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Understanding Parent Beliefs and Attitudes Regarding Healthy Relationships and Sexuality Education: Bridging the Inclusivity Gap

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Understanding Parent Beliefs and Attitudes Regarding Healthy Relationships and Sexuality Education: Bridging the Inclusivity Gap

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Marie Zarrilli, MS, OTR/L
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COLLEGE OF HEALTH SCIENCES
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This project, written by Marie Zarrilli under direction of Dr. Shirley O'Brien, Faculty Mentor, and approved by members of the project committee, has been presented and accepted in partial fulfillment of requirements for the degree of

DOCTOR OF OCCUPATIONAL THERAPY

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Certification

We hereby certify that this Capstone project, submitted by Marie Zarrilli, conforms to acceptable standards and is fully adequate in scope and quality to fulfill the project requirement for the Doctor of Occupational Therapy degree.

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Executive Summary

Background: Children, adolescents, and young adults with Intellectual and Developmental Disabilities (IDD) are often excluded from receiving Comprehensive Healthy Relationship and Sexuality Education (CHRSE), even though they are at increased vulnerability for sexual abuse and exploitation. Although some curricula is emerging that are adapted for individuals with IDD, rigorous effectiveness studies are sparse.

Purpose: The purpose of this capstone project was to empirically explore the beliefs, comfort level, preferred communication strategies, program type, content and parent training and resource needs to build a home and school collaboration that strengthens parent-child communication and understanding regarding healthy relationships and sexuality. In addition, data will be utilized to inform a parent training.

Theoretical Framework: Deci and Ryan's Self-Determination Theory shaped the research questions and is interwoven throughout the project as Comprehensive Healthy Relationship and Sexuality Education promotes autonomy, competence, and relatedness.

Methods: This capstone project used a quantitative, cross-sectional, descriptive survey design with one data point collection. The survey consisted of 27 questions most of which were multiple choice in nature with a few open-ended questions using Qualtrics. 41 parents completed the survey in its entirety, however, partial completion for 2 additional parents was utilized for some questions where relevant. Participants had children ages 6-21 who were enrolled at a private school in a mid-Atlantic state during the 2020-2021 school year.

Results: Most of the high school and middle school parents were in favor of Comprehensive Sexuality Education. High school and elementary school parents favored a middle school start for CHRSE. Of the 7 relationship and sexuality content areas, the most approved content across grade levels was human development at 97.56% and the lowest approval rate was for gender identity, sexual orientation, and gender expression at 73.17%.

Conclusions: Comprehensive Sexuality Education is the human right of all persons without exception. More inclusive curricula (LGBTQ+ community and individuals with IDD and other cognitively based disabilities) need to be developed and studied to determine their effectiveness. Most parents in this project were in favor of CSE being taught in the schools and for it to begin at the middle school level.

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I also want to thank my son and emotional support person, Andrew, who shared every step of this journey with me. He is wise beyond his years, patient, kind, and a life saver. I share this accomplishment with him. I want to thank my parents who courageously came to this country and lovingly made sacrifices so that their children could have a better future. Although my father Joseph passed away in 1994 prior to my becoming an occupational therapist, I have felt him with me and that has given me strength and courage. His brother, my Uncle Tony, stepped in and made me feel like I could do anything. He passed away prior to the completion of my doctoral work, but I know that he also celebrates this accomplishment with me.

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CERTIFICATION OF AUTHORSHIP

Submitted to (Faculty Mentor's Name): Dr. Shirley O'Brien
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Title of Submission: Understanding Parent Beliefs and Attitudes Regarding Comprehensive Healthy Relationships and Sexuality Education: Bridging the Inclusivity Gap

Certification of Authorship: I hereby certify that I am the author of this document and that any assistance I received in its preparation is fully acknowledged and disclosed in the document. I have also cited all sources from which I obtained data, ideas, or words that are copied directly or paraphrased in the document. Sources are properly credited according to accepted standards for professional publications. I also certify that this paper was prepared by me for this purpose.

Student's Signature: *Marie Zarrilli*

Date of Submission: 05/05/2021

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Section 1: Nature of Project and Problem Identification

According to a report by the National Association of Councils on Developmental Disabilities (NACDD, 2017), individuals with Intellectual and Developmental Disabilities (IDD) are not only 2.5 to 10 times more likely to be abused but are also 49% more likely to experience repeated abuse of up to 10 or more incidents in their lifetime. These are staggering numbers. Most cases of abuse and neglect against individuals with IDD go unreported (85% in group living settings) in part due to the individual's familiarity with the perpetrator.

IDD is not the only disability group experiencing an increased prevalence rate of sexual abuse or exploitation as supported by the findings of Helton and colleagues (2018). They examined a national sample of children and adolescents diagnosed with a Learning Disability (LD). Learning Disabilities are defined by the National Joint Committee on Learning Disabilities (NJCLD) as

> a heterogeneous group of disorders manifested by significant difficulties in the acquisition and use of listening, speaking, reading, writing, reasoning, or mathematical abilities. These disorders are intrinsic to the individual, presumed to be due to central nervous system dysfunction, and may occur across the life span. Problems in self-regulatory behaviors, social perception, and social interaction may exist with learning disabilities but do not by themselves constitute a learning disability. Although learning disabilities may occur concomitantly with other disabilities (for example, sensory impairment, intellectual disabilities, emotional disturbance), or with extrinsic influences (such as cultural or linguistic differences, insufficient or inappropriate instruction), they are not the result of those conditions or influences (NJCLD, 2016, para. 1).

Helton and colleagues (2018) set out to test three hypotheses using a US nationally representative sample that controlled for comorbid conditions of LD. Altogether, 2,033 cases of sexual allegations reported to Child Protective Services were examined. Inclusion criteria was set for children over 4 years of age with a sexual allegation case closed within the period of February 2008 through April 2009. Two out of the three hypotheses were supported by the data. First, children diagnosed with LD had a higher incidence of sexual assault allegations than children without a learning disability controlling for comorbid factors such as social deficits, feelings of loneliness, impaired daily living functionality and behavioral challenges. Second, the data

supported that females with a learning disability had a higher prevalence of sexual abuse allegations than females without a learning disability.

Although limited, research indicates that children, adolescents, and young adults with IDD and LD are at increased risk for sexual abuse or exploitation when compared to their peers without those disabilities. Comprehensive Healthy Relationships and Sexuality Education (CHRSE) has been proposed as an effective method to build self-determination skills which include the ability to identify potentially harmful relationships and situations; assert one's rights; and make informed decisions to maintain health and well-being (McDaniels & Fleming, 2016; Graff et al., 2018).

Regardless of whether a child, adolescent or young adult has a disability or not, the developmental process for maturation of the pre-frontal cortex is a significant factor to consider. Forsyth and Rogstad (2015) link the timing of typical pre-frontal cortex brain development (which continues into the mid-twenties) with an increased vulnerability of adolescents and young adults to engage in risky health behaviors. The pre-frontal cortex guides the capacity for executive function and self-regulation relying on working memory, mental flexibility, and self-control skills (Center on the Developing Child, 2012). Executive functioning skills include problem solving, regulating emotions and self-monitoring which are key to decision-making and maintaining healthy relationships. These skills develop in late childhood and are refined through adolescence and young adulthood. The Center on the Developing Child (2012) further emphasizes that children's relationships, engagement in activities and the environments where they live, learn and play have a significant role in developing a foundation from which executive skills and self-regulation can advance and mature. Students with disabilities are already cognitively compromised and need explicit instruction. A proactive approach is warranted given the potential risk for abuse and exploitation. Therefore, education that includes role modelling; providing medically accurate information; practice of skills through interactive activities; video modelling; fostering social connection; providing safe spaces; consideration of the consequences of potentially life-altering actions (such as unprotected sex); and knowledge of one's rights is necessary to develop and promote healthy relationships.

The Healthy People 2030 initiative supports adolescent sexual and reproductive health as a high priority health challenge in the United States. There are three objectives which relate directly to this capstone project. First is to increase the percentage of adolescents who receive sexuality education prior to reaching 18 years of age **(**baseline: 52.7% of adolescents in 9^{th}-12^{th} grade

received such education as reported in 2015-2017 via the National Survey of Family Growth). Second is to reduce sexual violence of adolescents by anyone (baseline: 9.7% were forced into performing a sexual behavior 1 or more times in the past year as reported through the Youth Risk Behavior Surveillance System). And third to reduce adolescent dating violence of either a sexual or a physical nature (baseline: 12.6 percent of students in 9th-12th grade were forced by someone they dated or went out with to participate in sexual behaviors or were intentionally physically harmed 1 or more times within the past year in 2017) as reported by the Youth Risk Behavior Surveillance System (Office of Disease Prevention and Health Promotion, n.d.).

Thus, Comprehensive Healthy Relationships and Sexuality Education is a topic of relevance in society as all adolescents are prone to more risky behaviors given the long-term process for the pre-frontal cortex to reach full maturation. Challenges to making healthy decisions are compounded for adolescents and young adults with a cognitively based disability.

CHRSE is not mandated at a national level, however, in 2012, a consortium of school education advocacy groups published the *National Sexuality Education Standards: Core Content and Skills, K-12* with a 2nd edition released in 2020 (Future of Sex Education Initiative, 2020). This document is a valuable reference for developing curriculum and lesson plans, however its use is not mandatory. Sexuality education standards have been left to the discretion of each state with no specific curriculum requirements (National Conference of State Legislatures, 2019). The definition of Comprehensive Sexuality Education, (CSE), according to the International Technical Guide published by the United Nations Educational, Scientific and Cultural Organization (UNESCO) is as follows:

> CSE is a curriculum-based process of teaching and learning about the cognitive, emotional, physical, and social aspects of sexuality. It aims to equip children and young people with knowledge, skills, attitudes, and values that will empower them to: realize their health, well-being, and dignity; develop respectful social and sexual relationships; consider how their choices affect their own well-being and that of others; and understand and ensure the protection of their rights throughout their lives (UNESCO, 2018, p. 16).

School-based CSE, which includes lessons regarding the proper use of contraception methods to prevent unintended pregnancies, Human Immunodeficiency Virus (HIV), and Sexually Transmitted Infections (STI) has been endorsed as effective by worldwide health agencies such as, UNESCO, the Centers for Disease Control and Prevention and Health and Human Services

(Ericksen & Weed, 2019). Ericksen and Weed (2019) call for the use of more rigorous, scientifically based criteria to evaluate program effectiveness before ruling out an Abstinence-Only approach as ineffective. The term CHRSE, is being used interchangeably with CSE as it emphasizes that healthy relationships are covered within the sexuality curriculum.

Also, of importance under the CHRSE umbrella is the use of inclusive language and covering important topics such as gender identity, gender expression, sexual orientation and respect and tolerance of all individuals. According to Sager (2017) only 5% of school-aged LGBTQ+ community members report discussions of gender identity and sexual orientation during sexuality education. Further research is necessary in this area as there are alarming statistics as well, for the LGBTQ + community in terms of bullying, depression and higher rates of suicide as compared to their non-LGBTQ+ peers. According to the 2015 national Youth Risk Behavior Survey, 29% of LGBTQ+ youth had attempted suicide at least once during the previous year compared to 6% of heterosexual youth. Also, in 2014, young gay and bisexual men accounted for 8 out of 10 new HIV diagnoses among youth (Centers for Disease Control and Prevention, 2017). Effective and inclusive school based CHRSE is the right of every individual. It can lead to reduced victimization of the more vulnerable IDD, LD and LGBTQ+ populations while decreasing rates of STIs, HIV and unintended pregnancies thus benefiting the broader society and country through significant healthcare dollar savings as prevention is less expensive than treating an illness (American College of Obstetricians and Gynecologists, 2016).

Using the *National Sexuality Education Standards: Core Content and Skills, K-12,2nd ed.,* as a guide, the researcher reviewed potential CHRSE curricula to determine which would best meet the needs of the students (Future of Sex Education Initiative, 2020). The *Sexuality Education Curriculum for High School Students and Adults with Developmental Disabilities* (McLaughlin et al., 2018) was chosen to be used in a private school setting as it was written in collaboration with disability advocates and could be adapted to meet the needs of students with or without a developmental disability.

It is the premise of this capstone project that every human being has the right to medically accurate, developmentally appropriate comprehensive healthy relationships and sexuality education. CHRSE promotes empowerment by increasing knowledge, confidence, and competence to make decisions that promote health, well-being, and quality of life. Human sexuality is multi-faceted going beyond an understanding of anatomy and physiology. Goldfarb

and Lieberman (2021) performed a systematic literature review spanning 30 years beginning with 1990 with the aim of finding effectiveness studies for school based CHRSE programs. Eighty percent of the articles were excluded as effectiveness was defined in terms of decreased unintended pregnancies and STI and HIV prevention exclusively. Key findings in the 80 articles reviewed included strong support for Comprehensive Sexuality Education beginning at the elementary school level continuing with scaffolded instruction occurring at multiple grade levels and across school environments and classes. Especially important in the elementary years was discussions of gender roles, gender identity, gender expression, and sexual orientation. In addition, the utilization of a social justice framework covering acceptance or tolerance of sexual diversity, development of healthy relationships, dating, intimate partner violence, and prevention of child sexual abuse was discussed (Goldfarb & Lieberman, 2021). Most healthy relationships and sexuality curricula have been developed for typical students, however, there has been an increase in interest and studies focusing on students with disabilities but rigorous scientific evidence to support their effectiveness is lacking (Treacy et al, 2018; Schaafsma et al., 2015). Graff and colleagues (2018) performed an effectiveness study for the Positive Choices curriculum developed for secondary students with IDD. Although a small sample size was utilized, results of a pre and posttest with an experimental and control group indicated that this curriculum had a statistically significant effect for the acquisition of knowledge in two units (relationships and self-awareness, and maturation) while the other two units (sexual health and being strong, staying safe) indicated a moderate effect with no gains for the control group.

Comprehensive Healthy Relationships and Sexuality Education emerged as a focus for this researcher's capstone project after a local high school student on the autism spectrum was sexually assaulted. The assault occurred on school grounds and was perpetrated by another student. It was clear that the student did not understand, nor could she communicate what had happened to her. This prompted the question what is the role and responsibility of schools to provide CHRSE? And could the provision of research based, inclusive CHRSE act as a protective factor against sexual abuse and exploitation?

CHRSE is not mandated on either the national or state level. It is left to each state to determine requirements for the schools in their jurisdiction. In Pennsylvania, schools are required to teach STI/HIV prevention with a focus on abstinence as the best method of prevention. Schools, however, do have guidance in health and sexuality through the *PA Department of*

Education Standards for Health, Safety and Physical Education (PA Department of Education, 2002). Health class content typically includes male and female sexual anatomy, the reproductive system, puberty, peer pressure, the dangers of drug and alcohol abuse, nutrition, and physical activity. However, discussions of consent, boundaries, and healthy versus unhealthy relationships are inconsistently covered.

During the summer of 2019, the researcher, with permission of the principal and education director at a private school, surveyed staff. Results indicated that most staff believed that healthy relationships and sexuality education was a priority; that all students have an equal right to receive this instruction; and that staff needed additional training if they were expected to provide this education to students. Staff felt that given training, they would feel more comfortable and better prepared to teach this subject matter.

To establish the use of a consistent school-wide curriculum, the researcher pursued training that would provide a train-the-trainer certificate for the CHRSE curriculum purchased by the private school. The researcher completed a three-day training taught by Katherine McLaughlin, the coauthor of the *Sexuality Education Curriculum for High School Students and Adults with Developmental Disabilities* and followed through with providing staff training at the private school in January 2020. The training was interactive with break- out discussion groups, reflective activities, and video clips of individuals with disabilities advocating for CHRSE and sharing their experiences. Next in the process, the researcher became the facilitator for the CHRSE curriculum committee that met twice monthly to promote program sustainability and fidelity in the implementation of the curriculum. Administration agreed that the *Sexuality Education Curriculum for High School Students and Adults with Developmental Disabilities* (McLaughlin et al., 2018) curriculum be piloted with a group of graduating seniors ranging in ages from 18-21. Students at the private school have the option to graduate at 21 years of age and many families decide to have their young adult benefit from the additional year(s) of instruction including vocational, on-the-job-training.

Problem Statement

Individuals with IDD and other cognitive disabilities often do not receive medically accurate CHRSE which may lead to an increased risk for sexual abuse, exploitation, unwanted pregnancies, STIs and HIV (De La Rue et al., 2014; Murphy& Elias, 2006). Developmentally appropriate CHRSE empowers individuals with IDD to make decisions that promote

reproductive and sexual health for physical well-being, as well as the development of one's sexual identity and intimate relationships for social-emotional well-being and the highest quality of life possible. Research indicates that collaboration between school and parents/caregivers has been effective to promote better communication between parent and child, adolescent, or young adult and for the generalization of skills (Wolfe et al., 2019). Health education teachers often provide sexuality education within school systems; however, an interdisciplinary approach is considered best practice. Sexuality is part of the scope and practice of occupational therapists (AOTA, 2020) however, this role is often not considered in school-based practice. There is a lack of rigorous and scientifically based research to support the effectiveness of existing relationship and sexuality education curricula adapted for individuals with IDD. Most troubling is the fact that there is often an assumption that "someone else" is teaching CHRSE either at school or home, when in fact no one may have taken on this important responsibility. The question remains: who is responsible to provide CHRSE to school-aged children, adolescents, and young adults? Do parents have all the responsibility? If so, are they equipped with the knowledge and resources to empower their children to make decisions that promote health, well-being, and the best quality of life possible? As there is no federal mandate for K-12 schools to teach CHRSE, the responsibility is passed to each state. Since requirements vary from state to state, can parents blindly rely on their schools to provide CHRSE that is developmentally appropriate and medically accurate?

A community effort is needed from a child's pediatrician, parent, health teacher, nurse, other trained school personnel and occupational therapists. An interdisciplinary group can create a flow of information that is supported by research; is consistently presented; and generalizable across all social contexts. Given ACOTE standards (AOTA, 2018) and the Occupational Therapy Practice Framework, 4th edition (AOTA, 2020), sexuality and the development of healthy relationships is identified within the profession of occupational therapy's professional training and scope of practice. Occupational therapists can expand their role to include CHRSE in the school system or as a consultant within school-based practice. Thus, this area is within the scope and practice of occupational therapy and is an essential educational element for individuals with IDD.

Purpose of the Project

The purpose of this capstone project was to empirically explore the beliefs, attitudes, comfort level and confidence of parents and guardians of school aged children, adolescents, and young adults regarding their discussions about healthy relationships and sexuality and to determine resource needs which align with the self-determination and social learning theories.

Theoretical Framework

The researcher has a worldview of equality for all people that allows authenticity and the freedom to express oneself in a healthy, safe, and confident way based on medically accurate information and connection with others.

The Self-Determination and Social Learning theories shaped the research questions and are interwoven throughout the entire research project. Firstly, according to Deci and Ryan (2012), the creators of the Self-Determination Theory, a person's internal motivation related to decision-making can be impacted by competence, relatedness (drive to interact and connect with others) and autonomy. Having this key information will allow individuals with IDD and other cognitively based disabilities to make responsible decisions that promote health, wellness, and the highest quality of life. It is necessary for individuals to get in touch with their values and what brings fulfillment and confidence to live their best life. Secondly, the Social Learning Theory fits with the study as medically accurate information is provided, followed up with practice (role play, discussions, hands on skill development) with application to everyday life situations.

Significance of the Project

This capstone project begins the process of understanding parent/guardian perspectives about providing CHRSE to students in a K-12 grade setting. By exploring parent/guardian beliefs, perceptions, attitudes, and comfort levels with the content according to program type and their current communication with their child, adolescent or young adult, an opportunity exists for collaboration to effectively share the responsibility of providing CHRSE between home and school.

Results of this capstone project guide the development of complementary programming for parents and guardians, along with the implementation of the CHRSE curriculum in a private school setting. School aged children, adolescents and young adults who receive instruction via the designated CHRSE curriculum delivered by trained school professionals with

parent/guardian collaboration and community supports will demonstrate better outcomes (increased knowledge, positive attitude and reduced risky behaviors in terms of sexuality expression). The occupational therapist is well suited to address the CHRSE as an interdisciplinary team member and leader given the occupational therapy scope of practice and educational preparation in the discipline.

Summary

This proposed project aimed to empirically explore parent beliefs, perceptions, attitudes, and comfort level in discussing healthy relationships and sexuality with their children, adolescents, and young adults. The researcher joins with the other advocates for CHRSE in the belief that it is the right of all persons and must be medically accurate, developmentally appropriate, culturally competent, and LGBTQ+-inclusive. Most curricula are not LGBTQ+ inclusive and so further research and curricula development are necessary to promote the sexual and social-emotional health of all students (Meadows, 2018). The curriculum developed by McLaughlin and colleagues (2018) and utilized by the researcher, is LGBTQ+ inclusive with a lesson dedicated to gender identity and expression and is integrated throughout the curriculum.

Section 2: Detailed Review of the Literature

A review of the literature was completed through a comprehensive search of the following Eastern Kentucky University library databases: Academic Search Ultimate, CINAHL Complete, ERIC (EBSCO Host Web), Nursing and Allied Health, and the Psychology and Behavioral Science Collection. The search strategy was to use the following terms: comprehensive sex education, sex education, sexuality education, sexuality education and parents, sexuality education and occupational therapy, healthy relationships, parent attitudes, comfort level, perceptions, beliefs about sexuality education and parent-adolescent communication about sexuality education. The literature review supports the need for this study. Based upon the searches, the following topics were found to shape an understanding of the relevant issues within the relationship and sexuality realm.

The Impact of Misperceptions and Myths

Comprehensive Sexuality Education (CSE), which includes healthy relationships, has been a highly debated topic in terms of its inclusion as part of a child's and adolescent's school education. Studies indicate that access to sexuality education is often denied or minimized for vulnerable populations such as individuals with IDD due to prevailing myths held by society.

Myths include thoughts that individuals with IDD are childlike, asexual, lack interest in intimate relationships or are incapable of safe decision making. Qualitative studies, however, indicate that these assumptions are untrue (Gil-Llario et al., 2018). For example, in a mixed method study conducted by Graff and colleagues (2018), a sample of fifty-three young adults with IDD, expressed a definite interest in romantic relationships. The participants completed a sexuality education program and were then asked to rank the lessons based upon their meaningfulness and usefulness. The top three responses were as follow: defining healthy relationships; recognizing red flags indicating unhealthy relationships and identifying gender-specific health care needs and how to access services (Graff et al., 2018). Overall, participants were also concerned about their vulnerability to abuse due to lack of information, misinformation, manipulation, or coercion.

State Policy and Consistency with Needs

According to Elia & Tokunaga, although progress has been made, we are still battling the status quo of "heteronormative, sex negative, ableist and discriminatory" messaging (2015, p. 106). Educational policies are a function of state governments. Hall and colleagues (2019) analyzed policy content for sexuality education across the fifty states and revealed some troubling statistics. Only 42% of states include lessons describing characteristics of healthy relationships; only 54% of states require content about sexual violence and only 36% of states require content about sexual consent to be taught to school aged children. There is a definite disconnect here given the significant increase in risky sexual behaviors that occur during adolescence. In addition, according to The National Intimate Partner and Sexual Violence Survey (2015), the most common age of first sexual violence victimization occurs between ages of 11-24. This suggests that CHRSE is crucial for school-aged children. Advocacy for state-wide policy changes is needed to empower children, adolescents, and young adults to understand their rights and demand that they be respected. The federal government plays a part as it can provide funding to support the implementation of CHRSE. However, the federal government, over past administrations, has exceeded a billion dollars of funding for Abstinence-Only-Until Marriage (AOUM) education approaches. This is counter intuitive given that studies have reported that Abstinence Only Until Marriage curricula are not effective in decreasing the rate of STI's, HIV, unwanted pregnancies, and sexual abuse. Hence the push for CHRSE. The Sexuality Information and Education Council of the United States (SIECUS) is dedicated to making CHRSE a national mandate. Elia and Tokunaga (2015, p. 106), propose that school-based sexuality education be

delivered using a “multidimensional approach” where the “physical, social, mental/emotional/psychological, intellectual and spiritual aspects” are integrated in sexual health and relationship curricula. There is little empirical support for the effectiveness of sexuality curricula as demonstrated by McDaniels and Fleming (2016) in their review of 92 articles. Results indicated that individuals with IDD who received inadequate sexuality education were at a greater risk of sexual abuse, STIs and misinformation. The researchers recommend “empirically developed, population specific sexuality content” for individuals with IDD (McDaniels & Fleming, 2016, p. 223). In addition, a study conducted by Ericksen and Weed (2019) was found indicating that the criteria used in the literature endorsed by worldwide agencies such as UNESCO may not have used criteria of enough scientific rigor to identify true program effectiveness. More studies with adequate scientific rigor are needed to determine the effectiveness of CHRSE.

Parent Beliefs and Perceptions of the Need for CHRSE for their Children, Adolescents and Young Adults with a Disability

The needs of parents with children with disabilities regarding CHRSE have been underrepresented in the literature. To begin to fill this gap, Clatos and Asare (2016) conducted a small sample study with a pre-test/post-test design. The sample consisted of 15 parents of children ages 10-25. Parents completed a 30-item questionnaire and participated in a one- hour sexuality education program. The aim was to determine if parent education provided by a trained professional could modify or change attitudes and beliefs toward sexuality education; improve understanding of and communication with their children and increase a parent’s self-efficacy for providing their child with sexuality education. Although overall beliefs about sexuality education for children and adolescents with disabilities did not significantly change, attitudes did. For example, at pre-test, only 60% of parents indicated that children with disabilities have sexual interests whereas, after the presentation the percentage of parent agreement rose to 86%. In addition, significant increases were reported in knowledge about sexuality education, sexual communication behavior and self-efficacy in their sexual communication skills. This study supports that sexuality education programs can provide the necessary knowledge and skills so that parents can confidently provide CHRSE to their children with disabilities.

Stein and colleagues (2018) conducted a survey of 62 parents (30 of which had a child with a developmental disability and 32 who did not) to determine their perceptions of the

importance of CHRSE; the vulnerability of their child to abuse and their preferred source of information for teaching their child. Most parents (89%) were in favor of relationship and sexuality education for their child. Of those parents, (58%) believed that CHRSE would be the best approach. Interestingly of the parents with a child with a developmental disability only 29% believed that their child was at risk for sexual victimization prior to age 18 as compared to 45% of parents with a child without a developmental disability. The top three preferred resources reported by parents were interactive websites (55.6%), workshops led by a professional (50%), and books with detailed lesson plans and activities (37%).

A meta-analysis consisting of 8 studies was conducted by Gonzalvez and colleagues (2018) to investigate the effectiveness of existing sexuality programs for individuals with IDD. The studies reviewed, from 1988- 2017, utilized a quasi-experimental design with a random assignment to an experimental group. Results include a moderate effect size for the intervention group; single sex groups were more effective in comparison to mixed groups; instructors with a high level of training were most effective; sessions lasting 40-45 minutes were more effective than those of longer duration and including a follow-up to the intervention over time also enhanced the effectiveness for the experimental group. Especially effective was educational content on inappropriate behaviors and decision-making in situations of abuse.

Parental Support for Earlier Sexuality Education

Barr and colleagues (2014) conducted a telephone survey, the Florida Child Health Survey, an extension of the larger state Behavioral Risk Factor Survey System survey. Participants consisted of 1715 parents with a child (under 18 years of age). Questions included the type of sexuality education preferred (Abstinence Only, Abstinence Plus or CSE), and of 5 sexuality related topics, which would parents approve of for elementary school level children? Questions were also posed regarding middle and high school level students, however, results for the elementary level were of most interest and are reported here. Most parents (79.3%) were in favor of their children participating in age-appropriate sexuality education. As for the type of sexuality program, results were as follow: 40.4% were in favor of CSE; 36.4% preferred abstinence-plus sexuality education and 23.3% supported abstinence-only sexuality education. Parents were asked to consider 5 sexuality topics and indicate which ones they believed were appropriate for elementary school level children. Parent approval percentages for each of the 5 topics were as follow: 88.7% agreed to communication; 64.7% agreed to anatomy; 61.3% were

in favor of abstinence; 53% agreed with the inclusion of HIV prevention and 51.7% agreed with the inclusion of gender and sexual orientation. Interestingly, although there is support by parents for sexuality education, Florida does not mandate sexuality education. Many students, therefore, do not receive sexuality education and when they do it occurs in junior and senior year of high school. Florida seems out of touch with the fact that children and adolescents need sexuality education and many parents are in favor of schools providing this developmentally appropriate sexuality education.

Another study by Fisher and colleagues (2015), found that 92% of parents of elementary students believed that sexuality education should be taught in the schools. 43% of those parents believed that sexuality education should begin in elementary school, while 47% felt that sexuality education should be taught in grades 6 through 8th. In addition, parents were presented with 12 sexuality topics and asked which topics should be taught at the elementary grade level. Most parents believed that 6 out of the 12 topics were appropriate for elementary aged children. The six topics are as follow: friendship and bullying prevention both at 91%; healthy relationships (75%); sexual abuse prevention (67%); identification of body parts using medically accurate terminology (65%) and different kinds of families (58%).

Tortolero and colleagues (2011) assessed the attitudes of parents living in Harris County, Texas (high rate of teen pregnancies) regarding sexuality education. Results indicated that 93% of parents were in favor of a school-based sexuality education program with 80% of parents believing sexuality education should begin at the middle school grade level.

Robinson and colleagues (2017) conducted a study of 342 parents living in Australia via online survey, 31 interviews and 6 focus groups. Most parents, 71%, agreed that sexuality education is important and should begin in elementary school. Most of the parents, 65%, believed that collaboration between home and school would be most effective in providing relationship and sexuality education to their child or adolescent.

Researchers (Marshall et al., 2020) conducted a study using separate focus groups of parents and students from four high schools in Arkansas to assess whether healthy relationships were covered as part of the sexuality curriculum. Arkansas was of particular interest due to the high teen pregnancy and STI rates. Both parent and focus groups indicated that they were in favor of CHRSE and that the curriculum currently in place was not adequate. Parents indicated that they felt ill prepared to talk to their children about healthy relationships as they had not

received this information when they were growing up. Both parents and students indicated that the characteristics of friendships including trust, support, respect, dating free of manipulation and coercion, consent and gender identities and sexual orientation were important to review and understand. A problem identified by both parents and students was the lack of realistic role models for healthy relationships. Some parents requested parent education in the areas of gender identity and sexual orientation as they were unfamiliar with inclusive terminology. Students indicated that they were interested in learning more about healthy versus unhealthy relationships including emotional abuse (58%), sexual abuse (55%) and sexual harassment (55%),

Parent Communication Style

Somers, Avendt and Sepsey (2019), in their cross-sectional survey design study of students in ninth through twelfth grade in two different mid-Atlantic high schools asked questions regarding their parent's approach to communication, the content of sexual conversations (fact based, discussion of different sexual situations and ways to make healthy choices; and the frequency of sexual communication). The aim of the study was to determine if adolescent attitudes and sexual behaviors vary by the parents' approach to communication about sexuality; by the content discussed and the frequency of parent communication. The study found that a correlation existed between parent communication style and sexual behaviors reported by their adolescents and young adults. Parents who either utilized a more open style of communication with their teens regarding sexuality or did not have any conservations with them about the topic, self-reported fewer sexual behaviors than adolescents receiving a lecture-style approach dominated by the parents. It is important to convey to parents in trainings that adolescents benefit most when parents are sensitive and open to adolescent questions. Increased frequency of conversation allows for more discussion of tools and review of different scenarios relating to relationships and sexuality.

Morawska and colleagues (2015) utilized an online survey and obtained 557 parent respondents who lived in Australia and had a child within the age range of 3 and 10. Results indicated that parent self-efficacy for providing CHRSE was not associated with demographics but to confidence. Parents were least confident with initiating a conversation with their child about sexuality, accessing resources and providing related resources to their children. Parents rated the following topics as being of highest importance: prevention of child abuse and encouraging a positive sense of self and body image.

Barriers to Communication and Misperceptions of Support for CHRSE

Malacane and Beckmeyer (2016) performed a literature review to discover barriers to parent-adolescent communication about sexuality and highlighted four barriers. First, parents who perceived that they lack adequate knowledge about sexuality and sexual behaviors typically do not engage in discussions about sexuality with their children or do so in an indirect and superficial way. A second barrier is a parent's perception that their adolescent is too young and not ready for discussions about sexuality. Some parents believe that exposure to sexuality topics too early will encourage sexual behaviors. A third barrier is parent discomfort with discussing sexuality topics. This is problematic as children and adolescents sense this unwillingness to communicate and may seek alternative means of answering questions which may be unreliable and inaccurate. The fourth category of barriers to parent-adolescent communication include cultural, political, and demographic factors. Therefore, parent education can provide knowledge, strategies on how to use teachable moments from related sexuality discussion using movies, television shows and the news to initiate conversation. Given that parents have the potential to empower their children and adolescents to make healthy decisions reducing risky sexual behaviors, more emphasis should be placed on parent education.

Jerman and Constantine (2010) completed a study of 907 parents with children between the ages of 8-18 using a random digit dial survey within the state of California. In terms of comfort level to discuss CHRSE, 52.4% of parents reported they were very comfortable; 25.8% were somewhat comfortable, 15.3% were somewhat uncomfortable and 5.8% felt very uncomfortable. The greater the parent perceived comfort and knowledge level, the greater the number of relationship and sexuality topics discussed. Parent education can be key to improving parent-child and adolescent communication.

Pariera (2016) examined what factors facilitated parent-child conversations regarding relationships and sexuality and which acted as barriers. A telephone survey of 186 parents (with an even distribution of sons versus daughters) found that the most common barriers were parent's belief that their child was too young or that their child would not want to hear what they would say about sexuality. Facilitators of parent-child sexuality discussions are the following: onset of puberty, dating; child starts participating in a school-based relationship and sexuality program and child initiates a question. Also, neither the child's nor parent's gender had an impact on barriers.

Turnball (2012) conducted a qualitative study of 20 parents living in the UK to identify facilitators and barriers to parent-child communication regarding relationships and sexuality. Facilitators of parent-child communication included the level of trust within the family; perception of parents as role models; perception that their parent has the knowledge to teach them; spending time together and child, adolescent, or young adult's participation in a school-based sexuality class. Barriers included the perception by a child that their parent did not have up-to-date knowledge; the sense of a parent's embarrassment; parent asking personal questions deemed by child as an invasion of privacy; and controlling behavior by the parent.

McKay and colleagues (2014) conducted a survey of 1002 parents in Ontario Canada to gain an understanding of their opinions and attitudes regarding sexual health education in the schools. A barrier to the implementation of sexual health curricula in Canada has been the perception that parents are opposed to broad based sexuality education. However, in their study, McKay, and colleagues (2014) reported the following results: 87% of parents approved of relationship and sexuality education being provided in school; 37% of parents felt sexuality health education should begin in elementary school, 47% in middle school and 14% in high school. 89% of parents responded that they felt comfortable or very comfortable to have relationship and sexuality discussions with their children and 83% agreed or strongly agreed that they had adequate knowledge to have these conversations with their children. In addition, parents rated themselves, nurses, doctors, and school as highly valued in their child's education which in turn demonstrates a willingness to collaborate and share responsibility for relationship and sexuality education.

Heller and Johnson (2013) completed a study that examined parental opinions about school sexuality education using a culturally diverse population of individuals living in the United States. Of the 191 participants only 32 were born in the US. The researchers found that there was no significant difference on approval of topic areas based on country of origin outside of the US versus the US. 80% or more of parents supported most of the topics.

The Role of Occupational Therapy in Sexual Health

Professional education prepares the occupational therapist to be a generalist with "broad exposure to the delivery models and systems" in all areas of practice including emerging practice with active involvement in leadership, advocacy, and professional development (AOTA, 2018, p. 1). By education and training, occupational therapists utilize current evidence and theory to

inform practice; facilitate performance and participation in occupations, activities, meaningful roles across settings that include home, school, workplace, and community; address the physical, sensory, cognitive, and psychosocial components that support occupational engagement that in turn affect health, well-being, and quality of life (ACOTE, 2018). Occupational therapy education has fostered competence and value in interdisciplinary collaboration with service providers and programs at the individual, group, and population levels. Occupational therapists' study and apply knowledge and experience of the structure and function of the human body, human development throughout the lifespan, and concepts of human behavior, being mindful of sociocultural, socio-economic diversity factors and social determinants of health. Occupational therapists strive to achieve cultural competence (a life-long endeavor) while utilizing the principles of teaching-learning along with educational methods and health literacy education to design clinical training and activities for individuals, groups, and populations. Occupational therapists have the educational background and skill to instruct and train clients, caregivers, families, and communities for the appropriate level of understanding, and as a core competency grade and adapt processes, tasks, activities and/or modify environments as needed. Given the emphasis on research in occupational therapy professional education, occupational therapists understand and utilize quantitative statistics and qualitative results considering the quality of the research (validity, reliability, methodological rigor) in analyzing and interpreting results.

The Occupational Therapy Practice Framework, 4th edition, (OTPF-4), (2020), has broadened the description of sexual activity as an Activity of Daily Living to include "sexual expression and experience with self or others (e.g., hugging, kissing, foreplay, masturbation, oral sex, intercourse)" (p. 30). In addition, OTPF-4 expanded upon social participation adding intimate partner relationships as "engaging in activities to initiate and maintain a close relationship, including giving and receiving affection and interacting in desired roles; intimate partners may or may not engage in sexual activity" (p. 34).

A comprehensive description of the occupational therapy's domain and process is "achieving health, well-being and participation in life through engagement in occupation" (AOTA, 2020, p.5). Occupational therapy considers a person holistically (mind-body-spirit) to target all aspects of humanity for full expression or engagement in meaningful occupation. Addressing sexuality is within the domain of occupational therapy practice, however, this is a practice area many therapists are not comfortable addressing, as it is tied to values and cultural

beliefs. *Vision 2025* (AOTA, 2017) guides occupational therapy practitioners through its five pillars which are as follows: to be effective (client-centered, evidence-based and cost effective); a leader (using influence on effect policy change; to collaborate (work within structure and systems); be accessible (culturally responsive); and work toward equity, inclusion, and celebration of diversity. These five pillars align well with the healthy relationship and sexuality program implementation and were considered in the selection and implementation of the program.

Occupational therapists need to step up and address issues of sexuality for health promotion and the well-being of their clients. The researcher took a lead role in the education of the key stakeholders within the current practice setting at a private school resulting in increased awareness, understanding, collaboration, and empowerment. Sexuality has been addressed by occupational therapists with adults in the rehabilitation practice setting after an injury or disease process impacts function. Walker, an occupational therapist, and colleagues (2020) have completed phase one in the development of the Occupational Performance Inventory of Sexuality and Intimacy (OPISI). This tool guides therapists to ask a client questions that they may otherwise be uncomfortable asking so that all their needs can be met, or a referral made.

For occupational therapy to be a leader in health care, Pizzi and Richards (2017), call for a paradigm shift in which occupational participation is linked to prevention of illness, disease and disability and the promotion of health, well-being, and quality of life. CHRSE offers students many more opportunities to practice and further develop problem solving and decision-making and self-determination skills while learning to use strategies to maintain emotional regulation during challenging times

Summary

This literature review explored the inconsistent provision of healthy relationships and sexuality education based upon the different requirements set by each state. Although most parents favored CHRSE and that it should begin earlier, many states failed to provide this instead focusing on AOUM or abstinence plus programs. In addition, an open, honest, and positive parent communication style in discussing relationships and sexuality seemed to impact the timing and level of sexual behaviors engaged in by adolescents. Open, honest conversation was found to more likely be associated with the delay of sexual debut, a reduced number of partners and responsible use of contraception. Parents generally favor an earlier start for sexuality

education to begin in schools. Barriers to parent-child communication regarding relationships and sexuality exist and given a parent interest in training, knowledge and helpful strategies and resources can be provided. Also, as individuals with ID and other cognitively based disabilities are at an increased risk for sexual abuse and exploitation without CHRSE, this study is warranted to increase understanding and break down barriers in communication.

Section 3: Methods

Project Design

This study used a quantitative, cross-sectional, descriptive survey design with one pre-test data point collection. This approach allowed the researcher to obtain data about the perceptions, attitudes, and beliefs of the parent population studied regarding Healthy Relationships and Sexuality Education. The study design and questionnaire were approved by the Eastern Kentucky University Institutional Review Board (IRB) prior to data collection and with support from the private school's administration (Cresswell & Cresswell, p. 149).

Setting

This research took place in the virtual environment using Qualtrics, an online survey tool, offered through Eastern Kentucky University. The 27-question survey was shared with parents by the mid-Atlantic state private school directly through email. The researcher was blind to the parent email addresses and no identifying information was available to connect survey responses to specific email addresses.

Identification of Participants

The study participants were parents and guardians of school aged children enrolled at a private school in a mid-Atlantic state during the 2020-2021 school year, using a convenience sample. Participation was clearly stated as voluntary. Consent for participation in the survey was obtained as part of the survey itself within the paragraph preceding the survey questions requiring a yes or no to consent and participate. The researcher did not have direct access to parent emails. The email invitation with the link to the survey was emailed directly by an administrator at the private school selected for the study. Inclusion criteria was that a parent or guardian had a child in the 6 through 21 age range who was enrolled at the private school for the 2020-2021 school year. In addition, the parent or guardian needed to have an email address that was shared and on file with the private school.

Instruments

The researcher developed the *Healthy Relationships and Sexuality Education Survey* which was informed by a literature review (See Appendix B). The education director and school president reviewed the parent survey questions prior to it being sent as an attachment to the IRB application for committee approval. In addition, a pilot test of the survey was run prior to emailing the survey to the parents. The panel consisted of a school psychologist who has an elementary aged child and a social worker who added the benefit of a male perspective. Feedback for clarity and neutrality of the questions was provided by a panel of experts and incorporated as part of the final version of the survey. Finally, content validity was established through a panel of experts that included the capstone mentor and committee member.

Timeline

The IRB approval for this capstone project was received on January 19, 2021. The survey was then distributed on February 24, 2021. Two reminders were sent to parents and the survey closed on March 8, 2021.

Data Collection Methods and Data Analysis

Data were collected utilizing an online survey via Qualtrics with 27 questions most of which were multiple choice with a few that were open ended. Descriptive statistics were analyzed for continuous variables.

Ethical Considerations

The researcher was mindful to anticipate ethical issues at all phases of research that include the planning period prior to conducting research; at the beginning of the project; during the data collection phase; in analyzing the data and in the reporting, sharing, and storing of data (Creswell & Creswell, 2018). The researcher upheld the Occupational Therapy Code of Ethics (AOTA, 2015) throughout the entire research process. Potential risk to participants completing an online survey could include the following: survey fatigue, headache, or eye strain, finding questions offensive or feeling uncomfortable and electronic hacking. The benefit to participants is that they have an opportunity to take part in a voluntary parent training that will provide education and resources to promote improved parent-child communication regarding Healthy Relationships and Sexuality Education later. Nonmaleficence, do no harm, was upheld by avoiding conflicts of interest and maintaining clear professional boundaries. In terms of justice, the researcher obtained all necessary approvals including that of the private school, Eastern

Kentucky University's Institutional Review Board, and consent from the respondents to the parent survey. Veracity was exercised through honesty and accuracy in communication and reporting results. Fidelity was upheld through respect and integrity. The researcher was ultimately responsible for conducting the study in an ethical manner including the implementation of participants' protections. To achieve a sustainable collaboration between parent, school, and community, buy-in from all stakeholders and ongoing training was key and needs to continue in the future.

Section 4: Results and Discussion

Response Rate

Surveys were sent to 216 parent email addresses representing 165 families. The breakdown of the total population of 165 students by grade level is as follows: 14 elementary students; 39 middle school students and 112 high school students. Some families had more than one email address, as this was part of the directory information. A total of 43 parents participated in the survey for an overall response rate of approximately 26% (43/165), however, one respondent did not include their child's age and so their child could not be included in grade level counts. Also, another parent skipped questions 6 through 14 and so they were not represented in the data for those questions. Forty-one respondents answered all survey questions and were included as part of the data for all questions. Response rates by child grade level are as follow: 35.71% of elementary parents; 30.77% of middle school parents and 21.43% of high school parents. Additionally, 32 of the parents provided their ages which ranged from 29 years to 71 years of age, with a mean age of 44.97. Most respondents were mothers (80.95%) with fathers and others (7.14%) each and guardians (4.76%). There was a relationship between the family structure of the household and the person who was reported to be the most likely to have discussions about healthy relationships and sexuality with their child, adolescent, or young adult. The 19 respondents (45.24%) who reported that they were married or in a committed relationship and living together as a family, indicated that both parents would have these discussions. The 15 respondents identifying as single mothers (35.71%) reported that they would take the responsibility to discuss healthy relationships and sexuality with their child while the two single parent fathers indicated they would have the discussions with their child. The sociodemographic information for the parent/guardian respondents is summarized in Table 1.

Table 1

Sociodemographic Characteristics of Parent/Guardian Participants

Item	Total	(%)
Gender		
Female	38	(90.48%)
Male	4	(9.52%)
Race/ethnicity		
Asian/Pacific Islander	1	(2.38%)
Black/African American	14	(33.33%)
White/Caucasian	24	(57.14%)
Other	3	(7.14%)
Highest grade or level of education		
High School	6	(14.63%)
1 to 3 years of college	10	(24.39%)
College graduate	9	(21.95%)
Completed graduate courses or earned graduate degree	14	(34.15%)
None of the above	2	(4.88%)
Household income for 2020		
$0-$50-000	17	(43.59%)
$50,000-$100,000	13	(33.33%)
$100,001 and up	9	(23.08%)
Household family structure		
Live with both parents/married or in a committed relationship	19	(45.42%)
Single parent – mother	15	(35.71%)
Single parent – father	2	(4.76%)
Lives with extended family member	3	(7.14%)
Other	3	(7.14%)

Note. ***N** = 42 (n = 39 for household income; n = 41 for highest level of education); % do not equal 100 due to rounding.

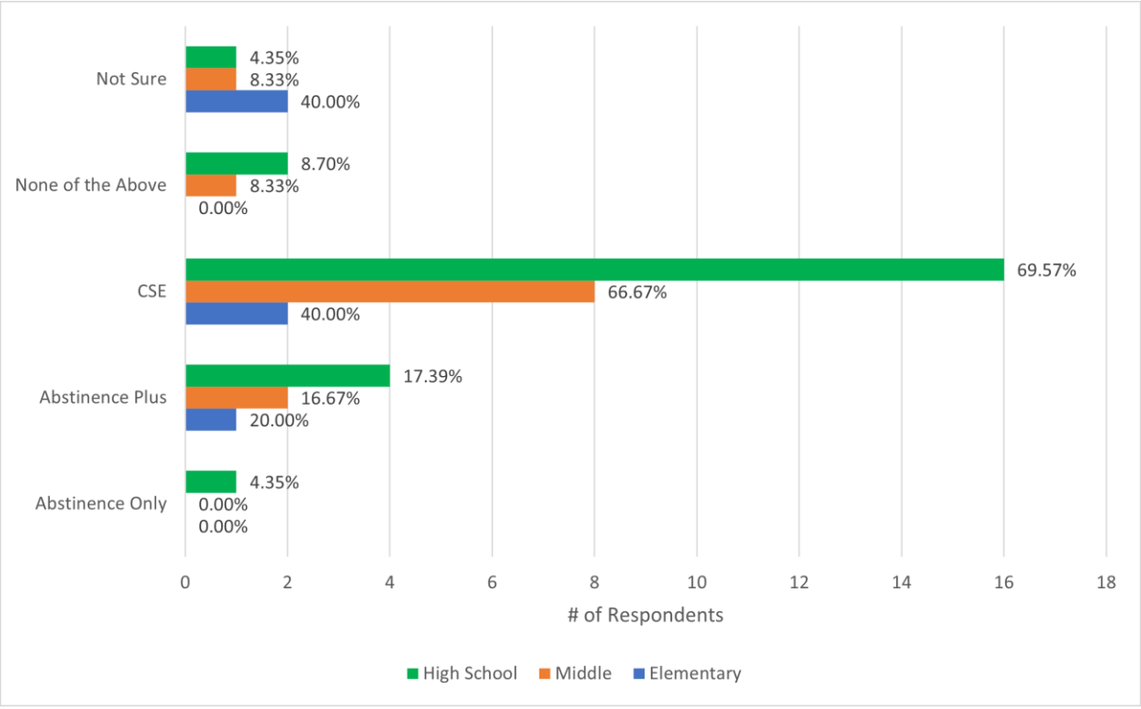
The majority (90.48%) of respondents were female with 57.14% identifying as white and 33.33% identifying as Black/African American. Most respondents reported having an annual income up to $50,000 (43.59%) while 33.33% earned between $50,000 - $100,000 and 23.08% reported income of over $100,000. Additionally, 21.95% of respondents earned a college degree while 34.14% of respondents took some graduate courses or completed a graduate degree.

Fifty percent of respondents believed that the responsibility for teaching their children about relationships and sexuality should be shared between parent/guardian, health professionals and trained school staff. Another 47.62% believed that the parent/guardian had the primary responsibility for teaching HRSE with only one parent indicating that the school should have the primary responsibility.

Most parents approved of a CSE approach across grade levels for a total of 63.41% comprised of parents of 2 elementary, 8 middle and 16 high school students. Only one parent of a high school student preferred an abstinence only approach while 16.67% of parents (1 elementary, 2 middle and 4 high school) favored an Abstinence Plus approach. In addition, 3 parents did not agree with any of the education approaches. This data is summarized in Figure 1.

Figure 1

Parent/Guardian Program Type Preference According to Their Child's Grade Level



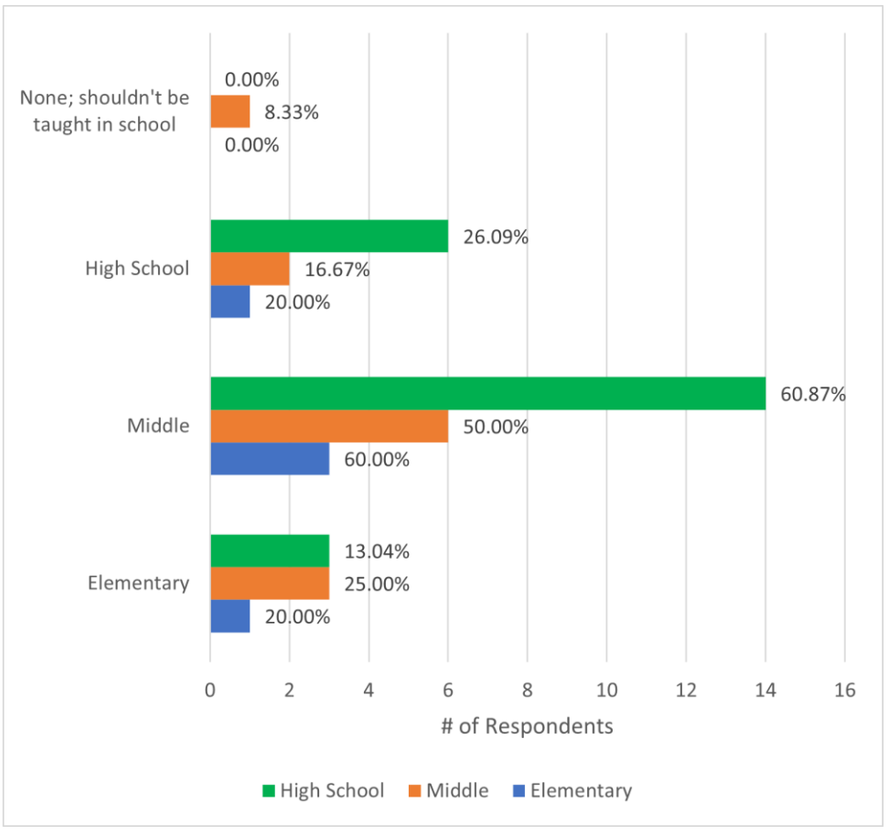
When parents were asked if they believe that their child, adolescent, or young adult was more at risk for sexual exploitation or abuse without CSE, the responses were as follow: 75.61% said yes; 14.63% said possibly but not sure and 9.76% answered no. There was a 12.20% differential in parents approving of CSE (63.40%) to parents who acknowledged the increased risk of abuse or exploitation without CSE (75.61%). This could be due to a parent substituting their preference of HRSE program type rather than considering all the content covered as part of CSE.

More than half of parent respondents (54.76%) believed that HRSE should begin in middle school (ages 11-13) while 21.43% believed it should begin in high school and 19.05% agreed it should begin in elementary school. Only 2 parents believed HRSE should not be taught in school at all. Additionally, parents were asked if they could envision their child, adolescent or young adult being in a healthy, safe, romantic relationship. Most parents (73.81%) responded *no,*

not at this age or maturity level (3 elementary, 11 middle and 18 high school parents). 19.05% of parents answered yes (2 elementary, 2 middle school and 3 high school parents) and 3 parents (7.14%) responded *no, I do not believe they have any interest in a romantic relationship now or in the future.* Their children were ages 14, 19 and 20. This data is summarized in Figure 2.

Figure 2

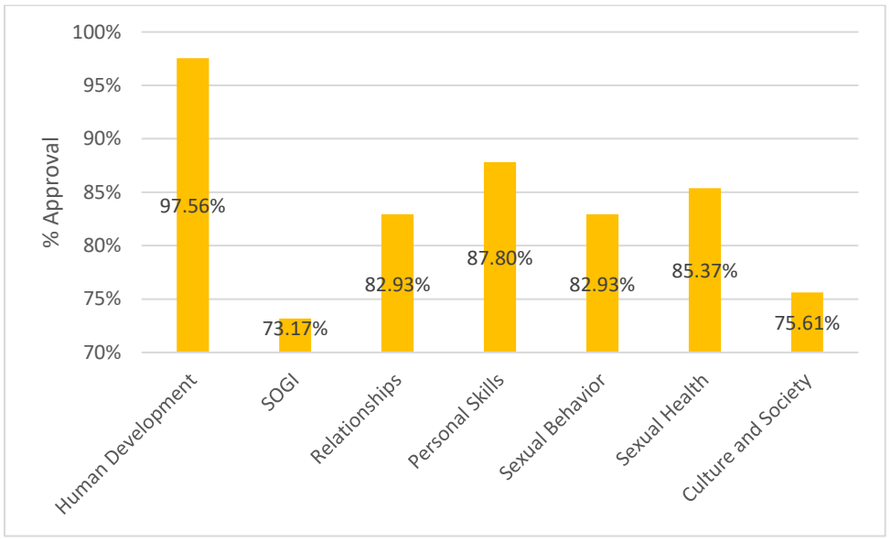
Parent Preference of Grade Level to Begin Relationship and Sexuality Education



Parent approval rates for each of the seven content areas are represented in Figure 3 based on total respondent answers and are as follows: human development 97.56%; personal skills 87.80%; sexual health 85.37%; relationships 82.93%; sexual behavior 82.93%; culture and society 75.61%; and sexual orientation and gender identity 73.17%. Sexual orientation and gender identity (SOGI) received the lowest approval rating for a difference of 24.39% from the highest approved content area of human development.

Figure 3

Total Parent Approval Rates for Relationship and Sexuality Program Content

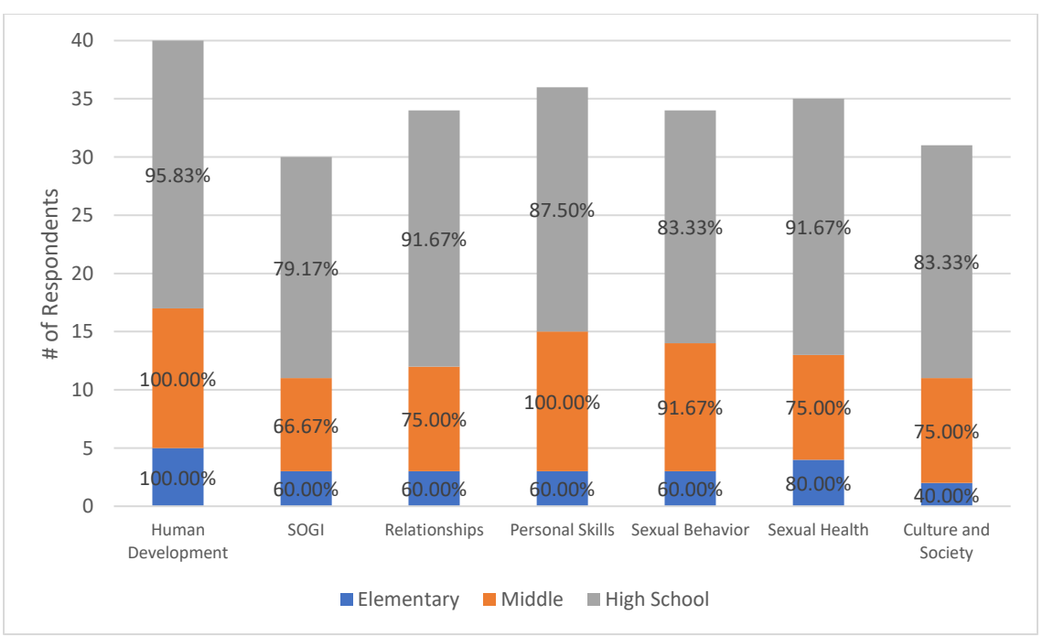


**Note.* This figure begins with a value of 70% as there were no content areas below that value. This provides a clearer visual representation of differences. SOGI is an abbreviated form for sexual orientation and gender identity.

Figure 4 represents parent preferences for each of the seven content areas by grade level. Given that puberty generally occurs during middle school, it makes sense that the following content areas had a high approval rate among the parents of middle schoolers: human development 100%; personal skills 100% and sexual behavior 91.67%.

Figure 4

Parent Approval Rates for Relationship and Sexuality Content by Grade Level



Parents were also provided the opportunity to write in any topics they felt should be off limits for a school-based relationship and sexuality class. Only ten parents answered this question, and the responses are detailed in Table 2.

Table 2

Parent Responses for Off Limit Topics

# Respondents	**Response**
7	*everything needs to be explained; no, this is so important*
1	*"no transvestite, no gay/lesbian"*
1	*"the threat of predators especially with regards to individuals with intellectual disabilities"*
1	*"Families come from different worldviews. Regardless of what may be trending in society, there are those who have different beliefs Though we are accepting and loving towards all people, regardless of background,* ***issues of sexual orientation we believe are a moral issue and should be left to the parent to inform their child about.*** *My child will have his worldview shaped by many influences, but the* ***role of the school is to educate with information and teach social skills of which kindness and acceptance*** *is a part of that. But not try to* ***intentionally shape my child's worldview or beliefs*** *on such matters*
10 Total	

Communication

When asked to describe their parent/child communication given options, parents responded as follow: 57.14% (5 elementary, 6 middle and 13 high school) encouraged their child to share their thoughts and feelings about relationships and sexuality; 14.29% (3 middle, 3 high school) of parents noted that it was challenging to get a conversation started but that they used teachable moments to break the ice (examples from television shows, movies etc.); 16.67% (1 middle and 5 high school) of parents indicated that their child does not want to talk about these matters with them; no parents selected the answer of preferring a trusted adult or professional to have these conversations with their child; and 11.90% (2 middle and 3 high school) of parents answered that none of these answers apply.

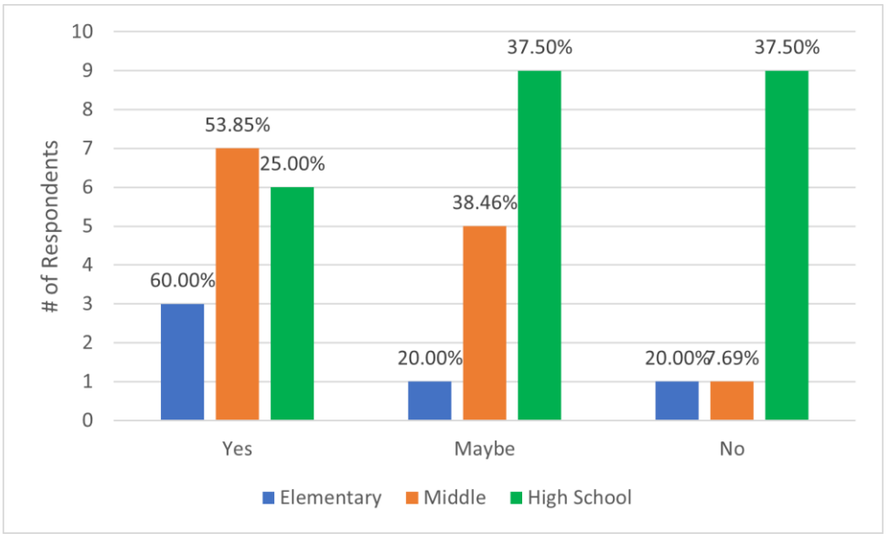
Additionally, the question, *have you ever started a conversation with your child about HRSE* was asked with the following responses: *yes, but only once* – 11.90% (2 middle and 3 high school parents); *yes, two or more times*- 57.14% (2 elementary, 4 middle and 17 high school parents); and *no* – 30.95% (3 elementary, 7 middle and 4 high school parents). Conversely, the question *has your child, adolescent or young adult ever asked you about romantic relationships*

or sexuality? The total of yes responses were 54.76% of which 42.86% (2 elementary, 5 middle and 11 high school parents) were comfortable and confident in answering those questions. 45.24% of parents (3 elementary, 7 middle and 9 high school) responded no.

When parents were asked if they were interested in attending an interactive training on HRSE that includes discussion about what to expect in each phase of human sexuality development, gender identity, tips on methods of improving communication and developmentally appropriate resources. Responses were as follow: 28.57% said no (1 elementary, 0 middle school and 9 high school); 35.71% said maybe (1 elementary, 5 middle school and 9 high school) and 35.71% said yes (3 elementary, 7 middle and 6 high school). Perhaps the parents of high schoolers who said no, are at a point where they feel they have already worked through any challenges and are comfortable. The middle school parents who said yes and may possibly need more supports and resources as puberty occurs during this time frame bringing many physiological and emotional changes and challenges to navigate.

Figure 5

Parent Interest in Training



Parents were also asked to write in any topics that they felt were most important to include in a HRSE training. Answers were as follows: “hygiene, mutual respect, boundaries”; “inappropriate touching”; “gender identity”; “sexual diseases and pregnancy”; “schools need to teach basic curriculum and leave the work politics out of the schools. Stop trying to indoctrinate our children”; “what if the adolescent has no desire for intimacy, relationships, or physical companionship?”; “the differences in the definition of love. I love my son but I also love my husband and what this means”; “respect people, no means no, no hitting, no sex until mature

enough to handle it, don't follow the crowd, talk to someone if you have questions about sexual diseases"; "self-advocacy"; "protection"; and "consent is a big one, as a mother of a boy, it is important that he respects women and their ability to say no at any time and that he respects that".

Parents were also asked how they learned about relationships and sexuality and responses are provided as a percentage of total respondents: 69.05% indicated parent or guardian; 52.38% school; 45.24% friends and siblings; 7.14% internet; and 23.80% books, movies and/or social media. When respondents were asked if they felt adequately prepared to discuss HRSE with their child, adolescent or young adult at their appropriate developmental level using medically accurate terminology, their responses were as follow: 61.90% felt somewhat prepared; 33.33% felt very prepared and only 4.76% answered not at all. When asked if they felt comfortable speaking to their child, adolescent, or young adult about HRSE, 52.38% said very much; 45.24% said somewhat and only one respondent said not at all. Additionally, most parent/guardians (64.29%) indicated that they were able to access all the resources they need for HRSE while 16.67% said no and that they could use support as to what developmentally appropriate resources were available and 19.05% were not sure but open to learning about supports and resources available.

Discussion

This capstone project focused on the beliefs and attitudes of parents and guardians of children with a disability regarding Healthy CHRSE. Despite the small sample size, this study adds to the literature addressing the underrepresented population of students with disabilities as all students attending the private school in this project qualified for an Individualized Education Plan (IEP). Most parents in this survey (see Figure 1) were in favor of CSE being taught in the schools. The elementary school parents were split between CSE, not sure and Abstinence Plus. This could be attributed in part to the barrier of thinking that their child is too young as identified by Malacane and Beckmeyer (2016) and Pariera (2016).

Parents and their communication style can impact decisions made by their children, adolescents and young adults as previous literature supports a link between an open, positive encouraging approach to discussions about relationships and sexuality with fewer self-reported teen sexual behaviors. In this project, 57.14% of parents (5 elementary, 6 middle and 13 high school) reported that they encourage an open and honest dialogue with their children about

relationships and sexuality. It logically follows then that the same percentage of parents indicated that they had initiated conversations about these topics two or more times as does the result that nearly as many parents, 52.38%, felt very comfortable in discussing relationships and sexuality with their child. In addition, parents responded that their child, adolescent, or young adult initiated the asking of questions at 54.76%. Parents have the potential to empower their children to make informed healthy decisions. Without parental support, children, adolescents, and young adults may turn to unreliable or inaccurate sources of information, resulting in judgement errors resulting in serious consequences such as unintended pregnancy, STIs, and HIV. Many young people with IDD and other cognitively based disabilities do not have the benefit of a reliable peer group with whom to share information and experiences making the education of both parents and students critical. Future support for parent training and collaboration is that only 33.33% of parents felt that they were very prepared to meaningfully discuss relationships and sexuality. There is no way to discern the level of preparedness for parents who answered that they felt somewhat prepared (61.90%) again supporting parent education.

The total support for school-based relationship and sexuality education (82.93%) and specific support for CSE (63.41%) were consistent with the support identified in the literature (Stein et al, 2018; Fisher et al, 2015; McKay et al., 2014). Administrators and teachers need to be aware of this fact as a common assumption and barrier to the provision of CHRSE is that parents oppose it, which is not the case. In addition, there is a disconnect by state and federal governments, who still primarily promote Abstinence Only Until Marriage and Abstinence Plus programs.

Most parents surveyed in this capstone project believed that relationship and sexuality education should begin in middle school which differs from previous literature which supports an elementary school start (Robinson et al., 2017; Fisher et al., 2015). The small convenience sample used for this project may have been a contributing factor for this difference.

Another important area to address is that only 19% of parents could definitively see their child, adolescent, or young adult in a safe, healthy romantic relationship. This was troubling, considering relatedness is a key component of self-determination skills, and connection is a basic human need. Graff and colleagues (2018) found that when individuals with IDD were asked if they had romantic, sexual interests, the response was overwhelmingly yes. In addition, the

expressed a desire for more education about how to recognize unhealthy relationships and decrease their vulnerability.

When considering that the pre-frontal cortex does not fully mature until the mid-twenties for all humans and is necessary for decision-making and executive functioning (Forsyth & Rogstad, 2015), it should be acknowledged and understood that the added layer of IDD, LD or another cognitively based disability, there is an increased vulnerability for sexual abuse or exploitation (NACDD, 2017; Helton et al., 2018). Parents have good reason to be concerned. However, to overprotect and deny education and the opportunity for meaningful human connection denies one's rights to fully reach their potential and satisfy innate human needs for overall health and wellbeing. Comprehensive Healthy Relationships and Sexuality Education then is necessary to provide medically accurate and developmentally appropriate relationship and sexuality education to empower autonomy and achieve competence, using social cognitive learning strategies to achieve relatedness or the connection that gives life meaning through occupation and role fulfillment. Although the need for connection is inherent, explicit instruction must be provided to navigate the process of initiating and maintaining relationships and to understand how one's decisions impact their health and wellness and that of others.

The training needs of parents found in this study were consistent with previous literature. Clatos and Asare's (2016) findings were particularly hopeful, as parents' ability to envision their child with a disability in a sexual or romantic relationship rose from 60% before intervention to 86% after a one-hour training. If a one-hour training can have this level of impact, imagine what a consistent collaboration and dialogue with parents can achieve. Parents in this study were interested in participating in a training, as noted in Figure 5. Of concern were some of the limitations mentioned in Figures 3 and 4. The content area of Sexual Orientation and Gender Identity (SOGI) had the lowest approval rate for inclusion in the healthy relationships and sexuality lessons. This is problematic because excluding SOGI from relationship and sexuality education would in essence be perpetuating heteronormative societal views denying the rights of the LGBTQ+ community to receive relationship and sexuality education that would meet their needs and allow for discussion to promote understanding, respect, and acceptance by all people. Since individuals with IDD and other developmental disabilities have often been excluded from CHRSE, we must make it a priority to respect their human rights equally as we do for their non-disabled peers. Prior to this study, the researcher had thought that it might be possible to avoid a

total parent opt out for their child from healthy relationships and sexuality education by providing parents with the content areas and allowing an opt out for certain topics. It became clear that this was not possible as all content is interconnected and omitting content such as SOGI or excluding individuals with disabilities from education would make instructors complicit in perpetuating heteronormative and ableist ideologies (Bottema-Beutel, 2021).

Parent education and ongoing collaboration is key to the success of any relationship and sexuality education curricula. The open-ended questions in this parent survey were critical in identifying underlying parent fears that schools through their teaching of CHRSE (specifically the inclusion of SOGI), were trying to impose their values onto their children. A common theme was that SOGI is a moral issue that should be addressed in the home, with one parent asking not to "indoctrinate" their child. Again, parent education, including the ability to review the curriculum and experience the lessons that their children would be taught, could spark the realization that school and home goals are one and the same. It comes down to acceptance, tolerance, and respect for all people, even though one may have a culture, values or religious beliefs that lead them to make different personal choices on how they live their own lives.

Limitations

There are several potentially limiting factors to consider in this study. First, 216 surveys were distributed to family email addresses representing 165 students enrolled at the mid-Atlantic private school. This could have resulted in multiple surveys being completed for one student. This is somewhat mitigated by the overwhelming response of mothers completing the survey (80.95%) fathers (7.14%), leaving only 11.91%, as a guardian or other. Second, this study relies on self-reported responses to survey questions that may impact the internal validity of research findings. Third, although the survey was anonymous, respondents may have felt social pressure to respond to a question in a way that was not totally aligned with their beliefs or attitudes. Fourth, in asking respondents to select healthy relationships and sexuality content areas that would be important to include the abbreviated descriptions may not have had adequate information for the respondent to understand the full nature of the topics and this may have influenced their response. Other answers may represent inaccuracies as well, if the parent/guardian was unsure of an answer based on the answer options provided. Fifth, given the limited response rate of 25%, the external validity may potentially be impacted. Use of technology to complete the survey could be a limitation, given answers skipped, and/or

inconsistent bandwidth for completion. And finally, the impact of parents utilizing computers and mobile devices may contribute to inaccuracies based on the respondents' computer literacy and accessibility.

Implications for Occupational Therapy Practice

As relationships and sexuality are an essential part of one's humanity and identity, education is a right that aligns with the innate drive for human connection beginning at birth. Parents are primary in the developmental process and due to the integral nature of school in a child, adolescent, and young adult's life, it naturally follows that a collaboration between school and parent would be most effective to increase knowledge and build skills for a safe, healthy, and fulfilling life.

Occupational therapy has made strides in addressing sexuality in their practice setting, but this has been limited to adult rehabilitation practice. Walker and colleagues (2020) for instance have completed phase one in the development of the Occupational Performance Inventory of Sexuality and Intimacy (OPISI). Occupational therapists need to expand their school-based role to include healthy relationships and sexuality education. This can be done through advocacy with school administration to ensure that research based CHRSE is being utilized and adapted so that no students are excluded. In addition, occupational therapists could take a leadership role within interdisciplinary teams to teach lessons and provide training for teachers and parents. Occupational therapists can also join advocacy efforts to achieve statewide mandates for comprehensive sexuality education utilizing curricula that align with National Sexuality Education Standards. Also, occupational therapists can collaborate with individuals with disabilities and the LGBTQ+ community to achieve a better understanding and to ensure inclusivity.

Future Research

Reflexivity and cultural sensitivity are paramount when providing healthy relationship and sexuality education, as the content intersects with different value systems, culture, and one's sense of morality. In being reflexive, one takes note of any personal bias to ensure that this is not imposed upon students. Bias can be spread by excluding individuals with disabilities from CHRSE or providing less content as "deemed" appropriate. In addition, one must be cognizant of language choices, tone and examples shared as part of the lessons. One area for future research is to include members of the LGBTQ+ community and individuals with IDD, LD and other

cognitively based disabilities in curriculum development and as guest speakers. Therapists can also engage in more scientifically rigorous research to determine the effectiveness of new and existing curricula. The parent survey in this study was meant to begin the conversation realizing that most parents approve of CHRSE being taught at school and understand the value of collaboration.

Conclusion

In summary, Brené Brown (2012, pp. 10-11) has touched on the heart of this capstone project with her quote: "Love and belonging are irreducible needs of all men, women, and children. We are hardwired for connection; it is what gives purpose and meaning to our lives. The absence of love, belonging, and connection always leads to suffering." This capstone project has validated that CHRSE is critically important and the human right of every person without exception. CHRSE builds self-determination skills so that individuals can exercise control over their life, feel competent to make informed decisions that promote their health and well-being and satisfy their inherent need for connection with others.

Timeline of Project Procedures

Action	Date Completed
Earned Training Certificate from Katherine McLaughlin, author of *Sexuality Education Curriculum for High School Students and Adults with Developmental Disabilities*	November 13,14, &15, 2019 – Live in Baltimore, Maryland
Provided Training during a school-wide in-service – 2 half days – interactive small group activities, lecture, video, role play	January 2 & 3, 2020
Facilitated the 1st Healthy Relationships Curriculum Committee Meeting-Interdisciplinary Team (special education teachers, clinical and behavior service director, social worker, speech and language pathologist, occupational therapist)	January 22, 2020
2nd Healthy Relationships Curriculum Meeting – reviewed parent letter draft and student pre-test – feedback obtained, and revisions made	February 5, 2020

Facilitated meeting with high school program teachers for input on student groupings for classes (pilot program) and to review student pre-test; revisions made as needed	February 6, 2020
Emailed Parent Letters explaining Healthy Relationships content and format of classes	February 13, 2020
Facilitated 3rd Healthy Relationships Curriculum meeting	February 19, 2020
Researcher started HR pilot program for 3 groups of high schoolers pre-test given and class meeting times 2x's per week for 45-minutes each session	February 21, 2020
PA mandated school closure due to COVID-19 19 – pilot program ended	March 12, 2020
Zoom Meeting with Dr. O'Brien, capstone mentor, to discuss and finalize plans for alternate capstone project – parent survey and development of a parent training regarding Healthy Relationships and Sexuality Education	October 23, 2020
Parent Survey was developed informed by a literature review; questions were reviewed by the education director, the school president and 3 related service providers. Feedback was obtained and revisions were made, as necessary.	November 2020
Completed and submitted IRB application with attachments including agency approval letter;	December 2020
IRB Approval Received	January 19, 2021
Piloting of survey before emailing to parents (psychologist/parent, speech and language pathologist/parent and social worker (with male perspective)	February 9, 2021
Parent surveys (Qualtrics) sent out via email by education secretary to 216 email addresses	February 18, 2021
Send out 1st parent survey email reminder	February 25, 2021
Send out 2nd parent survey email reminder	March 3, 2021
Data collection, data analysis, report writing	March 2021
Complete Capstone Project and Presentation	April 2021

References

American College of Obstetricians and Gynecologists. (2016). *ACOG committee opinion*. Washington, DC: American College of Obstetricians and Gynecologists.

American Occupational Therapy Association. (2017). Vision 2025. *American Journal of Occupational Therapy, 71*(3), 1. https://doi.org/10.5014/ajot.2017.713002

American Occupational Therapy Association (2018). *Accreditation Council for Occupational Therapy Education (ACOTE) Standards and interpretive guide.* https://www.aota.org/~/media/Corporate/Files/EducationCareers/Accredit/

American Occupational Therapy Association. (2020). Occupational therapy practice framework: Domain and process, 4th edition. *American Journal of Occupational Therapy*, 74, 1-87. https://doi.org/10.5014/ajot.2020.74S2001

Barr, E.M., Moore, M.J., Johnson, T., Forrest J., & Jordan, M. (2014). New evidence: Data documenting parental support for earlier sexuality education. *Journal of School Health, 84*, 10-17.

Bottema-Beutel, K., Kapp, S. K., Lester, J. N., Sasson, N. J., & Hand, B. N. (2021). Avoiding ableist language: Suggestions for autism researchers. *Autism in Adulthood, 3*(1), 18-29. https://doi.org/10.1089/aut.2020.0014

Brown, B. (2012). *Daring greatly: How the courage to be vulnerable transforms the way we live, love parent, and lead.* New York: Gotham Books.

Center on the Developing Child (2012). *Executive Function* (In Brief). https://developingchild.harvard.edu/

Centers for Disease Control and Prevention. (2017). *Lesbian, Gay, Bisexual, and Transgender Health.* Atlanta, GA: US Department of Health and Human Services. Retrieved from https://www.cdc.gov/lgbthealth/youth.htm

Centers for Disease Control and Prevention. (2019). "United States, High School Youth Risk Behavior Survey, 2019", available at https://bit.ly/3r3KhBv (accessed February 15, 2021)

Clatos, K. & Asare, M. (2016). Sexuality education intervention for parents of children with disabilities: A pilot training program. *American Journal of Health Studies, 31* (3), 151-162.

Creswell, J. W. & Creswell, J. D. (2018). *Research design: qualitative, quantitative, and mixed methods approach* (5th ed.), SAGE Publications, Inc.

De La Rue L, Polanin JR, Espelage DL, & Piggot, T. D. (2014). School-based interventions to reduce dating and sexual violence: A systematic review. *Campbell Systematic Reviews, 7,* 1-111. https://doi.org/10.4073/csr.2014.7

Elia, J. P. & Tokunaga, J. (2015). Sexuality education: Implications for health, equity, and social justice in the United States. *Health Education, 115*(1), 105-120. https://doi.org/10.1108/HE-01-2014-0001

Ericksen, I. H. & Weed, S. E. (2019). Re-examining the evidence for school-based comprehensive sex education: A global research review. *Issues in Law and Medicine, 34*(2), 161-182.

Fisher, C.M., Telljohann, S. K., Price, J.H., Dake, J.A., & Glassman, T. (2015). Perceptions of elementary school children's parents regarding sexuality education. *American Journal of Sexuality Education, 10,* 1-20. https://doi.org/10.1080/15546128.2015.1009595

Forsyth, S. & Rogstad, K. (2015). Sexual health issues in adolescents and young adults. *Clinical Medicine, 15*(5), 447-451.

Future of Sex Education Initiative. National sexuality education standards: Core content and skills, K-12. 2nd ed. Washington, DC: American School Health Association; 2020.

Gil-Llario, M. D., Morell-Mengual, V., Ballester-Arnal, R., & Diaz-Rodriguez, I. (2018). The experience of sexuality in adults with intellectual disability. *Journal of Intellectual Disability Research, 62,* 72-80. https://doi.org/10.1111/jir.12455

Goldfarb, E. S., & Lieberman, L. D. (2021). Three decades of research: The case for comprehensive sex education. *Journal of Adolescent Health, 68,* 13-27. https://doi.org/10.1016/j.jadohealth.2020.07.036

Gonzalvez, C., Fernandez-Sogorb, A., Sanmartin, R., Vicent, M., Granados, L., & Garcia-Fernandez, J., M. (2018). Efficacy of sex education program for people with intellectual disabilities: A meta-analysis. *Sexuality and Disability, 36,* 331 – 347. https://doi.org/10.1007/s11195-018-9545-9

Graff, H. J., Moyher, R. E., Bair, J., Foster, C., Gorden, M. E., & Clem, J. (2018). Relationships and sexuality: How is a young adult with an intellectual disability supposed to navigate? *Sexuality and Disability, 36,* 175-183. https://doi.org/10.1007/s11195-017-9499-3

Grossman, J. M., Sarwar, P. F., Richer, A. M., & Erkut, S. (2017). "We talked about sex." "No, we didn't": Exploring adolescent and parent agreement about sexuality communication. *American Journal of Sexuality Education, 12*(4), 343 – 357. https://doi.org/10.1080/15546128.2017.1372829

Hall, W.J., Jones, B.L.J., Witkemper, K.D., Collins, T.L., & Rodgers, G.K. (2019). State policy on school-based sex education: A content analysis focused on sexual behaviors, relationships, and identities. *American Journal of Health Behavior, 43*(3), 506-519 https://doi.org/10.5993/AJHB.43.3.6

Helton, J.J., Gochez-Kerr, T., & Gruber, E. (2018). Sexual abuse of children with learning

disabilities. *Child Maltreatment, 23*(2), 157-165. https://doi.org/10.1177/1077559517733814

Holmes, L. G., Himle, M. B., & Strassberg, D. S. (2016). Parental romantic expectations and parent-child sexuality communication in autism spectrum disorders. *Autism, 20*(6), 687 – 699. https://doi.org/10.1177/1362361315602371

Jerman, P., & Constantine, N. A. (2010). Demographic and psychological predictors of parent-adolescent communication about sex: A representative statewide analysis. *Journal of Youth and Adolescence, 39,* 1164 – 1174.

Malacane, M., & Beckmeyer, J. J. (2016). A review or parent-based barriers to parent-adolescent communication about sex and sexuality: Implications for sex and family educators. *American Journal of Sexuality Education, 11*(1), 27-40. https://dx.doi.org/10.1080/15546128.2016.1146187

Marshall, S. A., Hudson, H. K., & Stigar, L. V. (2020). Perceptions of a school-based sexuality curriculum: Findings from focus groups with parents and teens in a southern state. *The Health Educator, 52*(1), 37 – 51.

McDaniels, B. W., & Fleming, A. R. (2018). Sexual health education: A missing piece in transition services for youth with intellectual and developmental disabilities. *Journal of Rehabilitation, 84*(3), 28-38.

McDaniels, B., & Fleming, A. (2016). Sexuality education and intellectual disability: Time to address the challenge. *Sexuality and Disability, 34,* 215-225. https://doi.org/10.1007/s11195-016-9427-y

McKay, A., Byers, E. S., Voyer, S. D., Humphreys, T. P., & Markham, C. (2014). Ontario parents' opinions and attitudes towards sexual health education in the schools. *The Canadian Journal of Human Sexuality, 23*(3), 159-166.

https://doi.org/10.3138/cjhs.23.3-A1

McLaughlin, K., Topper, K. & Lindert, J. (2018). *Sexuality Education for people with developmental disabilities: Evidence-informed and trauma-informed curriculum for high school students and adults with developmental disabilities.* Elevatus Training, LLC, and Green Mountain Self-Advocates.

Meadows, E. (2018). Sexual health equity in schools: Inclusive sexuality and relationship education for gender and sexual minority students. *American Journal of Sexuality Education, 13*(3), 297 – 309. https://doi.org/10.1080/15546128.2018.1431988

Morawska, A., Walsh, A., Grabski, M., & Fletcher, R. (2015). Parental confidence and preferences for communicating with their child about sexuality. *Sex Education, 15*(3), 235 – 248. http://dx.doi.org/10.1080/14681811.2014.996213

Murphy, N.A., & Elias, E.R. (2006). Sexuality of children and adolescents with developmental disabilities. *Pediatrics,118,* 398-403. https://doi.org/10.1542/peds.2006-1115

National Association of Councils on Developmental Disabilities (NACDD). (2017, November 30). *Special Publication: Councils on Developmental Disabilities Addressing Sexual Violence and Neglect.* https://nacdd.org/wp-content/uploads/2017/11/DD-Councils-Special-Publication.pdf

National Joint Committee on Learning Disabilities. (2016). *Definition of learning disabilities*. https://njcld.org/ld-topics/

Office of Disease Prevention and Health Promotion. (n.d.). Improve the health and well-being of adolescents. *Healthy People 2030*. U.S. Department of Health and Human Services. https://health.gov/healthypeople/objectives-and-data/browse-objectives/adolescents

Pariera, K. L. (2016). Barriers and prompts to parent-child sexual communication. *Journal of Family Communication, 16*(3), 277 – 283. http://dx.doi.org/10.1080/15267431.2016.1181068

Pennsylvania Department of Education. (2002, July 18). Academic standards for health, safety and physical education. 22 Pa. Code, Chapter 4, Appendix D (#006-276). https://www.stateboard.education.pa.gov/Documents/Regulations%20and%20Statements/State%20Academic%20Standards/SandyHealth.pdf

Pizzi, M. A., & Richards, L. G. (2017). Guest Editorial-Promoting health, well-being, and quality of life in occupational therapy: A commitment to a paradigm shift for the next 100 years. *American Journal of Occupational Therapy, 71*, 1-5. https://doi.org/10.5014/ajot.2017.028456

Robinson, K. H., Smith, E., & Davies, C. (2017). Responsibilities, tensions, and ways forward: Parents' perspectives on children's sexuality education. *Sex Education, 17*(3), 333-347.

Sager, J. (2017, July). The power of inclusive sex education. *The Atlantic*, 1-8. https://www.theatlantic.com/education/archive/2017/07/the-power-of-inclusive-sex-ed/533772/

Schaafsma, D., Kok, G., Stoffelen, J. M., & Curfs, L. M. (2015). Identifying effective methods for teaching sex education to individuals with intellectual disabilities: A systematic review. *Journal of Sex Research, 52*, 412-432.

Somers, C., Avendt, E., & Sepsey, A. (2019). Parent-adolescent sexual dialogue: Does content and approach matter in adolescent sexual attitudes and behaviors? *Health Education, 119*(3), 215-229. https://doi.org/10.1108/HE-08-2018-00380

Stein, S., Kohut, T., & Dillenburger, K. (2018). The importance of sexuality education for children with and without intellectual disabilities: What parents think. *Sex and Disability, 36,* 141 – 148. https://doi.org/10.1007/s11195-017-9513-9

Tortolero, S.R., Johnson, K., Peskin, M., Cuccaro, P.M., & Markham, C. (2011). Dispelling the myth: What parents really think about sex education in schools. *Journal of Applied Research on Children: Informing Policy for Children at Risk, 2*(2), 1-19.

Treacy, A. C., Taylor, S. S., & Abernathy, T. V. (2018). Sexual health education for individuals with disabilities: A call for action. *American Journal of Sexuality Education, 13,* 65-93.

Turnbull, T. (2012). Communicating about sexual matters within the family: Facilitators and barriers. *Education and Health, 30*(2), 40-47.

United Nations Educational, Scientific and Cultural Organization (UNESCO), *International Guidelines on Sexuality Education: An evidence informed approach to effective sex, relationships and HIV/STI education,* (2018). https://www.unaids.org/sites/default/files/media_asset/ITGSE_en.pdf

U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. (2018). Reproductive and sexual health. In *Healthy People 2020*. https://www.healthypeople.gov/2020/leading-health-indicators/2020-lhi-topics/Reproductive-ed/533772/

Walker, B., Otte, K., LeMond, K., Hess, P., Kaizer, K., Faulkner, T., & Christy, D. (2020). Development of the occupational performance inventory of sexuality and intimacy (OPISI): Phase one. *The Open Journal of Occupational Therapy, 8*(2), 1-18. https://doi.org/10.15453/2168-6408.1694

Wolfe, P. S., Wertalik, J. L., Monaco, S. D., & Gardner, S. (2019). Review of curricular features of socio-sexuality curricula for individuals with developmental disabilities. *Sexuality and*

Disability, 37, 315-327. https://doi.org/10.1007/s11195-019-09585-4

Appendix A: IRB Approval

From: support@inforeadyreview.com on behalf of Sponsored Programs To: Zarrilli, Marie C. Cc: O'Brien, Shirley; Zarrilli, Marie C.; mzarrilli@pathwayschool.org Subject: [EXTERNAL] IRB Exemption Approval Notification: Research Protocol Number #3729 Date: Tuesday, January 19, 2021 10:41:52 AM CAUTION: This email originated from outside of the organization. Do not click links or open attachments unless you recognize the sender and know the content is safe. Hello Marie C. Zarrilli, Congratulations! Using a limited review process, the Institutional Review Board at Eastern Kentucky University (FWA00003332) has approved your request for an exemption determination for your study entitled, "Ready for the "Sex"uality Talk? Parent Empowerment Through Collaboration with School Personnel" This status is effective immediately and is valid for a period of three years as long as no changes are made to the study as outlined in your limited review application. If your study will continue beyond three years, you are required to reapply for exemption and receive approval from the IRB prior to continuing the study. As the principal investigator for this study, it is your responsibility to ensure that all investigators and staff associated with this study meet the training requirements for conducting research involving human subjects and comply with applicable University policies and state and federal regulations. Please read through the remainder of this notification for specific details on these requirements. Adverse Events: Any adverse or unexpected events that occur in conjunction with this study should reported to the IRB immediately and must be reported within ten calendar days of the occurrence. Changes to Approved Research Protocol: If changes to the approved research protocol become necessary, a Protocol Revision Request must be submitted for IRB review, and approval must be granted prior to the implementation of changes. If the proposed changes result in a change in your project's exempt status, you will be required to submit an application for expedited or full review and receive approval from the IRB prior to implementing changes to the study. Changes include, but are not limited to, those involving study personnel, subjects, recruitment materials and procedures, and data collection instruments and procedures. Registration at ClinicalTrials.gov: If your study is classified as a clinical trial, you may be required by the terms of an externally sponsored award to register it at ClinicalTrials.gov. In addition, some medical journals require registration as a condition for publication. In the case of journals with membership in the International Committee of Medical Journal Editors, clinical trials must be registered prior to enrolling subjects. It is important that investigators understand

the requirements for specific journals in which they intend to publish. In the case of sponsored project awards, timeline requirements will vary for awards that require registration. Approved consent forms must be uploaded in the system for all Federally funded clinical trials after subject enrollment has closed, but earlier registration is not required for all agencies. If you have questions about whether a sponsored project award requires registration and on what timeline, please send an email to tiffany.hamblin@eku.edu before beginning recruitment so that the specific terms of the award can be reviewed. If you have a need to register your study and do not have an account in the system, please send an email to lisa.royalty@eku.edu and request to have a user account created. If you have questions about this approval or reporting requirements, contact the IRB administrator at lisa.royalty@eku.edu or 859-622-3636. For your reference, comments that were submitted during the review process are included below. Any comments that do not accompany an “I approve” response have been provided to you previously and were addressed prior to the review process being completed.

Appendix B: Healthy Relationships and Sexuality Education Survey

You are being invited to take part in a survey about Healthy Relationships and Sexuality Education as part of a research study. The study is being conducted by Marie Zarrilli, MS, OTR/L, a doctoral student at Eastern Kentucky University and a school-based occupational therapist.

The purpose of the study is to better understand parent perceptions, attitudes and beliefs about aspects of healthy relationships and sexuality education such as the age you believe it should begin; the content that is important to include who you believe has the primary responsibility to provide sexuality education; and the nature and frequency of your discussions with your child, adolescent or young adult regarding sexuality education. All responses are anonymous and can't be tracked to a specific email address to assure confidentiality.

Participation is completely voluntary. If you decide to participate, the survey will take approximately 15 minutes to complete. Results of the survey will be used to provide an optional parent training based on the needs you express in the survey.

If you have any questions about the study or any survey question, please contact Marie Zarrilli at (484) 919-0279.

By completing the survey, you agree that you (1) are at least 18 years of age; (2) have read and understand the information above; and (3) voluntarily agree to participate in the study.

Thank you for your time and consideration.

- Yes, I will participate in this survey.
- No, I do not want to participate in this survey.

Q1. What is your relationship to the student?

- Mother
- Father
- Guardian
- Other

Q2. Please describe the family structure of your household.

- Married or in a committed relationship with both parents living in the household
- Single parent - mother
- Single parent - father
- Lives with extended family member
- Lives with guardian
- Other

Q3. Is there a person in the home or community who has or will most likely have discussions with your child, adolescent or young adult regarding relationships and sexuality?

- Mother
- Father
- Both parents
- Guardian
- Community member - nurse, pediatrician, church group, etc.
- Don't really know at this time

Q4. From Q3 above, what is the age of the person who will provide the discussions about healthy relationships and sexuality? If you do not know, enter N/A.

Q5. What is your child, adolescent or young adult's age? If you have more than one student enrolled at this school, please answer the question in terms of your oldest child.

Q6. Who do you believe has the primary responsibility for teaching your child, adolescent or young adult about healthy relationships and sexuality?

- Parent or guardian
- Health professional - pediatrician/nurse
- School - health teacher or other appropriately trained teaching staff
- Other community member
- Shared responsibility between parent/guardian, health professionals and trained school staff

Q7. What was your primary way of getting information about relationships and sexuality? You may select more than one answer it applies.

- [ ] Parent or guardian
- [ ] School - health teacher and/or nurse
- [ ] Friends or siblings
- [ ] Internet
- [ ] Books, movies and/or social media
- [ ] None of the above

Q8. Do you feel that you were adequately prepared to discuss relationships and sexuality with your child, adolescent or young adult at their appropriate developmental level using medically accurate terminology?

- ○ Not at all
- ○ Somewhat
- ○ Very much

Q9. Do you feel comfortable speaking with your child, adolescent or young adult about relationships and sexuality?

- ○ Not at all
- ○ Somewhat
- ○ Very much

Q10. Do you feel that you have adequate resources regarding sexuality and relationships to answer your child, adolescent or young adult's questions?

- ○ Yes, I am able to access all the resources I feel I need
- ○ No, I could use some support as to what developmentally appropriate resources are available
- ○ I'm not sure but am open to supports and resources that are available

Q11. Which of the following most closely matches your view on how healthy relationships and sexuality education should be taught in school?

- ○ Abstinence Only until Marriage
- ○ Abstinence Plus (still focuses on Abstinence but also provides medically accurate information on contraception options)
- ○ Comprehensive Sexuality Education (provides medically accurate, developmentally appropriate information about healthy relationships and sexuality including gender equality, maintaining boundaries, informed decision-making, consent, recognizing healthy versus unhealthy relationships and contraception options to prevent unintended pregnancy, STIs, HIV or AIDS)

- None of the above, it should not be taught in schools
- I'm not sure at this time

Q12. At what grade level do you believe that developmentally appropriate healthy relationships and sexuality education should begin?

- Elementary school (ages 6-10)
- Middle school (ages 11-13)
- High school (ages 14-21)
- None of the above, it should not be taught in school

Q13. What content is important to include at the appropriate developmental level? Check all answers that apply.

- Human Development - includes reproductive anatomy and physiology, puberty, and body image
- Gender Identity, gender expression and sexual orientation
- Relationships - includes families, friendships, love. romantic relationships and dating, marriage, committed partnerships and raising children
- Personal Skills - includes healthy decision-making, communication, assertiveness, negotiation, advocacy
- Sexual Behavior - includes sexuality throughout the life span, human sexual response and abstinence
- Sexual Health - includes reproductive health, gender related health screens, contraception, prevention of Sexually Transmitted Infections, HIV and AIDS, sexual violence and harassment and where to get help
- Society and Culture - includes gender roles, sexuality and the law, diversity, the media, internet and cyberbullying
- All of the above

Q14. Do you believe that children, adolescents and young adults are at a greater risk for sexual exploitation or abuse if they do not receive Comprehensive Sexuality Education?

- Yes
- No
- Possibly but not sure

Q15. Are there any topics that you believe should not be taught in a Healthy Relationships and Sexuality curriculum? If yes, please specify which topics.

Q16. Do you envision your child adolescent or young adult in a healthy, safe, romantic relationship?

- Yes
- No, not at this age or maturity level
- No, I don't believe they have any interest in a romantic relationship now or in the future

Q17. Have you ever started a conversation with your child, adolescent or young adult about sexuality or relationships?

- Yes, but only once
- Yes, two or more times
- No

Q18. Has your child, adolescent or young adult ever asked you about romantic relationships or sexuality?

- Yes, and I felt comfortable and confident answering the question
- Yes, but I was uncomfortable or embarrassed answering it
- Yes, but I was unsure how to answer it
- No, they have not asked yet

Q19. How would you describe your parent/child communication?

- I encourage my child, adolescent or young adult to share their thoughts and feelings about relationships and sexuality
- It is difficult to get a conversation going but I use examples from movies, television shows or the news to get a conversation going
- My child, adolescent or young adult does not want to talk about relationships and sexuality with me
- I prefer that another trusted adult or professional have these conversations with my child
- None of these answers apply

Q20. Do you feel that it is important to monitor your child, adolescent or young adult's internet, television and/or video game use?

- No, it is not an issue in our household
- Yes, but it is challenging

- It depends on the situation and time of day or night and if school and home expectations have been met first

Q21. Are you interested in attending an interactive parent training on Healthy Relationships and Sexuality that includes discussion about what to expect in each phase of human sexuality development, gender identity, tips on methods of improving parent-child/adolescent/young adult communication and provides resources?

- Yes
- Maybe
- No

Q22. Please write in any topics that you feel are most important to include in a training about Healthy Relationships and Sexuality.

Q23. What is your gender?

- Female
- Male
- Nonbinary

Q24. What is your child, adolescent or young adult's gender?

- Female
- Male
- Nonbinary

Q25. Which race/ethnicity best describes you? (Please choose only 1 answer)

- American Indian or Alaskan Native
- Asian/Pacific Islander
- Black or African American
- Hispanic American
- White/Caucasian
- Other

26. What is the highest level of education that you have completed?

- High School
- 1 to 3 years of college
- College graduate
- Completed graduate courses or earned a graduate degree
- None of the above

Q27. What is your average annual household income?

- $0 - $50,000
- $50,000 - $100,000
- over $100,000