#### **European Disability Forum ("EDF")**

## Re: Proposed EU Regulation on the protection of adults

Opinio	on	

#### I. Introduction

- 1. We are instructed by EDF to advise on the compatibility of a proposed EU Regulation on the protection of adults deprived of their legal capacity with the EU's existing international human rights law obligations.
- 2. The proposal to be put before the European Parliament and the Council of the EU is entitled 'Proposal for a Regulation on jurisdiction, applicable law, recognition and enforcement of measures and cooperation in matters relating to the protection of adults'.
- 3. The EU has competence over judicial cooperation in civil and commercial matters under Article 81(2) of the Treaty on the Functioning of the EU, and it is on this legal basis that the proposal is made.

# 4. We are specifically asked to:

- a. Advise on the compatibility of the proposal with the UN Convention on the Rights of Persons with Disabilities ("CRPD"), the EU Charter of Fundamental Rights ("EU Charter"), and other regional or international human rights frameworks binding on the EU; and
- b. In the event of any conflicts, if and where appropriate, to propose amendments that could harmonise the proposal with the CRPD.

### II. Relevant background

- 5. The European Commission published the proposal on 31 May 2023.<sup>1</sup>
- 6. This mirrors the Hague Convention on the International Protection of Adults, 2000 ("HCCH"),<sup>2</sup> with the aim of incorporating its provisions into the EU legal framework.<sup>3</sup>
- 7. The European Commission intends to align EU law with the HCCH as a means of meeting the EU's longstanding objective of ratifying the Convention to establish a streamlined international law framework for the protection of adults deprived of their legal capacity in international situations.
- 8. In so doing, the Commission also seeks to improve upon the protection provided by the HCCH, and to encourage EU-wide judicial cooperation in this area based on the principle of mutual trust.
- 9. The HCCH creates a system for the protection in international situations of individuals who 'by reason of an impairment or insufficiency in their personal faculties, are not in a position to protect their interests'.<sup>4</sup>
- 10. Within this system, Contracting Parties are permitted to 'take any necessary measures of protection' in respect of such an individual within their jurisdiction.<sup>5</sup>
- 11. While the proposal is expressly intended to align with and build upon the protection provided by HCCH, its Recitals also make clear that the EU's international human rights law obligations remain paramount.

<sup>&</sup>lt;sup>1</sup>https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A52023PC0280

<sup>&</sup>lt;sup>2</sup>https://assets.hcch.net/docs/c2b94b6b-c54e-4886-ae9f-c5bbef93b8f3.pdf

<sup>&</sup>lt;sup>3</sup>Recital 8, The Proposal.

<sup>&</sup>lt;sup>4</sup>Article 1, HCCH.

<sup>&</sup>lt;sup>5</sup>Article 10, HCCH.

- 12. Recital 10 of the proposal provides that its rules 'should be guided by its objectives that are to enhance the protection of fundamental rights and freedoms ... [building] on the [EU Charter] ... and on international human rights law in this area' (our emphasis).
- 13. Recital 10 goes further to confirm its intention that the 'rights safeguarded in the UNCRPD are to be protected both in national and cross-border cases, and where measures are taken in relation to persons with disabilities, those measures are to be in line with the UNCRPD.'

#### III. HCCH: an overview

- 14. The measures that can be taken under the HCCH are defined at Article 3:
  - 'a. the determination of incapacity and the institution of a protective regime;
  - b. the placing of the 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, representing or assisting the adult;
  - e. the placement of the adult in an establishment or other place where protection can be provided;
  - f. the administration, conservation or disposal of the adult's property;
  - g. the authorisation of a specific intervention for the protection of the person or property of the adult.'
- 15. It is also necessary to bear in mind the HCCH rules as to (i) jurisdiction and (ii) the law applicable to any dispute concerning the protection of such persons, because it is proposed in Chapters II and III of the Regulation that (subject to one or two minor qualifications) these are to be incorporated within the Regulation.
  - a. The HCCH rules as to jurisdiction are contained within Chapter II HCCH (Articles 5 to 12). The basic rule is that jurisdiction is granted to the authorities of the state where the adult is habitually resident but can transfer

to another state in the event of a change in that person's state of habitual residence.<sup>6</sup> By Article 8, the authorities in the state of habitual residence may ask the authorities of another state to take certain measures. The basic rule is subject to the exceptions and qualifications contained in the other Articles of Chapter II.

- b. The HCCH rules as to applicable law may be summarised thus.
  - i. By Article 13, each authority exercising jurisdiction over an adult applies its own law but may exceptionally apply or take into account the law of another state with which that person has substantial connection.
  - ii. By Article 15, absent an express choice or determination of some other law, the law applicable to the powers granted to the representative of that adult are the laws of the state of the habitual residence of that adult at the time of the grant of any such powers of representation.

# IV. The UNCRPD and legal capacity

- 16. We are of the view that the proposal contrary to its Recitals does not align with the EU's existing obligations under the CRPD, EU Charter, and other international human rights law instruments binding on the EU.
- 17. We are particularly concerned about Article 21, which would enable a person to be transferred from one Member State to another for the purposes of placement:
  - '1. If an authority of a Member State contemplates the placement of the adult in another Member State in an establishment or other institution where protection can be provided, it shall first obtain the consent of a Central Authority of that other Member State. To that effect, it shall transmit to the Central Authority of the requested Member State a report on the adult together with the reasons for the proposed measure, using the form set out in Annex VI.

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<sup>&</sup>lt;sup>6</sup>Article 5.

- 2. Paragraph (1) shall not apply where the placement is contemplated with a private person.
- 3. Except where exceptional circumstances make this impossible, the decision granting or refusing consent shall be transmitted to the requesting authority no later than six weeks following the receipt of the request.
- 4. Paragraphs (1), (2) and (3) shall not preclude Central Authorities or competent authorities from entering or maintaining existing agreements or arrangements with Central Authorities or competent authorities of one or more other Member States simplifying the consultation procedure for obtaining consent in their mutual relations.'
- 18. We are also concerned about the proposal's apparent departure from the principle of supported decision-making the principle that adults with a disability should receive all the support they need so as to enable them to retain their legal capacity to take decisions towards an apparent facilitation of the transfer across borders in order to institutionalise persons who may be deemed not to have legal capacity, without sufficient supported decision-making being a pre-requisite and/or without there being in place sufficient safeguards to guarantee their human rights.<sup>7</sup>
- 19. Legal capacity can be described as 'a person's power or possibility to act within the framework of the law'.8
- 20. The deprivation of legal capacity often but not always there are a very wide range of different mechanisms adopted by the different EU Member States to cater both for supported decision-making and for substitute decision-making in the event of a lack of legal capacity involves a person being placed under a guardianship regime on the basis that they are unable to make informed decisions for themselves due to a mental and/or physical impairment.

<sup>&</sup>lt;sup>7</sup> ENIL, "Shadow report on the implementation of the UN Convention on the Rights of Persons with Disabilities in the European Union," February 2022.

<sup>8</sup> https://rm.coe.int/16806da5c0 'Who gets to decide?', Commissioner for Human Rights – Council of Europe, 20 February 2012, §1.1.

- 21. Guardianship regimes may in turn have different structures. They often involve a third party making decisions for the person in defined areas of their life – for example, healthcare, property dealings, financial affairs, and even sexual and familial relations. Depending on the individual's needs, this can be for a specified or indefinite period. In so far as healthcare decisions are concerned that person may be required to make that decision after consulting with a multi-disciplinary team of clinicians and will be required to follow a principled approach defined by the law to determine what treatment is in the disabled person's best interests. A court and not a guardian may be required to decide the issue.
- 22. Article 12 CRPD stipulates that every person, regardless of their mental capacity, has legal capacity. This provision is to be interpreted as drawing a distinction between both concepts. Paragraph 13 of General Comment No. 1 on Article 12 sheds light on this:9

'Legal capacity and mental capacity are distinct concepts. Legal capacity is the ability to hold rights and duties (legal standing) and to exercise those rights and duties (legal agency). It is the key to accessing meaningful participation in society. Mental capacity refers to the decision-making skills of a person, which naturally vary from one person to another and may be different for a given person depending on many factors, including environmental and social factors.

... Article 12 ... makes it clear that "unsoundness of mind" and other discriminatory labels are not legitimate reasons for the denial of legal capacity (both legal standing and legal agency). Under [A]rticle 12 ... perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity.'

23. The CRPD forms part of the backdrop of the EU's move towards supported decisionmaking, as distinct from traditional models of guardianship which focus on institutionalisation and substituted decision-making by a 'representative'. 10

<sup>&</sup>lt;sup>9</sup>2014.

<sup>&</sup>lt;sup>10</sup>General Comment No. 1 (2014) regarding Article 12, §3.

- 24. The CRPD represents a move towards a system which better provides individuals with the appropriate support they need based on individual assessments to be able to make their own choices and communicate them; rather than to deprive them of such agency by implementing substituted decision-making measures.
- 25. This is expressed at Paragraph 28 of General Comment No.1: 'The development of supported decision-making systems in parallel with the maintenance of substitute decision-making regimes is not sufficient to comply with article 12 of the Convention.'

### V. Summary of findings

- 26. We advise that the proposed Regulation, and in particular Article 21 thereof, if enacted in its current draft form risks failing to adequately safeguard a number of fundamental human rights as provided for by the CRPD, EU Charter, and European Convention on Human Rights ("ECHR"), and hence will fail to achieve its purpose as stated in the Recitals.
- 27. We propose to deal with the human rights at risk by category and as follows.
  - a. Torture or cruel, inhuman or degrading treatment
  - b. Liberty and security
  - c. Family and private life
  - d. Equality and non-discrimination
  - e. Healthcare
- 28. We are also concerned about the lack of express provision within the Regulation to enshrine a system of supported decision-making requiring Member States to ensure that all individuals receive the necessary support they need to exercise their legal capacity in respect of any decision before they are deemed or assumed to lack such capacity. Alternatively, if such person lacks capacity after a properly supported approach, the Regulations fails to expressly provide, at least in the context of Article 21, that any decisions as to whether a person should be transferred to another state for treatment must always be based on a multidisciplinary assessment of what is in

that person's best interests; and that should in itself incorporate the principle that a person lacking capacity should prima facie be supported within their own community.<sup>11</sup>

29. We have a further concern, in the context of Articles 21 and 22 of the proposed Regulation, surrounding the lack of provision stipulating which representative would be the ultimate decision-maker in an international situation (i.e., the domestic guardian or the representative appointed abroad).

30. We now turn to develop these concerns in turn and in greater detail.

# VI. Torture or cruel, inhuman or degrading treatment

31. Article 21 of the proposal would permit the 'placement' of an adult in an establishment or institution within another Member State, with the consent of the designated 'Central Authority' of that other Member State.

32. This would in effect allow individuals deprived of their legal capacity to be forcibly transferred across borders for treatment purposes. Forced treatment, coercive measures, and forced medication in psychiatric interventions and institutions have in some cases amounted to a breach of the human right against torture or ill-treatment.<sup>12</sup>

33. The CRPD Committee has recently expressed concerns about such practices. In its Concluding observations on the initial report of Andorra, <sup>13</sup> the Committee recommended that the Andorran government repeal the laws that permit 'forced treatment, including coercive measures and forced medication', <sup>14</sup> and 'adopt protocols to ensure free and informed consent concerning medical or scientific interventions'. <sup>15</sup>

<sup>&</sup>lt;sup>11</sup>See Articles 19 and 26(b), CRPD; and Article 26, EU Charter.

<sup>&</sup>lt;sup>12</sup>Article 15, CRPD; Article 3, ECHR; Article 4, EU Charter.

<sup>&</sup>lt;sup>13</sup>CRPD/C/AND/CO/1, 8 September 2023.

<sup>&</sup>lt;sup>14</sup>§32.

<sup>15§32.</sup> 

- 34. The European Court of Human Rights (ECtHR) has expressed similar concerns about forced treatment, in the context of forced sterilisations and abortions under the guise of 'best interests of the patient' in cases concerning women and girls with mental disabilities.<sup>16</sup>
- 35. We advise that the proposal, in particular Article 21, risks resulting in individuals with mental disabilities being subjected to forced treatments and coercive measures in the name of their own protection without sufficient safeguards, in a manner falling foul of the prohibitions against torture and other ill-treatment.

### VII. Liberty and security

- 36. The transfer of an individual to another jurisdiction for 'protection' purposes may also constitute a violation of the right to liberty.<sup>17</sup> This is particularly so in cases where the individual does not have a meaningful and effective opportunity to legally challenge a decision to deprive them of their liberty.<sup>18</sup>
- 37. The CRPD Committee has recently assessed the right to liberty in the context of involuntary medical treatment. In doing so, the Committee has expressed concerns over the practice of restricting an individual's movements merely on the basis of their psychological impairment or perceived dangerousness.
- 38. For example, in its <u>Concluding observations on the initial report of France</u>, <sup>19</sup> the Committee has recommended that French government repeal 'all legal provisions allowing for involuntary treatment and restrictions of liberty in institutions or community-based settings on the grounds of psychological impairment', prevent

<sup>&</sup>lt;sup>16</sup>Gauer and Others v. France, no. 61521/08, March 2011; V.C. v. Slovakia, no. 18968/07, 8<sup>th</sup> November 2011; N.B. v. Slovakia, no. 29518/10, 12<sup>th</sup> June 2012; I.G., M.K. and R.H. v. Slovakia, no. 15966/04, 13<sup>th</sup> November 2012; Joint Statement by the United Nations Committee against Torture, the Subcommittee on Prevention of Torture, the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, the Committee on the Rights of Persons with Disabilities. See also: Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Article 1(1); International Covenant on Civil and Political Rights, Article 7; UN Convention on the Rights of Persons with Disabilities, Article 15(1); Report of the Special Rapporteur on violence against women, its causes and consequences, I.G., M.K. and R.H. v. Slovakia, no. 15966/04, 13<sup>th</sup> November 2012; R.R. v. Poland, no. 27617/04, 26<sup>th</sup> May 2011; Committee Against Torture, General Comment No. 2, CAT/C/GC/2, 24<sup>th</sup> January 2008, §20.

<sup>&</sup>lt;sup>17</sup>Article 14, CRPD; Article 5, ECHR; Article 6, EU Charter.

<sup>&</sup>lt;sup>18</sup>Article 14, CRPD; Article 5, ECHR; Article 6, EU Charter.

<sup>&</sup>lt;sup>19</sup>CRPD/C/FRA/CO/1, 4 October 2021.

'placement in institutions, including prolonged or undetermined hospitalisations', 'ensure the free and informed consent of persons with disabilities', and 'develop human rights-based support methods that respect their dignity, freedom and autonomy, including peer support.'<sup>20</sup>

- 39. The ECtHR has not yet prohibited guardianship regimes and forced placement.<sup>21</sup> Instead, its jurisprudence recognises that in some instances, forced treatment may be justified to protect the individual themselves and others.<sup>22</sup>
- 40. The ECtHR does however require that any restrictions on liberty for these purposes must be exercised with safeguards,<sup>23</sup> including procedural regulation and limits,<sup>24</sup> and such safeguards must be exercised without delay.<sup>25</sup>
- 41. Read in light of the CRPD or ECHR, the proposal does not provide any clear safeguards to protect an individual's right to liberty. For example, the proposal does not clearly outline the grounds upon which a decision to transfer abroad can be taken, nor the grounds on which it could be challenged; nor does it specify what the functions or limits of a 'representative abroad' are and whether they would have the authority to conduct such a challenge.<sup>26</sup>
- 42. On this basis, the proposal is not in our opinion sufficiently aligned with the EU's obligations to protect and respect all individuals' right to liberty.

<sup>&</sup>lt;sup>20</sup>§31.

<sup>&</sup>lt;sup>21</sup>DD v Lithuania, no 13469/06, 14 February 2012.

<sup>&</sup>lt;sup>22</sup>ECtHR, 'Guide on Article 8 of the European Convention on Human Rights Right to respect for private and family life', 30 April 2018, <a href="https://fln.dk/-/media/FLN/Publikationer-og-notater/EMRK/Guide-on-Article-8-of-the-European-Convention-on-Human-public respect to the European-Convention-on-Human-public respect to the European-Convention-on-Human-public respect to the European-Convention-on-Human-public respect to the European-Convention on Human Rights Right to respect for private and family life', 30 April 2018, <a href="https://fln.dk/-/media/FLN/Publikationer-og-notater/EMRK/Guide-on-Article-8-of-the-European-Convention-on-Human-public respect to the European Convention on Human Rights Right to respect for private and family life', 30 April 2018, <a href="https://fln.dk/-/media/FLN/Publikationer-og-notater/EMRK/Guide-on-Article-8-of-the-European-Convention-on-Human-public respect to the European Convention-on-Human-public respect to the European C

Rights.pdf?la=da&hash=9A53A909656A705FFE4CFF499EC5862343A9B2AA.>

<sup>&</sup>lt;sup>23</sup>N. v Romania, application no. 38048/18, 16 November 2022.

<sup>&</sup>lt;sup>24</sup>H.L. v. the United Kingdom (no. 45508/99), 5 October 2004.

<sup>&</sup>lt;sup>25</sup>Stanev v. Bulgaria, Grand Chamber, 17 January 2012.

<sup>&</sup>lt;sup>26</sup>Article 22, the proposal.

### VIII. Family and private life

### Living independently and being included in the community

- 43. The removal of an individual to a place of residence for protection purposes may amount to a breach of their right to live independently in their community.<sup>27</sup> This includes the right to choose one's own place of residence,<sup>28</sup> and to live as close as possible in cases of medical placements to their own community.<sup>29</sup>
- 44. To this, the CRPD Committee has recently expressed concerns to the Andorran government about the absence of deinstitutionalisation strategies for persons with disabilities, the difficulty in accessing independent living programmes, and public funding used to maintain institutions.<sup>30</sup>
- 45. In doing so, the Committee has recommended that the government 'provide community-based services aimed at enabling persons to live independently and to participate in the community', and '[s]trengthen support arrangements for persons with disabilities to live independently in the community, including accessible and affordable housing'.<sup>31</sup>
- 46. In its <u>Concluding observations on the initial report of France</u>, <sup>32</sup> the Committee has recommended that the government '[e]nd *the institutionalization of children and adults with disabilities, including in small residential homes, and launch a national strategy and action plans to end the institutionalization of persons with disabilities'.* <sup>33</sup>
- 47. With specific reference to the accommodation and residence of persons with disabilities, the Committee has recommended that the government in question ensure 'the availability of support to live independently and in the community, such as user-led budgets and personalized support, and enable persons with disabilities to exercise

<sup>&</sup>lt;sup>27</sup>Article 19, CRPD; Article 26, EU Charter.

<sup>&</sup>lt;sup>28</sup>Article 19, CRPD; Article 26, EU Charter.

<sup>&</sup>lt;sup>29</sup>Article 25, CRPD.

<sup>&</sup>lt;sup>30</sup>Concluding observations on the initial report of Andorra, CRPD/C/AND/CO/1, 8 September 2023, §39.

<sup>&</sup>lt;sup>31</sup>Concluding observations on the initial report of Andorra, CRPD/C/AND/CO/1, 8 September 2023, §40.

<sup>&</sup>lt;sup>32</sup>CRPD/C/FRA/CO/1, 4 October 2021.

<sup>&</sup>lt;sup>33</sup>§41.

choice and control over their lives and to make decisions concerning where and with whom to live ... [and] [a]dopt measures to ensure the access of persons with disabilities to affordable and accessible housing on the basis of individual choice and outside any type of congregated premises.'34

- 48. Consideration must also be given to the rights to equality and non-discrimination in this context, which are provided for by the CRPD, ECHR, and EU Charter.<sup>35</sup>
- 49. The CRPD Committee has found that the denial of reasonable accommodation to persons with disabilities ought to be regarded as a form of discrimination.<sup>36</sup> In recommending measures to prevent discrimination based on disabilities, the Committee has also recommended that guidelines are adopted which address state and non-state actors 'on their obligations to provide reasonable accommodation in a broad range of areas, including health ... and access to services in the community.'<sup>37</sup>
- 50. We are firmly of the view that Article 21 runs contrary to the provisions of CRPD to which we have referred, particularly in so far as there is presumption that persons lacking capacity should wherever possible be treated within their own community. The proposed Article 21 risks providing Member States with the scope to deviate from these responsibilities by moving an individual away from their community to another jurisdiction under the auspices of protection and treatment, without adopting measures to provide individuals with such resources in their own communities. In doing so, the proposal also creates risks of breaching the rights to equality and non-discrimination.

<sup>&</sup>lt;sup>34</sup>841.

<sup>&</sup>lt;sup>35</sup>Articles 5 and 12, CRPD; Article 14, ECHR; Articles 20 and 21, EU Charter.

<sup>&</sup>lt;sup>36</sup>Concluding observations on the initial report of France, CRPD/C/FRA/CO/1, 4 October 2021.

<sup>&</sup>lt;sup>37</sup>Concluding observations on the initial report of Andorra, CRPD/C/AND/CO/1, 8 September 2023, §12,

### Family life

- 51. The transfer of an individual to another jurisdiction would necessarily involve their separation from any family members they have relationships with within their own community.
- 52. Of particular concern is the potential this creates for parent-child separation on the basis that the parent with a disability requires protection and cannot care for their child. The CRPD Committee has warned against the separation of children and their parents with intellectual disabilities when there has also been a lack of support to such parents.<sup>38</sup>
- 53. In doing so, the Committee has recommended that measures are adopted 'to replace parental capacity assessments with evaluation of the support needs of parents with disabilities ... and providing legal aid and appropriate procedural accommodations.' 39
- 54. The Committee has further recommended that states '[p]rovide early and comprehensive information and support to ... autistic parents and parents with intellectual or psychosocial disabilities, to assist them to exercise their rights with respect to family life. '40
- 55. In our opinion the right to family life<sup>41</sup> risks being undermined by measures taken under Article 21, noting that the proposal does not contain any expressed provisions seeking to safeguard this specific right.

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<sup>&</sup>lt;sup>38</sup>Concluding observations on the initial report of Israel, CRPD/C/ISR/CO/1, 8 September 2023, §49.

<sup>&</sup>lt;sup>39</sup>Concluding observations on the initial report of Israel, CRPD/C/ISR/CO/1, 8 September 2023, §50.

<sup>&</sup>lt;sup>40</sup>Concluding observations on the initial report of France, CRPD/C/FRA/CO/1, 4 October 2021, §49.

<sup>&</sup>lt;sup>41</sup>Article 23, CRPD; Article 8, ECHR; Article 7, EU Charter.

### Physical and personal integrity

- 56. The forcible transfer of an individual to another jurisdiction for protection purposes, which may involve forced medical treatment, may also impact their physical and personal integrity.<sup>42</sup>
- 57. Article 17 CRPD requires states to respect and protect the integrity of the person. Read in conjunction with the right to health under Article 25, the Committee has confirmed that the CRPD requires states 'to abolish the use of physical, chemical, and other medical non-consensual measures, with regard to persons with psychosocial disabilities in institutions. '43
- 58. The ECtHR has similarly found violations of the right to private life on the basis that the forced administration of medical treatment of an individual with a mental disability constitutes a violation of their physical integrity.<sup>44</sup>

#### IX. Healthcare

- 59. The CRPD and EU Charter provide for the right to healthcare, which includes the requirement that Member States provide adequate healthcare services to all persons in their jurisdiction without discrimination,<sup>45</sup> and to provide for individuals' habilitation and rehabilitation.<sup>46</sup>
- 60. In its <u>Concluding observations on the initial report of Andorra</u>, <sup>47</sup> the CRPD Committee addressed 'the barriers faced by persons with disabilities, particularly persons with intellectual and/or psychosocial disabilities, in accessing health-care services, which include inaccessible health-care facilities and information, and lack of reasonable accommodation'. <sup>48</sup>

<sup>&</sup>lt;sup>42</sup>Article 17; CRPD; Article 8, ECHR; Article 3, EU Charter.

<sup>&</sup>lt;sup>43</sup>Views adopted by the Committee under Article 5 of the Optional Protocol, concerning communication No. 61/2019, 28 August 2023, §10.

<sup>&</sup>lt;sup>44</sup>Shtukaturov v Russia, application no. 44009/05, 27 March 2008; and X v. Finland, application no. 34806/04, 3 July 2012.

<sup>&</sup>lt;sup>45</sup>Article 25, CRPD; Article 35, EU Charter.

<sup>&</sup>lt;sup>46</sup>Article 26, CRPD.

<sup>&</sup>lt;sup>47</sup>CRPD/C/AND/CO/1, 8 September 2023.

<sup>&</sup>lt;sup>48</sup>§51.

61. It recommended that the Andorran government '[s]trengthen action plans to ensure the accessibility and availability of quality health services, information and equipment for persons with disabilities, including the provision of reasonable accommodation by public and private health-care providers'.<sup>49</sup>

62. The Committee went further to require that the government 'develop cross-sectoral habilitation and rehabilitation services, programmes and technology available to persons with disabilities, within their community'. 50

63. Article 21, as currently drafted, risks allowing Member States to evade these responsibilities by permitting individuals to be transferred away from their communities including to other states for the purposes of healthcare, habilitation, and rehabilitation; without taking all reasonable steps to provide these facilities and services in or close to their own community, and without any multidisciplinary assessment determining what the individual's needs and best interests require.<sup>51</sup>

#### X. Harmonisation

64. The CRPD necessarily requires the EU to protect the autonomy of persons with disabilities. In the context of legal and mental capacity issues, in practice this requires the EU to advance supported decision-making frameworks and move away from regimes which institutionalise persons with disabilities.

65. Member States enjoy a margin of appreciation with respect to how they choose to implement their international human rights law obligations, depending on a variety of factors including their domestic norms and practices.<sup>52</sup>

66. It is therefore not possible to propose a blanket formula providing for supported decision-making measures.

<sup>50</sup>854.

<sup>&</sup>lt;sup>49</sup>852.

<sup>&</sup>lt;sup>51</sup>Article 26(1)(b), CRPD; Article 26, EU Charter.

<sup>&</sup>lt;sup>52</sup>Save for the human rights which do not afford such margins.

#### XI. Conclusions

- 67. We do not think it appropriate for us to suggest the precise form in which amendments should be made to the proposed EU Regulation. That is properly a matter for the EU institutions themselves.
- 68. We are firmly of the view, however, that substantial changes are required to the current proposed Regulation if it is to achieve its expressly stated aim, which is to incorporate and build upon the spirit and provisions of the CRPD, ECHR, and EU Charter, as well as the HCCH:
  - a. For the reasons set out above we regard Article 21 and Recital 33 as incompatible with the CRPD, ECHR, and EU Charter. We suggest these provisions require removal, or very substantial amendment paying regard to the multiple concerns we have expressed herein.
  - b. We recommend consideration be given to the inclusion of one or more Recitals and Articles focussing primarily on Article 12 of the CRPD, drawing a firm distinction between the concepts of legal capacity and mental capacity, enshrining the principle of supported capacity, and making it clear that the fundamental principle that all persons with compromised mental capacity should be entitled to receive all necessary and appropriate support in order to assist them to retain and exercise their legal capacity.
  - c. We recommend the inclusion of an Article further providing that measures and interventions must take into account the wishes and preferences of the individual, expressed through a supported decision-making process tailored to their individual needs, and must at all times and in all respects be in their best interests (taking into account their fundamental human rights).
  - d. We recommend that Article 22 be developed and refined so as to specify which of the two representatives in an international situation retains ultimate responsibility for the protected adult, and the nature and limits of their functions. In our view prima facie the guardian and/or authority of the originating or

domestic state should retain ultimate control, and the representative in the receiving state should act subject to the authority of that person. We also recommend that the Article should ensure that the notion of representation is intended as a support for decision-making purposes, as opposed to transferring the rights of personhood.<sup>53</sup>

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Date: 2<sup>nd</sup> November 2023

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<sup>&</sup>lt;sup>53</sup>See also: 'Joint Submission: Towards Greater Coherence of International Law', UN Special Rapporteur on the rights of persons with disabilities and the UN Independent Expert on the enjoyment of all human rights by older persons, 2 August 2023.