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# Domains of Importance for Parents, Medical Professionals, and Youth with Cerebral Palsy Considering Treatment Outcomes

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## Abstract

**Background—**The aim of this study was to assess the domains of importance in therapeutic intervention for cerebral palsy (CP) using categories of the International Classification of Functioning, Disability, and Health - Version for Children & Youth (ICF-CY).

**Methods—**17 youth, 19 parents and 39 medical professionals responded to the open-ended query: "What are the things you find most important to consider when you evaluate the effects of an intervention for yourself/your child/your patient with cerebral palsy?" Surveys were either mailed or conducted on-line. Responses were coded by two reviewers using the ICF-CY and discrepancies were resolved.

**Results—**Responses were distributed across the ICF-CY domains of Body Functions and Structures, Activities and Participation, and Environmental Factors, as well as non-ICF-CY concepts including quality of life. The most common responses overall were pain, motor function, mobility, community life, and public services. Youth identified strength, gait pattern, hand/arm use, and use of assistive technologies as priorities whereas parents were concerned with motor function, communication, mobility, and provision of public services. Medical professionals listed pain, function, mobility, community life, and participation most often.

**Conclusions—**All surveyed groups indicate a desire to see changes in body functions and structures (pain, mental function, strength, movement), activities and participation (communication, hand/arm use, walking, school, recreation/community life), and quality of life following therapeutic interventions for CP. These results demonstrate the multiple, varied concerns regarding CP across the spectrum of functioning and health.

### Keywords

cerebral palsy; childrens' views; parent perceptions; professionals

## Introduction

Cerebral palsy (CP) is the most common physical disability of childhood and has variable manifestations and co morbidities (Yeargin-Allsopp *et al*. 2008). Many interventions are pursued to help children with CP, but robust evidence regarding treatment is limited.

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Therefore, parents, children, and medical professionals struggle with choosing interventions and deciding whether those interventions have been efficacious. A challenging process ensues wherein families must decide what they want to see happen and care providers endeavor to identify interventions that might achieve those goals. In the end, it may be difficult to determine if the right choices were made, whether for individual patients or for clinical trials, unless care is taken to determine the goals of the treatments and to measure and track the outcomes of interest.

To date, standardized outcome measures have gained prominence in clinical and research settings for CP and individualized goal setting has also been endorsed. Some recent work has addressed the interface between goals and needs (Nijhuis *et al*. 2008) and between goals and measures(Vitale *et al*. 2001, Engelen *et al*. 2007) largely within the scope of documentation of service delivery for young children. Less effort has been directed toward understanding the types of outcomes and goals that are most important or most commonly identified in relation to therapeutic interventions employed with children with CP. Furthermore, the preferences or desires for treatment outcomes have not been systematically reported for groups of patients with CP, parents, or medical professionals. A broad understanding of the important domains related to outcomes and goals within CP would assist clinicians and researchers to explore the efficacy of interventions by evaluating treatment effects with relevant outcome measures.

The International Classification of Functioning, Disability, and Health (ICF) (World Health Organization 2001) was developed to describe health status. An individual's health, function, and disability are viewed as highly inter-related and also influenced by the individual's environment and personal factors. The ICF includes description of health conditions categorized in the domains of body function [b] and structure [s] as well as activities (execution of tasks and activities) and participation (involvement in a life situation) [d]. These domains are supplemented with contextual factors, which may be environmental [e] or personal factors. All domains except that of personal factors have multiple categories and codes to allow precise descriptions. These codes include a letter (denoting the domain b, s, d, or e) and at least one number, with greater specificity of concept as the codes expand from single digits to up to five digits. For example, the chapter classification of d5 indicates 'self-care', while the second level classification of d570 is 'looking after one's health.' Further detail is provided with third and fourth level classifications of d5702, 'maintaining one's health', and d57020, 'managing medications and following health advice.'

The ICF is useful as a means for describing the status of children with CP (Rosenbaum and Stewart 2004) but the ICF required revision and augmentation for direct use with children and youth, especially those with disabilities (Simeonsson *et al*. 2003). The International Classification of Functioning, Disability, and Health – Children and Youth Version (ICF-CY) (World Health Organization 2007) includes codes that are specific to children including, for example, gestural language, pubertal development, acquisition of language, pretending, and informal care of a child by family or friends. These codes are useful throughout growth and development and may be used to describe current status, including degree of impairment, capacity, performance, or barriers. Concepts or goal states, such as those described as anticipated or desired outcomes of therapy, may be mapped to ICF codes as well.

This study sought to employ ICF terminology in categorizing the goals or concerns regarding therapeutic interventions for CP from the perspective of youth with CP, parents, and medical professionals. This was the first step in a larger Delphi Technique project seeking to establish the domains of importance for children with CP and the best means of measuring them.

## Methods

Subjects were recruited in two phases. Youth with CP and parents of children with CP were recruited from the outpatient clinics of a tertiary care center. Parents or youth were approached in person or via letter to request participation. Because children under 10 years of age do not typically have the cognitive skills to reliably participate in a Delphi process and rank their choices, they were not included in the sample. Similarly, youth with significant intellectual disability were not enrolled. Youth were eligible to enroll if they were aged 10–18 years, had CP, had the cognitive capacity to respond to questionnaires in writing or by interview, and did not have a serious concurrent illness not typically associated with CP. An effort was made to enroll youth with a range of levels of physical impairment. In order to incorporate the perspectives of younger children and those with cognitive impairment, parents of 2–10 year old children with CP and parents of children with cognitive impairment were specifically recruited. Again, parents were recruited to include those who had children with a large range of physical disability. Medical professionals with expertise in CP were individually selected to represent a broad range of backgrounds, including physicians (physiatrists, developmental pediatricians, orthopedic surgeons, and neurologists), therapists (occupational, physical, and speech), educators, and nurses, mostly from North America. The parent perspectives as well as the views of the medical professionals were included in part to represent the concerns of younger children or those with cognitive impairment. The sample size of at least 30 parents or youth and at least 30 medical professionals was selected because a total of 30 respondents is sufficient for maximal input of ideas in the Delphi Technique (Delbecq *et al*. 1975).

Subjects were contacted by mail or e-mail to complete the survey. Subjects were asked to provide general demographic information and to answer a single open-ended question: “What are the things you find most important to consider when you evaluate the effects of an intervention for yourself/your child/your patient with cerebral palsy?” This question was pilot tested in a subset of parents and youth to ensure that it was understandable and no concerns were raised. The document was provided to the pilot test individuals who provided answers and explained the rationale for their choices. None of these pilot subjects had difficulty responding. Youth and parents responded based on their own or their child’s status while medical professionals were to consider the entire group of individuals with CP with whom them work. Each subject could supply up to 10 responses. Surveys were either mailed or conducted on-line. Respondents who did not respond within two weeks were contacted by telephone, fax, and/or email with reminders and repeat survey forms or web links. The project received expedited review and approval by the local Institutional Review Board. By completing the surveys that included a paragraph describing consent, participants indicated their consent.

All responses were coded using the ICF-CY. Two independent raters coded the responses. Initially, each rater coded approximately 100 responses and then these codes were compared. The responses with discrepant coding were re-examined and the raters agreed upon the most appropriate codes. This process resulted in the creation of several coding rules for responses that were initially ambiguous (for example, ‘better looking gait’ was coded as *b770 Gait pattern functions* rather than *d450 Walking* because it emphasized gait pattern or appearance more than the activity of walking). The process continued and discordant codes were again resolved by discussion between the raters until consensus was achieved. Responses were aggregated into chapters and second level categories within the ICF-CY. A second level category was defined as a single concept out to four digits of specificity in the ICF-CY. Chapters and categories were grouped into the three ICF domains of Body Structure & Function, Activities and Participation, and Environmental Factors. Additional categories were permitted for broad concepts (such as ‘function’ or ‘independence’) or those not reflected in the ICF, if provided by at least three respondents.

The primary analyses were qualitative in nature, examining core ideas and themes that emerged from the responses. In addition, ICF-CY code frequencies were calculated for the responses.

## Results

75 individuals completed the initial questionnaire including 17 youth and 19 parents (Table 1) from 33 separate families and 39 medical professionals (seven physiatrists, seven developmental pediatricians, six orthopedic surgeons, three neurologists, five occupational therapists, five physical therapists, six others). The youth and parents either responded to posted signs about the study or enrolled after learning about the study from a clinician and, therefore, should be considered a convenience sample. 45 medical professionals were approached directly on an individual basis, 39 of whom participated. All respondents provided multiple items with an average of 5.6 responses reflecting 4.3 chapter-levels per respondent.

In the initial analysis of approximately 100 codes, the raters demonstrated over 80% agreement. Subsequent coding, using clarified processes, resulted in fewer discordant codes (<5%) for the remainder of the responses.

91% of the responses could be coded with the ICF-CY, including those that were broad reflections of ICF domains or chapters (‘function’, ‘impairment’, ‘nutrition’, ‘activity’, ‘participation’, and ‘independence’). The remaining responses that were supplied by at least 3 individuals were classified as Miscellaneous and included quality of life, meeting patient- or family-generated goals, satisfaction, and cost. Around 9% of responses involved Environmental Factors with the remainder split between the domains of Body Structure & Function (36%) and Activities & Participation (46%) (Table 2). In total, 18 out of a possible 30 ICF chapter-level areas were mentioned.

For the overall sample, the most common responses were pain and motor function in the Body Structure and Function domain, mobility (including hand and arm use) and recreation/community life in the Activities & Participation domain, and services/systems in the Environmental Factors domain. Youth most commonly identified strength, gait pattern, functional upper extremity use, and assistive technology, while parents endorsed communication, motor skills, mobility, and public services. Medical professionals reported a greater number of areas of importance overall with pain, function, mobility, and recreation being most frequent (Tables 2 and 3).

## Discussion

This study demonstrates the extremely broad range of important domains for individuals with CP. When asked to provide the domains that they would want to see change as a result of intervention(s) for CP, youth, parents and medical professionals all endorsed items across the domains of the ICF as well as outside the ICF. This breadth of concerns is not surprising and should be considered fairly comprehensive, as the characteristics of the children and youth involved with this study were quite disparate in age, functional ability, and co-morbidities. Even with the variety of responses, primary concerns were fairly consistent and included pain, motor function, mobility, and integration in community life.

Minor differences between groups may represent their particular perspectives. For example, medical professionals were more comprehensive in their responses, including greater identification of community integration and pain, likely because they are knowledgeable about many different experiences with CP and have witnessed significant family stressors.

On the other hand, youth did not mention caregiver issues, perhaps because they, like typically developing adolescents, are more inwardly focused. Areas of import unique to youth included strengthening, new skills (especially writing), use of assistive technology, and gait pattern; perhaps youth have recent or even lifelong experience with therapy that has been directed toward strengthening and gait pattern, thus reinforcing these goals. Concerns with writing and assistive technology may represent the desire among youth for greater independence, for conformity with their peers, and for formal communication. Youth respondents did not have significant intellectual disability, as they needed to be able to respond to the question independently. Due to their higher intellectual functioning, these youth probably had fewer concerns regarding mental processes, as parents and professionals more frequently listed mental functions as important.

Communication was a high frequency concern for parents which may be attributable to the large proportion of parents whose children had significant intellectual disability and therefore could not express their needs and wants. Parents in this study, similar to a European cohort (McManus *et al*. 2006), voiced concern with environmental factors addressing provision of services. We postulate that this may be a voice of frustration regarding inadequate services to meet their child’s needs rather than a true expectation for better provision of services as an outcome of most CP interventions. No parents reported concerns about effects on school, play, or work life. This may be because parents focus on their children at home, because they did not consider these issues as pertinent to the question asked, because they don’t expect medical interventions to affect school, play, or work, or because they feel there are no useful means to do so.

This study has several limitations. These data represent only the first step of a larger Delphi process to establish consensus on the important domains to address with interventions for CP. Thus, this is just one snapshot of opinions and not a full understanding of the most important issues. The numbers are small in the subgroups, so comparisons between groups should be interpreted with caution. Furthermore, the participants were not randomly selected and may not be representative of those groups as a whole, thus, although we believe the results are fairly comprehensive given the sample size, the relative frequencies of the responses should not be assumed to apply to all populations. Also, this survey very clearly asked about participants’ perspectives regarding interventions for CP. The results, therefore, cannot be applied to overall concerns or needs, although it is quite possible that some of the respondents had this broader view when they completed the survey. Nonetheless, this survey has provided valuable information to drive further study.

All respondents provided many concerns, which clustered in similar areas of comfort, movement and mobility, and community integration. With identification and clarification of the domains of importance, further work can address issues of assessment of change in these domains.

**Key Messages**

- Cerebral palsy is prevalent in childhood and affects many aspects of life.
- This study found that medical professionals, parents, and youth with CP endorse wide-ranging domains of impact for therapeutic interventions.

- With greater understanding of the important domains for assessment in childhood CP, better means of measuring change may be developed.

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## Table 1

Demographics

| | **GMFCS I–III Ambulatory** | **GMFCS IV–V Non-ambulatory** | **< 10 yrs old** | **≥ 10 yrs old** | **+ intellectual disability** |
|---|---|---|---|---|---|
| Parents | 10 | 9 | 13 | 6 | 8 |
| Youth | 12 | 5 | 0 | 17 (mean age 13 yrs) | 0 |

GMFCS Gross Motor Function Classification System

## Table 2

Number of responses at each chapter level

| | **17 Youth respondents** | **19 Parent respondents** | **39 Medical Professional respondents** | **75 total respondents** |
|---|---|---|---|---|
| Body Structure & Function | 15 | 19 | 83 | 117 |
| Activities & Participation | 26 | 22 | 99 | 147 |
| Environmental Factors | 7 | 12 | 11 | 30 |
| Miscellaneous | 1 | 5 | 22 | 28 |
| Total | 49 | 58 | 215 | 322 |

## Table 3

Categories Provided by at least 20% of a Respondent Group

| **Domain/Chapter/** ***second level category*** | **Youth %** | **Parents %** | **Med Prof %** | **Total %** |
|---|---|---|---|---|
| Body Structure & Function | | | | |
| Mental Functions | 0 | 21 | 26 | 19 |
| Sensory Functions and Pain | 24 | 16 | 46 | 33 |
| Neuromusculoskeletal and movement-related functions | 65 | 58 | 31 | 45 |
| - *Strength* | *41* | *16* | *5* | *16* |
| - *Voluntary movement control* | *6* | *32* | *3* | *11* |
| - *Gait pattern* | *41* | *2* | *15* | *20* |
| “Function” | 0 | 5 | 62 | 33 |
| Activities and Participation | | | | |
| Learning and Applying Knowledge | 24 | 0 | 0 | 5 |
| Communication | 6 | 26 | 10 | 13 |
| Mobility | 59 | 47 | 38 | 45 |
| - *Fine Hand, Hand and Arm Use* | *35* | *21* | *8* | *17* |
| - *Walking and Moving Around* | *18* | *37* | *26* | *27* |
| Self-Care | 12 | 5 | 23 | 16 |
| Interpersonal interactions and Relationships | 0 | 5 | 26 | 15 |
| Major Life Areas (School, Play, Work) | 18 | 0 | 31 | 20 |
| Community, Social, and Civic Life | 18 | 5 | 44 | 28 |
| “Activity” | 0 | 0 | 21 | 11 |
| “Participation” | 0 | 0 | 33 | 17 |
| Environmental Factors | | | | |
| Products and Technology | 29 | 11 | 8 | 13 |
| Services, Systems, and Policies | 12 | 47 | 21 | 25 |
| - *Social Support Services* | *6* | *11* | *21* | *15* |
| Non-ICF-CY concepts | | | | |
| Quality of Life | 0 | 16 | 28 | 19 |