

# Sexual Assault Prevention for Women With Intellectual Disabilities: A Critical Review of the Evidence

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## Abstract

Although research has indicated that women with intellectual disabilities are significantly burdened with sexual violence, there is a dearth of sexual assault prevention research for them. To help address this serious knowledge gap, the authors summarize the findings of general sexual assault prevention research and discuss its implications for women with intellectual disabilities. Next, the authors evaluate interventions published in both the peer-reviewed and non-peer-reviewed literature from a comprehensive search of the scientific literature as well as from recommendations made by disability and sexual assault service providers in the United States. The results of this comprehensive literature review found 4 sexual violence prevention programs that were designed for participants with intellectual disabilities and that had undergone some type of evaluation. Each program and its evaluation are critically and systematically reviewed. Based on the authors' review of these programs as well as the wider literature, they conclude with recommendations and discuss the work that remains to decrease the incidence of sexual violence against women with intellectual disabilities.

DOI: 10.1352/1934-9556-47.4.249

Sexual violence is pervasive, with alarming prevalence rates. One in six women in the United States is likely to experience sexual assault, including forced sexual intercourse or attempted forced sexual intercourse, in her lifetime (Tjaden & Thoennes, 2006). Furthermore, research has now established that perpetrators are most likely men known to their victims (Campbell & Wasco, 2005). Although the incidence of sexual violence victimization among the general female population is daunting, the likelihood that a woman with intellectual disabilities will be assaulted is estimated to be significantly higher than the risk nondisabled women face (Sobsey & Doe, 1991; Tyiska, 1998). Women with intellectual disabilities are also likely to endure abuse from their caregivers, a situation that has no analog among nondisabled women (Carlson, 1997).

A growing body of interventions and research is aimed at preventing sexual violence (for reviews, see Rozee & Koss, 2001; Yeater & O'Donohue, 1999), and promising practices for preventing

sexual violence have been evaluated (Schewe, 2007). However, the bulk of the prevention work and research has focused on preventing sexual violence among college students. Even though research has indicated that women with intellectual disabilities are significantly burdened with sexual violence, there is a dearth of sexual assault prevention research for them.

To help address this knowledge gap, this article critiques international sexual assault prevention efforts designed specifically for women with intellectual disabilities. The American Association on Intellectual and Developmental Disabilities (AAIDD) defines *intellectual disabilities* as significantly below average cognitive functioning, with impairments in daily living, beginning before adulthood (AAIDD, 2008). Historically, these conditions have been referred to as *mental retardation*. In this review, we first summarize the findings of general sexual assault prevention research and discuss its implications for women with intellectual disabilities. Furthermore, we evaluate interventions

published in both the peer-reviewed and non-peer-reviewed literature and assess these programs for their efficacy and evidence-based results. We conclude with recommendations and discuss the work that remains to decrease the incidence of sexual violence against women with intellectual disabilities.

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## Sexual Assault Prevention

In response to the alarming rates of violence against women with and without disabilities, sexual assault researchers and service providers continue to develop, implement, and refine prevention programs. Varying in length, structure, and design, program developers have tried an array of prevention strategies. Some programs teach self-defense strategies to women, some strive to alter attitudes that may facilitate sexual aggression, and others focus on increasing awareness and knowledge of sexual violence for both women and men (Schewe, 2007). Considerable effort has been applied to evaluate prevention interventions directed at university students. Unfortunately, few prevention programs have demonstrated that they decrease the incidence of assault (Roze & Koss, 2001; Schewe, 2007). Compounding the challenge of prevention efforts, empirical evaluation of sexual assault prevention programs remains difficult at best, given funding and logistical constraints. As a result, many prevention programs are implemented or continued despite a paucity of evidence that they actually prevent sexual assault. Yeater and O'Donohue (1999, p. 750) have characterized such efforts as “deliver and hope” strategies.

Sexual assault prevention programs are further limited by various factors, including their frequent focus on changing perpetrators' adherence to rape myths (Lonsway & Fitzgerald, 1994). Rape myths are attitudes that condone and facilitate sexual violence against women, including beliefs such as the following: A woman can resist a rapist if she really wants to resist or women in short skirts are asking for trouble (Burt, 1980). Although limited evidence suggests that such programs may be effective in changing perpetrators' attitudes, there is no evidence demonstrating that these interventions change perpetrators' behavior (Schewe, 2007; Yeater & O'Donohue, 1999). In fact, Brecklin and Forde (2000) found that men who had committed sexual assault were more likely to develop attitudes that supported or condoned rape. The authors

speculated that attitudes assumed to be predictive of sexually violent behavior may have simply been afterthoughts that functioned post-assault to assuage perpetrator guilt.

Sexual assault prevention programs suffer from other limitations as well. The sessions are generally voluntary, and tend to attract both women who are at low risk for being victimized as well as men with less likelihood of perpetrating such acts (Schewe & O'Donohue, 1993). When evaluated, social desirability characteristics (participants offering a response they believe will garner trainer approval) are rarely addressed. Furthermore, long-term maintenance of treatment effects has not been demonstrated or evaluated, and, although treatments might yield statistically significant results, the clinical (i.e., “real-world”) significance is less certain (Schewe & O'Donohue, 1993).

Other criticisms of sexual assault prevention programs relate to their questionable long-term effects at the population level. Several sexual violence researchers have argued that self-defense prevention programs directed at women are more aptly named *deterrence* programs, for they do not actually prevent sexual violence but deflect the perpetrator away from one victim and toward another, and often more vulnerable, target (Lonsway & Fitzgerald, 1994; Schewe & O'Donohue, 1993). An individual woman may be able to avoid victimization in a single circumstance; however, women collectively are not safer as a result. Compounding this limitation of deterrence strategies is the likelihood that victims of sexual assault remain at high risk for revictimization (Macy, 2007; Schewe & O'Donohue, 1993).

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## Sexual Assault Prevention and Women With Intellectual Disabilities

To design and implement sexual assault prevention programs, service providers must rely on what is known about precursors to sexual violence. To this end, various researchers have explored the contributing and mitigating factors related to why sexual violence occurs and, most important for our purposes, how to prevent it. The evidence remains mixed, however. Numerous factors are associated with sexual assault, including prior victimization, the victim's abuse of substances, nonassertive behavior, low socioeconomic status, acquaintance with the perpetrator, and lack of knowledge of risk factors (Roze & Koss, 2001;

Yeater & O'Donohue, 1999). None of these, however, are known causes of sexual assault. Rather, women with these factors are more significantly burdened with sexual assault experiences.

These risk factors are found with greater prevalence or severity among women with intellectual disabilities. These women are less likely to receive any form of sexual education in school or elsewhere, including training on assertiveness, healthy relationships, proper feel and touch, or warning signs of sexual abuse (Kempton & Kahn, 1991). Women with intellectual disabilities are often socialized to be compliant, are more likely to live in poverty, and remain substantially more dependent on caregivers than nondisabled women (Andrews & Veronen, 1993; Carlson, 1997; Wacker, Parish, & Macy, 2008).

In addition to personal risk factors, situational characteristics associated with sexual assault are more threatening when viewed in the context of a victim with intellectual disabilities. Perpetrators are likely to target the most vulnerable and easily manipulated woman to whom they have access, women who they believe will not report, and women who are socially isolated (Andrews & Veronen, 1993; Carlson, 1997; Sobsey & Doe, 1991). Most women with intellectual disabilities generally receive some paid or unpaid support services, which often causes them to be dependent on others in secluded environments (Andrews & Veronen, 1993). In one study, women with cognitive limitations were more likely to be raped by friends or family than women with other disabilities (Nannini, 2006). In addition, these women have limited access to reporting systems, which increases the likelihood that the crime may pass unpunished (Wilson & Brewer, 1992) but also causes them to be assault targets (Wacker et al., 2008). Given the context of their lives, women with intellectual disabilities are uniquely susceptible to being victimized.

In summary, the incidence of sexual violence among all women is disturbingly high. However, contrasted to nondisabled women, the incidence of sexual violence among women with intellectual disabilities is significantly elevated. Most existing research to develop evidence-based prevention programs has addressed college students, whose life circumstances and resources are vastly different than those of most women with intellectual disabilities. Furthermore, solidly efficacious preven-

tion strategies have yet to be determined. Research has helped identify factors associated with an increased risk of sexual violence victimization, and women with intellectual disabilities seem to be more likely to have these factors.

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## Method

To determine the scope and nature of available sexual assault programs geared for participants with intellectual disabilities, we conducted a comprehensive search of the international research literature and sought unpublished programs that met our inclusion criteria.

### *Criteria for Inclusion*

In our review of the programs and studies, we included only those with tested outcomes or documented evaluation results. We reviewed only programs or studies with an explicit focus on preventing sexual violence against women with intellectual disabilities and specifically designed for participants with intellectual disabilities. Our primary purpose was to investigate sexual assault preventions for women with intellectual disabilities because of the distressingly high prevalence rate for this group. As a result, we did not review abuse prevention programs designed for caregivers, men, or children with intellectual disabilities.

### *Research Process*

Our process began with a thorough search of peer-reviewed journals for articles related to women with intellectual disabilities and the prevention of sexual assault. We used the following databases: Academic Search Premier, PsycINFO, HealthSource, ERIC, Google Scholar, PubMed, Worldcat, and ISI Citation Databases (Web of Science). We consulted with librarians to ensure that our literature search efforts would locate all relevant publications. Rigorous searches yielded several articles; however, most articles examined the prevalence of sexual assault against women with intellectual disabilities, rather than described sexual assault prevention efforts.

We used an electronic library to manage the research, which enabled us to effectively manage the results. Search terms included *women with developmental disabilities or cognitive or mental retardation, sexual abuse or sexual assault or rape or incest, and prevention or support or education*. These

terms were applied, and then all possible variations were entered to exhaust the search. Despite this level and intensity of our search, the findings were as follows: (a) 22 articles related researchers' recommendations for prevention of sexual assault, (b) 42 articles described the prevalence of the problem, and (c) 19 articles discussed the impact of the abuse and the supports necessary to address individual's trauma. Last, 9 articles discussed implications of implementation or evaluation of a prevention program (Bowen, 2000; Drum, 2000; Hickson & Khemka, 2004; Hogg, 2001; Johnson, Frawley, Hillier, & Harrison, 2002; Khemka, 2000; Khemka, Hickson, & Reynolds, 2005; Rappaport, Burkhardt, & Rotatori 1997; Singer, 1996).

Of these findings, four were eliminated from the review based on their lack of availability and the absence of program evaluation: (a) Drum (2000), owing to the availability of an abstract only, with no data or article to review; (b) Hogg (2001), due to a lack of data and evaluation, as well as the target audience being staff members working with persons with intellectual disabilities rather than the individuals themselves; (c) Rappaport and colleagues (1997) because the curriculum has not been evaluated (S. Rappaport, personal communication, November 12, 2007); and (d) Singer (1996), which was a University of London student dissertation, and neither a copy of this dissertation nor contact information for Singer was available (A. Knox, personal communication, November 21, 2007). Our search of peer-reviewed literature, therefore, resulted in the following articles: Bowen, 2000; Hickson & Khemka, 2004; Johnson et al., 2002; Khemka 2000; and Khemka et al., 2005.

In addition to this literature review, our research team investigated prevention programs currently implemented by service providers in the fields of sexual assault prevention and intellectual disabilities. To learn about current interventions, we contacted each of the 50 state sexual assault coalitions, as well as each of the 50 state developmental disabilities councils, which are funded by the federal Developmental Disabilities Act to coordinate policy and planning related to people with developmental disabilities in the states (Developmental Disabilities Assistance and Bill of Rights Act of 2000). Each organization was contacted by e-mail or telephone and was asked to nominate programs for inclusion in this review. Twenty-three sexual assault coalition staff and 32 developmental disabilities council staff responded.

This strategy resulted in no additional programs meeting our inclusion criteria, though some of the organizations nominated the programs that were determined in the literature search.

### *Standards for Review*

We evaluated only studies or programs with a clear focus on reducing sexual assault against women with intellectual disabilities. Four studies or programs met the criteria. The standards by which we reviewed each of the programs or studies varied, owing to the diversity of the program formats and research methods. In assessing the efficacy of each intervention, we examined: the focus on and presence of suspected risk factors for assault against women with intellectual disabilities, clear explanations that were intellectually appropriate, a test for relevant outcomes (e.g., decreased incidence of victimization, increased knowledge of personal safety strategies, or warning signs of abuse) versus consumer satisfaction, and the connection between theoretical and practical application. We also assessed the degree to which the prevention effort acknowledged other common challenges relevant to assault against women with intellectual disabilities (e.g., perpetrator likely being known to or the caregiver for the victim and the challenges associated with developing feasible safety plans).

### **Results**

This section delineates the results of our review of four programs aimed at sexual assault prevention for women with intellectual disabilities, highlighting the strengths and limitations of each. We evaluated three peer-reviewed studies and one intervention from the non-peer-reviewed literature. These studies include reports of interventions from Maryland; Wollongong, Australia; Melbourne, Australia; and New York state. Table 1 summarizes each of the four programs, highlighting the sample and methods used, significant findings, as well as strengths and limitations of the study or program. As the table indicates, participants of all four programs self-reported increased knowledge or skills related to sexual assault prevention. Only one of these programs, however, tested for outcomes other than participant satisfaction. Problems associated with the limited evaluation of the prevention programs are discussed in greater detail below.

**Table 1** Sexual Violence and Women With Intellectual Disabilities

Author, publication year, study or program aims	Sample and methods	Major findings	Study or program strengths and limitations
Arc of Maryland's Gender Violence Prevention Research and Development Team (1999): "Personal SPACE" Program	Sample size unstated; recommended group size: 8–10 women. Program curriculum (8-week course) developed by women with developmental disabilities, family members, and human service professionals. Two pilots held (1999, 2000); second included revisions based on feedback from first.	Research and development (RD) team developed pre- and posttests to measure program effectiveness, which assessed participants' attitudes, knowledge, and skills. According to RD team, participants' attitudes changed more than knowledge, which changed more than behavior.	<p>Strengths</p> <ul style="list-style-type: none"> <li>• Reports of increased self-determination by participants</li> <li>• Inclusive of women with developmental disabilities in planning process</li> </ul> <p>Limitations</p> <ul style="list-style-type: none"> <li>• Evaluation did not measure sexual assault outcomes</li> <li>• Inadequate guide to safety planning</li> </ul>
Bowen (2000): "Taking Care of Me"	Sample size unknown (but facilitator recommended doing program with 6–8 women); purpose was to produce a training program that prevented violence against women with mild intellectual disability who lived in community	Rated on a 3-point Likert scale by participants and facilitators (after completion of the program). All participants rated program positively, with 2 persons stating some material was very difficult. Facilitators rated the program as <i>excellent</i> , and participants' understanding of the material as <i>good</i> .	<p>Strengths</p> <ul style="list-style-type: none"> <li>• Integrated a variety of resources and curriculum material was clearly presented (visually)</li> </ul> <p>Limitations</p> <ul style="list-style-type: none"> <li>• Dense evaluation form may not effectively word or format questions to solicit response from people with intellectual disabilities</li> </ul>
Johnson et al. (2000): "Living Safer Lives"	Sample size: 25 participants with intellectual disabilities. Purpose: "to gain an understanding of how people with intellectual disabilities saw their sexual lives and relationships and to develop interventions from the research that would assist them to lead safer sexual lives."	Due to negative or fearful attitudes regarding sexuality and persons with intellectual disabilities, these individuals lead secret sexual lives that put them at greater risk for abuse. Sexual knowledge of individuals with intellectual disabilities gained primarily from friends, siblings, neighbors, lovers, and, less frequently, from parents.	<p>Strengths</p> <ul style="list-style-type: none"> <li>• Participants self-reported greater understanding of sexuality</li> <li>• Participants had the opportunity to share their sexual experiences, which may serve to empower them and increase self-efficacy</li> </ul> <p>Limitations</p> <ul style="list-style-type: none"> <li>• No information provided relative to how workshop content was developed</li> </ul>



**Table 1** Continued

Author, publication year, study or program aims	Sample and methods	Major findings	Study or program strengths and limitations
	Method: participatory action research; i.e., collecting narratives from potential participant groups (men and women with intellectual disabilities) and using this material, with the help of the same groups, to develop a curriculum. Curriculum presented in workshops, which consisted of eight workshops with 38 women with intellectual disabilities for 6 weeks.	Experiences of persons with intellectual disabilities with sex education reported as fragmented, embarrassing, and/or irrelevant to real life. In storytelling, men were more active participants in their sexuality; women often described sex as something that was done “to them”.	<ul style="list-style-type: none"> <li>• No detail regarding a test on this content for reliability, validity, or effectiveness</li> <li>• Only outcomes reported were various positive responses by training participants given via questionnaires</li> </ul>
Khemka (2000) “Increasing independent decision-making skills of women with mental retardation in simulated interpersonal situations of abuse”; Khemka et al. (2005) “An Effective Strategy-Based Curriculum for Abuse Prevention and Empowerment” (ESCAPE)	Sample: 36 women with diagnoses of “mental retardation.” Purpose: compare decision-making strategies to enhance decision-making skills of individuals with intellectual disabilities in interpersonal situations involving abuse. Pretest–posttest control group design used to compare effects of two training conditions and a control condition (decision-making training, self-directed decision-making training, and no training) on independent decision-making performance of women with intellectual disabilities	Participants in the self-directed decision-making training group provided more independent decision-making responses than did those in the decision-making training or control group (with little difference between the latter two groups on decision-making scores). Participants in self-directed decision-making training group held significantly more internal perceptions of control than participants in decision-making training and control groups (but participation in the decision-making training yielded a greater internal perception of control than did those in the control group). Findings suggest that ability of an individual with	<p>Strengths</p> <ul style="list-style-type: none"> <li>• Experimental design, including control group and evidence-based outcomes measures</li> <li>• Curriculum recognized and addressed the vulnerability of individuals with intellectual disabilities to various forms of abuse, finding its origin in a lack of empowerment, learned helplessness, and support systems that teach compliance.</li> </ul> <p>Limitations</p> <ul style="list-style-type: none"> <li>• Some factors that would likely influence effectiveness of an individual’s response to an abusive situation were not addressed, including level of physical dependence on others, communication difficulties, ability to cope with extreme stress.</li> </ul>

**Table 1** Continued

Author, publication year, study or program aims	Sample and methods	Major findings	Study or program strengths and limitations
	in response to simulated situations of abuse. The training was conducted in groups of 2 to 3 persons (with some participants opting for individual sessions). Individuals in the training conditions attended 10 trainings, occurring over several weeks; those in the control condition did not receive decision-making training but continued to receive regular agency services (social skills, sex education curricula).	intellectual disabilities to make an effective decision against abuse not only related to cognitive strategies being available but to factors related to self-motivation (establishing greater self-confidence, motivation to act, sense of empowerment).	<ul style="list-style-type: none"> <li>• Sample size amounted to treatment groups of only 12 individuals each</li> <li>• Screening of individuals with communication difficulties limits the applicability of findings to persons with more severe intellectual disabilities, who are likely the most vulnerable and most in need of effective intervention efforts.</li> </ul>

### *The Arc of Maryland's (1999) "Personal SPACE" Program*

In 1999, the Arc (formerly the Association for Retarded Citizens, an advocacy and service organization for people with developmental disabilities and their families) of Maryland created a violence prevention program entitled Personal SPACE (Safety, Planning, Awareness, Choice, Empowerment). The curriculum included a planning guide, lesson plans, and results of the program's evaluation. Intended for use with women with intellectual disabilities, the training covered a range of topics, including the definitions of sexuality, healthy relationships, sexual harassment, sexual assault, domestic violence, acquaintance assault, and safety planning.

Personal SPACE had several notable strengths. Most important, and consistent with the anti-sexual violence movement philosophy, the individual perspectives of women with intellectual disabilities were central to the program's planning and development. Also, Personal SPACE provided a framework that may be altered or refined for specific audiences and circumstances. The curriculum did not purport to be all inclusive or definitive

but claimed to serve as an initial effort in the colossal task of sexual violence prevention. The lesson plans outlined a framework for a prevention discussion with women with intellectual disabilities and included safety planning and acquaintance assault as training components.

To evaluate the program's effectiveness, the Arc of Maryland's Research and Development Team administered pre- and postprogram surveys, which measured attitudes, knowledge, and skills relative to sexual assault prevention (i.e., understanding of appropriate and inappropriate touch and ability to identify individuals to whom they should report). The survey responses, however, showed only a change in participant attitudes and knowledge, not their behavior (Arc of Maryland, 1999). It is notable that this evaluation did not measure actual experiences of sexual assault incidence following the program delivery.

In addition, the Personal SPACE program had limitations. One of the training's prevention strategies was a three-step safety plan, "Say no, get away, and tell someone." Although such a strategy was straightforward and practical, it

neglected the very real possibility that a victim with intellectual disabilities may be wholly unable to escape the dangerous situation. Furthermore, the suggested safety plan did not address the emotional coercion often present in acquaintance assault situations, as well as the dilemma that a woman with intellectual disabilities would face when the perpetrator had served as a care provider or trusted friend.

In summary, the Arc of Maryland's consumer-directed violence prevention program, Personal SPACE, offers a promising, yet limited, training template. The training proved successful in increasing participants' self-determination, which could serve as a protective factor against potential sexual assault. However, there was no evidence that the training effectively changed participants' behavior or, ultimately, prevented sexual assault.

### *Bowen's (2000) Violence Prevention Study, "Taking Care of Me"*

The peer-reviewed research literature on sexual assault prevention for women with intellectual disabilities offers an expanded understanding of the efficacy of various prevention efforts. Even so, research remains scarce; we found only three research teams (Bowen, 2000; Johnson et al., 2002; Hickson & Khemka 2004; Khemka, 2000; Khemka et al., 2005) who focused on preventing sexual assault, and two of these teams did not test for outcomes beyond participant satisfaction (Bowen, 2000; Johnson et al., 2002).

Isla Bowen, a researcher from Australia's Wollongong University, developed a violence prevention program for women with mild intellectual disabilities, titled "Taking Care of Me." Bowen conducted the intervention as a pilot program, and involved four groups of 6 to 8 women each. The program included four training modules: living in the community, awareness of violence, prevention of violence, and coping after victimization.

Taking Care of Me integrated a variety of resources and provided recommendations for the development of future interventions. Namely, Bowen posited that a curriculum intended to prevent the sexual assault of women with intellectual disabilities must serve as part of a comprehensive program that includes themes of assertiveness, social skills, relationships, and self-confidence training. Taking Care of Me also implemented personalized safety plans for participants, a preven-

tion strategy commonly used in the larger violence-services field to improve women's preparation when they encounter abusive situations (Anderson & Whiston, 2005; Brecklin & Forde, 2001).

The strength of the Taking Care of Me curriculum was its use of existing best practices in violence services, such as the emphasis on assertiveness and safety planning. In addition, the curriculum was comprehensive; it attended to the psychosocial context of women's lives. However, the curriculum evaluation did not measure specific outcomes, including knowledge, attitude, skill, or behavioral changes. Participants rated their satisfaction with the program, and the instrument that was used to gather participant responses was limited in construct validity: The evaluation tool asked questions using undefined terminology and did not target responses that generalize to behaviors (e.g. "Did you find the exercises useful?"). Considering the intended audience of women with intellectual disabilities, who often have receptive communication difficulties, the evaluation's language may have been unclear. Longitudinal outcomes, such as reduced incidence of sexual assault or changes in rape-avoidance behavior, were not evaluated. All of the Taking Care of Me participants were affiliated with service agencies, so the program's generalizability to women who were not receiving services, women living with their families, or women living independently is not possible.

A final limitation of Taking Care of Me pertained to the curriculum's omission of a primary risk factor: the likelihood that perpetrators are closely acquainted with the women with intellectual disabilities whom they abuse. The Taking Care of Me curriculum neglected the common and yet complex situation in which women are assaulted by their caregivers or otherwise trusted individuals (Andrews & Veronen, 1993; Carlson, 1997; Powers et al., 2002; Sobsey & Doe, 1991).

### *Johnson et al.'s (2001) Disability and Health Program, "Living Safer Lives"*

In 2001, scholars from LaTrobe University in Melbourne, Australia, designed "Living Safer Lives" as a participatory action research project. The purpose of the project was to understand people with intellectual disabilities' perceptions of their sexuality and relationships. The researchers intended to develop research-based interventions to increase the safety of their decision making



related to sexuality and relationship issues (Johnson et al., 2002).

After compiling personal narratives from 25 women and men with intellectual disabilities about their sexual and relationship experiences, the researchers developed “Living Safer Lives.” The intervention consisted of a 6-week workshop, initially piloted with 38 women with intellectual disabilities, during which the previously developed narratives served as the basis for discussion about safe and fulfilling sexual relationships as well as assault prevention. Details about the workshop procedures or activities were not reported.

Living Safer Lives had several strengths. The participatory action research process offered real-life examples of sexual experiences of people with intellectual disabilities and then used the narratives to inform the intervention. For example, the researchers identified several unifying themes throughout the narratives: Sex education was fragmented, irrelevant, and/or embarrassing; some individuals with intellectual disabilities led secret sexual lives that put them at greater risk for abuse because of a climate of fear, stigma, or negativity surrounding their sexuality; and participants were essentially at the mercy of care providers for the education they received about sexuality and their consequent freedom of sexual expression. These specific findings highlighted the importance of general sexuality education and the critical roles that care providers and support systems played in the lives of people with intellectual disabilities. Furthermore, the Living Safer Lives program aimed to increase individual empowerment, which some researchers identify as a protective factor (Roze & Koss, 2001), by providing a space for people with intellectual disabilities to discuss aspects of their sexual identities.

The central limitation of Living Safer Lives was the program’s lack of evaluation apart from participant satisfaction surveys. Without testing for additional outcomes, such as changes in participant behavior or decision-making strategies relevant to sexual behavior, determining the true effectiveness of the program was difficult.

#### *Khemka and Hickson’s (2000, 2005) Decision-Making Study and Program*

To date, Khemka and Hickson’s (2000, 2005) program, entitled “Increasing Independent Decision-Making Skills of Women With Mental

Retardation in Simulated Interpersonal Situations of Abuse,” remains the only published intervention that measured outcomes and used an experimental design. The research team created the curriculum (2000) and then refined and evaluated it (Hickson & Khemka, 2004; Khemka & Hickson, 2000, 2005). The project examined individuals’ decision-making abilities by presenting them with vignettes that posed interpersonal psychological, physical, and sexual abuse situations. A pretest assessed the 36 participants’ decision-making abilities. The authors then randomly assigned the sample into treatment and control groups. Participants in the treatment group responded to the various vignettes related to abuse after undergoing decision-making training. The authors used three different scales to evaluate decision-making performance: the Social-Interpersonal Decision-Making Video Scale, the Self Social Interpersonal Decision-Making Scale, and the Nowicki-Strickland Internal-External Scale (Khemka, 2000).

The self-directed decision-making training approach (vs. those in the control group) proved most effective in increasing participants’ ability to make decisions in abusive situations. This finding suggests that women with intellectual disabilities effectively make decisions in abusive situations, not only on the basis of cognitive strategies but on factors related to self-direction, such as increased self-confidence, motivation to act, and a sense of empowerment. Participants in the self-directed training group had more internal perceptions (locus) of control, a key variable in decision making in dangerous situations (Khemka, 2000).

Building from their earlier work, Khemka and her colleagues (2005; Hickson & Khemka, 2004) developed and evaluated an abuse-prevention curriculum for disability service providers, entitled “An Effective Strategy-Based Curriculum for Abuse Prevention and Empowerment” (ESCAPE). The ESCAPE project outlined a framework that added specificity to the decision-making process tested previously. This framework was divided into four parts: framing the problem, generating alternatives, evaluating anticipated consequences of possible alternatives, and choosing a course of action (Hickson & Khemka, 2004; Khemka et al., 2005).

The ESCAPE curriculum expanded the scope of Khemka’s (2000) earlier research by adding three new dimensions: (a) concepts necessary for differentiating between abuse and healthy interaction; (b) the emotional and cognitive aspects of decision

making in situations of abuse; and (c) a support group that provided participants an opportunity to connect decision-making strategies with their own real-life experiences (Hickson & Khemka 2004; Khemka et al., 2005).

The improvements in the 2005 ESCAPE curriculum, over the 2000 study, appear in three units: knowledge of abuse and empowerment, decision-making strategy training, and structured support group. After completing the first two (out of the three) units, participants showed significant positive differences from the control group on the knowledge of abuse concepts, empowerment, and self-determined decision making. Intervention participants demonstrated statistically significant post-test gains in all three measures, although effect sizes were not reported (Khemka et al., 2005).

Although the ESCAPE curriculum and research was innovative and rigorous, it also had limitations. Only about half of participants were able to define certain concepts related to consent and abuse after the training. Although participants who received the intervention were able, posttraining, to define these concepts at a significantly higher rate than the control group, variability remained among the former group in their ability to give adequate definitions of abuse concepts. Even fewer participants were able to accurately define verbal abuse and consent. The authors noted that, although women in the intervention group showed significantly more decision-making skills in simulated abuse situations, their level of ability (as measured by production of effective responses only 58% of the time) implied a skill level well below mastery (Khemka et al., 2005). As with other studies, this project did not address the challenges that women with intellectual disabilities face when victimized by someone they know, trust, or depend for their care needs. Furthermore, the intervention did not evaluate the most salient issue of all: whether the program actually reduced sexual assault victimization.

Despite its limitations, the ESCAPE study laid the groundwork for development in this critically needed area. Significant strengths include the experimental design and evaluation of outcomes. In addition, the ESCAPE curriculum addressed a critical component of sexual assault prevention among women with intellectual disabilities—*individual empowerment*, which the researchers defined as perceptions of control and self-efficacy. Significant posttest differences between the control and

treatment groups on the Empowerment Scale revealed that this program effectively addressed empowerment: The control and treatment groups obtained approximately 53% and 64% of the maximum empowerment score, respectively (Khemka et al., 2005).

In summary, the sexual violence prevention programs designed for participants with intellectual disabilities have shortcomings. However, all of these programs are innovative, appear promising, and can inform future prevention efforts for women with intellectual disabilities. Furthermore, given the lack of programming and research in this area, all of these prevention efforts are noteworthy. The one program with tested outcomes other than participant satisfaction (Khemka et al., 2005) may serve as an especially useful starting point for additional work, offering promising findings regarding the prevention of sexual assault against women with intellectual disabilities.

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## Discussion

We have demonstrated several points in the previous sections. First, women with intellectual disabilities are at increased risk for sexual violence victimization (Sobsey & Doe, 1991; Tyiska, 1998). Second, few sexual assault and developmental disabilities service agencies or researchers have been able to devote the resources needed to study and reduce the incidence of sexual violence against women with disabilities. Third, although service providers and researchers have offered important preliminary contributions, much work remains before an evidence-based sexual assault prevention program exists for women with intellectual and developmental disabilities.

### *The Need to Incorporate Prevention Science Into Prevention Practice*

Our review of the current prevention research and interventions, which stretched well beyond the programs summarized in the previous section, suggests that few sexual assault prevention efforts geared toward victims with intellectual disabilities exist. Despite the number of women with intellectual disabilities who suffer experiences of sexual violence, we found fewer than 100 articles about this important topic in the scientific literature. Of the programs and studies we found, few had been rigorously evaluated and most were not evaluated at all.

The shortage of evidence-based programs to prevent sexual assault against women with intellectual disabilities is illustrative of a larger problem prevalent throughout prevention efforts in the social services: the gap between prevention practice and prevention science. Too seldom do program developers consult the scientific literature or incorporate rigorous evaluation into their program planning and implementation. Likewise, researchers often delve into a program evaluation without fully understanding the goals and intentions of the program developers (Botvin, 2004; Morrissey et al., 1997).

The limited crossover between research and practice as relevant to programs designed to prevent sexual assault against women with disabilities is likely the result of a convergence of several factors. These include the logistical difficulties of rigorously evaluating such interventions, particularly over the long term, as well as the sometimes prohibitively high cost of program evaluation. However, without conducting a stringent evaluation of what efforts are successful in reducing the incidence of sexual assault against women with intellectual disabilities, program developers are designing curriculums that seem to have face validity and hoping for the best. The worry of implementing prevention programs without evaluation or evidence is that they may be, at best, ineffective and a waste of limited resources, or, at worst, harmful to women.

### *Future Research Needs*

Existing research on sexual violence prevention for women with intellectual disabilities highlights several areas for future research. Existing promising interventions require rigorous evaluation. Related to the limited sexual assault prevention research pertaining to the nondisabled population, longitudinal studies are needed to help determine the efficacy of particular interventions. Specifically, future evaluations should include long-term postintervention follow up with participants to measure the incidence of assault victimization.

Furthermore, future research should incorporate variables that are appropriate to sexual assault prevention for people with disabilities. To date, rape-myth acceptance remains the most commonly used outcome measured in sexual assault prevention research (Breitenbecher, 2000). However, the empirical link between rape-myth acceptance and

sexual assault perpetration behavior is unclear and not fully established. Moreover, regardless of the utility of measuring rape-myth acceptance, research into sexual assault prevention for women with disabilities should reflect not only existing research on sexual violence prevention for the general population but the specific concerns of women with intellectual disabilities.

Future studies should also address the methodological problems common to sexual assault prevention research, several of which may prove even more problematic when considering victims with disabilities. For example, the validity of prevention studies that fail to address social desirability bias is particularly threatened when participants have intellectual disabilities. This is the case because people with intellectual disabilities have been shown to demonstrate substantially higher rates of social desirability bias than nondisabled people (Shaw & Budd, 1982), which may be linked to their efforts to pass as nondisabled (Edgerton, 1967).

### *Key Aspects of a Comprehensive Prevention Program*

The need for rigorous evaluation of prevention programs represents only one of the many tasks before researchers and service providers committed to ending sexual assault against women with intellectual disabilities. Another concern is the fact that most current sexual assault prevention programs for women with intellectual disabilities focus on one aspect of sexual violence prevention, rather than taking a more comprehensive approach. Programs may target assertiveness, sexual education, or staff education alone, but few address a combination. However, although we do not have the necessary evaluation data to fully understand the long-term impact of any of these programs, we suspect that training that targets a single issue will be less effective than a comprehensive approach, given the complexities of both sexual assault against women with intellectual disabilities and the factors that elevate their risk of assault.

We also note that it is likely that teaching women with intellectual disabilities to resist sexual assault has limited potential for ending this pervasive form of violence. The cognitive and often accompanying physical challenges that increase their vulnerability make their resistance less likely to succeed. A more comprehensive approach,

which engages the entire service system that supports women with intellectual disabilities and their families, is likely necessary. Furthermore, such a systemic approach would likely need to incorporate a host of concerns, including the reliance of these women on care providers and family, limited material resources, and limited communication abilities. As Powers et al. (2002) noted, women with disabilities themselves offer an array of strategies that would prevent the abuse they experience, including having back-up staff and a selection of staff, as well as access to crisis hotlines, emergency transportation, and a host of other strategies. However, for some women, and particularly those with the most severe impairments, even these strategies will have limited efficacy.

As a relevant evidence base remains largely unavailable, program developers intending to prevent sexual violence against women with intellectual disabilities should draw on the prevention science literature and what is known about effective prevention programs in general. Morrissey et al. (1997) have developed a set of evidence-based criteria for effective programs, all of which should be applied to the prevention of sexual violence against women with intellectual disabilities.

- *Comprehensive.* The program should involve all the systems that have a direct impact on the participants. For a woman with intellectual disabilities, this may include family, friends, partners, caretakers, case workers, therapists, or employment support professionals.
- *Theoretically based.* The program should be based on a clear theoretical model that explains the problem of sexual violence against women with intellectual disabilities. Applying a theoretical foundation encourages consistency throughout all aspects of the program.
- *Intensive.* The program should offer sufficient contact between the trainer and participants. For participants with intellectual disabilities, short and frequent sessions that use a variety of teaching methods may prove most effective.
- *Tailored to the needs of the participants.* The program should account for participants' age, communication abilities, care needs, cognitive functioning, and developmental level. The material should be intellectually appropriate and flexible enough to accommodate the varying communication and learning needs of the participants.

- *Focused on skill development.* The program's curriculum should be active and provide hands-on experiences to increase participants' skill level. The program should offer practical and feasible tools that are relevant to real life for women with intellectual disabilities.
- *Sufficient follow up.* In general, the positive effects of prevention programs wane over time without appropriate follow up. Participants with intellectual disabilities may need to attend supplemental sessions (i.e., "booster" sessions) while the program is continuously evaluated.
- *Consumer ownership.* The people for whom the program is intended (women with intellectual disabilities) should be involved in all levels of the program development, including planning, implementation, evaluation, and advisory boards.

### *Advocating for Policy Changes*

Disability and sexual violence prevention service providers should also consider the design of their prevention efforts within the larger context of disability, women's rights, and discrimination. Limited evidence suggests certain system reform measures can decrease violence against women with disabilities. Examples include staff screening with criminal checks, policies mandating that offenders are not only dismissed but also charged with a crime, legal obligations for institutions to protect clients, and decreasing isolation in care facilities (Denno, 1997; Kempton & Kahn, 1991; Nosek et al., 2001). Although disability advocates may be currently working to address each of these issues in isolation, partnering with violence prevention trainings and sexual assault coalitions remains a critical strategy, as has been noted for effective prevention programs in general (Kellam & Langevin, 2003).

Sexual assault prevention and disability advocates must commit to a collaborative fight against such violence that draws on the advances of each field. Doing so not only reaps the benefits of both areas of study but serves to curtail the notion of "victim blaming" that may be reinforced by a program geared specifically and only for women with intellectual disabilities (Breitenbecher, 2000; Wacker et al., 2008). For example, we propose that disability-focused prevention efforts remain gender specific, consistent with the approach to the prevention of sexual violence against nondisabled women and men.



In summary, as sexual violence against women with intellectual disabilities continues to pose a pervasive and largely overlooked problem, disability and sexual assault prevention advocates must coordinate their resources and efforts to develop an evidence-based program that will limit such violence. Interventions must be as multifaceted as the lives of women with intellectual disabilities, incorporating the many service systems and individuals involved to meet their complex needs. Similarly, sexual violence practitioners must feel necessarily concerned with the needs of women with disabilities, as no woman is truly safe if she is not assured that her most vulnerable peers enjoy the same protection.

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Received 6/6/08, first decision 10/7/08, accepted 10/23/08.

Editor-in-Charge: Steven J. Taylor

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