

COLLOQUIUM

FALL 2016

- The right to be heard: violence, justice, & access -- Experiences at ISAAC 2016:
- What are the experiences, perspectives, and needs of people who use AAC as their primary mode of communication in regards to their own sexuality?
 - Next steps & future directions
 - Questions

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THE RIGHT TO BE HEARD: VIOLENCE, JUSTICE, & ACCESS

ISAAC 2016: Presentations by: Barbara Collier, Diane Nelson-Bryen, Juan Bornman

Testifying in court - necessary vocabulary

Police training- South Africa, sensitivity training program

Fight, Flight, Fright - police officers perceptions of interviewing people with CCN

Access to justice - communication can and should be a part of the broader disability rights movement

Prevalence of Abuse

- 70% of people with disabilities reported that they were victims of abuse
- 63% of parents/immediate family reported that a loved one with a disability experienced abuse
- Children with a reported disability are 68 percent more likely to be victims of maltreatment than children with no reported disability.
- Women with developmental disabilities are at a 4 to 10 times greater risk of sexual assault than women in the general population.

Types of Abuse

- Verbal-emotional (87.2%): This may not be considered a crime
- Physical (50.6%)
- Sexual (41.6%)
- Financial (31.5%)

Frequency of Abuse

- More than 90% of people with disabilities who were victims of abuse on multiple occasions
- From 15,000 to 19,000 people with developmental disabilities are raped each year in the United States.

Rates of Reporting

- Nearly 2/3 did not report it to authorities due to futility, fear, and lack of information
- Outcomes of reporting: Most noted that nothing happened (52.9%)

<http://www.ncd.gov/publications/2007/May212007>

Victims of crime/abuse

- National and international studies reveal that people with disabilities are more likely to be victims of crime than other groups in the general population.
- A growing body of evidence also finds that crime towards people with disabilities starts early and in many cases continues throughout their lives.
- The experience of crime is particularly acute for: women and children with disabilities and people with cognitive and communication disabilities.**
- People with disabilities experience multiple instances of violence and crime
- People with disabilities who are victims of crime are: less likely to report, less likely to go to court, less likely to get needed counseling

Disability rights are civil rights. Disability rights are human rights and disability justice is intersectional.

- People with CCN need access to all levels of justice (police, legal services, criminal, civil, and family courts)
- Lack of supports within the justice system
- Lack of recognition of the need for communication accommodations and supports by professionals in the judicial system

https://issuu.com/rudermanfoundation/docs/ruderman_white_paper/5?e=23350426/33988851

SO WHAT?

Our Role

- We need to know our role in the justice system
 - What that means in the US
- The justice system needs to learn how to USE us, not BE us.
- Promotion of a culture where no form of violence is tolerated
- Continued advocacy to ratify the UNCRPD
- Education
- Research
- Policy
- Programs/Services
- Leadership
- Access to vocabulary - to communicate who, what, when, where, and how a crime has occurred
- AAC/Disability resource kit, AAC kit for interrogation and testimony (Israel)

RESEARCH QUESTION

- What are the experiences, perspectives, and needs of people who use AAC as their primary mode of communication in regards to their own sexuality?

RATIONALE

- Sexuality
- Disability & Sexuality
- CCN & Sexuality – Use of AAC
- Current research literature: AAC & Sexuality
 - Preventing abuse
 - Capacity to consent
 - Vocabulary
 - Education
- Contributions to the CSD field

METHODS

Data Collection

- Interviews
- Semi-structured
- Email

Participants

- 4 individuals
- Diagnosis of cerebral palsy
- Primarily use AAC to communicate
- 35-60 years of age
- 3 men, 1 woman
- 3 identified as heterosexual, 1 identified as homosexual
- All identified as white

Screening Questionnaire

- Name:
- Date of Birth:
- Age:
- Race:
- Sexual Orientation:
- Disability/Medical Diagnosis:
- AAC System Used:

METHODS

Semi-Structured Interview Questions

- Tell me about relationships
- Tell me about sex/uality
- Tell me how you learned about sex
- Tell me your thoughts on marriage and/or family
- How has your sexuality been impacted by your use of AAC? What are barriers? How can barriers be solved? How does AAC impact the development and maintenance of intimate and/or sexual relationships.

Data Analysis

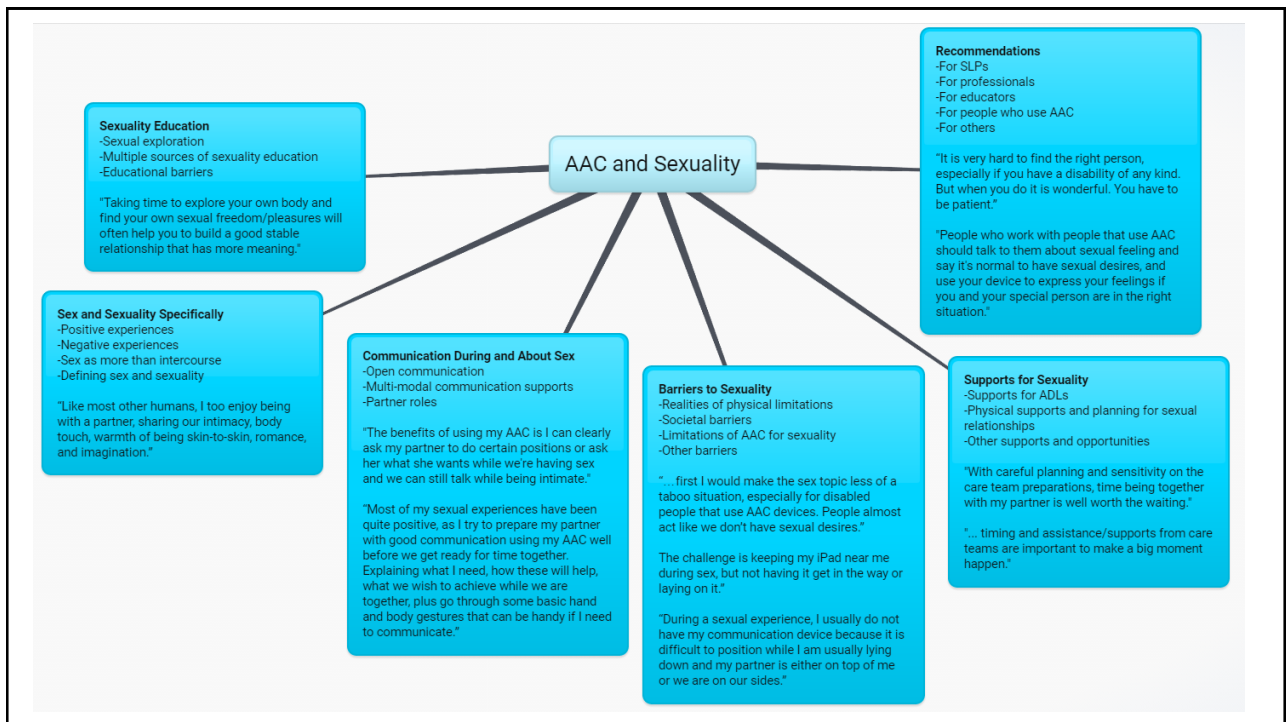
- Data unitizing
- Data coding
- Theme development
- Negotiating agreement
- Calculating agreement and reliability
- Confirming the summary with participants
- adapted from Yin (1994) & Vaughn et al. (1996)

THEORETICAL ORIENTATION

(Linton, 1998)

- “Research, whether aimed at disability as subject matter and disabled people as subjects or erroneously ignoring disability, plays a role in constructing disability”
- “How does the structure and focus of research contribute to ableist notions of disability? What perspectives inform the choice of variables, theories to be tested, interpretative frameworks to be employed, and subjects to be studied?”
- “These newer (qualitative) methods have not succeeded in placing disabled people in a more central role in research production, nor in explicating the power differences between predominantly nondisabled researchers and their disabled ‘subjects’”.
- Importance of stating one’s position relative to the subject matter

Nothing about us without us



RESULTS – DISCUSSION QUESTIONS

"It is almost impossible to have good sex without good communication"

(Kaufman, Silverberg, & Odette, 2007, p.69)

Limitations of AAC: 3 participants discussed the limitations of using AAC during sexual experiences.

- How can AAC system(s) be better designed and implemented to be dynamic and functional across settings and partners, including in sexual circumstances?

Open communication: 4 participants identified this as especially important.

- How does this differ from communication in relationships between two nondisabled individuals? How is it the same?

Physical supports and planning: 4 participants discussed the importance of physical supports, aides, and planning.

- Do people who use AAC, especially if they are using a symbol-based system, have ways to communicate and organize these logistics? To what extent can professionals be a support for this?

“If you use your AAC from the beginning of a relationship, it will be normal for you and your partner, even during sex.”

RESULTS – DISCUSSION QUESTIONS

Recommendations for people who use AAC:

Participants provided recommendations for other people who use AAC.

- What is the best way to share information like this? Who is responsible?

Recommendations for SLPs:

2 participants recommended that SLPs should bring up discussions around sexuality.

- Many SLPs do not receive a comprehensive training in AAC, let alone training in sexuality. Are SLPs qualified to do this? Are they comfortable doing this? Should they be?

Implications for clinical practice: Professionals working with people who use AAC must consider that sexuality has been, is, or will be an important aspect of their life at some point.

- This means ensuring access to vocabulary, education, and resources.
- Because of the societal barriers retain a strong impact on this group of people, it is crucial that advocacy and activism continue across disciplines and disability groups

Limitations

Low sample size - Cannot generalize findings to all people who use AAC.

Emails vs. face-to-face interviews - More difficult to build rapport.

- Could not observe communication systems in use.

Future Directions

- More conversation about the experiences, perspectives, and recommendations about sexuality by and for individuals who use AAC.
- Disseminating the recommendations made for individuals who use AAC and professionals.
- Further research about how to best support individuals with CCN in developing relationships and sexuality.
- Ensuring that professionals have easy access to research about people who use AAC in order to provide information and support.

THANK YOU!

“Providing disabled adults with access to sexual lives is not just crucial for a life with dignity. It is an issue of fundamental social justice with far reaching consequences for everyone”

(Kulick & Rydstrom, 2015, description)