



Position of the European Network on Independent Living (ENIL)

To the Proposal for a Regulation of the European Parliament and of the Council on jurisdiction, applicable law, recognition and enforcement of measures and cooperation in matters relating to the protection of adults COM(2023) 280 final

The European Union is working on a regulation on jurisdiction, applicable law, recognition and enforcement of measures and cooperation in matters relating to the protection of adults, COM (2023) 280 final. The proposed regulation aims to implement the 2000 Convention on the International Protection of Adults of the Hague Conference on Private International Law (HCCH Convention).

The regulation on the protection of adults will, to a large extent, affect disabled people.

The European Network on Independent Living regards the following articles of the regulation as highly problematic:

Article 1 (a) defines the most important subject matter of the proposed legislation, which is to “determine the Member State whose authorities have jurisdiction to take measures directed to the protection of the person or property of the adult”.

Article 2, 1 clarifies the scope: “This Regulation shall apply in civil matters to the protection in cross-border situations of adults who, by reason of an impairment or insufficiency of their personal faculties, are not in a position to protect their interests.”

Article 3 adds that the matters may include: “(a) the determination of the incapacity of an adult and the institution of a protective regime, (b) the placing of an adult under the protection of a judicial or administrative authority, (c) guardianship, curatorship and analogous institutions, (d) the designation and functions of any person or body having charge of the adult’s person or property..., (e) decisions concerning the placement of the adult in an establishment or other place where protection can be provided”.

Articles 11 and articles 12 permit the enforcement of measures across borders.

Article 21 intends to grant authorities the power to institutionalise, disabled people under their control.



Articles 45, 46, 47 would oblige member states to establish compulsory, interconnected, central protection registers, containing all details of measures taken against a person. While the regulation on the protection of adults would largely be procedural, those articles would introduce new substantial rules. Every EU country would have to introduce such registers and insert all disabled people, for example under guardianship in that country.

The European Network on Independent Living regards those articles as problematic for the following reasons:

1. The EU is state party to the United Nations Convention on the Rights of Persons with Disabilities

The United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) was adopted by the UN General Assembly on the 13th of December 2006 and entered into force on 3 May 2008.

In May 2004 the Council had authorised the Commission to negotiate the EU's accession to the UN CRPD. Council Decision of 26 November 2009 "concerning the conclusion, by the European Community, of the United Nations Convention on the Rights of Persons with Disabilities (2010/48/EC)" approved the UN CRPD on behalf of the EU.

On the 5th of January 2011 ratification of UN CRPD was completed. The EU thus became a state party. "For the EU, this means ensuring that all legislation, policies and programmes at EU level comply with the Convention's provisions on disability rights, within the limits of EU responsibilities."¹

The UN CRPD is legally binding.

"The Committee on the Rights of Persons with Disabilities (CRPD) is the body of independent experts which monitors the implementation of the Convention by the States parties".² The Committee provides authoritative guidance about the provisions of the Convention on the rights of persons with disabilities through general comments."³

Resolution A/HRC/RES/53/14 adopted by the Human Rights Council of the UN General Assembly on 13 July 2023 grants the Special Rapporteur on the rights of persons with disabilities a mandate among others "(a) to develop a regular dialogue and to

¹ https://ec.europa.eu/commission/presscorner/detail/en/ip_11_4

² <https://www.ohchr.org/en/treaty-bodies/crpd>

³ <https://www.ohchr.org/en/treaty-bodies/crpd/general-comments>

consult with states and other relevant stakeholders...”; (b) to gather, request, receive and exchange information and communications ... on violations and abuses of the rights of persons with disabilities”:

2. The Proposal for a Regulation of Vulnerable Adults is in conflict with the UN CRPD

The high-standing scholars on disability law Prof. Dr. Theresia Degener and Prof. Dr. Kathrin Römisch have revived the regulation and concluded that “the directive would violate the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD); should it enter into force”.⁴

These are the reason for the assessment:

- a) “The HCCH Convention is to be considered superseded by the UN CRPD, adopted six years later.
- b) Article 12 of the UN CRPD grants all persons with disabilities equal legal capacity and obliges member states to replace all forms of deprivation of legal capacity with forms of supported decision-making. This was confirmed by General Comment No. 1.⁵
- c) The HCCH Convention and the proposed regulation are calling into question Art. 14 on the right to freedom from (forced) institutionalisation.
- d) The HCCH Convention and the proposed regulation are calling into question Art. 19 on the Rights to Independent Living
- e) The HCCH Convention and the proposed regulation are calling into question Art 5 on the right to protection from discrimination.

The then UN Special Rapporteur on the rights of persons with disabilities (Gerard Quinn) and the Independent Expert on the enjoyment of all human rights by older persons (Claudia Mahler) came to the same conclusions and advised to reaffirm the primacy of the UN CRPD.⁶ In a second statement, they reaffirmed their concerns and

⁴ https://enil.eu/wp-content/uploads/2024/07/BODYS_Directive-on-the-Protection-of-Adults_Position_TD.pdf

⁵ <https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no-1-article-12-equal-recognition-1>

⁶ Joint statement by the Special Rapporteur on the rights of persons with disabilities, Gerard Quinn, and the Independent Expert on the enjoyment of all human rights by older persons, Claudia Mahler (8 July 2021)

urged a clarifying revision of the regulation on the protection of adults.

The registers foreseen in articles 45, 46, 47 are not only supposed to contain mandatory information on cross-border cases but all measures of protection and all confirmed powers of representation established over all persons deprived of their legal capacity in a Member State. The registers are supposed to be interconnected and provide central access for Authorities. The European Commission estimates that the register would only be relevant in 2,7% of cross-border situations. Despite that negligible number all adults in need of protection would have to be included.

The information to be included in the register includes highly sensitive data on disabled people. Gathering and storing highly personal data on the grounds of disability constitutes discrimination and a breach of privacy.

The proposal for central registers calls into question article 22 of the UN CRPD on the right to privacy. Disabled people need to be able to escape from the reach of authorities in case of practices in breach of the UN CRPD.

Establishing and maintaining such registers would involve costs to be born from national budgets. Policy makers have a responsibility not to spent tax-payer's resources on unsustainable projects. Especially in times of economic stagnation and budgetary deficits such expenditures should especially be avoided.

The regulation pursues a very centralised approach which might call into question the principle of subsidiarity as expressed in article 5(3) of the Treaty on European Union. Main responsibility for supported-decision making arrangements should rest with local authorities. Authorities should communicate directly with each other for individual cases falling within their area of responsibility.

3. Supported-decision making is an effective and human rights compliant alternative

Once disabled people are deprived of their legal capacity-they are usually placed under substituted-decision making. They lose the ability to dispose of their financial resource or to enter into legal contracts.

General Comment 1 on the equal recognition before the law of the UN Committee on the Rights of Persons with Disabilities established supported decision making as an

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alternative to substituted decision making. Under supported decision-making, the disabled person retains full legal capacity and the persons providing support are only to explain the consequences of possible choices but never to take the decision for the disabled person.

It has also been shown that supported decision-making works effectively. Many ENIL members benefit from this form of support. One of them is Nicolas Joncour from France⁷, a non-speaking autistic young man. Together with personal assistants who support him in taking decisions (which means that options and implications are explained, but the decision remains with him), Nicolas lives in his own apartment and studies at a university. Another example is Fionn Crombie Angus from Ireland, who has Down Syndrome and was an intern at the ENIL Secretariat for six months. Fionn is supported in his decisions by his family, who also act as his personal assistants (for which he receives a personal budget).⁸

Supported decision making has been tested and applied in systematic ways and on a larger scale in several countries. For example, the Personal Assistance User Cooperative Uloba, from Norway, successfully tested the method of supported decision-making boards during a multiannual project.⁹ The project drew inspiration from the organization Vela Canada in British Columbia, which is running 1,100 supported decision-making boards. Such boards generate measurable impact on the amount of control individuals have over their lives.

To date, supported decision-making is successfully practised in 13 EU-member states while 6 countries have largely abolished substituted-decision making in favour of supported decision-making.¹⁰

Concepts to support legislative activity are well-developed. The legal scholar Prof. Dr. Kjetil Mujezinovic Larsen has undertaken groundbreaking work in this regard by preparing a UN CRPD compliant draft law.¹¹

4. Recommendation to amend or terminate the regulation

The proposed regulation is based on an outdated approach to disability which confuses “protection” with “deprivation of liberty”. The European Union must not adopt legislation

⁷ <https://www.facebook.com/NicolasJoncour99/>

⁸ <https://enil.eu/wed-like-to-welcome-our-new-intern/>

⁹ <https://www.uloba.no/wp-content/uploads/2023/06/My-life-my-choice-2.pdf>

¹⁰ <https://www.edf-feph.org/publications/human-rights-report-2024-legal-capacity/>

¹¹ <https://enil.eu/wp-content/uploads/2024/12/Draft-new-act-supported-decision-making-EN.pdf>



which is in breach with human rights and interferes in citizens freedom to be protected from the control of authorities in their private life.

To safeguard the rights of disabled citizens, articles 45, 46 and 47 on the introduction of protection registers must be removed entirely. Article 21 needs to be adjusted to the legal context of the EU which has been shaped by the UN CRPD. Institutionalisation and deprivation of liberty are not permitted by the Convention. Automatic cross-border recognitions of support arrangements, for example when a disabled person is a user of [personal assistance](#), would be beneficial.

The draft regulation adds legitimacy to the practice of deprivation of legal capacity. We are recommending far reaching changes to the Commission proposal for regulation on jurisdiction, applicable law, recognition and enforcement of measures and cooperation in matters relating to the protection of adults, COM (2023) 280 final.

Instead of allowing countries, to cooperate on depriving disabled people of their legal capacity, we need a regulation that reinforces cooperation on supported-decision making. To do that, articles 1, 2 and 3 on the subject matter, scope and definitions, must be substantially revised.

Should far reaching changes not be possible, we recommend the complete withdrawal of this regulation.

The European Network on Independent Living - ENIL is a Europe-wide network of disabled people, with members throughout Europe. ENIL is a forum for all disabled people, Independent Living organisations and their non-disabled allies on the issues of Independent Living. ENIL represents the disability movement for human rights and social inclusion based on solidarity, peer support, deinstitutionalisation, democracy, self-representation, cross disability and self-determination.

For additional input please visit www.enil.eu or contact:

Florian Sanden

ENIL Policy Coordinator, florian.sanden@enil.eu

Contact information

ENIL Brussels Office vzw/asbl

Mundo J - 6th Floor

Rue de l'Industrie 10



1000 Brussels
Belgium



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