

School outcomes of adolescents with cerebral palsy in Sweden

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ABBREVIATIONS

CFCS	Communication Function Classification System
CPUP	Cerebral Palsy Follow-Up Program and National Quality Registry
MACS	Manual Ability Classification System

AIM To study school outcomes of adolescents with cerebral palsy (CP) compared with a matched comparison group from the general population, and to observe to what extent sociodemographic and disability-specific factors are associated with school outcomes.

METHOD This was a register study of persons with CP in Sweden, born between 1990 and 1999, with a matched comparison group. Logistic regressions were used to estimate the associations between CP and disability-specific factors and school outcomes (receiving final grades, grade scores, fulfilling the requirements for progressing to secondary school/university, and attending secondary school).

RESULTS Children with CP had substantially lower school achievement compared with a general population sample. Much of the difference can be attributed to intellectual disability; however, CP remained strongly negatively associated with school outcomes. Ability to communicate in an effective manner explained most of the variation in children with CP, whereas motor function played a smaller role.

INTERPRETATION The results suggest that school achievements might be improved if the communication barrier could be reduced, for example by ascertaining access to appropriate communication devices and by educators being aware that communicative difficulties do not necessarily imply intellectual disability. This might enhance the school experience and create an environment where children with CP can reach their full potential.

Individuals with disabilities are marginalized in society with limited access to education, employment, and financial resources.¹ While individuals with disabilities are worse off in countries with limited resources, disability has also been linked to reduced participation in Sweden,² a country with universal health care, free education, an extensive social insurance system, and legislation prohibiting discrimination against individuals with disabilities.

Cerebral palsy (CP) is one of the most common early-onset disabilities^{3,4} and is associated with progressive musculoskeletal complications and reduced participation in society.^{3–5} Levels of function and comorbidities vary; many with CP function independently, whereas others require full-time assistance. CP is caused by brain damage occurring before 2 years of age, which might also affect the cognitive development of the individual.⁶ Standardized, normed, cognitive assessments (e.g. the Wechsler scales) can be difficult to use in individuals whose gross motor and manual functions or verbal abilities are compromised.⁷ Even among individuals able to communicate, expressive language might be affected, which can in turn affect aspects of cognitive testing that are timed. More subtle, specific cognitive impairments, such as executive dysfunction⁸ and visual–perceptual impairments,⁹ can affect academic performance and it is likely that the ramifications

increase at older ages, given higher expectations. Research has shown that many individuals with CP can indeed complete cognitive assessments, provided the assessments are adapted.¹⁰ It is difficult to know the prevalence of intellectual disabilities in individuals with CP, because of a lack of research among representative samples that individually assess persons with CP.¹¹ Assumptions of intellectual function are often made based on interacting with individuals and caregivers in clinics, making assessments prone to clinician bias. Moreover, adaptive behaviour—generally a criterion for intellectual disability—is not always considered. A recent narrative review on CP and cognition estimated that 30% to 40% of children with CP in Western countries had IQ scores below 70. Cognitive function is also dependent on the type of CP.¹¹

Education plays a central role in enabling children and adolescents to participate in the labour market as adults, but it is unknown to what extent low rates of labour market participation are due to lower educational levels among persons with CP. Although level of education has been shown to be lower among adults with CP compared with the general population,^{12,13} an Australian study showed that around 30% of children with CP obtained scores in the range of population norms in standardized educational testing.¹⁴ Children with more severe motor symptoms were

less likely to undergo educational assessments or to obtain population-norm scores. Socioeconomic and demographic factors are associated with education in the general population, but it is unknown if this is the case for children with CP.

The purpose of this study was to investigate whether adolescents with CP in Sweden have lower school achievement and if school achievement varies by disability-specific factors. It was hypothesized that CP is negatively associated with school outcomes, but that this association is mainly explained by intellectual disability, everyday communication effectiveness, and fine motor ability.

METHOD

This was a population-based register study where all individuals with a diagnosis of CP (International Classification of Diseases, 10th Revision [ICD-10]: G80) in the National Inpatient register, the Birth Defect register, and the Cerebral Palsy Follow-Up Program and National Quality Registry (CPUP) between 1990 and 2015 were identified, and a general population comparison group matched on sex, birth year, and municipality of residence was drawn at a 5:1 ratio. Siblings of the identified cases were excluded from the comparison group. The CPUP is a national follow-up programme and registry for people with CP in Sweden,¹⁵ and includes 95% of all children with CP.¹⁶ Parents of individuals with CP and comparators were identified using the multigenerational register from Statistics Sweden. Annual information from registers at Statistics Sweden for the years 1990 to 2015 was linked to this population: socioeconomic factors from the Integrated Database for Labour Market Research, school outcomes from the Grade Registers, and disability-specific factors from the CPUP.

In Sweden, the first 9 years of school are compulsory, while secondary school (the following 3 years of education) is voluntary. The sample was limited to the birth cohorts between 1990 and 1999 for compulsory school, and 1990 and 1996 for secondary school. The upper limit was set to ensure everyone was old enough to have completed school by 2015 (latest year of school outcomes), which is normally the year the adolescent turns 16 years for compulsory school and 19 years for secondary school. The lower limit was set because it was the first year that parents' socioeconomic information was available. The adolescents also had to have been registered in Sweden the year they turned 16 or 19 years of age. This resulted in a study population of 3465 cases and 16 838 comparators for the compulsory school outcomes (receiving final grades and fulfilling the requirements for secondary school), while grade score was conditioned on receiving final grades and had a lower sample size (1648 cases and 16 204 comparators). The study population for the secondary school outcomes (attending secondary school and fulfilling the requirements for university) included 2541 cases and 12 299 comparators. Disability-specific information was only available for individuals

What this study adds

- There are reduced educational outcomes associated with cerebral palsy.
- Negative outcomes are mainly driven by reduced communicative and intellectual ability.
- Gross motor function is associated with outcomes, but plays a smaller part.

participating in the CPUP (31% and 27% of the birth cohorts).

School achievements were measured as five different outcome variables. First, whether the adolescent had received final grades in compulsory school (i.e. had been evaluated based on the national learning objectives). The grade scores (i.e. the sum of 16 grades as reported in the Grade Register, ranging between 0–320) were included as an outcome, conditioned on having received final grades. Two variables related to fulfilling the basic requirements for continuing studies at the next educational level (secondary school for compulsory school and university for secondary school) were included. These are set requirements determined nationally by grades and completed courses. Students still had the opportunity to attend secondary school in specialized programmes, even if they had not fulfilled the basic requirement, although this would not have led to a diploma. Therefore, one outcome variable regarding whether the adolescent attended secondary school, measured as participating in the final (third) year of secondary school, was included. As we analysed five different outcomes testing the same hypothesis, we applied the two-step procedure proposed by Benjamini et al.¹⁷ to control for false discovery rate.

Disability-specific factors included measures of functional abilities: the Communication Function Classification System (CFCS);¹⁸ the Manual Ability Classification System (MACS);¹⁹ and the expanded, revised version of the Gross Motor Function Classification System (GMFCS)^{20,21} for those adolescents who participate in the CPUP. As repeated measures of functional abilities are available for most individuals, the assessments conducted closest to the age of 5 years were used. Five years of age is a suitable cut-off point to capture children's functional abilities before compulsory schooling starts, as this has been associated with 'school readiness', which is associated with future school achievements.²² While the GMFCS and MACS have been included in the CPUP for many years, the CFCS is a newer instrument and consequently has a higher average age at assessment. Intellectual disability, defined herein as any diagnosis (ICD-10: F70-79) in inpatient or outpatient care registered in the national patient register between 1990 and 2015 (the outpatient register started in 2001), was also included. The national patient register is managed by the Swedish National Board of Health and Welfare and records details of all health care episodes in Sweden. Non-Swedish and socioeconomic background were also included as potential confounding factors. Non-Swedish background is defined as being born outside of Sweden or having been born in Sweden to foreign-born parents. The adolescent's socioeconomic background was

defined as the mother's educational level at the time of the child's birth, categorized according to the Swedish educational system: compulsory school (≤ 9 years of schooling), secondary school (12 years of schooling), and higher education (>12 years of schooling). Sex and year of birth of the child and maternal age at the time of the child's birth were controlled for, as well as second-order polynomial of maternal age to allow for a non-linear relationship.

Statistical analysis

Statistical significance in the univariable analyses was assessed using χ^2 tests for categorical variables and simple linear regression via ordinary least squares for continuous variables. Logistic regression was used to estimate the likelihood of a school achievement in multivariable analyses, presented as odds ratios with 95% confidence intervals. Ordinary least squares linear regression was used for grade scores; the results present the difference in grade scores associated with a discrete/one-unit change in the independent variables. All multivariable analyses controlled for birth year to capture potential changes over time that can affect educational outcomes. Model fit was assessed with R^2 and (McFadden) Pseudo R^2 . For each school outcome, the association between CP and the outcome in the full sample was estimated. Analyses were then run on the CPUP subsample, controlling for CFCS, MACS, and GMFCS levels respectively. Observations with missing information were dropped. Because of the high correlation between communication skills and gross motor functioning,²³ the final model controlling for sociodemographic factors excluded the GMFCS. Analyses with the GMFCS were run when applicable, and results are reported when relevant. Significance was considered at a 5% level. Stata version 15 (Stacorp, College Station, TX, USA) was used for all statistical analyses.

RESULTS

Table 1 describes the study samples included in the analyses of school outcomes in compulsory and secondary school. Non-Swedish background was more common among persons with CP. Maternal education at the time of the birth of the child was higher among the comparison group, the difference was only significant for compulsory school. Although there was a statistical difference in terms of mother's age, the actual mean difference was less than 1 year. Prevalence of intellectual disability was, as expected, significantly higher among adolescents with CP compared with the comparison group.

School outcomes were much lower in adolescents with CP in the univariable analysis. About one-half received final grades from the ninth grade; of those, the grade score was lower for adolescents with CP. About 36% of the adolescents with CP fulfilled the requirements to study at secondary school, and approximately the same proportion attended secondary school. Of those attending secondary school, 69% fulfilled the basic requirements for university studies compared with 76% of the comparison group.

Table 2 describes the sample stratified by CFCS level. Adolescents with intellectual disabilities and foreign backgrounds were more likely to have reduced communication effectiveness (i.e. higher CFCS levels). School achievement was also significantly negatively associated with communication effectiveness. Results stratified by GMFCS and MACS were similar, but the associations were weaker (Tables S1 and S2, online supporting information).

Tables S3 to S5 (online supporting information) report the results of the multivariable regression analyses: first, in the full sample where persons with CP are compared with the matched general population sample; then, in cases identified in the CPUP only. CP was strongly negatively associated (model 1) with the likelihood of receiving grades in compulsory school (Table S3), fulfilling the requirements for progressing to secondary school (Table S4), and attending secondary school (Table S5). However, the negative associations were substantially smaller in the conditional estimates; conditioned on receiving a final grade, CP was associated with a 29-point lower grade score, which was comparable with the association found for sex at 23 grade points (Table S3). The analysis on fulfilling the requirements for proceeding to university studies was conditioned on attending secondary school and showed a smaller association with CP than other school outcomes (Table S4). All results remain strongly significant when adjusting for multiple hypothesis testing. Controlling for functional abilities—communication, gross motor function, and manual ability (model 2)—indicated that the CFCS had a stronger association with schooling outcomes than MACS or GMFCS. Gross motor function was generally only borderline significant after controlling for the CFCS and MACS.

In the full model (model 3), CFCS was negatively associated with all outcomes, except for fulfilling the requirements for university studies, which is conditioned upon attending secondary school. Manual ability was generally not significant, except for the likelihood of attending secondary school. As expected, controlling for intellectual disability captured a large part of the association between functional ability and school outcomes.

Mother's socioeconomic status and age at birth of the child were associated with grade score in compulsory school, but not for other outcomes when controlling for functional abilities. They were, as expected, strongly associated with school outcomes in the case and comparison group samples.

In model 1 (Tables S3–5), intellectual disability was not adjusted for in order to capture the total association between CP and school outcomes. In Table 3, these results are compared with the regression results controlling for intellectual disability. This reduced the negative association between CP and school outcomes, indicating that although a part of the effect can be explained by intellectual disability, a substantial effect of CP on education remains.

Table 1: Characteristics and school outcomes of adolescents with CP in compulsory school and secondary school, birth cohorts 1990–1996

	Compulsory school			Secondary school		
	CP n=3465	Comparison group n=16 838	Total n=20 303	CP n=2541	Comparison group n=12 299	Total n=14 840
Females	42.1	42.0	42.1	41.9	41.7	41.8
Birth year (mean)	1994	1994	1994	1993	1993	1993
Non-Swedish background	22.2	10.4	12.4	20.5	9.6	11.5
Intellectual disability	44.3	1.1	8.4	44.4	1.0	8.5
Mother's age at birth of child, y:mo	29:11	29:2	29:2	29:4	29:0	29:1
Mother's education at birth of child						
Compulsory	17.9	16.1	16.3	17.8	16.4	16.5
Secondary	56.7	56.4	56.4	57.9	57.1	57.2
Higher	25.5	27.6	27.2	24.3	26.6	26.3
Mother employed at the time of the birth of child	67.8	66.8	67.0	70.4	69.1	69.4
School outcomes						
Received final grades	47.6	96.2	87.9			
Grade score given final grades (mean)	183.7	214.3	211.5			
Fulfilled basic requirements to attend secondary school	35.7	88.4	79.4			
Attended secondary school (final year)				37.3	86.1	77.8
Fulfilled basic requirements for attending university				68.5	75.8	75.2

Data are % unless otherwise stated. Significant differences between cases and comparison group at the 5% level are indicated by bold font (χ^2 test and simple ordinary least squares). CP, cerebral palsy.

Table 2: Characteristics and school outcomes of adolescents with CP in compulsory school and secondary school, birth cohorts 1990–1996, stratified by CFCS level

	Compulsory school					Secondary school				
	CFCS level I (n=414)	CFCS level II (n=120)	CFCS level III (n=110)	CFCS level IV (n=121)	CFCS level V (n=113)	CFCS level I (n=257)	CFCS level II (n=75)	CFCS level III (n=64)	CFCS level IV (n=79)	CFCS level V (n=78)
Females	41.6	42.5	46.4	39.7	40.7	42.4	40.0	43.8	38.0	41.0
Intellectual disability	23.4	55.8	71.8	82.6	93.8	24.5	65.3	73.4	82.3	93.6
Birth year	1995	1995	1995	1995	1995	1993	1993	1993	1993	1993
Non-Swedish background	18.8	25.8	29.1	32.2	26.6	16.0	22.7	20.3	30.4	28.2
Mother's age at birth of child, y:mo	29:5	29:4	29:5	30:11	29:7	29:5	28:10	28:8	30:6	29:6
Mother's education at birth of child										
Compulsory	16.8	15.2	17.1	11.8	17.1	15.3	15.6	20.8	14.0	15.3
Secondary	56.7	61.6	53.7	55.3	59.1	58.7	71.9	62.3	54.4	62.7
Higher	26.5	23.2	29.3	32.9	23.9	26.0	12.5	17.0	31.6	22.0
School outcomes										
Final grades	71.5	32.5	20.9	5.8	0.9					
Grade score given final grades ^a	187.0	163.5	98.4	86.8						
Fulfil basic requirements for attending secondary school ^a	52.9	19.2	6.4	0.8						
Attended secondary school						56.4	18.7	10.9	3.8	1.3
Fulfil basic requirements for attending university						74.3	57.1	14.3	0.0	0.0

Data are % unless otherwise stated. Only participants in the Cerebral Palsy Follow-Up Program in Sweden were included. Significant differences between cases and comparison group at the 5% level are indicated by bold font (χ^2 test and simple ordinary least squares). ^aOnly one individual at Communication Function Classification System (CFCS) level V in the sample received final grades and thus a grade score, and was evaluated for fulfilling the requirement for secondary school. In order not to risk identifying this individual, these results are not shown. CP, cerebral palsy.

DISCUSSION

Adolescents with CP, compared with a matched general population sample, experienced a substantial reduction in school outcomes. This can partly be explained by a higher prevalence of intellectual disability, although CP remains strongly associated with negative school outcomes when controlling for intellectual disability. A wide variation in

school outcomes was noted in adolescents with CP, and a substantial drop in results was noted for any change from level I (i.e. the highest function) in the CFCS, MACS, and GMFCS. The results indicated that, in addition to intellectual disability, it was the inability to communicate effectively that hindered adolescents with CP in their educational endeavours. This is perhaps not surprising, as

Table 3: Sensitivity analysis on the effect of the association between CP and school outcomes when controlling for intellectual disability with 95% confidence intervals

	Base case estimates	Controlling for intellectual disability
Final grades mandatory school	0.04 (0.03–0.04)	0.15 (0.13–0.17)
Attending secondary school	0.10 (0.09–0.11)	0.31 (0.27–0.35)
Fulfilling requirement for secondary school	0.07 (0.07–0.08)	0.21 (0.18–0.23)
Fulfilling requirement for university	0.66 (0.57–0.78)	0.70 (0.59–0.82)
Grade score mandatory school	–28.66 (–31.58 to –25.74)	–25.21 (–28.16 to –22.26)

Base case estimates as shown in column 1 in Tables S3–5 (online supporting information) and are the results of the full case/comparison group sample, where persons with CP are compared with the matched general population sample. Significance indicated at 1% level. CP, cerebral palsy.

effective communication is essential for teachers to be able to evaluate the adolescents' knowledge. However, it does highlight the importance of ensuring that students with CP have access to assistive devices to enable more effective communication. It might also be worthwhile to remind educators not to equate difficulties with communication with intellectual disability. This would entail close collaboration among parents, school professionals, and health practitioners to create a school environment where children with CP can reach their fullest potential.²⁴ Also noteworthy is the indication that children with CP who have a foreign background tend to have lower communication abilities, which could indicate a double burden. However, the underlying reasons for this (e.g. language difficulties or reduced access to assistive devices) are left to future research. The univariable associations between the MACS and GMFCS and school outcomes were almost as large as for the CFCS. However, the results for gross and manual motor functional ability were less clear and difficult to interpret in multivariate analyses. A larger sample size might have indicated a gradient across motor functional levels, at least for compulsory school outcomes. However, it is unclear why gross motor function would be associated with school outcomes to an equal or even higher extent than the MACS while controlling for other disability-specific aspects, including intellectual disability. The GMFCS might capture a functional aspect important in the learning process that MACS failed to capture, or gross motor function level could affect school attendance directly through health status, or indirectly through physical barriers or the rate at which health care services are sought during school hours.

Children with CP, even those in GMFCS level I without intellectual disability, have been found to have lower education than the general population.²⁵ Our results are in line with previous results. It is likely that the findings of lower school achievement are due to both short- and long-term factors. Preschool-aged children with CP have been shown to have less effective communication and other 'school readiness' skills compared with children with typical development.^{22,23} Thus, lower school outcomes of children with CP could partly be due to them having fallen behind from the start. Early intervention might be warranted, or perhaps early intervention

strategies should be re-evaluated. It is also possible that the expectations are lower than for other students, even when not justified.

In a study based on two health care regions in Sweden with a cohort born between 1991 and 1994, 46% and 41% of children with CP, with and without intellectual disability, attended regular schools, although in both cases with extra support.²⁶ This is comparable with the 48% of all adolescents with CP who were evaluated according to the knowledge-based Swedish curriculum in compulsory school in the current study. Overall, this is lower than the 67% of children with CP in mainstream school as noted for Australia.^{13,14} In our study, 36% of children with CP finished compulsory school fulfilling the requirements to proceed to secondary school. This can be compared with an Australian study in which around 30% of the children with CP scored in the range of population norms in standardized educational testing.¹⁴ In Denmark, around 50% of children with CP had continued studies after lower secondary school, which is equivalent in age to compulsory school in the current study.¹² This is higher than what the current study would indicate, but the measures differ, as the current study does not indicate the highest 'lifetime' education, but rather school achievements in connection to 'typical' school progression. Children with CP may take longer to finish formal education or partake in adult education as young adults.

This study had a number of limitations. The extent to which the grades reflect actual educational achievement in the sample is unknown. Although students in Sweden take standardized national tests, these were unavailable for the current study. Data on whether students attending International Baccalaureate or Waldorf secondary schools had fulfilled the basic requirements for university studies were not included and these were therefore excluded ($n=88$). Intellectual disability was identified in the current study as having an ICD-10 F70-79 diagnosis. Given the difficulty and hesitancy of measuring cognition in less clear-cut cases, it is possible that the number of children with CP with a concurrent intellectual disability is either over- or underestimated. More specific information on visual-perceptive and executive functions would have been informative. Given an association between being diagnosed with an intellectual disability and communication difficulties, it

could be difficult to disentangle the associations between the CFCS and intellectual disability and school outcomes. Thus, the relative strength of the estimated results of these two variables should be interpreted with care. Furthermore, other types of disabilities were not assessed in the comparison group.

CONCLUSION

Although gross motor function has been shown to be associated with participation in education and intellectual disability,^{13,25,26} we hypothesized that gross motor function was a proxy of intellectual disability, and that communication ability and fine motor function were more crucial to children's school outcomes.^{26,27} We found that intellectual and communicative disability were the strongest factors associated with school outcomes. However, manual ability appears no more important than gross motor function. It is possible that access to assistive devices can help overcome some issues caused by reduced motor function in the school context.

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DATA AVAILABILITY STATEMENT

Deidentified individual participant data will not be made available by the authors but are available from the register holders after typical application procedures.

SUPPORTING INFORMATION

The following additional material may be found online:

Table S1: Characteristics and school outcomes of adolescents with CP stratified by GMFCS level

Table S2: Characteristics and school outcomes of adolescents with CP stratified by MACS level

Table S3: Multivariable logistic regression on factors associated with the likelihood of receiving final grades in compulsory school and grade score given final grades

Table S4: Multivariable logistic regression on factors associated with the likelihood of fulfilling basic requirements for next educational level

Table S5: Multivariable logistic regression on factors associated with the likelihood of attending secondary school

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