Mandates of the Special Rapporteur on the rights of persons with disabilities and the Special Rapporteur on adequate housing as a component of the right to an adequate standard of living, and on the right to non-discrimination in this context

REFERENCE: AL OTH 38/2020

18 May 2020

Ms. Van der Leyen,

We have the honour to address you in our capacities as Special Rapporteur on the rights of persons with disabilities and Special Rapporteur on adequate housing as a component of the right to an adequate standard of living, and on the right to non-discrimination in this context, pursuant to Human Rights Council resolutions 35/6 and 34/9.

In this connection, we would like to bring to your attention, in your capacity as the President of the European Commission, our concern about the European Commission's authorizing the inappropriate use of European Structural and Investment Funds (ESIFs) to maintain institutional care, including by replacing large institutions for persons with disabilities with smaller institutions in several countries of the European Union. We make reference to the letter sent on the same issue by the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (ref. no AL OTH 3/2020).

According to the information received:

Between 2007 and 2013, the European Commission invested more than 150 million Euros of its structural funds (ESIFs) into renovating or building new institutions for persons with disabilities, and into institutional care, in several EU countries.

On 17 December 2013, the European Parliament and the Council took positive action by adopting Regulation EU no. No 1303/2013, which revised the European Commission's European Structural and Investment Funds Regulations for 2014-2020 and related guidance¹, clarifying that these funds should support the fulfilment of the European Union's obligations under the Convention on the Rights of Persons with Disabilities and to promote the transition from institutional care to community living. The Regulations also specify that funds should not support any action that contributes to segregation or social exclusion.

¹ See Guidance on Ex ante Conditionalities for the European Structural and Investment Funds PART II at: http://ec.europa.eu/regional_policy/sources/docgener/informat/2014/eac_guidance_esif_part2_en.pdf, and Thematic Guidance Fiche: Transition from Institutional to Community-based care (De-Institutionalisation) at: https://ec.europa.eu/regional_policy/en/information/publications/guidelines/2014/thematic-guidance-fiche-transition-from-institutional-to-community-based-care-de-institutionalisation-di-thematic-objective-9-en.

Despite this important development, in the programming period 2014-2020, the European Commission has continued to authorize projects where ESIFs have been used to invest in existing institutions or to replace large-scale institutions for persons with disabilities with smaller ones (i.e., transinstitutionalization) in some EU countries.

For instance, this has been the case in the following projects:

- ALT20-06-4842-FEDER-000157 (2019): "Residential Home Operation D. Dinis";
- ALT20-06-4842-FEDER-000087 (2018): "Expansion of Social Response Residential Structure for Elderly People in Santa Casa da Misericórdia de Azaruja";
- BG16RFOP001-5.002 (2018): "Support for the deinstitutionalisation of services for elderly people and people with disabilities";
- P.O.R./8/8.1/8.3/B/1 (2017): "Vulnerable group of people with disabilities";
- HRDOP-2.2.2. (2017): "Promoting transfer from institutional care to community-based services";
- Measure No. 08.4.1-ESFA-V-405 (2015): "Reorganisation of Institutionalised Care".

In this respect, we wish to express our serious concern that ESIFs continue to be used to maintain the out-dated, discriminatory and dangerous practice of institutionalization, including in smaller facilities, with services that fail to address the deeply ingrained discrimination, social exclusion and segregation faced by persons with disabilities.

Furthermore, as institutional settings have become COVID-19 hotspots, this pandemic highlights systemic challenges in these settings. Emerging evidence indicates that persons with disabilities in institutional settings are experiencing the highest rates of infection and mortality from COVID-19.² Their situation is compounded by greater risks of human rights abuses, such as neglect, restraint, isolation and violence.

The building and sustaining of institutions, whether large or small, stand in direct contravention with the Convention on the Rights of Persons with Disabilities, including particularly the rights to non-discrimination and living independently in the community. Similarly, the institutionalization of individuals, whether due to impairments, age or other factors, stands in contravention with the right to live in dignity and autonomy. Institutionalization also raises a number of other human rights concerns.

We would like to remind you that the European Union is party to the Convention on the Rights of Persons with Disabilities (CRPD) since 22 January 2011. Moreover, all

² A. Comas-Herrera et al. (2020), "<u>Mortality associated with COVID-19 outbreaks in care homes: early international</u> evidence"

the 28 Member States of the European Union have ratified the CRPD. Under its article 19, the European Union is obliged to respect, protect and fulfil the right to live independently and be included in the community of persons with disabilities, including: (a) the right to choose one's residence and where, how and with whom to live; (b) the right to access rights-based disability-specific support services; and (c) the right to access services and facilities for the general population on an equal basis with others.

This obligation is interrelated with the enjoyment of other human rights provided for in the CRPD, including equality and non-discrimination (art. 5); equal recognition before the law (art. 12); access to justice (art. 13); liberty and security of persons (art. 14); freedom from exploitation, violence and abuse (art. 16); personal mobility (art. 20); freedom of expression and opinion, and access to information (art. 21), respect for privacy (art. 22); respect for home and the family (art. 23), inclusive education (article 23); health (art. 25); habilitation and rehabilitation (art. 26); work and employment (art. 27); adequate standard of living (art. 28); participation in political and public life (art. 29); and cultural life, recreation, leisure and sport (art. 30).

We therefore call upon the European Commission to implement robust policies to stop funding that is used to build smaller institutions for persons with disabilities and to ensure that EU funding is used in line with human rights norms and standards. ESIFs should be used to support the initiation, acceleration and completion of deinstitutionalization strategies and transition to community-based solutions in EU countries. This includes investing and developing support services and implementing inclusive services at local level, such as education and primary health care, including rehabilitation, as cornerstones for achieving the SDG targets for persons with disabilities. Effective monitoring and accountability mechanisms in the allocation and disbursement of ESIFs for services are essential to ensure that these funds do not finance initiatives that violate human rights.

By continuing to provide financial support to projects that promote and entrench the institutionalization of persons with disabilities, the European Commission endorses, legitimises and actively contributes to the continuation of the medical model of disability, thus undermining the progress achieved with the adoption and ratification of the CRPD, and encourages States to maintain out-dated, ineffective and discriminatory frameworks that violate the rights of persons with disabilities.

For further elaboration on the international human rights instruments and standards relevant to the above, please refer to the **Annex on Reference to international human rights law** attached to this letter.

As it is our responsibility, under the mandates provided to us by the Human Rights Council, to seek to clarify all cases brought to our attention, we would be grateful for your observations on the following matters:

1. Please provide any additional information and/or comment(s) you may have on the above-mentioned allegations.

- 2. Please provide information on the steps taken by the European Commission to protect the rights of persons with disabilities and older persons and to address the deeply ingrained discrimination, social exclusion and segregation experienced by these groups.
- 3. Please explain the rationale for approving the disbursement of funding through the European Structural and Investment Fund for the replacement of large institutions with smaller institutions for persons with disabilities, and whether any human rights assessments were made prior to taking such decisions.
- 4. Please explain how the funding of institutions complies with the European Commission's obligations, in particular those under the Convention on the Rights of Persons with Disabilities.
- 5. Please explain what safeguards are being taken to ensure that funding from the European Commission do no longer support projects that are incompatible with EU's obligations under international human rights law.

This communication and any response received from the European Commission will be made public via the communications reporting website within 60 days. They will also subsequently be made available in the usual report to be presented to the Human Rights Council. We stand available to engage further with the European Commission in this process through a constructive dialogue.

While awaiting a reply, we urge that all necessary interim measures be taken to halt the alleged violations and prevent their re-occurrence and in the event that the investigations support or suggest the allegations to be correct, to ensure the accountability of any person(s) responsible for the alleged violations.

We may publicly express our concerns in the near future as, in our view, the information upon which the press release will be based is sufficiently reliable to indicate a matter warranting immediate attention. We also believe that the wider public should be alerted to the potential implications of the above-mentioned allegations. The press release will indicate that we have been in contact with the European Commission to clarify the issue/s in question.

Please accept, Ms. Van der Leven, the assurances of our highest consideration.

Catalina Devandas-Aguilar Special Rapporteur on the rights of persons with disabilities

Balakrishnan Rajagopal

Special Rapporteur on adequate housing as a component of the right to an adequate standard of living, and on the right to non-discrimination in this context

Annex Reference to international human rights law

In connection with above alleged facts and concerns, and without prejudge to the accuracy of these allegations, we would like to draw the attention of the European Commission to the relevant international norms and standards.

Institutionalization as a prima facie form of discrimination

Segregation and separate treatment of persons with disabilities in residential institutions constitute a *prima facie* form of discrimination and, thus, a breach of the right to non-discrimination. Equality and non-discrimination are fundamental principles of international human rights law, enshrined in all core human rights instruments. Article 5 of the CRPD requires States to, inter alia, prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.

In interpreting Article 5 of the CRPD, the Committee on the Rights of Persons with Disabilities has established that institutionalization is discriminatory as it demonstrates a failure to create support and services in the community for persons with disabilities, who are forced to relinquish their participation in community life to receive services (general comment No 6, para. 58). For example, the institutionalization of persons with psychosocial disabilities as a condition to receive mental health services constitutes differential treatment on the basis of disability and, as such, is discriminatory. Similarly, the Committee on Economic, Social and Cultural Rights has highlighted that "segregation and isolation achieved through the imposition of social barriers" is a form of discrimination against persons with disabilities (general comment No. 5, para. 15).

Rationales and justifications for the institutionalization of persons with disabilities often lie in stigma and on the view that persons with disabilities are unable to live in the community, as they need "specialized care" provided in institutions, which stem from the medical model of disability. The creation of institutions means that resources that should be invested in developing possibilities for persons with disabilities, including older persons with disabilities, to live independently in the community, instead are spent on establishing out-dated systems of institutional care, thereby defeating the potential of these funds to advance social inclusion of persons with disabilities. With the entry into force of the CRPD, the failure to take immediate measures towards the full and meaningful inclusion of persons with disabilities in society on an equal basis as everyone else is no longer acceptable.

Institutionalization is contrary to the right to live independently in the community

Article 19 of the CRPD elaborates on Article 5 of the CRPD in that it recognizes the equal right to live independently in the community, with choices equal to others. States parties have an obligation to take effective and appropriate positive measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community.

The right to live independently in the community entails living outside residential institutions of all kinds. Article 19 expressly recognizes the right not to be obliged to live in a "particular living arrangement" on account of one's disability. As interpreted by the Committee on the Rights of Persons with Disabilities, independent living cannot be understood as "just" not living in a particular building or setting; it implies more broadly not losing personal choice and autonomy as a result of the imposition of certain life and living arrangements. Therefore, neither large-scale institutions nor smaller group homes with five to eight individuals, nor even individual homes can be called independent living arrangements if they have other defining elements of institutions or institutionalization (general comment No. 5, para. 16).

To realize the right to live independently in the community, States parties must provide persons with disabilities with all necessary means enabling them to exercise choice and control over their lives and make all decisions concerning their lives. That is, access to a range of individualized support services, such as personal assistance and support services for family carers; and access to non-disability-specific support services and facilities available for the general population, such as accessible and affordable housing, and access to inclusive education.

As underlined by the Committee on the Rights of Persons with Disabilities, persons with disabilities cannot exercise choice when there is a lack of options to choose from; this is the case, for instance, where support is unavailable outside of institutions, or where support is provided only within specified forms of residence such as group homes or small institutions (general comment No. 5, para. 25). Persons with disabilities should not be placed in segregated facilities for the purpose of receiving support services or social protection (A/70/297). All support services must be designed to be supporting living included within the community and preventing isolation and segregation from others (A/HRC/34/58).

In addition, States parties to the CRPD are required to adopt strategies and concrete plans of action for deinstitutionalization, with specific time frames and adequate budget. This requires a systemic transformation of service provision, which includes the closure of institutions, the establishment of a range of individualized support services, accessibility improvements within the community, and awareness-raising efforts. The closure of large institutions in itself is not enough. Moreover, the development of small institutions cannot be part of a deinstitutionalization process and represents a regressive measure in relation to a state's obligations with respect to the right to live independently in the community.

Institutionalization is contrary to the right to family life

The right to live independently in the community is intimately linked with the right to family life. Article 23 of the CRPD guarantees the equal respect for home and family life of persons with disabilities, including by ensuring that children with disabilities ensure have equal rights with respect to family life. States parties must ensure

that children with disabilities are not separated from their parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child (article 23(4)). Separating a child from their parents on the basis of a disability of either the child or one or both of the parents is contrary to the CRPD. Where the immediate family is unable to care for a child with disabilities, States parties must undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting (article 23(4)).

The standards set forth in article 23 of the CRPD are purposely higher than those established in the Convention on the Rights of the Child and other international instruments, given the widespread practice of institutionalization of children with disabilities, who are denied the right to grow up in their families. States Parties must prevent children with disabilities from being institutionalized and support them and their families to live in the community.

Institutionalization as form of deprivation of liberty

Article 14 of the CRPD, requires that all persons with disabilities, on an equal basis with others, enjoy the right to liberty and security of person, and explicitly prohibits unlawful or arbitrary detention of persons with disabilities. Article 14 specifies that the existence of a disability shall in no case justify a deprivation of liberty.

Article 14, in conjunction with articles 12 on equal recognition before the law and 19 on independent living in the community, outlaws forced institutionalization as a form of disability-specific deprivation of liberty. Placing a person with disabilities into an institution, either without their consent or with the consent of a substitute decision maker, represents a unique, disability-specific form of deprivation of liberty. The failure of the State to provide persons with disabilities with the appropriate support to live independently in the community cannot constitute a legitimate ground for deprivation of liberty (A/HRC/40/54).

Institutionalization fosters rights violations

Persons in segregated service systems and residential settings are particularly vulnerable to violations of their human rights. Due to their closed nature, the restriction of choice, the need for control by staff, the group nature of their management practices and policies, and the power imbalance between residents and staff, institutions cannot but, by their very nature, foster ill treatment and other rights violations. Institutional environments breed cultures of violence, stigmatization and helplessness, which can be conducive to physical, sexual and other forms of abuse (A/HRC/41/34).

In this respect, article 16 of the CRPD affirms the States' obligation to protect persons with disabilities from all forms of exploitation, violence and abuse, including their gender-based aspects. It sets an obligation for States to prevent the occurrence of all forms of abuse by ensuring the independent monitoring of all facilities and programmes

designed to serve persons with disabilities and calls for thorough investigations of allegations concerning serious human rights violations. In addition, according to article 15, States parties must take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment.

It is worth noting that institutionalization further reinforces a vicious cycle of inequality and social exclusion, preventing the exercise of rights such as education, work and political participation.

International cooperation must support the realization of human rights

International cooperation must be consistent with the human rights of persons with disabilities. According to Article 32 of the CRPD, international cooperation efforts must be oriented to support national efforts for the realization of the purpose and objectives of the CRPD. Therefore, international assistance, including ESIFs, should not support practices contrary to the human rights-based approach to disability. The European Commission, as part of its international obligations, including the Charter of Fundamental Rights of the European Union, should refrain from supporting projects that violate the rights of persons with disabilities, such as the development or maintenance of institutions.

Institutionalization is not only contrary to human rights, but also represent an unnecessary and ineffective use of public resources. Providing adequate support to persons with disabilities is a much more successful and cost-effective option than putting them in institutions of any kind. Where institutions are prioritised for financing, one of the effects is that people end up being placed there regardless of their support needs, because there is no real alternative. Moreover, institutionalization exposes governments to expensive safeguards systems, as well as protracted and expensive litigation (A/HRC/40/54).