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Characteristics influencing participation of Australian children with cerebral palsy

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Abstract

Purpose. To investigate the extent to which selected individual, family and environmental variables were associated with participation of children who have cerebral palsy in activities outside school.

Methods. Data were gathered through a population-based survey of 114 children born in 1994 or 1995 in Victoria, Australia. Participation was measured using the Children's Assessment of Participation and Enjoyment. Selected independent variables were classified as related to the child, family or environment. Linear regression analysis was used to identify variables associated with participation in informal (activities that require little planning) and formal (those with structure and leaders) activities.

Results. Participation in informal activities tended to be greater in children who preferred informal activities and who had higher manual ability (adjusted $R^2 = 36.3\%$). Girls and those with better gross motor function also tended to participate in more activities. The explanatory power of the regression model for participation in formal activities was limited (adjusted $R^2 = 4.2\%$).

Conclusion. Knowing a child's activity preferences is critical to intervention planning. Being exposed to a range of activities within supportive environments may provide the opportunity to develop preferences, especially in activities where children with cerebral palsy have reduced participation, such as in physical activities.

Keywords: *Cerebral palsy, children, participation*

Introduction

Active and pleasurable involvement of disabled children in activities outside school is one of the key measures of successful participation. Engagement in activities outside school provides children with the opportunity to develop skills, make friends and find satisfaction [1] and successful participation is the ultimate goal of health interventions [2]. Health interventions for children with cerebral palsy are often aimed at changing the individual's impairment, although disablement is a phenomenon that occurs to an individual rather than arising from within [3]. Interventions that focus on changing impairments or improving skills may or may not result in improved participation. Interventions intent on changing participation should also address factors outside the individual – environmental factors such as physical access, transport availability or social attitudes [4,5] and on factors identified as important in the interaction between the individual and the environment [6]. Research that builds evidence towards understanding which factors or combination of factors influence participation will support the development of interventions aimed at promoting participation.

In 2003, King et al. [7] proposed a model describing the factors that influenced children's

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participation in recreation and leisure activities. This model described factors from the child, family and environment hypothesising both direct and indirect influences on participation. King et al. [8] later tested this model using structural equation modeling (SEM) of data from the Canadian Participate study. The Canadian study involved 427 children with physical disability and participation was measured using the Children's Assessment of Participation and Enjoyment (CAPE) [9]. King et al.'s analyses resulted in two participation models – one for intensity of participation in informal activities (accounting for 30% of the variance) and one for formal activities (accounting for 18% of the variance). Intensity, as defined in the CAPE, is a measure of relative frequency of participation. The factors with direct effect on participation intensity in informal activities were child functional ability, child preference for informal activity and family participation in social and recreational activity. The factors with direct effect on formal participation intensity were child preference for activity, family participation in social and recreational activity, family intellectual and cultural orientation and child functional ability. In addition, parent perception of unsupportive environments, family cohesion and supportive relationships for the child had indirect effects on participation. There were no moderating effects of gender or age, suggesting the model was applicable to both boys and girls across the age range of the study (6–14 years).

King et al.'s [8] findings reinforced the direct importance of factors related to the child and the environment closely connected to the child – the family preference for activity – on participation. Granlund and Björk-Åkesson [6] stressed the importance of factors within and between systems, including environments close to the child and those more distant. These authors suggested that rather than specific variables being important, different patterns of factors may support participation and that research must identify the critical factors to measure. Functional performance factors have been studied in cerebral palsy with findings consistently indicating that increased severity of condition negatively impacts participation [10–16]. Other child factors related to personal characteristics such as autonomy, temperament or social skill are less well researched [6], although King et al. [8] found that the child's emotional functioning, including self esteem, was not a predictor of leisure and recreational participation.

Factors more distant to the child such as district of residence, family income, availability of transport, physical accessibility of venues and social attitudes have all been shown to have an effect on participation [17–19]. Desire to understand the influence of the environment, including health, social and educational environments, on participation has led to a large European study of participation of children with cerebral palsy [20]. The premise is that children in different countries, or regions, will experience variable participation outcomes due to differing policies and practices resulting in varying barriers and facilitators [20]. Although recent research suggests that the participation of Australian children with cerebral palsy in activities outside school is similar to that of Canadian children [11], the factors that influence participation of Australian children have not been reported.

The purpose of this study was to understand the extent to which selected individual, family and environmental variables predicted participation in formal and informal activities outside school, in Australian children with cerebral palsy.

Methods

Participants

Participants of this study were enrolled in a longitudinal study of the participation of children with cerebral palsy and were born in Victoria, Australia in 1994 or 1995. The Victorian Cerebral Palsy Register (VCPR) was used to identify eligible children. At the beginning of data collection in September 2006, there were 233 children registered to the two birth years (1994 births = 107; 1995 births = 126), thus ascertainment rates were 1.66 and 1.99 per 1000 live births for each year respectively (personal communication, Sue Reid, Manager of the VCPR, 5 September 2006). Of the 233 registered children, 148 agree to receive questionnaires and 114 returned them, with 108 providing sufficient data for this study (Figure 1). These 108 children were 49.3% of the registered living population of children with cerebral palsy. Ethical approval was obtained from The Royal Children's Hospital and La Trobe University, Melbourne.

Measures

The dependent variable: Participation

Measures of participation pertinent to children with physical disability such as cerebral palsy, are the Lifestyle Assessment Questionnaire [21], the Assessment of Life Habits [15], activity pattern questionnaires, the CAPE [9] and the School Function Assessment [22]. Each measure conceptualises participation slightly differently. We chose the CAPE and its companion measure the Preferences for Activity of

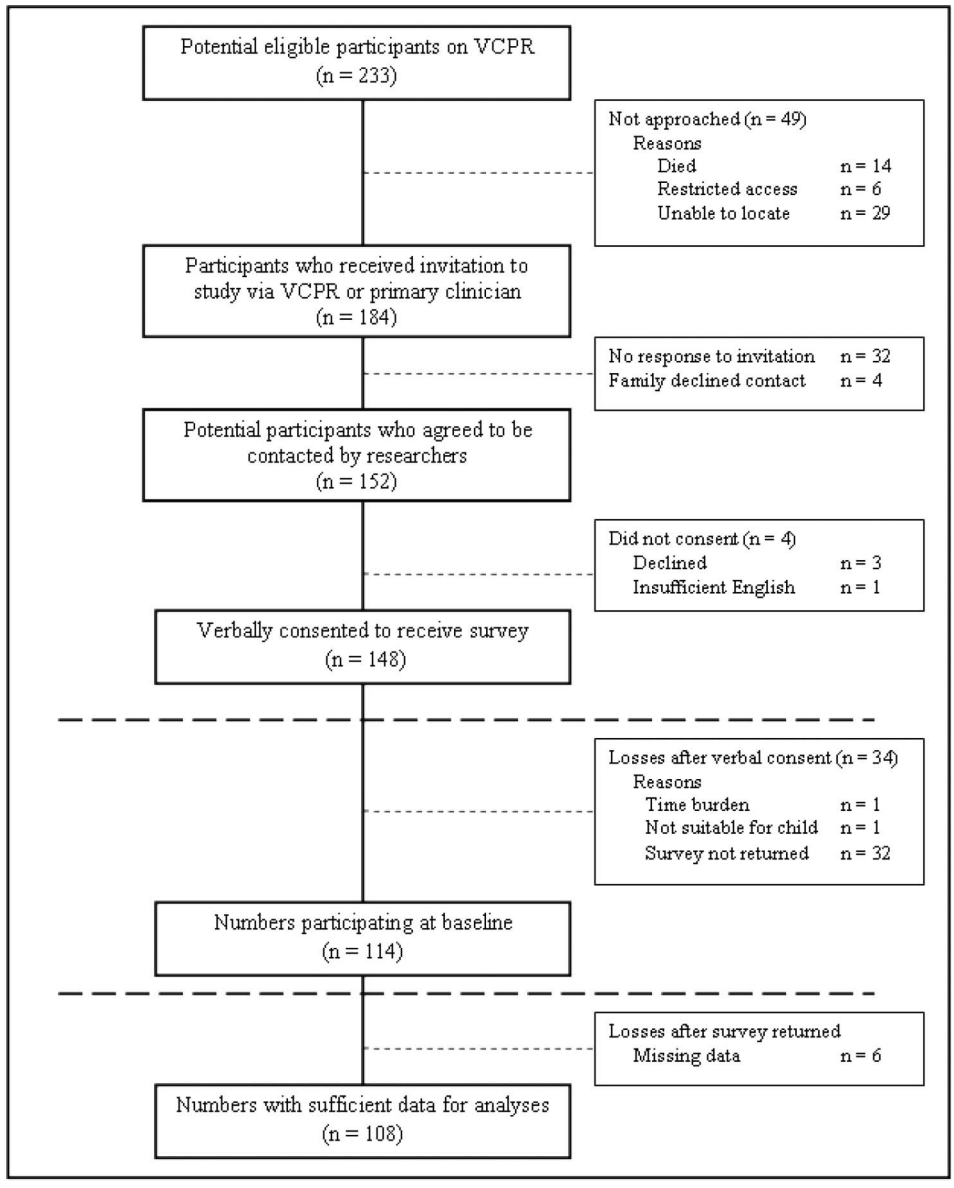

Figure 1. Flow diagram of eligible and included participants. VCPR, Victorian Cerebral Palsy Register.

Children (PAC) as our outcome measures because unlike the other tools, they measured the range and frequency of participation in activities outside school as well as the child's preference for activity.

The CAPE is designed to measure the patterns of participation of children in activities outside of mandated school. The CAPE measures activities in two domains (informal and formal), and five activity types (recreational, social, active-physical, skill-based and self-improvement) across six participation elements: diversity, intensity, with whom, where, enjoyment and preference. King et al. defined formal activities as those that have structure, such as the use of leaders or teachers, and informal activities as those that occur with little planning, and which are primarily instigated by the child.

In this study, the CAPE was completed by the children and a parent, or by a parent alone if the child was unable to contribute. As diversity and intensity of participation in informal and formal activities were highly correlated ($r = 0.936$ informal participation; $r = 0.948$ formal participation) and the resultant analyses produced final regression models with the same predictor variables, only data related to diversity of participation will be presented. The diversity score is a count of the number of activities a child does. Informal diversity scores range from 0 to 40 and formal diversity scores range from 0 to 15. Although there was some evidence of positively skewed distributions in the formal domain and a potential outlier, initial regression analyses were undertaken with raw data and

transformations considered based on the fit of the resulting models.

Independent variables

Selection of independent variables was undertaken following a review of the literature [23] and included child, family or environmental characteristics. Age was not included in the analyses, as all children were born in 1 of 2 years thus restricting the range of values, nor were specific comorbidies. The child's sex, cognitive and communication ability, specific diagnostic characteristics and temperament were considered as potential variables, as was the child's preference for activity that was measured using the PAC [9]. Evidence supporting the construct validity [24], internal consistency and reliability [9] of the PAC has been reported. Manual ability was classified using the Manual Ability Classification System (MACS) [25]. The MACS is a newly published tool with growing evidence of validity and reliability including very good reliability of parent ratings [10,25]. Gross motor function was classified using the Gross Motor Function Classification System (GMFCS) [26], which has strong evidence of its validity and reliability, again including reliability of parent ratings [27].

Temperament was selected as a key construct to represent personal attributes. Temperament is defined as 'individual differences in attentional, emotional, and behavioural self-regulation, along with the relative level of emotional reactivity, which together give a unique flavour to an individual' [28, p. 3]. Temperament is about how individuals approach their lives, not what they do, but is likely to also influence the individuals activity and participation choices. Temperament was measured using a modified version of The School Aged Temperament Inventory (SATI) [29,30], a parent-response questionnaire designed for 8–11 year olds. Four temperament domain scores (Negative Reactivity, Task Persistence, Approach/Withdrawal and Activity) are obtained with high scores suggesting that a child is highly reactive, shy, lacks persistence and is highly active [31]. The SATI has been shown to be a reliable and valid instrument to use with Australian children [28]. Although validity, reliability and applicability to an Australian population were all excellent in the SATI, face validity of items within the activity domain were problematic for children who have cerebral palsy. Simple modifications to the activity domain items were undertaken in consultation with the author of the SATI and the chief investigator of the Australian Temperament Study [28]. Internal consistency of the modified Activity scale was high (Cronbach's alpha = 0.806; details available on request). As well as completing the modified SATI, parents gave an overall rating of their child's temperament in comparison to other children on a Likert scale ranging from 1 (very easy) to 5 (very difficult).

Family variables included whether children were in single or two-parent households, parental birthplace and first language and socioeconomic advantage/disadvantage. The socioeconomic advantage/disadvantage score was obtained using the Australian Bureau of Statistics (ABS) Socio-Economic Index for Areas (SEIFA) data [32]. This SEIFA score has a national mean of 1000 and standard deviation (SD) of 100 with high scores indicating relatively high proportions of people with high incomes or in skilled work. Environmental variables included whether families lived in rural or metropolitan regions and frequency of medical appointments. Because children in middle childhood seek to participate with school friends even in activities outside school, we also examined the influence of the type and size of school the child attended.

Independent variable selection and data analyses

The number of variables made available to the multiple regression analyses was limited by the sample size. Missing data occurred in both the PAC ($n = 6$ missing) and temperament domain scores (up to 24 cases with missing data). Missing data in these variables appeared most frequently for children with significant physical impairment or physical and intellectual impairment, which made it difficult for families to answer temperament domain questions or for children to indicate preferences. All parents provided a measure of overall temperament and this score was used in the primary regression analyses. The main analyses were conducted with the slightly reduced sample of children for whom PAC scores were available ($n = 108$). To examine the effect of SATI temperament domain scores on participation, separate regressions were conducted including only those children in GMFCS Levels I to IV ($n = 86$), as most parents were able to provide information related to temperament for these children.

Variables were included in the regression analyses based on theoretical reasons, or if there was evidence of an association between them and the dependent variables with $p < 0.15$ as the criteria [33]. Although initially considered within the analyses, two family level variables were not included (whether children lived in one or two parent households and if parents were born in Australia or not) as there was no evidence of a univariate association between these variables and participation.

The independent variables were a mix of both continuous and categorical level data. Nominal variables were coded to create dichotomous variables and ordinal variables were treated as linear [34]. All observations were independent and data were assumed to be representative of Victorian children with cerebral palsy in middle childhood [11]. Regression models were systematically developed by first examining univariate and bivariate distributions for distributional properties and unusual observations, and then fitting a multiple regression model including all potentially useful independent variables. Following appropriate diagnostic checks for goodness of fit, an initial reduction of independent variables was made using a threshold of $p > 0.15$, with a further reduction to variables satisfying $p < 0.05$. This process allowed evaluation of the influence of all the variables, independently and together, to understand their effect on participation in this sample. Probability (p) values are presented to quantify the strength of the evidence, but as the analysis process involved searching for important variables, the p-values presented may underestimate the risk of a Type 1 error [35].

Results

The 108 children included in primary analysis had an average age of 11.7 years (SD: 0.54) and there were 63 boys and 45 girls. The proportion of children with hemiplegia was 39% ($n = 42$), diplegia 24% ($n = 26$), triplegia 4% ($n = 4$) and quadriplegia 32% ($n = 34$), and the predominant motor type was spasticity (69%). Only 21% of the children had no co-morbidities, 32% had one, and 47% had two to five different co-morbidities. These included epilepsy (29%) learning disorder (48%), intellectual impairment (36%), vision (27%) or hearing impairment (9%). Table I presents summary statistics for each of the independent variables. The mean diversity of participation score was 22.5 (SD: 6.1) for the informal and 3.1 (SD: 1.9) for the formal activity domain.

Table I. Summary statistics for each independent variable.

Characteristic	n	%	Mean	SD
Child level variables				
Gender				
Boys	63	58.3		
Girls	45	41.7		
GMFCS				
Level I	25	23.1		
Level II	40	37.0		
Level III	12	11.1		
Level IV	10	9.3		
Level V	21	19.4		
MACS				
Level I	22	20.4		
Level II	43	39.8		
Level III	15	13.9		
Level IV	10	9.3		
Level V	18	16.7		
Difficulty communicating	53	49.1		
Cognitive impairment	79	73.1		
Temperament				
Very easy	19	17.6		
Easy	23	21.3		
Average	37	34.3		
Difficult	22	20.4		
Very difficult	7	6.5		
SATI				
Negative reactivity ($n = 97$)			3.15	0.9
Task persistence ($n = 88$)			2.89	0.8
Approach/withdrawal ($n = 96$)			2.63	0.8
Activity ($n = 91$)			2.62	0.9
PAC				
Informal activities			2.29	0.3
Formal activities			2.02	0.4
Family level variables				
Family				
Single parent household	27	25.0		
Two parent household	81	75.0		
Family background				
Australian	80	74.6		
Other – 16 countries	28	25.4		
SEIFA score			1005.7	90.3
Environment level variables				
Community type				
Major city	77	71.3		
Regional	31	28.7		
School				
Mainstream school	69	63.9		
Special school	39	36.1		
School size			271.1	192.5
Number of medical appointments/year			29.3	33.66

Note: Sample size = 108 unless indicated. GMFCS, Gross Motor Function Classification System; MACS, Manual Ability Classification System; SATI, School Aged Temperament Inventory; PAC, Preferences for Activity of Children; SEIFA, Socioeconomic index for areas for which the Australian mean = 1000 (SD = 100); cognitive impairment defined as performing below grade level or in ungraded class; SD, standard deviation.

Factors that support diversity of participation in informal activities

There was evidence of a univariate association between each independent variable and participation in informal activities except for whether children lived in a major city or not (Table II). The 10 independent variables together explained 39.1% (adjusted R^2) of the variance in informal participation. At the first reduction, only sex, severity of cerebral palsy as measured by MACS, preference for informal activity, overall temperament and socio-economic advantage/disadvantage (SEIFA) remained as influential variables. The reduced model also explained 39.1% (adjusted R^2) of the variance. Although temperament and SEIFA did not meet the

Table II. Regression coefficients from univariate, full model, first reduction and final reduction models for diversity of informal participation for 108 children with cerebral palsy.

	Univariate associations			Full model			First reduction			Final reduction		
Variable	*B*	CI	*p*	*B*	CI	*p*	*B*	CI	*p*	*B*	CI	*p*
Male	−3.50	−5.70 to −1.20	0.003	−1.97	−3.96 to 0.02	0.05	−2.22	−4.15 to −0.28	0.03	−2.05	−3.97 to −0.12	0.04
MACS	−2.30	−3.08 to −1.6	<0.001	−1.34	−2.45 to −0.23	0.02	−2.08	−2.77 to −1.39	<0.001	−2.17	−2.87 to −1.47	<0.001
GMFCS	−2.03	−2.7 to −1.31	<0.001	−0.54	−1.54 to 0.46	0.29	–	–	–	–	–	–
Temperament	1.01	0.01 to 2.01	0.05	0.62	−0.22 to 1.47	0.15	0.77	−0.05 to 1.58	0.06	–	–	–
PAC informal	6.01	2.48 to 9.7	0.001	4.82	1.82 to 7.83	0.002	4.77	1.79 to 7.75	0.002	5.22	2.20 to 8.24	0.001
Communicate OK	4.63	2.47 to 6.80	<0.001	0.62	−1.71 to 2.94	0.60	–	–	–	–	–	–
SEIFA (/100)	1.20	−0.08 to 2.5	0.07	0.94	−0.14 to 2.02	0.09	0.91	−0.11 to 1.94	0.08	–	–	–
Major city	−0.85	−3.4 to 1.7	0.52	−0.92	−3.19 to 1.34	0.42	–	–	–	–	–	–
Mainstream school	4.62	2.35 to 6.89	<0.001	0.86	−1.88 to 3.61	0.53	–	–	–	–	–	–
School size (√Y)	0.27	0.08 to 0.46	0.006	0.06	−0.15 to 0.27	0.59	–	–	–	–	–	–
				$R^2 = 0.391^{\star}$; $p < 0.001$			$R^2 = 0.391^{\star}$; $p < 0.001$			$R^2 = 0.363^{\star}$; $p < 0.001$		

Note: $N = 108$. *B*, unstandardised regression coefficient interpreted as the amount of change in the outcome per 1-unit change in the independent variable; CI, confidence interval; *p*, *p*-value of *t*-statistic; independent variables with *p*-value > 0.15 dropped in first reduction; independent variables with *p*-value > 0.05 dropped in final reduction.
$^{\star}R^2$, adjusted regression coefficient; Temperament is overall measure; *B* for SEIFA (/100) variable is interpreted as change per 100 points of SEIFA; B for school size (√Y) variable is interpreted as change per school size squared.

strict criteria for inclusion in the final model with *p*-values just over 0.05, there was little evidence that they were less important than the other variables. The final model included sex, MACS and PAC with the resulting model accounting for 36.3% (adjusted R^2; $p \leq 0.001$). In this model, manual ability (MACS) independently accounted for 22.6% of the variance, preference for informal activities accounted for 7.0% and being male accounted for 2.6% of the variance in informal participation. The estimated regression coefficients indicate that after accounting for activity preference and gender, diversity of informal participation decreased by about two activities (of its overall range 0–40) for each increase in MACS level. Similarly, with other variables held constant, diversity of informal participation increased by around five activities for each unit increase in preference for informal activities. Likewise, diversity of informal participation was reduced by an average of 2.1 activities if the participant was male.

Review of raw correlations with partial correlations within the full model did not reveal suppression effects amongst variables: all partial order correlations were equal to or less than the raw correlations. Although GMFCS, communication ability and school type and size each had strong univariate associations with diversity of informal participation, they were also moderately correlated with MACS (Pearson's $r = 0.75$ GMFCS; $r = -0.56$ communication ability; $r = -0.47$ mainstream school) and thus provided little additional information to the regression model. Review of diagnostic criteria suggested that the regression model fitted the data adequately, although there was some evidence of unequal variance with a very mild fanning out of the data on the scatter plot of standardised residuals versus standardised predicted values.

The influence of the individual temperament domains on diversity of informal participation was examined for children in GMFCS levels I to IV. Univariate analyses identified task persistence, negative reactivity and activity as potentially important temperament variables (Table III). The full model accounted for 29.9% (adjusted R^2; $p \leq 0.001$) of the variance, with MACS, preference for informal activities, task persistence and number of medical visits/year as the important variables. Once preference for informal activities, MACS level and frequency of medical visits were accounted for, task persistence only explained an additional 2.1% of the variance.

Factors that support diversity of participation in formal activities

There was evidence that six of the nine independent variables had strong univariate associations with

Table III. Regression coefficients from univariate, full model, first reduction and final reduction models for children in GMFCS levels I to IV with diversity of informal participation as the dependent variables and including the four temperament domains.

Variable	Univariate associations			Full model			First reduction			Final reduction		
	B	CI	*p*	*B*	CI	*p*	*B*	CI	*p*	*B*	CI	*p*
Male	−2.54	−4.65 to −0.43	0.02	−0.45	−2.61 to 1.71	0.68	–	–	–	–	–	–
MACS	−1.13	−2.5 to −0.15	0.03	−1.07	−2.21 to 0.07	0.07	−1.33	−2.4 to −0.28	0.01	−1.48	−2.5 to −0.48	0.004
PAC informal	6.96	3.39 to 10.5	<0.001	6.93	3.24 to 10.61	<0.001	7.97	4.67 to 11.3	<0.001	8.17	4.91 to 11.4	<0.001
SEIFA/100	0.92	−0.27 to 2.11	0.13	0.65	−0.47 to 1.77	0.25	–	–	–	–	–	–
Medical visits	1.84	0.42 to 3.26	0.01	1.86	0.44 to 3.29	0.01	2.17	0.89 to 3.45	0.001	2.2	0.97 to 3.4	0.001
Negative react	0.94	−0.26 to 2.15	0.12	0.44	−1.06 to 1.93	0.56	–	–	–	–	–	–
App./withdraw.	0.81	−0.51 to 2.1	0.23	0.44	−0.82 to 1.71	0.49	–	–	–	–	–	–
Task persistence	−1.31	−2.77 to 0.16	0.08	−1.36	−2.91 to 0.20	0.09	−0.98	−2.2 to 0.26	0.12	–	–	–
Activity	0.94	−0.25 to 2.1	0.12	0.49	−0.91 to 1.88	0.49	–	–	–	–	–	–
				$R^2 = 0.299$*; $p < 0.001$			$R^2 = 0.309$*; $p < 0.001$			$R^2 = 0.305$*; $p < 0.001$		

Note: *B*, unstandardised regression coefficient interpreted as the amount of change in the outcome per 1-unit change in the independent variable; CI, confidence interval; *p*, *p*-value of *t*-statistic.
*R^2, adjusted *R* squared; Negative react, negative reactivity temperament domain; App./withdraw, approach withdrawal.

diversity of formal participation (Table IV). Temperament, SEIFA score, and whether children lived in a major city had no independent influence on participation in formal activities. However, all nine independent variables together only explained 4.2% (adjusted R^2) of the variance in formal participation. In the reduced model, only preference for formal activity and attendance at a mainstream school were important variables, together explaining 8.1% (adjusted R^2) of the variance. Attendance at a mainstream school independently accounted for 7.1% and preference for formal activities independently accounted for 2.9% of the variance. After accounting for preference for formal activities, diversity of participation in formal activities increased, on average, by one activity (range 0–15), for children who attended mainstream schools.

No suppression effects were evident amongst variables in the full model: all partial order correlations were equal to or less than the raw correlations. While MACS, GMFCS and communication ability had some univariate association with diversity of formal participation, moderate correlations between each of these variables and mainstream school attendance limited their usefulness in a multivariate model (Pearson's $r = -0.47$ MACS; $r = -0.47$ GMFCS and $r = 0.46$ communication ability). Review of diagnostic criteria suggested adequate fit of the regression model to the data.

Univariate analysis of the temperament domain scores with diversity of formal participation identified Task Persistence as the only important temperament variable (Table V). The full model, including mainstream school attendance and preference for formal activity, gender and the four temperament domains, accounted for only 8.8% (adjusted R^2) of the variance. There was weak evidence of a linear association between any of the variables and diversity of participation in formal activities and none of the temperament domains were important in this model.

Discussion

This study included 108 children with all types and severities of cerebral palsy and examined predictors of participation in informal and formal activities outside of school. Because the scores for diversity and intensity of participation in this study were highly related ($r > 0.9$) only the models for diversity were presented. There was strong evidence that girls, children with higher manual ability and those with a preference for informal activities participated in more informal activities. Scores on overall temperament and socioeconomic advantage/disadvantage also appeared to be weakly predictive of diversity of participation in informal activities. There was no

Table IV. Regression coefficients from univariate, full model and reduced model for diversity of participation in formal activities for $n = 108$ children with cerebral palsy.

	Univariate associations			Full model			First/final reduction		
Variable	*B*	CI	*p*	*B*	CI	*p*	*B*	CI	*p*
Male	−0.69	−1.43 to 0.04	0.06	−0.38	−1.15 to 0.39	0.33	–	–	–
MACS	−0.28	−0.54 to −0.01	0.04	−0.05	−0.49 to 0.38	0.81	–	–	–
GMFCS	−0.25	−0.50 to .003	0.05	−0.05	−0.44 to .34	0.81	–	–	–
Temperament	−0.08	−0.40 to 0.24	0.61	−0.13	−0.46 to 0.21	0.45	–	–	–
PAC formal	0.82	−0.11 to 1.76	0.08	0.92	−0.26 to 2.11	0.12	1.05	−0.08 to 2.18	0.07
Communicate OK	0.74	0.01 to 1.46	0.05	0.17	−0.74 to 1.09	0.71	–	–	–
SEIFA /100	0.12	−0.29 to 0.53	0.55	0.05	−0.38 to 0.47	0.84	–	–	–
Major city	−0.04	−0.86 to 0.77	0.91	−0.08	−0.94 to 0.78	0.85	–	–	–
Mainstream school	1.05	0.31 to 1.79	0.006	0.79	−0.11 to 1.7	0.08	1.06	0.33 to 1.80	0.005
				$R^2 = 0.042$*; $p = 0.15$			$R^2 = 0.081$*; $p = 0.004$		

Note: *B*, unstandardised regression coefficient interpreted as the amount of change in the outcome per 1-unit change in the independent variable; CI, confidence interval; *p*, *p*-value of *t*-statistic; independent variables with *p*-value > 0.15 dropped in first reduction; final reduction not required.
*R^2, adjusted *R* squared; Temperament is overall measure. *B* for SEIFA variable is interpreted as change per 100 points of SEIFA.

evidence for association with variables related to the environment (whether children lived in the city or regional areas, family background, school type and size).

These findings are consistent with those presented by King et al. [8]. King et al.'s structural equation model of predictors of *intensity* of informal participation found three direct pathways: the child's preference for informal activities, their functional ability (measured using three tools) and the family's participation in social and recreational activities. This study did not formally measure family activity orientation, but the importance of the other two factors, child's ability and preference for activity, are consistent in each study. In King et al.'s model, family income had an indirect effect on the child's participation through the family's orientation to recreational activity.

Diversity of participation in formal activities tended to be higher in children who attended mainstream schools and preferred formal activities. However, the regression model was limited. The univariate associations were not strong and the formal participation scores of this group of children were predominantly in the first half of the diversity scale. The somewhat limited variation in formal participation may have restricted the potential for associations to be identified, but it is also highly likely that important variables were not identified for inclusion. King et al.'s [8] comprehensive structural equation model of formal participation accounted for 18% of the variance, also suggesting not all important characteristics were included. King et al. found that parental perception of unsupportive environments and family cohesion had indirect effects on formal participation through the families' orientation to intellectual or cultural activities and their participation in social and recreational activities.

In contrast to informal participation, formal participation was directly associated with one environmental factor: attendance at mainstream school. Mainstream school attendance may appear as an overall measure of the child's ability, but children with all levels of motor severity and with specific learning disabilities or intellectual impairment were attending mainstream schools. School type was included as a potential variable as Simeonsson et al. [36] found that school type and size was associated with participation of disabled children at school. These authors postulated that the availability of the larger peer base in large mainstream schools might be important. Although this study did not investigate school participation, peers are also important to out-of-school activity. These findings appear to support this assumption for formal activity participation. In addition, opportunities, and perhaps support, for formal out-of-school activities such as team sports or music lessons may be greater in mainstream school settings than special schools. Alternately, it may simply be that the children with the most complex forms of cerebral palsy are attending special schools, and that these children are more restricted in their formal participation.

Environmental variables

Other than mainstream school attendance, there was no strong evidence that characteristics external to the child in this study were important predictors of participation. To a small extent socioeconomic status was associated with informal participation, but contrary to other Australian studies [37–39] family

Table V. Regression coefficients from univariate, full model, first reduction and final reduction models for children in GMFCS levels I to IV with diversity of formal participation as the dependent variable and including the four temperament domains.

	Univariate associations			Full model			First reduction			Final reduction		
Variable	*B*	95%CI	*p*	*B*	95%CI	*p*	*B*	95%CI	*p*	*B*	95%CI	*p*
Gender	−0.89	−1.71 to −0.07	0.03	−0.71	−1.63 to 0.21	0.13	−0.61	−1.43 to 0.22	0.15	–	–	–
PAC formal	1.05	−0.02 to 2.12	0.05	1.15	−0.01 to 2.31	0.05	1.10	0.27 to 2.18	0.05	1.28	0.22 to 2.34	*0.02*
Mainstream school	0.92	−0.04 to 1.87	0.06	0.82	−0.27 to 1.92	0.14	1.00	0.05 to 1.96	0.04	1.13	0.18 to 2.08	*0.02*
Negative reactivity	−0.01	−0.48 to 0.46	0.97	0.24	−0.39 to 0.87	0.45	–	–	–	–	–	–
App./withdrawal	0.12	−0.39 to 0.64	0.64	0.19	−0.36 to 0.73	0.50	–	–	–	–	–	–
Task persistence	0.51	−0.06 to 1.08	0.08	0.28	−0.40 to 0.96	0.42	–	–	–	–	–	–
Activity	−0.16	−0.63 to 0.30	0.49	−0.30	−0.89 to 0.29	0.32	–	–	–	–	–	–
					$R^2=0.088$*; $p=0.05$			$R^2=0.095$*; $p=0.01$			$R^2=0.082$*; $p=0.01$	

Note: $N=81$ full model; $n=86$ first and final reduction; *B*, unstandardised regression coefficient interpreted as the amount of change in the outcome per 1-unit change in the independent variable; 95%CI, confidence interval; *p*, probability of *t*-statistic.
*R^2, adjusted *R* squared; App./withdrawal, approach withdrawal.

configuration such as living in a one or two parents household was not, nor was whether children lived in the city rather than a rural environment.

Child variables

Despite strong univariate associations between a number of impairment characteristics and participation, MACS was the variable that best predicted the outcome. The ability to use the hands to achieve the tasks of everyday life is influenced by many factors including motor, sensory, cognitive and affective skills [40]. If each factor is measured individually, knowledge about the components themselves is gained, but not about how they interrelate. For example, how one child might compensate for poor sensation by using vision and another, despite good motor function, might not achieve because of poor cognition. The MACS pulls all aspects of hand function together into a gestalt of ability, making it an extremely useful classification tool. The five classification levels of the MACS thus describe groups of children with varying severities of cerebral palsy measured in a manner that illustrates a meaningful increase in the impact on the daily lives of the children and that assists with predicting outcomes. Preliminary evidence suggests that a child's manual ability classification is relatively stable [41]. Quality of performance may be influenced by intervention thus making manual ability smoother and more flexible, but whether interventions are effective enough to enable a child to move up one or more levels on the MACS is yet to be shown.

Once manual ability was accounted for there was no evidence that GMFCS level contributed to the outcome. Differences in findings between this and previous research may relate to the different participation outcomes used, because how each tool defines and measures the construct of interest will influence the outcome. Previous researchers have used the Lifestyle Assessment Questionnaire [10], the Life-Habits [16] and the ICF participation codes [12]. To varying extents, these tools capture the ability of the individual to achieve the items of interest and so are likely to be more strongly related to physical functioning than the CAPE, which does not aim to measure the ability of the child.

Temperament was selected as a variable of interest on the assumption that a more active, persistent, outgoing child might participate more. Although none of the temperament domains had strong univariate associations with participation diversity, there was some evidence that task persistence was important. Children who persist more are those who have developed strategies for dealing with situations that are difficult [42] and these results suggest that

this is an important characteristic to support in children with cerebral palsy.

Limitations of the study

The number of cases included in a regression analysis influences both the stability of the estimate and the power to detect relationships. In this study, the number of independent variables included was limited so that the resulting models were likely to be stable, and this was supported by findings that were consistent with previous research. The limitation, however, lies in the power to detect moderately small effects. A much larger study, perhaps including four or five birth cohorts, would have sufficient power to detect smaller effects, to include a greater number of variables, and to undertake more sophisticated analytical techniques such as structural equation modelling.

Family and environment variables in this study were measured using parental responses to the study-designed questions. None of these characteristics were strongly associated with the children's participation. Knowing this is important, but as the regression models did not account for all of the variance in participation, it is clear that some variables were missing. There are now measures of environment, including the CHIEF [43] and the European Child Environment Questionnaire [4] that would provide a more in-depth understanding of social, policy and physical environmental factors that may influence participation.

Children with very severe cerebral palsy were excluded from the analyses because of missing data. This occurred because of the difficulty in measuring important characteristics such as preference and temperament, each of which was associated with participation. If participation is simply performance then severely impaired children are disenfranchised by virtue of their impairments. If participation is more than performance, rather it is also being a part of a community and family, of taking part in activity at any level for any amount of enjoyment or satisfaction, then we need to understand better what affects severely disabled children's participation.

Clinical implications

Knowing which variables were associated with informal participation provides a focus for intervention at an individual and family level. Knowing children's preferences can be used to locate activities that are accessible, or available. It may also be necessary to try to influence a child's preferences as a mechanism for increasing motivation [9]. King et al.'s model suggested one pathway to a child's preferences was through family activity preference, which was influenced by financial burden. The small association between socioeconomic advantage/disadvantage and informal participation in this study supported this finding. Relieving socioeconomic hardship may allow families to take part in the activities they prefer, thus providing opportunity for children to develop preferences. Schmitt-Rodermund and Vondracek [44] found that an early opportunity to experience a broad range of activities assisted adolescents in establishing their identity, providing additional support to the notion that children should be helped to experience a wide variety of activities. This may help them find the ones they prefer, or indeed to develop preferences.

Supporting participation requires more than knowing what children prefer. The context of the activity, who it is done with and how it is supported, may be more important, or be the reason for the preference. In addition, continued engagement in an activity is influenced by enjoyment and the development of competency in the activity [45,46]. Some parents in this study reported a growing gap in performance between their children and the children's peers that led to embarrassment and withdrawal from activity as the children got older. Access to supported formal activities where disabled children can develop skills and compete at their level was identified as important by some parents and by previous qualitative research [47–49]. Communities that can provide a range of formal activities that meet the needs of children with a broad range of abilities may meet the philosophical need to support participation within the least restrictive environment.

Further research

Further research is needed to identify the variables that are important to participation in formal activities. Caregivers in this study identified the level of acceptance of peers and organisers, the amount of support required by family members and the availability of activities that matched the level of their child's ability, as important to their child's participation. Research that investigates formal participation will need to include variables related to the perception of individuals about the availability and accessibility of activities.

Because participation is a multidimensional construct, it is likely that interventions aimed at enhancing participation will need to be multifaceted to facilitate change. Almqvist and Granlund [50]

suggested that the number of positive factors may be more important to participation than any specific factor or constellation of factors. If this is so, how many positive characteristics are needed, or whether it is necessary to influence only one or two of many potential factors to change participation, is unknown and should be one focus of future research.

This study could not report on the characteristics that supported or limited the participation of children who were severely and multiply disabled. One family reported that their child participated in no activities due to the extent and severity of disability. This child also gave no indication of pleasure or enjoyment of activity happening around her. What is participation in this context? Whose participation should we be measuring and trying to influence? Family participation is an important outcome in this group of children. Ehrmann et al. [51] reported that families whose children had an intellectual impairment participated in fewer family enrichment activities such as going to the movies, or taking part in community recreation. Greater understanding of the impact of having a child with cerebral palsy on family participation is required, as is the development of interventions that support the participation of families in leisure activities and investigates the impact of those interventions on both the family and the child.

Summary

In this study, characteristics related to the child were more strongly associated with informal participation than those related to the family or the broader environment. Knowing a child's activity preferences is critical to intervention planning. Assisting children to experience a range of activities within supportive environments may provide the opportunity to develop preferences, especially in activities where children with cerebral palsy have reduced participation, such as in physical activities.

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References

1. Law M. Enhancing participation. Phys Occup Ther Pediatr 2002;22:1–3.
2. WHO. International classification of functioning, disability and health: short version. Geneva: World Health Organisation; 2001. p 228.
3. Law M, Dunn W. Perspectives on understanding and changing the environments of children with disabilities. Phys Occup Ther Pediatr 1993;13:1–17.
4. Forsyth R, Colver A, Alvanides S, Woolley M, Lowe M. Participation of young severely disabled children is influenced by their intrinsic impairments and environment. Dev Med Child Neurol 2007;49:345–349.
5. Heah T, Case T, McGuire B, Law M. Successful participation: the lived experience among children with disabilities. Can J Occup Ther 2007;74:38–47.
6. Granlund M, Björk-Åkesson E. Participation and general competence: do type and degree of disability really matter? In: Traustadottir R, Gustavsson A, Tøsselbro J, Sandvin JT, editors. Change, resistance and reflection: current Nordic disability research. Lund, Sweden: Studentlitteratur; 2005. pp 277–294.
7. King GA, Law M, King S, Rosenbaum PL, Kertoy MK, Young NL. A conceptual model of the factors affecting the recreation and leisure participation of children with disabilities. Phys Occup Ther Pediatr 2003;23:63–90.
8. King GA, Law M, Hanna S, King S, Hurley P, Rosenbaum PL, Kertoy MK, Petrenchik T. Predictors of the leisure and recreation participation of children with physical disabilities: a structural equation modeling analysis. Children's Health Care 2006;35:209–234.
9. King GA, Law M, King S, Hurley P, Rosenbaum PL, Hanna S, Kertoy MK, Young N. Children's assessment of participation and enjoyment and preferences for activities of kids. San Antonio, Texas: PsychCorp; 2004. p 117.
10. Morris C, Kurinczuk JJ, Fitzpatrick R, Rosenbaum PL. Do the abilities of children with cerebral palsy explain their activities and participation? Dev Med Child Neurol 2006;48:954–961.
11. Imms C, Reilly S, Carlin J, Dodd K. Diversity of participation in children with cerebral palsy. Dev Med Child Neurol 2008; 50:363–369.
12. Beckung E, Hagberg G. Neuroimpairments, activity limitations, and participation restrictions in children with cerebral palsy. Dev Med Child Neurol 2002;44:309–316.
13. Kerr C, McDowell B, McDonough S. The relationship between gross motor function and participation restriction in children with cerebral palsy: an exploratory analyses. Child Care Health Dev 2007;33:22–27.
14. Law M, Finkelman S, Hurley P, Rosenbaum PL, King S, King G, Hanna S. Participation of children with physical disabilities: relationships with diagnosis, physical function and demographic variables. Scand J Occup Ther 2004;11:156–162.
15. Lepage C, Noreau L, Bernard P-M, Fougeyrollas P. Profile of handicap situations in children with cerebral palsy. Scand J Rehabil Med 1998;30:263–272.
16. Donkervoort M, Roebroeck M, Wiegerink D, van der Heijden-Maessen H, Stam H, The Transition Research Group South West N. Determinants of functioning of adolescents and young adults with cerebral palsy. Disabil Rehabil 2007;29:453–463.
17. Hammal D, Jarvis SN, Colver AF. Participation of children with cerebral palsy is influenced by where they live. Dev Med Child Neurol 2004;46:292–298.
18. Lawlor K, Mihaylov SI, Welsh B, Jarvis S, Colver A. A qualitative study of the physical, social and attitudinal environments influencing the participation of children with cerebral palsy in northeast England. Pediatr Rehabil 2006; 9:219–228.

19. Welsh B, Jarvis S, Hammal D, Colver A. How might districts identify local barriers to participation for children with cerebral palsy? Public Health 2006;120:167–175.
20. Colver A, The SPARCLE Group. Study protocol: SPARCLE – a multicentre European study of the relationship of environment to participation and quality of life in children with cerebral palsy. BMC Public Health 2006;105. DOI: 10.1186/1471-2458-6-105.
21. Mackie PC, Jessen EC, Jarvis SN. The lifestyle assessment questionnaire: an instrument to measure the impact of disability on the lives of children with cerebral palsy and their families. Child Care Health Dev 1998;24:473–486.
22. Coster W, Deeney TA, Haltiwanger JT, Haley SM. School function assessment. San Antonio, Texas: The Psychological Corporation; 1998.
23. Imms C. Children with cerebral palsy participate: a review of the literature. Disabil Rehabil 2008;30:1867–1884.
24. King GA, Law M, King S, Hurley P, Hanna S, Kertoy MK, Rosenbaum PL. Measuring children's participation in recreation and leisure activities: construct validation of the CAPE and PAC. Child Care Health Dev 2006;33:28–39.
25. Eliasson AC, Krumlinde-Sundholm L, Rosblad B, Beckung E, Arner M, Ohrvall A, Rosenbaum PL. The Manual Ability Classification System (MACS) for children with cerebral palsy: scale development and evidence of validity and reliability. Dev Med Child Neurol 2006;48:549–554.
26. Palisano RJ, Rosenbaum PL, Walter S, Russell D, Wood E, Galuppi B. Development and reliability of a system to classify gross motor function in children with cerebral palsy. Dev Med Child Neurol 1997;39:214–223.
27. Morris C, Galuppi B, Rosenbaum PL. Reliability of family report for the Gross Motor Function Classification System. Dev Med Child Neurol 2004;46:455–460.
28. Prior M, Sanson A, Smart D, Oberklaid F. Pathways from infancy to adolescence: Australian Temperament project 1983 – 2000. Australian Institute of Family Studies. Available at: http://www.aifs.gov.au/institute/pubs/resreport4/aifsreport4.pdf; 2000. Accessed 21 January 2009.
29. McClowry SG. The development of the School Aged Temperament Inventory. Merril Palmer Q 1995;41:271–285.
30. McClowry SG, Hegvik RL, Teglasi H. An examination of the construct validity of the Middle Childhood Temperament Questionnaire. Merril Palmer Q 1993;39:279–293.
31. McClowry SG, Halverson C, Sanson A. A re-examination of the validity and reliability of the School-Aged Temperament Inventory. Nurs Res 2003;52:176–182.
32. Australian Bureau of Statistics. SEIFA 2001. Australian Bureau of Statistics Available at: http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/2033.0.55.0012001?OpenDocument; 2001. Accessed 23 January 2007.
33. Katz MH. Multivariable analysis: a practical guide for clinicians. Cambridge, United Kingdom: Cambridge University Press; 1999. p 192.
34. Tabachnick BG, Fidell LS. Using multivariate statistics. Boston, MA: Pearson Education; 2007.
35. Hamilton LC. Regression with graphics: a second course in applied statistics. Belmont, California: Duxbury Press; 1992. p 363.
36. Simeonsson RJ, Carlson D, Huntington GS, McMillen JS, Brent JL. Students with disabilities: a national survey of participation in school activities. Disabil Rehabil 2001;23:49–63.
37. Australian Bureau of Statistics. Disability, ageing and carers: summary of findings. Australia 2003. (Catalogue number 4430.0).ABS Available at: www.abs.gov.au/ausstats/abs@nsf/mf/4430.0. Accessed 7 June 2005.
38. Stratton M, Conn L, Smallacombe T. The young and the restful: the effects of recreational choices and demographic factors on children's participation in sport. Sydney: Commonwealth of Australia; 2005.
39. Gordon WR, Caltabiano ML. Urban-rural differences in adolescent self-esteem, leisure boredom and sensation-seeking as predictors of leisure-time usage and satisfaction. Adolescence 1996;31:883–901.
40. Eliasson AC. Improving the use of hands in daily activities: aspects of treatment of children with cerebral palsy. Phys Occup Ther Pediatr 2005;25:37–60.
41. Imms C, Carlin J, Eliasson AC. Stability of parent reported manual ability and gross motor function classification of cerebral palsy. Dev Med Child Neurol, in press.
42. Ruschena E, Prior M, Sanson A, Smart D. A longitudinal study of adolescent adjustment following family transitions. J Child Psychol Psychiatr 2005;46:353–363.
43. Whiteneck GG, Harrison-Felix CL, Mellick DC, Brooks CA, Charlifue SB, Gerhart KA. Quantifying environmental factors: a measure of physical, attitudinal, service, productivity and policy barriers. Arch Phys Med Rehabil 2004;85:1324–1335.
44. Schmitt-Rodermund E, Vondracek FW. Breadth of interests, exploration and identity development in adolescence. J Vocational Behav 1999;55:298–317.
45. Martin JJ. Psychosocial aspects of youth disability sport. Adapt Phys Activ Q 2006;23:65–77.
46. Wiseman JO, Davis JA, Polatajko HJ. Occupational development: towards an understanding of children's doing. J Occup Sci 2005;12:26–35.
47. Devine MA, Lashua B. Constructing social acceptance in inclusive leisure contexts: the role of individuals with disabilities. Ther Recreation J 2002;36:65–83.
48. Devine MA, Wilhite B. The meaning of disability: implications for inclusive leisure services for youth with and without disabilities. Ther Recreation J 2000;18:35–52.
49. Wilhite B, Devine MA, Goldenberg L. Perceptions of youth with and without disabilities: implications for inclusive leisure programs and services. Ther Recreation J 1999;33:15–28.
50. Almqvist L, Granlund M. Participation in school environment of children and youth with disabilities: a person-oriented approach. Scand J Psychol 2005;46:305–314.
51. Ehrmann LC, Aeschleman SR, Svanum S. Parental reports of community activity patterns: a comparison between young children with disabilities and their non-disabled peers. Res Dev Disabil 1995;16:331–343.