

# Predictors of needs for community and financial resources for families of pre-school children with cerebral palsy

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**Abstract.** An understanding of predictors of family needs for the families of preschool children with cerebral palsy (CP) is important for provision of efficient and cost-effective services. The aim of this study was to identify the characteristics of children, families and services that are risk factors to meeting family needs for community and financial resources. 234 parents of pre-school children with CP completed a modified version of the Family Needs Survey (FNS), the Measure of Processes of Care (MPOC-20), and a demographic questionnaire. The gross motor function level and communication function level of children were classified on the basis of the Gross Motor Function Classification System (GMFCS) and the Communication Function Classification System (CFCS) respectively. Two hierarchical multiple regression models were generated to determine the predictors of unmet family needs. The socialisation and communication skills of children, as well as caregiver employment and family income levels were significant predictors of family needs for community resources (adjusted  $R^2=0.44$ ). Significant risk factors in terms of family needs for financial resources included the child's gross motor limitations, caregiver employment, low levels of family income and no ability to receive services on the basis of enabling and partnership principles (adjusted  $R^2=0.51$ ). A child's limitations in terms of communication, gross motor functions and socialisation, as well as the socioeconomic status of the child's family, must be taken into account when planning services for families with preschool children with CP.

**Key words:** children, cerebral palsy, family needs

## Introduction

Cerebral palsy (CP) describes group of movement and posture disorders caused by non-progressive disturbance of the developing fetal and infant brain [1]. The CP rate in Europe is between 2 and 3 per 1000 live births and it is the most common cause of physical disability in early childhood [2]. Parents of children with CP face daily challenges related to care, co-ordination of services and advocacy.

The functional problems of children often limit the ability of the family to become involved in social activities. The inability to help one's children causes stress, conflicts and health problems [3]. This means that social and service support are needed not just by the child, but by the whole family.

It is known that families with children who suffer from functional disturbances usually need additional support. Such families require various kinds of information, community and financial support, as well as social support [4–8]. Identification of the specific needs for

families is an important prerequisite for providing health care and social services, as well as for planning the necessary types of scope of services [9].

According to Almasri and Palisano, parents of children with CP tend to have common profiles of needs, while determinants of those needs are variable. It has been shown that families with a higher socioeconomic status and more financial resources are likely to have fewer needs. The child's functional ability, adaptive behaviour and co-morbid conditions have also been shown as predictors of overall family needs [10, 11]. The way in which services are provided can have an impact on the type and amount of family needs. Family-centred services (FCS) are considered to be the best practice when providing services to families with disabled children [12]. Recent studies have revealed that such services are linked to a decreased need for community, financial and family functioning resources [10, 13].

Most of the studies that discuss the particular needs of families with children with CP and the determinants and risk factors of these needs have been conducted in the United States, China, Japan and Western Europe [8, 10, 11, 13–16]. Still, the characteristic cultural environment, historical experience and socioeconomic conditions of our region can influence family needs and, particularly, the possible determinants.

A recent study found that the most frequently cited unmet needs of parents of preschool children with CP in our region included the need for information about services and education for the child, assistance in co-ordinating care procedures, and the location of rehabilitation services. Most parents need financial aid to pay for therapy, specialised equipment and childcare. The results showed that financial assistance and the provision of state and local government services are of key importance for families in our region [17]. It is known, however, that this type of help is not important for all parents with children who have CP.

It is important to identify risk factors that are related to determinants for the community and financial needs of the families of preschool children with cerebral palsy so as to ensure collaborative approaches toward healthcare and social services. Currently there is very little information about the presumptive determinants of family needs in terms of community and financial resources in our region. According to Bertule and Vetra, the gross motor ability of children has an impact on the need for community services and finances [17], but it is also known that the provision of healthcare services is determined by individual, societal and healthcare service system factors [18]. This means that it is not just the characteristics of children, but also those of families and services that must be considered as hypothetically protective and risk-related factors for family needs [13].

The aim of this study is to identify the characteristics of children, families and services that are risk factors in terms of satisfying family needs for community and financial resources.

## **Methods**

### **Participants**

The survey that was part of this study covered 252 families of preschool (age 2–7) children with a primary diagnosis of CP, all of them receiving services from two rehabilitation centres and one hospital in Latvia. Excluded were families with children having a developmental disorder other than CP or an illness that may affect quality of life (cancer, cystic fibrosis, major mental health disorders). Local institutional ethics committees approved the study. Potential participants were contacted in person during a visit to the clinic or by phone. 234 parents or legal guardians agreed to participate and provided informed consent.

## Measures

### *Outcome variable*

#### *Family Needs Survey [19]*

Data related to community and financial needs were obtained through the *Family Needs Survey* (FNS), which included a 35-item questionnaire completed by parents. The items were grouped into six areas – the need for information, the need for support, explaining the situation to others, community services, financial needs, and family functioning.

Each item is rated on a 3-point scale, with 1 = *I definitely do not need help with this*, 2 = *Not sure* and 3 = *I definitely need help with this*. In this study, only the items that received a score of “3” (*I definitely need help with this*) were defined as an unmet need. The FNS was translated into Latvian, and only the subscales of needs for community services and financial aid were taken into account in the data analysis. With the written permission of the authors of the survey, the researchers in Latvia added three more subscale items to identify needs that might be more specific in this country:

- Locating rehabilitation services;
- Co-ordinating medical, developmental, educational and other community services;
- Paying for home modification.

Internal consistency (Cronbach’s alpha) and test – retest reliability (ICC 2,1) of the translated and modified version of FNS were tested before the original study. The Cronbach’s alpha coefficient for items in the subscales of needs for community services and finances was 0.78 and 0.89 respectively. ICC 2,1 for items in the community services subscale was 0.88, and 0.98 for the items in the subscale of financial needs.

### *Predictors’ variables*

#### *Child characteristics*

The Gross Motor Function Classification System (GMFCS) level was used to describe each child’s gross motor function level. This is a five-level classification system for children with CP to classify their gross motor functions on the basis of usual performance. Particular emphasis is on sitting, walking and wheeled mobility. At Level I, children walk independently, while at Level V children require complete assistance for mobility and self-care [20].

The Communication Function Classification System (CFCS) level was used to describe the child’s communication ability. Again, this is a five-level system developed to classify the everyday communication performance of an individual with CP, regardless of the communication method that is used (speech, gestures, gazes, alternative communication, etc.). At Level I, children can communicate effectively with a familiar or an unfamiliar partner, while at Level V, children are seldom able to communicate even with a familiar partner [21].

The Family Demographic Questionnaire was developed by the researchers to obtain data about parents and the children. Four factors related to the characteristics of the children were analysed – the age of the child, the total number of co-morbidities, an assessment of the child’s overall health, and the issue of socialisation.

#### *Family characteristics*

Five items from the Family Demographic Questionnaire were used as predictor variables to describe family characteristics – marital status, family income, the number of children in

the family, the residence of the family (geographic location), and the educational level and employment of caregivers.

#### *Services characteristics*

The Measure of Processes of Care (MPCO-20) is a 20-item self-report about parental perceptions about the extent to which the health services that they and their child receive are family-centred. The survey includes five scales – enabling and partnership (three items), providing general information (five items), providing specific information (three items), co-ordinated and comprehensive care (four items), and respectful and supportive care (five items). The items are rated on the Licert scale, ranging from 1 to 7 (1 = the described event or situation was not perceived; 7 = the described event or situation was perceived to a very great extent) [22].

This study made use of a version of the MPOC-20 that was translated into Latvian. Internal consistency (Cronbach's alpha) and test-retest reliability (ICC 2,1) of the translated version of the MOPC-20 were tested before the original study. The Cronbach's alpha coefficient for all 20 items was 0.87 and varied between 0.77 and 0.94 for each subscale. The ICC 2,1 for all items was 0.94, and the coefficient varied between 0.93 and 0.96.

One item from the demographic questionnaire (access to rehabilitation services) was included as a predictor variable in relation to services.

### **Procedure**

The children's GMFCS and CFCS levels were determined on the basis of consensus between parents and professionals (physiotherapists and speech therapists respectively) during clinical visits. The parents or legal guardians of children completed the Family Needs Survey, the Family Demographic Questionnaire, and the Measure of Processes of Care (MPOC-20).

### **Data analyses**

Hierarchical multiple regression models were generated to determine the predictors of unmet family needs. The analysis was conducted in two steps. In order to reduce the number of predictor variables included in the regression analysis, bivariate associations (Spearman, Pearson, or one-way ANOVA) were tested to examine the relationship between the total number of unmet needs for community services on the one hand and financial support and hypothesised risk factors on the other hand. Only those variables that had statistically significant associations ( $p < 0.05$ ) with the total number of needs were included in the model.

Predictor variables were entered by blocks – child characteristics and then family and service characteristics. This was based on the assumption that the condition of the child would have to greater influence on family needs related to community services and necessary financial support.

### **Results**

234 parents or legal guardians of children with CP participated in the study, with 18 families declining to take part for various reasons. Most (93.2%) respondents were mothers with a mean age of 35.03 years (standard deviation (SD) = 8.05). The mean age of the children was 4.8 (SD = 1.7). One-half (50.0%) of respondents were unemployed. The majority (82.1%) were married, and for one-half (49.1%) the child with CP was their only child. Children were mostly classified with the spastic form of CP (79.9%). At least one form of co-morbidity was

**Table 1.** Characteristics of parents, families and children; children classification according Gross Motor Function Classification System level (GMFCS) and Communication Function Classification System level (CFCS).

Family Characteristics	n (%)	Child Characteristics	n (%)
Relationship to the child		Gender	
Mother	218 (93.2)	Male	130 (55.6)
Father	4 (1.7)	Female	104 (44.4)
Grandmother	8 (3.4)	Co-morbidities*	
Guardian	4 (1.7)	Visual impairment	93 (39.7)
Education		Hearing impairment	28 (12.0)
Bachelor's/Master's degree	92 (39.3)	Cognitive impairment	158 (67.5)
Secondary school	122 (52.1)	Seizure	58 (24.8)
Lower than secondary school	20 (8.5)	Child health*	
Employment		Rather good	93 (39.7)
Employed	117 (50.0)	Rather poor	141 (60.3)
Not employed	117 (50.0)	Type of cerebral palsy	
Marital status		Spastic unilateral	77 (32.9)
Married or living with partner	192 (82.1)	Spastic bilateral	110 (47.0)
Widowed	3 (1.3)	Dyskinetic	25 (10.7)
Divorced or separated	21 (9.0)	Ataxic	9 (3.8)
Single	18 (7.7)	Not specified /mixed	13 (5.6)
Geographic location		Socialization	
Rural	61 (26.1)	Yes (pre – school etc.)	139 (59.4)
Urban	173 (73.9)	No (home)	95 (40.6)
Children in household		GMFCS level	
One	115 (49.1)	I	78 (33.3)
Two	81 (34.6)	II	45 (19.2)
Three or more	38 (16.2)	III	42 (17.9)
Family income (EUR per month)		IV	49 (20.9)
Less than 419	42 (18.0)	V	20 (8.5)
420 – 839	136 (58.1)	CFCS level	
840 – 1119	39 (16.6)	I	55 (23.5)
More than 1120	17 (7.3)	II	42 (17.9)
Access to rehabilitation services		III	43 (18.4)
Yes	149 (63.7)	IV	56 (23.9)
No	85 (36.3)	V	38 (16.2)

\* Parent – reported.

reported in 187 (78.6%) of children. The demographics of parents, families and children, as well as the classification of children in accordance with the GMFCS and CFCS, are presented in Table 1.

Of the 234 parents, 210 (89.7%) indicated at least one unmet need for financial aid, with 193 (82.5%) speaking of lack of some community resources. As seen in Table 2, the most frequently cited needs related to locating and co-ordinating rehabilitation and medical and other community services, as well as for help in paying for the therapy and special equipment which children need. Only a few participants reported the need for child care during worship services at a church or synagogue (1.3%), or for help in paying for toys for their children (10.3%).

After examination of bivariate correlations between the total number of needs for community resources and hypothesised risk factors, three family characteristics (the education level of caregivers, marital status and the number of children in the family) and one child characteristic (age) were excluded from further analysis. The same hypothetical risk factors were not correlated with the total number of needs for financial resources.

**Table 2.** Unmet needs reported by families.

Specific need	% with definite need	% with at least one unmet need
<b>Community services</b>		<b>82.5</b>
Locating a child care centre or pre-school for my child	42.2	
Locating babysitter who are willing and able to care for my child	31.6	
Getting care for my child in our church/synagogue during services	1.3	
Locating a doctor who understands me and my child's needs	34.2	
Locating rehabilitation services	61.1	
Coordinating medical, developmental, educational, and other community services for my child	72.6	
<b>Financial needs</b>		<b>89.7</b>
Help in paying for expenses such as food, housing, medical care, clothing, or transportation	39.3	
Help getting special equipment for my child's needs	57.3	
Help in paying for therapy, child care, or other services child needs	76.9	
Help in paying for babysitting or respite care	35.0	
Help in paying for home modifications	29.1	
Help in paying for toys that my child needs	10.3	
Counselling or help for myself/my spouse in getting a job	19.2	

Before performing hierarchical multiple regression, the relevant assumptions of this analysis were tested. An examination of the correlations showed that no independent variables were highly correlated. The collinear statistics (Tolerance and VIF) was within accepted limits. Residual and scattered plots indicated that the assumptions of normality, linearity and homoscedasticity were satisfied.

#### *Predictors of the need for community resources*

A three step hierarchical multiple regression was conducted with total number of needs for community resources as a dependent variable. In the first step five predictor variables of child characteristics were entered: general health, total number of co-morbidities, socialization, the GMFCS level, and the CFCS level. The model was statistically significant  $F(5, 231) = 21.99$ ;  $p = 0.000$  and explained 33% of variances of unmet needs for community resources. After the entry of three variables of family characteristics (level of income, caregiver's employment, and geographic location) at step 2, the total variance, explained by model as a whole, was 39% ( $F(8, 231) = 15.99$ ;  $p = 0.000$ ). The family characteristics explained additional 7% variance in needs for community resources, and the change in  $R^2$  was significant. Adding service characteristics (five scales of MOPC – 20 and access to rehabilitation services) to the regression model explained an additional 5% of the variance and this change in  $R^2$  was significant,  $F(14, 233) = 11.46$ ;  $p = 0.004$ . Taken together, the independent variables accounted for 44.4% of the variance of unmet family needs for community services. When all variables were included in step 3, only two child characteristics (socialization and CFCS level) and two family characteristics (caregiver employment and level of income) were significant predictors of needs for community resources (Table 3).

#### *Predictors of need for financial resources.*

Three-step hierarchical multiple regression was conducted with total number of needs for financial resources as a dependent variable. Child characteristics (general health, total number

**Table 3.** Hierarchical regression model predicting needs for community services.

Step and predictor variable	R <sup>2</sup>	ΔR <sup>2</sup>	β step 1	β step 2	β step 3
<b>Step 1. Child characteristics</b>	<b>0.33</b>				
General health			-.12	-.09	-.07
Socialization			.24***	.15*	.18**
Co-morbidities (total number)			.12	.09	.04
GMFCS level			.17*	.14*	.09
CFCS level			.18*	.19*	.19*
<b>Step 2. Family characteristics</b>	<b>0.39</b>	<b>0.07***</b>			
Level of income <sup>a</sup>				-.16**	-.11*
Caregiver employment				.14*	.15**
Geographic location				-.07	-.05
<b>Step 3. Service characteristics</b>	<b>0.44</b>	<b>0.05**</b>			
Enabling and Partnership					-.14
Providing General Information					-.01
Providing Specific Information					-.05
Coordinated and Comprehensive Care					-.01
Respectful and Supportive Care					-.14
Access to rehabilitation services					.04

\*p < 0.05; \*\*p < 0.01; \*\*\*p < 0.001.

<sup>a</sup>Level of income (self reported): 1 = rather high; 0 = rather low.

of co-morbidities, socialization, the GMFCS level, and the CFCS level) were entered at step one. Family characteristics (income level, caregiver employment, and geographic location) were entered at step two, and service characteristics (five scales of MOPC – 20 and access to rehabilitation services) as the third step.

The hierarchical multiple regression revealed that at step one, child characteristics contributed significantly to the regression model,  $F(5, 231) = 14.71$ ,  $p = 0.000$  accounting for 25% of the variation in needs for financial resources. Introducing the family characteristics explained an additional 22% of variation, and the change in  $R^2$  was significant,  $F(8, 231) = 21.11$ ,  $p = 0.000$ . The addition of the service characteristics explained an additional 5% of the variation in needs for financial resources and the change in  $R^2$  was significant,  $F(14, 231) = 14.79$ ,  $p < 0.000$ . In the final model only four predictor variables were statistically significant, with family income recording a higher Beta value ( $\beta = .38$ ,  $p < 0.001$ ) than child's GMFCS level ( $\beta = .27$ ,  $p < 0.001$ ), providing services according the enabling and partnership principles ( $\beta = .23$ ,  $p < 0.01$ ), and caregiver employment ( $\beta = .22$ ,  $p < 0.001$ ). Taken together, the independent variables accounted for 51% of the variance in family needs for financial resources (Table 4).

## Discussion

This study complements previous findings about the prevalence and predictors of unmet needs among families of children with cerebral palsy. Consistent with earlier findings [6, 15], high percentage of parents in our sample did express the need for community and financial resources. Most respondents said that they need financial aid to pay for treatment and care services, as well as to purchase things that are necessary for the child. These results are no surprise. The range of services financed by the state or local governments has expanded in recent years, but the availability of such services is still insufficient. Limited state financing means that ancillary resources for child care and treatment are simply not available. This forces parents to buy such items with their own money or to see financial support from charitable organisations.

**Table 4.** Hierarchical regression model predicting needs for financial resources.

Step and predictor variable	R <sup>2</sup>	ΔR <sup>2</sup>	β step 1	β step 2	β step 3
<b>Step 1. Child characteristics</b>	<b>0.25</b>				
General health			-.01	-.05	-.05
Socialization			-.07	-.07	-.05
Co-morbidities (total number)			.23**	.17**	.12
GMFCS level			.34***	.28***	.27***
CFCS level			.01	.01	.02
<b>Step 2. Family characteristics</b>	<b>0.46</b>	<b>0.24***</b>			
Level of income <sup>a</sup>				-.41***	-.38***
Caregiver employment				.22***	.22***
Geographic location				-.09	-.06
<b>Step 3. Service characteristics</b>	<b>0.51</b>	<b>0.05**</b>			
Enabling and Partnership					-.23**
Providing General Information					-.05
Providing Specific Information					-.02
Coordinated and Comprehensive Care					-.15
Respectful and Supportive Care					-.07
Access to rehabilitation services					.03

\*p < 0.05; \*\*p < 0.01; \*\*\*p < 0.001.

<sup>a</sup>Level of income (self reported): 1 = rather high; 0 = rather low.

Problems with the provision of inter-section services could be a reason why many respondents said that their families need help in co-ordinating medical, educational and rehabilitation services.

The focus of this study was to examine the contribution of child, family and service characteristics as risk factors in the family needs for community and financial resources. In contrast to claims by other authors [7, 10], the age of the child was not an important predictor of family needs for community and financial resources. This may be because our cohort only included the parents of children who were 2–7 years old. It may be that when children get older and go to school, there are increased financial demands and greater needs for community services.

Still, other child characteristics were significant predictors of needs for financial resources, but especially for community resources. Whether the child attends preschool or stays at home (an issue of socialisation) and how great the child's communications abilities are (the CFCS level) – these were the most important predictors of the needs for community services. This suggests that families with children who have greater limitations in their communications skills and who do not attend preschool are more likely to express the need for community services. Interestingly, another departure from previous findings [10, 13] was that the GMFCS level of children was not a significant predictor of the needs for community resources. It appears that services for children with limited motor functions are at a better level in Latvia than is the case for those with communications limitations that are often accompanied by intellectual and behavioural disorders. Nevertheless, the GMFCS level was the only significant risk factor among the characteristics of children when it comes to the need for financial resources. This is consistent with other studies [13, 15], and it is understandable in that children with more severe limitations in their gross motor functions may mean higher expenditures for services and equipment.

Unsurprisingly, the most significant risk factor of the needs for financial resources was the level of family income, as well as the issue of whether a caregiver was employed. Families with such caregivers and with comparatively high levels of family income were less likely to need additional help to pay for services or specialised equipment. The same

family variables were significant predictors of the need for community services, as well, but the child characteristics (socialisation and CFCS level) were more important risk factors in relation to these needs.

Service variables did not add significantly to the prediction of needs for community services or financial resources. Interestingly, service characteristics such as receiving family-centred services (FCS) and even the accessibility of rehabilitation services were not significant risk factors when it came to family needs in our study. Our results are not consistent with the overall opinion that FCS is the best option in providing services to children with CP [3, 12] and that FCS is a protective factor in terms of family needs [13]. In our study, only one component of FCS – enabling and partnership – were found to be important protective factors in this regard. It seems that a model of co-operation that is based on partnership allows families to be more satisfied with the services that they receive. Therefore they are less likely to seek additional treatment and rehabilitation that are not financed by government and the families do not need additional finances to pay for the services. Service providers, however, must be aware of the fact that the provision of services that are based on enabling and partnerships might have a positive effect on decreasing family needs for financial resources and reduce health care costs in the long term.

## Conclusions

- Higher socioeconomic status for families (employment and higher level of income) are significant protective factors against family needs for community and financial resources;
- A child with severe communications limitations who does not attend preschool is an important risk factor in terms of family needs for community resources;
- Provision of services that are based on enabling and partnerships can have a positive effect on the decreasing family need for financial resources for families of pre-school children with cerebral palsy.

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