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# **EQUITY AMONG CHILDREN AND YOUTH WITH CEREBRAL PALSY**

**Physical leisure activity, Physical education,  
Physiotherapy and Quality of life**

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## **Akademisk avhandling**

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Equity among Children and Youth with Cerebral Palsy: Physical leisure activity, Physical education, Physiotherapy and Quality of life

## Abstract

**Background and aim:** Cerebral palsy (CP) is the most common reason for movement difficulties among children and youth in Sweden. Physiotherapy is usually introduced early in order to develop mobility and facilitate activity and participation. Physiotherapy is connected with physical activity, both as a goal and a mean. Physical activity contributes to aspects of health, in turn associated with quality of life (QoL). Physical education as well as physical leisure activity and physiotherapy are important parts of the total physical activity participation among children and youth, but are insufficiently explored from an equity point of view. The overall aim of the current thesis is to explore participation in physiotherapeutic interventions, physical leisure activity and physical education, as well as analyze the association between physical activity and quality of life, from an equity perspective for children and adolescents with CP in Sweden. **Methods:** The four papers that comprise this thesis are based upon three studies: a National cross-sectional registry study (Papers I and II), based on the National Quality Registry Cerebral Palsy Follow-up Program (CPUP); an interview study with a qualitative approach (Paper III); and a national survey complemented with registry data (IV). Quantitative data were analyzed with multivariable regressions. Qualitative content analysis was used for the interview study. **Results:** The number of participants were 2855 aged 0-18 years (Paper I) and 1935 aged 6-18 years (Paper II). The interview study (Paper III) included 11 participants aged 15-18 years, and the survey study (Paper IV) 149 participants, aged 15-18 years. Being born in Sweden entailed higher odds for participating in physiotherapy, physical leisure activity, physical education and physiotherapy, respectively, compared to those born outside Sweden (Paper I) or outside Europe (Paper II). More severe gross motor function difficulties were associated with higher odds of receiving physiotherapy, and lower odds of physical activity participation (Paper II). Participants in the interviews report several examples of exclusion, struggles and (in-) sufficient support and inclusion in physical education and leisure activity through the categories 'Exclusion and lack of support', 'Resistance, struggle and guilt', and 'Empowerment and support'. Gender as a vector in physical activity is mainly seen through the qualitative results (Paper III). Frequent participation in physical leisure activity was associated with the domain Communication and physical health. Domains of QoL that referred to participation or function were negatively associated with having greater motor function difficulties. Pain and bother is negatively associated with all five domains of QoL. Low caregiver educational level was associated with higher QoL-scores in the domain of social well-being (Paper IV). **Conclusions:** The results that reveals differences regarding birth country indicates the relevance to raise awareness about possible inequity in participation in physical leisure activity, physical education, and physiotherapy for children and youth who have CP, as a prerequisite for improvement. Physiotherapists, school, and leisure sport leaders, as well as their organizations, need to be attentive to norms and bias in order to prevent inequity and discrimination due to for example birth country, gender or function, which is included in the compensatory assignment of the schools and health care. This is emphasized by the experiences of exclusion expressed by participating youth with CP. Frequent physical activity participation is in part associated with higher QoL while Pain and bother is negatively associated with QoL, as is partly gross motor function difficulties. Prevention and treatment of pain and facilitation of physical activity is therefore important for children and youth with CP. Future studies should carefully consider targeting youth with a non-Nordic birth country and with large gross motor function difficulties or associated difficulties to widen knowledge about equity in physical activity- and physiotherapy participation, and QoL.

## Keywords

Birth country, Cerebral palsy, equity, disability, gender, physical activity, physiotherapy, quality of life

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