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 cere-
bral 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.
Frequency of participation for each question was dichotomised about the median; multivariable 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. 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. Impairment and socio-economic position partly predict participation. However, the ICF emphasises that participation is also influenced by a person’s environment and evidence for this has been reported. 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, 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 measures participation across the ICF domains; it was designed for disabled children and has been used by children with cerebral palsy. 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. 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. 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
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, 2 months and 50% were male. The question on relaxing leisure pursuits was omitted from subsequent analyses because almost all answers indicated 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. Frequency and severity of pain were captured using the two questions about pain in the Child Health Questionnaire.15

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

For children with cerebral palsy, multivariable logistic re-
gression was used to assess whether high/low participation
on each item was related to age, gender, type and level of im-
pairment, 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 in-
cluded in the model and backwards elimination was per-
formed, 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 inter-
action 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 logis-
tic 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. Interac-
tions were not considered due to the sparseness of the data.

| 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). |
|---------------------------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|
| Children participating (N)      | North England  | West Sweden  | Northern Ireland | Southwest France | East Denmark  | Central Italy | Southwest France | Northwest Germany | All             |
| Mean age                        | 116            | 83             | 102             | 67              | 98             | 115            | 85              | 77              | 75              | 818             |
| 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          | 7–13 y          |
| Gender: % males                 | 64             | 53             | 62              | 58              | 54             | 63             | 55              | 62              | 57              | 59              |
| Siblings                        | 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               |
| Type of school                  | 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               |
| Gross motor function            | 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              |
| Intellectual impairment         | 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                         | 1              | 0              | 1               | 1               | 0              | 0              | 1               | 1               | 1               |
| Pain                            | 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               | 1               |
| Parents’ educational qualifications | 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               |
| Parents’ employment             | Full time      | 22             | 19             | 23              | 27             | 21             | 36              | 32              | 31              | 40              | 28              |
| Full time trade                 | 34             | 59             | 43              | 57              | 57             | 57             | 47              | 48              | 61              | 45              | 49              |
| Part time                       | 8              | 16             | 9               | 7               | 7              | 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              |
| 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 |
| **Recruitment** | | | | | | | |
| Selection criteria for schools | Socio-economic | Socio-economic | Geographic | Geographic | Geographic | Socio-economic and geographic | Socio-economic and geographic |
| **Number of schools participating/approached** | 5/8 | 5/1 | 5/5 | 7/8 | 2/2 | 10/13 | 30/39 |
| **Type of material distributed** | Letters to headmaster and parents. | Letters to headmaster 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 teachers to pupils. | By teachers to pupils. | By teachers to pupils. | By headmaster 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. |
| **Response rate (%)** | 51 | 51 | 63 | 89 | Unknown | 64 | 62 |
| **Number of included children** | 379 | 102 | 448 | 336 | 247 | 280 | 1124 | 2939 |
| **Mean age** (y) | 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 |
| **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 | 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...
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 central Italy participated less 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. 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
the FPQ at a home visit whereas parents of children in the general population were not visited. Although we cannot be certain that 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...
and England are more often physically active than children in Italy, France and Germany\textsuperscript{17}; 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, learning, speech and language.\textsuperscript{18} 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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.
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

Fig. 2 – (Continued).
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, while France, Germany, Ireland and Italy have a strong tradition of family care. 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. 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. 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 subject to budgetary limits, while in Denmark, Sweden and increasingly in Germany it is widely provided. 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 work had shown that Italian parents valued their childrens 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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