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# Social Workers' Roles in Supporting the Sexual and Relational Health of Children with Disabilities

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## Abstract

The purpose of this study was to understand social workers' roles in meeting the sexual and relational health needs of children (aged 3–11) with disabilities. We conducted semi-structured interviews with 12 social workers from a range of practice settings. A phenomenological lens privileged the perspectives of social workers in their definitions of disability and sought to convey the meaning they assigned to their experiences of working with children in practice concerning matters related to sexual and relational health. Social workers enacted a broad definition of disability and often came to work with youth in contexts labeled as sexually problematic. In the provision of sexual health services, social workers embodied commonly adhered to roles including as practitioners, enablers, advocates, brokers, and managers. Services are needed that promote positive sexuality and relational health among children with disabilities. It is important that social workers be proactive advocates for the full inclusion of people with disabilities as equal sexual citizens.

## Keywords

Social work roles, Children with disabilities, Direct social work practice, Positive sexuality, Sex education, Sexual behavior problems

## Introduction

The development of sexual and relational health of people with disabilities throughout their lifespan has been doubly restricted by exclusion of both children and people with disabilities from discourse and education regarding sexuality both in the United States (Barnard-Brak, Schmidt, Chesnut, Wei, & Richman, 2014), and abroad (Parchomiuk, 2012; Taylor Gomez, 2012). Children have historically been excluded from knowledge about sexuality due to social constructs of them as asexual and innocent, and because society views sexuality as a boundary separating childhood from adulthood (Robinson, 2012). Adolescents and adults with disabilities likewise have been excluded, as they are thought of as asexual or face obstacles to expressing their sexuality (Stinson, Christian, & Dodson, 2002; Swango-Wilson, 2010; Wings-Yanez, 2014). There is a growing recognition of the need to address the sexuality of children and of people with disabilities from a lifespan perspective, with a broader definition that includes sexuality as integral to humanity, and includes concepts such as self-esteem, socialization, physical maturation, privacy and safety, and the need for intimacy and life-long relationships (Murphy & Elias, 2006; Parchomiuk, 2012; Taylor Gomez, 2012). Social workers also seek both to acknowledge this population's increased vulnerability to various forms of abuse, including sexual (Jones et al., 2012), and to maximize personal development and autonomy (Lafferty, McConkey, & Simpson, 2012). We situate our study in the United States, where social workers abide by the National Association of Social Workers (NASW) *Code of Ethics* (2008); similar to global social work foci (International Federation of Social Workers, 2016), this code centralizes the importance of human relationships as a core value.

Social workers' roles in supporting the developing sexual and relational health of children with disabilities (CWD) are understudied (Rueda, Linton, & Williams, 2014); however, social workers and other professionals, including educators and health care providers caring for people with disabilities, are uniquely positioned to offer support and education to this population (Parchomiuk, 2012; Rueda et al., 2014), including through their care-givers (Ballan, 2012; Holmes & Himle, 2014). As children with disabilities are more likely to live in poverty with single mothers (Parish, Roderick, Swaine, Dababnah, & Mayra, 2012), this increases their likelihood to interact with social workers in various

educational or social welfare contexts. This research will add to the literature through its exploration of the perspectives of social workers in a metropolitan area of the Southern United States who work directly with CWD across a variety of practice settings. We sought to better understand how and in which contexts children with disabilities are being served by these social workers. This is an important contribution since CWD present with unique sexual and relationship challenges and no studies to our knowledge have asked social workers directly about their roles in providing services to address these needs.

### **Sexual and Relationship Challenges of Children with Disabilities**

Approximately 2.8 million (5.2%) school-aged children in the U.S. have a disability, according to the U.S. Census Bureau (Brault, 2011). A study of school social workers' perspectives concerning their work with adolescents with disabilities found that they held important roles in helping them make decisions concerning contraceptive use, pregnancy, navigating sexual peer pressures, and teaching socioemotional skills, including those pertaining to communication, self-esteem, and handling impulsivity (Linton & Rueda, 2014). These data coincide with nationally representative findings that youth with disabilities are less likely to receive sexual health education in public schools (Barnard-Brak et al., 2014). A qualitative study found that children with intellectual disabilities may also be less likely to receive such education at home than non-disabled youth (Pownall, Jahoda, & Hastings, 2012), pointing to the importance of professional services.

Although adolescence is a key developmental time period for sexuality and romantic relationship development (Collins, Welsh, & Furman, 2009), sexual feelings, behaviors, and thoughts are present at all stages of life (Kellogg, 2010). CWD are a heterogeneous group with varying experiences and sexual development needs; however, we know that some have difficulty expressing sexual thoughts and feelings in a socially acceptable manner (see McLay, Carnett, Tyler-Merrick, & van der Meer, 2015 for a review). This may negatively impact their relationships with peers as such behaviors are misinterpreted, feared, and stigmatized as abnormal; this may further isolate CWD and prevent them from participating in positive peer interactions (Ballan,

2012; Nichols & Blakeley-Smith, 2010). Indeed, children with a variety of disabilities often struggle with friendships (De Boer, Pijl, Post, & Minnaert, 2013), and with low self-esteem (Foley et al., 2012; Pinquart, 2013). Relationships with parents and peers lay the foundation for later intimate partnerships, and research has indicated that adolescents and adults with disabilities both desire such partnerships (Holmes & Himle, 2014), and may need additional support during the childhood years in order to foster healthy relationships (Ballan, 2012).

The nature and variety of sexual and relationship challenges CWD may experience depend in part on the type and severity of disability, including behavioral, developmental, affective, and physical. For example, youth with autism spectrum disorders have been found to know less about sexuality and to display more sexually expressive (i.e., often deemed inappropriate) behaviors than their peers (Ray, Marks, & Bray-Garretson, 2004; Stokes & Kaur, 2005). Additionally, sensory needs may lead to sensory-motivated sexual behavior deemed inappropriate (Nichols & Blakeley-Smith, 2010), and social deficits that correspond with the disability may cause a child to not differentiate between public and private spaces, to misread other's intentions, to act impulsively without accurate assessment of the context and social environment, or to involve themselves in risky or even illegal sexual situations as a result of desiring relationships and acceptance (see Ballan, 2012). Children with intellectual and developmental disabilities, including autism, may struggle with personal hygiene (Ballan, 2012; Nichols & Blakeley-Smith, 2010; Stokes & Kaur, 2005), which may impact friendships. Children with prolonged physical illnesses, including chronic fatigue syndrome and headaches, are particularly prone to low self-esteem as compared to healthy peers (Pinquart, 2013). Parents of children with a variety of physical disabilities (e.g., cerebral palsy, brain injury, spina bifida), compared to children without disabilities, have reported that such youth have significantly lower health related quality of life including psychosocial domains (e.g., self-esteem, emotional well-being; Law et al., 2014). Finally, a number of disabilities, including some genetic syndromes as well as developmental disorders, may affect children's sexual development, experiences with and responses to maturation, and expression of sexuality (e.g., Down, Prader-Willi, Williams syndromes; Watson, Richards, Miodrag, & Fedoroff, 2012). Each child's

unique personality attributes as intersected with disability types and learning needs may require sexual and relationship health education uniquely tailored to the individual (Barnard-Brak et al., 2014).

### **Children with Disabilities' Vulnerability to Violence Victimization**

Children with disabilities are more likely than typically developing children to experience various forms of violence, including physical, emotional, and sexual abuse (Jones et al., 2012; Sullivan & Knutson, 2000). They are also more likely to experience repeat offenses, more severe forms of abuse (e.g., threats, bodily injury), and are less likely to report abuse (Hershkowitz, Lamb, & Horowitz, 2007; Sobsey & Doe, 1991). More severe disabilities are associated with increased risk for victimization. Hershkowitz et al.' (2007) study of over 40 000 investigators' reports found that youth with more severe disabilities (e.g., severe learning disorders, autism, severe behavioral disorders) did not understand the perpetrator's motives and context of the sexual interaction. Another study found that CWD were more than three times more likely than those without disability to experience maltreatment and often experienced their first abuse incidence before completing elementary school (Sullivan & Knutson, 2000). CWD may also experience bullying by peers; however, in focus groups divided by disability type, Foley et al. (2012) found across groups that many children had developed positive coping strategies and a sense of resilience in handling negative peer experiences. The increased risk of victimization among CWD is a call for practitioners to recognize their role in the provision of effective sexual and relational health services to this population (McKenzie & Swartz, 2011).

### **Social Workers' Roles in Serving Children with Disabilities**

Social workers are called upon to serve youth with a variety of disabilities including those with emotional, behavioral, intellectual, physical, or other health impairments. Often such conditions are co-occurring (Leppo, Cawthon, & Bond, 2013; Schieve, Clayton, Durkin, Win- gate, & Drews-Botsch, 2015). Their experiences in doing so are understudied, but their duties are defined by their place of employment, their distinct skill sets, the NASW *Code of Ethics* (2008), and at times (e.g., within the school

system) under the tenants of the Individuals with Disabilities Education Act (IDEA, 2004; P.L. 108-146). Broadly, social workers place an emphasis on client empowerment, strengths, and resiliency. In practice, social workers may assume a number of roles and functions to include as practitioners, enablers, brokers, advocates, and managers, many of which are often interwoven (Kirst-Ashman & Hull, 2015; Miley, O'Melia, & DuBois, 2013; NASW, 2005; Sheafor & Horejsi, 2008). As practitioners, social workers work collaboratively with clients to select and utilize appropriate clinical interventions, treat and prevent psychosocial dysfunction, and provide psychoeducation (NASW, 2005). As enablers, social workers provide support, empowerment, and help clients to cope with individual stressors. As brokers, social workers navigate systems to link clients to resources and services, as well as facilitate and strengthen the continuing interactions amongst the client and various programs, agencies, and individual service providers (Sheafor & Horejsi, 2008). Social workers function as advocates on behalf of clients to engender equitable treatment and gain required resources to solve larger societal problems or call attention to issues of social injustice (Kirst-Ashman & Hull, 2015). As managers, social workers are in an administrative role for an agency or organizational system (Sheafor & Horejsi, 2008).

Helping professionals may be instrumental in supporting CWD and their families towards positive sexual and relational health (Ballan, 2012). Research finds, however, that both parents and individuals themselves desire more information and professional support in this arena (Ballan, 2012; Pownhall, Johoda, & Hastings, 2012; Swango-Wilson, 2011). Kellogg (2010) recommends that health care practitioners be equipped to understand sexual behavior across the developmental spectrum, conduct biopsychosocial assessments that include a sexual behavior component, report suspected abuse, and work with parents to normalize sexual behavior. Foley et al. (2012) also recommend helping professionals' roles in serving CWD to include fostering opportunities for meaningful relationships with friends and family members, recognizing and helping youth to cope with stressors (e.g., school, bullying), promoting positive self-image to include body image, and educating the community about how to adjust the environment to benefit all types of individuals.

## **The Present Study**

Practicing social workers that serve CWD are in a unique position to inform our understanding of how we can support this population's sexual and relational health. This study utilized a phenomenological study design to privilege the perspectives of social workers as they described their roles and experiences (Padgett, 2008). Our aim was to better understand social workers' roles in supporting the developing sexuality of CWD, utilizing a broad definition that included attention to self-concept, relationship development, physical maturation, sexual expression, gender identity, intimacy, privacy, and safety. Given that the realm of social workers' descriptions were primarily classifiable utilizing the commonly adhered to definitions of social workers' roles (e.g., enabler; Kirst-Ashman & Hull, 2015), we utilized this framework as a starting template to differentiate and communicate their various responsibilities. We also asked social workers to articulate their definition of disability as well as how they came to serve CWD' sexual and relational health development, and include these critical contexts as part of the results.

## **Methods**

### **Sampling and Procedure**

This research took place in a large Southern state, which has a majority Hispanic population (U.S. Census Bureau, 2010). In the metropolitan area where this study was conducted, approximately 6.5% of school-aged children have a disability, similar to state and national rates (Brault, 2011). Following approval of the governing Institutional Review Board, we utilized purposive sampling methods to recruit social workers serving CWD in a wide variety of practice settings (see Table 1). There were two requirements to participate in the study; first, that the interviewee hold a BSW or MSW degree from an accredited institution and second, that they work with CWD, defined for recruiting purposes as including any type of individual education plan or otherwise defined by them or their institution. We defined children as between the ages of 3 and 11 given that around age three is when many children are entering pre-school and age 11 marks the end of middle childhood years (Centers for Disease Control and Prevention, 2015). Social workers were told that the purpose of the study was to elicit their perceptions



concerning the relational and sexual health of the CWD they served, including their roles in meeting the needs of CWD in these areas. They were also told our broad definition of sexuality. Finally, we discussed this data collection as part of a larger project aimed at understanding the perspectives of social workers in serving individuals with disabilities across the lifespan (see Linton & Rueda, 2014; Linton, Rueda, Williams, Sandoval, & Bolin, 2016; Rueda et al., 2014).

Table 1 Participant overview, selected characteristics

Participant	Current placement	Population served
1	Private practice	All ages
2	Community family social service agency	All ages
3	Private practice	All ages
4	Elementary school social worker	4–11
5	Medical support	0–26
6	Elementary school social worker, parent liaison	4–11
7	School for children with emotional disabilities	5–18
8	School for children with physical disabilities	0–18
9	Elementary school social worker	4–11
10	Generalist private	All ages
11	Community family social service agency	All ages
12	Private practice	3–11

Social workers interviewed also held past experience in adoption or post-adoption services ( $n = 3$ ), sex offender treatment provision ( $n = 1$ ), forensic social work ( $n = 1$ ), program/grant administration ( $n = 2$ ), child protective services ( $n = 1$ ), and early childhood intervention ( $n = 1$ )

Social workers were sought via websites of schools and community agencies supporting people with disabilities. We also contacted professionals we knew through practice, and utilized convenience and snowball sampling techniques to identify others that met the study criteria. Potential participants ( $n = 23$ ) were invited via an email that included the purpose of the study, screening criteria, and our contact information. We aimed to reach saturation (i.e., the point at which no new information is emerging as pertinent to the study), which typically requires between 8 to 10 interviews (Padgett, 2008). Five potential participants did not respond; five declined. Our final study sample included 12 social workers. One additional interview was excluded from the study as the

participant did not meet inclusion criteria. Eleven had their MSW degrees (five holding clinical licensures; one also holding a PhD); one had a BSW degree. Social workers ranged from 3 to 25 years of practice experience serving CWD ( $M = 18.00$ ;  $SD = 9.12$ ). They ranged in age from 29 to 66, and were diverse in ethnicity (2 Hispanic; 2 Black; 4 multi-racial; 4 Caucasian) and gender (7 females; 5 males). Interviews lasted approximately 1 h, and took place in a quiet space at social workers' places of work ( $n = 11$ ) or in a quiet room at the University ( $n = 1$ ). All signed a written consent, which also included permission to be audio recorded. Interviewees were given a \$5 gift card in appreciation of their time.

## **Analysis**

Interviews were transcribed verbatim by a professional transcription service and two of the authors on this study and entered into NVivo 10 (QSR International Pty Ltd., 2010), which helped us to manage and sort a large amount of data. We utilized a semi-structured interview guide (see Appendix), which included key questions and probes pertaining to the relationship and sexuality experiences and needs of CWD, including social workers' roles in working with these youth. Data were coded inductively, whereby text were grouped into meaningful themes and subthemes via operationalizations clearly communicated in a code- book created by the second author. In creating this code- book, the second author and others on this study had been sensitized by the literature and our practice experience to social work roles; however, utilizing a phenomenological study lens, our aim was to stay close to the data in communicating the lived realities of the interviewed social workers including how they adapted existing roles and interventions in their service of CWD. Thus, the codebook underwent numerous reiterations as the first and second authors assessed the fit of the data, assuring that the roles were flexible enough to accurately convey social workers' unique and often combined practice modalities (e.g., practitioner as inclusive of counseling and psychoeducation). Finally, the second author coded all of the data utilizing the final version of the codebook. A third and independent researcher also coded the data, yielding an inter-reliability kappa of 0.81. Data resulting from all questions were included as part of these analyses, and some were double coded across multiple themes and

subthemes. Areas of disagreement were reconciled via a meeting between the independent researcher and the first and second authors. Multiple steps were taken to ensure the trustworthiness of the study throughout the analysis stage. The interviewers (second and fifth authors) engaged in reflexivity throughout the entire research process, including the utilization of a research journal. Credibility was further enhanced via peer debriefing and observer triangulation, whereby all authors on the present study and representing various fields of research and practice engaged in dialogue concerning research decisions. Thick descriptions, whereby individual interviewees offered rich examples from practice to convey their roles in serving CWD, aid in establishing both credibility and transferability by helping the reader to assess the context of key findings and how they might apply to other locations (Creswell & Miller, 2000; Lietz & Zayas, 2010). We also provide details concerning the steps we took in conducting this research, including the interview guide, for replication by other interested parties (Creswell & Miller, 2000). Finally, an audit trail was kept of all research activity to ensure the auditability of the project (Lietz & Zayas, 2010; Lincoln & Guba, 1985).

We communicate each theme and subtheme below. Privileging a phenomenological lens, we adhere closely to social workers' descriptions of their work, using direct quotations to convey meaning. We enact a numeric system to preserve anonymity, but which also allows the reader to match dialogue with social workers' professional contexts (see Table 1).

## **Results**

Social workers performed a number of different roles in supporting CWD regarding sexuality and relationships, and utilized a broad definition of disability in their workplaces. They most commonly came to serve CWD in the context of referral for problematic behavior. Specifically, their roles were categorized as practitioner, enabler, advocate, broker, and manager. We expand below on each of these themes.

## **Disability Definition**

Social workers were asked to define disability at the beginning of each interview, and many defined it broadly as "*...some aspect of a person that is getting in the way of*

*their healthy functioning that's causing problems for them*" (SW 1). While some indicated that their workplace relied on a certain definition of disability, such as qualifying for special education services, most, even those in specialized settings, viewed disability as encompassing a wide range of conditions and circumstances, for example, "*mental health issues, core emotional challenges, or struggles that individuals also face or endure, that can also have a significant impact on their ability to you know, make connections...and navigate through the various challenges that life presents*" (SW 10). Social workers listed a wide range of disabilities in the children they served, including developmental disorders (e.g., autism, Down Syndrome, attention deficit hyperactivity disorders, spina bifida, cerebral palsy), intellectual disabilities (e.g., Global Developmental Delay), exposure to in utero teratogens (e.g., methamphetamine), physical, sensory, or other medical disabilities (e.g., mobility impairment, vision impairment, organ transplant), and acquired disabilities (e.g., burn victim). These were often noted as co-occurring with mental health concerns (e.g., schizophrenia, depression, anxiety), "*Most of the children I see have fairly significant mental health diagnoses*" (SW 12). Finally, a salient theme in defining disability was experience of childhood trauma, "*She's a severe sexual abuse child*" (SW 7).

## **Referrals**

Social workers served CWD' relational and sexual health both as the primary reason for referral and within the context of a broader social work relationship (i.e., sexuality-related discussion arose but was not the reason for referral). Social workers received referrals from parents, teachers, other professionals, and rarely, also from the child.

**Problematic Referrals:** "*The kids that are masturbating in the hallway*". A salient theme was that social workers often came to work with CWD for problems related to sexuality. Social workers discussed ways in which a child's disability could lead to sexual behavior deemed inappropriate via increased impulsivity, restricted/repetitive interests (e.g., touching others inappropriately, preoccupation with sexual matters), or other sexual behavior problems, "*The kids that are masturbating in the hallway, a lot of it is...he's autistic and he's self-stimming [stimulating]*" (SW 7). Some

social workers reported that CWD had exposure to pornography or other inappropriate content on the web, and may have had difficulty contextualizing what they saw, *“For instance, the kids with the impulse control problems, if they get stimulated by something on the internet... they may act on it without having any concept of exactly what it means or what kinds of problems it could create, or how much trouble they could get in for that matter”* (SW 3). A child’s disability could also lead to boundary violations regarding affection. Regarding a youth with autism, a social worker said, *“That’s not appropriate for him to you know hug and kiss strangers and want to sit in people’s laps that he doesn’t know”* (SW 10). Social workers also described problematic referrals due lack of social awareness. For example, a school social worker discussed that, *“the ALE [Alternative Learning Environment] unit...the kids aren’t as inhibited, or they don’t grasp the social norms of a kid, that’s not appropriate to be touching yourself in front of people or trying to touch the teacher”* (SW4).

A few social workers also indicated impending puberty, or early maturation, as a challenge for CWD, and described referrals for physical aggression and emotional regulation that came with these changes. For example, this social worker described that CWD often had limited avenues for expressing distress associated with bodily changes:

A lot more aggression, a lot more anger, a lot of outbursts, particularly around the time of puberty and reaching adolescence. And for some of these children who can’t necessarily express themselves verbally...can be a real challenge... when their only way of communicating to you that’s something’s wrong or that they are upset or that they don’t feel right is by lashing out. (SW 10)

Finally, social workers referenced working with CWD who had experienced trauma, and often interfaced with these youth via the child welfare system or through adoption-related services. These children’s sexual behaviors were discussed at the intersection of trauma and disability:

They had been abused and neglected and removed from their birth families, gone into the foster system and then adopted into new families. Those kids did a lot of sexual acting out...mostly because...stuff had been done to them and they mostly had disabilities too. (SW 1)

Some social workers contextualized these referrals as related to the

development of disability (i.e., mental health diagnoses) and also noted the heightened vulnerability of CWD to experiencing trauma.

**Non-problematic Referrals:** *“Do they have the same feelings as other children?”*. Most social workers also supported CWD’ sexuality in non-problematic contexts, although these were discussed less frequently. These contexts related to puberty, maturation, hygiene support, and sometimes, to social skills, peer relationships, and self-image support. Social workers were approached by parents for questions regarding puberty and maturation, *“She [mom] would be like, he’s getting bigger and he’s getting older, do kids with autism—do they have the same feelings as other children?”* (SW 9). Sometimes these questions included unique issues related to menstruation, toiletry training and bathroom etiquette, *“Do you have any female or women that would be able to talk about cycle training [menstruation] for the girls?”*; *“A lot of the parents that had the blind kids wanted to know items like, well, bathroom etiquette. How will my son be able to go to the bathroom just like everyone else?”* (SW 8). School social workers noted working together with other helping professionals and parents to improve students’ hygiene, *“When there’s hygiene issues, either myself or the nurse addresses it with the child and I usually address it with the family and we kind of work together”* (SW 7). Social workers also supported teachers directly:

...even though they’re not mentally functioning at their age, you know their body still continues to grow and develop and they go through puberty so teachers just being really uncomfortable...and then being afraid to talk to parents about it because it’s awkward for them. So it’s more teachers coming to me than kids... (SW4)

And teachers and parents referred students with disabilities for peer relationship support, *“So colleagues approach me ...most of the referrals are, even through fifth grade it’s peer relationships and getting along with each other”* (SW 4), and for social skills support, *“These are kids who have either been identified by their teacher, or by their parents as needing some additional support with social skills”* (SW 7). CWD were referred for self-esteem concerns as well, *“...the teachers do bring them and it’s usually that self-esteem is connected with their academic achievement...And when they*

*get older they're like fourth or fifth grade, even at that age their esteem is dependent upon how they look and their weight.” (SW 4).*

## **Social Work Roles**

Social workers described working with CWD using a variety of different roles. We were sensitized to these roles as defined by social workers' typical positions and responsibilities (Kirst-Ashman & Hull, 2015; Miley et al., 2013; NASW, 2005; Sheafor & Horejsi, 2008). Roles that were supported by these data included practitioner, enabler, advocate, broker, and manager. To ensure that definitions fully captured the creativity of social workers' lived realities, we describe each of many functions that were performed by fully operationalizing how each role was enacted and providing examples using their language. Social workers often worked with families in their support of CWD' relational and sexual health, and many performed multiple roles, which were thereby double coded (e.g. advocating for the child in his or her microsystem and providing enabling support to the child), thus supporting that social workers often interweave roles (Miley et al., 2013). The reader will therefore note substantial overlap in themes, highlighting the nature of social workers' flexibility in enacting multiple roles, and the fluidity of the roles themselves.

**Practitioner:** “...*teach them about appropriate touch...*”. The practitioner role was the most salient among social workers. While the term practitioner is used frequently in social work literature, it may encompass various functions. In this study, practitioner includes all references to social workers providing individual, family, or group counseling, as well as individual or community psychoeducation, thus encompassing some aspects of the counselor/clinician and teacher social work roles (Sheafor & Horejsi, 2008; NASW, 2005). While few described specific intervention modalities (e.g., CBT), numerous practice examples were given (e.g., playing social skills games), as embedded within the text below.

In working with CWD directly, practitioners provided counseling and psychoeducation regarding sexual development. Much of this dialogue consisted of discussion and modeling concerning appropriate sexual behaviors and boundary issues. Social workers emphasized keeping children safe through teaching appropriate sexual

behaviors, *“We have some picture cues and we stop the behavior [masturbation] right away ‘cuz he can get arrested for that”* (SW 7), and through relationship education, *“You have to help them learn, you know, what’s going to be a safe relationship for you, what’s going to be a safe place?”* (SW 10). Providing education on boundaries in affection sharing was a reiterated notion, *“So, showing affection, you know with ADHD kids sometimes you have to reign them in, uh, kids from trauma, oftentimes you have to teach them about appropriate touch, and how you touch your friends...”* (SW 12). Specific to sexual boundaries, social workers bolstered their direct work with children through educating parents about behaviors related to the disability, *“And so kind of help them understand, ‘This is just a way kids are self-soothing’, or ‘They’re trying to interact.’”* (SW 1). Some social workers also provided direct sexual health education to CWD about puberty, hygiene, and maturation, *“...You’re ten, you’re eleven, and you’re getting to this point and things are going to start changing. Ya know, so we did have that conversation.”* (SW 2).

The practitioner role also involved helping CWD with peer relationships and social skills, both individually and through group work. Social workers viewed these as lacking in many youth with a range of disabilities, *“We do a lot of work on social skills here because their social skills are extremely lacking.”* (SW 7). Skills taught included communication (e.g., *“So we work a lot on how to read body language and how to communicate better with others...”* SW 6), impulse control (e.g., *“We might do something as simple as lay out all 50 playing cards and have them play concentration. And there was consequences for interrupting somebody else or pointing out when it wasn’t your turn...”* SW 3), as well as empathy development, (e.g., *“So we have [scenario] cards that have a problem. ‘There’s a new kid in school and he comes to school dirty and kids are making fun of him. What do you do to make him feel welcome?’”* SW 6). Part of developing social skills also included working with CWD to develop emotional regulation in support of positive relationships, *“...it’s not okay to throw the game across the room or go after your friend because you lost.”* (SW 7).

Given that peer relationships were often challenged, some social workers discussed the importance of fostering the belief that the child with a disability was capable of meaningful present and future relationships:



Sometimes I feel like parents...they're sort of convinced that their child is maybe not capable of certain things... giving up on some of those hopes and dreams that their child could develop meaningful connections or relationships with other people... Even the idea of dating - they just don't envision that for their child, because they just feel like it's just not something that's going to be possible for them. (SW 10)

**Enabler: “He felt like he had no power...”.** Often within their role as practitioners, social workers discussed providing enabling support. This role captured providing emotional support and empowerment to CWD, their family unit, or other professionals who served CWD, through supportive listening, supporting CWD' dignity and self-esteem, helping CWD to discover their strengths and reinforcing those strengths, as well as recognition of sexuality as part of the human experience.

A salient theme within this role was supporting CWD' dignity and self-esteem, often through creative modalities, *“I buy sticky notes by the millions and I make them every day write something good about themselves”* (SW 11), which promoted a sense of accomplishment, *“We want to encourage them to something they can be successful at so that they can feel good about that.”* (SW 8). Children with physical disabilities were supported with regard to body image, *“...there's been a surgery and you can tell her feet are not normal looking. And she hides them and still has some shame about it. But...we talk about it. Sometimes just getting it out in the open...”* (SW 1). School social workers also provided clean or appropriate clothing or helped with hair care. One school social worker acknowledged the special role she felt social workers had in supporting dignity, *“Honestly, it's – for me, it's not hard to recognize your dignity. That's our discipline.”* (SW 7). However, she acknowledged societal challenges, *“Yes, there are dignity issues....You're at the special school....There's something wrong with you and it's [there's] not. It's just that you need a little bit more support.”* One social worker expressed frustration, *“The teacher asks her a question and then everybody laughs when she doesn't get it right. [Sighs] I don't know what to do about some of those cases. I'm trying to come up with things.”* (SW 3).

Social workers also described working with CWD to empower them in their relationships. A social worker described working with a child with schizophrenia and

developmental delay regarding the child's relationship with a school administrator, *"He felt like he had no power, and I said 'Well you know, you do... you need to problem solve and figure it out....he was able to do that within a week. I mean, he's a pretty amazing kid.'" (SW 12).* Additionally, social workers both normalized struggles in peer relationships, and worked to help CWD recognize and understand discrimination (e.g., *"...to give them a better understanding that it may not be them that is causing anything to happen, it's the other children" SW 3*), as well as to enhance their understanding of other children's fear or ignorance of disability as underpinning mean or distancing behavior, *"'He doesn't want to play with me? Why do you think?' And so, having those conversations openly with the kids about what their disability may mean to others."* (SW 11). They also empowered CWD toward healthy peer relationships, *"....sometimes in life we have to pick and choose carefully whom we decide to be friends with."* (SW 10).

Normalizing sexuality was also important. This included providing a safe environment to discuss sexuality, *"You're trying to get them at ease and talk about these things....this is an okay topic, it's just part of life you know, these are just body parts...."* (SW 1), helping children with underlying issues related to sexual behaviors, and working in groups as a way of normalizing sexuality and promoting positive feelings, *"...we did lots of groups for kids, and uh, to me, that's the way you help them normalize sexual behavior and help them feel good about it."* (SW 12). Empowering parents to plan for and talk about sexuality was noted, and included helping to identify an appropriate person to talk with the child, *"We still do talk to them about 'hey, how are you going to address this? Because he or she is nine, ten, eleven, they're going to be twelve, thirteen, fourteen one day...Let's talk about that.'" (SW 2).*

**Advocate:** *"...treat with respect and love. And that is a human right".* A highly salient theme from social workers was the need to advocate for more resources and support for CWD. Specifically regarding sexual and relational health, social workers described advocating for resources and services related to social functioning and opportunities for socialization, *"...we do attend the ARDs [Acceptance, Review and Dismissal for special education services]...and part of that is to help address those social issues."* (SW 2). Social workers also advocated for proper diagnosis and

treatment when CWD were referred related to sexuality. A private practice social worker was animated as he spoke about advocating for testing and a residential group treatment setting instead of individual outpatient treatment for a young client who had committed a sexual offense:

I said, "Well the appropriate treatment is - he has to have this particular testing, he has to be in a group treatment setting"...So there was no money to treat him...And I bucked the system, and...I downloaded all the.... [state] family code and highlighted the fourteen different things that said why we shouldn't do this, why it was inappropriate treatment, inappropriate place, everything about it was wrong. (SW 3)

Social workers also advocated for children within their home and school environments, the following illustrative of a CWD who had experienced sexual trauma, "*She doesn't feel safe with the male [teaching] staff and so I've arranged that the female staff always be present with her...so that she feels safe because she was sexually abused.*" (SW 7). Reflecting challenges while working with teachers serving CWD, one participant described, "*...I honestly have heard some teachers say, 'He's not good for anything,' and I have to go and remind, 'But he did this and this and this', and it's like, 'Oh yeah, Miss (name). I'm just tired.'*" (SW 7). This value of social justice was reflected by another school social worker, "*...the different ways of letting people understand, you know, they're human beings, and do have some needs, but you still have to treat with respect and love. And that is a human right.*" (SW 9).

**Broker:** "*My role is more...to be the mediator...*". Social workers acted as brokers when supporting CWD' relational and sexual health by connecting CWD and their families to services and facilitating their receipt of services. A family support agency social worker summarized this function, "*...the knowledge to go and 'this is who you're going to ask' these type of things...I think having the tools to navigate the system is what families need.*" (SW 2).

Several social workers discussed brokering services for social skills training, primarily through school special education services, "*...starting from the ARD you've got to be there to tell them how to help...so it may be, social skills from the special ed department...*" (SW2), and to community resources for socialization, to include Big

Brothers/Big Sisters, community mentors, other families for social support, and within limits of scarcely available resources, to childcare programs, *“If you have a child with autism and you need daycare, well, here’s the (name of organization).”* (SW 7).

Social workers also referred CWD to school or community-based mental health services. This included support for specialized referrals, such as to an autism specialist for sexual behavior management, to a therapist for body dysmorphia, and for gender identity support, *“...it shifted to this gender identity stuff and kind of exploring...I found them some resources and I wound up finding a therapist that was more expert in that for her and then made the referral.”* (SW 1). Brokering to services for sexuality support also included helping to find a same-gender helping professional to support maturation issues, *“...Dad’s not equipped to talk about periods or he’s not willing to do it...if they’re only male counselors, we ask maybe a nurse...So we would try to find a female in the school.”* (SW 2). Similarly, brokering communication across systems was discussed by a school social worker, *“My role is more to support the special education department...and then the parents, and be the mediator and be the contact person.”* (SW 9).

**Manager: “I’m the one to oversee training...”**. Two social workers in this study acted as managers or administrators of programs supporting children which included CWD. We are careful to not provide details concerning the roles of these individuals in order to protect their anonymity, but both described how their prior practice directly serving CWD provided them with skills and knowledge that better equipped them to serve as managers/ administrators, themes reflective of those described thus far:

Since my particular role now as an administrator of all the programs, I deal very little with the kids. I’m the one to oversee the training and stuff...if there’s counseling that’s needed, I have contract with about seven, eight therapists that will provide psychosocial counseling. We go out and do activities. We’ll even pick ‘em up from home. We have a peer relation group with the kids and with the parents as well. (SW 8)

## **Discussion**

Social workers are uniquely situated to address the multi-faceted needs of children with disabilities, although no studies to our knowledge have assessed their roles in serving these youth in the development of their sexual and relational health. We found that social workers across a diverse range of practice contexts served children with disabilities, families, and other individuals in their lives directly as practitioners, and also within a number of other roles including as enablers, advocates, brokers, and managers. The services they provided reflected both contexts viewed as problematic (e.g., public masturbation) and non-problematic (e.g., discussing menstruation), however the former was more salient. This reflects challenges that social workers face amidst a societal discourse that problematizes sexuality among people with disabilities. These challenges draw attention to the need for positive sexual health education not only for the child with a disability and their family, but also for professionals, families, and children of all abilities that would foster appreciation for disability as an element of diversity and normalize sexuality as an inherent and appreciated aspect of personhood.

The demand for health and mental health professionals that are trained to work with CWD and their families concerning sexual health is great and outweighs the current supply (Ballan, 2012). Our results are promising in that the social workers interviewed as part of this study were enacting various roles to strengthen foundations for healthy sexuality and relationship development among children with disabilities. They utilized a wide variety of practice modalities, often referring to creative and resourceful practice tools, as well as their reliance on foundational social work skills and voiced commitment to social work values (e.g., “...*it’s not hard to recognize your dignity. That’s our discipline.*”; *NASW Code of Ethics*, 2008). However, findings also reiterate concerns regarding the neglect of sexual health advancement. As Ballan (2012) states at the conclusion of her qualitative study with parents of autism spectrum disorder (ASD), “Too often, the discussion when it does occur with providers, is restricted to problematic sexual behaviors exhibited by a child. Such discussions are reactive versus proactive and fail to contextualize the normative developmental sexual needs of children with ASD” (p. 683). Our finding that referrals were primarily related to problematic contexts reiterates this conclusion; similarly, social workers’ dialogue reflected societal views that CWD are often viewed as asexual (“*She [mom] would be like...do they have the*

*same feelings as other children?"* SW 9). Findings point to the need for sexuality disability awareness education for parents, children, and professionals alike.

As practitioners, social workers aimed to enhance peer relationships through providing counseling and education on social skills. They also aimed to keep children safe, including through education on boundaries and appropriate touch. A salient theme in supporting CWD was the experience of trauma. As mentioned by participants in this study, it was common for CWD to have histories of sexual abuse or other types of victimization. Social workers supporting adolescents and adults with disabilities also described how sexual victimization complicated their clients' intimate partnerships and made intervention more complex (Linton et al., 2016; Linton & Rueda, 2015). There is a correlation between receipt of special education and child welfare services (Lightfoot, Hill, & LaLiberte, 2011). It is important to intervene with CWD with sensitivity and informed practice with regard to potential triggers to past and perhaps ongoing trauma.

Attending to the health of children with disabilities requires advanced diagnostic and practice skill sets, as well as what Ng et al. (2015) refer to as orienting skills, the ability of a practitioner to navigate the special education landscape in order that the needs and rights of a child with disabilities be met for their full participation in society. Within the context of this study, social workers enacting the broker role assisted CWD and their parents in accessing and navigating that landscape and strengthened engagement in the specialized receipt and delivery of services related to sexual and relational health. As current practice and reimbursement frameworks may prioritize delivery of evidence-based modalities, valuing the importance of this broker role within social work education and practice settings as a modality for meeting NASW ethical obligations (e.g., social justice, centrality of human relationships; *NASW Code of Ethics*, 2008) will continue to be of importance. While supporting families with CWD, it is important to remember that many may struggle with basic needs and families may be juggling single parenting, full time or multiple employment, and minimal financial and supportive resources (Parish et al., 2012), further emphasizing the importance of sensitive and competent brokering roles.

Social workers in our study functioning as advocates promoted both interventions and environments that supported relational development, feelings of safety and

empowerment, as well as supporting the human rights and dignity of CWD to others. Our findings seem to reiterate those as suggested by Ng et al. (2015), who propose that practitioners not only equip parents to meet the needs of their own children, but also that practitioners advocate *directly* for the services and education that children with disabilities require. Wings-Yanez (2014) also calls for greater advocacy roles within the macro sphere, particularly regarding legislation for policies that would provide quality, inclusive sexual education. Examples of social workers taking direct macrosystemic advocacy action, including legislative appeal, were limited, reflecting an opportunity to enhance social work roles in ensuring equal access to appropriate sexual health education. This is particularly important in light of sociocultural contexts whereby parents of lower socioeconomic status may work multiple jobs and not be able to attend sessions or go to the child's school, and/or for whom English is not their first language.

We are aware of few interventions that address the sexual education needs of CWD specifically, with the exception of the "Growing Up Aware" program, which teaches parents to be sexual health educators to their child with autism (Ballan, 2012). The Dibble Institute has designed "Mike's Crush", a healthy relationship intervention for adolescents with autism. It focuses on social skills, how to identify meanings of body language, to recognize when people want to be friends, and to understand social and legal boundaries (Mitelman & Von Kohorn, 2012). Another is "Friendships and Dating", designed for adults with developmental disabilities and with a focus on defining healthy versus abusive relationships (Ward, Atkinson, Smith, & Windsor, 2013). These interventions may be adaptable, at least in part, for CWD. Hartman and Brangan (2013) have written a thorough guide for practitioners, along with books for youth with autism that focus on sexual health knowledge, prevention, support, and response, with clear illustrations that could be adapted for a range of needs and may be helpful for discussions with younger children. In autism research, social stories have been used in a small pilot study to teach menstrual care (Klett & Turan, 2012); adapting this widely used intervention to other topics and needs could be useful.

## **Limitations**

Although it may be considered a limitation of this study that a broad range of

disabilities was included, social workers also identified disability broadly. This likely reflects their work with individuals having various, some- times multiple, and often undifferentiated disability types as aligned with policy in this area (IDEA, 2004). Still, future research should consider how social workers tailor their services to individuals with various disabilities and take into account severity of disability. Future work should also include the voices of children themselves, as well as their caregivers. Further, this study sampled social workers from a specific geographic area and may be limited in its transferability to other states or regions. Of important note, some social workers evidenced hesitancy to participate in the study; although we do not know why social workers that declined did so, some social workers interviewed described that they had not thought of sexuality using the broad definition utilized, and stated that they had experienced initial hesitancy because the study title contained the words children with disabilities and sexuality. We may infer that our inclusion of a broad definition of sexuality in the invitation email encouraged some social workers to participate that may not have otherwise (e.g., *“Yes...see, now I understand what you’re talking about. You’re talkin’ about self-esteem; you’re talkin’ about hygiene...about ‘so and so’ was kissing ‘so and so’...”* SW 7) and perhaps also that others may have decided not to participate based on discomfort with the topic.

## **Conclusion**

When CWD are supported to develop healthy knowledge and views of themselves, and skills to relate well to others, many acquire the competencies to form romantic partner- ships in adolescence and adulthood (Ballan, 2012). Noted as a challenge, social workers voiced that parents and other caretakers often did not view sexual and romantic relationships as part of CWD’ futures. To the contrary, youth with disabilities hope for meaningful intimate partnerships (Mckenzie & Swartz, 2011). As adolescents, they tend to experience pregnancy and parenting at higher rates than youth without disabilities (Shandra, 2011), partially as a result of lacking sexual health information and in risk contexts reflective of childhood experiences (e.g., lacking self-esteem; Linton & Rueda, 2014). Cultural notions of adult relationships and sexuality shape childhood education and responses to sexual and relational behaviors, often in



stigmatized ways that children internalize (Mckenzie & Swartz, 2011). Social workers should embrace relational and sexual competencies as part of their roles in serving those with disabilities, including the development of these competencies in children.

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### **Appendix: Interview Guide**

1. How do you define disability?
2. What are children with disabilities' experiences in their peer relationships or interactions?
  - a. (*Probes*) What are their experiences initiating peer relationships?  
Terminating relationships or inter- actions? Advocating for themselves in their relationship interactions?
  - b. (*Probes*) What are their experiences giving and receiving affection?
3. Do the children you serve present with issues pertaining to gender identity or gender expression?
  - a. (*Probes*) What are their experiences expressing and recognizing gender?
4. Do the children present with issues pertaining to self- esteem, self-concept, or body image?
  - a. (*Probes*) How do you support children in these areas?
5. Do the children present with issues pertaining to puberty, maturation, reproduction, or sexual behavior?
  - a. (*Probes*) How do you support them in these areas?
6. Do the children present with issues pertaining to personal safety and dignity?
  - a. (*Probes*) Do they experience peer pressure or bullying related to their sexual or relationship behaviors? Can you describe any instances that come to mind concerning sexual play, exploration, sexual pressure, or sexual assault among children with disabilities you work or have worked

with?

- b. (*Probes*) How do you help your clients to deal with or prevent these experiences? To cope with these experiences once they've occurred?
7. Are you approached by families, educators, or other professionals regarding sexuality?
  - a. (*Probes*) What types of conversations have you had?
8. How do you support the sexual development and relationship needs of children with disabilities?
  - a. (*Probes*) Do you have any unique training, tools, or materials to provide this type of support to this population?
  - b. (*Probes*) What kinds of sexual health and development education do children with disabilities you serve receive? How is this information helpful to them?

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