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Pleasure is paramount: Adults with intellectual disabilities discuss sensuality and intimacy

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Abstract
The purpose of this qualitative case study research was to explore how adults with mild intellectual disabilities (ID) live out their social-sexual lives. Findings revealed the importance of both physical and emotional pleasure to five adults with ID. Research and educational efforts with this population have focused largely on reproduction and abuse prevention, emphasizing safety over the possibilities of human connectedness. Data sources included observations and a series of interviews. Findings in five areas – sensuality, intimacy, sexual experience, sexual attitudes, and sexual self-identity – demonstrate the richness of data that can be obtained with this population using qualitative research. Participants' own words about their social-sexual lives are poignant, mirroring core social work pillars: self-determination and strengths perspective. Discussion includes recommendations for ways that social workers, as well as, sexuality and disability professionals can support individuals' quality of life by addressing sexual pleasure as a key component of sexual health services.

Keywords
Case management, intellectual disabilities, learning difficulties, policies, sexual pleasure, sexuality education, sexual rights, social work, strengths perspective

Pleasure is paramount, and this case study research provides evidence that this is true for women and men with intellectual disabilities (ID). In a series of interviews, five adults with ID broke the silence that so often surrounds this topic with this population. According to Virginia Johnson (Masters and Johnson, 1974), pleasure is,

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'the authentic, abiding satisfaction that makes us feel like complete human beings' (1974: 28). Certainly sexual pleasure, which includes (physical) sensuality and (emotional) intimacy, is a key element of humans' experience of pleasure. Yet consideration of sexuality and adults with intellectual disabilities (ID) too often comes from a skewed framework that portrays them as either angels, i.e. sexually austere heavenly beings, or devils, i.e. lascivious predators (Dotson et al., 2003). These stereotypes may sabotage development of a realistic representation of the social-sexuality of adults with intellectual disabilities (ID). In this study, the term social-sexuality is used as an alternative to 'intercourse only' views, as a way to highlight the importance of a more holistic view of sexuality.

Findings are based on interviews and observations related to our research question: How do adults with ID describe their subjective experience and expression of romantic, and/or sexual relationships? While a previous publication presented in-depth case study descriptions of the five individuals' social-sexual lives (Turner, 2012), this paper is based on cross-case thematic findings related to the theme of pleasure. Findings reify how, for these participants, sexuality is much more than merely sex. Robinson and Skinner (1985) asserted that sexuality is significant and ever-present for all human beings, expressed in all daily activities such as touching, talking, embracing, fantasizing, kissing, caressing, and holding hands. By focusing exclusively on the 'sex' of sexuality, the diversity, beauty, and necessity of sexuality are overlooked among adults with ID.

According to The Arc, an advocacy and services organization for persons with developmental disabilities, an estimated 7.2 million Americans have mental retardation [*sic*] and related developmental disabilities (The Arc, n.d.). Yet, awareness of the social, romantic and sexual desires of this population is low in both mainstream and professional discourse, as noted by George Turner in his role as a licensed social worker and disability professional. George Turner observed that if/when sexuality for adults with ID is on the radar, a paternalistically focused protection model is evident, or a dismissive action, infantilizing desire as 'puppy love'. Sensual pleasure and intimacy are not acknowledged as a right or a goal. Perhaps this is because adults with intellectual disabilities seem to be sexual outsiders living on the fringe of normative sexual experiences. While major benchmarks for adults with ID have been achieved in the areas of community living, vocational choices, and integrated recreation, their sexuality has been largely ignored (Brantingler, 1988a, 1988b). Lingering effects of eugenics, based on evolutionary theory, still affect policies and attitudes about people with ID possibly reproducing. The reality is that the reasons why an individual with ID might have a limitation in intelligence are many and varied, including pregnancy and childbirth challenges, as well as early childhood illnesses (Hatton, 2012). All too often the assumption is made that it must be genetic and therefore such individuals should not be allowed a sexual life.

Viewing adults with ID through the lens of a medical (pathology) model sees them as personally deficient (Oliver, 1983). Moreover, Hollomotz (2011) argues

this individualizing approach labels them inherently sexually vulnerable, thus needing protection. Furthermore, this 'exclusive focus ... can be oppressive' (2011: 11) and thus overprotection becomes a self-fulfilling prophecy, disabling adults with ID from becoming socially and sexually competent and making them more sexually vulnerable. The 'personal tragedy theory' (2011: 16) that conceptualizes disability as a health issue, she asserts, ignores the social model of disability that considers how social processes and systems cause disadvantages or restrictions.

Professional discourse on disability and sexuality covers a range of prevention-oriented topics, including: sexual abuse (Razza and Tomasulo, 2004); HIV/AIDS (Alford and Arrufo, 1994); sexual offending behaviors (Lindsay et al., 2002); and education (Garwood and McCabe, 2000). Preventing sexual misuse of adults with ID is indeed important, given the gravity of the subject and the fact that individuals with ID are at a greater risk (Hingsburger and Tough, 2002). Yet, it cannot be the only area of importance.

Absent in professional discourse is a positive, strengths-based discussion of the social-sexuality of adults with ID; one that counters the current disaster, disease and dysfunction approach and reframes sexuality, among other things, as a basic universal human right '... based on the inherent freedom, dignity, and equality of all human beings' (World Association of Sexuality, 1999). Enjoyment and celebration of our sexuality, an essential aspect of the human experience, is as important as its management (Matich-Maroney et al., 2005). Pleasure would be a natural fit within this conversation, epitomizing core pillars of social work: 'self-determination' and the 'strengths perspective'.

Adults with ID rely on others for advocacy in many areas of community integration such as employment. Including sex and relationships as rights would challenge advocates for those with disabilities to step into the role of sexuality advocate, viewing access to pleasure as a social justice issue. Access to dating partners depends on one's support system, thus transportation and freedom of movement without supervision must also be provided. Moreover, Shakespeare suggests: 'The problem of disabled sexuality is not how to do it, but who to do it with' (2000: 161). Tepper argues:

> What are we doing it all for? Full inclusion means access to pleasure. It means a reasonable chance for relationships ... We must be advocates for the inclusion of sexual pleasure in disability studies, politics, and public discourse. (2000: 289).

This study has grounded the idea of pleasure and disability in Fine's (1988) discourse of desire. As she has asserted, 'a genuine discourse of desire would invite adolescents to explore what feels good and bad, desirable and undesirable, grounded in experiences, needs, and limits' (1988: 33). While Fine saw this process as taking place during adolescence, it applies as well to the process of individuals with ID coming to know about themselves sexually, continuing into their adulthood.

Significance

Findings may spark further research challenging the discourse surrounding sexuality and disability, helping professionals and parents gain insight into this under-explored and often taboo area, and helping to shape a more holistic sexual view beyond an intercourse-centric focus on persons with ID. By expanding the conversation into pleasure, needs, feelings, and relationships, participants in this research were given a personal voice as it relates to their social-sexuality. Perhaps first-hand accounts of adults with ID as self-advocates might spur action beyond mere professional discourse.

A policy reorientation is called for that focuses on sexuality as positive and inherent in all people with disabilities, combating a view towards adults with ID as a mix of asexual, oversexed, uninterested, incapable, child-like victims. Findings from this study support changes in policies, such as how the planning process related to individuals' goals is conducted. If taken seriously as relating to the ability of adults with ID to engage with others around their romantic and sexual goals, workers could be encouraged to help adults with ID to enrich their social skills and pursue their social-sexual goals.

Methods

This qualitative case study, informed by heuristic inquiry (Creswell, 2007), described and interpreted the lived sexual experience of five adults with ID. After approval of the study by the university's Institutional Research Board (IRB), participants were recruited with the help of agency professionals. Desiring information-rich cases, we used purposeful sampling (Patton, 2002) to recruit participants. Inclusion criteria included: diagnosis: 'mild mental retardation' or mild intellectual disability; guardianship: being their own legal guardian; age: 21–70 years; and system support: receiving case management services.

This study occurred in a large mid-western city in the United States. Participants included two women and three men between the ages of 21 and 54: one in his 20s, one in her 30s, two in their 40s and one in his 50s. All identified as heterosexual. In regards to relationship status, two participants were in monogamous relationships; one was dating, but no one in particular; and one was single.

Data collection

Data were collected through semi-structured interviews and observations. Three interview meetings occurred, with the first at the participant's home, followed by the second and third in an author's therapy office; each lasted one to two hours, conducted in a conversational style. A female research assistant was present to assuage any concerns about a male interviewer discussing sex with these individuals. The research assistant, a licensed social worker, disability professional, and certified sex therapist, was also a doctoral student in human sexuality. During each

interview, she observed and recorded the participant's affective responses and aided in the interviews having a conversational nature.

An interview guide was adapted from questions used by Timmers, DuCharme and Jacob (1981). To facilitate communication, picture-placards saying 'I don't know' and 'I don't want to answer' were used to help participants express any hesitancy. The open-ended questions and placards were steps to address adults with ID's tendency to want to please or always answer 'yes' (Sigelman et al., 1981).

Establishing rapport and informed consent occurred at the first meeting in participants' homes. Staff and parents participated in this meeting so they would be oriented to the research project. They were viewed as important research constituents, as providers of transportation and support. As participants showed us their homes and personal belongings, we commented on and asked probing questions about items such as photos, artwork, and music, using the personal artifacts to introduce discussions of sexual and/or romantic relationships.

During meetings two and three, conversations were enhanced by a collection of images from a Google search that illustrated Dailey's (1981) Circle of Sexuality model, i.e. sensuality, intimacy, identity, reproduction, and sexualization. Pictures were sexualized in nature, which ideally elicits feelings and emotions, allowing participants to explore their affect and attitudes (Stayton, 1998). Participants seemed comfortable with the pictures, which helped to focus their attention on topics to be discussed. Audio recording and note-taking were used to collect data.

We asked more intimate interview questions during the third meeting, when a higher degree of rapport and trust had been established that would increase the quality of data gathered (Yacoub and Hall, 2008). While we did not specifically explore sexual misuse/abuse with participants, we were prepared to support the participant's choice to discuss this issue and to make any necessary referrals.

One participant brought in two personal artifacts: a photograph of his girlfriend and a magazine advertisement for a phone sex line. The artifacts seemed to enhance his voice by providing an opportunity for him to personalize his story with content he found relevant. Two of the participants had cell phones, which provided a conversational prompt to explore technology and sex.

Data analysis

Audiotapes were transcribed and pseudonyms created to protect participant confidentially. We first created five case studies, written in a narrative style, with the intention of providing voice to their experiences (Murray, 2003). Interviews, observations, and field notes were then analyzed for emergent themes. Coding involved a combination of deductive and inductive analysis.

Quality

Vigorous field procedures were used to obtain credible and quality data. Instead of *validity*, Lincoln and Guba (1985: 300) advised the use of credibility and *dependability*

for qualitative studies. To increase credibility, Padgett (1998) suggested strategies used in this study: (a) prolonged engagement, (b) triangulation, and (c) peer debriefing. Three meetings with each participant, lasting over 60 minutes each over a course of several weeks, provided prolonged engagement. Triangulation was achieved through multiple contacts with participants and more than one data source: (a) field notes/analytical logs, (b) two interviews, and (c) observations by the researcher and the research assistant. Peer debriefing occurred through discussions with the research assistant, who was present for all contacts with participants. These discussions enhanced quality significantly because the meaning that emerged from the data was brought to the surface for reflection and feedback by talking about the findings. Turner also carried out peer debriefing with a special education transition teacher. Additionally, the research assistant reviewed the case profiles and cross-case thematic analysis for credibility. To increase dependability we used an auditing process, keeping a log of the analytic decisions as the code book was revised and codes became themes.

Participants

Data analysis for this research involved first creating case study descriptions of the social-sexuality of each participant. A summary is presented here, starting with the participant with the least developed sexual voice and progressing to the person with the richest and strongest sexual voice. Pseudonyms are used. The purpose of these descriptions of participants is that they be seen as people who have social, romantic, and sexual needs and goals.

Milton

Milton is a 54-year-old white male who works at an area-sheltered workshop and likes country music. He has difficulty with speech, speaking very loudly and stammering. Milton described his attraction template as 'tall,' 'skinny,' 'gorgeous,' 'cute,' 'courteous,' 'young women,' 'about in their 30s,' 'good to get along with,' 'nice and friendly.'

Milton had a tidy twin bed in his bedroom, reminiscent of a 1950s sitcom, including a religious calendar and some car photos on the wall. Milton's apartment is situated on the grounds of a non-profit that provides him with services. When asked to tell us about his life, Milton described feeling alone:

> Well, uh, I've probably been – myself for a long time. Uh, living on my own. Uh, seeing, uh, people, uh, tons people – um – I – I like to be friends with them and sometimes, uh, they don't want to be friends with me. Or I don't want – or, uh, socialis- – socializing with me. And, uh, uh – uh, some- – sometimes it makes me – lonely at times. And – and, um, sad – um, but, uh – I just go on do my, you know what I'm saying, just do what I want to do. And just be alone and stuff.

Terri

Terri is a 31-year-old white woman who lives in a group home with several other women with ID. She is very proud of her bedroom; however, the room was reminiscent of pre-teen girl's room with pink walls, a 'Drama Queen' sign, and posters of a shirtless Jacob, from the movies *Twilight* and *Hannah Montana*. When asked 'what do you think is cute about Jacob?' she responded, 'I like it when he cuts his hair short, I like it.' With no embellishment about his physique, she concludes, 'He's nice.' Terri had a twin bed, which seemed more in line with a little girl's room or, in the case of an adult, seemed institutional.

Terri works at a sheltered workshop where she has a boyfriend, Brad. Her attraction to Brad seems at least partially based on convenience or attention. Terri shared, 'Uh, Brad's very interested in me. So that's why, um, I've been dating with him … he flirts with me at work.' Terri reported that she 'just held hands', 'sometimes, yeah' to hugging and that she had never kissed but, 'maybe one of these days I will.' She said she thinks Brad would like to kiss her, 'because he thinks I'm really pretty and stuff like that.'

Richard

Richard is a 48-year-old white male. Richard seems to see himself as a sexually desirable person, boasting, 'Uh, because, uh, I was raised up in England. So they always like my British accent.' Richard moved to the USA with his parents and has lived here for approximately 20 years. Richard lives in his own home and has a full-sized bed. Richard had no pictures of his girlfriend, Cathy, in his home, describing that they were 'in a box somewhere.' Additionally, despite a lengthy dating history, Richard has never met Cathy's parents, which seemed atypical.

When I asked if he knew his neighbors, he disclosed, 'Yeah. I know one.' Yet, he has never visited their homes, nor have any of his neighbors been to his house. Richard lives within walking distance of his job where he works as an administrative assistant answering phones for the residential nonprofit that provides him with services.

When we asked Richard to describe the type of sexual activities that he and Cathy enjoyed, he exposed, 'going to bed together. Or me and her have shower together. And lay on top of each other. She always likes her clothes on. She don't like the clothes off. But I like clothes off.' He identified his parents as an obstacle, declaring his feelings for Cathy, 'Um, 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.' Richard expressed frustration with the fact that no one would support his desire for an overnight guest. 'I always talk to Bonnie [administration] about it. She wants me to ask my mom first. … like I want to spend the night with Cathy, but it didn't work.'

Lionel

Lionel is a 21-year-old African-American male who works at a local non-profit agency that provides transportation and other services to adults with disabilities. During our home visit, Lionel had a laptop playing downloaded music. He shared that he uses his laptop to chat with people and search for porn.

In asking Lionel, 'What type of person do you think is sexy?' he provided an age-appropriate TV star, Ashly Tisdale. When probed what was it that he liked about her, he initially provided generic answers, 'her hair – uh, her eyes, uh – her lips.' Lionel laughed nervously when I probed further with, 'any other parts of the body that you like about her?' He then shared, 'uh, her boobs.' Lionel also shared, 'Um, I like to tongue kiss.'

Lionel demonstrated a higher level of comfort and ease with communication as compared with previous participants. He had an affinity for social media not experienced by any other participants. Also, he seemed more street smart and less restricted by years of institutional living, as evidenced by his description of going to a club in China, revealing, 'I usually have sex in the bedroom or in the bathroom or wherever.'

Kristy

Kristy is a 48-year-old white woman who is unemployed, having been laid off from a fast food restaurant. She lives in an apartment with her husband, Duane, who has cerebral palsy. Their home is situated among several other apartments and a group home. Kristy regularly used street slang such as 'sucking cock', but also seemed familiar with more medical terms, like 'penis'.

Kristy stated with a big smile, 'I love it – we have our time together and you just lay together, kiss and cuddle – fondle.' Kristy shared that she has been married to Duane for one year. The couple had a ceremonial religious wedding, but they opted not to have a legal ceremony in order to protect their governmental benefits. Kristy happily shared her wedding photos, beaming as she discussed the event. Kristy noted that she had considerable support from her staff and agency in making her marriage possible.

Kristy had a prideful voice as she shared her attraction and an expressiveness that was not matched by the other participants. When asked, 'What would you like for your sexual future or love future?', with her typical zeal for a rich story, she gave voice to her dreams.

> I love to be married to my husband about 50 years – or longer. And our sex lives are the best that it can be. Well, we'd try. [laughter]. Don't promise anything but – we'll be trying, you know.

Findings: Pleasure is paramount!

The two major concepts that emerged from thematic analysis of the observations and interviews were sexual voice and pleasure. For this paper we are reporting

findings related to the concept of pleasure, which had five themes: 1) sensuality (i.e. physical pleasure), 2) intimacy (i.e. emotional pleasure), 3) sexual experience, 4) sexual attitude, and 5) sexual self-identity. The rationale for the order in which they are reported is that sensuality and intimacy are core aspects of social-sexual pleasure. Those aspects, along with sexual experience, affect individuals' attitudes about sex and their sexual self-identity. We provide selected excerpts from interviews to honor the participant's voice and elucidate the theme or subtheme.

Theme 1: Sensuality. Dailey (1981) described sensuality as physical closeness; having an awareness of the pleasure that our body or the bodies of others can provide us. The three sub-themes for sensuality are: (a) tension release, (b) skin hunger, and (c) attraction template.

Tension release is described as arousal continuing through to orgasm, either by self-pleasuring or with another person (Dailey, 1981). Richard provided substantiation that pleasure is indeed a part of the lives of adults with ID when he excitingly proclaimed, 'I want – I like them too much!', meaning kissing, orgasms and touching. Kristy provided further verification of its existence, defining masturbation as, 'Get the release out.' She named two local erotica stores where she could purchase a vibrator; though she did not own one, she said she could ask staff to provide transportation for her. Kristy articulated her views on pleasure as she described 'love making' with her husband Duane.

> Then we go into love making. I'm on top. And longest it lasts is 15 minutes. Wow. It's exciting, and you know you're loved when he's doing that. And we're kissing and my crazy. We do love to kiss. And hold each other. Very romantic. We get in bed and just kiss and I fondle him mostly. He loves it. Yeah. And he fondles my breast. He's a boob man.

Skin hunger includes caressing, holding, hugging, and hair stroking. Given that, for individuals whose lives are monitored by agency staff and/or families, there is typically a prohibition on intercourse and other sexual behaviors that require nudity, these ways of meeting one's skin hunger needs are often the only allowable form of sexual contact sanctioned for individuals with ID. Kristy demonstrated this sub-theme by sharing, 'Me and [Duane] like to have our time together and just lay together, kiss and cuddle – fondle.' Kristy began to smile and laugh, as I asked if she enjoyed that activity. She affirmed, 'Both of us!'

The third sub-theme, *attraction template* is a strong physical and emotional reaction to particular people (Dailey, 1981). For example, Kristy narrated her own erotic description of Duane's physique, saying, 'His eyes drive me crazy. He has blue eyes and I just look into them. It's like I see his soul or something. I love his eyes, his eyes, his chest. And muscular. Duane's muscular right here.' She cupped the space above her biceps and chest as if to define Duane's build. Other participants seemed as if their erotic voice had never seen the light of day. They needed more prompting, perhaps due to shyness or the unfamiliar territory of public discourse of pleasure.

Implications for policy include acknowledgement of physical pleasure in the scope of essential services. Tying outcome evaluation and funding to pleasure institutionalizes this concept as an important measurement of quality of life. To fulfill this mandate, agency policy should be grounded in a competency-based curriculum that extends beyond mere management of participant sexuality through pregnancy prevention or STI programs to incorporating a celebration of sexual/physical pleasure.

Theme 2: Intimacy. Intimacy is based on emotional closeness rather than physical closeness. This sense of belonging or connection can be with romantic partners, but also with others. It is accomplished through an individual's willingness to be known by others and taking emotional risks. Participants routinely voiced a desire for this type of bond, yet it is typically absent from the professional discourse on sexuality and disability. Intimacy had two interrelated sub-themes: *loneliness* and *choosing to be known*.

The first sub-theme, loneliness, surfaced when participants talked about intimacy by their lived experience of its absence. When asked what it feels like when he doesn't have anybody to talk to, Milton expressed profound loneliness, stating, 'lonely, sad times, stressed out'. He added:

> I – I like to be friends with them and sometimes, uh, they don't want to be friends with me or, uh, socializing with me. And, uh, sometimes it makes me lonely at times. And, um, sad, but, I just go on, do my, just do what I want to do. And just be alone and stuff. Part of the time it – it's bad when I want, uh, when you don't have nobody to talk to.

Richard also echoed this idea of isolation and loneliness. He shared, 'Um, like I, always get lonely and play my games. No one to talk to.' When asked about his feelings regarding the stonewalling from his mother and staff about Cathy spending the night, he despondently shared, 'It feels sad and miserable. And I want – I want let them know I want to spend the night with her. And I don't want to be alone in the house.'

Lionel highlighted the concept when he interrupted the interviewer discussing intimacy, stating, 'It's like sh-sharing your expression and talking and not being so shy and not being so scared, talking for yourself.' Skating on the surface of relationships is not unique to people with disabilities, but the depth of emotional disconnection, isolation, and loneliness can be exacerbated by a culture of disability professionals who mistake activities and groups as inoculations to loneliness, missing opportunities to facilitate significant and real relationships for adults with ID.

The second sub-theme was evidenced by how participants *chose to be known*. Kristy provided a window into this, reflecting on her ability to openly communicate with Duane about their sex life: 'At first he didn't, but he kind of opened up a little later, you know. I gave him about a couple days or two – just to kind of think about it.' Kristy concluded:

> I just know – I'm beginning to know more and more about him and I think I will until . . ., and that's what's good about our relationship. You've got to learn, . . . their quirks

> and everything, uh, it's like he makes me feel loved, more loved than my other two. My other two just ignored me. It's important to me, because, you know, everybody loves to be loved. Everybody needs someone they can depend on. If you have a problem at work or you're just having a tough time or tough day, he brightens up my day. Yeah. I love him.

Implications for policy include a greater recognition of participant isolation by service providers. It is not enough to merely provide opportunity, such as community integration, but it is critical to provide skill development around emotional intimacy that includes vulnerability, risk-taking and choosing to be known by others. This not only includes friendships but also education and advocacy support in developing romantic loving relationships. The participants in this study hungered for connectivity on many levels, but mirrored the larger social norm to have emotional bonding through dating and marriage. Policies that restrict 'flirting' in the sheltered workshop, as experienced by Terri, are paternalistic and punitive.

Theme 3: Sexual experience. This includes relationships and sexual behaviors. The interviews illuminated multifarious sexual experiences, impugning the myth that adults with ID lack sexual desire or are puerile in their sexual interests. Activities included kissing, having a crush, sexual talk, 'lovemaking,' anal intercourse, 'playing doctor', marriage, dating, expressing 'I love you', fantasy, masturbation, fellatio, vibrators, and pornography.

Flirting was frequently reported. Terri discussed how it made her feel good for Brad to stare at her at work and make noises. Kristy revealed that she and Duane would 'play fight' and that they had several pet names for one another. She called Duane, 'sweet pea', 'prince charming', and 'Tarzan', while he used 'Sweetheart' to refer to her. In describing her thoughts about *making out* and *flirting,* Kristy shared:

> Well, I like the touching, of his penis. And he gets excited by kissing, passionately. And I said, 'we're getting a little excited there, aren't we?' Yeah. We tease each other and I think that's what makes a great relationship.

While behaviors such as hand-holding and hugging were reported, a more beguiling expression was shared by Milton of a *someday hope* that he would engage in a variety of sexual activities. Still other participants disclosed a much richer sexual experience. Of the five participants, three shared having sexual intercourse. The other two discussed other forms of sexual behaviors such as kissing. Richard detailed his experience of sexual experimentation when he was 13 with a girl who was 14 by *playing doctor* and perhaps engaging in *peeping:* I had a girlfriend in – in England – in school. I remem– remember I pull her pants down. Um, I went in the girls' restroom; Uh, I got in trouble by the [teachers].'

Richard described intercourse, using the word 'hole' instead of vagina. He stated that he learned how to have sex from movies. He said they had no prior conversation but rather 'just did it' one time, and that they used a condom. Laughing, Lionel also described having intercourse, doing the 'same thing that they do in the

porno – it was my first time. Like put their penis inside a vagina, and uh, put it in the mouth and, uh, put it in their butt.'

When we asked Kristy if she and Duane did any other activities beyond intercourse, Kristy, with her same sense of ease, shared, 'We touch. I suck his dick.' Answering my follow-up question, 'And, how often do you guys have sex?', she effortlessly shared, 'Once a week. Yeah. Probably on a Saturday.' Sharing an additional example of pride, Kristy discussed kissing.

> I like to touch and kiss. You know, what's wrong with kissing? There's nothing wrong with it. Yeah. We kiss all the time. You know, we just like – we – he comes from work, I give him a kiss. I say, how was your day?

Implications for policy include comprehensive sexuality education for persons with ID but also training related to sexuality for direct support staff, mid and senior management and support professionals such as van drivers and recreational aides. In the United States, sexuality education often gets framed as a moral discussion, but framing sexuality education as a human right that is essential to sexual empowerment could be a successful alternative. Policy should strongly advocate for its inclusion and state that denying accessing to sexuality education is 'tantamount to oppression' (Fine and McClelland, 2006).

Theme 4: Sexual attitude. Participants expressed a range of comfort levels with sexuality in general and demonstrated a continuum of their own personal and unique way of *being* sexual that were coded as 'sexual attitude'. Two sub-themes were *shame* and *pride*.

A sense that sex is bad delineates *shame*. For example, Kristy talked about when Duane had expressed shame toward pre-marital sex. In the end she attempted to normalize their experience, as if trying to superimpose her own sense of sexual pride onto Duane's shame.

> And yes, we had sex before marriage, but we went to the pastor. The pastor says, you need to ask Father for forgiveness and he didn't. It took Duane a long time. He's very stubborn. I love him, but it's like he finally, I think at the end, finally. You know, we really didn't have sex until after the wedding and I think we had had it once and, you know, the preacher made him feel so guilty that … But it's just normal, you know.

Kristy, who shared the most statements of *sexual pride*, also had moments when she expressed *sexual shame*. This may be because she was also the most vocal of the five participants. The *shame* statements were usually when she straddled between her own sexual past or desires and that of her husband's wishes.

Pride repudiates shame through a positive view of sexuality and it is approbatory of one's own potential to engage in relationships and to be sexual. Kristy's interviews were filled with pride examples, as exemplified when she shared her excitement and re-celebrated her ceremony with us, through her wedding video and photos, which contrasted with Richard keeping his girlfriend's photos in a shoebox.

Implications for policy include implementing a major shift in the culture of professional service providers to recognize and celebrate the emotional and physical pleasure needs of persons with ID. Policy could begin to dismantle the able-normative attitudes regarding sexuality prevalent within agency practices. It is often the subtlety of a nod and wink that dismisses desire, sexual pleasure and romantic relationships for persons with ID to a lesser value. These micro-aggressions segregate persons with ID and their sexual pleasure from the continuum of typical human behaviors afforded the staff who support them.

Theme 5: Sexual self-identity: The erotic me. *Sexual self-identity* was illustrated when participants acknowledged or embraced their erotic potential. Participant statements coded within the sub-theme 'erotic' were sexually suggestive, identified themselves or others as sexy, embraced their eroticism, or exhibited physical enjoyment of bodies. An erotic self-identity was seen in subtle contexts, such as hope for the future. When asked, 'Do you have anyone special in your life; are you dating anyone?' Lionel expressed anticipation for the possibility of romance by responding, 'not – not usually. But I'm finding someone.' Additionally, Richard provided examples of the subtlety of erotic potential, acknowledging that his accent had sexual appeal to others, sharing, 'It's my accent. Uh, because, uh, I was raised up in England. So they always like my British accent.' Lionel elaborated on erotic potential, describing going 'out to dances and stuff', and that he chose not to dress in sandals or flip-flops because 'you want to look – look fancy'.

Overt expressions of erotic potential included Lionel's description of where he could potentially have sex. He was the only participant who referenced clubs and seemed to know that non-disabled peers have sex at dance clubs, specifically in the bathrooms. Of interest was his cousin's feedback, recognizing Lionel as sexual. When asked, 'Where would you have sex at?' he responded, 'I usually have sex in the bedroom and, uh-or in the bathroom or wherever. Sometimes in the club.' Asked if anyone had ever discussed condoms, Lionel responded 'yeah' and laughingly shared that he carried them.

> I: You kind of smiled a little bit. [laughter] Where do you get those at?
> L: Well, I – I got them from – from my cousin, – uh, Dante.
> I: And did he tell you how to use them?
> L: Yeah.

In contrast, some responses were *sexually generic* or sexually ambiguous, hiding or suppressing their erotic potential as if they did not identify as sexual people. For example, as Milton discussed porn, he confirmed that he had several magazines. Yet, when asked about the use of porn for self-pleasuring or fantasy, he seemed to whitewash their purpose:

> I: What do people use those magazines for?
> M: Um, uh, just look at them and – and see if, uh – they be the right couple. And having good relationship.

I: Sometimes people look at those pictures and it makes them feel horny. And they use the pictures to fantasize and masturbate.
M: Mm-hmm.
I: Did you know that?
M: Mm-hmm.
I: Have you ever used pictures for that?
M: N – no. No.

Implications for policy would suggest that all annual plans address the innate erotic potential of those receiving support. In addition to the typical vocational and residential goals, plans should routinely cover relational and sexual goals for persons with ID. Furthermore, professionals should take the lead in introducing and supporting these goals, if not first mentioned by the person receiving services. This would be a shift from the current approach where relational and social goals are typically an afterthought, addressed only if the person receiving services brings it up. Policies that encourage access to sexual toys, masturbatory aides, sexuality education, and dating skill development would be as revolutionary as community employment and living once were.

Discussion

This qualitative case study research looked at the sexuality of adults with ID from a unique and sometimes taboo perspective: sexual pleasure. This was in response to the call by Shakespeare, Gillespie-Sells and Davies (1996) to capture the stories of individuals with disabilities as an attempt to reverse the invisibility of their sexuality. The most important finding was that sexual pleasure is important to these participants with ID. Individuals with intellectual disabilities are often not asked how they feel about their sexuality (Garwood and McCabe, 2000); these interviews demonstrated that they have much to say that could benefit the professional discourse of the topic.

As Hollomotz (2011) suggests, the belief that adults with ID are sexually vulnerable often defaults to overprotection over decision-making autonomy, becoming invasive and preventing sexual autonomy. Findings from this study strongly suggest that participants' sexuality should not be viewed only through the narrow lens of *safety* as in abuse or pregnancy prevention programs. As Tepper stated, 'pleasure is an affirmation of life' and sexual pleasure 'is particularly powerful in making one feel alive' (2000: 288). He noted that it is an antidote to both physical and emotional pain, enhances intimate relationships, strengthens social connectedness, alleviates isolation, and counters negative media messages. However, as he stated, 'the pleasurable aspect of sex in our culture has been largely ignored, vilified, or exploited' (2000: 284). Furthermore, Cambridge and Mellan asserted that within disability services and research much attention has been paid to the pathology of sexuality, specifically sexual abuse, and this focus 'tends to deflect attention from the wider sexuality and sexual needs' (2000: 294) of adults with ID.

While they go on to identify a range of key issues for sexuality for men who have learning disabilities, they never give pleasure a spotlight.

Only three studies in our literature review came close to looking at pleasure. Lesseliers and Van Hove (2002) and Lesseliers, Van Hove and Vandevelde (2009) addressed desire for romantic relationships while Siebelink, De Jong, Taal and Roelvink (2006) discussed participants' need for sexual contact. However, it was pleasure, including both physical and emotional closeness, which captured the attention of participants in this research.

In regards to sensuality and intimacy, this research mirrors the findings of Lunsky and Benson (2000) that participants can experience profound loneliness. According to Rubin (1980), friends serve a specific and primary function beyond a parent's influence in shaping children's social skills and their sense of identity. Romantic and sexual partners have the same effect on a person's continued social development.

This study reflected previous research indicating that many adults with ID have little sexual knowledge or experience (McCabe and Cummins, 1996; Szollos and McCabe, 1995; Wolfe and Blanchett, 2000). However, in contrast to McCabe (1999), who reported that dating experiences for individuals with disabilities are rare, all the participants in this study had dated, two were in a long-term, continuous dating relationship, one had an active dating life, and one was married after dating several partners. As was found by Leutar and Mihokovic (2007), these participants said they wanted to date. Dating allows individuals with ID to practice social skills, uncover their likes and desires and reconfirm their relationship goals (Wiegerink et al., 2006).

In regards to sexual attitudes, findings from this study were similar to Dotson et al. (2003), whose participants noted aspects of shame. Additionally, they were consistent with Brantingler where some participants 'showed varying degrees of reluctance' (1985: 101) in discussing certain topics. However, in this study, pride as well as shame was a strong sub-theme.

Sexual self-identification or 'awareness of one's self as a sexual being' (Howard, 2000: 377) emerged when participants acknowledged or embraced the erotic. Individuals are consumers, as well as active architects, of sexuality messages, values and beliefs. Typically, individuals journey along customary milestones of sexual development including cultural, peer, and family expectations that shape their perceptions of who they are as a sexual person. Acknowledgment by others that one has transcended to a new sexual plateau spurs behavior and self-expression. This circular mirroring creates new sexual identity labels for an individual to interpret and play out for consumption by others, perpetuating an ever-evolving sexual identity. Unfortunately, this feedback is often absent for adults with ID (Duncan and Canty-Lemke, 1986).

The erotic potential of a person with ID is often overlooked, but according to Moin, Duvdevany and Mazor, sexual identity is very important to the 'overall psychological well-being and life satisfaction of all human beings' (2009: 84). One should keep in mind that a person's sexuality does not develop in isolation from other aspects of identity (Edwards and Elkins, 1988).

Recommendations for future research

Further research is warranted on the social-sexual experiences of adults with ID utilizing both qualitative and quantitative methods. A larger sample size of participants representing a fuller spectrum of adults with ID could provide knowledge that transcends the limitations of this study, as could exploring more fully the theme of sexual misuse. Additionally, it is critical to fully define the subjective measurements of 'experience', though it was a common mistake in many of the studies in the literature review that use vague definitions such as 'considerable experience with many facets of romantic relationships' (Siebelink et al., 2006). Researchers also need to inquire about sexual activity beyond intercourse or masturbation (Dotson et al., 2003; McCabe and Cummins, 1996).

Other recommendations include replicating this study by including:

- More diverse ethnic backgrounds and differing sexual orientations
- Graduates of formalized sex education
- Participants labeled as having 'problem sexual behaviors' or legal problems
- Staff and parent data for rich triangulated layers of information
- Participant interactions with romantic partners or attending social events

Implications for practitioners

Findings may lead to changes in policies, helping practices, and attitudes of family members of those with ID, leading to an improved quality of life. Such changes might help participants establish a stronger identity as sexual persons, becoming 'competent social and sexual actors' (Hollomotz, 2011: 11), which may decrease their vulnerability to abuse.

This study has implications for daily practice for both disability professionals and sexual health professionals. Both professions should view this marginalized population as needing increased support to help facilitate quality of life. Sexuality experts, educators and therapists can network with area disability service providers, educating them on how sexuality complements their mandate to provide quality services. They can address the severe shortage of adequate sexuality materials, as well as quality sexuality education for the clients they serve (Wolfe and Blanchett, 2002).

This need was seen when Kristy thought of asking her husband Duane's physical therapist for help regarding sex education and couple sexual negotiations. This is the arena of social workers, sexuality educators and sex therapists. They would be well qualified to help teach Kristy sexual self-advocacy skills, facilitate a dialogue on sexual negotiations with the couple, brainstorm sexual position accommodations, or to address sexual myths and misinformation, e.g. regarding cunnilingus.

Sexuality experts could elevate conversations about sexuality during client annual planning meetings above the assumption of sexual vulnerability that Hollomotz (2011) describes as on a continuum of violence, along with low

expectations, overprotection, stigma and sexual segregation, thus helping everyone through what may be an uncomfortable discussion. This might include helping clients develop a sexuality portfolio of interests, histories, views, challenges and suggestions that could be shared in life planning meetings with agency staff. A portfolio of photos or other visual representations could serve as an alternative to difficult verbal communication.

Sexual health educators could help create access to dating services, sexuality information, and products and services from the sex industry that are legally available to non-disabled adults (Hollomotz, 2011). They could be cheerleaders for agency-sponsored social opportunities for persons with disabilities, and for the creation of a lesbian, gay, bisexual and transgender (LGBT) group for individuals with ID. Finally, professional sexuality groups such as the American Association of Sexuality Educators, Counselors and Therapists (AASECT) and the Society for the Scientific Study of Sexuality (SSSS) need to increase their outreach to disability professional organizations and service providers to network and collaborate to address this challenge. Each organization could actively market their conferences to the host cities' local special education teachers, social workers, and other disability professionals. Offering conference scholarships to students entering the disability field could cross-pollinate a new generation of disability sexuality advocates.

Final reflections

A quality life is one filled with pleasure, not with overprotection. Increasing a person's sexual self-efficacy gives them access to a larger social community. Additionally, we propose that increasing the sexual literacy of adults with ID by acknowledging their right to pleasure may be a successful strategy for reducing sexual misuse of this community. Professionals must acknowledge the legitimacy of pleasure for adults with ID and, most importantly, create the bridges that will provide access to these meaningful experiences. Addressing sexuality only from a pathology or crisis stance would be akin to preparing for the holidays by only talking about all the negatives, e.g. financial hardship, family feuding, and individual stress. What fun would that be? Instead we tend to focus the holidays on all the celebratory positives like hope, community, memories, and happiness. We focus on the pleasure it brings. Should our approach to sexuality and adults with ID be any different?

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