United Nations A/HRC/52/32/Add.1

General Assembly

Distr.: General
28 December 2022

Original: English

Human Rights Council
Fifty-second session
27 February–31 March 2023
Agenda item 3
Promotion and protection of all human rights, civil, political, economic, social and cultural rights, including the right to development

Visit to the European Union

Report of the Special Rapporteur on the rights of persons with disabilities, Gerard Quinn*

Summary

The Special Rapporteur on the rights of persons with disabilities, Gerard Quinn, visited the institutions of the European Union from 21 to 31 March 2022. In his report, he welcomes the strong and sincere commitment of the European Union to implementing the Convention on the Rights of Persons with Disabilities, including through a number of legislative and policy initiatives, such as the new European Union Disability Strategy, 2021–2030. He applauds the objective to mainstream disability perspectives into all policy domains, as observed during his discussions with various European Union institutions and offices, including on internal staff matters within the European Union, legislation and policies applied in member States of the European Union in relation to employment and independent living, and the way disability rights are articulated in the external relations and cooperation of the European Union. Going forward, the Special Rapporteur recommends consistently harmonizing European Union laws and policies with the Convention on the Rights of Persons with Disabilities in the field of independent living and deinstitutionalization. To this end, the significant funds at the disposal of the European Union should be once and for all shifted from investments in residential institutions towards building up community-based services to enable community living.

* The summary of the present report is being circulated in all official languages. The report itself, which is annexed to the summary, is being circulated in the language of submission only

Annex

Report of the Special Rapporteur on the rights of persons with disabilities, Gerard Quinn, on his visit to the European Union

I. Introduction

1. The Special Rapporteur on the rights of persons with disabilities, Gerard Quinn, visited the European Union from 21 to 31 March 2022. He is grateful to the European Union for openly welcoming him to visit its institutions and to assess, in a spirit of dialogue and cooperation, the record and future ambitions of the European Union in advancing the rights of persons with disabilities. He wishes to particularly express his appreciation to the focal points within the European Commission and the European External Action Service, who were designated to coordinate the visit, for their professionalism and courtesy. He would also like to extend his deepest gratitude to all the persons with disabilities and their representative organizations with whom he met for their honesty, realism and high expectations for the European Union.

2. During the visit, the Special Rapporteur met with high-level representatives and services across the European Union institutions, including the European Commissioners for Equality and for Budget and Administration. He thanks them for their leadership and openness. The Special Rapporteur had intensive dialogues with a wide array of directorates-general and services of the European Commission, as well as with representatives of the other European Union Institutions, including the European Parliament and the Council of the European Union (specifically the Council's Working Party on Human Rights). He also met with some important ancillary bodies of the European Union, such as the European Union Special Representative for Human Rights, the European Ombudsman and the European Union Agency for Fundamental Rights.

3. A brief account of some of those meetings, together with some conclusions and priority recommendations, are set out below.

4. The Special Rapporteur decided to conduct a visit to the European Union for three reasons. Firstly, there are approximately 87 million persons with some form of disability living in the European Union. These numbers alone point to a natural concern to ensure that the inherent potential of the European Union to act as a force for good in the world and for its own residents with disabilities is optimized. Secondly, the European Union – alongside its member States – ratified (technically, "confirmed") the Convention on the Rights of Persons with Disabilities in 2010.[1] This creates an important legal impetus to align European Union law and policy with the Convention, with a view to achieving its aims. Thirdly, the European Union does, indeed, possess its own powers and competencies to act, in addition to the many important competencies it shares with its member States. Even where such powers are lacking, the European Union nevertheless has the intrinsic ability to support its member States in their own efforts. Furthermore, and unlike most other regional arrangements of States, the European Union can leverage significant financial and other assets to facilitate and accelerate positive change. An incidental feature of the visit was to gain an insight into the lessons that might be usefully shared with other regional organizations of States. Such regional bodies are indeed active in facilitating the implementation of human rights in their own member States, and all stand to gain by sharing this experience.

5. Overall, the Special Rapporteur got the clear impression of a dedicated, sincere and earnest public service intent to implement both the letter and the spirit of the Convention on the Rights of Persons with Disabilities. The spread of legislative and other innovations is impressive. But these positive aspects are perhaps undercut somewhat by the ongoing ambiguity over the legal status of the Convention in European Union law and policy and,

[1] The text of the decision on ratification, Council Decision 2010/48/EC, is available at https://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=CELEX:32010D0048&from=EN.

relatedly, by the lack of a consistent approach with regard to the use of European Union funds to advance the Convention's implementation, especially in the field of independent living. These drawbacks can be easily rectified with a deeper understanding of the jurisprudence of the Convention, together with a clear commitment to follow it consistently when crafting European Union law and policy and with sufficient political will.

II. Background

A. The close historic links between the European Union and the United Nations on disability policy

6. There has always been a long and mutually beneficial relationship between European Union action and global disability standards, dating back as far as the early 1980s. At that point in time, the European Commission set up a dedicated unit on disability as its contribution to the United Nations Decade of Disabled Persons (1983–1992). This was the first such unit in any regional organization in the world.

7. Global disability policy in the early 1980s was trending towards a newer model based on equality. At the United Nations level, this was crystallized in the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, adopted in 1993 by the General Assembly in its resolution 48/96. Directly inspired by the Standard Rules of the United Nations, there was a major policy shift in the European Union in 1996, and it henceforth adopted the broad philosophy of equality of opportunities in the context of disability policy.[2] This policy shift was further consolidated by underlying changes to the treaties of the European Union in 1997 that enabled the European Union to adopt legislative measures to combat discrimination on the grounds, inter alia, of disability.

8. Partly because of the shift to using equality of opportunities to frame policy on disability, and partly because it was evident that the Convention on the Rights of Persons with Disabilities (which was then being drafted) would use an equality of opportunities framework, the European Union took an active part in the drafting process.[3] Indeed, it was the very same equality changes in the European Union treaties in 1997 that enabled the European Union to ratify (confirm) the Convention in 2010. The combination of these new equality powers with existing internal market powers (the power to regulate trade across national boundaries) provided and continues to provide a robust legal basis for European Union action on disability.

9. Self-evidently, the equality concept is the key bridge that links the Convention on the Rights of Persons with Disabilities with European Union law and policy. It matters therefore that the philosophy of equality that is operationalized within European Union law and policy on disability is aligned as closely as possible with universal understandings of equality as reflected in the Convention and in the authoritative pronouncements of the Committee on the Rights of Persons with Disabilities.

B. The European Union journey – successive disability strategies

10. Many European Union disability strategies have been adopted since 1996. The strategy of 1996 marked a turning point, moving away from policies of the past based on charity towards a model based on equality of opportunities. Even in 1996, the strategy promised better use of European Structural and Investment Funds – used to reduce inequality across the European Union – as an integral part of delivering on its objectives.

[2] See European Commission, "Communication of the Commission on Equality of Opportunity for People with Disabilities: A New European Community Strategy", COM(96) 406 final (July 1996).

[3] See Grainne de Burca, "The EU in the Negotiation of the UN Disability Convention", *European Law Review*, vol. 35, No. 2 (2010).

11. The European Disability Strategy 2010–2020: A Renewed Commitment to A Barrier-Free Europe[4] was the first disability strategy to be adopted by the European Union after it ratified the Convention on the Rights of Persons with Disabilities. It itemized several areas for action, including external action (foreign policy). Innovations with respect to accessibility featured prominently, and indeed many legislative measures have been adopted to implement them. For example, the European Accessibility Act of 2019[5] was clearly a step in the right direction. But gaps remain. The built environment was included only as an option for member States, and other essential products and goods, such as household appliances (e.g., kettles), were not included. Presumably, the European Union will work hard to close these gaps during the lifetime of the new Disability Strategy.

12. The most recent Disability Strategy, 2021–2030,[6] is even more explicitly tied to the overarching ideal of equality and the overall European Union effort to give effect to the Convention on the Rights of Persons with Disabilities. The Strategy can be seen as a programmatic approach to implementing the Convention within the confines of existing European Union-level powers. On its face, the Disability Strategy does not seem attuned to the particular rights and needs of specific groups, like persons with intellectual disabilities, autism, psycho-social disabilities, the deaf community or persons with Alzheimer's disease. The Special Rapporteur assumes this narrow focus can be expanded as the Strategy is rolled out. It needs to be. And some obvious issues of law reform, like the granting of official European Union language status to sign language (which already has official status in all the member States), ought to be contemplated and put on the agenda for change.

13. Mainstreaming of disability perspectives into all policy domains remains a key objective. Many advances in this regard are reported – for example, in proposed directives on combatting violence against women and on victims' rights. This is a welcome development. However, this practice needs to become more systematic across the board. The process by which the European Commission consults with the population at large about intended policy changes also needs to be made much more accessible (especially in online platforms), to include a wider diversity of groups.

14. Furthermore, European Union treaty provisions on equality have now been strengthened with the entry into force of the Charter of Fundamental Rights of the European Union, which also contains a robust provision on equality that explicitly embraces disability (art. 21), as well as a specific provision on the integration of persons with disabilities (art. 26). The focus in article 26 on community inclusion would seem to reinforce the view that the segregation of persons with disabilities into institutions is a form of discrimination prohibited by article 21. The Charter of Fundamental Rights is rounded out by the European Pillar of Social Rights, with an associated action plan.

C. Ratification of the Convention by the European Union – legal implications and problems

15. European Union ratification (confirmation) of the Convention on the Rights of Persons with Disabilities means the European Union is bound by the Convention with respect to powers within its exclusive domain. If it shares powers with the member States (which covers the majority of its powers) then it must "declare" when they trigger European Union-level accountability under the Convention. Such a declaration of competence is required under article 44 of the Convention.

16. One technical matter – but an important one – to take into consideration is that the Convention on the Rights of Persons with Disabilities is what is called a "mixed" Convention, owing to the fact that both its member States and the European Union itself have ratified it.

[4] Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions, COM(2010) 636 final, 15 November 2010.

[5] Directive 2019/882 of the European Parliament and of the Council of 17 April 2019 on the accessibility requirements for products and services.

[6] "Union of Equality: Strategy for the Rights of Persons with Disabilities", COM(2021) 101 final, Brussels, 3 March 2021.

Both the European Union and its member States have the responsibility to implement the Convention. This gives rise to a European Union treaty-based duty of "sincere cooperation" by and between the European Union and its member States.[7] The use of European Union funds constitutes an important contribution to the implementation of the Convention, which requires strong cooperation between the European Union and its member States, and the respective obligations should not be shifted from one side to the other. This places a premium on effective processes for coordination.

17. However, some doubt about the legal status of the Convention in European Union law has been expressed by the Legal Service of the European Commission in a widely circulating legal opinion of 2018.[8] A series of questions were put to the Legal Service, enquiring whether the expenditure of European Union taxpayer funds on long-stay institutions for persons with disabilities (including older persons) could be supported by European Union funds or whether it was contrary to the underlying regulations governing the funds and therefore "irregular". A separate question focused on the legal force or status of general comment No. 5 (2017) of the Committee on the Rights of Persons with Disabilities concerning the right to live independently and be included in the community. A final question probed whether the Commission could (or should) be obliged to impose a financial correction (i.e., claw monies back from member States) if there had been a "breach of fundamental rights in residential institutions which received support from the [European funds]". Note, the question did not ask whether institutions were themselves a per se violation of human rights. The jurisprudence of the Committee on the Rights of Persons with Disabilities has steadily crystallized on this issue.

18. Perhaps the way the questions were put helped to shape the rather narrow answers given in the legal opinion. The Legal Service came to the conclusion that neither the relevant European Union regulations nor article 19 of the Convention "establish a general and absolute prohibition to support long-stay residential institutions".[9] It framed deinstitutionalization as a process with a considerable amount of discretion. It asserted that the relevant regulations did not contain any explicit prohibition on institutionalization. What is conspicuously missing from the Legal Service's line of reasoning is the effect of the overall non-discrimination provisions either in the underlying regulations or under article 5 of the Convention. Furthermore, in its opinion, the Legal Service asserted that other policy goals (e.g., supporting the shift to a carbon-neutral economy and promoting climate change adaptation) could be used to embrace investment in institutions. This seems curious as it would mean that one set of key imperatives (i.e., human rights) could be made to subserve another set of policy goals. The Legal Service did assert that member States were nevertheless required to "progress on ensuring independent living arrangements and deinstitutionalization".[10] There was no extended analysis in the legal opinion of the requirements of such "progressive realization" under international law, much less the Convention.

19. In addition, in its opinion, the Legal Service asserted that general comment No. 5 (2017) was not legally binding. This misses the point. The prohibition on discrimination in the Convention (art. 5) is legally binding and there is a consensus among jurists that segregation in its most extreme form – institutionalization – is a per se example of discrimination. The Supreme Court of the United States of America has explicitly ruled on this point (albeit with some important caveats that do not apply in the case of the Convention).[11]

[7] The duty of sincere cooperation is laid down in article 4 (3) of the Treaty on European Union.

[8] "Programming Period 2014–2020: United National Convention on the Rights of Persons with Disabilities – Eligibility – Investments in Long-stay Institutions", 29 June 2018, available at https://enil.eu/wp-content/uploads/2022/07/Opinion-of-the-Legal-Service-of-the-European-Commission.pdf.

[9] Ibid., sect. 2.1, p. 2.

[10] Ibid., p. 3.

[11] See *Olmstead v. L.C.,* 527 U.S. 581 (1999). For a review of the decision 20 years on, see Stacie Kershner and Susan Walker Goico, eds., "*Olmstead* at Twenty: The Past and Future of Community Integration", *Journal of Legal Medicine*, vol. 40, No. 1 (May 2020).

20. The last question – whether a financial correction could be imposed – was also answered in the negative. It was correctly pointed out that the Charter of Fundamental Rights only applies to member States when they are implementing European Union law, and it was asserted that this was not the case in the expenditure of European Union monies through the funds. This view is directly contradicted by the European Ombudsman.[12] The accompanying analysis in the opinion contains no consideration of the non-discrimination provisions in the Charter of Fundamental Rights (or the Convention).

21. The Legal Service concludes its opinion by asserting that member States can "choose to co-finance infrastructures and services concerning long-stay institutions with [European Structural and Investment] funds. … Member States are however required to progress in general on ensuring independent living arrangements and deinstitutionalization".[13] Implicit in this reasoning is a view of progressive realization that simply does not fit with international legal obligations. The concept of progressive realization is not developed – nor are the parameters that normally apply to the concept discussed. Downsizing from a large institution (say, 100 people) to a smaller one (say, 10 people) does not amount to progressive realization as understood under international law.

22. Naturally, the Special Rapporteur raised the issue of the legal opinion with the European Commission's Legal Service during the visit. That meeting was frank, courteous and professional. Afterwards, the Special Rapporteur received a clarificatory note from the Legal Service.[14] The clarificatory note stated that the main issue of principal raised in the discussions with the Special Rapporteur – whether institutionalization amounts to discrimination – was not posed in the questions put to the Legal Service. The note stated that the core question posed was whether "under the regulations [obtaining at the time] the conditions for applying the financial correction were not met". However, the Legal Service's opinion did not consider the legal effect of the overarching provision of non-discrimination in the relevant regulations – nor those set out in article 5 of the Convention.

23. More usefully, concerning the question of whether institutionalization amounts to discrimination, the clarificatory note stated that the "Legal Service's [legal opinion of 2018] cannot be interpreted as endorsing any view on that matter". The clarificatory note further states that "it is not excluded that [such] segregation of persons on the basis of their disability, in the future, and as long as the issue would fall within the material scope of [European Union] law, could as well be regarded as discrimination within the meaning of [European Union] law by the Court of Justice." The observation that institutionalization might be framed as discrimination is welcome. However, given that many courts around the world, as well as the Committee on the Rights of Persons with Disabilities, regard it to be so means that there should be no need to wait for permission from the European Court of Justice to enforce the clear non-discrimination provisions of the underlying European Union regulations and the Convention. Certainly, the European Commission, as guardian of the European Union treaties, has not hesitated to take action to enforce the Charter of Fundamental Rights on other grounds, and it seems anomalous to have to wait for permission from the courts to do so in this field.

24. Given the narrowness of the original questions posed and the resulting gaps in the legal reasoning of the Legal Service's opinion, there appears ample space for a reconsideration of the issues.

25. During helpful discussions with the Directorate-General for Justice and Consumers it was emphasized that there was a new strategy to strengthen the application of the Charter of Fundamental Rights.[15] It contains a commitment to ensure that programmes supported by

[12] See "Decision on the Own Initiative Inquiry into How the European Commission Monitors EU Structural and Investment Funds to Ensure They Are Used to Promote the Right of Persons with Disabilities to Independent Living and Inclusion in the Community" (OI/2/2021/MHZ) of 27 April 2022.

[13] Sect. 3, p. 6.

[14] Email dated 30 March 2022, on file with the Special Rapporteur.

[15] Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions, "Strategy to Strengthen the

relevant European Union funds comply with the relevant provisions of this Charter.[16] This is very welcome, provided of course that institutionalization is seen as a form of discrimination contrary to article 21 of the Charter. The Disability Strategy, 2021–2030, also envisages that national human rights institutions should have a role on national monitoring committees overseeing the implementation of the programmes using these funds, in compliance with the Charter. This, too, is welcome, provided that national human rights institutions have a consensus view on the impermissibility of spending funds on institutions. And it is also welcome if national human rights institutions are given a role in assessing complaints about the use of the funds involving national authorities. It was mentioned in discussions that there was a difference of culture on this issue between the Directorate-General for Justice and Consumers (which was more open to the framing of institutions as discrimination) and the directorates-general spending the funds.

26. The issue of legal capacity arose during discussions with the Directorate-General for Justice and Consumers. It appears that, prior to Brexit, up to 800,000 European Union citizens were denied the right to vote in European Parliament elections due to national legal incapacity laws. That number has been reduced since Brexit but is still considerable. In this regard, the European Parliament has the right of legislative initiative and it appears that reform legislation is being proposed that would eliminate this obvious discrimination. While this is a welcome development, the Special Rapporteur did express the view that the European Union could probably do more (for example, through technical assistance, guidance and platforms) to assist its member States to migrate away from guardianship regimes.

27. The question of the ratification by member States of the Convention on the International Protection of Adults also arose in discussions with the Directorate-General for Justice and Consumers. The Special Rapporteur emphasized the imperative of ensuring that such ratifications, if carried out, should not be used to block the trajectory of reform under the Convention towards eliminating guardianship. He pointed to a joint position on the matter issued by himself and the Independent Expert on the equal enjoyment of all human rights by older persons, [17] and to a model declaration that States could make when ratifying the Convention on the International Protection of Adults to ensure that this did not happen.[18] There seemed to be agreement on this point, which was very welcome.

D. The record to date: the European Union before the Committee on the Rights of Persons with Disabilities

28. To date, the European Union has reported once to the Committee on the Rights of Persons with Disabilities, in 2014. Its initial report [19] provides an extensive and clear background of the history of European Union law and policy and the nature of European Union powers in the context of disability. Following the Convention's structure, it provides an article-by-article account of European Union laws and policies.

29. In its concluding observations on the initial report of the European Union,[20] the Committee recommended that the European Union ratify the Optional Protocol to the Convention, conduct a cross-cutting, comprehensive review of its legislation in order to ensure full harmonization with the provisions of the Convention, and initiate a structured dialogue for coordination across European Union institutions, agencies and bodies and for meaningful consultation with and the participation of persons with disabilities, through their

Application of the Charter of Fundamental Rights in the EU", COM(2020) 711 final, 2 December 2020.

16 Ibid., sect. 1.2.

17 "Toward Greater Coherence of International Law: Reflections on the Hague Convention (2000) on the International Protection of Adults", 8 July 2021, available from https://www.ohchr.org/en/special-procedures/ie-older-persons/comments-legislation-and-policy.

18 See Sonia E. Rolland and Alex Ruck Keene, "Interpreting the 2000 Hague Convention on the International Protection of Adults Consistently with the 2007 UN Convention on the Rights of Persons with Disabilities", study commissioned by the Special Rapporteur on Disability, 3 June 2021

19 CRPD/C/EU/1.

20 CRPD/C/EU/CO/1.

representative organizations. Tellingly, the Committee specifically recommended in crystal clear language that the European Union should develop an approach to guide and foster deinstitutionalization and to strengthen the monitoring of the use of European Structural and Investment Funds to ensure they were used to develop community services and not for the redevelopment or expansion of institutions.[21]

30. In 2022, the Committee issued a list of issues that the European Union should address prior to drafting its next report to the Committee.[22] In that document, the Committee specifically requests information on efforts to revise the legal opinion of 2018 and to immediately discontinue European Union investments and actions that maintain institutionalization of persons with disabilities, with a focus instead on developing a range of in-home and community support services.[23]

31. It is fair to assume that the legal opinion of 2018, as well as the seeming lack of progress in shifting funding away from all forms of institutionalization, will be a cause for deep concern for the Committee in the next reporting cycle. The focus of the next review will likely be on "trans-institutionalization" (spending funds on smaller-sized institutions, which are nevertheless institutions, and therefore possibly leading to persons with disabilities moving between institutions rather than moving into community settings) and on the use of funding mechanisms to improve institutions, thus extending their longevity. It is also likely that there will be a clearer and deeper focus on the concept of progressive realization and whether investment in smaller institutions is permissible.

III. Substance: policy and legislative initiatives

32. During his meetings with many European Union services, the Special Rapporteur was impressed by the wide array of initiatives and legislative measures adopted by the European Union to advance the rights of persons with disabilities and the Convention. What follows is a summary of some of the highlights.

A. European Union laws and policies

Employment

33. To date, only one legal instrument has been adopted by the European Union to prohibit discrimination on the ground of disability and only in the field of employment: European Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation. A significant body of case law has emerged from the European Court of Justice on the prohibition of discrimination on the ground of disability.[24]

34. A long-standing proposal by the European Commission, dating back to 2008, to adopt a more horizontal directive covering disability as a ground of discrimination in many different policy fields has not made it past the Council of the European Union, which must vote unanimously for its adoption.

35. Certainly, the adoption of such a directive could be seen as a major step in implementing article 4 of the Convention on the Rights of Persons with Disabilities, which requires parties to adopt all appropriate legislative measures and to end discrimination by all appropriate measures. The Special Rapporteur encourages the European Union to redouble its efforts to enact such a directive, as it would round-out the deep logic of Directive 2000/78/EC and would be a very visible way to advance the Convention through European Union law.

[21] Ibid., para. 51.
[22] CRPD/C/EU/QPR/2-3.
[23] Ibid., para. 21 (b) and (c).
[24] See Lisa Waddington and Anna Lawson, eds., *The UN Convention on the Rights of Persons with Disabilities: A Comparative Analysis of the Role of Courts* (Oxford University Press, 2018).

Independent living

36. The Special Rapporteur's discussions on the right to independent living with the Directorate-General for Regional and Urban Policy revolved around the Legal Service's legal opinion of 2018. The European Union is unusual among regional organizations in having at its disposal funds that can be used for a variety of purposes in the broader public interest. Principally, these include the European Structural and Investment Funds and, in particular, the European Regional Development Fund, which primarily focuses on infrastructure, and the European Social Fund Plus, which focuses on employment and social support.

37. The overall philosophy of the European Structural and Investment Funds, as part of European Union cohesion policy, is one of ironing out development wrinkles across the European Union to ensure that underdeveloped regions have an opportunity to level up. A key overarching principle is that of European Union "additionality" – the idea that the funds are not to be used to substitute for the regular fiscal responsibilities of the receiving States but to stimulate innovation.

38. The relevant set of underlying regulations for the European structural and investment funds were enacted in 2012 and again in 2020. Prior to that, the funds were openly used to build institutions for persons with disabilities. A public campaign was initiated to change the regulations in 2012 to try to ensure that future spending would be focused on building up community-based services to enable community living.

39. So-called ex-ante conditionalities were added to the regulations in 2012 to the effect that the funds could be spent to assist the transition from institutions to community-based care (although the use of the word "care" is now somewhat outdated). The regulations do not, on their face, prohibit the spending of funds on institutions – or on trans-institutionalization. It was simply assumed that member States of the European Union would take their cue from the ex-ante conditionalities and not do this, or propose it.

40. It is to be recalled that article 19 of the Convention contains a very positive philosophy of flourishing in the community. It nowhere mentions the word institution or institutionalization – precisely because it was intended to paint a picture of a more positive set of obligations and outcomes. One can certainly infer from article 19 a predilection against any form of congregated setting. The negative side of this picture is more explicitly drawn in article 5 of the Convention (equality and non-discrimination). Put simply, any form of segregation in its most extreme form (institutionalization) is presumed to be discrimination.

41. Although the regulations underlying the European Union funds do not specifically prohibit spending on institutions (whether to improve them or otherwise) they do contain a reference to the relevant equality provision in the Charter of Fundamental Rights (as a transversal principle) and, indeed, to that of the Convention. The references to the Charter of Fundamental Rights and the Convention are even more pronounced in the newer, 2020 iteration of the regulations.

42. In meetings with the Directorate-General for Regional and Urban Policy, the Special Rapporteur pressed the argument that any form of expenditure of European Union taxpayers' money on institutions falls foul of this guarantee of equality.

43. From this meeting it appears that the relevant authorities in the Directorate-General for Regional and Urban Policy do not believe that segregating persons with disabilities into institutions amounts to discrimination. It is unclear how this view was arrived at, since it is strikingly at odds with the Convention. On the other hand, it was suggested that the spatial segregation of entire communities might amount to actionable discrimination – but not the segregation of persons with disabilities. Again, the foundation for this belief is unclear. It was also indicated to the Special Rapporteur during the meeting that there exists an inter-service consensus paper on this issue and associated points.

44. The consensus paper on "Deinstitutionalization and Financial Support from the European Union Budget for Residential Care Facilities"[25] lists the conditions under which investments in residential care facilities can be envisaged on a case-by-case basis and "in accordance with the requirements of the Convention".

45. This presumes that such expenditures can be in accordance with the Convention. It takes no account of the Convention's non-discrimination norms (art. 5). It places an accent on the individual's right to choose, even though article 19 of the Convention specifically recognizes "the equal right of all persons with disabilities to live in the community, with choices equal to others". So, as set out in article 19, the primary choice in the Convention is not whether to live in the community, but how. There is no need for a case-by-case approach, since the assumption that any form of institutionalization amounts to discrimination should be controlling. In any event, if European Union additionality is understood to mean genuine innovation (in spending taxpayers' money) then there can be no value in spending that money to reinforce outdated policy solutions.

46. The Special Rapporteur suggests that this consensus paper needs to be withdrawn and reconsidered in the full light of the jurisprudence of the Committee on the Rights of Persons with Disabilities, not just on article 19 but also on article 5.

47. There are, of course, some real human rights issues affecting the quality of life in institutions across Europe. These issues have accumulated over the years. But they are not directly or indirectly the fault of the European Union. There can be no European Union "additionality" in fixing human rights problems that are due to the historic and accumulated policies of the member States. It is the view of the Special Rapporteur, which he fully shared with the Directorate-General for Regional and Urban Policy, that going forward European Union funds (representing taxpayers' money) should be used exclusively to assist States to initiate social and health-care reforms to build up a completely different model of community living and to innovate in the public interest. Otherwise, temporary measures may easily rob an entire generation of their chance to flourish as human beings in the community.

48. The European Union Disability Strategy, 2021–2030, proposes to deliver new guidelines on independent living and deinstitutionalization. This should be used as an opportunity to press for a fresh start based explicitly on the Convention. The Special Rapporteur strongly suggests that a thorough re-examination of the situation is warranted. It is a pity that this issue – which has existed for years – continues to linger. It somewhat undercuts the extremely valuable work being done across the various services of the European Union. Great care will be needed to ensure that the promised European Union guidelines on the future of long-term care will not embrace or endorse outdated ideas about the acceptability of institutions. The promised care package should not rely on medical understandings of care; it should be an opportunity to completely reframe the concept of long-term care to mean investing in community-based support services as a viable alternative to any form of institutionalization. The intersectional benefits (e.g., for persons with disabilities and older persons) are obvious.

B. European Union foreign policy

49. The European Union is a major force in the world. It gives pride of place to human rights in its foreign policy, is the single largest donor of development assistance in the world and provides support to neighbouring States in a myriad of ways. The European Union also has a strong and visible presence in many multilateral and regional forums and strongly supports the idea of an international rules-based order. It therefore matters that this prowess is used wisely to help advance the rights of persons with disabilities elsewhere in the world.

50. Two specific articles of the Convention are directly relevant: article 32, on international cooperation, and article 11, on situations of risk and humanitarian emergencies. These articles contain a web of contemplated actions ranging from inclusive development

[25] Upon publication of the Special Rapporteur's end-of-mission statement in March 2022, the Validity Foundation requested a copy of the consensus note from the European Commission through a transparency request. A copy is on file with the Special Rapporteur.

assistance to supporting capacity-building within civil society and throughout the world.[26] What is strikingly impressive about the European Union Disability Strategy, 2021–2030, is a substantial section on promoting the rights of persons with disabilities globally (sect. 6). This is extremely welcome and a model of sorts for other regional arrangements.

Human rights and European Union foreign policy

51. The Special Rapporteur was very impressed with the overall philosophy adopted by the European Union External Action Service and by the European Union Special Representative for Human Rights on this matter. His meetings with both were highly informative.

52. The European Union Action Plan on Human Rights and Democracy, 2020–2024, contains many references to disability, including encouraging the ratification of the Convention by third countries. The Special Rapporteur was particularly impressed to learn that representations of the European Union around the world now have their own focal points on development and disability. The Action Plan is also attentive to international humanitarian law (a key concern for persons with disabilities) and to cooperation with multilateral and regional forums, such as the special procedures of the Human Rights Council, including the mandate of the Special Rapporteur. The Special Rapporteur was gratified to see a section in the *European Union Annual Report on Human Rights and Democracy in the World, 2020* dealing with the rights of persons with disabilities. It would be useful if, in the future, the report might also encompass some analysis of European Union actions to support civil society as interlocutors around the world. Several excellent thematic human rights guidance notes have been issued by the European External Action Service. The Special Rapporteur suggests that one such guidance might be developed on disability rights to further consolidate good practice and guide action.

53. The Special Rapporteur was assured that disability rights feature regularly in bilateral dialogues of the European Union on human rights, and that plans are under way to raise relevant issues in upcoming country visits by the High Representative. There was indeed a consciousness of how important deinstitutionalization issues were across the world.

54. The European External Action Service is active in the Conference of States Parties to the Convention on the Rights of Persons with Disabilities as well as in the Third Committee of the General Assembly, among others. It also contributes regularly to debates on disability rights at the Human Rights Council in Geneva. The Service might explore how it could step up this engagement with the Council and the Office of the United Nations High Commissioner for Human Rights (OHCHR), which would make sense given the prominence of the Convention on the Rights of Persons with Disabilities as the only United Nations human rights treaty ratified by the European Union to date.

55. The engagement of the European External Action Service in regional forums around world is equally impressive. The Special Rapporteur suggests that, given its long history of involvement in disability policy, the European Union is in a prime position to help provide a platform for regional bodies around the world to share good practices and policy perspectives.

56. Closer to home in the European region, it would make sense for the European External Action Service to make its voice heard on disability issues in the Council of Europe system. A good example would be to visibly oppose the adoption of the proposed protocol to the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine. To do so would be fully in keeping with its stated intention to be active and vocal in regional forums on human rights and disability and would certainly bring it closer to the non-coercive model on mental health contemplated by the Convention on the Rights of Persons with Disabilities and, indeed, the World Health Organization.

57. The disability policy and road map for action of the European External Action Service was well thought through and includes plans to make the buildings for European Union

[26] See A/75/186.

representations (embassies) around the world accessible. This is both symbolically as well as practically important.

Directorate-General for Neighbourhood and Enlargement Negotiations

58. The Special Rapporteur was also impressed by the actions – and more importantly the operating philosophy – of the Commission's Directorate-General for Neighbourhood and Enlargement Negotiations, which takes responsibility for policy towards (and support of) accession candidate countries as well as European neighbouring States. Several technical and financial instruments at the disposal of this Directorate-General (e.g., the Neighbourhood, Development and International Cooperation Instrument) have been used to support disability civil society in accession and neighbouring States. The Special Rapporteur was also provided with some examples of funding to put in place community support services to enable community living for persons with disabilities. He was impressed that the Directorate-General for Neighbourhood and Enlargement Negotiations is committed to using the disability marker of the Development Assistance Committee of the Organization for Economic Cooperation and Development (OECD) to ensure the inclusive nature of its projects and programmes.

Directorate-General for International Partnerships and Directorate-General for European Civil Protection and Humanitarian Aid Operations

59. The Special Rapporteur was equally impressed with the openness and willingness of the Commission's Directorate-General for International Partnerships and the Directorate-General for European Civil Protection and Humanitarian Aid Operations to factor relevant disability perspectives into their work and their earnest commitment to implementing the Convention.

60. For example, the Directorate-General for International Partnerships applies the OECD disability marker to assess the inclusiveness of its programmes. It aims to develop the capacity of organizations of persons with disabilities to ensure they can interact effectively with their governments, and its upcoming youth action plan will include persons with disabilities. The Directorate-General co-funded a major project in 2021 with OHCHR resulting in a set of human rights indicators on the Convention in support of a disability inclusive 2030 Agenda for Sustainable Development.[27] There seemed to be a consciousness in the Directorate-General for International Partnerships of the damage done by institutions, especially during the coronavirus (COVID-19) pandemic. The Directorate-General also seemed highly attuned to the exigencies of post-conflict countries and countries with limited health-care systems. Again, the issue of institutionalization arose and the need to avoid exporting outdated Western models. Recent research by the European Network on Independent Living suggests that support for community living is not even across European Union foreign policy funding streams.[28] This warrants closer examination.

61. The Directorate-General for European Civil Protection and Humanitarian Aid Operations seemed especially aware of the vulnerable situations persons with disabilities find themselves in during humanitarian emergencies. In the discussions with the Special Rapporteur, it emphasized the prominence given to international humanitarian law by the European Commissioner for Crisis Management. The Special Rapporteur was also informed about the welcome existence of an inter-service group on international humanitarian law. This news is especially welcome, since persons with disabilities are an object of special protection under the Geneva Convention relative to the Protection of Civilian Persons in Time of War. As a hybrid organization working on both civilian protection as well as humanitarian relief (as exemplified in the Ukraine crisis), the Directorate-General was keenly aware of the many difficulties faced by persons with disabilities during conflicts, and

[27] See https://www.ohchr.org/en/disabilities/human-rights-indicators-convention-rights-persons-disabilities-support-disability-inclusive-2030#Indicators. The indicators are available from https://www.ohchr.org/en/disabilities/sdg-crpd-resource-package.

[28] See Ines Bulić Cojocariu, *Role of the European Union Funding in Supporting Deinstitutionalisation around the World: A Call to Action* (Brussels, European Network on Independent Living and the European Disability Forum, 2022).

especially the impact of non-inclusive means of evacuation. It also seemed highly attuned to the many human rights issues connected with institutionalization, and its ripple effects in reception States.

IV. Process: European Union institutional architecture to drive and monitor change

A. European Union focal points and coordination mechanism

62. Much pride was shown across the European Union services that the European Union has ratified the Convention on the Rights of Persons with Disabilities. In meetings with the Directorate-General for Employment, Social Affairs and Inclusion, the bedrock principle of equality was highlighted. There is now a Taskforce on Equality, whose main purpose is to mainstream equality issues across all European Union policy areas. All directorates-general now have their own equality coordinators who work collaboratively across all services. This information (contact points) should be made more widely available. Neither the Council of the European Union nor the European Parliament appears to have any equivalent focal point or coordination mechanism.

63. Article 33 (1) of the Convention essentially requires a joined-up Government on disability matters. At national level, this ought to be straightforward and entails one central and authoritative body with a voice across the system of governance. Mapping this onto the European Union is intrinsically difficult given the separation (and independence) of the main European Union institutions, including the European Commission, the European Parliament and the Council of the European Union.

64. The European Commission acts as the focal point for the European Union internationally and is the face of the European Union when it reports to the Committee on the Rights of Persons with Disabilities. The body designated within the European Commission to coordinate the European Union response to the Committee is the unit on disability and inclusion within the Directorate-General for Employment, Social Affairs and Inclusion. The Directorate-General for Human Resources and Security also contributes to the reporting process with regard to internal matters, such as the employment of persons with disabilities within European Union institutions and the accessibility of European Union buildings. It would make sense to strengthen this unit and designate it as the central European Union focal point on the Convention. The Special Rapporteur's meetings with the unit were positive and demonstrated the unit's professionalism and keen commitment to implement the Convention in European Union laws and policies. Logically, the unit should perhaps be situated within the Directorate-General for Justice and Consumers, given its centrality and close relationship to the Commissioner for Equality.

65. The European Commission obviously lacks authority to act as focal point for the Council of the European Union and the European Parliament. The Special Rapporteur suggests that some intentional means should be found of ensuring greater coherence across all focal points in the different institutions so that the underlying intention of article 33 (1) – policy coherence within a system qua system – is optimized.

66. The Commission has set up a European Union Disability Platform to replace the former European Union High Level Group on Disabilities.[29] The Platform consists of the national focal points on disability, 12 civil society organizations and observers (United Nations agencies may be invited as observers depending on the topic). Its role is to provide a forum for the exchange of policy perspectives on the implementation of the Convention as well as to provide a space for reflection on how best to implement the recommendations of the Committee on the Rights of Persons with Disabilities. Independent experts (which might include United Nations Agencies, as relevant) can be invited to attend and participate as the

[29] Commission Decision of 27 October 2021 setting up a group of experts "Disability Platform" (2021/C 475 I/01), art. 3.

topic requires. Again, this is a welcome development and sets a model of sorts for other regional groupings of States.

67. As the discussion with the Directorate-General for Justice and Consumers indicated, the European Commission has an elaborate coordination mechanism on disability matters across its services. Each directorate-general has already established its own disability liaison focal point. This is most welcome and critically important since, in most domains, the European Commission retains the sole right to propose legislative and other initiatives. The true test of this mechanism over time will be to see whether proposals in fields as diverse as agriculture, banking, external action and digital Europe will incorporate relevant disability perspectives.

B. European Union monitoring framework

68. Since 2016, the Convention's article 33 monitoring functions have been performed by the European Parliament, the European Union Agency for Fundamental Rights, the European Ombudsman and the European Disability Forum. Apparently, this arrangement is under review in 2022 and further developments or refinements are expected. A way needs to be found to make this framework fully functional with a common focus and way of working. This is crucial to avoid needless mistakes.

69. The European Union is assisted by its Agency for Fundamental Rights, whose main task is to provide evidence-based advice on human rights to member States when implementing European Union law. The Special Rapporteur's meeting with the Agency was fruitful. The work of this Agency on disability rights is admirable and even extends to providing practical advice on how to change budgeting systems to ensure monies are diverted away from institutions towards community living. The European Ombudsman can entertain complaints from citizens (and staff members) about maladministration and has developed an impressive body of work on disability matters.

70. The European Network of Equality Bodies is also active on disability matters. This is important, since the doctrine of sincere cooperation requires such bodies to provide assistance in determining what is happening on the ground. The Network periodically clarifies core concepts like "reasonable accommodation", which is a great contribution to reform.

71. European-level philanthropies also play a major role in building capacity, especially among civil society. The Special Rapporteur had excellent meetings with the European Network of Equality Bodies and Philea – Philanthropy Europe Association (formerly, the European Foundation Centre), a network of philanthropies supporting the Convention's implementation across Europe. Philanthropy could play a major role in assisting the monitoring of the expenditure of European Union funds and in equipping civil society with the tools to do so.

V. Leading by example: internal European Union issues

72. In its declaration of competence under article 44 (1) of the Convention, the European Union declared its exclusive competence with respect to its own public administration, including recruitment, conditions of service, remuneration and training, among others. Furthermore, the new European Union Disability Strategy aims to lead by example and to make the European Union a model in this area.

73. Considerable progress can be reported in this regard. The Special Rapporteur was very impressed with the earnest commitment of the Directorate-General for Human Resources and Security to advance the agenda of an inclusive and diverse workplace across the European Union.

74. One unusual feature of the process was the breadth of medical testing allowable in the hiring process. It was explained to the Special Rapporteur that a person is not hired for a specific post but for any potential post across the services, and that therefore a generalized medical testing regimen was required. This struck him as unusual and not in keeping with the global migration away from the medical model of disability towards one more informed

by a social model. Furthermore, it appears that if one fails the medical test then admission to invalidity and death benefits can be suspended for new employees for up to five years. This seems discriminatory on its face and extreme and warrants revision.

75. Also, it appears that medical services are also engaged when determining whether a "reasonable accommodation" is needed for an employee. Again, this gives some pause for thought as many disabilities do not constitute illnesses as such. Perhaps some more reflection is needed as to the proper admixture of a medical model with the rights-based model of disability.

76. The new innovation of reasonable accommodation committees within each service is to be greatly welcomed.

77. The medical character of the social benefits packages available to staff was also highlighted in many meetings. For example, to obtain certain reimbursements a family with an autistic child must get a medical declaration (or the administrative equivalent) that the autism in question represents a long-term illness. Maybe a way could be found of allowing such reimbursements but without recourse to such administrative labelling.

78. As an aspect of leading by example, the European Commission is making strenuous efforts to ensure its buildings and web platforms meet universal design standards. This ongoing work is to be strongly encouraged. It has tangible benefits, for example, for employees with visual impairments who can perform just well as others once given the needed accessibility tools.

79. A longstanding issue is the European Schools. These schools (open to employees of the European Union) are funded in part by the European Union but run autonomously and led by a board, comprised of representatives of each of the member States and the European Commission. These schools had a reputation in the past for not being fully inclusive of diverse learning needs. It seems tangible progress is now being made after the adoption of an action plan in 2018, which is due to be updated. This is to be greatly welcomed and encouraged. At a minimum, the Commission should ensure that European taxpayers' money is not spent on a non-inclusive educational system and, optimally, the European Schools should lead the rest of Europe by example. If the European Union member States have to meet certain threshold criteria (e.g., non-discrimination or inclusion) in how they spend European Union funds then, all the more so, the European Union should insist that monies it spends on institutions like the European Schools lead by example.

VI. Conclusions and recommendations

80. To conclude, the Special Rapporteur wishes to highlight that he was greatly heartened to see that services in all the main European Union institutions were both knowledgeable about and committed to the implementation of the rights of persons with disabilities and the provisions of the Convention on the Rights of Persons with Disabilities. He was especially heartened to learn about the passion, energy and enthusiasm of the services to do their bit to advance the goals of the Convention in their respective domains.

81. The new European Union Disability Strategy, 2021–2030, sets out a good framework for action both within the European Union and with respect to the European Union on the world stage. What struck the Special Rapporteur was how the individual services had already internalized the core messages of the Disability Strategy and the Convention. So, it is not really a question of the Convention driving change from the outside within the European Union – change is now being driven from the inside, because its values have sunk deep roots. This is as it should be.

82. Much of the excellent developments across the various policy domains are somewhat undercut by the continuing problematic investments in large and small-scale residential institutions in several member States of the European Union in recent years and the Commission's Legal Service opinion of 2018. This has real-life implications as it gives space to continue funding institutions for persons with disabilities in clear breach of the Convention. The narrowness of the original questions posed to the Legal Service perhaps helps to explain the answers it provided. One thing that clearly emerged in the discussions

held with the Special Rapporteur was that the view that such investments were acceptable was certainly not endorsed across all the services.

83. The priority recommendation of the Special Rapporteur, therefore, is that the Legal Opinion of 2018 should be revisited and substantially revised. Likewise, the joint cabinet consensus paper should also be revisited and substantially revised. There is ample scope to do so. This time around, a fuller consideration should be given to the norm of non-discrimination set out in the Convention (art. 5) and in the Charter of Fundamental Rights of the European Union and the common provisions regulation.[30] In addition, a clearer commitment needs to be made to understand and more consistently apply the norms of the Convention and the authoritative pronouncements thereon by the Committee on the Rights of Persons with Disabilities. From a process point of view, the Special Rapporteur hopes that the new institutional arrangements being set up as a result of the European Union Disability Strategy (the Disability Platform and the new monitoring arrangements to be decided after the review conducted in 2022) will prevent such missteps being made in the future.

84. As the programming documents for the period 2021–2030 are now being finalized, the Special Rapporteur requests that the European Institutions ensure that the European Union funds only support allocations for independent living arrangements and especially innovations in building up community support services, such as personal assistance, adaptable housing, personalized services and devolved budgets. The European Union additionality principle is clearly visible when this is done. No large or small institution should be funded in future European Union funding programmes. This is the only way to respect the Convention on the Rights of Persons with Disabilities and the Charter of Fundamental Freedoms of the European Union. This would be fully in keeping with the European Commission's stated intention to produce a "framework for social services of excellence for persons with disabilities" by 2024 to improve service delivery for persons with disabilities.[31]

85. The European Commission has recently stated that national human rights institutions will have a role in monitoring compliance of the use of European Union funds under the Charter of Fundamental Freedoms. This is very welcome. It would be fully consistent with this intention to directly involve national human rights institutions in any investigations into the use of the funds. Furthermore, it would make sense that purely national monitoring bodies designated under article 33 (2) of the Convention would also have an explicit role in monitoring the national expenditure of European Union monies. This would be fully in keeping with the idea of the shared management of the funds.

86. The Special Rapporteur would also strongly recommend that the European Union might consider facilitating a dialogue with other regional bodies around the world, in close alliance with civil society groups, on the role of regional arrangements to advance the Convention. This would visibly build on the European Union Disability Strategy, which promises that the European Union will step up its engagement in the world to support disability rights. It would be a logical extension of the valuable work of the European Union Special Representative for Human Rights, the European External Action Service and related funding services (Directorates-General for International Partnerships, for European Civil Protection and Humanitarian Aid Operations and for Neighbourhood and Enlargement Negotiations) on disability rights.

[30] Regulation (EU) 2021/1060 of the European Parliament and of the Council of 24 June 2021 laying down common provisions on the European Regional Development Fund, the European Social Fund Plus, the Cohesion Fund, the Just Transition Fund and the European Maritime, Fisheries and Aquaculture Fund and financial rules for those and for the Asylum, Migration and Integration Fund, the Internal Security Fund and the Instrument for Financial Support for Border Management and Visa Policy.

[31] European Union Disability Strategy, 2021–2030, sect. 4.1, p. 12.