

COMMENTS ON THE DRAFT GENERAL COMMENT ON ARTICLE 19

From : The Interfederal Centre for Equal Opportunities (Unia)

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I. IDENTIFICATION OF THE SUBMITTING ORGANISATION

Unia is an independent public institution that fights discrimination and promotes equal opportunities. We have interfederal competence, which means that, in Belgium, we are active at the federal state level as well as the level of the Regions and Communities.

Unia is responsible for assisting victims of discrimination based on the protected grounds (one of which is disability) of the anti-discrimination laws which implement the European directives 2000/43 and 2000/78. As an independent mechanism on the basis of article 33.2 of the Convention on the Rights of Persons with Disabilities (CRPD), Unia has also been responsible for promoting, protecting and monitoring the implementation of the CRPD in Belgium since 2012.

II. COMMENTS ON SPECIFIC PARAGRAPHS OF THE GENERAL COMMENT

Paragraph 15 c: Unia agrees with the Committee's view that institutionalization is not primarily about living in a particular setting, but first and foremost about losing choice and control over one's life as a result of a certain living arrangement and being segregated from society. The approach of identifying institutionalized settings by means of certain defining elements, is consistent with this view.

However, the Committee deviates from this approach where it states that "neither large scale institutions with more than a hundred residents nor smaller group homes with five to eight individuals can be called independent living or community living arrangements". Here, the Committee states that certain settings are by definition institutionalized settings. This statement may not be untrue but it is not consistent with the overall approach taken in the rest of paragraph 15 c.

In its alternative report of 2014, the Belgian Disability Forum (BDF) mentions "inclusive alternative units on smaller scale" as an alternative to "institutions"¹ (which BDF does not necessarily want to close down, but transform). Unia is of the opinion in this issue that such group homes should not automatically be regarded as institutionalized settings, certainly when, for example, the management of these disability-specific facilities is provided by persons with disabilities themselves and their networks. This type of (voluntary) shared use of (personal) support budgets seems to be a reasonable way of making the most of limited financial resources for disability related support.

¹ Belgian Disability Forum asbl, *Position of the representative associations and structures of persons with disabilities. Alternative report initiated and coordinated by the Belgian Disability Forum*, 20 February 2014, http://bdf.belgium.be/resource/static/files/pdf_uncrpd/2014-02-20---alternative-report---belgian-disability-forum.pdf, p. 141, no. 61.

Paragraph 15 d: This paragraph addresses aspects such as the funding of personal assistance, and emphasises that this funding should be *allocated to* and *controlled by* persons with a disability. Perhaps it would be a good idea to more clearly make the link with the *personalized support* and *personal budgets* mentioned in paragraph 62?

Unia also poses the following question: in a system of personal assistance, does there always need to be the explicit possibility for the person with a disability to personally act as the employer of his/her assistants (without this being obligatory)? Is a system in which this is not taken into account a system of “personal assistance” in the sense of the UN-convention?

Paragraph 16: Unia feels that the sentence “Independent and community living can also not be counted as personal assistance if the assistance is only provided within certain arrangements, such as a group home” is confusing and superfluous, as the 3 central concepts in the sentence (independent living – community living – personal assistance) are clarified in paragraph 15.

Paragraph 25: The first part of this paragraph explains that persons with disabilities often cannot exercise choice because of a lack of options to choose from. The second part highlights other reasons why persons with disabilities sometimes cannot exercise choice: they might not be allowed to exercise legal capacity or may suffer from “informal guardianship”, sometimes exercised by family members or caregivers. We think that the second part would be better placed in paragraph 26, that covers the importance of “legal capacity”.

Paragraph 28: In this paragraph, residential services are described as temporary residential support facilities for persons making the transition from institutional settings to community based settings. According to the reasoning in this paragraph, residential services should therefore be regarded as a temporary form of service within the framework of the progressive realisation of deinstitutionalisation. However, Article 19 explicitly mentions that the States bound by the Convention must ensure that persons with a disability have access to residential services. This appears to suggest that these facilities have to be available on a more permanent basis – and therefore not only during a transitional period. Is there not some incompatibility here? What should be understood exactly by residential services? Do they need to stay available after a process of deinstitutionalisation?

Paragraph 34: In Unia’s view, it is (often) impossible, but above all undesirable, to carry out the collection of disability-specific data in order to use these data as a basis for accessibility planning or for defining the necessary range of community based services in a given neighbourhood . In our view, this type of approach contradicts the principles of Universal Design, and can ultimately form an obstacle for the freedom of movement and choice of residence for persons with a disability. Could this paragraph be clarified in order to prevent any potential misunderstanding of the text?

Paragraph 35: Sufficiently affordable and accessible housing is necessary in order to enable full participation in society. According to Unia, these two aspects – both the affordability and accessibility of housing – should always be considered together. With regard to the affordability of housing, in its alternative report of 2014, the BDF highlighted the major challenges that exist around

this issue in Belgium². In this context, Unia feels it is important that the General Comment also refers to article 12 (5) of the UN-convention. This provision stipulates that persons with a disability should be given access on equal basis with others to bank loans and mortgages (and the related life insurance). Neither paragraph 35 nor paragraph 78 emphasises the importance of that provision. In processing cases of discrimination, Unia regularly observes problems in this area.

With regard to the accessibility of housing, in Unia's view – in line with paragraph 24 of General Comment number 2 (2014) on accessibility – there should also be reference to the responsibility of private project developers and construction contractors to improve the accessibility of the built environment. Specifically, Unia also refers to the problems with enforcing the reasonable adaptations towards the co-owners' associations in apartment buildings. The Belgian antidiscrimination law does not impose a mandatory obligation to make reasonable adjustments in these situations.

Paragraph 47 (comment 1): Unia would like to emphasise that the choice for institutional care settings is not always a positive choice. Often, it is a case of having no other alternative on account of the insufficient availability of disability support services and/or the lack of accessible community based settings. For Unia, the freedom of choice in living arrangements above all means enabling a person with a disability to really choose from a wide range of forms of (inclusive) support services. The same applies for children and senior citizens with a disability³. Freedom of choice in living arrangements does not mean that persons with a disability can expect that institutional care settings will continue to be offered, certainly not if these are to be understood as living arrangements in which the freedom of choice and control over one's own life is not upheld.

However, before closing institutional care settings, states are obligated to provide sufficient disability-specific alternatives and accessible community based services. Deinstitutionalisation should not form grounds for the States bound by the Convention to fail to provide necessary support for persons with a disability who need it (paragraph 56).

Unia would also like to point out that it is very important for paragraph 47 not to contradict paragraph 52 of the General Comment number 4 (2016) concerning education. According to this provision, achieving inclusive education must go hand-in-hand with "*a strategic commitment to ending the practice of placing persons with disabilities in institutions*". This idea is also expressed in

² Belgian Disability Forum asbl, *Position of the representative associations and structures of persons with disabilities. Alternative report initiated and coordinated by the Belgian Disability Forum*, 20 February 2014, http://bdf.belgium.be/resource/static/files/pdf_uncrpd/2014-02-20---alternative-report---belgian-disability-forum.pdf, p. 133, no. 6.

³ The European Network of National Human Rights Institutions (ENNHRI), of which Unia is a member, published a paper in 2016 on community based long-term care services. Although the majority of senior citizens with long-term care needs receive care and support at home, since 1995, there has been a marked increase in the number of beds at facilities for senior citizens in most European countries. The major investment in residential care has resulted in a relative underdevelopment of community based support. In the conclusions of the paper, ENNHRI refers to aspects such as the significant greying of the European population as momentum for investing in alternatives to institutional care settings and to support informal caregivers, not as a way of meeting increased demand at a low cost, but rather in order to better safeguard human rights for senior citizens (source: www.ennhri.org/IMG/pdf/policy_brief_final_version-2.pdf).

paragraph 85 of this draft General Comment. Deinstitutionalisation and inclusive education are closely interrelated and influence each other.

Paragraph 47 (comment 2): According to this paragraph, the States bound by the Convention are not obligated to guarantee the availability of “residential support services”. In this paragraph, what is the scope of the term “residential support services”? How is this different from the “residential services” referred to in paragraph 28?

Paragraph 58: Unia wholeheartedly supports the view that the right to live independently and fully integrated into society cannot be reserved for or denied to certain groups of persons with disabilities. People with multiple disabilities or intellectual disabilities and people of all ages with disabilities, including senior citizens and young people, must be eligible for community based support services, including personal assistance.

Unia is pleased that this paragraph explicitly states that “support [...] must be provided irrespective of persons with disabilities having a family or the income of the individual or family”. According to paragraph 89 of the draft, disability-specific expenditures must be accompanied by supplementary benefits for persons with a disability, in order to prevent them from having to bear the costs of disability support out of their own pocket, thereby compromising their overall standard of living.

Unia observes that in Belgium, the level of the overall family income is often taken into account to determine the level of certain disability-specific cash transfers. The result of this is that persons with a disability may lose (a part of) their benefits when they decide to move in together with their partner.

Paragraph 60 (comment 1): This paragraph refers to allowances in cash and the importance of these benefits for covering disability related costs and promoting inclusion. On this point, Unia has the following question: is it defensible that some of these allowances have a fixed nature and do not have any strict connection with the concrete participation issues or risk of poverty of the disabled person in question⁴? Is such a policy, albeit designed to gradually implement article 19 b, compatible with paragraph 60 and paragraph 89?

Paragraph 60 (comment 2): In the final sentence of paragraph 60, among other places, reference is made to the current economic climate and cutbacks that governments (are forced to) introduce. Of course, Unia acknowledges this reality. But we would only like to point out that the reference to the present economic context may somewhat undermine the timeless character of this General Comment.

Paragraph 61 (comment 1): Unia finds the formulation of this paragraph to be ambiguous. What exactly does the UN committee mean by “conditionality regime” and “respond to a distribution criteria”?

⁴ The context of this question is as follows. Since September 2016, in Flanders, specific individuals who are waiting for disability-specific support have been eligible for what is known as basic support, a fixed payment of 300 euros on the grounds of the need for support demonstrated by means of certificates. Is such a policy in compliance with the provisions of article 19 b?

Paragraph 61 (comment 2): In observation 33 of the concluding observations⁵, the UN committee urged Belgium to make a concerted effort to reduce waiting lists. To what extent and under what conditions can applications for support (and more specifically, for access to cash transfers) be given priority?

Paragraph 64: Unia considers it important that professionals who support people in living independently and participating in society be given appropriate training and education in order to operate according to the will and preferences of the persons with a disability. Here, Unia would also like to point out the importance of the need for decent salary and working conditions for the professionals who work with people with a disability, also within systems for personal assistance.

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⁵ Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Belgium, 28 October 2014, CRPD/C/BEL/CO/1.