

# Sexually Silenced No More, Adults with Learning Disabilities Speak Up: A Call to Action for Social Work to Frame Sexual Voice as a Social Justice Issue

George W. Turner<sup>1,\*</sup> and Betsy Crane<sup>2</sup>

<sup>1</sup>4010 Washington, Kansas City, MO 64110, USA

<sup>2</sup>Center for Human Sexuality Studies, Widener University, USA

\*Correspondence to George Turner, MSW, Ph.D., 4010 Washington, Suite 405, Kansas City, MO 64110, USA. E-mail: george@turnerprofessionalgroup.com

## Abstract

This qualitative study provides insight into the personal experiences and perceptions of adults with learning difficulties regarding their social-sexual lives. Case studies of five adults with learning difficulties based on two in-depth interviews and a home observation revealed five key elements needed to have a sexual voice: sexual self-advocacy, sexuality education, sexual script, sexual vocabulary and sexual-relational support. Social workers are encouraged to see sexual voice for adults with intellectual disabilities as a social justice issue. Challenging structural systems that contribute to marginalisation is fundamental to the efforts of social workers to advance human rights and social justice. Social work educators can increase student competency around advocacy related to disability and sexuality as well as assisting clinicians to improve their practice skills in these areas.

**Keywords:** Learning disabilities, intellectual disabilities, qualitative research, sexuality education, social justice, social work advocacy

*Accepted: August 2016*

## Introduction

Social work is deeply rooted in social justice (Reamer, 1998). The International Federation of Social Workers (2014) 'strives to alleviate

poverty, liberate the vulnerable and oppressed, and promote social inclusion and social cohesion' (para. 4). A critical strategy in their efforts to advance human rights and social justices is dismantling systems of oppression, which contribute to the marginalisation. However, it may be argued that social work advocacy has not been prominent in disability rights, specifically around sexuality. The academy is not without culpability, as some might posit that social work education rarely acknowledges the intersection of sexuality and disability. For adults with learning disabilities (LD), [Turner \(2012\)](#) states, "here in the shadows, their sexuality can be shamed, segregated, and silenced" (p. 5). Having sexually literate social workers could facilitate client sexual health, yet better academic training is needed ([Diaz and Kelly, 1991](#)). This separation from sexuality maintains the status of adults with LD as other. This article aims to bridge the gap back to sameness.

While a previous publication presented in-depth case-study descriptions of the social-sexual lives of five people with LD ([Turner, 2012](#)) and a second paper reviewed cross-case thematic findings related to sexual pleasure ([Turner and Crane, 2016](#)), this paper explores the importance of a sexual voice. We first address the meaning of sexual voice and then review related literature. Next, we introduce study participants and present cross-case thematic findings related to sexual voice. We conclude with implications for social work education, practice and research.

## Sexual voice

We use the term 'sexual voice' to describe how a person reveals their social-sexual self through communication. Without a voice, adults with LD are defined by others, and treated as voiceless objects. Supporting adults with LD to have a sexual voice can help them move to being the subject of their own lives. bell hooks asserted that minority voices often conform to what the majority wants or needs to hear. Helping adults with LD find a sexual voice is 'a move in the direction of freedom' ([hooks, 1989](#), p. 17).

The benefits of a sexual voice are numerous. A sexual voice is about power or the lack of power in the case of adults with LD. It is insurance against the 'curiosity-muting behaviors of ordinary people that silence those who want to better understand themselves and their bodies' ([Loren, 2011](#), para. 1). A sexual voice is a tool of self-determination. It releases them from a passive position where sexuality happens to them; it acknowledges that they own their story. It provides them the tool to exercise that right, to tell their own story. By owning their stories, they answer the call by [Shakespeare, Gillespie-Sells and Davies \(1996\)](#) to counter the invisibility of their sexuality. By having a sexual voice,

people with LD come out of sterilised imaginary bedrooms to mirror the realities of bedrooms everywhere.

Advocating for adults with LD to have a sexual voice can move the conversation beyond the sex negativity associated with viewing them as perpetrators or victims of sexual misuse, or at risk of unwanted pregnancy. Sexual voice embraces the privileged positivity of sex, specifically pleasure, that is experienced by abled others, owning pleasure as ‘the authentic, abiding satisfaction that makes us feel like complete human beings’ (Masters and Johnson, 1974, p. 28).

Beyond mere sexual advocacy, having a sexual voice affirms one’s right to be sexual and to reach one’s social potential. As the *Declaration of Sexual Rights* of the World Association for Sexual Health (2014) states, ‘sexual rights are grounded in universal human rights’ (p. 1). A strong sexual voice can assert one’s rights to amorous potential; it can demand carnal pleasure; it can showcase the erotic self; it can claim sexual desires; it can challenge conversations that diminish or misrepresent views of one as less than a full human being. A sexual voice can say ‘No’ and ‘Yes’.

## Literature review

Previous research revealed that, when given the chance, adults with LD are ‘pleased to have someone to talk to about [sexuality]’ (Brantlinger, 1985, p. 107) and they have much to say, expressing positive feelings even when discussing complicated or stressful sexual experiences (McCarthy, 1998). However, the social work research literature on adults with LD and sexuality is strikingly bereft of first-person accounts giving voice to their *social-sexual life*.

Using search terms ‘sex’ and ‘intellectual disabilities’ or ‘learning disabilities’, we conducted a literature search in databases such as Academic Search Premier. We found that researchers from other disciplines have identified powerful themes meriting the attention of social workers, including: social services support regarding sexuality and relationships (Yacoub and Hall, 2010); decision making on sterilisation (Chou and Lu, 2011); importance of touch and sexual stigma (Sullivan *et al.*, 2013); gay adults with LD (Stoffelen *et al.*, 2013); and finally sexual rights and non-reproductive sexual behaviour (Yueh-Ching *et al.*, 2015).

Researchers recognise the value of first-hand accounts and opinions of adults with LD. For example, Owen, Arnold, Friedman and Sandman (2016) investigated how members viewed sexuality and relationships through a lens of self-advocacy. Sitter (2012) reported on an action research study carried out by nine adults with developmental disabilities

and three allies. They created videos about love and sexuality as a critical human rights issue in the disability community.

Researchers have also noted missed opportunities where the voice of people with LD was discounted (Lesseliers *et al.*, 2009) attempting to 're-grant identity to these silenced narratives' (p. 411). However, honouring the voice of participants with LD is not without controversy. A potentially salacious topic, facilitated sex (Yacoub and Hall, 2008), which asks care workers to help participants in sexual expression, highlights the social justice nature of sexuality and disability. In response, social workers might be able to use a person-centred, psycho-educational approach from a rights-based perspective (Cambridge, 2013).

Relatively new to the professional discourse and also potentially salacious is the notion of sexual pleasure as a human right. Turner and Crane (2016) note that conversation around people with LD often ignore the concept of pleasure, yet, for social workers addressing sexuality and social justice, 'pleasure would be a natural fit within this conversation, epitomising core pillars of social work: "self-determination" and the "strengths perspective"' (p. 3).

Social work was the focus in 2014 of a special issue of *Sexuality and Disability: The Emerging Intersection of Sexuality and Disability in the Profession of Social Work*. Of seven articles, two addressed people with LD. Friedman, Arnold, Owen and Sandman (2014) looked at sexual self-advocacy and Wings-Yanez, (2014) examined a sexuality curriculum for special education. A review of the *British Journal of Social Work* surfaced ten articles on disability; however, only two looked at LD and sexuality. Hollomotz (2009) addressed the sexual violence risk of people with LD, and Dixon and Robb (2015) focused on domestic violence against women with LD. There were no articles found in the social work literature based on original research examining adults with LD and human sexuality, specifically how social work addresses sexual voice as a social justice issue.

## Methods

This qualitative case study, informed by heuristic inquiry (Creswell, 2013), explored and described the lived sexual experience of five adults with LD living in the Midwestern region of the USA, by exploring the meaning they attached to their sexual lives, and by examining their social-sexual voice through the use of discourse analysis. The research question related to sexual voice was: How do adults with learning disabilities describe their subjective experience and expression of romantic, and/or sexual relationships? To be included in the study, participants had to be their own legal guardian (their autonomy to make personal choice had not been legally transferred to another person or limited by

the court), have a diagnosis of 'mild' mental retardation or intellectual disability made by a mental health professional, and be receiving case management support.

After receiving permission to proceed from the university research ethics board, Turner contacted local disabilities professionals, providing an introduction letter they could read to potential participants. A 'release of information' form from possible participants allowed agency workers to share names and contact information with the researcher.

## Data collection

Data collection occurred through observations made during an initial home visit and two audio recorded, semi-structured interviews. The decision to do just two interviews, of about 1.5 hours each, was made in part due to the participants needing to rely on staff for transportation. The home meeting allowed participants to show us aspects of their lives that might be relevant to the research, such as photos of people in their lives and ownership in décor. At this first meeting, Turner read a consent form and asked questions to confirm understanding.

A female research assistant who was a licensed social worker and human sexuality doctoral student was present for all meetings to assuage any concerns about a male interviewer asking sexual questions. She also took observational notes that provided additional data for the case studies. She observed and recorded the participants' degree of comfort or embarrassment with the topics or responses sparked by the interview question and pictures, and the nature of questions. Following the suggestions of many scholars (e.g. [Bogdan and Biklen, 1998](#); [McCarthy, 1999](#)), we attempted to build rapport and gain trust by being respectful, friendly and interested towards each participant. Knowing that the length of interviews and subject matter may be demanding, frequent breaks and beverages were offered to minimise fatigue.

During our first meeting, participants seemed at ease and were excited to give us a tour of their homes. We presented ourselves as [McCormick \(1988\)](#) suggests, as that of 'a friendly consultant, doing my best to present myself as someone who values their opinion' (p. 2). As participants showed us their personal belongings, we would comment on and ask probing questions about items such as photos, artwork and music. We used the personal artefacts to discuss the idea of sexual and/or romantic relationships. Based on [Booth and Booth's \(1996\)](#) suggestion of using personal objects to help facilitate the interview process with this population, highlighting relevant personal items and discussing the sexual and/or romantic nature of these items helped normalise the subject. Immediately after leaving the homes, Turner met with the research assistant to process the meeting and to take notes of observational details.

The two interviews were conducted in a conversational style. The interview guide was adapted from questions used by Timmers, DuCharme and Jacob (1981) in six categories: (i) attraction, (ii) dating, boy/girlfriend, (iii) romantic love, (iv) sex, (v) sex education and (vi) seeking help. We followed McCarthy's (1996) suggestions to ask for details and not to make assumptions about people's sexual lives. We used easy-to-understand questions, providing alternative wording when participants did not understand. Participants could use an 'I don't know' picture-placard and an 'I don't want to answer' picture-placard when experiencing any apparent hesitancy.

## Data analysis

Data analysis was iterative, in that field notes captured initial impressions immediately after each participant contact. The first level of analysis was creation of five case studies, based on what emerged from the interviews, observations and field notes regarding each of the five participants. These were written in a narrative style with the intention of providing voice to participants' experiences (Murray, 2003). For cross-case analysis, coding of all documents involved a combination of deductive and inductive analysis. For the deductive mode, a preliminary set of codes was, as Crabtree and Miller (1999) described, 'based on an initial conceptual model and/or literature review' (p. 168). The inductive technique (Strauss and Corbin, 1990) involved adding codes as we segmented and coded the transcripts, observational notes and field notes. Themes emerged using a constant comparative method (Denzin and Lincoln, 2005) where newly gathered data are compared to previously gathered data to develop categories.

Data triangulation enhanced the quality of findings, as did multiple contacts with participants. Peer debriefing (Patton, 2003) occurred throughout the research process through discussions with the research assistant. These discussions enhanced quality significantly because the meaning that emerged from the data was brought to the surface for reflection and feedback.

## Findings

Pseudonyms are used for participants who are presented here, starting with the participant with the least developed sexual voice and progressing to the person with the richest sexual voice. Milton is a fifty-four-year-old male, Terri is a thirty-one-year-old female, Richard is a forty-eight-year-old male, Lionel is a twenty-one-year-old male and Kristy is a forty-eight-year-old female. Four were white and one African-American. Richard owns a home in the community, while the

others live in segregated apartments or group homes. Kristy was married in a ceremonial wedding but not legally and lives with her husband. For rich case-study descriptions of each individual, see [Turner \(2012\)](#).

Five themes emerged as relates to sexual voice: (1) sexual self-advocacy, (2) sexual education, (3) sexual scripts, (4) sexual vocabulary and (5) sexual/relational support. Capturing the spoken word legitimises participants' sexual voice, while also normalising their relational and sexual desires and dreams, and ownership of their sexuality.

## Theme 1: Sexual self-advocacy

Sexual self-advocacy is the ability to express one's own sexual needs or promote one's own sexual interests. Participants demonstrated self-determination when they took a stand for something that was important to them. Terri acknowledged that her mother, whom she routinely deferred to for guidance and support, did not approve of her marriage goal. However, Terri managed to exert her sexual voice, sharing: 'I told my mom . . . one of these days I have to get married and I'll be moving out. I'll be living with Brad probably.' Asked how her mother responded, she replied: 'She doesn't like it, but . . . I think that it would be a good plan for me to do.' Kristy consistently expressed self-determination in her sexual life. She pondered why her husband Duane did not perform cunnilingus on her:

I don't really want to embarrass him. But, you know, I said, we need to talk about this, honey . . . . And explain; is there something that's really blocking you from doing that? Or you don't want to do that or what?

In order to have a voice, one needs to be able to identify what one wants with conviction. Not being alone was crucial; participants consistently spoke about desiring companionship. They routinely identified that having someone special in their life would add to the quality of their life. Even Milton, who had seemed like a confirmed bachelor, expressed a sincere desire for finding the 'right person' with whom to share his life:

Hopefully in the future I'll find the right person and dance with them or if they want to have sex with me. Or have a love life for me. And, be friends and, try to have a relationship with them . . . somebody that's, like, real nice and kind and, will be nice to go with.

Seeing the benefits of marriage and sex can bolster sexual self-advocacy. Asked about being married, Kristy exclaimed: 'I love it! It taught me patience; that I have to be very patient with Duane.' Asked about sex, she shared:

You're getting closer to the person you love . . . . And it's good. You know, it's just once a week. Sometimes twice, if we're lucky, but, I like

touching and feeling and trying to get him in the mood and ... to me it's part of life. If you're ready for it, go for it. If you're not, don't.

Richard continually expressed his needs to staff and family. To the question 'What would you want [staff and parents] to help you with?', he responded passionately:

I like to go out to a meal, ... to the movies, dances. I'd like to invite her over to my place. I want to marry Cathy so much. I want to learn about, ... look after her. And, take care of her [clears throat]. And have sex with her.

Yet, such self-advocacy can be squelched. He continued:

I told my mom about it. [I asked if] ... Cathy could spend the night with me. She said, no. But (Cathy's) mother won't let her too ... I always talk to Bonnie [agency manager] about it. But she wants me to ask my mom first. But it didn't work.

Permission seeking is seen when adults with LD search for approval or acquiesce. Richard frequently referred to needing his mother's permission, although he lacked the sexual voice to state his desire. When asked how he might solicit his mom's blessing to marry Cathy (one of his goals), he stated: 'If I ask her again and again.' Earlier, he had said: 'I love her a lot. I want to marry her, but I have to wait and see what happens. When—if I tell my parents.' When asked 'Do your parents know that you want to marry her?', he responded: 'No!' When asked whether he had ever considered a roommate, since he expressed being lonely, he responded: 'If my mom lets me have a roommate.' He understood the basic definition of guardianship, yet routinely expressed a need to garner his mother's permission.

## Theme 2: Sexuality education

Sexuality education includes formal and informal receipt of sexual information. Participants received sexual information from school, parents/family and media, with pornography cited by four participants. Richard said he looked at *Playboy* and referred to scenes from pornographic videos, such as 'having sex in a carwash'. Kristy learned from watching television: 'I just watched stuff, you know, Dr. Ruth, ... Dr. Phil, you know. And that's where I learned a lot of my maturity.' For Lionel, a cousin was a key source of sex information. He also knew how to access sexual information on his computer, stating that 'you can get questions from off a website. I don't know the name of it, but I know if you type it in it might lead you into it'. He knew how to go to a chat room, access porn sites, send e-mails and text a girl that he was dating. When asked where



he meets people to go on dates with, he said: 'I talk to people on Facebook.'

Most participants demonstrated knowledge poverty in regard to sexuality, such as Richard, who said Cathy 'don't like having babies' and could not identify any methods to prevent them. He knew babies grow in a woman's 'tummy', but thought the baby came out the 'backside', meaning the anus. While Milton did not demonstrate a rich sexual knowledge base—he said he had never heard of a condom—he was able to identify a description of rape. Two participants did not show any knowledge of rape. Only one participant seemed to know the meaning of sexual orientation.

### Theme 3: Sexual scripts

A sexual script includes sexual role expectations, which, for these individuals, often seemed to come from someone else, not fully understood or believed; it had a rehearsed and regurgitated quality. Milton exemplified this when asked 'What would you like to happen during sex?'. You can almost hear his mother's voice in his response: 'Uh, just have a good girl, a relationship. Uh, to try to get along with people. Um, don't fight, don't argue.' Lionel appeared to have been coached many times on his social skills, as he would periodically unveil a lesson learned, such as:

Because she has to ask me first if you want to. If she says she don't want to do it, I will just say, okay. We won't do it. So if someone says, no, it means no. Don't force anybody on them . . . . Because if somebody forced me I have to say, no,—if I don't like it I won't do it.

At times, participants did express their own individual sexual scripts. For example, Lionel declared: 'I like to tongue kiss.' Richard, without hesitation, professed: 'I see [want to see] Cathy much and spend the night and have sex with her.' After telling me that Cathy only lies with him with her clothes on, his own script quickly surfaced as he added: 'But I like clothes off.' Kristy provided an example of how she and her husband Duane evolved their sexual script, sharing:

I asked him, what do you want? Do you want this? Or he'll tell me not to do that, you know, like I used to kiss him on—in the ear. That drove him crazy. So I've stopped doing that.

An incongruent sexual script was exemplified when Terri talked about how touching was restricted for her and her boyfriend, Brad, during work hours. When asked what kind of touching they did outside of work, she responded: 'We high five each other.' This behaviour seems more in line with friends, not romantic partners.

Participants' scripts drew from their awareness of normal life expectations. They shared desires to meet cultural/family norms or to fulfil the

perceived role of an adult. Asked whether he wanted to have a child, Richard reflected: ‘Yes. Because my brothers have, a boy and girl and boy. My mom just love . . . I should be . . . like with my brothers.’ He expressed a belief that marriage was the ideal, perhaps seeing it as a way to meet his sexual desires.

Soliciting participants’ opinions on topics and asking for them to provide tips provided a window into their sexual scripts and their ability to exercise a rarely tapped aspect of their voice—my voice matters, I have value. Kristy was quite comfortable with offering recommendations. When asked what knowledge she would bestow upon a group of college students regarding adults with learning difficulties and sex, she responded:

I think people need to learn we need to know the stuff . . . about sex . . . It just depends on . . . the maturity level you’re at. We might not be as bright as your students right now, but we have the same feelings and same sexual activity as other people. And it might take us longer to get there, but we understand and it’s just—we’re just a little slower at times.

#### Theme 4: Sexual vocabulary

A sexual voice involves having sexual language and understanding key concepts. This varied, with a limited set of simplistic, one-word answers being used at times. Word choices often lacked sophistication or depth and were seemingly incongruous descriptors for typical adult responses. Language patterns characterised by the overuse of words such as ‘nice’ and ‘good’ as sexual descriptors were common. Sexual default vocabulary was common. An example is seen in Milton’s definition of dating as ‘to find a right girl, right companion, that’s friendly, courteous and kind’. When asked ‘What do you think is pretty or attractive about Brad?’, Terri, with little emotion, responded: ‘He’s handsome.’

In contrast, Kristy demonstrated a significant pattern of animated conversation skills, often using colloquialisms such as ‘like trying to pull teeth sometimes’. She was also prone to hyperbolic statements such as ‘we looked into each other’s eyes and was like kids might. I mean, we were a match. I think I’m going to have that until the day we die’.

Concepts explored during the interviews included love and sex, along with romance and dating. Two additional concepts—friends with benefits and hooking up—were also explored, but were not understood by four of the participants; only Kristy understood those ideas.

*Love* was seen as a strong passionate feeling for a person, represented by acts such as gift giving and gift receiving. With a huge smile, Richard detailed: ‘Yes, she always gave me a present. Last time she bought me a candle. And she bought me some flowers for my house.’

Kristy offered: 'You know when you're in love ... when you look at somebody, and the communication's there, and you're holding hands, and you just feel those sparks. It's like fireworks. I think I'd seen fireworks when he first kissed me.'

Participants described *sex* in various ways. Some had almost a spiritual conception of sex, as 'becoming one', or having a 'special relationship'. Others were more graphic, even if they had not actually experienced it. Lionel said: 'It's like putting ... it's like put your penis inside the woman's butt and then you put inside the woman's vagina. They can put it in their mouth. They kiss. They can kiss on their thing and hump each other.' Asked whether he had ever done any of those things, he said: 'Well, I'd like to.'

### Theme 5: Sexual-relationship support

This final theme relates to the support that individuals with LD need if they are to be able to explore their sexual and relational desires. A person-centred approach encourages participants to guide their own lives within the least restrictive environment. Support from family is often lacking, yet there were positive examples. Kristy mused about her wedding:

My dad just walked me down the aisle. The bridesmaid was my stepmother. Because I thought I'd include her in there. [And Duane's] brother was there. He stood up with him. So it was kind of like it's all the family.

It took community support to make this wedding possible. For example, after providing two weeks of couples counselling, Kristy's minister pronounced them ready and officiated at their ceremony.

The reality of these individuals' lives is that staff support has a great deal to do with their social-sexual autonomy. Personal pleas for assistance from staff included: more sex information, help with dating, help with acquiring sex and talking to parents on behalf of participants. Some participants had negative perceptions of staff support, not feeling they could talk about sex with them. Milton stated: 'Well, the thing is it wouldn't be a good subject to talk about. Or it wouldn't be appropriate.' Participants did not see staff as a resource for sexual information, which was a disadvantage, since direct support professionals are often participants' main access point to health care, including sexual health. But staff can be critical to the success of participant romantic relationships as demonstrated by Kristy: '[staff] made it look like a perfect little wedding.'

Agency support could be viewed in a variety of ways, from staffing to policy. Kristy reported that her relationship with Duane was stalled

while the agency found housing for Duane's roommate. Participants were unsure as to whether staff had sexuality training from their agency or whether there was an agency sexuality policy. However, there was a default sense of sex being off limits. Kristy stated: 'Well, if you're in the other apartments, you're not supposed to have sex or anything. No touching or anything like that. For us, anything goes because we're married.'

## Discussion

As these findings reveal, adults with LD in this study were quite able to express their own voice regarding their social-sexual lives, which has implications for the profession as relates to research, education and practice. The lens of social justice provides not only a viewpoint, but also a mandate to bring the sexuality of individuals with LD into what are seen as the many facets of social work: 'In communities where people are denied self-determination and sexual pleasure, health and wellbeing are also denied. Having control over one's body is a building block of social change' (Sloane, 2014, p. 454).

However, for people with LD, control over their body has been historically denied, most notably through institutional living and the medical model. These systems were routinely sexually repressive, punitive and restrictive. Because sexuality has often been a tool for discrimination against people with LD, Siebers (2008) asserted that 'sexual agency becomes central to political agency' (p. 135). He claimed that sexual citizens claim their sexual agency by demanding access to sexuality information, by increasing their sexual knowledge beyond a narrow medical focus and by insisting on the inclusion of other than mainstream bodies and traditional forms of sexual expressions. We assert that having a sexual voice facilitates control over one's body and is crucial to social work's focus on providing inclusive communities with access to resources, thus elevating marginalised communities.

### Sexual justice is social justice

Comparing this group with other marginalised groups such as the Lesbian, Gay, Bisexual, Transgender & Questioning (LGBTQ) community might help situate the topic so that social workers can engage in this somewhat challenging conversation. Additionally, a sexual voice may allow people with LD to own how they identify elements of their sexuality such as gender and sexual orientation. This power may enable them to correct misperceptions, which was the case with two participants who were assumed by staff to be gay. Social workers with an expertise

in sexual health can provide disability professionals with education on sexual orientation versus gender presentation or situational same-sex behaviour, whereby someone may engage in same-sex behaviour due to lack of other sexual partners. Segregated group living with limited access to sexual partners speaks to this as a sexual justice issue.

Helping clients have needed information and resources in order to embrace a romantic/sexual life is an important area of advocacy for social workers. The following access issues were evident in our findings:

1. Access to sexual information was limited and participants were unaware of resources such as the library. Most were unaware that their primary care physician could provide sexual health information. When asked, Milton said that he might seek the assistance of a 'preacher or a psychiatrist'. Of note, none listed social workers as a potential resource for sexual information.
2. Access to transportation is especially critical for people who do not drive. It can be difficult to access the typical routes for transportation provided by agencies when you are embarrassed about the nature of your trip, such as going to pick up lube, condoms or a sex toy. Staff judgement and outright denial of assistance also is an issue. Richard talked about if he wanted to buy a 'porno', he would have to take the bus by himself, because a staff person would get into trouble if they took him.
3. Technology can be a source of connection, especially in the realm of sexuality. Does the person have the economic resources to have a home computer or phone to connect through social media to others? Can they afford paid pornography sites? Is there hard-copy erotica written at an appropriate literacy level? Is it offered in multiple formats such as pictorial brochures and audio-recordings?
4. Larger barriers or supports affect access. Systemic denial may be imposed by the legal system or other governmental entities. Kristy reported that she and Duane could not get legally married due to the changes it would cause in their (disability) benefits.

A focus on building sexuality capacity is within the scope of social work practice because it promotes an increase in self-determination and self-advocacy. For example, persons with LD who want romantic or sexual relationships, yet lack dating skills such as flirting, knowledge of safer sex or practice with reading social cues and group norms, will have little capacity to make informed choices leading to healthy relationships (Travers *et al.*, 2014). Helping improve the social-sexual life of adults with LD should be part of social work practice, given the profession's values of self-determination, client choice, strengths perspective, dignity of risk, community integration and recognising the worth of all individuals.

## Implications for social work education

As [Ballan \(2008\)](#) urged, ‘international associations should identify pioneering strategies and best practices to instruct students on the sexual oppression of disabled people from a social model lens within social work education’ (p. 200). Social work educators, dedicated to teaching practice based in cultural humility, must incorporate sexuality and disability into the curriculum, challenging students to a critical audit of their own beliefs, values and myths about sexuality and people with disabilities. As students unpack their bias and stereotypes, they should be supported to reframe their practice from the medicalised model typically used to pathologise people with disabilities and their sexuality, to a social model of disability lens.

## Implications for social work practice

The social model of disability urges movement away from an individual impairment approach to disability to an examination of systemic barriers such as societal policies, discriminatory acts, economic disparity, resource access and stigmatising beliefs ([Taylor, 2005](#)). It is not enough for us to advocate for policy change for inclusive classrooms or to build coalitions of people with LD and their parents so that they can gain community based employment and housing. To continue to demand inclusivity, we must prepare people with LD to have a sexual voice. Our findings outline a blueprint (i.e. five themes) for a sexual voice. Helping adults find, practise and hone their own sexual voice changes the power dynamics allowing people with LD to challenge normative sexual privilege. Routinely including goals related to their social-sexual lives within plans made with people with LD may reveal long-withheld needs and desires.

Social workers experienced with systems theory, which addresses the equity of value of all participants within a system, will be better prepared than perhaps other health care providers in seeing sexual voice as a social justice issue. As [Swango-Wilson \(2010\)](#) noted, ‘determination of what can be achieved by the individual with a disability is in large part a function of systems expectations and values’ (p. 161). From a macro-practice stance, regional and national policies that perpetuate systemic barriers need to be addressed, such as the highlighted policy dissuading [Kristy and Duane](#) from having a legal marriage because of the risk of losing benefits. The voice of people with LD may be heard as more legitimate by policy makers. Moreover, these first-hand accounts may help to mobilise self-advocates to action by framing the discourse around sexual voice as an issue of social justice and quality of life. With practice, individuals might demand more sexually literate providers and sex-positive

programming that is grounded in policies inclusive of sexual minority and gender non-conforming participants.

### Recommendations for further research

Further research is warranted on the sexual voice of adults with LD, utilising both qualitative and quantitative methods. Useful data may come from staff and parents, from observation of participant interactions with romantic partners by attending social events and by having participants with more diverse ethnic backgrounds and differing sexual orientations, who received formalised sex education and/or have been labelled as having ‘problem sexual behaviours’ or legal problems. Illuminating the sexual voice of adults with LD fulfils an important criterion of good disability research: respect (McCarthy, 1999). These findings may encourage researchers to gain a better appreciation of sexuality as an under-studied innate aspect of adults with LD. Research that elevates sexual voice might influence policy, advocating for more equitable funding in line with current vocational and residential spending.

### Conclusion

Reframing the sometimes taboo and difficult topic of sexuality within social work’s long-standing history in social justice is one way that social workers can approach the intersectionality of sexuality and learning difficulties. Social workers can stand with people with disabilities against the systemic silencing of their sexual voice, refuting ablest privilege and sex negativity lodged against those with LD, and advocating for a professional discourse that acknowledges the inherent erotic rights of the disability community. By using a social justice lens, social workers can examine how the sexuality of people with LD can become a target of marginalisation, rendering them disposable. A sexual voice can be a tool for individuals with disabilities to own their authentic sexual self in a world that so readily denies it. A sexual voice is a revolutionary act of moving from silence to speech. It is an act of defiance, and of empowerment.

### Acknowledgements

We would like to thank Dr Lisa Meyers, research assistant, for her role. Her expertise was invaluable during the interviews.

## References

- Ballan, M. S. (2008) 'Disability and sexuality within social work education in the USA and Canada: The social model of disability as a lens for practice', *Social Work Education*, **27**(2), pp. 194–202.
- Bogdan, R. C. and Biklen, S. K. (1998) *Qualitative Research for Education: An Introduction to Theory and Methods*, Needham Heights, MA, Allyn & Bacon.
- Booth, T. and Booth, W. (1996) 'Sounds of silence: Narrative research with inarticulate subjects', *Disability and Society*, **11**, pp. 55–69.
- Brantingler, E. A. (1985) 'Mildly mentally retarded secondary students' information about and attitudes toward sexuality and sexuality education', *Education and Training in Mental Retardation*, **20**, pp. 99–108.
- Cambridge, P. (2013) 'A rights approach to supporting the sexual fetish of a man with learning disability: Method, process and applied learning', *British Journal of Learning Disabilities*, **41**(4), pp. 259–65.
- Chou, Y.-C. and Lu, Z.-Y. (2011) 'Deciding about sterilization: Perspectives from women with an intellectual disability and their families in Taiwan', *Journal of Intellectual Disability Research*, **55**(1), pp. 63–74.
- Crabtree, B. F. and Miller, W. (1999) 'Researching practice settings: A case study approach', in Crabtree, B. F. and Miller, W. L. (eds), *Doing Qualitative Research*, 2nd edn, Thousand Oaks, CA, Sage, pp. 293–312.
- Creswell, J. W. (2013) *Qualitative Inquiry and Research Design: Choosing among Five Approaches*, 3rd edn, Thousand Oaks, CA, Sage.
- Denzin, N. K. and Lincoln, Y. S. (eds) (2005) *Handbook of Qualitative Research*, Thousand Oaks, CA, Sage.
- Diaz, Y. E. and Kelly, J. A. (1991) 'AIDS-related training in U.S. schools of social work', *Social Work*, **36**(1), pp. 38–42.
- Dixon, J. and Robb, M. (2015) 'Working with women with a learning disability experiencing domestic abuse: How social workers can negotiate competing definitions of risk', *British Journal of Social Work*, **46**(3), pp. 773–8.
- Friedman, C., Arnold, C., Owen, A. and Sandman, L. (2014) 'Remember our voices are our tools: Sexual self-advocacy as defined by people with intellectual and developmental disabilities', *Sexuality and Disability*, **32**, pp. 515–32.
- Hollomotz, A. (2009) 'Beyond "vulnerability": An ecological model approach to conceptualizing risk of sexual violence against people with learning difficulties', *British Journal of Social Work*, **39**, pp. 99–112.
- hooks, b. (1989) *Talking Back: Thinking Feminist, Thinking Black*, Boston, MA, South End Press.
- International Federation of Social Workers (2014) *Global Definition of Social Work*, available online at <http://ifsw.org/get-involved/global-definition-of-social-work/>.
- Lesseliers, J., Van Hove, G. and Vandeveldel, S. (2009) 'Regranting identity to the outraced-narratives of persons with learning disabilities: Methodological considerations', *Disability and Society*, **24**, pp. 411–23.
- Loren, A. (2011) 'Ten black women teaching us about sex', 19 October, available online at <http://clutchmagonline.com/2011/10/10-black-women-teaching-us-about-sex/>.
- Masters, W. H. and Johnson, V. H. (1974) *The Pleasure Bond: A New Look at Sexuality and Commitment*, Boston, MA, Little, Brown and Company.



- McCarthy, M. (1996) 'The sexual support needs of people with learning disabilities: A profile of those referred for sex education', *Sexuality and Disability*, **14**, pp. 265–79.
- McCarthy, M. (1998) 'Whose body is it anyway? Pressures and control for women with learning disabilities', *Disability & Society*, **13**, pp. 557–69.
- McCarthy, M. (1999) *Sexuality and Women with Learning Disabilities*, London, UK, Jessica Kingsley.
- McCormick, N. (1988) 'Student debates in sex education courses', paper presented at the Mid-continent meeting of the Society for the Scientific Study of Sex, Chicago, IL.
- Murray, M. (2003) 'Narrative psychology', in Smith J. (ed.), *Qualitative Psychology: A Practical Guide to Research Methods*, London, UK, Sage, pp. 111–31.
- Owen, A., Arnold, K., Friedman C. and Sandman, L. (2016) 'Nominal Group Technique: An accessible and interactive method for conceptualizing the sexual self-advocacy of adults with intellectual and developmental disabilities', *Qualitative Social Work*, **15**(2), pp. 175–89.
- Patton, M. Q. (2003) *Qualitative Research & Evaluation Methods*, Thousand Oaks, CA, Sage.
- Reamer, F. (1998) 'The evolution of social work ethics', *Social Work*, **43**(6), pp. 488–500.
- Shakespeare T., Gillespie-Sells K. and Davies D. (1996) *The Sexual Politics of Disability: Untold Desires*, New York, NY, Cassell.
- Siebers, T. (2008) *Disability Theory*, Ann Arbor, MI, University of Michigan Press.
- Sitter, K. C. (2012) 'Participatory video: Toward a method, advocacy and voice (MAV) framework', *Intercultural Education*, **23**(6), pp. 541–54.
- Sloane, H. (2014) 'Tales of a reluctant sex radical: Barriers to teaching the importance of pleasure for wellbeing', *Sexuality and Disability*, **32**, pp. 453–67.
- Stoffelen, J., Kok, G., Hospers, H. and Curfs, L. M. G. (2013) 'Homosexuality among people with a mild intellectual disability: An explorative study on the lived experiences of homosexual people in the Netherlands with a mild intellectual disability', *Journal of Intellectual Disability Research*, **57**(3), pp. 257–67.
- Strauss, A. and Corbin, J. (1990) *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*, Newbury Park, CA, Sage.
- Sullivan, F., Bowden, K., McKenzie, K. and Quayle, E. (2013) 'Touching people in relationships: A qualitative study of close relationships for people with an intellectual disability', *Journal of Clinical Nursing: Special Issue on Sexual Reproduction and Health*, **22**(23–24), pp. 3456–66.
- Swango-Wilson, A. (2010) 'Systems theory and the development of sexual identity for individuals with intellectual/developmental disability', *Sexuality and Disability*, **28**, pp. 157–64.
- Taylor, R. (2005) 'Can the social model explain all of disability experience? Perspectives of persons with Chronic Fatigue Syndrome', *American Journal of Occupational Therapy*, **59**(5), pp. 497–506.
- Timmers, R., DuCharme, P. and Jacob, G. (1981) 'Sexual knowledge, attitudes and behaviors of developmental disabled adults living in normalized apartment setting', *Sexuality and Disability*, **4**, pp. 27–39.
- Travers, J., Tincani, M., Schaefer-Whitby, P. and Boutot, E. (2014) 'Alignment of sexuality education with self-determination for people with significant disabilities:

- A review of research and future directions', *Education and Training in Autism and Developmental Disabilities*, **49**, pp. 232–47.
- Turner, G. W. (2012) 'The social-sexual voice of adults with mild intellectual disabilities: A qualitative case study', Order No. 3532686, Widener University, ProQuest Dissertations and Theses 355, available online at <http://search.proquest.com/docview/1170751934?accountid=1414556>. (1170751934).
- Turner, G. W. and Crane, B. (2016) 'Pleasure is paramount: Adults with intellectual disabilities discuss sensuality and intimacy', *Sexualities Special Issue: Intellectual Disability and Sexuality: On the Agenda?*, **19**(5–6), pp. 677–97.
- Winges-Yanez, N. (2014) 'Discourse analysis of sexuality education curriculum: FLASH for special education', *Sexuality and Disability*, **32**, pp. 515–32.
- World Association for Sexual Health (2014) *Declaration of Sexual Rights*, available online at [www.worldsexology.org/wpcontent/uploads/2013/08/declaration\\_of\\_sexual\\_rights\\_sep03\\_2014.pdf](http://www.worldsexology.org/wpcontent/uploads/2013/08/declaration_of_sexual_rights_sep03_2014.pdf).
- Yacoub, E. and Hall, I. (2008) 'The sexual lives of men with mild learning disability: A qualitative study', *British Journal of Learning Disabilities*, **37**, pp. 5–11.
- Yacoub, E. and Hall, I. (2010) 'A qualitative study of people with an intellectual disability's perception of the support received from services with regards to their sexual lives and relationships', in Stanovic, J., and Lalic, M. (eds), *Sexuality Education and Attitudes*, Hauppauge, NY, Nova Sciences Publishers, pp. 193–204.
- Yueh-Ching, C., Zxy-Yann, J. and Cheng-Yun, P. (2015) 'Attitudes toward male and female sexuality among men and women with intellectual disabilities', *Women & Health*, **55**(6), pp. 663–78.