

8 Access to sexuality

Disabled people's experiences of multiple barriers

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My most important right is to be respected for the trans person I am. (...) My most important right is to decide over my own life.

(RFSL Stockholm, 2020: 21)

In the past few decades research as well as disability rights activism have shown the different kinds of problems that many disabled people experience when trying to express their sexuality (Shakespeare et al., 1996; Chappell & de Beer, 2019; Shuttleworth & Mona, 2021). The issues faced include being prevented from expressing one's sexual identity by family members or staff in group homes (Gill, 2015; Toft, Franklin & Langley, 2019), inadequate sexuality and relationships education (Löfgren-Mårtenson, 2011), or a lack of information in rehabilitation about how an injury may change the way one can have sex (Angel & Kroll, 2020).

The international scope of the research and activism highlights that the problems described are not individual, but are often shared across contexts as well as impairments. Disabled wheelchair users may experience physical inaccessibility, while lack of access to appropriate disability services can hinder a Deaf or a Blind person from accessing social gatherings or online dating communities. Prejudice about disabled people's perceived attractiveness or abilities in the sexual realm – compared to normative standards – are experiences shared by many, albeit with different connotations depending on the specific context. For instance, insecurity and low self-esteem can lead to barriers in exploring one's body and sexuality (Wiseman, 2014; Liddiard, 2018; Abbott et al., 2019).

Against this background, I will in this chapter¹ explore *sexual access*, namely the various barriers that disabled people face when trying to access opportunities for sexual expression (Shuttleworth & Mona, 2002).

Perspectives on sexual access

Access to sexuality must be understood within a general framework of disability experience. The shared experiences of barriers to sexual access can be attributed to widespread disability discrimination, i.e. *disablism* (Oliver, 1990),

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and societal structures that are not constructed accessibly and therefore hinder disabled people from leading full lives, i.e. *ableism* (Campbell, 2009). In other words, my perspective rests on a social model understanding of disability, meaning that disability is understood as something that people with impairments may experience in inaccessible environments and societies – and not as an inherent fact due to a bodily or mental feature (Oliver, 1990).

To this perspective I add necessary aspects of the political and relational nature of the experience of disability, namely how cultural imagery of disabled existence often impacts negatively upon disabled people's views of themselves and what life opportunities they can imagine (Kafer, 2013). In other words, impairment cannot easily be separated from disability; both are influenced by political and cultural views. Similarly, not everything is about inaccessibility or discrimination: some impairments entail, for example, chronic pain or fatigue, which can be negatively experienced by the individual even when they have access to medication, a supportive work environment or otherwise accessible surroundings (*ibid.*). While the medical model of disability one-sidedly emphasises disability as a problem of impairment requiring medical solutions, the social and relational–political models of disability further expand both the perceived problem and its solutions to the social and structural domains. My approach thereby rests on a *multifactorial understanding* of disability, which highlights the interaction between individual and structural factors (Shakespeare, 2013).

Taking a similar approach, anthropologist Russell Shuttleworth (2007) argues that *access* is often understood in a narrow and technical way, with focus on contexts such as schools, workplaces and the built environment – obscuring more complex, cultural and psychological domains such as sexuality. Although access to various physical environments also interferes with opportunities for sexual expression, unique aspects in relation to sexuality 'are the cultural meanings of sexual attractiveness and desirability, which often combine with other barriers to compound the problem of sexual access for disabled people' (Shuttleworth & Mona, 2002: pagination missing). Thus, in their pursuit for sexual expression and relationships, many disabled people face a combination of logistical and sociocultural factors (*cf.* Bahner, 2020).

These barriers to sexual access can be understood within a social hierarchy in which disabled people are marginalised and devalued compared to non-disabled people in general, and in the 'dating market' and 'sexual attraction hierarchy' in particular (Emens, 2009). Not least the psycho-emotional impact of living in an ableist and disabling society can demand special consideration, acknowledgement, peer support and specialist services in order for disabled people to access desired psychological, social and cultural contexts of sexual expression (Shuttleworth & Mona, 2002). While there are, of course, many disabled people who have been successful in realising their wishes in the sexual domain, this chapter focuses on issues described by those disabled people who struggle in various ways.

By analysing narratives about barriers that disabled people experience in different situations related to sexuality and relationships, I aim to illuminate the interaction between individual and structural factors. The chapter is based on an analysis of materials published between 2000 and 2020 dealing with sexuality and disability from disabled people's perspectives. These were produced by Swedish civil society organisations with the aim of educating disabled people about their sexual and reproductive rights. The projects were run by self-advocacy organisations, sexual rights organisations and organisations led by non-disabled people and working on behalf of disabled people. Materials from ten organisations' projects were collected, comprising books, handbooks, videos, websites and other online materials.²

Building on a qualitative content analysis (Altheide & Schneider, 2013), my approach combines a first-stage descriptive analysis of manifest content followed by a more interpretive analysis of latent content. Specifically, I started with categorising the materials according to project aims. This resulted in three themes: (1) information about sexuality and relationships, (2) sexual and gender identity, and (3) disability services. However, several projects have multiple foci. The themes corresponded directly with the organisation type responsible for the specific project. For instance, RFSL, a national association for Lesbian, Gay, Bisexual, Transgender, Queer and Intersex Rights conducted several projects about disabled people who identified as lesbian, gay, bisexual, transgender or queer (LGBTQ).

When analysing the materials further within each category, the main guiding question was: what kind of (sexual) accessibility problem is described? The following themes were categorised: (1) inadequate information, (2) psycho-emotional barriers, (3) relational barriers, (4) support-related barriers, and (5) policy barriers. From this analysis it became apparent that projects aimed at certain groups catered to those groups' particular needs, for instance, those targeting people with intellectual disability focused on issues around autonomy and self-determination in group homes, relationships with staff and family members, and the need for specialised sexuality and relationships education. Likewise, a project by an organisation representing persons with spinal cord injury focused on how to handle bodily changes following injury and offered tips on sex aids and toys, among other things.

In other words, the latent content analysis revealed that materials differed in terms of aims, scope, target group and so on. The results must therefore be interpreted with this in mind: they are based on different understandings of disability and the problems that are in focus, which relates to the kinds of organisations and the aims they had for the project. I will now analyse examples from the materials within each category.

Inadequate information

The background to a majority of the materials is an experience of inadequate sexuality and relationships education in special schools, which can be

understood against the fact that seven out of the ten projects targeted people with intellectual disability. Additionally, however, two projects by an organisation representing youth with mobility impairments were based on the notion that these young people had not received adequate sexuality and relationships education in relation to their specific lived experiences of disability. Inadequate sexuality and relationships education leads to a lack of knowledge about all things relating to sex, sexual identity and relationships. When, for instance, in the case of persons with intellectual disability, young adults and adults move to assisted living facilities or start working in assisted workplaces, they may be happy to meet new peers and potential sex partners – but often lack adequate resources to access information and support.

A project called *The right to live my life* was conducted by a cultural pedagogy association in the city of Uppsala in 2014–2017. The resulting report details the thoughts and experiences of participants with intellectual disability who use disability services. One of the participants, who was interviewed about experiences of barriers in their group home, said: ‘Many people need training about relationships, body language and boundaries – like when you get training about other things, like shopping or taking the bus’ (Kulturparken Uppsala, 2018: 17). Other participants in this project described their insecurity about whom to talk to about sex and relationships when not wanting to involve parents, and the lack of information in group homes about sex and relationships, including not knowing how to find information on the internet. For some this resulted in questions about practical things such as how to masturbate or use sex toys and aids, but also in a more profound lack of knowledge and understanding about personal integrity, boundaries and what constitutes sexual abuse. The project aimed to present alternatives for improvement in these settings, and many of the participants’ suggestions revolved around education for both service users and staff.

The *Sex in movement* project was conducted by the Swedish Youth Federation of Mobility Impaired, a self-advocacy organisation, together with a local branch of the Swedish Association for Sexuality Education (RFSU) in 2016–2019. It explored questions such as: What possibilities do I have to have sex? Which practices work? How can I give and receive pleasure? A number of short films were produced and uploaded on a dedicated website, which is still available.

The film *Something New* depicts two young men having sex in bed (RFSU Stockholm, 2019a). Simultaneously, we see a young woman pleasuring herself with various objects on different parts of her body. But while the young men express boredom both during and after sex, the young woman exhibits pleasure and excitement. In the following scene it turns out that one of the men is friends with the woman. She tells him what great sexual experience she had last night when her partner was away: ‘It feels like every time [I masturbate] I find new ways to explore my body. And it’s so cool with all the different sex toys that are available nowadays!’ The conversation inspires the man to start exploring new ways to have sex with his partner using an electric toothbrush,

olive oil and candles. The films were intended to be both educational and inspirational examples of ways to explore one's body and sexuality as a disabled young person, and fill an experienced lack of imagery and information for this particular group.

In 2006, an organisation of spinal cord injury survivors produced films and a handbook in the *Lame limbs and dry panties* project (RG, 2006). These films were also meant to inspire and educate by showing discussions among young adult and middle-aged women and men with spinal cord injury. One of the topics of discussion dealt with physical changes to the body following injury which necessitate new ways to have sex or to be intimate with a partner. A middle-aged man talked about the long process of getting to know his 'new' body, to build confidence and integrity, and to eventually find ways to have sexual pleasure. Masturbating, experimenting with aids and having open communication with one's partner were stressed. Other discussants also shared tips on bowel and bladder control and on sex aids that stimulate erection or vaginal sensation, as well as the need to mentally allow oneself to explore the body in new ways. These films have a somewhat more individual and medical focus, which is not surprising considering that the project was conducted in collaboration with a rehabilitation centre. Like the *Sex in movement* project, however, the films were intended to fill experienced gaps in information and support in a particular context.

Another example of peer support comes from the 2011 *KISS* project of the Swedish National Association for People with Intellectual Disability (FUB). This association is primarily run by parents of children, youth and adults with intellectual disability, as was the project. Youth and adults with intellectual disability were interviewed and asked to submit stories about their experiences around sexuality and relationships. The project resulted in a website and accompanying teacher's guide (Granér et al., 2009). One of the participants shared a story about parenthood:

One day a week we receive help from a support pedagogue. We got the contact through the habilitation services. We get help with planning and shopping. We also discuss a lot. [...] We have a good life and sometimes I'm surprised how well it has turned out for me. Planning and a good network are important. Don't be afraid of asking for help!

This and other examples on the website offer both a description of a problem but also possible solutions, showing that not everything about disabled people's sexuality is 'doom and gloom' but that there are also good examples. A difference with this material is that it also directed participants toward other sources of information and support, that is, not only within the community of disabled people but also professionals. This may be due to the fact that *KISS* was aimed at people with intellectual disability who may have greater need for help from professionals in accessing information and support, and that the material was produced by non-disabled people.

Psycho-emotional barriers

Multiple materials illuminate how disabling barriers and ableism in society can lead to emotional and mental health issues. For example, participants with intellectual disability in *The right to live my life* project introduced previously shared stories of having been bullied in their youth and how this resulted in a general sense of insecurity and low self-esteem and, with regards to sexuality, constant worries about what others would think about a disabled potential partner and about looking and acting ‘right’ (Kulturparken Uppsala, 2018). Insecurity and low self-esteem can also be risk factors for being abused or tricked when dating and socialising online, when there is a stronger desire to meet someone and be able to show others that one is ‘normal’ than to stay safe and thereby lose the opportunity to meet someone at all (cf. Hollomotz, 2011). As one of the participants explained: ‘Everybody wants love or friendship, sex or affirmation. You would rather have bad relationships than no relationships’ (Kulturparken Uppsala, 2018: 23). Examples like this shed light on the need to combine educational opportunities with empowerment and sometimes more individual therapeutic support, according to the project report.

Similar experiences were shared by persons with other types of disability experiences who identified as LGBTQ in *The disability project* of the Swedish Federation for Lesbian, Gay, Bisexual, Transgender, Queer and Intersex Rights (RFSL) in 2014–2017. The project report highlights a theme of psycho-emotional strain related to not being able to express one’s sexual identity in the disability community (RFSL Stockholm, 2013). Participants who were interviewed for the project reported that having to hide their sexual identity resulted in feelings of loneliness, lack of energy and difficulties meeting people. One person reflected:

I imagine that the intersection of being disabled and LGBTQ makes a person quite invisible everywhere. That I generally fall outside of some kind of gender matrix or desire because my body is not perceived as normal, and therefore I’m not read as lesbian or queer because I kind of don’t have a sexuality.

(ibid., p. 29)

This experience recurs in other materials, for example in the *Prejudice and pride* project by Forum Skill, a resource organisation which runs projects and activities with human rights as a starting point. This project focused on norms around love and sexuality and included an easy-to-read book with reflections by disabled and non-disabled persons on their identity, sexuality and family life, including queer, trans and various family formations. The project also released a short film, *Tessan=Victor* (Forum Skill, 2011), about a physically disabled trans man’s quest for recognition as disabled *and* trans. This followed Victor’s journey through the gender reassignment process with

its ups and downs, both mentally and practically, in relation to disability services and the health care system.

A more recent project by RFSL focused on similar issues but in relation to people with intellectual disability. The project resulted in three books based on stories told by persons with intellectual disability who identified as LGBTQ. These stories add another dimension to the problems described by Victor, namely that people with intellectual disability seem to have more difficulties making their voices heard and opinions believed compared to disabled persons without intellectual disability. One example dealt with not being allowed to decide one's own name even as an adult trans person, illuminating the paternalistic approach to persons with intellectual disability in general and those with LGBTQ identities in particular (RFSL Stockholm, 2018). In both the film about Victor and the books, the aim was to combine information about rights with offering role models for how rights can be asserted.

Another theme relating to psycho-emotional barriers concerns insecurity and low self-esteem and how these could raise barriers to exploring one's body and sexuality. In another project by Forum Skill, *This is how sex works*, the focus was on developing easy-to-read sexuality and relationships education materials in collaboration with people with intellectual disability. The resulting handbook is full of facts and images about the body, sexual identity and sex, and examples from disabled people's lives. One of the examples details a physically disabled man's insecurity about the willingness of personal assistants to provide support during masturbation or non-normative sexual activities such as threesomes and BDSM³: 'I can regret not [trying out different kinds of sex] earlier in life. Maybe I didn't want to earlier. Or was the wait due to me thinking about what my surroundings would say and think?' (Forum Skill, 2015: 103). Similar thoughts were described by a participant in another handbook published by the Swedish Federation of Youth with Mobility Impairments for the project *A secret known by many* which focused on sex, relationships and personal assistance (Svensk, 2011):

It can be difficult to like one's body when it doesn't obey or do as one wishes – it can influence one's charisma, and one's belief in oneself and one's ability to meet a partner or to have sex.

This example relates to issues around personal and bodily integrity in general, as well as integrity in relation to personal assistants specifically. Using the example of this participant's situation, the handbook discusses how to negotiate potential needs for assistance around sexual situations. It emphasises the importance of choosing assistants with whom one feels safe, and thinking through the type of help needed and discussing it with them beforehand. As such, this and the previous example about BDSM show how difficult it can be to be in a situation of dependence with disability service staff when one has a non-normative body and/or sexuality. Difficulties can arise both on a personal level, in terms of low self-esteem or insecurity about one's body in relation to societal ideals, as well as in relationships with others. This will be discussed further in the following section.

Relational barriers

Participants in the various projects shared their thoughts and experiences of social barriers in terms of self-presentation and relationships. A film with discussions among spinal cord injury survivors began with the questions ‘Who regards you as attractive?’ and ‘How do you meet someone?’ (RG, 2006). One of the women replied that it is important to be ‘clean and tidy’, to wear nice clothes, to look as ‘ordinary’ as possible, and to ‘use what you’ve got’, for instance your eyes. In short, to have confidence, flirt and use one’s charm. Other women talked about learning to accept one’s new body, to continue using makeup and to be outgoing. The male discussants agreed, one of the young men said that he sometimes even used his wheelchair to attract attention from women, but also acknowledged the need to look fresh and wear nice clothes. Another added that eating healthily and exercising is especially important when one is a wheelchair user. In other words, the potential social barriers with prejudice and breaking bodily norms were not discussed as social and normative barriers but were met with solutions that were ascribed to individual responsibility, illuminating a more medical approach to disability.

By contrast, another theme emerges in the materials focusing on issues among persons who identified as LGBTQ, namely prejudice about disability, including invisible impairments, and the ways in which this affects one’s opportunities at social events and in the dating scene. Many participants in various projects felt a need for peer support groups and arenas for disabled LGBTQ people, especially since there were common experiences of not feeling welcome or included in LGBTQ spaces due to inaccessible venues and/or lack of knowledge about disability. A project report by the LGBTQ rights organisation RFSL (2013) gives examples of participants who said that the lack of role models who are ‘both disabled and sexual’ led to insecurity in their identity as well as in navigating different communities. Some participants recounted having to compensate for their accessibility needs in order to be able to attend LGBTQ events, which took a lot of energy and resulted in impairment effects. At the same time there were experiences of not being able to express an LGBTQ identity in the disability movement due to its strong heteronormativity. One of the participants spoke of their lack of ‘erotic capital’ in the ‘dating market’, communicating a more structural view of disability:

I don’t think I’m that affected when having sex, but instead it’s my sexual capital, my erotic capital, my value is devaluated with my impairment. I mean, say what you want but aids are not sexy.

(*ibid.*: 23)

As such, the participants who identified as LGBTQ argued for a need to understand dating issues beyond the individual level, and pointed to the societal norms and value hierarchy around gender, the body and sexuality.

For participants with intellectual disability family members could become an added problem. Some spoke of barriers to expressing their sexuality to parents or other family members: ‘Parents decide if sex is allowed’ and ‘Parents can be overprotective and continue to view their adult children as children’ (Kulturparken Uppsala, 2018: 16). The latter can include issues with parents acting as limited guardians and restricting how the individual uses their money (limited guardians are appointed according to the LSS law⁴ to support decision-making). This relationship with parents is not wholly negative; many rely on them for necessary support, both social and practical. However, participants also reported feelings of involuntary dependency on parents’ help in daily life with things that were not covered by formal support systems, making desired levels of independence more difficult to achieve. For LGBTQ participants with intellectual disability these issues could become even more complicated, for instance when deciding if and how to come out:

I didn’t want to have a bad relationship with my family. ... I didn’t want to risk that my family would disappear. ... I was afraid to hear: We don’t want to see you ever again. Afraid that the family would ostracise me.
(RFSL Stockholm, 2019: 13)

This example illustrates the complex relationship between the sometimes-necessary informal support and societal norms. In other words, while there are generally expectations on young adults to start preparing for a more independent lifestyle, with less influence from parents, those with intellectual disability often face a different situation. The type of impairment can therefore also be a factor in sexual access. The next section will dig deeper into the formal support structure.

Support-related barriers

For persons with intellectual disability who rely on professional support to exercise their independence, things can become difficult when staff reluctance and organisational boundaries hinder sexual access. This is discussed at length in the report by the *The right to live my life* project. For example, some of the participants with intellectual disability said that staff lacked education on how to talk about sex and relationships, that staff acted unprofessionally (based on their own values rather than on knowledge), that there was a lack of staff of the same gender with whom they felt comfortable talking, and that there were many new staff with whom they didn’t feel comfortable talking about sex. As one participant said, ‘When they ask about what support you need they should also ask about relationships, boundaries and sexuality’ (Kulturparken Uppsala, 2018: 17).

The report also gives examples of organisational routines or decisions by individual staff that hindered residents’ sexual expression, including lack of privacy or inadequate routines for ensuring privacy, staff deciding that sex

was not allowed in group homes, that sleepovers were not allowed due to organisational routines or fire safety, or that staff were not willing to assist with and around sex due to insecurity around legal or other regulatory frameworks. Furthermore, there were problems with accessing support around social activities where one would potentially meet sexual partners, for example when such support was only available during office hours due to staff scheduling or there were not enough staff to help with attending events. Some participants felt that they did not have any influence on decisions about activities (*ibid.*).

Similar experiences were recounted in one of the other projects by an interviewee who was a physically disabled male user of personal assistance:

It turned out that her assistants had said that they would resign if we had sex. I don't know why they said that. It was only one assistant who wanted to help us. But they only worked one night every other week. Talk about scheduling one's sex life....

(Forum Skill, 2015: 96)

A comparable scenario plays out in a film produced by the self-advocacy organisation Grunden. Their project, *We breathe the same air: about gender equality in LSS and SoL*, specifically targeted persons with intellectual disability who receive support through the Social Services Act (SoL) and the Support and Services to Certain Persons with Functional Disabilities Act (LSS). The project aimed at supporting individuals in understanding and securing their rights to be treated fairly in issues to do with relationships, parenthood, and choosing activities and work placement outside of the traditional gender norms. In five films and a handbook, different scenarios exemplify difficulties that can arise. The film *Anna & Linnéa* tells the story of how a lesbian couple are hindered from spending time together in Linnéa's group home due to a previously set time for washing hair (Grunden, 2012a). The staff member says: 'If you can't keep your routines when Anna is here, then Anna needs to go home'. Linnéa argues for her position, to which the staff member replies that if so, they may have to make a note in her file about this situation. Linnéa gets upset and takes Anna to her room, where Anna tries to calm her as they lie together on the bed. Soon, a staff member enters the room and Linnéa exclaims: 'What are you doing? You're supposed to knock!' The staff member explains that they are just trying to do their job.

The film *Alone* from the project *Sex in movement* which focused on youth with mobility impairments, shows a more positive narrative (RFSU Stockholm, 2019b). It starts with a young man who, after a few tries, is finally content with how his assistant styles his hair. In the next scene he is sitting on the couch with his boyfriend and says 'closer', prompting the assistant to help him move closer. He then signals through eye contact to the assistant to leave the room, and the two young men start to kiss and cuddle. Suddenly, the assistant comes in with a glass of water – clearly interrupting. Although this

situation is uncomfortable, the young men continue to cuddle and enjoy themselves after the assistant has left. In both this and the previously discussed film, a key message is that disabled service users have a right to privacy and to relationships, and that staff should not be obstacles to this.

An older project directed at young personal assistance users with mobility impairment, *A secret known by many*, emphasises the need for courage and strong self-esteem as important for standing up for oneself and demanding one's rights. To illustrate some of these points it tells the story of 'Stefan' who uses personal assistance around the clock. He says that he wants his relationship with his assistants to be social and informal, and that he discusses everything with them, including sex, love and relationships (Svensk, 2011: 33). Dating is also discussed and not least how to manage assistance during intimate moments. Talking about such issues beforehand is recommended. Similarly, the handbook discusses how to manage assistance whilst cohabiting with a partner. Various opportunities for employing partners or family members as assistants are discussed in relation to independence and their influence on the romantic relationship: 'The partner can help out during the night so that the couple can avoid having an assistant in the bedroom and ensure privacy' (ibid.: 46, 49). This example gives a somewhat different idea of how to manage potential support-related barriers, namely to develop self-esteem, demand a certain type of service relationship – or simply arrange support within other relationships.

The examples in this section are intended to show how reliance on staff can put service users in a position of dependency, and that their sexual opportunities may be circumscribed by negative attitudes, lack of knowledge or organisational boundaries. This hinders sexual access which may be further compounded when organisations are not willing to allocate adequate resources for educating staff or hiring more staff. However, the more positive examples can also be read as wishful thinking by the projects or individual participants and as describing how things should be rather than as examples of how disabled service users experience such situations in general. On the other hand, the choice to give such examples is also understandable as they offer positive role models to individuals who may feel isolated with their thoughts and insecurities – indeed, this was one of the explicit aims of some of the projects.

Policy barriers

Some of the access barriers that informants in the various materials discuss relate to (lack of) support at a societal level, and the way that the construction of services and their implementation pose barriers to living independently in general and for sexuality and relationships in particular. A blog post in the project aimed at young personal assistance users with mobility impairment details the experiences of the special transport system under the rubric 'A barrier to love?' (Förbundet Unga Rörelsehindrade, 2012). The author, who

uses a power chair, describes various problems that arise when she travels with her husband, who is also a power chair user: there is not enough space for two chairs on special transport or trains, which makes travel more expensive and impractical, and they do not have enough assistance hours to cover the extra time needed for longer travels (see also Vanessa Stjernborg's chapter and Kristofer Hansson's chapter in this book). Overcoming these problems would mean 'feeling normal' and 'being able to live a life like others'. The example illustrates how social policy impacts on service users' possibilities for sexual access – but also how it influences their feelings of self-worth and being seen as a 'normal' citizen.

Another issue concerns the economic situation, which was highlighted by interviewees in *The right to live my life* project. Participants who live in group homes or similar supported accommodation reported high living costs in relation to their incomes, leading to difficulties attending social events with a financial cost, including visits to coffee shops, pubs and the cinema – all popular dating activities (Kulturparken Uppsala, 2018). Participants, primarily those with intellectual disability, also spoke of a lack of meeting places (online and offline) where they felt safe and welcome.

Other issues detailed in this project concerned couples in which one or both live in special accommodations, and who experience a range of issues: finding accessible housing, difficulty when meeting someone belonging to another municipality with different policies, issues with secrecy regulations in relation to sharing information about support needs, and a risk of losing assistance following marriage (Kulturparken Uppsala, 2019). The lack of regulation of limited guardianship, especially when family members act as informal guardians, can also pose obstacles to couples whose family members do not approve of the relationship for some reason (*ibid.*).

As mentioned earlier, the *We breathe the same air* project dealt with issues relating to disability services and the ways in which different laws and policies influence the daily lives of people with intellectual disability. One of the examples in the project handbook concerns a situation where the Public Health Agency declined an application for adoption by disabled parents on the grounds that personal assistance services may impact negatively upon parenting abilities and the mother–child connection (Grunden, 2012b). Although it is not possible to know the extent to which this problem occurs generally, the project's examples were all based on participants' experiences. The example does not give enough background information on the details behind the agency's decision, and it is therefore difficult to interpret its meaning. However, the point that Grunden makes is that everybody should have the same opportunities for fair and equal treatment in applications for support, and that decisions should not be based on prejudice about disabled persons' parenting abilities.

The examples in this section show how the lack of a policy on sexual rights for disabled people exacerbates many of the problems discussed: when no one is responsible for ensuring sexual access, it is easily left aside by otherwise

busy and often underfunded service organisations. If sexual access is not recognised as a legitimate issue, opposition towards it can more easily continue. The projects' materials therefore have a strongly educational slant, informing about disabled people's rights in order for individuals to be able to counter barriers, but also giving examples of how we can work together to achieve change on individual, organisational and structural levels.

Conclusion: the struggle for sexual access

This chapter has analysed various types of materials from ten projects dealing with sexuality and disability from disabled people's perspectives. The following themes were categorised: inadequate information; psycho-emotional barriers; relational barriers; support-related barriers; and policy barriers. The analytical framework of the social and the political-relational models of disability, in combination with the concept of sexual access, has shown that multiple aspects shape the totality of sexual inaccessibility for people regardless of impairment type. The complex relationship between the personal, social, cultural and policy levels – and the ways these intersect – greatly impacts on disabled people's opportunities in their sexual lives, including psycho-emotionally.

Mirroring general power hierarchies in society to do with gender, racism, heterosexism and ageism, it is evident that, in certain respects, some groups of disabled people fare worse than others. A majority, seven projects, were aimed at people with intellectual disability. The need for information about the body, sexual expression, sexual identity, as well as support with communication and accessing spaces for dating and socialisation, indicates a widespread lack of adequate sexuality and relationships education and inclusion in mainstream society (Löfgren-Mårtenson, 2011; Lukkerz, 2014; Gill, 2015). Many participants' experiences reveal attitudes and practices of paternalism based on a view of intellectual disability as incompatible with adulthood (Lövgren, 2013) and especially for persons with intellectual disability who identified as LGBTQ (Toft et al., 2019). The materials give several examples about feeling pressure to be bold and forward in order to be seen as an adult, resulting instead in even more insecurity. This insecurity and low self-esteem can also lead to barriers in exploring the body and sexuality (Wiseman, 2014; Lid-diard, 2018; Bahner, 2018, 2020).

There are also major issues concerning lack of knowledge among staff about sexual rights, and organisational aspects that lead to limitations on privacy and relationships. Here, issues related to gender and sexual identity are also evident (Vehmas, 2019; Björnsdóttir et al., 2017). These obstacles necessitate careful analysis within the specific contexts of the types of opposition that individuals face when demanding sexual access. But, as some projects suggest, individual education and empowerment may not be sufficient when organisational structures allow staff to circumscribe freedom and rights – illuminating the structural nature of ableism and disablism.

Furthermore, sexual access is also a question of access to necessary and desired support at the policy level. When a disabled person is reliant on a segregated system of housing, transport, education and work, their economic and social situation is undoubtedly negatively influenced, and thereby their feeling of being part of society: of being a full citizen (Pettersson, 2015; FUB, 2020; S epulchre, 2020).

Kafer's (2013) notion of the relational–political here comes to the fore again: it is difficult to separate impairment from disability; they are intertwined and both are influenced by culture. Furthermore, Shakespeare's (2013) multifactorial model of disability shows that when citizens are categorised based on impairment, they are disabled by inaccessibility in various situations, as well as psycho-emotionally by prejudice. Lived experiences vary depending on type of disability or access needs, but the common denominator is the need for careful contextual analysis. Adding the perspective of sexuality to this complexity necessitates an understanding of sexual access as highly influenced by what surrounds it (Shuttleworth & Mona, 2002). The fight against sexual inaccessibility therefore entails a fight against general inaccessibility – and vice versa (Karlsson, 2020).

When analysing sexual access barriers – perhaps the most intimate in a person's life – it is therefore necessary to consider solutions from multiple perspectives, including societal, organisational and cultural. Opposition to a more accessible society thus impacts upon disabled people's opportunities to realise their sexual rights – and in a broader sense, disabled people's rights to citizenship, independence and to autonomous lives.

Notes

- 1 The chapter is based on research carried out within the project *Sexuality – an access issue*. It was funded by FORTE: *Swedish Research Council for Health, Working Life and Welfare* (dnr 2018–01830) and ethically approved (dnr 2019–05817).
- 2 The projects included are: (1) *Lame limbs and dry panties* (2004–2006) by RG Active Rehabilitation, focusing on spinal cord injury rehabilitation, (2) *Prejudice and pride* (2008–2011) by Forum Skill, about sexual identity and norms and aimed at people with intellectual disability, (3) *A secret known by many* (2009–2012) by the Swedish Youth Federation of Mobility Impaired, about sexuality and personal assistance services (4) *We breathe the same air* (2009–2012) by Grunden, a self-advocacy organisation aimed at people with intellectual disability, about gender equality in disability services (5) *KISS – About the body, feelings and sexuality* (2011), sex education materials by FUB – The Swedish National Association for People with Intellectual Disability, (6) *This is how sex works* (2012–2015) by Forum Skill, sex education materials developed in collaboration with people with intellectual disability, (7) *The right to live my life* (2014–2017) by Kulturparken Uppsala (a culture pedagogy association), aimed at policy development for people with intellectual disability in group homes or day centres, (8) *The disability project* (2014–2017) by RFSL and RFSL Stockholm (the Swedish Federation for Lesbian, Gay, Bisexual, Transgender, Queer and Intersex Rights), aimed at disabled LGBTQ people, disability rights organisations and disability services organisations (9) *Sex in movement* (2016–2019) by RFSU Stockholm and the Swedish Youth Federation of

- Mobility Impaired, focusing on sex education and cultural representation, and (10) *I am the storyteller* (2017–2020) by RFSL Stockholm, a narrative storytelling project with LGBTQ people with intellectual disability.
- 3 BDSM is an acronym for bondage and discipline, domination and submission, sadism and masochism: a variety of often erotic practices or roleplaying and fetishes.
 - 4 The Act concerning Support and Service to Persons with Certain Functional Disabilities.

References

- Abbott, David, Carpenter, John, Gibson, Barbara E., Hastie, Jon, Jepson, Marcus & Smith, Brett (2019) Disabled Men with Muscular Dystrophy Negotiate Gender. *Disability & Society*, 34 (5): 683–703. doi:10.1080/09687599.2019.1584093.
- Altheide, David L. & Schneider, Christopher J. (2013) *Qualitative Media Analysis*. Second ed. Los Angeles: Sage.
- Angel, Sanne & Kroll, Thilo (2020) Sex Life During the First 10 Years After Spinal Cord Injury: A Qualitative Exploration. *Sexuality and Disability*, 38 (1): 107–121. doi:10.1007/s11195-020-09620-9.
- Bahner, Julia (2018) Crippling Sex Education: Lessons Learned From a Programme Aimed at Young People with Mobility Impairments. *Sex Education*, 18 (6): 640–654. doi:10.1080/14681811.2018.1456417.
- Bahner, Julia (2020) *Sexual Citizenship and Disability: Understanding Sexual Support in Policy, Practice and Theory*. London & New York: Routledge.
- Björnsdóttir, Kristín, Stefánsdóttir, Ástríður & Stefánsdóttir, Guðrún Valgerður (2017) People with Intellectual Disabilities Negotiate Autonomy, Gender and Sexuality. *Sexuality and Disability*, 35 (3): 295–311. doi:10.1007/s11195-017-9492-x.
- Campbell, Fiona A. Kumari (2009) *Contours of Ableism. The Production of Disability and Abledness*. Basingstoke: Palgrave Macmillan.
- Chappell, Paul & De Beer, Marlene (eds) (2019) *Diverse Voices of Disabled Sexualities in the Global South*. Cham, Switzerland: Palgrave Macmillan.
- Emens, Elizabeth F. (2009) Intimate Discrimination: The State's Role in the Accidents of Sex and Love. *Harvard Law Review*, 122: 1307–1314. doi:10.2139/ssrn.1694174.
- Forum Skill (2011) *Tessan = Viktor*. Film directed by Forum Skill.
- Forum Skill (2015) *Sex för alla* [Sex for everyone], Göteborg: Forum Skill.
- FUB (2020) *Fångad i fattigdom? Inkomster och utgifter för vuxna med intellektuell funktionsnedsättning* [Caught in poverty? Income and costs of adults with intellectual disability]. Solna: Riksförbundet FUB.
- Förbundet Unga Rörelsehindrade (2012) Blog post: Färdtjänst – ett hinder för kärleken? [Special transport – a barrier to love?]. *En hemlighet känd av många* [A secret known by many] [Online]. <http://enhemlighet.se/2012/08/fardtjanst-ett-hinder-for-karleken/> (accessed on 18 January 2021).
- Gill, Michael (2015) *Already Doing It: Intellectual Disability and Sexual Agency*, Minneapolis: University of Minnesota Press.
- Granér, Lotta, Lundén-Weldén, Åse, Myrberg, Tomas & Åhlund, Irene (2009) *Puss – Om kroppen, känslor och sexualitet* [Kiss – About the body, feelings and sexuality]. Stockholm: ALA – FUB:s forskningsstiftelse.
- Grunden (2012a) *Anna & Linnéa*. Film directed by Föreningen Grunden.
- Grunden (2012b) *Vi andas samma luft: om jämställdhet inom LSS och SoL* [We breathe the same air: about gender equality in LSS and SoL]. Göteborg: Föreningen Grunden.

- Hollomotz, Andrea (2011) *Learning Difficulties and Sexual Vulnerability: A Social Approach*. London: Jessica Kingsley Publishers.
- Kafer, Alison (2013) *Feminist, Queer, Crip*. Bloomington: Indiana University Press.
- Karlsson, Mikael Mery (2020) 'Gå eller rulla – alla vill knulla'. *Funktionsrättsaktivism i nyliberala landskap* ['Walking or rolling – Everybody wants to fuck!'. Disability rights activism in neoliberal landscapes]. Lund: Arkiv.
- Kulturparken Uppsala (2018) *Jag har lust! Rapport med deltagarnas röster ur 'Rätten att leva mitt liv'* [I have lust! Report with participants' voices from 'The right to live my life']. Uppsala: Kulturparken Uppsala.
- Kulturparken Uppsala (2019) *Relationer som funkar* [Relationships that work]. Uppsala: Kulturparken Uppsala.
- Liddiard, Kirsty (2018) *The Intimate Lives of Disabled People*, Abingdon, Oxon; New York, NY: Routledge.
- Lukkerz, Jack (2014) 'En tom arena'. *Gymnasiesärskole- och habiliteringspersonals perspektiv på sex- och samlevnadsundervisning* ['An empty arena'. Special upper secondary school- and habilitation personnel's perspectives on sex and relationship education]. Licentiate Thesis, Malmö University.
- Löfgren-Mårtenson, Lotta (2011) 'I Want to Do it Right!' A Pilot Study of Swedish Sex Education and Young People with Intellectual Disabilities. *Sexuality and Disability*, 30 (2): 209–225. doi:10.1007/s11195-011-9239-z.
- Lövgren, Veronica (2013) *Villkorat vuxenskap: Levd erfarenhet av intellektuellt funktionshinder, kön och ålder* [Conditioned adulthood: Lived experience of intellectual disability, gender and age]. PhD thesis, Umeå University.
- Oliver, Mike (1990) *The Politics of Disablement*. London: Macmillan.
- Pettersson, Andreas (2015) *Out and About in the Welfare State – the Right to Transport in Everyday Life for People with Disabilities in Swedish, Danish and Norwegian Law*. PhD thesis, Umeå University.
- RFSL Stockholm (2013) 'Och aldrig mötas de två' – *En förstudie om hbtq-personer med erfarenheter av funktionsnedsättningar* ['And the two never meet' – A pilot study about disabled lgbtq persons]. Stockholm: RFSL.
- RFSL Stockholm (2018) *Min verklighet* [My reality]. Stockholm: RFSL Stockholm.
- RFSL Stockholm (2019) *Min stolthet* [My pride]. Stockholm: RFSL Stockholm.
- RFSL Stockholm (2020) *Min makt* [My power]. Stockholm: RFSL Stockholm.
- RFSU Stockholm (2019a) *Någonting nytt* [Something new]. Film directed by RFSU Stockholm & Förbundet Unga Rörelsehindrade.
- RFSU Stockholm (2019b) *Ensamma* [Alone]. Film directed by RFSU Stockholm & Förbundet Unga Rörelsehindrade.
- RG (2006) *Grupp 6* [Group 6]. Film directed by RG Aktiv Rehabilitering.
- Sépulchre, Marie (2020) *Disability and Citizenship Studies*. London & New York: Routledge.
- Shakespeare, Tom (2013) *Disability Rights and Wrongs Revisited*. Hoboken: Taylor and Francis.
- Shakespeare, Tom, Gillespie-Sells, Kath & Davies, Dominic (1996) *The Sexual Politics of Disability: Untold Desires*. London: Cassell.
- Shuttleworth, Russell (2007) Disability and Sexuality: Toward a Constructionist Focus on Access and the Inclusion of Disabled People in the Sexual Rights Movement. In: Teunis, Niels & Herdt, Gilbert H. (eds), *Sexual Inequalities and Social Justice*. Berkeley and Los Angeles, CA: University of California Press.

- Shuttleworth, Russell & Mona, Linda R. (2002) Disability and Sexuality: Toward a Focus on Sexual Access. *Disability Studies Quarterly*, 22 (4): pagination missing.
- Shuttleworth, Russel & Mona, Linda R. (eds) (2021) *The Routledge Handbook of Disability and Sexuality*. London & New York: Routledge.
- Svensk, Veronica (2011) *Hemligheter kända av många – En metod och handbok för dig som har personlig assistans* [Secrets known by many. A method and handbook for you who have personal assistance]. Farsta: Förbundet Unga Rörelsehindrade.
- Toft, Alex, Franklin, Anita & Langley, Emma (2019) 'You're not sure that you are gay yet': The Perpetuation of the 'Phase' in the Lives of Young Disabled LGBT+ People. *Sexualities*, 23 (4): 516–529. doi:10.1177/1363460719842135.
- Vehmas, Simo (2019) Persons with Profound Intellectual Disability and Their Right to Sex. *Disability & Society*, 34 (4): 519–539. doi:10.1080/09687599.2018.1545110.
- Wiseman, Phillippa (2014) *Reconciling the 'Private' and 'Public': Disabled Young People's Experiences of Everyday Embodied Citizenship*. PhD thesis, University of Glasgow.