

Taking part in everyday life—adolescents with and without impairments speak up

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Research has shown that participating in home, school and community activities has a positive influence on a person's health and wellbeing. For an adolescent with an impairment or disability, how much does this affect their participation? In a new study, Frida Lygnegård from the CHILD research environment at the School of Health and Welfare at Jönköping University decided to let Swedish adolescents answer this for themselves.

Giving adolescents a voice to express their opinions on matters that relate to their participation in [everyday activities](#) is a driving force in Frida Lygnegård's thesis.

"Many studies start with an assumption on how participants with certain disabilities will think. My opinion is that we should be asking the adolescents how they feel about the things they do in everyday life," she argues.

Frida Lygnegård carried out her research into how Swedish adolescents participate in and outside school in conjunction with the unique LoRDIA research program, following approximately 1500 school students in four municipalities in south and southwest Sweden. This included students with no diagnosed impairments as well as those with diagnosed impairments who were following the curriculum for pupils with intellectual disabilities.

In a carefully crafted questionnaire, the students were asked to self-rate

(to give answers unprompted by parents, teachers or carers) their participation at home, at school and with peers.

"Our questions to the students had two dimensions: firstly, we asked them how often they did certain things; secondly, we asked them how important taking part in this was for them," explains Frida Lyngegård.

Data was collected at two time points – when the students were 12-13 years old and later when they were 15-16 years old—to see how participation changed over time. The results showed that perceptions of participation are relatively stable over time but that the reasons for participating changed.

"I saw that the type of impairment a person perceives to have is not a predictor for how they feel about participation in activities. We can't assume that because an [adolescent](#) has, for example, autism, it will make them feel in a certain way about doing something with their friends or helping out with domestic activities at home."

Frida Lyngegård saw that it was a combined effect of many other factors, such as support from siblings and what the atmosphere is like in the family, that mattered for how adolescents rated their experiences. She argues that we should be focusing on the biopsychosocial impact (a combination of the impairment, how the individual feels and the effect of their social environment) when it comes to explaining their participation in activities.

"We shouldn't underestimate a diagnosis, but neither should we be overly focused on it," she explains. "My thesis shows that the effect of the impairment itself is more evident at school, so interventions to increase participation should be focused there."

Many adolescents have sub-threshold symptoms that occur although no

official diagnosis is evident, and yet these adolescents still have difficulties with participation. How do we reach them? For Frida Lyngegård, the answer is simple:

"Can we ask them if they think they have an impairment or if they experience any difficulties in their everyday activities? Yes! We need to ask adolescents how they feel, and we need to put more trust in them. They have the right to own knowledge about themselves."

Frida Lyngegård successfully defended her thesis "Participation in and outside [school](#). Self-ratings by Swedish adolescents with and without impairments and long-term conditions" at the School of Health and Welfare, Jönköping University on 26th October.

Provided by Jonkoping University

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