Unintended Consequences of Working on Sexuality Education with Young People with Disabilities: Experiences from the Breaking the Silence Project

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“It doesn’t matter whether they are in special schools or mainstream school but children have a right to be aware about their rights in terms of sex and sexuality.”

Teacher at a special school 2012
Literature on Sexuality, HIV and Disability in Africa suggested that:

**People with Disabilities**
- Lack HIV knowledge and are exposed to all HIV risk factors \(\text{(Groce 2004)}\)
- Are at increased risk of abuse and exploitation \(\text{(Kvam 2004, Hughes, K. 2012, Johnes 2012)}\)
- Have similar or higher HIV prevalence than the general population \(\text{(Shisana 2009/12, Taegmayer 2008, Touko 2009, Beaudrap de, P. 2013),}\)
- Youth with disability use a “secret language of sex” \(\text{(Chapel 2013/15)}\)

**Teacher’s**

**In addition, there were no evidence based interventions addressing disability and sexuality education in Africa** \(\text{(Hanass-Hancock 2009)}\)
The Breaking the Silence Project

This is a three year pilot project that aims to develop an evidence based curriculum innovation to improve sexual and HIV education including prevention of sexual violence for the South African Life Orientation subject, targeting teachers in order to reach learners with disabilities

- **Pre-phase (2010/11):** Comprehensive literature reviews and provincial stakeholder engagement
- **Phase 1 (2012):** Needs assessment with survey and FGD (including validation of research tools)
- **Phase 2 (2013):** Intervention development
- **Phase 3 (2014/2015):** Pilot and formative evaluation (survey, FGD, IDI, observations)
Study Design for Formative Evaluation

Framework:
Adapted Theory of Planned Behaviour (TPB)

Formative Evaluation:
Pre- and post evaluation before workshops and at 12 months

Tools:
Cross-sectional survey with teachers pre and post
IDI with teachers pre and post & FGD with students post

Sampling:
100 teachers and support staff of special schools in KZN
(Covering disability spectrum and urban-rural divide)

Analysis:
Descriptive, bivariate, regression and conventional content analysis
Pilot Intervention March 2014

100 participants were trained in 3 workshops across KwaZulu-Natal, South Africa
The Breaking the Silence Intervention

It's a curriculum innovation including a manual, tools and 3 day training that considers:

1) Concepts and intersection of disability and sexuality
2) Beliefs, values and challenges
3) Policy and legal obligations
4) Child and adolescent sexual development
5) Teaching and presentation skills
6) Activities for the classroom in 6 modules with alternatives for 5 different disability types
7) Toolkit with worksheets, pictures and policy examples etc.
Teachers Reported on four major themes

1) Perceptions of learners sexuality and sexual activities (incl. change)
2) Perceptions of learners knowledge, attitudes and beliefs (incl. change)
3) Perceptions of implementing the Breaking the Silence approaches
4) Contextual factors providing facilitators or barriers to sexuality education
5) Personal factors as enablers or barriers
Unintended Consequences
Learners Reflecting on ‘Able Bodied’ Perceptions

Learners develop not only ways of talking about their bodies and sexuality but also to question ‘nondisabled adults or peers’ and increasingly disclose sexual violence or exploitation.

“They [able bodied adults and peers] think you are not wise enough if you are from our school. They don’t expect you to say a sensible thing. We also learned that not only girls get raped even boys too. Others take learners from special school for granted. They say we are crazy, thinking we can’t talk or stand for ourselves. They don’t know we can see if someone is doing wrong. In their mind they think they can have sex and give us 50 cents and that’s it. Some takes you for granted thinking they can do as they please because they know you can’t talk or say anything.”

(Learners with intellectual disabilties in FGD)
Sexual Violence and Exploitation overshadows Intervention

In all workshops stories of sexual violence and exploitation were shared. This included girls and boys, learners, community and family members as perpetrators (not teachers).

“In our school [SMH] we had a boy who continuously raped the other learners. We tried to tell him that this is wrong and he was also a couple of times at the police station. However because he has an intellectual disability nothing happened. Eventually when he was past 15 he was expelled from our school, but then he would wait in the bushes for the learners to go past and get them like this.” (teacher in workshop)
Sexual violence or exploitation practised by learners was sometimes misinterpreted as being part of the health condition / disability.

“One child got off from the bus with a girl and he pulled her into the bush and hoped his friends went with. They were laughing and giggling. What they did to her really I don’t want to know … We have to prepare them because some of them respond to their bodies very, what do you call it basic instinct …. “

(teacher IDI)
Sexual Violence was often discussed in relation to family or community members and work with these groups was challenging because of financial situations of the families but also related to the distance between schools and home environment.

“I said to her (mother): your daughter will be turning twenty one next year, but we get a terrible smell coming out from her. She said, … that her brother is supporting the family … to keep that money in her home, she allowed the daughter to sleep with that.” (teacher IDI)

This teacher was worried to report the case, because the girl was already past compulsory school going age and the mother would take her out of school as soon as they ‘would cause trouble’.
“But why do people jump from one girl to another girl like me, I can jump from one girl to another girl, we are not in love we have no feelings for girls, we just want the girl for now, like I had a lot of girls, why don’t we feel like we want be forever with them, we fall in love with them because we want to fall in love with them not because we have to fall in love with them. Like I am in love with a girl for one week and then I decide you are boring, why does that happen. I want to realise that one girl is right for me so I can stay with one girl, stay with one girls … because it is like sin now ….. I don’t like jumping on them, you got one girl cross and then another one … because the one girl tried to kill herself, the one girl she slit her hand one day … the one girl … got to hospital.” (learner with intellectual disability)

This case had already been dealt with by the school, police and social services, however the girl went back to the same boy (who was the perpetrator)
How can we deal with the Ethical Challenges of this kind of Intervention?

How can we support the trainers and teachers in dealing with the increased reporting of sexual violence and exploitation?

- How do we facilitate quick and adequate referral and support in the absence of services
- What psychosocial support is needed for teacher and trainer

How do we deal with disclosure of sexual violence during workshops or interviews?

- What support mechanisms need to be in place
- What is different when working with learners with disabilities

How can special schools engage the families and communities of learners with disabilities or do we think that inclusion is the answer to the issue?
Project Publications from needs assessment:
