



4-1-2016

What do Adolescents with Developmental Disabilities Learn about Sexuality and Dating? A Potential Role for Occupational Therapy

Grace Krantz
gkrantz89@midwestern.edu

Veronica Tolan
vtolan89@midwestern.edu

See next page for additional authors

Credentials Display

Grace Krantz, MOT, OTR/L; Veronica Tolan, MOT, OTR/L; Kimmi Pontarelli, MOT, OTR/L; Susan M. Cahill, PhD, OTR/L

Follow this and additional works at: <https://scholarworks.wmich.edu/ojot>

 Part of the [Occupational Therapy Commons](#)

Copyright transfer agreements are not obtained by The Open Journal of Occupational Therapy (OJOT). Reprint permission for this article should be obtained from the corresponding author(s).

[Click here to view our open access statement regarding user rights and distribution of this article.](#)

DOI: 10.15453/2168-6408.1208

Recommended Citation

Krantz, Grace; Tolan, Veronica; Pontarelli, Kimmi; and Cahill, Susan M. (2016) "What do Adolescents with Developmental Disabilities Learn about Sexuality and Dating? A Potential Role for Occupational Therapy," *The Open Journal of Occupational Therapy*, Vol. 4: Iss. 2, Article 5.

Available at: <https://doi.org/10.15453/2168-6408.1208>

This document has been accepted for inclusion in The Open Journal of Occupational Therapy by the editors. Free, open access is provided by ScholarWorks at WMU. For more information, please contact wmu-scholarworks@wmich.edu.



What do Adolescents with Developmental Disabilities Learn about Sexuality and Dating? A Potential Role for Occupational Therapy

Abstract

Background: The objective of the qualitative study was to describe the perspectives of high school educators regarding how adolescents with developmental disabilities are taught about sexuality and dating. In addition, the investigators sought to examine how occupational therapy practitioners could be better integrated into the educational team to address this need.

Method: Data was collected through semi-structured interviews and analyzed using the constant comparative method.

Results: Three major themes emerged: (a) sexuality is unique to each student, (b) teachers and parents do not know what to do, and (c) a potential role for OT.

Conclusions: Occupational therapy practitioners may be well suited to address the needs identified through this study given their unique expertise.

Comments

The first three authors were Masters of Occupational Therapy students at the time of the investigation.

Keywords

Sexuality, Developmental Disabilities, Occupational Therapy

Complete Author List

Grace Krantz, Veronica Tolan, Kimmi Pontarelli, and Susan M. Cahill

Occupational therapists view the expression of sexuality as an area of occupation and address sexuality in various settings and with a variety of populations (American Occupational Therapy Association [AOTA], 2013; AOTA, 2014; Evans, 1985). Occupational therapy (OT) practitioners have addressed sexuality since at least the 1980s (Couldrick, 1998). However, consumers often view sexual expression as an aspect of health that has been forgotten, or all together neglected, by health professionals (Couldrick, 2005).

The current dearth of literature regarding OT intervention to support sexual expression mirrors consumers' perspectives. There are few studies that document the role of OT in addressing sexuality. The studies that do exist focus primarily on rehabilitation and specifically on adults (Lichtenberg, 2014) and individuals with various physical conditions, such as spinal cord injury (Sakellariou & Swada, 2006). Although the *Occupational Therapy Practice Framework* (AOTA, 2014) identifies sexual activity and personal device care, including the use of contraception and sexual devices, as activities of daily living, many OT practitioners are not routinely addressing sexuality (Hattjar, 2012). OT practitioners often do not address sexuality because of their discomfort with the topic, a lack of education related to the topic, or the belief that other professionals will address the client's needs (Evans, 1985; Hattjar, 2012; Shepherd, 2015). The absence of literature regarding OT with adolescents and young adults with developmental disabilities (DD) is of particular concern, as this population may be most at-risk for sexual abuse and exploitation

(Bowman, Scotti, & Morris, 2010; Linkie & Hattjar, 2012; Shepherd, 2015). The purpose of this study was to describe the perspectives of high school special education team members regarding how adolescents with DD are taught about sexuality and dating and to identify potential roles for OT practitioners.

Sexuality is defined as a collection of attitudes and feelings that are influenced by biological, emotional, social, and cultural factors (AOTA, 2014; National Sexual Violence Resource Center, 2013). One's sense of sexuality contributes to one's gender identity (e.g., that of a man, a woman, or a person in transition), the adoption of behaviors typically associated with that identity (e.g., many women apply makeup and many men wear aftershave), and one's sexual orientation (e.g., heterosexual, homosexual, or bisexual) (Evans, 1985; Greydanus & Omar, 2008). Sex education programs are part of many people's typical high school experience and are often considered a rite of passage. Nearly 80% of Americans believe that adolescents should have some form of sex education in school (Advocates for Youth, 2009). Comprehensive sex education programs that do not focus exclusively on abstinence have been found to delay the onset of sexual activity, reduce an individual's number of sexual partners, reduce the frequency of sexual activity, and increase the use of contraceptives (Advocates for Youth, 2009).

Understanding sexuality, sexual feelings, and sexual actions are critical parts of human development (AOTA, 2014; Evans, 1985). However, society tends to ignore the sexual development of individuals with DD (Parker, 2012).

Adolescents with DD, defined here as those individuals with intelligence quotient scores below 70 and a medical diagnoses of autism spectrum disorder and/or intellectual disabilities, are often viewed as childlike, asexual, and in need of protection by well-intentioned members of society (Greydanus & Omar, 2008; Konstantareas & Lunskey, 1997; Murphy & Elias, 2006). As a result of how society views them, many adolescents with DD encounter obstacles associated with expressing their sexuality in social contexts because they have insufficient levels of personal knowledge and because adults often express discomfort with this topic (Caruso et al., 1997; Hamilton, 2009; Koller, 2000).

Adolescents with DD are often taught, either intentionally or unintentionally, to view their sexuality and their desire to express their sexuality as forbidden, dangerous, and inappropriate (Leutar & Mihoković, 2009; Milligan & Neufeldt, 2001). Misinformation about pregnancy and disease transmission, sexually explicit media images, and a risk of exploitation further complicate how adolescents with DD learn about different aspects of sexuality (Parker, 2012). Inappropriate and insufficient education about sexuality has the potential to further compromise this already vulnerable population, as individuals with DD have historically been at-risk for receiving inaccurate sexual health information (Greydanus & Omar, 2008; Parker, 2012), being victims of sexual abuse (Irwin, 1997), and unknowingly engaging in predatory sexual behaviors (Ballan, 2012; Realmuto & Ruble, 1999).

OT practitioners collaborate with a variety of different team members across educational and community settings to address the needs of adolescents and adults with DD (Shepherd, 2015). Further, OT practitioners use education and training as one mechanism to address the occupational participation needs of their clients (AOTA, 2014). More information is needed to understand how OT practitioners can use educational interventions to collaborate with school teams to address sexuality with individuals with DD.

Methodology

Research Design

The researchers used a basic qualitative interpretive design to answer the questions:

- What are the perspectives of high school special education team members regarding how adolescents with DD are taught about sexuality and dating?
- How might OT practitioners be integrated into the educational team to address sexuality and dating with adolescents with DD?

The investigators included three entry-level Masters of Occupational Therapy students and their faculty research advisor. All of the investigators were interested in better understanding how OT practitioners could more effectively support adolescents and young adults with DD with issues related to sexuality.

Participants

The target population for this study was English-speaking high school special education team members working with or providing services to high school students with DD. Team members were defined as any certified personnel (e.g.,

teacher, administrator), related service provider (e.g., occupational therapist, physical therapist, speech language pathologist), or paraprofessional (i.e., teacher's assistant or aide). The investigators identified team members as participants (rather than as teachers or OT practitioners only) because many professionals work closely with high school students in special education and the investigators wanted to gain a broader understanding of this phenomenon. The investigators suspected that based on each team member's training, experience, and individual role on the team, that he or she may offer different insights compared to other team members. The participants for this study were recruited from Chicago and the vicinity through the investigators' professional network (i.e., other OT practitioners and students identified as individuals who met the inclusion criteria and might show interest in participating in this study) using key informants initially and then a snowball sampling approach. Potential participants were informed of the study via electronic flyers, phone calls, and emails. This form of recruitment was selected over recruiting participants from a specific school or schools in order to protect the identities of the participants, as people with authority over them, such as supervisors and building principals, may deem their views related to this subject matter as controversial. The participants were selected for

inclusion in this study based on their willingness to be interviewed by two of the investigators and to share their thoughts about sexuality as they pertain to adolescents with DD. An effort was made to recruit participants who worked across the least restrictive environment (LRE) continuum. For example, educators were sought from typical high schools that included students with DD, as well as from therapeutic day schools. Prior to giving consent, potential participants were screened by one of the investigators to ensure that they worked with at least 12 high school students with DD between the ages of 14 and 18 years (i.e., average class size for segregated or "self-contained" classrooms). A sample of eight to 10 participants was initially sought to represent the depth and variability associated with phenomenon of study. In addition, the investigators intentionally sought a sample of individuals that represented diverse professional roles. Each individual was interviewed as he or she was recruited and consented to participate. Six participants were recruited for this IRB approved study (IRB # 2436). The participants included: two high school teachers, one administrator, one occupational therapist, one paraprofessional, and one speech-language pathologist. Pseudonyms were used in order to maintain the participants' confidentiality. See Table 1 for the participants' demographic information.

Table 1

Participants' Demographic Information

Pseudonym	Type of Educator	Years of Experience	Type of School
Barbara	Special education teacher	37	Public high school
Nancy	Special education teacher	32	Public high school
Linda	Speech and language pathologist	26	Public high school
Rachel	Occupational therapist	20	Public high school

Cindy	Special education administrator	12	Public high school
Ashley	Paraprofessional	3	Therapeutic day school

Data Collection

Six individuals met the inclusion criteria and provided consent to participate. Data were collected through semi-structured interviews lasting between 45 and 90 min each (see Appendix for the interview guide). The interviews were audio-recorded and transcribed verbatim. The participants were asked to select a setting for their interviews. The interviews took place in the participants' homes or private work offices during non-work hours. Two investigators were present during each of the interviews. During the interviews, one investigator primarily asked the participant questions and the other took field notes and contributed follow-up questions at the end of the interview. Member checking (Patton, 2002) took place after the interviews were analyzed and was used to ensure that the investigators had accurately captured each participant's account.

Data Analysis

Data were analyzed using the constant comparative method (Glaser & Strauss, 1999). The constant comparative method was chosen because it highlights the similarities and emerging themes that were found among all of the participants. Each transcript from the six interviews was generated immediately. Initial themes were developed after line-by-line open coding was performed for the first transcript by the four investigators. Once the second transcript was completed, it was coded for

the initial themes and then open coded for new emerging themes. When new themes were apparent in each subsequent interview, the investigators returned to the first interview to re-code line-by-line for the new themes. Quotes related to each of the themes were organized in data displays (Miles & Huberman, 1994) coded for initial themes. The initial themes were analyzed separately and then compared across the four investigators; the themes were then further refined and defined using axial coding which involved reordering and grouping them into the final themes.

Results

The purpose of this study was to describe the perspectives of high school educators regarding how adolescents with DD are taught about sexuality and dating and to identify potential roles for OT practitioners. All of the participants described their experiences working with and providing services to adolescents with DD in high school. In addition, they shared their perspectives related to sexuality, as well as the issues associated with sexuality that are encountered by this population of youth. Three major themes emerged: (a) sexuality is unique to each student, (b) teachers and parents do not know what to do, and (c) a potential role for OT. In each major theme, several subthemes emerged.

Sexuality is Unique to Each Student

All of the participants spoke about how issues related to sexuality and the expression of

sexuality in high school are different for each student. The participants discussed circumstances where they, as educators, needed to take into account a particular student's attributes, strengths, and weakness while broaching the topic of sexuality or responding to a student's questions, concerns, or actions. The following subthemes were identified: (a) sexuality is not applicable and (b) students do not understand.

Sexuality is not applicable. The participants described how parents and other school personnel were "in denial" or "acted patronizing" to students with DD when they exhibited age-appropriate behaviors associated with sexuality (e.g., expressing a desire to go on a date). For example, Cindy said:

We have blatantly called home and said, "Listen, your student is interested in going to this dance or this activity with another student. May we make this connection?" Most parents are surprised and are like, "Oh really?" You know, I mean, it's just not on their radar.

The participants described how this view was particularly common with parents who felt that the subject of sexuality "did not apply" to their child with a developmental disability.

Ashley explained:

There's like this idea that parents have that people with disabilities shouldn't be allowed to be sexual but I don't think that's right. I think everybody deserves to be loved and be

in a relationship and if they want to have sex or do sexual things they should be educated about it. I feel like parents of kids who have disabilities are like, "Oh, that's farfetched. My kid wouldn't want to [have a romantic relationship]". I feel that parents think that there's a stigma for people who have disabilities because they're [viewed as] asexual. [Parents say], "Oh they have a disability, they don't even think about stuff like that," but I mean, some of [the students with DD] do.

The participants stated that this view is not uncommon among parents who feel that the subject of sexuality should not or "did not apply" to their child with DD because of their level of cognitive functioning. For example, Barbara said:

Here's this widely sexually practicing society. Everybody's doing it. [Typically developing] kids at 12 and 15 are [engaging in sexual behaviors] and [the adults around them] are so puritanical we can't even talk about it with them at all. It's exacerbated when teenagers have DD because then people are like, "Oh they're children. We can't tell them [about sex]." Well, their body parts are telling them. And then some parents of students with DD will say that sex education is teaching their kids to have sex.

Students do not understand. The participants all spoke about times when the students with DD with whom they work did not understand

the information that was presented to them about issues related to sexuality (e.g., rules about public displays of affection in the hallways) and how they had to make this information more clear. For example, Linda said:

I had a boy with autism and he grabbed a girl's breast in the hallway. He knew the rule was keeping his hands to himself, but she was a student aide. He thought he knew her and so it was ok. So sometimes it's handled by going to the dean and sometimes it's handled with a behavior program.

Sometimes you have to write something up in a social story. We have had to do those kinds of things so that they understand that [this type of behavior] is not acceptable.

All of the participants spoke about differences in cognitive abilities and how these differences would affect how students with DD interpret and understand concepts associated with sexuality. The concepts associated with sexuality ranged in topics from rules about dress codes (e.g., lengths of skirts and shorts) to discussing relationship constellations (i.e., boy/girl, boy/boy, girl/girl). Linda said:

One thing I've noticed is that the students with DD have a hard time with boundaries. They don't know how to react to members of the opposite sex. If they are interested in them, they don't know how to approach them. Or, if they think the teacher's aide in the class is cute, they might say, "This is my

girlfriend". They don't understand, you know, what actually a relationship is.

Each of the participants expressed some concern that their students with DD do not understand when they are doing something or saying something that it is viewed as "wrong" in terms of public sexual acts (e.g., putting their hands in their own pants during class or kissing in the hallway) at school. Rachel said:

[Sexuality] has to be talked about because they're just not getting it. They do not understand. Some kids think that having sex with a boy is the same as sharing a kiss. We're going to have to go into a little more detail and share what sex is and [let them know if they] are doing these kinds of [sexual behaviors] that are unsafe behaviors, they could result in pregnancy and sexually transmitted diseases and things like that.

Finally, masturbation was identified by each of the participants as one of the topics that students with DD "don't understand". Nancy explained:

So I think that the majority of my experience has been with young men and masturbation. That has been, I think, the biggest issue we have dealt with in high school [related to sex and sexuality] and that they don't realize that touching themselves in public is a bad thing. They only know that it feels good.

Teachers and Parents Do Not Know What to Do

All of the participants spoke about how teachers and parents do not know how to address

the issue of sexuality and that they assume someone else should address the subject. The following subthemes were identified: (a) who is responsible? (b) we do not want to talk about it, and (c) we do not have the right training.

Who is responsible? The participants spoke about the lack of consensus regarding who is responsible for teaching students with DD about sexuality. Linda said:

Somebody needs to be in charge of this issue. Or maybe a partnership with the parents and [the school] and we offer [some type of formal education] and give the parents an option of whether or not they want their child to be part of it. So, it's just so hard though. Everything is a time thing. Who is responsible for this? Who is going to do this? It's getting harder and harder, with the Common Core and all these goals.

The participants also talked about "passing the buck" to other educators. For example, Ashley said, "I don't know if any of the teachers or administration really want to address sexuality with any of the kids." Barbara said:

The students with DD are in class every minute. They are English. They are in Math. Why would any one of those teachers think, "It's my job to teach them about sexuality"? They just don't.

We do not want to talk about it. The participants all expressed that the primary reason that topics associated with sexuality are not

formally addressed at school is simply because many individuals (i.e., parents and educators) are uncomfortable speaking about sexuality themselves. Linda explained how one's own attitudes related to sexuality could affect how proactive of a stance a teacher takes when broaching sexual topics. Linda said:

It's your own feelings about sex that influence how and when you think about [discussing sexuality]. And when the teachers are uncomfortable talking about it, it's going to be very hard to talk about it and get very graphic with students with disabilities.

We do not have the right training. All of the participants, except for the occupational therapist, spoke about how a lack of training added to an educator's sense of not knowing how to address the issue of sexuality with students with DD. Barbara said:

I think almost no teachers that I know of know how address it. They'll do reproduction in the health unit but they don't take on [other topics]. I find that I know teachers who are teaching kids with severe and profound intellectual disabilities, so IQs below 40, and they don't even address wiping [after going to the bathroom]. So they're sure not equipped to cross the road to talk about sexuality.

In contrast, the occupational therapist, Rachel, said:

[Addressing sexuality] kind of falls to whomever is the best to address the issues at the time. In the past, occupational therapists addressed issues related to menstrual cycles with kids. I am not bothered by much of anything. So, if the team feels that I need to help from an ADL standpoint that's how I'll kind of come into that situation.

A Potential Role for OT

All of the participants spoke about the need for knowledgeable professionals to address issues related to sexuality with high school students with DD, as well as specific topics that should be formally addressed. The participants mentioned OT as one of the professions that could work with the team to address these sensitive topics. The following subthemes were identified: (a) part of a team, (b) need for a formal program, and (c) potential topics.

Part of a team. The participants all supported a team approach to addressing sexuality. For example, when Linda was asked who should address sexuality, she said:

Who? Would they have to talk about how to put on a condom? Do they have to talk about those things? I don't even know that kind of thing. I can handle [sexuality] more in you like a girl, how do you approach her. But again, there is a fine line there. So we really know how to do job skills and how to talk to your boss. I think it really needs to be a team approach and you can get the OT

and Speech Pathologist and the other teachers involved in it. That would be helpful.

Need for a formal program. The educators all described a reactive, rather than proactive, approach to addressing sexuality. All of the participants agreed that a formal program was necessary. Some of the participants spoke about a program for students only. Others spoke more specifically about a program that would include a high level of parent involvement. For example, Nancy said:

I really think that if you teach [the parents how to address sexuality] and then you couple it with their values at home, [the team] can do it. And I feel like if we could just educate the parents, especially with the lower functioning kids, I think that we could communicate just a little bit more openly and kind of coordinate [everything] and I think that would be a good way to be respectful of each families' feelings.

Potential topics. The participants also spoke about what high school students with DD should know about sexuality, as well as how knowledge on this topic should be conveyed at school. Table 2 includes a list of the topics that were suggested by the participants. The most frequently cited topics were those related to safety (i.e., consenting to sexual activity, body awareness and boundaries, and understanding abuse) and

understanding appropriate public behavior. In relation to safety, Cindy said:

The first thing they need to know is just personal safety and personal boundaries, whatever that means for them. I think they obviously are at a heightened risk of being

taken advantage of and I think that is one of the key components. I also think we need to discuss what companionship looks like and [explore] appropriate sorts of dating in the disability community and what does that look like.

Table 2

Topics to be Included in an Ideal Program

Topics	Participants Who Suggested Topic
Appropriate public behaviors	Cindy, Linda, Rachel, Ashley, Barbara, Nancy
Dating	Cindy, Linda, Rachel, Barbara
Sexual intercourse	Rachel, Ashley
Birth control/ safe sex/ STD's	Rachel, Rachel, Ashley, Barbara
Terminology related to sexuality and anatomy	Rachel, Nancy
Topics related to safety: Consenting to sexual activity, body awareness and boundaries, and abuse	Cindy, Ashley, Rachel, Barbara, Nancy
Education for the parents	Nancy
Gender identity	Nancy

Discussion

Learning about sexuality is often considered to be a typical rite of passage for adolescents (Evans, 1985; Lickie & Hattjar, 2012). However, adolescents with DD are often “protected” from opportunities to learn about themselves and how their bodies and feelings are changing until they engage in inappropriate sexual behaviors (Swango-Wilson, 2011). The literature suggests that individuals with DD would generally benefit from sexuality-related education during their adolescent years (Lickie & Hattjar, 2012; Murphy & Elias, 2006; Shepherd, 2015). However, the participants in this study discussed the lack of formal sexual education for adolescents with DD due to beliefs held by parents and other adults that these

individuals are “asexual,” “not ready,” and/or “not able” to engage in such learning. Such views of individuals with DD are well-documented in the literature (Greydanus & Omar, 2008; Konstantareas & Lunskey, 1997; Murphy & Elias, 2006; Shepherd, 2015).

The continuous and predominant portrayal of individuals with DD as “sexless” may inadvertently put them at further risk for sexual abuse and exploitation (Shepherd, 2015). The participants in this study described the critical need to educate adolescents with DD on topics related to sexual safety, including consent and privacy boundaries. These topics are congruent with the Guidelines for Comprehensive Sexuality Education developed by the Sexuality Information and

Education Council of the United States (2004).

Adolescents with DD are perhaps even more at risk than their peers to be taken advantage of by adults who interact with them on a daily basis (Bowman et al., 2010). This may be due, in part, to the blurring of professional and intimate boundaries (e.g., the need to redirect a student who is masturbating or assisting with hygiene) that are inextricable when working with adolescents with DD who have not received appropriate sexual education (Shepherd, 2015).

Although the participants in this study readily identified the need to provide graded and responsive sexual education to adolescents with DD, they further explained that the tendency to ignore the sexual education of individuals with DD was a consequence of being uncomfortable discussing sexuality and generally “not knowing what to do.” A lack of knowledge about how to offer facilitative services with a focus on sexuality has previously been cited as a concern of OT practitioners (Evans, 1985) and is the focus of recent textbook published by the AOTA called *Sexuality and Occupational Therapy: Strategies for Person with Disabilities* (Hattjar, 2012). When asked to discuss topics that should be included in sexual education for adolescents with DD, only one participant discussed gender identity and none of the participants mentioned sexual orientation. It is unclear if the participants neglected to discuss these topics because they were not directly asked questions about them or if they held a hetero- and

fixed-gender normative bias. Including topics related to gender identity, transgender, and sexual orientation in sexual education curricula is particularly important for practitioners who work with adolescents with DD (Morgan, Mancl, Kaffar, & Ferreira, 2011). School personnel are oftentimes not supportive of adolescents with DD who identify as lesbian, gay, bisexual, or transgender (LGBT) and, as a result, adolescents with DD often feel like they are unable to join the school’s LGBT community (Morgan et al., 2011).

OT practitioners may be well suited to address the present gap related to sexual education by applying principles from occupation-focused models of practice to design, evaluate, and grade the instructional interventions being provided to adolescents with DD regarding sexuality (Evans, 1985; Lee, 2010). However, OT practitioners may need additional training and education to feel adept at providing such instructional interventions (Evans, 1985; Hattjar, 2012). With the right preparation, OT practitioners may lead school teams in the design of safe and supportive environments where students with DD who want to express their sexuality or identify as LGBT can feel accepted and part of a larger community (Evans, 1985). Creating such environments has the potential to increase the representation of students with disabilities in typical school activities (e.g., dances) where they can further explore their sexual identity (Morgan et al., 2011).

The participants in this study discussed a lack of training in their discipline-specific preparation programs. The literature suggests that there has long been a lack of personal knowledge regarding this topic, as well as a lack of targeted training to equip special educators to address the complex sexuality concerns of adolescents with DD (Caruso et al., 1997; Hamilton, 2009; Koller, 2000; May & Kundert, 1996). The participants' understanding of the need for sexual education, along with their own lack of personal knowledge and training on the topic, may have led them to believe that a team approach would be the most beneficial in addressing the needs of adolescents with DD. Although OT practitioners also identify a lack of training related to the expression of sexuality (Evans, 1985; Hattjar, 2012), the Occupational Therapy Practice Framework (AOTA, 2014) clearly includes sexual activity and the use of personal care devices, including contraception and sexual devices, as part of our scope of practice.

Unlike most teachers and many other related service providers, OT practitioners have a long history of addressing sexuality with a variety of different client populations (AOTA, 2014; Couldrick, 1998; Evans, 1985). Although much of the current literature is geared at helping adults with physical disabilities express their sexuality, OT practitioners may be able to translate their skills to the adolescent DD population and lead school teams in addressing sexuality to promote the safety and well-being of these adolescents. One of the ways

that OT practitioners could do this is by using the PLISSIT model and teaching other professionals to use it (Annon, 1977). The PLISSIT model is designed to help practitioners discuss matters related to sexuality with people with disabilities and includes four different phases:

1. giving permission to ask about sexuality,
2. providing limited information to answer direct questions,
3. providing specific suggestions, and
4. providing intensive therapy (Annon, 1977).

When practitioners use the PLISSIT model, they are letting their clients know that it is safe and appropriate for them to ask questions, that the practitioner will follow their lead in terms of the amount of information that will be shared, and that if a practitioner is not able to meet their needs, then the client will be referred to another specialist (like in the case of intensive therapy) (Shepherd, 2015). OT practitioners view sexuality as a component of occupational identity and are concerned with how one's view of sexuality influences life roles and occupational participation (Evans, 1985; Sakellariou & Algado, 2006). Additional training and preparation that targets Phase 3 of the PLISSIT model (providing specific suggestions) may help OT practitioners to feel more comfortable when collaborating with teams and conveying the understanding that restricting an individual's ability to exercise his or her sexuality may result in reduced life satisfaction (Evans, 1985).

Implications for OT

Several of the topics identified by the participants in this study (see Table 2) are those that OT practitioners can address beginning in childhood (Shepherd, 2015). In doing so, OT practitioners may play a significant role in meeting the sexual education needs of adolescents with DD (Lickie & Hattjar, 2012; Shepherd, 2015). Prior to entering a high school environment, OT practitioners can provide education to individuals with DD and their parents and caregivers on appropriate privacy boundaries related to toileting and hygiene (Shepherd, 2015). In addition, OT practitioners can lead education teams in fostering the self-advocacy and self-determination skills of children and adolescents with DD by helping them to exercise volitional behaviors and establish supportive habits and routines (Lickie & Hattjar, 2012; Shepherd, 2015). OT practitioners can also work with teams to understand the complexities of expecting individuals with DD to constantly and unquestioningly follow the directions of authority figures in all contexts (Shepherd, 2015). More research is needed to develop models of practice in this area and to explore fully what an OT-led team approach would look like.

OT practitioners may also collaborate with school personnel to grade formal sexual education programs to meet the individual cognitive and developmental needs of specific students with DD (Lickie & Hattjar, 2012; Shepherd, 2015). For example, OT practitioners may adapt and modify

instructional materials. In addition, OT practitioners may also work with individual students to meet their specific needs in order to support greater social participation at school. For example, an OT practitioner might develop a social script or visual support to help a student maintain appropriate personal boundaries or reduce inappropriate sexual behaviors, teach social skills that can be used in a variety of different situations, or modify the environment to promote safety.

Finally, OT practitioners can help parents and educational teams to understand that sexuality is part of the human experience and that sex is an area of occupation that should be addressed with all individuals, regardless of disability (Shepherd, 2015). In doing this, OT practitioners could assist teams as they prioritize the scope and sequence of a sexual education curriculum designed to meet the local needs of adolescents with disabilities in their school community.

Limitations

As the investigators were trying to obtain a broad range of perspectives, the professional disciplines, years of experience, and work setting varied among the participants. This variability may suggest a need for different types of OT services based on the specific school environment and experiences of the educators on the team. In addition, the generalizability of this work is limited by the study design. Methods that seek perspectives from a more robust participant population (e.g., surveys) would provide even greater insights into

how adolescents with DD are taught about sexuality. Future research is also needed to determine how OT practitioners' approaches to addressing sexuality with high school students with DD are different from those of other professionals. Further, more research is needed to determine which strategies for addressing sexuality with this population are the most effective.

Conclusion

The purpose of this study was to describe the perspectives of high school educators regarding how adolescents with DD are taught about sexuality and dating and to identify potential roles for OT providers. The results of this study suggest that educators feel that sexuality is unique to each student with DD; in addition, teachers and parents do not know how best to address the sexual education needs of this population of adolescents. With additional preparation, OT practitioners may be well suited to address the needs identified through this study given their unique expertise.

References

- Advocates for Youth. (2009). Comprehensive sex education: Research and results. Retrieved from <http://www.advocatesforyouth.org/storage/advfy/documents/fscse.pdf>
- American Occupational Therapy Association. (2013). *Fact Sheet: Sexuality and the role of occupational therapy*. Retrieved from <http://www.aota.org/-/media/Corporate/Files/AboutOT/Professionals/WhatIsOT/RDP/Facts/Sexuality.pdf>
- American Occupational Therapy Association. (2014). Occupational therapy framework: Domain and process (3rd edition). *American Journal of Occupational Therapy*, 68(Suppl. 1), S1-S48. <http://dx.doi.org/10.5014/ajot.2014.682006>
- Annon, J. S. (1977). The PLISSIT model: A proposed conceptual scheme for the behavioral treatment of sexual problems. *Handbook of Behavior Therapy with Sexual Problems*, 70-83. <http://dx.doi.org/10.1016/b978-0-08-020373-7.50019-x>
- Ballan, M. S. (2012). Parental perspectives of communication about sexuality in families of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 42(5), 676-684. <http://dx.doi.org/10.1007/s10803-011-1293-y>
- Bowman, R. A., Scotti, J. R., & Morris, T. L. (2010). Sexual abuse prevention: A training program for developmental disabilities service providers. *Journal of Child Sexual Abuse*, 19(2), 119-127. <http://dx.doi.org/10.1080/10538711003614718>
- Caruso, S. M., Baum, R. B., Hopkins, D., Lauer, M., Russell, S., Meranto, E., & Stisser, K. (1997). The development of a regional association to address the sexuality needs of individuals with disabilities. *Sexuality and Disability*, 15(4), 285-291. <http://dx.doi.org/10.1023/A:1024725515740>
- Couldrick, L. (1998). Sexuality issues: An area of concern for occupational therapists? *British Journal of Occupational Therapy*, 61(11), 493-496. <http://dx.doi.org/10.1177/030802269806101102>
- Couldrick, L. (2005). Sexual expression and occupational therapy. *British Journal of Occupational Therapy*, 68(7), 315-318. <http://dx.doi.org/10.1177/030802260506800705>
- Evans, J. (1985). Performance and attitudes of occupational therapists regarding sexual habilitation of pediatric patients. *American Journal of Occupational Therapy*, 39(10), 664-670. <http://dx.doi.org/10.5014/ajot.39.10.664>
- Glaser, B., & Strauss, A. (1999). *The discovery of grounded theory: Strategies for qualitative research*. New York, NY: Aldine de Gruyter.
- Greydanus, D. E., & Omar, H. A. (2008). Sexuality issues and gynecologic care of adolescents with developmental disabilities. *Pediatric Clinics of North America*, 55(6), 1315-1335. <http://dx.doi.org/10.1016/j.pcl.2008.08.002>
- Hamilton, C. A. (2009). 'Now I'd like to sleep with Rachael'—Researching sexuality support in a service agency group home. *Disability & Society*, 24(3), 303-315. <http://dx.doi.org/10.1080/09687590902789461>
- Hattjar, B. (2012). Overview of occupational therapy and sexuality. In B. Hattjar (Ed.), *Sexuality and occupational therapy: Strategies for persons with disabilities* (pp. 1-10). Bethesda, MD: American Occupational Therapy Association Press.

- Irwin, M. (1997). *Sexuality and people with disabilities*. Bloomington, IN: Institute for the Study of Developmental Disabilities.
- Koller, R. (2000). Sexuality and adolescents with autism. *Sexuality and Disability, 18*(2), 125-135. <http://dx.doi.org/10.1023/A:1005567030442>
- Konstantareas, M. M., & Lunsky, Y. (1997). Sociosexual knowledge, experience, attitudes, and interests of individuals with autistic disorder and developmental delay. *Journal of Autism and Developmental Disorders, 27*(4), 397-413. <http://dx.doi.org/10.1023/A:1025805405188>
- Lee, J. (2010). Achieving best practice: A review of evidence linked to occupation-focused practice models. *Occupational Therapy in Health Care, 24*(3), 206–222. <http://dx.doi.org/10.3109/07380577.2010.483270>
- Leutar, Z., & Mihoković, M. (2007). Level of knowledge about sexuality of people with mental disabilities. *Sexuality and Disability, 25*(3), 93-109. <http://dx.doi.org/10.1007/s1195-007-9046-8>
- Lichtenberg, P. A. (2014). Sexuality and physical intimacy in long-term care. *Occupational Therapy in Health Care, 28*(1), 42-50. <http://dx.doi.org/10.3109/07380577.2013.865858>
- Linkie, C., & Hattjar, B. (2012). Adolescents with disabilities and sexuality. In B. Hattjar (Ed.), *Sexuality and occupational therapy: Strategies for persons with disabilities* (pp. 229-284). Bethesda, MD: American Occupational Therapy Association Press.
- May, D. C., & Kundert, D. K. (1996). Are special educators prepared to meet the sex education needs of their students? A progress report. *The Journal of Special Education, 29*(4), 433-441. <http://dx.doi.org/10.1177/002246699602900405>
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: A methods sourcebook*. Thousand Oaks, CA: Sage.
- Milligan, M. S., & Neufeldt, A. H. (2001). The myth of asexuality: A survey of social and empirical evidence. *Sexuality and Disability, 19*(2), 91-109. <http://dx.doi.org/10.1023/A:1010621705591>
- Morgan, J. J., Mancl, D. B., Kaffar, B. J., & Ferreira, D. (2011). Creating safe environments for students with disabilities who identify as lesbian, gay, bisexual, or transgender. *Intervention in School and Clinic, 47*(1), 3-13. <http://dx.doi.org/10.1177/1053451211406546>
- Murphy, N. A., & Elias, E. R. (2006). Sexuality of children and adolescents with developmental disabilities. *Pediatrics, 118*(1), 398-403. <http://dx.doi.org/10.1542/peds.2006-1115>
- National Sexual Violence Resource Center. (2013). *An overview of healthy childhood sexual development*. Retrieved from: http://www.nsvrc.org/sites/default/files/saam_2013_an-overview-of-healthy-childhood-sexual-development.pdf
- Parker, L. P. (2012). *High school counselors' attitudes toward the sexuality of students with intellectual disabilities*. (Doctoral dissertation, University of Alabama, Tuscaloosa). Retrieved from: http://acumen.lib.ua.edu/content/u0015/0000001/0001076/u0015_0000001_0001076.pdf
- Patton, M. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.
- Realmuto, G. M., & Ruble, L. A. (1999). Sexual behaviors in autism: Problems of definition and management. *Journal of Autism and Developmental Disorders, 29*(2), 121-127. <http://dx.doi.org/10.1023/A:1023088526314>
- Sakellariou, D., & Algado, S. S. (2006). Sexuality and occupational therapy: Exploring the link. *British Journal of Occupational Therapy, 69*(8), 350-356. <http://dx.doi.org/10.1177/030802260606900802>
- Sakellariou, D., & Swada, Y. (2006). Sexuality after spinal cord injury: The Greek male's perspective. *American Journal of Occupational Therapy, 60*(3), 311-319. <http://dx.doi.org/10.5014/ajot.60.3.311>
- Sexuality Information and Education Council of the United States. (2004). *Guidelines for comprehensive sexuality education: Kindergarten-12th grade* (3rd ed.). Retrieved from: <http://www.siecus.org/data/global/images/guidelines.pdf>
- Shepherd, J. (2015). Activities of daily living and sleep and rest. In J. Case-Smith, & J. O'Brien (Eds), *Occupational therapy for children and adolescents* (7th ed) (pp. 416-460). St. Louis: Elsevier.
- Swango-Wilson, A. (2011). Meaningful sex education programs for individuals with intellectual/developmental disabilities. *Sexuality and Disability, 29*(2), 113-118. <http://dx.doi.org/10.1007/s1195-010-9168-2>

Appendix

Semi-structured Interview Guide

1. How do you define sexuality?
2. What issues related to sexuality and the expression of sexuality do adolescents with DD encounter in high school?
3. How do high school educators formally and informally address sexuality with adolescents with DD?
4. According to high school educators what knowledge and skills do adolescents with DD need to successfully navigate issues related to sexuality? Who should teach them?
5. Do you feel that there are any barriers to teaching adolescents with developmental disabilities about sexuality?