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Disability and sexuality in France: sketch of a social history

Pierre Brasseur

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We have chosen to start this article with the evocation of this study day because it is symptomatic of the way in which the actors (are) mobilised to promote the cause of ‘sexuality of people with disabilities’ and, more specifically, ‘sexual assistance’. The place given to the speeches of people directly affected in their daily life, or to those of their distraught relatives, the attention given to a professional of erotic accompaniment describing the benefits of her interventions, as well as the appeal to experts of sexuality aim, in fact, at consolidating the contemporary movement in favour of sexual assistance to people with disabilities. More precisely, this day of reflection vividly shows how emotions, often absent from sociological explanation (Déchaux, 2015), are in fact essential to reach the sensitivity of an audience and convert it to a cause. However, this emotional register alone is not enough to win over the public: convincing people of the rightness of a cause also implies a work of delimitation and legitimisation allowing it to exist independently of the concrete examples that can give it substance.

In what follows, it will not be a question of passing judgement on the contrasting opinions that sexual assistance arouses; rather, the objective is to analyse the rhetoric used by the supporters of sexual assistance to set up this practice as a cause to be defended, a rhetoric that mixes recourse to emotions and figures, to lay and learned expertise. In doing so, this article would like to contribute to a set of studies (Mathieu, 2014; Traini, 2009) which, at a distance from a spontaneous conception of mobilisations or social movements, insist on the strategies that allow a cause to emerge, and then to be structured – in this case, sexual assistance to people with disabilities. Therefore, after a quick presentation of this practice, its origins and its current developments (1), it will focus on describing the awareness-raising devices used by the advocates of the ‘sexual assistance’ cause (2).

Sexual Assistance: The Emergence of a Public Concern

In the early 2000s, a movement for the implementation of sexual assistance was born in France. This question was probably not totally new at the time. As early as the 1950s, certain voices were trying – in vain – to be heard to change the emotional and sexual condition of people with disabilities (Brasseur, 2014). In the 1970s, and particularly after the 1975 law on disability was passed, protest groups such as Les Handicapés Méchants denounced the functioning of specialised institutions and what some called the ‘sexual misery’ that reigned there. However, at that time, sexuality issues were hardly relayed by the historical actors of the disability sector, in particular the Association des paralysés de France (APF), which remained focused on claims considered more legitimate – the opening of the world of work or the accessibility of transport and buildings. The politicisation of the issue of ‘disability and sexuality’ thus appears to be relatively late in France; however, it is quite strong since this issue now takes precedence over others, such as the parenthood of people with disabilities, which do not enjoy the same official recognition.

If we can say that the question of sexual support for people with disabilities was raised late in France, it is not only because of the unsuccessful demands that were expressed in France throughout the previous century. This question, in fact, was debated very early in other countries, in the Anglo-Saxon countries for example, and in the United States. There, the sexological theories elaborated in the 1960s and 1970s by William Masters and Virginia

Johnson, the heroes of the successful series *Masters of Sex*, justified the use of replacement partners for people with problems with their sexuality – first men, then women and people with disabilities. These analyses, which are often considered sulphurous, even scandalous, and which inspire today's practices of sexual accompaniment, were hardly ever put into practice at the time. But they soon resonated with Anglo-Saxon disability studies, which denounced the oppression of the sexuality of the 'disabled' in a valid-centric world and militated very early on, in the columns of *Sexuality and Disability* in particular, for a politicisation of the sexual question (Finger, 1992; Waxman, 1991). Similarly, in Northern Europe, in Belgium, the Netherlands and Germany, forms of sexual assistance for physically disabled people began to appear in the 1980s and 1990s. It is essentially a question of arrangements between brothels and certain associations to facilitate the connection of disabled clients with sex workers. The question remains, however, as to who exactly should be entrusted with the task of dealing with the sexuality of people with disabilities – sexual surrogates, as proposed by Masters and Johnson, prostitutes who may receive specific training, or professional escorts, duly selected sexual assistants, as is the case in Switzerland?

The measures taken in Switzerland in 2003, namely the recognition of the activity of sex assistants and the setting up of an ad hoc training (Kessler, 2008; Nayak, 2013), and then the vote, in France, of the law of February 2005 'for equal rights and opportunities, participation and citizenship of disabled people', opened a window of opportunity in France for the defenders of the cause of 'disability and sexuality'. In fact, since the law affirms the right to compensation for all the effects of disability, can sexuality remain in the blind spot? And can it remain a taboo subject when it comes to people with disabilities while other countries propose innovative solutions, which distinguish a priori sexual support from prostitution? Obviously, this kind of consideration seems to widen the field of political possibilities for the French associative militants. And from then on, in the wake of some academics, such as René-Claude Lachal or the psychologist Michel Mercier, it is the very media figure of Marcel Nuss who is going to impose himself and to embody, in France, the fight in favour of the sexual accompaniment of the disabled persons. Afflicted himself with a particularly severe progressive disability (spinal muscular atrophy), Nuss is at the same time a seasoned lecturer, an active activist and a prolific writer, author of an erotic novel (*Libertinage à Bel-Amour*, 2014), several love autobiographies (*en dépit du bon sens*, 1989; *à contre-courant*, 1999), but also a manifesto for emotional and sexual support (*je veux faire l'amour*, 2011). As such, he emerges as the primary 'owner' of the 'sexual assistance' cause, in Gusfield's terminology, that is, an actor in a hegemonic – even monopolistic – position with the ability to 'create or direct the public definition of an issue' (Gusfield, 2009, p. 11). In 2008, he edited the publication of the book *Handicaps and Sexualities*, a volume that brings together the proceedings of the major symposium held in April 2007 at the European Parliament on the theme of 'Physical Dependence: Intimacy and Sexuality', of which Nuss had already been one of the key figures.

The Strasbourg Conference, which was co-organized by Handicap International, the APF, the Association française contre les myopathies and the Coordination 'handicap et autonomie' led by Marcel Nuss, can also be seen as the founding moment of the movement in France that promotes sexual assistance. In a way, this event allows a 'cognitive liberation', to use McAdam's expression, a 'process by which potential activists decode the openings of the opportunity structure' (Mathieu, 2002). Following this conference, several associations of people with disabilities set up a group called 'Handicap et sexualité' (Disability and Sexuality), which set itself the goal of creating a specialised training program and a diploma for sexual assistants within two years. This tight schedule will certainly not be respected, but

in France as in Switzerland, there are several structures that now provide training for sex assistants: the Swiss association 'Sexualité et Handicap Pluriels' (SEHP), the association for the promotion of sexual accompaniment (APPAS), founded by Marcel Nuss, which is organising its first training cycle in 2015, and the Swiss association 'Corps solidaires', which brings together certified sex assistants.

Of course, the opposition remains strong and sexual assistance struggles to appear, in France, as this form of self-giving or care that its defenders exalt. Most political leaders maintain that sexuality is by no means a subjective right that can be opposed and that the 'dignity' of some cannot be sacrificed for that of others – a viewpoint that is in line with the opinion given in 2012 by the National Consultative Ethics Committee. Moreover, even within the associative world, the promotion – highly mediatised – of sexual accompaniment aroused hostility that became more and more vocal from 2010 on. The psychoanalyst Maudy Piot, president of the association 'Femmes pour le dire, femmes pour agir', is one of the main leaders; she relentlessly denounces a practice which, violin nouns, would contribute, according to her, to an increased commodification of women's bodies and to a greater marginalisation of disabled people, made dependent on an essentially compassionate service. And in general, for these opponents of 'sexual assistance', who also mobilise the press and the media, such a service would in fact be like a form of paid sexuality, and therefore to prostitution, and its organisation, to pimping.

The strength of this opposition, embodied by Maudy Piot or the Mouvement du Nid, has contributed – paradoxically – to structuring a universe of specific mobilisations around the issue of sexual assistance. Indeed, on this theme, what we could call, by taking up the conceptualisation proposed by Lilian Mathieu (2008) or Laure Bereni (2012), a 'space of the cause', a set of actors and actions dedicated, in this case, to the defence of the sexual assistance of people with disabilities. As in the case of the women's cause studied by Laure Bereni, this space with vague contours is weakly unified on the internal level; it is also composed of heterogeneous actors (associations of the handicap, associations specialised in sexual assistance, such as the APPAS, professionals of the sex or health, artists, intellectuals, etc.) whose protests or claims are sometimes plural, even dissonant. But the issue at stake often manages to reduce these tensions and to silence these possible divisions, because it is above all a question of mobilising and, to do so, of convincing people of the merits of the cause. Like the study day organised by the association CH[s] OSE, which was mentioned in the introduction, activists combine different awareness-raising mechanisms to make the issues of sexual assistance known and recognised.

Sexual Assistance: The Springs of a Combat Rhetoric

How to advance the cause of 'sexual assistance' and persuade public opinion of its merits? There is every indication that activists use a combination of methods to do so, depending on the nature of the audience they are addressing. In the wake of the work of rhetoric specialists (Preti, 1968; Scarantino, 2007), we observe that the discourse – classically – adapts to the target audience: on the one hand, a 'logical discourse' intended for a large audience; on the other hand, a 'rhetorical discourse' based more on feelings and aimed at a narrower, better identified audience.

The use of figures and statistics falls into the first category. Thus, one of the battles waged by the associations militating for the implementation of sexual assistance was to quantify the phenomenon by showing that, by its magnitude, the affective and intimate situation of

disabled people justified the establishment of ad hoc support. The objective here is to ‘solicit the cold objectivity of figures to reach the sensibility of the public that one wishes to convert to the cause’ (Mathieu, 2012, p. 173). In November 2006, for example, the Association des paralysés de France (French Association of Paralyzed Persons) wanted to carry out a survey and, to do so, commissioned a poll from the Ifop Institute. As it does regularly on other issues, the association is striving, once again, to objectify its positions on various public problems and to bring them into the realm of ‘indisputable facts, established by rational methods’ (Neveu, 2015, p. 127).

In 2006, respondents were asked two main questions, ‘Would you say that many, most, or few people think that being in a relationship with a person with a disability requires courage?’ and ‘Would you say that many, most, or few people think that people with disabilities do not have a sex life?’ To the first question, 87% of the interviewees answered ‘most people’ while 61% of them indicated that most people (answers ‘many’ or ‘most’) dissociate disability and sexuality. As we can see, this type of survey is very similar to the famous example of the ‘beauty contest’ in which the economist John Maynard Keynes (1936) illustrated the functioning of speculative logic: the people questioned are not asked to make a judgement on the sex life of the disabled, any more than the actors of Keynesian economics sought to discover the ‘real’ value of assets; in this case, everyone is only trying to find out what others think, to identify their beliefs on the issue. In this case, however, what is simply an estimate of the common opinion on the relationship between disability and sexuality is quickly transformed, particularly in the press, into a true reflection of the state of opinion. An article entitled ‘Handicap et couple: les préjugés ont la vie dure’ (Disability and couples: prejudices are hard to get rid of), published in *Le Figaro*, states that ‘87% of French people think that living as a couple with a disabled person is a hardship’. The same sleight of hand is also found in the pages of *Ouest-France*, where one can read that ‘61% of French people think that disabled people do not have a sexual life’.

This is undoubtedly a clumsy statement by journalists, which is also validated by a press release from Agence France Presse. But these distorted and erroneous statistics are also mobilised – quite opportunely – by the militants of the ‘sexual assistance’ cause. They appear in commitment no. 8 of the ‘APF 2012’ Pact, entitled ‘An emotional, sentimental and sexual life for all’, which the association is addressing to all the presidential candidates; they also appear in Jean-Luc Letellier’s committed book, *Their sexuality is not a handicap*, and regularly punctuate the various speeches of the sexual assistance propagandists. In so doing, they suggest that opinion is, so to speak, on their side, that the French are fully aware of the intimate distress of people with disabilities and that they are ready, finally, to recognise the need for appropriate compensatory measures. So that such figures are in fact very similar to those evoked by Gusfield (2009) in his book devoted to the culture of public problems – in particular those 9 million individuals affected by alcoholism in the United States: however fragile they may be, they seem a priori to be able to reach a consensus; however contestable they may be, they focus attention, shape the reality on which it is appropriate to act, and contribute to the emergence of a public formulation of the problem in preference to any other.

But there is more to it than that. For producing their own statistics and being identified as purveyors of up-to-date knowledge allows advocates not only to get their name out there and gain visibility, but also to be gradually integrated into the ‘field of expertise’ (Mathieu, 2012). However, in the strategy of the activists of the ‘sexual assistance’ cause, expertise allows them to consolidate a ‘logical discourse’ intended to convince, in reason, the largest audience. In the colloquia organised in France, we note in this respect that the experts have often

mastered the debates on the question of disability and sexuality. For example, at the symposium organised by the Association laïque pour l'éducation, la formation, la prévention at l'autonomie (ALEFPA) in November 2006, a few days after the APF survey was published, the floor was taken by the heads of medical and social establishments and by the appointed experts – a child psychiatrist, a psychiatrist, and Jacques Waynberg, the sexologist who initiated the first meetings on the theme of 'disability and sexuality. As Bourdieu clearly saw in his analysis of the relationship between the social and the language, they have a symbolic capital commensurate with the social authority of the group they represent – since “the power of words is nothing other than the delegated power of the spokesperson” (Bourdieu, 1982). They are thus at the origin of an “authorised language” which is also, in fact, a “language of authority”. However, this 2006 conference, which gave pride of place to clinical expertise and the medical approach to disability, was also one of the last of its kind. Little by little, in fact, expertise is changing in nature: it is diversifying and opening to laymen, especially when it is a question of convincing by means of a “rhetorical discourse”; moreover, it is becoming more and more like what Robert Castel has called an “instituting” expertise, which produces knowledge while at the same time promoting a point of view and solutions (Castel, 1985).

The first notable change concerns the experts called upon by associations advocating for sexual assistance for people with disabilities. This evolution is clear, for example, from a comparison of the above-mentioned 2006 conference with those organised a decade later similar themes – namely intimacy or sexuality – and by the same structure (ALEFPA). In these latter events, doctors are much less present: without disappearing completely, they are somewhat marginalised by other speakers, who are more numerous and now occupy the front of the stage – political leaders highlighting their action, jurists, or specialists in the human and social sciences. Let us also consider, in this respect, the “specialists” invited by the association CH[s]OSE in February 2013 and mentioned in the introduction: there are no doctors but researchers in anthropology and sociology, a “politician” and a representative of cults. In a way, Jacques Waynberg is emblematic of this loss of influence of medical sciences and of the lesser role given to doctors in the communication strategy followed by the main actors of the cause. Waynberg, it should be remembered, was the instigator, as early as 1980, of the first symposium held in France on the theme of “Handicaps and sexuality”, and it is under this title that he published the proceedings (Waynberg, 1981). However, reading the summary of the book, doctors have a monopoly on expertise on the issue – whether they are psychiatrists, sexologists, specialists in rehabilitation medicine, etc. – and that they are not the only ones to have a role to play. The composition of the book directed by Marcel Nuss at the end of the Strasbourg colloquium of 2007, in which Waynberg participated, but this time as a simple speaker, is quite different. In the latter book, the doctors disappear completely in favour of Swiss “sex educators”, anthropologists such as Henri-Jacques Sticker, various professionals, in particular physiotherapists and masseurs, politicians and, above all, people suffering from a disability themselves (Nuss, 2008). Jacques Waynberg disappears from the proceedings.

This transformation of the scope of expertise can be interpreted in various ways. Firstly, it suggests that the associations' fight is being waged on new grounds. It is no longer a question of making the public aware of the pathologies they suffer from or the limits they encounter in terms of sexuality: from now on, it is the real living conditions of people with disabilities, the indissociable natural and social character of sexuality, the discriminatory representations of which these people are victims or the limitation of their rights, that are addressed by experts closer to the human and social sciences. In other words, the activists of the “sexual assistance” cause today place less emphasis on disability than on sexuality, less on the

physical or physiological obstacles than on the social and political obstacles to the full development of the persons concerned. Secondly, this broadening of expertise towards professionals from different backgrounds indicates that the field of sexual assistance is very weakly structured and that it is easy, in the end, to reach the status of “disability and sexuality” expert. Some particularly vague and unprotected names, such as “sex educators” or “therapist”, can thus shelter a certain number of self-proclaimed experts. Finally, everything indicates that this reconfiguration of the perimeter of expertise also allows activists to combine more closely a “logical discourse” and a “persuasive discourse”, to reinforce one with the other by expressing and arousing emotions. Increasingly, indeed, advocates for “sexual assistance” are mobilising individuals whose expertise is rooted primarily in personal experience and trial (Trépos, 2000) – whether they are sex assistants or people with disabilities themselves. The expert is therefore a layman or, more precisely, an “ex-peer” whose account and testimony, as close as possible to reality, is an effective instrument of persuasion. For the emotion he provokes by sharing his experience – depending on the case, his commitment, or his distress – is from the outset a way of assessing the situation in general and taking a stand (Déchaux, 2015). Suddenly, the cause becomes embodied: it is no longer a theoretical debate, an essentially legal or moral issue, but a concrete problem that concerns and challenges everyone – as a victim, relative, friend, etc. (Padioleau, 1982.) In short, the “logical discourse” of the “learned expert”, which tends to disregard any content in order to convince the audience in reason, is reinforced by the “rhetorical discourse” produced by the “knowing expert”, the one who, by modestly evoking his handicap or his sexuality, often gives the case that “extra soul” that can win over the audience

Conclusion

Objectivity through figures, soliciting experts to increase generality and appealing to the experience of laymen, “ex-peers” likely to give substance to the claim: these are the main elements of the strategy deployed by the activists of the “sexual assistance” cause. In this, the latter does not present a great originality, nor remarkable specificities. But the interesting thing about this study is that it shows, so to speak, in vivo, how a cause is structured, how activists try to convince people of the validity of their claim, a strong claim which, in this case, challenges social norms and contravenes legal norms.

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