Background: To improve the utility of the International Classification of Functioning (ICF) framework in the clinical and/or research settings, ICF-based tools like the ICF Core Sets need to be developed. The ICF Core Sets standardize what should be measured and reported for a given population; therefore, facilitating the use of the classification system.

The ICF defines functioning as “what a child can or cannot do” every day. Functioning is influenced by contextual factors which are the personal characteristics of the child and environmental factors (physical and social environment).

Aims: In the context of the development of the ICF Core Sets for children and youth with cerebral palsy (CP), we conducted a qualitative study to identify strengths and limitations in functioning important to children and caregivers, and to describe contextual factors that positively and negatively influence functioning.

Methods: We conducted semi-structured interviews with 10 children with CP and 22 caregivers (10 children-caregiver dyads) (75% male, age 10.5 (4-16)yr). A convenience sample was recruited representing all GMFCS levels I-V. Interviews were audio taped. Questionnaires covered all ICF components (body structures, body functions, activity and participation, environmental and personal factors). Interviews were transcribed verbatim and coded by two health professionals in N vivo 10 using the ICF for children and youth version (ICF CY) coding system.

Participants were included in this qualitative study until saturation and good representation of the sample were reached (e.g. all GMFCS levels, and age groups -6 years, ≥ 6 to -14 years, ≥ 14 to 18 years). Saturation of data was reached after 32 interviews.

Analysis: A two-stage process with an initial identification of meaningful concepts and subsequent linking to the ICF-CY categories was conducted. Frequency distribution of ICF-CY categories was calculated and summarized.

Results: We identified 1956 themes that linked to 175 ICF-CY categories. Out of 175 unique categories, 41% were activity and participation, 32% environmental factors, 17% body functions and 10% body structures. Children talked more about activities they were able to do and what helped them perform these activities. In contrast, caregivers discussed more about what they were able to do and what helped them perform these activities. The main contextual factors identified in the study were related to products, technology, services, systems and policies related to health, education and social services.

Discussion, this study:

- Illustrates the discordance between children and caregivers perspectives on functioning
- Demonstrates that children with CP embrace their abilities
- Shows that caregivers value acquisition of skills for future independence
- Demonstrates the importance of considering the clients’ opinions on functioning
- Highlights the role of the environment on everyday functioning

Conclusion: Children and caregivers described many of the same areas of functioning, but each also provided unique perspectives.

Veronica Schiariti was funded by a CIHR Doctoral Research Award and received an AACPDM student scholarship award to present the results of this qualitative study at the 67th Annual AACPDM meeting in Milwaukee, US, 2013.

A: How would you describe yourself/your child?

Boy, 14 years, GMFCS IV: "I’m a painter in my room. I can do it by myself."

Caregiver, boy, 10 years, GMFCS I: "Mom: The riding a bicycle and the swimming would be the two because there’s so much more going on. There’s your environment, then you’ve got to deal with all different body parts and they all have to work together and tell them and coordinate together."

Body Structures Tell me about what parts of your body/child's body give you/him trouble, if any?

Boy, 14 years, GMFCS IV: a talking "...I: What parts of your body give you trouble? Youth: My right hand." His mother clarified: "...For him, his wheelchair is an extension of his body and that; his wheelchair makes it hard for him to do the things he wants because of technology. ...I: Like you were saying, he sees himself as being no different. Mom: Yes, he fits in right and that’s why he says, when you ask him for body-wise, the only thing he sees a problem with is his right hand. Not anything else."

Body Functions Tell me about what parts of your body/child's body make it hard to do the things you/your child wants, if any?

Boy, 10 years, GMFCS II: "...Sports. Um, the only thing I can do is tai-kwan-do which I'm getting my yellow belt. M: Good for you! Youth: Thanks. I: What’s the yellow belt? Youth: Ok. Um, so it’s basically a different level of self-defense. Like I can’t show you any right now cause there’s too many breakable things in here."

Caregiver, boy, 14 years, GMFCS IV: "Mom: The amount of time it takes him to write out one paragraph is an hour. And so, but yet he needs to keep up. And so it’s been some anxiety with grade 9, how’s he going to keep up with this work load?"

Girl, 16 years, GMFCS III: "...I use the bus all the time...recently I’ve been using my crutches on the bus and it’s pretty easy. I just, like we obviously put down the ramp even if it’s just, they usually do. And then I just sit down and get up once it’s fully stopped. And it’s fine"
Disclosure information

AACPDM 67th Annual meeting Oct 16-19th 2013

**Speaker name:** Veronica Schiariti

**Disclosure of relevant financial relationships**

Veronica Schiariti was funded by a CIHR Doctoral Research Award and received an AACPDM student scholarship award to present the results of this qualitative study at the 67th Annual AACPDM meeting in Milwaukee, US, 2013.

**Disclosure of Off-label and/or investigative uses**

I will not use any Off label and/or investigational use in my presentation