

Children with spina bifida need personal 'starter'

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Children born with spina bifida often have difficulties to perform everyday activities. This is not primarily due to being confined to a wheelchair or to parental overprotection as was previously believed - new research from the University of Gothenburg shows that it is down to an inability to initiate and complete a task towards a specific goal.

Spina bifida is a birth defect in the spine which normally results in a degree of paralysis in the lower part of the body, difficulty controlling the bladder and bowel, and a risk of hydrocephalus. Recent research shows that spina bifida often also leads to other neurologically-related problems, such as varying degrees of executive function impairment.

A study of children with spina bifida at the Queen Silvia Children's Hospital and the Sahlgrenska Academy in Gothenburg reveals that the majority of these children struggle to "get things done" independently in daily life. This inability affects their autonomy in daily life and their participation in various school situations.

Although both the children themselves and their parents understand that they are capable of performing [everyday activities](#) in terms of motor skills, they still do not get done. As many parents put it: "I suppose he/she can do it is somehow just never done"

Previously children with spina bifida were often seen as over-helped due to their loss of motor function, and in some cases the children were even considered lazy. In her thesis, Marie Peny-Dahlstrand, licensed occupational therapist and doctoral student at the Sahlgrenska Academy, can now show that it is not a matter of laziness or reluctance but an inability to independently see activities through from start to finish, initiate new steps in an activity, and resolve problems arising during the course of an activity.

"Children born with spina bifida are probably held back more by this reduced ability to 'get things done' than by their motor difficulties," she explains. "The conclusion is that many children (and indeed adults) with spina bifida could do with assistance or some other form of support to act as a starter and problem solver."

The difficulties in daily life described in the thesis can probably also be seen in children and adults with other neurological disorders. Often these difficulties are hidden behind more obvious motor function impairments, which means that those with these difficulties are often misconstrued as being unwilling or having bad habits, Peny-Dahlstrand explains.

It is now important for the findings presented in the thesis to be communicated to parents, school and habilitation staff, and, not least, needs assessors.

"[Children](#) with spina bifida can then get the right kind of support, and an opportunity to realise their potential and be as involved as possible in everyday life, school and social activities - and, as adults, in society and working life."

More information: The thesis "To get things done, the challenge in everyday life in children with spina bifida. Quality of performance, autonomy and participation" was successfully defended on September the 16th 2011.

Provided by University of Gothenburg

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