

The Global Voice for People with Cerebral Palsy

Written Submission for the Day of General Discussion on Article 29 of the Convention on the Rights of Persons with Disabilities (20 March 2025)

Executive Summary	2
Who is ICPS?	2
What is cerebral palsy?	2
Article 29 CRPD - Participation in political and public life	3
Legal capacity	3
Accessibility	3
Awareness	4
Representation	5
Support	5
Credits	5

Executive Summary

Cerebral palsy (CP) is the most common form of lifelong physical disability, often combined with cognitive, communicational, visual or other challenges. Persons living with CP often experience intersectional discrimination on the grounds of the combined characteristics of their condition.

Across the world, from low to high-income countries, persons with cerebral palsy are prevented from exercising their right to participation in political and public life by restrictions due to legal capacity, multiple barriers to accessibility, a lack of awareness of their rights enshrined in the Convention, insufficient visibility for the potential role of persons with disability in the conduct of public affairs, and a failure to provide appropriate support to persons with disability seeking public office.

Examples of good practice and solutions to overcome these obstacles exist and should be promoted actively around the world.

Who is ICPS?

The International Cerebral Palsy Society (ICPS) brings together organisations of persons with cerebral palsy, caregivers and frontline professionals in over 60 countries on every continent. ICPS was established in 1969 and is registered as a charity in the United Kingdom.

ICPS provides a network for CP organisations to connect, learn from one another and cooperate in joint projects, and represents the voice for people with CP in dialogue with policymakers and the scientific community at global level.

ICPS is an active member of the World Health Organization Civil Society Commission and strives to raise the visibility and understanding of cerebral palsy as a complex disability in all relevant fora on the international scene.

What is cerebral palsy?

Cerebral palsy is the most common form of lifelong, childhood-onset physical disability. It is estimated that up to 50 million people live with CP around the world¹. Both the prevalence and the severity of cerebral palsy are significantly greater in low-income than in high-income countries², due to factors including poor newborn and maternal healthcare, malnutrition, as well as lack of access to (re)habilitation and assistive technology.

CP is a lifelong condition and there is no known cure. It is caused by an early brain injury that affects movement, but most people with CP reach adult life and even old age. While the original injury does not change, musculoskeletal complications become more painful and difficult to manage as the individual ages. In addition to the physical aspects of their disability, people with CP have to cope with its psychological impact.

¹ Cieza A, Causey K, Kamenov K, Hanson SW, Chatterji S, Vos T. Global estimates of the need for rehabilitation based on the Global Burden of Disease study 2019: a systematic analysis for the Global Burden of Disease Study 2019. Lancet. 2021 Dec 19;396(10267):2006-2017. doi: 10.1016/S0140-6736(20)32340-0. Epub 2020 Dec 1.

² McIntyre S, Goldsmith S, Webb A, Ehlinger V, Hollung SJ, McConnell K, Arnaud C, Smithers-Sheedy H, Oskoui M, Khandaker G, Himmelmann K; Global CP Prevalence Group*. Global prevalence of cerebral palsy: A systematic analysis. Dev Med Child Neurol. 2022 Dec;64(12):1494-1506. doi: 10.1111/dmcn.15346. Epub 2022 Aug 11. PMID: 35952356; PMCID: PMC9804547.

CP is complex: one in four persons with CP cannot walk; one in four cannot talk; one in two have an intellectual disability. People with CP often have secondary challenges such as epilepsy or difficulties of cognition, communication, feeding, vision or hearing.

No two persons with CP are the same. Their condition can range from a weakness in one hand to an almost complete lack of voluntary movement. Solutions to ensure mobility, care, social inclusion, participation and employment, especially of those more severely affected, can be expensive and labour-intensive. Social stigma around disability makes the challenge even greater.

Article 29 CRPD - Participation in political and public life

Persons with cerebral palsy and complex disabilities, who may have a combination of motor, cognitive, visual or other impairments, face multiple barriers to participation in political and public life. These include restrictions on voting rights for persons under legal guardianship, the inaccessibility of polling stations or the voting process itself, or obstacles to participation in political campaigns and public office. These barriers exist in low-, middle- and high-income settings.

Legal capacity

Persons with more severe cerebral palsy may require the assistance of another person to perform daily tasks such as bathing, eating, and getting dressed. In certain cases, it may also be in their interest to have another person support them in their decision-making in order to avoid abuse. In many countries, however, the status of legal guardianship limits the rights of persons with disabilities rather than protecting them³. Taking Europe as an example, 400,000 EU citizens were disenfranchised at the European Parliament elections in 2019 on the grounds of lack of legal capacity due to their disability⁴. Simply having a disability should not restrict individuals' ability to exercise their right to public participation.

Persons with disabilities and their advocates have campaigned to address this situation. A recent successful example led by the Slovenian Cerebral Palsy Association resulted in changing the law to ensure that all adults can exercise their right to vote in line with Article 29⁵.

In many countries, however, such restrictions on the right of persons with disabilities to vote remain in place. Civil society-led campaigns have made progress, but it is ultimately the responsibility of the State signatory to the Convention to ensure that this right is upheld without exception.

Accessibility

Inaccessible voting facilities

Even when the right of persons with disabilities to vote is legally protected, the most blatant obstacle to implementation of that right is the lack of accessibility to voting facilities, including:

³ EDF Human Rights Report 2024 - Legal capacity: Personal choice and control (https://www.edf-feph.org/publications/human-rights-report-2024-legal-capacity/)

⁴ EDF Human Rights Report 2022: political participation of persons with disabilities (https://www.edf-feph.org/publications/human-rights-report-2022-political-participation-of-persons-with-disabilities/)

⁵ https://eeagrants.org/archive/2014-2021/projects/SI-ACTIVECITIZENS-0072

- Polling stations that are inaccessible to persons with reduced mobility or other impairments;
- Manual voting procedures that are not accessible to all;
- · Automated voting machines that are not accessible to all;
- Restrictions on alternative voting methods such as postal voting;
- Lack of accessible transportation to polling stations.

Inaccessible election materials

Participation in political and public life is not only a question of exercising the right to vote but also of access to full information about the candidates, campaigns and manifestos proposed. Even in countries with the highest standards of accessibility for persons with disabilities, information and materials from political parties regularly fail to meet basic standards of accessibility, whether it be website design, plain language or another aspect. This also extends to ballots, which can be complex. Ballots should be accessible to individuals who may have a cognitive disability; they should not be so complex that they cannot be understood.

Inaccessible political events

Participation in political and public life includes the possibility that persons with a disability may wish to engage actively in electoral politics. Campaign events, meetings of political parties and other opportunities to engage in political life are often not accessible, however. If they were organised by public authorities, they would be required to meet certain standards of accessibility in many countries. Yet they are also the key for persons with a disability to become part of the political process that lead and shape public authorities. For this reason, it makes sense for them to be held to the same standard as if they were organised by those public authorities.

Proxy and accompanied voting

One of the solutions proposed to overcome the systematic inaccessibility of the voting process is to allow for persons with a disability to vote by proxy or to be accompanied by another person in the polling station. Neither of these solutions fulfils the requirements of Article 29 that the right to vote be exercised by secret ballot and free from intimidation (unless, in the case of accompanied voting, the accompanying person is chosen by the person with disability).

Solutions

Accessible solutions exist that take account of concerns surrounding the independence and secrecy of the electoral process. A standout example is the AccessibleVote projected developed by the Portuguese Cerebral Palsy Federation, which was awarded a ZeroProject prize in 2023⁶. Legislators and electoral authorities have proven reluctant to implement such solutions, however. A concerted effort based on international cooperation is needed to demonstrate that they are an effective and resilient solution to the disenfranchisement of a significant portion of the population.

Awareness

Even when solutions do exist, awareness of them often remains low. Public information campaigns are needed to educate persons with disabilities on their rights and how to claim them. During the recent general election in Ireland, the Electoral Commission produced a TV advert showing a person with Down Syndrome going out to vote⁷, and its website presents detailed information on how to make voting more accessible featuring an image of a person who appears to have severe cerebral palsy⁸. Such initiatives are rare and should be encouraged more widely.

⁶ https://zeroproject.org/view/project/d750a7f3-22ac-4444-ad1b-95b6d1c40f37

⁷ https://www.facebook.com/watch/?v=2019919465104059

⁸ https://www.electoralcommission.ie/accessible-voting/

Representation

Article 29 safeguards not only the right to vote but also the right to participate in the conduct of public affairs. For persons with a disability, it may not be obvious how they can play a role in public affairs. Canada openly encourages persons with lived experience of disability to put themselves forward as members of technical committees on issues such as accessibility⁹. This example of ensuring that the right not only exists on paper but is exercised in real life should be recommended as best practice.

Support

Article 29 also safeguards the right "to stand for elections, to effectively hold office and perform all public functions at all levels of government, facilitating the use of assistive and new technologies where appropriate". In reality, multiple barriers stand in the way of persons with a disability - especially of a more complex one such as cerebral palsy - becoming electoral candidates and then exercising public office. These mirror many of the barriers to political participation in the first place, including legal restrictions, accessibility and awareness. Such formal barriers must of course be removed, but States parties must also recognise that Article 29 also requires them to support actively persons with disabilities seeking political office. New Zealand has a dedicated fund to support candidates with a disability to run for office at both local and national levels¹⁰. Sadly, this is the exception that proves the rule, which is that in most States parties, no such support exists.

Credits

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⁹ https://accessible.canada.ca/creating-accessibility-standards/technical-committee-application

¹⁰ https://elections.nz/getting-involved/election-access-fund/