

# YOUTH INTERNATIONAL CONFERENCE

**#loveSAFe-SBH. Sexuality, Affectivity and Fertility:  
youth with Spina Bifida and Hydrocephalus between  
desires and taboos**



*5-6 October 2019  
Varese, Italy*

The background features abstract, overlapping geometric shapes in various shades of green, ranging from light lime to dark forest green. These shapes are primarily located on the left and right sides of the frame, creating a modern, layered effect. The central area is a plain white space where the text is placed.

# INTRODUCTION: ABOUT US

# Youth Working Group members

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 Garcia 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)

Rasmus Isaksson (Sweden)

Matteo Dadomo

Pierpaolo Innaimo

Mariapia Lestingi

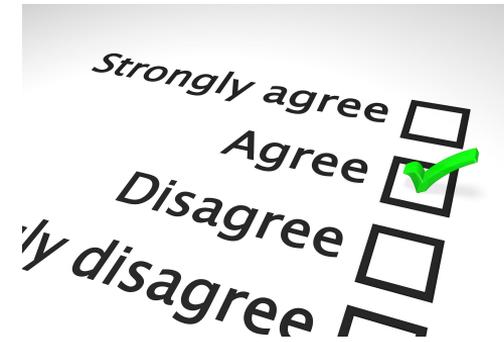
The **Youth Working Group** was born in 2018 with the idea of discussing about a **taboo topic**: sexuality.

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

1

- Aimed at both, minors and over 18 people with SBH

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- IF intended to reach out to Young people from any nationality.
- However, the majority of responses were from Europe (80%)

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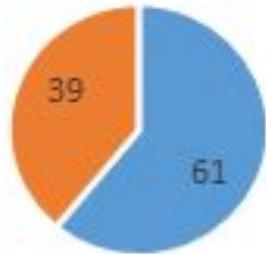
- More or less gender parity in responses:
- 58% females vs 42% males
- 4 gender fluid

4

- 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).

## 2. SEXUAL EDUCATION

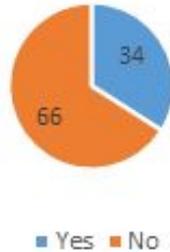
Have you received any kind of sex education?



■ Yes ■ No

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.

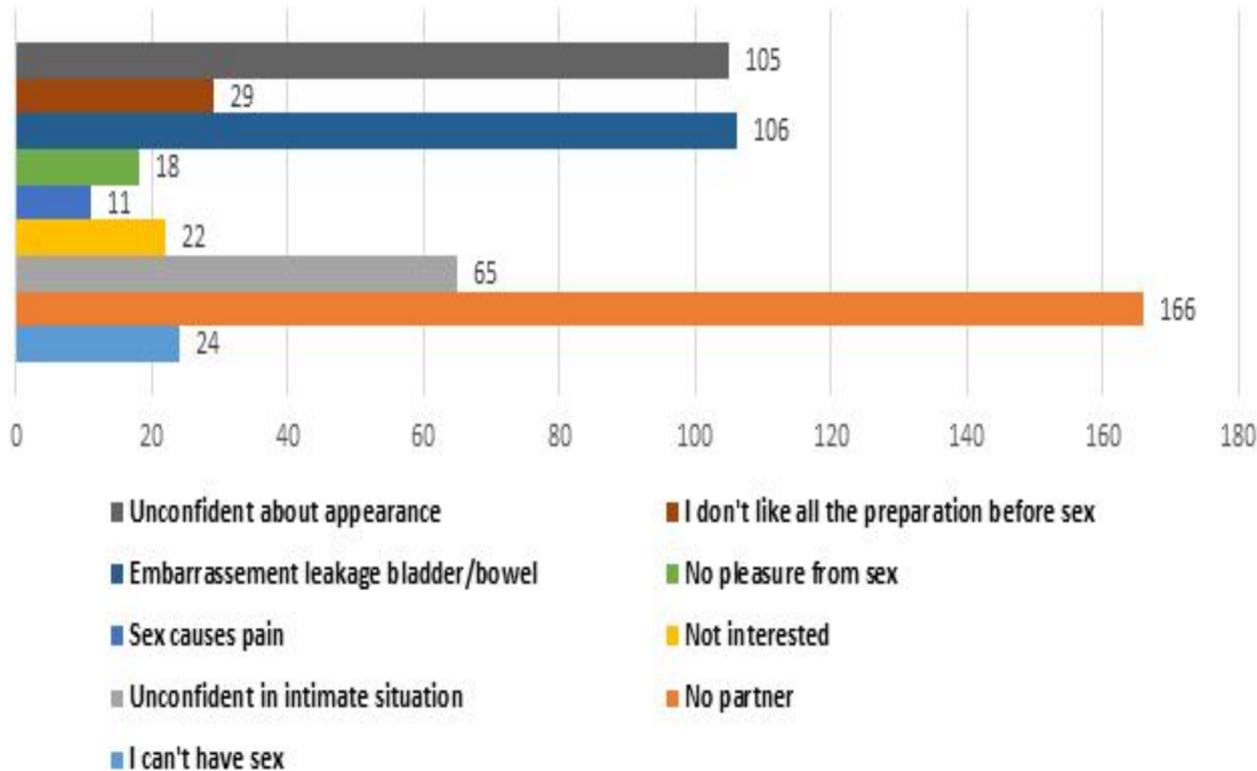
Have you received any sex education and/or information specific to Spina Bifida and Hydrocephalus?



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).

## Reasons people are not sexually active



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).

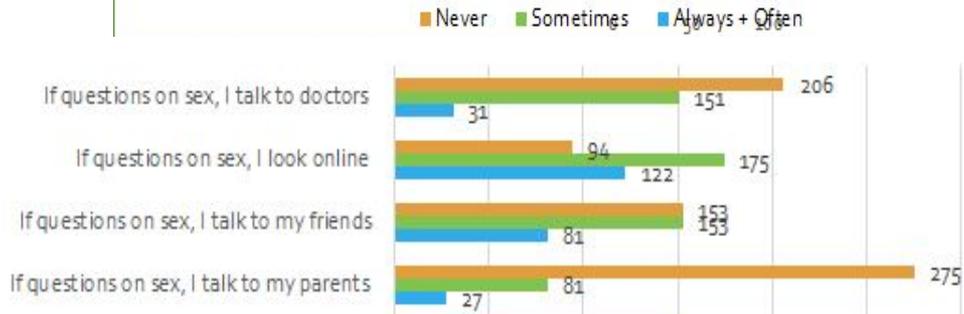
<b>ERECTION %</b>		<b>QUALITY %</b>	
Yes	58	Hard	65
No	14	Soft	21
I don't know	28	Unknown	14
<b>Total</b>	<b>100 (218)</b>	<b>Total</b>	<b>100 (141)</b>

<b>VAGINAL LUBRICATION %</b>	
Sparse	7
Normal	58
Unknown	35
<b>Total</b>	<b>100 (253)</b>

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

Level of agreement with the following statements:



- ❖ 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



Talk to doctors %	Go to the gynecologist				
	Every 6 months	Once a year	Every 2 years	Less than 2 years	I have never been
Never	41	48	60	64	60
Sometimes	47	41	36	32	36
Often	4	9		1	4
Always	8	2	4	3	
Total	100 (59)	100 (157)	100 (45)	100 (73)	100 (50)
Missing values: 15					

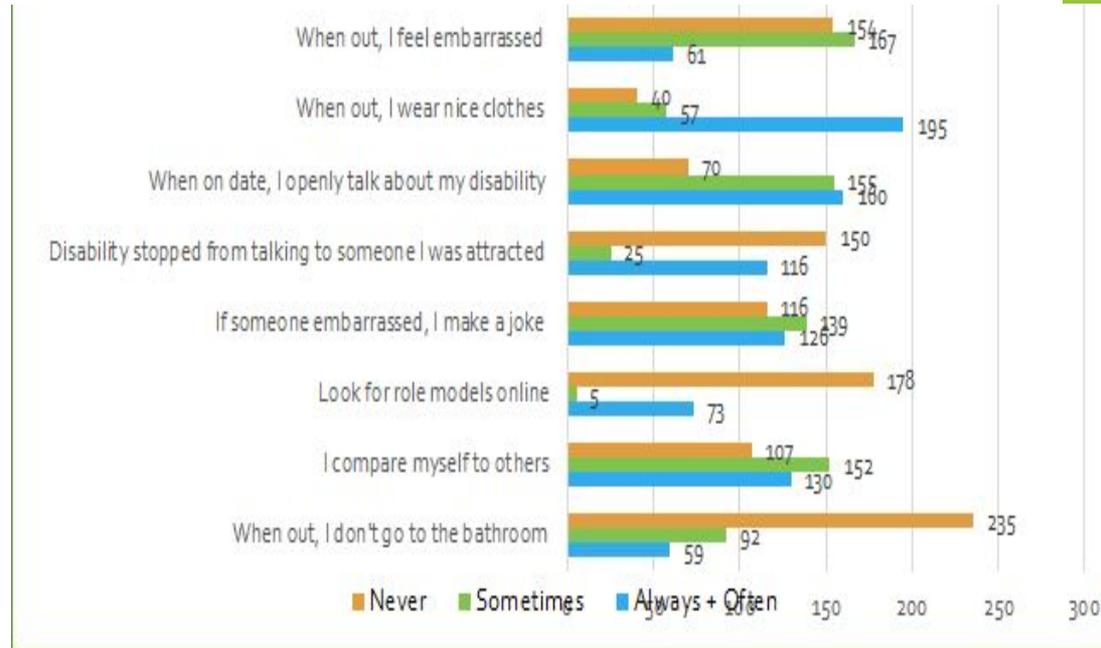
### ❖ General body confidence:

- 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:

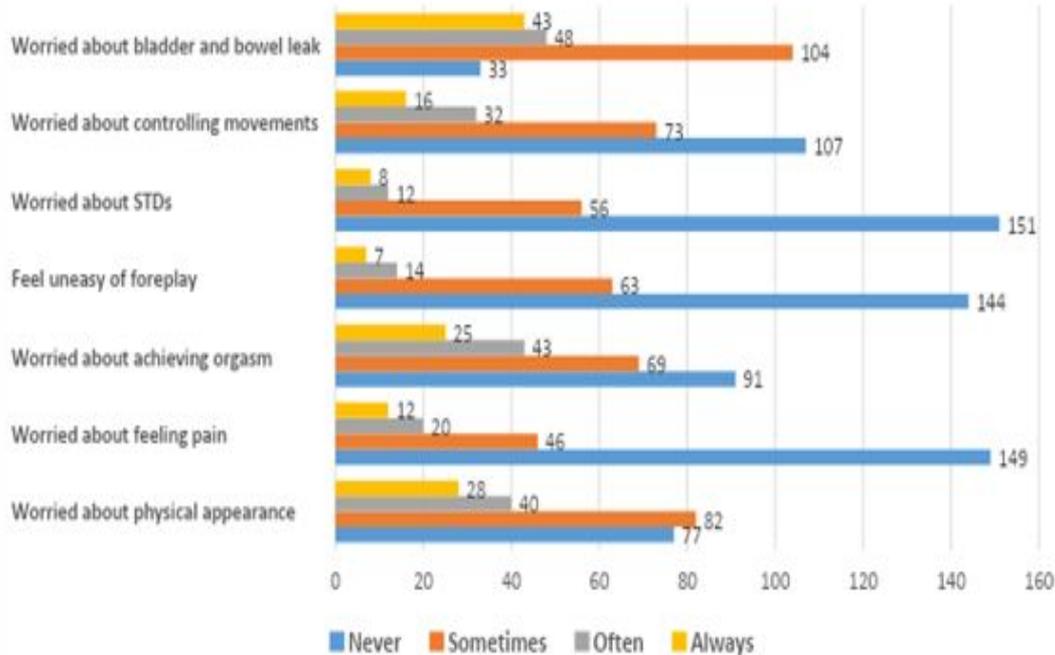
- talking about SBH (160 always/often)
- engagement in social interactions (150 says that are not limited, 116 always)
- managing problems while outside (i.e catheter): 235 any problem/shame

### Level of agreement with the following statements:



## HOW DO BODY AWARENESS AND CONFIDENCE AFFECT SEXUALITY?

Agreement with the statements



### 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

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# 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!*