Workshop Briefing:

Disabled Under-18s: Rights to Online information/Communication about Sexual Relationships

Organised by Aoife Daly, Rachel Heah and Jamie-Lee Saunt of the European Children's Rights Unit, School of Law and Social Justice, Liverpool

Summer 2018
This full-day workshop was held on the 13th of June 2018 at the Forecourt Centre, University of Liverpool. It was attended by approximately 30 participants comprising of researchers, service providers, teachers, and members of the public who were interested in discussing the importance of, and how best to further, the rights of disabled young people to receive information about sexuality and sexual relationships online. There were eight presentations on the day (including opening thoughts) and the floor was opened for Q&A and audience discussions after each presentation.

The following is a summary of each presentation.

**Opening thoughts**
by Aoife Daly, Rachel Heah and Jamie-Lee Saunt; University of Liverpool

This comprised of a welcome to all participants, followed by an outline of the aims of the workshop. Participants had previously been provided with a literature review summarising the available literature on the topic.

The opening presentation therefore highlighted some of the key points raised in the literature review, particularly around the barriers preventing people with disabilities from exercising their sexual rights, the importance of providing disabled people (under-18s in particular) with information relating to sexuality and sexual relationships, and how such access could be facilitated via the internet/online environment.

Questions posed for discussion in the workshop include:
1. What are the pressing issues for disabled under-18s online?
2. What are the pressing issues for disabled under-18s when it comes to education on sex and relationships?
3. How do we balance access and protection rights for children online?
4. What are the crucial issues for research with disabled children?
5. How do we bring participatory research forward in a way that is genuinely inclusive of disabled under-18s?

In the brief discussion/ Q&A after the opening presentation, participants asked about, and discussed, some of the other barriers faced by disabled people in relation to the exercise of sexuality, which were not mentioned in the literature review. One particularly strong opinion related to forced medical sterilization, particularly of women, and forced abortions.

**The intimate lives of disabled people**
by Dr Kirsty Liddiard; University of Sheffield

Kirsty’s presentations started with an overview of how disability intersects with intimacy and sexuality. Although pleasure is a key aspect of being human, disabled people are often denied access to their bodies and to sexual pleasure. This sexual marginalisation stems from a culture that privileges “corporeal wholeness”, thereby refusing the sexual agency and sexual rights of disabled people. This also negatively impacts the self-worth and emotional wellbeing of disabled people – they ‘internalise ableism’ and are therefore unable to see themselves as sexual beings who are worthy of sexual rights.

Crip theory therefore has introduced crip sexuality and pleasure – which centres around the sexual, intimate and erotic lives of disabled people, and calls for disabled people’s sexual and intimate citizenship.

Online spaces allow disabled people to “build identities of choice”, in that they are more accessible, and allow the bypassing of aspects of bodily function, whilst at the same time allowing them to avoid the power of the gaze. In that sense, they are “affirmatory spaces” which allows disabled people to claim new forms of citizenship. However, online spaces are also “violent spaces” because they often re-enforce and reproduce existing “ableist” notions, e.g. that disabled people are “objects of pity, in need of sympathy”, etc. Online spaces also enable hate speech to be directed at disabled people, serving as the “ultimate dustbin for disavowal”.

The next part of the presentation discussed young people’s online sexual stories, providing valuable insight into the narratives around disabled young people’s intimate lives. Some of the issues highlighted included:
- The internet as a space of performance – usually where disability is downplayed
- The internet as a space of violence and emotional abuse – including name-calling and rejection
- The internet as a facilitator for access to commercial sex work markets for disabled young people

These were then illustrated with the findings from the Life, Death, Disability and the Human: Living Life to the Full (ESRC 2017-2020) project.

**The appropriate relationships and keeping yourself safe programme**
Rita Jones; Advanced Solutions

Rita is Director of Learning, Coaching and Mentoring Development at Advanced Solutions, a Community Interest Company which offers community based learning, coaching and mentoring programmes and health, wellbeing and enrichment activities for families living with Neurodevelopmental conditions. In her presentation, Rita highlighted the role of Advanced solutions in offering support for people with autism spectrum disorder, HFA, sensory processing difficulties, ADHD, dyslexia, dyspraxia, dyscalculia, dysgraphia, fragile X, communication difficulties, special educational needs and disability.

In relation to children and young people with neurodevelopmental conditions, the organisation aims to equip and empower them with the necessary skills, tools, knowledge and confidence to participate in society. Rita spoke about how the ability to socialize, make and keep friends, is often taken for granted, where in actual fact, these are challenges to people living with neurodevelopmental conditions. For example, young people with autism sometimes struggle with reading social cues and understanding social norms and conventions, and therefore find it difficult to make friends, much less get intimate with other people.

Advanced solutions offers an innovative response to this, by allowing clients to experience social situations – as opposed to merely theorising what would happen in social encounters. Rita recounted examples of activities where young clients were taken out on day trips, such that they could discuss social norms and build their confidence around social interactions.

The audience were also showed a video, produced by young Advanced solutions service users, highlighting the importance of treating them equally and viewing them “just like anyone else”.

On the subject of the internet and online access, Rita acknowledged that the internet does provide children and young people with more opportunities, but one key issue is the determination of competence. Because young people with neurodevelopmental conditions (specifically autism) often do not question or look beyond what is said verbally or written, they sometimes take things written on the internet literally. In that sense, they may be exposed to the risk of exploitation, abuse, and emotional upset. Hence, it is important to equip these young people with digital literacy skills in order to help them navigate to the available resources on the internet, and to fully utilise the internet for their own benefit.

**Experiences of people with a learning disability of online risk and support for risk management and digital inclusion**
Dr Darren Chadwick; University of Wolverhampton

Darren’s started by outlining the discrimination and unequal treatment faced by people with intellectual disabilities, which leaves them excluded from many of the significant life experiences that most people without intellectual disabilities take for granted. In his presentation, he highlights how the digital world continues to perpetuate the inequalities for people with intellectual disabilities. The digital world, in this case, is broadly defined to include all usage of technology, including mobile phones, computers, laptops, tablets, as well as use of social media and access to the internet.

The “digital divide” – referring to the separation between those with and without access to the digital world - continues to marginalise people with intellectual disabilities, and denies them access to the online environment that has become a fundamental part of the human experience. There are fewer opportunities for people with intellectual disabilities to go online, and even where they do, it is hard for them to gain full access to the internet. For example, statistic shows that 25% of people with intellectual disabilities in the UK have never been online, although this applies less to the younger generation, who have slightly more access to the digital environment.

Some of the barriers to digital inclusion for individuals with intellectual disabilities include:
- Financial and economic barriers
- Lack of policy and governmental support
- Lack of training and education to support people
- Lack of universal design – in that internet sites are designed with little consideration of the needs of people with intellectual disabilities;

**The project focussed on co-researching and virtual leadership for participants**
- It explores the lives, hopes, desires and contributions of disabled children and young people with life-limiting or life-threatening impairments.
- One of the relevant findings was that online spaces allow or facilitate access to activist community and solidarity, particularly around sexual citizenship. In that sense, the online environment was seen as beneficial to the research participants.
- Kirsty concluded her presentation with three specific points for further discussion:
  - Online spaces are not immune from the disablist and ableism inherent to disability life in ableist cultures – but we should try to move away from the binary in the ways we think and approach theorising young people’s online citizenship and experiences (as being merely “good” or “bad”)
  - Online spaces can facilitate “sexual selfhood” in a number of ways – how might this close down opportunities for more radical forms of sexual citizenship and selfhood?
  - How can we better utilise online and virtual methods within critical disability studies research?

**Financial and economic barriers**
- Lack of policy and governmental support
- Lack of training and education to support people
- Lack of universal design – in that internet sites are designed with little consideration of the needs of people with intellectual disabilities;
Societal and carer views of people with disability as non-adults, unable and more vulnerable may to lead to less support for people with access the online world without risk taking.

Carers may lack the skill and will to facilitate digital inclusion and participation

Undoubtedly, the online environment poses some risk to people with disabilities, but it also confers benefits. Some risks include:

• Negative contact online
• Exposure to harmful content
• Engagement in antisocial conduct

The levels of online crime and victimisation for people with a learning disability are currently unknown, largely because these often go unreported but also because these online crime are currently less well recorded and defined.

People of intellectual disabilities may be particularly at risk online, because of:

• Limited social networks and desire for acceptance;
• Greater loneliness, depression and lower self-esteem;
• Poorer insight and judgement.

Despite the risks, people with intellectual disabilities are often motivated to engage with the digital world—and this can confer benefits such as:

• Education and learning
• Communication, social interaction and connectedness
• Participation, advocacy and civic engagement
• Identity expression and development
• Empowerment, agency and self-esteem

Hence, the "You want to know that you're safe" project, carried out in collaboration between the University of Wolverhampton, WiDeN, Friends 2 Friends, Dudley Voices for Choices & Building Bridges. Training sought to explore the experiences and perceptions of adults with a learning disability in relation to online risks.

Their findings centred around 4 main points:

1. The experiences and risk-taking of people with learning difficulties online; including contact risks, contact risks and content risks, although the latter was rarely mentioned.
2. Their awareness of online risks, desire to develop knowledge to manage online risks, and availability of support for their digital inclusion;
3. Their independence and resilience demonstrated online;
4. Online risks, restrictions and digital exclusions affecting them, including restriction by carers as well as self-imposed digital exclusion

It was then discussed whether ‘positive risk taking’ should be encouraged for people with learning difficulties, in relation to their online presence. Such an approach places more emphasis on their growth, self-determination and wellbeing, as opposed to the potential harm, failure or disappointment from being online. This could have the potential to increase their coping and resilience.

The presentation concluded with the posing of 3 questions, or thoughts:

• Why is it not possible to adequately protect people with intellectual disabilities, whilst still respecting their choices to be online?
• Should we adopt the approach of ‘positive risk taking’?
• Are we in danger of minimising the risks faced by people with intellectual disabilities if we adopt this approach?

How can we try to safeguard people with intellectual disabilities while trying to promote their online participation and positive risk-taking?

Engagement and participation in relationship education – reflections from a SEND school

Janette Porter, Liverpool John Moores University

Janette was invited to present her work on the Tender Healthy Relationships project, a collaboration between Liverpool John Moores University (LJMU) and Tender. The project has been used in 24 schools across the Greater Merseyside area, including two SEND schools, and aims to use drama and art to teach secondary school pupils about healthy relationships and violence prevention.

Education on healthy relationships is crucial, especially to secondary school pupils, because those aged 16-24 are most at risk of violence in a relationship, yet only 33% of teenagers that are involved in a violent relationship talk to someone about it.

Further, disabled people are more likely to experience abuse, including sexual abuse, than non-disabled people. This disproportionately affects women and girls with any type of disability, as well as people with cognitive disabilities, which is therefore important to equip young people, especially disabled young people, with the necessary tools to recognise and report abusive behaviour.

Janette discussed how the pre-prepared materials for the project had been adapted for use with the SEND schools. They used readers, scripts, braile, large print, audio and sign language to deliver the sessions to the disabled young people, who were then able to express themselves, and their opinions on relationships and healthy relationships, in various ways, including drawing, poetry, drama and art.

On the project, teachers themselves are also given a few sessions on teaching, and dealing with questions on, healthy relationships more specifically and RSE more generally, so that they will have the confidence to assist pupils even when the external deliverers are not present in school.

Brook education and learning disabled young people

Lucy Dahner, Brook

Brook’s main aim is to assist young people to develop the confidence, skills and understanding necessary to enjoy and take responsibility for their sexual lives, sexual health and emotional wellbeing, and in line with this aim, their 3 core areas of activity are:

i. Clinical and support services
ii. Education and training
iii. Advocacy, campaigning, lobbying and influencing

In the Merseyside area, Brook has worked with 56% of high schools and special schools in Liverpool, and 68% of high schools and special schools in the Wirral, providing information, education, counselling, confidential clinical and mental health support services, professional advice, and training.

A 2015-16 service review identified a gap in service provision for disabled young people, and therefore in 2017-18 there was an attempt to increase the access to Brook for disabled young people. Services provided to disabled young people focused around sexual health and contraception, healthy relationships, gender and sexuality, and one-to-one interventions.

Because disabled young people often face barriers in exercising their sexual rights, predominately because of de-sexualisation, fetishisation and infantilisation, as well as lack of access to sex education and sexual health services, Brook is attempting to change this by providing current, relevant and appropriate relationships and sex education, promoting bodily autonomy for young people, and promoting equality and diversity, particularly around gender and sexuality. They also offer support sessions for parents, carers and other RSE professionals, so that young people will be well-supported to develop and exercise their sexuality in a safe and healthy manner.

Catherine’s presentation was focussed on the importance of teaching consent to children and young people through relationships and sex education (RSE). She presented some really worrying figures about children and young people’s lack of knowledge of sexual consent issues, largely due to the fact that they had not been taught about them, either by their parents or at school. For example, the survey results show that 31.7% of males surveyed would use force to obtain intercourse and 13.6% said they would rape a woman if no-one found out. On the other hand, there was an exceptionally low rate of reporting of unwanted sexual contact, mostly because victims felt that the incident was not serious enough, or did not think that the incident amounted to a criminal offence.

It is clear therefore that consent should be well-defined and taught clearly to children and young people. Consent involves 3 aspects: feeling it, saying it, and showing it, and that if there is doubt as to any of these elements, children and young people should be taught not to proceed with sexual activity. Pleasure is an essential part of consent — if young people are taught that sex is, and should be, pleasurable, then they are more likely to be able to decline sexual activity that they are uncomfortable with, or might not enjoy.

An effective RSE education programme should therefore have identified the relevant health goals, identify behaviours that can be changed and the factors affecting these behaviours, and then create multiple activities to change each factor.

Catherine also touched on the theory of ‘dignity of risk’, which is the idea that self-determination and the right to take reasonable risks are essential for dignity and self-esteem, and should therefore not be impeded by excessive caution exercised on the part of parents or carers. Hence, the crucial consideration is one of how to create multiple educational activities to engage with young people and to teach consent through the promotion of pleasure in educational discourse.

Teaching Relationships and Sex Education (RSE) in a special school setting

Marie Armstrong, Bank View High School

Marie had been invited to speak about her experiences of teaching RSE in Bank View High School, which caters to pupils aged 7-19 with complex learning difficulties.

In her presentation, she outlined the challenges of teaching RSE in schools, and how RSE is currently inadequately taught across schools, leaving children and young people vulnerable to inappropriate behaviours and sexual exploitation. Some challenges include:

• The language used in RSE lessons, and how to make lessons age-appropriate
• The parental right to withdraw children from RSE

She also highlighted the importance of teaching RSE in a special needs school. RSE aims to help and support young people through their physical, emotional and moral development, and as such, it is as much an entitlement for young people with special needs, as with any other young person. It is a fallacy to assume that young people with special needs will not want to have sex, or will not need sex education.

At the moment, children and young people are exposed to higher risks of sexual abuse online, and this risk is 3x higher in relation to disabled children. It is therefore even more important to teach RSE to disabled children and young people.

Marie’s presentation covered some examples of Bank View High School’s good practices in providing RSE to their pupils, and she also highlighted some of the topics that the school will cover once the new curriculum for RSE is rolled out into schools, in 2019/2020.
- Different types of relationships, including friendships, family relationships, dealing with strangers and intimate relationships;
- Sexuality and same sex relationships
- How to recognise, understand and build healthy relationships, including self-respect and respect for others, commitment, tolerance, boundaries and consent, and how to manage conflict, and also how to recognise unhealthy relationships;
- How relationships may affect health and wellbeing, including mental health
- Safety online and pornography
- Factual knowledge around sex, sexual health and sexuality
- The media and its influences

Comments and Suggestions from Participants

All participants were asked to provide feedback and further comments on the discussions taking place at the workshop. The following reflect all the comments that were returned:

- BME disabled children's/cultural diversity
- Online web site protection/internet filtering
- Improved RSE programmes in primary/secondary school, in conjunction with Ofsted
- Information provided to disabled under-18s should be: accessible, from reliable sources, suitable to the viewer, and supported by the school/home environment
- Pressing issues for disabled under-18s in relation to their sexuality education include: the lack of sexuality education; sexuality education is poorly delivered by school/home, misinformation; restricted information by school/home
- Pressing issues for service providers and practitioners: insufficient knowledge/training in the field; lack of confidence to deliver the material; lack of third party agencies to support requests, funding.
- Crucial issues for research with disabled under-18s: listening to what these young people feel needs to be researched; providing a forum for their concerns nationally.
- Participatory research should involve young people from the onset, and be fully inclusive.

One crucial issue which arose repeatedly in the presentations was the lack of resources/funding available to commission sexual health and educational services for disabled young people. This seems to be particularly prevalent in the age of austerity and budget cuts.

Another significant point was that disabled children (for example those with behaviour issues) are sometimes excluded from mainstream lessons on sexuality education due to perceptions by teachers that it was not suitable for them, or that they would be disruptive in class.
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