

Love and Sexuality among Youth with Intellectual Disability

NYRIS 2016

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Dispositions

Interview studies with youth with ID, staff members and parents:

- Study 1 – May I? On love and sexuality
- Study 2 – I want to do it right! Sex Education
- Study 3 – T@ngled Up in Blue. Internet

Who are they, and what is an Intellectual Disability (ID)?

- A heterogeneous group: variations due to disability, gender, age, ethnicity, sexual orientation, social class etc.
- Deficient abstraction, verbal and communicative ability
- Obstructs possibilities to understand sexual norms, codes and signals
- Limited knowledge of sexuality, the body and relationships
- In need of life-long support (e.g. staff, parents)
- Many want to be like “everyone else”



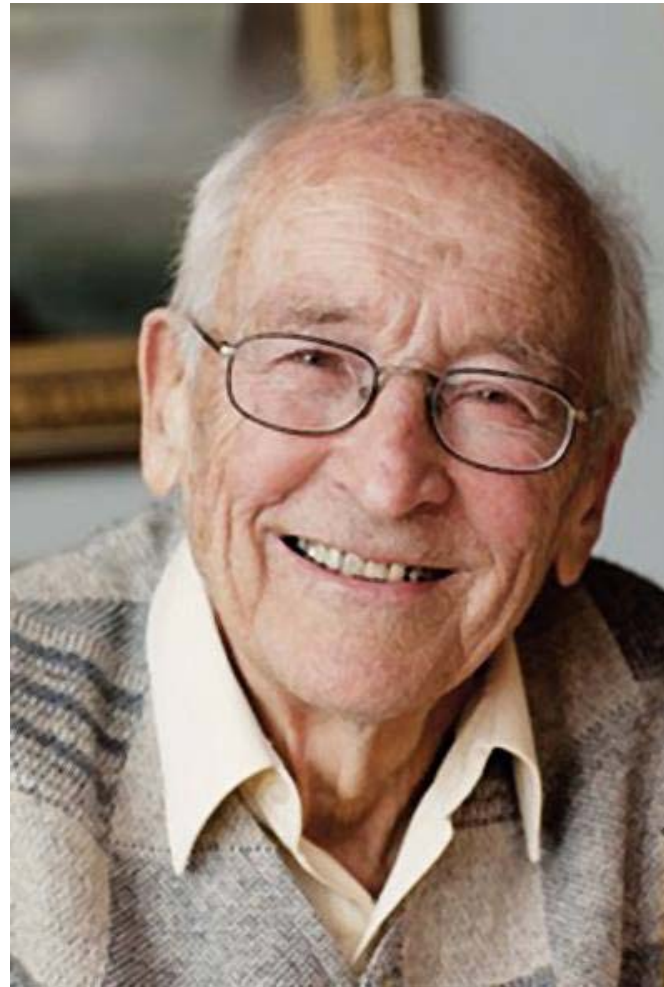


Historical and Societal Context

- Institutionalization and repressive societal attitudes, including forced sterilization, during the first half of the 20th century.
- Generalizations about the group as either asexual and non-gendered or hyper-sexual individuals.
- During the 1970s living conditions changed through normalization and integration reforms.
- Today, many still live sheltered based on a sense of responsibility and worry in their surroundings, e.g. of unwanted pregnancies, sexual assaults, exploitation.



Karl Grunewald 5 april 1921-15 juni 2016



On/Off Stage - Options for Privacy



Sexual Scripts

Time period-specific, cultural and social norms

- Who may a person have sexual relations with?
- What is acceptable/unacceptable behavior?
- When is it right to have sexual relations?
- Where is it permitted/not permitted to have sexual relations?
- Why do people have sexual relations?



Sexual Conduct and Experiences

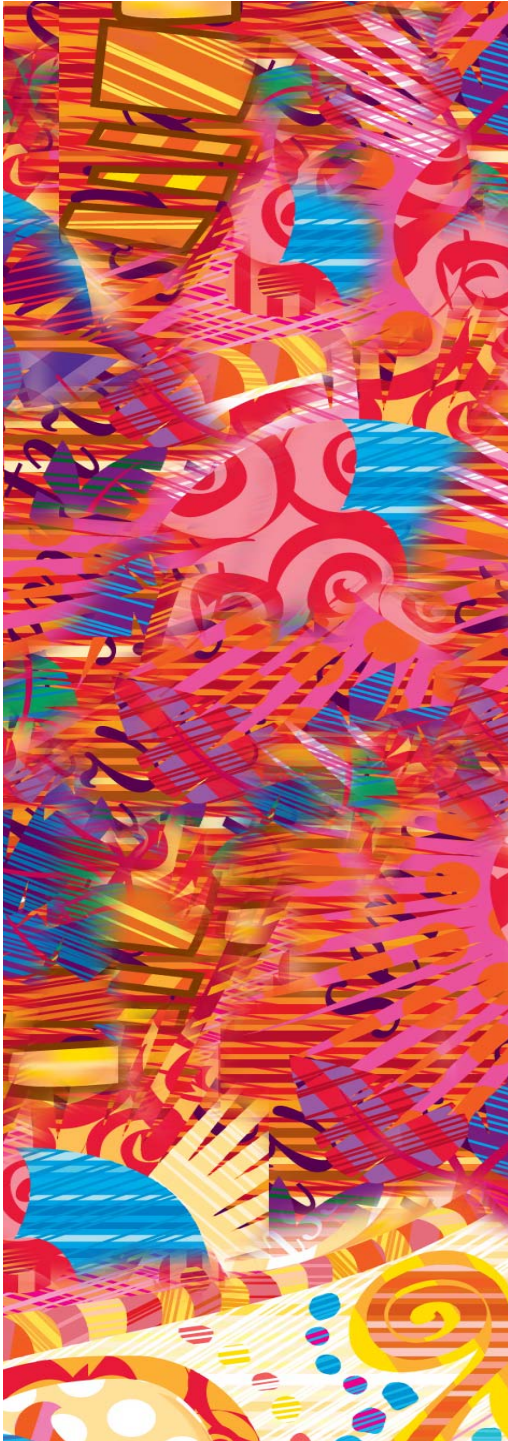
- International research show extensive experiences of sexual assault and exploitation among females with ID.
- However, Swedish youth with ID also describe pleasurable sexual experiences.
- Experiences of masturbation, hugs, kisses, caresses and petting seem to be more common than intercourse.
- A few have experiences of relationships.
- Very few have experiences of parenthood.
- Current Swedish research points out experiences of prostitution in the target group.



A Heterosexual and Gender Stereotype World

- The normalization principle has a built-in stereotypical conception of gender.
- Society does not want persons with ID to further deviate from the norm.
- Swedish research show that young females take more initiative to sexual activities than males (who are afraid of assaulting the females).
- It seems to be unusual for persons with ID to come out as homo-, bi- or transsexual.





Limited Sex Education

- Even in Sweden (with compulsory sex ed. since 1955), sex education in special education for youth with ID is rare.
- Limited or non-existing sex education leads to inaccurate sexual behavior and low self-esteem.
- The national standards are too general.
- Lack of methods and knowledge among staff.

Listen to the Young People's Own Voices



Experiences of Sex Education

R: What is sex education to you?

I: No idea... but having sex, I think (male, age 18)

“And then she (the teacher) showed a film about how a child is born... and after that, I would NEVER want to have children!” (female, age 18)

- Limited experiences on their own premises



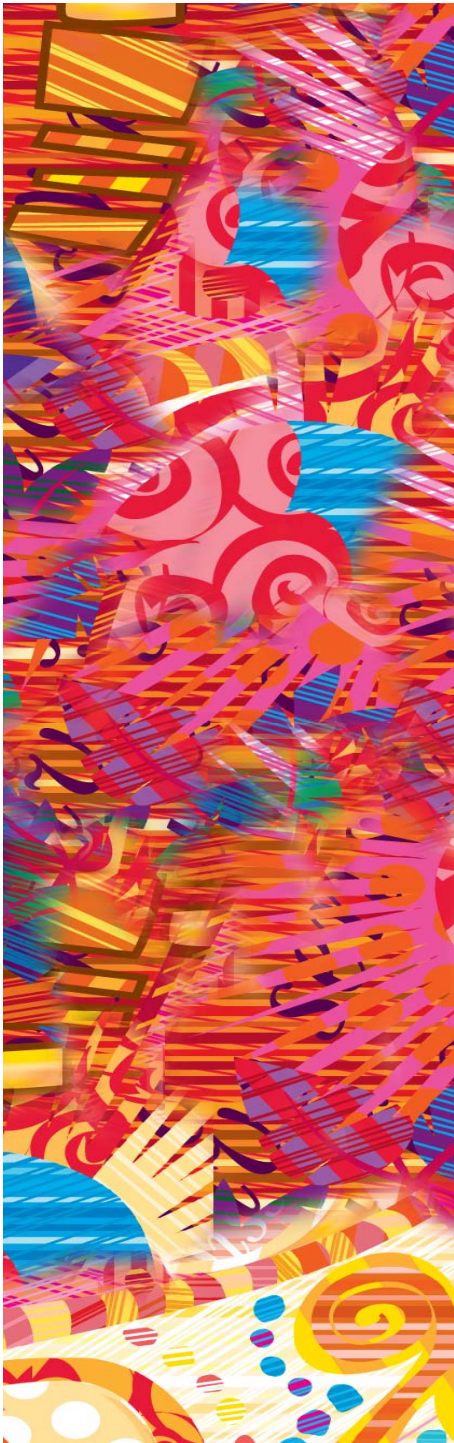
What do they learn?

I learned that if you do not have a condom, you can get diseases down there! (female, age 17)

The egg will hatch in the Mommy's tummy and then the baby comes out! (male, age 19)

- A focus on sexually transmitted diseases and contraception is not considered important by youth with ID based on their sexual experiences.
- A heteronormative perspective which diminishes other sexual experiences and/or orientations.





"It's like she's satisfied with how it's decided"

The Surrounding's (staff, parents) Views and Experiences

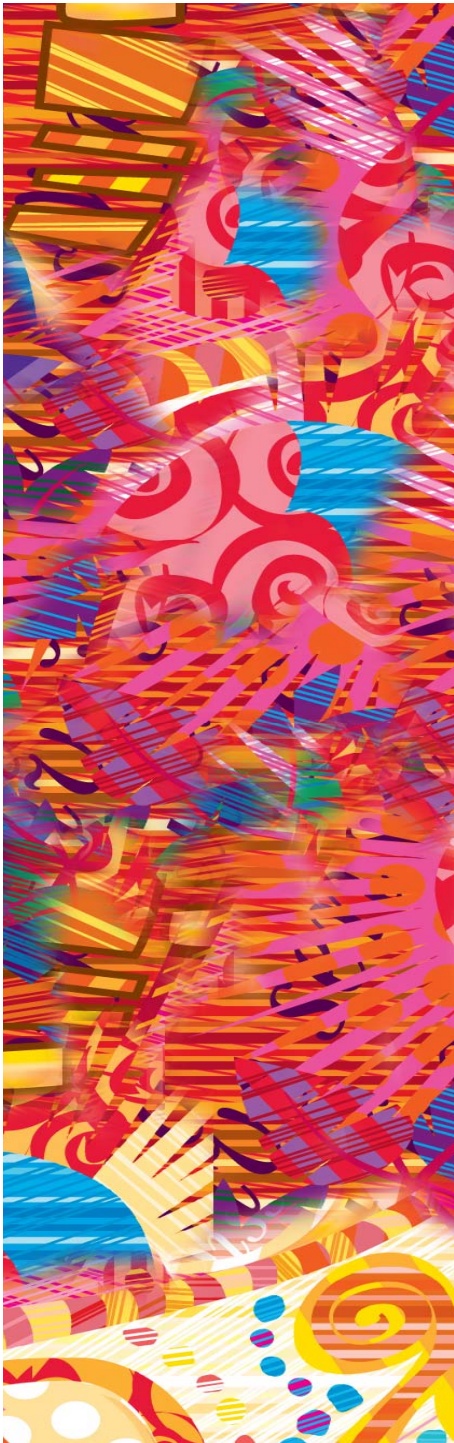
- Normative and protected world
- What is different is linked to the functional reduction
- Ambivalent parents – worry about negative consequences of sexuality, desire for a good life
- Staff dilemma – responsibility, permission, control



“Sex can be good, if you say how you want it”

Sexual Expression and Behavior Patterns

- Socialized into a hetero world – different enough having an ID
- Lack of models, alternative social arenas and an openness to different sexualities
- Major variations: hugs, kisses, petting, body contact/feeling more common than intercourse
- Gradual experiences – many positive

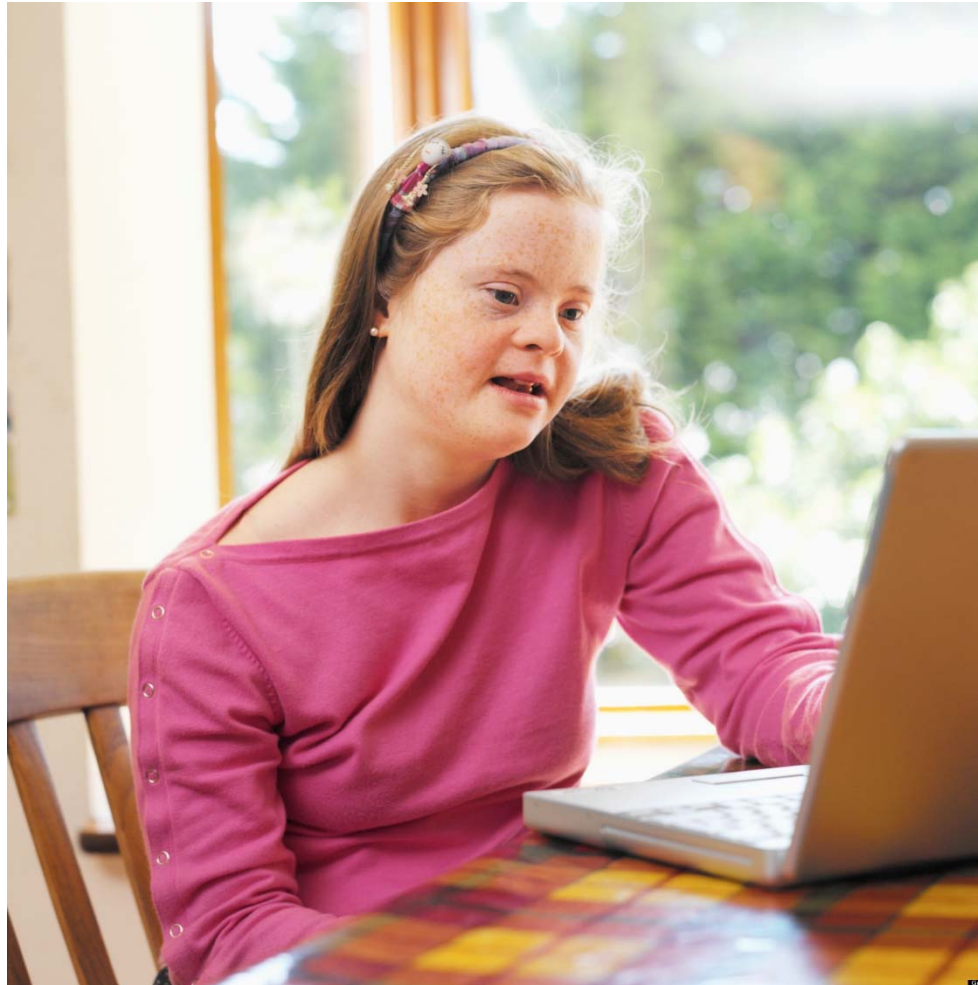


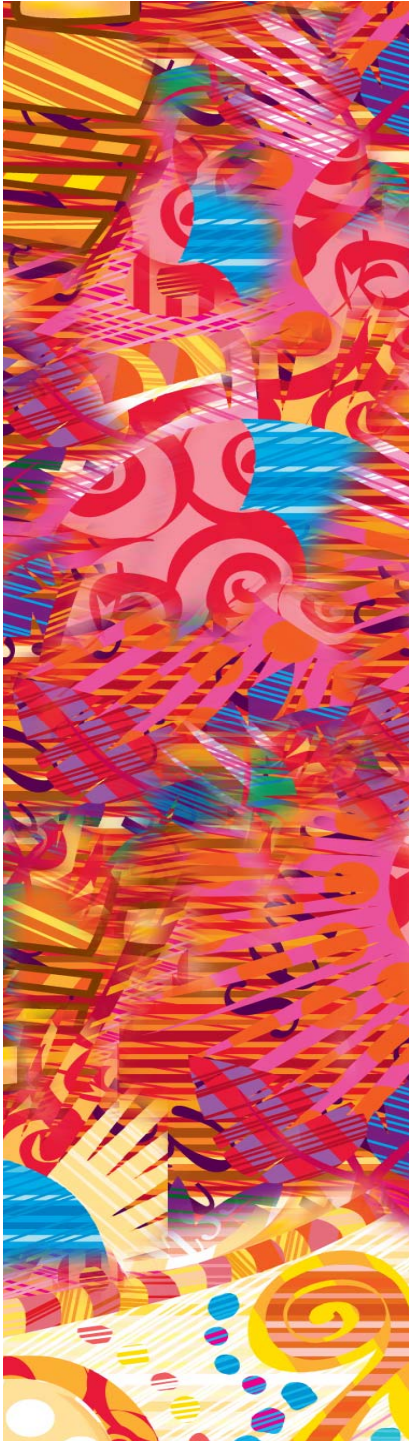
“Her mom thought we should grow up first”

Interplay among the Youth

- Uncertainty about when/where/IF sexual actions and relations are permitted (especially among the young men)
- Many dream of a partner, few think that parenthood is realistic. Those who become parents often have mild ID
- The art of flirting – attraction hierarchy

Internet and social media are a part of everyday life – use it in sexuality education!

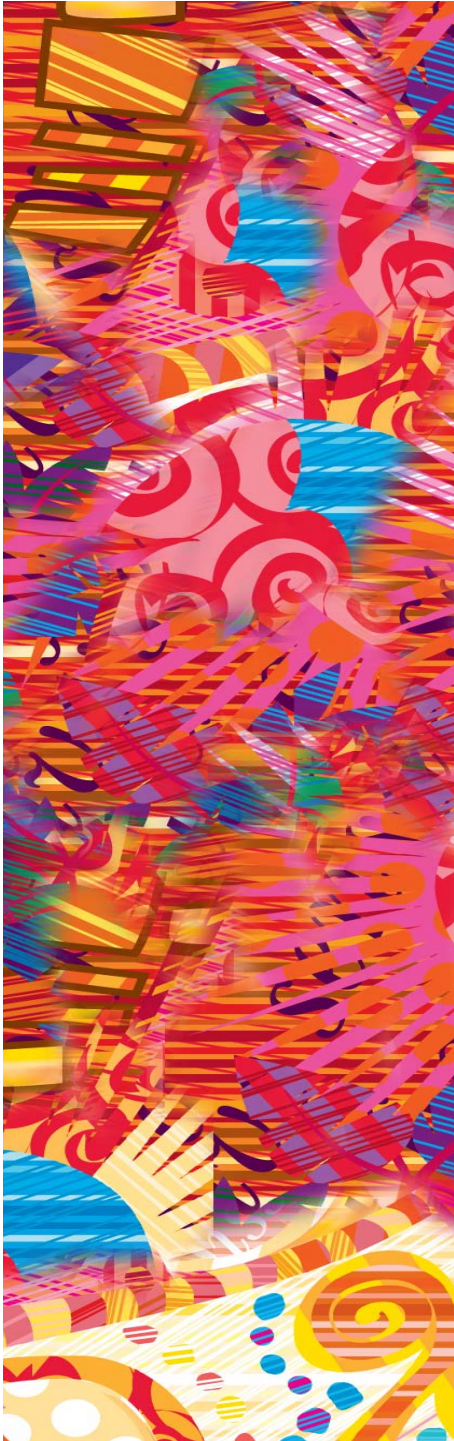




“Internet is the best place to shag!”

Internet and Youth with ID

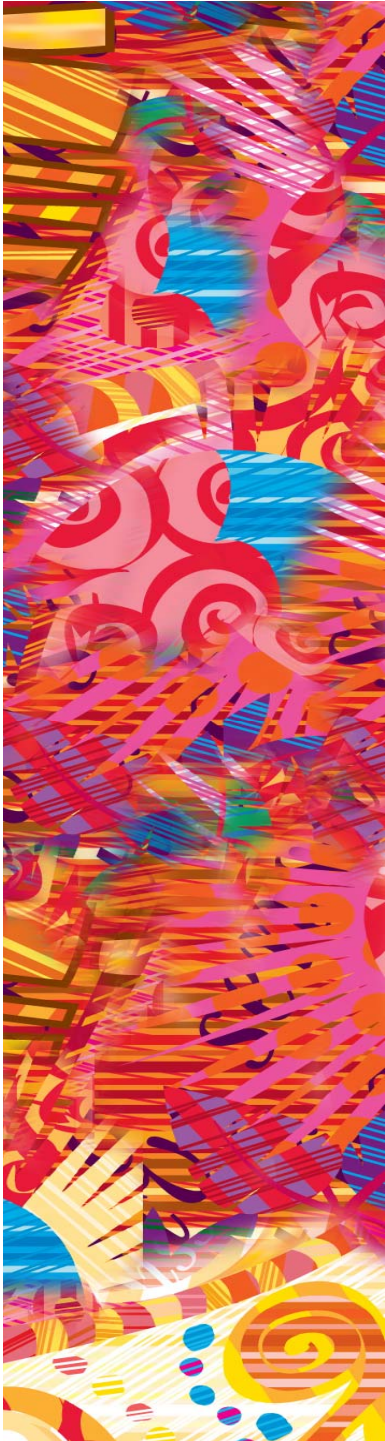
- “Everyone” uses social media today
- Social and love reasons
- Mostly contacts with already known friends and partners
- A few meet potential unknown partners IRL (mostly females)
- Positive risk taking – “follows” and “blocks”
- A few consume porn, mainly males



"I don't find anyone even here..."

Experiences of Youth with ID

- Uses the same sites as "every one else"
- Alternative identities
- A few realize the dream of finding a partner via the Internet
- Risk of disappointment and unfulfilled hopes
- Monogamous relationships on the Internet, ideology of love prevails
- Aware of risks, but don't always act based on this



“It’s all this about broken hearts and all...”

Views among staff and parents

- Today, staff and parents are on the Internet too
- Not as negative attitudes as in previous studies
- New technology makes it hard to have time limits and/or control of content
- Ambivalence – risk of sexual assault and “trickery”, but also new social possibilities

“I don’t think we have any gay people here”

A Norm-Critical Perspective

- Allow for a variety of sexual conduct, sexual orientations and sexual life styles.
- It can challenge gender-stereotyped views and make a more nuanced way of meeting young women and men with ID possible.
- A voice can be given to a discourse that focuses on enjoyment based on the individual’s prerequisites, instead of the problematizing discourse that focuses on heterosexual penetration.





Hip to be Crip?

- Crip theory has parallels to gay and queer
- Examines the “abnormal and normal”
- Analyzes concepts of the ideal life
- Functionally reduced – functionally complete
- Embrace one’s “stigma”
- Perhaps better suited for staff than for persons with ID?



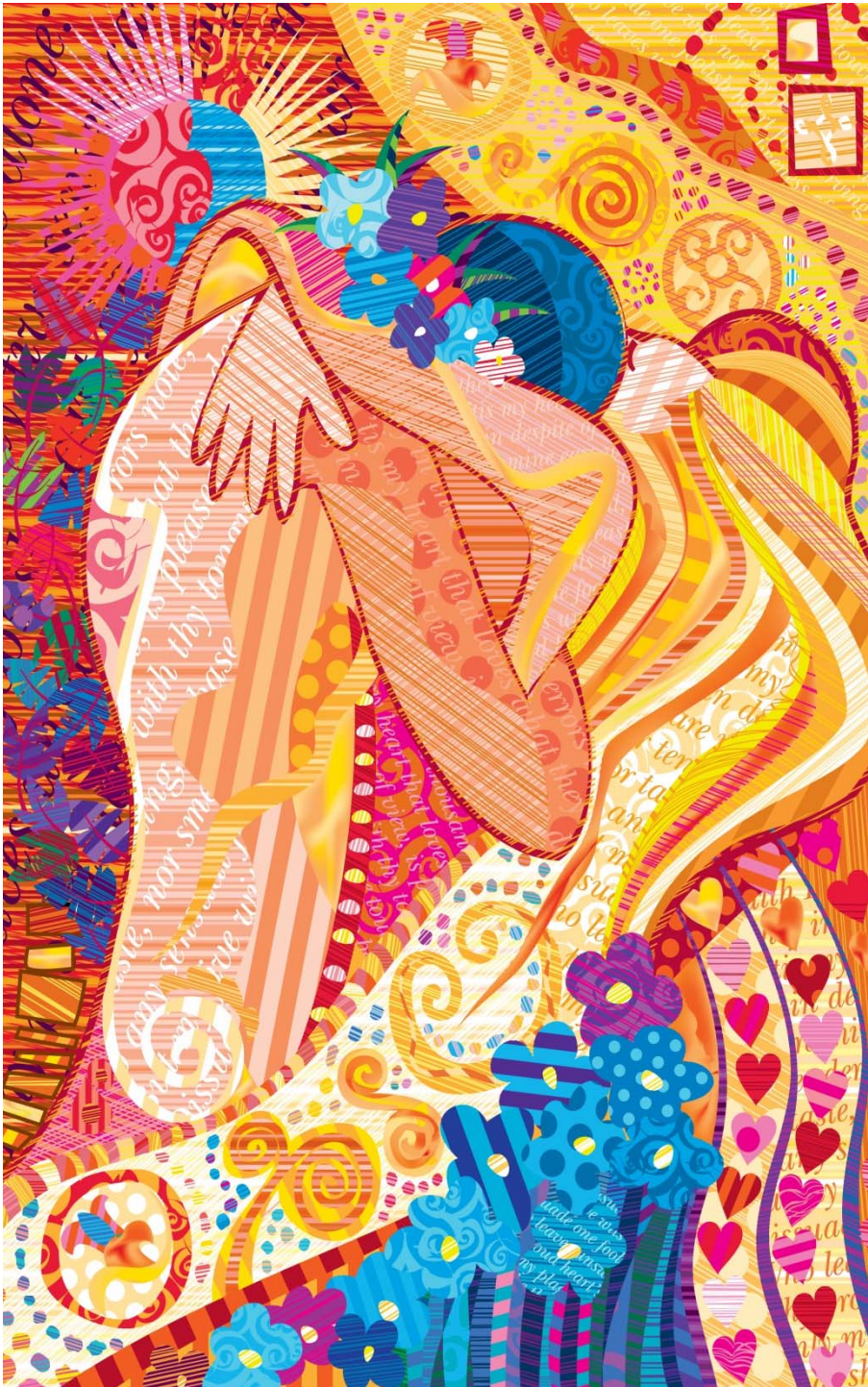




Conclusions

- So far, a restrictive sexual “script” focusing on risk instead of pleasure, desire, intimacy.
- Educate staff members and parents on sexuality among youth with ID.
- Offer young people with ID sex ed on their premises.
- Apply a norm-critical view and allow for sexual and gender varieties.
- See sexuality as a valuable part of life, possible for youth with ID, as well as for others!





THANK YOU!

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