



Insights from Focus Group Discussions on Sexual Health between Individuals with Spina Bifida and or Hydrocephalus

by
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Introduction

As parties to the UN Convention on the Rights of Persons with Disabilities the European Union and its Member States are obligated to 'combat stereotypes, prejudices and harmful practices relating to persons with disabilities in all areas of life' as per article 8 and to 'provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes' as per article 25 of the UNCRPD.

Individuals with Spina Bifida and/or Hydrocephalus and other disabilities face prejudice, misconceptions and stereotypes when it comes to sex education, this creates barriers to accessing information, knowledge and experiences which is crucial for one's health and wellbeing. Of which discrimination, inaccessibility, marginalisations and even exclusion when accessing sex education and sexual health programmes is one of the first and most serious manifestations of those barriers.

For many individuals with Spina Bifida and Hydrocephalus and also for persons with other forms of disabilities, there often is no sex education available at all. Access to sex education and sexual health programmes is a vital foundation for people of all ages to be empowered and safe when embarking on healthy romantic and sexual relationships. These societal barriers to sex education and sexual health programmes are symptomatic of a wider misconception in our societies regarding the lives of persons with disabilities.

Persons with disabilities want to be seen as human beings who have sex, just like everyone else. Continued discrimination and exclusion for persons with disabilities in accessing these services and information resources is a serious breach of human rights which increases their vulnerability to abuse and risk of social exclusion.

The International Federation for Spina Bifida and Hydrocephalus (IF) presents this document to provide steps in braking the taboo on the important topic of sexual health for persons with disabilities. This document builds upon an earlier by the IF Task Force SBH and Sexual Health who conducted survey (2019) on sexual health and body awareness among youth with spina bifida and hydrocephalus (<https://www.ifglobal.org/our-work/youth-group-sexuality-body-awareness/>).

To support IF members' efforts to bring the most appropriate care and support to persons with SBH, IF facilitated several focus group discussions on the important topic of sexual health among its members. The results and recommendations for the way forward are presented in this report.

Method

Invitations to participate in an online focus group discussion were sent to all IF's members through social media channels and newsletters. Members were able to show interest in joining focus group discussion through registration. An online anonymous registration form was created in Survey Monkey and shared with IF's members through social media channels and newsletters. Upon registration, interested participants received further information to join the focus group discussion by email.

To take into account the wide range of ages, gender, and time zone differences, multiple focus group discussion were scheduled during November 2020. Registrations of a total of 43 interested participants resulted in five initial scheduled meetings.

In preparation for the focus group discussions the members of the IF Task Force SBH and Sexual Health developed questions to pose during the sessions. These included:

1. Do you feel the topic of sexuality and disability (specifically SBH) is open to conversation to the disability community and overall society? Why do you think this is? (e.g., disclosure)
2. What does sexuality / sexual health mean to you?
3. Does your disability influence your relationship with people you are attracted to?
4. Do you feel you have the necessary support from your healthcare provider(s)? What are possible barriers?
5. What can we do to support the needs on sexual health for persons with disabilities/ you?

The focus group sessions were led by trained members of the IF Task Force SBH and Sexual Health who are themselves individuals with spina bifida and hydrocephalus. During the sessions participants were asked to provide consent for the meeting to be recorded. Furthermore, an explanation was provided that recording will be used in an anonymous manner for the purpose of this report.

Results

Characteristics participants

In total, 43 interested participants with spina bifida and or hydrocephalus registered to receive further information on the focus group discussions (22 females/21 males). Further inspection of registrants showed the following totals per age category: eight between the ages of 18 and 30 years (5 female); seven were 30 years old (4 females); 21 between the ages of 31 and 50 years (13 female); and seven above the age of 50 years (all male). Five focus group meetings were scheduled. Upon registration, no cancellations were received.

Focus Group Sessions

A total of four group sessions were held including 14 participants. Outcomes of these sessions are described below.

Focus Group I

The first focus group session included a total of two participants, both females aged 28 and 31 years.

Challenges

In summary, the following challenges were highlighted: lack of communication on this topic; lack of examples in sexual education and disability; lack of knowledge and information from healthcare providers (e.g., gynaecologists); lack of self-acceptance; the need to overcompensate in a relation; mental health problems; uncomfortable to start the conversation; need to build confidence; consent.

Sexuality/sexual health

One participant explained in a clear way what sexuality means to her: "Sexuality is about being a woman, being responsible about my choices, being in a relationship". When discussing the topic of sexual health the following key themes were mentioned: receiving proper education, use of condoms, knowing what precautions to take, and as one participant said "what to do in the event of catching something and where to go to".

Opportunities

The following suggestions were provided by participants to enhance sexual health: increase places where people can meet (e.g., online forums); providing workshops on themes relevant to sexuality; discuss a broad range of topics incl. STD's and consent; the need for further informative documents on issues relevant for individuals with SBH.

Focus Group II

A total of four people participated in this session, all males aged between 27 and 30 years.

Challenges

The following challenges were highlighted: being seen as asexual; experiencing fear of rejection; there is an important role of religion/culture; existing taboo of LGBT and disability; feeling rejected when dating online/ in bed; intimidating topic (exposing yourself to someone); learning more on what is OK behavior when meeting people you like (e.g., flirting); afraid the disability scares people off; incontinence issues being a big problem; no available healthcare provider for this topic; not knowing who to go to for support; strict laws on prostitution (in some countries: being paid to go to a sex worker).

Positive

It was mentioned and confirmed by participants that doctors sometimes listen well and provide support despite a lack of knowledge on SBH;

Opportunities

The following opportunities were mentioned to bring the topic of sexuality broader under the attention for individuals with SBH. These included: having meetings to exchange experiences; making sexuality part of care/needs to have access to; society as a whole can learn and recognize people with disability as sexual.

Focus Group III

In this session, one woman and one man participated (ages 33 and 34).

Challenges

The following challenges were mentioned by the participants: sexuality is still a taboo; individuals with SBH are perceived as a-sexual; possible relationships are depending on medical status ("waiting until I feel better"); lack of confidence and self-esteem (body perceived as the problem); feeling afraid to openly communicate about experienced challenges; lack of knowledge and information from healthcare providers ("doctors asking silly questions"); seeing different doctors for different problems but no possibility to ask questions on sex.

Opportunities

Several opportunities were highlighted: talking about the topic increases better understanding and support; need for more scientific studies; educating doctors; talking with parents about sexual health & SBH.

Focus Group IV

During the second focus group session, three people were present of which two females (40, 45 years) and one male (42 years).

Challenges

The following challenges were highlighted: individuals with SBH are perceived as asexual; there is a lack of information on sexual intercourse and disability; low self perception and/or feeling insecure to talk about sex; lack of information from medical doctors and their understanding; need for healthcare services; barriers to talk about the topic with healthcare providers.

Positive

Several positive elements were mentioned such as that sex is a basic human right. Also, the participants shared that individuals with SBH can explore different alternative ways to be sexual interactive; learning from other people with SBH on the topic of sex.

Opportunities

The following opportunities were mentioned: the need for more information; providing inclusive education; invest to find solutions to medical problems; providing platforms for interaction; the international federation for spina bifida and hydrocephalus can assist national SBH associations with their work on sexual health.

Focus Group V

Three males participated with an age above 50 years.

Challenges

The following challenges were highlighted: lack of access to information on the topic; perceptions of others creating possible distance in online dating; there are existing stereotypes to overcome; and a clear need to provide more communicate on this topic with one another.

Positive

The participants mentioned several positive elements. For example, sexuality is no longer seen as a taboo; overall there is a large acceptance; individuals with SBH can be honest and open about their problems; improved communication on the topic of sexuality; feeling confident to discuss sex with partner (not anyone else); learning from other members within parent/patient associations; and an interest to share experiences through stories to empower others.

Opportunities

Three opportunities were summarized: need to collect information and further research (also by learning from existing documents); providing more information and make it accessible; providing opportunities to talk about the issue together with other individuals with SBH.

Conclusion

The relevance of sexual health as an important health aspect for individuals with spina bifida and hydrocephalus was highlighted. As illustrated in this report, for the topic of sexual health for individuals with spina bifida and hydrocephalus, there is ample room for improvement. Discussions among the in total 14 participants reflect the importance of sexual health as an important aspect of human right. Participants have emphasized on the need for further initiatives and provided several suggestions on the way forward.

With respect to future studies into the topic of sexual health for individuals with spina bifida and hydrocephalus, it is recommended to also investigate aspects including, but not limited to, common beliefs held by the general public, mental health interpersonal communication, and improvement of management and care.

Besides our current understanding on the important topic of sexual health, it is also meaningful to take into account possible factors prohibiting effective integrative approaches on (inter) national level. Analyzing interactions between science, practice, and policy is therefore of utmost importance.

On a European level, joint action plans have been carried out. For example, during December 2020 IF together with MEP Stelios Kympouropoulos and in close collaboration with the European Disability Forum (EDF), and the European Network for Independent Living (ENIL) host the first online event on disability rights and sexual health at the European Parliament. Through this partnership further actions are developed to breaking the taboo of disability and sexual health. As well as steps to advance the rights of individuals with spina bifida and hydrocephalus to ensure full implementation of the UNCRPD.

Given the importance of this topic, the clear signals from this reports, and recognizable aspects to all IF's members, in the near future further actions will be planned and prioritized.

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