

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

## **Quality of performance, autonomy and participation**

Akademisk avhandling

som för avläggande av medicine doktorsexamen vid Sahlgrenska akademien vid Göteborgs Universitet  
kommer att offentligen försvaras  
i hörsal Arvid Carlsson Medicinargatan 3, Göteborg  
fredagen den 16 september 2011 kl. 9.00

Av  
Marie Peny-Dahlstrand  
Leg. arbetsterapeut

Fakultetsopponent:  
Professor Wendy Coster  
Department of Occupational Therapy, Boston University,  
College of Health and Rehabilitation Sciences, Sargent College, Boston MA, USA

Disputationsakten kommer att hållas på engelska

Avhandlingen baserar sig på följande delarbeten:

- I. Marie Peny-Dahlstrand, Anne-Christine Åhlander, Lena Krumlinde-Sundholm, Gunilla Gosman-Hedström  
**Quality of performance of everyday activities in children with spina bifida: a population-based study**  
Acta Paediatr 2009;98:1674-1679
- II. Marie Peny-Dahlstrand, Gunilla Gosman-Hedström, Lena Krumlinde-Sundholm,  
**Are there cross-cultural differences of ADL ability in children measured with the Assessment of Motor and Process Skills (AMPS)?**  
Scand J Occup Ther 2011; Feb 25 [epub ahead of print]
- III. Marie Peny-Dahlstrand, Lena Krumlinde-Sundholm, Gunilla Gosman-Hedström  
**Is autonomy related to the quality of performance of everyday activities in children with spina bifida?**  
Accepted for publication in Disabil Rehabil 2011
- IV. Marie Peny-Dahlstrand, Lena Krumlinde-Sundholm, Gunilla Gosman-Hedström  
**Patterns of participation in school-related activities and settings in children with spina bifida; a population based study.**  
Manuscript 2011

Göteborg 2011



UNIVERSITY OF GOTHENBURG

# Abstract

The overall **aim** of this thesis was to increase knowledge of the quality of performance of everyday activities, autonomy and participation in children with spina bifida (SB) and to explore how they relate to each other.

**Methods:** In *Study I*, the quality of performance of everyday activities in 50 children with SB (of the 65 in a population-based cohort) aged 6 to 14 years was assessed with the Assessment of Motor and Process Skills (AMPS). Their ability measures were compared with international age norms and with the ability measures from a control group of typically developed Nordic children. In *study II*, the cross-cultural differences in the ADL motor and process ability measured with the AMPS between children from the Nordic countries, (n=2374), and from North America (n= 2239), aged 3-15 years, without known disabilities were analysed using a two-way ANOVA. In *Study III* the autonomy levels of the 50 children with SB were rated both by the children themselves and by their parents. The agreement between the children's and the parents' ratings was analysed, and the relationship between the autonomy levels and the child's age, motor and process ability measures from the AMPS assessment in study I was analysed with binary logistic regression. *Study IV:* The frequency of participation in school-related activities in the 50 children with SB was rated both by the children themselves and by their teachers (in 48/50 cases). The teachers also rated the children's level of active participation using the School Function Assessment (SFA). The relationship between the children's level of active participation and their motor and process ability measures was analysed with binary logistic regression.

**Results:** The majority of the children had difficulties performing well-known everyday activities in an effortless, efficient, safe and independent way, demonstrated by low ADL motor- and process ability measures. This deficient quality of task performance, in particular the process skills, was strongly related to both their level of autonomy in daily life and their level of active participation in school. The children with SB had low autonomy levels in goal-directed situations that needed personal initiation. The agreement between parents' and children's ratings of the children's autonomy level was low. The frequency of participation among the children was high in school activities, although their teachers rated their active participation as restricted. The results also showed that the age norm in the AMPS is valid for use in a Nordic context.

**Conclusions:** This thesis demonstrates that children with SB have difficulties getting things done due to deficient quality of task performance. It is therefore crucial for Occupational Therapists to assess, understand and support the development of the performance skills in children with SB, in order to enhance their autonomy and active participation in everyday life, school and society.

**Keywords:** spina bifida, myelomeningocele, lipo-myelomenigocele, performance skills autonomy, participation, Assessment of Motor and Process Skills (AMPS), School Function Assessment (SFA)

Correspondence to: marie.peny-dahlstrand@neuro.gu.se  
or: marie.peny-dahlstrand@vgregion.se

ISBN: 978-91-628-8323-2

Göteborg 2011