

Recommendations of the European Network on Independent Living (ENIL)

to the Belgian presidency of the EU Council concerning the European Commission proposal for a regulation on the cross-border protection of vulnerable adults

The European Network on Independent Living (ENIL) has taken notice of the European Commission proposal for regulation on jurisdiction, applicable law, recognition and enforcement of measures and cooperation in maters relating to the protection of adults, COM (2023) 280 final. We are shocked and appalled that a piece of legislation which is so clearly in violation of the United Nations Convention on the Rights of Persons with Disabilities was proposed. This was confirmed in a joint submission by the 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), addressed to the European Commission and dated 2 August 2023.

Not only does the draft regulation run counter to international human rights law, there is also extensive evidence that there are better ways to support disabled and older people. Instead of installing cross-border regimes of guardianship and institutionalisation, we need universal access to supported decision making and decisive deinstitutionalisation. We are asking the Belgian Council Presidency to return the document to the European Commission for a redraft in that spirit, so it can become a tool to protect the human rights of disabled and older people instead of increasing discrimination of these groups. Should that not be possible, the European Commission should be asked to withdraw the proposal completely.

Articles of the draft regulation

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".

In violation of the UN CRPD

The core objectives of the Commission proposal run contrary to the human rights of disabled people, as expressed in the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). Under the Convention, the notion of incapacity and a transfer of the rights of personhood do not exist. Article 5 of the UN CRPD states that all persons are equal before the law. Article 12 on Equal Recognition before the law states adds that "persons with disabilities enjoy legal capacity on an equal basis with others".

The recitals, as wells as articles 1, 2 and 3 of the draft regulation, formulate textbook descriptions of guardianship and substituted decision-making regimes. The idea to establish cross-border regimes of that type is outrageous, as it would severely violate the dignity of the people affected, restrict their personal freedom, and expose them to a high risk of abuse.

To make matters worse, the Commission proposal wants to grant public authorities or private individuals the power to place disabled people under their guardianship in institutions, when in a cross-border situation. The concepts formulated in the legislation violate article 19 of the UN CRPD on Independent Living and article 14 on the Right to liberty and security of person.

The UN Special Rapporteur on the Rights of Persons with Disabilities and the Independent Expert on the full enjoyment of all human rights by older people have examined the Commission proposal and share the conclusion that it runs counter to the UN CRPD.¹

There is a better way

Not only does the draft regulation propose to advance outdated concepts that were made obsolete and unacceptable by the adoption of the UN CRPD, it has also been shown that there are more effective ways to support disabled people, including those with intellectual and/or neurodiverse impairments.

¹ Joint Submission. Towards Greater Coherence on International Law. Reflections on the adequacy of the European Commission's proposal for a Regulation and Council Decision governing the Hague Convention on the Protection of Adults. Available at: https://www.ohchr.org/sites/default/files/documents/issues/disability/olderpersons/Annex-Joint-Submission-Towards-Greater-Coherence-International-Law.pdf



ENIL has many members who might be negatively affected by this regulation, if it is adopted, including facing the risk of being institutionalized or placed under guardianship. One of them is Nicolas Joncour from France², 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 budged).³

It also happens that people who are neurodiverse or have psychosocial impairments are committed to institutions against their will and have to leave their country to be safe. Eric Lucas from France is such an example.⁴ With the proposed regulation, there would be no safe haven for such people, since it proposes cross-border enforcements of placement measures.

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.⁵ 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.

ENIL policy recommendation

We are strongly recommending to the EU to abandon all attempts to perpetuate out-dated and repressive concepts of guardianship and institutionalisation of disabled people. Instead, solutions that respect of human rights and are in compliance with the UN CRPD need to be adopted. The proposal for a regulation on the cross-border protection of adults needs to be redrafted or withdrawn altogether. In order to ensure equal rights for disabled people and to prevent discrimination, we need supported decision making and better support in the community. Universal access to supported decision making in all Member States and cross-border recognition of supported decision-making boards and others forms of support would greatly further that objective.

² https://www.facebook.com/NicolasJoncour99/

³ https://enil.eu/wed-like-to-welcome-our-new-intern/

⁴ https://ericlucas.org/psychiatristan-reponses-au-questionnaire-pour-les-rescapes-de-hospitalisations-ou-institutionnalisations-psychiatriques-forcees/

⁵ https://www.uloba.no/wp-content/uploads/2023/06/My-life-my-choice-2.pdf



Our Norwegian members at Uloba have meticulously documented the outcomes of their project and also produced a draft legislation on supported decision-making, in cooperation with legal experts. We are attaching both documents to this statement and hope that they might provide inspiration.

For additional input please visit <u>www.enil.eu</u> or contact:

Florian Sanden

ENIL Policy Coordinator, florian.sanden@enil.eu

About the European Network on Independent Living - ENIL

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 organizations 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.

Contact information

ENIL Brussels Office vzw/asbl Mundo J - 6th Floor Rue de l'Industrie 10 1000 Brussels Belgium









Co-funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the European Commission. Neither the European Union nor the granting authority can be held responsible for them.