

Sexuality and Autism: culture,

ethics, rights and intervention.

Let's talk about it!

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Introduction

Many researches have been conducted to evaluate outcomes of interventions for Individuals with Autism.

Most of them focused on:

- Communication Skills (Koegel, Koegel, Frea e Smith, 1995)
- Social Skills
- Independent Living Skills

Introduction

Although the progress in effectiveness of Interventions, in research little attention has beed dedicated to the area of Sexuality for

Individuals with



My personal experience!

We started intervention when they were 4-5 years old. Goals were to improve communication skills, social skills, play skills, academic and independent skills...and now?

Autism and Sexual Desire

An anonymous survey of adults on the autism spectrum across several nations revealed that their sexual desire and satisfaction was generally equivalent to the published data for adults without autism

30. Dewinter J, Vermeiren R, Vanwesenbeeck I, Lobbestael J, Van Nieuwenhuizen C: Sexuality in adolescent boys with autism spectrum disorder: self-reported behaviours and attitudes. *J. Autism Dev. Disord* 45(3), 731–741 (2015) [PubMed] [Google Scholar] [Ref list]

Autismand Sexual Desire

spectrum generally have fewer opportunities to engage in sexual relationships due to poor social communication or being in an environment that limits their ability to meet sexual partners.

30. Dewinter J, Vermeiren R, Vanwesenbeeck I, Lobbestael J, Van Nieuwenhuizen C: Sexuality in adolescent boys with autism spectrum disorder: self-reported behaviours and attitudes. *J. Autism Dev. Disord* 45(3), 731–741 (2015) [PubMed] [Google Scholar] [Ref list]

Autism and Sexual Desire

At the same time some people in the ASD spectrum may have not have the ability to make decisions regarding some their sexuality

Autism and Sexual Desire

Core impairments of ASD lead to difficulties establishing requisite knowledge and skills necessary to attain a healthy sexuality and facilitate relationships.

What Rights?

Teenagers, young adults and adults on the autism spectrum:

- have the right to satisfy their sexual needs and desires?
- have the right to a romantic relationship?
- have the right to have a sexual partner regardless of sex or gender?
- have the right to be intimate with their sexual partner?
- have the right to privacy?
- have the right to have children?

What is ethical to do?

Different ethical and moral values may lead to different answers and actions

A first ethical action:

to develop an Autism Specific Sexual Education

In order to develop such a program we need to define Sexuality...and it is a difficult matter!

Can you define with a few words what is sexuality?

...NO!



Defining Sexuality

Often human sexuality is wrongly interpreted as the results of specific sexual behaviors (NCASH, 1995).

Instead human sexuality includes a variety of:

- physical elements
- hormonal elements
- emotional elements

Definition of Sexuality or Sexual Health





(...) a central aspect of being human throughout life (that) encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors."

75 World Health Organization, Sexual and reproductive health, Defining sexual health

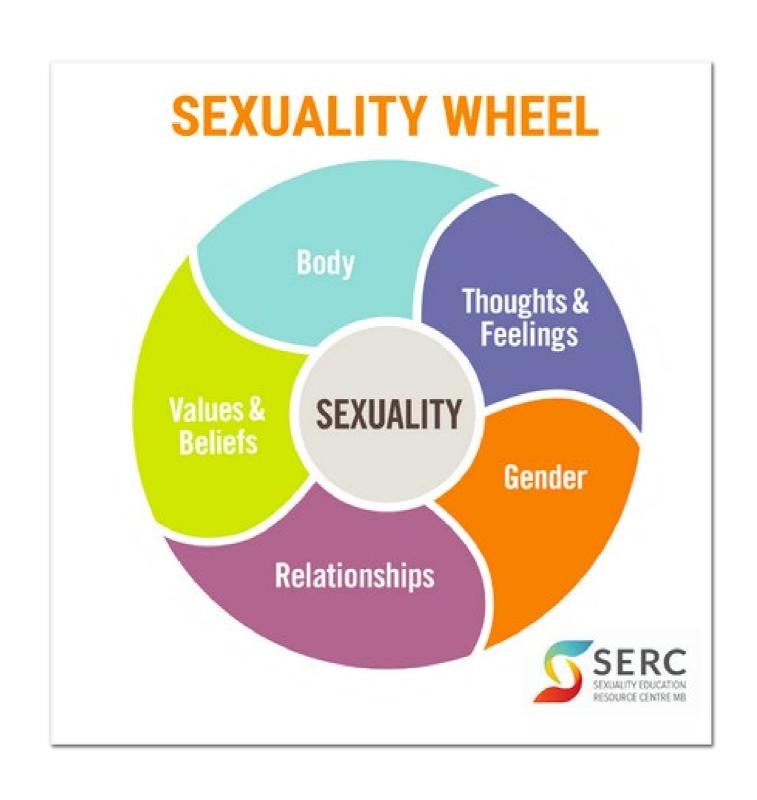
Definition of Sexuality

The National Commission on Adolescent Sexual Health (NCASH) says:

Sexuality is a natural and healthy part of life. It includes:

- sexual knowledge
- beliefs
- behaviors
- values
- It concerns anatomy, physiology and biochemestry
- but also identity, personality, thoughts, feelings, and relations

Definition of Sexuality





Comprehensive sexuality education: why is it important?

In 2022 FEMM (the European Parliament's Committee on Women's Rights and Gender Equality) published the results from the study "Comprehensive sexuality education: why is it important?".

The study presents the status of sexuality education in the EU as well as recommendations for improving it.

STUDY

Requested by the FEMM committee



Comprehensive sexuality education: why is it important?

2.2. Effectiveness of sexuality education

In recent years, a number of systematic reviews have been published that report on the effectiveness of sexuality education. This Section examines key publications, mainly systematic literature review articles, that complement each other and paint a comprehensive picture of the available evidence for the effectiveness of sexuality education. In the first sub-section, the effectiveness of general sexuality



Comprehensive sexuality education: why is it important?

The Lancet Commission on Adolescent Health and Wellbeing (2016) analyzed the available evidence of effectiveness and cost-effectiveness of SRH interventions for adolescents. Their key findings regarding effectiveness and cost-effectiveness of sexuality education on certain key indicators are:

Improvements in knowledge and attitude, safe sex behaviors, unwanted pregnancy, decreased dating violence, reduced homophobic bullying, recognition of gender equity, social emotional learning...and many more!!!

Requested by the FEMM committee



Comprehensive sexuality education: why is it important?

2.2.4. Effectiveness of abstinence-only education

Three studies adding to the available up-to-date evidence studies are analysed below.

 The Lancet Commission on Adolescent Health and Wellbeing (2016) analysed the available evidence of effectiveness and cost-effectiveness of SRH interventions for adolescents. They found high-quality evidence that abstinence-only education is ineffective in preventing HIV, incidence of sexually transmitted infections and adolescent pregnancy and recommend against implementing abstinence-only sexuality education²⁶.

What's up in Latvia?

THE IMPORTANCE OF SEX EDUCATION AS VIEWED BY THE LATVIAN POPULATION (SOCIOLOGICAL ANALYSIS)

Lukjanova, Julija; Ostrovska, Inta. Reģionālais Ziņojums. Pētījumu Materiāli; Daugavpils Fasc. 11, (2015): 152-168,193.

it is concluded that, despite the fact that the question considered still remains episodic and spontaneous in families and schools, young people are aware of the importance of sex education in human life. Thus, within the context of sustainable development of the state of Latvia, it is important to promote sex education both in schools and the society as a whole.



HOME BALTICS SOCIAL POLITICS MONEY INTERVIEWS OPINIONS INVESTIGATION

Home > Baltics

BALTICS LATVIA POLITICS

AS puts Latvian minister on blast about sexual education study materials for nine-year-olds

LETA September 14, 2023





Sexuality Education in the WHO European Region

LATVIA

Status of sexuality education

In Latvia, there is no specific law or policy concerning sexuality education, though several governmental regulations and guidelines do provide the legal framework for sexuality education. Delivery of sexuality education varies in practice because of a fair degree of municipal and school autonomy in this respect. There is also considerable opposition to sexuality education in Latvia.





Sexuality Education in the WHO European Region

LATVIA

Laws and policies

Seven different governmental regulations and guidelines provide the legal framework for sexuality education in Latvia, all of which are concerned with education in general and not specifically with sexuality education. Local governments can also develop their own health promotion strategies and decide on the inclusion of sexuality issues.

The Ministry of Education and Science and the related National Centre for Education are responsible for curriculum development. Educational and health professionals are invited to participate in technical expert groups that review the curriculum. Religious groups and non-governmental organisations (NGOs) are sometimes invited to participate in working groups for curriculum development at the municipal level. Parents can be members of advisory boards of schools, and in this role they can influence educational programmes.



Elements of sexuality education are included in various classroom subjects, such as social studies, biology, health studies, natural sciences and ethics. Thus, because of its integration into other subjects, sexuality education is effectively mandatory. The potential number of teaching hours, however, differs from school to school. Teachers choose the

those aged 16 years or older it is approx. 5–6 hours. Topics relating to biological aspects are covered more extensively, while topics related to contraception, gender roles, sexually transmitted infections, relationships and violence are touched upon only briefly.





Sexuality Education in the WHO European Region

LATVIA

Training of teachers on sexuality education

Only few teachers have been trained to provide sexuality education. The National Centre for Education, Centre for Disease Prevention and Control of Latvia and 'Papardes zieds' (IPPF member association) have developed teaching materials and recommendations, including video films about sexuality education.



Sexuality education outside the formal school setting

Papardes zieds organises special lessons and activities for teaching children about sexual (health) topics. It also provides information and an option to ask questions and obtain answers on its website. Papardes zieds has developed sexuality-education training for the teachers and people working with young people living with intellectual disabilities. It has also developed a sexuality-education programme for young people living in correctional institutions. However, it is unknown whether these programmes are still being implemented. Church organisations provide

https://papardeszieds.lv





Conservative and nationalist political powers, the opposition party, parents' movements, the Russian-speaking media and conservative family-based NGOs oppose sexuality education. Their main arguments are that sexuality education will have an adverse effect on the demographic situation, and that it damages children's morality and threatens a 'right' and 'healthy' concept of the family.

STUDY

Requested by the FEMM committee



Comprehensive sexuality education: why is it important?

5.3.1. Young people living with disabilities

a number of studies demonstrated positive effects of sexuality education in addressing those needs and promoting well-being. Despite these arguments, research has revealed that children and young people with disabilities receive less sexuality education than their peers without disabilities. This has been demonstrated in different settings and for different disability types

Lack of sex education was associated with more anxiety and reduced ability to make accurate judgments

Adults and teenagers in the Autism Spectrum are twice as likely to experience:

- unintended pregnancies
- sexually transmitted diseases
- increased anxiety with regard to puberty
- sexual abuse

than people in the general population (Jahoda and

Pownall²⁰¹⁴: Baines et al.²⁰¹⁸).

Then we need more Sexual Education for our students! It is an Ethical action!



When developing a Program in Sexual Education for students in the ASD spectrum

- What are the possible goals? What should we teach it?
- How should we teach those goals?

Journal of Intellectual Disability Research

doi: 10.1111/jir.12952

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Systematic Review

A systematic review of relationships and sex education outcomes for students with intellectual disability reported in the international literature

- L. Paulauskaite, D. C. Rivas, D. A. Paris D. & V. Totsika 2,3,4,5
- Social Research Institute, University College London, London, UK
- 2 Centre for Educational Development Appraisal and Research, University of Warwick, Coventry, UK
- 3 Division of Psychiatry, University College London, London, UK
- 4 Department of Psychiatry, Monash University, Melbourne, Victoria, Australia
- 5 Tavistock and Portman NHS Foundation Trust, London, UK

What should be the outcomes of Relationship and sex <u>Education?</u>

Very few studies reported outcomes for students in Primary Education (5-10 years)

- understanding of hygiene
- the human body (e.g. what menstruation and wet dreams are)
- relationships (e.g. what dating, love and marriage is)
- human sexuality (heterosexuality, homosexuality and bisexuality),
- sex and its consequences (e.g. sexual intercourse and sexually transmitted diseases)
- appropriate social behaviour
- and ability to protect yourself from sexual abuse.

Outcomes for students in Secondary Education (11-16 years) extracted from 15 studies and grouped under 11 outcome domains:

- understanding of the human life cycle
- the human body
- relationships
- hygiene
- keeping safe
- appropriate and inappropriate behaviours
- human sexuality
- sex and its consequences
- rights and responsibilities
- emotional vocabulary
- positive self-esteem.

The most reported outcomes of RSE for students aged 11–16 years were:

- understanding of private body parts
- understanding of areas of a body that should not be touched by others
- understanding what pregnancy is

Out of 43 extracted outcomes

- 85% (36) of outcomes were knowledge based (e.g. understanding of what contraception is)
- 4% (2) of outcomes were skills based (e.g. friendship skills and hygiene skills)
- 9% (4) of outcomes were behaviour based (e.g. protective behaviour)
- 2% (1) of outcomes were attitudes based (e.g. positive self esteem).

Outcomes reported by parents and teachers

- understanding of personal hygiene
- appropriate and inappropriate social and sexual behaviour
- consequences of sexual activities
- contraception
- protection from sexual abuse.

Parents and teachers did not agree that understanding of menstruation, masturbation, and sexual intercourse should be outcomes of RSE for students with intellectual disability.

Students with intellectual disability in secondary education (aged 11–16 years) reported six RSE outcomes:

- understanding of puberty -related body changes for males and females
- understanding of relationships (e.g. how to make close friends)
- understanding of sexual intercourse (e.g. understanding of appropriate sexual behaviour and contraception).

Outcomes for students in further education (aged 16 -25):

- · understanding of the human body
- · hygiene,
- menstruation
- human sexuality
- · sex and its consequences
- · appropriate and inappropriate behaviours
- relationships
- · keeping safe
- assertiveness skills
- social skills
- positive self-esteem
- emotional vocabulary
- improvement in attitudes towards sexuality topics

what do young adult say?

Students (aged 16-25) reported that in RSE they would like to learn

- how to identify problems with menstruation
- how to have sex and enjoy it
- how to use contraception (e.g. how to apply condoms)
- how to take care of a baby
- what are homosexual sexual experiences
- what it is like living with a partner,
- how to flirt
- how to break up in relationships
- how to love and accept yourself
- what to do in case of abuse.

but...

On the other hand, outcomes reported by parents and teachers were about:

- how to protect yourself
- appropriate and inappropriate behaviours.

How do you feel about that?

How to teach?

JOURNAL OF SEX RESEARCH, 52(4), 412-432, 2015

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ANNUAL REVIEW OF SEX RESEARCH SPECIAL ISSUE

Identifying Effective Methods for Teaching Sex Education to Individuals With Intellectual Disabilities: A Systematic Review

Dilana Schaafsma, Gerjo Kok, and Joke M. T. Stoffelen

Work and Social Psychology, Maastricht University; Gouverneur Kremers Centrum, Maastricht

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How to teach?

- It seems that methods such as modeling, roleplay, rehearsal, and practice skills can be quite useful for improving the skills of individuals with intellectual disabilities.
- It was used by Bruder and Kroese (2005) when teaching protective behaviors

Conclusions

Evidence is suggesting that people on the Autism Spectrum have sexual and relationship desire but less opportunity to engage in it

Sexual and Relationships education can be effective in determining a better quality life and healthy sexual life but people on the Autism Spectrum receive less education than their peers

Conclusions

It is the right time for Parents, Teachers, School Administrators, Policy Makers, Experts, to meet and try to listen to what Teenagers and Adult on the Autism Spectrum are telling us (sometime in different ways!):

"Give us skills and knowledge to satisfy our sexual and relationship desires!"

Additional Resources



https://www.youtube.com/watch?v=wZ6T8wrqjAE

Paldies!

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