






## EXPERT-CONSENSUS REPORT

# Proposed updated description of cerebral palsy

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### Abstract

‘Cerebral palsy’ (‘CP’) is a widely used descriptive label for a spectrum of motor impairments caused by non-progressive brain injury or malformation occurring during early development. Advances in research have significantly refined our understanding of CP, including insights into its genetic, inflammatory, and neurophysiological underpinnings. Research across global contexts, including low- and middle-income countries, has expanded knowledge of clinical features. Shifting societal perceptions, driven by individuals with lived experience, have further influenced how CP is understood, challenging ableist attitudes and promoting inclusive frameworks. Additionally, increased recognition of the needs and experiences of adults with CP has highlighted the importance of further developing appropriate services. The primary aim of this paper is to propose an updated description of CP, developed through a collaborative, multidisciplinary process, as a preliminary formulation that integrates stakeholder perspectives at this stage of the process. By framing it as a foundation for further discussion and refinement, the manuscript emphasizes the output itself rather than the process of its development. A comprehensive stakeholder analysis and mapping approach ensured broad representation, including individuals with CP, families, clinicians, researchers, advocacy groups, and others. Data were collected through surveys, interviews, focus groups, and workshops, facilitating a global dialogue that combined the expertise of those with lived experience with that of clinicians. The description is intended to serve as a preliminary framework to guide clinical practice, research, and policy, emphasizing a shared understanding of CP. The proposed updated description thus lays the foundation for continued refinement, emphasizing the importance of collaboration in advancing the care and inclusion of individuals with CP.

The term ‘cerebral palsy’ (‘CP’) has long been used to describe a broad range of motor impairments caused by non-progressive brain injury or malformation during the early stages of development. Like many medical diagnoses, CP is not a singular, concrete entity but rather a construct, an evolving conceptual framework used to categorize and understand a diverse set of neurological conditions. The role of descriptive diagnoses, such as CP, is both to serve as a starting point in identifying a specific underlying pathology or aetiology, and to offer a broad functional categorization

that can guide management and understanding. Descriptive terms allow clinicians to identify patterns of symptoms that help structure care and provide a basis for communication across medical, educational, and social domains. Thus, the need for a descriptive diagnosis stems from the necessity to create actionable frameworks for intervention, prognosis, and research despite the absence of a single definitive cause or uniform presentation.

The process of diagnosis, especially in complex conditions such as CP, is inherently shaped by both scientific and

**Abbreviation:** ICF, International Classification of Functioning, Disability and Health

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societal contexts, and is evolving with new insights into the underlying mechanisms, as well as changing perspectives on clinical practice, service organization, and even society as a whole. Therefore, while 'CP' serves as a descriptive label, our understanding of the condition is constantly being refined and redefined by advances in research, diagnostic criteria, framework-oriented constructs (e.g. International Classification of Functioning, Disability and Health [ICF]), and clinical experiences.

The history of CP as a diagnosis reflects the interplay between scientific advancements and evolving concepts of disability.<sup>1</sup> Since William Little's pioneering description in the 1860s, the concept has remained a consistent yet evolving construct. Over time, it has adapted to incorporate new discoveries, theoretical frameworks, and language, with different aspects emphasized as the field has progressed. For instance, Sigmund Freud expanded the understanding of CP by including fetal causes alongside perinatal ones. In the 1950s, Meyer Perlstein, one of the founding members of the American Academy for Cerebral Palsy, drew attention to the multifaceted nature of motor control impairments associated with the condition. From the end of that decade, Ronnie Mac Keith and Paul Polani organized and hosted the 'Little Club', an international group of physicians who met regularly to discuss issues related to CP. Their work culminated in Martin Bax's definition in the 1960s, which focused on the core issues of movement and posture, introducing the concept of the 'immature brain'—a term later revised to 'developing brain' as scientific advancements shifted the understanding of neurological development. Definitions put forth in the 1970s, 1990s, and 2000s highlighted the heterogeneity of the clinical presentation of CP, the chronic nature of its course, associated non-motor features (including cognitive, sensory, and social aspects), and evolving perspectives on disability.

The two-sentence definition published in 2007 is most widely used and cited today:<sup>2</sup> 'Cerebral palsy describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, behaviour, epilepsy, and by secondary musculoskeletal problems.' The authors of this iteration of the definition of CP hoped that it would be directly useful to many stakeholders including people with lived experience (people with CP, their families), health-care professionals (involved in diagnosis and management), epidemiologists and other scientists, service providers, and policymakers. We must admit now that this ambition may not have been fully realized.

In the past few years, two of us (BD, PR) who were co-authors of the 2007 definition were contacted by several groups to discuss the need for an update. With growing understanding of CP and the broader field of neurological conditions, the question arises as to whether further revisions are necessary. Since 2007, there has been progress in

### What this paper adds

- An updated description of cerebral palsy was developed through a collaborative, multidisciplinary process.
- The description is a preliminary formulation that integrates stakeholder perspectives at this stage of the process.

aetiological understanding of CP, including insights from genetics and documentation of inflammatory, other biochemical, and neurophysiological processes. There have been several important reports characterizing clinical features from many settings across the world, including from low- and middle-income countries, providing clearer insights into the clinical manifestations and raising awareness of CP-related issues. There is also increasing reporting on adults with CP, and general (but slow) development of more adult services, further supporting the need for continuous refinement. Additionally, evolving societal and cultural perceptions of people with CP are also contributing to a shift in how the condition is understood and addressed, with individuals with lived experience gaining more agency over their condition. This shift is aligned with broader changes in the language and concepts surrounding disability, as well as growing awareness of ableist attitudes.

In line with this continuing evolution, Mac Keith Press, which has published many of the key descriptions of CP since the 1950s, has once again taken a leading role in providing a platform for global discussion, involving professionals and people with lived experience from around the world, participating both individually and in groups through a series of constructive workshops and online consultations. We reflected on the role of diagnostic labels and their potential benefits and harmful effects in various contexts (scientific, therapeutic, social, administrative).<sup>3</sup> We were aware, in particular, that any such definition involves a restriction or circumscription of the individuality of people with CP. Philosophers have long cautioned us that categorizing individuals as objects of knowledge or placing them within a specific discourse carries an inherent form of violence.<sup>4,5</sup> This 'violence' refers to the way complex lived experiences get reduced to simplified or rigid frameworks, thereby distorting or limiting the true essence of a person. To mitigate this risk and enhance our awareness of possible ableist prejudice, we worked with several individuals with lived experience in various settings. In the context of making a diagnosis of CP in a child, providing the family with a category to which their child's situation belongs helps them to understand better both present and future challenges, to identify sources of information and peer groups that can support them, and thus to cope better with the stress, which is beneficial for the child's own development. The diagnostic approach can thus be seen as caring rather than violent, and any risk of limiting

the true essence of the person can be addressed by emphasizing their individuality at all times. When compared with the experience of families of children with rare diseases and undiagnosed conditions, the benefit for families of children with CP of receiving an early diagnosis is clear.

Our aim was to collaboratively conceive an up-to-date description of CP primarily intended for professionals in the areas of clinical practice, health research, and health care and social service.

## METHOD

To suggest an update of the 2007 definition of CP for broader discussion, we undertook a stakeholder analysis and mapping approach.<sup>6,7</sup> We thus aimed to engage a broad and diverse array of stakeholders involved in improving the lives of people with CP. Stakeholders were identified and categorized on the basis of their roles and positions relative to CP, ensuring representation across a wide spectrum of perspectives. The groups included (1) people with CP; (2) family members and caregivers; (3) support and advocacy groups; (4) medical doctors; (5) therapists; (6) health-care service providers; (7) CP registries; (8) researchers; (9) organizations funding research; (10) academic societies. Individuals in these groups may overlap across multiple categories. To maintain a focus on the lived and professional experience of CP rather than regulatory or commercial interests, we excluded stakeholders whose primary roles pertained to policy and regulation, as well as representatives from pharmaceutical or biotechnological industries.

To ensure the inclusion of diverse perspectives, we used multiple data collection methods. We initiated the process with an online focus group discussion in July 2022, involving members of the International Cerebral Palsy Society to identify common themes and points of divergence. The Society is a non-profit organization with members in more than 60 countries on five continents that aims to make sure that the voice of people with CP be heard whenever medical research, technological advances, or policy developments that might affect them are being discussed. Participants included people with lived experience of CP who were executive committee members of the Society from Argentina, France, Luxembourg, Nigeria, and Sri Lanka, as well as members from Nepal, Slovenia, and South Africa. Later in the process the geographical reach was extended through international CP groups, many of whom collaborated with their family forums.

We asked this focus group whether they thought that the term 'cerebral palsy' should be retained. The main positive aspects that were felt to be related to the potential for self-identification with an advocacy and support community, and being entitled to receive appropriate service designed for people with CP or conditionally provided on the basis of the term. Therefore, there was strong support for retaining the use of the term. Among the reported negative aspects, the focus on brain impairment was felt to misrepresent abilities and potential of people with CP.

Based on the conclusions of this focus group discussion, we were able to formulate clearer questions for a first e-mail survey, which was conducted in April 2023 to broadly invite stakeholders to share their insights flexibly. This survey addressed the following five questions: (1) What aspects of the 2007 definition of CP – if any – should be retained as written in an updated description? (2) What aspects of the 2007 definition need to be removed – if any – and for what reasons? (3) What aspects of the 2007 definition need to be changed – if any – and for what reasons? (4) Are there components of the concept of 'CP' that are missing from the 2007 definition and need to be added? (5) Who benefits from a change in description? Who might be harmed?

We subsequently organized a hybrid workshop (in person and online) in May 2023 as a pre-symposium event before the annual meeting of the European Academy of Childhood Disability that took place in Ljubljana, Slovenia, where these five questions were expanded through collaborative dialogue and synthesis of ideas. We compiled a spreadsheet of 99 participants in this workshop, comprising representatives of societies, doctors, therapists, and those with lived experience from all continents, and synthesized their comments.

On the basis of the obtained input, we drafted a first version of an updated description of CP and conducted a second e-mail survey in February 2024 to gain stakeholders' viewpoints on each of the specific terms (words or phrases) in this description. Further modifications were made after the second e-mail survey.

Resulting progress from this work was presented in October 2024 at the Presidential Guest Lecture of the Annual Meeting of the American Academy for Cerebral Palsy and Developmental Medicine in Quebec City, Canada, where it was the topic of a panel and plenary discussion.

Throughout the process, we categorized responses to identify areas of broad agreement, unresolved issues, and specific points of contention to capture the full spectrum of stakeholder perspectives. This approach prioritized the inclusion of nuanced insights, ensuring that minority opinions and dissenting views were discussed with equal weight alongside prevailing agreement. The methodology facilitated the identification of recurring themes, areas of agreement, and contested issues, providing a comprehensive basis for refining the concept of CP.

The primary aim of this paper is to present the proposed update to the definition of CP, as a preliminary description that integrates stakeholder perspectives at this stage of the process. By framing it as a foundation for further discussion and refinement, the manuscript emphasizes the output itself rather than the detailed mapping and analysis conducted during its development.

## FINDINGS

In addition to individual contributions, members from the following groups contributed to the process. Here is the list sorted alphabetically: Academia Latinoamericana de

Desarrollo Infantil y Discapacidad (ALDID), Academia Mexicana para la Parálisis Cerebral y los Trastornos del Neurodesarrollo (AMEXPCTND), American Academy for Cerebral Palsy and Developmental Medicine (AACPDM), AACPDM Community Council, American Neurology Association (ANA), Association of Paediatric Chartered Physiotherapists (APCP), Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM), Australian Cerebral Palsy Register (ACPR), British Academy of Childhood Disability (BACD), British Paediatric Neurology Association (BPNA), Canadian Cerebral Palsy Registry, CanChild, Cerebral Palsy Alliance (CPA), Cerebral Palsy Cymru, Cerebral Palsy Foundation, Cerebral Palsy Research Network, Child Neurology Society (CNS), Chinese Association of Rehabilitation Medicine: Pediatric Rehabilitation Committee (CARM-PRC), CP-Achieve, CPTeaching, Eastern African Academy of Childhood Disability (EAACD), European Academy of Childhood-onset Disability (EACD), EACD Families & Users' Forum, European Bobath Tutor Association, Federação das Associações Portuguesas de Paralisia Cerebral (FAPPC), Fondation Paralysie Cérébrale, Indian Academy of Cerebral Palsy (IACP), International Alliance of Academies of Childhood Disability (IAACD), International Cerebral Palsy Genomics Consortium (ICPGC), International Cerebral Palsy Society (ICPS), International Child Neurology Association (ICNA), Mac Keith Press Editorial Board, National Institute for Health and Care Research (NIHR), Paediatric Neurology and Development Association of Southern Africa (PANDA-SA), Self-Help Group for Cerebral Palsy (SGCP, Nepal), Surveillance of Cerebral Palsy in Europe (SCPE), Sri Lanka Association for Child Development (SLACD), United Cerebral Palsy (UCP).

The questions arising early in the process included the following:<sup>8</sup> Should we continue to use the term 'cerebral palsy'? Is it a disorder or a way of being? Is it appropriate and useful to regard CP as a spectrum?<sup>9</sup> How operational can or should a definition or description be? Can we better delineate timing and non-progressiveness?<sup>10</sup> How do we describe motor and non-motor features? Can 'objective' identification of clinical features relying on advances in technology improve the description?<sup>11</sup> Can we better define the causes?<sup>12</sup> Is the description sufficiently accurate to allow progress in genetic understanding?<sup>13</sup> Should we emphasize the lifelong course and the impact on participation?<sup>14</sup> How do we account for the medical, social, global, political, and personal dimensions of CP?

### Aligned opinions

Stakeholders expressed general agreement on the following foundational elements, which should inform the updated description of CP:

- There was widespread recognition of CP as a valuable clinical construct within the current state of knowledge and practice, serving critical diagnostic, therapeutic, and

research purposes, as well as social and political ones, including access to services, benefits, support, and more.

- Stakeholders broadly agreed that CP should remain a clinical formulation, despite the absence of a pathognomonic characterization and continuing uncertainties about pathophysiology.
- There was strong agreement that the description should emphasize the lived experiences of individuals with CP, incorporating the diversity of challenges they face across different contexts.
- A strong agreement emerged around framing CP in terms of its impact on functional abilities and social participation, moving beyond a primary focus on motor impairments.
- Stakeholders emphasized the importance of recognizing CP as a lifelong condition, with explicit consideration of age-specific needs and experiences.
- There was broad agreement that the description must remain relevant across all resource settings, including those with limited resources, ensuring equity in its application.
- Many stakeholders supported using the 2007 definition as a starting point for updates, while addressing contemporary needs and understandings.

### Divergent opinions

Certain topics elicited mixed or conflicting views, highlighting areas for further exploration:

- Stakeholders were divided on whether a precise 'definition' or a more flexible 'description' would better serve the needs of the lives of people with lived experience, clinical practice, and research.
- There was no agreement on whether the description should explicitly address measurability or include procedural elements for diagnosis and management.
- Opinions varied about whether the oldest age at which brain injury can lead to CP should be specified.
- While some stakeholders advocated including common co-occurring conditions (e.g. epilepsy, intellectual disability) to reflect the multidimensional nature of CP, others cautioned against diluting the focus on motor impairments as the defining feature.
- The role of subtypes in the description was contested. Some stakeholders highlighted the value of subtype specificity for clinical and research purposes, while others worried this could complicate broader understanding and accessibility.
- The balance between clinical precision and accessible, inclusive language was debated. Some specific terms (e.g. 'disorder', 'disability') elicited mixed reactions—some viewed these as stigmatizing, while others argued they were necessary for medical or sociopolitical clarity.

The general agreement themes provide a foundation for drafting an updated description that aligns with

contemporary understandings of CP and prioritizes inclusivity. The unresolved issues highlight areas requiring further deliberation and validation. As we continue to refine our understanding of CP, we must acknowledge the complexities inherent in both the condition itself and the act of diagnosing it. CP is a construct that reflects a broad, multifaceted spectrum of experiences and challenges.

## PROPOSED UPDATED DESCRIPTION

Cerebral palsy (CP) is an early-onset lifelong neurodevelopmental condition characterized by limitations in activity due to impaired development of movement and posture, manifesting as spasticity, dystonia, choreoathetosis, and/or ataxia. It results from maldevelopment attributed to dysplasia of or injury to the fetal or infant brain that is not degenerative, although the manifestations may change with age. The phenotype of CP is complex and heterogeneous, with each person experiencing a unique presentation. In addition to motor dysfunction, people with CP frequently encounter primary and secondary impairments across various areas of development and functioning, which can significantly impact their participation in daily life.

## ANNOTATION

We annotated 25 specific terms of the proposed updated description. Each term is identified in the following paragraph by a superscript letter and is discussed below.

Cerebral palsy<sup>a</sup> (CP)<sup>b</sup> is an early-onset<sup>c</sup> lifelong<sup>d</sup> neurodevelopmental<sup>e</sup> condition<sup>f</sup> characterized by limitations in activity<sup>g</sup> due to impaired<sup>h</sup> development<sup>i</sup> of movement and posture<sup>j</sup>, manifesting as spasticity, dystonia, choreoathetosis, and/or ataxia<sup>k</sup>. It results from maldevelopment attributed to<sup>l</sup> dysplasia of or injury<sup>m</sup> to the fetal or infant<sup>n</sup> brain<sup>o</sup> that is not degenerative<sup>p</sup>, although the manifestations may change with age<sup>q</sup>. The phenotype<sup>r</sup> of CP is complex<sup>s</sup> and heterogeneous<sup>t</sup>, with each person experiencing a unique presentation<sup>u</sup>. In addition to motor dysfunction, people with CP frequently encounter primary<sup>v</sup> and secondary<sup>w</sup> impairments across various areas of development and functioning<sup>x</sup>, which can significantly impact their participation in daily life<sup>y</sup>.

### (a) Cerebral palsy

The term ‘cerebral palsy’ was originally coined, independently, by William Osler, Adolf Wallenberg, and William Gowers in the 1880s. It is still very widely used by clinicians, people with lived experience, health-care and social service providers, and researchers. The term, now almost

150 years old, is retained for this description because it is felt to be helpful in the current state of understanding, research, and service organization. This is proposed to ensure continuity in developing and sharing relevant and impactful knowledge to optimize the present situation and future prospects of individuals with CP. One determining argument was that changing the diagnostic label at this stage might pose the risk of jeopardizing funding of services and research that relies on it. However, the need to continue to update and clarify the description has been emphasized. We acknowledge that the specific term ‘palsy’ is no longer used in isolation in medical nosography and lay language, but it still appears in the names of a handful of medical conditions that are characterized by muscle weakness, such as oculomotor (or third nerve) palsy, Bell (or facial nerve) palsy, Erb (or brachial plexus birth) palsy, or Saturday night (or radial nerve) palsy. It must be noted that the core feature in CP is motor control rather than muscle force.

### (b) CP

There was also strong agreement in using the acronym ‘CP’, which has been in wide use even in non-English-speaking settings. This is similar to other medical acronyms that de-emphasize the original description that presided over coining diagnostic labels while referring to continuing history of those conditions, such as MS for multiple sclerosis, SLE for systemic lupus erythematosus, or TSC for tuberous sclerosis complex. Other medical acronyms that are widely used include ADHD, COVID-19, and AIDS. They can promote consistent communication, advocacy, linkage of relevant research, and health-related as well as societal change.

### (c) Early-onset

The clinical manifestations are present from infancy or early childhood.

### (d) Lifelong

CP is a permanent condition starting very early in life, not a transient one. Children who received the diagnosis of CP but ‘outgrew’ it never had CP.<sup>15–17</sup> The choice of this term also draws attention to transitions that take place across the lifespan. Most people with CP in high-income countries are adults.<sup>14</sup>

### (e) Neurodevelopmental

The neurodevelopmental aspect is essential to CP. This requires explicit mention because the fact that some nosographic systems (e.g. International Classification of Diseases, 11th Revision; Diagnostic and Statistical Manual

of Mental Disorders, Fifth Edition, Text Revision) still fail to list CP among neurodevelopmental disorders results in impeding individuals with CP from accessing services organized for people with neurodevelopmental conditions. This term also speaks to the impact of the condition on the developmental trajectories of people with it.

### **(f) Condition**

This term was chosen in preference to ‘disorder’ to emphasize the life situation of people with CP as a way of being and to promote a person-centred approach.<sup>18</sup> We hope this term can be used to recognize the integrity, dignity, freedom, and independence of individuals with CP.<sup>19</sup>

### **(g) Limitations in activity**

The focus on the activity dimension of the ICF framework relates directly to how CP affects a person's ability to function in daily life. This approach aligns with a holistic, biopsychosocial understanding of health and disability. It also allows early diagnosis of CP in infants showing limitations in activities such as reaching, grasping, or rolling, while precluding very early diagnosis of CP before the appearance of activity limitations, for example in a fetus or a newborn infant. However, it is important to recognize features that signal a high probability of CP in order to promote early detection and early intervention programmes even before a formal diagnosis has been reached.<sup>20</sup>

### **(h) Due to impaired**

This clarifies the relationship between the activity dimension of the ICF and an impairment in body function and structure.

### **(i) Development**

The impact of the impairment on functional development is a core defining feature of CP.

### **(j) Movement and posture**

The motor features of CP relate to sensorimotor control of movement and posture.

### **(k) Spasticity, dystonia, choreoathetosis, and/or ataxia**

CP registries, which have played a key role in advancing knowledge about CP, register individuals on the basis of a

descriptive classification of the motor type corresponding to predominant motor impairments,<sup>21</sup> bearing in mind that multiple motor disorders are commonly present in individuals with CP.<sup>22</sup> Many CP registries use the following motor categories: spastic CP, dyskinetic CP, mixed-type CP (i.e. both spastic and dyskinetic features are prominent), and ataxic CP. Such categorization of individuals into groups has proved useful for clinical, research, and service provision purposes.

Spasticity, which refers to dynamic resistance to passive movement of a joint,<sup>23,24</sup> is seen as a hallmark of upper motor neuron impairment.

In the context of CP registries, the term ‘dyskinesia’ refers to extrapyramidal features, which are caused by injury to the basal ganglia, but it is often used more restrictively in clinical neurology to refer to a complication of long-term levodopa treatment in patients with Parkinson disease.<sup>25</sup> In CP, this description refers directly to dystonia and choreoathetosis, which are the two major extrapyramidal manifestations seen in dyskinetic CP.<sup>26</sup> Dystonia reflects both a muscle tone regulation disorder and a movement disorder.<sup>27</sup> In this context, dystonia refers to involuntary sustained or intermittent muscle contractions that result in abnormal postures, twisting, and repetitive movements. A similar presentation of involuntary tonic muscle contraction occurring in the context of an upper motor neuron injury has been termed spastic dystonia.<sup>28</sup> Choreoathetosis in CP is characterized by involuntary movements. Although it can be separated phenomenologically into chorea (i.e. rapid, brief, jerky, and often fragmented movements) and athetosis (i.e. slower, ongoing, constantly changing, writhing, or contorting movements), this distinction does not seem to be clinically useful in people with dyskinetic CP.<sup>26</sup>

In CP, ataxia refers specifically to lack of coordination in voluntary muscle movements that is non-progressive and presumed to be of cerebellar origin.<sup>29</sup> It is important to distinguish between ataxia in CP and progressive cerebellar disorders. This is at times challenging owing to the comparatively late development of motor coordination and the continued maturation of the cerebellum into the postnatal period. There is currently limited understanding of the pathophysiological mechanisms of ataxia in CP and clinical interpretation is controversial, in part because ataxia has been insufficiently described in the CP literature.<sup>30</sup>

It is important to note that multiple motor presentations can occur in combination in individuals with CP, sometimes with varying prominence across the lifespan.<sup>31</sup> Motor disorders other than spasticity, dystonia, choreoathetosis, and/or ataxia typically occur, including impaired motor planning and execution, various types of tremor, muscle weakness, and crucially hypotonia.<sup>22</sup> Axial (or core) hypotonia is common in individuals with CP who show limb spasticity, dystonia, choreoathetosis, or ataxia. Indeed, hypotonia of brain origin is often an early, non-specific feature of neurodevelopmental disorders.<sup>32</sup> Several CP registers currently include individuals with hypotonia alone as the motor type, but this category is not defined by clear inclusion and exclusion criteria, particularly with respect to genetic conditions, which

raises the risk of blurring the increasingly recognized role of genetics in CP.<sup>13</sup>

### (l) Attributed to

CP is a descriptive diagnosis made on a clinical base by integrating clinical history and observation. The clinical work-up mandates the need for an aetiological diagnosis that tentatively identifies the causal pathway on the basis of history, clinical examination, and wherever possible additional investigations. Use of the term 'attributed to' acknowledges that a full understanding of causal pathways and mechanisms leading to CP currently remains elusive.

### (m) Dysplasia of or injury to

Dysplasia relates to abnormal structural maturation (e.g. cerebral malformation due to genetic causes, toxic agents, or dietary deficiency); injury to any acquired process (e.g. periventricular white matter injury following chorioamnionitis, kernicterus). Dysplasia and injury are not mutually exclusive, as early injury typically alters maturational trajectory.<sup>33</sup> Some brain dysplasias or injuries may not be visible with current technology.<sup>34,35</sup>

### (n) Fetal or infant

The disruption of brain maturation of motor pathways occurs very early pre-, peri-, or postnatally. No explicit upper age limit is defined, as this would have to be arbitrary on the basis of current knowledge, but it is acknowledged that the first 2 to 3 years of life, particularly before affected functions such as walking or manipulation have fully developed, are critically sensitive to the impact on development of impairments leading to CP. This highlights the notion that disruptions occurring very early in human biological development have distinct effects on the development of motor function compared with those occurring later, even in childhood. It is also compatible with requirements to consider a set age limit for specific purposes.

### (o) Brain

The brain refers to the supraspinal part of the central nervous system, which includes the cerebrum, the cerebellum, and the brainstem. This excludes motor disorders of spinal, peripheral nerve, muscular, or mechanical origin without prominent involvement of the brain.

### (p) Not degenerative

This relates to pathophysiology of the brain insult that is static on the basis of current knowledge. It therefore excludes

degenerative diseases, which are characterized by evolution of the pathological processes leading to continuing and worsening of the underlying brain damage over time, for example neurometabolic diseases or brain tumours.

### (q) Manifestations may change with age

The non-degenerative pathophysiology does not rule out that the functional outcomes may change over time, for example because of growth, development, environmental factors including increased physical demands, or secondary changes, for example in the musculoskeletal system. This is a reminder of the notion that CP is 'not unchanging'.<sup>36,37</sup>

### (r) Phenotype

This refers to the characterization of observable features that can relate to clinical knowledge and serve its methodology. Careful phenomenological observation of the phenotype is the only way to make a clinical diagnosis of CP (there are no pathognomonic features), and it provides a base for pathophysiological reasoning to tentatively explain observed features by known physiology and, where applicable, gene function.<sup>38</sup>

### (s) Complex

CP is characterized by clinical complexity that can result in difficulties in recognizing and interpreting clinical signs,<sup>39</sup> symptoms such as pain or psychological manifestations, as well as impacts on development. Many individuals with CP present with medical frailty and challenging care needs due to the neurological disorder, complications such as respiratory, skeletal, and gastrointestinal problems, separate clinical conditions, or dependence on technological support. Additional factors contribute to the complexity, including developmental, psychological, cultural, and social determinants, as well as some relating to caregivers and societal dynamics.<sup>40</sup>

### (t) Heterogeneous

Heterogeneity and variability concern manifestations and functioning as well as their interaction with environmental factors, including marked differences between high- and low-income countries, where the vast majority of people with CP live.<sup>41</sup>

### (u) Each person experiencing a unique presentation

This emphasizes that CP manifests differently in every individual, shaping their distinct way of living and being, and ultimately corresponds to irreducible individual experiences.

### (v) Primary

Non-motor primary impairments are thought to result directly from the same aetiology as the one causing the motor manifestations. For example, epilepsy can be seen as a manifestation of cortical dysplasia or injury. Another example is visual impairment, which can be attributed to white matter injury along the thalamo-occipital radiations while concomitant motor manifestations are associated with white matter injury along motor pathways, both attributed to inflammation. Some primary impairments can originate in dysplasia or injury outside the brain, for example visual impairment due to retinopathy of prematurity.<sup>42</sup>

### (w) Secondary impairments

Secondary impairments are considered consequences of motor impairment or activity limitations that restrict learning and perceptual developmental experiences, for example visual impairment due to deficit in early head control, limited mobility, or interaction with the environment. The coexistence of primary and secondary processes contributes to the complexity of CP. Another example is cognitive impairment, which can limit exploration and motor activity, which can in turn constrain further development of cognitive function. Disuse of the sensorimotor system during development can also enhance motor impairment in CP.

### (x) Across various areas of development and functioning

The impairments can, for example, involve the musculoskeletal system, sensation, feeding, communication, cognition, mental health, sleep, as well as pain and epilepsy. These impairments are considered to be part of the clinical picture of CP rather than comorbidity. In addition, there may be complications, such as respiratory infections, impaired lung function secondary to aspiration associated with impaired feeding (eating and drinking) capacity or acquired scoliosis, or disorders such as cardiovascular disease or type 2 diabetes that are associated with the increased risk of metabolic syndrome associated with sedentary lifestyle (i.e. acquired underlying metabolic dysfunction including elevated serum triglyceride levels, reduced high-density lipoprotein cholesterol, and elevated fasting blood glucose).

### (y) Participation in daily life

Activity limitations can result in restricted participation, as described in the ICF framework.

## PLAIN-LANGUAGE VERSION

To enhance accessibility and understanding, we propose a plain-language version of the CP description. This simplified description aims to make the concept more approachable for a broader audience, particularly those without technical expertise, while retaining the essence of the original definition. However, we recognize the need to mitigate potential risks associated with such a version. One concern is the possibility of the plain-language description being mistakenly used as a substitute for the clinical description, which could lead to misinterpretation or misuse. Another challenge is the risk that readers incorporate elements not present in the original definition, thereby diluting its precision and intent. To address these issues, we emphasize the intended purpose of the plain-language description: (1) it is intended to clarify the definition for those unfamiliar with technical terminology; (2) it is designed as an educational tool to help non-specialists understand the core concepts of the CP description without requiring technical expertise; (3) it aims to raise awareness and facilitate engagement among broader audiences, including policymakers, community stakeholders, and the general public; (4) it can serve as a complementary reference to the clinical description, providing a foundation for discussion and promoting shared understanding among diverse groups. Hopefully, this version therefore has the potential to enhance communication and dialogue around the CP description without altering its meaning or scope, bearing in mind that it is not a substitute for the clinical description and should not be used in contexts requiring technical precision or as a basis for decision-making. We hope that these elements can effectively serve the purpose of balancing clarity with fidelity to the update of the concept.

## PROPOSED PLAIN-LANGUAGE DESCRIPTION

People living with cerebral palsy have a complex physical disability that makes their muscles unusually stiff and affects their movements. Cerebral palsy is caused by early damage to a part of the brain, which does not get worse in itself but whose consequences become more severe over time. Each person with cerebral palsy is unique and, while all have some degree of physical disability, many face additional learning, communication, visual, or other challenges. With the right resources, therapies, and support from family, people with cerebral palsy can thrive and live fulfilling lives.

We are aware that some of the choices that were made decrease the accuracy that can be found in the more

comprehensive clinical description, but we trust that the simple language will make the clinical concept more accessible, in particular to people with CP, their families, and people around them. For example, the term 'stiff' was chosen to reflect increased muscle tone (spasticity or dystonia), which epidemiological studies suggest it is present in well over 90%, but not 100%, of people with CP. Similarly, we emphasize that only part of the brain is directly affected to imply that many parts of the brain are not, which is important information for non-specialists, although this overlooks very rare instances of extreme brain anomaly (e.g. hydranencephaly). Another example is our choice of the phrase 'early damage', which is meant to capture ante-, peri-, and postnatal causes ('early' refers to early in life, early in development).

For the specific purpose of the plain-language description, we have opted not to use the 'CP' acronym because it is currently recognized by search engines, spam filters, and other automated systems as an acronym not only for 'cerebral palsy' but also for 'child pornography'. This coincidence leads to searches for 'CP' on websites, social media pages, and the internet being downgraded and more difficult to find, which is a real obstacle for people with an interest in CP to access information. For this reason, we do not propose to actually replace the term 'cerebral palsy' by 'CP' but to use the terms interchangeably.

When considering adaptation of the concept in non-English-speaking contexts, we must also be particularly mindful about the translation of the term 'palsy'. Some languages commonly use the equivalent of the current medical term 'paralysis'. People living with CP, their families, and other non-professionals may therefore interpret these terms as suggesting actual paralysis, which can be misleading and arguably even more prone to reinforcing stereotypes and stigma, whereas the fact that the original meaning of 'palsy' has been lost in lay language might make it more socially acceptable, as it has no meaning beyond the name of the condition itself.

## FURTHER REFINEMENTS OF THE PROPOSED DESCRIPTION: INVITATION TO COMMENT

We are not presenting this description and commentary as completed work, but rather a process in evolution. At this stage, we warmly invite readers to provide their feedback on the proposed updates to the CP description, including the annotation of key terms and accompanying plain-language description. Your comments, whether focused on the clarity, scope, utility, or any other aspect, are invaluable in ensuring that the description evolves to reflect diverse perspectives and address any potential ambiguities or areas for improvement. We think that it is particularly relevant to address the conceptual clarity and coherence of the proposed updated description, as well as its alignment with current evidence and theoretical frameworks. It is also important to consider its practical applicability in research, clinical, or educational settings, and broader implications for policy, ethics, or

interdisciplinary collaboration. By compiling and analysing your contributions, we aim to refine and enhance the description to better serve its purpose while addressing any concerns raised. By engaging with readers' insights through this iterative approach, we aim to ensure that the updated CP description serves as a robust and shared foundation for understanding and action in the coming years. We hope the improved description will provide a useful framework for applications in clinical practice and future research across diverse contexts. We look forward to your contributions and thank you for being part of this continuing process.\*

## DATA AVAILABILITY STATEMENT

Not required.

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## CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

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## REFERENCES

- Rosenbaum PL, Dan B. The continuing evolution of "Cerebral Palsy". *Ann Phys Rehabil Med*. 2020; 63: 387–8.
- Rosenbaum P, Paneth N, Leviton A, Goldstein M et al. A report: the definition and classification of cerebral palsy April 2006. *Dev Med Child Neurol Suppl*. 2007; 109: 8–14.
- Werkhoven S, Anderson JH, Robeyns IAM. Who benefits from diagnostic labels for developmental disorders? *Dev Med Child Neurol*. 2022; 64(8): 944–9. <https://doi.org/10.1111/dmcn.15177>.
- Derrida J. Violence et métaphysique: Essai sur la pensée d'Emmanuel Levinas. *Rev Metaphys Morale*. 1964; 69(4): 425–73
- Foucault M. *L'ordre du discours*. Paris: Gallimard, 1971
- Schiller C, Winters M, Hanson HM, Ashe MC. A framework for stakeholder identification in concept mapping and health research: a novel process and its application to older adult mobility and the built environment. *BMC Public Health*. 2013; 13: 428. <https://doi.org/10.1186/1471-2458-13-428>.
- Concannon TW, Grant S, Welch V, Petkovic J et al. Practical guidance for involving stakeholders in health research. *J Gen Intern Med*. 2019; 34(3): 458–63. <https://doi.org/10.1007/s11606-018-4738-6>.
- Dan B. A new description of cerebral palsy: Framing, wording, and perspective. *Dev Med Child Neurol*. 2024; 66(7): 822–3. <https://doi.org/10.1111/dmcn.15922>.

\*To contribute, please submit any short comments by using this form on the Mac Keith Press website: <https://www.macketh.co.uk/proposed-update-description-of-cerebral-palsy/> If you would like to submit a longer commentary, please do so through our online submission portal <https://mc.manuscriptcentral.com/dmcn> by 16th June 2025. These longer commentaries should have a specific title, a word count between 350 and 600, and strictly up to five references (including a reference to this paper). Selected commentaries will be published in a subsequent issue of *Developmental Medicine and Child Neurology* and will contribute to a continuing discourse within the academic community. We look forward to your perspectives on this critical topic.

9. Shevell M. Cerebral palsy to cerebral palsy spectrum disorder: Time for a name change? *Neurology*. 2019; 92(5): 233–5. <https://doi.org/10.1212/WNL.0000000000006747>.
10. Aravamuthan BR, Fehlings DL, Novak I, Gross P et al. Uncertainties regarding cerebral palsy diagnosis: Opportunities to clarify the consensus definition. *Neurol Clin Pract*. 2024; 14(2): e200353. <https://doi.org/10.1212/CPJ.0000000000200353>.
11. Leviton A. Identifying cerebral palsy phenotypes objectively. *Dev Med Child Neurol*. 2020; 62(9): 1006. <https://doi.org/10.1111/dmcn.14604>.
12. Chabrier S, Pouyfaucou M, Chatelin A, Bleyenheuft Y et al. From congenial paralysis to post-early brain injury developmental condition: Where does cerebral palsy actually stand? *Ann Phys Rehabil Med*. 2020; 63(5): 431–8. <https://doi.org/10.1016/j.rehab.2019.07.003>.
13. Pham R, Mol BW, Gecz J, MacLennan AH et al. Definition and diagnosis of cerebral palsy in genetic studies: a systematic review. *Dev Med Child Neurol*. 2020; 62(9): 1024–30. <https://doi.org/10.1111/dmcn.14585>.
14. Peterson MD. Reframing Cerebral palsy as a lifelong physical disability. *N Engl J Med*. 2024; 391(18): 1668–70. <https://doi.org/10.1056/NEJMp2403366>.
15. Nelson KB, Ellenberg JH. Children who 'outgrew' cerebral palsy. *Pediatrics* 1982; 69: 529–36.
16. Chen A, Dyck Holzinger S, Oskoui M, Shevell M, Canadian cerebral palsy registry. Losing a diagnosis of cerebral palsy: a comparison of variables at 2 and 5 years. *Dev Med Child Neurol* 2020; 62: 83–8.
17. Nelson KB. 'Outgrowing' a cerebral palsy diagnosis. *Dev Med Child Neurol*. 2020; 62: 12.
18. Grandits J, Davis A, Rikard B, Vatrano A, Martin H, Taylor MA. Disability terminology: the use of "disability", "disorder", and "illness" in academic writing. *Disabil Rehabil*. 2024; 46: 4664–74.
19. Coughlan J, Chatelin M, Kojc A. A manifesto for cerebral palsy. *Dev Med Child Neurol*. 2024; 66: 1400.
20. Maitre NL, Byrne R, Duncan A, Dusing S et al. "High-risk for cerebral palsy" designation: A clinical consensus statement. *J Pediatr Rehabil Med*. 2022; 15: 165–74.
21. Goldsmith S, Smithers-Sheedy H, Almasri N, Andersen GL et al. Cerebral palsy registers around the world: A survey. *Dev Med Child Neurol*. 2024; 66: 765–77.
22. Dar H, Stewart K, McIntyre S, Paget S. Multiple motor disorders in cerebral palsy. *Dev Med Child Neurol*. 2024; 66: 317–25.
23. Lance JW. The control of muscle tone, reflexes, and movement: Robert Wartenberg Lecture. *Neurology*. 1980; 30: 1303–13.
24. van den Noort JC, Bar-On L, Aertbeliën E, Bonikowski M et al. European consensus on the concepts and measurement of the pathophysiological neuromuscular responses to passive muscle stretch. *Eur J Neurol*. 2017;24(7):981–e38.
25. Cenci MA, Riggare S, Pahwa R, Eidelberg D, Hauser RA. Dyskinesia matters. *Mov Disord*. 2020; 35: 392–6.
26. Monbaliu E, Himmelmann K, Lin JP, Ortibus E, Bonouvrié L et al. Clinical presentation and management of dyskinetic cerebral palsy. *Lancet Neurol*. 2017; 16: 741–9.
27. Sanger TD, Delgado MR, Gaebler-Spira D, Hallett M, Mink JW; Task Force on Childhood Motor Disorders. Classification and definition of disorders causing hypertonia in childhood. *Pediatrics*. 2003; 111: e89–97.
28. Lumsden DE. Spastic dystonia: Still a valid term. *Dev Med Child Neurol*. 2023; 65:1308–15.
29. Horber V, Andersen GL, Arnaud C, De La Cruz J et al. Prevalence, clinical features, neuroimaging, and genetic findings in children with ataxic cerebral palsy in Europe. *Neurology*. 2023; 101: e2509–e2521.
30. Dan B. How useful is the diagnosis of ataxic cerebral palsy? *Dev Med Child Neurol*. 2020; 62: 264.
31. Bekteshi S, Monbaliu E, McIntyre S, Saloojee G et al. Towards functional improvement of motor disorders associated with cerebral palsy. *Lancet Neurol*. 2023; 22: 229–43.
32. Dan B. Developmental central hypotonia: implications for counseling, prognosis, and management. *Dev Med Child Neurol*. 2022; 64: 4.
33. Sarnat HB. (2023). *Neuropathology of cerebral palsy*. In: Eisenstat, D.D., Goldowitz, D., Oberlander, T.F., Yager, J.Y. (eds) *Neurodevelopmental Pediatrics*. Springer, Cham.
34. Reid SM, Dagia CD, Ditchfield MR, Carlin JB, Reddihough DS. Population-based studies of brain imaging patterns in cerebral palsy. *Dev Med Child Neurol*. 2014; 56: 222–32.
35. Reid SM, Hinwood GL, Guzys AT, Hunt RW, Reddihough DS. Neonatal well-being and timing of brain injury in persons with cerebral palsy born at term or late preterm. *Dev Med Child Neurol*. 2024; 66: 892–901.
36. Mutch L, Alberman E, Hagberg B, Kodama K, Perat MV. Cerebral palsy epidemiology: where are we now and where are we going? *Dev Med Child Neurol*. 1992; 34: 547–51.
37. Rosenbaum P. Is cerebral palsy progressive? Why do we ask? *Dev Med Child Neurol*. 2022; 64: 672.
38. Dan B, Pelc K, de Meirleir L, Cheron G. Phenotypic plasticity and the perception-action-cognition-environment paradigm in neurodevelopmental genetic disorders. *Dev Med Child Neurol*. 2015; Suppl 2: 52–4.
39. Eggink H, Kremer D, Brouwer OF, Contarino MF et al. Spasticity, dyskinesia and ataxia in cerebral palsy: Are we sure we can differentiate them? *Eur J Paediatr Neurol*. 2017; 21: 703–6.
40. Dan B. Complex developmental disability: a case of 'simplexity'? *Dev Med Child Neurol*. 2021; 63: 1240.
41. Jahan I, Muhit M, Hardianto D, Laryea F et al. Epidemiology of cerebral palsy in low- and middle-income countries: preliminary findings from an international multi-centre cerebral palsy register. *Dev Med Child Neurol*. 2021; 63: 1327–36.
42. Dammann O, Hartnett ME, Stahl A. Retinopathy of prematurity. *Dev Med Child Neurol*. 2023; 65: 625–31.

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