estimated prevalence worldwide
  - 110 – 190 million (2.2 – 3.8%)
- Examples
  - Cerebral palsy
  - Rett syndrome

Language learning requirements

- Perception of short sounds
- Attention for these sounds
- Ability to use symbols and invent syntax
- Enough processing capacity to do this simultaneously

Johnston, 1991
Difficult for individuals with SMD

- Perception of short sounds
  - impaired sensory awareness
- Attention for these sounds
  - behavioral problems
- Ability to use symbols and invent syntax
  - poor cognition and motor function
- Enough processing capacity to do this simultaneously
  - after compensating for the other disabilities
Which skills are impaired?

<table>
<thead>
<tr>
<th>Skill</th>
<th>impaired (%)</th>
<th>unimpaired (%)</th>
<th>unknown (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perception</td>
<td>89.5</td>
<td>0.0</td>
<td>10.5</td>
</tr>
<tr>
<td>Attention</td>
<td>47.4</td>
<td>5.3</td>
<td>42.1</td>
</tr>
<tr>
<td>Memory</td>
<td>84.2</td>
<td>15.8</td>
<td>0.0</td>
</tr>
<tr>
<td>Motor Function</td>
<td>100.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Understanding language</td>
<td>42.1</td>
<td>26.3</td>
<td>31.6</td>
</tr>
<tr>
<td>Producing language</td>
<td>89.5</td>
<td>0.0</td>
<td>10.5</td>
</tr>
</tbody>
</table>

What does the communicative development of children and young adults with severe multiple disabilities look like?
Communication and development of individuals with SMD

• Pre-symbolic communication\(^1\)
  - body language, facial expressions, eye gaze and (unconventional) manual gestures

• Early cognitive stage of development
  - no large effect of chronological age\(^2\)

1. Olsson, 2006
2. Axelsson, Granlund & Wilder, 2013; Granlund, 1993
Symbolic communicators with SMD

- (Limited) spoken and/or gestured language
- TD: developmental milestones for spoken and gestured language are comparable\(^1\)
- Gestured language facilitates language learning and compensates limitations in spoken language\(^2\)

1. Bates & Dick, 2002
2. Capone & McGregor, 2004
Methodology

How to assess communicative development in individuals with severe multiple disabilities?

1. Tests
Receptive vocabulary

Receptive One Word Picture Vocabulary Task:
Brownell, 2000
Expressive vocabulary
Auditory discrimination
2. Questionnaires

- Receptive vocabulary$^{1,2}$
- Expressive vocabulary$^1$
- Emergent literacy$^3$

1. McArthur-Bates Communicative Development Inventory: Fenson, Dale, Reznick, Bates, Thal, Pethick, Tomasello, Mervis and Stiles, 1994
2. Lexilijst for Language Comprehension: Schlichting and lutje Spelberg, 2007
3. Bridge: Pierce, Summer and O'deKirk, 2009
Participants – skill-based groups

• pre-symbolic communicators (N=16/38)

• symbolic communicators (N=22/38)
  - spoken language users (N=8/38)
  - gestured language users (N=7/38)
  - both spoken and gestured language users (N=7/38)
Pre-symbolic communicators

• No significant progress or regression between assessments on any test or questionnaire.
  – Not unexpected

• Mainly floor-level scores with some outliers.

• Tests/questionnaires not suitable for target group.
  – criterion- instead of norm-referenced?
Receptive vocabulary test
Symbolic communicators

Score (%)

Assessment moment

170 items
Expressive vocabulary test
Symbolic communicators

Score (%)

Assessment moment

170 items
Auditory discrimination test
Symbolic communicators

20 items
Receptive vocabulary questionnaire
Symbolic communicators

Score (%)

Assessment moment

720 items
Receptive vocabulary questionnaire

Assessment moment

Score (%)

Gestures 3: 216 words – 648 words
Expressive vocabulary questionnaire

Symbolic communicators

Score (%)

Assessment moment

1

3

720 items
Expressive vocabulary questionnaire

Speech 1: 11 words → 169 words
Emergent literacy - Reading
Symbolic communicators

max = 18 points
Emergent literacy - Writing
Symbolic communicators

max = 18 points
Emergent literacy - Phonological awareness

Symbolic communicators

max = 12 points

Assessment moment
Discussion

- Presymbolic: floor level

- Symbolic: limited data, no change
  - Clinically relevant
Participants – age-based groups

- 2-6 years of age (N=14/38)
- 6-12 years of age (N=13/38)
- 12-24 years of age (N=11/38)

- Effect of chronological age?
Receptive vocabulary test
2-6 year olds
Auditory discrimination test
2-6 year olds

Score (%)

Assessment moment

1 2 3
Receptive vocabulary test
6-12 year olds

Score (%) vs. Assessment moment
Auditory discrimination test
6-12 year olds
Receptive vocabulary test
12-24 year olds

Score (%)

Assessment moment

1  2  3
Auditory discrimination task
12-24 year olds
Discussion

• Significant developmental progress in age group 2-6 on receptive vocabulary and auditory discrimination.

• No effects in later age groups.
  - critical age?
Communicative development of individuals with SMD

• Much variability
  – clinically relevant improvement at case level possible

• Groups or case studies?

• Tests and questionnaires or other observation instruments?
Conclusion

- Broad perspective on communication of SMD necessary to describe development
  - language, communicative competence/intention
  - attention, perception, memory, motor function
Questions?

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I cannot talk...
but I want to communicate!

Weighted selection
Augmentative and Alternative Communication aids
RAAK-PRO