



I don't know what I don't know

*Sexual & relational development in the
lifecycle of people with visual impairment*

Expertise group RIS (Relations, Intimacy & Sexuality)

Royal Dutch Visio

Bartiméus

Robert Coppes Foundation

Message & goals for today

Talk about sexuality, intimacy & relationships throughout the lifecycle!

- Knowledge transfer
- Exchange of experiences

Provide all people with a VI with information...



Mo
Ahmadi



Hans
Gerrits



Sonja
Jansen



Delano
Badal



Mevrouw
Wolfs



Wilma
Klaassen

... of all ages, cultural background and gender!



Question!

Take a minute
to think about
this question:

What comes to mind
when you think
about the topic of
today - relations,
intimacy & sexuality and
visual impairment?



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Programme

- RIS: relations, intimacy & sexuality
- Sexual & relational development in general
- Sexual & relational development in people with visual impairment (VI)
- Materials
- Research project: *I don't know what I don't know*
- Break
- RIS according to experts by experience
- Time for action - cases
- Our tasks as health care and education professionals
- Competences
- Working with culture and religion

RIS: relations, intimacy & sexuality

The expertise group RIS sets the goal that people aged 0-100 who are blind or have a partially sighted, regardless their intellectual ability, can have social contacts, have access to correct knowledge about intimacy and sexuality and are given the opportunity to experience this all according to their wants and needs. To be able to gain this, it is necessary for clients, parents, family members and professionals to be informed about the consequences of visual impairment on connecting to other people and experiencing intimacy and sexuality. We plea for an open attitude and respect in conversations on this topic. That way, a safe environment can be created where questions and feelings can be shared and discussed, between clients, parents, professionals and among professionals.

Sexual development in general



4

6

8

10

12

15

18

24

Exploring own body

Exploring wishes and limits

Exploring gender ID

Exploring friendships

First crush

Body changes

Insecurity about own body

Interest in sex (also in media)

First relations

Sexual feelings

Experimenting with relationships (also online)

Sexual behaviour (also online)

Dealing with emotions (rejection, jealousy, love sickness)

Relations, sexuality and media

Sexual & relational development in general

0-4: exploring

Body contact, exploring bodies (self and others)

4-6: learning and playing

Learning the rules, playing doctor, the origin of babies, boys/girls

6-9: already a bit exciting

Crushes, sexual function of genitals, friendship, comparison, embarrassment

Sexual & relational development in general

9-12: teenager, early adolescence

Embarrassment, dating, curiosity (or aversion!), physical changes, social media

12-15: mid adolescence

Autonomy, friends, social media, sexual appeal, kissing

15-18: late adolescence, nearly adult

Experimenting relationships/sexuality, wishes and limits, LHBTIQQA+

Sexual & relational development in general

25-50: adulthood

Mostly (sexual activity within) long term relationships, parenthood (slightly less sexual satisfaction)

± 50-70: mid life

Hormonal changes in men & women (less sexual arousal, bodily changes), retirement

70+: elderly ages

Health problems, dependency / informal care

Sexual & relational development of children with VI

- Sara - 'How can a male person ride a bike? He has a penis between his legs!'
- Max - 'A bikini is worn on the hips, right? That's where breasts are located.'
- Lili - 'For me, flirting is not very different from connecting to people in general. I come across the same difficulties.'
- Sil - 'My visual impairment is of influence of course, but I've become very accurate in flirting verbally.'
- Stijn - 'Is there anyone out there waiting for me? It will probably be a total disaster for me...'

Nothing can be
taken for granted



Sexual & relational development of children with VI

- VI has a pervasive character, it influences all aspects of the development and life of a child (and adult!), thus also the sexual and relational development
- Difference between low vision and blindness: even if you have very limited vision, you'll be able to gain knowledge by peeking secretly
- Influence of attitude of parents, health care and education professionals and society
- Influence of co-morbidity
- Limited research, plenty of clinical knowledge and experiences

Sexual & relational development of children with VI: early development

- Attachment: more often anxiously attached children; influence on friendships and relationships
- Creating a body image and the difference between boys and girls: exploring and feeling own body and other bodies (!), hearing descriptions of others, sounds/voices, scents
- Development of play is often delayed: lack of chance to pretend play
- The physical development runs the same course, the perception differs: lack of comparison



Sexual & relational development of children with VI: sex education

- Parents think sex education is the responsibility of school
- Stigma: people with VI are sexually insecure, dependant and incapable (or even not interested and a-sexual)
- Parents can be over-protective, avoidant or averse on the topic
- Sex education often highlights contraception and sexual abuse / risks
- Sex education is generally verbal and not explicit enough: children often appear to not (exactly) have understood the message/lesson

Sexual & relational development of children with VI: teenagers and adolescents

- Belonging/fitting in is difficult when being different: many children feel insecure and are being bullied
- Many adolescents mainly spend time at home and at school, they spend less time with friends (and therefore lack chances to meet new people)
- Socialisation and communication: missing social cues, peeking at peers, lower level of autonomy
- Less access to information and less ability to talk about sex: parents, friends, social media (incl. dating apps)



Sexual & relational development of children with VI: teenagers and adolescents

- Lack of privacy for sex (solo-sex and with a partner)
- More psychopathology, lower self-image and self-worth
- Less experiences with dating, romantic relationships and sex
- Relatively late experiences with dating, romantic relationships and sex
- The better the vision, the more experiences
- The higher the level of self-worth and disability processing, the more experiences
- Vulnerability for abuse



Sexual & relational development of adults & elderly people with VI

- Ben (30) - 'Oh, this is what they mean when they talk about wings in commercials!', when holding a sanitary pad with wings for the first time.
- Anna (25) - She was never told that the plastic film of tampons need to be removed before use.
- Sanne (29) - 'Last week I received an unusual picture on my phone, and my iPhone tells me it is a picture of a mushroom. But it turned out to be a dickpick...'
- Maarten (40) - 'My wife and I are thinking about starting a family, but how can I ever take care of my children and be a good father?'
- Maria (82) - 'Since my husband moved to a nursing home, we never have some privacy or time alone. We never sleep together anymore...'

Sexual & relational development of adults with VI

- Also in adulthood: less & later experiences with dating, romantic relationships and sex
- Harder to form (long term) relationships
- Questions about parenthood & heredity
- Autonomy & romantic relationships



Sexual & relational development of elderly people with VI

- Mobility & autonomy issues lead to more loneliness
- Exclusion from day care services
- Informal care
- Privacy & autonomy in institutional care



Materials: suitcases



Materials: books & games



Research: *I don't know what I don't know*

- Goal: creating a blueprint of sexual education of people with VI (focus on blind people), making adaptations to regular sex education programs
- Partners: Fontys University of applied sciences, Bartiméus, Robert Coppes Foundation, Royal Dutch Visio, experts by experience (zorgbelang & de ongeziene blinden).
- Informants: young adults with VI, health care/education professionals, parents
- Target audience: adolescents aged 12-18 with average intelligence
- Themes collected: developing proper tangible material, developing a body concept, being a worthy partner as a person with VI, acceptable touching/being touched, non-verbal communication, a-sexuality

Trial versions of new tangible material



Take a break (5 min.)



WELCOME

BACK

RIS according to experts by experience

Joris: 'In a relationship with somebody without an impairment you always develop a certain dependency or inequality.'

Gyuri: 'I assumed nobody would be interested in a guy with a white stick and a flowing beard who looks like Quasimodo.'

Gaby: 'My solution is to keep communicating: from flirting, dating, and getting into a relationship.'

Amy: 'When it comes to sex I don't know what most people do, I can't watch films, so I use my fantasy instead of a script and that's even more fun.'

Time for action!

Read the cases and...

1. Decide (swiftly!) with the people in your break-out which case you would like to discuss
2. Think it over for yourself for a couple of minutes and take notes
3. Share your thoughts and ideas in your group
4. Please feel free to share your experiences or insights in the chat afterwards

Case 1 : a toddler

An early interventionist confides in you and tells you she feels very uncomfortable when helping a blind toddler to gain a body concept by exploring and identifying his own body. She teaches the child the name of every body part except the genitals.

- What is your opinion about this case?
- How will you respond to her?
- What can you do to help her?

Case 2: an adult

A 60 year old man had surgery and came out blind. He is a hands on man, head of the family, company owner, always busy. But since he became blind, he needs help and the relationship with his family members is changing. The relationship with his wife is under pressure. He is seeking more intimacy, especially during the evening & night, because in the dark he feels they are equals. She is keeping her distance. It hurts him a lot and he is afraid he will lose his wife and asks for help.

- What is your opinion about this case?
- What would you do to help him?

Our task as professionals

It is our task to provide:
well-timed and well-coordinated information
positively stated
open and concrete
focussed on solo-sex and sex with a partner
(according to the choice and pace of the client)
matching our professional position.

Our task as professionals

- Focus on social and communicative skills in general
- Focus on variation in social situations to provide experience with friendships (and later with relationships)
- Focus on disability processing
- Give children, adolescents and young adults the chance to ask questions and gather information. Knowledge makes them stronger!
- Normalize sexuality. Realize that this subject is part of life from our clients in every stage of life and that they are more vulnerable because of their disability

Competences

- Make this subject discussable in your own style, remain true to yourself
- Use the knowledge and experience you have with your target group
- Mention that RIS can be an awkward topic, that it can make you can feel uncomfortable - this way, you normalize it
- Use a current event as a starter for a conversation

Competences

- Use materials supporting your conversation or do something together
- Ask a lot of questions to discover what knowledge, thoughts and assumptions a client has before you provide information
- Ask for help or support when you feel uncomfortable or averse
- Make use of existing materials and publications (books, websites, etc.)

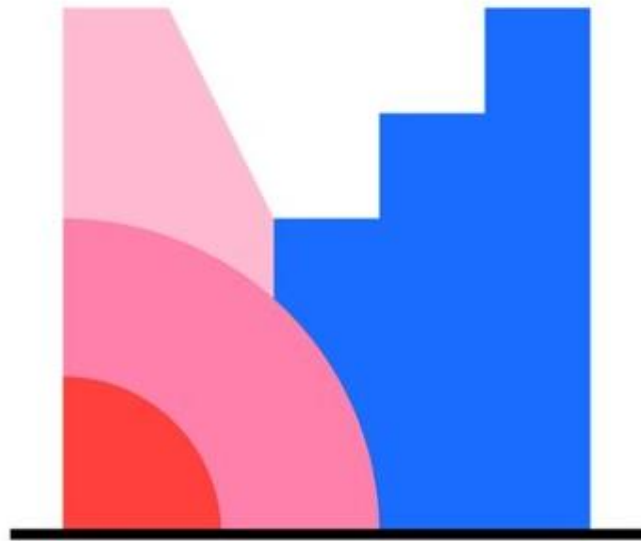
Working with culture and religion

- Be sensitive to cultural and religious diversity: be open to new information, gain knowledge: read, ask question to people you know, but do not generalize or make assumptions
- Talk to your clients/students, be genuinely interested
- Follow a **two-track-policy**: respect culture, religion, values AND make sure you take your responsibility as a school or health care professional
- Offer regular education where possible, and make adaptations where needed
- A great example: the lady from Uganda

Eye opener

Your personal eye-
opener

We can learn from you
all!



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Many thanks!

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