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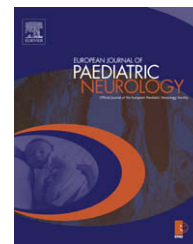
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Original article

Frequency of participation of 8–12-year-old children with cerebral palsy: A multi-centre cross-sectional European study

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ABSTRACT

Participation in home, school and community is important for all children; and little is known about the frequency of participation of disabled children. Frequency of participation is a valuable outcome measure for evaluating habilitation programmes for disabled children and for planning social and health services.

We investigated how frequency of participation varied between children with cerebral palsy and the general population; and examined variation across countries to understand better how the environmental factors such as legislation, public attitudes and regulation in different countries might influence participation.

We undertook a multi-centre, population-based study in children with and without cerebral palsy. Working from the Life-H instrument, we developed a questionnaire to capture frequency of participation in 8–12-year-old children. In nine regions of seven European countries, parents of 813 children with cerebral palsy and 2939 children from the general populations completed the questionnaire.

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Frequency of participation for each question was dichotomised about the median; multi-variable logistic regressions were carried out.

In the general population, frequency of participation varied between countries. Children with cerebral palsy participated less frequently in many but not all areas of everyday life, compared with children from the general population. There was regional variation in the domains with reduced participation and in the magnitude of the differences. We discuss how this regional variation might be explained by the different environments in which children live. Attending a special school or class was not associated with further reduction in participation in most areas of everyday life.

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1. Introduction

Participation in home, school and community life is important for all children if they are to develop a healthy identity and become active, independent members of society.

The International Classification of Functioning, Disability and Health (ICF) defines participation as involvement in life situations.¹ Participation is the extent to which a person is actively involved in, for example, getting about, doing sports or meeting friends; it is not what a person can or wants to do.

From the point of view of equity and human rights, it is important to know whether disabled children participate less than the general population. Measuring participation of disabled children is also important at the population level for planning habilitation and public health interventions; and at the individual level to allow monitoring over time and to provide a baseline from which to judge the effectiveness of interventions.² Impairment and socio-economic position partly predict participation.^{3–5} However, the ICF emphasises that participation is also influenced by a person's environment and evidence for this has been reported.⁶ Comparison of participation of children with similar levels of impairment in different countries – after allowing for differences between countries in participation of children in the general population – might help us to understand which parts of the environment such as legislation, public attitudes and regulation are important for participation.

Children with cerebral palsy (CP) have a range of physical and mental impairments, typically present in many disabled children. The aim of the paper is to see if there are differences in frequency of participation between children with CP and children in the general population and, if so, whether such differences persist across nine European regions once adjustment has been made for the variation across the regions in the frequency of participation of the general population.

2. Materials and methods

2.1. Instrument to measure frequency of participation

The ICF recognises potential overlap in the concepts of activity (execution of a task by an individual) with participation (involvement in a life situation) and therefore classifies both across the same domains. We consider the concepts to be distinct and wanted to examine frequency of participation in its

associated social context,⁷ because it is of intrinsic importance and allows comparison with the general population. We also wanted to capture participation independently of any adaptations or assistance needed by the child to accomplish it.

We used the Life-H instrument as the conceptual and content framework for the items on frequency. This instrument^{2,4,8,9} measures participation across the ICF domains; it was designed for disabled children and has been used by children with cerebral palsy.¹³ It assesses whether participation is achieved and with how much difficulty and assistance, but does not capture frequency. We chose items so that frequency was meaningful to the concept – items such as “maintaining a loving relationship with someone” or “communication with someone” being excluded. And also so that items were relevant to both disabled children and the general population. In practice this meant the items were discretionary and “activity type” items in Life-H such as toileting, sleeping, moving around the home were excluded because they would always be done by children in the general population without difficulty. Two topics from the Life-H to do with helping in the garden and using a telephone were excluded because of their similarity to other items.

The resulting Frequency of Participation Questionnaire (FPQ) had 14 questions, each with six response options for different frequencies (from never to a few times a week). Parents completed the questionnaire. The questions are shown in Table 1.

The FPQ was translated into French, Italian, Danish, Swedish and German according to international guidelines.¹⁰ The translations allowed for cultural differences and so some questions were slightly modified for different countries. However, an inconsistency in translation was observed after administration of the Danish questionnaire to the general population; consequently the question on using a computer was excluded from analyses of Danish children.

2.2. Children with cerebral palsy

The study was part of a wider study of children with CP living in Europe (SPARCLE) which examines how participation and quality of life of 8–12-year-old children with CP relate to their environment.¹¹ Eight regions, from six European countries with population-based registers of children with CP, participated in the study: north England, west Sweden, northern Ireland, southeast France, southwest Ireland, east Denmark, central Italy and southwest France. A further region in

Table 1 – Relationship of items in the Frequency of Participation Questionnaire to the domains of LIFE-H and ICF.

FPQ item	Content	LIFE-H domain	ICF domain
1. Eating out	Eat out at restaurants, cafes or fast food outlets	Nutrition	Interpersonal interactions and relationships
2. Relaxing pursuits	Do relaxing leisure activities	Fitness	Self-care
3. Using a computer	Use a computer	Communication	Communication
4. Housework	Help with housework (e.g. light cleaning, making bed, tidying up, etc.)	Residence	Domestic life
5. Riding a bicycle or wheelchair	Ride a bicycle, tricycle, rollerblades, wheelchair for pleasure	Mobility	Mobility
6. Shopping	Shop or do things for others outside of the home (e.g. choosing and paying for things, going to shops, etc.)	Responsibility	Domestic life
7. Community groups	Join in organised group activities outside school (e.g. scouts, brownies, youth club, etc.)	Community	Community, social and civic life
8. School pursuits	Join in activities organised by the school (e.g. school trips, field days, etc.)	Education	Major areas of life
9. Sports	Play sports or outdoor games	Recreation	Community, social and civic life
10. Non-sporting games	Play non-sporting games (e.g. card games, board games, electronic games, etc.)	Recreation	Community, social and civic life
11. Watching sports	Go to sports events (e.g. football, cricket, hockey, etc.)	Recreation	Community, social and civic life
12. Craft pursuits	Do art or craft activities (e.g. music, dance, arts and crafts, etc.)	Recreation	Community, social and civic life
13. Watching cultural events	Go to concerts, cinema, theatre, etc.	Recreation	Community, social and civic life
14. Tourist pursuits	Take part in touristic activities (e.g. holidays, travelling, weekend breaks, etc.)	Recreation	Community, social and civic life

northwest Germany recruited children from multiple sources; the age, gender, and levels of impairment were similar to those of children on the population-based registers.¹²

Children with CP born between 31/07/1991 and 01/04/1997 were eligible and interviewed, if possible, between their 8th and 13th birthdays. In regions with sufficient numbers, children were grouped by walking ability and random samples selected from within strata. In other regions, all eligible children were approached. Thirty-seven percent of the families sampled did not participate in the study, due to families not being traceable or declining to participate.¹²

Table 2 shows the characteristics of the 818 children with CP who joined the study; The children had a mean age of 10 years and 5 months, 59% were male and the FPQ was completed by a parent for 813 (99%) of them.

Parents provided information about their employment status, educational qualifications, and their child's gross motor function,¹³ fine motor function,¹⁴ seizures, feeding, communication, intellectual ability, vision, hearing, school type and siblings. CP type was available from the registers. Frequency and severity of pain were captured using the two questions about pain in the Child Health Questionnaire.¹⁵

2.3. Children in the general population

The FPQ was distributed to the parents of around 4800 children aged 8–12 years in schools in areas covered by the CP registers (Table 3); 2939 complete questionnaires were returned, an overall response rate of 62% (ranging from 51–89% between regions). The mean age of the children was 10 years, 2 months and 50% were male.

Schools were selected according to geographical environments (rural, provincial, urban, metropolitan) and socioeconomic characteristics (for example, percentage of children

receiving free-school meals). Teachers facilitated the distribution and collection of questionnaires. Parents were also asked about their child's age and gender and indicators of family affluence (number of cars, bedrooms, holidays and computers) which allowed the family affluence score to be calculated.^{16,17}

In the SPARCLE study two countries, France and UK, had two regions involved. General population data were collected from only one region in each of these countries: southwest France and north England.

2.4. Statistical methods

The FPQ has face validity as the questions are derived from the content of the Life-H.⁹ The responses to each FPQ question were dichotomised into “high” or “low” participation at the median of the combined general and CP population. The median was chosen as the lowest value (0–5), which at least half the children had answered lower than or equal to. In a few questions all children used only a few of the values, so using the aforementioned definition gave a cut off value which more than three quarters of the children had answered either above or below. In these cases the closest (either lower or greater) value which gave a dichotomisation into groups of at least 25/75% was used. We investigated the use of a sum-score of the six questions in the recreation domain, but found that this was not a valid summary measure since each of the items depended not only on the sum-score but also on other factors. Therefore, each FPQ question was considered separately. We did not undertake assessment of intra- and inter-observer reliability.

The question on relaxing leisure pursuits was omitted from subsequent analyses because almost all answers indicated a high frequency of participation. Children with CP were assigned sampling weights that allowed for both the sampling

Table 2 – Socio-economic, demographic and impairment characteristics of children with cerebral palsy for each region, the percentage of children in each group is shown (except for number and age of children).

	North England	West Sweden	Northern Ireland	Southeast France	Southwest Ireland	East Denmark	Central Italy	Southwest France	Northwest Germany	All
Children participating (N)	116	83	102	67	98	115	85	77	75	818
Mean age	10 y 4 m	10 y 7 m	10 y 4 m	10 y 5 m	10 y 5 m	10 y 6 m	10 y 5 m	10 y 3 m	10 y 1 m	10 y 5 m
Range	7–13 y	8–12 y	8–13 y	8–12 y	7–13 y	7–13 y	7–13 y	7–13 y	7–12 y	7–13 y
Gender: % males	64	53	62	58	54	63	55	62	57	59
<i>Siblings</i>										
None	17	16	21	13	11	21	34	23	19	19
One or more, none disabled	66	78	68	75	69	69	59	66	65	68
One or more, some disabled	15	5	9	12	15	10	2	10	16	11
Unknown	2	1	2	0	4	0	5	0	0	2
<i>Type of school</i>										
Normal	59	47	41	33	68	45	93	55	20	52
Special	41	52	56	66	27	53	7	45	80	46
Unknown	1	2	3	1	5	2	0	0	0	2
<i>Gross motor function</i>										
I Walks and climbs stairs	33	18	17	42	38	39	28	47	24	31
II Walks inside	20	18	31	15	22	16	20	14	21	20
III Walks with limitations	27	12	17	13	11	22	15	16	23	17
IV Moving about is limited	11	22	14	6	12	14	22	10	12	14
V Moving about is severely limited	15	30	22	24	16	10	14	13	20	18
<i>Intellectual impairment</i>										
None or mild: IQ > 70	54	35	48	39	55	49	38	56	44	47
Moderate: IQ 50–70	17	29	23	31	23	32	14	18	17	23
Severe: IQ < 50	28	35	29	28	20	19	48	25	39	30
Unknown	0	1	0	1	1	0	0	1	1	1
<i>Pain</i>										
No pain in previous month	29	25	22	24	36	29	16	27	43	28
Pain in previous month	70	72	77	72	62	70	82	71	57	71
Unknown	1	2	1	4	2	1	1	1	0	1
<i>Parents' educational qualifications</i>										
Above university entrance	16	23	9	33	23	53	31	27	4	25
Higher school qualification	45	66	42	46	47	43	49	55	80	51
Lowest formal school qualification or no school qualification	38	8	48	27	29	4	20	16	16	24
Unknown	0	2	1	0	1	0	0	3	0	1
<i>Parents' employment</i>										
Full time	22	19	23	27	21	36	32	31	40	28
Full time trade	34	59	43	57	57	47	48	61	45	49
Part time	8	16	9	7	8	7	2	3	9	8
Neither works	35	6	25	7	12	10	15	4	5	15
Unknown	0	0	0	1	1	1	2	1	0	<1

strategy and family non-response. Sampling weights were not used in the frequency tables.

For children with cerebral palsy, multivariable logistic regression was used to assess whether high/low participation on each item was related to age, gender, type and level of impairment, pain, socio-economic and demographic variables and region. Age was grouped as 7–9, 10–11 and 12–13 years to ensure adequate cell frequencies. Initially all variables were included in the model and backwards elimination was performed, successively removing the least significant variables ($p > 0.01$). All analyses excluded children with missing values

on relevant covariates. Interactions were not considered due to the sparseness of the data. As severity and type of school are heavily correlated, we did not include type of school. In a further logistic regression we additionally included the interaction between type of school and country to investigate the effects of severity and of type of school simultaneously.

For children in the general population, multivariable logistic regression was used to assess how high/low participation on each item was related to their region of residence, after adjusting for age, gender and family affluence score. Interactions were not considered due to the sparseness of the data.

Table 3 – Recruitment, socio-economic and demographic characteristics of children from the general population.

	North England	West Sweden	Southwest Ireland	East Denmark	Central Italy	Southwest France	Northwest Germany	All
<i>Recruitment</i>								
Selection criteria for schools	Socio-economic	Socio-economic	Geographic	Geographic	Geographic	Socio-economic and geographic	Socio-economic and geographic	
Representativeness of selected schools in relation to area covered by the CP register	Yes	Partly: ethnic minority and middle-class children over-represented.	Yes	Partly: urban environment missing.	Partly: urban environment missing.	Partly: rural area missing.	Yes	
Approach method	Letter and telephone call to headmaster. Children collectively addressed in hall.	Letter and telephone call to headmaster. Colleagues/friends approached. ¹	Personal conversation with headmaster followed by letter.	Letter and telephone call to headmaster.	Personal conversation with and telephone call to headmaster.	Telephone call and letter to headmaster.	Letter and telephone call to headmaster.	
Number of schools participating/ approached	5/8	1/1	2/2	3/5	7/8	2/2	10/13	30/39
Type of material distributed	Letters to headmaster and parents.	Letters to headmaster and parents, e-mail to teacher.	Letters to headmaster, teacher and parents.	Letters to headmaster, teacher and parents.	Letters to headmaster, teacher and parents.	Letters to headmaster, teacher and parents.	Letters to headmaster and parents.	
Distribution method	By research associate to pupils.	By teachers to pupils.	By headmaster to pupils.	By teachers to pupils.	By teachers to pupils.	By teachers to pupils.	By headmaster, teacher and research associate to pupils.	
Collection method	By mail to research associate.	By mail to research associate.	By pupils to school then collected by research associate.	By mail to research associate. By pupils to school then collected by research associate.	By pupils to school then collected by research associate.	By pupils to school then collected.	By pupils to school then collected by research associate.	
Response rate (%)	51	51	60	63	89	Unknown ²	64	62 ²
Number of included children	379	102	448	336	247	280	1124	2939
Mean age	10 y 10 m	10 y 3 m	10 y 4 m	10 y	10 y 2 m	10 y 11 m	9 y 10 m	10 y 2 m
Age range	8–14 y	8–13 y	8–13 y	7–14 y	8–12 y	8–14 y	7–14	7–14 y
Gender: % males	52	60	54	49	45	50	48	50
Family affluence score (%)								
1 Low	19	11	7	10	23	6	24	17
2 Medium	53	38	53	46	50	28	48	47
3 High	26	51	40	43	25	66	26	35
Unknown	1	0	0	2	2	<1	2	1

1 In Sweden 160 questionnaires were distributed at school and 40 to colleagues and friends with children. Sixty-two of the questionnaires distributed at the school were returned. All questionnaires distributed to colleagues were returned.

2 Response rate was 62% excluding questionnaires from southwest France, where the number of questionnaires distributed was unknown.

Next, the participation of children with CP at each level of walking ability (gross motor function classification system; GMFCS) was compared with that of children in the general population by constructing a dummy variable with one category for each level of GMFCS and assignment of children in the general population to the reference category. Multivariable logistic regression was then used to assess how high/low participation on each item was related to GMFCS, after adjusting for age, gender and region. A similar logistic regression was performed to compare the participation of children with CP at each level of IQ with that of children in the general population.

Finally, multivariable logistic regression was used to compare the participation of children with CP with that of children in the general population within each region, after adjusting for age and gender. As two regions did not sample children in the general population, a variable was constructed to indicate at country level: children in the general population, or children with CP with general population data from the same region, or children with CP with general population data available from a different region in the same country. All two-factor interactions were included. In a further analysis

we excluded children with CP attending special schools or special classes in order to compare children with CP in mainstream schools with children from the general population in mainstream schools.

SAS version 9.1 was used for the statistical analysis.

2.5. Ethics

All parents gave written consent, and all children with sufficient cognitive capacity gave written consent or communicated consent if unable to write. Ethics approval and/or data protection approval was obtained as appropriate in each country.

3. Results

Table 4 shows actual frequencies of participation. Nearly all children participated in relaxing pursuits more than once a week and more than half of the children played non-sporting games at least weekly. However, in most areas

Table 4 – Frequency of participation in 13 areas of everyday life of children with CP and the general population.

Activity	Group of children	>Once/week (%)	Once/week (%)	Once/fortnight (%)	Once/month (%)	<Once/month (%)	Never (%)	Unknown (%)
1. Eating out	With CP:	5	15	16	30	26	7	1
	General population:	2	12	16	32	32	5	<1
2. Relaxing leisure pursuits	With CP:	90	6	1	<1	1	1	1
	General population:	93	4	1	1	1	<1	<1
3. Using a computer	With CP:	60	17	3	2	4	13	1
	General population:	50	23	9	6	6	5	1
4. Housework	With CP:	26	18	6	6	8	34	1
	General population:	50	28	7	6	6	4	<1
5. Riding a bicycle or wheelchair	With CP:	43	15	5	6	6	23	1
	General population:	53	18	8	7	9	4	1
6. Shopping	With CP:	15	23	8	8	9	37	1
	General population:	19	29	14	12	14	12	1
7. Community groups	With CP:	21	21	2	3	5	48	1
	General population:	34	23	2	3		30	1
8. School pursuits	With CP:	6	10	6	21	50	6	2
	General population:	7	9	3	18	54	6	4
9. Sports	With CP:	33	25	4	5	8	24	1
	General population:	66	21	3	2	4	5	1
10. Non-sporting games	With CP:	57	13	5	4	3	17	1
	General population:	63	19	7	4	4	3	1
11. Watching sports	With CP:	2	8	4	9	22	54	1
	General population:	17	14	4	9	25	31	1
12. Craft pursuits	With CP:	31	26	5	4	7	25	1
	General population:	43	27	6	5	9	11	1
13. Watching cultural events	With CP:	<1	2	6	32	43	1	1
	General population:	1	3	8	34	48	5	1
		>Once/month	Once/3 months	Once/6 months	Once/year	<Once/year	Never	Unknown
14. Tourist pursuits	With CP:	13	18	24	29	9	5	2
	General population:	9	23	24	21	17	5	1

children with CP had a lower frequency of participation. Sixty-six percent of the children in the general population, compared with 33% of children with CP, played sport at least twice a week. Additionally, 24% of children with CP never rode a bicycle or wheelchair for fun, compared with 5% in the general population. One in every four child with CP helped with housework more than twice a week, compared with half of all children in the general population.

3.1. Children with CP

Older children more often used a computer; whilst younger children more often participated in craft pursuits, sport or outdoor games, community groups, cycling or housework. Boys more often watched sport events, played non-sporting games or used a bicycle or wheelchair for fun, whereas girls more often participated in craft pursuits or shopping.

After adjustment for severity of impairment, children in special schools or special classes participated less frequently in eating out, shopping, playing sports and watching sport events compared with children in mainstream schools. Presence of pain in the previous month was associated with lower participation in areas of community groups and those arranged by the school.

3.2. Children in the general population

Frequency of participation of children from the general population varied between regions. After adjustment for age, gender and family affluence, children in southwest Ireland and north England participated more often in recreational pursuits, while children in Italy, southwest France and Germany participated less often in many areas of everyday life.

3.3. Comparisons of frequency of participation of children with CP and the general population by motor impairment (GMFCS) and IQ

Fig. 1 shows how frequency of participation decreased with increasing severity of motor and intellectual impairment in most areas of everyday life.

However, children with mild to moderate motor or intellectual impairment used a computer, played non-sporting games and ate out more often than children in the general population. Children with CP of all severities participated as much or more than children from the general population in pursuits organised by their school.

3.4. Comparison of frequency of participation of the children with CP with children from the general population in the same region

Because frequency of participation in children from the general populations showed variation between regions, we investigated frequency of participation in children with CP compared with that of children in the general populations in the same country, after adjusting for age and gender. Fig. 2 shows odds ratios (ORs) for high frequency of participation in children with CP compared with children in the general populations, in the nine regions.

Doing crafts was the only area where children with CP participated as often as children from the general populations in all regions. Children with CP in most regions participated less frequently than children from the general populations in playing sports, watching sports events, eating out, shopping, helping with housework, and joining in tourist pursuits and community groups. Children with CP in most regions participated as often as children from the general populations in using a computer, pursuits arranged by the school and in riding a bicycle or wheelchair for fun. Regional variation was found both in the domains where there were differences between children with CP and the general populations and in the magnitude of these differences.

Denmark was the only country where children with CP participated as often as or more than children from the general population in the same country in most domains assessed. In addition, children with CP in northwest Germany and north England participated as often as children from the general populations in many domains. Children with CP in Sweden, southwest Ireland and central Italy participated less often in most domains than children in the general population.

3.5. Children in mainstream schools

We then undertook a restricted comparison between children in the general population and children with CP attending mainstream schools. In all regions children with CP in mainstream school used a computer, did crafts, played non-sporting games, watched art or cultural events and watched sports as often as children from the general population; while in most regions the children with CP participated less often in tourist pursuits.

4. Discussion

Children (8–12-year-old) with CP participated less frequently in many areas of everyday life than children in the general population. There were pronounced differences between regions in participation of the children from the general population which are probably culturally determined. When children with CP were compared with children in the general population from the same region, the magnitude of the differences in participation varied between countries, which may reflect the extent to which environments in the different countries promote participation of disabled children.

This is the first large, multi-centre, population-based study of the participation of children with and without disabilities. The 818 children with CP were sampled from nine geographic regions, eight of which had population-based registers. Weights were assigned to allow for sampling and non-response.¹² The concept of participation used in the FPQ is based on the framework of the ICF. Participation was assessed directly and independently of any assistance or environmental adjustment which the children may have needed. We asked parents to complete the questionnaires so that we could include the children with severe CP. The schools chosen for sampling children in the general population were in the same regions as the registries and selected on socio-economic and geographic criteria. Parents of children with CP completed

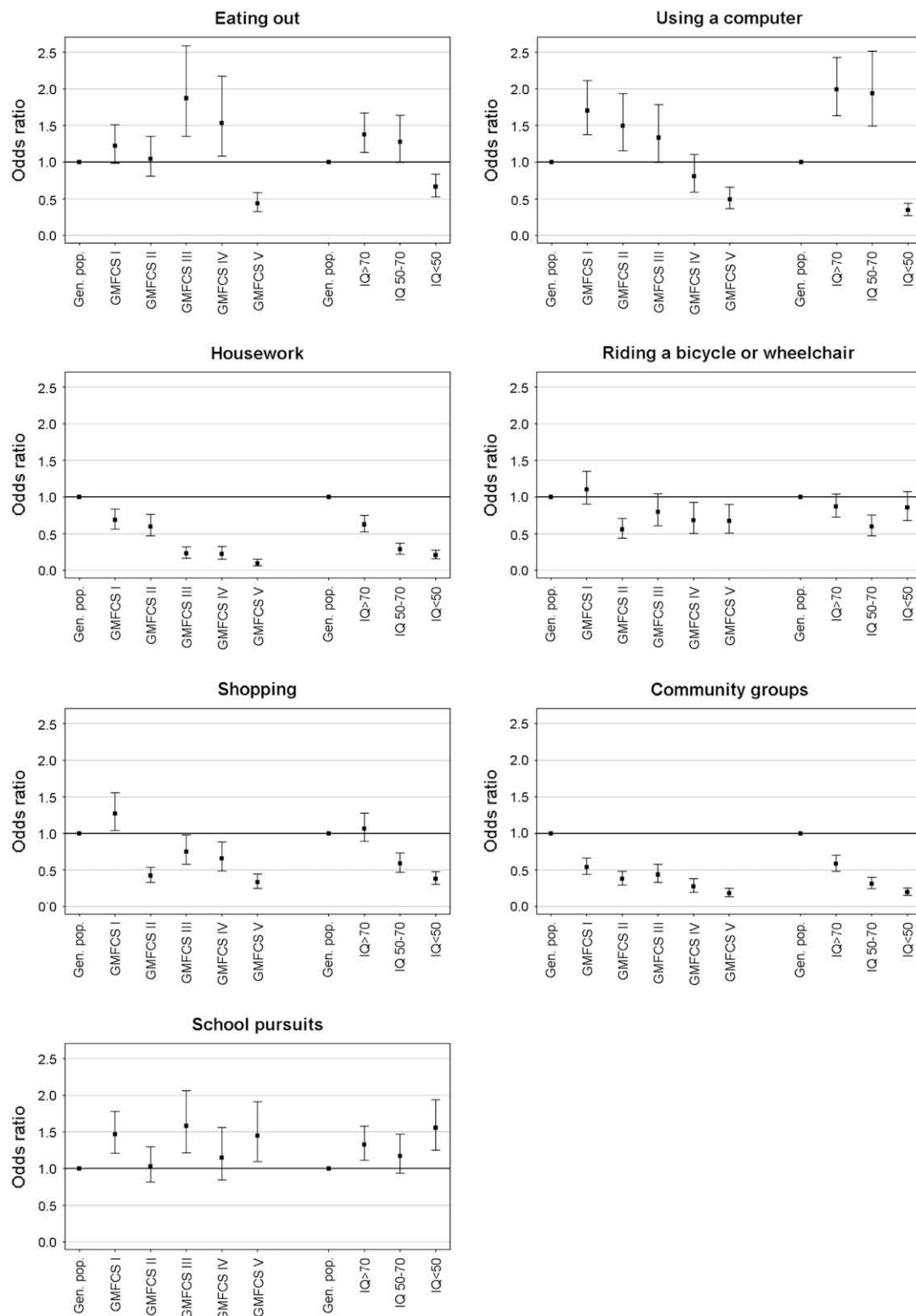


Fig. 1 – Frequency of high participation in 13 areas of everyday life, by level of walking ability (GMFCS) and IQ. The figures show odds ratios and 95% confidence intervals for high participation in children with various levels of severity of CP compared with children in the general population, adjusted for age, gender and region. GMFCS and IQ were analysed separately.

the FPQ at a home visit whereas parents of children in the general population were not visited. Although we cannot be certain the 62% response rate in the general population is representative, it is reassuring that cross-country differences in

participation of children from the general populations are consistent with other studies of children's everyday activities. For example, the European cross-country study of Health Behaviour in School-aged Children found that children in Ireland

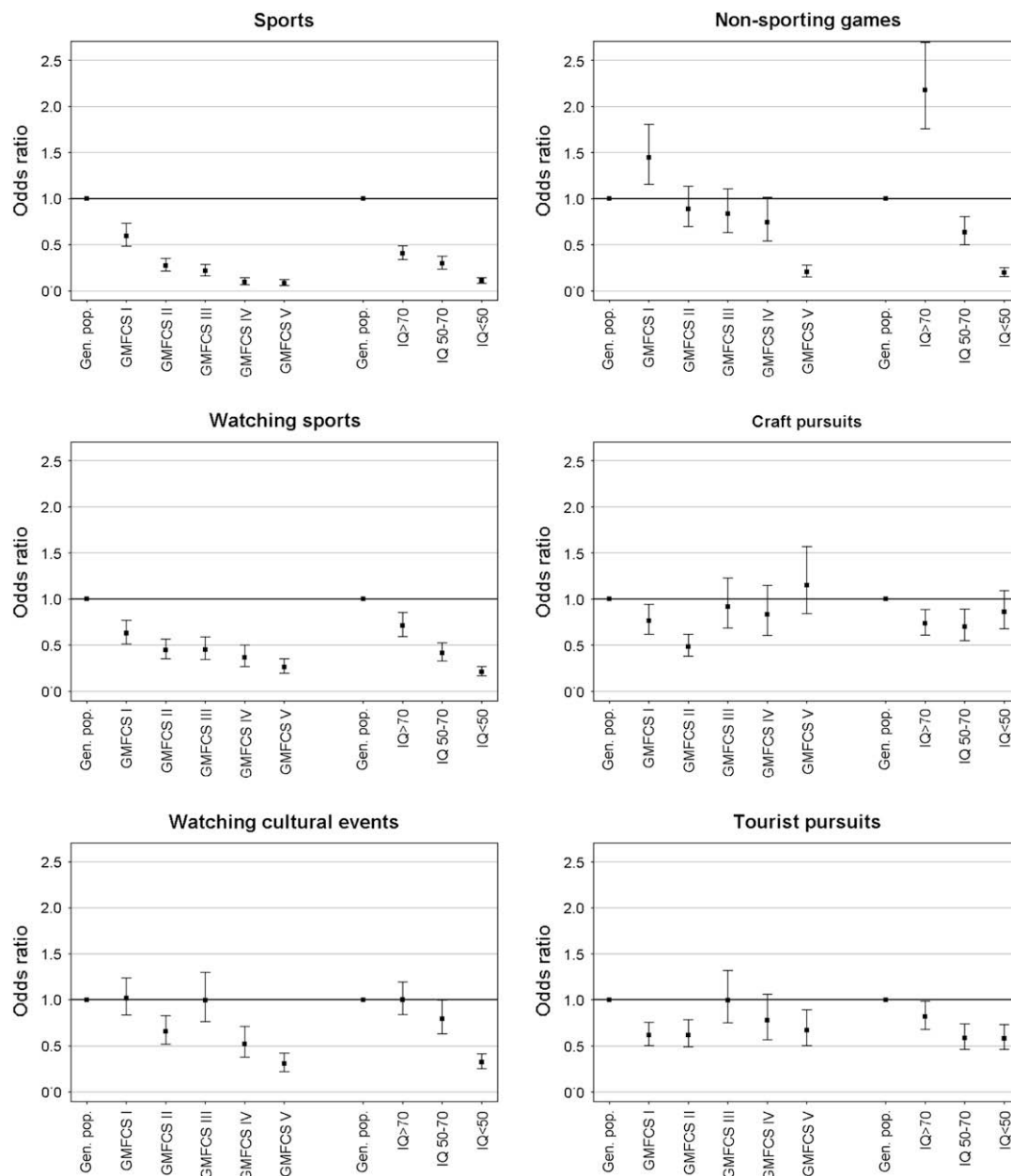


Fig. 1 – (Continued).

and England are more often physically active than children in Italy, France and Germany¹⁷; and in countries with a tradition of bicycling (Denmark and Germany), we found the highest frequency of children riding a bicycle.

Our finding that severity of CP affects frequency of participation is confirmed by national studies of children with problems of mobility,¹⁸ learning,^{14,18} speech and language.¹⁹ The finding is also consistent with results from a UK study of 129 children with CP aged 6–12 years whose parents completed the ASKp questionnaire.²⁰ Our finding that children with mild to moderate CP used a computer and played non-sporting games more often than children in the general population might indicate that children with CP compensate for a lower frequency of participation in other areas such as sports. The gender and age differences among children with CP found in our study

are consistent with results from a Canadian study of 427 children aged 6–14 years with complex physical impairments.⁵ This study used the Children's Assessment of Participation and Enjoyment – a recently developed measure of diversity and frequency of participation for children with and without disability.^{5,21} The study found that girls participated more frequently in craft pursuits, whereas boys more often rode a bicycle and younger children participated more in craft pursuits than older children. Additionally the Canadian study found that children with cerebral palsy in particular had reduced diversity and frequency of participation compared with the general population (Gillian King, personal communication).

It is interesting that pain was only associated with lower participation in organised pursuits or those arranged by schools; this contrasts with the finding in the same population

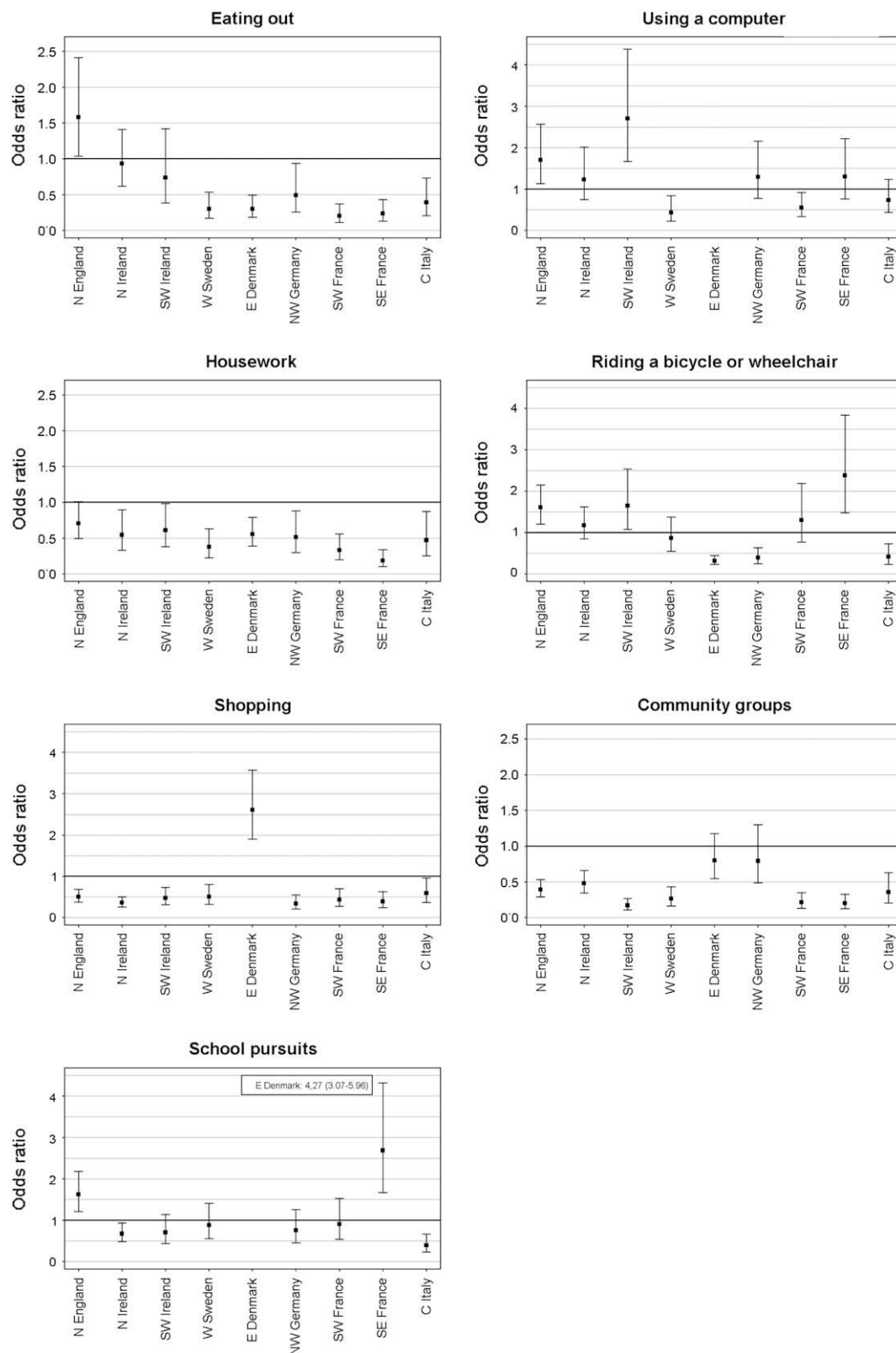


Fig. 2 – Frequency of high participation in 13 areas of everyday life, by region. The figures show odds ratios and 95% confidence intervals for high participation in children with CP compared with children in the general population, adjusted for age and gender.

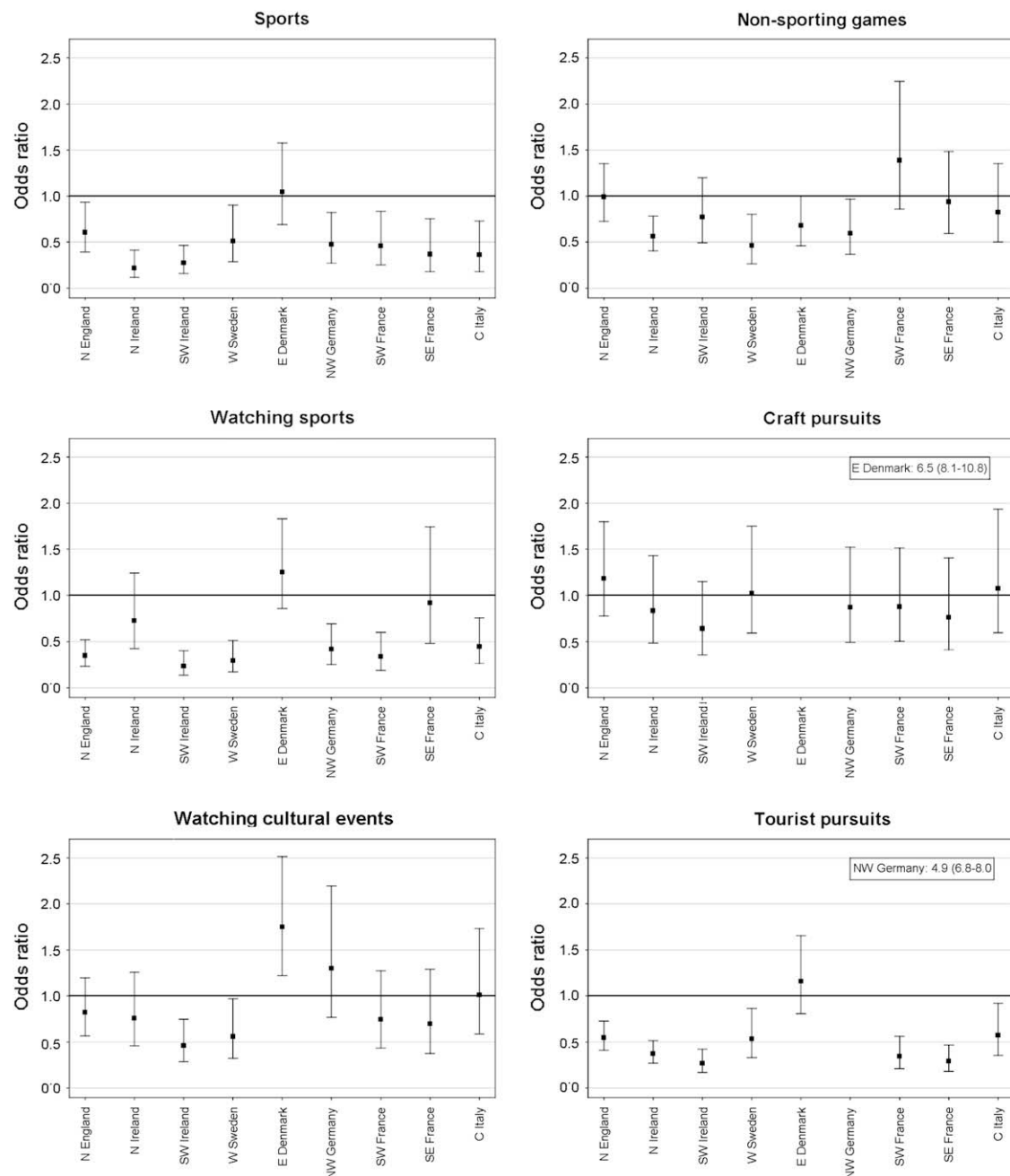


Fig. 2 – (Continued).

of children of a pervasive association of pain with all domains of quality of life.²²

As part of the SPARCLE study a review of environmental factors, relevant to the lives of disabled children which operate at national level in the seven SPARCLE countries, was carried out and published.^{23,24} Information was assembled for the themes of: attitudes, equality & information, education, social security, support & care services, health services & assistive technology and physical environment. In the report, the environmental factors are described by theme in Volume 1²³ and by country in Volume 2.²⁴

Only in Denmark did children with CP have a frequency of participation that was similar to or better than children in the

general population. Denmark is considered as a forerunner in inclusion and in valuing both children and disabled people²⁴ and has a leading position in redistributing resources to families on social assistance.²³ Advocacy groups for disabled people have worked with policy makers in Denmark to ensure that every sector implements the principle of equal access.²³ This results in, for example, sports clubs, restaurants and cultural centres having to ensure they are suitable for disabled children. This is consistent with our results, although not consistent with Denmark being described as one of the least accessible countries for people with physical disabilities.²⁵ We found no difference in how often Danish children with CP and children from the general population participated in

organised group activities and playing sports. This is likely to be explained by Denmark having a public system of after-school clubs, attended everyday by most children up to age 12, whether disabled or not. Danish children with CP also had a high frequency of participation in craft pursuits, consistent with them being common in the after-school clubs.

The two Nordic regions, Sweden and Denmark, might have been expected to have similar results. They both have a strong tradition of state provided services and care for children,²⁴ while France, Germany, Ireland and Italy have a strong tradition of family care.²³ In addition, Sweden is reported to be the most accessible European country for disabled people and the country where people feel most at ease in the presence of disabled people.²⁵ In our study, children with CP in Sweden participated less frequently in many areas than children in the general population. The difference between the two Nordic countries in areas of participating in community groups and sports or outdoor games might be partly explained by different traditions of using childcare. In Sweden, after-school clubs exist but less than half of the children attend them.²³ However, the low participation in Swedish children with CP might also be due to the relatively few children with a mild CP in the Swedish sample (Table 2) even though results were weighted according to sampling strategies and non-response.

Children with CP participated less often in community groups, sports and outdoor games than children in the general population. National policies on transport might contribute to the lower participation for disabled children in some countries. In France and Ireland special transport for disabled children is only provided for school; in the UK it depends on the local authority whether special transport is available; in Italy it is provided but subjected to budgetary limits, while in Denmark, Sweden and increasingly in Germany it is widely provided.^{23,24} In Italy, Germany, UK and southwest Ireland children are usually taken home after school unless special arrangements about transport to and from after-school pursuits are available; children with physical impairment may not be able to participate in these.

After controlling for severity of impairment, children in special schools or special classes participated less in eating out, shopping, playing and watching sports than children in mainstream schools. However, in other areas of everyday life such as using a computer, taking part in organised group activities and in non-sporting games, severity of impairment was more strongly associated with reduced participation, than was type of school. Although most disabled children in Italy attend mainstream school, Italy was the country where children with CP participated least in pursuits arranged by the school, compared with children in the general population. Earlier focus group work²⁶ had shown that Italian parents valued their children's integration in mainstream schools as a potent force for facilitating social participation but found that specialised personnel were lacking in mainstream schools.

5. Conclusion

We found differences between countries in frequency of participation in areas of everyday life of children with CP that are only partly explained by differences in participation in the

general populations. Environmental factors are believed to contribute to these differences. Parents and children should be encouraged to make use of adaptations or assistance that promote participation. Clinicians should be aware that environmental adjustment might have a dramatic effect on participation. However, severity of impairment predicts frequency of participation and reduction of impairment through clinical interventions is also likely to improve frequency of participation.

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