Alignment of Sexuality Education with Self Determination for People with Significant Disabilities: A Review of Research and Future Directions

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Abstract: Sexual development is a complex but vital part of the human experience. People with significant disabilities are not excluded from this principle, but often may be prevented from receiving high-quality and comprehensive instruction necessary for a healthy sexual life. The functional model of self-determination emphasizes increasing knowledge, access to environments, and positive self-perceptions and may be an effective framework for the delivery of sexuality education to people with significant disabilities. We explored ways in which self-determination and sexuality education for people with significant disabilities are aligned. We also conducted a systematic review of sexuality education intervention research for this population and found significant gaps related to self-determined sexuality. Suggestions for sexuality education for persons with significant disabilities as well as barriers are presented and implications for stakeholders and future researchers are discussed.

Human sexuality is comprised of sexual knowledge, beliefs, attitudes, values, and behaviors and deals with anatomy, physiology biochemistry, gender roles, identity, personality, thoughts, feelings, and relationships (National Commission on Adolescent Sexual Health [NCASH], 1995). People with significant disabilities consistently demonstrate low levels of knowledge about their sexuality, including safe sex practices, sexually transmitted diseases, contraception, pregnancy, dating, intimacy, and marriage (Galea, Butler, Iacono, & Leighton, 2004; McCabe, 1999; Cabe & Cummins, 1996; Swango-Wilson, 2011). This places people with significant disabilities at great vulnerability for being abused, exploited, and marginalized in society. Sexuality education goes beyond traditional sex education in that it focuses on all aspects of human sexuality, including relationships. Justification for providing sexuality education to people with significant disabilities is not limited to abuse prevention. Rather, sexuality education is critical for facilitating relationships, marriage, parenthood, preventing challenging behavior, and promoting health and hygiene (Travers & Tincani, 2010). Learning about the aspects of sexual development is a lifelong process for all people, including people with disabilities, that begins in childhood and continues throughout adulthood (Sexuality Information and Education Council of the United States [SIECUS], 2004).

Given the critical importance of sexuality education to the wellbeing of persons with significant disabilities (e.g., intellectual disability, autistic disorder, multiple disabilities), one purpose of our paper is to explore how a functional model of self-determination (Wehmeyer, Kelchner, & Richards, 1996) aligns with the philosophy and practical delivery of sexuality education. We then seek to understand what intervention research exists for illuminating best practices for teaching sexuality-related skills to persons with significant disabilities. We also discuss aspects of self-ad-
vocacy and self-determination as a conceptual framework to guide practitioners in the delivery of sexuality education to students and adults with significant disabilities. Potential concepts for teaching sexuality as they relate to the functional model of self-determination are then presented followed by guidance for practitioners and future directions for researchers.

Importantly, we use the term “significant disabilities” to describe individuals with disorders, disabilities, and conditions that significantly impact development (and who traditionally were labeled as having a “severe disability”). For many good reasons, outdated and stigmatic terminology associated with deficit perspectives has been abandoned in favor of language that emphasizes levels of supports needed to achieve desirable outcomes (Thompson et al., 2004). However, in our review of the research literature, we felt it important to include the original terms the authors used to describe their participants in order to maintain cogency when drawing conclusions from the findings.

Self-Advocacy, Self Determination, and Sexuality

Achieving civil rights of people with significant disabilities began with a movement that focused on deinstitutionalization, community inclusion, and basic human rights (Test, Fowler, Wood, Brewer, & Eddy, 2005). As more rights were afforded and the voices of people with significant disabilities increased in volume, a second wave of advocacy formed in the late 1990s (Wehmeyer, Bersani, & Cagne, 2000). This second wave was characterized by both self-advocacy and self-determination. Self-advocacy is the extent to which a person has the ability to speak up for one’s self, to make requests relative to one’s needs, and to understand and rely on one’s lawful rights as a citizen when others fail to treat them equitably (Van-Belle, Marks, Martin, & Chun, 2006). Self-advocacy marked a critical shift in the way individuals with significant disabilities were viewed by society. Instead of others making decisions on the presumption that people with significant disabilities were incapable, families and professionals became increasingly aware of the potential of individuals to make meaningful decisions about their own lives (Van-Belle et al.). However, while the philosophy of self-advocacy became widely accepted, practitioners have frequently excluded self-advocacy instruction from the curriculum of students with significant disabilities (Test et al.).

Self-advocacy is only one aspect of a broader set of skills related to self-determination. Self-determination requires an individual to have capacity, opportunities, and positive self-perceptions to make decisions about his or her life. Self-determination encapsulates skills like choice-making, decision-making, problem solving, goal setting, self-monitoring, self-advocacy, leadership, and resiliency, to name a few (Taylor, Richards, & Brady, 2005). Achievement of these skills is heavily dependent on the capacity of the individual with a significant disability, opportunities and experiences provided by the person’s environment, and perceptions the person has about him or herself (Wehmeyer, 2001; Wehmeyer & Garner, 2003; Wehmeyer et al., 1996; Wehmeyer & Schwartz, 1997). Limits in any of these areas will limit self-determination because the degree to which a person is self-determined exists on a continuum. A person may have greater capacity, opportunities, and self-perceptions in some areas (e.g., vocation, employment) while experiencing limits in others (e.g., sexuality, social skills).

The philosophy of self-determination aligns well with that of sexuality education. Comprehensive sexuality education (i.e., building sexuality capacity) is a right of people with significant disabilities because it leads to enhanced self-determination and self-advocacy. For instance, an individual who wants romantic or sexual relationships, but lacks skills related to social interactions, dating, intimacy, and safe sex, will have little capacity to make informed choices leading to healthy relationships. Conversely, a person who has capacity in social interactions, dating, intimacy, and safe sex is more likely to have healthy platonic, romantic, and sexual relationships. Because positive self-perception about one’s own sexuality is critical to healthy sexual development (NCASH, 1995) a functional model of self-determination (Wehmeyer, 1999) seems a perfect conceptual framework for the delivery
of life-long sexuality education to persons with significant disabilities.

Many aspects of human sexuality remain taboo in American society. Despite the bombardment of sexual images in popular media, explicit and frank discussions regarding human development, relationships, sexual behavior, and sexual health may be difficult and elusive for professionals and caregivers of people with significant disabilities. Other issues also likely act as major barriers to achieving self-determination as it relates to sexuality. People with significant disabilities have less social opportunity to express their sexuality than their peers (Guralnick, 1999). Students with significant disabilities report they receive less education on STDs, contraceptives, and pregnancy than their nondisabled peers as well as less discussion on sexuality issues with parents and peers (Cheng & Udry, 2005). Cheng and Udry also found that only 38% of students with significant disabilities had discussed contraception with parents, but 45–66% had discussed birth control with their peers. Despite their lack of sexual knowledge, 24% of males and 3% of females with significant disabilities were sexually experienced by the age of 16. Negative perceptions about persons with significant disabilities regarding aspects of sexuality, particularly masturbation, oral sex, and sexual behavior with same sex partners, also have been reported (Cabe & Cummins, 1996). Although increased sexual knowledge has led to a better ability to consent to sexual behavior in persons with significant disabilities (Niederbuhl & Morris, 1993), stakeholders may still withhold sexuality education based on assumptions that the person is incapable of giving consent (McCabe, 1999). Each of these barriers can be directly linked to capacity, opportunity, and perceptions/beliefs associated with self-determination.

**Review of Sexuality Education Research**

Given the importance of sexuality to self-determination, we conducted a systematic literature review to identify studies on teaching sexuality to people with significant disabilities, with an emphasis on instructional interventions, self-determination and self-advocacy. Our goal was to evaluate the extent to which a body of research exists to support sexuality education of persons with significant disabilities, and to identify specific strategies for promoting self-determination and self-advocacy through sexuality education. Two research questions guided our search: (a) to what extent are strategies to teach sexuality to persons with significant disabilities validated by peer-reviewed research? And (b) what, if any, recommendations about best practices or future research directions result from an analysis of existing research?

**Method**

To conduct the review, PsychINFO, ERIC, and Academic Search Premier databases were searched. Only peer-reviewed journal articles were included in the searches, which yielded articles published between 1957 and 2011. Search terms entered into the databases and corresponding number of results were “sexuality and developmental disability” (PsyclnFO, 133; ERIC, 21; Academic Search Premier, 55), “sexuality and mental retardation” (PsyclnFO, 194; ERIC, 40; Academic Search Premier, 41), “sexuality and intellectual disability” (PsyclnFO, 110; ERIC, 35; Academic Search Premier, 69), “sex education and developmental disability” (PsyclnFO, 23; ERIC, 87; Academic Search Premier, 23), “sex education and mental retardation” (PsyclnFO, 131; ERIC, 131; Academic Search Premier, 19), “sex education and intellectual disability” (PsyclnFO, 63; ERIC, 63; Academic Search Premier, 25), “sexuality and self-advocacy” (PsyclnFO, 3; ERIC, 2; Academic Search Premier, 5), and “sexuality and self-determination” (PsyclnFO, 19; ERIC, 4; Academic Search Premier, 22).

Of these results, articles were screened for review and included only if they (a) reported a study on one or more interventions for teaching sexuality to persons with significant disabilities and (b) reported data on the results of the intervention(s). Because of our focus on teaching self-determined sexuality to individuals with significant disabilities, articles were excluded from review if the intervention focused (a) only on measuring the behaviors and perceptions of family members or staff, but not those of persons with significant disabilities, (b) only on skills to promote prevention of sexual abuse or (c) only on reduction
of inappropriate sexual behaviors. Thus, the resulting studies centered on improving sexuality skills of persons with significant disabilities in terms of body awareness, hygiene, interpersonal relationships, decision making, intimacy, and contextually appropriate romantic and sexual behaviors.

Results

The vast majority of articles resulting from database searches were position papers on sexuality, program descriptions, surveys of sexual knowledge, attitudes, and behaviors, surveys of caregivers and parents, studies focusing exclusively on prevention of sexual abuse, and studies treating sexual activity as challenging behavior. Conversely, the literature search resulted in only twelve articles on sexuality education that satisfied the inclusion criteria. One article by Foxx and Mc Morrow (1985) was a follow-up to a previous study by Foxx, Mc Morrow, Storey, and Rogers (1984), and thus they were grouped as one study. References of each article were then scanned to identify any additional articles not found through database searches. An additional article by Valenti-Hein, Yarnold, and Mueser (1994) met criteria for inclusion; therefore, the final review was comprised of 11 research reports on teaching sexuality to persons with significant disabilities. Table 1 shows results by author, year of publication, purpose of the study, subjects, independent variable(s), dependent variable(s), and results.

Purposes of research. Nine of eleven studies sought to evaluate effects of a comprehensive sexuality education program on multiple skills, including body awareness, sexual functioning, grooming, birth control, initiating and maintaining appropriate social interactions, asking for a date, resisting unwanted advances, interpersonal relationships, and intimacy. Only two studies focused a specific subset of sexual behaviors. Scotti, Slack, Bowman, and Morris (1996) evaluated effects of a HIV/AIDS education program on AIDS risk knowledge of adults with significant disabilities, and Shapiro and Sheridan (1985) assessed effects of a training package on knowledge of body parts and sexual exams of an adult woman with intellectual disability (ID).

Participants. Almost all participants in the eleven studies were adults; only one study (Robinson, 1984) included adolescents who were less than 18-years-old. No studies included children under 16-years-old. Most participants were reported to be in their 20s or 30s. Both males and females were represented, although three studies (Foxx et al., 1984; McDermott, Martin, Weinrich, & Kelly, 1999; Shapiro & Sheridan, 1985) incorporated only female participants. Most participants were reported to have mild or moderate ID, with only three studies incorporating individuals with severe/profound ID (Hayashi, Arakida, & Ohashi, 2011; McDermott et al., 1999; Scotti et al., 1996).

Designs. Studies used group and single-subject designs. Of eight studies employing group designs, only three conducted randomized control trials, while the others used quasi-experimental, pre-test, post-test comparisons, or non-random group comparisons. Two studies used a multiple baseline across behaviors design and a multiple baseline across groups design and one study used a multiple probe across behaviors design.

Independent variables. Researchers employed a variety of different sexuality education programs using varying instructional techniques. In addition to lectures and didactic presentations, most studies reported interactive procedures, such as question and answer (Foxx et al., 1984), role play (Mueser, Valenti-Hein, & Yarnold, 1987), guided practice (Hayashi et al., 2011), and group discussion (Penny & Chataway, 1982). Most articles did not describe instructional procedures in sufficient detail for a naive reader to replicate, but instead provided a general overview of content areas and strategies. Only two studies evaluated an existing sexuality education curriculum or program (Dukes & McGuire, 2009; McDermott et al., 1999). Nine studies reported the number of sessions for sexuality education. While intensity of programs varied, most were relatively brief in duration, ranging from one session (Scotti et al., 1996) to twenty sessions (Dukes & McGuire, 2009). Only one study by McDermott et al. (1999) evaluated effects of a long-term intervention, which was comprised of a one year family planning and health program including sexuality education.
<table>
<thead>
<tr>
<th>Reference</th>
<th>Purpose</th>
<th>Number of Subjects, Gender; Ages; Functioning Levels</th>
<th>Design</th>
<th>Independent Variable(s)</th>
<th>Dependent Variable(s)</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caspar &amp; Glidden (2001)</td>
<td>Evaluate effects of a sex education program on sexual awareness, knowledge, and attitudes of adults with ID</td>
<td>12 male and female; ( \bar{x} = 39 ) yrs.; 6 mild ID, 6 moderate ID</td>
<td>Quasi-experimental pre-test, post-test</td>
<td>6 session sexuality education program</td>
<td>Test of sexual awareness, knowledge, and attitudes.</td>
<td>Significant increase in posttest scores compared to pre-test scores</td>
</tr>
<tr>
<td>Foxx et al. (1984); Foxx &amp; Mc Morrow (1985)</td>
<td>Evaluate effects of an interactive game on social/sexual skills of adults with ID</td>
<td>4 females; ( \bar{x} = 25 ) yrs.; mild – moderate ID</td>
<td>Multiple baseline across two groups</td>
<td>12 sessions of the board game Sorry™ with scenario questions to teach social/sexual skills</td>
<td>Percent of scenario questions correct</td>
<td>Increase in correct responses following training; generalization to novel scenarios; gains maintained for six months</td>
</tr>
<tr>
<td>Dukes &amp; McGuire (2009)</td>
<td>Evaluate effects of an individualized sex education program on social knowledge of adults with ID</td>
<td>2 male and 2 female; 22-23 yrs.; moderate ID</td>
<td>Multiple baseline across behaviors</td>
<td>20 session, 10 week individualized program adapted from the Living Your Life sex education curriculum</td>
<td>Sexual Consent and Education Assessment</td>
<td>Increase in knowledge of safety practices, the physical-self, sexual functioning, and sexual choices and consequences following training, which maintained for six months</td>
</tr>
<tr>
<td>Hayashi et al. (2011)</td>
<td>Evaluate effects of a sex education program on social skills of adults with ID</td>
<td>17 males and female; ( \bar{x} = 29 ) yrs.; 9 mild ID; 7 moderate ID; 1 severe ID</td>
<td>Quasi-experimental pre-test, post-test control group</td>
<td>8 session sexuality education program</td>
<td>Kikuchi’s Scale of Social Skills</td>
<td>Significant increase in social skills following training for experimental group; no change in social skills for the control group</td>
</tr>
<tr>
<td>McDermott et al. (1999)</td>
<td>Evaluate effects of a sex education program on sexual behavior, hygiene, social interaction, and sexual knowledge of female adults with ID</td>
<td>252 females; ( \bar{x} = 32 ) yrs.; mild, moderate, and severe ID</td>
<td>Quasi-experimental pre-test, post-test</td>
<td>One year family planning and health program including sexuality education</td>
<td>Social Sexual Assessment, number of instructional contacts</td>
<td>Significant increases in hygiene and sexual knowledge at 1 year follow-up post-training; positive relationship between hygiene and sexual knowledge and number of instructional contacts</td>
</tr>
<tr>
<td>Mueser, Valenti-Hein, &amp; Yarnold (1987)</td>
<td>Compare effects of three different approaches to teach dating skills to adults with ID</td>
<td>26 male and female; ( \bar{x} = 28 ) yrs.; mild – moderate ID</td>
<td>Randomized control trial</td>
<td>Three dating skills programs for 12 sessions, 12 weeks: flexible problem solving (FPS), traditional problem solving (TFS), or relaxation training (RT)</td>
<td>Role plays, behavioral observations, information test, significant other ratings, self-monitoring</td>
<td>All groups improved social skills following training; only FPS and TFS groups retained skills at follow-up; only FPS and TFS groups increased social interactions after training</td>
</tr>
</tbody>
</table>
### Table 1

**Summary of Articles Included in Methodological Review—Continued**

<table>
<thead>
<tr>
<th>Reference</th>
<th>Purpose</th>
<th>Number of Subjects, Gender; Ages; Functioning Levels</th>
<th>Design</th>
<th>Independent Variable(s)</th>
<th>Dependent Variable(s)</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Penny &amp; Chataway (1982)</td>
<td>Evaluate effects of a sex education program on sexual knowledge of adults with ID</td>
<td>49 male and female; 22 yrs.; 44 mild ID, 5 moderate ID</td>
<td>Quasi-experimental pre-test, post-test</td>
<td>6 session, 6 week comprehensive sex education program</td>
<td>Sex Vocabulary Test</td>
<td>Increase in sexual knowledge after program compared to pre-test</td>
</tr>
<tr>
<td>Robinson (1984)</td>
<td>Evaluate effects of a sex education program on socio-sexual knowledge and attitudes of adults with ID</td>
<td>83 male and female; 16–52 yrs.; mild ID</td>
<td>Randomized control trial</td>
<td>10 week comprehensive sex education program</td>
<td>Socio-Sexual Knowledge and Attitude Test</td>
<td>Significant increase in sexual knowledge and positive attitudes toward sex for experimental group compared to control</td>
</tr>
<tr>
<td>Scotti et al. (1996)</td>
<td>Evaluate effects of a HIV/AIDS education program on risk knowledge of adults with ID</td>
<td>31 male and female; 35 yrs.; mild, moderate, and severe ID</td>
<td>Quasi-experimental pre-test, post-test</td>
<td>1 session, 90 minute HIV/AIDS education program</td>
<td>Sexuality survey, AIDS Risk Knowledge Test</td>
<td>Increase in HIV/AIDS knowledge following training for subjects with mild ID only</td>
</tr>
<tr>
<td>Shapiro &amp; Sheridan (1985)</td>
<td>Evaluate effects of a sex education program on knowledge of body parts and sex-related examinations</td>
<td>1 female; 30 yrs.; mild ID</td>
<td>Multiple-probe across behaviors</td>
<td>14 session, 2 week training package with instructions, modeling, and guided practice</td>
<td>Knowledge tests of body parts, breast exam, pap test, and pelvic exam</td>
<td>Substantial increase in test scores following training, which maintained for 5 weeks</td>
</tr>
<tr>
<td>Valenti-Hein, Yarnold, &amp; Mueser (1994)</td>
<td>Evaluate effects of a dating skills program on opposite-sex interactions, anxiety, socio-sexual knowledge, and role play skills</td>
<td>26 male and female; 18–50 yrs.; borderline, mild, and moderate ID</td>
<td>Randomized control trial</td>
<td>12 session, 6 week dating skills program with problem solving, role play, and feedback</td>
<td>Behavioral observations, Social Avoidance and Distress Scale, socio-sexual knowledge questions, Role Play Test</td>
<td>Significant increase in role play skills and socio-sexual knowledge for experimental group compared to control group; significant increase in opposite-sex interactions for experimental group; no difference in anxiety between groups</td>
</tr>
</tbody>
</table>
Dependent variables. Nine of eleven studies relied exclusively on indirect measures to evaluate intervention effects. Most of the nine studies employed surveys and questionnaires to measure social and sexual knowledge, attitudes, and skills, but did not include evidence of reliability and validity of the assessments, with exception of Dukes and McGuire (2009), McDermott et al. (1999), and Scotti et al. (1996). Only two studies used direct behavioral measures to evaluate outcomes. Mueser et al. (1987) and Valenti-Hein et al. (1994) collected data on opposite sex interactions using interval recording to evaluate dating skills programs for adults with significant disabilities.

Results of studies. All studies reported positive effects of sexuality education programs on knowledge, skills, attitudes, and behaviors of adults with IDs. Studies employing group comparison designs found that participants improved on performance measures following training, or in comparison to control groups. Single subject studies reported increases in sexuality skills after intervention compared to baseline. No articles reported effect size measures. Most researchers measured effects immediately after the program; however, Dukes and McGuire (2009), McDermott et al. (1999), Mueser et al. (1987), Sheridan and Shapiro (1985), Valenti-Hein et al. (1994), and Fox et al. (1985) included follow-up measures ranging from three weeks to one year.

Conclusions and Implications

People with significant disabilities consistently demonstrate low levels of knowledge about their sexuality, including safe sex practices, sexually transmitted diseases, and contraception (Galea et al., 2004), pregnancy (Cabe & Cummins, 1996), and dating, intimacy, and marriage (McCabe, 1999). Despite obvious need, this literature review discovered few research studies on teaching sexuality to persons with significant disabilities. Given that sexual knowledge, skill, and experiences are critical to individuals’ ability to make informed choices about relationships, intimacy, and sex (i.e., to be self-determined), it is apparent that more research with this population is urgently needed.

Perhaps the most dismaying finding was that only one of twelve studies in the review included adolescents under 18-years-old (Robinson, 1984). Sexual activity is a typical part of adolescent behavior (Herbenick et al., 2010), and lack of sexual knowledge among younger persons with a significant disability may place them at heightened risk for sexually transmitted diseases and unwanted pregnancy (Cheng & Udry, 2005). Thus, our review underscores the critical importance of research studies that examine sexuality education as key components of secondary transition programs for children and adolescents with significant disabilities.

Also concerning is the lack of research on curricula or published programs to teach sexuality. Only two studies by Dukes and McGuire (2009) and McDermott et al. (1999) evaluated published sexuality education programs, while the others evaluated short-term sexuality education programs designed solely for the purpose of the study. Blanchett and Wolfe (2002) identified twelve sexuality education curricula for people with intellectual and other disabilities; none of these curricula were used as interventions in the studies we reviewed. This finding strongly suggests that published curricula currently in use have little empirical support for teaching sexuality to people with significant disabilities. Relatedly, sexuality education programs in our review used a variety of strategies and techniques, such as lectures, role-play, guided practice, and discussion. However, no studies systematically evaluated components of programs to see which was more effective. Research indicates that explicit teaching strategies involving active responding are most effective for teaching skills to people with significant disabilities (Swango-Wilson, 2009), yet several programs relied mainly on passive approaches to teach sexuality, such as lectures, while others did not describe procedures in sufficient detail to understand which techniques were used. Only four studies described explicit approaches to teach sexuality, such as guided practice and role play (Hayashi et al., 2011; Mueser et al., 1987; Sheridan & Shapiro, 1985; Valenti-Hein et al., 1994).

All studies reported positive effects of sexuality education; however, results should be interpreted with caution because experimental
rigor and quality of studies varied considerably. Five studies used quasi-experimental group designs to evaluate sexuality education, and only three reported evidence of validity and reliability of assessments. No studies reported effect size measures, thus in most cases it is difficult to assess the degree to which programs resulted in clinically or educationally significant treatment gains. Only two studies employed direct behavioral measures to evaluate outcomes (Mueser et al., 1987; Valenti-Hein et al., 1994), while others relied on indirect measures, such as surveys of knowledge and attitudes. Importantly, positive changes in survey responses do not necessarily translate to actual changes in behavior. For example, there is ample evidence to suggest that people who verbally report that they will engage in safe sex following HIV/AIDS awareness training often continue to engage in unsafe sex (Withers et al., 2001). Therefore, programs that seek to change participants’ knowledge, awareness, or attitudes do not necessarily result in measureable changes in sexuality, intimacy, and relationship behaviors and, consequently, also may not result in self-determination.

Developing Capacity for Sexual Development and Expression

While many of the intervention studies we reviewed indirectly addressed aspects of self-determination as it relates to sexuality (e.g., building the individual’s capacity), most of the interventions focused on narrow aspects of sexuality. While general instruction in body awareness, hygiene, social and interpersonal relationships, intimacy, and abuse prevention are important; they represent a limited scope of human sexual development (SIECUS, 2004). The SIECUS provides 39 specific topics to guide sexuality education, each of which is comprised of several sub-concepts to be conveyed (see Table 2). Even when the studies we reviewed used a comprehensive curriculum to teach sexuality, direct measures of opportunities to use skills and self-perceptions were missing. These are not shortfalls of any particular study, but rather an indicator of the large gaps that exist in the research literature on sexuality education for this population. Although there does not exist sufficient research to serve as a reliable guide for the delivery of sexuality education for persons with significant disabilities, the need for practical information seems urgent. What follows are suggestions regarding how the functional model of self-determination can be used to devise and deliver sexuality education to persons with significant disabilities in order to promote broader self-determination outcomes.

The National Guidelines Taskforce on Sexuality Education provides guidelines for comprehensive sexuality education for student’s grade k-12 (SIECUS, 2004). The guidelines include six key concepts that should be addressed across all grades: human development, relationships, personal skills, sexual behavior, sexual health, and society/culture. Each concept is comprised of age-appropriate skills to be learned throughout the life span that are vital to becoming healthy sexual adults.

Traditional sexuality education may be ineffective for achieving sufficient capacity to be a causal agent in the life of a person with a significant disability, which prohibits self-determination (Wehmeyer & Garner, 2003). Swango-Wilson (2009) found that traditional sexuality education was too broad and overwhelming for persons with significant disabilities despite major interests in relationship development and responsible sexual activities reported by the participants. The SIECUS (2004) provided a comprehensive sexuality curriculum evaluation tool that can be used when selecting a curriculum guide. Curricula that provide for learning using a variety of learning modalities, including three-dimensional models, videos, photographs, and diagrams are more effective than passive delivery of information for persons with significant disabilities (Dukes & Maguire, 2009; McDermott et al., 1999). Because people with visual impairments will need to manually interact with materials (feeling and touching) to understand information, tactile models should be easy to handle and feel like human skin (Krupa & Esmail, 2010). Social stories and video modeling have been suggested as possible interventions to teach students with autism spectrum disorders about aspects of sexuality (e.g., hygiene, privacy, social skills) (Tarnai & Wolfe, 2008). As with any instruction for a person with a disability, materials should be adapted to meet unique learning needs and
## TABLE 2

Developing Capacity for Sexual Development and Expression Across the Lifespan

<table>
<thead>
<tr>
<th>SIECUS Key Concepts</th>
<th>SIECUS Topics</th>
<th>Example Concepts During Elementary School Years</th>
<th>Example Concepts During Adolescence &amp; Young Adulthood</th>
<th>Example Concepts Throughout Adulthood</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Human Development</strong></td>
<td>Reproductive &amp; Sexual Anatomy &amp; Physiology; Puberty; Reproduction; body image; sexual orientation; gender identify</td>
<td>Body part names &amp; functions; Bodily changes; Reproduction; healthy diet; Respect;</td>
<td>Sperm &amp; menstruation; Sexual feelings; Intercourse &amp; contraception; Appearance; Attractions; Gender &amp; biological sex</td>
<td>Fertility and conception; Adoption or surrogacy; Menopause; Understanding sexual orientation</td>
</tr>
<tr>
<td><strong>Relationships</strong></td>
<td>Families; Friendship; Love; Romantic Relationships &amp; Dating; Marriage &amp; Life Commitments; Raising Children</td>
<td>Concept of “family” &amp; different family types; Types of friendships; choosing friends; Concept of &amp; different types of love; Commitments, marriage, and divorce; Parenting</td>
<td>Independence; Communication &amp; conflict resolution; Positive &amp; negative influences of friends; Love, attraction, &amp; infatuation; Love is not always reciprocated; Dating readiness; Responsibility of parenthood</td>
<td>Ways to support family members; Love changes with time &amp; in long-term relationships</td>
</tr>
<tr>
<td><strong>Personal Skills</strong></td>
<td>Values; Decision-Making; Communication; Assertiveness; Negotiation; Looking for help</td>
<td>Concept of values; Making choices; Ways of communicating; Communicating wants and needs; Concept of negotiation; Asking for help</td>
<td>Freedom of choice in determining one’s values; Critically considering choices; Good listening skills; Ways to be assertive; Setting sexual limits</td>
<td>Legal implications of some decisions; Consent for sexual relationships; Communicating limits; getting professional help</td>
</tr>
<tr>
<td><strong>Sexual Behavior</strong></td>
<td>Sexuality throughout life; Masturbation; Shared sexual behavior; Abstinence; Human sexual response; Sexual fantasy; Sexual Dysfunction</td>
<td>Touching feels good; Talking to parents or trusted adults about sexual issues is okay; Concept of masturbation; Masturbation is done in private</td>
<td>Humans are sexual beings; Sex can be experienced different ways; Sexual feelings &amp; fantasies are normal, but do not always need to be acted upon; Myths about masturbation; STDs including HIV; Abstinence; Psychological responses to sexual arousal; Sexual dysfunction</td>
<td>Interest in sexual activity changes with age; Concept of orgasm</td>
</tr>
<tr>
<td>SIECUS Key Concepts</td>
<td>SIECUS Topics</td>
<td>Example Concepts During Elementary School Years</td>
<td>Example Concepts During Adolescence &amp; Young Adulthood</td>
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<tr>
<td>Sexual Health</td>
<td>Reproductive health; Contraception; Pregnancy &amp; prenatal care; Abortion; STDs/HIV/AIDS, Sexual abuse, violence, &amp; harassment</td>
<td>Taking care of one’s body; Contraception; Pregnancy as result of unprotected intercourse; Care during pregnancy; Concept of abortion; STDs and HIV; One’s body is private; Sexual abuse</td>
<td>Breast self-examination; Testicular self-examination; Gynecological and sexual health exams; Types of contraception; Prenatal care; Childbirth and miscarriages; Pregnancy complications; State laws regarding abortion; Symptoms of STDs and prevention; Sexual abuse and assault are criminal acts</td>
<td>Regular exams for breast or prostate cancer; Emergency contraception; Fertility issues</td>
</tr>
<tr>
<td>Society &amp; Culture</td>
<td>Sexuality &amp; society; Gender roles; Sexuality &amp; the law; Sexuality &amp; religion; Diversity; Sexuality &amp; the media; Sexuality &amp; the arts</td>
<td>Sexual decisions are an individual choice; Similarities and differences between males and females; Differences in religion, gender, and culture; Stereotype; Discrimination; Websites or other media may have content that is inappropriate for children</td>
<td>Different cultures and communities have varying sexual norms and values; women’s and men’s rights; age of consent; laws concerning discrimination; media’s portrayal of sexuality and relationships may be unrealistic or inaccurate</td>
<td>Understanding sexual diversity; Understanding gender role stereotypes</td>
</tr>
</tbody>
</table>
should be age-appropriate. Explicit instruction using frank language and concrete representation of information that is void of euphemisms will be necessary because many people with significant disabilities have difficulty understanding information presented in abstract ways (Boehning, 2006).

Sexual development and becoming self-determined are both life long processes (Heller, Schindler, Palmer, Wehmeyer, Parent, Jenson et al., 2011). Therefore, sexuality education within a functional self-determination model should begin in early elementary school and continue throughout adulthood. Rather than turning towards sexuality education as a reactive strategy when inappropriate behavior occurs, educators and caregivers should proactively teach a comprehensive set of age-appropriate skills related to sexuality throughout childhood, adolescence, and adulthood. This requires stakeholders to have sufficient knowledge about life-long sexual development. Table 2 provides a summary of guidelines for comprehensive sexuality education provided by SIECUS (2004) as well as age-appropriate examples of skills taught to build capacity towards sexual self-determination. However, in accordance with the self-determination model, following this table, the SIECUS guidelines, or an empirically-supported curriculum alone is not enough to achieve self-determination as it relates to sexuality. Authentic opportunities to use skills also are necessary.

Creating Opportunities to Overcome Societal Barriers

While effective sexuality education may build capacity for becoming healthy sexual adults, the functional model of self-determination requires access to authentic and inclusive environments where skills can be used. People with significant disabilities are often under the supervision of a special education teacher during the school years or caregivers in a group settings (e.g., respite care, group homes, day programs, etc.) as adults. Educators and caregivers often are not prepared to provide opportunities to use the appropriate sexuality-related skills of people with significant disabilities (e.g., affording individuals opportunities to date or to interact with romantically with others under limited supervision) (Mc-Conkey & Ryan, 2001). Also, agencies may have strict privacy policies that effectively prevent designing environments conducive to healthy sexual development, (e.g., restricting dating, masturbation, intercourse). Further, personal ideology (i.e., culture and values) of stakeholders complicates sexuality education for students with significant disabilities (Blanchett & Wolfe, 2002; Boehning, 2006). In some cases, the characteristics of specific disabilities (e.g., poor social development in autism) may lead to stereotyped beliefs about the social and sexual desires of the person (Travers & Tincani, 2010), and also may prohibit opportunities to be sexually self-determined.

Currently, 30 states do not mandate sexuality education and an additional 38 states do not mandate HIV education (Guttmacher Institute, 2011). However, thirty-six states require that sex education include abstinence. Of the thirty-six, 27 require that abstinence be emphasized as the preferred method of birth control. Thirty-two states do not require that contraception be included in the curriculum (Guttmacher Institute). Students with significant disabilities are less likely to access to inclusive environments in schools or places in their community. Collectively, these findings suggest that schools are environments where opportunities to learn and use sexuality-related skills are considerably constrained by statutes that prohibit (or do not mandate) comprehensive individualized sexuality education, and, consequently, limit opportunities for students with significant disabilities to learn and practice sexuality skills in inclusive settings.

The behavior of professionals and caregivers also may result in environments that limit opportunities. They may react negatively, express disapproval, and perpetuate negative emotions (e.g. guilt, remorse, shame, etc.) when encountering sexual expression and/or normal sexual behaviors in people with significant disabilities (Swango-Wilson, 2008). Also, stigmatic environments may result in reliance on semi-private places that are unsafe and socially inappropriate for sexual exploration and expression and, consequently, put the individual at greater risk for abuse, exploitation, and placement in more restrictive settings (Hollomotz & The Speak Up Committee,
Fear of punishing consequences (i.e., shame, embarrassment, physical pain) in sexually repressive environments also may result in retreat from intimacy (Milligan & Neufeldt, 2001), poor self-esteem and reduced quality of life (Brodwin & Frederick, 2010), and ultimately decreased self-determination. Careful planning will be necessary for achieving sufficient and healthy opportunities to experience usual sexuality-related skills. Travers and Tincani (2010) provided individualized education plan teams with a framework for making decisions about sexuality education for students with autism. This framework may be extended when planning sexuality education for individuals with significant disabilities. Person-centered planning (PCP) is considered a best practice for transition planning (Greene & Kochar-Bryant, 2003). Person-centered planning is a collaborative process involving the student, family, school team members, and non-school support team members (Bambara, Browder, & Koger, 2006). The goal of PCP is to generate a goal-orientated plan based on future the desires of the focus person and to delineate the activities and supports needed to achieve the goals (Vandercook, York, & Forest, 1989). This planning approach can be extended to include the person’s sexual development (e.g., dating) and environmental contexts can be arranged accordingly (e.g., placement in settings with people the person may want to date). Making Actions Plans (MAPS) as well as Planning Alternative Tomorrows with Hope (PATH) (Obrien & Pearpoint, 2003) are two structured action-planning systems conducive to the integration of aspects of the focus person’s sexuality. The five fundamental questions to be considered when using these approaches (e.g., What is the person’s history and current life situation? What are the person’s strengths and weaknesses? What is the vision or dream of the person? What are the team’s fears, obstacles or barriers? What are the priority goals (Bambara, Browder, & Koger, 2006)?)? Importantly, planning should also include extensive consideration of capacity and opportunities for sexual development. However, because self-determination requires positive perceptions and beliefs by the person as well as the individuals supporting them (Wehmeyer, 1999), self-determination may be limited even when the person has the capacity and opportunities to engage in sexual exploration and expression. Therefore, changing perceptions of and beliefs also will be critical to promoting sexual health and, self-determination.

Changing Perceptions and Beliefs

Caregiver beliefs and perceptions influence the development of sexual identity (Halstead, 2002; NCASH, 1995; Shepperdson, 1995). While there seems to be consensus about sexuality education in terms of content and instructional methods for non-disabled individuals, it seems that people with significant disabilities are being excluded from these principles and, subsequently, are prevented from achieving positive self-perceptions and beliefs requisite for self-determination. For example, caregivers may assume a protective stance in which persons with significant disabilities are rarely left alone or given opportunities to participate in activities that may lead to friendships or sexual relationships. The social taboos surrounding sexual pleasure and intimacy also may result in students learning that sexuality should be repressed. Previous myths and misperceptions that people with significant disabilities are asexual, child-like, incapable and unworthy of parenting (Cornelius, Chipouras, Makas, & Daniels, 1982) may persist in our society and serve as justification for withholding sexuality education that leads to self-determination. These factors reflect a negative attitude about sexual exploration and expression and likely influence how people with significant disabilities feel about their sexuality. The cultural influences are evident in assessments used for person-centered planning (PCP). The Supports Intensity Scale (SIS) (Thompson et al., 2004), an assessment tool for identifying the service needs of people with significant disabilities, addresses meaningful friendships and intimate relationships, but does not explicitly address the teaching of appropriate sexual behavior. Rather, the SIS emphasizes monitoring of inappropriate sexual behaviors (e.g., sexual aggression, public exposure). MAPS and PATHS provide opportunities to address some aspects of sexuality, but do not explicitly address most of the guidelines provided by the
SIECUS (2005). Planning and adaptation of curricula and materials tools will likely be necessary to meet the individual need of the person with disabilities.

Without capacity and opportunity, a person will not develop a positive perception or confidence in his or her own abilities. Conversely, enhancing capacity and opportunities may contribute to increases in self-perception and beliefs about sexuality. Thus, professionals, caregivers and parents, support staff, and other relevant stakeholders will likely need training on how to build capacity and provide opportunities for sexual development in persons with significant disabilities. Changing self-perceptions and achieving self-determination also will depend heavily on the extent to which the values of professionals, caregivers, and other stakeholders influence sexuality education. If stakeholders understand how their own values regarding sexuality might prohibit sexual development and self-determination, then they may be more inclined to respect the needs of persons with significant disabilities even when they conflict with their personal beliefs. Parental/caregiver modeling of positive relationships is critical to healthy sexual development (NCASH, 1995) and also may enhance perceptions. Stakeholders will also likely need to encourage healthy relationships for people with significant disabilities until positive self-perceptions and beliefs are achieved. When the individual has the capacity, opportunity, and perception necessary for sexuality, they are likely to achieve greater self-determination and better quality of life.

Practice Implications

People with significant disabilities need instruction in accordance with their abilities in order to develop the capacity for self-determination and self-advocacy as they relate to their sexuality. Similarly, educators and other service providers will need to arrange environments where opportunities for normal and socially appropriate sexual development and expression can occur. Encouragement to use skills that have been learned in natural environments may lead to increased positive perception. Beginning in the preschool years, achievement of a self-determined sexual life should be considered a long-term goal by intervention and education teams. If capacity, opportunities, and perceptions are built up throughout childhood and adolescence, then the chances of achieving a self-determined lifestyle are increased. As self-determined sexual adults, these individuals will serve as positive role models and will challenge assumptions and perceptions of the rest of society. We encourage adults with significant disabilities to express their sexuality in safe and socially appropriate ways.

Caregivers, professionals, and other stakeholders will need to develop a deep understanding of how their own knowledge and beliefs about sexuality impact policy and practices related to the sexuality of people with significant disabilities. Where a person with a significant disability lives and with whom they interact influences their opportunity for relationships and intimacy. For example, the values and beliefs of those in charge of the group home or other living setting may influence the policies on sexuality and the sexual practices of those living in that setting. Policies that restrict or prohibit normal and healthy sexual expression may be in place as a precaution against abuse and exploitation. While the risk for abuse and exploitation are increased for people with disabilities (Brown & Percy, 2007) the use of restrictive policies that prohibit healthy sexual development may in fact contribute to increased risk for abuse. Therefore, policies and individualized plans for sexual development should be developed that both support sexual development while preventing abuse of individuals with disabilities in those settings without sacrificing self-determination. Accordingly, stakeholders will need extensive training in myriad topics regarding sexuality and self-determination.

Future Research

Findings from our review and our perspective of sexuality from a functional self-determination model indicate a need for studies that focus on building the capacity necessary for self-determined sexuality. Specifically, studies are needed that: (a) teach various aspects of sexuality to children, adolescents, and adults with significant disabilities, (b) continue to evaluate curricula published for teaching sex-
uality education, and (c) compare intervention methods for delivering sexuality education to students with significant disabilities. Studies that focus on increasing the opportunities for sexual exploration and expression of learned skills are also needed. Finally, research that examines the self-perceptions/beliefs of persons with significant disabilities regarding their sexuality once capacity and opportunities are established also is warranted.

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