

## **Open Letter to Regional Politicians in Halland**

### **When Region Halland Fails to Fulfill Its Statutory Responsibility for Children's Development**

In homes, preschools, and playgrounds this week, many children have been running, playing, and participating on their own terms. I would like to draw your attention to the children who do not have these motor abilities — and to the region's responsibility regarding their right to development, training, and participation.

I want to tell you about Kalle.

Kalle was four years old when his mother contacted me. At that time, he had still not learned to walk, something most children do around one year of age. Kalle has cerebral palsy and is classified at functional level 3 out of 5 according to the GMFCS (Gross Motor Function Classification System).

The family had been informed that it is difficult to influence walking ability, that Kalle is cautious, and that they would have to wait and see. They were told that if a child has not learned to walk by a certain age, a wheelchair is recommended.

Scientifically, there is an established view that children at GMFCS level 3 do not achieve independent walking. What is often lacking, however, is an analysis of why — and, above all, which interventions according to law and knowledge should be attempted before accepting such an outcome.

### **The Region's Legal Mandate Is Clear**

Under the Swedish Health and Medical Services Act (HSL), care must be evidence-based, individualized, and provided on equal terms. Interventions must be designed in consultation with the patient and, in the case of children, with the child's best interests as the primary consideration.

The UN Convention on the Rights of the Child, which is Swedish law, establishes children's right to the highest attainable health and development as well as to rehabilitation and habilitation.

The National Board of Health and Welfare's regulations and guidelines for prescribing assistive devices clearly state that such devices must:

- be based on individual needs,
- promote activity, function, and participation, and
- enable training and development.

These are not recommendations. They are binding principles.

## Reality Looks Different

I have been a pediatric physiotherapist for 40 years, with research and clinical work in Sweden and internationally. During these years, I have seen a striking lack of development and innovation regarding assistive devices for children. Many devices immobilize rather than stimulate; children are placed strapped in or in biomechanically disadvantageous positions instead of being allowed to train balance and active control.

When I myself sought assistive devices for balance training during walking, I found that they were essentially nonexistent. This led to the development of *Learn to Walk*, a walking aid designed to train balance and enable independent walking, specifically for children at GMFCS level 3.

During the development process, several children in this group have learned to walk independently — with dramatically improved function, participation, and future prospects. This is fully in line with the healthcare system's mandate.

## Administrative Arguments Replace Medical Assessment

Despite *Learn to Walk* being approved under MDR (Medical Device Regulation), assistive device centers have consistently rejected the device. The justifications have varied: “wrong code,” administrative obstacles, and ultimately the claim that training devices may not be prescribed.

This directly conflicts with applicable legislation and regulations, in which training and development are explicitly included in healthcare's responsibility. Referring to procurement rules or internal policies cannot justify deviations from the law.

When internal procedures are allowed to outweigh statutory rights, a rule-of-law problem arises.

## Kalle's Case Shows the Consequences

When Kalle's mother contacted me, I initially tried to guide the family in balance training. It soon became clear that Kalle needed *Learn to Walk*. The assistive device center allowed him to try the device, but without any guarantee of receiving it. There were opinions that it would be unethical to let him try it if prescription was not guaranteed.

Kalle tried it anyway — and the need was obvious.

Despite this, he was denied the device on the grounds that it was a training aid and due to cost. *Learn to Walk* costs approximately SEK 60,000.

At the same time, other interventions with significantly higher costs are routinely prescribed, even when scientific evidence is limited. There is a lack of consistency, transparency, and equitable assessment.

Kalle was eventually allowed to borrow the device. Today he walks independently. He has developed physically and mentally, gained increased self-confidence, and new opportunities for play and participation.

Not giving him this opportunity, despite its availability, would in my assessment have been unethical — and contrary to the healthcare system's mandate.

### **Parents Are Left Alone in a Legally Insecure System**

Kalle's mother and many other parents describe long processing times, unclear decisions without justification, absence of a responsible decision-maker, and a culture where standard solutions replace individual assessment. Parents are forced to pursue cases themselves, argue legally, and search for solutions — in a system where the power imbalance is obvious — a David versus Goliath situation.

This is not compatible with a legally secure healthcare system.

### **A Socioeconomically and Legally Unsustainable Path**

Early, individualized interventions that promote independent walking can reduce the need for future healthcare, assistive devices, and personal assistance over a lifetime. Refusing relatively limited one-time costs instead leads to far greater long-term expenses — both economic and human.

Children with physical disabilities are not cured with medication. They need to teach the brain to control the body through tasks and training that mirror normal motor development. This is well known and should be guiding practice.

### **The Question to Regional Leadership**

The question is therefore not whether Region Halland can afford this.

The question is:

- How does the region ensure that the Health and Medical Services Act and the Convention on the Rights of the Child are implemented in practice?
- How are decisions justified that limit children's right to training and development?
- Who bears the legal and ethical responsibility when administrative systems are given precedence over the child's best interests?

Children like Kalle do not have time to wait for a system that fails to fulfill its mandate.

It is the region's responsibility to ensure that the law is followed.

**Sincerely,**

Ulrika Myhr

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Learn to Move