

## **OPINION N°118**

### **The emotional and sexual lives of people with disabilities The issue of sexual assistance**

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## National Consultative Ethics Committee for Health and Life Sciences

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## Context of the referral

In the wake of the 2005 law, a large number of associations representing people with disabilities are calling for complementary and specific regulations to cope with frequent deficiencies in their emotional and sexual lives. Among these groups, some are also in favour of regulations allowing for the provision of sexual assistance services of the type existing in neighbouring European countries, such as Germany, the Netherlands, Switzerland and Denmark.

In this context, Madame Roselyne Bachelot, at the time Minister for Solidarity and Social Cohesion referred the matter to CCNE, with emphasis on three questions:

- What services could society provide to help disabled people to overcome unsatisfied emotional and sexual needs, in particular those people “*whose disability prevents them for engaging in unassisted sexual activity*” and who are enquiring about “*the provision of sexual assistance services*”?
- What analysis should be made of the possibility of such assistance being given by members of the health caring and social services professions and, were that to be the case, how should the issue of rights to compensation be dealt with?
- What are CCNE’s findings on the current state of affairs and what are the Committee’s proposals on how the health caring and social services professions could be encouraged to adopt good practices regarding the privacy, autonomy and dignity of people with disabilities?

A specific, unambiguous question on the subject of sexuality is therefore being submitted to society’s consideration and it deserves careful reflection even though it is disturbing in that it touches on matters that are generally thought to be private and personal.

All the associations supporting disabled persons are particularly insistent on the recognition of the emotional and sexual needs of people whose lives are frequently very lonely.

CCNE is being asked to make an in depth evaluation of the possible contribution of science or future scientific development to alleviate, to the extent possible, the vulnerability of some of our fellow citizens. The Committee’s role is closely connected to the principles laid out in the Bioethics Laws, with which it has been very much involved since 1994. The questions in the referral have a bearing on the status of the human body, the use made of another’s body and patrimonial principles, so that CCNE is acting well within its terms of reference. The Committee has also published two previous Opinions on related subjects, numbers 49 and 50, dated April 3, 1996 on “Contraception for the mentally handicapped” and “Sterilisation considered as a means of permanent contraception.”

Several ethical considerations are involved in the particular attention to be given to the sufferings of people who are dependent because of disability, and therefore are certainly more than others in need of support from loved ones and the community.

The state's concern must include the deontological ethics of the law and compliance with the law, but must also allow for the dictates of utilitarian ethics seeking the greatest good for the greatest number, signifying that choices have to be made between different priorities. (See CCNE's Opinion N° 101- Health, ethics and money: ethical issues as a result of budgetary constraints on public health expenditure in hospitals, which points out that economics and ethics are not incompatible.

Nor should the ethics of virtue be neglected: the virtue of solidarity and compassion for fellow human beings. These various ethical positions serve to distinguish between the respective responsibilities of the state, civil society and what is to be expected from associations.

The Committee's work was supported by written documents (publications, compositions and reports), but mainly by the testimony of those directly concerned and representatives of associations. Information on practices in neighbouring European countries were also considered. After endeavouring to define the scope of sexuality, the Committee's report will broach the following subjects: constructing an identity in the presence of disability, society's outlook on the multiple forms of disability and finally, the ethical debate on sexual counselling in general and sexual assistance in particular.

### **The scope of sexuality: general and specific**

Relationships with others in a sexual context, that is in the most intimate and mysterious aspects of the body, are the subject of this ethical reflection.

“No one knows what the body can do”, said Spinoza in “Ethics”<sup>1</sup> to emphasise how confused may be our perception of bodies — disabled or not — and their interaction.

How can bodies interact when freedom of action is limited by mental or physical impairment?

For all of us, sexuality is still a private matter, despite recent developments in the expression of socially acceptable speech and deeds which could give an impression of greater permissiveness. Sexual fulfilment is a liberty that no adult human being should be deprived of. We are all sexual beings, but this dimension can, like other human dimensions, be impeded or impaired by the circumstances of gestation, birth or life's misfortunes.

That which is described by the general term “sexuality” is mainly expressed by urge and desire<sup>2</sup>.

- **Urge** is a usually spontaneous tension calling for satisfaction, unlike need pure and simple which is characterised solely by want.

- **Desire** expresses attraction, impetus, demand. The desire for sex, spontaneous or induced by an erotic situation, cannot be equated to a simple physical or physiological need. It is first and foremost the consequence of an interpersonal relationship in which eroticism may play a predominant role.

The sexual gratification arising out of desire involves the body's, and therefore the person's, most intimate constituents, all the sensorial dimensions as well as emotions and affections. Most frequently, for that matter, it is not so much the satisfaction of an urge that is sought after, or sexual sensation, but rather an interpersonal relationship.

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<sup>1</sup> Collection Idées édition NRF 1954 page 150 livre 3 proposition 2 scolie

<sup>2</sup> Xavier Lacroix *Les mirages de l'amour* Bayard, Paris, 1997, p. 84.

The importance of emotional bonding and of a loving relationship cannot be over emphasized in any discussion on sexuality.

As regards people with disabilities, it must be stressed that the notion of sexual specificity has not entirely disappeared. Be it in connection with a purely motor disability or a mental handicap, sex was long considered to be a “problem”, to which the only appropriate response from families or institutions was to make it taboo (not to be talked about), censorship (to be prohibited), or discreetly convenient arrangements “which we prefer to ignore”.

Now that the subject can be openly discussed, certain practices have come to light, in some cases the only resort but never spoken of, which are disrespectful of disabled people themselves, of those who care for them and of their loved ones. Several of the persons heard by the Committee spoke of the problems facing the parents of young motor impaired adults who, despite their reluctance, felt obliged to masturbate their child...

Disabled people, because of psychological fragility or inability to move unaided, are vulnerable to sexual abuse, sometimes unknowingly, and this too must not remain unsaid.

Discussion of the issue of sexuality originated in the wish of all those concerned — relatives, professionals working in the area of disability, but particularly people with disabilities themselves — to request a change in practices and above all, changes in society’s attitudes to disability. For example, as regards polytraumatic injury following road accidents, progress in medical care and resuscitation techniques have reduced mortality so that many young people with a motor or mental handicap now survive.

Similarly, progress in the treatment of some neuromuscular diseases prolongs the life of affected children who, becoming adult and attaining hormonal maturity, themselves raise the question of their sexual and emotional needs.

## **People with disability and identity**

We are all inhabited by a sexual identity with claim to expression in various forms depending on age. It may — or may not — be in keeping and coherent with our sexual phenotype, independently of the presence or absence of disability.

### ***The claim to sexual identity***

A large number of associations of people with disabilities have combined their efforts as the CNCPH - *Conseil National Consultatif des Personnes Handicapées* (national consultative council for people with disabilities), to work on the recognition of rights for the disabled, focusing on a demand that is common to them all, i.e. the mental or motor handicap which restricts their autonomy should cease to be the primary, and often single distinguishing aspect of their identity.

As is the case for everyone, the priorities of people with disability are satisfactory relationships and bonds with others, in particular, recognition of all aspects of their identity, the first of which is to be perceived or situated as a man or a woman even before the issue of sexual activity arises:

to be recognised as having a sexual identity instead of being some kind of asexual “angelic creature”. This comparison is used in many of their writings to illustrate the frequent social denial of this personal dimension of disabled people. All the relationships of our life within society are linked to sexuality; we exist in the eyes of others as human beings, but also as men or women.

Sexuality, like the need for sexual activity, evolves with the age of the person concerned: adolescents, adults or the elderly are not swayed by tensions in the same way. Recognition as evolving human beings, whose personalities and concerns adjust along with their stage of development, is demanded by all those affected by disability: recognition that a disabled child is above all a child and, as such has a right to education and to attend school; recognition that, whatever the degree of disablement and even in the case of bed-ridden children, they will one day become adolescents with the specific wants and preoccupations of that age-group and later adults with a need for love and “need” for sex, for parenting, or for entering into a partnership<sup>3</sup>.

Sexual life and emotional life are tightly associated. One of the principal claims of people with disabilities is to have access to the emotional life which everyone normally enjoys, to be recognised as a person who experiences desire and may be desirable and may be entering into a mutual seduction relationship. They want to be seen as people who can enter into the kind of relationship with another person that carries with it desire and fantasy, but also eroticisation and sexual fulfilment.

### *Construction and recognition of sexual identity*

Parents of a disabled child are often late in becoming aware of the issue of sexual identity and its initial recognition is more or less tardy. When mental or motor impairment becomes apparent or first sets in, the most immediate priority for parents is survival and then basic learning skills. Their initial efforts are directed at making sure that their child acquires what is needed for a maximum degree of autonomy and knowledge of the social codes facilitating integration. Fragility very frequently leads to an exclusive, excessively prolonged and intensely close-knit relationship with parents, in whose eyes the child’s disability may become the child’s identity. At puberty, families whose attention to the needs of their disabled young was necessarily very close and caring, are faced with difficult and worrying problems. For the youngster with a physical or sensory deficit, this is the time when ambitions to be recognised as an individual are confronted by growing awareness of differences, generating feelings of frustration, violence and exclusion opening the way for reclusive behaviour, regression into childhood or a “damaged identity”.

People with mental impairment, for example, tend to be overly trustful of strangers, so that parents may be justifiably worried about the danger of sexual abuse, forced or submitted to, or

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<sup>3</sup> And furthermore, as underlined by CCNE’s Opinion N° 50, “...in an anthropological dimension, procreative capacity is significant in human and existential terms for each individual: the feeling that one is physically present and has a place in the world; the possibility of expressing oneself as a sexual being and of relating in procreative terms to others; the ability to make an alliance and prolong a blood line; the possibility of assuming in a web of relationships and in an existential plane, both interpersonal and social, all of the consequences of one’s personality.”

the risk of contracting STIs<sup>4</sup> and the possibility of pregnancies which furthermore are a ready source of anxiety concerning the possible transmission of the disability.

Depending on the extent and severity of mental impairment, expectations and manifestations vary considerably. The need for sex depends to a important degree on the results of education, but also on the aspiration to recognition as a person and the possibility of satisfying urges.

People with a mental deficit may express their emotions clumsily and invasively so that there is room for confusing them with some form of sexual desire. In fact, their need for affection may just as well be completely devoid of any expression of sexual activity.

Faced with the sexuality of their disabled child, parents may alternate between permissivity and prohibition because they find it difficult to decide on an attitude respectful of everyone's position in a situation where they may feel responsible for, or even obliged to make up for the lack of autonomy brought about by the disability. Frequently, a disabled child is not seen as a girl or a boy, but first and foremost as a special and different person who needs to be protected against a seemingly hostile world.

In the same way as the distress experienced by young disabled people themselves must be borne in mind, the distress endured by families as they endeavour to care for their handicapped child must never be disregarded. Appropriate attention and understanding is required to respond to each of these very different situations.

In addition to the tendency to treat disabled people as though they were children, the constant lack of privacy to which they are exposed is unlikely to facilitate awareness of the limits beyond which urges or yearnings should be voiced. Nevertheless, physical familiarity, made inevitable by reason of the disability, must not be abused by those who would be excluded from such intimacy were it not for that same disability.

Associations and institutions should look out for such issues as they emerge at puberty and later in early adulthood. They can help parents and children to deal with them and to overcome the difficulties inherent in the construction of a sexual identity and those arising out of impending maturity. Parents must be counselled so that they understand that certain limits have been reached and that disability service providers can and should take on certain duties in their stead, toileting and personal hygiene for example. Such assistance from outside the family circle can pre-empt extreme situations in which none of its members are any longer in their proper place and where the dignity of those involved may be compromised.

## **Diversity of disability and of sexual expectations**

In these matters, the various forms of disability need to be examined on a case by case basis and the existence or absence of autonomous and responsible sexual activity before the onset of impairment is also a discriminating factor. It must, however, be noted at this point that for people with a severe motor disability, there may exist a "technical" impossibility which impedes access to the body of the disabled person or the body of a partner and that it is mainly in view of this type of disability that some associations would like to put specific sexual assistance on the

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<sup>4</sup> STIs - Sexually Transmitted Infections

agenda. Before reviewing their proposals, those which concern sexual assistance in particular, more thought must be given to the issues raised by sexuality for people with disabilities and the people who provide them with support, be they family members or professionals.

***Disability may affect the body, or the higher cognitive functions of the mind, or both.***

Disability puts people at a disadvantage or in a position of deficiency compared to others and affects their autonomy. The disorder may be congenital — genetic anomalies (Down's syndrome or other birth defects), cerebral palsy, early-onset epilepsy, etc., or acquired (neurological conditions or injury following an accident). Disability may have become apparent in childhood or once a person is adult, or be a consequence of extreme old age. CCNE considered that in view of the complexity of the subject<sup>5</sup>, it would be preferable to limit the scope of this Opinion to people with physical and mental disabilities.

Encountering disabled people, irrespective of the nature of the impairment, often generates unease and a deliberate or unconscious propensity to exclude them precisely because of their difference from the accepted norm. A conscious effort of thought is needed to "reintegrate" that person into a state of "non-difference", or indifference. In fact, most people who feel that they are in a minority and side-lined for that very reason, claim this right to indifference. But the right to indifference, obviously, does not imply lack of solidarity.

Care and compassion can be the result of education and raised awareness<sup>6</sup>.

The law dated February 11, 2005<sup>7</sup> on equal rights and opportunities for disabled people was a major turning point in the national community's perception of people with disabilities in that their autonomy and right to participate entirely in the life of society were recognised. For that matter, it was in the new context created by this law and the in-depth discussions that took place when it was drafted that, in the name of equality and solidarity, were expressed the claim for access by all to a sexual life and the request for sexual assistance — taking into account the fact that the sexuality of disabled persons is not explicitly and specifically broached in any legal document, of any kind, currently in use in France.

As regards awareness, autonomy and accountability, the physically disabled and the mentally disabled are not on the same footing. Those who are physically disabled are entirely responsible in the eyes of the law and they may exercise this status in any and every domain, sexual or emotional included. In contrast, the mentally disabled may not be fully aware of the complexity

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<sup>5</sup> Anomalies due to specific psychiatric disorders and those acquired in extreme old age would deserve further separate consideration in another Opinion.

<sup>6</sup> In this connection, mention should be made of the positive impact and popularity with viewers of films on the subject of disability, such as "The Intouchables", a French film directed by Olivier Nakache and Eric Toledano, released in November 2011, and also "Come as You Are", otherwise known as "Hasta la Vista", a Belgian film directed by Geoffrey Enthoven, released in March 2012, which address squarely the issue of sexuality and help to make the public at large aware of the subject of this Opinion.

<sup>7</sup> Law n° 2005-102 dated February 11, 2005 on equal rights and opportunities, participation and citizenship of disabled people.

of sexual matters in general and therefore of their own sexual life, of their relationships with other people nor of the social conventions which apply in the expression of their sexuality<sup>8</sup>.

Furthermore, for those whose handicap is physical, situations differ and this results in different attitudes depending on their previous history in emotional as well as sexual terms, and on whether their impairment was acquired in infancy.

- People who have had some experience of full autonomy retain the memory of a sexual life which they have been obliged to relinquish because of disability or advancing age. This sexual background may have left persistent fantasies and be the origin of a longing for sexual activity, out of nostalgia<sup>9</sup> and remembrance of days gone by.

- For those whose disability dates back to early childhood, sexual fantasies may have been induced by partially inappropriate education (e.g. no sexual education at all during development followed by the viewing of pornographic films), or urges or even desires experienced but misunderstood, that no one they know was able to explain. For lack of education on the subject, such urges are not mediated by a critical analysis of what it is acceptable to expose or express to others without being disrespectful, so that they can lead to negative reactions from those present. For that matter, intensive exposure at too early an age to pornography, be it in the presence of disability or not, is in itself a cause of distortion of the representation of sexuality. This is in fact a serious problem, which goes beyond the scope of this document but to which society should give some thought.

Those who were disabled at a very early age may, on becoming adolescent and later adult, be distressed mainly by solitude brought on by being “different”, without that necessarily inducing any yearning for any real sexual activity. They may, however, express a great desire for affection and recognition of their feeling of loneliness.

### **Sexual assistance or support: a controversial issue**

Attention once drawn to the diversity of nature and the consequences of disability, it would appear that “*sexual*” assistance, meaning the actual performance of sexual acts, would mainly be considered in the context of motor impairment. The proposal to arrange for sexual assistants is in fact only one component of the recognition of presumed expectations.

In the presence of a motor impairment, the help provided by a third party, either professionally or voluntarily, should therefore above all aim to “facilitate” so that a couple with disabilities can engage in sexual intercourse or in the event of a process of self-satisfaction.

With mental impairment, there is also, even though it is frequently “ignored” an element of learning to relate emotionally with others. Certain associations in fact insisted on the notion that, for a person with mental disability, support should be designed as help with the capacity to relate

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<sup>8</sup> Mercier M, Agthe C and Vatre F. *Eléments pour une éthique de l'intervention en éducation affective et sexuelle auprès des personnes vivant avec un handicap sexuel*. (Suggestions for the ethics of emotional and sexual education of people with a sexual handicap). Revue francophone de la déficience intellectuelle 2002 13 ;81-92

<sup>9</sup> Nostalgia: a bittersweet longing for the past or for an object or a pleasure that could not be obtained (translation of definition of the French word “nostalgie” given in Le Robert, historical dictionary of the French language).

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emotionally rather than relate sexually. People with mental disability generally are less concerned by sexual problems than they are with relating.

In some of France's neighbouring countries, the issue of providing for sexual assistance has been dealt with pragmatically in recent years: i.e. a practical solution to a problem. Sexual assistance is becoming a special service or even part of the training of certain disability service providers. Trained sexual assistants provide various services which may range from erotic assistance to fondling and sexual relations. In some countries, sexual assistants were for a time equated to prostitutes.

By claiming respect for intimacy in everyday life and access to that most intimate aspect of an individual's personal life, the right to sexuality, disabled people and those who assist them are reminding society that the satisfaction of sexual needs contributes to a state of well being and stability. That being said however, as was emphasised by several of the personalities heard by the Committee, there must be a clear distinction between sexual assistance and support services.

As they go about their professional duties and in the framework of their relationship with the person they are looking after, carers and service providers for disabled people frequently encounter situations that encroach on their own personal circumstances and history. They can and must, however, find a way to maintain a certain critical distance so that these intrusive elements can be identified and dismissed. Contact with another body, the intimacy of daily nursing, washing and toileting leads to contact with private parts, sometimes resulting in voluntary or involuntary arousal. Such physical proximity can embarrass or disturb both patient and carer and during the hearings these difficulties were mentioned more than once. Professional carers, however, learn to ease them away by talking to colleagues. Awareness of such problems are among the concerns professional carers attend to. Patients and their families are distressed by these difficulties, as are the professionals themselves, particularly when they are unable to defuse the situations they are witness to.

The associations calling for sexual support consider that much thought must be given to the subject and a certain number of principles should be defined. Sexual support must not be provided by carers already tasked with day-to-day nursing, in particular bathing and toileting. Otherwise, the quality of the carer/patient relationship might be vitiated and an ambiguous situation created for one or both of the people concerned.

The point has also been made that turning sexual assistance into a paid professional activity<sup>10</sup> would be one way of breaking free from the ambivalence of a compassionate relationship. In the same way as some professionals are competent to broach the subject of sex verbally — in all simplicity and dispassionately — professionals working with disabled people could be trained, become “competent” in appropriate gestures and touch, and acquire the ability to respond to mainly emotional needs of which one object would be of a sexual nature.

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François Violla, « vies affective et sexuelle en institution » in gazette santésocial  
*“Several of our European neighbours — in particular Denmark, Germany, Switzerland (German-speaking Switzerland at first, followed by French-speaking Switzerland) and the Netherlands — have already regulated sexual assistance in their various ways. For instance, in the Netherlands, these activities are sometimes paid for by local social services. The status of such professionals also varies from one country to the other, but all are particular insistent on the quality of “recruitment” and training of assistants. Notwithstanding fine words about the profile of these workers (the majority being drawn from paramedical circles: psychologists, physiotherapists and junior nurses), there is still some concern regarding the tenuous borderline with prostitution.”*

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Physical and intimate involvement on the part of sex assistants could never be an obligation imposed on them or the result of any kind of pressure. For those providing such services, the emotional and physical consequences of involving their own bodies cannot be ignored. Associations calling for the provision of sexual assistance recognise that it could only be one aspect of the professional services rendered by the carers concerned and that therefore they would also be performing other professional duties. They further recognise that sexual assistance should only be continued for a limited time by each carer for the same beneficiary. In this way, they seek to protect both disabled people and those who assist them.

This list of precautions is clear evidence that it would indeed be difficult for sexual assistance to become a full time profession or occupation. Legitimate doubts spring to mind on the concept of a lasting “specialisation” on the part of sexual assistants. Even associations in favour of sexual assistance are well aware of its limits. Furthermore, sexual assistance as a health caring activity seems to be a questionable theory<sup>11</sup>.

Providing sexual services to people with disabilities could easily lead to undesirable consequences. On the one hand, the beneficiaries are vulnerable people who could be transferring their affections to the sexual assistant, with a painful situation ensuing; on the other hand, there is no guarantee that sexual assistants themselves might not become vulnerable through excessive emotional involvement following on the service they are providing. There is a marked difference between being competent and knowledgeable in the exercise of one’s profession and involving oneself intimately in the pursuit of a professional relationship. There is no less a difference between “talking” about sex and “being trained” for responding actively to requests involving one’s own body and sexual contact with another person’s body.

For a team of carers, the management of sexual issues implies hearing and paying attention to what their disabled patient has to say, while taking care not to indulge in projection bias and preconceived ideas. The team should discuss the matter collectively to reduce the impact, but it would be illusory to suppose that there could be an entirely satisfactory solution for the person concerned in every case.

When instead of a team of carers, a sexual assistant is asked for help, he or she may not feel able to respond positively to all spoken or unspoken needs for sexual intercourse, which could contribute to the creation of new frustrations and more distress. It would be cruel to refuse to hear the distress of the disabled person and to refuse to consider possible pragmatic solutions. But the risks of such practices must be clearly analysed: it is a fact that relationships involving feelings, affects and desires always contain an element of danger.

Sexual support conveys notions of companionship, reciprocity, absence of payment, whereas assistance would be closer to a mechanical response. If so, people with a single physical disability are hardly likely to be content with the kind of satisfaction provided by sexual assistance. Like anyone else (of sound health or otherwise), they need the much broader satisfaction of a sex life founded on a relationship in which feelings play a role. Sexual assistance, however perfectly provided by well trained professionals, cannot suffice to respond to

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<sup>11</sup> This was mentioned by several carers whose patients seemed to be referring to this possibility.

the complex needs brought about by the blanks in the emotional and sexual lives of people with disabilities.

To reply to a question contained in the referral, associations requesting the organisation of services by sexual assistants reject the assertion that such services are a form of prostitution. Nevertheless, recognising sexual assistance as a profession in its own right with entitlement to payment would require a modification to legislation prohibiting immoral earnings by procuring. Simply making the arrangements for a sexual assistant and a disabled person to meet could be assimilated to pimping. How could the possibility be excluded when it is a fact that in certain countries, prostitutes are sometimes asked to provide this sexual assistance?

Acting as a go-between for people who prostitute themselves and those who avail themselves of their services is, in the eyes of the law, procuring. The French criminal code lists such offenses in a section of the chapter on “*Offenses against the dignity of the human person*”. When, for ethical reasons, certain actions are prohibited and this applies to all without exception, would it not be difficult to consider that these actions would be permissible in individual cases for the benefit of certain specific people ?

By virtue of the principle of “discretionary prosecution”, a prosecutor of the French Republic may consider that the circumstances of a particular case do not call for criminal proceedings even though there is a clear breach of law.

## **Freedom and autonomy for people with disabilities**

Associations campaigning in favour of sexual assistance are aware of the difficulties and dangers. Information gathered on similar structures in other countries shows that the number of people who sign up for training as a sexual assistant is far in excess of the number of those who actually go on to practice what they have learnt. Furthermore, the majority of those who do are sex workers, and those who are not tend to move on to other occupations very swiftly.

As regards the disabled people involved, they may also feel ill at ease with their sexual assistant. In a relationship for payment whose participants did not choose each other, can the idea of pressure exerted on one or other of the two individuals concerned be altogether excluded?

Some disabled people made it clear that they would view the setting up of a sexual assistance service as a form of charity and an indignity. “Sexual assistance, yet another example of discrimination!”, wrote one young woman in the correspondence columns of the May-June 2011 issue of *Ombres et Lumière*.

*“So, just because we are not like everybody else, sexuality for us should be a contract between someone buying a “service” and someone providing a “service.”*

It would be oversimplifying to argue that people with disabilities are only affected by “urges”. If the response to the sexual and emotional needs of disabled people were to be solely professional, practical and technical, as one of the personalities heard by the Committee said, “would this not be just a way of getting rid of the problem”? To relegate certain people to a life of sexuality expressed only as the satisfaction of an urge and “responding to their need only in that respect” would be an additional wound for them to bear and in no way respectful of the founding principles of medical and nursing ethics.

Although obvious risks are attached to sexual assistance, it is a fact that a wide variety of circumstances prevail. One of the people heard by the Committee gave the example of help provided to a couple, both suffering from motor handicaps and unable, physically, to approach each other. In such a situation, another person's assistance would be required and there does not seem to be any valid reason for objection.

In effect, French associations advocating professional sexual assistance are solely concerned with situations in which physical disability alone prevents someone from engaging in sexual activity. It would not be possible to find a remedy for every form of frustration, but help could be given in a particular situation to overcome the frustration and hurt brought on by motor disability.

### **The right to sexuality, the right to compensation**

Some associations consider that setting up sexual assistance services, in France, could be covered by the articles on compensation for handicap in the law dated February 11, 2005<sup>12</sup>.

*“People with disabilities have a right to compensation for the consequences of their handicap irrespective of the origin or the nature of the deficiency, or their age or their lifestyle.”* (Art. L. 114-1-1).

Although there are in fact rights in connection with sexuality (the right to contraception, the right to sexuality without unwanted pregnancy), that cannot lead to considering that the state is under obligation to “compensate” people with disabilities for their specific sexual situation, as though the state could be held responsible for their loss. Solidarity is the single consideration in this instance, not ethical principles.

To affirm the opposite view could lead to the “disintegration of subjective rights” that Professor Carbonnier, dean of the law faculty, saw as a trend in current societies. To sum up: to every freedom does not correspond an obligation on the part of society.

Undeniably, even when disability is in no way involved, many people experience difficulties in their emotional and sexual lives, but this does not impose any “duty” on the community.

The essence of a relational bond is that no commercial or financial reward is attached. Would not recognition in terms of law and finance be likely to distort the situation?

Ideally, everyone should have the opportunity to enter into a loving relationship based on emotions, feelings and moral commitment. For this to happen there must be a possibility of meeting other people, but society does not always act in ways which facilitate such an occurrence and may even make it difficult, not to say impossible.

Borrowing from the subtitle of a recent publication<sup>13</sup> on the sexuality of disabled people, it should be regarded as one of the recognised rights of individuals, not as a subject for tolerance or

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<sup>12</sup> The “right to” could in that event take two forms: either the creation of a structured public service tasked for this purpose, or the creation of a system for reimbursing those using certain services.

<sup>13</sup> Campagna N *La sexualité des handicapés faut-il seulement la tolérer ou aussi l'encourager ?* Editions Labor et Fides Paris, 2012 (Should the sexuality of people with disabilities be only tolerated or should it also be encouraged ?)

encouragement.

For people who are disabled, if they are not at liberty to meet others in school, or at work or if they are not living within the community along with everyone else, if they live in an institution or congregate care facilities, if their only link to the outside world is their family protecting them, but in so doing also isolating them, then the lack of an emotional and sexual life may well be due to the nature of their impairment, but also to the fact that their chances of forming bonds of affection and constructing relationships, including sexual ones, are compromised at the outset.

Even if the State were to do its duty and do it to the full (this seems far from being the case, as regards schooling for children, access to work and health care for the disabled, to mention only a few examples) this would not prevent disabled people and their families from continuing to be isolated and suffer a high degree of social and personal deprivation. This is truly an ethical issue. How people with disabilities are integrated into the community, including as regards the subject of this Opinion, is above all a matter for compassion, assistance, easing their way and benevolence on the part of each and every one of us and cannot, as a matter of course, be left in the sole care of the State.

## **Conclusions and recommendations**

The three questions raised in the referral on the personal life of people with disabilities, with due respect for their emotional and sexual autonomy, have been discussed from three angles: what is accepted, what is refused and what is disputed.

The first two questions enquired about the role of the State and of society generally.

- The State is responsible for providing disabled people with sufficient financial support, for developing their access to the community in the form of, for example, services and housing, and for organising the training of professional carers. Recent modifications to existing legislation are consistent with the requirement for solidarity extended to the disabled and their families. But the law needs to be known and applied. However, improving the lot of people with disabilities is not entirely a matter of public policies. Not everything can be left to the State and asserting the contrary amounts to sidestepping the issue.

- 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. Isolation and the exclusion that stems from it brought about by various forms of disability causes a great deal of suffering, and reduces the number of occasions when disabled people have a chance of being recognised as ordinary men and women seeking to enter into the social and emotional relationships to which they aspire. In this respect, the integration of people with disabilities must be attended to in early childhood. Be they sound of health or disabled, very young children should learn to live together so that they can see and accept differences and be educated to do so.

- Before sexuality even enters into the picture, how people perceive each other delineates the possibility of meeting and relating. This is just as true for people who are disabled as it is for people who are not. Neither the State nor associations can bring about unaided a change in the perception by society of the various forms of handicap, nor make social bonding less difficult. The community as a whole must make that commitment.

**But the claim for a life in which sexuality plays a part cannot be nullified by the claim for a life with its share of emotion, even though the two are tightly knit.**

Such a claim is related to the issue of the body and exclusion, to empathy with others, linked both to the body itself and to how it is perceived.

This leads to a response to the third question in the referral, the way in which the health caring and social services professions could be encouraged to adopt good practices regarding the privacy, autonomy and dignity of people with disabilities.

**Requests for sexual assistance are very diverse in nature and do not all involve another person's body in the same way.**

Helping to make those concerned and their families more comfortable requires an approach based on an understanding of sexual issues. Appropriate training is a necessity.

- Steps should be taken to further the progress of training for healthcarers and educators on matters connected to sexuality but also on ethics, and they must be given support.

Such training must include a "technical" aspect, for example facilitating contact for people with physical disability or facilitating access to mechanical means of sexual satisfaction. It should aim to provide tuition specific to particular personal circumstances and respectful of each person's need for privacy and discretion.

With this in mind it would therefore be advisable to support existing research and ongoing projects: there are instances of experimental work in certain institutions designed in particular to help couples who are both disabled to live in mainstream housing.

**When a professional carer's body is involved in physical intimacy, CCNE considers that circumspection is required.**

Could professional carers decide to involve themselves in physical or sexual intimacy without also associating an element of desire? Could they manage to view such activity as no more of consequence than, for instance, physiotherapy?

- A parliamentary committee's report on prostitution<sup>14</sup> includes the issue of sexual assistance to people with disabilities. Associations of disabled people calling for such assistance to be provided reject any connection with prostitution. And yet, it is difficult to describe it otherwise, unless it were provided free of charge.

- As was clear from written documents and the hearings, working as a sexual assistant is by no means easy. It was found that assistants were sometimes mistreated, even involuntarily, when the sexual relationship became something other than that which had been initially and contractually agreed. References were made to situations in which assistants become abusive and the possibility that they could be the victims of blackmail. Rejecting naive optimism must not be

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<sup>14</sup> *Évolution des mentalités et changement de regard de la société sur les personnes handicapées: Passer de la prise en charge à la prise en compte* Jean François Chossy Report to M F Fillon, Mme R Bachelot Mme AM Monchamp (Changing outlooks and mindsets of society regarding people with disabilities: moving on from "taking care" to "taking account".)

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one-sided and must be applied equally to all concerned.

- The sensitive issue that one person's body is being instrumentalised for the personal satisfaction of someone else's cannot be ignored, even when the act is voluntary, paid for or compassionate. An act of society whereby situations of subjection are wilfully created, even to alleviate real suffering, cannot be classified as ethical. By reason of the principle that the human body must not be used for commercial purposes, CCNE considers that sexual assistance cannot be viewed as an unexceptional professional occupation.

Although sexuality can be a source of pleasure, it also opens the door to every kind of violence, including that of being unacceptable. There is no denying that there is no such thing as a single standard for harmony and equilibrium, but on the contrary a multiplicity of realities of which we must become aware, more or less bluntly, more or less crudely. The complexity of the subject compels us to face up to disturbing issues involving dignity, vulnerability and the boundaries of what is ethically acceptable.

**As a consequence of which, regarding the sexuality of people with disabilities, CCNE is unable to discern any duty or obligation on the part of the community or of individuals, apart from facilitating contacts and social interaction, in the context of the law as it is spelt out and applies to all. It would seem difficult to accept the concept that sexual assistance is an entitlement to benefit owed by society and that it is contingent on any but personal initiative.**

Paris, September 27, 2012