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Identifying significant components of a sexuality education program for students with severe disabilities

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Sexuality Education in Special Education

Abstract

The body of knowledge in the field of sex education that has been modified for individuals with disabilities is currently lacking. There are currently no evidence based practices for sexuality education. The programs that currently exist are either not effective for the severe population or there is no research to support its use. However, people that are considered in the population of severe special education could benefit greatly from a sexuality program that is evidence based.

The researcher conducted a study to determine the topics that are common in the literature and that are important to teachers and their with severe disabilities students. The study also identified common and effective methods of sexuality instruction and assessment. This study combined archival documentation and survey questionnaire responses of teachers to understand the issues related to sex education and special education. As a result, several significant discrepancies were identified. Despite these discrepancy, specific topics, assessment methods, and necessary resources for educators were identified.

Introduction

As defined by the World Health Organization in 2006, sexual health is the possibility of having positive/safe sexual relationships and the protection of a person's sexual rights. Operating under this definition, people with moderate to severe disabilities are unlikely to be considered sexually healthy. This is especially true for individuals with moderate to severe intellectual impairments. People with severe disabilities are typically defined as individuals that preform two or more academic grade levels behind their peers of the same chronological age. A person's sexual health is comprised of two different elements: positive sexual experience and the protection of sexual rights. Individuals with severe disabilities are often prevented from having

*A person with severe disabilities is an individual that preforms two or more academic grade levels in comparison to same age peers and may be considered for MCAS-alt.

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sexual relationships or they have negative sexual experiences. Some parents and care-givers are actively opposed to their disabled children procreating or having sexual relations (Aunos & Feldman 2002). Furthermore, the sexual rights of these individuals are not protected or valued. Individuals with severe disabilities have limited control over their body and they are not provided equitable access to sexuality education.

Equitable access to sexuality education can provide disabled individuals the tools that they require to experience better quality sexual health. Sexuality education can be defined as instruction about sexuality. Sexuality encompasses ideas like sexual orientation, gender roles, sexual behaviors, relationships, and various other topics (Sinclair et. al. 2015). A comprehensive sexuality program can teach individuals about these topical areas, but they can also teach individuals how to have a safe and positive intimate relationships. Additionally, these types of sexuality programs can help individuals express their sexuality in appropriate ways. A comprehensive program can also teach individuals to be better self-advocates and to exert more control over decision making about their bodies. Furthermore, by providing sexuality education, the rights of the disabled population could be better protected.

The following study explores significant components of sexuality education for individuals with severe disabilities. Components include the content of instruction, the methods of assessing student knowledge, support for instructors, and specific barriers that hinder instruction. It is important, within the field of special education, that the content of instruction is meaningful and accessible to students with disabilities. The methods of assessment should vary between both formal and informal methods. Specifically, working with individuals with severe disabilities, it is important to assess their understanding of sexuality across environments in order to assess the generalization.

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Literature Review

Sexuality Education in the United States of America is inadequate and obsolete when compared to other industrialized nations. Approximately ninety percent of high school age students receive school-based sexuality education. Despite school-based sexuality education, American youth are still the more likely to become pregnant or to contract a Sexual Transmitted Infection (STI) in comparison to the adolescent populations of other industrialized nations (Carrion & Jensen 2014). So despite efforts made to decrease risky sexual behaviors, there still exists this discrepancy between sexuality instruction and healthy sexual outcomes. Among the many issues associated with sexuality education, the most prominent include: the controversial nature of the topic, misconceptions and fear of sexuality instruction, inconsistency of instruction. (Carrion & Jensen 2014, Corngold 2013). Additionally, instructional time limitations and funding have also been addressed as issues in the literature.

There are many concerns related to Sexuality Education and as a result United States has increased funding for Sexuality Education programs. All states require public schools to provide some form of Sexuality Education; however, it varies from state to state what is included in that instruction. Since the early 2000s, funding for Sexuality Education programs has increased. (Williams & Jensen 2016). National agencies such as the Office of Adolescent Health (part of the U.S. Department of Health and Human Services) have conducted research and have evaluated the effectiveness of Sexuality Education programs. As a result there are lists of evidence-based programs and promising programs for Sexuality Education (Cushman 2014). Some issues that have been addressed in the literature are implementing programs with fidelity as well as time spent on instruction.

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There is promise, that the discrepancy between health outcomes and instruction will decrease overtime. However, a major issue with Sexuality Education is that not all students have access. Specifically, students with moderate to severe disabilities rarely receive Sexuality Education. Approximately sixteen percent of students with severe disabilities receive some form of Sexuality Education (Barnard-Brak et. al. 2014). Those who do receive Sexuality Education tend to receive it later in their school experience than their typically developing peers. Additionally, the focus of instruction is to prevent a person with disabilities from becoming a perpetrator of a sexually related crime (Martionello 2014). This exclusion from equitable Sexuality Education or the lack of scope of Sexuality Education is detrimental to individuals with severe disabilities.

Research has shown that individuals with severe disabilities are six times more likely to experience abuse and four times more likely to experience sexual abuse than their typically developing peers. There are several proposed reasons as to why this occurs. Some factors include: language ability, motor ability, taught compliance, and others. However, one significant factor is a lack of accurate sexual knowledge (Martinello 2014). It has been reported that many individuals do not know anatomical terminology, they cannot identify reproductive external anatomy, and are unaware of what sexual behavior entails. Often, language ability, social skills, and learned compliance are significant factors of sexual abuse in combination with lack of sexual knowledge. As a result, individuals with severe disabilities are ill-equipped to prevent and recognize abuse or to report it when it occurs (Kim 2015). These negative sexual experiences have deleterious effects on sexual health and quality of life for individuals with severe disabilities.

Another damaging effect that a lack of sexual knowledge can cause is an incomplete self-perception. Without access to sexual knowledge, individuals with disabilities tend to reject their

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sexuality. Many individuals report that although they have sexual desires, that they do not consider themselves sexual beings or they believe that their desires are wrong (Schaafsma et. al. 2015). Those who accept their sexuality and do not feel negatively about it, often do not have the opportunity to express their sexuality. Whether an individual lacks the privacy to have an intimate relationship or lacks the over-all ability to chose an intimate partner, they are prevented from experiencing what their same-age peers might be experiencing. Other individuals report that they are desirous of having relationships; however they do not have the knowledge or skill set to start or to maintain an intimate relationship (Sinclair et. al. 2015). A lack of sexual experiences or meaningful relationships can also negatively impact quality of life. With increased sexual knowledge and acceptance, a person may have more opportunities to have positive sexual experiences. Therefore, the level of access to Sexuality Education can drastically affect a person's life in a variety of ways. Spanning throughout the literature, researchers and authors have emphasized that Sexuality Education is a basic human right and that people can experience a better quality of life when granted access to more sexuality education programs.

Although there is established knowledge that sexuality education is beneficial, there are several substantial reasons as to why individuals with severe needs are excluded from sexuality education. The pervasive belief that individuals with disabilities are not sexual beings, is the part of the foundation of the argument that these individuals do not need Sexuality Education (Schaafsma et. al. 2015). This issue is, due in part to the fact, that many infantilize individuals with disabilities and they genuinely believe that these individuals cannot have sexual desires or intimate relationships. Contrary to this belief, individuals with severe disabilities are not physically different in terms of sexuality. There is no significant difference in terms of sexuality and fertility (Zacharin 2009). These individuals have the same natural desires, but they are

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denied access to vital sexual knowledge as a result of this misconception between a person's intellectual proficiency and their emotional and sexual maturity. This belief is so prevalent that one study found that only twenty-five percent of teachers polled believed that students with disabilities would benefit from Sexuality Education (Branard-Brak et. al. 2014). This misconception also affects how parents and other care givers provide support to an individual with severe disabilities. Often, these individuals are not afforded the opportunity to have privacy or to have relationships as a result of their care needs or as a result of parental rules (Aunos & Feldman 2002). Many parents are also opposed to Sexuality Education for fear that it will increase sexual behaviors and issues such as unintended pregnancy, defying parental wishes, and more. Unfortunately, many individuals who require a lot of support also experience an over-all lack of control over their bodies. Although, their care needs must be addressed and many of the decisions are made in the best interest of the individual, it does not afford them the same autonomy as their same age peers.

Another barrier that affects level of access to Sexuality Education is the instructor and the programs used to instruct students. There are some individuals who attend sexuality education with their peers; however much of this instruction is not made accessible to individuals with severe disabilities. Alternatively, many students with severe disabilities do not attend Sexuality instruction with their peers; therefore a student's academic teacher is responsible for addressing these needs. One study found that most teachers do not feel comfortable teaching topics of sexuality for a variety of reasons. However, many others simply feel ill-equipped to teach these topics because the instructor lacks the training or support from the school. Some do not feel that it even their responsibility to teach their students these topics, as an academic instructor (Schaafsma et. al. 2015). The lack of standards and mandates for this population creates an issue

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of responsibility. If academic teachers are responsible then they require some training or support to provide sexuality instruction. If sexuality educators are responsible for instruction, then they require training or support to provide instruction for the population of severely disabled individuals. At present, there are only few programs that are substantiated by research that are specialized for individuals with disabilities. There are many programs that are either not effective forms of instruction, have unidentified instructional methods, lack assessment methods, or are not cost effective (Grieveo et. al. 2006). Promising programs and research are outlined below.

Researchers like Wolfe and Blanchett, have identified ways parents and educators can evaluate an existing program by using a sexuality education protocol. This protocol highlights instructional materials, strategies, and identified goals of a program. This protocol also focuses on how a program is adapted for an individual's needs. Although this method does not identify specific programs of value, it can provide support to educators when they are choosing a program for their students (Wolfe & Blanchett 2003). Additionally some other researchers have identified topics that would be beneficial for individuals with severe disabilities. However, they do not include instructional methods, assessment methods, or the means to evaluate an existing program. Several researchers have emphasized the importance of teaching reproductive anatomy in combination with physical changes during puberty. Contraception and preventing the transmission of Sexually Transmitted Infections are also frequently mentioned in the literature. Many other researchers have stressed the importance of teaching appropriate sexual behaviors, dating behaviors, and differentiating types of relationships. Another prevalent topic is communication and communicating in relation to sexual desires or behaviors. Other topical areas are presented in the results section of this study.

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There are also some field-tested programs that are specifically aimed to help individuals prevent and or report abuse. In a 2015 study by Y. Kim, the research team created a program that utilized visuals, role play, and parental co-operation to instruct three Korean females with intellectual disabilities. The focus was specifically identifying inappropriate sexual behaviors and rejecting or leaving potentially abusive situations. Subjects' prior knowledge was assessed before instruction. The subjects were also assessed after instruction in the instructional setting and in other settings in order to assess the generalization of skills. This program was found to be effective for these individuals (Kim 2015). Due to the sample size, it may be difficult to generalize these results to the population of people with severe needs. This research study also has a narrow scope of topical areas, meaning that there is a sole focus on abuse prevention. Whereas other programs have a broader scope of topics that support sexuality development and encourage a positive sexual identity. However, the methods of instruction may prove to be useful for teaching other topics related to sexuality.

“Sexuality and Disability: a guide for parents” (2009/2017) and “Sexuality and Disability: a guide for teachers” (2017) are free guidelines provided for by Alberta Health Services. This program, although assessment is not part of the guides, has a wider scope than a program designed specifically about abuse-prevention. Furthermore, these guides not only include topics for instruction, but they also include suggestions for how to instruct students. The guides also recommend instructing individuals on these topics throughout the life-span, ensuring that there are age and developmentally appropriate ways to address these topics. Topics range from; differentiating public and private behaviors, differentiating between good and bad touching, and maintain a healthy self-esteem. The guides also offer suggestions on how to handle questions that a student might ask and how to help foster a positive sexual identity. Although the

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recommendations made in this guide have not been tested in the field; the information that these guides provide is useful and it is free for anyone to use.

Sexuality Education for People with Developmental Disabilities is a sexuality education curriculum designed for and in co-operation with individuals with disabilities. This is a field-tested curriculum produced by Planned Parenthood. This curriculum, as of now, is not heavily researched; however it is highly recommended by regarded individuals in the field such as Dr. Robb Weiss. Dr. Weiss is licensed psychologist and Board Certified Behavior Analyst who works with individuals with disabilities living in residential programs. This curriculum includes pre-written lesson plans, work sheets, and informal assessment methods across eighteen different topics. Additionally, the curriculum comes with a sexual knowledge pre and post test. Furthermore, The lesson plans are accompanied by sample scripts for the lesson as well as where to find the materials (i.e. worksheets and visuals) that are used in the lesson. Bruder and Krosse (2005), emphasized the importance of teaching meaningful content with the use of modeling and role play (Bruder and Krosse 2005). Sexuality Education for People with Developmental Disabilities includes all of these aspects in their lesson plans and scripts. This is a very comprehensive program with topics that range from sexual feelings, dating, relationships, and communication. It is also a very flexible program through which an educator is able to choose which topics best address the needs of his or her students. Sexuality Education for People with Developmental Disabilities, promotes self-advocacy, self-determination, and positive self-esteem. This curriculum also provides an introduction for instructors. This introduction is thorough. It provides support for answering personal questions, for dealing with admissions of abuse, and how to conduct the lessons in a classroom setting. A guide for interacting with and getting the support of parents, is also a unique feature of this curriculum guide. Planned

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Parenthood also offers training for individuals to become a Sexuality Educator. Although this program and training must be purchased through Planned Parenthood, the program has a wide scope, it provides support for educators (through the text and through other means), and it provides a means of assessment in the classroom.

Research Question

It is evident that there is a paucity in research in the field of Sexuality Education and Special Education. The researcher endeavored to analyze the current body of literature and to determine what is actually happening in special education classrooms, to answer how can sexuality education for individuals be defined at this time.

Methodology

The present study conducted a literature review of archival documents from disability advocacy organizations to analyze the history of sex education to persons with severe disabilities and the current methods of instruction and assessment for teaching sexuality to persons with severe disabilities. Articles were included in the literature review if the article pertained to barriers to sexuality education, sexuality education as a human right, and topical areas in sexuality education. All articles included studies relating to sexuality education in the United States that could be translated into a special education setting or directly related to sexuality education and special education, regardless of country of origin. Some articles were excluded from the literature review. The articles were related to sexuality education in the United States; however the information could not be translated into a special education setting. The included articles were analyzed by using a thematic matrix. The results were aggregated into three tables. Each table highlighted either barriers to sexuality education, sexuality education as a human

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right, or topical areas in sexuality education. Barriers to sexuality education and topical areas in sexuality education were further categorized in to thematic sub-areas. Sexuality education as a human right was not further categorized because it could not be deconstructed to any further extent. The a-fore mentioned tables denote frequency of themes and are located in the Appendix B and a narrative of the results is located in the results section. Twenty total articles were read for the purpose of this study, seventeen are cited within the confines of this study, and eleven research articles were analyzed through the use of the thematic matrices.

Utilizing the information from the literature review and analysis, a survey was designed and distributed through Survey Monkey. As a result, the survey was financially limited to ten close-ended questions (nine multiple choice and one ranking). The consent to participate as well as the survey can be found in Appendix A. Participants were chosen by using a selective sampling method. Local Massachusetts districts were researched to identify teachers labeled as special educators, focusing on individuals working at the middle and high school level. Utilizing online staff directories, the researcher obtained potential participants' email addresses. One-hundred-eighty-five survey invitations were delivered using this method. From these invitations, thirteen individuals responded to the survey. Additionally, the researcher dispersed live survey links to veteran teachers known to the researcher. These individuals were asked to further distribute the survey. From the live survey link, there were ten individuals that responded to the survey. There were a total of twenty-three total respondents. No responses were excluded from the study. Once the results of the survey were obtained, the results were aggregated in a summary table and recounted in the results section.

Results

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Literature Analysis Results: Within the body of literature analyzed within the confines of this particular study, topics were categorized into three main themes: barriers to sexuality education, sexuality education as a human right, and content/topical areas in sexuality education. Articles relating to barriers to sexuality education included seven sub-topics: misconceptions about individuals with disabilities, lack of privacy and/or control, lack of sexual knowledge, barriers related to the teacher/instructor, barriers related to a particular individual, issues related to sexuality education programs, and barriers related to public opinion or public policy. A majority of the articles (62%) describes flaws in sexuality education programs that decrease the likelihood of effective instruction. Sixty-two percent of articles also outlined teacher qualities that decrease the likelihood of effective instruction. Examples of qualities include comfort-level, personal-beliefs, and prior-training. Furthermore, fifty percent of the articles labeled misconceptions as barriers to sexuality education. Examples of misconceptions include the idea that individuals with disabilities cannot be sexual beings or that disabled individual are child-like; therefore sexuality education is not necessary. A summary of these results can be found in table 1, located in Appendix B.

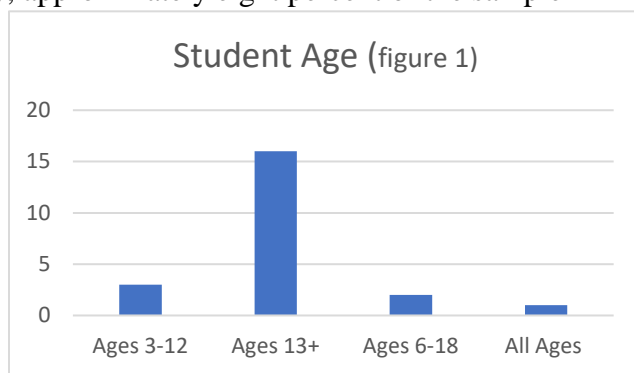
Articles explicating stating sexuality education as a human right included seven articles out of the seventeen that were analyzed. This accounts for approximately forty-one percent of the total articles. A summary of the articles in this topic can be found in table 2 located in Appendix B. Articles, published curriculums, and curriculum guide-lines that articulated specific topics for sexuality curriculum accounted for nearly thirty-five percent of the articles. Within this category, twelve broad sub-topics were identified: public vs. private spaces, good vs. bad touches, relationships/dating, communication, communicating about sex, diversity, sexual behaviors, attraction and sexual feelings, decision making, decisions about sex, avoiding pregnancy and

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STI, anatomy/puberty, esteem and bullying. A list of the articles as well as the frequency and definition of a sub-topic can be found in table 3, which is in Appendix B. The most frequently mentioned sub-topic was anatomy and puberty. This topic was found in approximately eighty-three percent of the articles. The second most frequent sub-topics included relationships/dating, communicating about sex, decision making, and avoiding pregnancy/STI. Each appearing in roughly sixty-six percent of the resources. Communication, esteem/bullying, public vs. private spaces, good vs. bad touches, and attraction/sexual feeling each appeared in fifty percent of the literature. Finally, the most infrequent topics included diversity and decision making about sex. Appearing in approximately thirty-three percent of resources and approximately sixteen percent of resources, respectively.

Survey Questionnaire Results: The sample of teachers was comprised mostly of individuals who service students thirteen and older (69.5%). Additionally thirteen percent of the sample services students between ages three and twelve. Finally, approximately eight percent of the sample

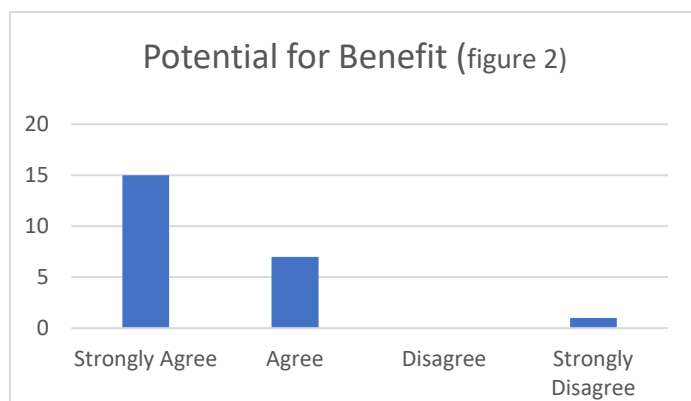
serviced ages six through thirteen. One respondent reported that he or she services all ages (ages 3+) and one respondent skipped this question. The graph depicting this data is represented in figure 1. A majority (56%) of



respondents reported that they have been in the field of special education for more than ten years. Nearly fifty-six percent of the teachers reported that their students receive Sexuality Education in school. Approximately ninety-five percent (22 respondents) reported that they agreed that individuals with severe disabilities could benefit from sexuality education. One respondent reported that he or she strongly disagreed with the statement “individuals with severe disabilities

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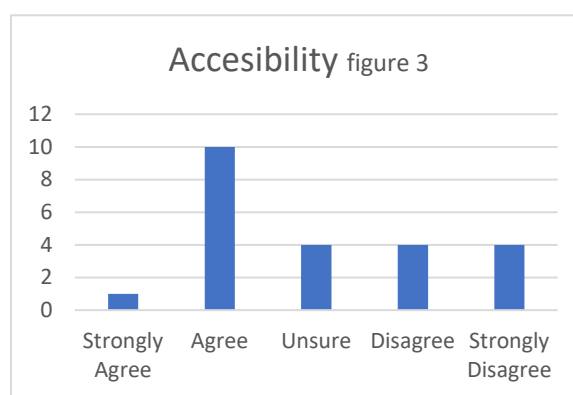
could benefit from sexuality education”. Data from this question is represented in figure 2. Fifty percent of the sample stated that they would feel comfortable or do feel comfortable instructing



Sexuality Education. However, only approximately 12.5% of teachers reported that they instruct their students in sexuality education. Fifty-eight percent of the respondents reported that another instructor provides sexuality education. In terms of

class-make in sexuality education, there were nine teachers that reported their students attend with same-age peers and eight that reported their student’s do not receive sexuality education. Furthermore, four respondents reported that their students receive sexuality education in a substantially separate setting without same-age peers and two that reported that their students attend both with and without peers.

In terms of the curriculum, roughly fifty-three percent of the respondents were either unsure or felt that the class materials or the curriculum for sexuality education was not accessible to students with severe disabilities (four unsure, four disagree, and four strongly disagree). This is compared to the forty-seven percent that agreed that curriculum is



accessible (one strongly agree and ten agree). A summary of this information is depicted in figure 3. Although, a majority (65%) of teachers do not teach sexuality education to their own students, the teachers that do provide instruction most write their own curriculum (17%) or use a

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published curriculum (13%). Sixty-six percent of teachers use an observational method to assess student knowledge. Twenty-eight percent use customizable worksheets. Some teachers also responded saying they use role-play activities and interviews. Finally, eighty-one percent of respondents reported that sexuality education training would help to provide better quality sexuality education. Fifty-nine percent reported that access to published curriculum and forty percent reported that access to better quality materials would help provide better quality sexuality education. Fifty-four percent reported that parental support would also help provide better quality sexuality education.

Finally respondents were asked to rank sexuality education topics in terms of importance to them and to their students. A score of one indicated that that topic was considered the most important, whereas a score of ten would indicate that that topic was considered the least important. For each topic an aggregate score was produced. The lower the number of the aggregate score indicated that a specific topic on average was ranked as being more important to respondents. Inversely a larger score indicated that , on average, that topic was ranked as being less important to respondents.

Table 4

Topic	Aggregate Average	Ranking
<i>Self Esteem and Sex</i>	4.33	1
<i>Preventing STI/Pregnancy</i>	4.58	2
<i>Reproductive Anatomy/Puberty</i>	4.63	3
<i>Decision Making about Sex and Pregnancy</i>	5.10	4
<i>Sexual Behaviors/Desires and Feelings of Attraction</i>	5.20	5
<i>Communicating About Sex</i>	5.60	6
<i>Dating and Types of Relationships</i>	6.10	7
<i>Personal Hygiene</i>	6.78	8
<i>Public vs. Private Spaces</i>	6.95	9
<i>Good vs. Bad Touches</i>	7.11	10

Discussion

Based upon the data collected from the literature review, there is a discrepancy between what is represented in the literature and what information is represented in the sample. Branard-Brak (et. al 2015), reported that only sixteen percent of students with severe disabilities receive sexuality education before graduating high school. The present sample indicated that fifty-six percent are currently receiving sexuality education in school. This is a significant increase of students that receive sexuality education. This discrepancy is most likely a result of varying educational laws in the context of the samples. Massachusetts allows the districts to decide sexuality education requirements; however in the prior study Massachusetts was not represented in the sample. According to the literature, one barrier to quality sexuality education is the discomfort felt by instructors when teach sexuality education. Whereas nearly fifty percent of the sample felt or would feel comfortable teaching sexuality topics compared to roughly thirteen percent of the sample that stated that they feel uncomfortable with the topics. This could be a result of sample size and the selectivity of the sample. Another barrier identified by the literature is the attitude of the teachers towards the benefits of sexuality education for disabled students. A prior study found that only twenty percent of teachers polled felt that students with disabilities could benefit from sexuality education (Branard- Brak et. al. 2014). In the present study, more than ninety-five percent of the sample either agreed or strongly agreed that individuals with severe disabilities could benefit from sexuality education. This could be explained by regional differences in values and attitudes. The prior study polled from a wider pool, whereas the present study selectively sampled certain districts in Massachusetts. This may also be explained by the same sample size and those who self-selected to complete the survey. However, if there were a more diverse and larger sample, and the trend were to continue, it may indicate a shift in

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perspective toward sexuality and disability. Finally a significant discrepancy exists between content areas for sexuality education. The most frequently appearing topic within the literature was anatomy and puberty whereas survey respondents on average ranked this topic as a three (third most important). Whereas the topic of self-esteem was infrequent in the literature, but was on average ranked the most important by respondents. Decision making about sex and pregnancy was also very infrequent within the literature, but on average respondents rated this topic as fourth most important. This discrepancy may be a result of what special educators view as necessary in a classroom setting compared to what publishers or researchers view as necessary in a research based setting. However, some of this discrepancy might also be a result of individuals being unaware of the implications of select topics or being unsure of what the select topic might entail. For example, differentiating between good and bad touches as well as differentiating between public and private places appear in fifty percent of the literature. Both are also identified as being two important skills involved in abuse prevention; however on average respondents rated these two topics as being the least important. A special educator might not be aware of sexual abuse statistics and many are unaware of skills that could prevent abuse whereas a researcher or clinician might focus more on abuse prevention. Despite their lower importance ranking, the researcher feels that these topics are still of value to individuals with severe disabilities.

The literature identified many potential barriers to sexuality education as well as outlined why sexuality education should be a valued aspect of special education. The survey results identified some key components in sexuality instruction that the literature lacked. A majority of survey respondents either felt that the sexuality curriculum was not accessible or they were unsure of the level of accessibility. This indicates that there is a issue with the sexuality program.

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The literature can confirm that program accessibility is identified as a barrier to sexuality education. Furthermore, respondents indicated that if students received sexuality education it was most likely provided for by another instructor (not the respondent). Therefore, the special educator most likely does not provide sexuality instruction. This result may also indicate why a majority of the students receiving sexuality education attend instruction with same-age peers. Therefore, students with severe disabilities, who receive sexuality education, tend to be in classroom with a separate instructor and same a peers. There may exist a correlation between accessibility and a non-special educator as an instructor. A component of this correlation may be that there is no special education support or modifications provided for by a student's sexuality instructor.

Additionally, the literature did not offer potential solutions for educator or program related issues that negatively impact sexuality education. However, the survey revealed that a vast majority of respondents indicated that educator trainings would be valuable in providing sexuality education in a special education setting. Additionally, respondents felt that increased parental support and access to better quality materials/curriculums would be beneficial. The literature provided a variety of available curriculums, guides, and suggested topics for sexuality curriculum; however no particular method was identified as being the most effective or most frequently used. The survey revealed that of the teachers who do provide sexuality education, a majority write their own curriculum. One respondent even shared that he or share writes a curriculum based on each student, which would indicate that his or her curriculum is customized even further. This may contribute to reasons why there are few evidence based programs and why the literature could not clearly identify one method. The literature also lacked an effective method of assessing student knowledge. A majority of teachers reported that observation was a

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means of assessing knowledge as well as the use of customized work sheets. Some respondents also reported the use of student interviews and observing role playing activities. The use of role playing activities as a method of instruction and assessment is also utilized in a study by Kim (2015).

Despite the limitations of what the literature can provide at this time and the discrepancies between the literature and the survey, there are some concepts that can be validated by the results. It can also be assumed through the literature analysis and the survey that there still exists some barriers to sexuality education for the severe population. Forty-three percent of respondents reported that their students receive no sexuality education. However, many of those that do receive sexuality education may not be receiving accessible information. In terms of sexuality curriculum, both the literature and the respondents view preventing pregnancy, communicating about sex, and feelings of attraction as moderately important topics. These topics appear in between fifty and sixty-six percent of the articles and were aggregated rated between 4.58 and 5.60. Furthermore, there are some strategies that appear in both the survey and the literature, such as role playing. Some of the strategies and frequently appearing topics could help guide educators that write their own curriculum.

Limitations: It is very clear that the study is quite limited. The literature review and analysis were restricted by the paucity in existing research and sexuality education programs. The survey results can also not be generalized to any specific population. The selective sampling as well as the low sample size make it unlikely that the population of respondents is a representative sample. The survey was also limited to ten questions, which also constrained the number of potential survey questions and therefore results. Additionally, due to the limit of ten questions, some valuable questions were combined which also may have affected the results.

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Future Research Implications: If another researcher were to academically re-work this particular study, it would be beneficial to determine if the trends from the survey results are similar. Furthermore, a future researcher should endeavor to obtain a larger sample size. Future researchers might also consider investigating available support for educators. Perhaps, one might develop a training or professional development course to support special educators in sexuality instruction. Another potential avenue for future research might be to investigate the correlation between increased sexuality education by a non-special educator and the decreased amount of perceived accessibility.

Conclusion

For students with severe disabilities, sexuality education can be beneficial by providing tools to enhance quality of life. Many individuals are not receiving and may never receive sexuality education. For those that do receive sexuality education, some of the information may not be accessible and therefore the person loses the potential benefit of sexuality education. This may be due in part to lack of special education support within the setting. There are some published curriculums designed for individuals with severe disabilities; however many of the special educators that were polled write their own curriculum if they were the sexuality instructor. This may be due to the need for increased differentiation or perhaps the lack of access to published materials. The teachers polled also tend to utilize observation and customizable worksheets. There are variety of potential topics within sexuality education, some topics of value may include but are not limited to self-esteem as it relates to sexuality, preventing pregnancy/STI, feelings of attraction, communicating about sex, and abuse prevention skills.

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Appendix A.

Hello,

My name is Amanda Brennen. I am a senior at Bridgewater State University and I am conducting a survey for my Honors Thesis. I have been researching Sexuality Education for individuals with severe disabilities. The following survey was created with that research in mind. Your participation is voluntary, but greatly appreciated. If you are a teacher, please fill out the survey. If you are an administrator, please pass on to a Special Educator. The responses from this survey will remain anonymous and no specific response will be published. When the research is complete, it will be made available on the Honors Thesis Database of Bridgewater State University.

By clicking begin, you consent to participate in the survey.

Thanks!

Amanda Brennen

Honors Thesis Survey

The following survey is about teacher opinions on Sexuality Education in Special Education. Your responses will be anonymous. Responses will be used as part of an Honors Thesis in Severe Special Education. Results of the survey will be published on Bridgewater State University's Honors Thesis Database, but no individual response will be published.

If you have any questions or would like to participate in a more in-depth interview please contact Amanda Brennen.

Email: Abrennen@student.bridgew.edu

Phone: 1 (781) 854-2927

Thank you for your participation!

1. A) As a special educator, what ages are you currently serving ? Please Select One in Category A

B) How long have you been in the field of special education? Please Select One in Category B

- (A) I service ages 3-5
- (A) I service ages 6-12
- (A) I service ages 13-18
- (A) I service ages 18+
- (B) 0-3 years as a special educator
- (B) 3-5 years as a special educator
- (B) 5-10 years as a special educator
- (B) 10-20 years as a special educator
- (B) 20+ years as a special educator

2. People with moderate to severe disabilities can benefit from sexuality education (Please check one of the following)

- Strongly Agree

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- Agree
- Disagree
- Strongly Disagree

3. Do your students currently receive sex education? (please select one)

- Yes, my students receive sex education while at school
- My students do not receive sex education while at school, but do elsewhere
- No, my students do not receive sex education at school or anywhere else

4. A) Do you provide sex education to your students? Please Select One in Category A**B) Are you comfortable teaching Sex Education Topics (regardless if you do or do not provide sex education).****Please select one in Category B**

- (A) Yes, I teach my students sex education
- (A) No, another instructor provides sex education to my students
- (A) No, my students are not receiving sex education from me or another instructor
- (B) Yes, I am comfortable teaching sex education topics
- (B) I am unsure of my comfort level with sex education topics
- (B) No, I am not comfortable teaching sex education topics

5. Do your students attend sex education with their same-age/model peers? (please select one)

- Yes, my students attend sex education with their same-age peers
- No, my students receive sex education in a substantially separate setting without same-age peers
- No, my students are not receiving sex education
- My students attend sex education with same age peers and receive sex education in a substantially separate setting

6. Sex Education material and curriculum is made accessible to my students (Please select one)

- Strongly Agree
- Agree
- Unsure
- Disagree
- Strongly Disagree

7. What material do you use to provide sexuality education? (Please select all that apply)

- I use a curriculum that is published by a third party and is independent of my school/district
- I use a curriculum that is provided by the school/district
- I write my own curriculum
- I do not provide sex education
- Other (please specify)

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8. Please rank the following sex education topics, by level of importance to you/your students (1 being most important and 10 being least important)

Communicating About Sex (consent, expressing desire or refusals, etc.)

Public vs. Private Spaces (What behavior is acceptable in these spaces)

Personal Hygiene

Decision Making (About Sex and Pregnancy)

Reproductive Anatomy and Puberty

Good Touches vs. Bad Touches (Do I want someone to touch me)

Sexuality Education in Special Education

Dating and Types of Relationships (Friendships, Family, Strangers, Intimate, etc.)

Sexual Behaviors/Desires and Feelings of Attraction

Self-Esteem and Sex

Preventing Pregnancy and Sexually Transmitted Diseases (STI)

9. How do you assess student knowledge in the sex education curriculum? (check all that apply)

- Observation
- Running Record
- Customized Worksheets
- Customized Tests
- Formal Sexual Knowledge Scales
- Tests provided by a published curriculum
- Tests provided by the school/district
- Other (please specify)

10. Which of the following options would help you provide better Sexuality Education? (Please Select All That Apply)

- Sexuality Education Training for Special Educators
- Access to published Sex Education curriculum
- Access to better quality materials
- More Instructional time set aside for Sexuality Education

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- Administrative Support from School or District
- Parental Support of Sex Education
- Other (please specify)

DONE

Table 1

<p>Barriers to Sexuality Education: reasons as to why a person with disabilities may not receive Sexuality Education</p> <p>[8 total articles: (Sinclair et. al. 2015), (Williams & Jensen 2016), (Schaafsma et. al. 2015), (Branard-Brak et. al. 2014), (Carrion & Jensen 2014), (Martinello 2014), (Corngold 2013), (Grieveo et. al. 2006)]</p>	<i>Misconceptions</i>	Belief that individuals with disabilities are asexual or child-like and as a result do not need Sexuality Education	4	(Schaafsma et. al. 2015), (Sinclair et. al. 2015), (Branard-Brak et. al. 2014), (Martinello 2014)
	<i>Privacy/Control</i>	No access to private spaces, a lack of control over personal spaces or of one's own body	3	(Schaafsma et. al. 2015), (Sinclair et. al. 2015), (Branard-Brak et. al. 2014)
	<i>Sexual Knowledge</i>	What a person does or does not know about Sex and related topics	3	(Sinclair et. al. 2015), (Branard-Brak et. al. 2014), (Martinello 2014)
	<i>Teacher/Instructor Related</i>	The comfort level of the instructor, an instructor's personal beliefs, an instructor's training level, etc.	5	(Schaafsma et. al. 2015), (Sinclair et. al. 2015), (Carrion & Jensen 2014), (Williams & Jensen 2016), (Branard-Brak et. al. 2014)
	<i>Related to the Individual</i>	A person's ability level in terms of Language, Cognition, and Adaptive skills is related to the likelihood of receiving sexuality education	4	(Schaafsma et. al. 2015), (Sinclair et. al. 2015), (Branard-Brak et. al. 2014), (Martinello 2014)
	<i>Issues with Sexuality Programs</i>	Programs' effectiveness, affordability, scope, etc. OR issues with implementation of a program or supporting research	5	(Sinclair et. al. 2015), (Carrion & Jensen 2014), (Martinello 2014), (Corngold 2013), (Grieveo et. al. 2006)
	<i>Public Opinion/Policy</i>	The district or school creates policies about what is and is not allowed to be taught (Abstinence-till marriage OR Comprehensive programs)	2	(Williams & Jensen 2016), (Carrion & Jensen 2014)

Table 2

<p>Sexuality Education as a Human Right: access to Sexuality Education and the ability to express one's sexual identity are fundamental human rights. Sexuality education can increase the likelihood of a better quality of life.</p>	7 Total articles	(Schaafsma et. al. 2015), (Branard-Brak et. al. 2014), (Martinello 2014), (Corngold 2013), (McLaughlin, 2009), (Alberta Health Services, 2009), (Grieveo et. al. 2006)
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Table 3

Sexuality Education Curriculum Topics: Broad topics for sexuality instruction [6 total articles: (Kim, 2016), (Martinello, 2014), (Corngold 2013), (McLaughlin, 2009), (Alberta Health Services, 2009), (Grieveo et. al. 2006)]	<i>Public and Private Spaces</i>	What behaviors are acceptable in public spaces and private spaces	3	(Kim, 2016), (Martinello, 2014), (Alberta Health Services, 2009)
	<i>Good and Bad Touches</i>	Is this touch hurtful or not? Is this touch appropriate or not? Do I want someone to touch me or not?	3	(Kim, 2016), (Martinello, 2014), (Alberta Health Services, 2009)
	<i>Relationships/Dating</i>	Types of relationships, appropriate behavior based on the type of relationship, and appropriate dating behavior, what is a good relationship vs. bad relationship.	4	(Kim, 2016), (Martinello, 2014), (Corngold 2013), (McLaughlin, 2009)
	<i>Communication</i>	Talking to others, Practicing Refusal and Reporting Skills	3	(Kim, 2016), (Martinello, 2014), (McLaughlin, 2009)
	<i>Communicating About Sex</i>	Expressing desire, obtaining consent, giving or refusing consent, etc.	4	(Martinello, 2014), (Corngold 2013), (McLaughlin, 2009), (Alberta Health Services, 2009)
	<i>Diversity</i>	Gender identity, sexual orientation or preference, stereotypes, culture and sex.	2	(Corngold, 2013), (Alberta Health Services, 2009)
	<i>Sexual Behaviors</i>	Sexual intercourse, masturbation, etc. are all sexual behaviors meant for private spaces	4	(Corngold 2013), (McLaughlin, 2009), (Alberta Health Services, 2009), (Grieveo et. al. 2006)
	<i>Attraction and Sexual Feelings</i>	It is okay and normal to have these feelings (arousal, attraction, etc.)	3	(Corngold 2013), (McLaughlin, 2009), (Alberta Health Services, 2009)
	<i>Decision Making</i>	Dealing with peer pressure, making decisions about your body, etc.	4	(Martinello, 2014), (Corngold 2013), (McLaughlin, 2009), (Alberta Health Services, 2009)
	<i>Decision Making and Sex</i>	Do you want to have sex? Making safe and smart decisions about sex?	1	(McLaughlin, 2009)
	<i>Avoiding Pregnancy and STI</i>	Do you want to have a baby? Contraception (hormonal birth control, condoms, etc.) and how to use contraception to prevent pregnancy and STI	4	(Corngold 2013), (McLaughlin, 2009), (Alberta Health Services, 2009), (Grieveo et. al. 2006)
	<i>Anatomy/Puberty</i>	Teaching about reproductive anatomy, teaching names for reproductive organs, teaching about body changes, Menstruation/Menopause, etc.	5	(Kim, 2016), (Corngold 2013), (McLaughlin, 2009), (Alberta Health Services, 2009), (Grieveo et. al. 2006)
<i>Esteem/Bullying</i>	Self-image as a sexual being, dealing with bullying as it relates to sex or disability.	3	(Martinello, 2014), (Alberta Health Services, 2009), (Grieveo et. al. 2006)	

Table 4

Topic	Aggregate Average	Ranking
<i>Self Esteem and Sex</i>	4.33	1
<i>Preventing STI/Pregnancy</i>	4.58	2
<i>Reproductive Anatomy/Puberty</i>	4.63	3
<i>Decision Making about Sex and Pregnancy</i>	5.10	4
<i>Sexual Behaviors/Desires and Feelings of Attraction</i>	5.20	5
<i>Communicating About Sex</i>	5.60	6
<i>Dating and Types of Relationships</i>	6.10	7
<i>Personal Hygiene</i>	6.78	8
<i>Public vs. Private Spaces</i>	6.95	9
<i>Good vs. Bad Touches</i>	7.11	10