SEXUALITY IN ADOLESCENTS WITH DISABILITIES

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Save the Children believes every child deserves a future. Around the world and in Albania, we give children a healthy start in life, the opportunity to learn and protection from harm. We do whatever it takes for children – every day and in times of crisis – transforming their lives and the future we share.

Author:
Dr. Besarta Taci, Clinical Psychologist, Psycho-Sexologist

Working Group:
Irena Çelaj, Project Officer, Save the Children
Eglantina Likaj, Project Coordinator, Help the Life Association

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Table of contents

Foreword

It is not easy at all to talk about sexuality as a series of issues inherited by our culture emerge, in which the moral aspect still dominates over private and even intimate behaviours. ***The way each individual understands and expresses sexuality is always dictated from their background, which includes lifestyle and feelings or suppressing emotions.***

It is not always possible for us to orally express why we behave in a certain manner, or to talk about our daily life, and all these remain trapped in our subconscious, in all those dimensions that the individual has difficulty in expressing.

Dr. Besarta Taçi
Centro Clinico Psicoterapia e Psicotraumatologia
Clinical psychologist, Psycho-sexologist, Practitioner at EMDR, deputy president of EMDR Albania

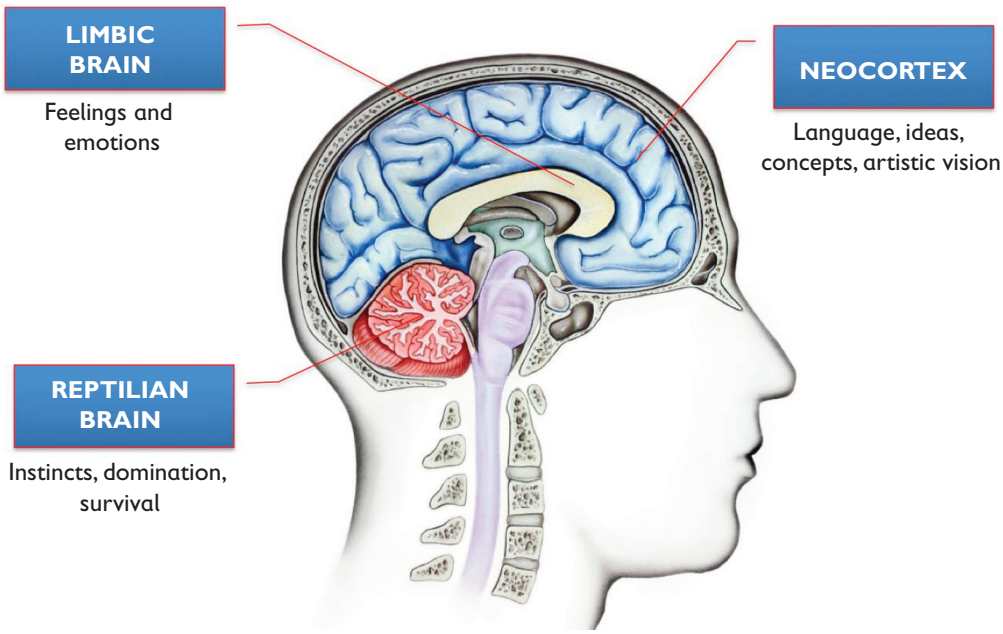
Sexuality – not simply a biological Process

Firstly, it is of importance for us to explain that this module is based on the most advanced scientific expertise in the field of sexology, and we will particularly follow the example of explaining the sexual evolution of humans, which presents the evolution stages of human beings (Veglia, 2001). In addition, we will adhere to the theory of Maclean, which divides our brain into three sections. The entire project is focused on explaining the sexual behaviours of adolescents by highlighting the identification of educational practices, which can simplify these behaviours, by parents. Thus, this is how the need to give an explanation on the sexual brain, a practice that informs parents and operators on the biophysical and psychological aspects of sexual stages emerged.

The evolution of human sexuality can be explained based on the evolution of species and the development of their brain up to the Homo sapiens, which is the earliest form of cerebral evolution that we have knowledge on: the human brain.

It is of importance to understand how we display our sexual needs and how we decide to start a relationship or even decide to have children who will inherit our genes, thus ensuring human survival on this planet.

This was not possible since the beginning of life, but thanks to the evolution of species, today we have a brain that is divided into three sections: the reptilian brain, limbic brain and neo-cortex, which are explained in detail below.



a. THE REPTILIAN BRAIN: the main function of the reptilian brain is *"to continuously reproduce by any means".* The reptilian brain controls reproduction and movement, impulses, "killing for food" and sexuality as a biological need.

Reproduction aspect: The reproductive capacity is related to reproduction, instincts, and self-preservation. It is the oldest and most primitive section of the brain, which is found in snakes, crocodiles, and lizards. In his book "Emotions and consciousness", Antonoi Damasoi has

stated that after the evolution from the reptilian brain, the function of mating was not simply to reproduce, meaning that alongside the emotional evolution of the brain, sexuality started to change as well. All living beings fight for their survival by protecting themselves, by attacking other living beings, by feeding, but also by having children, thus becoming a father or a mother. We all experience these intimate and touching feelings. Regarding fatherhood and motherhood in individuals with mental disabilities, the United Nations has adopted a Resolution stipulating the right to sexuality and parenting.

Play aspect: is the sexuality expressed through sexual play and seduction. Sexual play has been practiced since the beginning of time and it allows individuals to experience exploration, without having any responsibility. Even adults keep this play in their memory, which are not the traces of childhood or of the child that has been involved in sexual playing, yet while growing up we learnt the function of "petting" by someone who took care of us, thus we learned the effectiveness of this function by maintaining the same exploration methods. Through "pettings" by their mothers, children get familiar with love gestures, and then they play with their peers and experience different emotions. The brain cannot tolerate experiencing certain emotions before the individual reaching a specific biological maturity. This is considered as a form of protection. It is true that in terms of sexuality, many people with disabilities develop more slowly and other people take it for granted that people with disabilities do not have sexual impulses and think of them as children. It has been proven that this prejudice is harmful.

As professionals of mental health, we should be very careful with the dimensions of sexual play and should communicate by setting up groups that shall analyse the possible threats, the setting of boundaries, and the sound ways of expression.

b. THE LIMBIC/EMOTIONAL BRAIN: belongs to the social dimension. Social dimension stimulates emotions, the desire to be with someone or to couple.

Emotions give an overview of the individual's emotional state, but on the other hand, also diversify self-consciousness; they also give "life" to consciousness, which is related to an individual's emotional state. The idea of being a couple limits the freedom of an individual, which is determined by the partner. Society is not a feature attached only to human kind. For example, this feature is even stronger in wolves. The unique nature of human beings tries to give a meaning to every action it does. The way we feel for a person also affects how we behave towards them, thus creating a problem: the risk of a relationship. The evolution of the human brain has the duty to create a relationship, which provides individuals the security to raise children, where the concept of family and protecting cubs originates.

The fear of starting a relationship is interpreted differently by each individual. This interpretation depends on the background of the adult's childhood. The relationship can be *depressive*: the individual thinks that when starting a relationship, the risk of being alone becomes real and they constantly think that they are going to be abandoned, and in order to avoid this risk, they refuse to get involved in any type of relationship. This reaction is typical of individuals with an averting behaviour.

Phobic relationship. In this type of relationship, the individual strives for a relationship that is sentimentally safe, but once this relationship starts, the individual suffers from lack of freedom. When an individual that has always had disappointments in their life is called "darling" by someone else, experiences a self-assessment crisis. For example, if this was to happen to a girl that suffers from anorexia, she would think that she has a fragile and weak identity and that the intention of the "other person" was simply to hurt her.

Although these risks are experienced when someone is in a relationship (depending on different personalities), nature has found a way to help us link with others and start relationships. Individuals are motivated and they act based on the internal functionality to life. This is true especially for people with mental disabilities. The problem that these individuals face is that since they have a lower cognitive level, complex situations can come up in a relationship. This means that couples with mental disabilities are in need of more support.

c. NEO-CORTEX: its function, which is unique for human beings, is that an individual must carry out performing the two previous functions (reproduction and socializing), but by giving a more integrated understanding of the situation.
The neo-cortex corresponds with the understanding, narration and procreative-reproduction dimensions. These dimensions are possible because the neo-cortex enables us to understand our actions, and to carry them out experiencing emotions and also enables us to "perceive time", whilst in other mammals it only enables them to reach solely the social stage (limbic brain).

Semantic aspect - Make love!

The neo-cortex enables:

1. *Time perception*: it allows us to think hypothetically about the future.
2. *Detecting the information* that we need to understand something: people with disabilities have difficulties in doing this because they lack functionality, sometimes they lack even the communicative functions (they cannot find the appropriate words to express their feelings or they use words that are not normally used to explain a situation). Emotions can be understood simply through behaviours (for example: through paintings).
3. *The desire to talk* (to express our feelings, to talk with others, to create different realities). This is a new way to experience reality, to create new realities, and thus creating new cultures. All these aspects characterize us as human beings and sexuality must also perform this function. "Making love" means giving sex a specific time and a specific meaning, an arousal felt internally that can be shared with one another.

The presentation given to the parents and operators will be in compliance to the World Health Organisation, and the laws on sexual rights (WAS, 2008), and will inform parents and operators on these rights. The aim of this presentation is the conceptual assimilation of the universal right: "**Each human being has the right to sexuality which is a right that helps identifying the individual and contributing to global health".** Before we go any further, it is important that we discuss the historical evolution and social discussion of effectiveness-sensitivity of people with disabilities since the '80s. This discussion includes parents, operators, socio-educational, rehabilitation services and institutions. Throughout the years, requiring information on these topics has improved, however, much more needs to be done.

After assessing the importance of sexual rights in achieving the best possible health standards, the World Health Organization (World Association for Sexual Health, WAS) drafted this document:

Declares that sexual rights are found in the universal human rights, which are stated in all national and international documents, in constitutions and international laws, in standards and principles of all human rights, and in all scientific knowledge on human sexuality and sexual health.

Reaffirms that sexuality is a central aspect of human life activity, which includes: sex; identity; gender role; sexual orientation; erotism; pleasure; intimacy; and reproduction. Sexuality has been experimented and expressed through: thoughts; fantasies; desires; beliefs; worthiness; behaviours; practices; roles and relationships. Sexuality can be composed of all these dimensions, but not all of them can be experimented and expressed. Several factors intervene in sexuality. These factors include: biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual ones.

Values sexuality as a source of pleasure and well-being and that contributes to a feeling of self-realization and self-fulfilment.

Revalues sexual health as a physical, emotional, mental and social health condition interrelated to sexuality and cannot be expressed as lack of worry, a disorder or an illness. Sexual health requires a positive and respectable approach towards sexuality and sexual relationships, and also the opportunity to have likeable and safe sexual experiences, which are free from obligation, discrimination and violence.

Reaffirms that sexual health cannot be attributed a definition, understood or put to action without having extended knowledge on sexuality.

Reaffirms that the sexual rights of all individuals must be respected, protected and fulfilled in order to maintain sexual health.

Reaffirms that sexual rights are based on an internal freedom, dignity and equality among all human beings and includes taking care and protecting someone from pain.

Declares that equality and non-discrimination are the basis of the protection and promotion of all human rights that cover and forbid all forms of discrimination; exclusion on grounds of race, ethnicity, skin colour, gender, language, religion, political opinion and other typology; national and social origin; wealth, birth or other typology, including disabilities, age, nationality, marital and family status, sexual orientation and gender identity; health status, residence, economic and social situation.

Proves that the sexual orientation, gender identity, gender expression and physical changes of individuals require respecting human rights.

Proves that all forms of violence, abuse, discrimination, exclusion and stigmatization constitute a violation of human rights that affect the health of individuals, families and community.

Determines the obligation to: respect, protect and fulfil all human and sexual rights.

Proves that sexual rights enable all individuals to realize and express their sexuality and to maintain their sexual health, by respecting human rights.

Sexual rights

Sexual rights are human rights that include sexuality:

1. The right to equality and non-discrimination.
2. The right to life, liberty and security of person.
3. The right to independence and bodily integrity.
4. The right to be free from torture or cruel, inhumane or degrading treatment or punishment.
5. The right to be free from all forms of violence and threats.
6. The right to privacy.
7. The rights to the highest attainable standard of health, including sexual health, and enjoyable, pleasing and safe sexual experiences.
8. The right to enjoy the benefits of scientific progress and its application.
9. The right to information.
10. The right to education and the right to in-depth and exhaustive sexual education.
11. The right to marry, regulate and dissolve marriage, or to other similar types of relationships with the free and full consent and based on gender equality.
12. The right to decide the number and spacing of one's children, the right to be informed and the ways available for receiving information.
13. The right to freedom of opinion and expression.
14. The right to peaceful unification and reunification.
15. The right to participate in politics and public life.
16. The right to have access to the justice system, to judicial elections and to compensation.

Before talking about sex education we should raise parents and operators' awareness on the contextual aspects that contribute to the psychophysical health of the individual.

If we set on an educational project on this topic without pointing out the challenges faced, we risk missing out the information we need to obtain.

Self-control: intervention may aim at the self-control of cognitive and behavioural capacities, as well as the abilities to control anxiety and self-regulation. Two classic techniques of cognitive-reproductive orientation (Meichenbaum and Goodman, 1971) and stress injection can be learnt (Meichenbaum, 1977, 1985).

Initially, these two procedures can be followed and learnt for special cases, such as immediate response (especially at schools, therapy classes, or even at home with parents and family); control of frustration and anger, and control of anxiety when facing a difficult task, suggesting the technique of muscular easing.

Body care and information: When having accurate information, we can interpret what is happening and we will not experience anxiety when faced by crucial issues. It is important to do the following:

1. Moving and knowing how to use the body;
2. Knowing body parts;
3. Recognising the differences between males and females;
4. Maintaining body hygiene.

Communication and social abilities: many authors have proposed different categories of communication of persons with disabilities and often promotion programmes and social capacities trainings are proposed.

Authors such as McGinnis, Goldstein, Sprafkin and Gershaw (1984), have proposed 60 classes on behaviour divided in capabilities, regarding to the following:

- *Being in a classroom:* 13 capabilities, such as: "listening", "asking for help", "thanking"...
- *Creating and maintaining friendships*: 12 capabilities, "introducing", "starting a conversation"...
- *Managing emotions*: 10 capabilities, "knowing emotions", "facing fear"...
- *Controlling aggressiveness*: 9 capabilities, "showing self-control", "attempting to reach an agreement"…
- *Managing stress*: 15 capabilities, "facing rejection", "calming down", "coping with loss"...

What can parents and operators do to improve social skills?

The dual goal (parent-operator) should be improving social skills through the following procedures:

1. Simulating social interaction as if it is real life *(role playing)*;
2. Role modelling, through which the child sees how a well-prepared and capable person in terms of society would have behaved in the same situation;
3. Social reinforcement and feedback on the child's behaviour.

The operator emphasizes the positive aspects of the behaviour and provides suggestions to improve it (*coaching*).

Problem solving and decision-making issues

According to the classic definition of D'Zurilla and Goldfried (1971) and D'Zurilla (1986), the individual should be assisted in handling the problematic situation in the best way possible, considering all stages typical of the selection process:

General behaviour: The individual:

a) should be aware that he/she is facing a problematic situation *(such as social situations: e.g. If I touch myself in the classroom, my classmate may get angry at me),* which is a normal aspect of our human being;

b) should understand that these situations can be overcome;

c) should be able to understand when a problematic situation starts;

d) should refrain from reacting impulsively.

Determination of the issue: It should be approached using a specific and verifiable terminology, emphasising certain clear and reasonable results. Many times, failure to solve an issue comes as a result of the wrong determination.

Creating alternatives: Together we try to find as many solutions as possible (*brainstorming*).

Decision: Alternatives should be considered based on the anticipated result.

Verification: After choosing the alternative, it is necessary to see if it worked, and if not, the process of reassessing and solving the issue should start again.

This explanation may seem irrelevant, but before starting an educational process on new topics, we must ensure that the methodology of disseminating information is bilateral and educational actors understand it. Any information that is not understood by parents is worthless. Operators should make sure that parents have obtained and understood the information.

It has been scientifically proven that if an individual is placed in a context, where he/she feels accompanied and understood even when it comes to their mistakes, they have a higher probability to understand and repeat the methodology in other contexts as well. This applies to body information and sexual behaviour in individual with disabilities because if they are provided with the operational mental strategies to solve an issue, they are able to generalise their lessons. This aspect is one of the most difficult objectives to achieve in the field of mental abilities (Butterfield and Ferretti, 1982).

STAGE I

PARENTS AND OPERATORS ARE INVITED TO REFLECT ON SEXUALITY AND RAISE AWARENESS ON SEXUAL HEALTH

Parents and operators should reflect on sexual health and their experience with their bodies and emotions because any educational method would result unwelcoming and exclusive, if the former had difficulties themselves. Sexual health influences the biopsychosocial sphere of the individual, and in order to better understand this we should go back in time, in 1978, when the World Association of Sexual Health decided to draft a document promoting sexual health and sexual right for the entire world. For more than 35 years of sex education is taught in schools by biology teachers, who try to explain the sole chapter revealing the male and female genitals: "Sexual reproduction".

The international conference on global population and development in 1994 emphasized the role of sexual health as an essential demand for human health, well-being and development.

In 2007, World Association of Sexual Health drafted the *Declaration on Sexual Health for the Millennium,* which since the beginning stresses the promotion of sexual health as an essential element for any person's health and development, but also for enhancing life quality, finding peace and mitigating poverty, requesting everyone: *to recognise, promote and care for everyone's sexual rights; respect gender equality; condemn, fight and end any form of sexual violence; ensure the universal right to sexual information; stop and intervene in the spread of HIV/AIDS and other sexually transmitted diseases and address sexual problems, dysfunctions and disorders; recognise sexual pleasure as part of well-being".*

In each paragraph, WASH details how every country, institution and health professionals should intervene to reach optimal results.

If global health depends on sexual health, if in 2017 we lack "professional information and awareness on sexual pleasure, as an important factor for health, sexologists that treat sexual disorders, or emotion and sexuality education", how can we pretend or simply hope for a global well-being?

How can we pretend that collective prejudices and phobias on sex and sexuality will not be present in our society when having this document (*Declaration on Sexual Health for the Millennium)?* How can we hope eradicating STDs, reducing the number of abortions or improving sex life of the couples?

Beyond real issues that any individual experiences with these topics, I would like that each one of you wonders over what is your role in sexuality and sexual health. No matter if you are a young father, a teenage girl, mother of two little children, a grandmother during the stage of menopause, or a grandfather whose sexuality has been damaged by his diabetes. Our sexuality is related to gender and sexual identity that depend on our global identity.

Beyond gender, which is determined in birth, what qualifies the experience of sexual health are parental education, the way the child starts a friendship with his/her peers, puberty impact and sexuality experience as a couple. Therefore, there are many emotional and physical stages, which prepare us to experience sexuality in all its personal and social dimensions.

Moreover, sexual experience makes us self-conscious of our likings, likes and dislikes, as well as difficulties or prejudices with respect to this aspect.

Awareness-raising over personal difficulties regarding sexuality, be them misinformation or disorders that make us suffer sexual inactivity, any type of physical violence experience, that makes us be afraid every time someone comes close to us, are very important motives to ask the help of a psycho-sexologist, gynaecologist or andrologist, pointing out to the right to information.

Any parent that is present during physical and mental development of their child should be the first to promote sexual health.

Schools are the first educational agency where children make comparisons with each other, where questions on gender differences are raised, puberty topics or first sexual experiences occur. Classrooms should be the place where open talk on sensitive topics, such as emotions and sensuality should be frequently discussed topics, as lack of information is equal to denying this vital aspect.

Do not allow internet to teach your children as it is the parents that play the most important role on the child's sexual development.

Family clinics are the places where individuals may find answers on family planning, sexual diseases prevention or pharmacological therapies.

It is the right of each individual to knock on the doors of these public or non-public health agencies to ask for information or help on personal sexual health.

Nowadays, a time when we lack information on the support structures, the majority of people living in far-fetched regions who have a sexual problem do not talk over it and visit the professionals when the pathology has reached at an advanced stage.

Many young couples request sex consultations to improve their sexual experience and to boost their wellbeing. Unfortunately, even nowadays sexual taboos are still transmitted from one generation to the other.

Psychosexual health professionals should not cease teaching the importance of self-respect as the first rule to protect one's self from sexually transmitted diseases, and experience true sexual freedom making it an integral part of one's personal wellbeing.

STAGE II

What is sexuality to me? How does a child with disabilities experience sexuality?

- **Sexuality:** its biological definition states that it is a reproduction-oriented mode with the aim of producing off-springs. A biological mode which regulates interpersonal relationships to support creating and maintaining relationships between couples(Veglia, 2000). This aspect differentiates primates from mammals. The relationship between two individuals provides the following:
  - Raising children in a stable environment;
  - Having a strong affectionate relationship;
  - Developing a *Life Project* together.

- **Sex:** Physiological, endocrinological, anatomical integrity (nervous system functions), and NEUROPSYCHOLOGICAL functions.

What happens in reality?

- *Concentration* (lack of sex causes impulsivity and lack of concentration, and influences negatively sexual arousal: excitement);
- *Memory deficit* (partners feel like strangers);
- *Language and communication* (important in all stages of sexual response) may cause anxiety, stress and anger if they are problematic;
- *Being self-conscious* about themselves, their body and what they are missing is the first step towards rehab.

Sexuality in individuals with disabilities

(Collective imagination, which are the most frequent prejudices):

- Asexual individual;
- Unable to make love;
- Being forever a child;
- Being an angel.

Even though disability can bring about changes in motor functions, sensory perceptions, emotions and thoughts, individuals with disabilities have normal levels of compassion, affection and sexual desire (Rodarte and Muñoz, 2004).

The right to expression is unavoidable (Veglia, 2000) even though they lack the contexts, which provide for sentimental relationships that facilitate communication and getting to know other people.

Sexuality in individuals with physical disabilities

Distortion of sexual identity at the level of body ego (the ability to manage inner erotic desires, fantasies and pulsions is hindered from the physical functional difficulties).

A body ego wound is formed on a psychological perspective, which leads to self-isolation, sadness and withdrawal. Society contributes to experiencing intimate and affectionate relationships in an unpleasant manner.

Individuals born with a physical disability experience some differences in erotic and sexual/physical information between the genders (M:F), as well as in their overall development. The conflictual relationship with parents, but also with peers, during the puberty/adolescence stage (girls: deprivation from the object of desire by the feminine functional figure of a woman, of the mother, impacted by the fact of dependency); (boys: disadvantage over the father figure will make them withdraw and self-isolate, resorting only masturbation acts).

Physical contact

Is it different in individuals with disabilities?

It has already been proved by a series of experiments (Denenberg, 1963; Ader, 1977), even in mice, that stimulation, touch and physical contact with the mother through caresses and hugs helps in developing physical sensoriality, which sends impulses to the central nervous system, by empowering and making the individual stronger in coping with stress at an older age.

Physical contact and sensory stimulation, as an expression of love, are important for individuals with disabilities, as well as other individuals, but the evolution period of the former is longer. Thus, it may occur that some plays and ways of expressing love may be requested even at an age when it is not considered acceptable by our culture. This way parents and operators give it a sexual interpretation, which does not always have a real basis, but it is actually a demand for physical intimacy as an expression of feelings. Often parents fail to respond to this demand, depriving the individual with disabilities from this pleasing experience.

Recommended techniques:

a. **Discovering the body parts that one likes most and provide positive feelings, and those that one does not like;**

b. **Finding ways of touching, such as: squeeze, caress, hug, tickling, massage;**

c. **Distinguishing good touches from bad ones (bad: When someone touches one in the bus, or when one does not want to be caressed).**

Self-stimulation and nudity

Which behaviours concern parents?

Besides their surroundings, children are aroused even by their own bodies, which provide them with an exploration full of emotions. Sex organs provide supreme feelings and a pleasant stimulus, and we should not be concerned when we notice a child exploring their body. A child should be allowed to explore their body because the result will be a positive feeling. We should be careful not to frighten children and not to convey the message that sexuality is wrong, because this may cause hardships at an older age.

We should also be careful not to be obsessed with the genitals hygiene, because that way we give the image of something dirty.

Even though children with disabilities are prejudiced in these cases, we should know that self-stimulation is common in them, as well. However, parents may not tolerate this behaviour. Sometimes these children may resort to masturbation as:

a. A comforting activity in moments of sadness and loneliness;

b. A substitute activity in order not to react aggressively to someone;

c. A way to draw attention.

Due to the fact that they do not have many ways to overcome difficult situations, children with disabilities resort to this way of stimulation because it makes them feel good and they do not need anyone's help to achieve.

Reactions to non-tolerance of masturbation: the "exhibition" trend may be created, which is a way of displaying the nude body without any refrainment. In that case we should not prejudice and view this behaviour as an exceeded sexuality, but understand the child's provocative behaviour, which is also fuelled by the adults' reaction. On the other hand, this may result as a rule that has not been learnt yet. If it occurs often and anywhere, self-stimulation should be viewed as a symptom of a problem.

Determination of public/private boundaries: (Dixon, 1988) using pictures showing public places (restaurants, parks, schools, streets, supermarkets), as well as private places (bathrooms, bedrooms).

Suggestion: We should not prohibit this behaviour by threatening the child, but we should understand its function and provide alternative solutions. If the child feels frustrated, we should offer competences to solve this issue.

The body of the other - one more reason to be excited:
How should we behave towards children?

The self-exploration stage is followed by another stage which coincides with puberty and entering into adolescence, when they are physically attracted to other people's bodies. Erotic games and gender roles exchange (male-female) become more frequent during this stage. Adolescents realize that physical intimacy with the opposite sex, but with the same sex as well, causes body changes (excitement) and this feeling is very pleasant. The feeling of pleasure and other people's body exploration through play is a necessary stage to form their own identity, and if this stage is refrained, interrupted or refused, the effects will be experienced while growing up.

Parents' reactions: In our culture, reactions to these plays are various. Girls are punished or even maltreated, and boys are punished as well, but in a way which is interpreted by them as a silent encouragement.

It is important that sexual plays at this stage match with their development. To adolescents with disabilities, touching turns into a need for communication, as it is objective, their difficulty to freely communicate , thus their body turns into a means of communication. Thus, the motive is often cognitive (the urge to express oneself), but adults interpret it as a sexual motive.

Masturbation

Veglia (2000) suggests that families and operators may consider masturbation in persons with developmental delay is the right way to express sexual desire, but in some others it may be a stage that enables the transition to the relationship with a partner. Stakeholders should discuss about this and clarify objectives and application difficulties, religious interference and feelings of shame. We suggest holding a meeting to determine the ways of the functional intervention for the individual.

Double criterion: A way of assessing masturbation in girls and boys. Statistics show that this behaviour is mostly present in boys, due to the following reasons:

a. Boys demonstrate a higher sexual desire (biological/cultural intervening aspects);

b. It is easier for them to reach an orgasm;

c. Their genitals are more evident and easily explored;

d. There are cultural stereotypes that accept this type of behaviour in boys, but not in girls;

e. Girls are punished if they show sexual interest.

If the family or operators decide to educate the individual on functional masturbation, they should be aware of the capacity of the individual, inform him/her on the boundaries of practising it (private or public), and elaborate a way of expressing their need and monitor whether this need comes as a result of an issue or social communication difficulties. Therefore, collaboration is necessary in order to ensure a real reflection of the situation.

What code allows this behaviour?

The code that allows this behaviour is the code of caressing and familiarizing, which is taught in the relationship with the mother: sometimes mothers touch children in a functional manner; they match to the child's body and bond with each other.

Making love means creating a story; not touching a vagina or a penis.

Persons with disabilities are capable of making love, but they are not given this opportunity.

Steps to be followed by the operators

- *Storytelling dimension*: having a story. On a broader perspective, the idea of time has been already perceived.

Having a sentimental story enables the benefit of disfigurement (we can all be desirable until we are 80!). We are based on what we have built together and our desires lie within our stories.

- *Reproduction dimension*: having a child and deciding to create a life. The psychic importance of giving birth is extraordinary as compared to reproduction.

The couple extends their family, and the story includes more people. Adding to this, risks are even greater. This applies particularly to children who are born with disabilities because their parents have fewer expectations.

- *Lovemaking dimension* in this case is fragmented and divided in all individuals. The person with disabilities is thought to be a social person who lacks the most important characteristics of being a person.

The person with disabilities should be allowed to look for the meaning of his/her existence, by caring for that meaning, by enabling storytelling and by helping them draw boundaries.

Methodology for establishing sex education
What criteria should be followed?

First of all, it is necessary to talk to parents and inform them on:

- ✓ **The help to be provided to adolescents so that they can be self-conscious** (a disorganized and confused person may experience feelings of danger and lack access to their intimacy).
- ✓ **Being grateful to others.**
- ✓ **The ability to regulate their emotions** (intimacy is experienced emotionally, and inability to regulate emotions makes sexuality impossible).
- ✓ **The capacity to regulate emotions in relation to each other.**
- ✓ **Being able to share the understanding of what is experienced** (often during the stage of adolescence, people who have not transferred their feelings in sex, risk bonding only at the physical level and being left by their partners). You should know how to touch, familiarize and guide each other's bodies.

Sex education allows you to approach other people's bodies without being afraid. The greatest enemy of ignorance is knowledge and the greatest enemy of danger is sentimental education.

Using videos does not enhance knowledge because the information received is not processed, and slow processing methods provide more results. The fundamental rule of professional behaviour in educational relationships, one of the actors of the mental scene (mental representation), will not be present because it causes confusion: this is a taboo.

Sex education cannot be neutral; it is undoubtedly biased and responds to an ideology, and it should be "honest" and you should state which side you are on, and that no one knows the truth.

Information we can provide can be divided in four categories:

1. **Functionality:** what it is and how it functions.
2. **Aesthetics:** I should do what makes me feel beautiful and I should not do improper or indecent actions.
3. **Ethics:** I should feel good and do good things.
4. **Background/Personal:** There is no other vagina/penis like mine; I am a human being with my own feelings.

If we forget the value of these four groups, we exceed the boundaries of sex education.

Language

Which are the proper words to use?

It depends on the type of situation. There are different types of language:

- scientific language;
- family language;
- slang (vulgarisms).

It is important to use an appropriate vocabulary when describing an affectionate and sexual relationship. Youngsters should be talked to in the family and scientific language paired with slang. However, different situations determine the type of language to be used. What we convey should not be theoretical, distant and remote. Every educational project focusing on sexuality starts from the body, brain and organs functioning, to physiological changes and effects.

Language starts from the body (information): indicating and describing body parts, genitals and explaining the functioning of other parts, such as: eyes, nose, mouth, etc.

Parents should communicate with children through the following ways:

- *Organs comparison*: Learn about continuity. Persons with disabilities can better understand a topic if the following comparison is used. "My eyes are just like yours."
- *Boundaries which should initially be explained in simple words:* In the North, such as the Northern mountain (e.g. bone part) and discussing and explaining the flesh and hairs that cover it.
- *It is not advisable to distinguish between internal and external mutilation, but it is necessary to understand its function,* what is used and what is not, i.e. parts that can be easily touched and parts that cannot be easily touched. Vagina connects these two parts.
- *Comparison:* Using pictures, images or anatomical models.

STAGE III

How do adolescents with disabilities feel during this stage of growth?

1. Feelings of inferiority;
2. Fear of rejection;
3. Compulsive masturbation.

Sexuality in individuals with psychic disabilities:

1. **Cognitive level:** away from biological age.
2. **Body level:** sexual maturity follows the pace of puberty.
3. **Psychosexual level:** sexual/erotic experience comes to life.

In terms of sexuality, these individuals are mainly an object of limitations and rejections. Sex is part of our lives and it follows our evolution, thus it should become neocortical and reach the evolution of the third brain. Transition from the sexual/physical acts to lovemaking means giving sex a meaning.

Receiving love does not mean to make a body yours, because in reality the two bodies become one "place" where two individuals meet and engage and share the goal of desire. They are both looking for the meaning of their existence. While lovemaking feelings, which are not only expressed in words, become a fact If you do not feel the other person and their story, but you only desire what they have to offer (vagina or penis), you will have to often change partners because after a while they will be the same and you will get bored of them. There are people who avoid meeting each other because they may uncover their stories. With that being done they may start having feelings, something that they consider dangerous and troublesome, thus they only touch each other's bodies.

STAGE IV

Focusing on sexual abuse and violence: a real risk

This is a little elaborated topic in our society, and currently we lack research, information and statistical data, which would make us believe that this phenomenon does not exist in our country, though there are some specific cases. This is the reason why we should observe other countries' statistics and realize that they pay due attention to this topic. In the last 15 years, scientific research in the United States has focused on studies and clinical intervention of cases of violence against children with disabilities. A study of 445 individuals with developmental delays indicated that 11,5% of them have been victims of violence as compared to the 1,5% of the control group (individuals without developmental delays). A study of *National Incidence and Prevalence of Child Maltreatment* has proved that 35.5 in 1000 children with disabilities are maltreated, compared to 21.3 of other children. According to Baladerian, sexual violence is reported to be 4 to 10 times more likely among children with disabilities than among other children. The study of Crosse found that children with disabilities were 1.7 times more likely to be maltreated than children without disabilities.

Tasks of parents and operators	**Teach them to distinguish, but also...**
Observe them three times more than other children	Go/Run
Follow them	Yell
Check on them	Talk

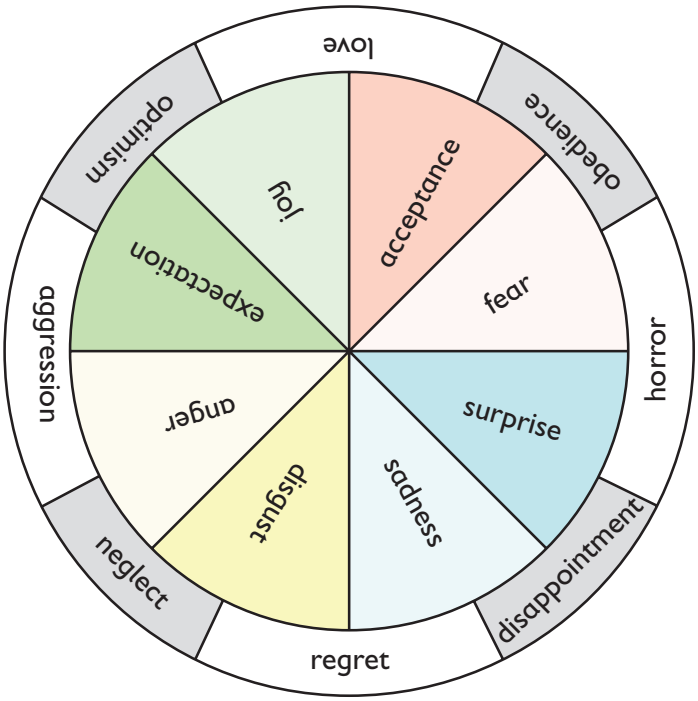
Because: they are less protected; more naive; cannot distinguish a violent situation from another one. We should be careful because sometimes the person, who is supposed to take care of child's safety, is the one who exerts violence. This hinders expression because the human brain cannot process the fact that the person who is supposed to protect me is actually violating me.

Ways of expressing emotions

Drawing emotions (happy, sad, angry, afraid, surprised, and disgusted):

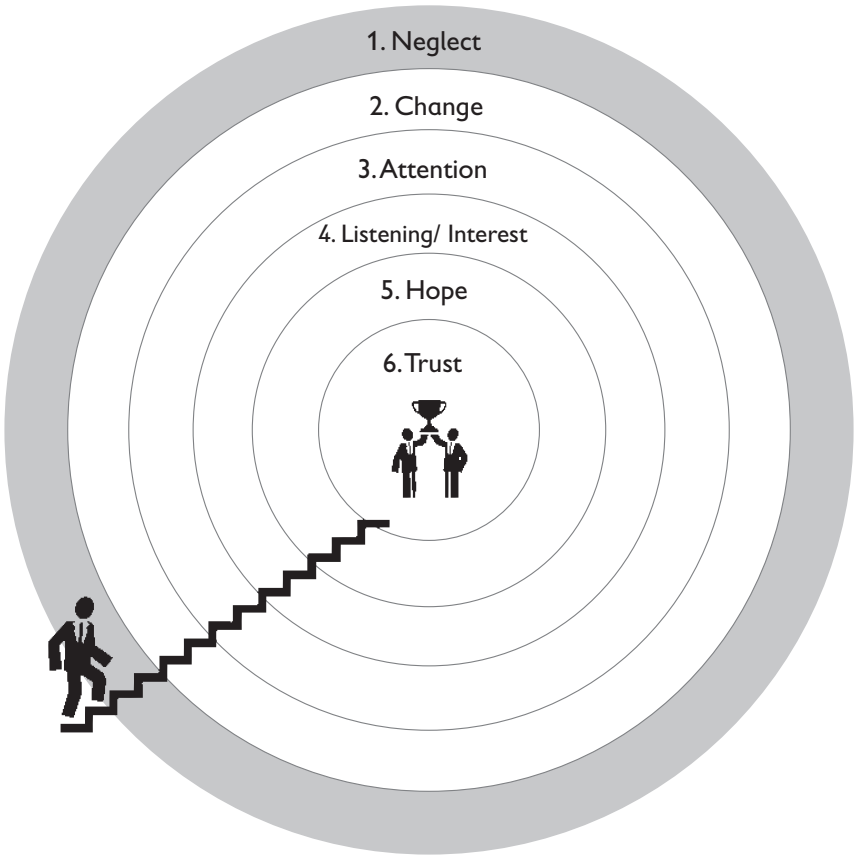
disgust sadness joy anger fear

The child is invited to draw the emotion that represents them, or stick the animated movies character that represents their emotional state (e.g. *Inside Out* characters). This methodology is taught to parents, and they automatically learn how to express themselves in different environments.



We understand the circle of trust (proper and improper caressing).

CIRCLE OF TRUST



In this case, you can use pictures of persons in public or private environments, of behaviours they can display, of proper and improper contact. Depending on the circle, they place the names of the people they can trust (far or close to them).

STAGE VI

AUTISM AND SEXUALITY

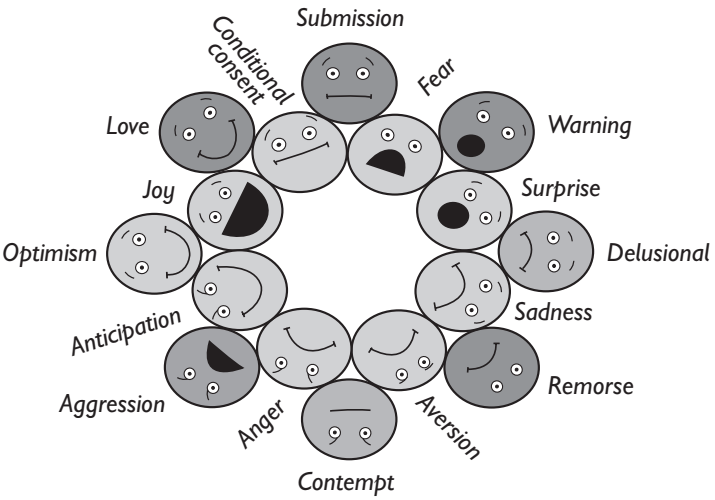
The golden rule: repeat and teach them to understand their pulsions because they will not be children forever.

Methodology for parents and operators

Mirror: start looking at and touching their faces.

Pictures: familiarise them with their selves and their physical changes over the years (feeling different from their family/operators).

Keeping a diary: something that they should always keep with them in order to understand which of their family members or cousins can be there for them.

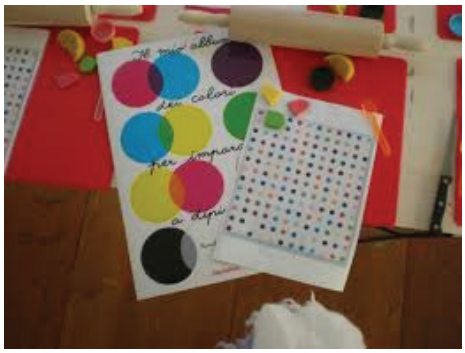


Drawing and localizing emotions: How do I feel today, where do I feel that emotion in my body?

Following rules: knocking before entering the bedroom - it is a private place for masturbation - and do not confuse them by using many different words to talk about organs.

Understand what arouses them: This way you can avoid masturbation in public.

Creating an album: You can make use of magazines that they can see in their room.



When we want to know what is happening to an adolescent with disabilities, we should wonder what is happening inside us.

Conclusion:

We could opt for either of the two directions:

a) Be a guide towards growing-up, creating moments of growth;

b) Limit effects by decreasing the risk of improper behaviours that may come as a result of autonomy.

Educational projects: suggestive, but if necessary: **prohibitive.**

Methodology used for:

- Instrumentology of the parents *(open lectures and group supervision)*
  - Stimulating words;
  - Brainstorming;
  - Rhetorical question;
  - Answer analysis;
  - Identification of emotional blockages;
  - Supervision of behavioural difficulties;
  - Encouragement of appropriate behaviours.

- Instrumentology of the operators *(group therapy)*
  - Stimulating words;
  - Group sexoanalysis;
  - Identification of dysfunctional emotions;
  - Identification of personal difficulties;
  - Supervision of clinical cases;
  - Analysis of parents' behaviour in the morning;
  - Focusing on incest and observing drawings.

GUIDING BEHAVIOUR

One should never substitute the person with disabilities *(it is neither functional nor educational if we make decisions for them)*

It is necessary to understand the real needs of the person with psychic disabilities when he/she attempts to express them through behaviours or words.

We should accept the connection between cognitive-affective needs and potential sexuality effects (pregnancy, STD).

Parents and operators should be informed and become self-conscious about their own sexual life and reflect how they feel about their relationship because this directly affects children identification. Beyond moral, social and religious explanations, it is important to be informed on the positive effects that sex has on the body, but before determining these benefits, it is necessary to emphasize sexuality functionalities.

The human sexual system during the evolution of our species and the development of neo-cortex has undergone radical changes, passing from a basal reproductive function to the emotional aspect, which serves for creating a family and allows two individuals to take care of their children. This aspect is not much evident in reptiles; emotions and desires to experience sexuality are formed in the brain of amphibians; in Homo sapiens, pleasure comes with the development of the cortex.

Presently, the effects of sexuality in self-esteem, well-being and health have been scientifically proved by analysing hormones' impact on our mood. The results of a study conducted by British Medical Journal with 1000 men were extraordinary: if a man has sex twice or more times a week and reaches orgasm, **it lowers the risk of death** by 50%, in comparison to men who have sex only once a month. The same results apply to the risk of strokes or prostate cancer. By increasing blood pressure in the genitals, pressure in other parts of the body decreases and it helps in **protecting from cardiac pathologies**.

In women, the health impact of sexuality is positive if she gets pleasure out of it. Desire, arousal and pleasure affect breast cancer thanks to the **protection effects** of oxytocin and *Dhea* hormones.

After every sexual intercourse, the dopamine hormone released in the body makes us **feel** pleasure, orgasm stimulates neurotransmitters, which give us the feeling of **well-being** and **calmness**; oestrogen and prostaglandin substances in the sperm fight bad mood, in other words, they serve as antidepressants.

Research on feminine sexuality shows that females who have sex continuously without using a condom, suffer less from depression symptoms, whereas females who have sex occasionally suffer from anxiety and depression. Orgasm helps in **strengthening muscles** around the vagina, and bladder in both gender, i.e. it is like an exercise for these muscles.

A German study, in which a sample 60% of the participants had problems with migraine and 30% suffered from it, indicates how sexual intercourse lowers the level of headache and heals it. Thus, it has a calming effect to pain.

Usually sex **helps in regulating sleep** in both genders, because the body releases prolactin, which helps in easing the muscles. In men, the release of oxytocin and serotonin after ejaculation has an immediate calming effect.
Even though the pace of our life is fast and stress does not allow us to have sexual intercourse, sex is what helps in **lowering the** level of **stress,** because the limbic system allows release of substances that send pleasure information to the brain.

Apart from physical benefits, we should bear in mind the effect of sexuality on the couple because the sexual system characterises the relationship between two partners. Sexuality is an integral part of human identity, it allows us to **shape our personalities,** present ourselves with a sexual identity in the society, **engage in a loving** relationship and have children. When there are no words, bodies do the talking. A good relationship with our body makes us experience **pleasure as a couple** calmly and emotionally, allowing intimacy to characterise the relationship.

Necessary information for operators

Having a child with disabilities makes parents cope with a complex *socio-emotive reset*. The role of the family as regards a child, which is *the chance of transition* from childhood to adulthood, and eventually to the society with disabilities, places the family in a difficult social position to be identified.

Adolescents' *sexuality* may pose difficulties and complicate the balance reached. Two factors of the family with a child with disabilities are: nightmares and isolation.

MOTHERS suffer from low self-esteem, provoked by narcissistic pain due to the fact that they did not manage to give birth to a healthy child. This important ambivalence and emotional confrontation provides a bilateral affective connection with the child: love/fear to hate them; acceptance/difficulties to tolerate them.

FATHERS see pain. Often a decrease of expectations and of being a man is observed.

GRANDPARENTS are victims of anxiety, seeing who was able to bring a healthy child to life and who was not.

Anxiety and depression are related to social desperation; a need for inner balance. **Society violently intervenes in the family of the child with disabilities, thus constantly fuelling the feeling of nightmares.** On the one hand, they would like to help, but they feel powerless because they cannot support their family in these moments, and the result is the feeling of anxiety. *Instead of accepting, they give advice/ instead of listening, they leave/ instead of supporting, they want to be supported.* In this complex situation, family will feel other people's mercy and guilt, and will be isolated: *It was meant to be, there is nothing we can do.* They try to solve the problem within the family.

The family addresses the child with disabilities as if he/she were forever a child, using the mechanisms of prohibition *and* rejection.

SUGGESTION: How to intervene when family members have questions on the emotional and sexual development of the child:

a) Understanding the most effective way to be listened to by the family (without complaining, blaming or questioning, we are not detectives!)

b) Intervening in the relationship between the mother and father by not allowing a symbiotic relationship or focusing on the individual with disabilities only;

c) Favouring the elaboration of grief for the child who is not born, protecting the family from blaming;

d) Allowing parents to have a personal life and not living only for the child;

e) Avoiding social isolation;

f) Leaving after they have set the balance allowing the family to reposition, but always being available when they are needed.

NECESSARY BEHAVIOURS FOR OPERATORS:

What should an operator do?

1. He/She should not be afraid, otherwise the child will be scared as well;

2. He/She should calm down the parents;

3. He/She should not depreciate parental figures, even though sometimes they are thought to complicate things. Instead he/she should understand and compassionate with their suffering;

4. The person who will represent the parents, will do so only after everything has been clarified. Operators should completely understand their sexuality otherwise, every unprocessed answer might be harmful.

Let us not forget that we are sexual beings from the cradle to the grave. Denying sexuality means denying human existence.

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Save the Children

Rruga: Mihal Popi, Ndërtesa 7, ish Pallatet 1 Maji, (Vila Lami);
PO Box 8185, Tiranë - Shqipëri; Tel: +355 4 2261840/ 4 2261929
E-mail: info.albania@savethechildren.org
https:// albania.savethechildren.net
Savethechildrenal SaveChildrenAlb