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RESEARCH

Participation in life situations of 8-12 year old children with cerebral palsy: cross sectional European study

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ABSTRACT

Objectives To evaluate how involvement in life situations (participation) in children with cerebral palsy varies with type and severity of impairment and to investigate geographical variation in participation.

Design Cross sectional study. Trained interviewers visited parents of children with cerebral palsy; multilevel multivariable regression related participation to impairments, pain, and sociodemographic characteristics.

Setting Eight European regions with population registers of children with cerebral palsy; one further region recruited children from multiple sources.

Participants 1174 children aged 8-12 with cerebral palsy randomly selected from the population registers, 743 (63%) joined in the study; the further region recruited 75 children.

Main outcome measure Children's participation assessed by the Life-H questionnaire covering 10 main areas of daily life. Scoring ignored adaptations or assistance required for participation.

Results Children with pain and those with more severely impaired walking, fine motor skills, communication, and intellectual abilities had lower participation across most domains. Type of cerebral palsy and problems with feeding and vision were associated with lower participation for specific domains, but the sociodemographic factors examined were not. Impairment and pain accounted for up to a sixth of the variation in participation. Participation on all domains varied substantially between regions: children in east Denmark had consistently higher participation than children in other regions. For most participation domains, about a third of the unexplained variation could be ascribed to variation between regions and about two thirds to variation between individuals.

Conclusions Participation in children with cerebral palsy should be assessed in clinical practice to guide intervention and assess its effect. Pain should be carefully assessed. Some European countries facilitate participation better than others, implying some countries could make better provision. Legislation and regulation should be directed to ensuring this happens.

INTRODUCTION

Article 23 of the UN Convention on the Rights of the Child, ratified by 192 nations, states that a mentally or physically disabled child should have the opportunity to participate and to have access to services to promote participation.[1] Articles 23-30 of the 2006 UN Convention on the Rights of Persons with Disabilities, so far ratified by 34 nations, state that children with disabilities should be able to participate on an equal basis with others in family life, health maintenance, education, public life, and recreational, leisure, and sporting activities.[2]

In the past decade, concepts of disability and disadvantage for children with impairments have become clearer, largely due to the World Health Organization's International Classification of Functioning, Disability and Health (ICF)[3] and its version for children and young people.[4] Since their publication, interest has focused less on actual impairments and more on the impact of the impairments on the personal and social life of the individual. The classification defines "participation" as involvement in life situations; it is understood to be a consequence of a dynamic interaction between a person and environmental factors rather than a direct consequence of illness. Disabled children experience difficulty in participating across a wide range of domains.[5,6] These include non-discretionary aspects of participation that are essential to daily life, such as eating, sleeping, and toileting.

The classification is consistent with the social model of disability,[7] which regards disability as a consequence of the failure of the environment to be adjusted sufficiently to meet the needs of the individual.[8,9] The social model predicts that participation will vary between countries.

Cerebral palsy is the commonest cause of severe motor impairment in childhood, with a rate of about 2.5 per 1000 live births.[10] Affected children have various types and severities of impairments[11,12] and so

might be regarded as typical of a wide range of disabled children.

Many studies of participation in affected children are unsatisfactory because of inadequate sample size,[13] non-representative convenience samples,[14 15] use of instruments that do not capture the modern concept of participation,[16-18] or neglect of social dimensions of participation.[19-21]

In a large representative sample of children with cerebral palsy we evaluated how participation varied with type and level of impairment and with pain and assessed the geographical variation predicted by the social model of disability.

METHODS

The study is part of a wider project, SPARCLE (www.ncl.ac.uk/sparcle),[22] which examines the relation of the quality of life and participation of children with cerebral palsy to their environment within the conceptual framework of the social model of disability.[7] The SPARCLE protocol, sampling strategy, recruitment rates, and potential for bias have been reported in detail elsewhere.[22 23]

Eligible children were those born from 31 July 1991 to 1 April 1997 and on population registers of children with cerebral palsy in eight regions of six European countries that share a standardised definition and classification of cerebral palsy[10]: south east France, south west France, south west Ireland, west Sweden, north England, Northern Ireland, east Denmark, and central Italy. There were 1884 such children. In regions with more than 200 registered children (west Sweden, north of England, Northern Ireland, east Denmark), we sampled so that the number agreeing to participate would be between 100 and 120 with similar numbers of children at each level of severity; we did this by grouping children by walking ability and selecting random samples within strata in each region.[23] In other regions we approached all eligible children. We sampled 1174 eligible families, of whom 743 (63%) took part. We were unable to trace 12% of families sampled; of those traced, 73% agreed to take part, 3% were not approached, and 24% declined to take part.[23] A further region in north west Germany recruited 75 children from multiple sources and used the same classification of cerebral palsy[10]; the age, sex, and levels of impairment of these children were similar to those of eligible children recorded on the population based registers.[23] Thus the sample comprised 818 children. Table 1 shows the numbers in each region.

Research associates visited children at home in 2004-5 to administer questionnaires to parents and children, if possible when the children were aged 8-12. To suit family circumstances, they interviewed 20 children just outside this age range.

Participation was assessed with the Life-H questionnaire.[13] This instrument was developed from a strong theoretical framework aligned with WHO's international classification,[3] is validated in disabled children,[13] and has been used with children with cerebral palsy.[24] It comprises 62 items grouped into 11 domains covering both daily activities and social roles. We omitted one question about sexual relations as it was not appropriate to this age group. Fifteen of the items concern non-discretionary participation regarded as essential to a child's daily life and for these the parent is asked if the child achieves it with or without difficulty. For the 47 other items the parent is asked if the child achieves it and, if so, whether with or without difficulty.

All items also ask whether the child needs help or the use of aids and adaptations to participate and, if so, what type of help. The scoring system scores participation as lower not only if the child has greater difficulty in participation but also if more assistance is needed. As we wanted to assess difficulty in participation without making assumptions about how it was influenced by environmental factors, our main analysis ignored the questions about assistance.

We assessed frequency and severity of pain in the previous week using the two questions about pain from the child health questionnaire.[25] We used parents' reports of their child's pain because we were examining participation for children of all cognitive abilities and we considered it more valid to report pain in a similar way across all the children (that is, those who could and could not self report).

Parents provided information about their employment and level of educational qualifications, whether they lived in an urban or rural area, their child's age, sex, impairments (gross motor function,[26] fine motor skills,[18] intellectual ability, vision, hearing, seizures, feeding, communication), and school type, and number and disability of any siblings. Data on type of cerebral palsy were available from the registers.

Statistical methods

The statistical methods are described in detail in appendix 1 on bmj.com and summarised here. We coded responses to non-discretionary items as binary variables (with or without difficulty) and responses to discretionary items as ordinal variables (performed without difficulty, performed with difficulty, not performed because too difficult, missing if not performed for other reasons).

We analysed each domain separately. We also analysed all non-discretionary items grouped together as

Table 1 | Number and percentage of children with cerebral palsy by region

Region	No (%)
South east France	67 (8)
South west France	77 (9)
North west Germany	75 (9)
South west Ireland	98 (12)
West Sweden	83 (10)
North England	116 (14)
Northern Ireland	102 (12)
East Denmark	115 (14)
Central Italy	85 (10)

non-discretionary participation might be less subject to cultural influences than discretionary participation and so might be a better indicator of how well a region facilitates participation of disabled children.

We assumed that children's participation within each domain could be summarised by a single variable and that, although this variable could not be observed or measured directly, it determined the parents' responses to the items. We refer to these unobserved variables as "factors" but they are sometimes referred to as latent variables or latent traits.[27] In the same way, we assumed that non-discretionary participation could be summarised by a single factor that determined parents' responses to all non-discretionary items. We estimated each factor (that is, the child's level of participation on each domain) and related it to covariates—sociodemographic characteristics, impairment, and pain—in a single, unified, multilevel model that allowed for clustering of children within regions. The mean child participation, after adjustment for significant covariates, was assumed to be zero.

Frequency and severity of pain were highly correlated (Spearman's rank correlation coefficient=0.83) so we arbitrarily included its frequency rather than its severity in the model. We used forwards stepwise regression followed by backwards steps to select covariates to enter into the model. To lessen the probability of chance findings caused by multiple hypothesis testing, we set the P value for entry and removal of covariates at 0.01. The final models exclude the 19 children with missing data on impairment and pain and, additionally, any children with missing data on participation. As an indicator of the variation in participation explained by the covariates, we noted the percentage reduction in the log likelihood relative to a multilevel model with no covariates. We present results as odds ratios with 95% confidence intervals. For each type of impairment, these odds ratios compare the participation of children with a specific severity of impairment with the participation of the least impaired children. We estimated the significance of heterogeneity between regions by comparing the final multilevel, multivariate model with a similar model that did not allow for clustering within regions. We report the proportion of the total residual variance that is between regions. To assess goodness of fit we examined the distribution of residuals for each item. For comparison purposes, we also performed multivariable, multilevel logistic regression analysis using the conventional scoring of Life-H, dividing children into those with participation above and below the median on each domain.

Statistical analysis was performed with the GLAMM suite of programs[28] in Stata 9.

RESULTS

The parents of 818 children were interviewed. Table 2 summarises the type and severity of the children's impairments and parental reports of their child's pain. Sociodemographic characteristics have been reported previously.[29]

Table 2 | Number and percentage of 818 children with cerebral palsy by impairment and level of pain

	No (%)
Gross motor function:	
I Walks and climbs stairs, without limitation	257 (31)
II Walks with limitations	164 (20)
III Walks with assistive devices	139 (17)
IV Unable to walk, limited self mobility	113 (14)
V Unable to walk, severely limited self mobility	145 (18)
Fine motor skills:	
I Without limitation	281 (34)
II Both hands limited in fine skills	205 (25)
III Needs help with tasks	131 (16)
IV Needs help and adapted equipment	91 (11)
V Needs total human assistance	110 (13)
Intellectual impairment:	
None or mild (IQ>70)	385 (47)
Moderate (IQ 50-70)	186 (23)
Severe (IQ<50)	242 (30)
Information not available	5 (1)
Vision:	
Has useful vision	759 (93)
Blind or no useful vision	59 (7)
Hearing:	
Does not need hearing aids	799 (98)
Needs hearing aids (>70 decibel loss)	18 (2)
Information not available	1 (0)
Seizures:	
No seizures in previous year	650 (79)
Seizures in previous year	167 (20)
Information not available	1 (0)
Feeding:	
No problems	583 (71)
Feeds orally with difficulty	176 (22)
Partial or complete feeding by tube	58 (7)
Information not available	1 (0)
Communication:	
Normal speech	463 (57)
Difficulty but uses speech	133 (16)
Uses non-speech for formal communication	98 (12)
No formal communication	123 (15)
Information not available	1 (0)
Cerebral palsy subtype:	
Unilateral spastic	279 (34)
Bilateral spastic	423 (52)
Dyskinetic	86 (11)
Ataxic	29 (4)
Information not available	1 (0)
Parental report of child pain in previous four weeks:	
Amount of pain:	
None	240 (29)
Very mild or mild	353 (43)
Moderate, severe, or very severe	213 (26)
Information not available	12 (1)
Frequency of pain:	
None of the time	237 (29)
Once or twice or a few times	414 (51)
More often	155 (19)
Information not available	12 (1)

Tables 3 and 4 show the distribution of responses for each item of Life-H. All items, except one about school participation, had response rates of over 97%. For 16 of the 47 discretionary items, however, over 10% of parents reported that their child did not participate for reasons other than difficulty—for example, the child was not interested or the activity was not available or not suitable for the child's age. We omitted community life from analysis because this domain was based on only two items (community groups and religious activities) and 18% of parents reported both items as irrelevant to their children; this problem was also encountered by the instrument's developers.[13]

In univariate analyses, all impairments except hearing and type of cerebral palsy were significantly associated with lower participation on all domains ($P<0.01$).

Table 3 | **Summary of responses to Life-H questions on daily activities in 818 children with cerebral palsy. Figures are numbers (percentages) of children**

	Achieved		Not achieved		
	Without difficulty	With difficulty	Too difficult	Other reasons	Response missing
Mealtimes					
Eating meals*	518 (63)	297 (36)	NA	NA	3 (0)
Selecting type and amount of food desired	548 (67)	94 (11)	94 (11)	66 (8)	16 (2)
Taking part in preparing meals	267 (33)	148 (18)	230 (28)	165 (20)	8 (1)
Eating out at restaurants, cafes, or fast food outlets	508 (62)	208 (25)	70 (9)	24 (3)	8 (1)
Health hygiene					
Getting in and out of bed*	563 (69)	255 (31)	NA	NA	0 (0)
Getting a good sleep	567 (69)	107 (13)	111 (14)	16 (2)	17 (2)
Doing physical exercise for health	366 (45)	310 (38)	90 (11)	44 (5)	8 (1)
Doing leisure pursuits for relaxation	690 (84)	82 (10)	12 (1)	27 (3)	7 (1)
Personal care					
Attending to personal hygiene*	391 (48)	424 (52)	NA	NA	3 (0)
Toileting at home*	495 (61)	317 (39)	NA	NA	6 (1)
Toileting away from home*	430 (53)	375 (46)	NA	NA	13 (2)
Dressing and undressing upper half of body*	358 (44)	457 (56)	NA	NA	3 (0)
Dressing and undressing lower half of body*	338 (41)	475 (58)	NA	NA	5 (1)
Taking part in their own health care*	476 (58)	329 (40)	NA	NA	13 (2)
Using services provided by local doctor, hospital, or rehabilitation centre*	522 (64)	277 (34)	NA	NA	19 (2)
Putting on and taking off his/her own aids	233 (28)	100 (12)	265 (32)	214 (26)	6 (1)
Communication					
Managing one-to-one communication with adults	512 (63)	192 (23)	105 (13)	2 (0)	7 (1)
Managing one-to-one communication with young people	495 (61)	168 (21)	145 (18)	4 (0)	6 (1)
Managing communication in group of people	448 (55)	177 (22)	182 (22)	6 (1)	5 (1)
Writing	301 (37)	181 (22)	320 (39)	14 (2)	2 (0)
Reading and understanding words, books, instructions, signs, etc	384 (47)	208 (25)	217 (27)	2 (0)	7 (1)
Using telephone	444 (54)	134 (16)	199 (24)	36 (4)	5 (1)
Using computer	479 (59)	207 (25)	94 (11)	33 (4)	5 (1)
Using audiovisual equipment	615 (75)	146 (18)	43 (5)	11 (1)	3 (0)
Home life					
Entering and leaving home*	560 (68)	255 (31)	NA	NA	3 (0)
Moving around home*	619 (76)	197 (24)	NA	NA	2 (0)
Helping with housework	301 (37)	145 (18)	259 (32)	112 (14)	1 (0)
Helping in garden or backyard	228 (28)	110 (13)	264 (32)	214 (26)	2 (0)
Managing common household things such as tables, light switches, cupboards, doors	522 (64)	116 (14)	169 (21)	5 (1)	6 (1)
Moving about just outside home	517 (63)	223 (27)	65 (8)	8 (1)	5 (1)
Getting about					
Moving about on streets and pavements*	410 (50)	401 (49)	NA	NA	7 (1)
Moving about on slippery or uneven surfaces	261 (32)	355 (43)	193 (24)	4 (0)	5 (1)
Riding a bicycle, tricycle, scooters, rollerblades, wheelchair for pleasure, etc	385 (47)	223 (27)	174 (21)	32 (4)	4 (0)
Travelling as passenger in vehicles	615 (75)	183 (22)	8 (1)	8 (1)	4 (0)

NA=not applicable as these non-discretionary items were assumed to be performed by all children.
*Non-discretionary item.

Table 4 | Summary of responses to Life-H questions on social roles in 818 children with cerebral palsy. Figures are numbers (percentages) of children

	Achieved		Not achieved		
	Without difficulty	With difficulty	Too difficult	Other reasons	Response missing
Responsibilities					
Recognising money and using it correctly	314 (38)	118 (14)	306 (37)	78 (10)	2 (0)
Managing pocket money	291 (36)	74 (9)	302 (37)	151 (18)	0 (0)
Using bank or post office account	101 (12)	25 (3)	278 (34)	411 (50)	3 (0)
Shopping or doing errands	300 (37)	88 (11)	307 (38)	117 (14)	6 (1)
Respecting other people's property and rights	547 (67)	88 (11)	159 (19)	14 (2)	10 (1)
Taking responsibility for him/herself	372 (45)	118 (14)	282 (34)	42 (5)	4 (0)
Supporting family members as needed	513 (63)	87 (11)	177 (22)	38 (5)	3 (0)
Relationships					
Maintaining loving relationship with parents	760 (93)	45 (6)	8 (1)	1 (0)	4 (0)
Maintaining loving relationship with other members of family living at home	635 (78)	57 (7)	7 (1)	116 (14)	3 (0)
Maintaining loving or social relationship with other relatives	729 (89)	45 (6)	17 (2)	20 (2)	7 (1)
Maintaining friendly links with other young people at school or at leisure, etc	626 (77)	127 (16)	43 (5)	14 (2)	8 (1)
Maintaining friendly links with other adults	719 (88)	71 (9)	19 (2)	4 (0)	5 (1)
Community life					
Taking part in activities of community groups	277 (34)	90 (11)	193 (24)	256 (31)	2 (0)
Taking part in religious or spiritual activities	210 (26)	70 (9)	117 (14)	406 (50)	15 (2)
School					
Getting to school, entering and moving about within school and yard*	539 (66)	265 (32)	NA	NA	14 (2)
Taking part in lessons, assignments, and assessments at school*	434 (53)	367 (45)	NA	NA	17 (2)
Using school facilities*	518 (63)	278 (34)	NA	NA	22 (3)
Taking part in range of extra classes including physical education, music, etc	270 (33)	144 (18)	154 (19)	187 (23)	63 (8)
Doing homework	295 (36)	285 (35)	75 (9)	152 (19)	11 (1)
Taking part in activities organised by the school	517 (63)	252 (31)	15 (2)	22 (3)	12 (1)
Recreation					
Playing sports or outdoor games	326 (40)	233 (28)	174 (21)	78 (10)	7 (1)
Playing non-sporting games	472 (58)	177 (22)	138 (17)	29 (4)	2 (0)
Going and watching sports events	246 (30)	81 (10)	128 (16)	358 (44)	5 (1)
Taking part in artistic, cultural, or craft activities	329 (40)	167 (20)	139 (17)	171 (21)	12 (1)
Going and watching artistic, or cultural events	472 (58)	186 (23)	93 (11)	63 (8)	4 (0)
Taking part in tourist activities	455 (56)	292 (36)	44 (5)	21 (3)	6 (1)
Getting to and moving about within local recreational facilities	399 (49)	167 (20)	148 (18)	87 (11)	17 (2)
Taking part in activities in local recreational facilities	285 (35)	135 (17)	189 (23)	190 (23)	19 (2)

NA=not applicable as these non-discretionary items were assumed to be performed by all children.
*Non-discretionary item.

Tables 5-7 summarise the final multivariable models. On most domains, except relationships, lower participation was associated with impairment of motor function (walking ability or fine motor skills, or both). Additionally, lower participation was associated with intellectual impairment, communication difficulties, and pain on most domains. Other specific impairments were associated with lower participation on specific domains. Odds ratios comparing difficulty in participation among children with the most and least severe impairment of walking ability ranged from 2.6 (95% confidence interval 1.3 to 5.1) for recreation (table 7) to 20.5 (10 to 41) for home life (table 6). Odds ratios among children who experienced pain fairly often and those with no pain ranged from 1.9 (1.4 to 2.6) for mobility (table 6) to 5.2 (2.2 to 12) for relationships (table 7). Impairment and pain, however, accounted for only 4% (for the school domain, table 7) to 16% (for mealtimes and home life, table 6) of the overall deviance.

For the non-discretionary items treated separately, participation was associated with pain and impairments of walking ability, fine motor skills, and communication with a clear trend of lower participation being associated with greater impairment of walking ability and more pain. Impaired walking ability was the most important impairment in reducing participation: the odds ratio comparing difficulty in participation among children with the most and least severe impairment of walking ability was 9.6 (4.5 to 20) (table 7).

Table 5 | Associations between participation on each domain and impairment and pain in final multilevel multivariable model

Life-H domain	Characteristics of children for whom parents reported lower participation
Daily activities	
Mealtimes	Walking ability, fine motor skills, intellectual ability, feeding ability
Health hygiene	Walking ability, communication, pain
Personal care	Walking ability, fine motor skills, intellectual ability, pain
Communication	Fine motor skills, intellectual ability, communication, ataxic cerebral palsy, vision
Home life	Walking ability, fine motor skills, intellectual ability, communication, bilateral cerebral palsy, pain
Mobility	Walking ability, intellectual ability, communication, pain
Social roles	
Responsibilities	Fine motor skills, intellectual ability, communication, vision
Relationships	Intellectual ability, communication, pain
Community life	Not analysed as items were not relevant to high proportion of children
School	Walking ability, intellectual ability, communication
Recreation	Walking ability, fine motor skills, intellectual ability, communication, vision, pain

Nevertheless, impairment and pain accounted for only 4% of the deviance.

None of the sociodemographic factors considered was significantly associated with participation on any domain or with non-discretionary participation. After adjustment for the child's impairment, the type of school attended was not associated with participation on any domain.

Participation—non-discretionary and on all domains except relationships—showed significant variation between regions ($P<0.001$) (tables 6 and 7). The figure shows the mean level of the children's participation in each region, after adjustment for impairment and pain. The average level of participation of children in east Denmark was much higher than that of children in other regions on all domains except relationships, generally by 1-2 SD. Children in the north of England and west Sweden also had consistently high levels of participation on all domains except relationships and home life. For all domains except relationships, the variation in participation between regions was substantial compared with the overall variation in participation (tables 6 and 7): it accounted for about a third of the total variation for personal care, communication, home life, school, recreation, and non-discretionary participation (tables 6 and 7) and was even higher for mobility (63%), mealtimes, and health hygiene (51%) (table 6).

Sensitivity analyses

We examined residuals—that is, the differences between the level of participation predicted for each child by the statistical models in tables 6 and 7 and the child's actual level of participation. This suggested that the items within a domain might have differing abilities to discriminate between children with different levels of participation, contravening the assumptions of the statistical model. Nevertheless, when we used more flexible models that allowed different items to have different discriminatory abilities, the associations between participation and impairments on each domain were similar to those shown in tables 6 and 7, except that the association of communication difficulties with lower participation in health hygiene (table 6) was no longer apparent.

Comparison with analysis using conventional scoring of Life-H

When we used the conventional scoring of Life-H,[13] in which help or the use of aids and adaptations lowers the participation score, most children with the greatest severity of each impairment had participation below the median. Therefore logistic regression analysis of participation above the median in each domain resulted in extremely high odds ratios for comparisons between severely impaired children and others. Furthermore, a high proportion of the deviance (42% to 60%) was explained by the models, with the exception of that for relationships. As in our main model, children with more severe impairment or pain had lower participation on most domains, but the types of impairment that were significantly associated with lower participation sometimes differed.

DISCUSSION

Among children with cerebral palsy, impairment of walking ability, fine motor skills, intellectual ability, communication, and parental report of pain were significantly associated with lower participation on most domains, whereas sociodemographic factors were not. Impairment and pain explained up to a sixth of the variation in participation. After adjustment for impairment and pain, children's participation varied substantially between regions, with children in Denmark having, on average, much higher participation than children in other countries on all domains except relationships. For most domains, about a third of the unexplained variation in participation could be ascribed to variation between regions and about two thirds to variation between individuals.

Measuring participation

Some instruments that measure participation such as Life-H and LAQ,[30] incorporate into their scoring

Table 6 | **Multilevel, multivariable regression models, relating participation for each Life-H domain in daily activities to type and level of impairment and pain of 799 children with cerebral palsy. Figures are odds ratios* (95% confidence intervals) unless stated otherwise**

	Mealtimes	Health hygiene	Personal care	Communication	Home life	Mobility
% Change in log likelihood due to impairment and pain	16%	9%	7%	14%	16%	8%
P for heterogeneity between regions	‹0.001	‹0.001	‹0.001	‹0.001	‹0.001	‹0.001
Variance between regions as % of total residual variance	51%	51%	27%	33%	36%	63%
Gross motor function						
I Walks and climbs stairs, without limitation	1.0	1.0	1.0	NS	1.0	1.0
II Walks inside	1.4 (1.0 to 2.1)	2.3 (1.7 to 3.2)	3.1 (2.1 to 4.6)	NS	3.4 (2.2 to 5.3)	4.0 (2.9 to 5.5)
III Walks with assistive devices	1.9 (1.2 to 2.8)	3.7 (2.7 to 5.2)	5.4 (3.6 to 8.3)	NS	14.8 (9.0 to 24)	5.5 (3.9 to 7.8)
IV Unable to walk, limited self-mobility	2.4 (1.5 to 3.9)	5.3 (3.7 to 7.6)	7.9 (4.8 to 13)	NS	17.6 (10 to 31)	5.2 (3.5 to 7.6)
V Unable to walk, severely limited self mobility	3.6 (2.0 to 6.5)	7.8 (5.1 to 12)	9.1 (4.7 to 18)	NS	20.5 (10 to 41)	7.6 (4.8 to 12)
Fine motor skills						
I Without limitation	1.0	NS	1.0	1.0	1.0	NS
II Both hands limited in fine skills	3.4 (2.3 to 4.8)	NS	3.4 (2.4 to 4.9)	1.9 (1.3 to 2.7)	2.0 (1.3 to 2.9)	NS
III Needs help with tasks	3.2 (2.1 to 4.8)	NS	4.0 (2.6 to 6.2)	2.1 (1.4 to 3.1)	2.6 (1.7 to 4.1)	NS
IV Needs help and adapted equipment	3.5 (2.0 to 6.2)	NS	4.6 (2.5 to 8.5)	2.2 (1.3 to 3.7)	4.3 (2.3 to 8.1)	NS
V Needs total human assistance	5.0 (2.6 to 9.7)	NS	3.1 (1.5 to 6.3)	2.9 (1.7 to 5.0)	4.1 (2.0 to 8.4)	NS
Intellectual impairment						
›70	1.0	NA	1.0	1.0	1.0	1.0
50-70	1.7 (1.2 to 2.3)	NA	1.5 (1.0 to 2.0)	4.3 (3.1 to 5.9)	1.7 (1.1 to 2.4)	1.7 (1.3 to 2.3)
‹50	4.8 (3.4 to 6.7)	NA	2.3 (1.6 to 3.3)	14.2 (9.5 to 21)	2.9 (1.9 to 4.5)	1.7 (1.2 to 2.4)
Communication						
Normal speech	NS	1.0	NS	1.0	1.0	1.0
Difficult but uses speech	NS	2.3 (1.7 to 3.1)	NS	5.2 (3.6 to 7.5)	1.8 (1.2 to 2.7)	1.8 (1.3 to 2.5)
Uses non-speech for formal communication	NS	1.4 (1.0 to 2.0)	NS	8.8 (5.4 to 14)	1.1 (0.7 to 1.9)	0.9 (0.6 to 1.4)
No formal communication	NS	2.1 (1.5 to 3.1)	NS	31.4 (17 to 57)	2.6 (1.4 to 4.8)	1.8 (1.1 to 3.0)
Type of cerebral palsy						
Spastic unilateral	NS	NS	NS	1.0	1.0	NS
Spastic bilateral	NS	NS	NS	1.2 (0.9 to 1.5)	1.9 (1.4 to 2.7)	NS
Dyskinetic	NS	NS	NS	1.5 (1.0 to 2.4)	2.0 (1.2 to 3.4)	NS
Ataxic	NS	NS	NS	4.1 (2.2 to 7.7)	2.0 (1.0 to 4.1)	NS
Feeding						
No problems	1.0	NS	NS	NS	NS	NS
Orally with difficulty	1.8 (1.3 to 2.6)	NS	NS	NS	NS	NS
Partial or complete feeding by tube	3.5 (2.0 to 6.3)	NS	NS	NS	NS	NS
Vision						
Has useful vision	NS	NS	NS	1.0	NS	NS
No useful vision	NS	NS	NS	2.8 (1.7 to 4.6)	NS	NS
Parental report of frequency of child pain in previous four weeks						
None of the time	NS	1.0	1.0	NS	1.0	1.0
Once or twice or a few times	NS	1.4 (1.1 to 1.8)	1.5 (1.2 to 2.1)	NS	1.8 (1.3 to 2.4)	1.5 (1.2 to 2.0)
More often	NS	2.3 (1.7 to 3.1)	2.6 (1.8 to 3.7)	NS	2.4 (1.6 to 3.5)	1.9 (1.4 to 2.6)

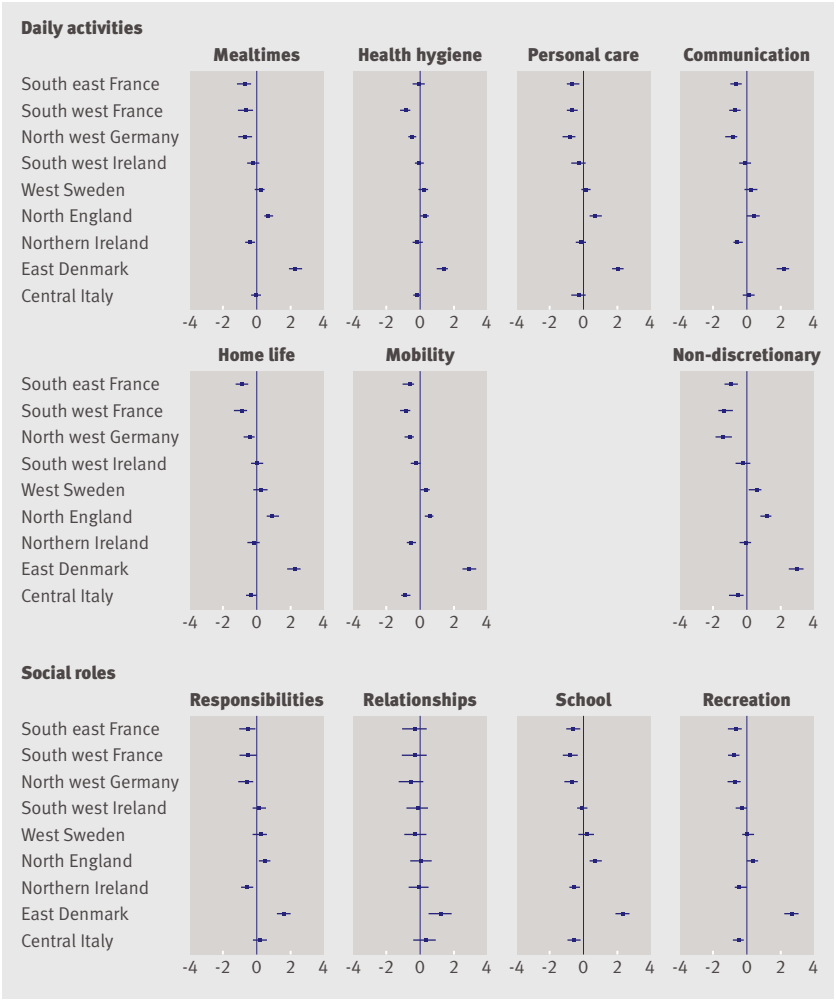
NS=factors not significantly associated with participation on specific domains. Additionally, none of the sociodemographic factors considered (child's age and sex, number of siblings and whether they were disabled, type of parental employment, level of parental educational qualifications, whether family lived in an urban or rural area) was significantly associated with participation on any domain.
*Odds ratios from latent regression ordinal item response models (see bmj.com). Odds ratios ›1 indicate greater difficulty in participation in children in that category.

Table 7 | **Multilevel, multivariable regression models, relating participation for each Life-H domain in social roles and non-discretionary to type and level of impairment and pain of children with cerebral palsy. Figures are odds ratios* (95% confidence intervals) unless stated otherwise**

	Responsibilities (n=798)	Relationships (n=798)	School (n=795)	Recreation (n=799)	Non-discretionary (n=799)
% Change in log likelihood due to impairment and pain	13%	5%	4%	8%	4%
P for heterogeneity between regions	<0.001	0.009	<0.001	<0.001	<0.001
Variance between regions as % of total residual variance	15%	5%	34%	35%	38%
Gross motor function					
Walks and climbs stairs, without limitation	NS	NS	1.0	1.0	1.0
Walks inside	NS	NS	2.3 (1.6 to 3.4)	2.5 (1.7 to 3.7)	3.4 (2.3 to 5.1)
Walks with assistive devices	NS	NS	3.0 (2.0 to 4.4)	3.6 (2.3 to 5.5)	6.4 (4.1 to 10)
Unable to walk, limited self mobility	NS	NS	3.3 (2.1 to 5.3)	2.5 (1.5 to 4.2)	9.6 (5.5 to 17)
Unable to walk, severely limited self mobility			3.5 (2.1 to 5.8)	2.6 (1.3 to 5.1)	9.6 (4.5 to 20)
Fine motor skills					
Without limitation	1.0	NS	NS	1.0	1.0 -
Both hands limited in fine skills	2.4 (1.6 to 3.6)	NS	NS	1.9 (1.3 to 2.7)	2.5 (1.7 to 3.7)
Needs help with tasks	2.6 (1.6 to 4.2)	NS	NS	2.8 (1.8 to 4.4)	3.3 (2.1 to 5.2)
Needs help and adapted equipment	1.9 (1.0 to 3.6)	NS	NS	2.7 (1.4 to 5.1)	4.0 (2.0 to 8.2)
Needs total human assistance	3.1 (1.5 to 6.3)	NS	NS	4.0 (1.9 to 8.5)	2.7 (1.2 to 6.3)
Intellectual impairment					
>70	1.0	1.0	1.0	1.0	NS
50-70	6.3 (4.2 to 9.4)	1.9 (0.8 to 4.2)	1.6 (1.1 to 2.2)	2.3 (1.6 to 3.2)	NS
<50	26.2 (15 to 44)	4.6 (1.7 to 12)	2.3 (1.5 to 3.5)	5.6 (3.6 to 8.7)	NS
Communication					
Normal speech	1.0	1.0	1.0	1.0	1.0 -
Difficulty but uses speech	2.5 (1.5 to 3.9)	3.3 (1.3 to 8.2)	2.0 (1.4 to 3.0)	1.8 (1.2 to 2.7)	3.0 (2.0 to 4.6)
Uses non-speech for formal communication	4.4 (2.3 to 8.2)	2.4 (0.8 to 6.9)	1.4 (0.8 to 2.3)	1.3 (0.8 to 2.2)	1.6 (1.0 to 2.8)
No formal communication	16.0 (7.4 to 35)	7.9 (2.6 to 24)	2.9 (1.6 to 5.4)	2.7 (1.5 to 5.1)	2.4 (1.3 to 4.4)
Type of cerebral palsy					
Spastic unilateral	NS	NS	NS	NS	NS
Spastic bilateral	NS	NS	NS	NS	NS
Dyskinetic	NS	NS	NS	NS	NS
Ataxic	NS	NS	NS	NS	NS
Feeding					
No problems	NS	NS	NS	NS	NS
Orally with difficulty	NS	NS	NS	NS	NS
Partial or complete feeding by tube	NS	NS	NS	NS	NS
Vision					
Has useful vision	1.0	NS	NS	1.0	NS
No useful vision	5.2 (2.5 to 11)	NS	NS	3.0 (1.8 to 5.1)	NS
Parental report of frequency of child pain in previous four weeks					
None of the time	NS	1.0	NS	1.0	1.0 -
Once or twice or a few times	NS	1.8 (0.9 to 3.6)	NS	1.6 (1.2 to 2.2)	1.6 (1.1 to 2.2)
More often	NS	5.2 (2.2 to 12)	NS	2.5 (1.7 to 3.6)	2.7 (1.8 to 4.1)

NS=factors not significantly associated with participation on specific domains. Additionally, no sociodemographic factor considered (child's age and sex, number of siblings and whether they were disabled, type of parental employment, level of parental educational qualifications, whether the family lived in an urban or rural area) was significantly associated with participation on any domain.
*Odds ratios from latent regression ordinal item response models, except for non-discretionary which are from latent regression Rasch model (see bmj.com). Odds ratios >1 indicate greater difficulty in participation in children in that category.

system the help required by the child to perform an activity. We used Life-H, grouping the items into the domains proposed by the developers of the instrument, but we based our main analysis on the responses to each item without modifying them if the child needed help to participate. This resulted in the magnitude of the effect of impairment on participation being much smaller and less of the variation in participation being accounted for by impairment, compared with analysis with the conventional scoring of Life-H. This



Mean level (with 95% confidence intervals) of children's participation in each region, adjusted for impairment and pain. Higher scores indicate higher participation. Mean adjusted participation is zero and each unit is 1 SD of residual variation between children

would explain why previous studies that included aids and adaptations in the scoring system found between 55% and 70% of the variation in participation explained by impairment.[31 32] Allowing aids, adaptations, and help to influence the participation score makes the implicit assumption that participation with environmental help is inferior to that without such help, and inevitably overestimates the strength of the relation between impairment and participation. Furthermore, our findings confirmed the limitations of the Life-H instrument in the domains of community life[13] and school and personal care.[33]

Simply recording whether or not children participate in life situations might not capture important differences between children. Frequency of participation might allow more appropriate comparison of discretionary participation between disabled children and children in the general population. Use of the CAPE instrument,[34] which captures frequency rather than difficulty of participation and does not incorporate assistance needed into the scoring system, should be considered in future studies.

Strengths and limitations of the study

We included a large representative sample of children with cerebral palsy in nine European regions, eight of which had population based registers. We included all children regardless of their impairments, carried out robust statistical analyses of participation in relation to a wide range of impairments, pain, and sociodemographic factors; and assessed geographical variation.

Although just over a third of the families of children with cerebral palsy who were sampled did not participate in the study, the regressions stratified the children by factors associated with non-response (region and walking ability), which should reduce bias.[23] Nevertheless the participation of non-responders might have been systematically different from that of responders, so some bias could be present.

We considered alternative explanations for the differences that we found between regions. As the rate of non-response varied between regions,[23] differences in the level of participation might, at least in part, be because of differences in response rates. This seems unlikely, however, as south west Ireland and central Italy had similar levels of non-response to east Denmark but different levels of participation. Different researchers visited the families in each region, which might have introduced systematic differences into parents' responses. We minimised this risk by training the researchers together at dedicated workshops. As the questionnaires were in different languages, the precise meaning of the questions might have been slightly different in each language. We minimised this risk by forward and backward translations according to international guidelines.[35 36] Language differences seem an unlikely explanation of the regional differences as children in north England had consistently higher participation than Irish children, despite their common language. Regions might differ in the type of participation to which they aspire for their children; however, non-discretionary participation—which is unlikely to be culturally determined—showed similar regional heterogeneity to discretionary participation. We plan to publish a further report assessing how environmental factors are associated with participation. We hope this will identify some of the factors that explain regional differences in levels of participation of children.

Comparison with other studies

The results of some studies that also used multivariable models differ from ours. The large number of children in our study, randomly sampled from population registers gives weight to our findings. We also considered a wider range of impairments than many studies. Because impairments are highly correlated with each other, studies that assessed fewer impairments might identify different dominant associations. Finally one of the studies cited below[37] reported participation using the PEDI,[38] which is closer to a measure of function than of participation.[39] The strong associations between severity of motor impairment and intellectual impairment and lower participation confirm results of

WHAT IS ALREADY KNOWN ON THIS TOPIC

Participation, defined as involvement in life situations, is important for all children

Disabled children have reduced participation, partly because of their intrinsic impairments

The social model of disability proposes that participation of disabled people depends not only on their impairments but also on the social, physical, and attitudinal environment in which they live

WHAT THIS STUDY ADDS

After adjustment for severity of impairment, pain is strongly associated with lower participation in children with cerebral palsy and should therefore be carefully assessed

Participation varies substantially across nine European regions, as predicted by the social model of disability

National regulation and legislation should be directed to ensuring all countries adapt environments to optimise the participation of disabled children, building on the experience of those countries that make best provision

other studies.[18 37 40 41] Results of studies of other impairments—such as epilepsy,[18 37 40 41] communication difficulty,[40 41] and sensory impairments[18 41]—were sometimes similar to ours and sometimes different.

Our results confirm the finding of geographical heterogeneity suggested by a smaller study.[40] We found substantial variation between regions in the participation of disabled children, with much better participation in Denmark across all domains except relationships. These differences might be partly explained by the different policies and legislation directed to equality and information, education, social security, support and care services, health services, assistive technology, and physical environment in the different countries. We have collated those affecting disabled children for the countries in our study.[42 43] Advocacy groups for disabled people have worked with policy makers in Denmark to ensure that every sector implements the principle of equal access. This results in, for example, sports clubs, restaurants, and cultural centres having to ensure they are suitable for disabled children. Denmark has a public system of after school clubs attended every day by most children up to age 12, whether disabled or not. Denmark and Sweden have central national resources for providing information to families of disabled children about assistive technology whereas the other countries do not. They also have policies for social care that explicitly emphasise the social model in determining access to support services. In terms of financial assistance to poor families (whether with a disabled child or not), Denmark is ahead of other countries, with UK and Ireland following and Italy well behind. National policies on transport are also likely to be relevant to participation of disabled children. All countries in the study except Italy had a national scheme to ensure that families could have an adapted private vehicle to transport their child. All countries make arrangements for adapted vehicles to take a child to and from school but in Denmark, Sweden, and increasingly Germany such transport is more widely provided to include taking children to after school clubs and other social events.

We did not examine the contribution of familial factors, which might partly account for the unexplained variation in participation between individuals, but a recent Canadian study did so. It found that child impairment, child behaviour and personality, and family recreational styles predicted about a third of the variation of leisure and recreational participation.[44] From a societal perspective, the most important predictors of participation are those that are amenable to change. Child personality and family recreational styles are not amenable to state intervention whereas the environment is. "The individual is rarely going to be altered very much whereas the environment slowly but surely can."[45]

Implications for research and practice

Children with cerebral palsy have lower participation than children in the general population,[21 46] and those with more types of impairment and with more severe impairments have lower participation across most domains. This picture is quite different from that for quality of life,[29] which is less influenced by impairment and is broadly similar between children with cerebral palsy and the general population. This contrast between participation and quality of life is strong evidence for their separate nature and for the need to assess both in clinical practice. Quality of life is a person's subjective assessment of what they feel about their life, whereas a person's participation is an objective account of what the person does. Assessment of participation should enable the child and family to identify areas of life in which they want greater participation and so influence the choice of medical, therapeutic, and environmental interventions. Such practice is beginning to happen.[47 48]

In recent years it has been recognised that many children with cerebral palsy have frequent and severe pain,[49-51] and our study makes clearer its association with lower participation. As pain is also known to have a pervasive effect on quality of life,[29] better assessment and treatment of pain should improve both participation and quality of life. Firstly, clinicians should ask about children's pain. Children with cerebral palsy might have always lived with pain and might assume this to be normal; discussion of such pain is itself helpful.[52] In one study, assisted stretching was the daily living activity most commonly identified as painful,[53] which reinforces the need to strengthen the evidence base for the long term benefit of therapeutic interventions if they have such an important disadvantage as pain. Psychological factors play an important part in most chronic pain, and the importance of the place of interventions such as cognitive behavioural therapy has been emphasised for older children with cerebral palsy.[54]

The considerable variation in participation between regions suggests that some countries promote participation better than others through policies and regulation at national level. Some variation might also be

accounted for by the extent to which families can actually access aspects of the environment they need; local availability might not correspond to what national guidance or policy intends. We will explore this possibility by using data from the same study from a questionnaire designed to capture these unmet needs. Analysis of the causes of the geographical heterogeneity should provide evidence for changes to regulation and legislation and for better direction of resources and so respond to the duty to provide accessibility under Article 9 of the UN Convention on the Rights of Persons with Disabilities.[2]

The best way to characterise and measure participation must continue to be debated.[5 33] New instruments need to be developed that incorporate frequency and quality of participation and fulfil modern psychometric requirements for scale development.

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Contributors: AC participated in planning, coordinated the study, wrote the paper, and took overall responsibility for the delivery of the work. AC had full access to all the data in the study, final responsibility for the decision to submit for publication, and is guarantor. JF participated in planning, was responsible for data collection, attended workshops planning analysis, and wrote the paper. UT, CA, EB, VMcM, SIM, and JP participated in planning the study, were responsible for data collection, and attended workshops planning analysis. HOD performed the statistical analysis, participated in maintaining the quality of the data, and wrote the paper. KNP was responsible for the day to day administration of the study and data collection in one centre and participated in maintaining the quality of the data. MM was involved in this study in its later stages and attended workshops. All authors saw and approved the final version.

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Competing interests: None declared.

Ethical approval: This study was approved by ethics committees in each country. All parents gave written consent. All children with sufficient cognitive capacity gave written consent or communicated consent if unable to write.

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