


Development of an ICF Core Set for adults with cerebral palsy: capturing their perspective on functioning

SUZIE NOTEN^{1,2}  | LORENZO A A TROENOSEMITO¹ | CHONNANID LIMSAKUL^{1,3} | MELISSA SELB^{4,5} | VINCENT DE GROOT⁶ | MANIN KONIJNENBELT⁷ | DANIËLLE M F DRIESSEN⁸ | SANDER R HILBERINK^{1,9} | MARIJ E ROEBROECK^{1,2} | ICF CORE SET FOR ADULTS WITH CEREBRAL PALSY STUDY GROUP

1 Department of Rehabilitation Medicine, Erasmus MC University Medical Center, Rotterdam; **2** Rijndam Rehabilitation, Rotterdam, the Netherlands. **3** Department of Orthopedic Surgery and Physical Medicine, Prince of Songkla University, Songkhla, Thailand. **4** ICF Research Branch, Nottwil; **5** Swiss Paraplegic Research, Nottwil, Switzerland. **6** Department of Rehabilitation Medicine, Amsterdam Movement Sciences, Amsterdam University Medical Center, Vrije Universiteit Amsterdam, Amsterdam; **7** De Hoogstraat Rehabilitation, Utrecht; **8** Libra Rehabilitation & Audiology, Eindhoven; **9** Research Centre Innovations in Care, Rotterdam University of Applied Sciences, Rotterdam, the Netherlands.

Correspondence to Suzie Noten, Erasmus MC University Medical Center, Department of Rehabilitation Medicine, PO Box 2040, 3000 CA Rotterdam, the Netherlands.
E-mail: s.noten@erasmusmc.nl

*Members of the ICF Core Set for Adults with Cerebral Palsy study group are listed in the Acknowledgements.
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ABBREVIATION

ICF International Classification of Functioning, Disability and Health

AIM To examine the most relevant aspects of functioning of adults with cerebral palsy (CP) from their perspective, in order to develop an International Classification of Functioning, Disability and Health (ICF) Core Set for adults with CP.

METHOD We conducted six focus group discussions with adults with CP without intellectual disability and seven interviews with adults with CP with intellectual disability and caregivers, addressing all ICF components. Meaningful concepts were identified from verbatim transcripts and linked to ICF categories by two independent researchers.

RESULTS In total, 31 adults with CP without intellectual disability (mean [SD] age 46y 1mo [14y 1mo]; 20 females, 11 males; Gross Motor Function Classification System [GMFCS] levels I–IV) and seven adults with CP and intellectual disability (mean [SD] age 25y 8mo [6y 8mo]; four females, three males; GMFCS levels III–V) participated. We identified 132 unique second-level categories: 47 body functions, seven body structures, 43 activities and participation, and 35 environmental factors. The most frequently mentioned categories were emotional function, pain, muscle tone function, support of family, products and technology, and health services.

INTERPRETATION Adults with CP experienced problems in a broad range of body functions and activities and indicated the importance of environmental factors for functioning. The identified categories will be added to the list of candidate items to reach consensus on an ICF Core Set for adults with CP.

Cerebral palsy (CP) is one of the most common developmental motor disorders amongst children, occurring in 2 to 2.5 per 1000 live births.^{1–3} Nowadays, most people with CP are adults due to an increase in life expectancy for this population in the last decades.⁴ Known determinants of functioning of people with CP are the level of gross motor functioning, manual ability, speech impairments, and intellectual functioning.^{5,6} Intellectual disability is present in about 49% to 51% of children and adolescents with CP.^{7,8} Intellectual disability limits daily activities,⁹ and social participation is more strongly influenced by intellectual disability than by the level of gross motor functioning.¹⁰ Therefore, it is important to specifically examine the relevant aspects of functioning of adults with and without intellectual disability. Despite the increasing attention on

adults with CP, research on adults with CP and intellectual disability is scarce.¹¹

Thus far, studies have shown that CP at adult age results in several impairments and limitations in activities and participation. The large variation and lack of standardization of outcomes of functioning make comparison across studies or countries difficult.¹² Clinical care and research would benefit from a standardized outcome assessment. In this study, we used the International Classification of Functioning, Disability and Health (ICF) as a framework for describing different aspects of functioning, disability, and health in adults with CP. The ICF encompasses the components: body functions, body structures, activities and participation, and environmental and personal factors.¹³ In total, the ICF model contains over 1400 categories, which

makes its implementation in clinical practice and research challenging. To address this challenge, ICF Core Sets have been developed. ICF Core Sets include the ICF categories that are most relevant for describing functioning of persons with specific health conditions and are available for children with CP,¹⁴ but an ICF Core Set for adults with CP was not available. An early decline of function in adults with CP¹⁵ and a shift to other areas of participation, such as independent living,¹⁶ highlights the importance of developing an ICF Core Set for adults with CP.

A scientific approach for developing an ICF Core Set consists of different steps.¹⁷ First, four preparatory studies are performed from different perspectives: a systematic literature study (researcher's perspective),¹¹ a qualitative study (patient's perspective), an expert survey (health professional's perspective),¹⁸ and an empirical study (clinical perspective). The results of these studies are included in a list of ICF candidate categories, from which experts will decide on the final ICF Core Set.

In the present qualitative study, we aimed to identify those aspects of functioning and environmental and personal factors that are considered the most important from the lived experience of adults with CP, with and without intellectual disability.

METHOD

Study design

A multicentre qualitative study with semi-structured focus group discussions and individual interviews was performed in adults with CP and/or their caregivers. Adults with CP without intellectual disability participated in focus groups in their geographical region. Caregivers as proxies of adults with CP with intellectual disability were individually interviewed and, where possible, the respective person with CP was present and answered for themselves. A moderator (SN or LT) and a research assistant led the focus groups and interviews. The medical ethics committee of Erasmus University Medical Center (MEC-2018-1126) and the participating centres approved this study. Participants or their caregivers signed informed consent before participation.

Participants

Individuals were included if they were adults with CP (≥ 18 y) and able to communicate in Dutch; individuals using augmentative communication systems were included in the sample. Participants were considered as having an intellectual disability if a health professional diagnosed the person as having an IQ level of less than 70 or a developmental age below 12 years old.¹⁹ Participants were recruited at Amsterdam UMC, Amsterdam, Libra Rehabilitation & Audiology, Eindhoven, De Hoogstraat Rehabilitation, Utrecht, and by advertising the study on the website of the patient organization, CP Netherlands.

Data collection

CP-related and demographic information was collected on age, sex, ethnicity, type of CP, Gross Motor Function

What this paper adds

- Including the lived experience is crucial for fully understanding functioning of adults with cerebral palsy (CP).
- Adults with CP perceive environmental factors as essential elements for everyday functioning.
- Adults with intellectual disability should be considered as a group with specific problems.

Classification System (GMFCS) level, educational level, working status, living status, marital status, and if the person had children.

The focus groups and interviews were semi-structured, addressing six questions covering all ICF components, as follows.¹⁷ (1) Body functions (b): 'If you think about your body and mind, what does not work the way it is supposed to?' (2) Body structures (s): 'If you think about your body, in which parts are the problems?' (3) Activities and participation (d): 'If you think about your daily life, what are your problems?' (4) Environmental factors (e): 'If you think about your environment and your living conditions, what do you find helpful or supportive?' (5) Environmental factors (e): 'If you think about your environment and your living conditions, what barriers do you experience?' (6) Personal factors (pf): 'If you think about yourself, what is important about you and the way you handle your condition/situation?' For the focus groups, an additional question was asked on the participants' strengths: (7) 'If you think about the positive side of living with CP, what would you like to mention?'

Illustrations and probes (e.g. pain, health services) were used to clarify the questions. The duration of the focus groups ranged between 95 and 130 minutes; the interviews lasted between 40 and 80 minutes. Each focus group discussion and interview was digitally recorded.

Data analysis

A two-step procedure was conducted, comprising a qualitative analysis and a linking process to the ICF. Focus group discussions and interviews were analyzed using a meaning condensation procedure, as follows.²⁰ First, verbatim transcripts were divided into meaning units (using ATLAS.ti 8; ATLAS.ti Scientific Software Development GmbH, Berlin, Germany), that include an overall theme, not naturally following linguistic or grammatical rules, but where a shift of meaning is detected. These themes get broken down further into meaningful concepts.^{20,21} For example, the meaningful concepts of the statement 'I use medication for the pain in my legs' are 'use of medication' and 'pain in legs'. Next, these concepts were linked to the most precise ICF categories following established linking rules.²¹ Each ICF component (b, s, d, e) consists of categories at different levels, starting with chapter or first-level categories (e.g. b2 sensory functions and pain), followed by a second-level (e.g. b280 sensation of pain), third-level (e.g. b2801 pain in body part), or fourth-level code (e.g. b28015 pain in lower limb). Personal factors were identified as 'pf'.

Two independent researchers (LT, SN) who received training on the ICF and linking methodology²² performed the linking process. The first focus group and interview were linked by the two researchers independently to affirm their consistent application of the linking methodology. The other focus groups and interviews were randomly allocated: 50% of the meaningful units was linked by both researchers, the remaining 50% was linked by one researcher (LT or SN). Interrater agreement was determined for second-level categories by calculating Cohen's kappa.²³ Linking results were compared and resolved in a consensus discussion. When consensus could not be reached, a third researcher was consulted (CL).

Concepts were linked to the most precise ICF category but were aggregated to the second-level for further analyses. A second-level category was only counted once for each focus group or interview. Frequency analysis of the second-level ICF categories was performed to identify the most frequently-reported categories. We aimed to include participants until a saturation level of 5% was reached, meaning that the focus groups and interviews resulted in no more than 5% of new second-level categories. ICF categories that were reported as a problem, facilitator, or barrier in more than one focus group or interview were included in the list of candidate categories provided for the subsequent consensus process.

RESULTS

Participants

We completed six focus groups with a total of 31 participants without intellectual disability (mean [SD] age 46y 1mo [14y 1mo], range 24–74y; 20 females, 11 males; 28 with spastic CP; GMFCS levels I–IV) and individual interviews representing seven participants with intellectual disability and/or their caregiver (mean [SD] age 25y 8mo [6y 8mo] range 19–38y; four females, three males; five with spastic and dyskinetic CP; GMFCS levels III–V). Participants' characteristics are presented in Table 1.

Relevant areas of functioning

In total, 2322 meaningful concepts (1390 in the focus groups, 932 in the interviews) were linked to 132 unique second-level categories, 47 addressing body functions, seven addressing body structures, 43 addressing activities and participation, and 35 addressing environmental factors. Additionally, 97 unique personal factors, 26 not covered codes, and 79 non-definable codes were identified. A saturation level of 3.4% (focus groups) to 5.8% (interviews) was reached, indicating that identified categories were fairly thorough for adults with CP in general. Interrater agreement between the two linkers was moderate, Cohen's kappa 0.41 (95% confidence interval 0.39–0.44).

A list of second-level ICF categories mentioned in more than half of the focus groups (4 out of 6) and/or interviews (4 out of 7) is presented in Table S1 (online supporting information) and quotes of typical examples of participants

Table 1: Characteristics of adults with cerebral palsy with and without intellectual disability

Participant characteristics	Adults without intellectual disability (n=31)	Adults with intellectual disability (n=7)
Age, mean (SD) range, y:mo	46:1 (14:1), 24–74y	25:8 (6:8), 19–38y
Sex, n (%)		
Male	11 (35.5)	3 (42.9)
Female	20 (64.5)	4 (57.1)
Type of CP, n (%)		
Spastic	28 (90.3)	1 (14.3)
Spastic and dyskinetic	2 (6.5)	5 (71.4)
Spastic and ataxic	1 (3.2)	1 (14.3)
Limb distribution, n (%)		
Unilateral	10 (32.3)	1 (14.3)
Bilateral	21 (67.7)	6 (85.7)
GMFCS level, n (%)		
I	9 (29.0)	0 (0.0)
II	8 (25.8)	0 (0.0)
III	9 (29.0)	1 (14.3)
IV	5 (16.2)	1 (14.3)
V	0 (0.0)	5 (71.4)
Special education, n (%)	16 (51.6)	5 (71.4)
Level of education, n (%)		
No education	0 (0.0)	3 (42.8)
Primary education	2 (6.4)	3 (42.8)
Lower secondary education	4 (12.9)	1 (14.4)
Upper secondary education	10 (32.3)	0 (0.0)
Higher education	15 (48.4)	0 (0.0)
Work status, n (%)		
Student	2 (4.9)	0 (0.0)
Competitive employment	13 (31.7)	0 (0.0)
Sheltered employment	1 (2.4)	0 (0.0)
Non-remunerative employment	5 (12.2)	0 (0.0)
Homemaker	3 (7.3)	0 (0.0)
Receiving benefit grants	13 (31.7)	7 (100)
Other	4 (9.8)	0 (0.0)
Living status, n (%)		
Living alone	10 (32.3)	1 (14.3)
Living with parents	2 (6.4)	2 (28.6)
Living with partner	19 (61.3)	0 (0.0)
With others	0 (0.0)	4 (57.1)
Partner, n (%)	21 (67.7)	0 (0.0)
Children, n (%)	7 (22.6)	0 (0.0)

GMFCS, Gross Motor Function Classification System.

are presented below. Figure 1 displays the ICF framework, including the second-level categories that were indicated in almost all focus groups (5 out of 6) or interviews (6 out of 7). Table S2 (online supporting information) shows all second-level ICF categories identified in more than one focus group or interview.

Body functions

'Walking costs a lot of energy and the muscles in my legs are weak, so sometimes I fall on the floor.' (57 year-old female, GMFCS level I). For body functions, the indicated problems mostly addressed the chapters: Mental functions (b1; e.g. emotional functions, such as depression), Sensory functions and pain (b2; e.g. sensation of pain),

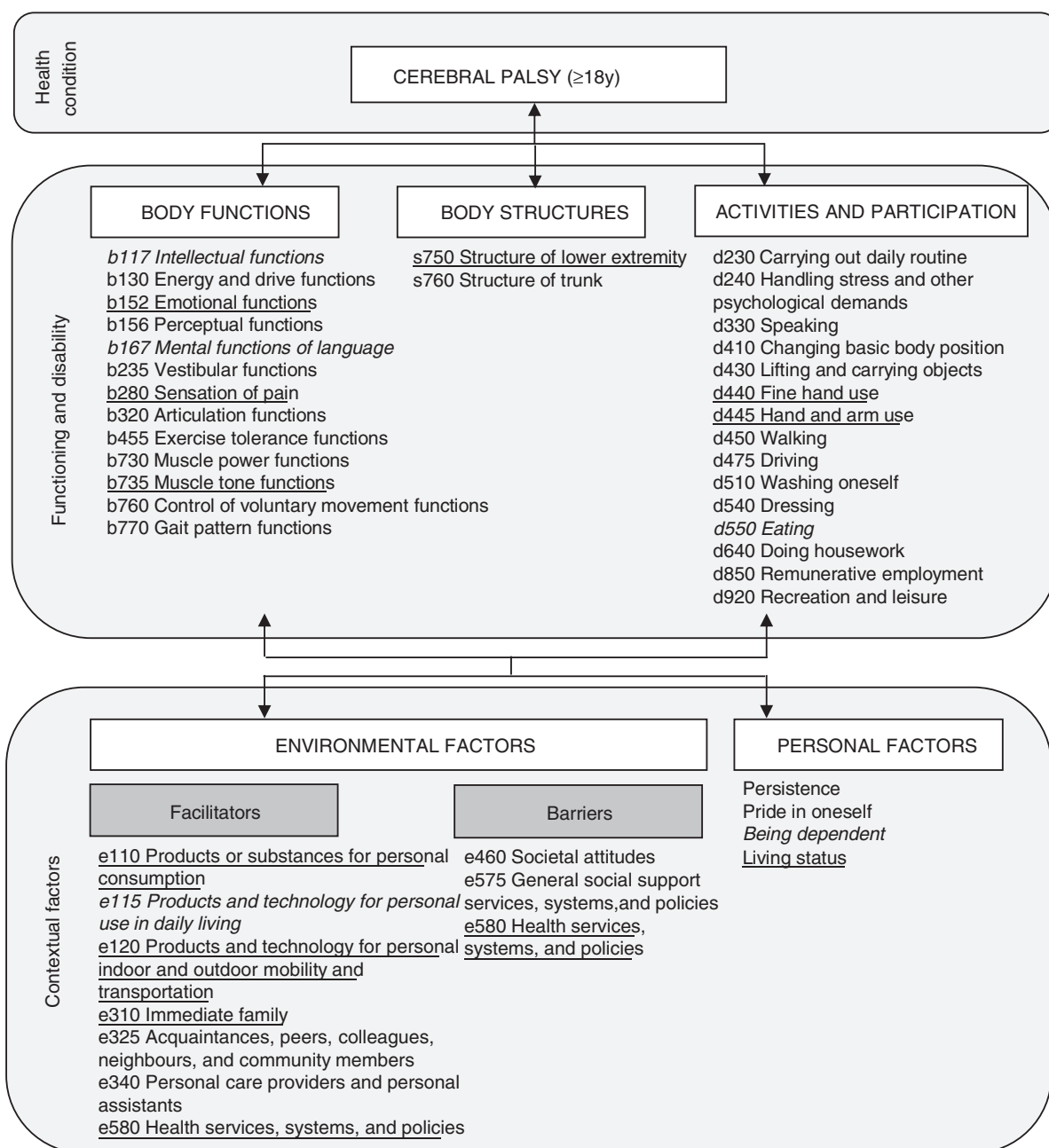


Figure 1: International Classification of Functioning, Disability and Health (ICF) framework including the second-level categories that were indicated in almost all focus groups (5 out of 6) or interviews (6 out of 7). Underlined categories: commonly mentioned in adults with and without intellectual disability; categories in normal font: commonly mentioned in adults without intellectual disability; categories in italics: commonly mentioned in adults with intellectual disability.

and Neuromusculoskeletal and movement-related functions (b7; e.g. muscle tone). In addition, those without intellectual disability often mentioned energy levels, exercise tolerance function, balance, control of voluntary movement, and gait pattern as relevant aspects of functioning. Adults with intellectual disability often described problems in mental function [language [e.g. reception and expression] and intellectual function).

Body structures

'I have contractures in my left arm and leg and I hardly have any muscles in my calf.' (24-year-old female, GMFCS level I). The majority of the categories linked to body structures addressed the chapter: Structures related to movement (s7). Participants mainly described structures of the lower extremity, such as contractures in legs and hip dislocation, as most relevant.

Activities and participation

I used to think that the only thing I couldn't do was walking. But you will discover that there is much more to it when you grow older. (37-year-old female, GMFCS level III). In the activities and participation component, the most frequently addressed chapters were: Mobility (d4; e.g. fine hand use and hand and arm use) and Self-care (d5). Adults without intellectual disability specifically mentioned problems in walking, driving, dressing, doing housework, remunerative employment, and recreation and leisure. In adults with intellectual disability, self-care was commonly mentioned as a problem, predominately eating.

Environmental factors

Facilitators. *The home of our friends is not wheelchair friendly, that's why they made a veranda for my daughter so that she can visit them.* (Caregiver of a 29-year-old female with intellectual disability, GMFCS level V). Environmental factors that facilitate functioning were mainly found in chapters: Products and technology (e1; e.g. for mobility and transportation, such as wheelchairs, for personal consumption, such as medication, or for use in daily living, such as orthopaedic shoes), Support and relationships (e3; e.g. immediate family), and Services, systems, and policies (e5; e.g. access to health services). Adults without intellectual disability often mentioned the support of acquaintances, peers, colleagues, neighbours, and community members as valuable to them.

Barriers. *It is a repetitive, occurring phenomenon that he encounters; people don't understand him because of his spasms and speech impairment. He gets no respect from, for example, the nursing staff; they just walk away.* (Caregiver of a 27-year-old male with intellectual disability, GMFCS level IV). Environmental factors that were frequently identified as a barrier were found in chapters: Support and relationships (e3), Attitudes (e4), and Health services, systems and policies (e5). The lack of collaboration across disciplines and transition from paediatric to adult health services were challenging for adults with and without intellectual disability. Adults without intellectual disability experienced societal attitudes as an important barrier.

Personal factors

Motivating yourself is sometimes difficult, but I'm very proud when I achieve something. Last year I competed in the Handbike Battle in Austria, and I managed to reach the finish line without any help. (48-year-old female, GMFCS level III). Personal factors commonly mentioned by adults without intellectual disability were persistence and pride in oneself. Adults with intellectual disability were described as dependent and calm. Living status (e.g. independent living or living in group homes) was identified in both groups.

Not covered and non-definable codes

My difficulties in walking and the movement of the upper body during walking caused a neck hernia. (45-year-old male, GMFCS level III). The most frequently reported not

covered codes referred to health conditions: burn-out and cervical disc herniation in adults without intellectual disability and asthma and epilepsy in adults with intellectual disability. Frequent non-definable codes were functioning and physical health for both groups and development for adults with intellectual disability.

Strengths associated with CP

The fact that I realize that I am different also gives room for other people to be different. (44-year-old male, GMFCS level IV). Participants in the focus groups were asked about the positive side of living with CP. For this question, 77 meaningful concepts were linked to 81 unique second-level categories, 26 addressing body functions, four addressing body structures, 49 addressing activities and participation, and two addressing environmental factors. In addition, 25 unique personal factors, four not covered codes, and seven non-definable codes, were found.

Adults without intellectual disability mentioned that they were proud of themselves and what they achieved, even though it took a lot of effort. They have a lot of empathy and persistence and were considered optimistic. Having CP gave them insight into behaviours of other people and a different perspective on the world; this helped them to appreciate things more.

DISCUSSION

This qualitative study identified a broad range of problems that adults with CP experience. They indicated products and technology for mobility and personal use in daily living as important facilitators, as well as health services and support of family or others. Those without intellectual disability were proud of what they had achieved and described themselves as persistent and optimistic.

Adults with CP indicated a range of difficulties that refer to common impairments and activity limitations known to be related to CP and addressed both physical and mental issues. Impairments such as reduced balance and deterioration in walking are previously described as early functional decline.^{24,25} Adults with intellectual disability often mentioned problems in mental function, also affecting language, related to their intellectual impairment. Commonly mentioned structures were related to movement, specifically, structure of the lower extremity, such as contractures in the legs and hip dislocation, which are known problems in CP.²⁶

Participants mainly explained difficulties in activities and participation by limited energy levels, affected mobility, and limited hand and arm use. In persons with intellectual disability, difficulties in self-care activities and moving around using equipment might be explained by their lower level of gross motor function, limited hand and arm use, or intellectual disability, which increased their dependency. Adults with CP experienced access to health care services as positive, but mentioned a lack of collaboration between disciplines and the transition to adult services as issues to be improved. Social support services were perceived as

facilitating for adults with intellectual disability, while hindering for those without intellectual disability, due to problems in receiving social support and facing challenges by changes in regulations. Regarding societal attitude, adults without intellectual disability often have to deal with prejudices. Those with intellectual disability experienced a lack of support from health professionals or their extended family, who were not able to cope with their disability. Notwithstanding similarities in relevant aspects of functioning, the important differences between adults with and without intellectual disability underline the need to identify adults with intellectual disability as a group with specific problems.

Comparing the qualitative studies of adults versus children with CP, both studies mostly identified similar issues. Notwithstanding some differences, problems addressing mobility, self-care, and health services seem to be important throughout the lifespan, whereas the focus on education changed towards employment. The study in children used a somewhat different methodology,²⁷ as they included only semi-structured interviews, and they linked items to the ICF for Children and Youth version.¹³ However, only one category mentioned by children with CP (e5853 special education and training services) was not covered by the ICF. Adults with CP considered sensation of pain, emotional function (e.g. depression), and energy levels as relevant impairments which children did not. In addition, other problems became important in adulthood, such as driving, lifting, carrying objects (e.g. groceries), and doing housework. Where children often mentioned the poor accessibility of buildings, adults did not.

The present results are in line with the systematic review of adults with CP by Benner et al., which was another preparatory study in the project to develop the ICF Core Set for adults with CP.¹¹ Some notable differences should be mentioned. Intellectual function was only put forward in the present study, which might be explained by the intentional inclusion of adults with intellectual disability. We also identified a larger number of environmental factors, which suggests that adults with CP recognize these as important factors that have been little studied so far.²⁸ This emphasizes the importance of including the perspective of adults with CP to get a complete picture of relevant aspects of their functioning.

Some limitations of the study should be mentioned. Participants were recruited in the Netherlands, which might not capture the global perspective of adults with CP because of cultural differences. We assume that a worldwide perspective will be obtained from the other preparatory studies for the ICF Core Set, which are performed internationally. In the present sample, participants with intellectual disability were younger than those without

intellectual disability, which might have influenced the outcomes. Despite additional efforts, we were not able to include older participants with intellectual disability. From other studies following up adults with CP during adulthood, we know that different problems might occur in older adults.²⁹ Finally, a different interview technique was used for adults with intellectual disability and without intellectual disability. Several caregivers of adults with intellectual disability expressed their preferences to take part in individual interviews rather than sharing their experiences in a group. In general, both methods are known to reveal rich and sensitive information, but sensitive topics are more likely to occur in focus groups.³⁰ In our study, rich information was obtained as saturation levels were adequate for both techniques, and intimate issues, such as romantic relationships or defecation, were also discussed during the interviews.

The present study supplied a comprehensive list of aspects of functioning and disability and environmental factors that are relevant to adults with CP, underlining the variability in the problems they experience. Overall, relevant aspects of functioning are mostly similar between those with and without intellectual disability, except for some notable differences in intellectual function, language function, mobility, and self-care activities, which suggests specific ICF Core Sets for adults with CP with and without intellectual disability should be considered.

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DATA AVAILABILITY STATEMENT

The data that supports the findings of this study are available in the supplementary material of this article.

SUPPORTING INFORMATION

The following additional material may be found online:

Table S1: Frequently mentioned second-level ICF categories in adults with cerebral palsy

Table S2: Second-level ICF categories identified in more than one focus group or interview

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CREACIÓN DE UN CONJUNTO BÁSICO DE LA CIF SOBRE EL FUNCIONAMIENTO DE ADULTOS CON PARÁLISIS CEREBRAL: UN ESTUDIO CUALITATIVO

OBJETIVO

Examinar los aspectos más relevantes del funcionamiento de los adultos con parálisis cerebral (PC) desde su perspectiva, con el fin de desarrollar un Conjunto Básico de la Clasificación Internacional del Funcionamiento, de la Discapacidad y de la Salud (CIF) para adultos con PC.

MÉTODO

Realizamos seis grupos focales con adultos con PC sin discapacidad intelectual y siete entrevistas con adultos con PC con discapacidad intelectual y cuidadores, abordando todos los componentes de la CIF. Se identificaron conceptos significativos a partir de transcripciones textuales y se vincularon a las categorías de la CIF por dos investigadores independientes.

RESULTADOS

En total, 31 adultos con PC sin discapacidad intelectual (edad media [DE] 46 años 1 mes [14 años 1 mes]; 20 mujeres, 11 hombres; sistema de clasificación de la función motora gruesa [GMFCS] niveles I-IV) y siete adultos con PC con discapacidad intelectual participaron (media [DE] edad 25 años 8 meses [6 años 8 meses]; cuatro mujeres, tres hombres; niveles de GMFCS III-V). Identificamos 132 categorías únicas de segundo nivel: 47 funciones corporales, siete estructuras corporales, 43 actividades y participación y 35 factores ambientales. Las categorías mencionadas con mayor frecuencia fueron función emocional, dolor, función del tono muscular, apoyo a la familia, productos y tecnología y servicios de salud.

INTERPRETACIÓN

Los adultos con PC experimentaron problemas en una amplia gama de funciones y actividades corporales e indicaron la importancia de los factores ambientales para su funcionamiento. Las categorías identificadas se agregarán a la lista de elementos candidatos para llegar a un consenso sobre un conjunto básico de la CIF para adultos con PC.

DESENVOLVIMENTO DE UM CONJUNTO PRINCIPAL DE ITENS SOBRE O FUNCIONAMENTO DE ADULTOS COM PARALISIA CEREBRAL: UM ESTUDO QUALITATIVO

OBJETIVO

Descrever os aspectos mais relevantes do funcionamento para adultos com paralisia cerebral (PC) a partir de sua perspectiva, a fim de desenvolver um Conjunto Principal de itens da Classificação Internacional de Incapacidade, Funcionalidade e Saúde (CIF) para adultos com PC.

MÉTODO

Conduzimos seis discussões em grupos focais com adultos com PC sem deficiência intelectual e sete entrevistas com adultos com PC e deficiência intelectual e seus cuidadores, abordando todos os componentes da CIF. Conceitos significativos foram identificados a partir das transcrições das falas e ligados a categorias da CIF por dois pesquisadores independentes.

RESULTADOS

No total, 31 adultos com PC sem deficiência intelectual (média [DP] de idade 46a 1m [14a 1m]; 20 do sexo masculino, 11 do sexo feminino; Sistema de Classificação da Função Motora Grossa [GMFCS] níveis I-IV) e sete adultos com PC e deficiência intelectual (média [DP] de idade 25a 8m [6a 8m]; quatro do sexo masculino, três do sexo feminino; níveis GMFCS III-V) participaram. Identificamos 132 categorias de segundo nível únicas: 47 em funções do corpo, sete em estruturas do corpo, 43 em atividades e participação, e 35 fatores ambientais. As categorias mais frequentemente mencionadas foram função emocional, dor, função do tônus muscular, suporte da família, produtos e tecnologia, e serviços de saúde.

INTERPRETAÇÃO

Adultos com PC experienciam problemas em uma ampla variedade de funções do corpo e atividades e participação, e indicaram a importância de fatores ambientais para o funcionamento. As categorias identificadas serão adicionadas à lista de itens candidatos a obter consenso em um conjunto principal de itens da CIF para adultos com PC.