Unequal physical activity among children with cerebral palsy in Sweden—A national registry study

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Abstract
Aim: To examine the extent to which sex, country of birth, and functional aspects influence participation in physical education and physical leisure activity among children with cerebral palsy (CP) in Sweden.

Methods: This national cross-sectional registry study included children with CP aged 6 to 18 years who participated in the Swedish national quality registry, the Cerebral Palsy Follow-up Program, CPUP, in 2015. Comparisons and associations between sex, country of birth, and functional aspects and physical leisure/physical education were examined using chi-squared and multivariable logistic regression analysis.

Results: The study included 1935 children. Of them, 1625 (87%) reported participating in physical education and 989 (53%) reported participating in physical leisure activity. Children born in Sweden had higher odds of participating in physical education (OR: 1.99; 95% CI: 1.20-3.28) and physical leisure activity (OR: 2.51; 95% CI: 1.70-3.72) compared with children born outside Europe. Greater impairment of gross motor function was associated with lower participation levels. Boys participated slightly more frequently in leisure activities than girls.

Conclusion: Enhancing social inclusion with regard to disability, birth country, and sex are important and achievable goals for policymakers and practitioners for promoting participation in physical activity for children and adolescents with CP.

KEYWORDS
inequality, leisure, norms, physical education, youth

1 | INTRODUCTION

Children and youth with cerebral palsy (CP) do not achieve the levels of physical activity that among children in general are presumed to be needed for health, according to Bratteby et al.1 Cerebral palsy is the most common cause of motor disability in children and youth,2,3 with a male-to-female prevalence ratio of about 1.4:1.4 Movement and posture disorders of CP are caused by nonprogressive disturbances in the immature brain and are commonly followed by disturbances of, for example, perception, cognition, and communication.5 CP entails limitations in activity, commonly associated with restrictions in participation, in general, as well as in physical activity specifically.5

Physical activity has numerous well-established health benefits.6,7 Achieving healthy levels of physical activity in childhood—meaning at least 60 minutes of daily, diverse physical activities1,7,8—is of particular significance, since it has been shown to increase the prerequisites for a lifelong healthy lifestyle.9,10 However, children in Sweden and other countries generally do not achieve these levels of physical activity.
activity\textsuperscript{9} and children with CP even less so.\textsuperscript{1,11} The lower participation of children with CP may be partly explained by low motor function and capacity, as earlier studies have shown.\textsuperscript{12,13} However, that in turn could supposedly indicate insufficient adaptations in order for the children to be able to participate on their own terms, in physical leisure or physical education. The latter is by the United Nations established as a right for all children.\textsuperscript{14}

Physical education and health is a school subject that makes an important contribution to children's total physical activity.\textsuperscript{15} Physical education aims at providing the conditions to develop practical and theoretical knowledge of a variety of physical activities, outdoor life, and healthy lifestyles. As with all school subjects, in Sweden, participation is mandatory from age 6 until at least ninth grade.\textsuperscript{16} Swedish schools are tasked with providing the same high-quality education to all children, regardless of background or personal and social circumstances, using compensatory measures.\textsuperscript{16}

In addition to functionality, social factors may affect participation in physical activity for children with CP. Studies have shown that boys participate more in physical leisure activity than girls, at a greater intensity.\textsuperscript{17-19} although one registry study found no differences with regard to sex in either leisure activity or physical education.\textsuperscript{12} Among children in general, the Swedish school oversight agency shows that, to the contrary, girls seem to participate more than boys in physical education.\textsuperscript{20} However, despite girls' higher participation, another study by Svennberg et al found that boys had higher odds of receiving better grades in physical education classes.\textsuperscript{21} Girls, in general, report feeling pressure to perform in physical activity and express doubts about their abilities,\textsuperscript{22} something that has been associated with gendered norms. Such norms commonly connect sports to masculine identity and an increase in the power of masculinity, while they do not correspondently enhance feminine identity.\textsuperscript{23} Other social parameters were also associated with high grades, such as having highly educated parents and having lived in Sweden since before reaching school age.\textsuperscript{21} Whether social categories, such as birth country, also affect children with CP's participation in physical education is not clear, nevertheless, of interest as a step towards providing equal prerequisites of participation in school for all children.

Because physical activity is a core contributor to health, and little research has been carried out on the association of social categories and participation in physical activity for children with CP in Sweden, we designed this study to examine the extent to which sex, country of birth, and aspects of functionality influence participation in physical education and physical leisure activity among children and teenagers with CP in Sweden.

2 \hspace{1cm} METHODS

This study is a national population-based study, with a cross-sectional design that used data from a Swedish national quality registry—the Cerebral Palsy Follow-up Program (CPUP).\textsuperscript{24} The CPUP is a registry with a high degree of coverage and is used for clinical purposes as well as for research. The registry's initial aims were to prevent contractures and hip dislocations in children with CP through regular surveillance and assessments, and also to increase knowledge about CP and facilitate cooperation among healthcare professionals. All children in Sweden with diagnosed or presumed CP are offered regular, standardized assessments (usually annual) by a physiotherapist and occupational therapist. Around the age of four, a neuropsychiatric assessment is offered to confirm the diagnosis. Furthermore, psychological and speech pediatric assessments are also performed according to the CPUP.\textsuperscript{24} This study included everyone aged 6 to 18 years living in Sweden who participated in the CPUP physiotherapy assessment in 2015. Here, we chose to refer to all participants as “children,” despite the fact that some are 18 years of age.

The data for this study were accessed through the registry keeper in December 2016 and include information from the CPUP assessment forms filled out by a physiotherapist, occupational therapist, and pediatric neurologist. These forms include information from the physical examinations, as well as the children's and families' verbal reports to the recording professional regarding their perception of the child's situation during the time since their last CPUP assessment. For consistency and ease of reading, it will hereafter be indicated that information was reported by the child. In cases where multiple assessments were made during the year, this study used the first. In order to discuss which independent variables to include, an advisory reference group was consulted. The group consisted of persons having CP and healthcare professionals working with persons with CP. The four outcome variables used were collected from the physiotherapist's form and measure whether the child participated in physical education and physical leisure activities (yes/no), and if yes, how frequently (<1 time/week, 1-2 times/week, or 3-5 times/week). The response alternatives covering frequency were dichotomized into frequent or infrequent physical education and frequent or infrequent physical leisure activity, with frequent defined as ≥1 time/week (Figure 1). The reporting referring to leisure activity concerns all kinds of voluntary bodily movement resulting in an increase of energy expenditure performed in leisure time and hence includes varying exercise activities, gymnastics, sports, or outdoor activities.\textsuperscript{24}

Table 1 summarizes the information on the demographics and characteristics of the children, which were used as independent variables. They are country of birth, sex, age, and the aspects of functionality; and gross motor function, cognitive level, manual ability, communication function, and pain. For all independent variables with missing values, a category called not reported was added. The variable country of birth included the alternatives (Sweden, Norway, Denmark, other), where Norway, Denmark, and countries listed under other were allocated to Europe (not Sweden) or outside Europe. The variable sex had two alternatives (boy/girl), and age at examination was included as a control. The aspects of functionality included gross motor function, measured with the Gross Motor Function Classification System—Expanded and Revised (GMFCS-E&R) levels I-V,\textsuperscript{25} which is a predictive, five-level classification that focuses on the preferred manner of movement rather than capability. The system ranges from level I, which includes children who walk independently but with minor functional differences, through level V, which covers children
who are very limited in their control of movement and independent transportation.\textsuperscript{25} Data on the cognitive level were reported according to the tenth version of the International Classification of Diseases and Related Health Problems (ICD-10).\textsuperscript{26} The cognitive level was categorized into intellectual disability, including the categorical answers severe/moderate intellectual disability and mild intellectual disability, and the category no intellectual disability, which included below average and average or higher. The category unknown/not assessed cognitive level was merged with not reported. Manual ability was assessed with the Manual Ability Classification System (MACS), which is a five-level system that classifies typical manual performance in children with CP.\textsuperscript{27} It ranges from level I, Handles objects easily with good results, through level V, Does not handle objects, including children who are very restricted in their ability to perform even simple tasks.\textsuperscript{27} The Communication Function Classification System (CFCS) classifies children's ability to communicate in everyday life, ranging from level I, Effective as a sender and receiver with familiar and unfamiliar partners, through level V, Seldom effective sender and receiver even with familiar partners.\textsuperscript{28} Lastly, a question of pain (yes/no) was also included as an aspect of functionality.

Participants in the CPUP registry have provided informed consent to participate in the registry, including sharing anonymized data for research. No additional consent from participants was required for using the registry data. This study's procedure followed the principles of the Declaration of Helsinki,\textsuperscript{29} and the data have been presented such that no individual can be identified. The Regional Ethical Review Board at Umeå University approved the study (Reg. No. 2016/343-31).

2.1 | Data analysis

The registry data were analyzed using the program SPSS (IBM Corp. Released 2017. IBM SPSS Statistics for Windows, version 25.0.). Spearman’s rank correlation coefficient between independent variables was calculated to assess potential multicollinearity. Frequencies were reported with numbers and percentages. Univariate and multivariable logistic regressions were used to analyze associations between the independent variables and outcome variables. For the outcome variables in the regression analyses, an affirmative answer to participation in physical education and participation in physical leisure activity, as well as scoring more than once a week on the variables frequent participation in physical education and frequent participation in physical leisure activity, was coded as 1, and the remaining alternatives were coded as 0. The category not reported for missing values in the independent variables was intended to maintain data in the multivariable models. Only the independent variables that, in the univariate analyses, were significantly associated at the 10% level, with either of the two outcome variables for physical education or physical leisure activity respectively, were included in the multivariable analyses. The characteristics of children with missing values in the outcome variables were analyzed using the chi-squared test, and values significantly differing from those of the children with reported data were described. Associations were reported as odds ratio (OR) and 95% confidence interval (95% CI). \(P\) values <.05 were considered statistically significant.

3 | RESULTS

Multicollinearity analyses showed correlation coefficients below 0.5 between all variables, except for MACS and CFCS, which were highly correlated \((r = 0.8)\).

Of the 1936 children who participated in the physiotherapeutic CPUP assessments, 807 were girls (42%). Of the children who reported country of birth, 231 (18%) were born outside Sweden, corresponding to 12% of the total group. Eighty-two children were born in Europe (not Sweden) (4%) and 149 outside Europe (8%) (Table 1). Most of the children born in Europe were born outside the Nordic countries \((n = 72, 88\%)\). Among those who reported their cognitive level, 373 children (39%) had an intellectual disability,
3.1 | Physical education in school

Among the 1827 children reporting on the question of physical education, 1625 (87%) did participate (answered yes); of them, 1496 (92%) reported frequent participation. Multivariable analysis showed that children born in Sweden had 1.99 times higher odds of participating in physical education compared with children born outside Europe (95% CI: 1.20-3.28) (Table 2). Less impaired gross motor function was also associated with higher participation in physical education; compared to children with GMFCS level V, children with GMFCS level I had 23.76 times higher odds of participating in physical education (95% CI: 13.99-40.34) and 5.51 times higher odds of participating frequently (95% CI: 3.17-9.59) (Table 2). Children with a level II CFCS were significantly more likely to participate in physical education frequently compared with children with CFCS level V (OR: 3.01; 95% CI: 1.17-7.73) (Table 2). Sex, MACS, and pain showed no statistically significant association with physical education and were therefore removed from the final multivariable model.

3.2 | Physical leisure activity

There were 1864 (96%) children who reported whether they participated in physical leisure activity, of whom 989 (53%) did participate. Of the 919 children who also reported their frequency of participation, 753 (82%) engaged in frequent physical leisure activity. Children born in Sweden had 2.51 times higher odds of participating in leisure activities compared with children born outside Europe (95% CI: 1.70-3.72). Boys had 1.46 times higher odds of frequently participating in physical leisure activity compared with girls (95% CI: 1.02-2.07) (Table 3). Better gross motor function was associated with higher odds of participating in physical leisure activity: compared to children with GMFCS level V, children with GMFCS level I had 2.51 times higher odds of participating in physical leisure activity (95% CI: 1.37-4.63) and 3.65 times higher odds of participating frequently (95% CI: 2.06-6.48) (Table 3) and children without any intellectual disability had 1.83 times higher odds of participating compared with those who did have an intellectual disability (95% CI: 1.32-2.55) (Table 3). Because MACS and CFCS were not significantly associated with physical leisure activity, they were excluded from the model.

3.3 | Missing data analysis

Out of the total study population, 59 children (3%) did not report on physical education, and 72 (4%) did not report on physical leisure activity. The children with missing data on the outcome variables corresponding to 19% of the total. For further characteristics and information on assessment forms where data were collected, see Table 1.
TABLE 2  Odds ratios and 95% confidence intervals for univariate and multivariable logistic regressions for associations between participation in physical education and frequent physical education as outcome variables, and country of birth, cognitive level, GMFCS-E&R, and CFCS as independent variables, controlled for age

| Country of birth            | Participation in physical education | Frequent participation in physical education |
|-----------------------------|-------------------------------------|---------------------------------------------|
|                             | Univariate | Multivariable | Univariate | Multivariable |
|                             | n 1936     | OR   95% CI    | n          | OR   95% CI    |
| Missing in dependent        | 59         | 1     1        | 311        | 1     1        |
| Country of birth            |            |            |            |            |
| Outside Europe              | 149        | 144 1 1     | 112        | 1     1        |
| Europe                      | 82         | 82 0.95 0.50-1.81 | 63         | 0.70 2.25-1.98 | 0.64 | 0.22-1.87 |
| Sweden                      | 1175       | 1142 2.37 1.53-3.66 | 1018       | 1.01 0.25-1.98 | 0.85 | 0.41-1.79 |
| Not reported                 | 530        | 509 1.58 1.00-2.50 | 432        | 1.09 0.51-2.36 | 1.13 | 0.50-2.53 |
| Cognitive level             |            |            |            |            |
| ID                          | 373        | 362 1 1     | 274        | 1     1        |
| No ID                       | 442        | 433 6.30 3.82-10.39 | 412        | 1.78 0.98-3.23 | 0.85 | 0.44-1.65 |
| Not reported                 | 1121       | 1082 2.11 1.57-2.84 | 939        | 1.05 0.66-1.68 | 0.63 | 0.37-1.08 |
| GMFCS-E&R                   |            |            |            |            |
| Level V                     | 356        | 343 1 1     | 197        | 1     1        |
| Level IV                    | 321        | 307 3.86 2.66-5.59 | 257        | 1.63 0.97-2.72 | 1.63 | 0.96-2.78 |
| Level III                   | 171        | 163 6.89 3.94-12.05 | 146        | 2.37 1.21-4.64 | 2.58 | 1.29-5.20 |
| Level II                    | 362        | 353 13.18 7.92-21.94 | 334        | 4.92 2.62-9.23 | 5.47 | 2.82-10.47 |
| Level I                     | 726        | 711 25.91 15.82-42.44 | 691        | 4.76 2.88-7.88 | 5.51 | 3.16-9.55 |
| CFCS                        |            |            |            |            |
| Level V                     | 224        | 218 1 1     | 190        | 1     1        |
| Level IV                    | 183        | 176 0.85 0.48-1.51 | 148        | 1.80 0.85-3.81 | 1.59 | 0.74-3.45 |
| Level III                   | 151        | 151 0.62 0.35-1.09 | 122        | 1.62 0.58-2.29 | 1.49 | 0.67-3.31 |
| Level II                    | 178        | 169 0.74 0.42-1.31 | 141        | 3.25 1.29-8.19 | 3.01 | 1.17-7.73 |
| Level I                     | 584        | 567 1.06 0.67-1.70 | 497        | 1.57 0.92-2.67 | 1.28 | 0.74-2.22 |
| Not reported                 | 616        | 596 1.07 0.67-1.71 | 527        | 1.97 1.14-3.40 | 1.69 | 0.96-2.97 |

Note: Significant results written in bold.
Abbreviations: CFCS, Communication Function Classification System; GMFCS-E&R, Gross Motor Function Classification System—Expanded and Revised; ID, intellectual disability.

4 | DISCUSSION

The current study shows differences in the participation in physical education and physical leisure activity among children with CP in Sweden. Children born in Sweden had higher odds of participating in both physical education and physical leisure activities compared with children born outside Europe, and boys participated more frequently in physical leisure activities than girls. With respect to the aspects of functionality, the GMFCS-E&R, in particular, was associated with physical education and physical leisure activity, with better gross motor function corresponding to more activity. Having CFCS level II was associated with higher odds of participating in physical education compared with level V, and having intellectual disability entailed lower odds of participating in physical education compared with those not having intellectual disability. Earlier studies identified environmental barriers to physical leisure activity besides physical availability, such as parental or trainer hesitation, as well as social attitudes and acceptance by peers and the child him- or herself as limitations to participation in leisure activities.30,31 The current study finds that country of birth, sex, and severity of impairment all play a role in this multifaceted phenomenon.

4.1 | Country of birth

Children born outside Europe were underrepresented in physical education and physical leisure activity compared with children born in Sweden. The reasons for immigration, its degree of voluntariness, and

(nonresponders) were compared with those who did respond, finding that the proportion of children aged 6-11 was higher among nonresponders on the physical education variable (44 children, 75%) versus responders (1077, 57%, P = .008), and on the physical leisure variable (53, 74%) versus responders (1068, 57%, P = .007).
the reception received from the host country are more likely to be the cause of differing levels of integration, as found by Vogel et al, rather than distance per se. Integration in turn may also play a part in participation in physical activity for children with CP. However, the current study does not have the data needed to analyze this point. Regardless of the cause of immigration, schools’ mandate to compensate for children’s background is valid but does not seem to be effectively accomplished. Moreover, children who are born outside Sweden are more likely to live in families facing socioeconomic challenges such as low educational attainment and low income, and these factors may also affect participation in leisure activities for children with CP.

4.2 | Sex and gender

Our results showed equal participation between the sexes in physical education, while boys had slightly higher odds of frequent participation in physical leisure activity than girls. The latter points in similar direction as earlier studies, showing that gender affects choice of activities; the boys are more prone to choose physical and team-based activities, whereas girls tend to be more active in recreational and social activities. While school activities such as physical education are governed by regulations, leisure time may be more influenced by social norms regarding gender, such as connecting sports and physical activity to masculine identities rather than feminine ones. As the data in the current study do not analyze the type of activities, a more thorough analysis of physical activity with regard to gender is not possible to perform.

4.3 | Functionality and disability

Greater impairment of gross motor function was associated with lower participation in both physical education and physical leisure activity. Children with higher levels of impairment were less likely to participate in physical leisure activity and physical education compared to those with lower levels of impairment. These findings highlight the importance of considering the physical ability of children with CP when designing physical education and leisure activities.
activities, as has been reported elsewhere. This finding is also in accordance with a review that concluded that physical capacity is strongly associated with habitual physical activity. Lauruschokus et al further showed that children with GMFCS levels IV and V participated in a narrow range of activities (mainly horseback riding and swimming). A limited range of available activities result in disadvantages, both from barriers to health-promoting physical activity and from limited access to the crucial social interactions associated with leisure activity. Moreover, normativity within sports is not only associated with gender but extols a male, nondisabled, and slender body and can thereby position girls/women and persons with disabled bodies as deviant. Altogether, these factors do not encourage participation for children with CP, in particular those with severe disabilities. The manual and communication function measures, MACS and CFCS, were included in our analyses after discussions with the advisory reference group. Nevertheless, levels of MACS showed neither significant nor borderline associations with physical education or leisure, which is in accordance with earlier studies. In contrast, the significant association of CFCS to participation support that communication function does play a role in the participation in physical education. However, to confirm the results, and to elucidate detailing about the association related to the grade of communication impairment, further studies are needed. Having an intellectual disability was associated with lower participation in physical leisure activity, which is in line with an earlier multinational study. Conceivably, this may derive from the additional stigma reported by Jahoda et al to be associated with intellectual disabilities, thus creating inequity and discrimination towards this group. However, such conclusions cannot be drawn based on the current results.

Schools’ insufficient compensatory measures for children’s functionality are, as with compensation for birth country, problematic, especially since children with severe disabilities commonly attend special adaptive schools in Sweden. These schools should be equipped to provide adequate participation in activities that also allow social inclusion with other students, rather than specifically designed individual activities, as earlier highlighted by adolescents with disabilities.

The results of this study indicate that the Swedish government has not achieved its 2010 target of full availability per the United Nations Convention on the Rights of Persons with Disabilities, when it comes to physical education and leisure activities. Moreover, during the last decade, the Swedish Law on Support and Service for Persons with Certain Functional Impairments (LSS) has become more strictly enforced, leading to restrictions in aid for persons with disabilities. This, together with the rare provision of technical aids needed specifically for leisure activities, by the Swedish county councils, means that children with severe impairments are dependent on the time, energy, and financial resources of their individual families in order to engage in leisure activities.

4.4 | Strengths and limitations

The current study provides valuable information on the distribution of physical activity, on social belongings among children with CP. However, by doing this, we have also grouped together persons who, in several aspects, may have as many differences among them as commonalities. Knowledge on the interaction between social belongings, and how they reinforce privileged or disadvantaged positions in society in relation to physical education and leisure activity, remains limited. Nevertheless, our results do reveal inequity that may entail greater disadvantages for certain children with CP than for others. In order to capture such experiences of children with CP, future studies should include in-depth interviews and intersectional analyses. Children in the current study are heterogeneous regardless if they are born in Sweden or not. They have backgrounds that reflect a variety of customs, cultures, financial conditions, religions, and ability to absorb education. Future studies may therefore benefit from further subgrouping.

The data used in the current study do not reveal whether children achieve healthy levels of physical activity. The reports in the CPUP registry refer to the children’s reported participation since their last assessment, usually the previous year. This form of reporting physical activity is clinically suitable to large populations, but its validity may be questioned and may suffer from recall bias.

The children with missing values on our outcome variables were, on average, younger; however, because of the low proportion of missing values (3%-4%), and the limited association between age and physical activity, we do not believe that this affected the results. Some children aged 16 to 18 years were assessed using the CPUP adult assessment form and thus were not included in the current study. Because pain increases with age, pain prevalence in our study may thereby be underestimated for the population of children with CP.

In conclusion, the current study shows that there is inequity among children and adolescents with CP in Sweden with regard to participation in physical leisure activity and physical education, despite regulations to prevent such inequity. It is important to improve social inclusion in a way that considers levels of disability and birth country, and this ought to be an achievable step for policymakers and practitioners in promoting participation in physical activity for children and adolescents with CP.

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CONFLICT OF INTEREST

The authors declare no conflicts of interest that could be perceived as prejudicing the impartiality of the research reported.

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Transparency Statement
The first author confirms that the manuscript is an honest, accurate, and transparent account of the study being reported, that no important aspects of the study have been omitted, and that any discrepancies from the study as planned have been explained.

Data Availability Statement
The data that support the findings of this study are available from the Cerebral Palsy Follow-Up Program (CPUP) in Sweden. Restrictions apply to the data that support the findings of this study are available from the study as planned have been explained.

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