



Interfederal Centre
for Equal Opportunities

Submission to the CRPD Committee

Day of General Discussion on the right of persons with disabilities to live independently and be included in the community (article 19)

15th Session – 19th April 2015

From :

Unia (independent CRPD mechanism in Belgium)

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I. INTRODUCTION

In its concluding observations on Belgium of 1 October 2014 regarding independent living¹, the Committee notes the high rate of referral to institutional care for persons with disabilities (here-after abbreviated as PwD) in the State party and the lack of de-institutionalization plans. The Committee recommends the State party to further work towards reducing investment in collective infrastructure and promoting personal choice. A nation-wide action should guarantee access to community services and should tackle the current waiting lists. PwD should have access to sufficient financial resources and communities should be more accessible.

Nils Muižnieks, the Commissioner for Human Rights with the Council of Europe, also addressed the issue of institutionalisation in his state report on Belgium, following a visit to the country from 14 to 18 September 2015².

Both the UN committee on the rights of people with disabilities as the High Commissioner on Human Rights of the Council of Europe note the high rate of institutional care in Belgium, as well as the general lack of resources for handicap-specific support (resulting in long waiting) and adequate measures to promote personal choice. There's is a general lack of information and guidance to facilitate and support independent and community based living.

II. REMINDER: BELGIUM AS A FEDERAL STATE

As a reminder, Belgium has been a federal State with three Communities (Flemish, French-speaking, German-speaking) and three regions (Flanders, Wallonia and Brussels) since the constitutional reform in 1993. Each level of government has competence in certain areas. Disability policy falls under the remit of a number of different bodies essentially at regional of community level.

Unia as CRPD-mechanism in Belgium

Unia³ – formerly known as the Interfederal Centre for Equal Opportunities – is an interfederal public service, specialised in equal opportunities policy and non-discrimination.

Unia is responsible for assisting victims of discrimination based on different protected criteria (one of which is disability) by the anti-discrimination laws which are the transposition of the European directives 2000/43 and 2000/78. Since 2011, Unia has also been responsible, as national independent follow up mechanism, for promoting, protecting and monitoring the implementation of the CRPD in Belgium⁴.

Convention on the Rights of Persons with Disabilities in Belgium

Belgium signed the CRPD on 30 March 2007 and ratified it on 2 July 2009. It came into force at the national level on 1 August 2009. All Communities and Regions also signed and ratified the Convention during 2009.

Belgium submitted its first periodical report in compliance with article 35 of the CRPD in July 2011⁵. Belgium's state report was followed by the parallel report submitted by Unia and alternative reports from several civil society organisations (Belgian Disability Forum and GRIP).

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http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fBEL%2fCO%2f1&Lang=en

² <https://wcd.coe.int/ViewDoc.jsp?Ref=CommDH%282016%291&Language=lanEnglish>

³ The Centre has chosen the shorter name Unia, which is valid for the country's three languages and easier for the target audience to identify.

⁴ Art. 33.2 CRPD

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http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fBEL%2f1&Lang=en

III. OVERVIEW OF THE RIGHT TO LIVE AND BE INCLUDED IN SOCIETY IN BELGIUM

General note

In the country's different Communities and Regions, the types of support available to persons with a disability, such as benefiting from housing or benefiting from support to participate in society, sometimes depend on the (social) housing⁶ and sometimes on the sector of services aimed at enabling a disabled person to stay at home⁷.

During recent legislative reforms, we can see (the beginning of) a shift from residential care to more community based and family support. We see a movement towards de-institutionalization in Flanders then in e.g. Wallonia and Brussels Capital Region.

Flemish Community

VAPH – the Flemish agency for PwD – offers a range of handicap specific care – ranging from in-home support, day care centres, group-homes to residential care. Some 2800 people receive a cash budget and can employ personal assistants.

As already mentioned, in the range of handicap specific support offered by VAPH, once can see a shift to more community based services and a higher flexibility in the way services are offered. With the reform of legislation towards FAM (Functioneel Aanbod Meerderjarigen) and MFC (multi-functioneel aanbod minderjarigen), institutions can more offer more flexible answers on individual support requests.

In Flemish Community, the financing of handicap-specific care is subject to a major policy reform with the adoption of the decree “*persoonsvolgende financiering*” (decree on the personalised budget) in April 2014. The general goal of this decree is to make the provision of handicap-specific support a more user-oriented system. It foresees a twin-track system of support funding to PwD. First, all people with a recognized disability and a support need who are not entitled to a personal budget, will gradually have access to a basic support budget, a monthly lump-sum of 300€ which they can freely use to pay for directly available services. Second — minors follow on a later date – all adult people with greater support will be able to apply for a personal budget, payable under the form of a cash budget or voucher-system. This handicap-specific support is attributed following priority rules (whereby the people with a higher support need get a budget sooner than others) and based on a personal support plan (whereby the availability of general available or family support is assessed).

In Flanders, as well as others regions, long waiting list in order to get handicap-specific support remain. Some 11.000 PwD wait for a suitable solution based on the latest available Zorgregierapport of 2014⁸.

Walloon region

AVIQ, the Walloon agency for integration of PwD, offers a range of support initiatives to help people to participate in society, ranging from residential care over supervised housing to supported housing for people with physical disabilities. Some 700 people benefit from a BAP (*budget d'assistance personnelle*) to pay for personalised assistance. PwD can only employ personal assistance via

⁶ Some of these services include: residential services, supervised accommodation, community housing, chore services, adapted social housing. More specifically, for persons with psychological problems: psychiatric hospitals, psychiatric care homes, sheltered housing initiatives, unofficial housing structures.

⁷ Some of these services include: personal assistance funding, home help services. Specifically for persons with psychological problems: mobile crisis teams.

⁸ <http://www.vaph.be/vlafo/view/nl/464335-Zorgvragen.html>

intermediate services. People with intellectual disabilities are explicitly excluded from access to a BAP.

The Walloon Government plans a major reform in the way PwD are supported, by introducing the “*assurance autonomie*” or “*independence insurance*” system similar to the Flemish Zorgverzekering, a system where to all Walloons will have to participate. The independence insurance will help PwD to longer stay at home and pay for a range of in-home services. Health services will organise the system and provide people with several forms of aid and home adaptations.

Unia regrets that the future beneficiaries of independence insurance weren’t up until now consulted in the legislative process introducing the system. It was only possible to consult the health insurance funds and the social partners.

Brussels Capital Region

In January 2014, “la Commission communautaire française” has adopted a decree⁹ to further implement inclusion in different policy areas in Brussels Capital Region, by further develop community based housing, group houses and provide additional family support. A personal assistance scheme is introduced as a pilot project, with a small group of participants. The inclusion decree doesn’t mention the structural introduction of a PA-system. PA is in Brussels Capital Region an experiment with only 8 participants.

A similar insurance system as in Wallonia is being considered.

German speaking Community

The specialised agency for PwD of the German speaking Community offers a variety of services to support living in society, ranging from in home support to groups homes. The concept of personal concept is not yet adopted in German-speaking Community. In the action plan DG Inklusiv 2025¹⁰ the creation of new support forms within society is foreseen. Residential institutions will be replaced by small group homes and in home support.

IV. CENTRE’S OBSERVATIONS

1. Lack of places, lack of choice

In general, **the means allocated to all the services and support allowing people to live independently are largely insufficient**. People suffering from a mental or cognitive disability, as well as highly dependent disabled persons, sometimes have no choice other than to live in a collective residential unit or to stay with their parents. This option is very often a default solution.¹¹

And yet, the residential offering also suffers from a **certain shortage**¹², and there are (very) long **waiting lists** to obtain a place. Available places are allocated, first and foremost, to emergency situations, when a person no longer can depend on someone to support or care for them.¹³

⁹ Decree of 17 January 2014 relating to the inclusion of persons with disabilities, M.B. of 3 October 2014, p.78 287

¹⁰ <http://dpc.be/Downloads/AktionsplanDGI25.pdf>

¹¹ BDF’s alternative report of 20 February 2014 to Belgium’s report on the application of the UN Convention on the Rights of Persons with Disabilities, see <http://bdf.belgium.be/fr/publications.html>, p.151

¹² Decision of the European Committee of Social Rights on collective complaint 75/2011 relating to the lack of care solutions for highly dependent persons, see <https://wcd.coe.int/ViewDoc.jsp?id=2115023&Site=CM>.

¹³ BDF’s alternative report of 20 February 2014 to Belgium’s report on the application of the UN Convention on the Rights of Persons with Disabilities, see <http://bdf.belgium.be/fr/publications.html>, p.151

Although the legislation in Belgium that governs how institutions are run is supposed to guarantee compliance with quality standards, **in reality, Unia can see that PwD can easily become victims of situations that don't comply with basic rights** (mistreatment, violation of the right to emotional and sexual life, etc.). There are auditing systems for these institutions, even though they are insufficient, but people may hesitate to blow the whistle for fear of reprisal. When support places are in short supply (and therefore a lack of choice), there is a very real risk of losing one's place and ending up without a care solution.

The same fear of reprisal has been observed among those who depend on home care services, where shortages also exist.

This lack of places forces people seeking a care solution to turn to inadequate services such as psychiatric hospitals, nursing homes¹⁴ and even (especially in Wallonia) "pirate institutions" that don't have any approval.

2. Institutionalisation, a culture

For Unia, the de-institutionalisation process also takes place within the setting of institutions themselves. The rules that govern community life in residential and day centres must be respectful of the disabled person's own life plan and their individual choices. Hence, these rules must utmost help to ease unwanted effects of institutional life as much as possible; they must take into account the person's own wishes and must respect the privacy, emotional and sexual lives of the residents.

Within the framework of a workgroup initiated by Unia with self-representative persons, an analysis of the internal regulations of residential services and day centres in Wallonia revealed archaic practices in complete contradiction with the UN Convention on the Rights of Persons with Disabilities¹⁵.

Subsequently, Unia insists that all the regulations, including regulations that govern the living environment of persons with disabilities, be regularly modernised and analysed with the participation of the residents. When they are updated and implemented, they should also be subjected to regular controls by the supervisory authority.

3. Lack of a global policy and funding

Unia emphasises that the freedom of choice as guaranteed by Article 19 of the Convention implies a diversification in the support and housing options offered to persons with disabilities. In this moment, as the Committee reveals in its "Concluding Observations" of 2014, Belgium hasn't set up a global plan for de-institutionalisation¹⁶.

The regulations in view of encouraging the inclusion of persons with disabilities – which only Flanders, Brussels Capital Region and German speaking Community – have adopted so far, haven't come into force in some cases, and in others, haven't yet been executed. The results of this policy change are therefore unknown for the time being.

In Wallonia and Brussels, Unia has noted that the development of inclusive alternatives in the form of small living units has been, in the majority of cases, left to the care of the friends or families of the

¹⁴ BDF's alternative report of 20 February 2014 to Belgium's report on the application of the UN Convention on the Rights of Persons with Disabilities, see <http://bdf.belgium.be/fr/publications.html>, p.153

¹⁵ For instance, internal regulations oblige residents to take contraceptives, forbid the choice of doctor, condone the use of punishment if a standard isn't respected, authorise staff to enter rooms at any moment, make it compulsory to submit a request for judicial protection (property placed under receivership), etc.

¹⁶ Concluding observations, p.5

disabled person, who are forced to find the funds and the staff required to operate this kind of structures¹⁷.

At the same time, the lack of an effective action plan that guarantees access to adapted services is also accompanied by a lack of statistical data¹⁸. Consequently, Belgium has no image of the life circumstances of persons with a disability, and isn't in a position to carry out an analysis of their needs.

4. Subsidiary intervention of public authorities

Finally, Unia laments the fact that the reforms in progress, which aim to favour a person's autonomy in their living environment, aren't accompanied by sufficient funding and services to encourage the actual implementation of Article 19 of the Convention. The result is, that it is essentially the family network that is mobilised and plays a leading role. Services funded by the authorities only intervene as an alternative, and insufficiently, to ensure the person's complete and real autonomy¹⁹.

Caregivers, who are family members in the majority of cases, are excluded from the labour market or are obliged to reduce their working hours, with the resulting consequences in terms of precarity, social isolation and personal fulfilment²⁰.

Compliance with Article 19 of the Convention should be associated with compliance with Articles 23 and 28 of the Convention, which are seriously compromised.

V. POINTS FOR ATTENTION AND QUESTIONS FOR THE GENERAL COMMENT ON ARTICLE 19 CRPD

- De-institutionalisation includes the closure of (some) handicap specific support units. This makes the wording of article 19b somewhat unclear. What exactly are residential community services (article 19b)? Can residential care units remain if they are responsive to the wishes of individual PwD? Unia adheres to the terms in the ad hoc expert group's report set up by the European Commission on the transition of care in institutions to local care, according to which « *these institutions are not defined primarily by their size but above all by features of "institutional culture" (depersonalisation, rigidity of routine, block treatment, social distance, paternalism). Size is merely an indicator - the larger the setting, the fewer the chances are to guarantee individualised, needs-tailored services as well as participation and inclusion in the community.* »²¹
- In practice, Unia often sees de-institutionalisation translated as replacing large handicap-specific residential care unit by smaller group homes within the community. Unia wishes to draw the Committee's attention to the vigilance required to ensure that these community

¹⁷ For instance, the not-for-profit association "Les Pilotis" initiated inclusive community living houses in neighbourhoods in Brussels. The association organised a seminar on the theme "I live in my house", see www.les-pilotis.be

¹⁸ In its decision on collective complaint 75/2011, the Committee firmly condemned the lack of adequate statistical data on a national and regional level concerning persons who require significant assistance, with a view to elaborating a structured and coordinated policy.

¹⁹ For example, the conditions for granting personalised funding, introduced in Flanders in 2016, take into account whether or not the person benefits from a network.

²⁰ See <http://www.aidants-proches.be/fr>

²¹ European Commission, Directorate-General for Employment, Social Affairs and Equal Opportunities, "Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care", p.6.

based support services don't adopt the same institutional culture as mentioned before. From this point of view, and in order to ensure support and adapted care, but also to respect the person's dignity and choices, the services and care providers must benefit from proper and specific training without fail.

- Art. 19b specifies that people with disability have the right to support to pursue a life in society and in order to prevent isolation and segregation. To what degree, giving priority to people with severe support needs in order to tackle waiting lists is admissible under the CRPD, giving the fact that this right is subject to the principle of progressive realisation. The exact right to support for all people with disability should be further clarified.
- Personal assistance touches strongly to the concept of personal choice of service provider and caretaker alike. Could a future general comment specify the right of PwD to choose a specific service provider and care taker and the freedom to negotiate the modalities of service provision?
- Similarly to article 24, there are according to Unia clear discrepancies between the authentic translation of the CRPD in English and French. The text in English speaks about residential support services (art. 19b), whereas the French text speaks about "*une gamme de services [] en établissement*". Services en établissement have a collective connotation. Établissement refers to institution, residential support services do not.