

GUIDANCE TOOLKIT

GAMES FOR IMPROVING AFFECTIVITY IN YOUNGSTERS WITH INTELLECTUAL DISABILITIES



Project n° BG01-KA220-YOU-000087092



Co-funded by
the European Union



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The project


The GIAff4ID (Games for Improving Affectivity in Youngsters with Intellectual Disabilities) project wants to break stereotypes around sexual education and affectivity of Young People with Intellectual Disabilities (YPWID), showing that gaining independence over choices regarding healthy sexual or sentimental relationships increases persons with disabilities' participation and involvement in community life.

The partnership

- Nationalna Asotsiatsia Na Resursnite Uchiteli (NART)
- Centro di Ricerche e Studi Europei - future business (CRES)
- European Association of Service Providers for Persons with Disabilities (EASPD)
- Eyropaiko Institoyto Topikhs Anaptykshs (EILD)
- Associacio Programmes Educatius Open Europe (Open Europe)
- Zihinsel Yetersiz Cocuklari Tetistirme Ve Koruma Vafki (ZICEV)



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The objectives of the project

GIAff4ID's general objective is to provide youth workers with adaptable tools to offer relevant Sexual and Affectivity education to YPWID.

In particular, this project:

- Promotes a shift from defensive to **positive discourse** when addressing the sexuality and affectivity of YPWID.
- Highlights a **community discourse** that represents the link between supporting YPWID to gain independence in making informed choices about their sexual or romantic relationships and their integration and participation in community life.
- Supports the creation of **tailored content** and enhances the skills and tools of youth workers in order to help them support YPWID to make informed and appropriate decisions about their sexuality and affectivity.
- Supports youth workers' understanding of the need to change the discourse, to **encourage self-advocacy** and to empower YPWIDs to express their sexual and emotional needs, expectations, and choices.
- Acknowledges the need to adapt to diverse learning needs and to be inclusive through flexible learning objectives and a game-based learning approach.



The Guidance Toolkit: one of the outputs produced under the project

Several other products have been developed as part of the project. One of these is a **Games Compendium** tailored to young persons with intellectual disabilities, created to familiarise youth workers and carers with **Game-Based Learning Activities (GBLA)** and to provide them with an adaptable tool for delivering relevant sexual and emotional education to them. Such an approach would greatly help both social workers - by providing them with new tools and teaching materials - as well as the young persons with intellectual disabilities who would be able to benefit from this brand new learning method by improving their overall understanding of the subject. The partnership strongly recommends reading this toolkit in conjunction with the other materials produced as part of this project.

Disclaimer

The European Commission support for the production of this publication does not constitute endorsement of the contents which reflects the views only of the authors, and the Commission cannot be held responsible for any use which may be made of the information contained therein.

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SECTION 1

Section 1

Legislative Introduction - Sexual and Reproductive Health Rights

Sexual and reproductive health and rights are human rights.

A wide range of laws and regulations, both at international and European levels, recognise and enshrine their importance.

Persons with disabilities have the equal right to free and full enjoyment of and access to their sexual and reproductive health, rights, and services.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), that is ratified by the European Union and its Member States, explicitly states that persons with disabilities have the same human rights as everyone in all areas of life.

The right of persons with disabilities to the free and full enjoyment of, and access to, their sexual and reproductive health and rights is affirmed in several articles.

A central article is Article 12:

- It covers the right of persons with disabilities to equal recognition before the law and to legal capacity on equal basis with others.
- Legal capacity is the ability to hold and exercise rights. It is key to the meaningful participation in society. It is an inherent right, granted to all individuals!
- Non-enjoyment of legal capacity may interfere with the right to employment, independent living, health, mental & physical integrity of the person, etc.
- Legal capacity also covers sexuality.
- It implies receiving appropriate support to effectively exercise one's own legal capacity.

Section 1

Legislative Introduction - Sexual and Reproductive Health Rights

What does Sexual and Reproductive Health (SRH) rights mean?

Every individual has the right to make their own choices about their sexual and reproductive health.

Every individual must have the ability to make free and informed decisions, and must have access to accurate, affordable, accessible and high-quality information and services.

The right to sexual and reproductive health includes a satisfying and safe sex life, as well as the ability to procreate and the freedom to decide if, when and how often do so.

Other articles of the UNCRPD enriching sexual and reproductive rights:

- Articles 3 and 4 emphasise the importance for persons with disabilities to have individual autonomy and independence, as well as to be actively involved in decision-making processes.
- Article 17 relates to physical and mental integrity.
- Article 22 stipulates the duty to refrain from interference with privacy.
- And Article 23 calls for the elimination of discrimination in all matters relating to marriage, family, parenthood and relationships, in order to ensure that persons with disabilities can enjoy the right to marry, retain fertility and decide freely and responsibly on the number and spacing of their children. In the exercise of these rights, persons with disabilities should have access to age-appropriate information, reproductive and family planning education, and should be provided with the necessary measures to this effect.
- Article 25 relates to the right of free and informed consent in the area of health.

Section 1

Legislative Introduction - Sexual and Reproductive Health Rights

Definition of Sexual Education ?

Providing a definition can be quite complex since every country has its own national legislation (or not) defining concepts related to sexuality, including sexual education.

In this Toolkit, we will refer to the definition provided by the WHO:

"Sexuality education means learning about the cognitive, emotional, social, interactive and physical aspects of sexuality. Sexuality education starts early in childhood and progresses through adolescence and adulthood. For children and young people, it aims at supporting and protecting sexual development. It gradually equips and empowers children and young people with information, skills and positive values to understand and enjoy their sexuality, have safe and fulfilling relationships and take responsibility for their own and other people's sexual health and well-being. It enables them to make choices which enhance the quality of their lives and contribute to a compassionate and just society" (WHO Regional Office for Europe, and Federal Centre for Health Education 2010)

"Accurate and developmentally appropriate sexual health education, which acknowledges and affirms all people's sexuality, is necessary for a young person to learn about self, relationship safety, and responsibility."

Positive
Approach

Empowerment

Section 1

Legislative Introduction - Sexual and Reproductive Health & Rights

In 2006, the World Health Organisation defined sexuality as "*a central aspect of being human throughout life*". It also emphasised the importance of promoting a positive approach to sexuality, which should be shared and promoted by policy makers, educators and health care providers in order to develop sexually healthy societies.

Young persons with disabilities have the same sexual and reproductive health and rights needs that their peers without disabilities do.

They are sexually active and similar needs and concerns about their sexuality, relationships and identify.

However, negative societal attitudes and stigma persist with regard to disability and sexuality.

Young persons with disabilities have been found to have low levels of sexual and reproductive health knowledge.

This low level exposes them to high risks of dangerous sexual behaviours, abuses, and overall negatively impact the exercise of their legal capacity and their ability to take free and informed decisions regarding their body and relationships.

Intersexectionality - Youth & Disability

Youth - Young persons with disabilities are disproportionately affected than young people without disabilities on the path to adulthood. They are more likely to be isolated and are less likely to achieve the same education, employment or health sexual relationships than their peers without disabilities.

The greatest barriers to inclusion of children with disabilities are stigma, prejudice, lack of knowledge, and lack of training and capacity building.

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Legislative Introduction - Sexual and Reproductive Health & Rights

Intellectual disability

Persons with intellectual or psychosocial disabilities, in particular women and girls, are exposed to greater risks of violence and abuses.

Persons with intellectual or psychosocial disabilities are often placed under guardianship or other regimes, depriving them of their legal capacity.

Persons with intellectual or psychosocial disabilities, especially women and girls, are often discriminated and subject to stereotypes and intense stigmatisation.

Persons with disabilities still face a lack of free and full access to and enjoyment of their sexual and reproductive health and rights.

Barriers are multiple and include:

Stigma and social misconception

Limited personal autonomy

Lack of empowerment

Lack of accessible SRH services and information

Insufficiently trained staff and unadapted services

Section 1

Legislative Introduction - Sexual and Reproductive Health & Rights

Sexual education and affectivity are stereotypically considered as non-fundamental topics for persons with disabilities.

When discussed, their sexuality and affectivity are examined in a defensive way, with a discourse focused on protection from harm, abuse and violence, to which they are more vulnerable.

It is essential to shift discourse from a negative to a positive approach when addressing the topic of affectivity and sexuality of YPWD.

All young people need access to and can benefit from sexual health information. Young people with disabilities have the same right to this education as their peers. However, considerations must be made in order to modify the program to allow for information to be understood and learned in a way that is meaningful to them.

It is essential to provide with accessible and high-quality education materials that are adaptable to the different learning needs.

Persons with disabilities have the right to freely and fully enjoy and access their sexual and reproductive health and rights as any other human being. **This contributes to their integration into the community, supports their autonomy and independence in making decisions in this area of life, and ultimately helps prevent abuse.**

Sexual education supports children and young people with disabilities in their sexual development and contribute to their health and wellbeing.

The important role of youth workers

"Education and skill practice are key to promoting healthy and mutually respectful behavior, regardless of the young person's abilities" (Advocate for Youth, 2016).

The desk research and interviews carried out as part of this project show that, in most countries, **sexual education is not sufficiently or not adequately covered in schools:**

- Sexual education often focuses primarily on reproductive biology and prevention of sexually transmitted infections;
- Even though these topics are essentials, other broader aspects of sexuality and affectivity, such as consent or gender identity, are often missing;
- Cultural, societal and religious factors, as well as in some cases outdated legislations, are the primary barriers to an homogenously completed and effective sexual and affective education in schools of a given country;

Additionally, results report that YPWID are disproportionately affected by this situation:

- **Stigma, negative societal attitudes and misconceptions surrounding disability and sexuality** hinder open and inclusive discussions and sexual education;
- Barriers in accessing comprehensive sexual education due to a **lack of inclusive curricula and appropriate teaching materials, as well as lack of trainings for teachers and educators;**
- **Limited access to support networks** that address their sexual health and affective needs;

The important role of youth workers

Educators and youth workers are in a unique position because they know the different skills and learning styles of their young audience and are therefore well placed to support decisions on when and how information about sexuality should be communicated to a young person.

- Educators have the responsibility of assisting students in their growth and development, and sexuality is part of that growth.
- Adequate sexual health education must be taught by trained educators/youth workers. Sexual education must be taught alongside a positive approach to sexuality, with the objective of empowering, responding to the needs and participating in improving the well-being of YPWID.
- Content and teaching methods must be flexible and modified to meet the individual's needs.
- Educators/youth workers should involve parents/guardians in the drawing up a positive and progressive educational plan that takes into account of factors including the level of development of the young, their cultural and familial context, etc.
- It is essential for youth workers to learn as much as possible about the young person they are working with, including the diversity of disability, learning abilities and sexual experiences.
- The legal capacity of young people with disabilities must always be at the centre of discussions. Educators should also include persons with disabilities in the development and implementation of sexual education, including monitoring and evaluation/feedback processes.
- Open discussions between parents, teachers, healthcare providers and other educators is required to clearly define their roles and responsibilities in sexuality education of the young.

Section 1

Some topics of sexual education and affectivity of YPWIDs

This section is a compilation of some of the topics on which YPWIDs have indicated that they feel unprepared and/or ill-equipped to deal with. The information that appears here is the result of a series of interviews conducted in each of the partner countries by YPWID youth workers.

General Conclusions

Young people with intellectual disabilities tend to be influenced by the negative discourse and stigma that society still holds with regard to their sexual and emotional capacities.

Sexual and emotional subjects are still largely taboo. During the interviews, this was reflected in a perceptible embarrassment and shyness when related questions were asked.

General Conclusions from Interviewers

Overall, the youth workers who took part in the interviews raised the following points:

- The target audience (12-17 year olds) was consistently considered too young for certain subjects to be discussed, both in terms of understanding and the ability to obtain parental consent.
- Some youth workers highlighted the lack of legal frameworks and formal training to enable them to address these topics in an effective and accessible way.
- Some sex-specific subjects, such as gender identity, were difficult to discuss in some countries due to social and religious factors.
- It was regularly reported that the target audience had difficulty expressing their *own* opinions.
- The importance of including graphic material as part of sex and emotional education, particularly through drawings, cartoons, videos, etc., was emphasised.
- Involvement of parents is essential and inevitable when addressing the topic with this target audience (minors).

Some topics of sexual education and affectivity of YPWIDs

About sexual education in general

Sexuality is not considered a priority in the lives of young people with intellectual disabilities.

- Overall, familiarity and knowledge of sex education is very limited. Additionally, the more topics discussed concerned personal sexual activity and decision-making (e.g. sexual pleasure, sexual desires), the less clear the understanding. Some interviewers said this reflected the fact that they saw themselves as more of a passive actor in relation to these topics.
- The more generic/non-tangible the words used (e.g. "love", "relationship"), the less clear the understanding.
- It was observed that the lack of a safe space or opportunity to talk about sexuality could be part of the reason why most respondents do not ask questions or seek advice about sexuality. For these reasons, parents were often cited as the main (but often occasional) contact person with whom they discuss sexual issues. Aside from parents, internet and social media were cited as a main source for young persons with intellectual disabilities to get information on sexuality. These sources, in the absence of appropriate guidelines, particularly with the spread of "fake news" and misleading information, could be more harmful than instructive.
- A gender component was reported: knowledge of sexual subjects and the ability to obtain parental consent to conduct interviews were lower in girls with intellectual disabilities than in boys.

Sexual information for young persons with intellectual disabilities was found to be largely based on the information they can get/hear from friends and family or social platforms, and not on the education they have received.

Section 1

Some topics of sexual education and affectivity of YPWIDs

About specific sex-related topics

- Among the respondents who had received some form of sex education, the topics covered only concerned privacy, personal hygiene and protection against abuse.
- Most respondents lacked knowledge about sexual orientation and gender identity.
- Most respondents lacked knowledge about sexual pleasure, sexual desire and autoeroticism.
- Most respondents communicated that they did not find the opportunity to talk about sex and that they felt embarrassed when they did.

- Most respondent showed some degree of comprehension for family and friendship.
- Most respondent can describe the activity of sex in a purely physical perspective.
- In some countries, respondent demonstrated strong awareness of the concept of consent.

Specific challenges identified by youth workers

- Absence of legal frameworks for sexual education of young persons with intellectual disabilities.
- Insufficient trainings, knowledge and materials on the subject for youth workers to provide personalised, flexible, accessible and efficient sexual education.
- Lack of structure and 'safe space' for young persons with disabilities and youth workers to communicate, as well as for including parental involvement.
- Resistance from parents
- Societal taboo
- Taboo among colleagues and within organisations

SECTION 2

Shift in narrative: a positive approach to the sexuality of persons with disabilities

Sexual education supports children and young people with disabilities in their sexual development and contributes to their health and wellbeing.

As previously said, many barriers exist, including social misconception of the sexuality of persons with disabilities, limited support and resources, untrained staff and inadequate materials. Additionally, due to competing priorities related to the general health and wellbeing of persons with disabilities, sexual and affective topics are seen as less important.

Many do not receive an appropriate education, namely an education that is adapted and oriented towards their empowerment, needs and development.

Sexual educational strategies and tools must be developed to empower young people with intellectual disabilities and help them express their needs, wishes and opinions. They must be made in a way that is adaptable to meet their individual needs and learning abilities.

- A **positive approach of sexuality** implies not only focusing on topics related to sexual health and protection, but also emphasizing the promotion of a satisfying sexual life and pleasurable sexual experiences.
- **Empowerment** should be at the centre of attention. It means supporting YPWID and equipping them with the tools they need to make their own well-informed decisions regarding their sexual health and sexuality. It also involves enabling them to ask questions or for support and access to services.
- It also includes **existence of positive structure, support mechanisms, materials, guidelines and trainings** for youth workers to understand their role and to teach sexuality to YPWID through a positive approach.

Recommendations for youth workers on how to foster YPWIDs speaking up for their sexual and emotional needs, wishes, and expectations

- **A safe space and punctual opportunities to talk about sexuality in a calm and accepting environment.**

In practice: youth workers need to be proactive and create learning opportunities for the young to see them as trusted referees to whom they can turn for advice. One practical implementation mentioned during the interviews was the practice of peer group activities on the topics, followed by individual meetings for more in-depth discussions.

- **Educators and social workers as political messengers:** sexuality and emotional relationships of young persons with disabilities are not taboo and must be considered as important as any other subject.

In practice: an example could be organizing events where all stakeholders are invited to raise awareness and foster discussion.

- **Involvement of parents/guardians in drawing up a positive and progressive educational plan.**

This is a key element, as educators need to take into account factors such as the young people's level of development, their cultural and family background, etc. It is essential to establish a climate of trust. This will also help to avoid situations where families and educators/carers shift responsibility onto each other.

In practice: Service providers should provide youth workers with guidelines to help them enter an open dialogue with parents on the division of responsibilities and on developing a progressive educational approach.

Recommendations for youth workers on how to foster YPWIDs speaking up for their sexual and emotional needs, wishes, and expectations

- **A personal approach:** youth workers to learn as much as possible about the young persons they are working with, including their surrounding environment, sensibilities and experiences on the topic.

In practice: Youth workers are generally in a unique position to know the young people they work with. However, additional work may be necessary. The involvement of parents/guardians is essential to get to know more about their personal environment. Games can also be a good way of finding out more about a young's sensitivities and personal experience.

- **An adaptable learning approach:** youth workers must always take into account the diversity of disabilities and learning abilities. While peer discussion can be a good approach to introducing certain topics and breaking down taboos, individual learning strategies may be necessary to ensure that every young person receives appropriate and accessible sexuality education.

In practice: the youth workers should decide which tools are the most appropriate. Creativity and adaptability are key. Here are some examples of techniques that may be used:

- Encourage **proactive behaviour**, for example through drawings.
- Use **concrete examples and words** rather than abstract concepts.
- Use **visual elements** to increase comprehension and stimulation, for example pictures, comics, books, magazines or mangas.
- **Encourage proactive behaviour ('building by creating')**, for example through drawings, interactive activities and games.

Recommendations for youth workers on how to foster YPWIDs speaking up for their sexual and emotional needs, wishes, and expectations

- **Young persons with disabilities at the centre:** young people must be directly involved in the development and implementation process to ensure a personal and adaptable approach that is truly effective. Materials and tools must take account of their opinions, wishes and expectations, and must be continuously evaluated in order to be improved. Confidentiality should be guaranteed.

- **Promote new threads of research and advocate for continuous trainings among your social service.**

In practice: youth workers must show their interest and commitment by participating in the implementation of research projects and by seeking further training.

- **Continuously encourage young persons with intellectual disabilities to speak up and express their wishes, needs and expectations.**

In practice: youth workers can do so, for example, by using storyboards that can portrait people advocating for their rights and expressing their wishes and needs. Additionally, implementation of mechanisms can be very useful, such as 'Supported Decision Making' mechanisms.

- **Use the support of external actors:** such as sex therapists or others, in order to offer training to youth workers, but also, whenever necessary, to provide direct support to young people.

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THANK YOU !

