



**To get things done,
the challenge in everyday life
for children with spina bifida.**

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reg OT PhD
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*”I am sure he can do
it, it is somehow just
never done”*



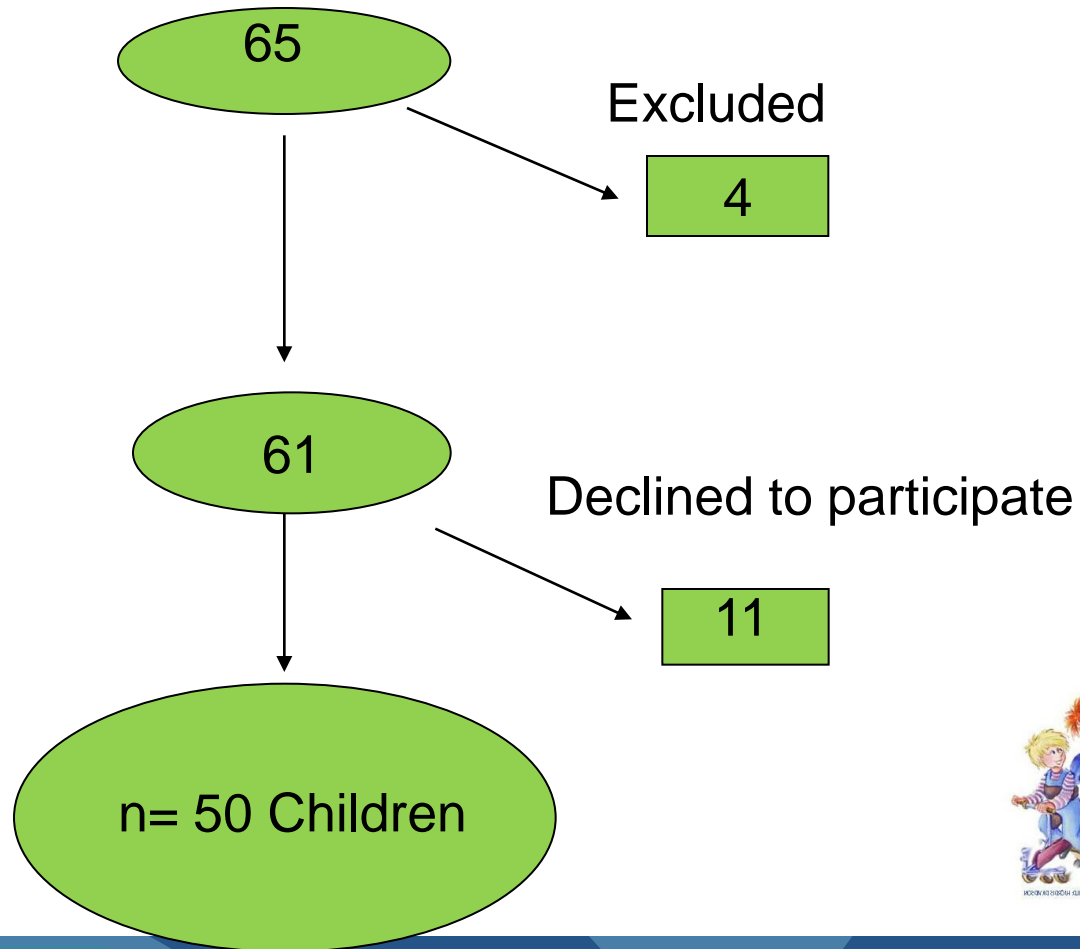
Knowledge base on spina bifida from an ICF perspective

- Participation restrictions -only 1/3 totally independent (Oekshott 2003, Bordous 2008, Barf 2009) often explained as due to motor- dysfunction, overprotective parents or inexperience.
- **Activity limitations**
- Motor dysfunction, bowel and bladder dysfunctions .
Modal cognitive profile — (Dennis 2010, Fletcher 2009)
- Hydrocephalus but also massive brain reorganisation (Martinez et al 2009, Chao et al 2010)
- Combination of folic acid and genetical factors and environmental factors (Juraneck et al 2010)



Participants

All Children born in 1993-1999 with spina bifida living in western Sweden
(1/4 of the Swedish population) on Dec 31, 2006
Aged 6-14 years



Quality of performance of everyday activities in children with spina bifida; a population based study.

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Gothenburg Acta Paediatrica 2009;98:1674-1679



Aim and method

- Investigate the quality of the performance of everyday activities in children with spina bifida.
- Assessment of Motor and Process Skills (AMPS)
Observational evaluation of performance skills, results in two measures:
 - ADL - motor ability
 - ADL - process ability

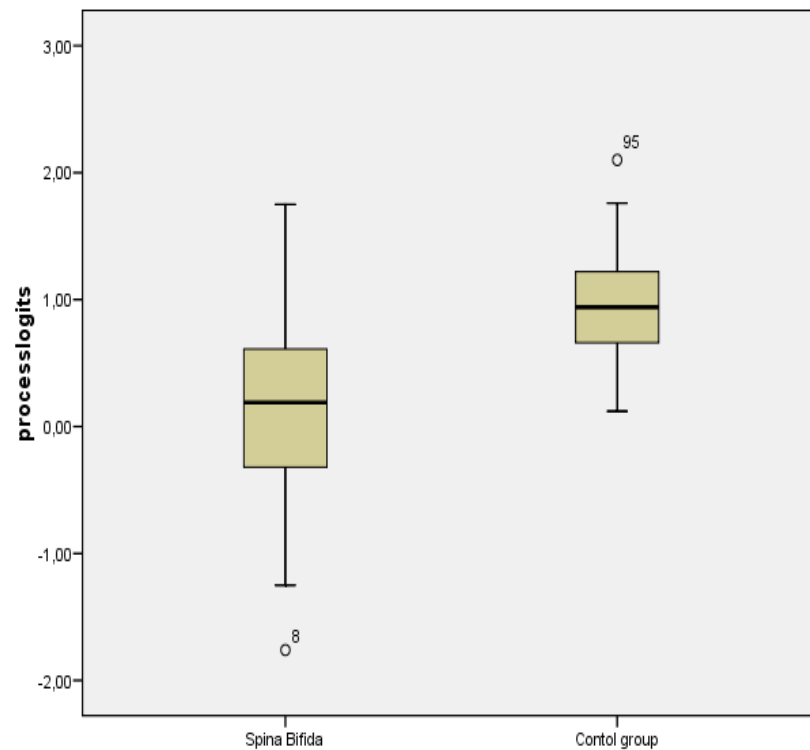
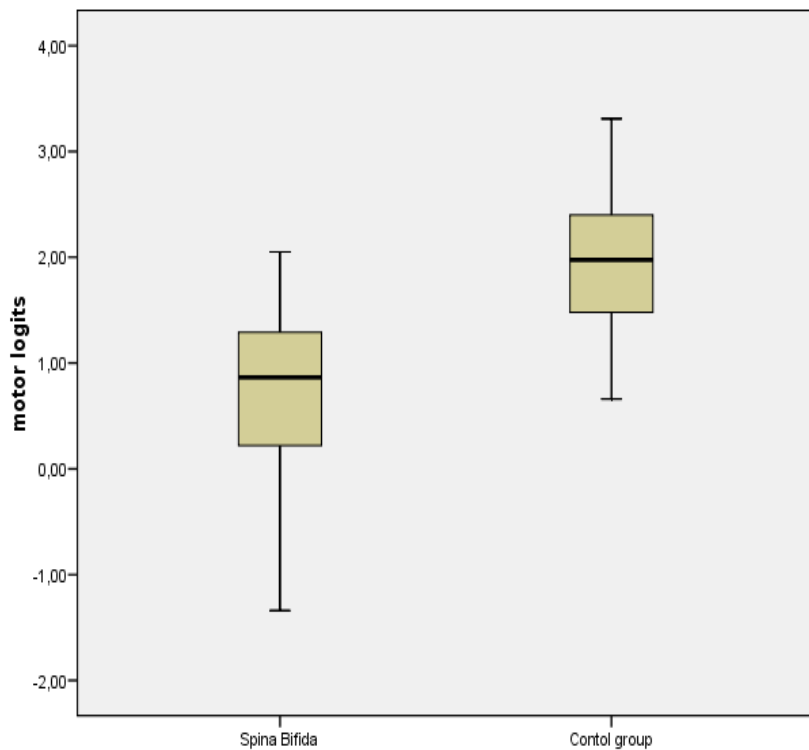


Results

- **ADL-motor ability; 60%** under age expectations (below 2SD)
- **Motor skills** often hard to accomplish were to place one self, to reach and to calibrate force
- **ADL-process ability; 48%** under age expectations (below 2SD)
- **Process skills** often hard to accomplish were to accommodate and to adjust for problems, to initiate new steps and to ask



RESULTS



Conclusions

- Most children with spina bifida have difficulties performing even well-known and self-chosen activities in an efficient and independent way.
- Strategy: To ASK



Is autonomy related to the quality of performance of everyday activities in children with spina bifida?

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Aim

To investigate the relationship between the level of autonomy and the quality of performance of everyday activities, in children with SB, and to study the agreement between the children's and the parents' ratings of autonomy



Methods

The child's level of autonomy was rated both by the children and their parents (separately) with a Swedish version of the "Autonomy Scale" (ARC)

- Analysis of agreement (PA, Kw, Sigttest)
- Analysis of the relationship between the autonomy levels and the child's age, motor skills and process skills from the AMPS assessment (binary logistic regression)



Results

Children with SB had low levels of autonomy in **goal-related activities**

There was **little agreement** between children and parents concerning the child's level of autonomy.

Low levels:

- Routine/personal care (Pack ones gym-bag)
- Interacting with the environment (being in time to meet friends)
- Personal expression (choosing)

High level:

- Recreational and leisure (what I do during leisure is my own choice)



Results

Process skills had the most striking relation to the autonomy level of the child with SB. Motor skills also had a significant, and for some items, a strong relation to the autonomy level.

Age had a moderate relation to autonomy.



Patterns of participation in school-related activities and settings in children with spina bifida

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Submitted



- **Aims:** To evaluate the patterns of participation in school and to explore how the child's performance ability were related to his/her level of active participation at school
- **Methods:** Frequency of participation in school-related activities, was rated both by the children and their teachers with the "Availability and Participation in School scale" (Simeonsson et al 2001)
- The level of active involvement/participation in school, rated by the teachers with the School Function Assessment (SFA) (Coster et al 1998)
- The relationship between the teacher's rating on the SFA and the child's motor and process skills measured with AMPS was analysed



Results

Frequencies of participation

- Always participate in all activities except for pupil's – councils, i.e “they are there”

Level of active participation

- On SFA 89.6% of the teachers rated the children's level of **active** participation as restricted.

Relationship active participation vs. performance skills:

- Significant relation between both motor and process skills and active participation



Conclusions of the thesis

Difficulties with getting things done, to initiate and to solve problems (i.e process skills) effect the child's autonomy development and school participation. Low process skills is probably more hindering for the child with spina bifida than motor dysfunction .



“Take-home message”;

- Don't just wait for them to catch up
- Learn how to get things done, by focusing on their process skills
- Important to get the **JUST RIGHT** support



Thesis; To get things done, the challenge in everyday life for children with spina bifida

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Table 1: Demographic characteristics of the study group of children with spina bifida and non- participants.

	<i>Study group</i> <i>n=50</i> <i>n (%)</i>	<i>Non participants</i> <i>n=11</i> <i>n (%)</i>	<i>p-value</i>
Gender			
Female	24 (48)	4 (36)	ns
Male	26 (52)	7 (63)	ns
Age			
Mean, years: months	10:5	10:8	ns
Range, years	6-14	6-13	
Hydrocephalus			
Shunted (HC+)	39 (78)	7 (64)	ns
Not shunted (HC-)	11 (22)	4 (36)	ns
Type of SB			
MMC	45 (90)	8 (73)	ns
Lipo-MMC	5 (10)	3 (27)	ns
Ambulation (Hofer)			
1- in community	23 (46)		
2- in household	7 (14)		
3 - for training, non-functional	8 (16)		
4 - non-ambulator	12 (24)		
School form			
Mainstream school	41 (82)		
Special education	5 (10)		
Preschool	4 (8)		
Additory diagnosis			
Epilepsy	3 (6)		
Cerebral palsy	1 (2)		
ADHD	1 (2)		
Corpus callosum malformation	1 (2)		

