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Disability Rights Meet Sex Workers' Rights: the Making of Sexual Assistance in Europe

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Abstract

The last decade has seen an expansion in initiatives promoting the development of special sex services oriented to people with disabilities, which in Europe are increasingly labelled 'sexual assistance'. These have become the object of political and media attention, and arguably call for a critical analysis incorporating both disability and sex workers' rights perspectives. Based on an 18-month embedded participant observation, I explore the case of a grassroots organisation which brings together sexual assistants, disabled activists and (potential) clients, and their allies in Switzerland. Opposing 'therapy', 'charity', and 'care' approaches to sexual assistance, members of this organisation work within their own model of 'ethical' services. While they place sexual pleasure at the centre of this approach, in practice, they promote forms of self-regulation aimed at limiting the risks of sex services, connected in particular to intimate violence, stigmatisation, sex normativity, and the role of intermediaries. Clearly rooted in a disability rights perspective, this grassroots initiative does not only concern sexual assistance but more largely sex services. In this sense, this study invites us to look at sexual assistance as an interesting space for alliance between sex workers' rights and the rights of people with disabilities, as a uniquely politicised group of (potential) clients.

Keywords Sexual assistance · Sexual surrogacy · Disability rights · Sex workers' rights · Sex workers' clients · Prostitution · Switzerland

Introduction

Over the last 20 years, the global sex industry has seen increased diversification, with new subjects coming into public light, as clients, as workers, and as so-called third parties organising or facilitating the trade. This diversification has been read in terms of increased risks of exploitation and trafficking, especially for new groups of workers who enter sex work with little or no alternative opportunities or awareness of their rights, or for clients who do not know any of the rules of the industry, which in many cases are both difficult to access and informal. However, from a perspective of organising for rights in the industry, the entry of new subjects may also be read as an opportunity to promote positive change and new insights into an industry which suffers from social and political isolation. This is how the present article considers the case

of disabled people as new subjects in the industry, focusing specifically on the context of Europe.

Arguably, the fact that disabled people, especially men, are clients is nothing new, and an increasing body of research shows that sex work has played, and still plays, an important role in the lives of disabled clients and their gender formations (Sanders, 2007; Liddiard, 2014). However, something new has been happening at the level of organising and policy making, and that is the conscious engagement of parts of the disability rights movement with the issue of sex services. In particular, in the last 15 years in the European context, there have been a number of initiatives which promote forms of access to sensual and sexual experiences with professionals, for people with disabilities. This has taken a variety of forms, including for instance requests made to the public system to train professionals in 'sexual facilitation' or 'practical sex education' for the disabled—examples of this exist in Denmark, with 'sexual advisors' (*seksualvejledere*); or collaborations directly with sex worker organisations and communities, such as *TLC Trust* in Britain, which is similar to *Touching Base* in Australia, facilitating a connection between disabled people and sex workers; or the creation of specialised sex services

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developed in the last decade across European countries, increasingly referred to as ‘sexual assistance’. Some of these practices may remind us of the more well-known ‘surrogacy’ for disabled people, but, as we will see, surrogacy is in fact quite distinct and is rooted in therapeutic approaches to address sexual dysfunctions, rather than in disabled people’s interventions, as is the case for the practices analysed here.

The development of these initiatives, as well as the policy and media attention they evoke, needs to be at least partly read in relation to a context in which European societies pay increasing attention to sexual expression as a central element of what is considered a positive way of living and of being a ‘good’ human being, and in which exclusion, stigmatisation, and abuse in the sphere of intimate relationships are articulated as fundamental violations of human rights (WHO, 2006; United Nations, 2006; Nussbaum, 2007; Fassin, 2010; Campagna, 2012; Richardson, 2017). Simultaneously, the debate on sexual assistance for people with disabilities inherits some of the specific features of the current debate on prostitution in Europe, as analysed for instance by Wagenaar and Jahnsen (2017). Namely, the field of sexual assistance suffers from a lack of interest in empirically based policies, and the actors’ views tend to be reduced to fitting into two polarised positions: one ‘pro’ and one ‘anti’ sexual assistance. The ‘pro’ position presents qualified, accountable, and (publicly) controlled sexual providers as a realistic option for people with disabilities who experience very limited or no access to sexual experience, and simultaneously as a solution to the tensions existing around sexual negotiation, harassment, and even exploitation between them and their carers, nurses, and relatives (Shakespeare 2000b; Tepper, 2000; Earle, 1999; Mona, 2003; Prayez, 2015; Vatré & Agthe Diserens 2012). The ‘anti’ position, while recognising problems of access to sexuality for people with disabilities, stresses the dangers of sexual assistance as part of larger processes of affirming the ‘male sex right’ and the commodification of women’s sexuality, and as promoting prostitution and the exploitation related to gender that proliferate in prostitution (Jeffreys, 2008). The debate generally remains highly gendered, and the assumption is often made that only male disabled people would need access to sexual assistance and that only women would provide services.

Within this scenario, few empirically based studies have been published on practices of sexual assistance, those involved in them, and how they are impacted by public policies, including policies on sex work and disability (Kulick & Rydström, 2015). Scholars have started interrogating whether paid services might facilitate concrete sexual rights and ‘accessibility’ in the sexual field (Shuttleworth, 2007; Shuttleworth & Sanders, 2010), while exploring the possible convergence or divergence of the field of disability rights and that of sex workers’ rights (Garofalo Geymonat, 2014; De Boer, 2015; Kulick & Rydström, 2015). Indeed, in the context of the retreat of public responsibility from the mechanisms of exclusion of people with disabilities across European

countries, policies demanding the recognition of specialised sexual services for the disabled run the risk of reproducing the idea that people with disabilities are undesirable, and that their sexuality can be treated—and got rid of—as yet another need of the disabled that non-disabled people can manage and profit from within a problematic frame of sexuality as a medicalised issue (Dufour, 2013; Nayak, 2013; Brasseur & Detuncq, 2014; Dufour & Thierry, 2014). Moreover, critics have stressed how in the context of public policies increasingly criminalising and stigmatising large parts of the sex industry in Europe (ICRSE, 2016; Wagenaar & Jahnsen, 2017) sexual assistants and their disabled clients run the risk of being used to represent the ‘good and clean’ version of the sex industry, worthy of recognition and protection, while the rest deserve to be left to their fate or actively persecuted.

The present article is situated within this intersectional critical perspective (Inckle, 2015; Taylor, Hines, & Casey, 2011), as I propose looking at these new kinds of services through the lenses of both disability rights and sex workers’ rights. My empirical underpinning is the ethnographic study of a grassroots organisation promoting sexual assistance based in Switzerland, which I call BodyUnity. Grassroots organisations may represent a rich source of knowledge in this field, as well as with respect to the politics of all sexual services. As I have argued elsewhere (Garofalo Geymonat & Maciotti, 2016), the richness of these organisations’ knowledge may emerge particularly where a participatory methodology is used. My findings indicate that when they are far away from the ableist and prostitution-abolitionist pressure of the public debate, BodyUnity activists—including disabled clients, sexual assistants, and their allies—may develop different discourses from those they may feel the need to mobilise in public. In public, they may decide, in order to protect themselves from stigma and even criminalisation, to stress the difference between sexual assistance and prostitution; downplaying the sexual content of their encounters, and the ‘sexiness’ of sexual assistants, and thus highlighting their ‘cleanness’ and normality (for example: ‘I have kids’, ‘She is married’); or insisting on the exceptionality of these services due to the fact that they/their clients are ‘very disabled’, or that they do not go ‘all the way’. Instead, when they are in a safe environment, away from the dominant discursive frame of ‘is this prostitution or not?’ and the sharp division between able and disabled people, BodyUnity members appear to worry much less about boundary-making with respect to other sexual services. By directly addressing the risks linked to the provision of sexual assistance, BodyUnity members develop ways to deal with the complexity of sexual services and to explore ‘what ethical ways of providing sexual services might look like’—as one of the BodyUnity sexual assistants I interviewed put it.

In the remainder of this article, I will first present the methodology used, before considering how BodyUnity members run their organisation, with respect to the activities and the

curriculum of training they propose. I will then show how they position themselves vis-a-vis mainstream sex workers but also, significantly, with respect to other people who play a determinant role in the (sexual) lives of people with disabilities, namely doctors, carers, and care givers. Paying particular attention to the rights of people with disabilities leads BodyUnity to develop an original view of sexual assistance, in opposition to what may be called the ‘therapy approach’, the ‘care approach’, and the ‘charity approach’ to sexual assistance. Their model foregrounds sexual pleasure and promotes in practice forms of self-regulation aimed at limiting the risks of sexual assistance, connected in particular to intimate violence, stigmatisation, sex normativity, and exploitation by third parties. In the final part, I show how, at the policy level, this approach interestingly resonates with the positions of the sex workers’ rights movement, supporting decriminalising integrative policies both in sexual assistance and in sex work more generally.

Methodology

The present article stems from a research project conducted between 2012 and 2015 on sex-related services for people with disabilities in Europe, whose main body of empirical material was a 2-year long ethnography with BodyUnity. BodyUnity are a grassroots organisation composed of about 20 members, led by sexual assistants, working with disabled activists, and their professional allies in order to build a safe space for sexual assistants to come together, train new sexual assistants, and provide ongoing training and peer supervision.

The opportunity to conduct this particular embedded participatory research with BodyUnity presented itself shortly after I started doing interviews with key informants in Italy and France in 2014. I heard that BodyUnity was launching a new training programme for sexual assistants in Switzerland. At that time, within the European context of this field of activism, Switzerland was considered a particularly active and experimental context, and four training courses were offered during the period of my fieldwork, in French and German speaking cantons, by four different organisations, in a country whose population is only eight million people. From the perspective of prostitution policies, BodyUnity is a particularly telling case because, while based in Switzerland, they see themselves as part of an international network of organisations, with people coming from Italy and France to join BodyUnity, a kind of organisation that would be semi-illegal in their own countries. Indeed, sexual assistance is still regulated by ordinary prostitution laws, which are however quite divergent: while in Switzerland, sex work is regulated through special laws that have introduced forms of legalisation, Italy and France adopt respectively an abolitionist and neo-abolitionist regime in which organisations such as

BodyUnity constantly run the risk of being criminalised as ‘exploiters’ or ‘facilitators’ (Wagenaar & Jahnsen, 2017). While BodyUnity is an organisation aiming to produce direct action rather than policy change, studying their ‘ethical’ practices could be useful in order to explore the public policies that may or may not facilitate these practices.

With these considerations in mind, I decided to apply to BodyUnity for positions as both researcher and trainee. The selection was quite complex, since it involved sending one’s CV and motivation letter, being interviewed, and participating in a weekend of group activities. In addition to the personal and relational skills that BodyUnity look for in any new candidate, in particular regarding disability and sexuality, the trainers were happy to have me as a participant researcher because—and they made this explicit—they believe in participatory research as a worthy research practice, and because I have a history of activist participatory research they could relate to, in the field of prostitution, feminism, and LGBT+ rights.

I believe that participant research, and in particular ethnography, or in other words embedded participant observation, is a particularly productive method in the study of activist organisations and social movements (Plows, 2008), for ‘the essence of this approach is to view events through the perspective of the people being studied’ (Bouma & Atkinson, 1995: 207), and because it allows participants to frame issues in their own terms. This is particularly relevant for a social sphere such as sexual services for people with disabilities, dominated by an ideology which positions both the sexuality of people with disabilities and sexual services as completely different from other forms of sex or labour, and that does not recognise sex providers or clients—even more so when they are disabled—as experts in their own experiences, whether negative or positive.

I was therefore able to participate in the BodyUnity training course, which consisted of 150 h of training over 18 months. In addition to my full participation, and taking notes during and after the numerous formal and informal meetings, I also conducted complementary semi-structured interviews with seven key informants from the movement, which included some of the members and trainers, and two of the most influential sexual assistants in Switzerland at the time.

In this research process, I have often occupied an uneasy and uncomfortable space, primarily as a researcher trained by the organisation I study, and as a researcher in the field of disability who does not identify as a person with disabilities. This kind of space challenges the insider/outsider division in ways that have attracted the attention of feminist scholarship (Stanley & Wise, 1990; Maxey, 1999; Gatenby & Humphries, 2000; Naples, 2003). My closeness to and entanglement with my object of study has certainly provided me with unique access to the (productive) contradictions of doing and receiving sexual assistance, and my practice as an activist means that I remain accountable to my activist friends and colleagues.

However, it has been an ongoing difficulty to become aware of the privileged position that, as an able-bodied researcher, I occupy in the field of sexuality and sexual services, as well as of the ways in which my research work at least partly responds to my need for self-accumulation as a professional academic (Stone & Priestley, 1997; Bournot-Trites & Belanger, 2005; Dewey & Zheng, 2013). For this reason, issues related to consent and the communication of research results have been central throughout the research process.

The issue of consent is very sensitive in the context of doing research with stigmatised groups, such as people with disabilities, sex providers, and their clients. Moreover, in participant observation, consent involves a process of gaining trust, giving back to the researched communities, and reminding people of the double role that the researcher occupies, as both a participant and a researcher (Gatenby & Humphries, 2000). In my case, all the members, the trainers, and the students of BodyUnity were aware of the fact that I was participating in the training also as a researcher. Any time we would meet a new person—sexual assistant, disabled activist, family member, lawyer, and so on—as part of the group activities, I introduced myself as a trainee and as a researcher. Everybody I met during the fieldwork with BodyUnity, including the people with disabilities who were contributing to the training programme, was able to fully understand and participate in the group conversations. To my knowledge, my ‘dual role’ did not provoke any particular resistance, only curiosity. Certainly, the fact that I was a very committed student helped, since the training involved a lot of intimate sharing about one’s life, body, and sexuality. Interestingly, the fact that on several occasions, I clarified that my research work would never include any personal details, or make people identifiable, was quickly made redundant in a context in which every participant had to commit to the highest protection of personal identities of all the others, and where the privacy and anonymity of sexual assistants and their clients, and anybody else involved, is a priority of the organisation.

For the semi-structured interviews I conducted, consent was obtained in standard ways as key informants agreed to the consent procedures that protected privacy and sensitive data. All interviewed participants agreed to being recorded, except one, and while I did not offer fee compensation, one sexual assistant asked for compensation for her time, which I was able to give.

I presented some of my preliminary research results to the group of trainees and trainers at the end of the training and am continuing to share via email with all members summaries of my publications on the topic of sexual assistance—usually I get some responses thanking me for sharing, and only rarely specific feedback. I currently remain in touch with the group, mostly via email, and I am still able to regularly meet one of the trainers and most active sexual assistants, as well as one of the speakers from the training programme, a woman who is also a regular client of BodyUnity sexual assistants.

The Organisation

In Switzerland, where sex work is recognised as a form of work, BodyUnity operates legally in its not-for-profit activities of peer training and peer supervision of sexual assistants, as well as its not-for-profit mediation between potential clients, their carers and institutions, and sexual assistants. However, legality does not imply that the state or other administrative bodies, such as Cantons, facilitate or support either BodyUnity or other initiatives around the provision of sexual assistance. In fact, at the time of research, BodyUnity was funding itself through membership fees only, was not seeking any external funding, and was particularly wary of seeking public funding. This position was grounded in the fear, quite widespread among the members, that this could create further forms of intrusion, control, and stigmatisation from the public authorities or other institutions in the sexual lives of people with disabilities, in particular that they might want to impose norms on what is a ‘good and just sexuality’, or who is suitable or not to offer a service or receive it. Another fear around depending on external funding that was mentioned by members was that it would somehow imply exposing the sexual assistants’ real identities. The anonymity of BodyUnity members is a priority for the organisation. Stigmatisation, discrimination, and violence are still problems in Switzerland, as evidenced by an episode of aggression reported to me by a member who exposed herself in the media as being a sexual assistant and was subsequently harassed at her residence. Having said this, many members consider themselves activists in the field of sexuality and disability, and some members of BodyUnity decide to engage in political and lobby work, especially raising awareness about practices of sexual assistance among the public, and more particularly people with disabilities, as well as their care givers and their carers, including residential institutions. A minority of them are also ‘out’ as practicing sexual assistants, although most only speak out as activists.

While the advantages in terms of organisational autonomy were clear to members, financial independence was also contested within the group for several reasons. Some members complained about the fact that everybody is a volunteer at BodyUnity—only the trainers were paid for some of their work. Importantly, no external funding also meant that training fees were significant, and entirely paid by the trainees, and this was noted by members as a clear barrier to access. In fact, some of the trainees had a hard time paying for the training, and motivated themselves by seeing it as an investment in their often precarious income generating activities. Sexual assistants, as well as trainees at BodyUnity, are women and men, mainly in their 40s and 50s, with work experience mostly in care and education jobs, art work, body work such as massage, but also in counselling, intellectual work, or NGO work. A minority also have past or current experience in the

mainstream sex industry. Interestingly, BodyUnity members are almost exclusively white European citizens, which is remarkable in countries in which the sex sector has a rather mixed labour force in terms of ethnicity and nationality (Tampep International Foundation, 2009; Andrijasevic, 2013). In terms of sexual identity, members identified as ‘weird in one way or another’—as one of the trainers put it—with respect to their sexual orientation, due to having disabled partners, or practicing BDSM, tantric sex, and so on. What is shared among the trainees and all BodyUnity members is a strong motivation to support disabled people’s rights. Most in fact have histories of direct intimate involvement with people with disabilities, either in their professional life or in their private and family life, with a minority actually having a disability themselves.

These specific characteristics and social belongings of the sexual assistants at BodyUnity are arguably reproduced not only in the training fees but also in the organisation of the training, in its publicity that was aimed mainly at reaching candidates among disability activists, and the selection of the candidate trainees. Additionally, in order to access the training, the candidates had to go through a long and complex process, including writing a motivation letter and a CV, as well as the sharing of one’s criminal record—apparently to check for sexual crimes. Moreover, candidates had to be over 30, and also had to have another source of income. As one of the trainers specified during an interview, following past disagreements, the group had made clear that the source of income could also consist of disability benefits or—to use an expression used by sexual assistant and sex worker Judith Aregger—of ‘ordinary’ sex work. I have already discussed in a previous article how BodyUnity members do not see these as potentially exclusionary criteria, but rather as elements within a process promoting consent and awareness formation (Garofalo Geymonat & Maciotti, 2016). While the issue of whiteness and nationality was not discussed by members at the time of research, I am aware that it is being challenged by some BodyUnity members at the time of writing, as is the issue of economic barriers to the training, which are identified as limiting access to workers of the sex industry.

BodyUnity is heavily involved in the training, through the selection process, as well as guiding the trainees during the training, offering recommendations and guidelines as to how to operate, and encouraging people not to use the word ‘sexual assistant’ until they have finished the training. However, once they successfully complete the training course, each BodyUnity assistant is essentially free to operate as they wish. This does not mean that BodyUnity disappears, but its role is that of a resource, rather than being organisational as such. An essential role is to continue sharing relevant information, including contact with potential clients, but also with other allied professionals, and to provide the space for assistants to meet up regularly to talk about their work, and to get support if

they have any problems related to their practicing of sexual assistance, in particular with clients or with their carers. In particular, BodyUnity appears to serve as some kind of ‘back-up’, or ‘protective belonging’, when interacting with families or residential institutions.

Having said this, members are not always able to meet up regularly, often find clients independently, and end up developing their own interpretation of sexual assistance that they may share with the group, creating new discussions and sometimes change in the recommendations and guidelines shared by the group. Therefore, the ways of operating that BodyUnity members adhere to need to be read more as informal recommendations and shared practices emerging from a community of specialised sex providers and activists, than as rules that are imposed by the organisation, as they may sometimes be misrepresented in the public debate. The creation of a community of sexual assistants and professional allies appears in fact to be one of the central goals of the training itself, which was very oriented to group processes. As one of the disabled activist trainers eloquently put it, the training is meant to be as much on ‘us, the Others’ as it is on the personal life of each of the trainees. Working on one’s motivations, one’s limits, one’s approach to intimacy, and sex was given priority throughout the training.

Importantly, the decision about whom to accept as a client, that in public debate often provokes anxiety about third party role and distinction from ‘ordinary’ sex work, is de facto left to individual sexual assistants. As a matter of fact, clients of BodyUnity’s sexual assistants, at the time of writing, are mostly men, but also include some women, with a variety of disabilities (including psychological and cognitive), living arrangements (including institutions), most straight but some gay or bisexual, all adults. Clients mostly need the help of others, their family members, or carers, in their everyday life, including—and this is crucial—for contacting and meeting their sexual assistants. Some also need the consent of their legal guardians in order to access and pay for sexual assistance. Experiences and knowledge of intimacy, sexuality, and the sexual body vary, with many clients gaining their first knowledge of erotic touch through encounters with their sexual assistants. Some assistants also work with elderly people, who have lived most of their life as non-disabled people.

Sex Workers or Sexual Assistants?

In public discourse, as well as in the academic literature, a lot of conversations in this field revolve around the question of whether sexual assistance is or is not prostitution or mainstream sex work. This worry may be based on various grounds, and interestingly cuts across different positions, both ‘pro’ and ‘against’ the development of sexual assistance. Those against sexual assistance usually are also against

prostitution and therefore tend to insist on the similarities between sexual assistance and mainstream prostitution, while many of those who are ‘pro’ stress the differences from prostitution, especially in order to legitimise it. In this respect, one might expect a group such as BodyUnity to be busy differentiating themselves, and what they do, from “ordinary” sex workers and sex work. However, interestingly, my findings indicate a different approach.

For the women and men practicing sexual assistance within or around BodyUnity, a multiplicity of identifications co-exists—although this does not come without moments of tension. Some of the sexual assistants at Body Unity identify strongly as sexual assistants only, and they could not imagine working with non-disabled clients, while a minority also call themselves sex workers. Some of the members are not so definite about this clear-cut division, and they adopt an extensive view of sexual assistance. Such an extensive view acknowledges that the reasons for a person needing their services might be due, at least partly, to disabling situations other than disability as usually conceived, typically being very old, but also being non-heterosexual in a homophobic environment, having a mastectomy, having been a victim of violence, and so on. The group often had conversations recognising that for a person to identify as ‘disabled’ is a complicated process, potentially involving stigmatisation, segregation, and oppression, and that the definition of who lies within the category ‘disabled’ is not neutral and instead needs to be politicised. In the collective discussions sometimes participants would bring up prostitution—mostly disabled activists who were sharing and reflecting on their experiences, both good and bad, as sex workers’ clients. In some of these conversations, stigmatisation of other forms of sexual services was present in participants’ discourses, especially ‘fast-food’ commercial sex. After all, organising a training programme, like BodyUnity does, means recognising that there is a need for something different from mainstream sex work, from both a providers’ and a clients’ perspective.

However, for BodyUnity members, producing a clear boundary between prostitution and sexual assistance was not a priority with respect to the ways they organise their training and their services, nor how they conceive of themselves. In fact, BodyUnity members appear to be busy with other kinds of boundary-making, vis-a-vis other categories of people who are very present in the (sexual) lives of people with disabilities—and whose roles are rarely discussed in the public debate or the research on sexual assistance: medical staff, care givers, and professional carers.

Against Therapy, Charity, and Care

The disability rights movement has at its core the critique of what is called the ‘medical model’ of disability, and activists and academics in this field have contributed to exposing the

ableism of material, discursive, and symbolic practices across societies (Abberley, 2002; Thomas, 2002; Oliver & Barnes, 2012). As part of the project of showing how disabling barriers are socially constructed rather than being organised by a person’s impairment itself, activists have, among other things, documented the concrete impact of medicalisation on the lives and bodies of disabled people, denouncing the abuses of power of health professionals and the negative effects this has on the bodily agency and integrity of disabled people. This line of critique was very present within BodyUnity, which fiercely opposes what could be called a ‘therapeutic model’ of sexual assistance, in other words a model that would see the sexuality of people with disabilities as a problem, and intervene via medical professionals. The concrete ways in which BodyUnity opposes a ‘therapeutic model’ became particularly clear to me when members discussed ‘sexual surrogacy’, a practice that is sometimes presented as the famous older cousin of sexual assistance, and that BodyUnity members became more familiar with thanks to the release of the 2012 movie *The Sessions* inspired by Marc O’Brien’s short story (O’Brien, 2003 [1990]). Sexual Partner Therapy (SPT) originated in the sexological practices of Masters and Johnson in the 1970s and is designed for anyone who has a sexual dysfunction (see IPSA www.surrogatetherapy.org). SPT is implemented as part of a treatment plan, led by a doctor or therapist who sets a clear goal and number of sessions, with the surrogate following their instructions and reporting to them about their meetings with the patient (Aloni, Keren, & Katz, 2007). Whenever it addresses people with disabilities, the concept tends to conflate disabilities in the sexual sphere with those in other spheres. For this reason, it was seen as highly problematic by BodyUnity members, who adopt the disabled activist slogan ‘my sexuality is not a disability’ and see the exclusion of disabled people from sexuality as rooted in social and political processes. In particular, they insist that these processes constitute them either as asexual, in need of protection, hypersexual, or monstrous and repulsive—as many disabled thinkers have shown (Shakespeare, Gillespie-Sells, & Davies, 1996; McCarthy, 1999; Milligan & Neufeldt 2001; Bonnie, 2004; Gerschick 2007; McReur & Mollow, 2012).

The intervention of a third party and the existence of a therapeutic plan were particularly criticised, for, in the approach developed by BodyUnity, the relationship with clients is, and should remain, personal, and personalised. According to the founding members of BodyUnity, the problem of interference from ‘experts’ was one of the main reasons for creating an organisation which would allocate central roles to those who can better understand questions of boundaries, intimacy, and consent, because they themselves have experience of sexual assistance—and that is why other kinds of members, including disabled activists,

therapists, and sexologists, have only limited decision-making authority within BodyUnity.

Along lines that are partly similar to the critique of medicalisation, disabled activists have contested care as a practice that is often disabling, for those who are cared for, including in terms of sexual agency (Fine & Glendinning 2005; Beckett, 2007; Bahner, 2015; McCarthy, 2016). Indeed, disabled people can end up profoundly disempowered, and culturally and psychologically damaged, through relationships of dependence with able people (Silvers, 1995; Shakespeare, 2000a; Galvin, 2004), in ways that may resemble colonial relationships (Campbell, 2008). Along the same lines, some disabled critics also see sexual assistance as a new frontier of ableist power, and a new care practice disqualifying disabled people as potential sexual partners and subjects who can give and receive sexual pleasure (Dufour & Thierry, 2014). Simultaneously, the actual need for support that disabled people may experience has led the disability movement to develop constructive critiques of caring practices. In many contexts, disabled activists have recommended that service provision is not organised according to expert care, as a result of which only a special category of people is allowed to interact with disabled people, in particularly isolating, hierarchical, and stigmatising ways (Kelly, 2015). Activists have also exposed the risks linked to an informal model of care provided by non-professionals, charity volunteers, or family members, whose care work often remains non-transparent, non-negotiable, non-accountable, and accompanied by a permanent sense of debt from the disabled person towards the carer, who may claim it back emotionally in abusive ways (Galvin, 2004; Kittay, Jennings, & Wasunna, 2005; Beckett, 2007).

These lines of critique were reflected in the conversations of BodyUnity members, who appeared to criticise both what can be called a ‘charity model’—by which I mean a view of sexual assistants as non-professionals offering disabled people sexual support based on goodwill—and what can be called a ‘care model’ of sexual assistance—by which I mean a view of sexual assistants as professionals offering disabled people sexual support according to ‘technical standards’, similar to what may happen with care workers helping out with a meal or personal hygiene. Indeed, the BodyUnity approach to sexual assistance was often discussed alongside condemnation of practices of ‘doing it for free’ or ‘saviour-like behaviours’ that care givers, family members, but also educators and nurses, do, at home or in residential settings, to ‘help out’ people with disabilities. Trainers, especially disabled activists, stressed how shame, abuse, symbiotic dependence, and incest proliferate in the sexual lives of people with disabilities, in the name of ‘helping them out’. Parents, nurses, and personal assistants in that sense were often identified as those who touch disabled bodies and control their sexual behaviour in ways that are seen as too distant, cold or desexualising, or else too close, confusing, non-negotiable, or ambivalent—and exposing all parties to abuse. At the same time, during conversations, trainers, and

older members often positioned sexual assistance as a form of intimate relationship, stressing that the relation clients and sexual assistants develop are inevitably complicated, and that there will be strong emotions on both sides, such as rage, jealousy, and love. Positioning sexual assistance as a form of intimate relationship, they would recommend that trainees remain aware of the responsibilities that they, as sexual assistants, can have in activating or reproducing these emotions, but that they treat and respect the client as their equal, and as an adult who has the right to take emotional risks, not as a person they ‘take care of’ and protect from pain or emotional mess.

For these reasons, it seems to me that BodyUnity sexual assistants occupy an uncomfortable position, struggling to position themselves as ‘experts’ or ‘professionals’—because they need to distance themselves from health or care professionals—and yet insisting on the importance of boundaries, contractuality, and accountability in their practice—always reminding each other of the risks of playing ‘saints’ or ‘saviours’.

Pleasure and its Opposites

Sexual assistants are men and women who, coming from a transparent and conscious motivation, have made it into their profession to give disabled people a direct support in living their sexuality. They create an opportunity for people with a mental and/or physical disability to have an erotic, sensual, sexual contact. They offer massage, body to body contact, touch, guidance on how to masturbate, they might bring people to an orgasm. Some will offer sexual intercourse and oral contact as well. They respect people with a disability as equals. (De Vries, 2013 - document to publicise a training event for sexual assistants)

Sexual assistance, as the term says, is something sexual. I cannot replace love. And of course they are people, like me and you, and like everybody, we look for love. But this, I cannot replace [...]

Pleasure is something rare in this life. People want to cure, they want to offer therapy, but me, instead, I would say that what sexual assistance is, it is a moment of pleasure. Pleasure, of course, may sometimes have therapeutical effects, certainly, but that is not the point. (Judith Aregger interview with author, Geneva 2015)

Nina de Vries and Judith Aregger are famous sexual assistants and trainers who have been particularly influential in the work of BodyUnity (Aregger, 2016). Remarkably, in these quotes,

they both refer to things that, as sexual assistants, they are *not* doing—such as for instance treating disabled people as unequal, having unclear motivations, giving non-professional support, offering therapy—all elements that, as I showed, can be traced back to a disability rights perspective, and to the necessity of carving out for themselves a space that is alternative to what I called the ‘therapy model’, the ‘charity model’, or the ‘care model’ of sexual assistance. The way that Nina de Vries and Judith Aregger, as well as sexual assistants at BodyUnity, carve out that space, is by mobilising images and a language that are linked to sex, sensuality, and sexual pleasure—discourse that is often missing in the field of sexuality and disability (Tepper, 2006).

Sexual and sensual pleasure was certainly a central and recurrent theme in the discourses and practices of BodyUnity, as well as in the training. Most group activities were bodily based sensual and sexual awareness exercises followed by group conversation. Trainees were invited to reconstruct and make sense of their sexual history, including positive and negative experiences, desires, fantasies, and experiments. Also, sexual assistants at BodyUnity gave themselves the space to talk about experiences of sensual and sexual pleasure with clients and about the dynamics of desire or lack of desire in the sessions. Pleasure and desire—both clients’ and their own—remained at the centre of many conversations, including those about the importance of what BodyUnity calls the ‘preliminary meeting’. This meeting—that BodyUnity sexual assistants adopt as a recommended practice—is a non-sexual first contact between potential client and potential assistant, which should ideally take place in person, be paid for, and whose goal is to make sure both sides are happy to start seeing each other, and that their basic visions and desires are compatible—‘can we imagine the possibility of pleasure being given and received?’ would be one of the underlying questions proposed to the trainees to guide them in the decision.

Interestingly, while pleasure and desire were often at the centre of conversations, these were never just discussed in simple ways, for instance as an easy expression of something like a need—even less as a realisation of something like a client’s right—or as a simple ‘liking or not liking’. Rather pleasure was seen as part of relationships, where issues of dependence, vulnerability, and power are often present—from the client’s side, but also from the side of sexual assistants—and sometimes involving ‘third parties’ such as family members from both sides, caregivers, and residential institutions, as well as organisers such as BodyUnity. These dynamics were openly discussed in the group, acknowledging that dependence, vulnerability, and power cannot be avoided completely, and they were addressed by members in pragmatic ways, and in particular through concrete elements of self-regulation, that were subject to collective contestations and change, but that, as I have discussed, covered both internal organisational practices and practices of sexual assistance.

This included organisational autonomy, the not-for-profit goal, the limited role of experts within the organisation, the selection of trainees, the preliminary meetings, and the personalised selection of clients. These ‘ethical’ practices may be seen as revolving around four recurrent worries which, as I have started to discuss elsewhere (Garofalo Geymonat & Maciotti, 2016), interestingly speak in creative ways to some of the most classic topics of the general sex workers’ rights field: intimate violence, stigmatisation, sex normativity, and intermediaries.

Intimate Violence

Members of BodyUnity tend to position sexual assistance as a form of intimate relation, recognising the particular psychological attachment and dependence that is established between client and sex provider, which includes possibilities of pleasure but also risks of abuse typical of intimate connections. In the context of sexual assistance—but often also other forms of sex services—people tend to feel strong and painful emotions such as adoration, frustration, guilt, and anger, and take on stereotyped roles of ‘victims’, ‘saviours’, and ‘villains’, potentially leading to intimate abuse (Karpman, 1968). Interestingly, during group conversations about actual situations of sexual assistance, many often contradictory aspects emerged that participants saw as being linked to the fact that when a disabled person and a sex provider meet both may tend to take on these roles, at least partially, because they both occupy stigmatised social positions—the ‘crip’ and the ‘whore’—and both may mobilise guilt and shame that may be projected onto others as aggression. However, at the same time, both of these stigmatised social positions tend to call for interventions from ‘saviours’ or ‘saints’, who may also end up feeling used and frustrated by the ‘victim’ they are trying to ‘save’ or ‘bless’.

Through reflections on sexual assistance BodyUnity members stress how to recognise these aspects as a starting point in finding ways to avoid suffering and possible violence, and in making interventions more professional and protective for all parties involved. They highlight, to this end, the importance of having a contract, actually an ongoing contractualisation process, involving clarity about payment/duration/space, and also clear conversations, with oneself and with the clients, about motivations and expectations, avoiding promises that might generate violent psychological games, such as the promise of experiencing sexual acts that might never happen, or the promise of love or friendship.

Stigmatisation

The second aspect that the work of BodyUnity brings to the fore is linked to the specific risks of stigmatisation, isolation, and burnout that providing sex services implies for the worker.

Some of these risks are institutional or legal discrimination, such as the risk of losing another job or losing custody of children, which are real risks for sex workers even where their services are not illegal. BodyUnity, in this respect, has a strict policy about the absolute importance of anonymity for all parties involved, even though it works to create a positive social image of sexual assistance. Moreover, stigma, isolation, and burnout also have an interactional and intrapsychic dimension to them—and disabled activists are particularly aware of that because of their own experience of stigmatisation. In this respect, the approach proposed by BodyUnity is that members are integrated into a collective of supportive peers, through regular meetings and peer supervisions, as well as being part of a network of other professionals and allies, in particular specialised educators, psychotherapists, massage therapists, and disabled activists. Also, trainees are invited and supported to be ‘out’ to their intimate partners.

Sex Normativity

Activists and sexual assistants at BodyUnity have a lot to say about how power is exercised in the sexual sphere on non-normative bodies—in line with recent disability studies thinkers (Gerschick, 2007; Shildrick, 2007; Siebers, 2012; Kafer, 2013). Sex is not therefore only discussed self-evidently as being about need and pleasure just waiting to be liberated, but also as a very power-laden sphere of life. In particular, disabled activists reminded trainees of how sex is a powerful tool for inclusion, but also for exclusion, and is an issue of identity, normativity, and social control—this is true for the client, and also for the worker, as they can become disciplinary and normative agents towards one another and themselves. Sexual assistants at BodyUnity explicitly contest this in their practice, by promoting a less normative and constraining vision of sex, less oriented to a linear process and homogenous results for all, and by training new members in an approach to sex that marginalises erection, penis penetration, and orgasm. Moreover, for this reason, BodyUnity recommends agreements with clients, or ‘contracts’, around time rather than results or sexual services—in fact, it strongly advises against agreeing on performing particular sexual services. What instead the ‘contract’ should include, according to BodyUnity members, is an agreement as to the payment per session, the duration of the session, and the meeting place. BodyUnity insisted on the importance of making sure that meetings occur in a place providing respect and privacy—which is often an issue in the lives of people with disabilities who live in spaces where people come and go at will (Fiduccia, 2000). Moreover, they recommend that each meeting last a minimum of 1 h, in order to allow for a certain intimacy to be reached—knowing that the rhythm of movement and preparation for a person with disabilities generally makes time feel different.

Intermediaries

The fourth aspect has to do with the role of third parties and ‘qualifications’ in sex services. Certainly, the creation of professional organisations and bodies of independent workers brings to the fore issues of exclusion for those workers who do not belong to an organisation—especially if we think that almost all members were white European citizens at the time of research—alongside other problems connected to standardisation in intimate services (Garofalo Geymonat & Maciotti, 2016). However, the approach proposed by BodyUnity points to the fact that having a third party behind the scenes may be useful especially in a sector as fragmented and informal as the sex service, that is moreover not recognised as legitimate work (Sanders, 2008; Cruz, 2013). Therefore, it is crucial, in BodyUnity’s approach, that this role of intermediary is not occupied by a for-profit, potentially exploitative third party, but instead that a self-organised, not-for-profit professional association is created, both to provide training and peer supervisions, but also to support interaction between sexual assistants and clients. In fact, while BodyUnity does not operate as an intermediary in a systematic way, certainly being a member of BodyUnity appears to create protection for the assistants, in terms of initial negotiation as well as in cases of conflict or problems. For instance, it allows individual sexual assistants to have a basic standard in the negotiation around duration and price, since there is a recommended price per hour (minimum 1 h) proposed by BodyUnity. This price has been collectively agreed upon as good value for the work, but simultaneously provides an accessible quality service for clients with disabilities. Moreover, the presence of an organisation works as a guarantee for people with disabilities, including women, who often feel particularly vulnerable, or those who have to negotiate their access to services with their caregivers or with residential institutions.

Policies and the Alliance with Sex Workers’ Rights Movements

Analysis of the concrete strategies through which BodyUnity addresses four of the central risks of sex services has illustrated what it may mean in practice to develop ‘ethical’ sex service practices through direct organisational services. Such a space of direct action, as we have pointed out, opens up the potential for an alliance between disabled rights perspectives and sex workers’ rights perspectives, and it does so by originally introducing a perspective of politicised (potential) clients in a field, that of commercial sex, where this is almost unheard of. Even though the interests of sex workers’ clients and workers diverge to a certain extent, political alliances between clients and workers may play a crucial role in this field, as they do in other forms of intimate labour—for the quality of

intimate services and the rights of workers often go hand in hand (Boris & Salazar Parreñas, 2010).

This potential alliance in sexual assistance becomes even clearer when one looks at BodyUnity's work from a policy perspective. As I already stressed, BodyUnity is not a classic activist group which has policy change as its main goal. However, it may be useful to examine the ways in which different policies may promote, or hinder, the collective practices that BodyUnity members put in place, and the views of disabled people's rights and sexual assistants' rights that they develop. It is worth looking at the policies regarding in particular sexual assistance, and at those regarding prostitution more generally.

With respect to policies specifically addressing sexual assistance, the work of BodyUnity warns us against those which would promote what I have called a 'therapy model', a 'charity model', or a 'care model' of sexual assistance. These models are exposed by BodyUnity members as furthering the stigmatisation of clients with disabilities but also of their sexual assistants, as well as potentially exposing them to abuse and exploitation. Such could be for instance the effect of policies that insert sexual assistance into the system of public health services, subjecting them to the control of public authorities and doctors, who would decide which sexual practices are allowed, create lists of subjects selected to operate as sexual assistants, and screen potential clients as 'real disabled people' in 'real need' of sexual assistance. In turn, this would restrict a central aspect of the 'pleasure model' that BodyUnity appears to support, which is the fact that all individuals involved—both clients with disabilities and sexual assistants—remain independent at any time in their decision to engage with any particular person, and in how they engage with them—in particular doing what, for how long, how much time, where, and for how much money. Examples of these restrictive regulations are contained in law proposals, such as, in Italy, Law Proposal 1442/2014, or in France the idea of creating an exception to the prostitution law—as publicly supported for instance in 2011 by MP Jean Francois Chossy. These proposals appear, at their core, to insist on the distinction between sexual assistance and prostitution, stressing that sexual assistants would only engage in masturbation and no other sexual contact, that they would be recruited from professions in the care sector, that they would not be paid directly by their clients, or that the number of sessions would be limited, following a 'therapy model'.

A clear-cut opposition to prostitution is not something that is reflected in the collective discourse of BodyUnity, for 'ordinary' sex work and sexual assistance are experienced as part of a continuum by several sexual assistants and their disabled clients. Instead, in the view of BodyUnity, the specificities of sexual assistance have to do with the creation of sustainable non-profit peer-led communities responsible for training and as intermediaries for potential disabled clients, their carers,

and institutions. The kinds of policies that would support this approach include those minimising intervention from public authorities or power attributed to 'experts', and instead focusing on allowing and supporting self-organised groups of sex providers with their activist allies—disabled activists and others—and their non-profit activities of intermediation, career development, training, peer supervision, and communication to the larger public about their activities and approach. The interaction between sex provider and client would be regulated by a contract between the two parties which would specify the 'frame', including duration, ethical approach, guarantee of the privacy of all, but not the specific contents of the service—in a way that is not dissimilar, for instance, from contracts within psychological counselling.

In turn, such an approach has important consequences in the field of prostitution policies, and this is where the alliance with sex workers' rights becomes more evident. Indeed, due to current laws on prostitution in most countries, all these developments in the field of 'ethical' sexual services for people with disabilities remain illegal. This is the case, not surprisingly, under so-called 'prohibitionist' laws—i.e., those that render all activities within the sex service exchange illegal—which are still prevalent worldwide, including for instance in most of the USA. However, policies supporting the BodyUnity approach also remain illegal in so-called 'abolitionist' regimes, where in principle, only exploiters are criminalised, such as for instance in Italy, Spain, the UK, or Denmark, as well as within 'neo-abolitionist' countries, i.e., those that have added to abolitionism the criminalisation of clients, such as in the case of Canada or Sweden. Any form of facilitation of and knowledge exchange about prostitution is prosecuted as 'pimping' in abolitionism and neo-abolitionism, and therefore organisations similar to BodyUnity operate at the edge of legality, even when they are activist projects careful to remain not for profit. Also, contracts between sex workers and clients are not legal, this being the case for France and Italy among many others. In addition to this, in France, following the introduction of client criminalisation (Law 444/2016), clients of sexual assistants are also deemed to have committed a crime.

BodyUnity members, who come from France and Italy in addition to Switzerland, are clear that the prostitution laws in Switzerland are crucial in allowing their organisation, and similar ones, to develop, and focus on their constructive mission, rather than avoiding or fighting against the law and public institutions, as they do in France or Italy. In fact, in Switzerland, prostitution is a tolerated activity based on economic freedom, with third party organising and soliciting decriminalised in 1992, although the 1942 Penal Code allows for Cantons to write their own specific regulations on sex work. The law frames sex work as a form of work, and sex workers are treated as workers,

in that they have to pay taxes and—at least in principle—enjoy some of the rights and protections associated with other forms of work, such as pensions and health insurance. Sex workers, and migrants even more so, are still subject to lasting forms of stigmatisation and discrimination, such as compulsory registration with the police in several cantons including Geneva and Zurich. Moreover, within a system that tends to promote intermediaries operating for profit, through complicated licencing, independent work may be discouraged. However, organisations protecting the rights of sex workers, which are grouped around the network *ProCoRe* (see <http://www.sexwork.ch>), have a significant public voice, and have been crucial both in improving and in criticising public policies (Bugnon, Chimienti, & Chiquet, 2009). In this sense, even though the country is still partially influenced by an understanding of commercial sex as a negative social phenomenon to be contained, Switzerland may be understood, along with, within Europe, Germany, and the Netherlands, as a case of rather ‘integrative’ prostitution policies when compared to Italian and French ‘restrictive’ and ‘repressive’ approaches. In Östergen’s policy classification (2017), integrative is an approach that tries to integrate the sector into societal, legal, and institutional frameworks in order to protect those selling sex from harm, and does so not through the use of criminal law, but aided by labour laws and other policy tools. This integrative approach in turn is based on an understanding that commercial sex ‘is a multifaceted phenomenon, consisting of a wide range of arrangements, relations and experiences, only some of which are directly harmful to women or socially unacceptable’ (Östergen, 2017: 10). The models which are more integrative, such as those of Switzerland, generally display a governance that is more collaborative compared to other policy regimes, and, as the BodyUnity case shows, they seem to allow for broader collective developments within communities of sex providers, as well as in collaboration with allied professionals and potential clients. For these reasons, sex workers’ rights organisations promote integrative policies in Europe and worldwide (ICRSE, 2016; NSWP, 2017), and together with sex workers’ rights oriented research (Scoular & Sanders, 2010; Pitcher, 2015), expose how the failure to recognise sex work as legitimate work, and to include sex providers in the public debate, has the effect of impeding the development of initiatives to improve their working conditions—as well as the quality of their intimate services.

Conclusion

The multiplication of initiatives promoting specialised sexual services for people with disabilities in Europe has raised concerns from disability rights and sex workers’

rights perspectives, and calls for more research. The present article has looked at the practices and approach developed by a grassroots group of sexual assistants and their allies, including disabled rights activists and clients, based in Switzerland, who offer training, peer supervision and non-profit intermediation with clients. During my 18 months of participant observations, I found that the reflections and practices these sexual assistants and activists develop, rooted in a disability rights perspective and a perspective of politicised (potential) clients, do not only concern sexual assistance but more broadly sex services. In this sense, this grassroots initiative invites us to look at sexual assistance and specialised sex workers for people with disabilities as an interesting space for alliance between disabled rights, as a uniquely politicised group of (potential) clients, and sex workers’ rights. This is an alliance which is also increasingly observed elsewhere, including in Canada (Fritsch, Heynen, Ross, & Van Der Meulen, 2016) and in Australia (Wotton, 2016).

Obviously, when looked at with respect to the complexity and extension of the contemporary sex industry, even just in Europe, the experience of BodyUnity may be thought of as a small experiment in a niche that is privileged in many ways, including in terms of policies on prostitution that do not criminalise providers, clients, associations of providers or support from third parties. Moreover, assistants involved in BodyUnity are all to some extent activists, white and European nationals, have intimate partners who support their engagement in sexual assistance, and have another source of income. The clients also have a supportive environment in their intimate life, and potential to pay for services. In other words, the particular modalities of this grassroots approach are largely not reproducible in other contexts within the contemporary European sex industry.

However, through their collective process of alliance crucially involving both politicised providers and politicised (potential) clients, BodyUnity produces original ways of looking at aspects that may be relevant to other sectors of the industry. While their model places at its centre sexual pleasure, it promotes in practice forms of self-regulation aimed at limiting the risks of sex services, connected in particular to intimate violence, stigmatisation, sex normativity, and the role of third party organisers—themes that are relevant to sex workers’ groups, and, at least in this context, also to their clients. Moreover, this approach to sexual assistance rooted in disabled rights, through opposing ‘therapy’, ‘charity’, and ‘care’ approaches, leads to a position close to the groups working for sex workers’ rights, for in practice, it can only be supported by decriminalising and integrative policies, not exclusively with respect to sexual assistance, but in the field of prostitution as a whole.

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