



Cerebral
Palsy
Europe

**Alternative Report for the Review of the
Implementation by the European Union of
the United Nations Convention on the
Rights of Persons with Disabilities**

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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.

Implementation of the UNCRPD in the European Union is characterised by many principles being protected on paper but many barriers and failures in practice. For almost all of the rights enshrined in the Convention, we describe how the right is respected or not, and what tools the EU has to improve this. Despite not having direct competence for many policy areas, the EU has the capacity to influence the respect of all rights enshrined in the Convention, whether it be through legislation, coordination, dissemination of best practice or funding.

This report by Cerebral Palsy Europe focuses on the lived experience of persons with cerebral palsy and similarly complex childhood-onset disabilities. It aims to complement the report presented by the European Disability Forum, to which Cerebral Palsy Europe has actively contributed and which it fully supports.

Cerebral Palsy Europe

The Cerebral Palsy European Union Association vzw (Cerebral Palsy Europe or CP-ECA) brings together associations of persons with CP, their caregivers and the frontline professionals who work with them in 20 EU Member States, as well as observer members in a further seven European countries. It aims to be the voice for persons with CP in the EU.

Cerebral Palsy Europe is established as a non-profit association with its seat in Belgium. It is a member of the European Disability Forum (EDF) and a framework partner of the European Commission under the EU4Health programme. Its members are simultaneously members of the International Cerebral Palsy Society.

What is cerebral palsy?

Cerebral palsy (CP) is the most common form of lifelong, childhood-onset physical disability. More than 800,000 citizens of the European Union live with CP and another 16 million EU citizens are closely connected to a child or adult with CP.

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. In addition to the physical aspects of their disability, people with CP have to cope with its cognitive and emotional impact.

CP is complex: one in four persons with CP cannot talk; one in four cannot walk; 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.

European Disability Forum alternative report

As a member of EDF, Cerebral Palsy Europe contributed to the drafting of the alternative report submitted by EDF for the review of EU implementation of the UNCRPD. We fully endorse the EDF alternative report.

Our aim in submitting an additional alternative report is to complement and reinforce the EDF alternative report on specific issues, drawing attention to their impact on persons with CP. This may be due to the complex nature of the disability, meaning that people with CP often face multiple barriers to the enjoyment of their rights, or the childhood-onset nature of the condition, which has implications for both children and adults with CP.

For this reason, we do not comment on the implementation by the EU of each individual right enshrined in the Convention. In all cases, it can be assumed that we subscribe to the comments on all rights contained in the EDF alternative report.

Review of implementation of the UNCRPD by the EU

Article 5 - Equality and non-discrimination

EU citizens living with CP enjoy the right to equality and non-discrimination on paper, but they face multiple barriers to its implementation in real life. These begin with the lack of truly inclusive schooling in many Member States (see Article 24 below), continue through obstacles to the physical and digital accessibility of public institutions (see Article 9 below) and lead to long-term exclusion from employment (see Article 27 below) and community life (see Articles 29 and 30 below).

Such barriers exist in even the most economically developed regions of the EU, but they are especially stark in peripheral and economically underdeveloped regions such as the Azores islands (Portugal) or southern Italy¹. Persons with CP in these regions often have to travel long distances to better-resourced regions or even to other countries to access the services and support they need, which adds to their out-of-pocket expenditure and makes their cost-of-living unaffordable. Through its Cohesion, Regional Development and Social Funds, the EU has the tools to reduce these disparities and could do more to address the needs of especially vulnerable groups such as persons with CP and other complex disabilities.

Recognition of the legal principle of equality and non-discrimination must be counter-balanced against the real-life experience of persons with CP who face prejudice and ableism on a daily basis. Failure to implement many of the rights enshrined in the Convention is often due not to a lack of legal provisions, but rather to misconceptions about persons with CP and their abilities. In particular through its funding programmes in diverse areas of economic and social life, the EU can support training and improve public understanding of complex disabilities across all regions. Mainstreaming awareness of disability, including CP and similar conditions, in such funding programmes - in the same way as gender mainstreaming is currently prioritised - would be a significant step towards true implementation of the right to equality and non-discrimination.

¹ <https://www.istat.it/it/files/2023/11/Report-presidi-assistenziali-Anno-2021.pdf>

Article 6 - Women with disabilities

Statistics show that more men than women have cerebral palsy but, at a ratio of approximately 4:3, women make up a significant proportion of the CP population². With approximately 25% being non-ambulant and many more living with other mobility limitations, they are especially vulnerable to physical violence. They face added discrimination in employment, as well as denial of access to adequate healthcare services, especially for sexual and reproductive health, due to ignorance, lack of training or unadapted medical equipment.

By recognising the intersectionality of discrimination against women with CP and similar conditions, the EU could strengthen its current emphasis on gender mainstreaming to address the situation of those in greatest need of additional support.

Article 7 - Children with disabilities

Children with CP face obstacles to inclusion in school, sports, recreational activities and other opportunities to participate in life. With the exception of a small number of highly motivated individuals, adults responsible for activities involving children often lack the knowledge, training and methodology to include children with complex disabilities effectively. It is therefore essential for the EU, in its actions to support education, sports and culture and to promote the rights of children, to be sensitive to the complexity of CP and similar conditions and to see the benefits in activities that address the specific needs of this neglected group.

Observations that apply to all persons with disability often apply even more strongly to children with disability. For example, while organisations for persons with disabilities already find it difficult to make their voice heard, “children with disabilities ... remain almost completely left out”.³ The EU Children’s Participation Platform⁴ is a significant effort to encourage the participation of children in the political process. The EU could do more to ensure that the voices of children with disabilities, who may need additional support, especially those requiring alternative communication methods, are heard in this context.

Children with CP and other complex disabilities often require the assistance of an adult in school, healthcare and other settings. The Committee on the Rights of Persons with Disabilities has already recommended that States parties in the European Union “cover the disability-related costs of assistance services or inpatient treatment of children with disabilities”⁵. The EU, which has responsibility for social security coordination and for ensuring free movement of persons, should ensure that this principle is applied equally across Member States and that children with disabilities continue to enjoy such entitlements when they cross borders.

Article 8 - Awareness-raising

Much remains to be done in the EU to combat prejudice, misconceptions and stereotypes regarding persons with CP and other disabilities. The EU has an important role to play in supporting public education programmes, especially in regions where cultural stigma around disability remains strong. In so doing, it is important to reflect the diversity of different conditions

² Romeo, D. M., Venezia, I., Pede, E., & Brogna, C. (2023). Cerebral palsy and sex differences in children: A narrative review of the literature. *Journal of Neuroscience Research*, 101, 783–795. <https://doi.org/10.1002/jnr.25020>

³ German Institute for Human Rights. (2023). Parallel Report to the UN Committee on the Rights of Persons with Disabilities for Germany’s 2nd/3rd State Party review procedure.

⁴ <https://eu-for-children.europa.eu/>

⁵ Committee on the Rights of Persons with Disabilities. (2023) Concluding observations on the combined second and third periodic reports of Germany. Adopted by the Committee at its twenty-ninth session (14 August-8 September 2023)

to avoid the risk of greater awareness of one form of disability compounding the neglect and lack of awareness of others.

By including awareness-raising of disability or a requirement to consult persons with disability as a condition for access to funds, programmes etc., the EU can also address the current lack of engagement by some national and local governments with persons with disability.

People with disabilities also need to be made aware of their rights and how to enforce them, including the grounds and methods to report discrimination. Proactive engagement by the EU through its funding programmes and public information campaigns can help to equip this target group with the knowledge they need.

Article 9 - Accessibility

The European Accessibility Act, the Web Accessibility Directive, the Air Travel Regulation for Disabled Persons and other EU legislative and regulatory measures have created a comprehensive - if not complete - legal framework to make the physical and digital environment accessible to persons with disabilities. In reality, however, many barriers continue to exist. When, in one of the EU's most economically developed Member States, 20% of train stations have still not been rendered physically accessible and none of the audited public websites were fully accessible⁶, the scale of the task cannot be underestimated.

When these barriers to accessibility are the result of failure to transpose or implement legislation, the European Commission should not hesitate to make use of its power to bring infringement proceedings to oblige Member States to comply. In many cases, however, they are the result of ignorance on the part of architects, planners, web designers, public officials and others responsible for turning the rules into reality. The problem is particularly acute given the number of older and historical buildings, which may require creativity in order to be rendered accessible. European legislation will only be effective if it is accompanied by large-scale and regular training programmes to ensure that it is implemented in practice. Engagement with the private sector is critical in this respect.

The President of the European Commission, Ursula von der Leyen, has made addressing the housing crisis in many EU Member States a priority of the Commission in its forthcoming mandate⁷. This presents an opportunity for the Commission to ensure that new housing projects across the EU are accessible as well as affordable, and supportive of independent living for persons living with disability.

Article 10 - Right to life

Research consistently shows that persons with CP in Europe die earlier than the general population⁸ ⁹. Health conditions aggravated by their disability as well as by inequitable access to healthcare are the main causes (see Article 25 below). Lack of independent mobility, which may also be combined with intellectual disability, makes many persons with CP especially vulnerable in life-and-death emergency situations (see Article 11 below) as well as to violent abuse (see Articles

⁶ Alliance of German Non-Governmental Organisations on the CRPD. (2023). Human Rights Now! Joint Civil Society Report on the 2nd and 3rd States Report of the German Federal Government on the Implementation of the United Nations Convention on the Rights of Persons with Disabilities by Germany.

⁷ Europe's Choice: Political Guidelines for the Next European Commission 2024–2029, Strasbourg, 18 July 2024

⁸ Himmelmann K, Sundh V. Survival with cerebral palsy over five decades in western Sweden. *Dev Med Child Neurol*. 2015 Aug;57(8):762-7. doi: 10.1111/dmcn.12718. Epub 2015 Feb 19. PMID: 25694102.

⁹ A. Duruflé-Tapin, A. Colin, B. Nicolas, C. Lebreton, F. Dauvergne, P. Gallien, Analysis of the medical causes of death in cerebral palsy, *Annals of Physical and Rehabilitation Medicine*, Volume 57, Issue 1, 2014, Pages 24-37, ISSN 1877-0657, <https://doi.org/10.1016/j.rehab.2013.11.002>.

15 and 16 below). In its areas of competence, including those shared with Member States, the EU can do more to be vigilant to the increased risk to the right to life of certain groups, such as those with cerebral palsy and other disabilities, compared to the general population.

Article 11 - Situations of risk and humanitarian emergencies

Persons with motor impairment, which include many persons with cerebral palsy, are especially vulnerable in situations of risk and humanitarian emergencies. Yet many of the problems in implementation already described in relation to other rights also apply in such situations. Persons with disability are not systematically involved in emergency planning; emergency plans are not made accessible to persons who need alternative communication methods; and emergency personnel are not adequately trained in dealing with persons with physical or other disabilities. The EU, which often plays a key role in coordinating emergency responses and providing support to Member States in such situations, can also play a role in raising the standard of disaster preparedness for persons with disabilities across all Member States.

Article 12 - Equal recognition before the law

Persons with more severe cerebral palsy require the assistance of another person to perform daily tasks. 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 several EU Member States, however, the status of legal guardianship limits the rights of persons with disability rather than protecting them¹⁰. The EU's efforts to facilitate the cross-border enforcement of decisions regarding the protection of vulnerable adults inadvertently perpetuates these unjust regimes. To mitigate against this, the EU could make compliance with Article 12 a precondition for the cross-border enforcement of protection decisions, in a similar way to how human-rights and rule-of-law considerations are embedded in the European Arrest Warrant.

Article 13 - Access to justice

Barriers to access to justice for persons with CP and complex disabilities in the EU are both physical and attitudinal. Court buildings, especially older ones, are often inaccessible. Information is not communicated in plain language and communication support services are not provided in police stations or courts. Lack of training leads to prejudice and misconceptions. Just as it has devoted significant resources to promoting child-friendly justice¹¹, the EU can raise awareness about and develop strategies that support persons with disability in the justice system, even if primary responsibility lies with the Member States.

Article 14 - Liberty and security of the person

Physical disability renders persons with CP vulnerable to physical attacks on their liberty and security (see Articles 15 and 16 below) but the online environment also presents challenges in the form of online fraud and cyberbullying alongside its many benefits for persons with reduced mobility. In its efforts to promote online safety¹², the EU should pay additional attention to the specific needs of persons with disability.

¹⁰ EDF Human Rights Report 2024 - Legal capacity: Personal choice and control (<https://www.edf-feph.org/publications/human-rights-report-2024-legal-capacity/>)

¹¹ https://commission.europa.eu/strategy-and-policy/policies/justice-and-fundamental-rights/rights-child/child-friendly-justice_en

¹² <https://digital-strategy.ec.europa.eu/en/policies/online-privacy>

Article 15 - Freedom from torture or cruel, inhuman or degrading treatment or punishment & Article 16 - Freedom from exploitation, violence and abuse

Dependency on the physical assistance of another person to perform daily tasks renders persons with cerebral palsy and similar disabilities more vulnerable to abuse and degrading treatment than the rest of the population. This may happen in care settings, educational and medical institutions, or even the family home. Privately-run residential care facilities, for which it is easy to acquire approval without demonstrating the skills necessary for professional care, represent a particular risk. The growing trend to provide state support for personal assistants to enable persons with severe disabilities to lead more independent lives is generally to be welcomed, but safeguards must be in place to ensure that personal assistants are properly trained and do not abuse their position. Formal and informal carers themselves are poorly or not paid, placed in stressful situations and obliged to work long and unsocial hours, which may contribute to the problem. The EU can make use of its competences to promote fair working conditions to ensure that the carer profession is both valued and regulated, ensuring better outcomes for all involved.

Article 18 - Liberty of movement and nationality

The EU guarantees the freedom of movement of persons between the Member States as one of its four “fundamental freedoms”. However, numerous barriers exist to the freedom of movement of persons with cerebral palsy and similar disabilities. For example, it is not guaranteed that a person with CP who relies on a personal assistant in their country of origin will be able to benefit from the same service in another Member State. The EU can influence such situations indirectly, in its role in social security coordination, and directly, in terms of the rules it applies to its Erasmus and Alma exchange programmes for students and young people.

Article 19 - Living independently and being included in the community

There is growing support in the European Union for the principle that persons with disabilities should be enabled to live as independently as possible and to be fully included in community life. The introduction of schemes to provide state funding for personal assistants in several Member States should be encouraged and promoted by the EU in others. Even where such schemes exist, however, there remain significant obstacles to independent living for persons with cerebral palsy and similar disabilities. While the entitlement to personal assistance may exist, lack of financial support and training make it difficult to implement in practice. The lack of accessible and affordable housing makes it difficult to find an appropriate place in which to live independently. In such circumstances, the only practical alternative to parental care remains residential institutions. The EU can support Member States to implement independent living policies by sharing know-how and examples of best practice. It can also make accessibility a priority in its proposed new strategy to develop more affordable housing (see Article 9 above).

Article 20 - Personal mobility

All persons with cerebral palsy have a physical disability and for many it is so severe that they cannot move without assistive technology (AT) in the form of a wheelchair, walking frame or other device. Access to such devices is limited in many EU Member States due to budgetary constraints on the one hand, but also lack of knowledge about and support for innovative AT solutions on the other. Given how transformational AT is for persons with severe disability, the EU should be doing everything in its power to facilitate access to it. This may include promoting innovative solutions to encourage Member States’ social security systems to fund them,

supporting their development through the use of research, cohesion and social funding, and ensuring that the value-added tax (VAT) rate is fixed at 0% across all Member States. Technology requires training, and the EU can support training programmes on AT both for persons with reduced mobility and for specialised professionals to support them.

Despite the best legislative efforts of the EU, the lack of accessible public transport remains a major barrier to persons with CP and other disabilities in most Member States. Beyond establishing the principle, the EU can facilitate change by supporting investment, training and awareness-raising in this field.

Article 21 - Freedom of expression and opinion, and access to information

The inaccessibility of websites, including those of public authorities, means that access to information for persons with cerebral palsy and other motor disabilities (as well as other persons with disabilities) is not guaranteed in many EU Member States¹³. While the EU has legislated to require public websites to be accessible, the scope is limited, and implementation requires awareness-raising, training and enforcement. There is still much to be done in this respect.

In many EU Member States, mainstream information channels (e.g. TV and radio) do not provide information in accessible formats. Through the Audiovisual Media Services Directive, the EU establishes a legal framework for broadcast services across all Member States and can make use of the opportunity to include accessibility requirements when it is next updated.

Article 22 - Respect for privacy

While the growing trend to provide state support for personal assistants to enable persons with severe disabilities to lead more independent lives is generally to be welcomed, the rule in some Member States requiring personal assistants to be with the person with disability at all times, including intimate situations, represents an infringement of the latter's right to privacy.

Article 23 - Respect for home and the family

As a childhood-onset disability, cerebral palsy impacts not only the person with the condition but also their parents and their wider family. Attention to the strain placed on the physical and mental health of caregivers is essential to ensure the well-being of persons with CP and other severe disabilities themselves. EU programmes that address disability rights should also take this dimension into account, as high levels of family breakdown place persons with CP and other disabilities at even greater risk of economic disadvantage and social exclusion.

Persons with CP face discrimination and prejudice when it comes to establishing intimate relationships, getting married and having children - not only from wider society but also from health and social care professionals. The EU must recognise that persons with CP have sexual and reproductive rights and act to protect them alongside those of the general population.

¹³ Alliance of German Non-Governmental Organisations on the CRPD. (2023). Human Rights Now! Joint Civil Society Report on the 2nd and 3rd States Report of the German Federal Government on the Implementation of the United Nations Convention on the Rights of Persons with Disabilities by Germany.

Article 24 - Education

While acceptance of the principle of inclusive education for children with CP and other disabilities has been growing across most EU Member States, it is not or poorly implemented in practice. In some countries, fully segregated school systems are still the norm. Even where schools are declared as inclusive, education is still delivered in segregated classrooms and/or by undertrained teachers who struggle to meet the needs of children, especially those with greater communication challenges. The lack of an alternative to an academic curriculum means that many children - both with and without disabilities - leave school without a qualification, leading to exclusion from the labour market. The failure to implement educational inclusion has a long-term impact not only on the prospects of children with disability but also on other pupils who miss out on the awareness and skills to engage with persons with disability later in life.

The inaccessibility of school and especially university buildings is a further barrier to education for young persons with CP and other physical disabilities. The EU can share and promote best practice in the adaptation of, for example, historic buildings to enable access for all.

While the EU's direct competences in the field of education may be limited, its sponsorship of the European Agency for Special Needs and Inclusive Education under the Erasmus+ programme puts it in a unique position to facilitate and promote progress in this field.

Article 25 - Health

The direct health impact of living with cerebral palsy and other disabilities is compounded by inequitable access to healthcare in the European Union. This may be the result of inaccessible buildings in healthcare facilities, inadequately adapted medical equipment, a lack of training for medical professionals on how to deal with persons with disability, a lack of specialised services (especially for adults with cerebral palsy - see Article 26 below) or simply prejudice. Stereotypes towards persons with CP are particularly evident in the field of sexual and reproductive health, where assumptions about the ability of women with CP to have and care for children makes doing so even more difficult than it should be. The lack of adequate support in public health systems causes additional out-of-pocket expenditure for persons with disability, who must travel further or use private services to obtain appropriate care. The EU can promote health equity for persons with disabilities through projects supported under the EU4Health programme.

Article 26 - Habilitation and rehabilitation

Cerebral palsy is a lifelong condition yet in many EU Member States, it is considered by the healthcare system as a primarily paediatric condition. State support for (re)habilitation ends at the age of 18 and specialised medical care becomes hard to find¹⁴. Through its support for national healthcare systems under the EU4Health programme, the EU can raise awareness that cerebral palsy and similar conditions require lifelong access to (re)habilitation services.

¹⁴ <https://www.stateofmind.it/2019/01/paralisi-cerebrale-adulti/>

Article 27 - Work and employment

The proportion of persons with cerebral palsy in genuine full-time employment compared to the general population is extremely low across all EU Member States^{15 16 17 18 19}. Sheltered workshops, in which persons with disability are paid wages far below the legal minimum wage, are no substitute for employment in the wider economy. EU law prohibits discrimination in employment on the grounds of disability, yet significant barriers remain. Prejudice is only one of the obstacles that persons with disability must overcome. In many Member States, social security payments to persons with disability are incompatible with income from full-time employment, even though such people incur significant additional out-of-pocket expenditure (see Article 28). Employers may even be open in principle to the prospect of employing a person with disability but have a lack of knowledge of to provide and fund the reasonable accommodation that might be required, which may be additionally challenging in the case of an employee with a complex disability such as cerebral palsy. The EU can support Member States and the Social Partners to develop a plan for inclusive employment drawing on examples of best practice from across the Union.

Article 28 - Adequate standard of living and social protection

Persons with cerebral palsy and similar disabilities incur significant additional out-of-pocket expenditure due, for example, to essential services such as (re)habilitation (see Article 26 above), certain assistive devices (see Article 20 above) or adequate healthcare provision (see Article 25 above) not being covered by the State. This means that their cost of living is higher than the average person, which their social protection in the form of disability allowance is too low to compensate. The situation is further compounded by the fact that disability allowance is usually incompatible with paid employment and withdrawn in the case that the person with disability finds a job. As a result, persons with disabilities are more likely to be poor, even more so if they experience intersectional disability, and are more likely to be homeless or in substandard housing. In the EU's efforts to address economic inequality, it must pay special attention to the vicious circle of poverty into which persons with disabilities are often forced.

Article 29 - Participation in political and public life

400,000 EU citizens were disenfranchised at the European Parliament elections in 2019 on the grounds of lack of legal capacity due to their disability²⁰. 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 accessibility of polling stations or the voting process itself, or denial of the right to be accompanied by a third party of their choice. Solutions exist that take account of concerns surrounding the independence and secrecy of the electoral

¹⁵ Pettersson K, Rodby-Bousquet E. Living Conditions and Social Outcomes in Adults With Cerebral Palsy. *Frontiers in Neurology*, 2021

¹⁶ Rožkalne Z, Mukāns M, Vētra A. Transition-Age Young Adults with Cerebral Palsy: Level of Participation and the Influencing Factors. *Medicina (Kaunas)*. 2019

¹⁷ Benner, J.L., Hilberink, S.R., Veenis, T., van der Slot, W.M.A. and Roebroek, M.E., Course of employment in adults with cerebral palsy over a 14-year period. *Dev Med Child Neurol*. 2017

¹⁸ Pagliano E, Casalino T, Mazzanti S, Bianchi E, Fazzi E, Picciolini O, Frigerio A, Rossi A, Gallino F, Villani A, Landi N, Roberti L, Militerni R, Di Brina C, Tornetta L, Martielli M, Brizio M, Rodocanachi M, Tessarollo V, Galli J, Dusi E, Meschini L, Malinconico E, Baranello G, Anderloni A, Fedrizzi E. Being adults with cerebral palsy: results of a multicenter Italian study on quality of life and participation. *Neurol Sci*. 2021

¹⁹ Vidart N, & SPARCLE team project. Employment and higher education in young adults with Cerebral Palsy: A cross-sectional analysis of the SPARCLE study. 2023 (Submitted)

²⁰ EDF 6th 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/>)

process, such as the AccessibleVote rewarded by a ZeroProject prize in 2023²¹, but legislators and electoral authorities in EU Member States have proven reluctant to implement them. While the competence of the EU in this field is limited, it can share knowledge and encourage the uptake of accessible voting solutions by highlighting examples of best practice.

Article 30 - Participation in cultural life, recreation, leisure and sport

Participation in culture, recreation, leisure and sport offers opportunities for social inclusion and personal wellbeing to all who benefit. For persons with CP and similar disabilities, many barriers unfortunately stand in their way. Sports facilities are often inaccessible, with the only accessible ones being located in big cities. Adapted or inclusive sporting activities are often small-scale and lack competitive opportunities, which can be demotivating for participants. Cultural associations are often unaware of their obligations regarding accessibility. When travelling to different venues, hotels often don't offer accessible rooms. In all cases, persons with disability are rarely consulted on the design of activities. To ensure that this right is better respected, the EU can use its funding programmes to prioritise activities that include persons with disability in a meaningful way.

Article 31 - Statistics and data collection

Lack of comparable official data on disability undermines efforts to demonstrate the extent to which the rights of persons with disability are infringed or respected²². In this regard, the European Union Statistical Office (EUROSTAT) is to be commended for beginning to publish Europe-wide comparable data on disability²³. Disability is, however, diverse, and drawing implementable conclusions may require more refined definitions of specific disability groups. Much work has been done to gather data for research purposes through cerebral palsy registers under the Surveillance of Cerebral Palsy in Europe (SCPE) network²⁴. At international level, the Global Burden of Disease studies are defining more clearly the impact of different conditions, including disabilities, at a fine level of detail²⁵. There are therefore important foundations on which the EU and other actors can build in order to improve statistics concerning the full range of disabilities. Involving organisations of persons with disabilities, which is rare at present, can also help to improve the quality of data collection.

It should be noted that the database of the SCPE network was until recently hosted by the European Commission's Joint Research Centre. This support was, however, withdrawn. For the EU to benefit from accurate and detailed statistics on persons with cerebral palsy on its territory, including their status in terms of health, education, employment and other factors, it would be advisable for the EU to renew its support for the SCPE network.

Article 32 - International cooperation

The European Union is the largest donor of developmental aid in the world. The latest estimates suggest that up to 50 million persons globally have cerebral palsy or a closely related condition²⁶. Both the prevalence and the severity of cerebral palsy are significantly greater in low-income than

²¹ <https://zeroproject.org/view/project/d750a7f3-22ac-4444-ad1b-95b6d1c40f37>

²² <https://alleyoop.ilssole24ore.com/2022/11/09/disabilita-dati/>

²³ https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Disability_statistics

²⁴ <https://scpe.edu.eacd.org/scpe.php>

²⁵ <https://www.healthdata.org/research-analysis/gbd>

²⁶ 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.

in high-income countries²⁷, due to factors including poor newborn and maternal healthcare, malnutrition, as well as lack of access to (re)habilitation and assistive technology. The EU can make a significant difference to international cooperation on cerebral palsy by prioritising programmes that address the root causes of millions of individuals with cerebral palsy and their family members being excluded from economic and social opportunities.

Credits

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²⁷ 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.