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# COMMUNITY DEVELOPMENT OF A SEXUAL HEALTH EDUCATION PROGRAM FOR PERSONS WITH INTELLECTUAL DISABILITIES: A CASE STUDY

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COMMUNITY DEVELOPMENT OF A SEXUAL HEALTH EDUCATION PROGRAM FOR  
PERSONS WITH INTELLECTUAL DISABILITIES: A CASE STUDY

(Spine title: Sexual Health Education for Persons with Intellectual Disabilities)

(Thesis format: Monograph)

by

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2

Graduate Program in Health and Rehabilitation Sciences

A thesis submitted in partial fulfillment of the requirements for the degree of  
Master of Science

The School of Graduate and Postdoctoral Studies  
The University of Western Ontario  
London, Ontario, Canada

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THE UNIVERSITY OF WESTERN ONTARIO  
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Community Development of a Sexual Health Education Program for  
Persons with Intellectual Disabilities: A Case Study

is accepted in partial fulfillment of the  
requirements for the degree of  
**Master of Science**

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## Abstract

This thesis documents a case study of the development of a community based sexual health education resource for persons with intellectual disabilities and those who live and work with them. *Able to Live, Able to Love* is a resource developed by the *Relationship, Sexuality, and Safety Education Network of Guelph- Wellington and Dufferin Counties*. The program consists of thirteen units and addresses issues including: human anatomy, intimacy, feelings, sexual expression, consent, and safety. *Able to Live, Able to Love* encourages positive communication and promotes persons with intellectual disabilities to celebrate healthy, respectful, and safe relationships. The case study inquired into the question: "What is the process by which stakeholders in the *Relationship, Sexuality, and Safety Education Network of Guelph-Wellington and Dufferin Counties* developed a sexual education program for persons living with intellectual disabilities?" The thesis documents the historical development of the sexual health education resource, and enablers, challenges, and motivations to the process, as conveyed by 8 key stakeholders. The findings of the thesis contribute to knowledge about the development process that may be of use for other community agencies wishing to develop similar projects. This study may also have important implications for persons with ID, those who live and work with them as well as educational institutions and curriculum developers.

**Keywords:** Sexuality, disability, sexual education, sexual health education, intellectual disability, developmental disability, case study

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## **Chapter One: Introduction**

Since the 1960s, the social climate for persons with intellectual disabilities has dramatically changed. Traditionally, persons with disabilities and mental health issues were routinely committed to institutions and denied privacy, social interaction, and human rights. However, in the past 30 years, persons with intellectual disabilities have, for the most part, lived outside of large institutions and hospitals and remained in community settings. There has been widespread recognition that the principle of inclusion is a more humane and appropriate approach to assisting those with special needs to develop social skills and healthy relationships. Today, many would expect individuals with intellectual disabilities to live in homes and to participate in the community. Though important strides have been made in the inclusion of persons with intellectual disabilities with respect to social services, support for issues of sexuality have still been largely ignored.

Sexuality and disability has only recently been considered a worthy area of discussion and research. Historically, persons with intellectual disabilities were not acknowledged to have a capacity for sexual relationships. Many persons with disabilities were considered on a black and white spectrum: they were viewed as either sexually deviant or asexual (Aylott, 1999). Though this dichotomy existed, there was agreement that sexuality was not appropriate for this population and thus persons living with intellectual disabilities did not need sexual education. In the 1970s, scholarly literature began to recognize that persons with disabilities were sexual beings and had sexual needs that were not being acknowledged or met (Tarnai, 2006; DiGiulio, 2003). Traditionally, forced sterilization was a highly acceptable method of

suppressing sexuality and reproduction in persons with intellectual disabilities (Servais, 2006). Also in the 1970s, nearly 80% of parents were supportive of sterilization for their children with ID as a means of birth control (Aunos & Feldman, 2002). Though sterilization still happens today, it was not until recently, that a more 'liberal' view of the sexuality of persons with intellectual disabilities has emerged.

The World Health Organization and the Government of Canada are recognizing new liberal attitudes towards the sexuality of persons with intellectual disabilities. For example, in 2005, the 58<sup>th</sup> World Health Assembly recognized the need to strengthen health services for persons living with disabilities as well as added the needs of persons with disabilities to the global sexual health agenda (World Health Organization, 2005). In 2008, the Public Health Agency of Canada revised the *Canadian Guidelines for Sexual Health Education* to recognize the unique needs of persons with intellectual disabilities (Public Health Agency of Canada, 2008).

More positive attitudes towards sexuality have also been seen through the establishment of nationally recognized sexuality organizations such as SIECCAN (Sexual Information and Education Council of Canada) and SIECUS (Sexuality Information and Education Council of the United States), which have been established to promote positive approaches to sexuality for all persons. SIECUS states, "that sexuality is a fundamental part of being human, one that is worthy of dignity and respect" and supports the rights of all people to have "accurate information and comprehensive education about sexuality and sexual health services" (SIECUS, 2009, para 2).

## Background

*Able to Live, Able to Love*, is a comprehensive sexual health education resource for persons with intellectual disabilities and those who live and work with them. Following an identified need in the community, an ad hoc committee called *The Relationship, Sexuality, and Safety Education Network of Guelph-Wellington and Dufferin Counties* came together to create the resource for persons with intellectual disabilities. *The Relationship, Sexuality, and Safety Education Network of Guelph-Wellington and Dufferin Counties*, comprised of many different social services agencies and parents of children with intellectual disabilities, applied for an Ontario Trillium Foundation grant to hire a consultant to develop the resource. As one of the writers hired by the consultant, I have been involved in the development of the resource since early 2008.

Following my recruitment, I became deeply engrossed in the development of *Able to Live, Able to Love*. I read extensively on the challenges that persons with intellectual disabilities faced in accessing accurate and supportive information about sexual health and became exceptionally concerned. As will be further expanded in chapter two, myths, misconceptions, and abuse are widely reported with this population and have contributed to the access to sexual health education resources in the past. In addition, after reviewing sexual health education resources available for persons with intellectual disabilities, the results were largely disappointing. As an outsider to the community, I was inspired by *The Relationship, Sexuality, and Safety Education Network of Guelph-Wellington and Dufferin Counties'* initiative to empower people with intellectual disabilities in their own community. I thought it would be important to contribute to knowledge by undertaking a case study to examine the process by which a

sexual health education resource for persons with intellectual disabilities was developed in Southwestern Ontario.

### **Purpose**

Thus, the purpose of the research is to undertake a case study that documents the community development of a sexual health education resource, *Able to Live, Able to Love*, for persons with intellectual disabilities. The information gained from the study may be beneficial to various community organizations interested in developing similar programs or for families and/or support workers of persons with intellectual disabilities interested in sexual health education for persons with intellectual disabilities.

### **Research questions.**

The guiding question of the research is "What is the process by which stakeholders in the *Relationship, Sexuality, and Safety Education Network of Guelph-Wellington and Dufferin Counties* developed a sexual education program for persons living with intellectual disabilities." Subquestions of the study include:

- Why was the program developed?
- How was the need for the program identified?
- How was the program developed? What helped the process along? Were there any challenges?
- What are stakeholder perceptions of the strengths of the program?
- What are stakeholder perceptions of potential limitations?
- How will the program be used in the community?

- How was the community involved in the design and development of the program? (i.e. persons with disabilities and those who live and work with them)

## **Defining Key Terms**

### **Intellectual disability.**

Before further discussing sexuality and persons with intellectual disabilities, a working definition of 'intellectual disability' (ID) is presented. The American Association on Intellectual and Developmental Disabilities (2009) defines an intellectual disability (ID) as a disability that causes significant limitations both in intellectual functioning and adaptive behavior. Specifically, persons with ID experience difficulties surrounding conceptual, social, and practical skills. According to the Public Health Agency of Canada (2005), persons with intellectual disabilities have unique needs for information processing and may have difficulties learning, problem solving, and planning in a way that affects the demands of everyday life. Though intellectual disability will be the preferred term used in this study, other terms often used interchangeably with intellectual disability include: cognitive impairment, mental challenge, mental handicap, mental retardation, and developmental disability (Public Health Agency of Canada, 2005).

Some definitions of 'intellectual disability' require that the disability be congenital (present from birth) or present before 18 years of age, rather than acquired through disease or injury (Public Health Agency of Canada, 2005; Special Olympics, 2004; The American Association on Intellectual and Developmental Disabilities, 2009). The severity of intellectual disabilities can range from mild to profound and are measured in

terms of IQ (intelligence quotient) scores. Persons with an IQ range from 50 to 70 are considered to have a mild intellectual disability, persons with an IQ range from 35 to 55 are considered to have a moderate intellectual disability, persons with an IQ range from 20 to 40 are considered to have a severe intellectual disability, and persons with an IQ below 40 are considered to have a profound intellectual disability (Algozzine & Ysseldyke, 2006). The use of the IQ test has been highly contested as a means of labeling persons with intellectual disabilities and will not be used in this study.

For the purpose of this study, the researcher will use the simple and inclusive definition as presented by Community Living Ontario: an "intellectual disability... is a disability that significantly affects a person's ability to learn and use information" (2008). Thus the origin (congenital or acquired) or severity (IQ range) of the disability is considered insignificant for this study.

### **Sexual health.**

Sexual health is often defined as the absence of sexually related diseases or infirmities. Murphy and Elias (2006) suggest, "sexuality should be considered in a context beyond genital sex," it should also include body image, social relationships, and socialization (p. 399). This is consistent with the view of the World Health Organization, the Pan-American Health Organization (PAHO) and the World Association of Sexology (2001) that define *Sexual Health* as:

[T]he experience of the ongoing process of physical, psychological, and socio-cultural well being related to sexuality. Sexual health is evidenced in the free and responsible expressions of sexual capabilities that foster harmonious personal and social wellness, enriching individual and social life. It is not merely the absence of dysfunction, disease and/or infirmity. For Sexual Health to be attained and maintained it is necessary that the sexual rights of all people be recognized and upheld (as cited in Magnus Hirschfeld Archive for Sexology, para 1).

Adopting this definition of sexual health is important to consider when providing sexual health education, especially when educating more vulnerable persons who may not understand the deep emotional and social impact sexuality can cultivate; thus, simply supplying 'the facts' is not enough (Kempton & Stiggall, 1989; Sugar, 1990).

For the purpose of this study, the researcher will adopt the World Health Organization, the Pan-American Health Organization (PAHO) and the World Association of Sexology's definition of sexual health that is inclusive of the physical, physiological, social, and emotional aspects of sexuality and recognizes the sexual rights of all people.

### **Presentation of Thesis**

Following this chapter introducing the study, chapter two presents a review of the literature on sexual health education resources for persons with intellectual disabilities. Chapter two presents the literature in terms of the challenges to sexual health education programming for persons with intellectual disabilities. In addition, chapter two reviews currently available sexual health education resources for persons with intellectual disabilities, as well as their strengths and limitations. Chapter three outlines the case study methodology, the parameters of the case, research methods, and the philosophical assumptions of the researcher. Chapter four presents the findings of the study by outlining the historical development of the sexual health education resource, highlighting enablers, challenges, and motivations to the development process and the strength and limitations of the resource. Chapter five discusses the implications of the process of development by drawing on the findings and current literature on sexual health education for persons with ID. The implications for the development of



future programs in this area are also discussed with suggestions for additional research in this area.

## **Chapter Two: A Review of the Literature**

This chapter presents a review of the literature relevant to the research. First literature related to the background and rationale for sexual health education programming for persons with intellectual disabilities is discussed. This section examines how myths and misconceptions, sexual attitudes, sexual assault and abuse, and a growing trend towards community living has had a substantial impact on sexual health education programming for persons with ID. Second, this review highlights currently available sexual health education resources for persons with intellectual disabilities, their strengths and limitations, and why a comprehensive sexual health education resource for persons with ID is important. This review identifies how currently available resources have not entirely addressed the needs of persons with ID.

### **Sexual Health Education Programming for Persons with ID**

#### **Background and rationale.**

Many organizations and researchers agree that it is essential to provide comprehensive and accurate sexual health education to individuals of all ages with ID (Kempton & Stiggall, 1989; Whitehouse & McCabe, 1997; Wolfe & Blanchett, 2003; Irvine, 2005; Murphy & Young, 2005; Sweeney, 2007). A number of studies have demonstrated that the sexual knowledge of persons with ID is generally limited and much lower than the general population (McCabe & Schreck, 1992; McCabe & Cummins, 1996; McCabe, 1999). For example, McCabe (1999) found that in an evaluation of persons with ID's sexual knowledge, scores obtained were significantly lower than that of the general population in all categories of the evaluation, including knowledge about: friendship, dating and intimacy, body part identification, menstruation, sexual

interaction, contraception, pregnancy, sexually transmitted diseases, masturbation and homosexuality. In addition, Galea, Butler, Iacono and Leighton (2004) report that in general, persons with ID score lowest when assessing sexual knowledge in the areas of; puberty and menstruation, menopause, sexually transmitted infection and sexual health screening, sexual rights, legal issues and assault, and especially contraception. Similarly, Leutar and Mihokovic (2007) found that study respondents with ID had the lowest level of knowledge in areas of contraception, pregnancy, and sexual misuse and abuse.

### **School-based sexual health education.**

In Canada, the school system is the primary institution responsible for sexual health education. The *Canadian Guidelines for Sexual Health Education* states:

Since schools are the only formal educational institution to have meaningful (and mandatory) contact with nearly every young person, they are in a unique position to provide children, adolescents, and young adults with the knowledge and skills they will need to make and act upon decisions that promote sexual health throughout their lives (Public Health Agency of Canada, 2008, p. 19).

In Ontario, sexual education curricular goals are specified under the *Healthy Living: Growth and Development* stream; however there is little regulation and implementing the curriculum is done "at the discretion of teachers, schools and/or school boards" (Connell, 2005). Due to the lack of standardization in implementation, much variation exists across the provinces and within the provinces.

Although views of sexuality education are becoming more liberal in terms of curricular goals (McKay, 1998), these views are not as readily translated into practice (Irvine, 2005). Most sexual education programs in the school systems have been

determined successful when a decrease in undesirable behaviours such as infection transmission, and unwanted pregnancies are observed (Allen, 2005). However, many recent studies have agreed that other aspects of sexual education are also very important to communicate to adolescents (Buston & Wight, 2004; Allen, 2005; Connell, 2005; Fine & McClelland, 2006; Gordon & Ellington, 2006; Hilton, 2007). Current curriculum extensively addresses the issue of STIs, however gives little attention to issues such as intercourse, masturbation, homosexuality, parenthood, and feelings and emotions (Allen, 2005). After arguing in 1988 for curriculum to address issues of sexual desire for women, Fine and McClelland (2006) assert that it is still not being addressed 20 years later. The authors state:

Today we can 'google' for information about the average young woman's age of 'sexual debut,' if she used a condom, got pregnant, the number of partners she had, if she aborted or gave birth, and what the baby weighed. However, we don't know if she enjoyed it, wanted it, or if she was violently concerned [about it] (Fine & McClelland, 2006, p.4).

Connell's (2005) evaluation of Ontario school-based sexual education also concluded that the dominant discourses found were 'victimization' (females as vulnerable to potential male predators) and 'morality' (choosing abstinence). When curriculum espouses the view that sexuality is a problem that needs to be managed and is not part of healthy development, Allen (2005) suggests that students begin to develop fearful attitudes of sex. Gordon and Ellington (2006) found that when surveying high school aged students, many believed that lessons were designed to teach that sexual behaviour was dangerous. Such attitudes cause students to feel uncomfortable with lesson plans and contribute to conditions in which students are less likely to ask questions and

contribute to class discussions and activities (Buston & Wight, 2004; Hilton, 2007). It has also been shown that promoting sexuality as dangerous has not been effective in ensuring abstinence (Murphy & Elias, 2006). In the United States, Brückner and Bearman (2005) sought to discover the effectiveness of “virginity pledges” in abstinence-only curricula that require young persons to vow they will remain virgins until marriage. The participants reported having delayed “sexual debut,” however 88% still engaged in sex before marriage.

Whether or not negative attitudes towards sexuality are consciously articulated, adolescents are finding that because of it, school-based curriculum are not meeting their needs (Allen, 2005; Cohall et al., 2007). Williams and Bonner (2006), found that young women were more satisfied with sexual education they had received from friends, books, and the Internet rather than from parents, schools, clinics, and doctors. Information that they had sought for themselves was more helpful than what they were provided with. Thus, some research has revealed limitations of school-based sexual education in terms of scope, attitude, and applicability to a young person’s life.

In 2009, the Ontario Curriculum Grades 9 and 10 as outlined by the Ministry of Education and Training highlighted specific expectations for healthy growth and sexuality in schools. By the end of Grade 10, students should be able to:

- Describe environmental influences on sexuality;
- Explain the effects of choices related to sexual intimacy (i.e. STDs, HIV/AIDS);
- Identify available information and support services related to sexual health concerns;
- Demonstrate understanding of how to use decision-making skills effectively to support choices related to responsible sexuality (p. 15).

These goals are a very good starting point, however they are quite vague and fail to identify positive aspects of sexuality and relationships. In many schools, extra sexual

health education resources are available to teachers, however what is covered in sexual education classes continues to vary between school boards, schools, and classrooms.

Apart from students who receive sexual health education through the school system, there are many marginalized youth who are not part of the mainstream school system. Adolescents of particular concern are teenage dropouts and some persons with ID (Fine & McClelland, 2006; Lall, 2007). Although some persons with mild ID are part of inclusive school settings, many do not report learning about sexual health education at school (Coren, 2003). Even if persons with ID are exposed to sexual health education in a mainstream classroom, the material may not be presented in a way that is easy for them to comprehend and/or translate into their everyday lives. Students with ID may be particularly intimidated to ask questions and unsure where else to obtain information if not provided in school (Sugar, 1990).

Fine and McClelland (2006) suggest that when adolescents are not part of a formal schooling system they are at further risk for unsafe sexual practices and unhealthy sexual views as they may be more vulnerable to sexual myths and misconceptions. For example, Rousso (2001) reports that the correlation of school dropouts and teen pregnancy rates are particularly high for young women with ID. Such students are also less likely to receive at-home sexual health instruction from parents (Coren, 2003). Thus, persons with ID are more likely to a) not receive sexual education at all, or b) receive sexual education from school or at home that does not appropriately meet their needs.

Weber and Bennett (2004) report that in Ontario special education classes, important topics to cover with students include: "physical health, hygiene, eating, and

dressings, use of the toilet, physical appearance" (p. 125). However, after reviewing databases, curriculum materials and consulting with the reference librarians at the Faculty of Education at the University of Western Ontario and the Ontario Institute for Studies in Education at the University of Toronto, guidelines for sexual education in special education classrooms in Ontario schools could not be found. Sexual health education classes for special education classrooms in Ontario are developed locally by teachers and schools (R. Heydon, personal communication, November 13, 2009). As such, without programs available in the secondary school system, social services and community organizations are placed with the burden of providing these resources to persons with ID.

This first part of the literature review examined and highlighted apparent gaps in the sexual health education of persons with ID within the Ontario school system. The next part of the literature review discusses challenges and barriers for community agencies providing sexual health education to persons with ID.

### **Challenges to Providing Sexual Health Education for Persons with ID**

Though sexual health education programs have been shown to be effective in fostering knowledge acquisition surrounding sexual health in persons with intellectual disabilities (Garwood & McCabe, 2000; Lindsay et al, 1992) creating effective and appropriate sexual health education resources is still a relatively new endeavour. Many sexual health education resources currently available are not comprehensive in content (Whitehouse & McCabe, 1997), do not justify the educational approaches or methods adopted (Grieco, McLaren, & Lindsay, 2006), are not accessible to individuals or

community organizations due to high costs [i.e. Couwenhoven, 2001) and are not accessible in Ontario (i.e. Frawley, Johnson, Hillier & Harrison, 2003; Sheppard, 2006).

### **Myths and misconceptions.**

Irvine (2005) suggests that the major barrier to sexuality for persons with disabilities is not the disability itself, but the myths and misconceptions of the community. Until recently, it was a prominent belief that persons with ID were asexual (Kempton & Stiggall, 1989; Aunos & Feldman, 2002). Today it is better accepted that although individuals may vary in terms of reproductive ability, sexual desire, and sexual response, persons with ID have the "same requirements for love, affection, and fulfilling interpersonal relationships as does any other person" (DiGiulio, 2003, p. 58). In fact, McCabe (1999) reports that persons with ID indicate a higher level of sexual need than the general population. However, due of a lack of exposure to sexual information, persons with ID can often become overwhelmed when presented with issues of sexual health (Irvine, 2005).

Chiver and Mathieson (2000) suggest that a biological discourse is prominent when considering sexual education and persons with disabilities; men are viewed as having desires that need to be controlled and women are viewed as vulnerable and in need of protection. Thus, support staff frequently address male sexual problems and urges by a) referring to a sexual education program to stop the problem; b) ignoring the problem and hope it goes away; or c) finding a sex worker to relieve desires (Chiver & Mathieson, 2000).

Also, persons with ID are more susceptible to myths and misconceptions surrounding sexual health information. As a result, the sexuality information many



persons with ID receive is more likely to be shaped through negative experiences and inaccurate information (Swango-Wilson, 2008). Kempton and Stiggall (1989) state that,

[T]he restrictions traditionally imposed upon these individuals have both ensured their ignorance and have, at the same time, prevented the accumulation of adequate, orderly knowledge about their true socio-sexual potential at successive stages of growth and learning (p. 204).

### **Sexual attitudes.**

According to numerous scholars, anxiety regarding the sexuality of persons with ID has historically created barriers to appropriate education (Van Dyke, McBrien & Sherbondy, 1995; Irvine, 2005; DiGiulio, 2003; Sweeney, 2007). Sweeney (2007) suggests that, "for young people with special needs there is a particular tension between healthy sexuality and personal safety, and frequently the desire to keep our children safe also unintentionally keeps them dangerously in the dark" (p.36). Many parents and caregivers experience anxiety surrounding sexual health education as sexuality is often narrowly defined as sexual intercourse, and overt sexual acts have historically been considered inappropriate for people with ID (Irvine, 2005; Douglas-Scott, 2004). Douglas-Scott (2004) suggests that parents and caregivers may experience fear and embarrassment when discussing issues of sexuality with persons with ID as they might not understand it themselves or may not have the appropriate language to discuss it.

Studies conducted on the attitudes of caregivers and support workers towards sexuality in persons with ID reported 'generally positive' feelings (Bazzo, Nota, Sores, Ferrari & Minnes, 2006; Yool, Langdon & Garner, 2003; Cuskelly & Bryde, 2007). Similarly, following interviews with support workers for persons with ID, Yool, Langdon, and Garner (2003) found that participants demonstrated liberal attitudes

towards sexuality and masturbation in their clients. However, the support workers showed less liberal attitudes surrounding sexual intercourse, homosexual relationships, and autonomous decision-making regarding sexuality (Yool, Langdon & Garner, 2003). Swango-Wilson (2008) found that many caregivers, who agreed with sexual education classes for persons with ID, were “uncertain” as to the appropriateness of sexual behaviours between these individuals (p. 172). Further, Cuskelly and Bryde (2007) found that parents held more conservative views of sexuality for their children with ID in comparison to professional caregivers in the community. The authors suggest that this disconnect between attitudes may make it difficult for both groups to work together effectively and will likely produce confusion around sexual issues for persons with ID. Similarly, Bazzo et al. (2006) showed significant differences in caregiver attitudes depending on the service provided; for example, outpatient, community service providers held more liberal attitudes towards sexuality than service providers in closed institutions. Pendler and Hinsburger (1991) advocate for the education of parents and support workers of children with ID via a support group that aims to: a) help reduce anxiety surrounding their child’s sexuality; b) help them become more accepting of their child’s sexuality; c) learn that sexuality is a natural part of development regardless of disability; d) develop realistic expectations of their child’s sexuality; and e) support each other in a group setting.

Some authors have also suggested that anxiety exists in caregivers due to the uncertainty of consequences of sexual activity (Irvine, 2005; DiGuilio, 2003). Many also hold the view that persons with ID are asexual, in that they have no desire or need for sexual relationships (Cuskelly & Bryde, 2007). Others develop anxiety surrounding the

sexual expression of persons with ID (especially men), as they are believed to not be able to control sexual impulses (Monat, 1992; Irvine, 2005). Swango-Wilson (2008) explains the significant impact a caregiver's attitudes of sexuality can have on the person with ID that they're supporting. Many persons with ID also have negative attitudes towards sexuality and believe that it is "bad," "forbidden," or "indecent" (Leutar & Mihokovic, 2007). However, though these negative attitudes exist, persons with ID still display a sexual need (Servais, 2006). Richards, Miodrag, and Watson (2006) suggest that such negative attitudes towards sexuality can be a large obstacle for persons with ID developing healthy relationships, as these attitudes are often a result of negative sexual experiences. McCabe (1999) and Murphy and Elias (2006) suggest that keeping the lines of communication open to discussions of sexuality can be beneficial for persons with ID; it can help prevent them from developing negative attitudes about their own sexuality.

### **Sexual assault and abuse.**

Another reason for anxiety surrounding sexuality may be that youth with ID are more likely to experience sexual assault and abuse. It has been reported that 39% to 68% of disabled girls and 16% to 30% of disabled boys are sexually abused before the age of 18 (Rousso, 2001). Stimpson and Best's (1991) study of Canadian women with a variety of disabilities reported that 73% of female participants had experienced violence in their lives, of those, 96% had experienced sexual violence.

One explanation for high levels of sexual assault and abuse in persons with ID may be due to lack of knowledge about physical and sexual rights and consent. For example, McCabe and Cummins (1996) sought to discover the sexual knowledge that young

adults with ID had in comparison to university students. The study used the 'Sexual knowledge, experience and needs scale,' that was especially designed to measure sexuality knowledge in persons with ID. The participants with ID scored lowest on topics of dating and intimacy, sexual interaction, contraception, pregnancy, abortion and childbirth, sexually transmitted infections, masturbation and sexual abuse. Most startling was that only 3% of young adults with ID were aware of what sexual abuse was, compared to 84% of the university students.

Similarly, O'Callaghan and Murphy (2007) compared the knowledge of sexuality and the law between adults with ID and young teenagers without ID. Questions surrounding sexual abuse, incest, minors, and consent were presented to both groups to assess their knowledge in these areas. More than half of adults with ID did not know that laws pertaining to sexual assault and abuse could protect them or that it was against the law for professional staff to engage in sexual relationships with them. Also, a study by Leutar and Mihokovic (2007) of the sexual knowledge of adults with ID showed that some of the lowest scores surrounded questions of "when to say no" during sexual activity.

Another explanation for prominent sexual assault and abuse of persons with ID is that from a young age, many are taught to be obedient to adults and caregivers (Kempton & Stiggall, 1989). Such obedience education does not nurture assertiveness and puts persons with ID in very vulnerable positions and may increase susceptibility to abusive situations. Section 273.1 of the Canadian Criminal Code states that vulnerable persons including those with intellectual disabilities, may not give valid consent to sexual activity to a care provider or anyone in a position of authority (Public

Health Agency of Canada, 2005). Unfortunately, it is probable that many incidents of abuse go unreported as persons with ID may have a difficult time understanding what is abusive or inappropriate behaviour by others (Irvine, 2005).

### **Community living.**

There has also been a growing trend in the past 30 years for persons with ID to continue living in the community after childhood (Grieco, McLaren & Lindsay, 2006). Traditionally, many persons with ID were committed to institutions in adulthood (Servais, 2006). With the growing amount of social services available, supportive living for individuals with ID has become better funded since committing persons with ID to institutions has become less common. However, these community supports are often limited to employment, housing, food, and hygiene. Although individuals are increasingly becoming independent and gaining personal autonomy, their sexual needs are still predominately being ignored by community agencies and caregivers (Hinsburger & Tough, 2002).

With many more persons with ID living in community-based residences, there is a greater need for this population to have access to education related to basic social, emotional, sexual, and practical skills that are required to function and live safely within the community (McCabe & Schreck, 1992; Grieco, McLaren & Lindsay, 2006). Aylott (1999) reports that though persons with ID may be living in the community, they often share a bedroom and may "not have the privacy or the support from appropriately trained staff to explore their sexuality and expression or be able to entertain friends or companions" (p. 438). In addition, women with ID living in the community are 3.5 times more likely to be victims of abuse than those living with families or in institutions

(Servais et al, 2002). In addition, DiGiulio (2003) suggests that persons with disabilities tend to be economically, educationally, and socially disadvantaged – increasing their risk for vulnerability. Thus, due to the sexual needs and desires of persons with ID, and the vulnerability they face in terms of myths, misconceptions, and abuse, it is important that this population have access to accurate and comprehensive sexual health education to ensure they enjoy healthy and safe sexual behaviour and relationships.

### **Sexual Health Education Programs for Persons with Intellectual Disabilities: Pedagogical Approaches**

In 2008, the Public Health Agency of Canada (PHAC) updated the *Canadian Sexual Health Education Guidelines* to acknowledge the unique educational needs of persons with ID. The PHAC suggests that sexual health education for all populations should be based on five principles: 1) accessibility, 2) comprehensiveness, 3) effectiveness of approaches, 4) training and administrative support, and 5) program planning, evaluation, updating and social development. The guidelines propose that sexual health education should be comprehensive; this is achieved by being broadly based on different disciplines, and integrated and coordinated between the stakeholders who offer the resource.

Educators Weber and Bennett (2004) suggest that persons with intellectual disabilities struggle with particular aspects of learning new information. Specific areas of concern include: “the ability to pay attention, verbal communication, motivation, ability to generalize, and the ability to understand similarities and differences” (p.122). Weber and Bennett (2004) also suggest that it is typical for persons with ID to have a limited short term memory, though once information has been transferred into the long term memory (through prolonged engagement and/or reinforcement) students with ID

can recall it as easily as anyone else “when conditions are appropriate” (p. 124). Thus, when developing resources for persons with ID, these common learning difficulties should be kept in mind and researchers and authors should use helpful pedagogical techniques to assist overcoming these learning barriers.

Sexual health education programs available for persons with ID vary in content and approach. Because of limited research in this area, and the lack of research into such programs, there has not been an established effective approach to sexual health education programs for persons with ID. Nonetheless many authors and researchers suggest important topics to be incorporated into sexual health education resources for persons with ID and specific pedagogical approaches for undertaking such education (Kempton & Stiggall, 1989; Muccigrosso, 1991; Carter, 1999; Monat-Haller, 1992; Wolfe & Blanchett, 2003; Sweeney, 2007; Gray, 1994). For example, many researchers suggest role-play and play-acting are useful approaches for reinforcing social skills during sexual health education (Carter, 1999; Irvine, 2005; Sweeney, 2007). Carter (1999) suggests that sexual education classes should remain co-ed to encourage open dialogue between males and females. Carter (1999) and Higgins, Barker & Begley (2006) suggest using audio and video resources can be effective in maintaining the learner’s attention. Also, using dolls and models to explain anatomical parts have been highlighted as especially helpful for those with low verbal skills (Kempton & Stiggall, 1989; Murphy & Elias, 2006). Bell & Cameron (2003) point out that it is also important to consider making material accessible to those with limited verbal ability and to use tools such as BlissSymbols or Talking Mats to assist with communication.

Irvine (2005) asserts that effective methods for teaching concepts and important information to persons with ID include: task analysis, use of concrete material, repetition of information, and practice of functional skills. Muccigrosso (1991) suggests that sexual education programs for persons with ID should be participatory as opposed to lecture-based to encourage open participation and that concepts should be taught in plain, concrete language. Richards, Miodrag, and Watson (2006) also state that in order for sexual health education training to be effective, "it must be continuous and persistent from the early formative years, through adolescence, and into adulthood" (p. 144).

Muccigrosso (1991) also reports that support staff should receive continuing education on sexuality topics to offer ongoing support in this area to persons with disabilities. Muccigrosso (1991) suggests that ongoing support is necessary as sexual health education services and programs for persons with ID usually offered are "fast-paced, short-term and time limited" (p. 263). Similarly, McCabe (1999) suggests: "It is not sufficient that people with disabilities receive information on sexual issues, but it is important that the information changes their knowledge about sexuality and improves their experiences of sexual interactions" (p. 168). To achieve this, McCabe (1999) suggests that it is important for persons with ID to feel comfortable discussing sexuality with individuals they trust. Thus, support workers should be knowledgeable and comfortable with sexual topics in order to continue supporting persons with ID after educational programs and workshops end.

In addition to using certain techniques, many articles also stress the importance of making seemingly common sense topics explicit (Monat-Haller, 1992; Irvine, 2005).



Persons with ID may be especially vulnerable to myths and misinformation about sexuality and thus, according to Monat (1992) the importance of starting with very basic concepts such as labeling body parts should not be underestimated. Monat-Haller (1992) also asserts that simply using coloured chalk to provide sexual education to adolescents with ID can be effective. She provides examples of how to depict certain issues such as identifying body parts and the mechanics of sexual intercourse by drawing one simple picture at a time. This program would likely be useful for persons with more severe disabilities, but is a limited technique when it comes to communicating more complicated information. The program might also require a significant amount of training for a tutor, as guidelines are very general. See Table 1 for a summary of pedagogical approaches for sexual health education resources for persons with ID.

Wolfe and Blanchett (2003) have developed a guide for teachers and parents to use when choosing a sexual education program for an adolescent with ID. The guide asks such questions as: does the curricula match with the student needs? Does the curricula reflect the values of the family? Are the goals and objectives written to aid in my instruction? Are the concepts covered suitable for the student? Are materials too childlike or advanced? A checklist is provided to assist in the decision making of those involved. However, deciding on a program for persons with ID can be a daunting task as many of the more popular programs are either out-of-date or limited in scope.

Table 1

*Pedagogical Approaches for Sexual Health Education Resources for Persons with ID*

| <b>Common Learning Difficulties</b>        | <b>Pedagogical Approach</b>           | <b>Pedagogical Techniques</b>  |
|--|---------------------------------------|--|
| Understanding similarities and differences | Practicing and reinforcing skills     | Role-play activities   |
| Motivation and paying attention            | Encourage open dialogue               | Co-ed group sessions<br>Participatory sessions (i.e. not lecture based)<br>Knowledgeable teachers/tutors |
| Verbal communication                       | Using alternate communication methods | Audio and video resources<br>Visuals and models<br>BlissSymbols<br>Talking mats                          |
| Ability to generalize                      | Use of concrete information           | Write in very clear, concise language  |
| Short-term memory retention                | Repetition of information             | Prolonged engagement with the material<br>Continuing education for teachers/tutors                       |

Many sexual education programs for persons with ID seek to increase knowledge in certain areas such as hygiene, physiology, and sexual abuse (i.e. Whitehouse & McCabe, 1997; McDermott, Martin, Weinrich, and Kelly, 1999; Garwood & McCabe, 2000).

However, many programs do not address participants' feelings and attitudes towards sexuality (Whitehouse & McCabe, 1997). DiGuilio (2003) suggests that youth with ID "often require sexuality education programs with particular emphasis on relationships and social skills training" (p. 9). Whitehouse and McCabe (1997) suggest that failing to address how persons with ID feel about sexuality and relationships causes "people to have the information but not the permission to use the information" (p. 233). Thus, the previous review of the literature, suggests that sexual education programs for persons with ID should: remain interactive, be communicated plainly, contain opportunities for

practice, and be repetitive. Most of the academic literature surrounding sexual health education programs for persons with ID is drawn from program evaluations of sexual health education resources (for example, see Lindsay, Bellshaw, Culross, Staines & Michie, 1992; Lumley, Miltenberger, Long, Rapp, & Roberts, 1998; McDermott, Martin, Weinrich, & Kelly, 1999; Garwood & McCabe, 2000). However, although the effectiveness of these programs are presented, the nature and content of the programs are often not discussed. Thus, there is very limited literature that offers examples of sexual health education programs and the process of developing them. In the next section, a review of sexual health education programs for persons with ID will be presented and include a) resources with supporting academic literature and b) local resources available in Ontario.

### **Sexual Health Education Programs for Persons with ID: Published Resources**

There have been a number of sexual health education resources developed for persons with ID. However, as will be discussed in this section, some of the most popular programs have significant limitations in terms of the comprehensiveness of the content and accessibility to the community. For a summary of these programs, see Table 2. The James Stanfield Company, a special education publishing company in California, has produced many different educational resources for persons with ID in the areas of relationships, social skills, and sexuality. Two of the most notable sexual education programs that they offer are Champagne and Walker-Hirsch's *Circles I & II* and Kempton's *Life Horizons I & 2*.

Table 2

*Sexual Health Education Programs for Persons with ID: Published Resources*

| Year | Program  | Author  | Focus   | Materials                                      | Limitations   |
|------|--|---|---|--|---|
| 1988 | Life Horizons I: The Physiological and Emotional Aspects of Being Male and Female<br><br>Life Horizons II: The Moral, Social, and Legal Aspects of Sexuality | W. Kempton<br><br>Produced by James Stanfield Publishing Co.                      | Life cycle, relationships, mechanics of sex, sexual health, and sexual abuse<br><br>Self-esteem, attitudes, parenting, preventing and coping with abuse | Audiovisual, colour slides, written curriculum | The program is \$700 to purchase, creating a financial barrier for many.  |
| 1983 | Circles I: Intimacy and Relationships  | L. Walker-Hirsch & M. Champagne<br><br>Produced by James Stanfield Publishing Co. | Relationships and physical boundaries. Abuse prevention   | Text, visual poster material                   | Limited content discussed. Program exclusively covers personal boundaries.  |
| 1986 | Circles: Stop Abuse  |   |   |  |   |
| 2005 | Growing Pains  | Ballart Specialist School<br><br>Produced in Victoria, Australia                  | Social skills, drug education, relationships, sexuality, protection, body parts, grieving and loss, life cycle, and hygiene                             | Classroom lectures/lessons                     | Evaluation of program does not show significant knowledge gains in many areas. Program is not available in Ontario. |
| 2003 | Living Safer Sexual Lives  | Frawley et al.  | Content emerging with different participants  | Training package, video                        | Program does not discuss homosexuality. Program is not available in Ontario.  |
| 1999 | Human Sexuality Course   | Produced by University of Alabama   | Comprehensive content: Physiology, social skills and concerns   | Online course                                  | Very extensive admission requirements that may prevent program from being inclusive.                                |

Champagne and Walker-Hirsch (1983) created *Circles I: Intimacy and Relationships* that teaches socially appropriate behaviour in relationships. For example, people in one's closest circle would include partners and/or lovers that one could kiss and be sexually expressive with; people in one's outermost circle such as strangers one would only exchange with verbally if at all. In 1986, *Circles: Stop Abuse* was created to build on the information presented in *Circles I* with a focus on abuse prevention and learning to recognize inappropriate touching. Many years later, both circles programs are still widely used, although there have been few attempts to evaluate the effectiveness of the programs to meet their objectives (Garwood & McCabe, 2000). Both *Circles* programs communicate important information about social skills and boundaries, but would likely be insufficient on their own as a comprehensive sexual health education program for persons with ID. The *Circles* programs are very simplified and focus on socially appropriate boundaries between people. The programs do not however discuss sexual relationships in detail or exceptions to the rules provided. For example, the *Circles* program outlines the closest circle, which includes individuals you may kiss and cuddle, as containing family members and relatives. However, this might not always be the case and these exceptions are not explained.

Kempton's (1988) *Life Horizons I: The Physiological and Emotional Aspects of Being Male and Female* is the most used and well-accepted program for persons with ID. The curriculum is composed of hundreds of picture slides covering a variety of topics such as the life cycle, relationships, mechanics of sex, sexual health, and sexual abuse. *Life Horizons II: the Moral, Social, and Legal Aspects of Sexuality*, was created to offer additional educational information after *Life Horizons I*; it focuses on self-esteem,

attitudes and behaviours, parenting, and preventing and coping with sexual abuse.

Strengths of this program include the use of visual representations, its ease of use, and its exceptionally comprehensive content. However, Grieveo, McLaren, and Lindsay (2006) suggest that the curriculum is limited to individuals with mild ID as many of the pictorial representations are quite complicated. In addition, there are estimates that purchasing the Life Horizons program costs approximately 700 American dollars; this high financial cost limits accessibility of the program especially for those with limited financial resources (Couwenhoven, 2001).

Carter (1999) outlines a program implemented by the University of Alabama Birmingham *Horizons Program*: a non-degree transition program for young adults with learning disabilities aged 18 to 26. The content involves topics of physiology (male and female anatomy; sexual intercourse; conception and fertilization; STDs; contraception) and social issues and concerns (developing sexual relationships; intimacy; communication and problem solving; abuse and harassment; marriage and divorce). Learning goals and teaching materials are not published, but requirements for success are outlined such as including parents in classes for consistency. Strengths of the program are that it can be completed online from home and does not require a specific time commitment. However, to be admitted to the *Horizons Program* requires that students be:

- Functionally literate and have a high school diploma, GED certificate, and/or a certificate of high school completion/attendance;
- Are capable of supervised apartment and work-related activities;
- Can manage their own medication and other health-related issues;
- Have parent/guardian support;
- Have a commitment to work and personal independence (Horizons School, 2009).

The admission criteria suggest that the program may exclude persons with less independent living skills. Thus, the program is not inclusive of all learning abilities.

Frawley, Johnson, Hillier, and Harrison's (2003) *Living Safer Sexual Lives*, covers a variety of sexual education topics through a training package and an accompanying video. The program was created through participatory action research with persons living with ID and topics covered were determined by stories told by research participants (Johnson, Hillier, Harrison & Frawley, 2001). Twenty-five people with intellectual disabilities told their life stories, focusing on experiences of sexuality and relationships. Johnson, Hillier, Harrison and Frawley (2001) report that:

The findings [from the stories] revealed that people with intellectual disabilities lead diverse sexual lives and that their desires and many of their experience reflect those of other adults. The stories were complex, emotional, passionate, and joyful. They were accounts of adults struggling with issues around sexual expression and relationships (pg. 1).

These stories were the basis of the program's goals and focus. Though this program is a great example of a community initiative for persons with ID, there has been criticism surrounding the program suggesting it adheres to a heteronormative discourse and fails to fully explore issues of homosexuality (Grieco, McLaren & Lindsay, 2006). This program is also not currently available in Canada.

Ballarat Specialist School in Victoria, Australia developed a personal development program for adolescents (aged 11 to 15) with intellectual and developmental disabilities (Sheppard, 2006). One of the first programs developed for persons with ID and delivered in a school setting, the *Growing Pains Program* included seven modules including: social skills; drug education; relationships and sexuality; protective and safe behaviours; public/private, body parts; grieving and loss; human life cycle, personal

hygiene. Ballarat Specialist School piloted this program with 90 students over a period of 20 weeks. Teachers scored the students on a personal development scale when certain behaviours and skills were demonstrated in the classroom. Significant knowledge gains were found in topics of social skills and protective behaviour (i.e. using condoms). As identified by the authors, a limitation of this evaluation is that teachers who were implementing the program were also completing the checklist, possibly causing teachers evaluations to be biased. In regards to the *Growing Pains Program*, the authors did not offer specific details of the content. Also, the program has not been made available in Canada.

### **Sexual Health Education Resources for Persons with ID: Local Resources**

The accessibility of sexual health education programs for persons with intellectual disabilities is important. Currently, sexual health education resources are available in the Guelph-Wellington and Dufferin community for persons with ID. However, though resources do exist, a comprehensive program covering a wide range of topics for persons with ID is unavailable in the community. Programs are available through the Developmental Services Access Centre, KidsAbility Centre for Child Development (KidsAbility), Diverse City Press, and the Sex Information and Education Council of Canada. Though academic publications are not available with respect to the following programs, they are available in the community and have been reviewed by the researcher. For a summary of these programs, see Table 3.



Table 3

*Sexual Health Education Program for Persons with ID: Local Resources Available in Ontario*

| Year | Program  | Author   | Focus  | Materials                | Limitations  |
|------|--|--|--|--------------------------|--|
| 2006 | You Go, Girl!  | A. Mia<br><br>Produced by KidsAbility  | Female adolescent and teen development   | Series of workshops      | Exclusively for young girls. Program delivered in week long camp.  |
| 2009 | Sex Esteem: Developing Sexuality Confidence                        | K. Klee<br><br>Produced by Developmental Services Access Centre  | Relationships, dating, STIs, birth control, gay/lesbian/transgender issues, consent, sexual assault and, online safety | Workshop                 | Program only a two-day workshop. Workshop excludes past sex offenders.   |
| 2008 | Hand Made Love<br><br>Finger Tips                                  | D. Hingsburger<br><br>Produced by Diverse City Press   | Masturbation   | Video                    | Limited content – videos only discuss masturbation.  |
| 1993 | Being Sexual: An Illustrated Series on Sexuality and Relationships | S. Ludwig<br><br>Produced by SIECCAN   | Feelings, social expectations, individual rights   | Booklets                 | Limited content – extensive pictures not supported by text or explanations. Program relies extensively on a tutor. |
| 2007 | S.N.A.P: Special Needs Abuse Prevention                            | M. Cressman<br><br>Produced by Rural Response for Healthy Children and Community Living and Community Support for Families in Huron County | Safety, personal boundaries, and abuse prevention  | Booklets, colouring book | Program designed only for young children.  |

*S.N.A.P: Special Needs Abuse Prevention* was written by Marg Cressman in collaboration between Rural Response for Healthy Children and Community Living and Community Support for Families Huron County. S.N.A.P. is a collection of booklets that discuss the importance of safety and personal boundaries for persons with ID. The booklets communicate important information, but would likely only be effective with young children. The booklets are made up of juvenile illustrations and very simple statements. Thus, though they contain important information, their application is limited to a younger audience (text and pictures suggest a target age of 6 to 10 years of age) and the focus is on the specific subject matter of safety and personal boundaries.

Developmental Services Access Centre (DSAC) offers a two-day workshop in Waterloo, Ontario called *Sex Esteem: Developing Sexual Confidence*. Topics include relationships, dating, STIs, birth control, gay/lesbian/transgender issues, consent, sexual assault and, online safety. The program is delivered in presentation format to a larger group of persons with ID and their support workers. The program is interactive and allows participants to ask questions and complete games and activities. Though the workshops have been developed to educate persons with ID, known sex-offenders are not allowed to attend (Developmental Services Access Centre, 2009). This seems unfortunate, as there are authors who report that persons with ID may sexually offend because they have not been exposed to sexual health education (Talbot & Langdon, 2006; McCabe 1999). Also, the program is not available for participants to take home and review the material, thus issues of retention of information may arise.

KidsAbility in the Wellington-Dufferin area offered a summer camp program for female youth and teens with ID called *You Go, Girl!* The program covered topics such as

body/puberty changes, hygiene and personal care, public and private body parts, community safety, nutrition, and friendships (Mia, 2007). The camps were very interactive with the youth providing games and activities to explain concepts. Though the program focused on important issues for young girls, camps excluded males and did not discuss more mature concepts of sexuality, safety, and relationships.

Diverse City Press, a small publishing company in Ontario, produces education resources for persons with disabilities and their families. Diverse City Press offers a series of different books, videos, and audio resources that mostly focus on sexual abuse prevention. Though a single comprehensive program is not available from this publisher, two very popular videos titled *Hand Made Love* for men, and *Finger Tips* for females, both by David Hinsburger discuss ways to enjoy safe masturbation in privacy (Diverse City Press, 2008). The videos are both instructive and informative for those interested in learning about masturbation techniques; they also promote the positive aspects of masturbation as part of healthy sexual development.

In 1993 the Sex Information and Education Council of Canada (SIECCAN) published *Being Sexual: An Illustrated Series on Sexuality and Relationships* written by sexuality consultant Susan Ludwig. *Being Sexual* is an educational tool for persons with ID or problems with learning and communication. The program is broken into 17 booklets addressing issues such as feelings, societal expectations, and individual rights. *Being Sexual* was out of print for a number of years; however, SIECCAN recently announced that the program would start to be republished in 2009 (SIECCAN, 2009). Concepts in *Being Sexual* are also translated into BlissSymbols. However, a review of the *Being Sexual* program revealed that although there is substantial pictorial support in the

booklets, the program requires significant support from a tutor or educator, as there is little text to explain the images and situations depicted.

Overall, the sexual health education resources currently available for adolescents with ID in Ontario are limited in terms of the age appropriateness of the curriculum and the scope of topics discussed. In terms of age limitations, KidsAbility's *You Go Girl!* is exclusive for young girls, and Rural Response for Healthy Children and Community Living and Community Support for Families Huron County's *S.N.A.P.* program is for very young people. In terms of content limitations, Diverse City Press's videos are exclusively about masturbation, and SIECCAN's booklets provide limited content and mostly textually unsupported illustrations. Thus, in Ontario, there still seems to be a gap in resources available that are:

- a) Comprehensive in content and topics
- b) Appropriate for a variety of ages and abilities
- c) Using a variety of teaching strategies
- d) Accessible from a financial perspective

Thus, a resource that covers each of these four criteria may assist persons with ID to develop healthy, safe, and fulfilling relationships. The *Relationship, Sexuality, and Safety Education Network of Guelph-Wellington and Dufferin Counties* developed *Able to Live, Able to Love* in an attempt to address these shortcomings.

## Summary

In this chapter, a review of the literature surrounding sexual health education for persons with ID was discussed. The background and rationale for educating persons with ID about sexual health was presented as well as challenges to providing this type

of education. In addition, programs currently published in the United States and Australia were outlined as well as local programs available in the Guelph-Wellington and Dufferin community. In chapter three, the philosophical assumptions of the researcher, case study methodology, and the research methods of this study are introduced.

### Chapter Three: Methodology

In light of the needs identified in the previous literature review, the purpose of this research is to study the development of a sexual health education program for persons living with intellectual disabilities. The particular sexual health education program examined in this case study is entitled *Able to Live, Able to Love*, a resource produced by the *Relationship, Sexuality, and Safety Education Network of Guelph-Wellington and Dufferin Counties*. This study examines how and why the resource was developed and discusses enablers and challenges to the development of the program. In addition, strengths, limitations, and future directions of the resource in the community from the perspective of stakeholders involved in the development of the educational materials are examined.

The information gained from the study may be beneficial to various community members and organizations interested in developing similar programs for persons with intellectual disabilities and those who live and work with them. The guiding question of the research was: "What is the process by which stakeholders in the *Relationship, Sexuality, and Safety Education Network of Guelph-Wellington and Dufferin Counties* developed a sexual education program for persons living with intellectual disabilities?" Subquestions of the study include:

- Why was the program developed?
- How was the need for the program identified?
- How was the program developed? What helped the process along? Were there any challenges?
- What are stakeholder perceptions of the strengths of the program?

- What are stakeholder perceptions of potential limitations?
- How will the program be used in the community?
- How was the community involved in the design and development of the program? (i.e. persons with disabilities and those who live and work with them)

This chapter will discuss the qualitative approach to the research, the philosophical assumptions of the researcher, case study methodology, the parameters of the case under investigation, and the role of the researcher. Research methods, quality criteria, and the ethical issues are also discussed.

### **A Qualitative Approach**

A qualitative research approach was chosen to study the process by which stakeholders developed the *Able to Live, Able to Love* resource for persons living with intellectual disabilities. According to Denzin and Lincoln (2005), "qualitative research stresses the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape reality" (p. 11). The researcher was interested in how and why the project was developed as understood by the different stakeholders. There has been little qualitative research conducted on sexual health education programs for persons with intellectual disabilities, while many studies surrounding the sexual health education for persons with ID have attempted to quantify knowledge gains and experiences (i.e. Whitehouse & McCabe, 1997; Garwood & McCabe, 2000). Qualitative researchers "study selected issues in depth and detail" (Patton, 1990, p. 13). The aim of the research is to study the process of developing the *Able to Live, Able to Love* program in detail as it may

contribute to further understanding of the enablers and challenges of developing sexual health education programs for persons with ID. Thus, adopting a qualitative research approach seemed appropriate given the research aims.

### Case Study Methodology

This research adopts a case study methodology to study the development of the *Able to Live, Able to Love* sexual health education resource. Philosophically the study is located in an interpretive paradigm, and informed by pragmatic philosophical assumptions. Case studies are “multifaceted strategies used to explore a bounded system” (Mertens, 2009, p.169). Case studies explore a) the nature of a case, b) its historical background, c) its physical setting, d) the context in which the case exists, and e) those informants through whom the case can be understood (Stake, 2005). Case study methodology was selected because it is an effective form of inquiry to use when the phenomenon of interest 1) does not involve a control of behaviour, and 2) focuses on contemporary events (Yin, 2003).

Merriam (2009) suggests that qualitative case studies have essential qualities; they are particularistic, descriptive, and heuristic. Case studies are *particularistic* because they focus on a particular phenomenon or case; *descriptive* because the end product contains thick descriptions of the phenomenon under study; and *heuristic* because they illuminate the reader’s understanding of the phenomenon by “bringing about discovery of a new meaning, extending the reader’s experience” or identifying with a similar phenomenon (p. 44).



### **Rationale for choice.**

A case study was deemed especially appropriate for this study as case study is both a process of inquiry and the product of such inquiry (Stake, 2005), and it provides a written record of a particular contextualized situation. Case studies allow researchers to thickly describe and analyze one particular case in great detail. However, though the researcher may aim to describe and report on the distinctive characteristics of one case, it may extend beyond a description and begin to theorize as well (Corrie & Zaklukiewicz, 2004). The case itself is “important for what it reveals about a phenomenon and for what it might represent” (Merriam, 2009, p. 43). Case studies are interested in the ‘how’ and ‘why’ questions of a particular phenomenon (Yin, 2003). Thus, because the study seeks to investigate: Why the program was developed; How the need for the program was identified; How the program was developed; How stakeholders perceive the program; How the program will be used in the community; and How the community was involved in the design and development of the program, adopting case study methodology seemed appropriate given the research aims.

### **Parameters of the Case**

A case study explores a phenomenon that is intrinsically bound by something such as time, space, or subjects (Merriam, 2009). For example, Stake (2005) explains, “A case is a noun, a thing, an entity” (p. 1); it is one particular person, one particular program, or one particular classroom. The *Able to Live, Able to Love* resource developed by the *Relationship, Sexuality, and Safety Education Network of Guelph-Wellington and Dufferin Counties* (hereafter referred to as *the Network*) was considered the bounded case for this study.

The Network, based in Guelph, Ontario, came together in 2004 after a parent of a son with Down's Syndrome expressed concern about the lack of comprehensive sexual health programming available for persons with intellectual disabilities. As a result, she invited many community agencies to come together to create a resource that would address this need. Various stakeholders joined together including parents and members of community agencies involved with counseling services, public health, school boards, and parents of children with intellectual disabilities. The participating agencies included: Trellis Mental Health and Developmental Services, Family Counselling and Support Services, Community Living Guelph-Wellington, Public Health Wellington and Dufferin, KidsAbility, the University of Guelph, and parents of persons with intellectual disabilities in the London, Guelph, and Wellington-Dufferin community. The group soon formed the Network and applied for an Ontario Trillium Foundation grant to create the resource. After being awarded the grant, an educational consultant was hired in the fall of 2007 to begin developing the program. The consultant recruited me in January 2008 to assist with the development and writing of the program. The program took one and a half years to develop, and consists of an introductory unit to the educator, 11 teachable units, and an accompanying activity booklet that addresses a variety of topics surrounding sexuality and relationships. Each teachable unit also has an accompanying Power Point presentation with the images of the booklet and the text in point form. More detail surrounding the development of the Network and the design of the resource was identified by participants and is presented in the Findings chapter of the thesis.

**Description of the sexual health education resource: Able to Live, Able to Love.**

*Able to Live, Able to Love* was designed to not just present sexual health information but to also encourage sex-positive attitudes, assertiveness, communication, and questioning. *Able to Live, Able to Love* ‘participants’ or ‘learners’ are encouraged to say “no” to any situation that causes them to be uncomfortable, and to be aware of their own personal values and to create healthy boundaries. Learners are encouraged to develop healthy relationships, free from emotional and physical harm.

The resource is comprehensive in scope, and uses a variety of pedagogical approaches to foster learning. These include: encouraging open dialogue, using pictures and models, and engaging in role-play. These pedagogical techniques were elaborated in chapter two. The program may be used one-on-one with an educator and a learner using the unit booklets and interactive activities as tools to navigate through the material. The program may also be facilitated in a group format, using the Power Point presentation as an additional tool. The learner could be any person with an intellectual disability and the educator a teacher, parent, or caregiver. The unit titles are:

- Unit 1: A Note to the Educator
- Unit 2: Being a Person, Being Sexual
- Unit 3: Understanding Our Bodies
- Unit 4: Healthy Relationships
- Unit 5: Intimacy and Sexuality
- Unit 6: Feelings and Self-Awareness
- Unit 7: Sexual Expression

- Unit 8: Language and Communication
- Unit 9: Sexuality Through the Lifecycle
- Unit 10: Sexual Rights, Consent, and Abuse
- Unit 11: Sexual Health and Safety
- Unit 12: Spirituality and Sexuality

Each of the 12 units are in separately bound booklets. The activities are in a separate booklet as well. Each unit is approximately 20 pages in length with at least one image per page. A more detailed description of the content in each unit is available in Appendix A. In addition, a more detailed description of the development of the content of each unit is presented in the findings chapter. Each unit has important components to foster learning and understanding by encouraging open dialogue, repeating important information, and practicing functional skills.

### **Role of the Researcher**

I come to this project as a graduate student in the Health Professional Education Field in the Faculty of Health and Rehabilitation Sciences at the University of Western Ontario. I have had some experience working with persons with ID in the community. I have held three summer placements at agencies for persons with mental health issues and intellectual disabilities over the past four years. I had a strong interest in disability issues and would consider myself an advocate for disability rights. My interest in sexual health education originated during my undergraduate degree in health sciences and psychology. I have since developed a feminist and liberal view of sexuality and sexual education.

### **Role in the development of the sexual health education resource.**

As the researcher, I was also intimately involved in the development of the program under study, *Able to Live, Able to Love*. I participated in the design of the resource by collaborating with the educational consultant about topics and issues to be addressed in the curriculum. I also co-wrote the resource content and resource activities with the educational consultant. I recognize that intimate involvement with multiple dimensions of the project presents both advantages and disadvantages to the research. Advantages include possessing expert knowledge of the program content, and the process of writing the program as well as having an already established rapport with some of the stakeholders. Disadvantages include the potential for preconceived ideas to infuse my interpretation of the data. As one of the writers of the sexual health educational resource I may have preconceived ideas regarding the usefulness and applicability of the program. Indeed, I may unintentionally overestimate the quality or applicability of the resource. However, despite these limitations, I think that researching the process by which the resource was developed is an exceptionally important goal, as it may assist future projects by other organizations.

Personally, I am most interested in stakeholders' perceptions of the use of the resource. I am invested in the usefulness of the resource and am interested in any information obtained from interviews that could help further develop the resource in the future. Thus, I am open to criticisms regarding the process and the resource itself in order to help develop a better tool for individuals with ID.

### **Role in the research.**

As the researcher I have assumed a variety of roles in this study. First of all, I have identified my philosophical assumptions, biases, values, and personal background and have attempted to be transparent about my position within the research. Second, I was involved in all aspects of data collection from designing the interview guide, to collecting data, to data analysis and interpretation. Third, I acted as a key instrument of the research (Creswell, 2009) by keeping reflexive notes and collaborating with participants to interpret meanings of the interview and our mutually created story (Fontana & Frey, 2005). Fourth, I used specific strategies to validate the research findings (see Quality Criteria). Finally, I suggested implications of the study for those who wish to design sexual health educational programs for persons living with ID, as well as for further research in sexuality and disability in general.

### **Sampling and Participant Recruitment**

#### **Ethics.**

Before proceeding with the study, an application to the Non-Medical Research Ethics Board at the Office of Research Ethics at the University of Western Ontario was submitted (see Appendix B). Following approval for the design of the study from the Research Ethics Board, participants were recruited to the study and data gathering proceeded. Participants were assured that tape-recorded interviews would be transcribed by the researcher and would only be available to the primary researchers. If participants were not comfortable being tape-recorded, they were still invited to participate in the study. Participants were ensured that all information collected for the study would be kept confidential. There were no known risks of participating in

this study and participants were given the option of refusing to answer specific questions or withdrawing from the study at any time.

### **Recruitment.**

Purposeful sampling of participants was used for this study. Stakeholders that were thought to best help the researcher address the research questions (Creswell, 2009) were recruited to participate. To recruit participants, the researcher attended a Network meeting in April 2009. Up until this point in time the researcher had only been in contact with one member of the Network. The Network knew that the researcher was involved in the development of the project, and knew that there were plans to begin a study surrounding the development of the resource. At the meeting in April 2009, the researcher explained to the Network her plans to explore and document the development of the resource and that she would be contacting all members of the Network following ethical approval from the University of Western Ontario. Once ethics approval was received, the researcher contacted stakeholders either by telephone or email with an invitation to participate in the study. A specific list of stakeholders who had assisted in the development of the resource that were not officially members of the *Relationship, Sexuality, and Safety Education Network of Guelph-Wellington and Dufferin Counties* was developed through a meeting with a key informant from the Network. The researcher also contacted these potential participants by either telephone or email.

In the initial meeting with each stakeholder, the researcher explained the study, provided a Letter of Information about the study (see Appendix C), and answered any

questions. If the stakeholder consented to participate in the study, a Consent Form (see Appendix D) was completed, and arrangements made for the interview.

### **Participants.**

Two male and six female participants between 20 and 65 years of age participated in the study. Inclusion criteria were that participants were key stakeholders of the *Able to Live, Able to Love* program. This is defined as anyone who contributed to the development of the educational resource *Able to live, Able to Love*. Since the researcher was interested in the specific case of the development of the *Able to Live, Able to Love* sexual education resource, only persons that had contributed to the development of the resource were included in the study. Persons with ID were not included in the study as there were not any persons with ID part of the *Relationship, Sexuality, and Safety Education Network of Guelph-Wellington and Dufferin Counties*. Stakeholders were drawn from the following groups: Trellis Mental Health and Developmental Services, Family Counselling and Support Services, Community Living Guelph-Wellington, Public Health Wellington and Dufferin, KidsAbility, the University of Guelph, and parents of persons with intellectual disabilities in the London, Guelph, and Wellington-Dufferin community.

Six participants were members of the *Relationship, Sexuality, and Safety Education Network of Guelph-Wellington and Dufferin Counties*. Of the Network participants, four were frontline service workers with people with ID, one was a parent of a child with ID, and one was a university student completing a placement with an involved agency. Of the two participants not members of the Network, one was an educational consultant,



and one was a parent of a child with ID who worked privately with the educational consultant on developing ideas for the resource.

## **Methods**

### **Data collection.**

Case studies often involve the use of interviews, observations, direct observations, archival records and document reviews (Yin, 2003; Mertens, 2009). Yin (2003) suggests that the opportunity to use many different sources of evidence is a major strength of case study data collection. For this study, the researcher obtained data pertinent to the case study through stakeholder interviews and document review. Reflexive field notes were maintained throughout the data gathering process.

### ***Stakeholder interviews.***

Yin (2003) suggests, "one of the most important sources of case study information is the interview" (p. 89). The researcher interviewed eight stakeholders who were involved in the development of the sexual education program: *Able to Live, Able to Love*. The researcher was interested in information surrounding the research question: What is the process by which stakeholders in the *Relationship, Sexuality, and Safety Education Network of Guelph-Wellington and Dufferin Counties* developed a sexual education program for persons living with intellectual disabilities? A semi-structured interview guide, developed by my graduate supervisor and myself, was used to facilitate the interviews (see Appendix E). The sub-questions of the study were used to develop the interview guide. Interviews were conducted by the researcher in a place of the participant's choice such as public restaurants, or participants' homes and places of

employment. Interviews were 45 to 90 minutes in length and tape-recorded and transcribed verbatim by the researcher. Only one interview was not tape-recorded at the request of the participant. In this instance, the researcher recorded detailed written notes both during and following the interview. During the transcription and analysis of the interviews, participants were assigned pseudonyms to preserve confidentiality.

### ***Document review.***

*Document review materials.* Document materials included: e-mail correspondence, meeting minutes, related community resources, and proposal applications that had been kept by the committee chair. The committee chair lent me a binder she had collected of these documents. E-mail correspondence reviewed included e-mails between Network members from June 2005 until January 2009 and emails between the subcommittee and the educational consultant from October 2007 and February 2009. Network meeting minutes were reviewed from June 2005 until April 2009. Two proposal applications to the Ontario Trillium Foundation, one submitted in 2007 and the other submitted in 2009, were reviewed as well.

*Document review process.* The researcher reviewed key organization documents relating to the development of the sexual education resource. Documentation was used to augment information obtained from interviews as well as to provide specific details to corroborate information from interviews. Emails, meeting minutes, and additional correspondence were used to corroborate information obtained through interviews. Grant applications were used to understand the future direction of the resource.

### ***Reflexive field notes.***

Throughout the study, the researcher kept a reflexive journal. Notes were made in the journal immediately before and after each interview and throughout the study as personal thoughts and ideas emerged. Following Lincoln and Guba's (1985) suggestion, the reflexive journal consisted of separate parts including: a) the logistics of the study; b) a personal diary used for "catharsis, for reflection upon what is happening in terms of one's own values and interests, and for speculation about growing insights" (p. 327); and c) a methodological log that includes methodological decisions and rationales.

### **Data analysis.**

Data was analysed continuously throughout the study by the researcher. All data was analyzed from text format. The texts included in the analysis were: transcribed interviews, documents, and reflexive field notes. Transcriptions of the interviews were coded and analyzed for themes, repeated phrases, relationships, patterns, differences, and common sequences (Miles & Huberman, 1994). The analysis was completed in multiple steps: coding, categorizing, and concepts (Litchman, 2006).

Step 1. The researcher engaged in "open coding" (Merriam, 2009) or "initial coding" (Litchman, 2006) after each interview was conducted and transcribed; this consisted of reading transcriptions and recording central ideas, notes, and observations. Documents and reflexive notes were also openly coded.

Step 2. After all interviews were completed, transcripts, documents, reflexive notes, and codes were revisited; some codes were redundant and overlapped so a tentative list of revised codes was developed from this process.

Step 3. With these codes, concept maps were created for each transcribed interview to visually represent codes and explore connections (Novak & Cañas, 2007). Eight concept maps were compared to one another and analysed for themes that represented “recurring regularities in the data” (Merriam, 2009, p. 177). Themes were considered salient or prominent if they were discussed by at least three participants, but generally there was a higher degree of consensus.

Step 4. A revised list of codes and themes was created to reflect the most important themes identified. Supporting quotations and raw data was organized to support these themes. Inconsistent data and themes were also considered in this process.

Step 5. Categories of themes were developed to sort the codes. Categories were developed in response to the research questions and were guided by attention to the study’s purpose (Merriam, 2009).

### **Quality Criteria and Strategies for Trustworthiness**

According to Yin (2003) in order for a case analysis to be of quality, the researcher must ensure that a) all the evidence from all participants will be considered and that interpretations will account for all evidence and not leave any ‘loose ends,’ b) all major rival interpretations will be considered, and c) the analysis will focus on the guiding questions of the research so the most significant aspects of the case study will be addressed. In qualitative interviewing, the researcher must recognize that “meaning is, to some degree, a function of the participant’s interaction with the interviewer” (Seidman, 2006, p. 23). Researchers influence the “collection, selection, and interpretation of data” and thus it is vital for researchers to analyze the integrity and trustworthiness of his or her research (Finlay, 2002, p. 531). The trustworthiness of

the research will be discussed through the credibility, transferability, and dependability of the study.

### **Credibility.**

The credibility of a study refers to its internal consistency (Morrow, 2005). In this study, the credibility of the findings were scrutinized to determine how congruent the researcher's interpretations were with the reality described by participants (Mertens, 2009). Specific strategies used to ensure the credibility of findings included: crystallization, member checking, and reflexivity.

### ***Crystallization.***

By using multiple sources and methods of evidence, the researcher can ensure that findings and interpretations are plausible (Mertens, 2009). Many qualitative methods recognize this process as triangulation (Miles & Huberman, 1994; Creswell, 2009; Merriam, 2009). Richardson and St. Pierre (2005) instead propose that by analyzing multiple sources of evidence, the metaphor of a prism is more appropriate: "what we see depends on our angle of repose" (p. 963). The process of crystallization recognizes that knowledge is multifaceted whereas triangulation assumes a fixed point upon which one can converge. Similarly, Mertens (2009) agrees: "triangulation suggests limits, whereas a crystal is a prism that grows, changes, and alters" (p. 62). For this study, the researcher explored the multiple perspectives of stakeholders through interviews and also consulted documents and the reflexive field note journal for data.

### ***Member checking.***

Member checking is essential to involving the research participants throughout the research process. Member checking gives participants the opportunity to clarify, confirm, or refute interpretations of the findings after the initial interpretations are made (Creswell, 2009). The researcher brought the emerging interpretations and themes of the data back to three participants from whom the data was originally collected. By involving participants in this process, the researcher sought to be inclusive by sharing plausible codes, clusters, and themes. Member checking provides participants the opportunity to assess the adequacy of the researcher's findings and constructions (Mertens, 2009).

### ***Reflexivity.***

For this study, reflexivity is defined as critical reflection on the process of research (Litchman, 2006). In order to be transparent, the researcher used an iterative reflexive process to clarify personal preconceived ideas, theoretical orientation, and assumptions at the beginning of the study, and throughout the study, to help the researcher explain how she was interpreting the findings. Through "thoughtful, [and] conscious self-awareness" (Finlay, 2002, p. 532), the researcher was able to work through interpretations and analysis by remaining self aware of how decisions were being made.

### ***Transferability.***

Transferability is "the ability of the researcher to present the findings to readers so that they can assess the transferability of the results of one study to another situation"

(Mertens, 2009, p. 195). Morrow (2005) suggests that transferability is achieved when “the researcher provides sufficient information about the self and the research context, processes, participants, and researcher-participant relationship” (p. 3). Thus, the researcher attempted to provide thick descriptions of the resource and the background of the case, as well as the study design and procedures, to facilitate the reader’s understanding of the context and details of the study.

### **Dependability.**

The dependability of a study refers to how consistent the findings of the data would be if the study was repeated. Exact replication of the study is not the aim in qualitative research as multiple interpretations and findings are possible. Instead, Merriam (1991) suggests that, “one wishes outsiders to concur that, given the data collected, the results make sense – they are consistent and dependable” (p. 171). Dependability can be accomplished by keeping a detailed log of research activities, practices, and decisions (Morrow, 2005). In order to enhance dependability, the researcher kept an audit trail or a “chain of evidence” (Yin, 2003).

### ***Audit trail.***

The researcher kept a detailed record of how data was collected, how codes and categories were created, and how decisions were made throughout the study. Descriptions of the process were thick to allow external readers to follow the researcher’s thinking process. Lincoln and Guba (1985) suggest that case reporting should be “sufficiently detailed so that if a reader of the case were suddenly to be transported to the site, he or she would experience a feeling of déjà vu” (p. 365).

Though another researcher might not make similar conclusions, the trail must be sufficiently transparent so that one would understand how decisions and interpretations were made.

### **Ethical Issues**

Many precautions were taken to protect the well being of participants. First of all, voluntary, informed consent was obtained prior to the study. Participants were instructed not to answer interview questions that made them uncomfortable, participants were encouraged to ask the researcher questions, and were informed that they are free to leave the study at any time and to have their information and data removed from record. Second, the researcher attempted to be transparent in her goals and intentions of the research did not actively deceive participants. Third, by taking care to preserve credibility, transferability, and dependability, the researcher will ensure that findings are plausible interpretations of the participants' views.

### **Summary**

In this chapter, the specific aims of the research were identified and case study methodology was discussed as an effective method to explore phenomena that is intrinsically bound. The parameters of the case and details of the *Able to Live, Able to Love* program were outlined to give context to the case under study. Specific research methods were identified to explain how data was collected and analyzed. The philosophical assumptions and the role of the researcher were also outlined to help the reader understand the personal viewpoints of the researcher that inform the interpretations and findings of this study. Chapter 4 will present the findings of the research.



## Chapter Four: Findings

In this chapter, the findings of the study are presented. The findings are organized in response to the questions of the research. The guiding question of the research is: “What is the process by which stakeholders in the *Relationship, Sexuality, and Safety Education Network of Guelph-Wellington and Dufferin Counties* developed a sexual education program for persons living with intellectual disabilities?” Subquestions include: Why was the program developed? How was the need for the program identified? How was the program developed? What helped the process along? Were there any challenges? What are stakeholder perceptions of the strengths of the program? What are stakeholder perceptions of potential limitations? How will the program be used in the community? How was the community involved in the design and development of the program? The findings are presented in three parts, which include:

Part 1: A portrait of the historical development of the Sexual Health Education Resource, including the development of the *Relationship, Sexuality, and Safety Education Network of Guelph-Wellington and Dufferin Counties* and the development of the *Able to Live, Able to Love* program. In this section, a historical account of the case, drawn from the interviews with participants and from key documents, is presented. The historical period of the case spans the beginning of the initiative in 2003 until the first draft was published in 2009.

Part 2: Enablers and challenges to, and motivations for the development process.

Part 3: Strengths and limitations of the program and further recommendations.

Throughout this chapter, direct quotations from the raw data are used except where clarification was provided, indicated by brackets [ ]. The researcher offered clarification by completing minor grammatical edits to improve the flow of the text at times. For example, pauses, interruptions, and unclear language have been deleted if they prevented the flow of the text. Names and workplaces of participants have not been identified. Pseudonyms have been used in place of some participants' names to ensure confidentiality.

### **Part 1: Historical development of the Sexual Health Education Resource**

A portrait of the historical development of the *Able to Live, Able to Love*, Sexual Education Resource and the *Relationship, Sexuality, and Safety Education Network of Guelph-Wellington and Dufferin Counties* was developed through an analysis of the interviews and documents.

#### **The inception of the project: A narrative.**

The *Relationship, Sexuality, and Safety Education Network of Guelph-Wellington and Dufferin Counties* originated with one individual. As a parent of a son with Downs Syndrome, June was unsatisfied with current information and resources available for adolescents and adults with intellectual disabilities in her community. While her son Bill was young, June began to hear of other students in Bill's school with similar disabilities having a difficult time expressing themselves sexually in a safe way. For example, some of Bill's classmates had issues with public and private behaviour and were found masturbating in the classroom. With this awareness, June became very proactive and found support to assist her in teaching Bill about sexual behaviours at a young age. She communicated basic information about feelings and explained to Bill

that sexual feelings were normal. She also communicated information about masturbation and privacy with much success and found that Bill never had an issue at home or at school with inappropriate behaviour. June explained, "we were very proactive. [W]e wanted to make sure he had the skills to cope with situations, whether it be social skills or sexuality."

As Bill became older and developed a relationship with a partner, June found there were fewer places to turn for information for individuals his age. Although some resources existed at Bill's school, a sexual health program was not being implemented in his special education class. June explained her disappointment that when Bill and his girlfriend were caught kissing in the school classroom, the "teachers started freaking out and took a really negative approach to it." June then contacted the special education consultant at Bill's school and suggested a more positive and proactive approach be taken to deal with students' displays of affection at school. The consultant ran a short program on relationships and feelings for students with intellectual disabilities at Bill's school. However, this program was not offered on a regular basis. June thought this was a good start, but still did not answer many of the questions that Bill had surrounding sexuality – there was still a gap there for him. Bill was now in high school and planning to move into a group home and while June was able to communicate information about safety, sexuality, and relationships to her son, she had little support from the school board or from other agencies. June called around to different agencies in her community and found that no one place, including the school board was taking responsibility for the sexual health education of youth with intellectual disabilities.

June saw that there was much more for Bill to learn. She thought it was important for him to obtain information not just about safety, but about healthy relationships and sexuality as well. She wanted to be able to support her son to make decisions about his body and partnerships and not to just focus on the dangers of sex and relationships. June was certain that a tool needed to be developed as a resource for the community that parents, teachers, and other agencies could draw upon to assist in the healthy sexual development of youth with intellectual disabilities.

### **Community support: Development of a network.**

Although there were different agencies such as Developmental Services Access Centre and Community Living that had been supporting people with ID to learn about sexual health, June explained:

I ran into problems because [other] agencies just don't have a curriculum. [There isn't a resource] in a form that could be passed off to somebody and say, 'here, use this' [...] I would say [to those working in the field], 'can I have your material?' And they would say, 'it's in my head.'

So, in 2004, June invited representatives from approximately ten different community agencies to a meeting to discuss the possibility of developing a resource that could be used by everyone in the community. The Waterloo Public Health Unit hosted the first meeting and it yielded only three attendees. June was initially discouraged but continued to call on the agencies again to explain the importance of this initiative. June explained, "I was pretty passionate about this stuff and I think [the agencies] realized I wasn't going to go away!" June continued to host meetings and slowly more agencies became interested. A network was then formed of agencies that were consistently attending meetings. With June as the chair, the network eventually expanded and

became an ad hoc committee comprised of representatives from: Trellis Mental Health and Developmental Services, KidsAbility, Kerry's Place Autism Services, Family Counseling and Support Services, Community Living, Grand Valley District School Board, Dufferin-Peel Catholic School Board, Region of Waterloo Public Health, other community members such as parents of children with ID, and most recently, Women in Crisis.

### **Resources used to develop the sexual health education program.**

Once the Network was formed in 2005, meetings were scheduled every four to six weeks to discuss how to go about developing a resource and what steps needed to be taken to complete the task. After the first few meetings, there was consensus among the agencies that a resource in the area of safety, sexuality, and relationships was needed, but how to go about developing a resource was still under discussion. There was also a consensus that members of the Network would not be able to commit to developing the resource themselves as most members already held full-time employment. One participant explained: "[At that time] we knew we needed the resource but we weren't sure how we were going to go about getting the resources [...] probably about a year and a half to two years into it, we decided that we needed to write a [grant] proposal."

So in 2007, the decision was made to apply for an Ontario Trillium Foundation (OTF) grant to hire a consultant to develop the resource on the Network's behalf. The grant proposal was written collectively by the Network members and submitted as a three-part proposal that included plans to: a) develop a resource, b) develop a train-the-trainer program to assist parents, teachers, and support workers how to use the

resource effectively, and c) plan and conduct an evaluation of the resource in the community. The OTF granting committee suggested that the proposal be altered to focus on the resource development and train-the-trainer program; subsequently, less funding was offered as the proposed evaluation was removed from the application. The proposal was revised and accepted and the grant, valued at \$55,900, was awarded to the Network under the supervision of Family Counseling and Support Services in Guelph in the spring of 2007.

### **Design of the resource: Able to Live, Able to Love.**

After the grant was awarded, the Network began the process to hire an educational consultant to develop the resource. Although the Network was not entirely sure about what qualifications and skills would be needed in a consultant, they did determine that the consultant would require: a) strong writing skills, and b) work experience with persons with intellectual disabilities. After advertising the consultant position, Danielle was referred to the Network by a prominent sexuality education consultant in Ontario. Danielle was interviewed and hired in the summer of 2007. At the time, Danielle was completing a doctoral degree in education and possessed many years experience working with the L'Arche community for persons with ID. Danielle also had experience developing an undergraduate course at a Canadian University about intimacy and sexuality for persons with ID.

At first, there were a number of contract issues that needed to be negotiated before the project could commence. Initially, the Network proposed a contract to Danielle that suggested the project be completed in three parts: a) develop the resource; b) develop a train-the-trainer manual; and c) plan and conduct an evaluation of the resource.

Danielle took a careful look at the budget, at their contract, consulted a lawyer and contract specialist at her faculty, as well as a faculty mentor and went back to them with what she saw as a more realistic proposal. She suggested that it might be more effective to focus on developing the resource as a starting point; she suggested that it was important to have a project with a clear end goal to work towards. Danielle offered a new three-part contract that focused specifically on a well-researched, high quality resource. This included: a) the collection of primary and secondary research by searching databases and conducting interviews with the community; b) use of the collected research to determine the components of the resource; and c) development of modules that reflected the components identified through primary and secondary research. Danielle explained: "For the amount of money the Network had, I felt it was important to focus on doing one thing really well and that was to develop a solid resource that they could use as a foundation for future." The Network agreed to this new contract agreement and Danielle began the preliminary work for the resource in the fall of 2007. From this point, the consultant was given much freedom in terms of content and layout. A subcommittee of three Network members was created to act as the main contact for the consultant for the rest of the contract. During this time, Danielle was required to develop each unit from this guideline with frequent checkpoints from the sub-committee. The larger Network was not involved in the development of the resource from this point on.

Danielle began the curriculum development process by meeting with the entire Network to undertake a needs assessment in order to identify what the needs of the community were. She also met with each committee member separately and conducted

a variety of interviews with parents and persons with intellectual disabilities. Danielle conducted a focus group attended by four mothers of children with ID who communicated their observations about what their children needed and asked for. Danielle also met with six other colleagues not associated with the Network to brainstorm about developing the resource. Through these meetings and interviews, Danielle compiled a list of topics and issues that were raised through her research. In her own words, Danielle interpreted the list of important topics to include:

- Self-esteem
- Periods and menstruation
- Masturbation
- Birth control and protection
- Boundaries
- "Yes" and "no" messages
- Spirituality
- Language
- Resources
- Medication
- Counseling
- Feelings
- Physical space for being together
- Education for parents
- Education for caregivers
- Sex toys
- Prevalent trends and being aware of current language. For example, understanding new phenomena such as: "rainbow parties"
- Sexual expression
- Health and nutrition
- Dressing up and being clean
- Same sex couples

Based on this research, Danielle proposed that the resource be developed in the format of a written curriculum divided into many booklets by topic so that teachers and learners could pick and choose which content area to use in their educational sessions. Based on the research undertaken and the interviews Danielle conducted, a table of contents was outlined by topic and presented to the Network. Dialogue about the



content of the modules ensued through network meetings and emails with Danielle. Once consensus was reached concerning content of the modules, Danielle hired Amber, an illustrator and editor and myself, a graduate student writer and researcher in the field of health professional education, to assist in the development of the resource.

### **Development of the resource: An iterative process.**

Over the next eight months, Danielle developed sections of the content and submitted it to the subcommittee and two community-based parents of persons with intellectual disability for review. This group edited the sections and offered feedback which Danielle used to develop the content further. To develop the content, Danielle and I took the lead role on the first draft of different units based on our respective backgrounds and content strengths. We then worked together to balance each module. Danielle came to the project with a background in pedagogy and spirituality and began the development of the units with more of a social and emotional focus. I came to the project with a background in health and science and thus began the development of the units with more of a physical health focus. Danielle maintained intellectual control and ultimate responsibility for the project.

The final layout of each unit is as follows. Each unit is about 20 pages long with five to ten illustrations per unit. The units are based around written text about a topic or issue. Social stories are also presented to use the information in context. Social stories are small excerpts used to put the information communicated in the unit into context for the learner. Social stories are presented in first person by a fictitious character explaining his or her feelings and thoughts on a scenario. Throughout each unit, there are also one to two sentence checkpoint messages that are used to break up the written

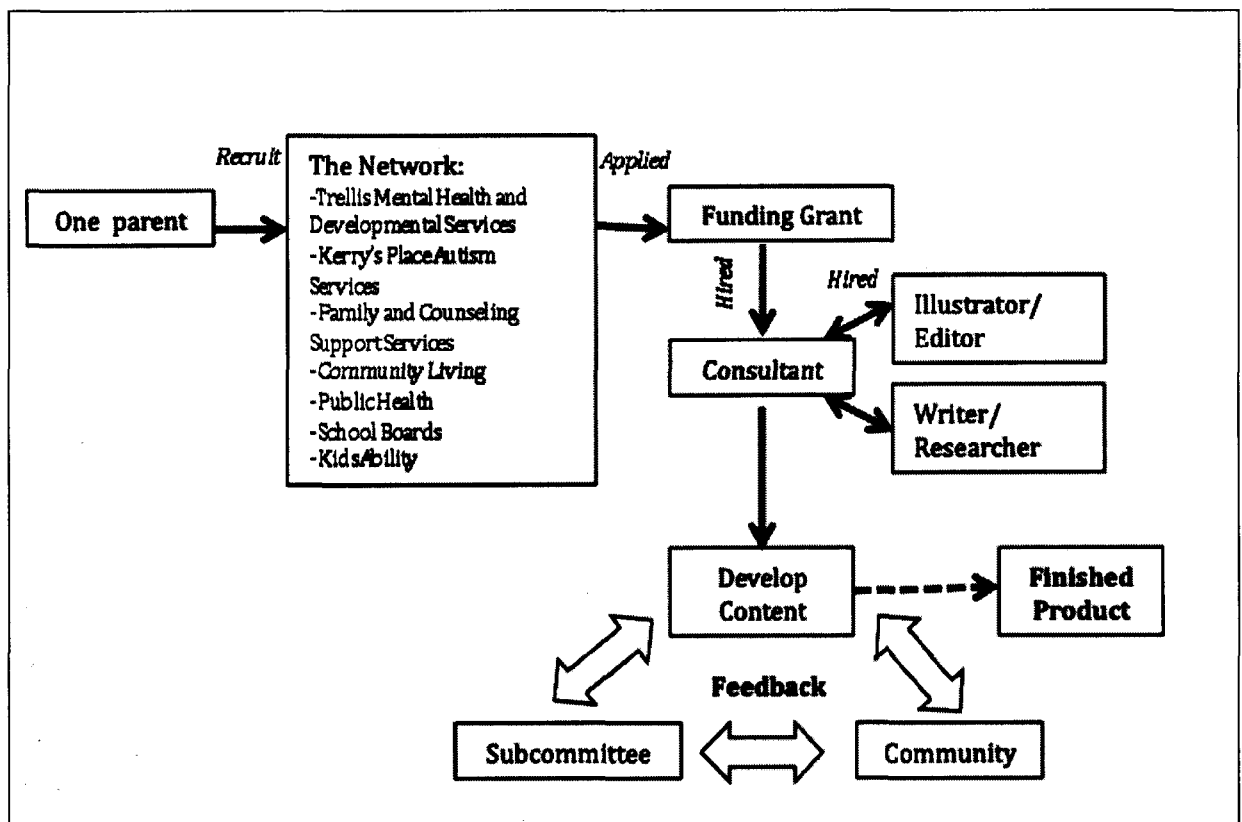
content. Some checkpoint messages summarize sections of the text and are used to repeat important information. In addition, after each important section in a unit, there is an opportunity to pause and complete an activity. There are six to nine activities per unit.

Amber created illustrations for the resource. Through her experience in special education, and the preparatory review of the literature, Danielle knew it was important from a pedagogical perspective to design a resource that included many detailed illustrations, and that this could assist learner's to understand the material. Danielle states: "[I knew there] should be a lot of pictures [in the resource] and it should capture their interest and trigger their curiosity and spark questions." Amber and Danielle used the table of contents of proposed modules as an outline to plan the illustrations for the resource. A large cover page illustration was created for each unit and six to ten illustrations were incorporated into the text of each unit (see Appendix F for an example).

The first full draft that included: the content in each of the twelve units, the Power Point presentations, and the accompanying activity booklet were completed in the late fall of 2008. In November 2008, the first full-length draft of the educational resource was presented to the Network during a day-long workshop. Each unit was presented in detail to the group. Network members received a copy of the curriculum as well as a take home evaluation to fill out regarding the format, content, and presentation of the resource. Feedback received was positive from Network members. All fifteen participants in the workshop rated aspects of the curriculum as either "good" or "excellent" on a take home evaluation with the rating scale of: 1) poor, 2) satisfactory,

3) good, or 4) excellent. A copy of the evaluation is provided in Appendix G. There was limited constructive feedback obtained from this exercise. After the workshop, editing continued guided by feedback provided by the network and parents until the end of December. The resource was then formatted into booklets and printed for use in February 2009. See Figure 1 for a timeline of events.

Figure 1 Historical Development of the Sexual Health Education Resource



#### **Pilot test of the resource: Able to Live, Able to Love.**

In February 2009, an informal pilot test of the resource was carried out in Guelph, Ontario. Three Network members planned to run eight workshops over eight weeks. Workshop sessions were run once a week for three hours. The three workshop facilitators met the day before each workshop to plan the sessions. Twelve adult

participants with ID attended the sessions; six participants (3 couples) were in relationships with each other and three support workers were present assisting five participants. The support workers who attended the sessions worked with the participants in a professional capacity as social workers or group home leaders. Each participant received a copy of the resource and workshop leaders discussed the content in a group format with accompanying illustrations, diagrams, and props. Workshops were very dialogical in format and encouraged discussion, questioning, and openness from the participants. These workshops were an effective informal way to assess how the community might receive the resource. Participants raised many interesting questions and issues that could potentially be elaborated in future versions of the resource, or by facilitators working with the resource. Participants and support workers also completed an evaluation of the workshops surrounding the resources' strengths and weaknesses, as well as future suggestions. The researcher took detailed notes during the workshops and will suggest incorporating these topics in subsequent resource revisions.

This concludes a historical portrait of the development of the sexual health education resource, from the inception of the network to the design process of the resource. In the next section, the enablers, challenges to, and motivations for, the development process are examined.

## **Part 2: Enablers and Challenges to, and Motivations for the Development Process**

Analysis of the data revealed salient themes related to the process of developing the sexual health education resource for persons with intellectual disabilities. Themes were categorized as enablers, challenges, or motivations (see Figure 2). Themes were

considered salient if they were identified by at least four (50%) of the participants. However, many of the themes were identified by more than four of the participants.

### **Enablers.**

A number of enablers to the process of developing the sexual health education resource were identified through analysis of the data. These included: collaboration, feedback, and flexibility.

### ***Collaboration.***

The most frequently mentioned enabler to the development of the sexual health education resource was the collaboration between various interested parties to develop a community initiative. It was frequently acknowledged that a resource for the community would not be successful without the involvement of as many members of the community as possible. Six participants credited collaboration as enabling the community to develop a list of needs, successfully obtain funding, and create a comprehensive resource. One participant suggested: "I don't think this project could have happened without so many people working together." Another participant stated: "I think it's important to have collaboration because without it, it would have been much more limited... it was good to have that conversation and interaction." Involving so many different representatives helped keep each agency accountable to one another. One participant elaborated:

People come with the expectation that there's going to be something that they need to do, some contribution that they need to make, and the agencies when they become involved have the expectation that they are going to be putting some of their resources towards this project.

The collaboration of agencies and community members was identified by six participants as having contributed to the development of a comprehensive resource that covered a variety of issues experienced by persons with ID, parents, and support workers. Collaborating on a large scale facilitated the Network's capacity to consider different issues and address gaps in knowledge. One participant explained:

I think when you create something like this and you don't involve [as] many people [from] the community you can't cover as many areas of concern that you can when it's just two people who create a course and deliver it. I think the ideas and concerns, whether it's Public Health, whether it's KidsAbility, Trellis, the school boards, I mean they see things that we don't see and vice versa.

Although collaboration was identified as an enabler, the benefits of even more collaboration were identified. One participant suggested she would advise another group approaching a similar project to:

Try to get as many people around the table as possible, and not limit it [...] I don't think we had any intention of limiting ourselves, but I think that inadvertently we did as we were seeing this as relating to people with developmental disabilities without an appreciation for how many little threads through the community that would involve.

So in retrospect I can sit and say, we should have had more involvement. Because... if we had police for example, it is just more education for them because I often find a lot of our folks are involved with the justice system [...] So I would say, expand it further; pull in more people.

Another participant suggested:

I think my advice would be to have [the development process] as a collaborative effort. Pull in everybody that's connected, or would ever be connected, to developmental services. So: school boards, mental health, developmental services, public health, hospitals, police, [...] justice, physicians, sexual assault centres – so bring in representation from all areas [that may] have contact with someone with [a] developmental disability someday.

In summary, collaboration was the most frequently identified enabler to the development of the sexual health education resource. Some participants indicated that upon retrospective reflection, broader collaboration might also have been beneficial.

### ***Feedback.***

In addition to collaboration, six participants acknowledged the feedback process as a significant enabler to developing the resource. The network offered feedback to the consultant in the form of written edits of the resource units, and through several face-to-face meetings. Whenever the consultant finished a written draft of a unit, it would be sent to the three, subcommittee members, and three community parents. Each of these six community editors would provide written feedback on the draft in the form of edits, comments, and suggestions. The feedback was primarily informal and reflective of each community editors' personal or professional experience of the topic or issue being discussed. One participant explained: "we would get feedback from [the three parents...] some would be focused on grammar and structure and format and some would be more focused on the content and the flavour of things." On the importance of gaining feedback from community parents, one participant suggested: "Families who deal with stuff everyday, they know the questions that their kids are asking." Two participants explained that feedback from parents was considered important to the development of the resource as it truly made it a community process. In their own words:

[The parents] could feel that they were involved in the process, and they could feel that yes, there was a progress happening.

And I think the community as a whole were really happy to have the opportunity to have that input. So they didn't one day get a finished product and say 'well this is

wrong and that's wrong and what about this and what about the other' – they were really involved throughout and made it a better product in the end.

Another participant explained the importance of feedback from the subcommittee, all of who were front line service workers with persons with ID:

Front line workers know the issues that are coming up, whether it be birth control, or same sex relationships, or lack of resources. Like these are the people doing the work everyday and they know what the people with developmental disabilities are asking for.

Feedback from persons with intellectual disabilities came mostly in the form of the evaluations of pilot test workshops. Seven participants considered feedback from persons with intellectual disabilities exceptionally important. With respect to participation in the feedback process, one participant suggested:

I don't think [persons with ID] even know their involvement really. I think through their feedback and questions that they ask [...] that might be something we go ahead and incorporate into the next session [...] So it's kind of like a trial and error basis, the feedback you get then will make changes to the following one and so on.

Another participant explained how feedback from persons with ID was obtained:

[During the pilot test workshops] we were constantly saying to them, you know, 'is this ok? Do you need more? What do you want to know about?' And there were questions that guided us in directions that were not always covered in the curriculum. So it gave a lot of food for thought for the next stage of development and any revisions that might be made.

Two participants explained the importance of feedback of persons with ID to the development of the resource. In their own words:

It isn't about what we want them to be; it's about exploring who they are and supporting what they need to live a fuller life and we don't know what that is until they tell us or until those who are supporting them can tell us what they've observed. So to have that feedback is crucial to developing something like this. We're dealing with issues of their relationships and we're dealing with enhancing their lives.

They're our intended audience, right? So if we don't know whether we're reaching them [...] then what is this all about?



Thus, the importance of a feedback process was another frequently identified enabler to the development of the resource.

### ***Flexibility.***

The need to be flexible was identified as another important enabler to the development of the sexual health education resource. Each of the four network members who participated in the facilitation of the pilot test workshops suggested that it was important to be flexible with their attitudes and lesson plans. In one participant's words, "we needed to think quickly on our feet." One facilitator discussed the ways in which flexibility was important during the workshops: "The flexibility to move our teaching style towards the needs of that group and when you deal with such a diverse group of needs, it's like I said, it's essential that we were flexible." A number of participants indicated that the flexibility of the resource enabled facilitators to try different methods during the pilot test that could be brought into future revisions of the resource. On how to be flexible while facilitating the resource, one participant suggested: "Remove all of your assumptions, remove all of your morals immediately, and just be open to listening to what they have to say." Thus these participants identified flexibility as an important enabler to the development of the resource as it allowed Network members to receive helpful suggestions for future revisions, and it allowed the resource to be used in ways that were responsible to different needs.

### **Challenges.**

In addition to enablers that assisted in the development of the resource, there were a number of challenges as well. The most salient challenges identified by participants

included: mediating value conflicts, a lack of clearly defined roles and responsibilities, and differences in expectations versus reality.

***Mediating value conflicts.***

Five participants identified value conflicts pertaining to the development of the resource as a challenge. Value conflicts occurred between various members of the Network and between the consultant and various network members in terms of the development of the resource. Each of the five participants indicated that when the resource units began to be sent to the subcommittee and parents for editing, there were particular spiritual or religious values present in the writing. One participant offered an example of this:

Originally the curriculum had been written with spirituality woven through each unit and the feedback from the community was, that's nice but it's going to be a barrier for some folks. Some folks are going to like that and some folks are going to read it and say: I can't use this.

Another participant stated: "When I first saw the writing was saturated with religion, I was concerned. It wasn't what we had asked for and it wasn't going to be applicable to the wider community." Five participants acknowledged that values, morals, and beliefs were important in relationships. Some participants noted that it was up to the readers to decide what they determined to be important values about relationships and not for the resource to make suggestions in this regard. A participant acknowledged:

You can't remove your morals. That's what makes you who you are. I guess that's why it's so important, you let everybody in the group be who they are and not try to implement or indoctrinate your morals onto them.

One participant explained: "The feedback from the community was, can you take [the religious aspects] and put it into a separate unit." So, the resource was edited to remove

references to spiritual perspectives and an additional unit was introduced for those who wished to consider sexuality and relationships from a spiritual perspective. Thus, value conflicts proved to be a challenge to developing the resource, however in the end it was mediated through revisions to the resource.

***Lack of clearly defined roles and responsibilities.***

*The Relationship, Sexuality, and Safety Education Network of Guelph-Wellington and Dufferin Counties* was an ad hoc committee comprised mostly of volunteers from community organizations and agencies. Each Network member from an agency was allocated some work time towards the development of the resource by his or her managers and executive directors. However, within the Network, a participant stated that members "had varying degrees of time available and commitment from the executive of their agencies." As a result, four participants indicated that meetings were difficult to schedule with a large committee of working professionals and attendance varied with every meeting. Because of the variable attendance, there was also a lack of clearly defined roles and responsibilities during the meetings so meeting minutes were not recorded consistently. The chair stated: "I stopped doing minutes because I didn't have the time and no one else volunteered." A lack of clearly defined roles and responsibilities also caused some Network members to take on much more responsibility than they expected. One participant explained the reality of ad hoc committees:

This is what happens in groups like this, you don't end up having a fair and equitable distribution of workload. People sort of do what they can. Even if [a network member] cannot make it to every meeting because they're really busy; we still need them and their representation of the different agencies.

Thus, even though not all Network members contributed equally, representation from many different organizations was considered important.

Another consequence of the lack of clearly defined roles was that there was a lack of clarity concerning budgetary control. One participant highlighted challenges with managing the budget. :

It would have been nice to have one person responsible for the budget, probably the lead agency who spent a little more time and effort ensuring that budgetary issues were not being made by [the consultant] instead of the committee.

Due to a lack of clarity regarding leadership roles, budgetary issues were difficult to manage. The consultant indicated that she prepared a budget for the editor, for an illustrator and for a research assistant that was approved by the network. One participant expressed a concern that the: "The consultant took control of the budget, which is something that shouldn't have happened." The consultant worked more independently than some members of the network appeared comfortable with, however ultimate approval for each invoice rested with the network.

Thus, the lack of clearly defined roles and responsibilities provided a logistical challenge in developing the resource in terms of leadership, keeping detailed notes and records and maintaining consistent attendance at Network meetings and budgetary decisions.

### ***Differences in expectations vs. reality.***

Four participants suggested that since this project was a new experience for them, expectations pertaining to the development of the resource were often different than the reality. Some participants indicated that they hadn't realized the scope of the project at its inception; the development of a quality resource took longer than they had

anticipated, and expectations were at times overly ambitious. One participant explained:

It was a much bigger project than any of us anticipated. We had hoped to have much more done, we had hoped to have the pilot test done last fall, we had hoped to have some feedback from that and that never really got done with the strict scrutiny that we hoped for it to be.

Many participants did not expect the project to take as long to complete as it did and timelines relating to the development process had to be renegotiated.

A disconnection between the expectations and reality was also identified in terms of the ease of the resource development process. Two participants explained how there was an expectation that the feedback and editing process would be simple, but in reality, the process was messy. One participant explains:

Where I ran into problems was the endless edits. I really bent over backwards [...] I mean I wanted anyone who had an idea to give it and they became quite unmanageable. I lost track of the drafts and who did what [...] I tried as much as I could to include the ideas but they came at different times, they came in different ways, electronically and hardcopies. I think it was ok, but it was not the best way to go about it.

Another participant added: "Edits were more extensive than I expected and that was difficult. It was hard to do intense editing on a document in a time limit. I had other commitments. I had a job."

Of the four participants that identified expectations vs. reality to be a challenge, three suggested that their overall satisfaction with the resource helped balance the fact that it was not possible to accomplish as much as they had initially hoped for (for instance it was not possible to complete a pilot test). In regards to not being able to complete the pilot test, one participant said: "In some ways that was somewhat a disappointment but balance that with the reality that we got a good quality product."

Thus, differences in expectations vs. reality were a challenge to the development process.

### **Motivations.**

Motivations for becoming involved in the development of the resource were identified by all eight participants. Motivations included: a desire to educate persons with ID about their sexuality, a desire to prevent abuse, a desire to create an accessible resource, and recognition of the need for a cohesive approach to sexual health education for persons with ID.

#### ***A desire to educate persons with ID about their sexuality.***

All eight participants suggested that a desire to educate persons with ID about their sexuality was a significant motivator to developing the resource. One participant suggested he had recognized a need for a sexual health education program for persons with ID "for years and years." Educating persons with ID about advocacy was identified as a program goal for four participants. One participant stated: "I wanted one big message in this resource to be one of advocacy for their rights, and for their needs as human beings." Another participant explained:

It's not necessarily what we taught them, but that we taught them something at all about this issue and that we created a safe environment for them to be in this world of sexuality, to be sexual people. When so often people with disabilities are excluded from exploring their sexuality, they've been castrated, you know, they've been sterilized, literally. So, this is a huge change when the one thing that they can learn from this, the one thing they can take away is that it's ok to be sexual, no matter what disability they are facing or what disability they have.

These four participants were concerned with the 'big picture' of the program in terms of advocating for human rights, and creating a safe environment to consider the sexuality of persons living with ID.

Four participants also expressed a desire to educate persons with ID about their sexuality and they had specific topics and issues that they suggested needed to be discussed. One participant explained how the particular elements of the resource were reflective of the needs she perceived in the community:

So when it came to what elements do we want to see in the curriculum, it was pretty much the same process of everyone just bringing their own experience, their own clinical experience to the table and saying ok, this is what I see in the community, this is a resource that I see is lacking, and these are the topics that need to be covered and these are the gaps in the resources that we see out there.

Thus, all participants expressed a motivation to educate persons with ID about their sexuality. In particular, four participants indicated that helping persons with ID develop to become advocates of their rights as sexual human beings, sexual self-advocacy was an important motivator toward their participation in the development of the resource.

### ***A desire to prevent abuse.***

A primary motivation for all eight participants becoming involved in the development of the resource was the desire to prevent persons with intellectual disabilities from becoming victims of sexual assault and abuse. One participant acknowledged the high rates of abuse in persons with ID and how education may help prevent these situations: "Well I think that it will give [persons with ID] a comfort level, and to know that it's ok to have those conversations with people [that they trust because;] the abuse thing is huge." Another participant suggested teaching about

consent as a means of preventing sexual abuse was important; she stated: “clear messages [need to be] given about consent, that you have to say yes if you want sex.”

Three participants shared personal anecdotes about sexual abuse experienced by a client with ID. One participant reported a disturbing story that “would not leave [her] mind”:

My coworker had a client who was very challenged and cognitively impaired [...] and there was a huge case where Community Living suspected or discovered she was pregnant and it turned out [that] her stepfather [was the father]. And that sticks with me. Because this girl is so vulnerable and she needs support 24/7 and someone who she is supposed to be able to trust and someone who’s supposed to support her in her life would abuse her in that fashion... just, yeah, gets me a little hot under the collar.

Another participant shared an upsetting story:

And personally I have a client that was actually abused by his doctor for years and years. And just to feel that sense of empowerment and learn the ability to self advocate and that you have the right to speak up and there are people here to help you... it’s just amazing.

One participant explained her motivation for wanting to prevent abuse by sharing her knowledge of sexual abuse statistics: “The abuse rates are so high, 80% of people with developmental disabilities are abused in some way shape or form.” All eight participants mentioned the prevalence of sexual assault and abuse to be disturbing.

About protecting her daughter from the high statistics of sexual abuse in persons with ID, one participant stated: “I don’t want her to be one of the stats. I’m so lucky she is not one of the stats. So if I can give all the info she needs to help her avoid that, of course I’m going to.” Thus, a strong motivation reported by participants for being involved with the development of the resource was a desire to prevent further cases of abuse and assault. Three participants had shared personal and professional examples of



sexual abuse incidents and all eight participants indicated concerned about the high incidence of sexual abuse in this population.

***A desire to create an accessible resource.***

Five participants suggested it was imperative to create a resource that was accessible to members of the community. The Network wanted to create a resource that could be used by a variety of different agencies, community groups, or individual families and not limit it to the agencies involved in the Network. One participant explained the importance of disseminating the material widely:

It's about keeping the material alive; it's not something we want shelved. And ensuring that groups are set up so that people in Guelph-Wellington county can be part of an education series [...] and it's really important for me that the curriculum [is] brought up there for people who reside in the North parts. So I would hope that it would get spread like wildfire that everyone can take and at least have a copy and understand it.

Three of these participants also noted that it was important to keep the resource financially accessible. Members of the Network made the decision to print the resource privately and sell it for the cost of printing – about \$50 CAD. The Network avoided using a publishing company with the expectation that costs would rise, and be prohibitive for some. One participant explained: “we want [the resource] to be accessible and palatable to as many people as possible.” Another participant explained his agency’s concern about accessibility and the desire to only advertise a resource that could actually be obtained by those who want it; he states: “everyone in our agency [...] is excited and I’ve had lots of questions about it and [they] want to know how [financially] accessible it is.” Thus, the Network took responsibility for printing the resource to

ensure that it remained accessible to anyone who wanted it, including people living with ID, their families, and agencies.

***A desire for a cohesive approach.***

Participants frequently indicated that a cohesive approach to sexual health education for persons with ID was required in the community. Five participants suggested that there were different resources available for specific topics related to relationships and sexuality, however that there were no comprehensive programs available that addressed a variety of issues. As one participant stated:

There isn't one source that you can go to and get all those things covered. You're really putting together makeshift stuff, a little bit from here, a little bit from there and a little from some place else and there's still gaps and there's not a smooth, coordinated approach to it.

Many participants reported that they were interested in a resource that was readily available in the community and covered a variety of topics. One participant explained that the public health unit presentations available in the community are great, however that public health nurses offer general education, that does not focus on special issues important within for persons with ID.

Public health nurses are great to come and discuss sexuality, and diseases, and condoms, but they do not help develop the same understanding about judgment. There is no comparison between [Able to Live, Able to Love Resource] and public health.

Thus, these participants were motivated to create a single resource that provided a "smooth, coordinated approach" to sexual health education for persons with ID.

Overall, enablers, challenges and motivations contributed to the development of the resource in different ways. Enablers helped the development process along, while challenges slowed the process but provided food for thought and the opportunity to

develop solutions to overcome the challenges. Motivations helped to inform the purpose of the resource inspire the overall development of the resource, and kept the Network members united and working together to accomplish their shared goals.

### **Part 3: Strengths and Limitations of the Program and Further Recommendations.**

Each participant reported important strengths and limitations of the resource. Participants offered their perceptions about what the program did well and where it could improve as well as offered insight into the future direction of the resource.

#### **Strengths.**

The strengths of the resource as identified by participants were: the comprehensiveness of the resource, the use of textual examples, and the flexibility of the resource.

#### ***Comprehensiveness of the resource.***

The most frequently identified strength of the resource was its comprehensiveness. All eight participants expressed satisfaction in the comprehensiveness of the completed resource. The resource was described as comprehensive because "it really encompasses everything." One participant commented on the breadth of content covered in the resource.

Again, this curriculum is not just about sex, it's the circles program about healthy relationships, its rights, its consent, and of course there is the sexual aspect too. It covers so many areas that aren't covered and I think that's wonderful.

All participants also explained that other sexual health education resources were available in the community, but that they were limited in some way. One participant highlighted these limitations:

[Before Able to Live, Able to Love] the areas were limited which was unfortunate. Public health has always been a wonderful resource as far as presentations [because] well even things like [people with ID are] on limited budgets so some people don't buy condoms because they can't afford them so public health has provided that. There have been workshops, I attended a 2 day seminar in Waterloo, the survivor workshop [through Developmental Services Access Centre] and it was good, it was fun and exciting and it was interactive and it kept the clients interested and they really got a lot from that. But this differs because its not just a 2 day, its not short [...] I keep saying intense, but it really tackles issues and it opens the door for questions they have that I don't think they feel they get that opportunity to ask questions.

Although aspects of the resource can always be improved, two participants explained their impressions of the resource. In their own words:

There [are] certainly a lot of good things about the curriculum and we, again, I say we feel we have a really good product. When I looked at it when it was finished, I thought: yeah this is good. But after having seen it put into practice I'm like just blown away by it – I think it's fabulous. And there's always going to be something you want to change so there are all those things that come out and I'm sure with every group that we do, there's going to be more things that we discover that certain people want.

I really like what we did with it, and obviously since it was the first time there's a lot that needs to be done to tweak it and make it more efficient; it obviously wasn't perfect, but I think it'll be interesting to see what other community organizations... what they do with it the first time and what they learn from it

Thus, the comprehensiveness of the resource was identified as a major strength as it contributed to the resource's overall quality, and distinguished it from other available resources in the community.

### ***The use of textual examples.***

Four participants indicated that the text and social stories provided helpful examples as to how to discuss certain topics and issues. One participant identified the benefit of having examples to draw from:

This program provides a benefit because [when teaching people with ID] you need to be specific with examples. You can't assume [people with ID] just know it or can

simply learn through life's experiences like through osmosis. Sometimes it has to be explicit.

One parent indicated her appreciation of examples in the text that reinforced important concepts. She explained: "as a parent of a child with an [intellectual disability], I know that unless he's getting reinforcement all the time, he's not remembering this stuff."

About the benefit of social stories in the resource, one participant said: "[in the resource...] you can tell that story and then add to it [...] So to me, it's all about making the program flexible to the target population." Another participant said:

I think [the resource] is a really good format to use [...] the booklet format because its broken into chapters is great and they can bring it home [...] you can incorporate those social stories and ... you can expand on them as well, and you can personalize them.

One of the participants who facilitated the pilot test identified the use of social stories as a strength that allows even those who are uncomfortable with discussing the content to use the stories and examples in the resource: "So if you aren't comfortable discussing it, you can jut read it. And that's one of the reasons why I like this resource specifically." Overall, the use of examples and social stories was identified as a strength of the resource that contributed to its ease of use.

### ***Flexibility of the resource.***

The flexibility of the resource in terms of its content and structure was identified as a strength by all eight participants. The content was flexible in that it covered a range of topics and was open to further expansion and revisions by the teacher or tutor. As two participants explained:

The program is like a springboard. There's something to start with and lead to more conversation.

The fact that this program is created as a skeleton, a very solid skeleton [...] I appreciated that. It allows the presenter but also the participants to build their own program around this core set of questions [...] it really hit the root questions and allowed for exploration if interested.

Participants also acknowledged the importance of designing the resource in a flexible format that could allow the learning needs of a variety of different learners to be met.

I think we also wanted the [units] to be stand alone, so that you didn't have to do unit 1 in order to do unit 2 and so on and so forth. So you could pull out one unit and it was stand alone material.

For example, a stakeholder suggested that users should be able to pick and choose topics that are relevant to the situation or developmental level of the learner:

Because there are things in there that wouldn't necessarily be presented to every person at every stage of development. If you just need to teach somebody about how their body works you wouldn't necessarily get into the sexual expression, for example if you're talking about a seven year old, right? So it's a really good format to have it in.

Thus, the flexibility of the resource was identified as a significant strength of the resource that allowed it to be tailored to different populations and abilities.

### **Limitations.**

Limitations of the resource that were identified by participants included the inclusiveness of the resource for all groups as well as the limited participation of persons with ID in the development of the resource.

#### ***Inclusiveness of the resource.***

Four participants suggested that the resource might not be written in a way that is inclusive of all learning abilities. For example, one participant suggested a limitation of the resource is that the activities may be difficult for some persons with ID to complete because "some people can't get up and role-play because they're in a wheelchair; some

people can't write down their answers [in the activity booklet] because they're illiterate or unable to form proper sentences." Thus, the way in which the resource is presented may prove to be a barrier for some who want to use it. However, when considering a resource that is fully accessible and takes into account all learning abilities and limitations, one participant defended the resource and suggested it would be too difficult to be truly inclusive. He stated: "I mean how many are you going to include? There's a huge [range] of disabilities. To be completely inclusive in a book form would require an encyclopedia." The same participant suggested that the onus should fall on the tutor to tailor the resource to the individual or group that is using it. He suggested: "Each time [the resource is used, there will be] a unique set of disabilities that will have to be addressed in a new way every time."

***Lack of participation of persons with ID.***

Another limitation identified by seven participants was the lack of participation of persons with ID in developing the resource. When discussing the participation of persons with ID in the development of the resource, one participant explained: "[they were involved] to a very limited extent, which may be one of the limits of the curriculum. I don't recollect having specific conversations with any persons with disabilities in Guelph." Another participant suggested: "I don't think the target population had been included enough in the development. I hope the next time around we can involve them more. I think the involvement is going to come more in the evaluation and rewrites." Though persons with ID were indirectly involved in the development of the resource through the pilot test and the experiences of their support workers and family members, few persons with ID were directly involved in the

development process. Danielle consulted with one parent and her daughter with ID continuously throughout development process, but other persons with ID were not consulted as directly. As will be discussed in chapter five, these limitations will be considered in the future plans for the resource.

### **Further Recommendations**

As identified above, all of the participants appeared pleased with the final resource because of its strengths. However, as with any community initiative, a number of recommendations were identified for those interested in approaching similar projects in the future. The most cited recommendation was the inclusion of more persons with ID in the development of the resource. Participants acknowledged that the consultant had experience working with persons with ID. One participant explains:

[Danielle] was very connected to L'Arche, [...] So I think that she was connected to people, so I believe that she had more contact with self-advocates. But with respect to the curriculum the meetings that were held that I was apart of there were no [persons with ID present]."

The consultant reported discussing topics of sexual health and relationships with one particular adolescent with ID throughout the development phase, however a recommendation to include representation from persons with intellectual disabilities on the *Relationship, Sexuality, and Safety Education Network of Guelph-Wellington and Dufferin Counties* was put forth. One participant stated: "You know I'm almost ashamed to say, or embarrassed to say that we didn't have from my knowledge, [persons with ID] advising us on this resource." Persons with ID participated in an informal pilot test in the community following the development of the resource, and so feedback was also solicited in this way, however they were not directly involved in the development of the resource through the Network.



A second recommendation highlighted by participants was the establishment of stronger group leadership in the future. Because the network came together as an ad hoc committee consisting entirely of volunteers, clearly defined leadership was an issue. As was mentioned earlier, one participant stated the challenges of working as an ad hoc committee: "This is what happens in groups like this, you don't end up having a fair and equitable distribution of workload. People sort of do what they can." However, how to go about developing strong group leadership was not identified.

A third recommendation identified by participants was that it would be important to expand the resource to be more inclusive for persons with lower cognitive levels and/or communication difficulties. Despite the designers' emphasis on the inclusion of pictures within the text, one participant said that a community parent expressed concern that despite the inclusion of pictures, there was also a lot of text within the resource. The participant explains: "I know we didn't satisfy one parent in particular. I know she said: this probably isn't going to work for my son." One participant suggested:

I think it's an excellent curriculum, what we have so far, but [...] videos and whatnot [...] I think it needs to be woven in somehow. Or maybe a video created for the people who are nonverbal. And I know some parents who were advising on the curriculum were quite concerned about that.

Another participant suggested: "having it online and interactive would help engage youth. Many students are drawn to the computer, it's their new medium of choice."

Thus, participants identified many opportunities for expanding the resource in future editions through including more persons with ID in the development of the resource, developing stronger group leadership, and making the resource more inclusive.

## Summary

In this chapter, the findings of the resource were discussed in three parts. Part one outlined the historical development of the sexual health education resource for persons with ID. Part two, the most substantive section of the findings, highlighted enablers, challenges, and motivations to the development process. Part three highlighted strengths, limitations, and recommendations for the future of the resource identified by stakeholders. In chapter five, the findings are discussed in light of the literature review. In addition, implications of the study for future practice are discussed, and conclusions are drawn.

## Chapter Five: Discussion

This study has undertaken a case study to address the research question: What is the process by which stakeholders in the *Relationship, Sexuality, and Safety Education Network of Guelph-Wellington and Dufferin Counties* developed a sexual health education program for persons living with intellectual disabilities. In this chapter, the findings of the study are analyzed in relation to the research question and the research literature. The chapter begins by discussing the identified needs for sexual health education programming in the local community and in the literature; this is followed by a discussion of the processes that contributed to the development of the resource and may be relevant to other groups, as well as further considerations in the development process which arises out of reflection on the process, lessons learned, and what might have been improved. Implications for those interested in developing similar programs in the future are highlighted throughout the text. Implications for persons with ID, those who support persons with ID, schools, and resource developers are also discussed. Finally, the strengths and limitations of the study, and directions for future research are identified.

### **Sexual Health Education Programs: Identifying the Need**

Both the findings and the literature identified a need for sexual health education programming for persons with ID. In light of this, one might speculate that a need for sexual health education programming is likely present in numerous communities across Canada and around other parts of the world. The findings identified a number of reasons why the *Able to Live, Able to Love* resource was developed. These included such things as: a need to enhance the general knowledge about sexual health of persons with

ID, the need to prevent assault and sexual abuse, and the need to develop specialized sexual health education programming.

### **Need to enhance knowledge about sexual health of persons with ID.**

The need perceived by parents and members of the community to enhance knowledge about sexual health of persons with ID was a main reason for the development of the resource in the current case. This is consistent with research literature that frequently identifies limited sexual health knowledge of persons with ID as an important social issue (McCabe & Schreck, 1992; McCabe & Cummins, 1996; McCabe, 1999; Galea, Butler, Iacono & Leighton, 2004; Leutar & Mihokovic, 2007). For example, McCabe (1999) found that persons with ID are overall less knowledgeable about sexuality than the general population. In terms of what those needs are, participants in this study acknowledged that as well as educating people about factual information about sexual health, STIs, and human anatomy that promoting self-advocacy and sexual rights education were equally important. The desire to create a safe environment for persons with ID to be in the world as sexual people was expressed by a number of participants. This is consistent with Kempton & Stiggall, (1989), Sugar (1990) and Whitehouse & McCabe (1997) who suggest that it is important to provide more than factual information during sexual health education, and to promote positive feelings about sexuality. Some participants suggested that a long history of negative attitudes towards the sexuality of persons with ID might have contributed to a context in which people were not aware of the needs for sexual health education. This was corroborated in the literature, which frequently identifies negative attitudes towards sexuality for persons with ID as a barrier to receiving sexual health education (Irvine,

2005; Douglas-Scott 2004; Cuskelly & Bryde, 2007). The study raises awareness of the importance of equipping persons with ID and those who care for them with broad knowledge about sexuality and sexual relationships. The resource developed by the group addresses this concern through presenting relationships and sexuality as a positive and a natural part of being human.

### **Need to prevent sexual assault and sexual abuse.**

The need to prevent sexual assault and sexual abuse was another reason identified by the community to develop the resource. The findings revealed that a number of stakeholders knew of professional and personal stories of sexual assault cases with persons with ID as victims. This concern is supported by statistics that document high rates of assault amongst people living with ID (Rousso, 2001; Stimpson & Best, 1991; Kempton & Stiggall, 1989). In particular, O'Callaghan & Murphy (2007) and Leutar & Mihokovic (2007) have reported low levels of knowledge on the part of persons with ID in terms of understanding consent and sexual assault laws. The resource developed by the group attended to this issue by focusing on personal rights and communicating that everyone owns his or her body and has the right to make decisions about physical contact and relationships. The resource also encourages persons with ID to identify an adult they trust who can provide support or guidance if they become uncomfortable in a relationship. Of relevance to others wishing to develop similar programs is recognizing that the persons with ID that their program targets may have been victims of sexual assault or be particularly vulnerable to becoming victims of sexual assault. Though all cases of assault cannot be prevented, it is plausible that educating persons with ID about sexual assault laws and consent could help individuals identify unsafe

situations and seek help. Thus, treating personal rights and consent as a priority during sexual health education programming is an important consideration for those wishing to develop similar programs.

### **Need to develop specialized sexual health education programming.**

The need for sexual health education programming that attends particularly to the unique needs of persons with ID, in the Guelph-Wellington and Dufferin community, was another reason identified in the findings for why the resource was developed. Extensive literature suggests that specialized sexual health education for persons with ID is important (Whitehouse & McCabe, 1997; Public Health Agency of Canada, 2008; Wolfe & Blanchett, 2003, Irvine, 2005; Murphy & Young, 2005; Sweeney, 2007). In particular, authors such as DiGiulio, (2003) and Whitehouse & McCabe (1997) have suggested that individuals with ID require more emphasis on social and emotional aspects of sexuality and relationships in sexual education programs. June's limited success in finding specialized sexual health education resources that targets the needs of persons with ID was consistent with findings reported in various studies which reveals a paucity of such programming at both the school and the community level (Coren, 2003; DiGiulio, 2003). When June began searching for programs for her son, a comprehensive program that covered a variety of sexual health education topics and issues for persons with ID, that was accessible to the community, could not be found. Public health units and the school system offered general resources that were not tailored to the special needs of persons with ID. Other resources did exist in the Guelph-Wellington and Dufferin community; however, as June mentioned, she would ask local educators and social workers: "Can I have your material?" And they would say,

‘it’s in my head.’” Of the written sexual health education resources tailored to people with ID reviewed, some limitations were that they were not comprehensive (i.e. Walker-Hirsch & Champagne, 1983; Cressman, 2007; Hinsburger, 2008), or not accessible due to financial restrictions (i.e. Kempton, 1988) admission requirements (i.e. Carter, 1999; Klee, 2009; Mia, 2007), or location (i.e. Frawley, Johnson, Hillier, and Harrison, 2003; Sheppard, 2006).

The need for sexual education programming that is tailored to the unique needs of persons with intellectual disabilities has clearly been identified in the literature and in the Guelph-Wellington and Dufferin community. In response to this challenge, the network developed the *Able to Live, Able to Live* sexual health education resource, which aims to respond to the challenges identified above, and is tailored to persons with ID. The effectiveness of the resource in terms of its educational purpose has still to be determined through future pilot testing and evaluation. The resource however will only be used to respond to needs identified at the local level. The findings and the review of the literature raise questions concerning sexual health education programming beyond the local level. The need for such education appears to be widespread, and this particular case suggests that it may well be applicable to other communities in Ontario, Canada, and communities across the world.

### **Strengths of the Development Process**

A discussion of strengths of the development process may be helpful to others who are designing similar programs in the future. Strengths of the development process that will be discussed are: the collaborative and iterative design process, using

pedagogical techniques, the resource's accessibility, and the commitment of stakeholders.

### **The collaborative and iterative design process.**

The process of collaboration between Network members, the community, and resource writers appeared to be one of the most important enablers to the development process. Though not frequently acknowledged in the literature, the Public Health Agency of Canada (2008) suggests that in order for sexual health education programming to be comprehensive it should be coordinated and integrated between different agencies and stakeholders. The collaborative process of the different Network members, community parents, the consultant, the illustrator, and myself was quite extensive. In addition, during the development of *Able to Live, Able to Love*, persons with ID indirectly participated in the design of the resource through feedback interpreted by their parents. As was discussed in the findings, chapters of the resource were developed and community parents would take it home to read to their children with ID and bring it back to the Network and the consultant with suggested edits.

The collaboration of the Network and the community likely contributed to a better resource. Extensive collaboration during the design and the iterative nature of the writing process, though at times chaotic, helped incorporate many different perspectives when developing the resource. Others undertaking such projects, may consider other strategies for optimizing collaboration and for obtaining, organizing and integrating feedback from various stakeholders in an iterative manner, as a means of optimizing the integration of different perspectives in the final product.



### **Comprehensive resource.**

A major strength of the design process was that it produced a comprehensive resource that addresses a variety of topics and issues. Participants indicated that the resource is a good starting point for any teacher, parent, or tutor to address topics of sexuality and relationships with someone with ID. While the resource is not exhaustive of all sexual health education topics and issues, participants suggested it provides a comprehensive base to begin conversations and open the lines of communication. While content specific resources are beneficial (i.e. Hinsburger, 2008; Walker-Hirsch & Champagne, 1983, 1986), their uses are limited to specific circumstances and learning objectives. Participants explained that there were resources available in the community; however there was not a comprehensive program that could be used as a resource to educate people with ID on a variety of topics and issues. For example, public health units offer a good program on sexual health and safety, however this programming does not discuss the intricacies of relationships; Diverse City Press offers videos about male and female masturbation but not about partnered relationships. The Public Health Agency of Canada (2008) suggests that comprehensive sexual health education is 'broadly based;' it should cover many different disciplines, and move beyond factual content to attend to broader issues of relationship. The *Able to Live, Able to Love* program offers a comprehensive sexual health education program by outlining 13 separate sections that deal with such things as: human anatomy and hygiene; healthy relationships and personal boundaries; intimacy; feelings and self-awareness; sexual expression; language and communication; sexuality throughout the

lifecycle; sexual rights, consent, and abuse; health, safety, birth control, and STI prevention; and sexuality and spirituality.

### **Pedagogically informed.**

A strength of the design process was that it was pedagogically informed. Others interested in designing similar material may benefit from thinking about pedagogical issues when designing sexual health education programs for persons with intellectual disabilities. The resource used a variety of pedagogical techniques which included: *supporting concrete learning through illustrations, encouraging open dialogue through captions, repeating information through checkpoint messages, and practicing social skills through role-play.* The resource also presents six to eight activities per chapter. Activities are designed to be completed either alone or with a partner or teacher and assist with learning throughout the resource. For group sessions, there are suggestions in the activity booklet to modify some activities to be done in a group format. Using different pedagogical approaches has the potential to contribute to the educational value and the physical and cognitive accessibility of the resource for persons with intellectual disabilities.

### ***Supporting concrete learning: Illustrations***

Another pedagogical strategy that facilitated the development process was the use of images within the resource. A professional illustrator was hired to develop pictures. This is consistent with the research literature. Muccigrosso (1991) reports that persons with ID are concrete learners and may require images to convey relevant concepts, and aid learning. Similarly, Kempton & Stiggall (1989) and Murphy & Elias (2006) suggest

that illustrations and models are an important aspect of sexual health education programs for persons with ID. *Able to Live, Able to Love* presents many illustrations per unit. Illustrations include displaying anatomical parts, sexual intercourse, interactions in relationships, and contraception methods. For an example of illustrations, see Appendix H.

Learners are also encouraged to expand their knowledge base through activities that encourage drawing and artistic games. In *Unit 3: Understanding Our Bodies*, the first activity asks learners to draw or paste a picture of themselves on the page and draw hearts over the body parts they love the most. In *Unit 8: Language and Communication*, an activity shows images of different characters interacting and asks learners to attempt to 'read' the body language of the pictures (see Appendix I).

### ***Encouraging open dialogue: Captions***

Another pedagogical strategy that informed the design process was to encourage open dialogue. Carter (1999) suggests encouraging open dialogue when teaching sexual health education. McCabe (1999) agrees that it is important for persons with ID to feel comfortable discussing sexual health topics with trusted individuals. *Able to Live, Able to Love* was designed to encourage open dialogue between learners and teachers. Because persons with ID may have difficulty maintaining motivation and attention (Weber & Bennett, 2004), encouraging open dialogue with the use of the resource may help users remain engaged. In this resource, captions were used throughout the text to stimulate conversation. Captions are small excerpts used to put the information communicated in the unit into context for the learner. Inserting captions in educational text are similar to Carol Gray's (1994) concept of Comic Strip Conversations – a

pedagogical technique used to assist persons with Autism Spectrum Disorder engage in conversation. Captions are presented in first person by a fictitious character explaining his or her feelings and thoughts on a scenario. Following a passage in *Unit 2:*

*Understanding Our Bodies* on how boys' bodies change during puberty, a caption is presented:

Mitchell: I sure have noticed a lot of changes lately. I have grown hair on my private areas, my chest, and even my face. I can't wait to grow a beard! My dad told me I should wash more often now that I sweat more. I also wear deodorant now too. This will take a while to get used to, but I know it is just part of growing up!

Captions may assist in explaining certain concepts and starting conversations. Users may relate to captions and be open to sharing similar experiences and questions with teachers.

### ***Repetition of information: Checkpoint messages***

Another pedagogical strategy that informed the design process was to increase memory retention through repetition. Irvine (2005) suggests that repetition is an effective way to help retain information. Throughout each unit, there are one to two sentence checkpoint messages that are used to break up the written content and summarize important points. Repeating information is important as some persons with ID may experience difficulty holding information in their short-term memory (Weber & Bennett, 2004). Some checkpoint messages summarize sections of the text and are used to repeat important information. For example, in *Unit 5: Intimacy and Sexuality* a checkpoint message explains the importance of consent: "we cannot force someone into an intimate relationship with us. Neither can we be forced into an intimate relationship;" and in *Unit 7: Sexual Expression* a checkpoint message explains the

difference between public and private behaviour: "I can express my sexual desires by masturbating in a private place."

There are also many checkpoint messages that reaffirm positive language and declarations. For example, in *Unit 3: Understanding Our Bodies* a checkpoint message encourages a positive body image: "I love my body! It's unique. It's me;" and in *Unit 4: Healthy Relationships*, a checkpoint message encourages healthy relationships: "I can make other people happy by caring about them and being thoughtful." The checkpoint messages are summarized on the last page of each unit. This summary page can be reviewed often with learners to assist with repetition of content and ideas.

### ***Practicing social skills: Role-play***

Another pedagogical strategy that informed the design process was to develop social skills through practice and role play. Throughout each unit, there are places for the learner to pause and complete activities. Weber and Bennett (2004) suggest that persons with ID have difficulty understanding similarities and differences and may need additional assistance in this regard. Activities are used as an opportunity to practice functional skills and understand similarities and differences, and communicate thoughts and feelings through role-play. Following a passage about conflicts and relationships in *Unit 4: Healthy Relationships*, an activity is presented that asks learners to practice using "I" messages when speaking to a partner to avoid blaming statements. In *Unit 9: Sexuality Through the Lifecycle*, an activity asks learners to practice ending relationships in a respectful way (see Appendix J).

Thus, the use of pedagogical techniques described by experienced educators and researchers appears to be an important dimension to consider when designing sexual

health educational programming for persons with intellectual disabilities. In the current case study, a number of such resources were used, with the aim of increasing accessibility and educational effectiveness of the resource. Although the results of the early pilot testing were positive, the extent to which the resource effectively communicates information through these pedagogical methods will need to be explored in future research.

### **Resource accessibility.**

The study points to financial accessibility, as an important consideration with respect to the development of sexual health education resources for persons with ID. Accessibility to the Guelph-Wellington and Dufferin community was viewed as a strength of the resource in the current study. DiGiulio (2003) suggests that persons with ID are generally economically disadvantaged and are more likely to experience financial hardship. In this study, the Network was conscious of optimizing the financial accessibility of the resource by printing it locally and selling it at cost - \$50. While researching other programs available for sale, it was found that Kempton's (1988) *Life Horizon's* program retails for \$700 (US) and content-specific programs available through Diverse City Press retail for about \$50 each (and users require numerous sections). Thus, although these two programs have strengths, the capacity to put together a comprehensive program for persons with ID in this fashion would require a large outlay of funds to purchase either the Kempton resource or the numerous specific programs required through the Diverse City Press resources, which could cost hundreds of dollars. Though school boards and agencies could potentially purchase

these more expensive programs, many families or individuals with ID, or smaller non-profit organizations may find such programs inaccessible due to costs.

The choice to printing the resource locally may present a challenge in terms of its dissemination, as only those who know about it, or have access to someone involved with the network may be able to purchase the resource. For instance people in other countries who may well benefit from the resource would be unlikely to know of it. Nonetheless, it is, in theory, available to any persons or agency that requests it. Indeed, first initiatives to 'spread-the-word' have been positively received across Ontario and the rest of Canada. Each agency in the *Relationship, Sexuality, and Safety Education Network of Guelph-Wellington and Dufferin Counties* has advertised the availability of the resource within their agency and across their wider networks. Locally, a representative from the Upper Grand District School Board provided an electronic copy of the resource to special education teachers across the school board. In addition, through a recent presentation of the resource at the Guelph Sexuality Conference in June 2009, (Moore, 2009), many different agencies, school boards, and educators across Ontario and Canada are now aware that the resource is available. In fact, a copy was sold to the Winnipeg School Division in Manitoba at the conference to be used by the sexual health education consultant at the school board. Thus, initial efforts have been made to disseminate *Able to Live, Able to Love* as widely as possible given the resources of the Network. For those developing a similar program, maximizing the availability of the resource is something to consider. Local access can often be achieved via the networks of agencies involved and community outreach initiatives. To increase accessibility to the larger community, academic publications, press releases,

presentations, and conferences are all avenues that may be useful to disseminate this information.

### **Commitment of stakeholders.**

The motivation of one pioneer who championed the cause, and continued to lead and coordinate the group, was instrumental in terms of bringing together different agencies to address the commonly identified need for sexual health education in the Guelph-Wellington and Dufferin community. June was motivated by a need for her son and her community; she created the Network, recruited agencies and community members, led the application for funding and kept the development of the resource moving forward. This display of initiative, persistence, and a willingness to take on challenges not only contributed to the development of the resource, but was also critical to it. This raises the question of whether a champion for the cause is an essential ingredient to the development of a resource of this nature. It is plausible that a community without a champion to initiate the process may not be as successful in initiating such a project.

However, the motivation and collaboration of many different community agencies also enabled the development of the resource. Network members volunteered a significant amount of their own time and resources to be a part of the development process. To date, the project has spanned over 3 years, and many Network members have remained committed. Members who came from community agencies were allotted a specific amount of time to be dedicated to the resource development via the executives of their agencies. However, many put in much more time than was covered by their workplace, which reveals how important the members found the project to be for their families and/or communities. Thus, the initiative to develop the resource was



in large part a labour of love on the part of various stakeholders, and greatly contributed to the project development.

The champion for the cause in the current case seemed to generate a snowball effect where by her enthusiasm inspired others to become involved in the project. Though the project may not have been initiated without June, it is unlikely that she would have been able to accomplish what was done with the resource on her own without the participation of the Network members. June remained as the committee chair and leader, and the Network members provided expertise and resources to develop the resource.

The consultant, the illustrator and myself also remained committed to the program. Despite setbacks and challenges, the consultant produced many different drafts of the resource to ensure she was meeting the needs of the Network. I remained motivated by recognizing that although the development process was at points challenging and strenuous, the goal of the project was more important than any stress I might endure by staying involved. The potential of the resource to positively affect a person's life was my motivator and assisted me to focus on the big picture. Remaining in close communication with the Network and with persons with ID provided an internal support network as well. By reminding each other of the common cause, it helped us work towards a common goal: to advocate for the sexual rights of persons with ID.

### **Funding and other resources.**

Financial support from the Ontario Trillium Foundation (OTF) enabled the development of the resource. Funding allowed the Network to hire a consultant, a researcher-writer, and an illustrator that otherwise could not have been accomplished.

Funding provided the stipends as well as administrative costs such as printing and editing. The Network also relied on in-kind donations from the different agencies involved. As aforementioned, Network members volunteered their time to the development of the project. In addition, some agencies donated office space, supplies, human resources, and other resources for which the Network otherwise could not have paid. Since the resource is not being sold for profit, donations were essential to the development of the project. Others interested in developing similar resources are advised to consider funding issues, and may wish to apply for external funding, garner tangible support from organizations, seek donations, and to find committed people to be involved (paid and/or volunteer). In Canada, funding is available for community projects from government organization (i.e. Ontario Trillium Foundation, the Social Sciences and Humanities Research Council of Canada, etc.) and non-government organizations (Ivey Foundation, Jean Ripley Foundation for Child Development, etc.). However, this will certainly vary in other communities across the world and may be a consideration before undertaking such a project. Other organizations might consider offering or advocating for release of time for such projects from workplaces, the possibility of working with volunteers, fundraising to raise money, or selling the resource for profit to help recover costs.

### **Further Considerations in the Development Process**

The findings highlight some areas for further consideration in the development process. A discussion of areas that participants identified for potential improvement may be helpful to others who are designing similar programs in the future. Areas for further consideration are: involvement of persons with ID, the inclusiveness of the

resource, consulting program development literature, working with limited resources, and discussions of values.

### **Involvement of persons with ID in the development process.**

Those developing sexual health education programming for people with ID might think about the ways they will include people with ID in the development process. One point identified in the findings was that it would have been ideal to have more input from persons with ID. The consultant was in constant contact with at least one person with ID during the development of the resource. Persons with ID were also indirectly involved in offering feedback through the pilot test workshop, and through the interpretations of their parents. Nonetheless, a number of participants in the case study indicated that more direct involvement of persons with ID in the development of the resource would have been beneficial. Interestingly, the participation of persons with ID in the development of sexual health education programs was not identified in the literature reviewed about sexual health education programs. One exception was Frawley, Johnson, Hillier & Harrison (2003) who reported using the first hand stories and experiences of persons with ID to develop their program, *Living Safer Sexual Lives*. These stories are published in their report, though the researchers do not explain exactly how they were used to inform the program.

### **Inclusiveness of the resource.**

Another factor that those interested in developing sexual education programming for persons with ID might consider is inclusiveness. Although the writers went to considerable lengths to make the resource inclusive, further measures could potentially

have made the resource more accessible for persons with lower cognitive levels and/or communication difficulties

The use of pedagogical techniques discussed earlier such as illustrations and activities contribute to inclusiveness, but there is room for improvement in this regard. The resource is fairly reliant on text and conversation and is likely best used with users who are capable of verbal communication. As suggested by researchers (Carter, 1999; Higgins, Barker & Begley, 2006), exploring ways to use audio and visual resources might help to address this limitation. Extending the resource to different mediums for those with verbal limitations such as computer assisted technology and BlissSymbols may also be areas for future consideration. However, it is important to consider that creating a program that is more inclusive may have significant financial implications and require additional financial resources. For the current project, a printed resource was deemed to be the most cost effective, given the amount of money received from the Ontario Trillium Foundation Grant.

Those interested in designing sexual health education programming may wish to build additional resources into their budget planning in order to continue to work toward greater inclusiveness. Additionally, planning for various phases of development that increase inclusiveness for different populations over time may be more viable.

### **Consulting the program development literature.**

During the development process sexual health education program development literature could not be found; however, upon reflection, perhaps consulting general program development literature may have been beneficial to the development of the resource. Though the consultant had experience in curriculum development, drawing

from program development literature may have helped in the process, particularly in terms of information about processes such as maintaining strong leadership, developing community partnerships, allocating roles and responsibilities, and group communication and collaboration. Consulting program development literature may have provided a framework to assist the program development phase, and may have prevented some of the trial and error that occurred.

### **Working with limited resources.**

Although the funding received by the Ontario Trillium Foundation (OTF) financially enabled the development of the resource, the amount of funding received limited the extent to which the resource could be developed. As identified in chapter four, the original budget proposed to the OTF was revised as the OTF suggested the project be broken into smaller parts with less monetary support. With additional funding, there is the chance that many of the aspects of the development process could have been improved. The majority of network members held full time employment in the community and had limited time they could commit to the Network. With increased funding, honorariums could potentially have been given to more of those involved in the development process, and more attention to specialized technology to increase inclusiveness could potentially have occurred. For example, a paid organizational position on the Network could have aided in co-ordination issues.

### **Discussions about values.**

Before engaging in curriculum development, groups interested in developing programs of this nature may be well advised to consider the various values and

different philosophical perspectives that underlie different approaches to sexual health education programming. For instance, some approaches to sexual health education emphasize abstinence and religious values (Halstead & Reiss, 2003) while others emphasize liberal values (McKay, 1998). In this case study, different values and perspectives emerged, which were at times contentious, and required negotiation and discussion as the project unfolded. The consultant suggested that this dialogue and the diversity of perspectives improved the resource in the end. In retrospect, I wonder if it may have been helpful to engage in dialogue, or to begin to think about such topics at the outset of the educational project. In addition, being transparent about philosophical assumptions is also something to consider when developing this type of resource, and in signing on to a project like this as a researcher, writer, or consultant.

The range of different sexual health education philosophies presented in the resource may have been attributable to the extensive collaboration with stakeholders. Though incorporating dissenting views and opinions may have developed a more comprehensive material, it appeared to cause many challenges as well. However, mediating through these differences provided the opportunity for different stakeholders to reflect on values, and to make often implicit values explicit. Those interested in designing sexual health education programming may consider engaging in open dialogue about different values and assumptions, as well as recognizing that values, either implicitly or explicitly, underpin educational programs.

Thus there are many opportunities for improvement related to increased funding in future efforts to develop similar programs. Though some challenges were out of the

Network's control, they provided an opportunity to apply for additional funding grants to address them.

### **Implications of Developing the Sexual Health Education Resource**

There are many implications that can be drawn from this study for many different groups including persons with ID, those who live and work with persons with ID, schools, educators, and community resource developers.

#### **Implications for persons with ID.**

The development of the *Able to Live, Able to Love* resource presents implications for persons with ID. First of all, professionals and family members in the Guelph-Wellington and Dufferin community have recognized a need for persons with ID to expand their knowledge base in sexual health education and enable them to develop healthy relationships and avoid assault and abuse. Thus, persons with ID's needs are being identified by those who are in the position to assist them in the area of sexual health education. Community recognition of this need means that persons with ID may have increased opportunities to engage with sexual health education programming and to be recognized as sexual people.

Secondly, the *Able to Live, Able to Love* resource is available for persons with ID in the Guelph-Wellington and Dufferin community. The resource is available for individuals, families, groups, or agencies for a low cost. Implications are that persons with ID who use the resource may become more educated about sexual topics and issues as well as more confident as sexual beings. As mentioned earlier, program evaluations will need to be conducted to study the usefulness of the resource; however, recognizing their needs and creating the resource presents the potential to enhance the

lives of persons with ID. Although the *Able to Live, Able to Love* resource has been tailored to the needs of persons with ID, it may be most applicable to persons with ID in the Guelph-Wellington and Dufferin community. However, the program may act as an example for other communities or other parts of the world to develop similar educational initiatives to meet the needs of the persons with ID in their own communities.

### **Implications for persons who support persons with ID.**

For those who support persons with ID – such as parents, support workers, and educators – a sexual health education program for persons with ID may have many important implications. First of all, as was mentioned in chapter two, many parents and caregivers experience anxiety surrounding sexual education and persons with ID (Van Dyke, McBrien & Sherbondy, 1995; Irvine, 2005; DiGiulio, 2003; Sweeney, 2007). As identified by participants, this resource may help educators find the positive language to initiate conversations about sexuality. In addition, in *Unit 1: A Note to the Educator* offers suggestions to those supporting persons with ID about how to be encouraging and answer questions and concerns when using the resource with a person with ID.

Since the resource is comprehensive and covers a wide range of technical information about sexuality as well as the social and emotional issues that arise in relationships, it may be a helpful resource to have available for those supporting persons with ID. *Able to Live, Able to Love* is presented as an all-in-one resource for parents, support workers, and educators to draw from. If more specific information is needed on a topic, supplemental information may be required. Thus, for those who support persons with ID, the implications are that a resource is now available that may



assist them in supporting persons with ID about sexual health. The resource has the potential to help initiate conversations and address a wide range of topics and issues that might otherwise be difficult to address without such a resource. The participants of the study seemed to be strong advocates for the sexual rights of persons with ID and may set an important example for support persons who have reservations or anxiety surrounding this topic.

### **Implications for schools.**

As was indicated in chapter two, learning expectations for sexual health education exist at the Grade 10 level in Ontario schools (Ministry of Education and Training, 2009). Learning expectations include the ability to: describe environmental influences on sexuality; explain the effects of choices related to sexual intimacy (i.e. STDs, HIV/AIDS); identify available information and support services related to sexual health concerns; demonstrate understanding of how to use decision-making skills effectively to support choices related to responsible sexuality (Ministry of Education and Training, 2009). However, since persons with ID do not report learning about sexual health education at school (Coren, 2003), there seems to be a gap between what the schools expect from students with ID and the general education that is provided. The implication for schools is that the resource may help bridge the gap between the knowledge base of persons with ID and the learning expectations of the school system.

Another implication for schools is that if schools were to adopt a resource like *Able to Live, Able to Love* it may prevent teachers from having to 'reinvent the wheel' in each special education classroom or school board. Instead, it would provide a common provincial wide or school board wide resource to draw from where teachers would

have the opportunity to collaborate and share experiences across classrooms. As was discussed in chapter four, sexual health education programs for persons with ID in schools are usually developed locally. Pending additional funding, the Network plans to complete an evaluation of the program in a special education classroom in Guelph. By completing an evaluation in the school board, the Network may consider publishing study results, further promoting the program to other agencies or classrooms across the country.

### **Implications for community resource development.**

The findings of the study raise considerations for future development of sexual education health resources by community members. These have been discussed earlier, and are summarized in Table 4. Communities wishing to work together to develop sexual health education programming may be well advised to consider the practical learning that occurred as a result of the community efforts documented in the case study. The resource, *Able to live, Able to love*, this thesis, the literature review and review of available resources, and the list of considerations generated may be practical resources for future groups developing work of this nature.

### **Strengths and Limitations of the Study**

As the researcher, I acknowledge that this study has both strengths and limitations. The strengths include: the researcher's prolonged engagement with the case, the richness of the interviews with participants, the opportunity to study an actual case in the real world, and the uniqueness of the contribution to knowledge made by this

Table 4

*Considerations for the Development of Sexual Health Education Programs for Persons with ID*

- Comprehensiveness
- Discussions of philosophical values
- Pedagogically informed
- Financially accessible
- Inclusiveness
- Collaboration
- Financial support
- Motivation and commitment of stakeholders
- Consult program development literature
- Involvement of persons with ID

study. The limitations include the lack of participation of persons with ID in the study, the messiness of being an insider/outsider, the time frame which precluded time to consult the program development literature.

**Strengths.**

One strength of this study is the research's prolonged engagement with the case. As a resource writer, I had contact with many members of the Network and the Guelph-Wellington Dufferin community for approximately a year and a half. This closeness to the research gave me as an opportunity to gain intimate knowledge about the case. I was involved in the planning, writing, and editing stages of development, and was privy to the perspective of many participants on the many sides of the development process. Participants trusted me, as I was an insider to the Network and members were very candid, disclosing a lot of important and sometimes controversial information during

the interviews. The interviews I conducted provided me with rich information about the case and the passion of the participants. Thus it is my hope that my analysis and interpretation of the findings are increasingly trustworthy in light of this unique perspective.

Another strength of this study is the richness of this case, and the unique contribution it makes to the sexual health education literature. This study documents a case study of one community's experience of the process of developing a sexual health education resource for persons with ID. This is an area of study that is currently missing in the literature, and the study of it represents a unique opportunity. Indeed, at the inception of this project it would have served the stakeholders well to have access to a study of this nature. It is hoped that this detailed account of process may be beneficial to other community networks or organizations who might plan to undertaking similar projects in the future.

### **Limitations.**

A limitation of the study is the lack of participation of persons with ID. Although I was in contact with some persons with disabilities during the development process, I did not interview any person with ID for this study. As a result, it is plausible that I may have omitted important interpretations or experiences that members of this population may have brought to the study. I was committed to developing a resource that would help transform the community by working to empower persons with ID and assist them to claim their rightful place as sexual beings, and to develop healthy relationships and avoid, where possible, victimization. Though I am open to the interpretations of participants and recognize their unique experiences in this research, the case was

undertaken as an attempt to document information that might be helpful to other organizations hoping to develop similar types of projects. This research highlights how one might go about developing a similar project, drawing on insights garnered through an analysis of the specific case at hand.

Although prolonged engagement with the case was identified as a strength, there was also considerable “messiness” in the process of working as an insider on the project at the same time as a researcher of the case. For instance, my thesis supervisor questioned my interpretations at times, suggesting that they were not representative of what she was reading in the data. At times my interpretations may have been less balanced than they might have been, and there were dimensions of the study that were easy to take for granted because I was so intimate with it. Also, as a very liberal thinker with respect to sexual health education, I became increasingly conscious of value conflicts that surfaced within myself during both the design and the research process. In addition, as a researcher trained in a quantitative paradigm, I struggled at times with learning to write in a more qualitative manner.

Another potential limitation is that I did not consult the program development or community development literature when conducting a literature review. This literature was not drawn upon while developing the resource, and it was not something I considered when beginning my research. In retrospect, I recognize that this literature could have been beneficial in examining how the experiences of participants compared to what is written in this area. This was, unfortunately, a realization I achieved very late in the study and may represent an opportunity for future research.

### **Future research.**

There are many opportunities for future research in the area of sexual health education for persons with ID. First, it is recommended that more research focus on program development literature and best practices for the pedagogy of sexual health education including techniques and approaches. Researchers and program developers should be transparent about how resource development is conducted so users can judge the pedagogical basis for the approach. In addition there is a large potential for more sexual health education resource program evaluations. Since quantitative program evaluations dominate the literature (Garwood & McCabe, 2000), mixed methods as well as qualitative methods could be explored to evaluate resources in the future.

There is an exciting potential for future programs in this area. *Able to Live, Able to Love* is one example of the possibilities in sexual health education for persons with ID, and there is still a significant need for other comprehensive resources in this area delivered through other mediums. Research into other delivery methods such as videos, CD-ROMs, and other technological interfaces such as bliss boards could be a significant area to explore. Depending on funding opportunities, the *Relationship, Sexuality, and Safety Education Network of Guelph-Wellington and Dufferin Counties* plans to investigate opportunities for the growth and expansion of the resource. Hopefully this opportunity becomes available, as there is so much possibility for growth. As demonstrated by this study, there is a clear need for future program

development and educational research in the area of sexual health education for persons with intellectual disabilities.

Secondly, future researchers may consider adopting critical perspectives when researching or developing sexual health education resources for persons with ID. Mertens (2005) concept of research from a transformative paradigm asserts that there are multiple viewpoints and many social realities and that research should include the “diverse voices from the margin” (p.26). In research, transformative theory places great importance on the lives and experiences of diverse groups of people who have traditionally been marginalized, especially those with disabilities (Mertens, 2005; Mertens, 2009). In transformative research, the community impacted should be involved to some degree in programmatic and/or methodological decisions (Mertens, 1999). Future researchers may consider involving persons with ID to a greater extent throughout the research process.

## **Conclusions**

The research gathered information about the process of developing a sexual health education resource for persons with ID and highlights important enablers, challenges, and motivations to developing this type of program. Overall, the purpose of the study was to undertake a case study that documents the community development of a sexual health education resource, *Able to Live, Able to Love*, for persons with intellectual disabilities. The guiding research question: “What was the process by which the *Relationship, Sexuality, Safety and Education Network of Guelph-Wellington and Dufferin Counties* developed a sexual education program for persons living with intellectual

disabilities?" was addressed by highlighting the experiences and perceptions of key stakeholders of the *Able to Live, Able to Live* resource.

By presenting the research as a case study, processes were discussed in detail which may be of use for other community agencies wishing to develop similar projects. Recommendations for future research and program development initiatives are also highlighted, and may help contribute to an effective development process, and a resource that is useful for persons with ID.

This study may have important implications for persons with ID, those who live and work with them as well as educational institutions and curriculum developers. The initiative set forth by the *Relationship, Sexuality, and Safety Education Network of Guelph-Wellington and Dufferin Counties* recognizes the needs of a group whose sexuality and personal rights have been historically ignored. By recognizing a need for increased knowledge, abuse prevention, and rights, persons with ID may have the opportunity to live fuller lives as sexual people. Hopefully other communities may be encouraged by the project and enabled by the case study to develop similar programs for the vulnerable persons of their communities.



## References

- Algozzine, R. and Ysseldyke, J.E. (2006). *Teaching Students with Mental Retardation: A Practical Guide for Every Teacher*. Thousand Oaks, CA: Corwin Press.
- Allen, L. (2005). 'Say everything:' Exploring young people's suggestions for improving sexuality education. *Sex Education*, 5(4), 389-404.
- American Association on Intellectual and Developmental Disabilities. (2009). *Definition of intellectual disability*. Retrieved February 10, 2009 from [http://www.aamr.org/content\\_100.cfm?navID=21](http://www.aamr.org/content_100.cfm?navID=21)
- Aunos, M. and Feldman, M.A. (2002). Attitudes towards sexuality, sterilization and parenting rights of persons with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15, 285-296.
- Aylott, J. (1999). Is the sexuality of people with a learning disability being denied? *British Journal of Nursing*, 8(7), 438-442.
- Bazzo, G., Nota, L., Sores, S., Ferrari, L. and Minnes, P. (2006). Attitudes of social service providers towards the sexuality of individuals with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 20, 110-115.
- Bell, D.M. and Cameron, L. (2003). The assessment of the sexual knowledge of a persons with a severe learning disability and a severe communication disorder. *British Journal of Learning Disabilities*, 31, 123-129.
- Brückner, H. and Bearman, P. (2005). After the promise: The STD consequences of adolescent virginity pledges. *Journal of Adolescent Health*, 36, 271-278.
- Buston, K., and Wight, D. (2004). Pupils' participation in sex education lessons: Understanding variation across classes. *Sex Education*, 4(3), 265-301.
- Carter, J.K. (1999). Sexuality education for students with specific learning disabilities. *Intervention in School and Clinic*, 34(4), 220-223.
- Champagne, M. and Walker-Hirsch, L. (1983). *Circles: Intimacy and Relationships*. Santa Monica: James Stanfield and Company.
- Chiver, J. and Mathieson, S. (2000). Training in sexuality and relationships: An Australian model. *Sexuality and Disability*, 18(1), 73-80.
- Cohall, A.T., Cohall, R., Dye, S., Dini, S., Vaughan, R.D. and Coots, S. (2007). Overheard in the halls: What adolescents are saying, and what teachers are hearing, about health issues. *Journal of School Health*, 77(7), 344-350.

- Community Living Ontario. (2008). *What is an intellectual disability?* Retrieved February 10, 2009 from <http://www.communitylivingontario.ca/page/what%20is%20an%20intellectual%20disability.aspx>
- Connell, E. (2005). Desire as interruption: Young women and sexuality education in Ontario, Canada. *Sex Education*, 5(3), 253-268.
- Coren, C. (2003). Teenagers with mental disability lack reproductive education and knowledge; Still, many had sex. *Perspectives on Sexual and Reproductive Health*, 35(4), 187-195.
- Corrie, M. and Zaklukiewicz, S. (2004). Qualitative research and case-study approaches: An introduction. In D.M. Mertens and J. McLaughlin's (Eds). *Research and Evaluation Methods in Special Education*. Thousand Oaks, CA: Corwin Press.
- Couwenhoven, T. (2001). Sexual education: Building on the foundation of healthy attitudes. *Disability Solutions*, 4(6), 2-20.
- Cressman, M. (2007). *S.N.A.P: Special Needs Abuse Prevention*. Produced by Rural Response for Healthy Children and Community Living and Community Support for Families in Huron County (unpublished).
- Creswell (2009). *Research Design: Qualitative, Quantitative and Mixed Methods Approaches*. Thousands, CA: SAGE Publications.
- Cuskelly, M. and Bryde, R. (2007). Attitudes towards the sexuality of adults with an intellectual disability: Parents, support staff, and a community sample. *Journal of Intellectual & Developmental Disability*, 29(3), 255-264.
- Denzin, N.K. and Lincoln, Y.S. (2005). Introduction: The discipline and practice of qualitative research. In N.K. Denzin and Y.S. Lincoln's (Ed.). *The SAGE Handbook of Qualitative Research* (3<sup>rd</sup> ed.). (pp. 1-32). Thousand Oaks, CA: Sage Publications
- DiGiulio, G. (2003). Sexuality and people living with physical or developmental disabilities: A review of key issues. *Canadian Journal of Human Sexuality*, 12(1), 53-68.
- Douglas-Scott, S. (2004). Sexuality and learning disability. In E. Burtney and M. Duffy (Eds), *Young People and Sexual Health: Individual, Society, and Policy Contexts*. (p. 139-154). Hampshire, NY: Palgrave Macmillon.
- Fine, M., and McClelland, S. (2006). Sexuality education and desire: Still missing after all these years. *Harvard Educational Review*, 76(3), 279-437.
- Finlay, L. (2002). "Outing" the research: The provenance, process, and practice of reflexivity. *Qualitative Health Research*, 12(4), 531-545.

- Fontana, A. and Frey, J.H. (2005). The interview: From neutral stance to political involvement. In N.K. Denzin and Y.S. Lincoln's (Ed.). *The SAGE Handbook of Qualitative Research* (3<sup>rd</sup> ed.). (pp. 695-727). Thousand Oaks, CA: Sage Publications
- Frawley, P., Johnson, K., Hillier, L. and Harrison, L. (2003). *Living safer sexual lives: A training and resource pack for people with learning disabilities and those who support them*. Brighton, Pavillion.
- Galea, J., Butler, F., Iacono, T., and Leighton, D. (2004). The assessment of sexual knowledge in people with intellectual disability. *Journal of Intellectual & Developmental Disability*, 29(4), 350-365.
- Garwood, M. and McCabe, M.P. (2000). Impact of sex education programs on sexual knowledge and feelings of men with a mild intellectual disability. *Education and Training in Mental Retardation and Developmental Disabilities*, 35(3), 269-283.
- Gordon, L.E., and Ellington, L. (2006). In the eyes of the beholder: Student interpretations of sexuality lessons. *Sex Education*, 6(3), 251-264.
- Gray, C. (1994). *Comic Strip Conversations*. Arlington, TX: Future Horizons, Inc.
- Grieveo, A., McLaren, S. and Lindsay, W. R. (2006). An evaluation of research and training resources for the sex education of people with moderate to severe learning disabilities. *British Journal of Learning Disabilities*, 35, 30-37.
- Halstead, J. and Reiss, M.J. (2003). *Values in Sex Education: From Principles to Practice*. New York: Routledge Falmer.
- Health Canada. (2003). *Canadian Guidelines for Sexual Health Education*. Ottawa: Centre for Infectious Disease Prevention and Control.
- Higgins, A., Barker, P. and Begley, C.M. (2006). Sexual health education for people with mental health problems: What can we learn from the literature. *Journal of Psychiatric & Mental Health Nursing*, 13, 687-697.
- Hilton, G.L.S. (2007). Listening to the boys again: An exploration of what boys want to learn in sex education classes and how they want to be taught. *Sex Education*, 7(2), 161-174.
- Hinsburger, D. (2008). *Hand Made Love* [Video]. Angus, Ontario: Diverse City Press.
- Hinsburger, D. and Tough, S. (2002). Health sexuality: Attitudes, systems and policies. *Research and Practice for Persons with Severe Disabilities*, 27(1), 48-56.

- Horizons Schools. (2009). "Admissions Criteria." University of Alabama at Birmingham. Retrieved July 29, 2009 from [http://www.horizonsschool.org/admissions/admissions\\_criteria.html](http://www.horizonsschool.org/admissions/admissions_criteria.html).
- Irvine, A. (2005). Issues in sexuality for individuals with developmental disabilities: Myths, misconceptions, and mistreatment. *Exceptionality Education Canada*, 15(3), 5-20.
- Johnson, K., Hillier, L. and Harrison, L. and Frawley, P. (2001) *Living safer sexual lives: Final Report*. La Trobe University, Melbourne, Australia: Australian Research Centre in Sex, Health, and Society.
- Kempton, W. (1988). *Life Horizons*. Santa Barbara, CA: James Stanfield Company.
- Kempton, W. and Stiggall, L. (1989). Sex education for persons who are mentally handicapped. *Theory Into Practice*, 28(3), 203-210.
- Klee, K. (2009). *Sex Esteem: Developing Sexuality Confidence*. Produced by Developmental Services Access Centre (unpublished).
- Lall, M. (2007). Exclusion from school: Teenage pregnancy and the denial of education. *Sex Education*, 7(3), 219-237.
- Leutar, Z. and Mihokovic, M. (2007). Levels of knowledge about sexuality of people with mental disabilities. *Sexuality and Disability*, 25, 93-109.
- Lincoln, Y.S. and Guba, E.G. (1985). *Naturalistic Inquiry*. Newbury Park: London.
- Lindsay, W.R., Bellshaw, E., Culross, G., Staines, C., and Michie, A. (1992). Increases in knowledge following a course of sex education for people with intellectual disabilities. *Journal of Intellectual Disability Research*, 36, 531-539.
- Litchman, M. (2006). *Qualitative Research in Education*. Thousand Oaks, CA: Sage Publications.
- Ludwig, S. (1993). *Being Sexual: An Illustrated Series on Sexuality and Relationships*. Produced by SIECCAN.
- Lumley, V.A., Miltenberger, R.G., Long, E.S., Rapp, J.T., and Roberts, J.A. (1998). Evaluation of a sexual abuse program for adults with mental retardation. *Journal of Applied Behavior Analysis*, 3, 91-101.
- Magnus Hirschfeld Archive for Sexology. *Definition of Sexual Health (WHO/PAHO/WAS)* [http://www2.hu-berlin.de/sexology/ECE5/meaning\\_of\\_sexual\\_health.html](http://www2.hu-berlin.de/sexology/ECE5/meaning_of_sexual_health.html)

- McCabe, M.P. (1999). Sexual knowledge, experience and feelings among people with disability. *Sexuality and Disability*, 17(2), 157-170.
- McCabe, M.P. and Cummins, R.A. (1996). The sexual knowledge, experience, feelings, and needs of people with mild intellectual disabilities. *Education and Training in Mental Retardation and Developmental Disabilities*, 13-21.
- McCabe, M.P. and Schreck, (1992). Before sex education: An evaluation of the sexual knowledge, experience, feelings, and needs of people with mild intellectual disabilities. *Journal of Intellectual and Developmental Disability*, 18(2), 75-82.
- McDermott, S., Martin, M., Weinrich, M., and Kelly, M. (1999). Program evaluation of a sex education curriculum for women with mental retardation. *Research in Developmental Disabilities*, 20(2), 93-106.
- McKay, A. (1998). *Sexual Ideology and Schooling: Towards Democratic Sexuality Education*. London, ON: The Althouse Press
- Merriam, S.B. (1991). *Case Study Research in Education: A Qualitative Approach*. San Francisco, CA: Jossey-Bass Publishers.
- Merriam, S. B. (2009). *Qualitative Research: A Guide to Design and Implementation*. San Francisco, CA: Jossey-Bass Publishers.
- Mertens, D.M. (1999). Inclusive evaluation: Implications of transformative theory for evaluation. *American Journal of Evaluation*, 20(1), 1999.
- Mertens, D.M. (2005). *Research and evaluation in education and psychology: Integrating diversity with quantitative, qualitative, and mixed methods*. (2nd ed.) Thousand Oaks, CA: Sage Publications.
- Mertens, D.M. (2009). *Transformative Research and Evaluation*. New York, NY: The Guilford Press.
- Mia, A. (2007). *You Go, Girl!* Produced by KidsAbility Centre for Child Development (unpublished).
- Miles, M.B. and Huberman, A.M. (1994). *Qualitative Data Analysis* (2<sup>nd</sup> ed.). Thousand Oaks, CA: Sage Publications.
- Ministry of Education and Training. (2009). *Health and physical education: The Ontario curriculum grade 9 and 10*. Ontario Government.
- Monat, R.K. (1992). *Sexuality and the Mentally Retarded*. San Diego, CA: College-Hill Press.

- Monat-Haller, R.K. (1992). Understanding & expressing sexuality: Responsible choices for individuals with developmental disabilities. Baltimore, MD: Brookes Publishing Co.
- Moore, E. (2009). A community based initiative: *Developing a sexual health education resource for persons with intellectual disabilities and those who live and work with them*. 31st Annual Guelph Sexuality Conference: Poster Presentation.
- Morrow, S. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of Counseling Psychology*, 52(2), 250-260.
- Muccigrosso, L. (1991). Sexual abuse prevention strategies nad programs for persons with developmental disabilities. *Sexuality and Disability*, 9(3), 261-271.
- Murphy, N.A. and Elias, E.R. (2006). Sexuality of children and adolescents with developmental disabilities. *Pediatrics*, 118(1), 398-403.
- Murphy, N.A. and Young, P.C. (2005). Sexuality in children and adolescents with disabilities. *Developmental Medicine and Child Neurology*, 47, 640-644.
- Novak, J.D. and Cañas, A.J. (2007). The theory underlying concept maps and how to construct them. Technical report IHMC CmapTools 2006-01. Florida Institute for Human and Machine Cognition. Retrieved from <http://cmap.ihmc.us/Publications/ResearchPapers/TheoryUnderlyingConceptMaps.pdf>
- O'Callaghan, A.C. and Murphy, G.H. (2007). Sexual relationships in adults with intellectual disabilities: Understanding the law. *Journal of Intellectual Disabilities*, 51(3), 197-206.
- Patton, M.Q. (1990). *Qualitative Evaluation and Research Methods*. Newbury Park, CA: SAGE Publications.
- Pendler, B. and Hinsburger, D. (1991). Sexuality: Dealing with parents. *Sexuality and Disability*, 9(2), 123-130.
- Public Health Agency of Canada. (2005). *Family Violence and People with Intellectual Disabilities*. Retrieved February 11, 2009 from [http://www.phac-aspc.gc.ca/ncfv-cnivf/familyviolence/html/fvintellectu\\_e.html](http://www.phac-aspc.gc.ca/ncfv-cnivf/familyviolence/html/fvintellectu_e.html)
- Public Health Agency of Canada. (2008). *Canadian Guidelines for Sexual Health Education*. Ottawa.
- Richards, D., Miodrag, N. and Watson, S.L. (2006). Sexuality and developmental disability: Obstacles to healthy sexuality throughout the lifespan. *Developmental Disabilities Bulletin*, 1&2, 137-155.

- Richardson, L. and Adams St. Pierre, E. (2005). Writing: A method of inquiry. In N.K. Denzin and Y.S. Lincoln's (Ed.). *The SAGE Handbook of Qualitative Research* (3<sup>rd</sup> ed.). (pp. 959-978). Thousand Oaks, CA: Sage Publications
- Rousso, H. (2001). *Strong, proud, sisters: Girls and young women with disabilities*. Washington, DC: Center for Women Policy Studies.
- Seidman, I. (2006). *Interviewing as Qualitative Research*. New York, NY: Teachers College Press.
- Servais, L., Jacques, D., Leach, R., Conod, L., Hoyois, P., Dan, B. and J.P. Roussaux. (2002). Contraception of women with intellectual disabilities: Prevalence and determinants. *Journal of Intellectual Disabilities Research*, 46(2), 108-119.
- Servais, L. (2006). Sexual health care in persons with intellectual disabilities. *Mental Retardation and Developmental Disabilities*, 12, 48-56.
- Sexuality and Information and Education Council of the United States (SIECUS). (2009). About us. Retrieved March 20, 2009 from <http://www.siecus.org/index.cfm?fuseaction=Page.viewPage&pageId=472>
- Sheppard, L. (2006). Growing pains: A personal development program for students with intellectual and developmental disabilities in a specialist school. *Journal of Intellectual Disabilities*, 10(2), 121-142.
- Special Olympics. (2004). *Intellectual Disability*. Retrieved February 10, 2009 from <http://www.2009worldgames.org/media-center/intellectual-disability>
- Stake, R.E. (2005). Qualitative case studies. In N.K. Denzin and Y.S. Lincoln's (Ed.). *The SAGE Handbook of Qualitative Research* (3<sup>rd</sup> ed.). (pp. 443-466). Thousand Oaks, CA: Sage Publications.
- Stimpson, L. and Best, M. (1991). *Courage above all: Sexual Assault Against Women with Disabilities*. DAWN: Toronto.
- Sugar, M. (1990). The atypical adolescent and sexuality. In M. Sugar (Ed.), *Atypical Adolescence and Sexuality* (pp. 1-18). London: W.W. Norton & Company.
- Swango-Wilson, A. (2008). Caregiver perceptions and implications for sex education for individuals with intellectual and developmental disabilities. *Sexuality and Disability*, 26, 167-174.
- Sweeney, L. (2007). The importance of human sexuality education for students with disabilities. *The Exceptional Parent*, 37(9), 36-39.

- Talbot, T.J. and Langdon, P.E. (2006). A revised sexual knowledge assessment tool for people with intellectual disabilities: Is sexual knowledge related to sexual offending behaviour? *Journal of Intellectual Disability Research*, 50(7), 523-531.
- Tarnai, B. (2006). Review of effective interventions for socially inappropriate masturbation in persons with cognitive disabilities. *Sexuality and Disability*, 24, 151-168.
- Van Dyke, D.C., McBrien, D.M., and Sherbondy, A. (1995) Issues of sexuality in down syndrome. *Down Syndrome Research and Practice*, 3(2), 65-69
- Walker-Hirsch, L. & Champagne, M. (1983). *Circles: Intimacy & Relationships*. Santa Barbara, CA: James Stanfield Company.
- Walker-Hirsch, L. & Champagne, M. (1986). *Circles: Stop Abuse*. Santa Barbara, CA: James Stanfield Company.
- Weber, K. and Bennett, S. (2004). *Special Education in Ontario*. (5<sup>th</sup> Ed.). Palgrave, ON: Highland Press.
- Whitehouse, M.A. and McCabe, M.P. (1997). Sex education programs for people with intellectual disability: How effective are they? *Education and Training in Mental Retardation and Developmental Disabilities*, 229-240.
- Williams, M.T. and Bonner, B.L. (2006). Sex education attitudes and outcomes among North American Women. *Adolescence*, 41, 1-14.
- Wolfe, P.S. and Blanchett, W.J. (2003). Sex education for students with disabilities: An evaluation guide. *Teaching Exceptional Children*, 36(1), 46-51
- World Health Organization. (2005). World Health Assembly commits to strengthen rehabilitation services for people with disabilities. Retrieved May 5, 2009 from [http://www.who.int/mediacentre/news/releases/2005/pr\\_wha07/en/index.html](http://www.who.int/mediacentre/news/releases/2005/pr_wha07/en/index.html)
- Yin, R.K. (2003). *Case Study Research Design and Methods*. (3<sup>rd</sup> ed.). Thousand Oaks, CA: Sage Publications.
- Yool, L., Langdon, P.E. and Garner, K. (2003). The attitudes of medium-secure unit staff toward the sexuality of adults with learning disabilities. *Sexuality and Disability*, 21(2), 137-150.



## **Appendix A: Able to Live, Able to Love Contents**

### **Unit 1: A Note to the Educator**

Unit 1 involves a foreword briefly explaining the creation of the program, an introduction to each unit, and a glossary of terms. Unit 1 is designed for the educator to gain ideas on how the resource could be used, how introduce each unit, and how to address learner questions. There is also a reminder to educators that not all questions will have immediate answers. Some questions about values, feelings, and relationships are subjective and instead of attempting to provide an answer, the educator can help guide the learner to think about what each issue means to them.

### **Unit 2: Being a Person, Being Special**

Unit 2 is an introduction to personhood, personal values, and relationships. Unit 2 is meant to show that sexual feelings and the desire to be in a relationship are perfectly normal. It also suggests that the desire to be on your own is normal as well. Unit 2 suggests that everyone has questions about sexuality and that asking questions should not be embarrassing. The most important message that Unit 2 conveys is that even though relationships can be exciting, being happy with yourself and your uniqueness is important before truly engaging yourself in a partnership.

### **Unit 3: Understanding Our Bodies**

Unit 3 is an introduction to the basic changes that happen to growing bodies throughout adolescence and into adulthood. It explains that as your body changes, the way you take care of your body changes as well. For example, as boys grow and sweat more, they need to wash more regularly and may choose to wear deodorant or antiperspirant; and as girls' bodies grow, they will need to learn about hygiene during

menstruation and may choose to wear a bra for developing breasts. Public and private areas of the body are discussed to help understand boundaries and privacy. There is an emphasis in this unit on learning how to love your body, be proud of it, to take care of it, and to promote self-respect through body image.

#### **Unit 4: Healthy Relationships**

Unit 4 is introduced by using a case study about a girl who is trying to understand the different relationships she has and what the appropriate emotional and physical boundaries are within each relationship. The Circles Concept produced by the James Stanfield Company was adapted and used for this unit (Champagne & Walker-Hirsch, 1983). The Circles Concept shows that the closer someone is to you emotionally, the closer they can be to you physically. Unit 4 explains that it is healthy to have appropriate boundaries in relationships and to have these boundaries clearly defined by both people. For example, the purple or 'me' circle would include yourself and your partner if you have one. Persons in your purple circle can share sexual intimacy. The blue or 'love' circle is defined as anyone you love or are very close to, like family members or best friends. It is usually acceptable to hug someone in this circle, however, you would not engage in sexual intimacy with a family member. Unit 4 also suggests that people may change circles as relationships develop or dissolve.

#### **Unit 5: Intimacy and Sexuality**

Unit 5 addresses intimacy and how it develops in relationships. There is an effort to distinguish the difference between different types of intimacy, and with whom they can be shared. For example, you might share sexual and emotional intimacy with a partner, and share emotional and spiritual intimacy with a sister. Unit 5 also discusses the

differences between short/casual and long-term relationships and the potential outcomes. Unit 5 does not suggest that one type of relationship is better than another, but asks the learner to consider what they value in relationships. Some may find that long-term relationships suit their needs and some may find that short-term relationships meet their needs. Unit 5 does suggest that if one is looking to develop a deep sense intimacy, than a long-term relationship may be a more satisfying choice.

### **Unit 6: Feelings and Self-Awareness**

Unit 6 addresses the different feelings that one may experience surrounding love, sex, and relationships. There are many difficult feelings that one could experience – for example liking someone that does not like you in return. Unit 6 also addresses sexual orientation and the normalcy of liking someone of the opposite gender or of the same gender. It also may be difficult to tell whether you are infatuated, in love, or in lust with someone. This unit emphasizes that love and feelings come in many shapes and forms and that there is not one way to love. Self-awareness is discussed as a way to help understand your own feelings and how to deal with these feelings effectively.

### **Unit 7: Sexual Expression**

Unit 7 describes ways to express your sexuality either by yourself or with a partner. Masturbation in a private place is discussed as a safe way to discover your own body and fulfill sexual desires. Unit 7 explains that once you agree to sexual activity with a partner, you should be aware of trust, consent, hygiene, and safety. In addition, sexual activity from foreplay to sexual intercourse is discussed as well as sexual preferences such as fetishes and toys. Unit 7 discusses the satisfaction that sexual relationships can bring as long as they are safe and consensual.

**Unit 8: Language and Communication**

Unit 8 emphasizes the importance of communication in relationships. It acknowledges that verbal language is important to express yourself and explain to your partner what you want and what you are comfortable with. However, non-verbal or body language is also important to show how you feel and to show you are listening. Partners cannot expect each other to know what they are thinking; so communicating and clarifying meaning can assist with the development of healthy and intimate relationships.

**Unit 9: Sexuality through the Lifecycle**

Unit 9 shows that sexuality is a part of every stage of your life. Many believe that sexuality is just something for married adults, but unit 9 seeks to break away from the idea that sexuality is just about overt sexual acts such as sexual intercourse. Humans are sexual beings and sexuality includes gender issues, menopause, dating, intimacy, childbirth, menopause/andropause, and more. Unit 9 highlights traditional gender roles by explaining the potential progression of dating to marriage to childbirth. This is presented not as an attempt to show this is the 'preferred' way of experiencing life and relationships, but to show how partners in such relationships may make important decisions. For example, what are important conversations/issues that should be considered before a couple decides to get married? Or have a child? Unit 9 attempts to be inclusive of all age groups and to consider age-specific issues as well.

**Unit 10: Sexual Rights, Consent, and Abuse**

Unit 10 is an important unit that conveys the essentialness of individual rights. This unit uses different scenarios of sexual harassment and sexual assault and abuse in an

attempt to help learners identify if they were ever to be a victim or a perpetrator. Though unit 10 explains how harassment and assault and abuse can be experienced by anyone from anyone, it also explains that people have rights in relationships as well. For example, it is important for consent between partners to be clear at each stage of the relationship and for issues such as past partners and STI/STD risks to be communicated. There is a list of Guelph community resources for the learner or educator to refer to as well.

### **Unit 11: Health and Safety**

Unit 11 covers the health risks involved in sexual activity. The unit urges the importance of preventative health measures such as contraception and STI protection and regular physical exams. Unit 11 again encourages communication between partners, caregivers, and health care professionals about these issues.

### **Unit 12: Sexuality and Spirituality**

Unit 12 is intended for learners with spiritual or religious beliefs to reflect on and consider how sexuality and spirituality can come together in their lives. This unit also addresses situations that may be sensitive to certain religious beliefs, for example homosexuality or abstinence until marriage. As each learner is individual and each spiritual belief is different, answers are not provided for these questions and concerns, but an invitation is extended to talk to those who might be of assistance.

### **Activity Booklet**

The accompanying activity booklet includes 6 to 9 activities per unit that are designed to assist program facilitators, educators and parents to offer the educational program and to assist learners to understand the material. Throughout the program,

there are spots where the facilitator is encouraged to pause and encourage the student to complete the activities alone or with a teacher, parent, or caregiver. For example, in *Unit 3: Understanding Our Bodies*, following a discussion of male and female body parts, students pause to complete an activity that asks them to colour and name these body parts on a diagram. In *Unit 8: Language and Communication*, following a discussion about communicating sensitive topics to your partner, students pause to complete a communication role playing activity. Activities are created at a variety of ability levels; some require visual and creative techniques and some require more verbal skills. When using the program one-to-one, the learner and educator can complete the activities together. When using the program in a group format, there are additional group activities suggested, as well as ideas how to alter existing activities for a group

## Appendix B: Research Ethics Board Submission



### Office of Research Ethics

The University of Western Ontario  
Room 4180 Support Services Building, London, ON, Canada N6A 5C1  
Telephone: (519) 661-3036 Fax: (519) 850-2466 Email: [ethics@uwo.ca](mailto:ethics@uwo.ca)  
Website: [www.uwo.ca/research/ethics](http://www.uwo.ca/research/ethics)

### Use of Human Subjects - Ethics Approval Notice

**Principal Investigator:** Dr. A. Kinsella

**Review Number:** 15835S

**Review Level:** Full Board

**Review Date:** April 03, 2009

**Protocol Title:** Developing a Sexual Health Education Program for Persons with Intellectual Disabilities: A Case Study.

**Department and Institution:** Occupational Therapy, University of Western Ontario

**Sponsor:**

**Ethics Approval Date:** May 06, 2009

**Expiry Date:** April 30, 2010

**Documents Reviewed and Approved:** UWO Protocol, Letter of Information and Consent (Stakeholders, parents, guardians and caregivers), Letter of Information and Consent (Program participant).

#### Documents Received for Information:

This is to notify you that The University of Western Ontario Research Ethics Board for Non-Medical Research Involving Human Subjects (NMREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the applicable laws and regulations of Ontario has granted approval to the above named research study on the approval date noted above.

This approval shall remain valid until the expiry date noted above assuming timely and acceptable responses to the NMREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

During the course of the research, no deviations from, or changes to, the study or consent form may be initiated without prior written approval from the NMREB except when necessary to eliminate immediate hazards to the subject or when the change(s) involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly also report to the NMREB:

- a) changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
- b) all adverse and unexpected experiences or events that are both serious and unexpected;
- c) new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

Members of the NMREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the NMREB.

Chair of NMREB: Dr. Jerry Paquette

| Ethics Officer to Contact for Further Information   |  |  |   |
|---|--|--|---|
| <input checked="" type="checkbox"/> Grace Kelly<br>( <a href="mailto:grace.kelly@uwo.ca">grace.kelly@uwo.ca</a> ) | <input type="checkbox"/> Janice Sutherland<br>( <a href="mailto:jsuther@uwo.ca">jsuther@uwo.ca</a> ) | <input type="checkbox"/> Elizabeth Wambolt<br>( <a href="mailto:ewambolt@uwo.ca">ewambolt@uwo.ca</a> ) | <input type="checkbox"/> Denise Grafton<br>( <a href="mailto:dgrafton@uwo.ca">dgrafton@uwo.ca</a> ) |

*This is an official document. Please retain the original in your files.*

cc: ORE File

## Appendix C: Letter of Information

### Development of a Sexual Health Education Program for Persons with Intellectual Disabilities: A Case Study

You are being invited to participate in a research study by Elizabeth Moore, a Master's student in the Faculty of Health and Rehabilitation Sciences at the University of Western Ontario. The purpose of this research is to undertake a case study of the *Able to Live, Able to Love* curriculum: a sexual education program for persons with intellectual disabilities and those who live and work with them. You are being invited to participate because you have contributed to the curriculum's design and/or development. A copy of this letter and the following consent form is for you to keep for your own reference if you choose to take part in this study.

If you agree to take part in this study, you will attend an interview with the researcher at the location of your choice. The interview will be approximately 60 to 90 minutes in length and will involve questions about the development of the *Able to Live, Able to Love* program, as well as your perceptions of the program and potential applications. Interviews will be tape-recorded and transcribed by the researcher. This allows for an accurate record of your perspective. Tapes will only be used to transcribe the interview, and will only be available to the primary researchers. If you do not wish to be tape recorded, you may still take part in the study. In this instance, the researcher will make notes about your comments during and following the interview.

The information collected will be used for research purposes only. Neither your name nor any personal information will be used in any publication or presentation of the study results. All information collected for the study will be kept confidential. There are no known risks of participating in this study. Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time.

If you have any questions about the conduct of this study or your rights as a research participant you may contact the Manager, Office of Research Ethics, The University of Western Ontario at 519-661-3036 or [ethics@uwo.ca](mailto:ethics@uwo.ca). If you have any questions about this study, please contact Elizabeth Moore at [REDACTED] or Anne Kinsella at [REDACTED]



**Appendix D: Research Consent Form**

**Developing a Sexual Health Education Program for Persons with Intellectual Disabilities: A Case Study**

I have read the Letter of Information and have had the nature of the study explained to me. I agree to participate in the study *Developing a Sexual Health Education Program for Persons with Intellectual Disabilities: A Case Study*. All questions have been answered to my satisfaction.

\_\_\_\_\_  
(Name of research participant)

\_\_\_\_\_  
(Signature of research participant)

\_\_\_\_\_  
(Date)

## **Appendix E: Research Interview Guide**

- Can you tell me about your role in the project?
- How were the needs for the program identified?
- Why was the program developed?
- From your perspective, how did the design/development roll out?
  - What helped the process along?
  - What were some challenges?
- How did the multiple agencies/stakeholders work together to develop this resource?
  - How were opinions/ideas disseminated in the group?
  - How were issues/conflicts addressed?
- How were persons with intellectual disabilities and those who live and work with them involved in the development of this resource?
  - Why was their involvement important?
- Why was partaking in the development of the resource important to you?
- How might this resource affect or be of use to your personal or professional work?
- Why is a sexual educational resource important for persons with intellectual disabilities?
  - How, if at all, do you perceive that this resource will benefit people with intellectual disabilities?
- How might this resource be further developed or improved in the future?
- From your perspective, how will the resource be used in the Wellington-Dufferin community?
  - What do you perceive as the potential application of this resource in the future?
- How would you advise other community organizations to approach similar projects for persons with intellectual disabilities?

## Appendix F: Example Title Page

# Able to Live, Able to Love

*A sexual education resource for persons with intellectual disabilities  
and those who live and work with them*



## Appendix G: Resource Evaluation

November 19, 2008

Hello Everyone,

As promised here is the evaluation form I spoke about yesterday. Your comments are important and most welcome. Please let us know if you have any issues and how best they might be fixed.

Thanks for your positive comments, enthusiasm, and suggestions at our workshop yesterday. Based on our discussion, you'll be happy to know that the following changes will be made:

1. We'll enhance the glossary to include terms that do not appear in the units, but have relevance to the content. Can you please include some of these terms (and what they mean) in your response to me? (I'm not up on all the current terminology.)
2. We'll develop an extra unit, "Unit 12: Notes to the Educator" which will include an orientation to the lesson, questions / scenarios that may arise, strategies for addressing them, and teachable moments. The concept of "universal design" and "differentiated instruction" will be included. Please send me any information that you feel would be helpful for this section.
3. We'll develop a more comprehensive resource section, adding to what we already have. If you know of any new and exciting resources, please send them along indicating in which unit you'd like to see them.
4. A few more ideas for units that are slight short on number of activities.

Please find below my contact information. You can e-mail, call or write to me. You can use the form to fill in your responses, and e-mail them back to me, or you can send me a hard copy. To use the evaluation scale, please highlight your response.

Thank you,

[Redacted]

[Redacted]

Name:  
Organization:  
E-mail/contact information:

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**Able to Live, Able to Love Orientation Workshop Evaluation**

- 1 = poor
- 2 = satisfactory
- 3 = good
- 4 = excellent

**Content**

|  |   |   |   |   |
|--|---|---|---|---|
| 1. Does the curriculum cover all necessary topics?       | 1 | 2 | 3 | 4 |
| 2. Is the tone and language use appropriate for readers? | 1 | 2 | 3 | 4 |
| 3. Do the topics follow a logical order?                 | 1 | 2 | 3 | 4 |
| 4. Are the images appropriate for the text?              | 1 | 2 | 3 | 4 |
| 5. Are the images appropriate for the reader?            | 1 | 2 | 3 | 4 |
| 6. Are the activities an effective learning tool?        | 1 | 2 | 3 | 4 |

**Orientation workshop**

|  |   |   |   |   |
|--|---|---|---|---|
| 1. Was the oral delivery effective?            | 1 | 2 | 3 | 4 |
| 2. Was the power point presentation effective? | 1 | 2 | 3 | 4 |

**1. Comments/ concerns/questions**

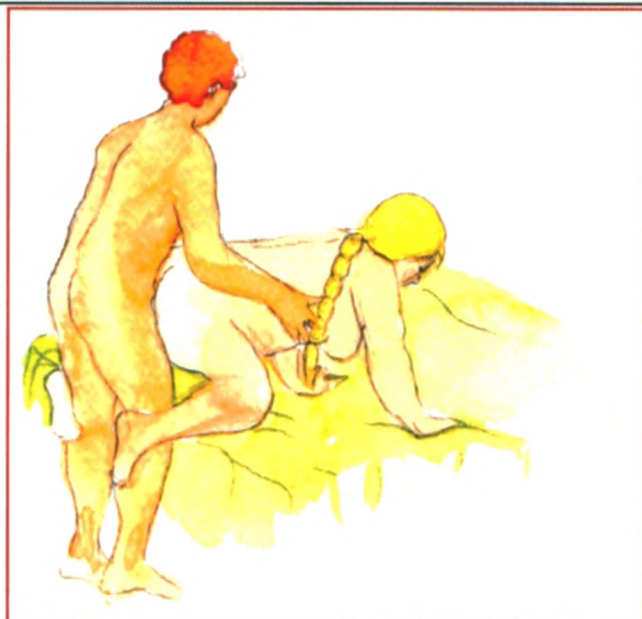
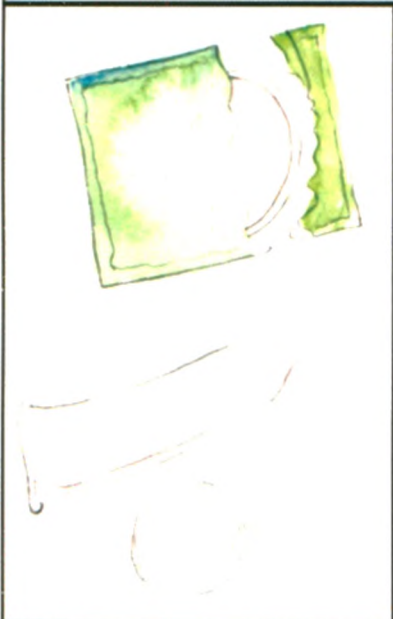
**2. Glossary terms and their meaning:**

**3. Ideas for Unit 12: Notes to the educator**

**4. Resources:**



## Appendix H: Illustrations



## Appendix I: Reading Body Language



What are they saying with their body language?

How should I approach them?



What are they saying with their body language?

How should I approach them?



What is this person telling me with their body language?

How should I approach them?



## Appendix J: Ending Relationships

It can be very difficult to end a relationship. It is hard when we want to end a relationship, but just can't think of the words to say to our partner. Try practicing these scripts to end relationships; once you are comfortable, try making your own script to end a relationship

### *Drifting apart*

*Sometimes in relationships we just start to drift apart from the other person. Often there is no specific reason. When partner drift apart, feelings start to disappear. This is usually not someone's fault. Here's what you might say if you are drifting away from your partner:*

"Iain, I have very much enjoyed our time together, but I no longer have the same romantic feelings for you that I once did. I thank you for all the times we've shared together, but I think it is time to end our relationships. I hope we can still be friends"

Try writing your own script:

### *Breaking up for a reason*

*Sometimes we end relationships for a reason. Maybe you and your partner got in a big fight or are in disagreement about a really big issue that you cannot seem to compromise on. Here's what you might say if you are breaking up with your partner for a reason:*

"Iamie, I have been thinking about the relationship problems we have been having lately (explain problems here). I think our problems are too big to fix, and I do not think we should be in a relationship any longer. I hope we can still be friends."

Try writing your own script: