

## Sexual health education for adolescents with developmental disabilities

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### Abstract

**Background:** While statistics related to the sexual abuse of people with developmental disabilities are alarming, there remains a gap in the services and supports available to promote sexual health and healthy relationships and prevent sexual abuse of this population.

**Objective:** To develop and deliver a sexual health education programme for adolescents with developmental disabilities and to identify the reactions and perceptions of students, teachers and parents involved in the programme.

**Methods:** Using an interprofessional collaborative community development model, we developed and delivered a sexual health programme to young people aged 16–21 years with developmental disabilities in five Saskatchewan, Canada high schools. The project adapted, modified and administered the Canadian Red Cross RespectED questionnaires to all participants following the programme to allow for the identification and implementation of best practices with regard to the project's future operation.

**Results:** Data collected from the feedback and comments were summarised, and major concepts were identified. The information gathered identified meaningful educational experiences for students, their parents and teachers.

**Conclusion:** Project findings reinforce the importance of sexual health education for people with developmental disabilities to increase opportunities for healthy sexual relationships and intimacy, to promote positive sexual identities and to decrease the risk of sexual victimisation.

### Keywords

Adolescents, developmental disability, intellectual disability, sex education, sexual health education

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## Introduction

While statistics related to the sexual abuse of people with developmental disabilities are alarming, there remains a gap in the services and supports available to promote healthy sexuality and healthy relationships, and to prevent sexual abuse of this population. In particular, there are limited programmes and resources to teach and assist young people with developmental disabilities how to develop healthy relationships and keep themselves safe. Teaching protective skills does not put the full responsibility on young people to keep themselves safe nor does it exclude the need to view them from a systemic perspective in the context of their environment and the social circumstances that put them at higher risk.

The vulnerability of young people with disabilities is intensified for a number of reasons, including social isolation, limited cognitive abilities, language, speech or vocabulary barriers, dependence on others for personal care, risk of low self-esteem, depersonalisation, powerlessness, lack of education on sexuality and abuse/harassment prevention, non-protective organisational structures and policies, physical defenselessness, compliance, and negative and inaccurate attitudes, myths, and stereotypes (Bowman et al., 2010; Martinello, 2014; Tourigny et al., 2001). One of the impacts of this vulnerability is an increase in the prevalence of sexual abuse. This vulnerability, however, does not justify their increased victimisation and ultimately the perpetrators are responsible for sexual abuse occurring.

Although statistics vary, the literature indicates that the frequency of sexual abuse is higher among adolescents with developmental disabilities compared to adolescents without a disability (Soylu et al., 2013). Studies show that individuals with a disability experience 4–10 times greater risk for sexual abuse compared to the general public (Frawley and Bigby, 2014; Martinello, 2014; Northway et al., 2013; Phasha, 2009; Soylu et al., 2013). Determining the extent to which adolescents with developmental disabilities are abused is difficult because definitions of abuse vary, and methods of recording differ. Abuse is often not reported for a number of reasons and when reported there are often no charges laid following allegation and, if charges are laid, conviction is rare (Cambridge et al., 2011). Children and adults with intellectual disabilities have a greater risk of being abused than do typically developing peers (Beadle-Brown et al., 2010; Bryne, 2017; Northway et al., 2013). In addition, young people with disabilities are more likely to experience dating violence compared to those without a disability (Bryne, 2017). In the USA, persons with intellectual disabilities experienced the highest rate of victimisation of all disability types (Harrell et al., 2017).

Education is important for parents to assist them in understanding the sexual development of their children and to promote and encourage them to accept the responsibility of sexual health education for their children (Travers and Tincani, 2010). A relatively high percentage of children and adolescents with developmental disabilities do not receive any formal sexual health education and increasingly, parents often rely on school teachers to provide this education rather than taking on that responsibility in the home (Barnard-Brak et al., 2014; Kaufman, 2011; Thompson et al., 2014). Parents are often not aware of what to teach their children or how to teach them due to a lack of knowledge, skills or awareness (Isler et al., 2009; Pownall et al., 2012). Parents may also believe that their children and adolescents with a disability do not require sexual health education as they will not have a sexually intimate relationship with another person. Moreover, some parents may be reluctant to discuss sexual health issues with their children (Gurol et al., 2014).

Sexual health education is not consistently included in special education programmes directed towards adolescents with developmental disabilities (Rohleder and Swartz, 2012). There is also a limited amount of information about the availability of sexual health education in special education classrooms, and teachers are often reluctant to teach sexuality without adequate preparation (Kok and Akyuz, 2015; Schaafsma et al., 2013, 2014). However, sexual health education has been shown to be effective in the prevention of sexual abuse, pregnancy and sexually transmitted diseases among at-risk populations (Kok and Akyuz, 2015). In addition, models of school-based mental health service

delivery have been found to be highly efficacious with this and other populations (Barnard-Brak et al., 2014; Evans et al., 2000; Nabors et al., 2001; Richards and Vostanis, 2004; Weist et al., 2000).

The literature on available and effective sex education for adolescents, their family and teachers guides project development and indicates a consensus that the following topics be included: sexual health promotion, body awareness, social behaviours, romantic relationships and intimacy, and the psychosocial determinants of health (Schaafsma et al., 2013, 2014; Travers and Tincani, 2010). However, Bruder and Kroese (2005) emphasise the importance of routinely teaching protection and prevention skills with an equal emphasis on helping students acquire skills to experience sexuality in a positive way. The focus needs to also address 'pleasure, desire and intimacy' (Löfgren-Mårtenson, 2012: 209), and the inclusion of youth as both participants and collaborators in planning the sessions and the research approach (Schaafsma et al., 2013, 2014; Travers and Tincani, 2010).

Adolescents with developmental disabilities are often perceived as not having the ability to learn how to protect themselves against abuse. Limited access to information and education restricts sexual health awareness of not only adolescents with developmental disabilities but also their teachers and parents, and society as a whole (Frawley and Bigby, 2014; Swango-Wilson, 2011). However, through education regarding sexual health and relationships, adolescents with developmental disabilities will be better equipped to protect themselves and more likely to have healthy peer relationships. Also, given the diverse, complex and challenging needs of this target population, a multidisciplinary-interprofessional approach offers the most suitable and potentially efficacious intervention model available (Barnard-Brak et al., 2014; Cowley et al., 2002; Glasby and Lester, 2004; Leipzig et al., 2002; Richards and Vostanis, 2004).

Currently, there exists a notable poverty of programmes and services available for the promotion of healthy sexuality and the prevention of sexual abuse for young people with developmental disabilities. The Creating Safe Environments Project discussed in this study attempts to fill this large gap in community programming by offering immediately accessible school-based mental health education to this underserved population using a community development model.

The purpose of the project was the provision of educational resources to increase personal safety, promote sexual health and prevent sexual abuse of this particular population. In addition, the project provided education, awareness, tools, and supports to parents and teachers enabling them to further educate and support adolescents in healthy relationships and healthy sexuality education. The project goes beyond teaching protection and prevention skills and promotes the skills necessary to develop healthy peer relationships, dating relationships and positive sexuality.

## Methods

### *Collaborative community development model*

According to Kajner (2015), academics need to be open, listen and take a position of not-knowing in their approach to community engaged scholarship. In addition, academia is encouraged to learn from and take direction from the community and negotiate a genuinely reciprocal relationship with mutual benefit for all. Using such a collaborative community development approach, the author listened and learned from a number of the community partners including the Greater Saskatoon Catholic Schools (GSCS), the Saskatoon Sexual Assault and Information Centre (SSAIC), the Saskatchewan Red Cross RespectED programme and additional organisations. Their main request was for a programme that met the sexual health needs of adolescents with developmental disabilities and involved all partners in the process.

The project explored three areas related to the provision of educational resources required to ensure appropriate and adequate sexual health education for adolescents with developmental

disabilities. Initially, the project identified the literature related to healthy sexuality education for adolescents with developmental disabilities and explored possible delivery modes for knowledge transfer in this area. Second, available resources for adolescents with developmental disabilities were identified and reviewed including human resources, institutional, and programming resources. Third, consultation took place with community organisations and partners as named above. The intent of the literature review and consultation was to determine the appropriate content and delivery mode for school-based presentations.

Recognising the intersection of disability and sexuality and the influence of the social determinants of health on the lives of adolescents with developmental disabilities, the community partners also worked with an interprofessional intervention team consisting of professionals and undergraduate students from the disciplines of nursing, social work, psychology and educational psychology. This team provided a consultative and supportive role and follow-up counselling and intervention if needed for participants. Undergraduate students from the various disciplines were trained in the delivery of the programme.

Following a number of meetings between the author and the community partners a collaborative decision was made to modify and adapt current educational resources, available through the Red Cross RespectED programme and the SSAIC, intended for neurotypical children and adolescents. The Red Cross RespectEd Coordinator assisted in adapting their storyboards to address the needs and comprehension level of this population and the RespectED concepts of ‘talk (say No)’, ‘walk’ (get away as quickly as you can), and ‘squawk’ (tell someone you trust and keep on telling until someone believes you), were integrated into the programme. The SSAIC collaborated in adapting their current puppet show script to address the needs, vulnerability and cognitive abilities of adolescents with developmental disabilities.

Once the programme had been developed, it was delivered over five, 1-hour sessions. The first two sessions included interactive learning, games and activities to introduce the programme and the subject of sexual health. The next two sessions included storyboards that depicted possible scenarios that young people might be involved in, related to both healthy and unhealthy relationships and situations. Following the storytelling, discussion and questions were encouraged and supported. The final session included a puppet show that focused on issues of consent, inappropriate touching and disclosure of sexual abuse. Following the puppet show, small group discussions took place facilitated by the university student puppeteers while remaining in character with their puppet.

### *Research instrument*

A collaborative decision was made to adapt, modify and administer the Red Cross RespectED questionnaires to all participants following the programme to allow the identification and implementation of best practices with regard to the project’s future operation. The questionnaires were reviewed by learning assistance teachers (LATs) prior to administration to assure the questions included were appropriate and understandable to the adolescents with developmental disabilities. Although the questionnaires were not tested for reliability, Red Cross worked closely with PREVNet (a national network of leading researchers and organisations, working together to stop bullying and violence against children in Canada) to have all questionnaires evaluated and the questionnaire development followed a standard process to assess for knowledge. The questionnaires were administered to all participants, including students, teachers and parents. The questionnaires included both closed and open-ended questions. Each questionnaire included five Likert-type scale questions (see tables inserted), as well as an opportunity to provide additional feedback and comments. Parents and teachers were asked if they had any further comments, feedback or

suggestions. Students were asked if they had any thoughts, feelings and/or experiences related to the information presented.

### *Participants*

The programme was implemented in the five Greater Saskatoon Catholic high schools and included a total of 101 adolescent/student participants that were identified in each of the schools as having a developmental disability. Students ranged in age from 16 to 21. Of those, 93 completed the questionnaire. The students who did not complete the questionnaire were unable to express themselves through speech and often had difficulties communicating in other ways.

Prior to delivery of the programme a parent information evening was held to explain the importance of sexual health education, describe the programme and answer questions. A similar information session was provided to teachers and included the appropriate response and protocol related to a possible disclosure of sexual abuse by one of the student participants. All parents, including the caregivers of young people living in alternative housing, and teachers were invited to participate in the study. Twenty parents completed the questionnaire in addition to 41 LATs and education assistants (EAs). All teachers invited to be part of the study completed the questionnaire. The low number of parents doing so may have been related to the living accommodation of the adolescent participants, as many lived in foster care, private care homes or group homes and there was limited response from caregivers.

Prior to the implementation of the project, written informed consent was obtained from the parents for their children to participate in data collection. Assent was obtained from the students themselves, when appropriate, and informed consent was also obtained from the teachers. The project was approved on ethical grounds by the University of Saskatchewan Behavioural Ethics Committee (Beh # 07-206) and GSCS.

### **Results**

Data collected from the feedback and comments were summarised and the major concepts identifiable within it were outlined. The information gathered enabled the identification of meaningful educational experiences for students, parents and teachers.

#### *Parent reaction to the programme*

Parent responses to the programme are shown in Table 1. The main topics students talked about with parents were the puppet show, inappropriate touching, secrets and body parts. Several parents indicated their child was 'non-verbal' and one parent indicated that their child was teaching her siblings how to 'talk, walk and squawk'.

Parents indicated that their child now understood what was related to inappropriate touching, appropriate boundaries, private body parts, how to protect themselves and say 'No', privacy and being able to make decisions about their body. They also indicated their children still might not understand their own responsibilities and their own inappropriate behaviour, and their children demonstrated some confusion about what is good or bad and how to ask for help. Parents indicated their children were more willing to talk about sexuality, and although some students did not want to attend the presentations at first, they did attend and enjoyed it and learned about being safe.

Retention was noted by parents as a challenge for some of the children and the importance of repetition of the material covered was mentioned. Many parents indicated they were hopeful that the information provided would help their child to be safe and that they were encouraged that their

**Table 1.** Parent responses ( $n=20$ ) to sexual health programme in percentages.

Questions	Yes	No	Don't know	No answer
Did you talk about the healthy sexuality and healthy peer relationship presentations at home?	80%	15%		5%
Do you think your child understood the message?	70%	15%		15%
Did your child respond positively to the presentations?	45%	10%	45%	
Do you think the presentations have contributed to the health and safety of your child?	55%	30%		15%
Are you more comfortable talking to your child about healthy sexuality and healthy peer relationships as a result of the presentations?	55%	20%	15%	10%

child would disclose abuse more readily now. Other parents indicated it was easier to discuss sexual health now that their child was more receptive and open to doing so. One parent commented, 'We weren't sure how to make it appropriate for her, but you have given us the tools to continue the dialogue'.

Some parents requested more information on how to be proactive, how to detect if sexual abuse might be happening, and how to discuss sexual health and sexual abuse prevention with a child who has a cognitive disability. Some said a simple picture book would be helpful and material available at a youth reading level, grades 3–6. One parent indicated that she would have liked to have information sent home following each presentation so she knew what had been talked about that day.

The majority of parents were complimentary of the programme and indicated the need for the programme. Others were curious as to what their child's reaction was during and immediately following the presentations. They indicated that they thought the puppets were a 'huge success'. One parent commented that her daughter seemed confused following the presentations, although she said she did enjoy the puppet show.

### *LATs' and EAs' reaction to the programme*

The responses of the LAT/EAs are shown in Table 2. LAT/EAs agreed that the presentations may have been more useful for the students who were better able to understand and participate in discussion due to their higher cognitive function. Teaching staff noted that the students were engaged, interested in the material, attentive, focused and motivated to come back for each presentation. They indicated that some students were quiet but when questioned they knew the answer to the questions posed. While some students were uncomfortable with terminology, most students enjoyed the presentations and were excited for any upcoming presentations. Students learned how to protect themselves and received other valuable information.

Teaching staff overwhelmingly identified the puppet show as most useful. The teachers indicated this was due to the script reflecting a possible at-risk circumstance relative to the students 'own experiences, as the students related very closely to the puppets, talking directly to them and asking important questions'. The teachers also indicated that seating the students in a circle for the presentations and the relaxed and accepting learning environment was very effective. They also noted the repetition of important concepts was particularly useful for learning and engagement.

The teaching staff also indicated the storyboards and visuals were engaging and useful in terms of aids to learning and understanding. One teacher commented, 'The large picture boards coupled with the simplified language made the discussions more comprehensible for students'. The LAT/EAs said that although students may have been uncomfortable about the correct names for body

**Table 2.** LAT/EA ( $n=41$ ) responses to sexual health programme in percentages.

Question	Yes	No	Don't know	No answer
Was the Healthy Sexuality presentation well received by the students in the classroom?	90%	10%		
In your opinion was the presentation effective or helpful?	98%	2%		
Was there anything you/your class did not find effective or helpful?	1%	99%		
Did any of the students come forward to ask questions or discuss their situation with you, the teacher, following the presentation	27%	63%		10%
Would you recommend these presentations to others?	99%	1%		

LAT: learning assistance teachers; EA: education assistants.

parts, this information was important and they also noted that the students became more comfortable over time and were able to discuss and name private body parts specifically. Also important was the clear direction given for what students could do if they were fearful or felt they were being abused or hurt. 'Talk, Walk, Squawk' was also noted as a catchy and interesting way to learn what to do in inappropriate and at-risk situations.

Suggestions were made related to further modifications needed for students who were unable to express themselves verbally. For example, teaching the students to physically push someone away if they are unable to say 'No'. Another suggestion was to be more hands-on and more kinaesthetic. Videos and multimedia were also mentioned as helpful suggestions.

Most of the LAT/EAs indicated that students had not approached them directly after the five presentations, but several students had told their parents and peers stories such as they had met a 'creep' on Facebook and they needed to end the relationship and they had learned how to do this from the presentations.

The reason the LAT/EAs believed the programme would be useful to others was that it was informative, appropriate and relevant to the life experiences of students with developmental disabilities. Some LAT/EAs indicated that it was helpful to share this information with parents as sometimes parents do not understand that their children are sexual beings with wants and needs related to sexuality. However, they indicated that a few students appeared bored and distracted.

Teaching staff frequently stated that the undergraduate students who did the presenting were mature, professional and accepting in their approach and offered a very welcoming learning environment. It was suggested that dividing students into groups related to their level of functioning and then adapting the presentation to each group was a productive way forward. Some also suggested dividing the groups according to gender. One teacher enquired about the appropriate approach to use in the event that a student might find the inappropriate touch pleasant, in particular when teaching and communicating with students about inappropriate touch when they require personal care at school.

Many LAT/EAs indicated the need for repetition and ongoing reminders about appropriate and inappropriate touch and healthy relationships.

### *Students' reactions to the programme*

Student responses to the programme are shown in Table 3. A large majority of the students referred positively to the puppet show and the concepts of 'talk, walk, and squawk' in their comments. They

**Table 3.** Student ( $n=93$ ) responses to sexual health programme in percentages.

Question	Yes	No	Don't know	No answer
Did you like the presentations?	81%	13%	6%	
Did you find the presentations helpful?	93%	4%	3%	
Do you think that others should get this information?	92%	5%	3%	
Would you like to have more information?	97%	0	3%	
Will you do anything differently as a result of the presentations?	75%	16%	9%	

also liked 'learning how to take care of their body, how not to get hurt (abused), and how to find someone to talk to about abuse if they needed to'.

Students were, however, more uncomfortable with the characterisations of nudity and learning the proper names for private body parts. Others indicated the presentations were 'boring or lame and that perhaps elementary kids would like it better'. Others said they were uncomfortable talking about inappropriate touching.

Overall, student participants commented that the information would help others 'not get hurt or abused' and if they had a problem, they would know how to get help. Some of the main concepts they said they learned about included body parts, emotional abuse, dating relationships, the fact that adults you know and like may still hurt or abuse kids, what do to if your parents won't give you privacy, bribing and 'how bodies work' and 'how to get your period'. Many indicated they would like to know more about having a 'girlfriend' or 'boyfriend'. They also indicated the importance of not keeping a secret about abuse or inappropriate behaviour.

## Discussion

Overall, the storyboards and puppet show appeared to be effective methods to connect with young people and an appropriate approach to introduce and discuss issues of sexual health. The majority of students enjoyed the stories and the puppet show and their interest and enthusiasm were transparent. They reflected on how they related personally to the stories, the puppets and the puppets' experiences. They not only related to the friendliness of the puppets but also the experience of inappropriate touching and abuse. The concepts of talk, walk, and squawk were seen as useful. The teachers noted how the students repeated talk, walk, and squawk on many occasions following the presentation and they interpreted the information without parroting the words. For example, one student said, 'I would tell my friends first, and then I would tell their moms and then my mom and then my boyfriend'.

Data revealed that students were interested in acquiring more information related to dating relationships, attaining privacy at home and where to go for help especially if you are not being heard or believed about a disclosure. They wanted the information they received to go beyond themselves and to be able to be shared with others. Some students reflected that they would like to be able to help others or help their friends and listen to their friends if they are in trouble. Students were very keen to learn more about healthy relationships and the skills required to experience sexuality in a positive way.

That said, there was sometimes a degree of conflict or mixed emotions. For example, one participant stated, 'I didn't like it at first, but it was good to know'. Others were unsure how they felt, stating, 'I don't know, I really did want to be here'. Some of the fear and discomfort seemed to be related to not knowing some of the information and thinking that perhaps they should have known

this already. Most said they really enjoyed the presentations, but many had mixed feelings that were a combination of interest and excitement, and sadness and discomfort. One participant summarised this in their statement, 'I feel sad, happy and sick: I feel that the presentation is good; it feels pretty good when it helps people'.

In general, the parents commented positively on the skills and information their children had learned. Many parents were not sure if their children fully understood the presentations and if they in fact would be able to put this learning into action. They also noted that their children seemed slightly confused about what was good and bad or what they should do in certain circumstances. There was a sense that the programme may have been more beneficial for students at a higher level of functioning. Parents were appreciative of the programme and discussed the need for ongoing education of the kind presented. The parents found that as the subject was discussed they became more comfortable about the topic, and it was easier for them to address this subject with their children.

The LATs and EAs expressed the view that the students needed some degree of autonomy over their sexual lives but balanced with protection from sexual abuse and victimisation. They supported the use of storyboards and puppet show as effective modalities to teach sexual health and sexual abuse prevention, as they included possible scenarios of risky or inappropriate situations as well as healthy or safe situations and relationships. Some teachers suggested using a more interactive approach to facilitate the involvement and participation of the students.

### *Limitations and strengths*

Several challenges were encountered to the use of questionnaires with individuals with developmental disabilities that may have limited capturing the full extent of the participants' experiences. Some participants, for example, required the assistance of an LAT or EA to complete the questionnaire. Although these individuals were used only to clarify questions and assist in writing responses, their presence and assistance may have influenced participants' answers.

Significant to the study is the fact that teachers showed a more positive response to the presentations and the benefits for students than did the parents. The teachers were in attendance and able to observe students during the presentations while parents did not experience it directly. Although a parent informational meeting had been arranged prior to the programme, only a limited number of parents attended.

Despite these limitations, findings from the study provide an indication of overall effectiveness of the programme's methods (puppetry, posters, and interactive sessions) for use in educating young people with developmental disabilities about sexuality. They also helped identify the weaknesses of using questionnaires for data collection with members of this population to guide future projects. Focus groups may offer a more appropriate means by which to understand the adolescents' perceptions of the educational sessions and a peer-to-peer model for educational delivery may be beneficial in the future (Gougeon, 2009).

### **Conclusion**

This project aimed to build capacity in community research, education and practice to improve the health and wellbeing of adolescents with developmental disabilities and their families. It also sought to build equitable conditions for mental health within this population especially with respect to sexual health and healthy peer relationships. The work undertaken utilised an interdisciplinary and intersectoral community development approach that aimed to bring about significant positive change in the lives of adolescents living in disadvantaged circumstances. The prevention of sexual

abuse is important; however, it is important to promote sexual well-being and health through a concern for intimacy, safety and desire, rather than fear and overprotection (Murray, 2016). Adolescents with developmental disabilities need to protect themselves while appreciating and having the opportunity to develop an intimate and healthy relationship with someone they care for (Murray, 2016).

Implications of this study for practice include the importance of sexual health education for people with developmental disabilities with a focus on healthy sexuality and intimate relationships, the use of an interprofessional community development approach, the inclusion of adolescents with developmental disabilities and their parents in the planning and development process of sexual health programme delivery, the use of interactive approaches to learning, and the repetition of key learning concepts. In general, the teachers, students and parents in this study seemed relieved to receive this kind of guidance and support and to begin a conversation around sexual health, a topic that remains somewhat taboo today, especially for young people with developmental disabilities.

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