Love and Sexuality among Youth with Intellectual Disability

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Charlotta Löfgren-Mårtenson
Professor, Director, CSS.

Malmö University
Centre for Sexology and Sexuality Studies
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?
What do you think they want?!

to make my own decisions

information I can access

to be treated with respect

to be asked
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!

