

This is a repository copy of *Cripping sex education: lessons learned from a programme aimed at young people with mobility impairments*.

White Rose Research Online URL for this paper: http://eprints.whiterose.ac.uk/129086/

Version: Accepted Version

## **Article:**

Bahner, J orcid.org/0000-0001-8526-3659 (2018) Cripping sex education: lessons learned from a programme aimed at young people with mobility impairments. Sex Education, 18 (6). pp. 650-654. ISSN 1468-1811

https://doi.org/10.1080/14681811.2018.1456417

© 2018 Informa UK Limited, trading as Taylor & Francis Group. This is an Accepted Manuscript of an article published by Taylor & Francis in Sex Education on 30th March 2018, available online: http://www.tandfonline.com/10.1080/14681811.2018.1456417.

### Reuse

Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

### **Takedown**

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



Cripping sex education: lessons learned from a programme aimed at youth with m	obility
impairments	

Julia Bahner

Department of Social Work, University of Gothenburg, Sweden<sup>1</sup>

<u>j.bahner@leeds.ac.uk</u>

 $^{1}$  Current affiliation: Centre for Disability Studies, School of Sociology and Social Policy, University of Leeds, UK.

### **ABSTRACT**

This paper analyses sexuality and relationship education (SRE) in a Swedish college programme aimed at youth with mobility impairments. Interviews and focus groups were conducted to explore students' experiences of the structure, content and usefulness of SRE, and college personnel's SRE practices. Results show that, although many of the issues covered are pertinent for all youth, being disabled raises additional concerns: for example how to handle de-sexualising attitudes, possible sexual practices, and how reliance on assistance impacts upon privacy. Crip theory is used as an analytical framework to identify, challenge and politicise sexual norms and practices. Students' experiences of living in a disablist, heteronormative society can be used as resources to develop cripistemologies, which challenge the private/public binary that often de-legitimises learners' experiences and separates them from teachers' 'proper' knowledge production. Crip SRE would likely hold benefits for nondisabled pupils as well, through its use of more inclusive pedagogy and in work to expand sexual possibilities. Crip SRE has the potential to disrupt taken-for-granted dis/ability and sexuality divides as well as to politicise issues that many young people presently experience as 'personal shortcomings'.

### **KEYWORDS**

Sexuality; disability; young disabled people; crip theory; special education; Sweden

## Sexuality and youth with mobility impairment

Young adulthood is an important time for developing identity, social relations and sexuality. For young people with mobility impairments, this socio-sexual development can be constrained by physical inaccessibility, judgemental attitudes and inaccessible sexuality and relationship education (SRE). Therefore, in addition to requiring basic SRE like all young people, customised education in relation to disability experiences is needed. This is especially important since young disabled people are often excluded from 'the hidden curriculum' (Gougeon 2009) – or the unsupervised time with peers when most non-disabled youth learn about sex and relationships (East and Orchard 2013). Some young disabled pupils are also excluded from SRE due to de-sexualisation (Heller et al. 2016, Jemtå, Fugl-Meyer, and Öberg 2008). Furthermore, other professionals and parents involved in young disabled people's daily lives rarely acknowledge issues relating to sexuality (East & Orchard 2013, Wiegerink et al. 2010, Akre et al. 2015). Such negative experiences in childhood and adolescence influence self-esteem, relationship formation and quality of life in adulthood (Shakespeare, Gillespie-Sells, and Davies 1996), and have intersectional dimensions (Drummond and Brotman 2014, Duke 2011, Liddiard 2014). Hence, SRE for young people with mobility impairments needs to acknowledge disability-specific needs as well as intersectional experiences of gender, sexual orientation, ethnicity, and so on, as these relate to all youth. Whether this is the case is previously unexplored in the Swedish context; a fact that informed the aims of this study.

### **Swedish SRE**

SRE became compulsory in Sweden 1955 and covers a wide range of topics from human anatomy, pregnancy and STIs, to relationships, love, gender equality, and the prevention of sexual harassment (RFSU 2011). Issues of norms, equality and anti-discrimination have been included in the school national curriculum since 1977 (Skolverket 2013). This is part of a ongoing move towards a 'norm-critical' approach in SRE, rooted in queer theory and the grassroots activism of non-governmental organisations such as the Swedish Association for Sexuality Education (*RFSU*) and the Swedish Federation for LGBT Rights (*RFSL*) (Sherlock 2012).

Within the school curriculu, SRE is not taight as an independent subject, but is integrated into other subject areas.

This can involve anything from a historic perspective on human sexuality and relationships, how different religions approach these issues, what we can learn from literary descriptions and how norms relating to gender and sexuality manifest in advertising, to what legislation governing relationships there is in Sweden today. (Skolverket 2014a, 5)

Teachers are expected to organise individual lessons or theme days as well as 'seizing every opportunity' (ibid., 6) in the school environment to address issues that arise. However, since SRE is not part of the education provided in Swedish *Gymnasieskolor* (upper secondary schools), many teachers feel – and indeed are – inadequately equipped to deal with either task (Myndigheten för skolutveckling 2005).

## Special programmes for disabled pupils

In Sweden, there are impairment-specific education programmes in both compulsory education (*Grundskolor*) and *Gymnasieskolor*, which follow the national curriculum, albeit with adaptations in the learning environment. The special programmes provided are in response to the policy rhetoric of inclusion and equality, according to which adjustments should be made to the framework of mainstream schooling (Isaksson and Lindqvist 2015). The right to inclusive education is contained in the United Nations Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities, both of which have been ratified by the Swedish government. Furthermore, at national level, the Discrimination Act (Diskrimineringslag 2008:567) was recently amended to include 'lack of accessibility' as a form of discrimination, specifically within the education system. However, due to budgetary constraints, a lack of specialist support teachers and knowledge about alternative pedagogies, this is seldom possible (Skolinspektionen 2010).

There are four special programmes for pupils with 'severe mobility impairments'. In addition to education they encompass residential housing and habilitation facilities, allowing eligible youth from across the country to attend. The programmes can last from three to four years, which may be necessary for pupils who need time away from school for habilitation purposes.<sup>2</sup> Pupils in these programmes do not usually have learning difficulties, for whom there are other special programmes, which also exist for pupils with other impairments.

The four programmes for pupils with mobility impairments are run by local authorities on behalf of the National Agency for Special Needs Education. They are delivered either adjacent to, or with special transport to *Gymnasieskolor*, enabling partial integration into mainstream programmes. Compared to regular classes with around 20–30 pupils, the programmes have between 5–10 pupils, allowing for individualised support by special education teachers.

The special programmes follow the national curriculum, which includes SRE. How pupils with mobility impairments experience SRE has not been studied in Sweden before, while the experience of pupils with learning difficulties has (Löfgren-Mårtenson 2011; Lukkerz 2014), including the use of special educational materials (Löfgren-Mårtenson 2009; Skolverket 2014b).

## Understanding disability and sexuality: analytical framework

This research adopts a disability studies perspective, which focuses on people with impairments' experiences of living in a disabling society, i.e. the social oppression which derives from 'the social imposition of restrictions of activity on people with impairments' (Thomas 1999, 156). Such *disablism* entails an unequal power relationship between 'those who are socially constructed as "impaired" and 'those who are identified as ... "normal" in society' (124). This understanding originates from the *social model of disability*, developed

<sup>&</sup>lt;sup>2</sup> As used here, the term habilitation refers to a process aimed at helping disabled people attain, keep or improve skills and functioning for daily living; its services include physical, occupational, and speech-language therapy, various treatments related to pain management, and audiology and other services that are offered in both hospital and outpatient locations. See <a href="http://www.riglobal.org/projects/habilitation-rehabilitation/">http://www.riglobal.org/projects/habilitation-rehabilitation/</a> (accessed 18 March 2018)

by disability rights activists to challenge individualising, medicalised understandings of impairment, while simultaneously empowering disabled people to work against such oppression (Oliver 2009).

Thomas (1999) extended this approach to develop a *social relational definition of disability*, as she found the social model's primary focus on societal barriers inadequate. She coined the notion of *impairment effects*, encompassing for example 'the difficulties of living with pain, discomfort, fatigue, limited functioning' and other experiences arising from impairment rather than social barriers (81) – albeit socially and culturally infused. Thomas also highlights the *psycho-emotional dimensions of disablism*, meaning that inaccessibility, prejudice and disability segregation not only restrict activity, but also impact upon 'our sense of *who we are* or *who we can be'* (45, emphasis in original). In summary, it is the combination of living with the effects of disability and impairment that shapes lived experience.

Although Thomas (1999) does not use the concept of intersectionality, her analysis points to how power relations based on gender, sexuality, race and age influence these experiences. Hirschmann (2012, 401) argues that disability 'presents intersectionality within intersectionality' because of the heterogeneity of the disability category in itself. In relation to sexuality, on the one hand, disabled individuals may have different sexual access needs depending on their impairment type. On the other hand, disabled people regardless of impairment, often experience being seen as non-sexual and less attractive by mainstream society, largely due to not being 'fit', 'healthy' and 'independent' (enough) by normative standards (Shakespeare et al. 1996). While some impairments may indeed impact 'sexual functioning', this functioning is heteronormatively framed as penetrative and orgasmoriented sex without professional assistance (Shuttleworth 2012).

This system of normative standards has many names in disability studies: constituting an ideology of ability (Siebers 2008), compulsory able-bodiedness (McRuer 2006), ableism (Campbell 2009) and the discipline of normality (Wendell 1996). When combined with queer theory, with which there are many connections (Sherry 2004), analyses reveal complex power dynamics at work. One example of this can be found in Sandahl's (2003) seminal work on the concept of 'cripping' by queer disabled ('crip-queer') performers. She defines cripping as '[spinning] mainstream representations or practices to reveal able-bodied assumptions and exclusionary effects' (38) through 'the public display of sexualised bodily difference and the process of bearing witness to past and present injustice' (28). Like queer, crip is closely connected to activism (McRuer 2006).

Crip analyses have often focused on cultural discourse, with crip identity and performativity in focus, not least in McRuers's (2006) development of *crip theory*. However, other writers have questioned the suitability of such analyses, for example in relation to people with learning difficulties living in institutional settings (Löfgren-Mårtenson 2012), people with impairments or chronic illness who do not necessarily identify as disabled in the first place (Bone 2017), or even disability rights activists who are offended by the sexually explicit language and visual discourse (García-Santesmases Fernández et al 2017). 'Crips' are in reality often 'supercrips', 'the easily assimilated able-disabled' with cultural and economic capital, while most disabled people do not share the privilege of 'noncompliance and moving across boundaries as a political strategy for social change' – but instead are striving to be regarded as normal, or simply surviving (Apelmo 2012, 37f; McRuer and Merri 2014, 157).

While Siebers (2008, 136) has also theorised disabled sexuality in identity-based terms and, in fact, as a specific sexual minority culture, he also emphasises how disabled sex

'broadens the definition of sexual behavior' so as to illuminate 'the fragile separation between the private and public spheres' when viewed within the framework of the ideology of ability. Likewise, Shuttleworth (2012) has theorised the many issues that disabled people face in their sexual lives, at a personal as well as a political level, as access issues. Even though the two researchers do not use the term crip, their work demonstrates how disability can 'transform sex, creating confusions about what and who is sexy' and 'what counts as sex', as described by McRuer and Mollow (2012, 32) in their introduction to crip understandings of disabled sex.

Turning to the educational context that is this paper's focus, I am inspired by a definition of '[c]ripping the curriculum' as 'a form of social justice pedagogy' (Connor and Gabel 2013, 113). Such analyses can '[shine] a light on able-bodied privilege; [confront] notions of diversity that exclude disability; and [challenge] educational structures that sort and rank students, labeling some students "special" and resulting in segregation and exclusion from full and equal participation in education' (112). Another recent definition targets SRE specifically, where cripping sex education means 'denaturalizing heterosexuality and able-bodiedness ... by centralizing crip bodies, pleasures, and desires' and 'offering a complex intersectional critique' (Passanante Elman 2012, 318).

In this paper, my focus is not on the pupils as 'crips', not least because they have not 'come out' as such. Instead, I use a crip analysis to suggest how pupils' experiences and perspectives can inform SRE through developing *cripistemologies* that aim to challenge traditional knowledge production (McRuer and Merri 2014, 162), while furthering empowerment, community building and sexual agency (Sandahl 2003, 48, 51). Cripping sex education through cripistemologies shares grounds with the concept of *sexual knowledge building*, which emphasises non-hierarchical and informal educational processes (outside the classroom) (White 2006 in Naezer, Jommes and Jansen 2017, 713) with the aim of challenging 'what are considered to be "good" knowledge and "acceptable" ways of learning about sexuality' (716). Herein, peer processes are essential: 'experiential knowledge is valuable for young people in transferring practical skills and information, providing support and inspiration, and confirming the 'normalcy' of experiences and feelings' (720).

Some of these tasks can be accomplished within the framework of the existing curriculum, while others require a more systemic transformation of the education system. With this dual approach, I hope to avoid the shortcomings of culturally focused crip analyses, which have tended to be somewhat distanced from disabled people's lived experiences, while still presenting options for a more radical agenda.

## **Methods**

This research described here adopted an exploratory approach. The starting point lay in pupils' perspectives and needs, but surrounding factors such as teachers' and other school personnel's approaches and teaching methods were also included.

Around 35 young people attended the programme for pupils with mobility impairments I studied, which was taught in a school with around 1000 students in one of Sweden's largest cities. Following receipts of the head teacher's approval, staff and pupils were approached with information about the study during the 2016–17 school year. Pupils aged over 18 were invited to participate, meaning they had completed their SRE (which took place when they were 16 to 17 years old). It also meant that parental approval was not needed, making it easier to recruit for the study. Few female students were enrolled in the

programme, which resulted in one female and five male study participants. This uneven gender distribution is typical of the population in general, whereby boys are more often born with or acquire impairments from accidents that cause mobility issues (Ds 1999). All but one of the students had moved from a smaller city and were housed in the school's residential facilities. The young woman and two of the young men were interviewed individually, while three young men wanted to participate in a group interview. Study participants were all 18 years old at the time of the interviews.

Members of staff interviewed had to have worked in the school for at least one year. All four participants were women in their 40s and 50s. I interviewed two subject teachers together, and the teacher responsible for the school's SRE curriculum and a habilitation counsellor who had initiated discussion groups around SRE issues, individually. All of the members of staff had past experience working with disabled people and/or disability issues in different contexts.

Individual, paired and group interviews were conducted using a semi-structured approach (Kvale and Brinkmann 2014). They took place in school and lasted 30–60 minutes. Interview topics for students covered how they understood SRE; what was covered and from what (intersectional) perspectives; whether anything was missed out; and whether they thought the lessons were useful. The paired interview with the subject teachers focused on their experience teaching a special programme and how they taught and dealt with SRE-related issues. In the interviews with the SRE teacher and the habilitation counsellor, the contents of their educational activities were discussed, as well as the social positioning of disabled youth in mainstream society more broadly. All members of staff were asked whether and how they worked with an intersectional perspective.

Interviews were transcribed verbatim and NVivo 11 software was used to aid qualitative content analysis (Patton 2002). I began by abstracting themes from the interviews: experiences of the special programmes; the content and structure of SRE; and experiences and valuation of SRE – with pupils' and school personnel's experiences, respectively, as subthemes. Besides the manifest content, I also sought out more latent content using an intersectional crip perspective, with a primary focus on disabling experiences. The approach was largely abductive, as it grew from my theoretical interests and the SRE curriculum guiding the interview themes, while also allowing for new themes to emerge inductively.

The study was granted ethical approval (061-16) by the Regional Ethics Board in Gothenburg. Interviewees were informed about the research's aims and procedures; that participants would be anonymised and were free to end their participation at any time during interviews or afterwards; and that the results would be shared in publications and at conferences. They were given details on how data would be stored and managed. Finally, contact information was provided to the local youth clinic for further information or counselling support if needed.

It was not possible to fully anonymise participants, since student recruitment took place through participating subject teachers. The pupils themselves did not seem concerned by this and said that they were often asked to participate in different kinds of projects during school hours. To protect students' identities as much as possible, their gender, ethnicity and sexual orientation are not specified and they have all been assigned gender neutral pseudonyms. However, since interview questions related to participants' experiences as students or school personnel, and they were not asked to share private sexual thoughts or experiences, the data is not of a particularly sensitive nature.

# **Research findings**

Interviews began by discussing participants' experiences of the special programme. One subject teacher mentioned the differences between it and more mainstream programmes. Smaller class size and more staff (special support teachers and personal assistants), resulted in multi-professional teamwork and there were often more adults than students in the classroom. She also described the major differences between pupils, all of whom had individual programmes based on their accessibility needs. The other subject teacher added that it was not easy to combine work in the mainstream programme, since teachers now needed to learn more about impairment/diagnosis and technical aids – an increased specialisation that can be seen as part of a more general special educational policy shift (Isaksson and Lindqvist 2015).

Pupils mentioned residential life as being different from most mainstream programmes; a good opportunity to leave the comfort of their homes and parents, learn to take care of themselves and become more independent. Several had chosen the programme to have their accessibility needs met more adequately, as well as hoping to find friends and community as some had been bullied in their previous, mainstream schools. The teachers were aware of this, leading them to include community building and strengthening the pupils' self-confidence, independence and identity development in the pedagogy. In general, pupils expressed positive opinions about the programme.

# The structure of SRE

SRE was taught by a specially trained team of school personnel. Subject teachers explained that they preferred this approach because 'you need a deeper knowledge to be able to stand for it [SRE]', which they felt they lacked (see also Van der Stege et al. 2014). Whenever pupils had SRE-related questions, the staff would refer them to more experienced colleagues. They also discussed not wanting to become too 'private' with the pupils, something they felt could happen more easily in SRE. These opinions are interesting in light of the national curriculum stating that SRE ought to be integrated into most subjects – however, many teachers lack the preparation to execute it well. Teachers' views also highlight the existence of a private/public binary, whereby education is seen as a public matter, while SRE is seen as private, and teachers are therefore uncomfortable about engaging with it.

SRE was structured as joint sessions with the first- and second-year pupils (16 to 17 year olds) twice a term. Sessions comprised lectures, group discussion, watching video clips and other activities. Young men in the focus group said they would have liked SRE to take place more frequently and as more structured lessons, since it could become 'giggly' sometimes. Others mentioned the importance of group discussion, which they felt made it easier to ask sensitive questions. They especially enjoyed the occasional mixed-sex discussion groups:

It's probably good that you are both [girls and boys] there because then you get more out of the conversation (...) Girls can have more experience in some area and guys in another, and then you get a discussion about both girls' and boys' views (pupil, interview).

Gender seemed significant to both the structure and content of SRE. Mixed-sex discussion groups were felt to be more rewarding as students expected to learn new things from members of the other sex – and not just in terms of anatomy.

An essentialist notion of gender differences is common in SRE (McEntarfer 2016), while often simultaneously, and somewhat paradoxically, being attended to in the curriculum in terms of norm-critical discussions. However, disabled people may feel the need to accentuate a norm-conforming gender identity in opposition to being de-gendered by society, highlighting the importance of analysing specific intersectional experiences of disability (Thomas 1999, Shuttleworth 2012).

### SRE content

Drawing on the themes prescribed in the curriculum I asked students what had been covered:

Interviewer: Did you talk about, like, what's normal, body ideals, and such?

Riley. Yes, I think we did. It evolved a lot around things like that.

Interviewer: Pornography and such?

Riley. Yes, that too. (...) Like stereotypes and such. How the different genders are portrayed (pupil, interview).

Interviewer: Did you already know about LGBT issues or learn about them in school?

Lou. I learned about it in SRE. And I have a close friend who likes guys but I don't judge him because of that, he's my friend anyway. (...) You have to help each other like that, nobody should be excluded (pupil, interview).

In other words, it would seem that the curriculum themes around gender norms and LGBT issues seem to have been covered. The SRE teacher said that LGBT issues are especially pertinent for disabled pupils, who may be seen as asexual and may therefore have a harder time coming out – something she had witnessed several times over the years. One pupil in this study who identified as non-heterosexual testified to such difficulties as well.

In the group interview, the young men debated whether they thought SRE had enough of a norm-critical perspective. They agreed that the teachers included examples of LGBT persons, however, that such were still less prevalent than heterosexual examples. This led to a discussion in which the young men proposed further development:

Blake: I've got an idea! I'm really thinking a bit experimentally here. But it feels like everything that's outside the norms are what there should be more of than what's normal...

Dylan: Or 'normal'.

Blake: ...if you understand what I mean. That it shouldn't just be, like I said, it should be less of straight-teaching and more LGBT-teaching to...

Dylan: Make it more accepted in society

Blake: Exactly. (...) 'Cause you already know about the usual things anyway!

In other words, the pupils thought that the teaching had not been sufficiently rooted in a norm-critical perspective. Being presented with non-heteronormative examples was felt to be insufficient when occurring within an overall heteronormative context. Their suggestion for how best to change it using norm-challenging examples as the starting point, is in line with a crip approach and will be discussed later.

A recurring theme that students mentioned concerned online risk.

A lot about the Internet, about not sending pictures or meeting people alone. To beware of what you post online. (...) It was actually more negative stuff, it felt like they wanted to scare us (laughs) (Sam, interview).

Some years beforehand, there had been heated public debate in Sweden about grooming and illegal and inappropriate social media use following some well publicised incidents, after which schools allocated extra resources to deal with such issues. However, the Internet can also be used positively to meet people, counter physical isolation and find good quality information. Students' accounts suggested there may be an over-emphasis on negative aspects in teaching, which probably reflects the previously mentioned public debates about young people's vulnerability when using the social media, and not necessarily the fact that they are disabled (cf. Naezer et al. 2017). Sam laughing about teachers trying to 'scare them off' online risks illustrates a flawed strategy. A more productive discussion might result from letting the pupils define what they are scared of and how they define risks, perhaps in smaller groups, which they seemed to appreciate.

Findings further suggest that while some pupils are content with SRE and how a disability perspective was included, others wanted more:

Interviewer: Did you talk about disability perspectives?

Sam: Yes, a bit, but not that much actually. Which I think is a shame, when you have a class of disabled... then you should actually focus more on that (...). What it's like to have a relationship when you have assistance, or with someone who is not disabled (pupil, interview).

Dylan: Or like, this position you can't do, because... Like, if someone has brittlebone disease, then you might not be able to do certain things (pupil, focus group).

It is interesting to note that contrary to these pupils' experiences, both the SRE teacher and the habilitation counsellor said that they addressed these kinds of issues in their teaching and in after-school discussion groups, respectively. The pupils' experiences could perhaps be

due to variations over the years, or it could be that the issues had not been discussed in the desired ways.

The habilitation counsellor described the discussion groups as an informal complement to SRE. Examples of discussion topics were whether to disclose your disability in online datin;, securing privacy when being reliant on assistants; what sex is, including masturbation;, and demonstrations of sex toys. The few pupils who had attended the groups (one of whom were interviewed in this study) were happy with them. However, the low attendance rate combined with some pupils' opinions of not having learned enough about disability-specific matters in SRE, suggest a need for better coordination between the SRE and habilitation teams.

Another explanation could be that pupils do not feel confident or comfortable raising certain issues in class, or attending special discussion groups (which can also be due to time constraints). The habilitation counsellor indeed stressed self-confidence as an important issue in the discussion groups:

I mean, we wanted to talk about sex but also about how people see themselves, that sex is not only about penetration, and if you feel attractive, and so on. And well, they were asked to mention positive things about their bodies, and many of them couldn't come up with anything (Habilitation counsellor, interview).

As mentioned earlier, many young people with mobility impairments have body image issues. Some pupils had also experienced disturbing comments from strangers:

Dylan: People can come up to me and ask, like, how do you have sex? And I'm like, that's none of your business!

(...)

Blake: I mean, essentially, we're just regular people except we have a certain situation, these barriers

De-sexualising attitudes still prevail. Constantly facing such misconceptions affects self-esteem and body image, while physical inaccessibility creates barriers to accessing social venues in which opportunities for sex and relationships exist. Working with self-confidence on several levels in both SRE and habilitation, is therefore very important. But more can been done to politicise disabled identity, and to crip understandings of sexual embodiment.

The SRE teacher explained what themes she emphasised with disabled pupils, compared to others:

Many [pupils] live with people in their surroundings who think of them as asexual – which of course gets even more difficult when parents are assistants. (...) What if [a young couple] needs help with taking out a condom, undressing, washing up afterwards, or whatever – it becomes very intrusive. (...) Or if you're going to the movies with your partner and need help in getting there and home, and having the assistant nearby, to hold your popcorn maybe – how can that couple have an intimate situation?

Comparing the disability-related themes that pupils wanted more of with the themes that SRE and habilitation discussion groups covered, a discrepancy became evident between what is offered and what was missed out. One reason for this may link to the limited classtime available for SRE, with students not feeling up to attending extra-curricular activities. Another reason may be that individual concerns were not dealt with in SRE, which the responsible teacher felt was inappropriate. Once again, the private/public binary comes to the fore.

# SRE is only one part of the solution

It is a well-established fact that, although Swedish SRE is comprehensive and compulsory, young people gain such knowledge from other sources (cf. Folkhälsomyndigheten 2017). Several pupils mentioned discussing sex, sexuality and relationships with friends, while one relied on one of their personal assistants for support. But the primary source of information mentioned was the Internet, and specifically the value of 'Googling things'. However, since only pupils without major assistance needs participated in the study, these findings cannot be generalised to all disabled youth. Searching for sensitive information will be much harder for youth needing major support, especially if their assistants are family members or people who they do not feel comfortable sharing sensitive things with.

One of the pupils in the focus group said that he probably learned more in his spare time than in school and mentioned online pornography:

Why should I be ashamed? I'm an adolescent – it's normal! I mean, you get curious. And if I can't have [sex] because I can't go out and pick someone up very easily, I still want to, I'm curious and want to see how two persons, or several, have [sex]. Ok, they do it like that. So that can be a kind of a lesson when you can't get out there yourself, then you have to watch it and try the theory later when you meet someone, when the time has come.

For Dylan, being restricted by lack of access and judgmental attitudes prompted the use of pornography as a substitute or alternative experience (see also Akre et al. 2015). Pornography may therefore carry a different meaning for disabled youth. The SRE teacher in this study acknowledged that pornography had not received enough attention as part of SRE. Although the student did not describe in detail the pornography he watched, nonnormative pornography can be empowering for disabled people, especially when it incorporates disability-specific dimensions (García-Santesmases Fernández et al 2017).

# **Developing crip SRE**

My analysis of the special programme illuminates how a compromise to the equality principle in Swedish education policy plays out in practice. When disabled pupils' needs are not met by mainstream education, they are forced to turn to segregated programmes. Even though the pupils in this study experienced this positively, their responses must be understood in the light of earlier negative experiences (eg. bullying and inaccessibility). Something that all pupils had in common were experiences of how disabling barriers of a physical, mental and social nature influenced the development of self-confidence and knowledge – confirming Thomas' (1999) relational understanding of living with impairment and disability. In the special programme, they found community among disabled peers and

were facilitated to build self-confidence and independence by their teachers' pedagogical approach.

However, the special programme and the empowerment framework comes with limitations. Segregated schooling is inherently ableist and counters equal participation. Disabled pupils and their needs are institutionalised as 'others' and thereby reproduce stereotypes and misconceptions. Even though the studied special programme was located in a mainstream school, socialisation between disabled and non-disabled pupils was rare. Future expectations in adulthood, for example in the labour market, build on these early experiences. Essentially, fundamental change is needed within the education system in the form of adequate resources and services to facilitate all students' needs (Isaksson and Lindqvist 2015).

With respect to SRE, the habilitation counsellor discussed the difficulties that young people with impaired mobility face in this respect, sometimes being belittled by well-meaning attempts to normalise disabled youth:

Sometimes I feel like personnel can be too quick to say that 'it's like that for everyone', because I think that – no, it's not really. (...) Everyone might not feel that their body is totally different, or be dependent on others for help with bodily... Whether you want it or not, they touch you and you might not have total control over your body, and what that does to you mentally in the long run. Not being able to always control your privacy. That of course does something to these people and it's important to talk about it.

In other words, as important as it is to stress that youth with mobility impairments are 'normal', in the sense of being young people with needs and aspirations like all youth, it is equally important to acknowledge their impairment-specific needs. Being 'normal' is often an important aspiration for most young people but is often problematised in SRE in the name of a norm-critical approach. However, highlighting others' subjective experiences of normality can be helpful, especially for minorities (Naezer et al. 2017). For disabled young people, essentially, such processes are what developing cripistemologies is about (McRuer and Merri 2014).

Developing cripistemologies requires structural as well as content-related change. Firstly, students should be allowed to talk about personal experiences in the classroom in order to legitimise other types of knowledge and challenge the traditional teacher-led hierarchy (Naezer et al. 2017). This requires that teachers, too, unlearn traditional knowledge production processes, not least the private/public binary, which it is so important to contest and which lies at the heart of crip critique (Sandahl 2003, McRuer 2006). Knowledge is neither neutral (public) nor separable (public *or* private). Discouraging pupils from sharing personal experiences simply because they are 'private' is unhelpful and devalues their experiences. Instead, discussing such boundaries and their meanings with the pupils, and letting them talk about how they want such discussions to be organised, could be a more productive way forward.

Taking advantage of the opportunities for building crip communities through dormitory life and habilitation discussion groups, and integrating these with SRE in the classroom, could serve to bridge the gap between experiences within and outside of SRE. A cripistemology would then include the broader process of sexual knowledge building (Naezer et al. 2017). The special programme's existing connections with the local disability

movement could also be deepened, not least by letting the students set the agenda. In particular for students arriving from other locations, the introduction to activist circles could facilitate the development of politicised disabled/crip identity and create awareness of other activist groups as well.

As García-Santesmases Fernández and colleagues (2017, 275) showed, crip activists who participated in workshops about sex, queerness and functional diversity described the experience as empowering and liberating as they became 'more aware of their social discrimination' and found agency in those positions. Seeing the documentary 'Yes, We Fuck!' in which bodies like theirs were sexualised provided possibilities of seeing themselves as desirable beings and '[reconciling]... with those parts of their bodies that were a source of embarrassment and pain'. In her work, Sandahl (2003, 51) stressess the need for safe spaces in which new identities can be 'safely rehearsed', which for pupils could be the classroom without teachers present – especially as they are non-disabled – or other places. What poses a challenge to this suggestion is the fact that many students have around-the-clock personal assistance, including for communication purposes. This challenge is also evident in this study's sample, as it might have been the most articulate ones participating – at the very least it was the pupils who did not use communication devices (see East and Orchard 2013 for similar findings).

Online communities could provide an alternative for those who do not feel safe or do not want to share their thoughts and experiences in the classroom or with their classmates. For many, the Internet provides the safest space, be it for learning or information purposes, or to explore alternative communities or one's identity and desires (Edwards 2015, Naezer et al. 2017). But again, the specific access needs of some disabled youth pose challenges here that need more detailed exploration, for SRE as well as for future research.

As was proposed by students in this study, including disability perspectives and non-normative/intersectional experiences in the curriculum is essential. Instead of showing only normative bodies, students can be facilitated to discuss among themselves the kind of practices they are curious about, and be encouraged to find previously unseen imagery (as discussed above). Searching online for content that they can then work with together and present to each other is another pedagogical technique that could prove both empowering and informative – highlighting pupils' specific intersectional experiences that teachers have not thought of or do not have access to (cf. Naezer et al. 2017).

Developing cripistemologies should not be normative and homogenising, but should take into account the differences in bodies (*impairment effects*), experiences and desires, while developing community in shared experiences of disablism. Cripistemologies are thus both individual and common, personal and political.

The instances discussed above require school personnel to take greater responsibility for SRE-related issues wherever they arise and to self-consciously out 'the ignored curriculum' (Gougeon 2009). Apart from teachers needing to re-learn the knowledge production processes as outlined above, teachers' lack of formal SRE education is a problem every school needs to address. While much can be done within a special programme, interaction with mainstream programmes would add real depth to crip development — otherwise it risks becoming irrelevant to pupils' wider experiences. For pupils in mainstream programmes, living and learning together with disabled pupils as opposed to seeing them as 'others' in separate parts of the school, would enhance disability awareness.

A crip approach is relevant to all forms and contexts of SRE considering all classrooms are intersectional. What mainstream SRE can learn from crip SRE is the emphasis given to

identifying, challenging and politisising the hegemonic ability ideals (Campbell 2009) that impact norms around sexual performance and bodily standards for most people (McRuer and Mollow 2012). SRE that develops from pupils' own experiences and needs, while also emphasising other 'normalities', can work to deepen knowledge about oneself and about others. Essentially, then, crip SRE has the potential to disrupt taken-for-granted dis/ability and sexuality divides as well as politicise issues that many young people presently experience as 'personal shortcomings'.

### **Funding**

This work was funded by the Norrbacka-Eugenia Foundation under Grant 805/15. Additional support was provided by the Department of Social Work at the University of Gothenburg.

## **Acknowledgments**

I am grateful to pupils and school personnel for generously sharing their experiences. I would like to thank Kamilla Peuravaara for fruitful discussions during the preparation of the grant application and Andrea Hollomotz and Hans Olsson for constructive feedback on a draft of this paper. Lastly, I appreciate comments from three anonymous reviewers whose feedbacks inspired me to deepen my analysis.

### References

- Akre, Christina, A. Light, L. Sherman, J. Polvinen & M. Rich. 2015. "What young people with spina bifida want to know about sex and are not being told." *Child: Care Health and Development* 41 (6): 963-9.
- Apelmo, Elisabet. 2012. "Crip heroes and social change." Lambda Nordica 2012 (1-2): 27-52.
- Baker, Karen Elizabeth. 2015. "Online pornography Should schools be teaching young people about the risks? An exploration of the views of young people and teaching professionals." Sex Education 16 (2):213–28.
- Bone, Kirstin Marie. 2017. "Trapped behind the glass: crip theory and disability identity." *Disability & Society* 32 (9): 1297-1314.
- Campbell, Fiona A. Kumari. 2009. *Contours of Ableism. The Production of Disability and Abledness*. Basingstoke: Palgrave Macmillan.
- Chirawu, Petronella, Jill Hanass-Hancock, Toyin Janet Aderemi, Liset de Reus & Anna Sophie Henken. 2014. "Protect or Enable? Teachers' Beliefs and Practices Regarding Provision of Sexuality Education to Learners with Disability in KwaZulu-Natal, South Africa." Sexuality and Disability 32 (3): 259-277.
- Connor, David J. & Susan L. Gabel. 2013. ""Cripping" the Curriculum Through Academic Activism: Working Toward Increasing Global Exchanges to Reframe (Dis)Ability and Education.' Equity & Excellence in Education 46 (1): 100-118.
- Ds. 1999:33. Genderanalys av riksgymnasieverksamheten för ungdomar med rörelsehinder [Gender analysis of upper secondary school programmes for youth with mobility impairments]. Stockholm: Socialdepartementet [State report].
- Drummond, J. D., and Shari Brotman. 2014. "Intersecting and Embodied Identities: A Queer Woman's Experience of Disability and Sexuality." *Sexuality and Disability* 32 (4):533-549.
- Duke, Thomas Scott. 2011. "Lesbian, Gay, Bisexual, and Transgender Youth with Disabilities: A Meta-Synthesis." *Journal of LGBT Youth* 8 (1):1-52.
- East, Lauri J. & Treena R. Orchard. 2013. "Somebody Else's Job: Experiences of Sex Education among Health Professionals, Parents and Adolescents with Physical Disabilities in Southwestern Ontario." Sexuality and Disability 32 (3): 335-350.
- Elman, Julie Passanante. 2012. "Cripping safe sex: Life Goes On's queer/disabled alliances." Bioethical Inquiry 9 (3): 317-26.
- Folkhälsomyndigheten [The Public Health Agency of Sweden] (2017) Sexualitet och hälsa bland unga i Sverige [Sexuality and health among youth in Sweden]. Stockholm: Folkhälsomyndigheten.
- García-Santesmases Fernández, Andrea, Núria Vergés Bosch & Elisabet Almeda Samaranch. 2017. "'From alliance to trust': constructing Crip-Queer intimacies.' *Journal of Gender Studies* 26 (3): 269-281.
- Gougeon, Nathalie A. 2009. "Sexuality education for students with intellectual disabilities, a critical pedagogical approach: outing the ignored curriculum." Sex Education 9 (3): 277-291.
- Heller, Mariel Kupfert, Sara Gambino, Paige Church, Sally Lindsay, Miriam Kaufman & Amy C. McPherson. 2016. "Sexuality and Relationships in Young People With Spina Bifida and Their Partners." Journal of Adolescent Health 59 (2): 182-8.
- Hirschmann, Nancy J. 2012. "Disability as a New Frontier for Feminist Intersectionality Research." *Politics & Gender* 8 (03):396-405.

- Isaksson, Joakim, and Rafael Lindqvist. 2015. "What is the meaning of special education? Problem representations in Swedish policy documents: late 1970s–2014." *European Journal of Special Needs Education* 30 (1):122-137.
- Jemtå, Lena, Kerstin S. Fugl-Meyer, and Karin Öberg. 2008. "On intimacy, sexual activities and exposure to sexual abuse among children and adolescents with mobility impairment." *Acta Paediatrica* 97 (5):641-6.
- Kvale, Steinar, and Svend Brinkmann. 2014. *Den kvalitativa forskningsintervjun [The qualitative research interview]*. Lund: Studentlitteratur.
- Liddiard, Kirsty. 2014. "The work of disabled identities in intimate relationships." *Disability & Society* 29 (1):115-28.
- 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. http://muep.mau.se/handle/2043/17496
- Löfgren-Mårtenson, Lotta. 2009. *Hur gör man? Om sex- och samlevnadskunskap i särskolan* [How do you do it? On sex and relationship education in special upper secondary school]. Varberg: Argument förlag.
- 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.
- Löfgren-Mårtenson, Lotta. 2012. "Hip to be crip?" Om cripteori, sexualitet och personer med intellektuell funktionsnedsättning [On crip theory, sexuality and people with intellectual impairments]'. Lambda Nordica (1-2): 53-76.
- McEntarfer, Heather Killelea. 2016. *Navigating gender and sexuality in the classroom:* narrative insights from students and educators. New York: Routledge.
- McRuer, Robert. 2006. *Crip Theory. Cultural Signs of Queerness and Disability.* New York: New York University Press.
- McRuer, Robert and Anna Mollow. 2012. "Introduction." In *Sex and Disability*, edited by Robert McRuer and Anna Mollow, 1–35. Durham: Duke University Press.
- McRuer, Robert and Merri Johnson. 2014. "Proliferating Cripistemologies." *Journal of Literary & Cultural Disability Studies* 8 (2): 149-170.
- Myndigheten för skolutveckling [The Agency for School Development]. 2005. *Hela livet. 50 år med sex- och samlevnadsundervisning.* [The whole life. 50 years of sex and relationship education]. Stockholm: Liber.
- Naezer, Marijke, Els Rommes, and Willy Jansen. 2017. "Empowerment through sex education? Rethinking paradoxical policies." *Sex Education* 17 (6):712-728.
- Oliver, Michael. 2009. *Understanding disability: from theory to practice*. Basingstoke: Palgrave Macmillan.
- Patton, Michael Quinn. 2002. Qualitative research & evaluation methods. London: Sage.
- RFSU. 2011. What's it all about? Information on sex and relationship education in the Swedish school. Stockholm: RFSU.
- Sandahl, Carrie. 2003. "Queering the Crip or Cripping the Queer?: Intersections of Queer and Crip Identities in Solo Autobiographical Performance." GLQ: A Journal of Lesbian and Gay Studies 9 (1–2): 25–56.
- Shakespeare, Tom, Kath Gillespie-Sells, and Dominic Davies. 1996. *The Sexual Politics of Disability: Untold Desires*. London: Cassell.

- Sherlock, Leslie. 2012. "Sociopolitical influences on sexuality education in Sweden and Ireland." *Sex Education* 12 (4):383-96.
- Sherry, Mark. 2004. "Overlaps and contradictions between queer theory and disability studies." *Disability & Society* 19 (7): 769-783.
- Shuttleworth, Russell. 2012. "Bridging Theory and Experience. A Critical-Interpretive Ethnography of Sexuality and Disability." In *Sex and Disability*, edited by Robert McRuer and Anna Mollow, 54-68. Durham: Duke University Press.
- Siebers, Tobin. 2008. Disability Theory. Ann Arbor: The University of Michigan Press.
- Skolinspektionen [The Swedish Schools Inspectorate]. 2010. Skolsituationen för elever med funktionsnedsättning i gymnasieskolan [The school situation for pupils with impairments in upper secondary school]. Stockholm: Skolinspektionen.
- Skolverket [The National Agency for Education]. 2013. Sex- och samlevnadsundervisning i gymnasieskolan. [Sex and relationship education in upper secondary school] Stockholm: Fritzes.
- Skolverket [The National Agency for Education]. 2014a. Sex Education. Gender equality, sexuality and human relationships in the Swedish Curricula. Stockholm: Skolverket.
- Skolverket [The National Agency for Education]. 2014b. Sex- och samlevnadsundervisning i särskolan [Sex and relationship education in special upper secondary school]. Stockholm: Fritzes.
- Thomas, Carol. 1999. Female Forms. Experiencing and Understanding Disability.

  Buckingham: Open University Press.
- Van der Stege, Heleen A., Sander R. Hilberink, Adriaan P. Visser, and AnneLoes Van Staa. 2014. "Motivational factors in discussing sexual health with young people with chronic conditions or disabilities." *Sex Education* 14 (6):635-51.
- Wendell, Susan. 1996. *The rejected body: Feminist philosophical reflections on disability*. London: Routledge.
- Wiegerink, Diana, Marij Roebroeck, Jim Bender, Henk Stam, and Peggy Cohen-Kettenis. 2010. "Sexuality of Young Adults with Cerebral Palsy: Experienced Limitations and Needs." *Sexuality and Disability* 29 (2):119-28.