

Mandate of the Special Rapporteur on the Right to Privacy
Thematic action stream 'A Better Understanding of Privacy'
Privacy rights of children under 18

Submission from the Belgian Disability Forum asbl (BDF)

The mission of the Belgian Disability Forum asbl (BDF) is¹ to follow international developments that bring about change for Belgian persons with disabilities. The BDF is not a specialist in children's issues.

Nevertheless, BDF would like to take this opportunity to draw your attention to the situation of children with disabilities whose right to privacy will remain of great concern until the principles of the UNCRPD are mainstreamed in all parts of our societies to make them truly inclusive organisations.

In this respect, BDF would like to briefly draw your attention to the right to "choose the place of live", the need for support, "affective and sexual life", situations of poverty, privacy in an increasingly real virtual world, and the lack of usable statistical data in the field of disability.

1° The choice of the place to live

The natural place of live for a disabled child is the family environment. Depending on the hazards of life, it may be necessary to find another solution.

In the absence of alternative solutions, institutionalisation remains the only option for some children with disabilities. Self-development in an institutional setting has specific implications for the privacy of children and adolescents. They are subject to strict and often rigid rules, perhaps understandable in terms of organisation, but which do not leave room for the flexibility which is necessary for the progressive development of autonomy which is the basis for a quality private life.

At this level, the BDF advocates that Belgian society should put in place the practical conditions for an informed choice for the child, in consultation with the child's family and the competent services. Of course, taking the child's opinion into account plays an essential role in this respect. It requires the implementation of specific communication techniques.

In any case, the place where a child lives is the framework in which he or she will develop his or her own identity, in which he or she will exercise his or her right to privacy.

2° The importance of support

Wherever the child lives, it is important that he or she can benefit from supervision, support and reference points with which to identify, relate to and refer to according to the different stages of his or her development.

Ideally, they will find these points of reference with their parents or the educational team in a host environment. In either case, it is possible that the "front-line" carers themselves may need support in order to orient their interaction to the child's or adolescent's need for privacy and intimacy.

BDF would like to stress that being a parent of a child with a disability in a non-inclusive society can be extremely difficult. This will have an impact on the development of the person concerned, but also on

¹ <http://bdf.belgium.be/>

the development of all members of his or her family, including siblings. It will also affect the life of each of them, including aspects of 'private life'. Some aspects will be very positive and that's good. Others will be quite negative and should be kept to a minimum.

Not only the disabled child, but also all the people looking after him or her may therefore, depending on the circumstances, need adapted support. Ideally, this will be a "multidisciplinary" approach capable of taking into account the different aspects of the child's development.

When we talk about supporting disabled children, we cannot forget the fact that this support must be carried out using the appropriate means of communication according to their needs: sign languages, lip reading, "easy to understand", etc. At this level, it should not be forgotten that these communicational aspects must be available to the persons concerned in all aspects of their lives, both private and public. This is far from being the case in Belgium at the moment...

3° Private life, emotional life, sexual life

Regular meetings with a support structure can also play an important role in preventing the risks of mistreatment and abuse.

As RUGent's 2018 study showed², sexual abuse of persons with disabilities is not uncommon. They are very often perpetrated by "trusted persons": family members, educational staff, medical staff (including doctors)... These are obviously extreme cases, but their existence is real and their seriousness justifies that they be duly taken into account.

Another aspect of the problem highlighted by the RUGent study is that the victim of such abuse generally has an extremely limited understanding of what is 'appropriate' behaviour at the emotional and sexual level. A truncated understanding of 'privacy' can thus have extremely serious consequences.

It is through childhood and adolescence that the foundations of a person's emotional and sexual life will develop. It is a learning process, a discovery which is eminently linked to the existence of the conditions of a private life.

Without going as far as the extremely serious abuses mentioned above, too systematic prohibitions or too much freedom, as is the case in some families or institutional living environments, can also have extremely negative consequences on the development of the child and his or her relationship with others.

Regular support should limit the number of negative biases in this area.

4° Privacy and use of communication technologies

It is important to note that the use of communication technologies plays a central role in our society.

Children with disabilities can benefit from the effective use of new information and communication technologies (NICTs). In this respect, the implementation of the *EC Directive 2016/2102 on the accessibility of public sector websites and mobile applications* is an *important* step towards making *ICT accessible to all*.

However, the disabled child or adolescent must not be locked into a virtual world in which he or she loses his or her identity.

² Dr. Tina GOETHALS, Prof. Dr. Geert VAN HOVE, Prof. Dr. Freya VANDER LAENEN, *Onderzoek in opdracht van Vlaams Minister van Gelijke Kansen in de periode 2014-2019*, Gent, 2018.

The main problem at this level is related to the ethics of technological developments. In recent years, we have seen an increasing number of developments at this level. New developments are following one another at a high pace and are systematically presented as essential progress. In some cases, we may wonder whether they are not rather gadgets imposed by the marketing force of producers whose sole objective is to produce more and more and gain market share?

It is quite disturbing to note that aspects that were perceived as critical in terms of respect for private life some thirty years ago when the State wanted to introduce them are now seen as entirely legitimate in the case of commercial enterprises: consumers accept that the company controls their actions whereas they refuse to allow the State to do so. This is the whole problem with geolocation, for example, which the youngest people take for granted.

Worse, it seems that technological progress is admitted by default, without any reflection on what this implies at the ethical level.

This has all the more impact as the younger generations are clearly the prime target of this movement and are not properly supported by the more experienced generations who are either overwhelmed by the movement or eager to be as much in the forefront as the younger ones .

The BDF has not carried out any in-depth reflection on this subject with its members, but it notes that there are ethical questions about the safety of children with disabilities in relation to their private lives and that they are not well equipped to deal with them in a comprehensive and sufficiently informed manner.

At this level, the BDF wishes to draw attention to the fact that parents, educators and teachers are not well equipped in these fields in order to carry out their educational mission. In this respect, are they sufficiently assisted by the authorities, who sometimes seem to be overwhelmed by the speed of development of NICTs and the scale of the economic challenges involved?

5° Poverty

In relation to all the aspects discussed above, the BDF notes that poverty acts as a magnifier of the difficulties that many disabled children face in their private lives.

This is what the “Silk study” of 2016 shows: poverty is on the rise, it is spreading to some workers and affects many families with a disabled person³.

Poverty also means fewer resources to meet the challenges of the modern world, particularly in the area of privacy.

6° Statistics

There is still no properly exploitable quantitative data on disability in Belgium.

The BDF regularly asks the authorities to put in place tools for the collection, analysis and dissemination of data disaggregated by sex, age and disability, which are not segmented, are sufficiently detailed and in accordance with the GDPR.

³ SPF Sécurité sociale, *Les tendances se confirment : le risque de pauvreté diminue pour les personnes âgées mais reste élevé chez les personnes peu qualifiées en Belgique*, Communiqué de presse sur l'enquête Silk, 26/08/2016.

This would greatly improve the development of desirable policies and actions, particularly in relation to the privacy of children with disabilities.