

Manifesto for Cerebral Palsy

European Elections 2024

Manifesto for Cerebral Palsy (Intro: 1/3)





Cerebral palsy (CP) is the most common form of childhood-onset physical disability.

An estimated 800,000 European Union citizens live with CP and another 16 million people are closely connected to a child or adult affected.

CP is a lifelong condition and there is no known cure.

Manifesto for Cerebral Palsy (Intro: 2/3)



The aim of this manifesto is to explain how the European Union (EU) can improve the lives of its citizens with CP.

It will help citizens with CP, their family members and the professionals who work with them to demand action from candidates for the European Parliament elections in 2024.

CP-ECA subscribes fully and has contributed actively to the European Disability Forum's Manifesto for the European Elections 2024.

This document focuses on the needs of the cerebral palsy community.



Manifesto for Cerebral Palsy (Intro: 3/3)





The EU can make a difference in many ways:

- through legislation,
- through standard-setting,
- through funding for research, innovation and support for civil society.

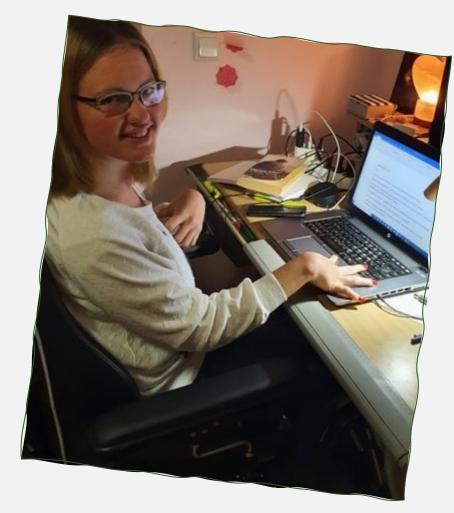
Each of these ways must be used to help people with CP.

In doing so, the EU will improve the lives of all its citizens, as what is good for citizens with CP, is good for everyone.



CP ECA Palsy Europe

- The European Union must provide resources and guidelines tailored to the specific needs of EU citizens with CP in relation to job hunting and the application process. These resources must be written in an accessible format, uploaded onto the EU relevant websites, such as EURES as well as Europass.
- The EU must highlight accessible resources relevant for persons with CP when they are job hunting. In that field, the EU could use some of the relevant expertise coming from IT partners and the work they have undertaken over the years, when it comes to accessible technology.
- Similarly, the EU must encourage the production of guidelines on effective communication when interacting with EU citizens with CP. Specifically, the EU must consider whether these could also encompass the employment context.
- The EU must support the organisations that help people with CP and complex disabilities to enter the labour market. The support of a mentor is essential, and the EU should encourage mentor financing.





ACCESSIBLE HEALTHCARE, PHYSICAL ACTIVITY & WELLBEING





- The EU must ensure alongside its partners, such as WHO and other relevant stakeholders, access to opportunities related to physical activity, wellbeing and accessible healthcare for citizens with CP in each member state. Where these do not exist the EU must work alongside the member states, so as to provide them with expertise on some type of physical activity and well-being opportunity which could be easily implemented in a given member state. In line with the WHO Rehabilitation 2030 call for action, these physical activities and wellbeing must be available throughout the human lifespan. Furthermore, their availability must be universal, which means that they must be provided free of charge or at affordable cost.
- All these opportunities must take into account the needs of families, loved ones as well as carers.
- A network of EU experts must be set up to spread knowledge, advise the member states, work alongside them and make good practices available to all. The network must coordinate the work among all member states.

INDEPENDENT LIVING WITHIN THE COMMUNITY



- The EU must coordinate and cooperate with the member states to produce best practices and guidelines, so that EU citizens with CP, their families and loved ones have access to affordable accessible housing in every member state. The EU must ensure that, at every level of this work, it considers the needs of all EU citizens wherever they live, including rural areas.
- The EU must encourage the development of accessible public places, including places of leisure, culture as well as education at every stage of life. This must be universally designed so as to take into account everyone's needs and be adapted to the greatest possible number of EU citizens, including those with CP.
- The EU and its partners must work towards the coordination of solutions offered to the EU citizens with CP throughout the member states.
- The EU must also protect and organise the status of carers. It must create a market for carers with fair payment and support.

- Given that personal assistance is a necessary precondition for many EU citizens with CP to a fully inclusive and accessible life within the community, the EU should redouble its efforts jointly with the member states to ensure their availability throughout the Union. Solutions must be developed to ensure that independent living solutions are available to any EU citizen with CP who wishes to use them, including those with intellectual disability.
- The EU must promote the idea that personal assistance is necessary, and does not represent economic burden to the member states. It must raise awareness about the meaning of personal assistance and build up the reputation of the profession of personal assistance.
- The EU must encourage the development of a community life/housing for citizens with CP and intellectual disabilities, following the example of the Swedish housing system.





- EU citizens with CP and their loved ones must have access to all freedom of movement rights and opportunities pertaining to their EU citizenship on an equal basis with other citizens of the EU.
- The EU must ensure full access for citizens with CP and their loved ones to all temporary mobility opportunities, such as Erasmus, internships, workrelated travel, including various job-seeking opportunities, on an equal basis with others.
- This means that personal assistance must be maintained by the member states of nationality throughout the duration of the temporary mobility. In case an EU citizen with CP becomes employed by or in another member state, the member state of nationality must continue to provide its full services, including the ones related to personal assistance, until the other member state is ready and capable of providing the services above mentioned.







 In cross-border situations when an individual with CP residing in a member state works for an employer situated in another member state, the two member states must cooperate with one another so that any needed services can be provided in time and without interruption by the member state of residence, where the person with CP is employed. The same logic must apply in all the above-mentioned scenarios, except in cases of temporary mobility, where the member states of origin remains competent. However, on the same basis that it is done for healthcare, in cases of citizens with disability requiring personal assistance the European insurance card must also enable someone needed to access the required PA services during the situation of temporary mobility.

- The EU must encourage air travel and train services to become more accessible to citizens with CP by providing more commutable, safer and larger spaces.
- The EU must set standards and fund training for air travel companies on how to deal properly with assistive devices (such as electric wheelchairs, scooters, etc.) to avoid damage, harm and stress.
- The EU must encourage the Erasmus and Alma programs to include people with CP in youth and student exchanges.



SCIENTIFIC RESEARCH





- The EU must prioritise the need for research and development in the field of CP, especially large-scale or collaborative studies that produce definitive and applicable recommendations on the most effective, evidence-based interventions.
- The EU must support cooperation between CP registers at national and regional level, and encourage their establishment where they do not already exist, as a proven effective tool to understand better the incidence of CP and the needs of the CP population.
- The EU must support research and scientific work that helps to empower EU citizens with CP by providing greater knowledge and deeper understanding of their situation, and must encourage EUfunded research institutions to carry out research that will benefit EU citizens with CP by highlighting their needs in every EU programme in the scientific area, in line with the Convention on the Rights of Persons with Disabilities.
- The results of EU-funded research must be made available quickly and in a way that is accessible to persons with CP.



ACCESSIBLE COMMUNICATIONS



- The EU must ensure that citizens with CP possess meaningful avenues to communicate effectively with people, exchange and interact with everyone. Accessible communication is a basic human right for all human beings. When communication remains inaccessible, it creates a barrier to the expression of a person's whole potential as well as to their full enablement within society. This, in turn, leads to social isolation, exclusion, and discrimination. On the other hand, because accessible communication in all its forms and diversity helps to break down the above-mentioned barriers and promote inclusion, citizens with CP, their families and loved ones no matter the intensity of their needs must have, on an equal basis with others, the same rights and possibilities to showcase their passion/talents and contribute to society, express their feelings, needs and wants in a way that others can understand, interact with and respond to.
- The EU must communicate about its own actions and policies using accessible methods such as simple language, augmentative and alternative communication (AAC) and related techniques.





- As the largest donor of development aid in the world, the EU must support the efforts of local communities in low- and middle-income countries to enable the inclusion, participation and care of people with CP in society.
- The EU must invest in projects that aim to improve the lives of persons with CP in lowand middle-income countries.
- The EU must ensure that the specific needs of people with CP are taken into consideration in planning for humanitarian operations, disaster relief and crisis management.



ACCESSIBLE VOTING & DEMOCRATIC PARTICIPATION



- The EU must make every effort to implement fully Article 29 of the UNCRPD, giving the same conditions for all citizens with cerebral palsy to exercise the right of vote as others, in particular:
 - to participate fully in political and public life on an equal basis with others;
 - to have voting systems that are accessible and easy to understand and use;
 - to be able to vote by secret ballot in elections;
 - to be able to use new technologies where appropriate;
 - to be free to vote without intimidation.





INCLUSIVE EDUCATION





- Since education is the basis of development, growth and progress, the EU must promote "one school for all" – meaning that students with cerebral palsy must not be excluded from the regular education system.
- The EU must encourage education programmes to be designed in such a way that everyone can participate, shaping their methods and standards so that they are accessible to students with CP. This must apply to all levels of education, including preschool, college and post-graduate level.
- The EU must support universities and other educational institution to make accessibility a higher property in the curriculum and to educate designers and architects about the principle of "universal design", which requires understanding the specifics of CP and creating technical guides.
- The EU must help to raise awareness about CP in schools and other educational institutions in order to prepare society better for the inclusion of citizens with CP in the future.





- The EU must harmonise VAT on assistive technology. In the EU, there are a lot of resources and opportunity for the development of assistive technology, yet there is a lack of tax harmonisation, meaning that citizens with CP in different member states have different levels of access to it.
- The EU must provide minimum guidelines for each member state to provide assistive technology for citizens with CP, recognising its benefits for the social, economic and cultural inclusion of persons with CP and other complex disabilities.



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Employment



Accessible Healthcare, Physical **Activity & Wellbeing**



Independent Living within the Community



Freedom of Movement



Scientific Research



Accessible Communications



Development Cooperation & Humanitarian Aid



Accessible Voting & Democratic **Participation**



Inclusive Education



Assistive Technology