



Determinants of inclusive education of 8–12 year-old children with cerebral palsy in 9 European regions

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ABSTRACT

The principle of inclusive education has been increasingly recognised over recent decades and most countries officially support schooling of children with disabilities in mainstream settings. The SPARCLE study offers the opportunity to report on the schooling practices for children with cerebral palsy according to the nature and severity of their impairments and the schooling policy in European regions. The aim of this paper is to describe the type of schooling of children with cerebral palsy in various European regions after controlling for relevant individual factors. Children aged 8–12 years with cerebral palsy from 9 European regions and their families were interviewed. Our findings support the hypothesis that between-region variations in the type of schooling are still significant after adjustment for individual factors; and that motor function and intellectual ability have different effects on inclusion in mainstream school, depending on the region.

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1. Introduction

The principle of inclusive education has been increasingly recognised over recent decades and all countries officially support schooling of children with disabilities (Graves & Tracy, 1998; Jenkins, Jewell, Leicester, Jenkins, & Troutner, 1991; Meijer, 2003) into mainstream settings as it is “the most effective means of building an inclusive society and achieving education for all” (UNESCO, 1994). However the United Nations Standard Rules (United Nations, 1993) allow education in special settings if the general school system does not yet adequately meet the needs of all children, for example by not providing suitable support and accessibility.

The European Agency for Development in Special Needs Education (EADSNE) classifies countries into three categories, according to their policy and practice for schooling of children with disabilities and the extent of exceptions to a mainstreaming principle (Meijer, 2003). In the one-track approach, almost all children receive mainstream education. In the two-track approach, two distinct systems are maintained, pupils with special educational needs (SEN) usually being placed in special schools or special classes which often do not follow the mainstream curriculum. The multi-track approach provides a variety of services ranging from the mainstream to the special needs education systems.

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Most European countries (such as Denmark, France, Ireland and England) currently have a multi-track approach, but a few countries like Italy and Sweden have a one-track approach. Since the 1970s, Italy has supported full inclusion of disabled pupils in ordinary schools. Sweden also supports “a school for all” and has closed many of its special schools or changed them to resource centres in recent years (National Agency for Special Needs Education and Schools, 2012). In France the right of disabled children to be schooled in mainstream settings was recognised in legislation as early as 1975 but the percentage of such children included in mainstream education remained substantially lower than the number attending special schools until recent years when a new policy (2005) reinforced the right to inclusive education for all disabled children and adolescents. In Denmark, the inclusion policy is not absolute and special education or educational assistance is provided for children whose development requires special consideration or support. The UK and Ireland explicitly assert the need to retain a continuum of provision, often with encouragement for pupils to move from one type to another. Germany is moving from a two-track to a multi-track approach. However despite the advocacy of inclusive education in all these countries, most report difficulties in practice, mainly due to lack of resources (Meijer, 2003; Tisdall, 2006a).

Data from official ministerial sources of European countries were compiled by EADSNE in 2008 (Watkins, 2008) and provide information on educational location of pupils with SEN in most European countries, indicating substantial variation between countries. In some countries that support a one-track approach, pupils with specific disabilities can attend special schools. In Sweden, pupils who have visual impairment, severe speech and language disorder, deafness and learning difficulties normally attend special schools. In Italy, there are a few special schools attended by a minority (2.1%) of pupils who are deaf, blind, or have multiple disabilities or severe communication disorders, especially autism (sources from the Ministry of Education, Universities and Research in Italy). Among countries with a multi-track approach, the percentages of pupils with SEN who attended special schools varied from 22% (in Denmark) to 41% (in England). However, this not only reflects different stages on the path to full inclusion, but also varying registration of SEN partly due to the diversity between countries in the legal definitions of SEN (Watkins, 2008). Therefore, well defined groups of children with SEN should be studied in order to evaluate different types of schooling and be confident about comparisons across countries.

In the Study of Participation of Children with Cerebral Palsy Living in Europe (SPARCLE) (Colver, 2006), we examined the role of environment in determining the participation and quality of life of children with cerebral palsy (CP) across nine European regions. The study provides the opportunity to report on the schooling practices for children with CP according to the nature and severity of their impairments and the schooling policy in each region. In this paper we aim to describe the type of schooling of children with CP in various European regions after controlling for relevant individual factors. We hypothesized (1) that between-region variations in the type of schooling would still be significant after adjustment for individual factors (child and family characteristics) and (2) that individual factors related to schooling would have a different effect on inclusion in a mainstream school, depending on the region.

2. Participants and methods

2.1. Participants

Children aged 8–12 years were recruited from eight CP population-based registers in North England, West Sweden, Northern Ireland, South-east France, South-west Ireland, East Denmark, Central Italy and South-west France; additionally, North-west Germany recruited children with CP from various sources. The participating regions shared the same definition of CP and classification according to the type and severity of impairments (Surveillance of Cerebral Palsy in Europe, 2000). A total of 818 children with CP born from 31 July 1991 to 1 April 1997 and families agreed to participate. The detailed protocol, sampling strategy, participation rates and potential bias in the SPARCLE study is described elsewhere (Colver, 2006; Dickinson et al., 2006). The children were visited at home by trained researchers in 2004–2005. Ethical approval was sought from the appropriate body in each country. Written parental informed consent and child assent were obtained.

2.2. Measures

Parents were asked to report on the type of school their child attended: (1) mainstream school, (2) mainstream school with visits to special unit, (3) special unit in mainstream school, or (4) special school. For analyses in this paper, groups (1) and (2) were collapsed to “mainstream school”. The following individual factors were collected: age, gender, gross motor function (according to the Gross Motor Function Classification System (GMFCS) (Palisano et al., 2000)), intellectual function, vision, seizures in the previous year, and communication. Child behaviour and emotional health were measured by the parent-completed version of the Strengths and Difficulties Questionnaire (SDQ) (Goodman, 2001). Socio-demographic variables collected were area of residence, family structure, parental level of education and child’s siblings (response options are detailed in Table 2).

2.3. Statistical analysis

Because regions with sufficient registered cases (North England, East Denmark, West Sweden, Northern Ireland) did not sample all children identified in the register but rather selected children with a probability that depended on their level of severity of the CP, weighted percentages (to take into account the sampling strategy (Dickinson et al., 2006)) of children in

each schooling category were calculated separately for each region and compared using a Chi-square test. The distribution of type of schooling by individual factors is reported for the total sample. To determine the influence of inclusion policy in each region on the likelihood of children with CP attending mainstream school, children were classified into two groups depending on whether they received mainstream education or special education (special units and special schools; respectively groups (3) and (4)). Multilevel logistic regression models were then constructed to relate region (considered as a random effect) and individual factors to schooling. The regression model did not take the weights from the sample strategy into account but the sources of unequal selection probabilities were controlled for in the covariates (with the random intercept for region and adjustment for motor impairment) (Dickinson et al., 2012). Visual impairment was not considered in the regression models because only two children with visual impairment attended mainstream school. Variables showing a significant univariate association with schooling at a 20% level were included in the first multivariable model. A backward stepwise procedure was then used to remove variables from the model. Likelihood ratio tests (LR-tests) were used to test for the significance of the association between the fixed effects and schooling. These analyses excluded children with at least one missing value for any of the variables included in the first model. All interactions between the individual factors were tested in the final multivariable model. The significance of the region effect (heterogeneity between regions) was tested by comparing the final multivariable multilevel model with a similar model that did not allow for clustering within region (LR-test). Regional level variations were quantified using the median odds ratio (MOR) based on the multilevel models (Merlo et al., 2006). A MOR of one indicates that there is no difference between regions in the odds of schooling in mainstream school; and the higher the MOR the more important the region effect for explaining type of schooling. Finally, interactions between individual factors and regions were tested in the final model by adding random slopes for the individual factors to the model. The significance of the random slopes was tested with a LR-test. The adequacy of the model was examined using ROC (receiver operating characteristic) curve analysis; and the assumption of normality of the random effects was verified. Data analyses were undertaken with Stata v.11 software (StataCorp, 2009). The *xtmelogit* command was used to implement the multilevel logistic regression models. For all the analyses, the significance level was set at 5%.

3. Results

Type of schooling was known for 804 out of the 818 children with CP in the study. The percentages of children by schooling categories in each region (and their 95% confidence intervals) are given in Table 1. Overall, 54% of the children with CP attended mainstream schools, with significant differences between regions (from 20% in North-west Germany to 98% in Central Italy; $p < 0.001$).

Table 2 summarizes the type of schooling according to individual factors. All the impairment variables were significantly related to schooling, children with more severe impairments being more likely to attend a special class/school. Regarding other factors, no statistical difference was found in type of schooling according to socio-demographic characteristics (gender and age) or family factors.

Fig. 1 shows the regional patterns of type of schooling of children with CP according to the nature of their impairments. Depending on the region, between 0% and 94% of the children with severe motor impairment (GMFCS IV–V) were in mainstream schools. Likewise, regions varied substantially in the proportion of children with seizures in the previous year who were in mainstream schools (proportion ranged from 0% to 95%). Regional variation was also found for inclusion of children with IQ ≤ 70 (proportion: 0–96%) and of those who had mild or severe communication problems (proportion: 0–96%). Children with severe visual impairment were mostly schooled in special classes or schools in all regions (not shown in Fig. 1).

Table 1
Type of schooling in nine European regions ($n = 804$ children with CP).

Centre	<i>n</i>	Type of schooling					
		Mainstream school		Special unit		Special school	
		% ^{a,b}	95%CI ^c	% ^b	95%CI ^c	% ^b	95%CI ^c
Central Italy	85	97.6	[91.1; 99.4]	0.0	–	2.4	[0.6; 8.9]
South-west Ireland	93	72.0	[62.1; 80.2]	5.4	[2.3; 12.3]	22.6	[15.2; 32.2]
North England	115	60.9	[51.1; 69.9]	5.5	[2.5; 11.7]	33.6	[25.1; 43.2]
Northern Ireland	99	50.8	[40.2; 61.4]	4.2	[1.3; 12.9]	45.0	[34.9; 55.5]
South-west France	77	48.1	[37.1; 59.1]	1.3	[0.2; 8.7]	50.6	[39.6; 61.6]
East Denmark	113	47.0	[37.6; 56.6]	16.8	[10.8; 25.3]	36.2	[27.8; 45.6]
Western Sweden	81	45.2	[33.8; 57.1]	24.5	[14.7; 37.9]	30.3	[20.6; 42.1]
South-east France	66	33.3	[23.0; 45.5]	15.2	[8.3; 26.0]	51.5	[39.6; 63.3]
North-west Germany	75	20.0	[12.4; 30.6]	12.0	[6.4; 21.5]	68.0	[56.6; 77.6]
Total	804	53.6	[49.7; 57.5]	10.0	[7.7; 12.8]	36.4	[32.8; 40.2]

^a In descending order of proportion in mainstream school.

^b Percentages taking the sampling weights into account.

^c CI: confidence interval.

Table 2

Distribution of children with CP according to type of schooling and individual factors (804 children with CP, nine European regions).

	Type of schooling			<i>p</i> -Value Pearson's χ^2
	Mainstream school % ^a	Special Unit % ^a	Special School % ^a	
Motor impairment (GMFCS)^b				<0.001
Walks and climbs stairs (GMFCS I)	75.6	8.4	16.0	
Walks inside (GMFCS II)	62.6	12.6	24.8	
Walks with limitations (GMFCS III)	40.5	12.5	47.0	
Moving about is limited (GMFCS IV)	35.3	13.0	51.7	
Moving about is severely limited (GMFCS V)	14.9	4.0	81.1	
Seizures during previous year				<0.001
No	60.2	9.9	29.9	
Yes	27.3	10.4	62.3	
Intellectual impairment				<0.001
IQ > 70	83.8	7.2	9.0	
IQ ≤ 70	22.5	12.9	64.6	
Vision				<0.001
Has useful vision	55.2	10.4	34.3	
Blind or no useful vision	25.6	1.6	72.8	
Communication				<0.001
Normal	72.5	10.6	16.9	
Mild or severe difficulties	24.3	9.0	66.6	
SDQ score total – grouped				0.036
Normal	60.0	9.0	31.0	
Borderline	47.3	12.4	40.3	
Abnormal	46.3	10.7	43.0	
Gender				0.137
Male	52.9	11.9	35.2	
Female	54.7	7.0	38.3	
Child's age (years)				0.128
7–10	56.6	8.6	34.8	
11–13	48.8	12.2	39.0	
Area of family domicile				0.260
Urban	54.2	11.0	34.8	
Rural	52.2	7.8	40.0	
Median qualification of parents				0.329
Above university entry	57.3	12.3	30.4	
Above lowest qualification up to university entry	53.7	9.4	36.9	
None or lowest formal qualification	49.6	8.7	41.7	
Family structure				0.245
Married or living with partner	54.8	8.9	36.3	
Single	49.7	13.9	36.3	
Siblings				0.410
No siblings	51.4	12.5	36.1	
Siblings – none disabled	55.1	9.7	35.2	
Siblings – some disabled	45.6	8.6	45.8	

^a Percentages taking the sampling weights into account.^b GMFCS: gross motor function classification system.

To determine which of the individual factors were independently associated with mainstream schooling and whether these factors could explain the heterogeneity between regions, we constructed multilevel logistic regression models relating mainstream schooling to both individual factors and region. We excluded Central Italy from these analyses because only two children there were in special educational settings. North-west Germany was also excluded because of the specific schooling profile according to impairments (i.e. all children with severely limited gross motor function (GMFCS IV or V), all of those with seizures or IQ ≤ 70 or severe visual impairment or communication problems were in special educational settings). After the additional exclusion of 29 observations due to missing values on some of the variables that were identified as significantly related to schooling at the 20% level in the univariate analyses, the analyses were performed on the remaining 615 children. GMFCS was treated as a continuous effect, as the outcome linearly increased as the GMFCS category decreased. After adjustment for individual impairments (GMFCS, IQ category, communication and seizures), the child's age became significant, and child's age and impairments remained significantly and independently related to schooling in the final

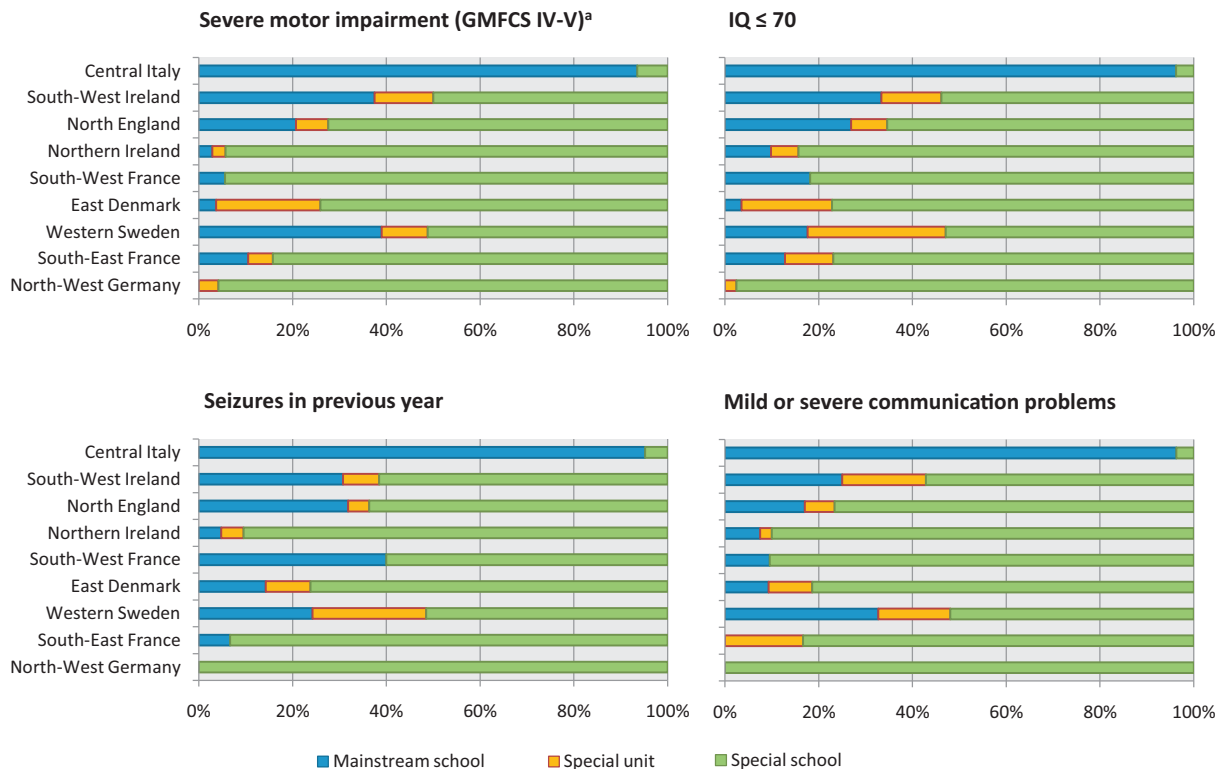


Fig. 1. Distribution of type of schooling (in %) according to the nature of impairments in children with CP in 9 European regions.

Note: Vision impairment is not represented because few children were classified as blind or with no useful vision.

^a Categories GMFCS IV and V were collapsed to "Severe motor impairment".

multivariable model (Table 3). We found a very strong association between IQ level and type of schooling, with a significant interaction with child's age: children with $IQ > 70$ were much more likely than children with $IQ \leq 70$ to be in a mainstream school if they were over 11 years old. However, the behavioural and emotional problems of the child with CP were not associated with the type of schooling, after controlling for other impairments. After adjustment for individual factors, the regional variations were still significant ($p < 0.001$ according to the LR-test). The increase in MOR values after adjustment for individual factors related to schooling (2.7 in the final model compared to 1.5 in the empty model) indicated that these factors (age, IQ category, GMFCS, seizures or communication) did not explain the variations between regions. On the contrary, they were hiding an even larger heterogeneity between regions in schooling of children with CP.

In addition a significant random slope variance was found for GMFCS, indicating that the relationship between GMFCS and the probability of inclusion in a mainstream school differed significantly between regions ($p = 0.010$ according to the LR-test). Moreover, we found that the model assuming that the random intercept and slope for GMFCS were correlated performed better than the model with an independent correlation matrix ($p = 0.004$ according to the LR-test). The association between IQ and the probability of inclusion in a mainstream school also varied significantly between regions. No regional variation was found in the relationship between mainstreaming and either seizures or communication.

4. Discussion

The SPARCLE study provided descriptive data on schooling of 8–12 year-old children with CP in various European regions. The child's age and impairments (gross motor impairments, IQ, seizures and communication) were significantly and independently related to the type of school they attended, but their emotional and behavioural problems were not. The regional variations related to schooling were still significant after adjustment for these factors, indicating that two children with the same impairment (in terms of motor impairment, IQ, seizures or communication) but from two different regions did not have the same chance of being in a mainstream school. In other words, our findings showed additional effects on inclusion in mainstream school related to region which were not explained by impairments. Further analyses indicated significant heterogeneity between regions in the relationship between schooling and severity of both motor impairment and IQ. Thus, our findings support the main hypotheses that national practices influence inclusion of children with CP, especially for those with motor impairment or intellectual impairment.

Table 3

Final multilevel multivariable logistic regression model of the school type (mainstream school versus special education) (615 children with CP; Central Italy and north-west Germany excluded).

	OR	[95% CI]	<i>p</i> > <i>z</i>
IQ category			
7–10 years old			
IQ ≤ 70	1.0		
IQ > 70	8.2	[4.3; 15.3]	<0.001
11–13 years old			
IQ ≤ 70	1.0		
IQ > 70	36.4	[14.8; 89.7]	<0.001
GMFCS			
Linear assumption ^a	1.7	[1.3; 2.0]	<0.001
Seizures during previous year			
Seizures	1.0		
No seizures	2.3	[1.1; 4.6]	0.021
Communication			
Mild or severe problems	1.0		
Normal	5.9	[3.2; 10.8]	<0.001

Note: Adjusted odds ratio (OR), confidence intervals (CI) and *p*-value from Wald test come from multilevel logistic regression models with random intercept for region.

Estimation of the median odds ratio (MOR) = 2.7.

^a Level of gross motor impairment (GMFCS) entered as continuous variable. The odds ratio thus indicates the increase “in chance” of being in mainstream school from the *i*th category to the (*i* – 1)th category of GMFCS.

All types of impairment studied were found to be independently associated with the type of schooling and, as expected, a particularly strong relationship was found with intellectual impairment, which was stronger for older children. Educational policy of all seven countries studied is in favour of inclusion of children with disability, and divisions between mainstream and special schools have become less and less marked (Tisdall, 2006a). However, two points are suggested by our results. Firstly, and as previously reported (Tisdall, 2006b; Watkins, 2008), children with visual impairment continue to attend segregated special schools in all countries (including Italy). Secondly, children with a more severe impairment are seldom schooled in a mainstream setting, whatever the type of their impairment. Additionally, we have observed that the association between emotional and behavioural problems and type of schooling was significant in bivariate analyses, but did not remain significant after adjustment for gross motor impairment, IQ, seizures and communication.

Several barriers have been identified to an inclusive school environment for children with physical disabilities: a lack of assistance for those with special needs (Pivik, McComas, & Laflamme, 2002); poorer access for children with a severe motor impairment than for less impaired children to the physical environment, transport and social support that they need at school (de Graaf, van Hove, & Haveman, 2011). Environmental barriers are not only physical; children with a disability generally experience lower social acceptance from peers. In a recent review, it was reported that children with a disability or chronic illness, such as a psychiatric diagnosis, learning difficulty or physical impairment were at an increased risk of peer victimization at school (Sentenac et al., 2012). Attitudes have been shown to be more negative towards peers with cognitive disabilities than those with physical disabilities (Furnham & Gibbs, 1984). In a study carried out in France, Vignes et al. (2009) found that the presence in the school of a special class for children with psychological and cognitive disabilities was independently associated with negative attitudes towards peers with disabilities.

Our findings are consistent with previous studies showing regional variations in type of schooling after controlling for individual factors (Meijer, 2003; Riddell, Tisdall, Kane, & Mulder, 2006). Initiating change in institutions and practices may present difficulties at national and especially at local level. Although it is important for countries to support principles of inclusive education, national policies need to be adapted to varying regional situations (Kyriazopoulou & Weber, 2009). According to the Italian government, the Italian model of full inclusion does present some problems. For example, services are not universally available throughout the country, “especially in small places like small towns and villages, where the involvement of the local administration is still insufficient to guarantee that all disabled pupils can exercise their right to study” (Tisdall, 2006b). Although the availability of services has a geographical component, the number of pupils with disability within a school is also decisive. Indeed, schools attended by a large number of pupils with disability tend to provide better services than schools with a small number of pupils, due to the fact that small administrations cannot afford big expenses. A complex picture also emerges regarding inclusiveness within Sweden’s school system (Göransson, Nilholm, & Karlsson, 2011). In a recent critical analysis of the national educational system, Göransson questioned Sweden’s one-track approach to inclusion. At the national level, official policy supports the concept of inclusive education, but in practice a lot of segregated solutions in terms of special settings are implemented at the local level. With more than 30% of CP children schooled in a special setting in Sweden, our findings concur with those of Göransson. Our study illustrates the heterogeneity of local policies within a country: in the two French regions (South-west France and South-east France), the percentage of children with CP in mainstream schools differed (48% and 33% respectively); likewise the percentage in special units

(1.3% and 15% respectively). In France, legislation in 1982 relating to decentralization of administrative and political power has given a greater role to departments and regions, whose role is especially important in the creation of special educational units. To better understand inclusive education, future research could examine policy and practice at the national level, at the local regional/municipality level and at the school level.

To our knowledge, this study is the first to explore the type of schooling of children with disability according to the nature and severity of their impairment, using a population-based sample from several European countries with different national inclusion practices. Our study is based on a large sample of European children with CP, representative of disabled children with a range of impairments. The study has some limitations. Regarding the schooling measure, in our analysis we chose to group children who were in a special unit in mainstream school with those in special school, because we suspected that most children in special units have few contacts with non-disabled children. However we have not actually measured this. The decision to analyse the type of schooling in two categories rather than four categories was also made because definitions of schooling categories may differ between countries, due to differences in national systems. Future research should explore this issue further. Also we had difficulties in modelling our hypothesis because of specific regional profiles. For this reason, Italy and Germany were not included in the multilevel analysis in order to allow analysis of a more homogenous sample. Further analyses indicate that for GMFCS, the random slope and random intercept model performed better than the random intercept model only if we allowed a non-zero correlation between the intercepts and the random slopes. These results lead to the conclusion that the regions where the probability of inclusion in mainstream was high were also the regions where GMFCS had a low impact on the probability of inclusion in mainstream school. However, as the correlation between the random intercepts and the random slopes was estimated at -1 exactly, we cannot affirm that this result is not an artefact. As for the random slope estimated for IQ, we recognize that our results may suffer from small samples by region. For example, we have very few children with a severe motor impairment (GMFCS IV and V) who are in mainstream school in Northern Ireland, South West France and East Denmark.

5. Conclusion

In conclusion, nearly half of all children with CP are currently educated in special settings, despite the common goal of inclusive education; and substantial regional variations in the proportions of children included in mainstream schools suggest national policies and/or their implementation are responsible for this. Further work in SPARCLE will allow exploration of how participation in everyday activities and the quality of life of children and adolescents with CP are related to the type of schooling in Europe, as well as how special and mainstream schools fulfil the needs of the children in the physical and attitudinal environment. Although every child has a fundamental right to be schooled in a mainstream setting, it is necessary to consider the well-being of the children in the process of selecting between special to mainstream settings.

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