#loveSAFe-SBH. Sexuality, Affectivity and Fertility: youth with Spina Bifida and Hydrocephalus between desires and taboos
INTRODUCTION:
ABOUT US
The group that is working on the project on sexuality consists of 16 young people with SBH from 9 different countries.

The original group was constituted by:

- **EU group**
  - Elisa García de Ceca (Spain)
  - Mirela Bukovac (Croatia)
  - Angela Radovanovic (Montenegro)
  - Ege Anli (Turkey)
  - Marcus Ward (Ireland)

- **Italian group**
  - Elide Bruna
  - Eleonora Giannetti
  - Francesco Ceppaglia
  - Ilaria Guidotti
  - Fabrizio Calza

During the activity, also other young people join the group:

- Rui Pedro (Portugal)
- Matteo Dadomo
- Rasmus Isaksson (Sweden)
- Pierpaolo Innaimo
- Mariapia Lestingi
The Youth Working Group was born in 2018 with the idea of discussing about a taboo topic: sexuality.

The targets of the group are young and young adults living with spina bifida and hydrocephalus.

The group has made a survey on the topic of sexuality that gathered 400 answers and will be analysed here.

The survey has been translated into 7 languages:
- English
- Spanish
- Flemish
- Turkish
- Montenegrin
- French
- Italian
WHAT AND WHY

- Why the topic of sexuality?
- Why a survey?
- How did we go about creating it?
- How did we collect our results?
- What did we learn?
Looking into...

1. GENERAL INFORMATION (Elisa)
2. SEXUAL EDUCATION (Rui)
3. SELF ESTEEM AND BODY AWARENESS (Eleonora)
4. MEDICAL INFORMATION (Angela)
5. CONCLUSIONS AND NEXT STEPS (Elisa & Carmen)
1. GENERAL INFORMATION

- Aimed at both, minors and over 18 people with SBH
- IF intended to reach out to Young people from any nationality.
- However, the majority of responses were from Europe (80%)
- More or less gender parity in responses:
  - 58% females vs 42% males
  - 4 gender fluid
- Most of responses from people over 35.
- For people over 35 they no longer live with their families (not the case for ages 18-35).
The majority of the participants, (61%), about 242 out of 396, have received some kind of sex education, against 39% who have not, about 154.
Out of all participants, 66% said that they had never received any sex education and/or information specific to Spina Bifida and Hydrocephalus.

- We can conclude that there still is a lack of sex education related to sexuality and SB/H;
- Schools and other sources of education still neglect the people with Spina Bifida by not giving them information related to sexuality and SB/H;
- There is still a lot of work to do on sexual education, for example to let people without disabilities understand how sexuality and disability work in order to fight stereotypes (i.e. people with disability have to be in a relationship with another person with disability).
The main reasons are:
- do not have a partner (166),
- embarrassment of leakage of bladder and bowel (106)
- lacking in confidence with their own physical appearance (105).
A great majority of participants knows their own body and this specific issue (only 14% of men said the quality of the erection is unknown and only 35% of women said that their vaginal lubrication is unknown).
3. SELF ESTEEM AND BODY AWARENESS

- Sources of information: online, friends, doctors, parents
- Clear difference between people with SBH and those without disabilities
- Role of the parents
- Gap between desired informations and available/provided ones

Level of agreement with the following statements:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Never</th>
<th>Sometimes</th>
<th>Always + Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>If questions on sex, I talk to doctors</td>
<td>31</td>
<td>96</td>
<td>151</td>
</tr>
<tr>
<td>If questions on sex, I look online</td>
<td>122</td>
<td>41</td>
<td>153</td>
</tr>
<tr>
<td>If questions on sex, I talk to my friends</td>
<td>81</td>
<td>153</td>
<td>153</td>
</tr>
<tr>
<td>If questions on sex, I talk to my parents</td>
<td>27</td>
<td>153</td>
<td>153</td>
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**Talk to doctors**

<table>
<thead>
<tr>
<th>%</th>
<th>Every months</th>
<th>6</th>
<th>Once a year</th>
<th>Every 2 years</th>
<th>Less than every 2 years</th>
<th>I have never been</th>
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<tbody>
<tr>
<td>Never</td>
<td>41</td>
<td>48</td>
<td>60</td>
<td>64</td>
<td>60</td>
<td>60</td>
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<tr>
<td>Sometimes</td>
<td>47</td>
<td>41</td>
<td>36</td>
<td>32</td>
<td>36</td>
<td>36</td>
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<tr>
<td>Often</td>
<td>4</td>
<td>9</td>
<td>1</td>
<td>1</td>
<td>4</td>
<td>4</td>
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<tr>
<td>Always</td>
<td>8</td>
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<td><strong>Total</strong></td>
<td><strong>100 (59)</strong></td>
<td><strong>100 (157)</strong></td>
<td><strong>100 (45)</strong></td>
<td><strong>100 (73)</strong></td>
<td><strong>100 (50)</strong></td>
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Missing values: 15

**Go to the gynecologist**

<table>
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<tr>
<th>%</th>
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Missing values: 15
**General body confidence:**
- embarrassment (167), need to wear nice clothes (195), comparison (152 sometimes)
- social comparison with people without disabilities
- social interaction based on care: limited experiences
- stereotyped models

**How does disability affects social life:**
- talking about SBH (160 always/often)
- engagement in social interactions (150 says that are not limited, 116 always)
- managing problems while outside (i.e catheter): 235 any problem/shame

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**Level of agreement with the following statements:**

- When out, I feel embarrassed
- When out, I wear nice clothes
- When on date, I openly talk about my disability
- Disability stopped from talking to someone I was attracted
- If someone embarrassed, I make a joke
- Look for role models online
- I compare myself to others
- When out, I don't go to the bathroom
HOW DO BODY AWARENESS AND CONFIDENCE AFFECT SEXUALITY?

MAIN CONCERNS:
- bowel and bladder leakage (91 answers)
- orgasm (68 answers)
- physical appearance (68 answers)

- People with SBH might not have the adequate information about their sensations/body management in intimate situations
- improving body awareness might help people with SBH being more confident and engaging in romantic/sexual relationships
4. MEDICAL INFORMATION
5. CONCLUSIONS

MAIN CONCERNS

- Lack of access to sex education focus on SBH
- Continence management
- Self-esteem
- Doctors - young people relationship
6. NEXT STEPS

- Incontinence management - Intl Youth Day
- Qualitative research survey
- European Parliament event
THANK YOU FOR THE ATTENTION!