BELGIAN ADVISORY COMMITTEE ON
Bioethics

Opinion no. 74 of 13 November 2017 on sexual assistance for persons with disabilities

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I. Request for an opinion

On 21 December 2012, Mr. Ph. Courard – at that time Secretary of State for Social Affairs, Families and Persons with a Disability – requested that the Committee examine the issue of the sexual life of persons with a disability. He referred to it as a particularly delicate issue, given that it touches on the most intimate area of the life of vulnerable persons, an area which in principle belongs to the inalienable freedom of an individual.

He asked the Committee for advice on the issue of sexual assistance, particularly related to the following questions and alternatives, referring on the one hand to a proposal for a resolution on the legislation surrounding sexual assistance for persons with disabilities submitted to the House of Representatives and the Wallonian parliament[1], and on the other hand to a recent film and a novel published around the same time[2]:
(own translation from the French)
"Should we consider persons with a disability to have specific sexual problems?
If so, how can these specific problems be responded to?
Have the opinions of the representative disability organisations been sought?
Is it the task of the public authorities to concern themselves with this issue, or should it remain the sole domain of the individual and informal social interactions?

If the role of the government proves to be relevant:
- can sexual assistance be a valid and legitimate means of contributing to the quality of the emotional and sexual life of persons with a disability? Can this assistance be considered to be conducive to the health (as defined by the WHO) of persons with a disability?
- how should sexual assistance be defined?
- should this assistance be recognised, and should a statute be assigned to those who provide it? If so, what should this statute be? How would it differ to that of a prostitute?

Assuming that the principle of sexual assistance is accepted:
- should the performance(s) of sexual assistants be defined and classified by the legislator? On the basis of which criteria?
- which type of disability should be allocated guidance of this type as a matter of priority?
- should practices be developed which are adapted to the type of disability (physical, mental)?
- how can the differences between the needs of women and men be taken into account?
- how can persons with disabilities be protected from the risk of sexual abuse in the context of

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[1] http://gouvernement.wallonie.be/un-centre-de-ressource-handicap-et-sexualit-en-wallonie

[2] The Belgian film *Hasta la Vista* and the novel of Régine Desforges, *Toutes les femmes s'appellent Marie*, Ed. Hugo et Compagnie, Paris, 2012.

sexual assistance?

- how can we avoid such a system becoming androcentric (male-focused) and contributing, voluntarily or otherwise, to a repetition of situations in which one gender exploits the other?

- how can we avoid giving the impression that the State plays the role of 'pimp'?

- have the various practical experiences that are already available in Switzerland and elsewhere been evaluated?

This issue was taken into consideration by the Committee on 8 September 2014, which decided to further investigate it in the context of a select committee (BC 2014/3).

Although there is a certain parallel between the experiences of the elderly and persons with disabilities in terms of sexuality, it was decided to limit the analysis in this opinion to the sexual assistance of persons with disabilities.

II. Juridical Aspects

The main legal provisions applicable in the case of sexual assistance to persons with disabilities are the following.

II.1. International law: the United Nations Convention on the Rights of Persons with Disabilities (CRPD) from 13 December 2006 [3]

The Convention from 13 December 2006 on the rights of persons with disabilities, signed by Belgium in 2007 and ratified in 2009, uses a 'social' approach to define persons with disabilities, rather than a medical model.[4] They are people with (a) “long-term physical, mental, intellectual or sensory impairment/s which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

The Convention states that its purpose is “to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.”

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[3] The text of the Convention can be consulted at: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

[4] Regarding this distinction, cf. III. Disability and the Experience of Sexuality: the Current Situation

The Convention prohibits all forms of discrimination on the basis of disability.
Article 23 stipulates that States who are party to the Convention should take "effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others," and more specifically that they should ensure that

> a) "the right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognised;
> b) the right of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognised, and the means necessary to enable them to exercise these rights are provided;
> c) persons with disabilities, including children, retain their fertility on an equal basis with others."

Article 25 continues that States who are party to the Convention should "provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes."

II.2. Belgian legislation

Are the fundamental rights of persons with disabilities enshrined in the Constitution?
A proposal to insert article 22*ter* in the Constitution was approved in the Senate and transferred to the House of Representatives in 2012 (no. 5-139/1). The proposal was as follows: "(Paragraph 1) Every person with a disability, depending on the nature and severity of the disability, has the right to measures which ensure his independence and cultural, social and professional integration. (Paragraph 2) The law, the decree of the rule referred to in article 134 guarantee the protection of that right." The commentary on the proposal cites the Convention of 13 December 2006, the continuing discrimination of persons with disabilities, and the intention of "giving [them] the certainty that they are truly taken seriously as a person and as an individual." However, this proposal expired due to the dissolution of the Houses on 28 April 2014.

II.2.1. The ability to consent

II.2.1.1. The adult person with a disability

As is the case for any adult, an adult person with a *physical* disability enjoys the full legal right to participate in and therefore freely consent to any sexual practice that he/she wishes.

It can happen that a person with a *mental* disability be subjected to the system of protection introduced by the law of 17 March 2013. This law reformed the disability regulations regarding competence and introduced a new protection status in line with human dignity. The general measure is competence, but the justice of the peace is free to choose other measures 'à la carte', in proportion and personalised. The justice of the peace decides which acts the protected person is incompetent to perform, taking into account the personal circumstances and the health of the protected person. Consent for "extremely personal" acts, including those "affecting the physical integrity and personal privacy of the protected person (article 497/1, 20° of the Civil Code; translation), which of course includes acts of sexual assistance, may not be the subject of assistance or representation by the protected person's trustee. The law of 17 March 2013 relates to sexual assistance for someone with a disability only in as far as "pocket money" is involved, made available to someone who falls under a trustee, in order to cover, if necessary, the costs associated with the disabled person's emotional and sexual life.

II.2.1.2. The underage person with a disability

Based on articles 372 and 373 of the Penal Code,[5] the age of so-called "sexual majority", that is the age from which intimate relations with a minor no longer constitute an offence of indecent assault, is 16 years in Belgium. Parental authority does not include the power to consent to or refuse sexual acts on behalf of the child.

II.2.1.3. Conclusion

It is difficult to apply the traditional system, in which a person with a disability who is legally incompetent to act is represented by others, to actions in the context of someone's personal and intimate life. Sexual assistance falls outside the scope of medical care. Those who are

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[5] Article 372 of the Penal Code (translation from the Dutch): "Any act of indecent assault, committed without violence or threat on a child or with assistance from a child of the male or female gender under the full age of sixteen years, shall be punished with an imprisonment of five years to ten years.

An act of indecent assault, committed without violence or threat by a blood relative in the ascending line or adoptive parent on a minor or with assistance from a minor, even if the latter has reached the full age of sixteen years, but is not emancipated through marriage, shall be punished with an imprisonment of ten to fifteen years. The same sentence shall apply if the guilty party is either the brother or sister of the minor victim or any person with a similar position in the family, regardless of whether this person habitually or occasionally resides with the victim and has authority over the victim."

Article 373 of the Penal Code (translation from the Dutch): "A term of imprisonment from six months to five years punishes an act of indecent assault on persons or with assistance from persons of the male or female gender, committed with violence, coercion, threat, surprise or cunning, or made possible by incompetence or a physical or mental disability of the victim.

If the act of indecent assault is committed on a minor or with assistance of a minor above the full age of sixteen years, the guilty party shall be punished with an imprisonment of five years to ten years.

If the minor has not yet reached the full age of sixteen years, the sentence shall be imprisonment of ten to fifteen years."

asked to take on the role of representation are not always the most suitable in this context, because they are too close to the disabled person (e.g. the parents) or too far away (e.g. the trustee). The legal incompetence of someone with a disability does not mean however that he/she does not feel or is unable to express a real sexual need. We must ensure that their request is correctly understood and that an adequate and prudent answer is offered. It is possible that consent or refusal be expressed during the exercise of sexual assistance, by means of words, sounds or body language. If the formalisation of consent is problematic, it will be necessary to switch to a specific model of assistance in which a key role is played by a trusted professional in sexual assistance.

II.2.2. The Penal Code

Based on the hearings organised by the Committee, it appears that, at the present moment, a sexual assistant is either a prostitute or someone who claims to have nothing to do with prostitution but who nonetheless is always reimbursed for the services rendered to a person with a disability.

In the current state of the criminal law, the activity that consists of prostitution is in itself not a crime. However, it is questionable whether or not the institution where the person with a disability resides or the association to which the sexual assistant belongs or with which the sexual assistant has contact and which proposes to render the intended service to a person with a disability, commits the offence referred to in article 380, § 1, 1° of the Penal Code which imposes a punishment on “he who, in order to satisfy the passions of others, hires or trains an adult, even with his permission, [...] with a view to committing fornication or prostitution.”

However, the experts interviewed strongly dispute the suggestion that their activity is in any way connected to prostitution or fornication. On the contrary, they emphasise that their sole aim is to meet a right, even a need, of the person with a disability. On the one hand, the Court of Cassation, in judgements of 3 January 1962 and 8 April 1981, decided that the term 'prostitution' does not necessarily presuppose sexual relations and applies to the fornication of someone who, for remuneration, commits an act of indecent touching of another person. Based on this case law, which has not yet been contradicted, it follows that *fornication* consists of “committing an act of indecent touching” or sexual relations outside of wedlock, without any further mention of remuneration or profit. On the other hand, someone's motivation is irrelevant in criminal law, given that the moral element required by law – in this case “satisfying the passions of another” - has been fixed. In view of the 19th century language used in the Penal Code, the term “passions” used in the law refers to the desire to surrender oneself to “indecent touching” or sexual relations outside of wedlock.

Attention should also be paid to article 380ter, § 2 of the Penal Code, which imposes penalties on “he who in any way, directly or indirectly, makes or causes to be made, distributes or disseminates advertising for an offer of sexual services, which are provided by means of some means of telecommunication, even if he makes his offer using covert wording”, and to § 3 of the same article which punishes “he who by means of any form of advertising, even if he conceals the nature of his offer or his question using covert wording, makes known that he indulges in prostitution, facilitates the prostitution of others or wishes to come into contact with someone who practices fornication.” (translated from the Dutch) On the basis of these provisions, the sexual assistant must be discreet about his activities.

Moreover, as stated above, it follows from articles 372 and 373 from the Penal Code that the age at which someone can validly consent to sexual relations has been set at 16 years. The first paragraph of article 373 punishes “an act of indecent assault on persons or with assistance from persons of the male or female gender, committed with violence, coercion, threat, surprise or cunning, or made possible by incompetence or a physical or mental disability of the victim”[6]; indecent assault is touching of a sexual nature; if the touching occurs with consent – and in the case of a sexual assistant, it is even requested by the person with a disability – no criminal offence is committed. It goes without saying that a physically disabled person can make such a request in a valid way; a physical disability which prevents someone making such a request presumes someone else – a trustee - who can make the request in their place. The question of whether a mentally disabled person can make such a request in a valid way is more problematic; here too, the intervention of someone with sufficient knowledge of the person with a disability to be able to interpret his behaviour correctly as a request, will be necessary.

Finally, article 375 of the Penal Code states rape to be a criminal offence, where rape is defined as “any act of sexual penetration of any kind and by any means, committed on a person who does not consent to the act,” and it is further specified that “consent is absent if the act [...] is made possible due to incompetence or a physical or mental disability of the victim”; the context in which the person affected by incompetence or disability requests penetration on their own initiative, could, on the reading of this text, be considered irrelevant; and the person who participates in the circumstances described in articles 66 or 67 could be convicted as co-perpetrator or accessory.

Irrespective of the discretionary power of the prosecution, available to every public prosecutor in his/her own district, it is therefore desirable that the competent legislators take the necessary measures with regard to the juridical aspects mentioned above.

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[6] This text is the result of a law from 1 February 2006 (art. 9,1°).

III. Disability and the Experience of Sexuality: the Current Situation

Preamble

The chapter which follows provides a summary of the essence of the results of the Committee's investigation of the current framework and social practices surrounding the sexual life of persons with a disability. This research is based on scientific and professional literature, or literature intended for users, combined with various interviews. This research forms the basis for the ethical issues outlined in chapter IV. The reader who is in a hurry can first read chapter IV, before later returning to chapter III if desired.

III. 1. Definition of (physical and mental) disability

The vocabulary chosen to indicate a disability is by definition sensitive, and can receive another connotation or frame of reference depending on the intention and background of the speaker. For example, the term "a person with a disability" can refer to various reference and analytical frameworks, such as a medical or a social approach (see below). The Committee considers that, beside the semantic issue and the speaker's choice of an expression such as "disabled", "person with a handicap", "person with special needs", and "person with a disability", it is primarily the social and political perspective on disability that should be examined and analysed.

According to the *Grand Robert*, a person with a disability is someone presenting with a certain (congenital or acquired) lack of physical or mental capacities. This is a definition which clearly bears the mark of the medical approach to disability which prevailed until the 1970's. Whereas disability, just as any form of sickness, used to be approached from a religious or moral framework, this way of thinking gradually made way for a more traditional medical approach, i.e. focussed on the disability as a negative individual characteristic considered to be different to or deviating from the norm – where the norm not only refers to the existence of a fact, but also to the 'value' attributed to this point of reference[7] and which focusses the medical activity on the restoration of what is considered to be normal. The medical model places the person with a disability in the situation of a patient in need of services, care and specific institutions. The person with a disability is primarily the target of rehabilitation provisions and practices, insofar as the limitations of his capacities are linked to his "defect".

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[7] Canguilhem, *Le normal et le pathologique* (1966), Paris, Presses Universitaires de France, 2003, p.75. See also: G. Canguilhem, « Le normal et le pathologique » (1951), in *La connaissance de la vie* (1965), Paris, Vrin, 1998, p. 155-169.

Conversely, the social model postulates that the disadvantages and difficulties experienced by someone with a disability are related to the inherent limitations of the social environment; disability is thus defined on the basis of the interaction between the individual and a more or less favourable environment; “Disability is thus a result of how society is organised [...] disability is about discrimination and social exclusion.”[8] Based on this perspective, the answer to disability is a change in this interaction, by acting on the (material, relational, ideological, etc.) environment. Moreover, it can be noted that, while it is the doctor or carer who is the agent of change in the medical model, in the social model the person with a disability him/herself, together with others, can grow into a full participant in this transformation. The social model does not of course exclude the intervention of the physician, when this is useful and necessary, just as it does not exclude taking into account the bodily and individual dimension of the lived experience of disability.[9]. The medical and individual approach is however framed within a totality of social provisions which focus on creating a more favourable environment, from the perspective of equality with others and full participation in social life. Equality means non-discrimination here, and results in a logic of universal accessibility.

Underlying the medical and social models, relational anthropological models emphasise at the same time the fundamental vulnerability of all (vulnerable and mortal) human persons, some of whom are also affected by a significant, coincidental vulnerability in the form of e.g. trauma or genetic disorders, precarious material circumstances, etc. This situation of vulnerability offers opportunities and imposes restrictions, all of which are decisive for individual projects. These anthropological models of disability emphasise both the principle of proportionality (which encourages shifting the boundaries of the disability according to e.g. a reasonableness criterion) and a principle of solidarity (which imposes the obligation to reduce injustice and inequality as much as possible).

Be that as it may, it is certainly the social model[10] that has been adopted in the formulation of the rights of persons with a disability at an international level (see the aforementioned Article 1 of the Convention of the United Nations from 13 December 2006 on the rights of persons with disabilities, cf. II. Juridical Aspects).

In Belgium, the Centre for Equal Opportunities and Anti-discrimination stated the following in its *Parallel report to the first periodic Belgian report in the context of the implementation of the*

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[8] Handicap international resources: http://www.hiproweb.org/fileadmin/cdroms/Handicap_Developpement/www/en_page31.html

[9] A. Dufour, *Dépasser les modèles dans le champ du handicap : un souci de soi, de l’autre, de soi avec l’autre*, from Handicap ou manières d’être, Carnet de recherches, 15 June 2013, http://homde.hypotheses.org/220; Shakespeare Tom, Watson Nicholas, *The social model of disability: an outdated ideology?*, Research in Social Science and Disability, vol. 2, 2002.

[10] Shakespeare Tom, Watson Nicholas, «The social model of disability: an outdated ideology?», *Research in Social Science and Disability*, vol. 2, 2002.

Convention of the United Nations on the rights of persons with disabilities from 2014: “Various definitions of disability exist side by side in Belgium. Except for a few exceptions, they are all based on a medical view on disability. They can be found in various juridical and regulatory texts, where they regulate the access to rights and/or benefits: income replacement allowances, social housing, tax benefits, employment quotas (in the public sector). Resistance to a social view on disability is especially strong in the field of employment, as this model – compared to the more restrictive medical view of disability – opens the right to more people, e.g. people who suffer from a chronic illness, to protection against discrimination and the right to reasonable adjustments. Based on the social model of disability, questions can also be asked regarding the inadequacy of the physical and organisational environment. The implementation of a social model of disability not only meets resistance, it also has to deal with a lack of information and conflicting habits and practices. For instance, in mental healthcare it is often not yet realised that mental health problems, which limit the possibilities of someone in a specific environment, can fall under the definition of disability. Similarly, the so-called disability sector does not automatically include people from the mental healthcare sector, except when a double diagnosis is made (for example, a person with an intellectual disability associated with mental disorders).”[11] (translation by the Committee) The Centre recommended that the government promote a social view on disability, in which the environment of the person with a disability is questioned and in order to raise awareness of the people or groups of people who are protected by the Convention.

III. 2. Disability and the experience of sexuality: fundamental rights and government policy

III.2.1. The context of the issue

After a long period in which the sexuality of people with a disability was either suppressed or simply ignored, the AIDS issue in the 1990's and the contamination of people with a disability in institutions suddenly brought the issue of their sexuality to the forefront. This led, among other things, to the approval by three French-speaking (Belgian) ministers of the '*Chatre pour agir*' ('Charter for Action') in the early 2000's. This charter was drafted by actors in the field, and its aim was, amongst other things, to develop the necessary information and support for the emotional and sexual development of people with a disability.[12] These days the emotional and sexual life of people with a disability is featured in films, television programmes and symposiums.[13]

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[11] Text at (in French): http://unia.be/fr/publications-et-statistiques/publications/rapport-parallele-convention-des-nations-unies-relative-aux-droits-des-personnes-handicapees

[12] https://www.aviq.be/handicap/pdf/AWIPH/projets_nationaux/charte_pour_agir/charte_pour_agir-ACCOK.pdf

[13] For example, cf. the film *Sexe, amour et handicap* from Jean-Michel Carré (prod. Grain de sable – 2010) : https://www.youtube.com/watch?v=ioyqmF4Jjio. For lists of films on this topic:

III. 2. 2. Expansion of the issue: from the International Convention to Belgian policy

The 2006 Convention of the United Nations alludes to sexual and emotional life when it mentions the right to the greatest possible degree of health in its list of fundamental rights. The definition of health promoted by the World Health Organisation (WHO) since 1946 is “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” The Centre for Equal Opportunities and Anti-discrimination (currently known as *Unia*) repeats in its *Parallel Report* (2014) that, according to the Convention, the right to a sexual and emotional life is one of the aspects of health in a broad sense, and that the same applies to the right to live as a couple.

In 2013, Mrs. E. Tillieux, Walloon Minister of Health, Social Action and Equal Opportunities, published a call for the submission of projects for the creation of a '*Centre de ressources Handicap et sexualité*' ('Disability and sexuality resource centre'), arguing that “sexual rights are universal human rights […] and that all people are equal and have the right to legal protection against all forms of violation of their sexual integrity.” The Minister also emphasised that “this is not a secondary right, but a right that is closely connected to the life of every person, and access to an emotional and sexual life is an indispensable factor in development and balance.”[14]

Another report published in 2014 by the Centre for Equal Opportunities and Anti-discrimination, titled *The situation of people with a disability in Belgium regarding their human rights and fundamental freedoms as guaranteed in the UN Convention on the rights of persons with disabilities,*[15] approaches the issue of the sexuality of persons with a disability mainly from the restrictive angle of protection against abuse, exploitation and violence and not from the angle of the positive actions which must be undertaken in order to promote relational, emotional and/or sexual development.

On 5 February 2014, the Walloon Parliament approved a resolution regarding the emotional and sexual life of people with a disability, in which the Government was requested to ensure that structures for advice, formation, information and exchange regarding the emotional and sexual life of persons with a disability be put in place. This is because, while the Government acknowledges the importance of the issue, it also admits that there are currently too few facilities in this area.

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http://www.senscritique.com/liste/Sexe_et_Handicap/347007 (in French), https://mubi.com/lists/disability-in-film (in English, and Dutch)

[14] Cabinet of Mrs. E. Tillieux; http://tillieux.wallonie.be/appel-projets-visant-la-cr-ation-d-un-centre-de-ressources-handicap-et-sexualit

[15] Study commissioned by the Interfederal Centre for Equal Opportunities, conducted by the consortium KU Leuven, ULB, UHasselt, UGent en Uantwerpen (final report 2014). The report was available on the Unia website, but is so no longer.

In Flanders, the Flemish Minister of Wellbeing, Public Health and Family Mr. Jo Vandeurzen subsidises associations which are active in the area of sexual assistance (cf. point III.V. Aditi and footnote number 29). In addition, a financial system 'attached' to a specific person ("persoonsvolgende financiering") is to be introduced, in which someone with a disability will have a certain budget at their disposal, tailored to his/her specific needs.[16.]

III. 3. Current responses to the needs of persons with disabilities at the level of their sexual and emotional life

It appears from the hearings organised by the Committee that people with a disability have similar desires to those of able people regarding their sexual and emotional life, just as complex and diverse. However, people with a functional disability experience enormous difficulties in being able to respond to this fundamental human need, due to various factors: (1) motor autonomy which is restricted or made more difficult as a consequence of the disability, (2) organisational restrictions related to life in a community, (3) specific bodily or physical experiences stemming from situations related to the daily care they receive from their family and/or professional environment. The mobilisation or manipulation of the body by third parties as part of the care provided is therefore cited as a primordial and structuring experience of a certain relationship to oneself and to others. Furthermore, it appears that this experience, unique to the provision of care, is for some people with a disability the only opportunity they have to come into bodily contact with others.

The ever-present care interferes with the sexual life of those in need. On the one hand, the care offered can be necessary for a better ownership of one's own body. On the other hand, the same care can also create a difficulty when it comes to knowledge about and empowerment over the bodily experiences connected with one's emotional and sexual life. Moreover, "the closeness and intimacy experienced during care can sometimes lead to an eroticisation of the care relationship"[17] (own translation) and that on the part of the professional or the person with a disability. There have been various recommendations formulated on the way in which carers

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[16] Cf (in Dutch): *"Vlaams beleid voor personen met een beperking : invoering van het decreet persoonsvolgende financiering"*: http://www.jovandeurzen.be/sites/jvandeurzen/files/Meerjarenplanfinaal_VR6feb2015_0.pdf)

"Beleidsnota 2014-2019" (policy paper) submitted by Mr. Jo Vandeurzen, Flemish Minister of Wellbeing, Public Health and Family, at: www.vlaanderen.be/nl/publicaties/detail/beleidsnota-2014-2019-welzijn-volksgezondheid-en-gezin .

[17] *Affectivité, sexualité et handicap,* Solidaris, 2011, p. 61. The document (in French) can be found at: http://www.solidaris-liege.be/mutualite/publications/nos-publications/affectivite-sexualite-et-handicap.html. The ASPH (a Walloon trade union for people with a disability) brought together a multidisciplinary workgroup (composed of animators, educators, psychologists, a sexologist), named PHAS, to draft this guide. The group came from four mixed institutions for people with a disability which differed in terms of functioning, population and daily routine.

should conduct themselves. [18]

These various factors lead to an important question: how can other physical interpersonal contacts be made possible, other than those related to care and family life? This question has already given rise to numerous initiatives by various professionals.

III. 3. 1. The plurality of responses

While a multitude of informal answers already existed, related to specific situations (singles, couples, physical and/or mental disabilities, mild or severe disabilities), many more formal responses have been introduced in recent years at the level of care (day-care centres, specialised education, housing facilities). Each and every one of these answers can be considered as a range of ***actions which support and accompany emotional, relational and sexual life***, similar to the support offered to people without a functional disability by community organisations and the Government, in the form of family planning, psychological consultations, etc. These actions take shape in function of the needs and specific situations in which people with a disability live, due to the nature of their disability and the place where they live. In addition, this support, more than in other contexts, is offered by a team.

With respect to this point, an overview can be given of these ***supporting and accompanying actions***.[19] For the sake of clarity, a distinction is made in what follows between actions which support emotional and sexual life and which do not involve the provision of sexual services (III. 3. 2) and those which do, such as guidance when using the facilities of a prostitute (III. 3. 3.) or other sexual assistance (III. 3. 4).

III. 3. 2. Actions which do not involve the provision of sexual services

A distinction can be made between actions which aim at providing information, actions surrounding material and spatial infrastructure, actions which aim at practical support of relational life, health actions, and actions regarding the protection and safety of users. In practice, both users and their families, as well as professionals, can be involved in these actions.

Actions which aim at providing information and formation regarding sexual and emotional life: at the present time, people with a disability have less access to information, which leads to a

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[18] *Affectivité, sexualité et handicap,* op. cit., p. 62.

[19] This overview is based on the guide mentioned above, *Affectivité, sexualité et handicap,* Solidaris, 2011.

lack of knowledge, misconceptions, a lack of skills and a lack of sensual physical experience(s).[20] For this reason, specialised day-care, education and/or residential institutions are involved in discussion groups, adapted information or training sessions,[21] wellness workshops, individual follow-ups, sex education classes, access to planning consultations and integration of the sexual dimension (and support methods) in the *individual* psychological, medical and pedagogical *project.*

Actions surrounding material and spatial infrastructure (intimacy, private life, personal space): living in community makes it more difficult to respect intimacy, private life and personal space, although all of this is indispensable for wellbeing in general and relational, sexual and emotional life in particular. As a result, actions are carried out which target the organisation and planning of the use of various locations, based on a clear distinction between private and public space. [22] In this way, possibilities for personal intimacy can be provided for those who have to share a (bed)room.

Actions which aim at practical support of relational life: the disability itself and life in an institution can hinder the development of fruitful and diverse social and human relationships: "Couples arise, separate, other couples form, … but the choice of partner is mostly restricted to the other residents of the institution. After a few years, everyone has been 'tried out', in spite of external activities [...] The greatest difficulty is [...] to ensure the follow-up of a relationship between two people from different institutions. [...] After all, the carers cannot always accompany their residents to another institution."[23] (translation by the Committee) Moreover, as was emphasised during the hearings, life in community often means that people with a disability have little opportunity to 'socialise' their feelings of happiness or other emotions.[24]. To respond to these difficulties, institutions can make resources available to encourage meeting and getting to know new people, such as organising activities between various centres or institutions as well as activities aimed at romantic and sexual relationships[25] and the accompaniment and continual support of possible cohabitation.

Health and hygiene actions: health is an issue in sexual life, whether it concerns pathologies related to sexually transmitted diseases (STD's), pregnancy and contraception, or specific

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[20] Regarding the latter point, see below: "Health and hygiene actions."

[21] Training sessions such as how to use the internet, e.g. dating sites, pornography sites, online sex etc.

[22] On the basis of specific arrangements and schedules related to access to specific rooms, or pictograms on the doors.

[23] *Affectivité, sexualité et handicap,* op. cit., p. 37.

[24] Select committee hearing of Mr. Guy Hubert (8 June 2015), psychologist, responsible for the courses offered by the association 'Inclusion' http://www.inclusion-asbl.be/ which supports people with a learning or mental disability.

[25] E.g. 'slow dating' activities, a dance project in the Arthur Regnier Centre (Henegouwen).

problems related to getting older. Institutions must therefore ensure that all involved parties can enjoy sufficient access to quality healthcare by way of medical consultations (gynaecology, urology) and family planning (psychology etc.).

However, this does not detract from the fact that life in an institution and the disability itself require a strict organisation of medical and healthcare follow-up for the users. This is also the reason why we should keep in mind, even more than in other contexts, the right of the person with a disability to act as the privileged discussion partner in matters of health, whereby professionals and parents play an accompanying role.[26]

In addition, it should be emphasised that intellectual disabilities and certain living conditions (e.g. one expert reported that there are often no mirrors in institutions) often lead to a relative denial of the body, i.e. a denial of one's own capacities, perceptions and personal hygiene needs (e.g. dental and oral hygiene or intimate hygiene to the extent that these play a role in contacts with other people).

Actions regarding the protection and safety of users: abuse and physical and/or psychological violence, whether or not of a sexual nature, can occur in institutions, just as in other settings. We define abuse in this context as obtaining something (an action or object) from someone else without their permission (through the exercise of power, authority, blackmail or manipulation). The problem becomes even more complex when a mental disability is involved, when people have difficulty expressing themselves or when they display submission habits or 'consent automatisms'.[27] In such cases, the requirement of consent can be compromised, or such consent may even be completely lacking. On the side of the professionals, distinguishing between what is true and false, noticing what cannot be put into words, understanding the nature of aggressive behaviour, including family members or guardians in the issue, and maintaining an appropriate distance in daily contact, can prove particularly difficult and complex.

Finally, apart from control actions (deterrence and medication in some cases) and possible sanctions (in the case of formally submitted and verified complaints), the literature points to the great importance of steps aimed at acquiring the necessary attitudes (such as discussion groups, information sessions, joint activities hosted by various centres, dialogue, a code of conduct). This also includes, if possible, teaching people with a disability to make choices and express themselves (learning to say 'no'), respect others and demand respect for themselves,

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[26] Affectivité, sexualité et handicap, op. cit., p. 54.

[27] The guide *Affectivité, sexualité et handicap* stresses that the benevolent authority under which the beneficiaries of services in institutions evolve, has the tendency to restrict their ability to make decisions, which results in decisions being made in their place and other people speaking for them.

and to learn the value of what belongs to them.

The creation of a climate of trust instead of simply focussing on supervision, of a place where things are taught and dialogue is possible instead of focussing on punishment, is essential for institutions. The staff themselves – which naturally occupy a position of authority and control, and come into daily contact with the intimate life of the people for whom they are responsible – must demonstrate fairness, respect and discretion, while at the same time being able to count on the support of their own team to solve the most complex problems.[28]

III. 3. 3. Guidance when utilising the services of a prostitute (male/female)

Based on the hearings held, it appears that only some institutions actually provide guidance to residents who wish to utilise the services of a prostitute (male/female), knowing of course that certain disabled people with more autonomy are able to utilise these services themselves.[29]. In such cases it is up to the professional guidance team to take on the role of (or act as substitute for) the natural accompanier (family, relative or neighbour). A prostitute (male/female) can be called upon to gain a first sexual experience or if it is the only possible way to experience genital sexuality; *this falls under one of the possible responses which can be offered in a range of support and accompaniment actions.*

It should be remembered that the Belgian Penal Code (Article 380) does not deem prostitution itself to be a punishable offence, but only those who instigate fornication and the prostitution of another person (cf. above, II.2.2), regardless of whether any profit is intended to be made by the offender.

The resident (male or female) must, as the primary and only decision-maker, make the request personally, albeit possibly by means of a trustee; this request can be either heterosexual or homosexual in nature. A conversation follows between the person making the request and the sexologist, aimed at determining whether the stated request is indeed in line with what the person involved wishes, what their needs are, and the material, (biological or psychological) perisexological and sexological circumstances in which the request was formulated and is able to be met.[30] If the request is accepted, the conversation between the applicant and the

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[28] *Affectivité, sexualité et handicap,* op. cit., p. 64-74 for the complete theme “Abus et violences” (“Abuse and violence”).

[29] Guidance when utilising the services of a prostitute (male/female) is given in the Arthur Regniers Centre (Henegouwen), but not the Queen Fabiola village number 1. This information is based upon the hearing of 9 March 2015 with Mr. Coquiart, specialised sexologist at the Arthur Regniers Centre.

[30] The material circumstances refer to the specific material needs, such as lifting or moving equipment, requirements directly related to the disability (diaper, urinal) which must be met, potential changes that must be made in terms of timetabling or the concrete organisation, pocket money, etc. The biological perisexological circumstances refer to the general health situation (e.g. high blood pressure or

professional will continue onto the act of prostitution itself, both at a relational level (a paid relationship, the matter of the fee, the prostitute involved) and an organisational level (location, time and frequency, accompanier, transport, parental and/or guardian's consent in the case of a minor or of extended minority). For reasons of discretion, the meeting place will always be somewhere *external* (not in the room of the resident).

Experience shows that parental consent is often requested, as occurs with all other important decisions. In the absence of such consent, the person with a disability can be faced with a conflict of loyalty that will have repercussions for the institution. Regarding this point, it was furthermore mentioned that, while the parent is often initially taken aback by the request, he/she will subsequently insist on an improvement of the circumstance in which his/her child invokes a prostitute (male/female).

The institution foresees the possibility of a feedback moment after the event, in which attention is not only paid to the positive effects of the step taken (life experience acquired, mental and physical relaxation, potential investment in a long-term relationship, sexological aspects or getting to know one's own sexuality better), but also to potential problems (difficulties experienced during the sexual contact, blackmail, extortion, etc.) for which social services can be called upon, if necessary. The parents are also kept informed, and invited to share their feelings.

The experiences reported point to various personal effects of utilising the services of a prostitute which serve as learning experiences: an increase in assertiveness, an increase in the capacity for seduction, the gradual adjustment of sexual behaviour, clarification of the emotional and/or genital needs of the person in question, various erotic investments for a long-term relationship, consolidation of the sexual identity with respect to others. Moreover, it appears that parents are generally satisfied, when they see and experience their child developing at this level, and some parents decide to continue the visits of a prostitute even after their child with a functional disability has left the institution.

Finally, the possibility of guidance when utilising the services of a prostitute (male/female) does not necessarily mean that a request will automatically be made, nor that the practice will be generalised: some people give up after the initial conversation, others because the experience led to an improvement in their emotional and sexual life, and others again because they leave the institution (in which case the parent can potentially take on the role of accompanier).

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diabetes), medication which should be stopped or ingested (with inadvertent negative consequences for sexuality, or conducive to sexuality). The psychological perisexological circumstances refer to, for example, potential anxiety surrounding the sexual act, depression, sexual knowledge and skills. Finally, the specific sexological circumstances are also taken into account.

III. 4. Sexual assistance in Belgium

From an historical point of view, the idea and practice of sexual assistance developed *outside* of the sector of care for people with a functional disability, but has found new, unforeseen applications in this area. This form of assistance meets a variety of objectives, takes on various forms and includes a diverse range of practices which vary from country to country.

Alongside the range of actions *supporting and accompanying emotional, relational and sexual life* which exist in Belgium (cf. III.3), an initiative emerged at the end of the 2000's which aimed at promoting sexual assistance. Given that this initiative is unique in our country, it requires some explanation.

The non-profit organisation Aditi was founded in Flanders in 2008 at the request of institutions and professional carers of people with disabilities, with the support of Sensoa (the Flemish expertise centrum for sexual health). These institutions and carers constitute the members of the organisation. These include special educators, psychologists and psychotherapists. Institutions can become a member of Aditi for 100€ per year.

From 2009 to 2013, the organisation functioned on the basis of volunteer work done outside working hours. Since 2014, the organisation employs two fulltime employers thanks to the membership fees of the affiliated institutions, subsidies from the Flemish Community,[31] the support of Sensoa (the Flemish expertise centrum for sexuality) and income from training courses. In 2016, an extra halftime employer was added. Aditi has also been active in Wallonia since 2014, although purely on a volunteer basis. This results in an organisation operating at two different speeds, different in the north and the south of the country. At this stage, the organisation receives on average 700 requests or questions each year, of which 300 are specific requests for sexual assistance in the strict sense of the word (see below), and 400 requests for formation, institutional support, etc. (see further below).

Finally, in 2012 Aditi, in cooperation with Professor G. Vandermeulen (University of Gent, Law and Criminology) and with provincial funding, conducted field research of the network of institutions and people with disabilities regarding requests, questions and problems in the area of sexual assistance. The principal conclusion of the study, in which overseas comparisons were also made, was simple: no framework exists for sexual assistance, and such a framework must be developed. The only framework which does exist is prostitution, and that is not suitable.

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[31] Funding from Mr. Jo Van Deurzen, Flemish Minister of Wellbeing, Public Health and Family.

III.4.1. Sexual assistance according to Aditi

Aditi views sexual assistance from a dual perspective: on the one hand, there is the juridical and paralegal framework of the rights of people with disabilities, and on the other hand, they have their own view on sexuality.

At a juridical and paralegal level, reference is made to the International Planned Parenthood Federation's charter (their charter on sexual and reproductive rights)[32] and the United Nations Convention on the Rights of Persons with Disabilities, signed by Belgium in 2007 and ratified in 2009.[33] Aditi takes six essential benchmarks from this framework, related to:

- freedom and autonomy, including sexual freedom (in the context of disability, the meaning of the word autonomy needs to be adapted in function of the specific situations determined by the various forms of dependence);
- equality (important for situations in which there is mention of various forms of dependence, situations in which people with a disability in need of care find themselves);
- respect for private life (how this can be provided in a context in which intermediaries are required in matters of sexual life; issue of shared professional confidentiality);
- provision of information (the right to information needs to be made concrete in the transmission of the knowledge that is necessary in situations of vulnerability, because knowledge protects, particularly against abuse);
- access to care (the action of Aditi can be seen as conducive to access to care in a broad, nonmedical sense, being sexual assistance or that which can enhance sexual development such as the use of sex toys, contraception, etc.);
- safety (protection against abuse, which is contributed to by the provision of information).

Concerning its vision on sexuality, Aditi defends the idea that sexuality is a fundamental basic need which accompanies people through all the various stages of life and only ceases to exist when life ends. The sexuality of people with a disability is in itself not a problem; it is only different or special because of the restrictions imposed by one or more disabilities. The 'problem' of the sexuality of people with a disability is in the first place a matter for the environment, not for the person themselves.

In this dual perspective, sexual assistance touches on sexuality in the broad sense of the word (from masturbation to effective penetration, across all forms of intimate interactions such as

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[32] The International Planned Parenthood Federation is an international federation for family planning (the highest decision-making body for family planning). On the basis of this charter, a commission set up by the IPPF in 2006 issued a declaration on sexual rights, which was submitted to the IPPF board in May 2008: http://www.ippf.org/resource/IPPF-Charter-Sexual-and-Reproductive-Rights. The texts in question are in line with international instruments and conventions on human rights; the authors have developed content in terms of sexuality, reproduction and health.

[33] Cf. II. Juridical aspects.

simple tenderness). Each person is unique and has their own needs, and that is no different for people with a disability: sexual assistance is the elaboration of an appropriate response to unique and personal needs, taking into account factors unique to a specific situation. Sexual assistance falls therefore under care in the broad, nonmedical meaning of the word (*care* as opposed to *cure*). Sexual assistance is about the attention which should be paid to the needs of people with a functional disability. The expert is not the sexual assistant, in such cases, but the person with a disability themselves.

The role of Aditi extends much further than just the provision of sexual assistance services. The association recognises four main tasks for itself:

1. Personal advice: the professionals of Aditi attempt to uncover the specific request by means of consultations or conversations in which people with a disability are involved, either alone or under guidance, and so to find a response which is as appropriate as possible. The consultation will also often thereby fulfil a mediatory role between the person with a disability and their environment (family and/or professionals), by helping to understand the request or by working out an answer to the request. In all of this, Aditi tries to take into account all parties involved, and provides an interesting alternative to the parents in the concrete search for solutions for the sexual needs of their child. Sexual assistance in the narrow sense is part of the cluster of possible answers, but Aditi can also help couples, for example.
2. Expertise regarding sexual assistance, intended for sexual assistants: by means of the training of sexual assistants and guidance during their work, as well as by means of contact between sexual assistants and institutions.
3. Expertise and support regarding sexuality, intended for institutions: helping institutions to acquire the necessary knowledge regarding the sexuality (in the broad sense of the word) of people with a disability; the formulation of a clear standpoint with respect to the answers that should be offered in order to meet the sexual needs of clients, and the specific procedures for receiving requests; the elaboration of charters laying down rules and thresholds (particularly with respect to boundary crossing behaviour); follow-up of the 'internal policy' in this area.
4. Raising societal awareness and instigating public debate on sexual assistance, aimed at its recognition and the elaboration of a legal framework that will not only provide social recognition but also a protective framework for users and the sexual assistants themselves. Through the establishment of EPSEAS (*European platform for sexual assistance*),[34] which brings together non-profit organisations involved in sexual assistance for people with a disability (Belgium, Italy, France, Spain, Switzerland), Aditi supports the provision of harmonised training for sexual assistants and various proposals for the elaboration of a legal framework.

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[34] http://www.epseas.eu/en/page/192

III.4.2. Sexual assistance in practice with Aditi

From the point of view of the user

In the case of an explicit request for sexual assistance in the narrow sense of the word, a conversation will be held, if possible and in the first place with the person with a disability, the primary 'expert' regarding his/her own sexuality. If such a conversation turns out not to be possible, people from the direct environment can be present. All aspects of the person in question will be taken into account (cognitive, emotional, social, relational, physical and mental disabilities, the particular situation). The primary aim of the conversation conducted is thus to clarify the formulated request by means of a detailed analysis, which can then be passed on to the environment. Once the request has been clarified, not only practical aspects will have to be examined (location, transport, concrete arrangements, payment); a preparatory phase will also have to be planned (e.g. the sexual assistant may have to learn certain signs, gestures or other communication techniques; the sharing of information and specific lessons aimed at people with a mental disability or beginners, given by a remedial educator). Special attention will be given to the setting of *boundaries*, especially in the case of people with a mental disability whose expectations and needs are sometimes more difficult to clarify because of their specific cognitive, bodily and emotional development. In such specific cases, Aditi provides mediation between user and sexual assistant as well as follow-up during the entire process of assistance.

From the point of view of the sexual assistant

Aditi does not actively recruit sexual assistants. So far, these are all volunteers, men and women, who have approached the organisation of their own volition. At the present time there are in Flanders 40 active sexual assistants, who respond to 300 requests (originating from the parents of people residing in an institution or from the people themselves). 75% (30) of the providers are women, 25% (10) are men. In Wallonia there are 8 active assistants, 3 of whom are bilingual (Dutch/French) and who helped with the launch of the activities. The sexual assistants must have a main job, as they are only allowed to be assistants on a secondary basis. The purpose of this rule is to avoid people who wish to give sexual assistance to people with a disability purely out of financial motives.

Aditi selects by means of interviews which aim at identifying the motivations of the candidate, as well as his/her vision of sexuality and knowledge regarding disability. Those who make it through this interview step, are invited to follow training (a full day, four times a year) and to participate in peer meetings (which bring together active sexual assistants) organised by province. Each new service provider is assigned a godmother/father in the beginning, who has more experience and can serve as contact person.

Once active, assistants can count on the mediation of Aditi to assign requests from users to particular assistants, taking into account their qualities and the request posed. Once contact has been made, Aditi provides a sort of follow-up, but it is up to the sexual assistant to further arrange the concrete organisation directly with the institution or family. The actual follow-up by Aditi occurs during peer meetings, during which the assistants exchange their experiences. One of the most important aspects of such a peer meeting is the identification and articulation of the boundaries assigned to both assistants and users (how should one respond to declarations of love? Presents? etc.). At the start of 2016, an additional 20 people were in the exploratory phase (in Flanders), meaning that they had made it through the initial interview and had progressed to the training and peer meeting phase.

Sexual assistants currently have no formally recognised statute, and Aditi determines the framework - namely by setting a lump sum payment amount which undercuts the competition (€100/hour plus transport costs, an identical amount regardless of the actions to be performed).

Finally, it should be noted that Aditi does attempt to establish contact with the prostitution community, in order to respond to requests from people with a purely functional disability, whose situation is relatively simpler. Since no contracts are signed between Aditi and the prostitutes (male/female), and given the fact that the organisation restricts its role to that of conversation partner, Aditi believes that it thereby stays within the limits of the law. There appear however to be few prostitutes (male/female) who wish to join the ranks of Aditi sexual assistants, possibly because of the compulsory training and the less profitable nature of the activity. Aditi is however not opposed to welcoming persons mainly active as prostitutes into their team.

III. 5. Experiences from French-speaking Switzerland with sexual assistance

French-speaking Switzerland is a good example and source of inspiration for initiatives which wish to set up an expert, supervised and officially recognised sexual assistance system. As this example also helped direct the thought exercise of the Committee, the most important elements are described in what follows.

Two organisations which provide a fee-based training for sexual assistants have been set up in French-speaking Switzerland, *Corps solidaires* (solidarity) and *Sexualité et handicaps pluriels* (SEHP; sexuality and multiple disabilities).[35] This training entitles one to a certificate which is

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[35] https://www.sehp.ch

recognised by the Swiss foundation for reproductive and sexual health.[36]

The history of sexual assistance for people with a disability in Switzerland dates back 40 years, during which time there has been a rapid evolution of social practices in the area of sexuality (contraception, recognition of sexuality as a basic need and as a dimension of self-affirmation, etc.), and, simultaneously with respect to disabilities, movements aimed at integration, empowerment and emancipation. The above-mentioned changes took place not just in a context of a broader view on the equality of the rights of all citizens, but also in the context of a promotion of individual norms in the area of sexual behaviour. In a context of persistent resistance and numerous obstacles, SEHP recognises that sexual assistance is both a pertinent and innovative response to certain needs, as well as a delicate social experiment involving people with a disability. As a result, not only moderation, prudence and correctness are needed, but also critical discussion.[37]

III. 5. 1. Objectives, principles and ethical framework

The objectives of sexual assistance are aligned with the values of *empowerment, integration and quality of life* of people with disabilities.

The basic principle is that *the responses must be tailored to 'sensual and sexual' needs, taking into account the unicity of each situation.* Sexual assistance is not a sales catalogue of performances, but a "proposal for guidance in line with the emotions and erotic and sensory expectations of people with a disability"; the sexual assistant awaits and deciphers the specific request of the beneficiary by signs and indications, without directing or counting on the performance in any way.[38].

The ethical framework is one of mutual respect (between the person with a disability and the service provider), of absolute respect for intimacy and confidentiality, of safety for both the beneficiaries and the service providers, and of taking into account the 'subtle role of third parties' in arranging the performance. Last but not least, sexual assistance fits within the principles of solidarity and personal commitment.

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[36] These organisations take up the baton passed on by German-speaking Switzerland, where such trainings have existed for much longer. Cf. C. Aghté-Diserens, La formation en assistance sexuelle. Toute innovation implique des risques, in *Reliance*, 2008/3 (n°29 : *Au risque du désir*), p. 46-52. The entire number is dedicated to sexual assistance and is available at: https://www.cairn.info/revue-reliance-2008-3-page-46.htm

[37] Cf. in this regard C. Aghté-Diserens, *art. cit*. p.47.

[38] A *conditio sine qua non* or precondition for the sexual assistant is that he/she be true to him/herself (sensations, thoughts, positive and negative emotions), in order to be able to listen to and understand the other (and their sensations, thoughts, positive and negative emotions). It comes down to the sexual assistant recognising the other as a subject who challenges his desires as well as facing up to his/her own limitations. It is a conscious commitment of self and the holistic person.

III. 5. 2. In practice: training and supervision

The objectives of the Swiss training are clearly formulated:

- to ensure a suitable theoretical and practical programme with a view to developing skills tailored to the individual and diverse needs of people with a disability
- to develop specific knowledge related to various disabilities and to promote preventive action against sexual violence and sexually transmitted infections
- to learn to clarify the specific expectations of people with a disability and to disconnect these from their own projections
- to increase listening skills (both listening to oneself and others), and skills involved in asking questions, analysing one's own motivations and sexual history, plus the ability to accurately determine one's own limitations
- to provide a training framework which will strengthen professional identity and personal development
- to strengthen cohesion and solidarity amongst the group of pioneers, by means of collective supervision.

Access to the Swiss training for sexual assistant is granted after a rigorous selection process based on a call for applications. This call is addressed to those who believe they can offer such an assistance relationship and who believe they have the necessary skills (listening skills, mastery of the art of touch, a clear picture of one's own limitations, a balanced personality and a good feeling about one's own sexuality). Those who pass on to the next stage must prove, amongst other things, that they are "courageous, gentle and capable of solidarity."[39] The selection process includes in-depth interviews, conducted in the presence of a sexologist-educator and someone affected by a specific physical disability, in order to clarify the exact motivations of the candidate assistant and to evaluate the conformity of his/her statements with the principles, objectives and ethics of approach. In addition, candidates must have a clean criminal record and a fixed professional activity, given that the role of sexual assistant may not be exercised as one's primary job.

The training programme provides an **integrative and progressive learning process**, by means of individual evaluations, some of which lead to obtaining a certificate, and in which both theoretical and practical didactic tools are used.

The scope of the **skills** to be acquired is extensive and multi-faceted. Alongside specific knowledge on disability (I), the necessary legal knowledge (II), the required sexological knowledge (III), knowledge related to the institutional context and the role of guiding third

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[39] Ph. Rodrick, *La Tribune de Genève*, 10-11 September 2003.

parties (IV), it should be emphasised that this training also provides for the acquisition of specific psycho-physical skills (V) as well as the development of an ethical reflection reflex integrated into the activity (VI).

In terms of psycho-physical skills, three dimensions are the object of reflection, formalisation and adaptation: 1) cognitive, 2) psychological and 3) physical skills, which mobilise the sexual assistant's introspective capacities and the management of their emotions.

In terms of ethical reflection, the training develops the ability to contextualise knowledge and develop skills. Becoming aware of and understanding deontological limitations, developing the ability to adapt to various disability situations, the unicity of the request of the person with a disability as well as ensuring the confidentiality of individual situations are all targets which should be aimed at by those with the ambition of becoming sexual assistant and integrating into society.

The formation team is multi-faceted and specialised. The conceptualisation and coordination of the training are ensured by two sexologist-educators and two men affected by a physical disability, who take turns to be present as contact people and trainers. The other members of the team are sexologists, medical psychiatrists, sexual assistants, HES training managers,[40] specialists in physical and sexual-physical approaches, psychologists, lawyers, ethicists, as well as specialists in various disabilities.

Supervision provides a collective framework. Although the training for sexual assistant includes a considerable amount of solo work, it is very important that candidates not become isolated. When confronted with an emotional investment which can lead to delusional projections or fantasies, the sexual assistant does well to call upon an external support, in the form of supervision based on group cohesion and solidarity between service providers.[41]

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[40] HES=Haute Ecole Spécialisée (specialised high school), such as the 'Haute Ecole de travail social et de la santé de Lausanne (HETS&Sa; High school of social work and health, Lausanne)'.

[41] "Sexual assistance involves a deeply human and often intense relational commitment which refers to the principle of reality, but also to unconscious manifestations, emotions, imagination, impulses and fantasies. This profession is a risky one where everyone is exposed to probable and obvious insufficiencies or possible excesses, and to the inherent risk of dangerous liaisons" (own translation, quoted from « Quelques mots pour ne pas se tromper », Boulet Yannick, Paris, February 2006, mentioned in footnote nr. 5 of the file coordinated by C. Agthe Diserens and Y. Jeanne and published in: Reliance nr. 29, 2009, Ed. ERES under the title « Au risque du désir »).

III. 5. 3. Official recognition by the government

Official recognition provides an institutional framework and consolidates the initiative by placing it within a broader health perspective. The task of sexual assistant is not without risk, and shows a positive approach to sexuality. It takes into account the differences and emotional and sexual particularities of each woman/man, as well as the skills which can contribute to an increased individual and collective wellbeing.[42]

IV. Ethical considerations

Preamble

In this opinion, the Committee assumes the principle that persons with a disability do not have a *special sexuality*, and that sexual assistance, which historically arose outside of the specific field of disability, is solely intended here to respond to the *needs related to the material and psychological living circumstances* of persons with a disability, and not specific sexual needs. As far as sexuality itself is concerned, this opinion adopts a standpoint of equality between people with and without disability.

In addition, it should be noted that the Committee is in general terms neutral regarding distinctions with respect to 1/ gender or sex, 2/ type of disability (physical or mental), 3/ form of lifestyle or care (independent living, in a family setting or in an institution).

Although this opinion, where necessary, cites situations in which the difference in gender or sex plays a role, it treats physical and mental disability in the same way, as well as living situations in a family, an institution or a context of independent living. While these general distinctions may be relevant for other issues, they are not relevant when it comes to sexual life, which in a sense, just as for able persons, only involves individual cases which should be considered as such. Besides the fact that it is in many cases difficult to distinguish physical and

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[42] It is in this spirit that the training for sexual assistant is recognised and supported by PLANeS, *Fondation Suisse pour la Santé Sexuelle et Reproductive* (Swiss Foundation for Sexual and Reproductive Health). PLANeS advocates competent information and advice on pregnancy, contraception and sexuality, and is committed to ensuring that everyone – women and men, couples, youth, immigrants – has access to these services. Special attention is given to the most vulnerable groups in society. The definition of the term 'sexual and reproductive health' in the programme of the ICPD (Conférence Internationale sur la Population et le Développement, International Conference on Population and Development, art.7, 2) is as follows: "general wellbeing – physical, mental and social – of the human person, for all that concerns the genital system, its functions and working, and not just the lack of disease or infirmity" (own translation) (cf. www.sante-sexuelle.ch/fr section « qui sommes-nous- « statuts »).

Cf. Also: letter of recommendation from PLANeS to SEHP, August 2007 (to be obtained on simple request from the secretariat of the Committee).

mental disabilities with precision, this opinion emphasises the necessity of starting from the personal capacity to desire, express oneself and act *of each person in his or her uniqueness, with his or her limitations*. Similarly, the distinctions between life in an institution, a family or independently are not impermeable either. Families and institutions can also strongly differ from one another. It is therefore not necessary to define specific categories of issues and answers for various lifestyles. Here, too, it is a matter of developing responses for the actors in the field to needs which will always be determined by various complex situations.

Finally, we highlight the fact that we restrict ourselves in our *Ethical considerations* to issues regarding the "sex life" of persons with a disability, regardless of the "relational and emotional life" with which it is very often associated in the existing texts.[43]

IV.1. The ethical position taken by the Committee is based on two ways in which disability are problematised (cf. III.1): *the social approach* situated in the perspective of resistance to all forms of discrimination, and *the anthropological approach,* which draws attention to the individual as a unique, relational and vulnerable being. While the positions vary as to the priority that should be given to either approach, the members are of the opinion that the two approaches are not mutually exclusive, but are in fact complementary: promoting the development of one's sexual life consists of proposing *social answers to the unique questions of persons.*

With regard to physical and mental disabilities, a number of countries have in recent decades gradually switched to a **social approach**, instead of the strictly medical approach which had long prevailed. The social model defines disability on the basis of the interactions of an individual with his or her living and working environment and, as a consequence, proposes a specific way of acting. It is first and foremost the environment, which is socially constructed, that is considered to be unadapted to the specific physical, mental, intellectual or sensory condition of some individuals. From this perspective, working on the environment is paramount: the aim of the design of physical spaces, technical facilities, support and reception institutions or even care is to reduce as far as possible the obstacles which the standard environment raises for certain people. The development of access and circulation possibilities in public places for those with restricted mobility is undoubtedly the simplest and best known illustration of this approach.

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[43] As may have been noted in *III. Current situation*, texts and existing facilities in Belgium usually use the expression "relational, emotional and sex life." This expression is not free from various moral implications which need to be discussed to the extent that some of these implications are incompatible with the ethical and moral implications of sexual assistance. For this reason, we restrict ourselves here, for this specific issue, to the neutral term "sex(ual) life", without expressing our opinion on the way in which this relates to relational and emotional life.

This social approach is part of a wider movement against discrimination and inequality, which forms the basis of the formulation of the rights of persons with a disability in international conventions (cf. II. Juridical aspects). Interventions in the environment include the improvement of the material and symbolic circumstances which prove to be discriminatory for certain persons due to their specific condition, by which their access to full participation in social life is restricted. The definition of specific rights corresponds to this logic of accessibility.

The concern for the relational, sexual and/or emotional life of persons with a disability, which emerged during the “AIDS years”, takes on a new meaning today in the light of the social approach to disability, the struggle against inequality (non-discrimination) and the right to health as formulated by the WHO (cf. III.2.2).

Based on this, a consensus has arisen in recent years in many countries, including Belgium, regarding a recognition of the need for governments to promote the “sexual rights” of persons with a disability. The support and guidance in this area are thereby not left to private initiatives, which are by definition susceptible to chance and economic and social inequalities.

Just as with education or work, sexual relational life is recognised as an area in which persons with a disability are discriminated against, in other words where they are faced with strong limitations on their possibilities to act and experiment: material, ideological, educational and symbolic obstacles. Policy programmes, both governmental and community, which aim at fighting for the rights of persons with a disability to lead a satisfying sex life, consider these obstacles as *discrimination*, that is, *socially changeable barriers*.

The right to experience one's sexuality is not a right which can be 'claimed', but more a commitment on the part of society to offer equal access to the exercise of this right to all its members, as far as possible. The question therefore is to work out how *possible obstacles can be removed* and how *the specific needs caused by the specific obstacles associated with disabilities can be responded to*, with a view to greater autonomy, integration and quality of life for persons with a disability.

The Committee believes that this social approach to disability does not exclude an **anthropological approach**. On the one hand, this anthropological approach serves as a reminder that a disability has an effect on the individual experiences of a person, who experiences the weight of social 'normality' to a varying degree. As a consequence, the support of the sex life of persons with a disability should likewise be seen as an answer to an individual request, a need or desire expressed by a person – and in no way as a restraining measure or a simple facilitation of the daily activities of the caregivers. On the other hand, the person with a disability, just as every other person, should not be seen as separate from his/her relationships (with family, friends, caregivers), which form the fabric of his/her existence; individual requests, needs or desires are in some disability situations strongly influenced by these relationships, which must be taken into account when formulating a response (cf. IV.2 below).

Furthermore, the anthropological approach considers disability as something which results from the vulnerability which is specific to human persons in general; it reminds every person of his/her fundamental vulnerability. According to this approach, the possibilities created in every human project always collide in one way or another with its own boundaries. This leads to the double normative principle which applies to the management of disability and which consists of extending the boundaries: the principle of proportionality (remaining in the order of reasonableness; in juridical terms, 'known reasonableness') and the principle of solidarity (to limit the injustice and inequality in the human condition as much as possible).

IV.2. The Committee considers sexual life to be an aspect of the relational life of people; the removal of obstacles for a satisfying sex life demands taking into account complex physical and symbolic interdependencies, characteristic of life in the context of disability, and providing possibilities for relationships *of a different nature*, in which the person with a disability plays the leading role.

The relational life of a large number of people with a disability, with respect to the sexual dimension, is not only complicated by the physical obstacles of the disability itself and life in an institution or family, mainly due to the lack of privacy (available place and time). Indeed, many people with a disability, when they are not suffering from isolation, engage daily in numerous close social relationships, *however* often without the sexual and emotional dimensions enjoyed by able people in their social relationships. The fact that someone is the object of care and is dependent on the help of others, parents or professional carers, can, as one gets older, become a major obstacle to the development of sexual and/or emotional relationships in the full meaning of the word, relationships which require not only intimacy but also autonomy and reciprocity.

The testimonials collected by the Committee, as well as the documents consulted, are in agreement regarding the following three points. Whether living in an institution or a family, the close presence of others (regardless of the degree of benevolence and ability to care), the lack of autonomy and often a place or room to oneself constitute an obstacle to the creation of a 'private sphere' or intimacy essential for the sexual relations of young people and adults. Being the object of daily care and help is essential for the emotional wellbeing of any child, regardless of his/her situation, but becomes problematic as one grows older, especially regarding sexuality.

The professional carer or helper must indeed, in the exercise of his/her work, sometimes neutralise the emotional and possible sexual advances which can arise in a care relationship; the same applies to the parents who have to treat the body of their child once this has reached an adult age. As a result, a young person or adult with a disability finds him/herself in an exceptional and for able people unknown situation: a situation in which one is daily touched or treated by others without the possibility of reciprocity.[44] These elements partially explain the 'asexualisation' to which people with a disability even now are subjected[45] and the resulting lack of experience (namely in terms of knowledge and enjoyment of one's own body and that of someone else's). According to experts, this 'asexualisation' is even greater for women with a disability.

Although a complex of interdependencies is involved here which negates the possibility for many people with a disability of acquiring the experience and knowledge indispensable for emotional and/or sexual development, it is of course not possible to eliminate these interdependencies. *Where social existence is saturated with help and (familial or professional) care relationships, possibilities for relationships of another nature must be created, relationships which differ from but are also related to the first type (cf. IV.5.1 below).*

For people with a disability, the challenge is, in the area of their sex life and within the web of interdependencies, to grow to a certain degree of independence or autonomy and personal responsibility, in which the freedom of movement will depend on the capacities of the person in question. The ideal remains to make the person with a disability the main actor in his/her own life.

In addition, parents of persons with a disability and professional carers (nurses, social workers, etc.) are overwhelmingly in favour of provisions[46] to define the boundaries of help and care relationships and to neutralise unwanted emotional advances as well as sexual advances – the so-called 'erotisation of the care relationship' – sometimes because of the carers themselves.

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[44] Testimony of Mrs C. (hearing of 13 May 2016). C. Aghté-Diserens has excellently demonstrated in her lecture "Le handicap vécu comme un troisième sexe" (“Disability lived as the third sex”) why the sexuality of people with a disability is, as often said, 'ignored' by the parents, who have a tendency to see their child as asexual. These parents find themselves in a unique position, given that they must continue a care relationship with their child which usually ends once the child reaches sexual maturity. In a certain sense it is the prohibition on incest which manifests itself here to a high degree: it is precisely in order to continue in their indispensable role that they *actively* must deny or repress the sexuality of their child. In this way, they respond to a deep social and moral need. (Colloquium *Tout ce que vous n’auriez jamais voulu savoir sur le sexe... Quand l’intime s’invite dans les interventions psychosociales*, organised by Parole d’enfants Asbl, Liège, Palais des Congrès, 26 and 27 May 2016.)

[45] The fact that people with a disability see their sexuality denied not only in reality but also in social representations.

[46] Such facilities can protect *both parties,* both the helper or carer and the person cared for.

This is of course only possible if these advances can be transferred to other people. As is naturally the case for able people who find themselves in a situation of close care (temporary incapacity, illness or old age), it is important that an obvious difference be made between the close help and care relationships and the relationships available for sexual and/or emotional approaches, if these already exist! Measures to support and guide sexual experience indirectly contribute to relieving help and care relationships, which are sometimes characterised by an ambiguity which helpers and carers find difficult to bear.

IV.3. According to the Committee, a range of material and symbolic actions are required in order to improve the conditions necessary to make fulfilling sexual relationships possible; in other words, a multitude of responses to unique needs and situations

The current situation in Belgium points to the existence of a multitude of initiatives which respond to various and complementary objectives, that can be grouped into five categories.[47]

Taken as a whole, they ensure the emergence of a culture of openness towards the sexuality of persons with a disability and the creation of a multitude of places accessible for everyone (people with a disability, family, (non-)professional caregivers) where these issues can be discussed and communicated about, with respect for confidentiality and privacy.

These initiatives are aimed at people with a disability, but also, in some cases, at the professional carers or families faced with the sexuality of their users or family members.

We recommend that these initiatives be developed together and that a harmony between public and private facilities be ensured.
(1) The initiative concerning physical infrastructures and the operating rules of residential communities aims at the creation of intimate spaces for users, protected from the intrusion of others (carers or other users);
(2) Initiatives for practical help for the development of social relationships separate from care and support: initiatives between shelters or institutions, where some focus on sexual relationships, such as the accompaniment of couples or guidance with prostitution;
(3) Information and training initiatives, individual (of the family planning sort) or in group (discussion groups, welfare workshops), adapted to people whose experiences and competencies regarding sex and/or emotional life can be very different from those of able people of the same age;
(4) Initiatives aimed at health and hygiene that cover a very broad spectrum, not just sexually transmitted diseases (STD's) etc. but also general sexual wellbeing. The personalised medical (gynaecological, urological) or paramedical (family planning, psychology, sexology,

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[47] For this list see chapter III. Disability and the experience of sexuality: the current situation

personalised hygiene advice) approach proves to be useful.

(5) Initiatives concerning protection and security, particularly for those visiting or living in an institution and people with a mental disability. Specific group activities which teach physical and moral respect for oneself and others, how to express choices and how to say "no", can prevent abuse and violence in a climate of trust; on the part of professional caregivers, the development of teamwork for complex problems and the encouragement of precision, respect and discretion can also contribute to a protective framework, which contributes to respect for privacy and the freedom of persons with a disability.

IV.4. The Committee believes that a provision for sexual assistance integrated in the range of existing initiatives is one of the relevant responses to the discrimination with which people with a disability are confronted in their sex life.

IV.4.1. General definition of sexual assistance

Sexual assistance is a personalised service for support and practical guidance in sexuality, carried out by someone who has been specially trained for this purpose, who takes on the role of partner, possibly on a regular basis, towards the user. The aim of the practice of sexual assistance is to develop physical (relaxation, touching, masturbation, penetration, etc.) and mental (emotional, affective, imaginative, etc.) competencies by means of concrete experiences, and to thereby promote sexual satisfaction in the broad sense of the word, more than simple genital pleasure.

The practice of sexual assistance, arising from clinical research in sexology in the 1960's in the United States,[48] is based on the idea that sexuality is not just a fundamental human need but also one of the dimensions of self-affirmation. It targets neither a specific public nor exceptional types of sexuality, but attempts to offer answers to specific needs and expectations on the part of the user (male/female).

IV.4.2. Sexual assistance offered in the situation of a disability (as distinct from other actions or utilising the services of a prostitute)

There have been a number of initiatives in French-speaking Switzerland and Belgium, amongst other countries, which offer sexual assistance as an answer to the specific needs regarding

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[48] Sexual assistance was defined by the pioneers of clinical sexology research, William Masters and Virginia Johnson. Since it was officially aimed at overcoming sexuality problems, sexology mainly focussed on the relationship with the body. In contrast to therapists specialised in psychology and social work, for whom all forms of sexual activity with the patient are forbidden when carrying out their function, a sexual assistant, just like a sex worker, is involved with the client in experiences which do not aim at sexual satisfaction as such, but at the development of the physical and mental competencies needed for sexual development.

sexual and/or emotional relational life which certain persons with a disability express. The following sketch is inspired by these initiatives and their expertise.

Just as with other support and guidance efforts, sexual assistance aims at a practical application of the rights of people with a disability, as defined in the Convention of the United Nations, signed by Belgium in 2007 and ratified in 2009. It fits into the range of initiatives in the struggle against discrimination, and is in line with the values of a higher degree of autonomy, integration and quality of life for persons in a context of disability.

Sexual assistance does not intend to replace other existing initiatives of support and guidance, as summarised in point IV.3; it offers users a *complementary* possibility within the expectations and boundaries of both the person with a disability and the service provider. Moreover, the success of sexual assistance depends to a great extent on the global development of a culture of openness towards the sexuality of persons with a disability, which of course includes the range of actions mentioned in IV.3.

Sexual assistance does indeed correspond with the objectives of the various existing initiatives:[49]

- it establishes an intimate place and time, separate from care and other forms of assistance (provided by care professionals and parents);
- it is a non-exclusive form of assistance for individuals or couples;
- it allows one to become acquainted with one's own body and desires, needs and boundaries;
- it allows one to acquire the physical and mental (emotional and other) competencies required for satisfying sexual and/or emotional relationships;
- it offers an opportunity to become informed and learn (about health, hygiene, contraception);
- it involves trained, competent people;
- it offers a framework which guarantees respect, protection, and physical and moral safety.

However, sexual assistance is also distinct from the other existing initiatives due to the fact that:

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[49] The effectiveness of the existing and already recognised initiatives, with respect to sexual assistance as introduced here, are based on the experience of associations in Switzerland and Belgium. In this respect, the following points in particular should be remembered, *both on the part of the service provider and on the part of the beneficiary*: training, the acquisition of psycho-physical competencies, the personal and unique delineation of the boundaries of erotic practices, protection and physical and moral safety. Cf. sections III. 4 (Sexual assistance in Belgium) and III. 5 (The experience in French-speaking Switzerland).

- it offers a learning process for relationships *through the relationship*, i.e. through an *experiment with others* (alone or as a couple);
- it gives a central place to the individuality or unique character of the person, his/her needs and experiences (from simple sensuality to sexuality in a strict sense);
- in itself, it offers the possibility to single people of possible regular meetings, in order to meet a fundamental need;
- it offers users with a disability the possibility to enter into relationships outside of the world of their disability.

Although in some cases guidance in prostitution is part of the initiatives proposed by some institutions, and prostitution can fulfil some of the functions of sexual assistance,[50] the latter, as it is currently practiced in for instance Belgium and Switzerland, differs because:

- sexual assistance involves trained and competent people who can deal with the specific requirements of a physical or mental disability;
- sexual assistance is very much a *framed* act, which guarantees the quality and accessibility of service by a moderate fixed fee and which guarantees respect, protection and physical and moral safety for both the users and the service providers (sexual assistants);
- sexual assistance is offered by motivated, voluntary and trained service providers. It is neither a salaried job nor a primary job. The fee set for the service provided is equivalent to a lump sum which covers the costs etc., and not to a salary. In addition, the financial transaction clearly defines the boundaries of the relationship, based on assistance and support and not on other relational resources such as love;
- sexual assistance is a service offered to both women and men.[51]

It goes without saying that prostitutes (male/female) are not excluded from providing sexual assistance and that they too may carry the title of “sexual service provider” if they, just like the other volunteers, complete the training and register themselves within the framework provided.

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[50] The actors in the field of sexual assistance in our country, however, find that the legal framework governing prostitution in Belgium is completely inadequate, and in no way suitable to being able to give an answer to the specific problems faced by persons in the context of disability (hearing with Aditi).

[51] The prostitution supply for men with a disability appears to be larger than that for women, on the basis of the testimonies collected.

IV.5. The Committee is of the opinion that sexual assistance, aimed at providing support and guidance for sexual life, must consist of a *professionally framed* offer of service (expertise, teamwork, regulations). [52]

This framework should provide for the following:

- the selection and training of the candidate assistants;
- teamwork and an exchange of experiences for the follow-up of the assistants;
- the possibility for the assistants to freely choose for themselves which services they are prepared to provide;
- a careful and precise analysis of the needs, if necessary in close consultation with third parties;
- the collective management of problems which arise during the provision of services;
- a careful matching between request and offer (user and service provider);
- a high level of expertise (from psychologists, sexologists, etc.) to support practice;
- precise regulations to define the services provided, the financial compensations, the obligations of both/all parties (protection against STD's), etc.

Such a framework should provide an answer to three objections to initiatives for the support and guidance of the sex lives of persons with a disability, namely:
(1) how should situations of complex interdependency be handled? (2) how should one act with respect to persons with a mental disability? (3) how can the protection of both the users and the service providers be guaranteed?

IV.5.1. Taking into account underlying dependencies and the close help and care relationships (with family and professionals) which characterise the life of certain persons with disabilities (cf. IV.2)

The intervention of third parties is common, and is often unavoidable anyway, in the sexual and/or emotional relationships of persons with a severe physical and/or mental disability, whether they are minors or adults; it often happens that sexual and/or emotional requests are not explicitly expressed by these persons, but are noticed and, if necessary, passed on by helpers (family or professionals). Although it is obvious that the latter do not themselves have the task of responding to the sexual needs and expectations or all emotional desires of the persons for whom they care, the relationship of assistance and care cannot always be turned

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[52] Here again we base ourselves on the study of the experiments conducted in French-speaking Switzerland and Belgium, conducted by a review of the literature and the hearings organised. As far as the absence of a prostitution framework is concerned, experts and people from the field appear to unanimously agree that there is a need for a *framed* practice regarding sexual assistance. Cf. III. 4 and III. 5. above.

off. The challenge is, in each case, to find a good balance between the help and care which is indispensable and the separate sexual and/or emotional relationships (cf. point 2, above). Sexual assistance can contribute to this.

The members of the Committee are of the opinion that the framing of the service of sexual assistance itself, as it is currently empirically being tested, is of such a nature that it will promote, if necessary, consultation and dialogue with the various people involved in the daily life of the person with a disability and with this person him/herself (e.g. when the 'request' is not sufficiently explicit or clear, and is passed on by various persons). The challenge is to create the conditions necessary for a certain degree of autonomy, by creating an atmosphere of intimacy and privacy, *within the complex relationships* which persons with a disability experience in their concrete situation (life in an institution, help from family members, etc.). The members of the Committee also believe that, as some actors in the field say, the 'first expert' in the sex life of a person with a disability is and must remain the person him/herself. Consultation with third party caregivers must always remain possible, if desired and needed, but must not be made compulsory. The empirical 'framework' that has currently been developed by non-profit organisations for sexual assistance is sufficient to offer this possibility.

IV.5.2. Taking into account mental disability

The situation of mental disability (intellectual, cognitive, emotional deficiency, etc.) results in special vulnerabilities and raises specific questions, such as the ability to verbally and physically express oneself, to give consent, or to adopt appropriate attitudes, gestures and behaviour. Experts agree that persons with a mental disability are more at risk of abuse.

Nevertheless, the Committee believes that the use of sexual assistance for persons in a situation of mental disability, both singles and couples, can provide an equally relevant response as for people with a physical disability. Sexual assistance, if properly framed and defined, not only poses no danger to persons in a situation of mental disability, but can provide a *means of protection* for persons considered to be vulnerable (whatever their disability). The service itself (with the expertise of the service providers, the possibility of consultation with third parties involved – parents or professionals – thorough prior analysis of requests in which the person involved may not be the first spokesperson, systematic follow-up), and the experience acquired through sexual assistance, are of such a nature as to reduce vulnerabilities and to create the conditions for a 'consent' which cannot always be easily formulated. Any legal incompetence on the part of the person making the request does not form an ethical problem, to the extent that the framework of the service proposed itself offers the necessary safety.

IV.5.3. The protection and safety of users and service providers

People in the situation of a mental and/or physical disability are exposed to the same risks as able-bodied people in sexual and/or emotional relationships: abuse, physical violence, moral pressure etc.[53] The *relational* nature of sexual assistance exposes both users and service providers to similar risks. The very aim of the framework described here is to offer both parties the safety and protection which may be absent when prostitution is used. The actors in the field are of the opinion that the existing legal framework in Belgium regarding prostitution is currently insufficient for sexual assistance.

While the presence of a *framework* offers a response to the objection of possible risks of sexual assistance – a response to the question of the protection of the parties when the service is carried out – it can also be argued that, if well framed, the sexual assistance *itself* will in the future contribute to the removal of the vulnerabilities of people with a disability, due to the possibility of experimentation, formation and mediation between people. The experience, the acquisition of skills and knowledge, the acquisition of autonomy or the self-image which can be attained due to sexual assistance, count as the best defence against abuse and violence.[54]

Moreover, the Committee believes that this framework also protects the sexual service providers, as it protects their activity from the social and economic exploitation seen in certain forms of prostitution, and which is punishable by law.

IV. 6. In contrast to the official opinion of the French CCNE[55], the Committee is of the opinion that sexual assistance must consist of an offer of service which is *recognised* by the Government through a regulatory framework, in order to meet the aims of supporting and guiding sexual life

The organisations which are currently experimenting with facilities for sexual assistance 'on the ground' in Belgium, are very attached to the 'institutional framework' that they are developing

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[53] Although a parallel can be drawn between people with a disability and able-bodied people, it should not be forgotten that, on both sides, women do not find themselves in a position of equality with men: they are more exposed to abuse and physical violence. Special attention should therefore be paid to women with a disability, whose sexuality is too often ignored by their environment.

[54] “Information makes individuals stronger. [...] Information is safety” (Hearing with the representatives of Aditi, 3 February 2016).

[55] Opinion nr. 118, published in 2012 by the Comité Consultatif National d’Ethique (*“The emotional and sexual lives of people with disabilities”*), is not unfavourable to sexual assistance itself, a term which is not very precisely defined in the opinion but rather defined in fairly general terms. The opinion is however negative towards any intervention by the Government in this area, as it argues that while problems related to the emotional and sexual lives of people with a disability can be reduced to collective responsibility, they should nevertheless be solved by interpersonal solidarity: “Giving the disabled their rightful and full place in society is, in fact, the business of the community as a whole and the responsibility of each of its members.” (cf. http://www.ccne-ethique.fr/en/publications/emotional-and-sexual-lives-people-disabilities)

for their activity, and request the setting up of an appropriate legal framework. The members of the Committee are in agreement on this issue, and are of the opinion that the existence of a regulatory framework, (legally) laid down by the Government, would not only recognise the legal nature of sexual assistance, but would also:

- make possible the harmonisation of services for sexual assistance, by placing the users and service providers involved throughout Belgium at the same level;
- make it possible to make a clear distinction between the acts performed in the context of sexual assistance and those performed in the context of prostitution, and to give a formally recognised and protected status to sexual assistants[56] (even if they engage in prostitution outside of their activity as sexual assistant);
- strengthen the protection which actors in the field are trying to develop, both for users and service providers, at the level of the practices themselves;
- promote the development of a solidarity initiative which has proven its relevance and usefulness in the field.

IV.7. The Committee is of the opinion that sexual assistance should be considered as a paid service

Users and service providers of sexual assistance are in general agreement on the importance of a financial transaction as a means to define the framework in which the sexual relationships take place: such a transaction clearly frees both parties from any mutual obligations or commitments beyond those inherent in the service. On the part of the service provider, the financial transaction does not in any way prevent an attitude similar to volunteer work:[57] in that case, the transaction is considered to be a compensation or reimbursement. In any case, the compensation is fixed in advance and is not dependent on the acts carried out during the sexual assistance.

IV.8. The Committee is of the opinion that sexual assistance should not be reimbursed by the Government (public health insurance or similar)

The Committee considers that, while it is important to ensure universal access to sexual assistance by a fixed and moderate fee (flat rate), the principle of a reimbursement by, for example, public health insurance, has two flaws: on the one hand, the risk that access be subjected to a type of 'prescription' procedure, necessitating the intervention of third parties;

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[56] The European platform EPSEAS (which brings together non-profit organisations which work to develop tools and guidance for sexual and/or emotional relationships, such as Aditi) was created in 2015 thanks to provincial subsidies in Flanders. The goal of the platform is to develop a harmonised training programme for the providers of sexual services and to make proposals for a legal framework.

[57] As is the case in the framework provided by Aditi, which determines that sexual assistance may not form the main source of income for the service provider, and that the amount of the performance can therefore not constitute a wage.

on the other hand, the risk that sexual assistance be included in the 'healthcare' category.

Many actors in the field emphasise that sexual assistance attempts to meet one of the most fundamental human needs, rather than providing care. This is consistent with the idea that disability and its concrete implications are not a pathology, but discriminatory environmental and social configurations, which should not be treated by healthcare policy but by social accessibility policies (although certain care provisions of the 'healthcare' type can be included of course).

Such a perspective emphasises the fact that the equality between people in a situation of disability and able-bodied people must be the main focus. The Government has the responsibility to introduce active measures whereby all members of society have access to sexual life.

V. Conclusions and Recommendations

Sexual assistance for people with a disability: at the limits of care

The recommendations of the Committee, which contrast with those of other institutions and workgroups that have been approached in recent years to address the issue of sexual assistance for persons with a disability, both in Belgium[58] and abroad, constitute the fruit of lengthy research and lively discussions. The explanations and testimonies of actors in the field who are expert in assisting persons with a disability with their sexual life (whether or not they provide sexual assistance), of service providers of sexual assistance and of a female user, played an important role in this process. The sharing of experiences which are largely unknown by able-bodied people and which usually remain hidden for a larger public, explains to a large extent the novel conclusions of the Committee.

This opinion has discussed the issue of sexual assistance for persons with a disability in a

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[58] For example: an opinion from 2012 from the ASPH (Association Socialiste de la Personne Handicapée – Socialist Association of Persons with a Disability), *Quelle place pour l'assistance sexuelle en Belgique* ('What is the place for sexual assistance in Belgium?'), without being completely opposed to sexual assistance, expresses serious reservations. "We do not want to be synonymous with 'comfort sex' or 'tenderness on demand'" (p. 11) are the conclusions in 2012. Opinions are however evolving. The opinion '*Quels sont les grands enjeux politiques et juridiques de l'assistance sexuelle en Belgique*' ('The major political and juridical challenges to sexual assistance in Belgium") from 2015 is more nuanced and closer to what the Committee defends: "Every project within the context of the emotional and sexual life of people with a disability deserves the time to identify the needs of each person in order to offer the most adequate response which may not necessarily be sexual assistance." (p. 7-8, own translation).
Cf: http://www.asph.be/PublicationsEtOutils/AnalysesEtEtudes/sante-et-ethique/Pages/default.aspx

social and anthropological framework. This fits within the movement which began 30 years ago, which tries to remove disability and limitations from the medical framework where they have been confined for so long in order to put them in a political perspective, with a focus on equal rights and the struggle against discrimination, as the International Convention on Persons with Disabilities also does.

According to the perspective adopted by the Committee, sexual assistance does not fall under care in the medical or paramedical meaning of the word. Just as the disability itself, the sexuality of people with disabilities is not pathological. It is therefore not an issue of personal behaviour, nor a moral issue, which the Committee obviously cannot comment on. The socio-anthropological approach used here is, as already explained in sections III and IV.1, the historical result of collective work, a pluralistic and contradictory reflection which has established that the medical framework of disability is outdated. This has enabled us to give an overview of the unequal access to certain rights, often experienced by people with a disability.

Even if sexual assistance does not fall under care, that does not mean, for multiple reasons, that it does not raise any bioethical questions. The Committee believes that sexual assistance, because of the link with sexuality, and as a possible component of someone's sex life, does fall under the term 'health' as defined by the WHO: “a state of complete physical, mental and social well-being”, in which sexual life is also recognised as a basic human need. Furthermore, sexual assistance is related to the body at various levels (whether that is the body of the person with a disability, of the sexual assistant or the sexual service provider). Finally, it is obvious that the Committee, in removing sexual assistance from a framework of care, also meets a request from care providers for a clear distinction between the provision of care and actions of a sexual nature. It should be noted that many people with a disability live in institutions, where they come in daily contact with 'carers'. Due to their physical proximity to people with a disability, these carers are often the first point of contact regarding problems experienced by people with a disability in their life and their sexual activity. Many carers therefore ask for a clear demarcation between caregiving on the one hand and sexual assistance, of whatever nature, on the other hand.

The current situation therefore shows that the 'limits' of care, whether this is medical care or facilities for social equality, the distinction between sickness and disability, or even health and sickness, are not predetermined. These limits or distinctions are not stable, they are not fixed, but are determined by historical constructions, ethical and political conflicts, and social interactions, harmonious or otherwise.

With this advice, the Belgian Advisory Committee on Bioethics positions itself as a participant, together with others, in the public debate. This debate will ideally foster the building and defining of boundaries, which can then be converted into concrete social practices.

Part II highlighted the juridical aspects of the issue. Part III, *Disability and the Experience of Sexuality: the current situation*, sought to account for the wide range of social responses to the sexual needs of people with a disability, on the one hand, and the reference frameworks and directives underlying these responses, on the other hand. Part IV, *Ethical considerations*, attempted to develop implications, by defining sexual assistance in opposition to prostitution. This section offered more generally a well-defined *problematisation* of sexual assistance, framing it in the range of existing support facilities.

The conclusions and recommendations form a summary of this ethical issue.

1.

The ethical position taken by the Committee is based on two ways of approaching disability: *the social approach* situated in the perspective of resistance to all forms of discrimination, and *the anthropological approach,* which draws attention to the individual as a unique, relational and vulnerable being. While the positions vary as to the priority that should be given to either approach, the members are of the opinion that the two approaches are not mutually exclusive, but are in fact complementary: promoting the development of one's sexual life consists of proposing *social answers to the unique questions of persons.*

2.

The Committee considers sexual life to be an aspect of the relational life of people; the removal of obstacles for a satisfying sex life demands taking into account complex physical and symbolic interdependencies, characteristic of life in the context of disability, and providing possibilities for relationships of a *different nature*, separate from familial and care relationships, in which the person with a disability plays the leading role. In the societal responses offered, the starting point should always be the personal capacities, expectations and limitations of the people involved.

3.

According to the Committee, a range of material and symbolic actions are required in order to improve the conditions necessary to make fulfilling sexual relationships possible; in other words, a multitude of responses to unique needs and situations

4.

The Committee believes that a provision for sexual assistance integrated in the range of existing initiatives is one of the relevant responses to the discrimination with which people with a disability are confronted in their sex life.

Sexual assistance is defined as a service for support and practical guidance in sexuality, carried out by someone who has been specially trained for this purpose, who takes on the role of partner, possibly on a regular basis, towards the user, and who meets the specific needs that persons with a disability due to their specific living circumstances have. This service is provided for a fixed lump sum, which does not depend on the type of service provided. Besides being a reimbursement for expenses, for the personal commitment and for the skills of the sexual assistance, the fee serves to highlight that sexual assistance is a *service*, such that both parties involved are freed from any further mutual obligations or commitments, especially of an emotional nature, outside of those inherent to the service provided.

5.

The Committee is of the opinion that sexual assistance – in order to meet the objectives of supporting and guiding sexual life – must meet certain conditions:

- a *strictly framed* offer of service (expertise, teamwork, regulations);
- take into account underlying dependencies and the close help and care relationships (with family and professionals), characteristic for the life of some people with a disability;
- mental disability is not considered to be a separate case, being careful to – regardless of the disability – take into account any possible related vulnerabilities
- guarantee the protection and safety of users *and* service providers by means of an appropriate framework.

In general, the Committee considers that sexual assistance itself can contribute to a reduction in the vulnerability of the users and to an increased resilience against abuse and violence, on condition that an appropriate framework is present, due to the potential experience, learning and consultation which are made possible.

6.

The Committee believes that, in order to adequately achieve the objectives of support and guidance of sexual life, sexual assistance must constitute an offer of service which is *recognised* by the Government by means of a regulatory framework. This recognition and the associated regulatory framework would ensure homogeneity in the services offered and equality for the users. The Committee does not question the position of prostitution in Belgian Law, but is well of the opinion that it is in no way an appropriate legal framework for sexual assistance as defined in this opinion.

The Committee therefore recommends that the competent legislators take the necessary measures to adapt the legal text on an exemption from criminal prosecution (cf. II.2.2) and consent (cf. II.2.1).

7.

The Committee is of the opinion that sexual assistance should not be reimbursed by the Government (public health insurance or similar)

8.

Conscious of the taboo that still hangs around the sexuality of persons with a disability, the Committee encourages those directly involved to overcome any possible restraint they may have and to engage in a dialogue on this matter, both within the family and in the institution.

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This opinion was prepared in the select committee 2014/3, consisting of:

Joint chairpersons	Joint reporters	Members	Member of the Bureau
J. Fierens	F. Caeymaex	M. Dupuis	P. Schotsmans
V. Draulans	V. Draulans	G. Lebeer	
		J. Libbrecht	
		D. Lossignol	
		J. Messinne	
		V. Pirard	
		F. Van De Merckt (until 28 October 2016, when he resigned from the Committee)	

Member of the secretariat
Monique Bosson

Experts heard
Paul Maes, ***vzw "Emmaüs"***, director of the service centre "*'t Zwart Goor*", Merksplas
"**Arthur Régniers" Centre:** Pascal Coquiart, psychologist specialised in sexology
"Reine Fabiola" Home, Braine-l'Alleud: - Dominique Linglart, psychologist, coordinator of support for emotional, relational and sexual life - Mélanie Lepoivre, educator, responsible for two groups for people with autism - Antony Artigas, anthropologist, educational leader
ASBL "Inclusion" (originating from AFrAHM): Guy Hubert, psychologist, intellectual disability unit, service formation
Fabienne Cornet, Master of Social Law, responsible for the "**centre de ressources Sexualité et Handicap"**
Testimony from a parent who wishes to remain anonymous
Vzw "ADITI": - Miek Scheepers, coordinator - Pascale Vanransbeeck, coworker Brussels/Wallonia project
Michel Mercier, prof. em. Fac. univ. ND Paix Namur
Mr. X, sexual assistant who wishes to remain anonymous
Mrs. X , user of sexual assistance who wishes to remain anonymous

Experts consulted
Catherine Agthé Diserens, pedagogue specialised in sexology, teacher of adult education, Switzerland
Nicole Gallus, member of the Committee

The working documents of the select committee 2014/3 - request for opinion, personal contributions of the members, minutes of the meetings, documents consulted – are stored at the Committee's Documentation Centre, where they may be consulted and copied.

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This opinion is available on the website www.health.belgium.be/bioeth, under the “Opinions” section.