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Sexuality and Romance in Individuals with Down Syndrome: Assessing the Relationship Between Parental Attitudes, Sexual Knowledge, and Experiences with Romance

THESIS

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By

Jessica Ann Greenwood

Thesis Committee:
Professor Maureen Bocian, MD, MS, Chair
Adjunct Professor, Pamela Flodman, MSc, MS, LCGC
Adjunct Professor, Kathryn Osann, PhD, MPH

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DEDICATION

This project is dedicated to my friends and favorite couple Alex and Kevin, and to Theresa for being such an amazing friend to me and everyone around her!

To participants: I would like to ask of you all to please accept my sincerest gratitude. The topic of this study is very important to me; so, thank you all for your enormous contributions.

-Jessica

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ABSTRACT OF THESIS

Sexuality and Romance in Individuals with Down Syndrome: Assessing the Relationship Between Parental Attitudes, Sexual Knowledge, and Experiences with Romance

By

Jessica Ann Greenwood

Master of Science in Genetic Counseling

University of California, Irvine, 2019

Professor Maureen Bocian, MD, Chair

The goal of this study is to explore factors associated with sexuality in children with Down Syndrome (DS), including demographic factors related to both parent and child (age, gender, ethnicity, etc.), child's knowledge of and experiences with sexuality, and attitudes of the parents. The study further investigates factors that are associated with parental attitudes, indicated by willingness to permit the child to be alone with a romantic partner. The hypothesis tested is that the child's age, gender, and developmental level, in addition to parental attitudes and concerns, are related to mothers' willingness to allow the child to be alone with a partner. Data are analyzed using multivariate logistic regression. The results show that age and developmental level, but not gender, are statistically significantly associated with parental permissiveness. Additional factors impacting permissiveness include knowledge about sexuality, understanding of consent, and the specific source of sexual education.

Understanding further the factors influencing and influenced by intimacy is vital in the effort to support autonomy for individuals with DS. Gaining insight into—and assessing the interplay of—these variables has the potential to influence advocacy for sexual independence among individuals with DS. This is the first study of its kind to look at sexuality in a broad age group and with a fine level of detail. We aspire to add to the currently limited depth of knowledge regarding this topic with hope that the results from this study may potentially lead to greater awareness of the importance of sexuality for individuals with DS.

I. Introduction

1.1 Defining Down Syndrome

As one of the most common causes of developmental disability, Down syndrome has been a topic of controversy since the identification of the condition, with steady advances toward acceptance and inclusion in the modern day. Down syndrome (DS) is a chromosomal disorder characterized by an increased risk for variable mild-moderate intellectual disability, specific dysmorphic features, and organ malformation. The condition was first described by Sir Langdon Down in his 1886 report on common features among a subset of children with intellectual disability (Down, 1887). It was not until 1930 that the condition was hypothesized by Waardenburg (1932) and Bleyer (1934) to be caused by a chromosome abnormality and then confirmed as such by Lejeune (1959) and Jacobs (1959). In the 1980s, the average life expectancy for individuals with Down syndrome was 25 years (Kucik, *et al., 2012)*. Today, many aspects of Down syndrome are well understood, including the associated physical and intellectual comorbidities and their management. With increased acceptance through the efforts of many advocate groups and advances in legislation, many individuals with Down syndrome are able to be contributing members of their communities and to live full and meaningful lives with an average life expectancy of 60 years (Graaf, *et al.,* 2016).

1.2 Genetics of Down syndrome

Down syndrome is a genetic condition that results from extra chromosomal material. The incidence of Down syndrome is 1 in every 700 live births (CDC), and the condition affects all genders and races equally (Bray, *et al*., 1998). The typical number of chromosomes in humans is 46, where the egg and sperm each contribute 22 autosomes and one sex chromosome (X or Y).

Individuals with Down syndrome have extra material from chromosome 21. In 95% of cases of Down syndrome, the extra chromosomal material is obtained through an error involving the failure of a pair of chromosomes No. 21 to separate during the division of an egg or a sperm in the process known as meiosis, resulting in a total number of 47 chromosomes. This error is called meiotic non-disjunction and is responsible for the majority of individuals with Down syndrome having an extra whole chromosome 21. This observation led to the other common name for Down syndrome–trisomy 21– where "tri" indicates three copies of chromosome, "-somy", 21. This nondisjunction event is not well understood, but it is seen in increasing incidence with advancing maternal age. The extra chromosome 21 arises from the egg in 92% of individuals with Down syndrome and from the sperm in 8% of affected individuals (Ballesta *et al*., 1999). The remaining cases of Down syndrome are due either to a postzygotic (somatic) nondisjunction event early in embryogenesis, meaning the extra chromosome arises from an abnormal cell division after fertilization, or from a rearrangement involving chromosome 21 and another chromosome. In the case of postzygotic nondisjunction of chromosome 21, individuals are said to have "mosaic" Down syndrome, meaning there are both trisomic and non-trisomic cell lines present. Individuals with mosaic Down syndrome may have a milder phenotype. Rearrangements between chromosomes are typically *de novo* (happening in an individual for the first time), but in a small percent of cases, rearrangements can be familial (inherited). In the case of a familial rearrangement, one parent has the correct amount of chromosomal material, but one copy of chromosome 21 is attached to another chromosome. When a parent carries this type of rearrangement, the offspring have a chance to inherit either the same "balanced" rearrangement as their parent, the typical arrangement of separate chromosomes in pairs, or extra or missing amounts of chromosome material (Antonarakis *et al.*, 1993).

1.3 Clinical description of Down syndrome

Individuals with Down syndrome share a common set of physical features, any of which can also be seen in the general population. It is when a majority of these features occur together in the same individual that one has the physical appearance of the Down syndrome phenotype. Facial features seen in individuals with Down syndrome include a flat middle portion of the face, upward slanting of the palpebral fissures (the opening between the eyelids), small and over-folded ears, and mild microcephaly (smaller than average head). Hands and feet are often short and broad with clinodactyly (curving) of the fifth finger and a wider separation than usual between the first and second toes. It is also common for individuals with Down syndrome to have a single transverse palmar crease on their hands, a thickened tongue, and fine, sparse hair (Jones, 1997).

In addition to the characteristic dysmorphic features, individuals with Down syndrome may experience any of a multitude of comorbidities. There is a higher incidence of thyroid dysfunction that leads to excess or deficient thyroid hormone levels in the body (Karlsson, *et al*., 1998). People with Down syndrome are also at a higher risk to develop infections due to a weakened immune system (Levitt, *et al*., 1990). About 50% are born with a heart defect, and 50% of those with heart defects specifically have an atrioventricular canal (a hole in the center of the heart where the tissue that separates the upper chambers of the heart meets the tissue separating the lower heart chambers) (Ferencz, *et al*., 1987). Some heart defects require surgical repair, while others do not because cardiac function is only minimally impacted. The ear canal is typically small and misshapen, which can lead to chronic ear infections and hearing loss in some cases (Strome, 1981). Other common features include a higher incidence than in the general

population of sleep apnea, Alzheimer disease, and gastrointestinal conditions such as celiac disease and Hirschsprung disease (Roizen and Patterson, 2003).

Intellectual disability is seen in all individuals with Down syndrome; however, cognitive ability lies on a spectrum. IQ scores in mid-childhood range from 30-70, with an average adult IQ of 50 (in the general adult population, the average IQ is 100, with most people falling between 85-115). The discrepancy in intellectual ability tends to increase with age in comparison to age-matched individuals, with an adult mental age equivalent of 1-9 years (Chapman, 1999). The stereotypical behavioral phenotype in Down syndrome includes being good-tempered, adaptable, affectionate, sociable, gregarious, and humorous and having a greater empathetic response than the general population (Gunn and Berry, 1985; Kasari *et al*., 2003). Although many individuals with Down syndrome meet this stereotype, it is also important to keep in mind that they too experience a wide variety of emotions and have their own personalities that make each individual with Down syndrome unique. Mental illnesses and psychiatric disorders such as depression and anxiety, autism, and dementia can also occur in Down syndrome, often with sudden onset (Dykens and Kasari, 1997; Collacott, *et al*., 1992).

Development has been shown to follow a different path than what is considered typical. Individuals with Down syndrome are usually delayed in gross and fine motor skills as well as speech and language. Delays typically present early with non-verbal communication and continue throughout the development of motor and cognitive milestones. Expressive communication is a deficit in Down syndrome, while receptive ability is a strength (Dykens, *et al*., 1994). Individuals with Down syndrome do eventually learn to walk (usually between 1 and 4 years) and talk unless limited by a separate physical condition. Sexual development shows a

pattern similar to typically developing individuals, with puberty taking place at the expected age (Walker-Hirsch, 2003).

Development of sexuality and sexual behavior in the Down syndrome population in particular is not well understood or documented. A study done in Brazil looked at sexual development in 50 adolescents with Down syndrome between the ages of 10 and 20 (Bononi et al., 2009) and found that 42% of the subjects masturbated, 36% were aware of sexual desire, and 18% had already dated. According to their future goals, more than half of the participants had interest in getting married and having children (Bononi et al., 2009). Additionally, Ginevra *et al*. (2016) found that sexual behaviors and sex education among individuals with Down Syndrome are significantly decreased when compared to typically developing individuals and that parental concerns are significantly increased. The sample population included in the Ginevra study was limited to minors with Down syndrome. These differences demonstrate the importance of future research that directly examines and addresses the understanding of sexuality among individuals with Down syndrome.

1.4 Sexuality and intellectual/developmental disability

Human sexuality is defined by the Sexuality Education and Information Council of the United States (SEICUS) as "encompassing the sexual knowledge, beliefs, attitudes, values, and behaviors of individuals. The dimensions of human sexuality include anatomy, physiology, and biochemistry of the sexual response system; identity, orientations, roles, and personality; thoughts, feelings and relationships. The expression of sexuality is often influenced by ethical, spiritual, cultural, and moral concerns" (SEICUS).

Sexuality among individuals with intellectual and developmental disabilities (IDD) to date has been a neglected topic among health care professionals, caregivers, and the general population. Shandra and Chowdhury suggest that caution and poor understanding of this subject may have led to unfair limitations and expectations regarding the expression and experience of sexuality in these individuals (Shandra and Chowdhury, 2012). According to the United Nations Convention for the Rights of Persons with Disabilities and the World Association for Sexual Health Declaration of Sexual Rights, people with disabilities have the right to express themselves sexually and thus have the potential to enhance their quality of life (Stein and Karola, 2017; Kaeser, 1992). As we move past the dark history of isolating and involuntarily sterilizing individuals with IDD, it is important to fully integrate them into society. This includes acknowledging that there are individuals with IDD who have sexual desires like those of any typically developing person. In order to better understand this topic, presented below is a summary of what is currently known in the literature involving sexuality and sexual behavior among individuals with intellectual and developmental disabilities. First, it is important to review the following definitions:

- Intellectual disability is a condition in which an individual exhibits significant limitations in intellectual functioning (reasoning, learning, problem solving, etc.) and adaptive behavior that creates deficits in a range of everyday social and practical skills. Typically, intellectual disability originates before the age 18 and lasts throughout the lifespan (AAIDD, 2019).
- A developmental disability is an impairment in physical, learning, language, or behavioral areas, typically beginning during the developmental period. This may impact day-to-day functioning and usually lasts throughout a person's lifetime (CDC).

1.4.a Childhood and adolescence

Research shows that regardless of the type of disability, many children with IDD have the same curiosities, drives, and interests about their bodies as typically developing children. Puberty for individuals with IDD may differ slightly in onset when compared to the general population; however, the majority of people with IDD fall in the normal range of 8.5 years to 14 years for pubertal onset (Murphy, *et al.,* 2006). Therefore, even at a young age, it is important for children with IDD to learn about privacy and boundaries, not only for others but for themselves as well (Richards, 2006). Youth with IDD tend to express the same sexual needs and desires as their peers and often act on these impulses, regardless of having appropriate sexual education that matches their level of cognitive comprehension (Pownall, *et al*., 2011). Parents vary on when they consider it a good time to start introducing specific issues of sexuality related to body changes and prevention of exploitation to their children. In most cases, this happens in late childhood and early adolescence (Mayo Clinic, 2017). Sex education for this age group should not only involve physical development or sexual behavior, but parents should also address issues of identity, privacy, independence, relationships, and socialization (Medina-Rico, *et al*., 2017).

1.4.b Sex education and sexual expression:

Literature that describes topics of sexuality in teenage-adult populations with IDD is largely focused on the self-perceptions of people with IDD, their knowledge of sexuality, their needs, risks, and the importance of having a support network (Medina-Rico, *et al*., 2017). Medina-Rico, *et al.*, conclude that the importance of sexual expression for people with IDD is underestimated and that sexual expression is necessary to allow the development of meaningful relationships and boundaries. Many caregivers and medical providers erroneously perceive

people with IDD as asexual because of their intellectual status and dependence on caretakers (Medina-Rico, *et al*., 2017). This viewpoint can lead or contribute to the isolation of people with IDD and can affect their ability to create meaningful and lasting relationships.

Only about 53-56% of adults with IDD have received any formal sexuality education, as compared to the 96% of typically developing teenagers ages 15-19 (Martinez, *et al.,* 2010). The low prevalence of this type of education is due to the majority of educators conflating mental age and chronological age (Barnard-Bark, *et al.,* 2014). Generally, when people with IDD do receive sexuality education, it is limited in scope, only covering anatomical and physiological topics such as menstruation and lacking topics such as sexual intercourse, contraception, sexually transmitted infections (STIs), and forming relationships. In one study analyzing behaviors such as dating, flirting, and sexuality, it was found that the age of initiation of sexual interest in this population is not different from typically developing individuals (Castelaõ, *et al*., 2010). Nevertheless, only approximately half of young people with IDD ages 15- 20 receive formal education on appropriate sexual behavior from school or from their parents (Dekker, *et al*., 2014). What this group lacks, however, is knowledge regarding the development of sexual relationships and the mechanism of sexual intercourse. This shortcoming in knowledge and understanding is associated with limited access to information on this topic. Because of this, individuals with IDD are more vulnerable to, and at increased risk for, unwanted pregnancies and STIs (Medina-Rico, *et al*., 2017). It has been postulated that due to poor sexual education when compared to the general population, people with IDD display a higher incidence of autoerotic behavior (van Schrojenstein Lantman-de Valk and Rook, 2011). This further suggests that sexual desire is present in this population but that due to the discussed lack of knowledge, these

individuals are limited in their capacity for sexual expression, and this can lead to the exhibition of certain inappropriate behaviors.

There are also gender differences in sexual behavior among adults and teens with IDD. It was found by Medina-Rico, *et al*., that the majority of women with IDD are not sexually active and that those who are had exclusively heterosexual intercourse. This research team examined girls aged 12-24 with mild IDD and showed that they had less knowledge about methods of contraception and, therefore, made less use of them with their sexual partners. In addition, women with IDD were more likely to want a pregnancy in their first sexual encounter when compared to women without IDD (Medina-Rico, *et al*., 2017). In contrast, men with IDD tend to show increased masturbatory behaviors, and sexual expression in this group is affected by a "biological urgency" causing an increased incidence of atypical sexual behaviors (Wilson, *et al*., 2011). With these differences in mind, the value of adequate sexual education in this group proves to be even more essential, not only to protect people with IDD from the dangers of inappropriate sexual behavior but also to allow them to enjoy the benefits of developing emotional relationships and a healthy sexual identity. In this way, sexual education for people with IDD is just as important as it is for typically developing individuals.

1.4.c Sexual abuse

Although there is an evident need for individuals with IDD to be taught the skills to appropriately express their sexuality, it is also clear that this population is at an increased risk for sexual abuse and exploitation. Research shows that young people with IDD have a reduced ability to recognize abusive behavior in others, with abuses usually being perpetrated by caregivers or other people close to them (Medina-Rico, *et al*., 2017). Given the high incidence of

abuse in this population, early intervention and education are imperative to help protect individuals with IDD from harm. There is limited awareness among caregivers and the affected individuals themselves of the legal protections that people with IDD have against sexual abuse (Kijak, 2013). Many people in this group are not fully aware of the minimum age of consent, and even fewer know that they have equal freedom to marry, a fact of which most of the general population is unaware (Kijak, 2013). All of these challenges lead to a reduction in the number and availability of opportunities for people with IDD to learn about their sexuality or to engage in appropriate social activities and healthy sexual exploration.

1.4.d Consent

It is clear that the majority of individuals with severe-profound IDD are incapable of giving informed consent for partnered sexual activities, and those who express consent might be subject to psychological manipulation and, therefore, may not be giving true consent (Medina-Rico, *et al*., 2017). For these reasons, people with IDD need protection from non-consensual sexual acts. Often, the issue of sexual consent for people with IDD involves the reality that many of them will not have the decision-making capacity to initiate or engage in consensual sex. However, an individual's capacity to consent can vary over time and circumstance. For example, consumption of alcohol or certain medications can prevent even an otherwise competent, typically developed adult from giving informed consent (Stein and Karola, 2017). Therefore, providing sex education has the potential to empower a group that previously was deemed incapable of making informed decisions about sex to achieve a greater level of self-determination. Because of this, longitudinal investigation for capacity to consent may result in differing outcomes across time. This may indicate that even an individual with IDD who was

previously deemed incapable of providing consent to sexual interaction can later develop the capacity to do so after sufficient sexuality education (Lyden, 2007). In addition, the capacity to consent may be situational, varying based on the nature of the sexual interaction. For this reason, Murphy and O'Callaghan (2004) concluded that ongoing sex education is necessary throughout the life span of individuals with IDD, not only to protect them from sexual abuse but also to increase their quality of life.

Consent can be broken down into various subcategories, and to deem a person incapable of consenting to sex, they must fail to meet the criteria for each. The crucial components of capacity to consent are knowledge, rationality, and volition. Being incapable of consent implies inability in each of these three components:

Sexual knowledge includes the ability to properly identify body parts and sexual behaviors and to understand where and when it is appropriate to engage in sexual activity. Adequate sexual knowledge also includes an appropriate understanding of pregnancy, STIs, and use of contraception (Lyden, 2007).

Rationality is the ability to evaluate the pros and cons of a sexual encounter and to make a rational decision on how to proceed. The determination of rationality is not limited to just an assessment of an individual's ability to accurately and appropriately assess and navigate various situations. It also includes the evaluation of an individual's awareness of person, place, and time and of his or her ability to accurately report events and to discriminate between fantasies, lies, and truth. The individual should be able to describe the process for deciding whether or not to engage in a partnered sexual interaction, to demonstrate an understanding of mutual consent, and to choose socially appropriate times and places to engage in any sexual behaviors. Finally, he or she should be able to perceive and appropriately respond to the vocal and non-vocal cues

communicated by his or her partner, specifically the desire to continue or discontinue the interaction (Lyden, 2007).

Volition means that a person can decide if and with whom he or she wants to engage in sexual activity without coercion. This person should also be able to take necessary measures to prevent against abuse and unwanted sexual advances. Furthermore, this person must have the ability to say "no" or "stop," either verbally or non-verbally, indicating a desire to discontinue a specific unwanted interaction.

Assessment of the ability of an individual to provide informed consent can consist of asking him or her questions to determine what information they can report that addresses rationality, voluntariness, and knowledge. For example, a mental status exam designed to assess cognitive ability, including orientation to person, place, time, attention, and recall, can aid in understanding an individual's capacity for rationality (Folstein, *et* al., 1975). Asking where babies come from or how a woman becomes pregnant can help evaluate one's level of knowledge and understanding, and asking the individual to provide proper responses to someone who wants undesired sexual acts can help to instill an understanding of volition. Consent assessments need not be limited to vocal communication. They can be administered via nonverbal interaction with picture symbols, sign language, or gestures, and they should always be completed using the method of communication in which the individual is most fluent (Stein and Karola, 2017).

1.4.e Privacy

A very significant impediment to healthy sexual expression for people with physical and developmental disabilities is a common lack of privacy. Individuals have the right both to

consent to sexual relations and to have the privacy to explore their sexuality. Obviously, these rights are restricted for children and also for those individuals who are determined to be incapable of consenting to sexual activities. It is always important to consider that adults with IDD are not the same as children. In contrast, however, the right to privacy is often restricted in the case of an individual who engages in severe self-injurious behavior, property destruction, or eloping (wandering). In these cases, caregivers frequently require 'line-of-sight' supervision of the person for whom they are caring, limiting their access to privacy. This is not an easily resolved issue because it exemplifies the conflict between concern for the wellbeing of the individual and upholding of his or her rights (Stein and Karola, 2017; Medina-Rico, *et al*., 2017).

1.4.f Intervention

There is general consensus that certain activities, such as masturbation and proper menstrual hygiene, may have to be taught to persons with IDD (Stein and Karola, 2017). An important question is who should provide this instruction. This is often not clearly established in laws and regulations or even among caretakers, and, therefore, there is the risk of accusing both staff and family of inappropriate behavior (Kaeser, 1992). Achieving clarity in standard state regulations for care facilities to follow is essential so that such concerns can be avoided and that inefficient service delivery due to fear of overstepping boundaries and potential repercussions can be prevented. However, the necessary ethical course involves ensuring that appropriate sexuality skills are taught to persons with IDD, reducing the likelihood of injury to self (Robinson, *et al*., 1992) or to others or the legal implications of engaging in sexual behavior in a public place (Stein and Karola, 2017).

1.4.g Support

Support networks are important for overall healthy functioning of people with IDD, particularly for achieving appropriate behavior when it comes to sexual health (Pownall, *et al*., 2011). The role of parents as supporters and educators in the process of delivering information to their children with IDD when physical changes and sexual thoughts emerge is important for adequate understanding of sexuality (Shandra and Chowdhury, 2012; Pownall, *et al*., 2011). Upon full-text review of 38 articles that address this topic, Medina-Rico concluded that there is a definite lack of resources needed for the proper education of parents to help them avoid making the mistake of ignoring the sexuality of their children and also to help them communicate the information necessary for their children to be safe (Medina-Rico, *et al*., 2017). The influences of family and community also play roles in the low rate of individuals with IDD identifying as homosexual or any sexual orientation other than heterosexual. Without appropriate support in the gender identification process, many individuals with IDD are limited in their sexual expression and preferences (Shandra and Chowdhury, 2012; Löfgren-Mårtenson, 2009). Support among all individuals, with and without IDD, must include encouragement and acceptance, allowing them to explore and understand themselves in ways not harmful to self or others.

1.5 Sexuality education for individuals with Down syndrome

Currently, there is a well-established sex education program for individuals with Down syndrome, developed by Terri Couwenhoven, that includes books and classes available for all ages (Couwenhoven, 2007). Even with this available resource, the literature to date suggests that many parents and caregivers of individuals with Down syndrome are hesitant to provide them with sex education or to allow them to engage in any sexual behaviors due to the lack of information in the literature surrounding this issue. Inherent to the wide spectrum of level of

functioning among individuals with Down syndrome, there are individuals in this group who have romantic and sexual desires that they wish to act on. Additionally, with access to the internet, social media, and other entertainment, all individuals with Down syndrome will inevitably learn about, and be exposed to, the concept of sexual behavior. This potentially could lead to their wanting to know how they can engage in sexual activities. To ensure that individuals with Down syndrome are safe and protected from the riskier aspects of sex, it is important not only that they receive adequate sex education but also that parents, caregivers, and health care professionals have an accurate understanding of their sexual and romantic interests and behaviors (Frank, 2016).

1.6 Aims of research

The first step toward understanding the factors that influence the exploration of sexuality for individuals with Down syndrome is to comprehend the level of parental influence regarding this subject. This study aims to describe the level at which parents of individuals with Down syndrome perceive their children's involvement with sexuality and what specific factors are associated with either increased or decreased experiences with romance, relationships, intimacy, and sex. The study further investigates factors that are associated with parental attitudes, indicated by willingness to permit the child to be alone with a romantic partner. The hypothesis tested is that the child's age, gender, and developmental level, in addition to parental attitudes and concerns, are related to mothers' willingness to allow the child to be alone with a partner

II. Materials and methods

This study was reviewed by the Institutional Review Board (IRB) at the University of California Irvine under category 1 of exempt research. IRB staff confirmed that the study met criteria for self-determination of exempt research. This information can be found in Appendix B.

2.1 Survey construction

The survey was developed in two steps. First, questions were selected from the Sexual Behavior Scale implemented by Ginevra, *et al*. (2016) and developed by Stokes and Kaur (2005); however, not all questions from this scale were selected. Next, we organized a small focus group of mothers of adolescents and young adults with Down syndrome at the Down Syndrome Association of Orange County to review the questions already selected and to suggest any additional questions they thought would be important to ask. The full list of survey questions for this study is available in Appendix A.

The original questions (minor modifications were made to some) retained from the Sexual Behavior Scale by Stokes and Kaur (2005) are:

1. Has your child received any sex education either by you or someone else (e.g. part of school program)?
2. Do you think your child has any knowledge about sexually related behavior?
3. Is your child aware of the physical changes that occur through puberty?
4. Do you think your child is aware of the different kinds of sexual relationships (dating, marriage, etc.)?
5. Does your child understand the human reproductive process?
6. Does your child understand what is and what is not acceptable behavior towards someone they are romantically interested in?
7. How did your child obtain their sex education?
    a. From you
    b. At school
    c. From another person
    d. Through pictures, videos, and/or reading
    e. From peers and friends
    f. Learnt this by themselves
8. Has your child ever had romantic interest in a person?
9. Are you worried that other persons might misinterpret your child's behavior as having sexual content that was not intended?
10. Are you concerned that your child has misconceptions about sex?
11. Are you concerned that your child may not find a life partner?

The survey included a total of 88 questions. The number of questions answered for each respondent could have differed due to branching logic used and to any questions that were skipped. The questions covered parent and child demographics, the child's experiences with sexuality and romance, and parental concern regarding these subjects.

2.2 Recruitment

Participants were recruited to take part in a 10-15-minute online survey that was implemented through UC Irvine Health's distribution of REDCap, a secure web platform for building and managing online databases and surveys (Vanderbilt University, 2004). In order to recruit the largest number of eligible subjects possible, the lead researcher contacted 125 Down syndrome organizations and associations (e.g. The Down Syndrome Association of Orange County) and support groups for parents of people with Down syndrome across the US. These groups and organizations were asked either to post information about this study with a link to the online survey on their websites and Facebook pages and/or to send the information to their members in a mass e-mail or as part of a mailer (via postal mail). A total of 15 groups confirmed that they sent out mass emails, and another 6 posted on social media (Facebook and Instagram). The survey information was also sent to the National Society of Genetic Counselors' listserv for genetic counselors to share the survey with eligible families. One genetic counselor responded and sent the survey information to her local Down syndrome support group.

Interested parents of individuals with Down syndrome were able to complete the online survey without providing the research team with their contact information. This approach allowed participants to complete the survey anonymously and in the privacy of their own homes.

Participants were also able to complete the survey at any time that was convenient for them within the time frame of the three months during which data was collected.

2.3 Informed consent

Prior to starting the survey, all participants were provided with a study information sheet that was approved by the IRB (Appendix A). By clicking "continue," they gave consent to participate in the study as indicated by the study information sheet This page included information about the purpose of the study and provided the lead researcher's contact information for any questions, comments, or concerns that the respondents might have had. The study information sheet also provided instructions to share the survey link with the respondent's child's other parent in order to connect families when possible.

2.4 Participants

Eligibility requirements to be in the study and complete the survey included being 18 years of age or older and the parent of a child with Down syndrome who is 12 years of age or older. Internet access was required to participate, and the survey was only provided in English. Respondents were also able to exit the survey at any time. First, middle, and last initials, and date of birth of the child with Down syndrome were collected and used to link parents in the same family if both parents responded. The research team was granted access only to non-identifiable data. An employee of the UC Irvine Institute of Clinical Translational Science served as an "honest broker" for this study and was granted access to the identifiable data. After the honest broker paired parents of the same family, all identifiers were removed from the dataset, and it was then shared with the research team. There were five male/female pairs and one

female/female pair. Due to the low yield in the number of linked pairs, an analysis of differences within families was not done; however, there is a small amount of information available in Appendix D.

There was a total of 161 individuals who opened the survey link. Of those 161, 12 did not click "continue" to start the survey, and 42 did not answer at least one of the three required questions (child's initials of first and last name and child's full date of birth), resulting in 54 individuals removed from the sample. Five of the male respondents were spouses of a female respondent. One additional female was the partner of a female respondent. Because paired spouses were likely to give similar responses (see Appendix D), only one respondent from a family unit was retained for analysis. Chi-square tests for significance were used to determine if responses from the 12 males differed significantly from female respondents. Results were suggestive of a gender difference; however, with an N of only 12 males there was insufficient power to find a significant difference between male and female respondents and similarly insufficient power to adjust for gender difference in a respondent. Therefore, all 12 males — including the 5 spouses— were removed from the study sample. One respondent from the female/female pair, chosen at random, was also removed to prevent two respondents reporting on the same individual with Down syndrome. A total of 94 female respondents made up the final study sample. Participation was voluntary, and respondents did not have to answer any questions that made them uncomfortable.

2.5 Statistical analysis

Data are presented using descriptive statistics (mean and standard deviation for continuous variables, frequency and percent for categorical variables) in Table 1. Responses to

the survey question, “Is your child allowed to be alone with a romantic partner or interest?” was compared by age, gender, and reading level of the person with Down syndrome as well as with answers to all other survey questions using two-way tables and Pearson Chi-square tests of significance.

Logistic regression was used to investigate the importance of the independent variables including child’s age, gender, and developmental level (assessed by reading level) for predicting responses to the question, “Is your child allowed to be alone with a romantic partner or interest?” as the dependent variable. After adjusting for age, gender and reading level, all significant variables from the univariate chi-square analyses were added separately as additional covariates to investigate which factors, if any, impact parents’ willingness to allow their children with Down syndrome to be alone with a romantic partner or interest. Ages of individuals with Down syndrome are divided into three groups (age <18, age 18-25, and age >25) and are represented as two dichotomous indicator variables in each regression.

III. Results

3.1 Demographics of Participants

Table 1 describes the demographics of the study population. The study population included 94 female participants with mean age of 53 (SD = 8.8) and range of 28-71 years. Seventy-nine (85%) participants were non-Hispanic white, 11 (12%) participants were Hispanic, and 3 (3%) were Asian. Twenty-eight (31%) participants reported that they have a graduate degree, 30 (33%) have a four-year college degree, 6 (7%) graduated from a technical or vocational school, 14 (15%) have a two-year college degree, 11 (12%) have a high school diploma, and 2 (2%) reported "none of these." For family composition, 84 (89%) respondents have at least one other child, and among these families, 63 (74%) have at least one other child who is male and 58 (70%) have at least one other child who is female. In 25 (30%) families with more than one child, the child with Down syndrome is the firstborn, in 45 (54%) families the child with Down syndrome is the last born, and in 14 (17%) families the child with Down syndrome is neither the first born or the last born.

Table 1: Select participant demographics

Variable	N	Mean	SD
Age of mother (years)	92	53.26	8.79
About Participants	N	(%)	
Parent Race			
White	79	85	
Hispanic	11	12	
Asian	3	3	
Total	93	100	
Parent education			
Graduate degree	28	31	
Four-year degree	30	33	
Technical school	6	7	
Two-year degree	14	15	
High school diploma	11	12	
None of these	2	2	
Total	91	100	
Family Composition	N	Yes (#)	Yes (%)
Do you have any other children?	94	84	89
Has at least one male child	84	63	74
Has at least one female child	83	58	70
Child with Down syndrome is first born	84	25	30
Child with Down syndrome is last born	84	45	54
Child with Down syndrome is the middle child	84	14	17

3.2 Demographics of respondents' children with Down syndrome

Table 2 describes demographics of the respondents' children with Down syndrome. Fifty-six (60%) individuals with Down syndrome were female and 38 (40%) were male. The mean age was 21 (SD=7.5) with a range of 12-43 years. Thirty (32%) of these individuals read at or above a 5th grade level, and 70 (74%) are reported to have verbal and fluent speech. Services received by individuals with Down syndrome include Applied Behavior Analysis (16%), speech therapy (95%), occupational therapy (88%), and physical therapy (86%). Fourteen (15%) parents reported that their child with Down syndrome uses sign language, and 10 (11%) use assistive technologies for communication, such as a smart tablet. Seven (7%) individuals do not live with their families. Forty-two (45%) use social media, and within social media use, 35 (37%) use Facebook, 10 (11%) use twitter, 27 (29%) use Instagram, 20 use Snapchat (22%), and seventy-four (79%) individuals use YouTube.

Table 2: Select demographics for persons with Down syndrome

Variable	N	Mean	Std. Deviation
Age of child with Down syndrome (years)	91	21.51	7.52
Age of female with Down syndrome (years)	55	22.3	7.52
Age of male with Down syndrome (years)	36	20.25	7.15
About child with Down syndrome	N	Yes (#)	Yes (%)
Female	94	56	60
Male	94	38	40
Reads at/above 5th grade level	94	30	32
Verbal and fluent speech	94	70	74
Has had ABA therapy	91	15	16
Has had speech therapy	94	89	95
Has had occupational therapy	94	83	88
Has had physical therapy	94	81	86
Uses sign language	93	14	15
Uses assistive technologies for communication	94	10	11
Uses social media	94	42	45
Facebook	94	35	37
Twitter	94	10	11
Instagram	93	27	29
Snapchat	92	20	22
YouTube	94	74	79
Has had sexuality education	94	80	85

3.3 Overall responses to survey questions

Table 3 describes responses to the remainder of the survey questions. Questions are reported in the following three categories: Child knowledge, child experience, and parental attitudes and concerns. All results are per parent report.

Knowledge: By parent report, 42 (47%) individuals with Down syndrome understand consent. Seventy (76%) parents believe their child can consent to kiss another person. Fifty-seven (61%) individuals with Down syndrome know about sexuality as a concept, 82 (87%)

know about the physical changes that occur during puberty, 76 (82%) are aware of romantic relationships, 43 (47%) know about sexual intercourse, and 40 (44%) know that intercourse can lead to a baby or pregnancy. Fifty-one (55%) parents reported that their child knows what is and what is not appropriate sexual behavior toward someone they are interested in and 44 (49%) know how to decline sexual advances by someone who is interested, in them. Seventy-two (77%) individuals with Down syndrome received sexuality education from the respondent, 34 (37%) from their other parent, 7 (8%) from a male sibling, 19 (21%) from a female sibling, 9 (10%) from another family member, 48 (53%) from a teacher, 16 (18%) from a therapist, and 22 (27%) from peers. Forty-seven (53%) received sexuality education from pictures or reading and 7 (8%) from pornographic media.

Experience: Twenty-eight (30%) mothers reported that their child has expressed desire to be alone with a romantic partner. Forty-seven (51%) children have participated in supervised group dates, 14 (15%) have participated in unsupervised group dates, 42 (45%) have been on a supervised one-on-one date, and 15 (16%) have been on an unsupervised one-on-one date. Twenty-one (23%) have been in an exclusive romantic relationship, and 7 (8%) have dated multiple people. Forty-two (54%) have been in love or said they were in love. Mothers of four (4%) individuals reported that their child has been intimate with another person, and no parent reported that their child has had sexual intercourse. Forty-nine (53%) masturbate, and 9 (10%) use contraception.

Parental attitudes and concerns: Sixty-two (66%) mothers have concerns about their child with Down syndrome being in a romantic relationship. Seventy-eight (83%) believe their child is interested in romance. A majority of mothers (98%) would allow their child with Down syndrome to date, and 82% would allow their child to participate in a sexually active

relationship, now or in the future. Thirty-one mothers (34%) reported that they would allow their child to be alone with a romantic partner. Fifty-four (59%) mothers are concerned that another person might misinterpret their child's behavior as having sexual content that was not intended, and 59 (63%) are concerned that their child has misconceptions about sex. Fifty-two (56%) mothers want their child to find a life partner. Seventy-four (80%) mothers have concerns for their child with respect to sexual abuse, 43 (46%) are concerned about pregnancy, 50 (54%) are concerned about STDs, and 64 (70%) have concerns for their child with respect to happiness. Thirty-seven (39%) mothers have received specialized parent training for educating their child about sexual behavior and romance. For the 11 children who did not receive sexuality education, 7 out of 11 (64%) parents believe their child would benefit from sex education.

Table 3: Responses to survey questions

Questions	N	Yes (#)	Yes (%)
Do you have concerns with your child being in a romantic relationship?	94	62	66
Do you believe your child is interested in romance?	94	78	83
Do you or would you allow your child to participate in dating?	94	92	98
Do you or would you allow your child to participate in a sexually active relationship, now or in the future?	87	71	82
Do you believe that your child understands consent?	90	42	47
Do you believe your child has the ability to consent to kiss another person?	92	70	76
Is your child allowed to be alone with a romantic partner or interest?	91	31	34

Table 3 (Continued): Responses to survey questions

Questions	N	Yes (#)	Yes (%)
Has your child expressed desire to be alone with a romantic partner?	93	28	30
Are you concerned that your child has misconceptions about sex?	93	59	63
Do you want your child to find a life partner?	93	52	56
Do you have concerns for your child with respect to sexual abuse?	93	74	80
Do you have concerns for your child with respect to pregnancy?	93	43	46
Do you have concerns for your child with respect to sexually transmitted diseases?	92	50	54
Do you have concerns for your child with respect to happiness?	92	64	70
Have you received any specialized parent education/training for educating your child about sexual behavior and romance?	94	37	39
Has your child received sexuality education from you?	93	72	77
Has your child received sexuality education from his or her other parent?	91	34	37
Has your child received sexuality education from a male sibling?	90	7	8
Has your child received sexuality education from a female sibling?	91	19	21
Has your child received sexuality education from another family member?	91	9	10

Table 3 (Continued): Responses to survey questions

Questions	N	Yes (#)	Yes (%)
Has your child received sexuality education from a teacher?	90	48	53
Has your child received sexuality education from a therapist?	89	16	18
Has your child received sexuality education from his or her peers?	83	22	27
Has your child received sexuality education from pictures/video/reading?	88	47	53
Has your child received sexuality education from pornographic media?	15	1	7
Do you think your child would benefit from sexuality education?	11	7	64
Do you think your child has any knowledge of the concept of sexuality?	94	57	61
Do you think your child is aware of different romantic relationships (dating, marriage, etc)?	93	76	82
Is your child aware of the physical changes that occur during puberty?	94	82	87
Does your child know about sexual intercourse?	91	43	47
Does your child understand what is and what is not acceptable behavior towards someone they are romantically interested in?	92	51	55
Does your child know how to decline sexual advances by someone who is interested in them?	90	44	49
Does your child understand that intercourse can lead to pregnancy/baby?	90	40	44

Table 3 (Continued): Responses to survey questions

Questions	N	Yes (#)	Yes (%)
Has your child participated in supervised group dates?	92	47	51
Has your child participated in unsupervised group dates?	94	14	15
Has your child participated in supervised one-on-one dates?	93	42	45
Has your child participated in unsupervised one-on-one dates?	94	15	16
Has your child participated in an exclusive romantic relationship?	91	21	23
Has your child participated in dating multiple partners?	91	7	8
Has your child been in love or said that he or she is in love?	94	51	54
To your knowledge, has your child been sexually intimate with another person?	94	4	4
To your knowledge, does your child masturbate?	92	49	53
To your knowledge, does your child use contraception?	92	9	10
Does your child use sign language?	93	14	15
Does your child use assistive technologies for communication? e.g. iPad, proloquo, etc.	94	10	11

3.4 Univariate analysis

3.4.a Person with Down syndrome: Age group

The child's knowledge of various aspects of sexuality, child's experience with sexuality and romance, and maternal permissiveness towards sexual expression varied significantly with respect to the ages of the individuals with Down syndrome. Table 4 contains responses to survey questions compared by child age group (age <18, age 18-25, and age >25). Questions are reported in the following three categories: Child knowledge, child experience, and parental attitudes and concerns. All results are per parent report.

Knowledge: Mothers who indicated that their child is under 18 differed from mothers whose child is 18-25 and from those whose child is over 25 with respect to beliefs that their child a) has received sex education from a female sibling (6% vs. 22% vs. 39%; p=0.010), b) has received sex education from peers (13% vs. 32% vs. 43%; p=0.047), c) is aware of different romantic relationships (68% vs. 90% vs. 92%; p=0.019), d) knows about sexual intercourse (24% vs. 58% vs. 70%; p=0.001), e) understands what is and what is not acceptable behavior toward someone they are romantically interested in (39% vs. 59% vs. 75%; p=0.025), f) knows how to decline unwanted sexual advances (28% vs. 45% vs. 79%; p=0.001), and g) understands that intercourse can lead to a pregnancy/baby (25% vs. 43% vs. 71%; p=0.003). The other "Knowledge" variables listed in table 4 are related to the ability to consent and to various other sources of sex education; however, differences between age groups were not statistically significant.

Experience: Individuals with Down syndrome who are under 18 differed from those who are 18-25 and those who are over 25 with respect to mothers' reports that their child a) has expressed desire to be alone with a romantic partner (12% vs. 34% vs. 44%; p=0.021), b) has

participated in a supervised group date (21% vs. 63% vs. 75%; p<0.001), c) has participated in an unsupervised group date (3% vs. 16% vs. 28%; p=0.024), d) has participated in a supervised one-on-one date (15% vs. 58% vs. 68%; p<0.001), e) has participated in an unsupervised one-on-one date (3% vs. 13% vs. 40%; p=0.001), f) has been in an exclusive romantic relationship (6% vs. 32% vs. 38%; p=0.009), g) has said that he or she is in love (35% vs. 63% vs. 68%; p=0.021), and h) uses the social media platform Facebook (12% vs. 12% vs. 44%; p<0.001). No significant differences by age were found for other "experience" variables not related to dating listed in table 4.

Parental attitudes and concerns: The majority of the "parental attitudes" variables that are related to permissiveness did not differ based on age of child. However, mothers who reported that their child is under 18 differed from mothers whose child is 18-25 and from those whose child is over 25 with respect to a) willingness to allow their child to be alone with a romantic partner (6% vs. 38% vs. 65%; p<0.001), b) concerns for their child with respect to sexual abuse (94% vs. 72% vs. 68%; p=0.027), and c) belief that their child would benefit from sex education – given the child had not yet received any (100% vs. 0% vs. 50%; p=0.022).

Table 4. Univariate analysis:
Person with Down syndrome age

Question	Age <18			Age 18-25			Age >25			p value
	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	
Do you have concerns with your child being in a romantic relationship?	34	25	74	32	20	63	25	15	60	0.488
Do you believe your child is interested in romance?	34	25	74	32	29	91	25	22	88	0.135
Do you or would you allow your child to participate in dating?	34	33	97	32	32	100	25	25	100	0.428
Do you or would you allow your child to participate in a sexually active relationship, now or in the future? Parent	30	26	87	32	28	87	22	18	82	0.501
Do you believe that your child understands consent?	33	15	46	32	13	41	25	13	52	0.735
Do you believe your child has the ability to consent to kiss another person?	33	23	70	31	23	74	25	22	88	0.250
Is your child allowed to be alone with a romantic partner or interest?	33	2	6	32	12	38	25	16	65	<0.001
Has your child expressed desire to be alone with a romantic partner?	33	4	12	32	11	34	25	11	44	0.021
Are you worried that another person might misinterpret your child's behavior as having sexual content that was not intended?	34	24	71	31	18	58	24	12	50	0.268

Table 4 (continued). Univariate analysis:
Person with Down syndrome age

Question	Age < 18			Age 18-25			Age > 25			p value
	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	
Are you concerned that your child has misconceptions about sex?	33	21	64	32	20	63	25	16	64	0.992
Do you want your child to find a life partner?	34	21	62	32	16	50	24	13	54	0.662
Do you have concerns for your child with respect to sexual abuse?	33	31	94	32	23	72	25	17	68	0.027
Do you have concerns for your child with respect to pregnancy?	33	20	61	32	14	44	25	9	36	0.151
Do you have concerns for your child with respect to sexually transmitted diseases?	32	20	63	32	18	56	25	9	36	0.123
Do you have concerns for your child with respect to happiness?	33	24	73	32	22	69	24	15	63	0.714
Have you received any specialized parent education/training for educating your child about sexual behavior and romance?	34	10	29	32	14	44	25	11	44	0.391
Has your child received sexuality education from you?	33	22	67	32	26	81	25	22	88	0.129
Has your child received sexuality education from his or her other parent?	33	11	33	32	14	44	23	8	35	0.654

Table 4 (continued). Univariate analysis:
Person with Down syndrome age

Question	Age >18			Age 18-25			Age >25			p value
	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	
Has your child received sexuality education from a male sibling?	33	1	3	32	4	13	22	2	9	0.336
Has your child received sexuality education from a female sibling?	33	2	6	32	7	22	25	10	39	0.010
Has your child received sexuality education from another family member?	33	2	6	32	3	9	23	4	17	0.380
Has your child received sexuality education from a teacher?	32	16	50	31	18	58	24	12	50	0.771
Has your child received sexuality education from a therapist?	32	3	9	30	6	20	24	6	25	0.282
Has your child received sexuality education from his or her peers?	31	4	13	28	9	32	21	9	43	0.047
Has your child received sexuality education from pictures?	32	12	38	29	19	66	24	14	58	0.075
Has your child received sexuality education from pornographic media?	3	1	33	8	0	0	4	0	0	0.117
Do you think your child would benefit from appropriate sex education?	6	6	100	2	0	0	2	1	50	0.022

Table 4 (Continued). Univariate analysis:
Person with Down syndrome age

Question	Age >18			Age 18-25			Age >25			p value
	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	
Do you think your child has any knowledge of the concept of sexuality?	34	16	47	32	23	72	25	16	64	0.109
Is your child aware of the physical changes that occur during puberty?	34	30	88	32	28	88	25	22	88	0.996
Do you think your child is aware of different romantic relationships (dating, marriage, etc)?	34	23	68	31	28	90	25	23	92	0.019
Does your child know about sexual intercourse?	34	8	24	31	18	58	23	16	70	0.001
Does your child understand what is and what is not acceptable behavior towards someone they are romantically interested in?	33	13	39	32	19	59	24	18	75	0.025
Does your child know how to decline sexual advances by someone who is interested in them?	32	9	28	31	14	45	24	19	79	0.001
Does your child understand that intercourse can lead to pregnancy/baby?	32	8	25	31	13	43	24	17	71	0.003
Has your child participated in supervised group dates?	33	7	21	32	20	63	24	18	75	<0.001

Table 4 (Continued). Univariate analysis:
Person with Down syndrome age

Question	Age >18			Age 18-25			Age >25			p value
	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	
Has your child participated in unsupervised group dates?	34	1	3	32	5	16	25	7	28	0.024
Has your child participated in supervised one-on-one dates?	34	5	15	31	18	58	25	17	68	<0.001
Has your child participated in unsupervised one-on-one dates?	34	1	3	32	4	13	25	10	40	0.001
Has your child participated in an exclusive romantic relationship?	33	2	6	31	10	32	24	9	38	0.009
Has your child participated in dating multiple partners?	33	1	3	31	3	10	24	3	13	0.388
Has your child been in love or said that he or she is in love?	34	12	35	32	20	63	25	17	68	0.021
To your knowledge, has your child been sexually intimate with another person?	34	0	0	32	1	3	25	2	8	0.235
To your knowledge, does your child masturbate?	34	19	56	32	14	44	23	14	61	0.420
To your knowledge, does your child use contraception?	33	2	6	32	4	13	24	3	13	0.623
Does your child use sign language?	34	6	18	31	5	16	25	2	8	0.551

Table 4 (Continued). Univariate analysis
Person with Down syndrome age

Question	Age >18			Age 18-25			Age >25			p value
	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	
Does your child use assistive technologies for communication? e.g. iPad, proloquo, etc.	34	5	15	32	4	13	25	1	4	0.406
Does your child use Facebook?	34	4	12	32	4	12	25	11	44	<0.001
Does your child use Twitter?	34	2	6	32	3	9	25	5	20	0.216
Does your child use Instagram?	33	6	18	32	10	31	25	10	40	0.180
Does your child use Snapchat?	33	5	15	31	8	26	25	6	24	0.542
Does your child use YouTube?	34	26	77	32	26	81	25	19	76	0.860

3.4.b Person with Down syndrome: Gender

Select variables related to the child's knowledge of various aspects of sexuality, the child's experience with sexuality and romance, and maternal permissiveness towards sexual expression varied significantly based on the gender of the child. Table 5 contains responses to survey questions compared by child gender (female or male). Questions are reported in the following three categories: Child knowledge, child experience, and parental attitudes and concerns. All results are per parent report.

Knowledge: Mothers who reported that their child is female differed from mothers whose child is male with respect to beliefs that their child a) has received sex education from the respondent (85% vs. 63%; p=0.012), b) has received sex education from his or her other parent (24% vs. 53%; p=0.002), c) has received sex education from a female sibling (25% vs. 9%; p=0.040), and d) is aware of the physical changes that occur during puberty (95% vs. 72%; p=0.002). No significant differences by gender were observed for other "knowledge" variables listed in Table 5 that are related to concepts of sexuality that are more complex (e.g. understanding consent and knowledge of sexual intercourse) and source of sex education.

Experience: Individuals with Down syndrome who are female differed from those who are male with respect to mothers' reports that their child a) masturbates (38% vs. 73%; p<0.001) and b) uses contraception (17% vs. 2%; p=0.022). Differences for other "experience" variables listed in Table 5 that are related to experiences with dating and social media use were not statistically significant.

Parental attitudes and concerns: Mothers who reported that their child is female differed from mothers whose child is male with respect to a) concern that their child has misconceptions about sex (72% vs. 35%; p=0.027), b) concerns regarding sexual abuse (88% vs. 61%; p=0.001), c) concerns regarding pregnancy (68% vs. 11%; p<0.001), and d) concerns regarding sexually transmitted diseases (63% vs. 38%; p=0.011). For other "parental attitudes" variables listed in Table 5 that are related to parental permissiveness for sexual expression and parental concern for happiness and appropriate sexual behavior, differences by gender were not statistically

Table 5. Univariate analysis:
Person with Down syndrome gender

Question	DS gender						
	Female with DS			Male with DS			p value
	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	
Do you have concerns with your child being in a romantic relationship?	61	40	71	46	26	57	0.156
Do you believe your child is interested in romance?	61	51	84	46	38	83	1.000
Do you or would you allow your child to participate in dating?	61	59	97	46	44	96	1.000
Do you or would you allow your child to participate in a sexually active relationship, now or in the future? Parent	55	42	76	45	38	84	0.452
Do you believe that your child understands consent?	57	26	46	46	22	48	0.845
Do you believe your child has the ability to consent to kiss another person?	59	48	81	46	31	67	0.115
Is your child allowed to be alone with a romantic partner or interest?	60	21	35	44	15	34	1.000
Has your child expressed desire to be alone with a romantic partner?	60	14	23	46	17	37	0.138
Are you worried that another person might misinterpret your child's behavior as having sexual content that was not intended?	59	33	56	46	28	61	0.692
Are you concerned that your child has misconceptions about sex?	60	43	72	46	16	35	0.027
Do you want your child to find a life partner?	60	38	63	46	24	52	0.320
Do you have concerns for your child with respect to sexual abuse?	60	53	88	46	28	61	0.001
Do you have concerns for your child with respect to pregnancy?	60	41	68	46	5	11	<0.001
Do you have concerns for your child with respect to sexually transmitted diseases?	60	38	63	45	17	38	0.011
Do you have concerns for your child with respect to happiness?	60	41	68	45	32	71	0.832
Have you received any specialized parent education/training for educating your child about sexual behavior and romance?	61	23	38	46	17	37	1.000

Table 5 (Continued). Univariate analysis: Person with Down syndrome gender

Question	DS gender						
	Female with DS			Male with DS			p value
	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	
Has your child received sexuality education from you?	60	51	85	46	29	63	0.012
Has your child received sexuality education from his or her other parent?	59	14	24	45	24	53	0.002
Has your child received sexuality education from a male sibling?	59	3	5	44	4	9	0.457
Has your child received sexuality education from a female sibling?	59	15	25	45	4	9	0.040
Has your child received sexuality education from another family member?	59	6	10	45	4	9	1.000
Has your child received sexuality education from a teacher?	58	32	55	45	21	47	0.431
Has your child received sexuality education from a therapist?	57	11	19	45	7	16	0.795
Has your child received sexuality education from his or her peers?	54	15	28	41	8	20	0.469
Has your child received sexuality education from pictures?	56	32	57	45	19	42	0.163
Do you think your child has any knowledge of the concept of sexuality?	61	36	59	45	27	60	1.000
Is your child aware of the physical changes that occur during puberty?	61	58	95	46	33	72	0.002
Do you think your child is aware of different romantic relationships (dating, marriage, etc)?	60	51	85	45	34	76	0.315
Does your child know about sexual intercourse?	58	30	52	46	17	37	0.166
Does your child understand what is and what is not acceptable behavior towards someone they are romantically interested in?	60	37	62	45	22	49	0.235

Table 5 (Continued). Univariate analysis: Person with Down syndrome gender

Question	DS gender						
	Female with DS			Male with DS			p value
	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	
Does your child know how to decline sexual advances by someone who is interested in them?	58	31	53	45	20	44	0.429
Does your child understand that intercourse can lead to pregnancy/baby?	58	29	50	45	15	33	0.110
Has your child participated in supervised group dates?	59	30	51	46	21	46	0.695
Has your child participated in unsupervised group dates?	61	8	13	46	9	20	0.428
Has your child participated in supervised one-on-one dates?	60	28	47	46	19	41	0.694
Has your child participated in unsupervised one-on-one dates?	61	10	16	46	7	15	1.000
Has your child participated in an exclusive romantic relationship?	60	16	27	44	8	18	0.354
Has your child participated in dating multiple partners?	60	5	8	44	2	5	0.696
Has your child been in love or said that he or she is in love?	61	29	48	45	28	62	0.169
To your knowledge, has your child been sexually intimate with another person?	61	4	7	46	0	0	0.133
To your knowledge, does your child masturbate?	60	23	38	45	33	73	<0.001
To your knowledge, does your child use contraception?	60	10	17	45	1	2	0.022
Does your child use sign language?	60	6	10	46	11	24	0.065
Does your child use assisted technologies for communication? e.g. iPad, proloquo, etc.	61	6	10	46	9	20	0.170
Does your child use Facebook?	61	22	36	46	17	37	1.000
Does your child use Twitter?	61	6	10	46	7	15	0.552
Does your child use Instagram?	60	17	28	45	13	29	1.000
Does your child use Snapchat?	60	13	22	45	10	22	1.000
Does your child use YouTube?	61	47	77	46	37	80	0.813

3.4.c Person with Down syndrome: Reading level

Variables that are related child's knowledge of and experiences with sexuality, and maternal permissiveness toward sexuality varied significantly based on reported reading levels of the children. Responses to survey questions are compared by child reading level (does not read through 2nd grade reading level; 3rd-4th grade reading level; and 5th grade reading level and higher; Table 6). Responses follow these categories: Child knowledge, child experience, and parental attitudes and concerns. All results are per parent report.

Knowledge: Responses from mothers who reported that their child reads at or above a 5th grade level differed from responses from mothers whose child reads at a 3rd-4th grade level and from those mothers whose child reads at 2nd grade level (and below) with respect to beliefs that their child a) understands consent (60% vs. 56% vs. 27%; p=0.018), b) can consent to kiss (93% vs. 78% vs. 60%; p=0.007), c) has received sex education from the respondent (90% vs. 86% vs. 60%; p=0.007), d) has received sex education from his or her peers (37% vs. 36% vs. 10%; p=0.027), e) has received sex education from pictures, videos, and/or reading (72% vs. 63% vs. 28%; p=0.001), f) has knowledge of the concept of sexuality (73% vs. 72% vs. 40%; p=0.007), g) is aware of the physical changes that occur during puberty (97% vs. 94% vs. 74%; p=0.014), h) knows about sexual intercourse (61% vs. 59% vs. 27%; p=0.009), i) understand what is and what is not acceptable behavior towards someone they are romantically interested in (73% vs. 52% vs. 42%; p=0.043), j) knows how to decline unwanted sexual advances (57% vs. 61% vs. 31%; p=0.043), and k) understands that intercourse can lead to pregnancy/baby (57% vs. 54% vs. 25%; p=0.022). Differences by reading level for other "knowledge" variables listed in Table 6 that are related to various other sources of sex education and mothers' belief that their child is aware of different romantic relationships (dating, marriage, etc.) were not statistically significant.

Experience: Experiences of the individuals with Down syndrome who read at or above a 5th grade level differed from those who read at a 3rd-4th grade level and those who read at 2nd grade level (and below) with respect to mothers' reports that their child a) has participated in a supervised group date (69% vs. 54% vs. 34%; p=0.021), b) has participated in an unsupervised group date (33% vs. 14% vs. 0%; p=0.001), c) has participated in a supervised one-on-one date (60% vs. 54% vs. 26%; p=0.012), d) has participated in an unsupervised one-on-one date (30% vs. 17% vs. 3%; p=0.012), e) has been in an exclusive romantic relationship (38% vs. 25% vs. 9%; p=0.023), f) masturbates (38% vs. 72% vs. 50%; p=0.028). Differences by reading level were not statistically significant for other "experience" variables listed in Table 6 that are related to sexual expression, use of contraception, and use of the social media platform Snapchat.

Parental attitudes and concerns: The attitudes of mothers who reported that their child reads at or above a 5th grade reading level differed from attitudes of mothers whose child reads at a 3rd-4th grade level and mothers whose child reads at 2nd grade level (and below) with respect to a) belief that their child is interested in romance (83% vs. 97% vs. 71%; p=0.029), b) willingness to allow their child to be sexually active at any point (90% vs. 89% vs. 68%; p=0.046), c) willingness to allow their child to be alone with a romantic partner (60% vs. 26% vs. 18%; p=0.001), d) concerns regarding sexually transmitted diseases (67% vs. 67% vs. 34%; p=0.010), and e) whether or not the respondent has received specialized parent training for educating their child about sexuality (43% vs. 59% vs. 20%; p=0.006). Differences by child's reading level for other "parental attitudes" variables listed in Table 6 that are related to concerns regarding appropriate sexual behavior and bigger picture attitudes towards their child's sexuality (i.e. whether or not respondent wants her child to find a life partner) did not reach statistical significance.

Table 6. Univariate analysis:
Child with Down syndrome reading level

Question	Does not read - 2nd grade reading level			3rd-4th grade reading level			5th grade reading level and higher			p value
	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	
Do you have concerns with your child being in a romantic relationship?	35	23	66	29	19	66	30	20	67	0.995
Do you believe your child is interested in romance?	35	25	71	29	28	97	30	25	83	0.029
Do you or would you allow your child to participate in dating?	35	35	100	29	28	97	30	29	97	0.545
Do you or would you allow your child to participate in a sexually active relationship, now or in the future? Parent	31	21	68	27	24	89	29	26	90	0.046
Do you believe that your child understands consent?	33	9	27	27	15	56	30	18	60	0.018
Do you believe your child has the ability to consent to kiss another person?	35	21	60	27	21	78	30	28	93	0.007

Table 6 (Continued). Univariate analysis:
Child with Down syndrome reading level

Question	Does not read - 2nd grade reading level			3rd-4th grade reading level			5th grade reading level and higher			p value
	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	
Is your child allowed to be alone with a romantic partner or interest?	34	6	18	27	7	26	30	18	60	0.001
Has your child expressed desire to be alone with a romantic partner?	34	7	21	29	11	38	30	10	33	0.293
Are you worried that another person might misinterpret your child's behavior as having sexual content that was not intended?	34	22	65	29	16	55	29	16	55	0.669
Are you concerned that your child has misconceptions about sex?	35	21	60	29	19	66	29	19	66	0.867
Do you want your child to find a life partner?	35	19	54	29	14	48	30	19	65	0.405
Do you have concerns for your child with respect to sexual abuse?	35	26	74	28	23	82	30	25	83	0.614
Do you have concerns for your child with respect to pregnancy?	35	13	37	28	13	46	30	17	57	0.290
Do you have concerns for your child with respect to sexually transmitted diseases?	35	12	34	27	18	67	30	20	67	0.010
Do you have concerns for your child with respect to happiness?	34	24	71	28	19	68	30	21	70	0.971

Table 6 (Continued). Univariate analysis:
Child with Down syndrome reading level

Question	Does not read - 2nd grade reading level			3rd-4th grade reading level			5th grade reading level and higher			p value
	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	
Have you received any specialized parent education/training for educating your child about sexual behavior and romance?	35	7	20	29	17	59	30	13	43	0.006
Has your child received sexuality education from you?	35	21	60	28	24	86	30	27	90	0.007
Has your child received sexuality education from his or her other parent?	35	10	29	27	11	41	29	13	45	0.372
Has your child received sexuality education from a male sibling?	35	3	9	27	2	7	28	2	7	0.975
Has your child received sexuality education from a female sibling?	35	5	14	27	5	19	29	9	31	0.244
Has your child received sexuality education from another family member?	33	5	14	27	0	0	29	4	14	0.121
Has your child received sexuality education from a teacher?	35	17	49	28	20	71	29	12	41	0.059
Has your child received sexuality education from a therapist?	33	4	12	28	4	14	28	8	29	0.206
Has your child received sexuality education from his or her peers?	31	3	10	25	9	36	27	10	37	0.027

Table 6 (Continued). Univariate analysis:
Child with Down syndrome reading level

Question	Does not read - 2nd grade reading level			3rd-4th grade reading level			5th grade reading level and higher			p value
	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	
Has your child received sexuality education from pictures?	32	9	28	27	17	63	29	21	72	0.001
Has your child received sexuality education from pornographic media?	6	0	0	4	0	0	5	1	20	0.343
Do you think your child would benefit from appropriate sex education?	8	5	63	1	0	0	2	2	100	0.235
Do you think your child has any knowledge of the concept of sexuality?	35	14	40	29	21	72	30	22	73	0.007
Is your child aware of the physical changes that occur during puberty?	35	26	74	29	27	94	29	28	97	0.014
Do you think your child is aware of different romantic relationships (dating, marriage, etc)?	35	25	71	28	25	89	30	26	87	0.132
Does your child know about sexual intercourse?	34	9	27	29	17	59	28	17	61	0.009
Does your child understand what is and what is not acceptable behavior towards someone they are romantically interested in?	33	14	42	29	15	52	30	22	73	0.043

Table 6 (Continued). Univariate analysis:
Child with Down syndrome reading level

Question	Does not read - 2nd grade reading level			3rd-4th grade reading level			5th grade reading level and higher			p value
	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	
Does your child know how to decline sexual advances by someone who is interested in them?	32	10	31	28	17	61	30	17	57	0.043
Does your child understand that intercourse can lead to pregnancy/baby?	32	8	25	28	15	54	30	17	57	0.022
Has your child participated in supervised group dates?	35	12	34	28	15	54	29	20	69	0.021
Has your child participated in unsupervised group dates?	35	0	0	29	4	14	30	10	33	0.001
Has your child participated in supervised one-on-one dates?	35	9	26	28	15	54	30	18	60	0.012
Has your child participated in unsupervised one-on-one dates?	35	1	3	29	5	17	30	9	30	0.012
Has your child participated in an exclusive romantic relationship?	34	3	9	28	7	25	29	11	38	0.023
Has your child participated in dating multiple partners?	34	1	3	28	3	11	30	3	10	0.421
Has your child been in love or said that he or she is in love?	35	15	43	29	17	59	30	19	63	0.218
To your knowledge, has your child been sexually intimate with another person?	35	1	3	29	1	3	30	2	7	0.725

Table 6 (Continued). Univariate analysis:
Child with Down syndrome reading level

Question	Does not read - 2nd grade reading level			3rd-4th grade reading level			5th grade reading level and higher			p value
	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	
To your knowledge, does your child masturbate?	34	17	50	29	21	72	29	11	38	0.028
To your knowledge, does your child use contraception?	35	3	9	29	2	7	28	4	14	0.614
Does your child use sign language?	34	10	29	29	2	7	30	2	7	0.013
Does your child use assisted technologies for communication? e.g. iPad, proloquo, etc.	35	10	29	29	0	0	30	0	0	<0.001
Does your child use Facebook?	35	7	20	29	11	38	30	17	57	0.010
Does your child use Twitter?	35	0	0	29	3	10	30	7	23	0.010
Does your child use Instagram?	35	5	14	28	8	29	30	14	47	0.016
Does your child use Snapchat?	34	3	9	28	7	25	30	10	33	0.053
Does your child use YouTube?	35	23	66	29	24	83	30	27	90	0.047

3.4.d "Is your child allowed to be alone with a romantic partner or interest?"

Responses to the question, "Is your child allowed to be alone with a romantic partner or interest?" varied significantly based on age of child, child's reading level, services received, and living arrangement. Mothers who allow their child with Down syndrome to be alone with a romantic partner are more likely to have a child who is over age 17 than are mothers who do not allow their child to be alone with a romantic partner (90% vs. 48% respectively; $p < 0.001$). Additionally, mothers who allow their child to be alone with a romantic partner are more likely to report that: a) their child reads at or above a 5th grade reading level (58% vs. 20%; p=0.001), and, b) their child does not live with family (16% vs. 3%; p=0.043). Alternatively, mothers who allow their child to be alone are less likely to report that their child has received speech therapy than are mothers who do not allow their child to be alone with a romantic partner (87% vs. 98%; p=0.026). The proportion of respondents who allow their child to be alone did not differ significantly by any of the other parental and child demographics listed in Table 7 with respect to this particular univariate model.

The remainder of results from Table 7 are reported in the following three categories: Child knowledge, child experience, and parental attitudes and concerns. All results are per parent report.

Knowledge: The attitudes of mothers who allow their child to be alone with a romantic partner differed from the attitudes of those who do not with respect to beliefs that their child a) understands consent (72% vs 35%, p=0.001), b) has the ability to consent to kiss (90% vs 67%, p=0.016), c) has received sex education (97% vs 78%, p=0.021), d) has received sex education from the respondent (90% vs 71%; p=0.038), e) has received sex education from a female sibling (37% vs. 14%; p=0.013), f) has received sex education from peers (42% vs. 20%; p=0.04), g) has

received sex education from pictures, videos, and/or reading (82%) vs. 42%; $p < 0.001$), h) has knowledge of the concept of sexuality (87%) vs. 47%; $p < 0.001$), i) understands the physical changes that occur during puberty (100%) vs. 82%; $p=0.011$), j) is aware of different types of romantic relationships (97%) vs. 73%; $p=0.006$), k) knows about sexual intercourse (75%) vs. 35%; $p < 0.001$), l) understands what is and what is not acceptable behavior towards someone they are romantically interested in (77%) vs. 44%; $p=0.002$), m) can decline unwanted sexual advances from another person (70%) vs. 36%; $p=0.003$), and, n) understands that intercourse can lead to a pregnancy/baby (67%) vs. 33%; $p=0.002$). When compared by response to other variables in the "knowledge" category, described in Table 7, that are related to various other sources of sex education and knowledge of the concept of sexuality, differences in the percent of mothers who allow their child to be alone did not reach statistical significance.

Experience: Individuals with Down syndrome who are allowed to be alone with a romantic partner differed from those who are not with respect to mothers' reports that their child a) has been on a supervised group date (80% vs. 36%; $p < 0.001$), b) has been on an unsupervised group date (39% vs. 3%; $p < 0.001$), c) has been on a supervised one-on-one date (80% vs. 29%; $p< 0.001$), d) has been on an unsupervised one-on-one date (45% vs. 2%; $p <0.001$), e) has been in an exclusive romantic relationship (40% vs. 14%; $p=0.005$), f) has dated multiple people (21% vs. 2%; $p=0.002$), g) is currently in a relationship (35% vs. 14%; $p=0.001$), h) has been intimate with another person (10% vs. 0%; $p=0.014$), and, i) uses contraception (20% vs. 5%; $p=0.027$). Individuals with Down syndrome who are allowed to be alone with a romantic partner differed from those who are not with respect to mothers' reports that their child uses the following social media platforms: Facebook (71% vs. 20%; $p < 0.001$), Twitter (23% vs. 5%; $p=0.011$), Instagram (48% vs. 19%; $p=0.003$), and YouTube (94% vs. 72%; $p=0.015$). All other

variables in the "experience" category described in Table 7 for which a significant effect was not identified are related to social media use and whether or not the person with Down syndrome masturbates.

Parental attitudes and concerns: Mothers who would allow their child to be alone differed from those who would not with respect to a) concerns for their child being in a romantic relationship (45% vs. 75%, p=0.005), b) allowing their child to be in a sexually active relationship now or in the future (93% vs. 75%; p=0.037), c) belief that another person might misinterpret their child's behavior as being sexual in content that was not intended (40% vs. 66%; p=0.019), and, d) concerns regarding pregnancy (32% vs. 54%; p=0.047). Differences in the other variables related to parental concerns were not statistically significant with respect to sexual behavior, risks associated with being sexually active (e.g. abuse, STDs), and broader expectations the parents have for their child's sexuality (e.g. allowing child to date).

Table 7. Univariate analysis:

Is your child allowed to be alone with a romantic partner or interest?

Variable	Is your child allowed to be alone with a romantic partner or interest?						
	Allowed			Not allowed			p value
	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	
Reads at/above 5th grade level	31	18	58	60	12	20	<0.001
Female with DS (1)	56	20	37	56	35	63	0.568
Male with DS (0)	36	11	31	36	25	69	
DS: Age <18	33	2	6	33	31	94	<0.001
DS: Age 18-25	32	12	38	32	20	62	
DS: Age >25	23	15	65	23	8	35	

Table 7 (Continued). Univariate analysis:

Is your child allowed to be alone with a romantic partner or interest?

Survey Question	Is your child allowed to be alone with a romantic partner or interest?						
	Allowed to be alone			Not allowed to be alone			p value
	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	
Do you have concerns with your child being in a romantic relationship?	31	14	45	60	45	75	0.005
Do you believe your child is interested in romance?	31	28	90	60	48	80	0.208
Do you or would you allow your child to participate in dating?	31	31	100	60	58	97	0.304
Do you or would you allow your child to participate in a sexually active relationship, now or in the future?	30	28	93	56	42	75	0.037
Do you believe that your child understands consent?	29	21	72	58	20	35	0.001
Do you believe your child has the ability to consent to kiss another person?	31	28	90	58	39	67	0.016
Has your child expressed desire to be alone with a romantic partner?	31	15	48	59	13	22	0.010
Are you worried that another person might misinterpret your child's behavior as having sexual content that was not intended?	30	12	40	59	39	66	0.019
Are you concerned that your child has misconceptions about sex?	31	17	55	59	40	68	0.255
Do you want your child to find a life partner?	30	17	57	60	33	55	0.881
Do you have concerns for your child with respect to sexual abuse?	31	22	71	59	50	85	0.120
Do you have concerns for your child with respect to pregnancy?	31	10	32	59	32	54	0.047
Do you have concerns for your child with respect to sexually transmitted diseases?	31	16	52	58	34	59	0.526

Table 7 (Continued). Univariate analysis:

Is your child allowed to be alone with a romantic partner or interest?

Survey Question	Is your child allowed to be alone with a romantic partner or interest?						
	Allowed to be alone			Not allowed to be alone			p value
	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	
Do you have concerns for your child with respect to happiness?	31	20	65	58	42	72	0.440
Have you received any specialized parent education/training for educating your child about sexual behavior and romance?	31	16	52	60	19	32	0.064
Has your child received sexuality education from you?	31	28	90	59	42	71	0.038
Has your child received sexuality education from his or her other parent?	30	15	50	58	18	31	0.082
Has your child received sexuality education from a male sibling?	29	4	14	58	3	5	0.163
Has your child received sexuality education from a female sibling?	30	11	37	58	8	14	0.013
Has your child received sexuality education from another family member?	30	5	17	58	4	7	0.152
Has your child received sexuality education from a teacher?	29	19	66	58	28	48	0.128
Has your child received sexuality education from a therapist?	28	5	18	58	10	17	0.944
Has your child received sexuality education from his or her peers?	26	11	42	54	11	20	0.040
Has your child received sexuality education from pictures?	28	23	82	57	24	42	<0.001
Has your child received sexuality education from pornographic media?	5	0	0	9	1	11	0.439
Do you think your child would benefit from appropriate sex education?	10	7	70	10	7	70	1.000
Do you think your child has any knowledge of the concept of sexuality?	31	27	87	60	28	47	<0.001
Is your child aware of the physical changes that occur during puberty?	31	31	100	60	49	82	0.011

Table 7 (Continued). Univariate analysis:

Is your child allowed to be alone with a romantic partner or interest?

Survey Question	Is your child allowed to be alone with a romantic partner or interest?						
	Allowed to be alone			Not allowed to be alone			p value
	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	
Do you think your child is aware of different romantic relationships (dating, marriage, etc)?	31	30	97	59	43	73	0.006
Does your child know about sexual intercourse?	28	21	75	60	21	35	<0.001
Does your child understand what is and what is not acceptable behavior towards someone they are romantically interested in?	31	24	77	59	26	44	0.002
Does your child know how to decline sexual advances by someone who is interested in them?	30	21	70	58	21	36	0.003
Does your child understand that intercourse can lead to pregnancy/baby?	30	20	67	58	19	33	0.002
Has your child participated in supervised group dates?	30	24	80	59	21	36	<0.001
Has your child participated in unsupervised group dates?	31	12	39	60	2	3	<0.001
Has your child participated in supervised one-on-one dates?	31	24	77	59	17	29	<0.001
Has your child participated in unsupervised one-on-one dates?	31	14	45	60	1	2	<0.001
Has your child participated in an exclusive romantic relationship?	30	12	40	58	8	14	0.005
Has your child participated in dating multiple partners?	29	6	21	59	1	2	0.002
Has your child been in love or said that he or she is in love?	31	21	68	60	28	47	0.056
To your knowledge, has your child been sexually intimate with another person?	31	3	10	60	0	0	0.014
To your knowledge, does your child masturbate?	30	18	60	59	29	49	0.333
To your knowledge, does your child use contraception?	30	6	20	59	3	5	0.027
Does your child use sign language?	30	3	10	60	11	18	0.304

Table 7 (Continued). Univariate analysis:

Is your child allowed to be alone with a romantic partner or interest?

Survey Question	Is your child allowed to be alone with a romantic partner or interest?						
	Allowed to be alone			Not allowed to be alone			p value
	N	Yes (#)	Yes (%)	N	Yes (#)	Yes (%)	
Does your child use assistive technologies for communication?	31	1	3	60	9	15	0.089
Does your child use Facebook?	31	22	71	60	12	20	<0.001
Does your child use Twitter?	31	7	23	60	3	5	0.011
Does your child use Instagram?	31	15	48	59	11	19	0.003
Does your child use Snapchat?	31	10	32	58	9	16	0.066
Does your child use YouTube?	31	29	94	60	43	72	0.015
Currently in a relationship	31	14	35	59	8	14	0.001
Communicates verbally and fluently	31	24	77	60	45	75	0.798
Had ABA therapy	31	2	7	58	13	22	0.055
Had Speech Therapy	31	27	87	60	59	98	0.026
Had Occupational therapy	31	27	87	60	54	90	0.675
Had physical therapy	31	27	87	60	51	85	0.786
Does not live with family	31	5	16	60	2	3	0.043
Had any sex education	31	30	97	60	47	78	0.021
Parent age >50	30	24	80	59	37	63	0.097
Parent race (not white)	31	3	10	59	11	19	0.265
Parent education: 4y or graduate degree	29	20	69	60	43	72	0.793
Do you have other children?	31	29	94	60	52	87	0.320
At least one brother	29	21	72	52	38	73	0.949
At least one sister	28	21	75	52	37	71	0.713
Birth order (oldest vs youngest)	21	9	43	47	16	34	0.486
Middle child	29	8	28	52	5	10	0.035
ANY social media (not including YouTube)	31	8	26	60	5	8	0.024

3.4.e Multivariable analysis

Multivariate logistic regression was used to investigate the importance of age, gender, developmental level and other parent attitudes/concerns as independent predictors of whether or not they would allow their child to be alone with a partner. Odds ratio is represented as "Exp(B)" in all regression tables. Responses to the question, "Is your child allowed to be alone with a romantic partner or interest?" varied significantly based on age and reading level—but not gender—of the child with Down syndrome when looked at together in a multivariate model (Table 5). Mothers are 30 times more likely to allow their child with Down syndrome to be with a romantic partner when their child is over 25 years old (OR=30.1, 95% CI=5.1-178.6; $p < 0.001$) and 10 times more likely when they are 18-25 years old ((OR=10.5, 95% CI=1.9-55.9; p=0.006) compared to when their child is less than 18 years old. Additionally, mothers are 6 times more likely to answer yes when their child can read at or above a 5th grade reading level (OR=5.8, 95% CI=1.8-18.7; p=0.003). Although the gender of the child with Down syndrome is a non-significant factor for mothers' decision to allow their child to be alone with a romantic partner in all of the multivariate models, the variable is retained in the model to control for possible confounding because of numerous non-significant differences observed by child's gender (see Table 5).

The importance of other parental attitudes/concerns for predicting the likelihood to allow their child to be alone with a partner is further investigated in multivariate logistic regression after adjusting for the child's age, gender and developmental level.

The fallowing variables were no longer significantly associated with prediction of whether or not parents would allow their child to be alone with a romantic partner (per parent report) after adjusting for age, gender and developmental level (in order of significance):

1) The individual with Down syndrome:
    a) Uses contraception (p=0.056).
    b) Knows what acceptable sexual behavior is (p=0.074).
    c) Had speech therapy (p=0.076)
    d) Knows that intercourse can lead to a pregnancy or baby (p=0.105).
    e) Has been on a supervised group dates (p=0.119).
    f) Is aware of different types of romantic relationships (p=0.136).
    g) Is currently in a relationship (p=0.143).
    h) Does not live with family (p=0.182).
    i) Has been in an exclusive romantic relationship (p=0.247).
    j) Has the ability to consent to kiss another person (p=0.316).
    k) Has expressed desire to be alone with a romantic partner (p=0.322).
    l) Uses twitter (p=0.165), Instagram (p=0.091), or any social media (p=0.328).
    m) Has the ability to decline unwanted sexual advances from others (p=0.384).
    n) Had sex education from the respondent (p=0.813), a female sibling (p=0.478), and/or peers (p=0. 402).
2) The respondent:
    a) Has concerns for their child regarding pregnancy (p=0.058).
    b) Has concern that others might misinterpret their child's behavior as sexual in content that was not intended (p=0. 128).

The following independent variables remained as significant factors impacting mothers' decision to allow their child with Down syndrome to be alone with a romantic partner (per parent report) after adjusting for age, gender and reading level:

1) The Individual with Down syndrome:
    a) Has been on an unsupervised one-on-one date (OR=28.1, 95% CI=3.1-258.3; p=0.003).
    b) Has dated multiple people (OR=16.3, 95% CI=1.6-168.1; p=0.019).
    c) Knows about the concept of sexuality (OR=7.7, 95% CI=1.7-34.1; p=0.007).
    d) Has been on an unsupervised group date (OR=7.6, 95% CI=1.3-45.4; p=0.025).
    e) Has received sex education from pictures, videos, and/or reading (OR=5.1, 95% CI=1.3-20.9; p=0.022).
    f) Uses Facebook (OR=4.2, 95% CI=1.3-13.3; p=0.017) and uses YouTube (OR=6.3, 95% CI=1.1-37.1; p=0.042)
    g) Knows about sexual intercourse (OR=3.8, 95% CI=1.1-13.5; p=0.036).
    h) Has been on a supervised one-on-one date (OR=3.7, 95% CI=1.1-12.3; p=0.033).
2) The respondent:
    a) Has concerns about their child with Down syndrome being in a romantic relationship (OR=0.12, 95% CI=0.03-0.49; p=0.003).
    b) Allows their child with Down syndrome to be sexually active (now or in the future) (OR=6.6, 95% CI=1.1-37.9; p=0.034).
    c) Believes their child understands consent (OR=4.9, 95% CI=1.4-17.6; p=0.013).

Table 8.1
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, and development:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	2.34	0.86	7.47	1	0.006	10.41	1.94	55.88
Age >25	3.40	0.91	14.04	1	<0.001	30.10	5.07	178.62
Female vs male	-0.20	0.60	0.11	1	0.745	0.82	0.26	2.66
Reads at/above Fifth grade level	1.76	0.60	8.77	1	0.003	5.82	1.82	18.69
Constant	-3.35	0.87	14.71	1	<0.001	0.04		

Included in analysis (N) = 88

Table 8.2
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and parental concern for child being in a romantic relationship:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	2.31	0.89	6.75	1	0.009	10.04	1.76	57.21
Age >25	3.48	0.98	12.69	1	<0.001	32.52	4.79	220.81
Female vs male	0.17	0.66	0.07	1	0.799	1.18	0.32	4.33
Reads at/above Fifth grade level	2.14	0.69	9.60	1	0.002	8.50	2.20	32.94
Parent is concerned about romantic relationship	-2.09	0.70	8.86	1	0.003	0.12	0.03	0.49
Constant	-2.43	0.91	7.18	1	0.007	0.09		

Included in analysis (N) = 86

Table 8.3
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and parent allows child to be sexually active:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	2.55	0.89	8.22	1	0.004	12.82	2.24	73.31
Age >25	3.57	0.96	13.87	1	<0.001	35.64	5.43	233.75
Female vs male	-0.19	0.63	0.09	1	0.765	0.83	0.24	2.84
Reads at/above Fifth grade level	1.66	0.63	6.94	1	0.008	5.27	1.53	18.11
Allowed to be sexually active	1.89	0.89	4.47	1	0.034	6.59	1.15	37.88
Constant	-5.04	1.29	15.40	1	<0.001	0.01		

Included in analysis (N) = 83

Table 8.4
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and parent believes child understands consent:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	2.31	0.92	6.31	1	0.012	10.10	1.66	61.39
Age >25	3.63	0.98	13.80	1	<0.001	37.66	5.55	255.40
Female vs male	-0.42	0.69	0.38	1	0.535	0.65	0.17	2.50
Reads at/above Fifth grade level	1.90	0.67	8.08	1	0.004	6.67	1.80	24.67
Understands consent	1.60	0.65	6.17	1	0.013	4.96	1.40	17.57
Constant	-4.26	1.05	16.45	1	<0.001	0.01		

Included in analysis (N) = 84

Table 8.5
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and parent believes child can consent to kiss another person:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	2.34	0.86	7.40	1	0.007	10.42	1.92	56.45
Age >25	3.31	0.91	13.35	1	<0.001	27.44	4.64	162.16
Female vs male	-0.23	0.61	0.15	1	0.704	0.79	0.24	2.63
Reads at/above Fifth grade level	1.56	0.61	6.53	1	0.011	4.77	1.44	15.78
Can consent to kiss another person	0.79	0.79	1.01	1	0.316	2.21	0.47	10.41
Constant	-3.84	1.04	13.54	1	<0.001	0.02		

Included in analysis (N) = 86

Table 8.6
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and Has your child expressed desire to be alone with a romantic partner:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	2.22	0.87	6.49	1	0.011	9.17	1.67	50.40
Age >25	3.19	0.93	11.68	1	0.001	24.17	3.89	150.14
Female vs male	-0.07	0.62	0.01	1	0.912	0.93	0.28	3.13
Reads at/above Fifth grade level	1.80	0.60	8.90	1	0.003	6.05	1.85	19.75
Expressed desire to be alone with romantic partner	0.61	0.62	0.98	1	0.322	1.84	0.55	6.13
Constant	-5.04	1.29	15.40	1	<0.001	0.01		

Included in analysis (N) = 87

Table 8.7
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and parental concern for others to misinterpret child's behavior as sexual

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	2.24	0.90	6.22	1	0.013	9.42	1.62	54.85
Age >25	3.65	0.99	13.74	1	<0.001	38.57	5.59	266.15
Female vs male	-0.31	0.64	0.23	1	0.635	0.74	0.21	2.60
Reads at/above Fifth grade level	2.20	0.67	10.80	1	0.001	9.06	2.43	33.71
Parental concern for others to misinterpret child's behavior as sexual	-0.94	0.62	2.32	1	0.128	0.39	0.12	1.31
Constant	-2.96	0.96	9.50	1	0.002	0.05		

Included in analysis (N) = 86

Table 8.8
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and parental concern for pregnancy:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	2.16	0.88	6.08	1	0.014	8.69	1.56	48.45
Age >25	2.98	0.95	9.80	1	0.002	19.63	3.04	126.66
Female vs male	0.67	0.75	0.79	1	0.374	1.95	0.45	8.53
Reads at/above Fifth grade level	2.14	0.67	10.10	1	0.001	8.48	2.27	31.70
Parent has concerns about pregnancy	-1.51	0.80	3.59	1	0.058	0.22	0.05	1.05
Constant	-3.13	0.88	12.56	1	<0.001	0.04		

Included in analysis (N) = 87

Table 8.9
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and child had sex education from respondent:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	2.29	0.87	6.86	1	0.009	9.82	1.78	54.30
Age >25	3.34	0.93	13.01	1	<0.001	28.23	4.60	173.44
Female vs male	-0.23	0.63	0.14	1	0.710	0.79	0.23	2.71
Reads at/above Fifth grade level	1.73	0.61	8.06	1	0.005	5.62	1.71	18.49
Had sex education from respondent	0.19	0.82	0.06	1	0.813	1.21	0.25	6.00
Constant	-3.41	0.95	13.02	1	<0.001	0.03		

Included in analysis (N) = 87

Table 8.10
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and child had sex education from a female sibling:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	2.24	0.86	6.81	1	0.009	9.42	1.75	50.72
Age >25	3.29	0.94	12.39	1	<0.001	26.92	4.30	168.47
Female vs male	-0.15	0.61	0.06	1	0.809	0.86	0.26	2.87
Reads at/above Fifth grade level	1.65	0.61	7.45	1	0.006	5.22	1.59	17.12
Had sex education from female sibling	0.47	0.67	0.50	1	0.478	1.61	0.43	5.94
Constant	-3.34	0.88	14.52	1	<0.001	0.04		

Included in analysis (N) = 85

Table 8.11
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and child had sex education from pictures/videos/reading:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	1.99	0.93	4.55	1	0.033	7.28	1.18	45.05
Age >25	3.57	1.02	12.34	1	<0.001	35.41	4.84	259.01
Female vs male	-0.66	0.71	0.88	1	0.349	0.52	0.13	2.07
Reads at/above Fifth grade level	1.86	0.66	7.90	1	0.005	6.41	1.75	23.40
Had sex education from pictures/video/reading	1.64	0.71	5.27	1	0.022	5.16	1.27	20.91
Constant	-4.20	1.07	15.30	1	<0.001	0.02		

Included in analysis (N) = 82

Table 8.12
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and child had sex education from peers:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	2.02	0.88	5.28	1	0.022	7.54	1.35	42.22
Age >25	3.16	0.96	10.92	1	0.001	23.45	3.61	152.29
Female vs male	-0.05	0.66	0.01	1	0.940	0.95	0.26	3.47
Reads at/above Fifth grade level	1.66	0.64	6.73	1	0.009	5.25	1.50	18.39
Had sex education from peers	0.53	0.63	0.70	1	0.402	1.70	0.49	5.85
Constant	-3.43	0.91	14.23	1	<0.001	0.03		

Included in analysis (N) = 77

Table 8.13
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and child knows what sexuality is:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	2.08	0.89	5.49	1	0.019	8.03	1.41	45.94
Age >25	3.61	0.99	13.28	1	<0.001	36.92	5.30	257.10
Female vs male	-0.47	0.67	0.48	1	0.488	0.63	0.17	2.34
Reads at/above Fifth grade level	1.68	0.64	6.84	1	0.009	5.37	1.52	18.92
Knows what sexuality is	2.04	0.76	7.24	1	0.007	7.71	1.74	34.12
Constant	-4.52	1.07	17.84	1	<0.001	0.01		

Included in analysis (N) = 88

Table 8.14
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and child is aware of different types of relationships:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	2.11	0.87	5.94	1	0.015	8.28	1.51	45.29
Age >25	3.19	0.92	12.00	1	0.001	24.25	3.99	147.26
Female vs male	-0.31	0.62	0.25	1	0.621	0.73	0.22	2.50
Reads at/above Fifth grade level	1.72	0.61	7.89	1	0.005	5.60	1.68	18.63
Aware of types of romantic relationships	1.70	1.14	2.23	1	0.136	5.47	0.59	50.97
Constant	-4.57	1.31	12.14	1	<0.001	0.01		

Included in analysis (N) = 87

Table 8.15
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and child knows about sexual intercourse:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	1.96	0.90	4.70	1	0.030	7.09	1.21	41.62
Age >25	3.02	0.96	9.89	1	0.002	20.55	3.12	135.20
Female vs male	-0.53	0.66	0.64	1	0.424	0.59	0.16	2.14
Reads at/above Fifth grade level	1.84	0.64	8.18	1	0.004	6.29	1.79	22.20
Knows about sexual intercourse	1.34	0.64	4.38	1	0.036	3.83	1.09	13.46
Constant	-3.76	0.98	14.78	1	<0.001	0.02		

Included in analysis (N) = 85

Table 8.16
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and child understands what is and what is not acceptable behavior towards someone they are romantically interested in:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	2.26	0.88	6.66	1	0.010	9.60	1.72	53.49
Age >25	3.25	0.93	12.31	1	<0.001	25.69	4.19	157.49
Female vs male	-0.26	0.61	0.18	1	0.670	0.77	0.23	2.56
Reads at/above Fifth grade level	1.66	0.61	7.39	1	0.007	5.24	1.59	17.29
Knows what acceptable sexual behavior is	1.12	0.62	3.19	1	0.074	3.05	0.90	10.36
Constant	-3.90	0.99	15.40	1	<0.001	0.02		

Included in analysis (N) = 87

Table 8.17
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and child knows how to decline unwanted sexual advances by someone who is interested in them:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	2.10	0.88	5.72	1	0.017	8.20	1.46	45.96
Age >25	3.16	0.97	10.66	1	0.001	23.45	3.53	155.83
Female vs male	-0.33	0.62	0.28	1	0.599	0.72	0.21	2.43
Reads at/above Fifth grade level	1.86	0.61	9.23	1	0.002	6.40	1.93	21.19
Has ability to decline unwanted sexual advances	0.54	0.62	0.76	1	0.384	1.72	0.51	5.84
Constant	-3.46	0.91	14.50	1	<0.001	0.03		

Included in analysis (N) = 85

Table 8.18
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and child understands that intercourse can lead to pregnancy/baby:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	2.14	0.89	5.78	1	0.016	8.46	1.48	48.28
Age >25	3.19	0.95	11.23	1	0.001	24.32	3.76	157.27
Female vs male	-0.46	0.64	0.52	1	0.472	0.63	0.18	2.22
Reads at/above Fifth grade level	1.88	0.62	9.13	1	0.003	6.58	1.94	22.36
Understands that intercourse can lead to baby/pregnancy	0.98	0.61	2.63	1	0.105	2.68	0.81	8.79
Constant	-3.63	0.95	14.73	1	<0.001	0.03		

Included in analysis (N) = 85

Table 8.19
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and child has participated in unsupervised group dates:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	2.20	0.90	6.06	1	0.014	9.06	1.57	52.40
Age >25	3.15	0.96	10.84	1	0.001	23.23	3.57	151.08
Female vs male	-0.01	0.65	0.00	1	0.984	0.99	0.28	3.49
Reads at/above Fifth grade level	1.47	0.63	5.43	1	0.020	4.34	1.26	14.89
Has been on an unsupervised group date	2.03	0.91	5.01	1	0.025	7.65	1.29	45.38
Constant	-3.52	0.92	14.64	1	<0.001	0.03		

Included in analysis (N) = 88

Table 8.20
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and child has participated in supervised group dates:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	1.94	0.88	4.81	1	0.028	6.95	1.23	39.28
Age >25	2.95	0.95	9.72	1	0.002	19.05	2.99	121.49
Female vs male	-0.19	0.61	0.10	1	0.757	0.83	0.25	2.72
Reads at/above Fifth grade level	1.54	0.62	6.29	1	0.012	4.67	1.40	15.60
Has been on a supervised group date	0.96	0.62	2.43	1	0.119	2.62	0.78	8.82
Constant	-3.50	0.90	15.17	1	<0.001	0.03		

Included in analysis (N) = 86

Table 8.21
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and child has participated in unsupervised one-on-one dates:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	2.40	0.99	5.94	1	0.015	11.05	1.60	76.36
Age >25	2.86	1.06	7.31	1	0.007	17.52	2.20	139.59
Female vs male	-0.11	0.67	0.03	1	0.866	0.89	0.24	3.35
Reads at/above Fifth grade level	1.64	0.66	6.21	1	0.013	5.17	1.42	18.78
Has been on an unsupervised one-on-one date	3.34	1.13	8.71	1	0.003	28.15	3.07	258.33
Constant	-3.77	1.02	13.51	1	<0.001	0.02		

Included in analysis (N) = 88

Table 8.22
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and child has participated in a supervised group date:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	1.92	0.90	4.60	1	0.032	6.85	1.18	39.74
Age >25	2.90	0.95	9.34	1	0.002	18.11	2.83	116.01
Female vs male	-0.16	0.62	0.07	1	0.795	0.85	0.26	2.85
Reads at/above Fifth grade level	1.69	0.62	7.45	1	0.006	5.41	1.61	18.20
Has been on a supervised one-on-one date	1.31	0.61	4.56	1	0.033	3.70	1.11	12.33
Constant	-3.69	0.94	15.34	1	<0.001	0.03		

Included in analysis (N) = 87

Table 8.23
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and child has participated in dating multiple partners:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	2.33	0.97	5.82	1	0.016	10.26	1.55	68.05
Age >25	3.45	1.02	11.47	1	0.001	31.57	4.28	232.80
Female vs male	0.00	0.65	0.00	1	0.999	1.00	0.28	3.58
Reads at/above Fifth grade level	1.90	0.64	8.93	1	0.003	6.71	1.93	23.40
Has dated multiple people	2.79	1.19	5.50	1	0.019	16.30	1.58	168.13
Constant	-3.90	1.02	14.67	1	<0.001	0.02		

Included in analysis (N) = 85

Table 8.24
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and child has participated in an exclusive romantic relationship:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	2.17	0.87	6.19	1	0.013	8.79	1.59	48.66
Age >25	3.20	0.93	11.89	1	0.001	24.55	3.98	151.43
Female vs male	-0.27	0.62	0.20	1	0.659	0.76	0.23	2.56
Reads at/above Fifth grade level	1.57	0.61	6.61	1	0.010	4.81	1.45	15.94
Has been in an exclusive romantic relationship	0.75	0.65	1.34	1	0.247	2.12	0.59	7.60
Constant	-3.27	0.87	14.19	1	<0.001	0.04		

Included in analysis (N) = 85

Table 8.25
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and child uses contraception:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	2.30	0.90	6.46	1	0.011	9.96	1.69	58.65
Age >25	3.39	0.96	12.41	1	<0.001	29.51	4.49	194.01
Female vs male	-0.50	0.62	0.63	1	0.426	0.61	0.18	2.07
Reads at/above Fifth grade level	1.76	0.61	8.25	1	0.004	5.84	1.75	19.45
Uses contraception	1.74	0.91	3.64	1	0.056	5.70	0.95	34.06
Constant	-3.36	0.92	13.39	1	<0.001	0.04		

Included in analysis (N) = 86

Table 8.26
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and child uses Facebook:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	1.99	0.89	4.95	1	0.026	7.29	1.27	41.89
Age >25	2.94	0.94	9.73	1	0.002	18.89	2.98	119.80
Female vs male	-0.14	0.62	0.05	1	0.827	0.87	0.26	2.96
Reads at/above Fifth grade level	1.57	0.62	6.42	1	0.011	4.81	1.43	16.24
Uses Facebook	1.42	0.60	5.72	1	0.017	4.15	1.29	13.32
Constant	-3.64	0.94	15.16	1	<0.001	0.03		

Included in analysis (N) = 88

Table 8.27
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and child uses Twitter:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	2.44	0.89	7.52	1	0.006	11.44	2.01	65.24
Age >25	3.42	0.94	13.26	1	<0.001	30.60	4.85	192.85
Female vs male	-0.08	0.60	0.02	1	0.894	0.92	0.28	3.02
Reads at/above Fifth grade level	1.63	0.61	7.17	1	0.007	5.09	1.55	16.74
Uses Twitter	1.24	0.90	1.93	1	0.165	3.46	0.60	19.99
Constant	-3.58	0.94	14.62	1	<0.001	0.03		

Included in analysis (N) = 88

Table 8.28
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and child uses Instagram:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	2.30	0.88	6.87	1	0.009	9.99	1.79	55.80
Age >25	3.34	0.92	13.10	1	<0.001	28.32	4.63	173.06
Female vs male	-0.18	0.61	0.09	1	0.766	0.84	0.26	2.74
Reads at/above Fifth grade level	1.60	0.61	6.90	1	0.009	4.93	1.50	16.21
Uses Instagram	1.03	0.61	2.85	1	0.091	2.80	0.85	9.24
Constant	-3.60	0.93	15.04	1	<0.001	0.03		

Included in analysis (N) = 87

Table 8.29
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and child uses YouTube:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	2.37	0.87	7.46	1	0.006	10.68	1.95	58.48
Age >25	3.65	0.95	14.79	1	<0.001	38.52	5.99	247.65
Female vs male	-0.28	0.63	0.20	1	0.656	0.76	0.22	2.60
Reads at/above Fifth grade level	1.61	0.62	6.75	1	0.009	5.02	1.49	16.95
Uses YouTube	1.84	0.90	4.16	1	0.042	6.31	1.07	37.09
Constant	-4.86	1.22	15.81	1	<0.001	0.01		

Included in analysis (N) = 88

Table 8.30
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and child uses ANY social media (not including YouTube):

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	2.31	0.86	7.19	1	0.007	10.10	1.86	54.76
Age >25	3.34	0.92	13.28	1	<0.001	28.29	4.69	170.78
Female vs male	-0.18	0.61	0.08	1	0.771	0.84	0.26	2.76
Reads at/above Fifth grade level	1.75	0.60	8.47	1	0.004	5.74	1.77	18.61
Uses social media (excluding YouTube)	0.56	0.57	0.96	1	0.328	1.74	0.57	5.30
Constant	-3.59	0.92	15.23	1	<0.001	0.03		

Included in analysis (N) = 88

Table 8.31
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and child relationship status:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	2.10	0.88	5.73	1	0.017	8.14	1.46	45.31
Age >25	3.10	0.93	11.25	1	0.001	22.27	3.63	136.56
Female vs male	-0.16	0.60	0.07	1	0.794	0.86	0.26	2.77
Reads at/above Fifth grade level	1.60	0.61	6.95	1	0.008	4.93	1.51	16.17
Currently in a relationship	0.92	0.63	2.14	1	0.143	2.50	0.73	8.52
Constant	-3.37	0.88	14.62	1	<0.001	0.03		

Included in analysis (N) = 87

Table 8.32
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and child had speech therapy:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	2.49	0.93	7.16	1	0.007	12.05	1.95	74.66
Age >25	3.70	1.00	13.57	1	<0.001	40.40	5.64	289.24
Female vs male	-0.28	0.61	0.21	1	0.646	0.76	0.23	2.51
Reads at/above Fifth grade level	1.81	0.61	8.75	1	0.003	6.08	1.84	20.09
Had speech therapy	2.28	1.29	3.15	1	0.076	9.77	0.79	121.31
Constant	-5.90	1.76	11.27	1	0.001	<0.01		

Included in analysis (N) = 88

Table 8.33
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and child's living arrangement:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	2.16	0.87	6.14	1	0.013	8.70	1.57	48.16
Age >25	3.37	0.93	13.27	1	<0.001	29.13	4.75	178.77
Female vs male	-0.12	0.62	0.04	1	0.847	0.89	0.27	2.97
Reads at/above Fifth grade level	1.87	0.62	9.12	1	0.003	6.47	1.93	21.75
Does not live with family	1.43	1.07	1.78	1	0.182	4.16	0.51	33.91
Constant	-3.45	0.89	15.07	1	<0.001	0.03		

Included in analysis (N) = 88

Table 8.34
Is your child allowed to be alone with a romantic partner or interest?
Effects of age, gender, development, and child is neither the oldest nor the oldest among siblings:

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Age <18						1		
Age 18-25	2.22	0.87	6.51	1	0.011	9.22	1.67	50.79
Age >25	3.22	0.93	11.95	1	0.001	24.91	4.02	154.13
Female vs male	-0.20	0.60	0.11	1	0.737	0.82	0.25	2.65
Reads at/above Fifth grade level	1.79	0.60	8.91	1	0.003	6.01	1.85	19.49
Middle child	0.66	0.73	0.82	1	0.366	1.93	0.46	8.01
Constant	-3.36	0.88	14.70	1	<0.001	0.04		

Included in analysis (N) = 79

IV. Discussion

The aim of this study is to identify potential factors that impact the exploration of sexuality by individuals with Down syndrome. There are many people, including parents, caregivers, and health care providers, who hold the belief that individuals with Down syndrome are inherently asexual (Medina-Rico, *et al*. 2017). As a result, when people with Down syndrome do eventually attempt to explore sexuality, there tend to be arbitrary limits placed upon them alongside a lack of privacy. The goal of this study was to investigate the ways in which parents of individuals with Down syndrome perceive their children's experience of sexuality as well as the specific factors associated with their children's experiences of romance, relationships, intimacy, and sex.

The question, "Is your child allowed to be alone with a romantic partner or interest?" is the primary dependent variable of interest in this study, allowing the testing of the following hypothesis: Parental willingness to allow sexual expression for their child with Down syndrome is positively correlated with the child's knowledge of, and experiences with, sexuality and with additional positive attitudes exhibited by parents regarding their child's sexual expression. This nuanced question was selected for investigation in order to allow for assessment of implicit attitudes less affected by unconscious biases. According to this study's results, before accounting for any other variables, 34% of mothers would allow their child with Down syndrome to be alone with a romantic partner. However, answers to questions that also directly pertain to parents' permissiveness of romantic behaviors (e.g., "Do you or would you allow your child to participate in dating?" and "Do you or would you allow your child to participate in a sexually active relationship, now or in the future?") tend to be overwhelmingly positive (98% and 82%, respectively). Given the near unanimity in results of the additional questions pertaining to

parents' permissiveness, one might intuitively expect the responses to the main question to have a similar positive skew. In fact, the opposite relationship is demonstrated in the results. As seen, many parents who responded that they would allow their child to participate in dating or in a sexually active relationship nonetheless responded that they would not allow their child to be alone with a romantic partner. Therefore, it appears that there are systematic contradictions in responses as indicated by the results of this study.

As anticipated, throughout each comparison in this study, the age of the child remained a significant factor affecting the considerations of mothers of individuals with Down syndrome when deciding whether or not they allow their child to be alone with a romantic partner. At baseline, the results show that mothers who have a child in the age group 18-25 are 10 times more likely to allow their child to be alone with a romantic partner than are those whose children are under 18 (as is likely the case with many mothers of typical children under the ages of 18), and mothers who have a child over 25 years old are 30 times more likely to do so.

Based on what is currently known in the literature, gender, in addition to age, is an immutable factor and is expected to have an influence on parents' decisions regarding their children's sexuality. While some significant differences by child's gender were observed in univariate analyses, after adjusting for child's age in multivariate analyses, gender does not significantly impact a mother's willingness to allow her child to be alone with a romantic partner. This is contrary to the findings of Medina-Rico, *et al*. (2017) and Wilson, *et al.* (2011), which suggest that there are, in fact, gender differences in sexual behavior among adults and teens with IDD. Although a significant effect was not demonstrated in multivariate analysis, females with Down syndrome exhibit an overall trend to be less likely to be allowed to be alone with romantic partners compared to males. Because of possible confounding due to this non-

significant difference and the fact that fewer surveys regarding male children were completed in comparison to those of female children, all analyses included gender as an independent covariable.

Despite the reality that individuals with Down syndrome have varying degrees of intellectual disability, there is often the potential for improvement of cognitive ability through early intervention and life-long education and support by those around them (Hines and Bennet, 1996; Pownall, *et al*., 2011). This study's results show that mothers who reported that their child reads at or above a 5th grade level are 6 times more likely to allow their child to be alone with a romantic partner than those whose children do not read at a 5th grade level (reading level and age explicitly remained as independent, significant, co-variates in all multivariate analyses – see Table 8.1-8.34) . This finding suggests that parents' permissiveness regarding sexuality is highly correlated with their children's reading level, as a metric of developmental level and academic achievement. Because cognitive ability for individuals with Down syndrome has the potential for improvement at any stage in life, it is feasible that there exists a capacity for further development of maturity and understanding of sexuality given an improvement in academic achievement. This adds to the conclusions of Murphy and O'Callaghan (2004) that not only is ongoing sex education necessary throughout the life span of individuals with IDD, but general education throughout the lifespan may be just as important for achieving the same goal: to protect individuals with IDD from sexual abuse and to increase their quality of life (Murphy and O'Callaghan, 2004).

While it has been shown that expressive communication is a deficit in Down syndrome, it is also accompanied by a relative strength in receptive ability and interpersonal understanding (Dykens, *et al*., 1994). Thus, an individual's ability to verbally convey thoughts and intentions

regarding sexuality may not reflect that individual's implicit understanding of the subject. Therefore, the benefit of fostering the intellectual capacity of individuals with Down syndrome through improvement of reading level cannot be underestimated as it relates to sexuality.

In addition to age and reading level, the survey results identified other important factors that mothers consider when making decisions about their child's sexuality. These factors were sorted into three categories: Child knowledge, child experience, and parental attitudes. The "knowledge" category comprises responses to survey questions regarding sexual education and understanding the consequences and certain aspects of sexual behavior. The "knowledge" variables that were found to have a significant effect on parental attitudes include the presence or absence of the child's understanding of consent, knowing about sexuality and intercourse, and having received sex education, specifically through pictures, videos, and/or reading. After adjusting for age, gender, and reading level, an individual with Down syndrome who has knowledge of the concept of sexuality is nearly 8 times more likely to be allowed to be alone with a romantic partner than are those who lack this knowledge. Additionally, those who understand consent, had sex education from pictures, videos, and/or reading, and know about sexual intercourse are roughly 5, 5, and 4 times more likely, respectively, to be allowed to be alone. These results support the section of the hypothesis that increased sexual knowledge is associated with parental permissiveness of sexual behavior.

The finding that only a specific subset of these results has a significant impact on parental permissiveness highlights some of the nuances inherent in parents' decisions to allow their child to be alone with a partner. For instance, although it might follow that a mother would be most permissive of her child with Down syndrome being alone with a partner if she, a teacher, or a therapist had provided sexual education to the child, the data show that the only sources of

sexual education with a statistically significant impact on parental permissiveness are media such as pictures, videos, and books. These seemingly counterintuitive results provide supporting evidence for the application of a narrower focus on the specific details regarding source, delivery, and execution of particular aspects of the broader interventions, such as sex education, for individuals with Down syndrome.

It seems intuitive that more than half of the significant findings in the univariate analysis for the question "Is your partner allowed to be alone with a romantic partner or interest?" were no longer significant in the multivariate model, such as the effects of age and developmental level. For example, responses given by mothers who believe their child understands what constitutes appropriate sexual behavior directed at others indicate that they are significantly more likely to allow their child to be with a partner alone in the univariate analysis but lost significance after adjusting for age, gender, and reading level in the multivariate analysis. This conclusion initially seems counterintuitive; if a parent thinks his or her child with Down syndrome understands what constitutes appropriate sexual behavior, it would seem congruous that the parent would be more likely to allow the child to be alone with a romantic partner after considering their child's age and developmental level (assessed by reading level). The lack of significance in these variables suggests the possibility of as yet unidentified factors impacting relevant parental attitudes. Potential considerations contributing to this effect could be social stigma, the fact of the presence of Down syndrome in the child could lead to both internal and external judgements regarding the parents' permissiveness.

The analysis of a second category of the elements stated in this study's hypothesis uncovers a significant relationship between certain variables related to "experience" and those regarding parental permissiveness of various aspects of sexuality. Those "experience" variables

concern whether or not the child has been on supervised one-on-one dates or any unsupervised dates, has dated multiple romantic partners, and has made use of the social media platforms, Facebook and YouTube. After adjusting for age, gender, and reading level, individuals with Down syndrome who were reported to have been on at least one unsupervised one-on-one date are 28 times more likely to be allowed to be alone with a romantic partner than those who have not participated in this type of dating. This finding appears to be contradictory, as there are evidently are a subset of mothers who selected both that their child has been on an unsupervised one-on-one date and is that they do *not* allow their child to be alone with a romantic partner. It should follow that if an individual with Down syndrome has been on an unsupervised group date that they *are* allowed to be alone with a romantic partner; the fact that this is not the case for all mothers who allow this type of dating is surprising and has implications for future research on this topic. Additionally, those who have dated multiple partners, been on an unsupervised group date, or been on a supervised one-on-one date are roughly 16, 8, and 4 times, respectively, more likely to be allowed to be alone with a romantic partner.

Interestingly, after controlling for age, gender, and reading level, not all of the social media platforms investigated made significant contributions to mothers' reported permissiveness. In the multivariate analysis, only a child's use of Facebook and YouTube remain significant factors contributing to mothers' permissiveness; usage of Facebook related to a 4-fold increase and usage of YouTube related to a 6-fold increase in the likelihood of being allowed to be alone with a partner when compared to their respective counterparts.

As expected, affirmative responses to the study's question of main focus are correlated with various experiences involving dating and romantic relationships. However, it is surprising that the responses regarding the use of social media are shown to have a statistically significant

association with mothers' willingness to let their child be alone with a partner. It is possible that mothers who allow their child access to social media – or who are *aware* that their child is accessing social media – are more likely to also allow them to be alone with a partner. On the other hand, after controlling for age and reading level, a child's expression of his or her desire to be alone with a partner was not shown to impact parents' decisions, which supports the theory that there are other complex factors underlying parental decision making.

In addition to sexual knowledge and experience, the hypothesis suggests that there are other parental attitudes that can independently impact responses to the main question investigated in this study, even after controlling for age, gender, and reading level. The variables used to assess "parental attitude" that were also found to have a significant association with parental permissiveness include the existence of maternal concerns with respect to a child's participation in a romantic relationship and willingness at any point to allow the child to be sexually active. After adjusting for age, gender, and reading level, the results demonstrate that mothers who are concerned about their child with Down syndrome's being in a romantic relationship are 8 times *less* likely to permit their child to be alone with a romantic partner compared to mothers who have not shown the same concern. Also, mothers who would reportedly allow their child to participate in a sexually active relationship are 6 times more likely to allow their child to be alone with a romantic partner than mothers who are less permissive (another example of contradictory findings by a subset of respondents).

There are many possible reasons why a parent may or may not express concern about their child being in a romantic relationship, and it is not possible based on the results of this study to fully understand what all of these factors may be. However, it is interesting that in the multivariate analyses, apparently related factors do not always have the same ability to predict

whether a mother would allow her child to be alone with a romantic partner. For example, the independent variables "child understanding consent" and "child's ability to decline unwanted sexual advances" would carry the expectation of being correlated because it should follow that if one understands consent, it is likely that one would as well be able to decline unwanted sexual advances. However, parental responses demonstrate that their child's understanding of consent has an influence on parental willingness to allow unsupervised time with a partner, whereas no connection has been demonstrated with respect to the ability to decline unwanted advances.

4.1 Limitations of current study

It is important to keep in mind the particular demographic makeup of the study sample Due to the low response rate from men, the analyses performed only reflect responses given by mothers. The majority of respondents are white (86%) and have higher education (88%). Also, to complete the survey, respondents were required to be English-speaking and to have access to the internet. Additionally, it is possible that the high dropout rate of a third of the total sample may indicate that those who were not comfortable with the topic did not complete the survey. The high percentage of mothers (85%) who reported that their child with Down syndrome has received sex education could be falsely elevated due to selection bias. This contrasts with what was previously stated in the literature – that only about 53-56% of adults with IDD have received sex education (Martinez, *et al.,* 2010). It remains unclear if sex education is actually provided to individuals with Down syndrome at a higher frequency than for individuals with other types of IDD, if something has changed over the years since the Martinez, *et al.,* (2010) study, or if the mothers who opted in to the survey are more likely than the greater population to have provided

some form of sexual education. Additionally, the study sample was relatively small (<100 respondents) and, therefore, subject to error.

There are minimal data available on respondents who did not complete the survey, but those surveys that were collected indicate various differences with respect to certain parental demographics and attitudes. There was a higher rate of survey non-completion among parents who are younger, Hispanic, have a lower level of education, and have a son with Down syndrome. The respondents of the non-completed surveys were also significantly less likely to have other children ($p=0.006$), to believe their child is interested in romance ($p=0.033$), to allow dating ($p=0.033$), and to believe their child understands what is and what is not acceptable behavior toward someone in whom they are romantically interested ($p=0.041$). Although the data on respondents who did not complete the survey are not robust enough to allow drawing firm conclusions regarding completion versus non-completion, it is clear that responses may not be representative of all parents of children with Down syndrome because the observed low response rate (high drop-out rate of 33%) and the findings that the drop-outs tended to differ with respect to ethnicity, education, age, and parental attitudes from those who did complete the survey.

Conducting research that examines a population for which the capacity to consent may be limited can be particularly difficult. One possible explanation is that the process of obtaining true informed consent becomes complex and resource-intensive; therefore, this type of research tends to rely heavily on parent report. As in the case of this study, all responses were obtained from parents and not from those with Down syndrome, so it is possible that the parents' opinions may not accurately reflect the experiences and desires of their children. With a larger, multidisciplinary research team, there would be the potential to obtain useful information that

can only be gained by obtaining the direct perspective of the individuals with Down syndrome themselves.

4.2 Conclusions and future directions

The ubiquity of the desire for romance and intimacy among all humans, being a product of environmental and evolutionary factors, has been demonstrated time and again (Popovic, 2007). The existence of an inherent "intimacy motive" among humans has been postulated is likely imperative for human development and is related to sincerity, warmth, and acceptance (Popovic, 2007). Popovic (2007) also noted the importance of a balance being established between allowing fulfillment of sexual desires while preventing unwanted advances in promoting psychological health.

The goal of the study was to gain insight into the different factors that might influence sexual independence for individuals with Down syndrome. The study design enabled identification of variables in addition to age, gender, and developmental level of a child with Down syndrome that impact a mother's willingness to allow her child to be alone with a romantic partner. Gaining insight into—and assessing—the interplay of these variables has the potential to influence advocacy for increased sexual independence among individuals with Down syndrome. This is the first study of its kind to look at sexuality in such a broad age group and with a fine level of detail.

Caregivers of individuals with IDD frequently require 'line-of-sight' supervision of those for whom they are caring, thus limiting the supervisees' access to privacy. This is not an easily resolved issue because it highlights the conflict between upholding the —while ensuring the safety—of an individual (Stein and Karola, 2017; Medina-Rico, et al., 2017). To improve the

practices of safe sex among this population, it is essential not only that individuals with Down syndrome receive adequate sex education but also that parents, caregivers, and health care professionals understand more about the issues related to sex and romance among individuals with Down syndrome (Frank, 2016).

Thus far there has been a scarcity of research involving sexuality among individuals with Down syndrome. In one of the few published studies, researchers in Brazil assessed sexual development among 50 adolescents with Down syndrome between the ages of 10 and 20 and found that 36% of participants affirmed that they know what sexual desire is and 50% expressed that they have already experienced sexual desire (Bononi et al., 2009). The survey developed for the present study comprises a varied list of questions when compared to Bononi; however, the results of the current study suggest that the desire for sexual expression among individuals with Down syndrome is higher than what was previously understood (e.g. 61% of mothers reported that their child knows about the concept of sexuality, and nearly 65% reported that their adult child has been in love). Shandra and Chowdhury (2012) suggest that excess parental caution and poor understanding of the topic of sexuality among individuals with Down syndrome may have led to the placement of unfair limitations and expectations surrounding the expression and experience of sexuality in these individuals. Based on the results of these studies, there is yet to be a balance found between permissiveness, caution, and protectiveness.

Information gained while studying this specific community of individuals has the potential to be applied to other types of IDD. The expression of, and desire for, sexuality among youth with IDD tends to be the same as for any of their peers, and it is not uncommon for these impulses to be acted upon, even with sexual education appropriately matching the level of cognitive development (Pownall, et al., 2011). The study of sexuality among individuals with

IDD needs further exploration so that the significance of these findings can continue to be defined.

The importance of explicit and, more significantly, of implicit parental attitudes has been clearly demonstrated, and accounting for a number of other factors has further unveiled the complex nature of decision making for parents regarding this subject. Breaking down and understanding more about factors influencing and influenced by intimacy is vital in the effort to support autonomy for individuals with Down syndrome. In future studies, interactions among many of the additional variables identified in this study should be explored. The complex interplay of a very wide variety of factors undoubtedly affects every aspect of sexual expression among individuals with Down syndrome, society's acceptance of that sexuality, and parents' willingness to allow that expression.

As with many phenomena and behaviors that were at some point mischaracterized and misunderstood, normalizing the exploration of sexuality among individuals with Down syndrome has the potential to greatly improve the quality of life for many. As steps are taken towards furthering global acceptance of the concept that sexuality is a human trait and comes in various shapes and sizes and from all walks of life, every person stands to benefit. Future investigators of this topic should consider focusing on including the perspectives of fathers, incorporating more direct measures of the experience and knowledge for the individuals with Down syndrome, expanding to a larger sample so that more complex relationships among the variables can be explored, and incorporating responses from groups who were less likely to have participated in this study.

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Appendix A: Complete list of survey questions and Study Information Sheet

University of California, Irvine

Study Information Sheet

Parental disparities in concerns regarding romance and sexuality in individuals with Down syndrome.

Lead Researcher: Jessica Ann Greenwood, BS

714-456-5837 jagreenw@uci.edu

Faculty Sponsor: Maureen Bocian, MD

714-456-6873 mebocian@uci.edu

We are asking you to take part in a study conducted by researchers at the University of California, Irvine. Participating in this study is optional. You must be at least 18-years-old to complete this survey and have a child with Down syndrome who is 12 years old or older.

If you choose to be in the study, you will complete a survey. The questions that will be asked are related to your child's experiences with romance and intimacy, and what concerns you may have as a parent regarding this topic. This survey will help us learn if disparities exist between how mothers and fathers of individuals with Down syndrome report concerns regarding their child's experiences with romance and intimacy. Because we are primarily interested in both mothers' and fathers' attitudes, we request that after completion of this survey you share the survey link with your child's other parent.

The survey will take about 15 minutes to complete.

You can skip questions that you do not want to answer or stop the survey at any time.The survey is anonymous, and no one will be able to link your answers back to you. In this study we will collect minimal identifying information to link parents of the same child with Down syndrome. After the links are made, this identifying information will be removed from your responses by an independent third party prior to the researchers obtaining your data. Please do not include your name or any additional information that could be used to identify you in the survey responses outside of what is requested.

If you have any comments, concerns, or questions regarding the conduct of this research please contact the researchers listed at the top of this form.

If you have questions or concerns about your rights as a research participant, you can contact the UCI Institutional Review Board by phone, (949) 824-6662, by e-mail at IRB@research.uci.eduor at 141 Innovation, Suite 250, Irvine, CA 92697.

What is an IRB? An Institutional Review Board (IRB) is a committee made up of scientists and non-scientists. The IRB's role is to protect the rights and welfare of human subjects involved in research. The IRB also assures that the research complies with applicable regulations, laws, and institutional policies.

If you want to participate in this study, click the "continue" button to start the survey.

Select continue if you would like to participate in this study:	◯ Continue
How did you hear about this survey?	◯ Regional/local Down syndrome support group ◯ Facebook ◯ Other Social Media (insagram, Reddit, buzzfeed, etc) ◯ Other
Please specify where you heard about this survey:	_____
What is your age?	_____
What is your gender?	◯ male ◯ female ◯ other (for example, non-binary)
What is your race/ethnicity?	◯ Asian or Pacific Islander ◯ Black or African ◯ Hispanic or Latino ◯ Native American ◯ White, non-hispanic ◯ Other
What is your highest level of education?	◯ High school or equivalent ◯ Two year college degree ◯ Four year college degree ◯ Graduate degree ◯ Other (Technical school, vocational school, etc.) ◯ No degree (Please choose one from the drop-down menu.)
Do you have multiple children with Down Syndrome?	◯ Yes ◯ No

You answered that you have multiple children with Down syndrome. For this survey, please respond regarding your OLDEST child with Down syndrome.

In this study we will collect minimal identifying information to link parents of the same child with Down syndrome. This will include your child's initials and date-of-birth. After the links are made, this identifying information will be removed from your responses by an independent third party prior to the researchers obtaining your data.

What is the first initial of your child's FIRST name who has Down syndrome?	◯ A ◯ B ◯ C ◯ D ◯ E ◯ F ◯ G ◯ H ◯ I ◯ J ◯ K ◯ L ◯ M ◯ N ◯ O ◯ P ◯ Q ◯ R ◯ S ◯ T ◯ U ◯ V ◯ W ◯ X ◯ Y ◯ Z (Please choose one from the drop-down menu.)
What is the first initial of your child's LAST name who has Down syndrome?	◯ A ◯ B ◯ C ◯ D ◯ E ◯ F ◯ G ◯ H ◯ I ◯ J ◯ K ◯ L ◯ M ◯ N ◯ O ◯ P ◯ Q ◯ R ◯ S ◯ T ◯ U ◯ V ◯ W ◯ X ◯ Y ◯ Z (Please choose one from the drop-down menu.)
What is his or her date of birth?	_____
What is his or her gender?	◯ female ◯ male ◯ other (for example, non-binary)

Do you have any other children?	◯ Yes ◯ No
How many other male children do you have?	◯ Zero ◯ One ◯ Two ◯ Three ◯ Four or more
How many other female children do you have?	◯ Zero ◯ One ◯ Two ◯ Three ◯ Four or more
Is your child with Down syndrome the oldest, youngest, or in the middle?	◯ Oldest ◯ Youngest ◯ Middle
Is your child with Down syndrome adopted?	◯ Yes ◯ No

Please answer the following questions regarding romance and sexuality for your child with Down syndrome.	
Do you have concerns with your child being in a romantic relationship?	◯ Yes ◯ No
Do you believe your child is interested in romance?	◯ Yes ◯ No
Do you believe your child is interested in intercourse?	◯ Yes ◯ No
Do you or would you allow your child to participate in dating?	◯ Yes ◯ No
Do you or would you allow your child to participate In a sexually active relationship, now or in the future?	◯ Yes ◯ No
Do you believe that your child understands consent?	◯ Yes ◯ No
Do you believe your child has the ability to consent to kiss another person?	◯ Yes ◯ No
Do you believe your child has the ability to consent to have intercourse with another consenting adult?	◯ Yes ◯ No
Is your child allowed to be alone with a romantic partner or interest?	◯ Yes ◯ No
Has your child expressed desire to be alone with a romantic partner?	◯ Yes ◯ No
Are you worried that another person might misinterpret your child's behavior as having sexual content that was not intended?	◯ Yes ◯ No
Are you concerned that your child has misconceptions about sex?	◯ Yes ◯ No
Do you want your child to find a life partner?	◯ Yes ◯ No
Are you concerned that your child may become pregnant?	◯ Yes ◯ No
Are you concerned that your child will get their sexual partner pregnant?	◯ Yes ◯ No

Do you have concerns about your child with respect to:		
	Yes	No
Sexual abuse	○	○
Pregnancy	○	○
Sexually transmitted diseases	○	○
Happiness	○	○

What is most concerning to you regarding romance and sexuality for your child with Down syndrome?

_____

Please answer the following questions on your child with Down syndrome's sexuality education and behavior.

Have you received any specialized parent education/training for educating your child about sexual behavior and romance?	◯ Yes ◯ No

Has your child received sexuality education from any of the following entities?		
	Yes	No
From you	◯	◯
From his or her other parent	◯	◯
From his or her male sibling(s)	◯	◯
From his or her female sibling(s)	◯	◯
From another family member, e.g. aunt, uncle, grandparent	◯	◯
From a teacher	◯	◯
From a therapist	◯	◯
From his or her peers	◯	◯
From pictures, videos, and/or reading material	◯	◯
Ssexed	◯	◯

Do you think your child would benefit from appropriate sex education?	◯ Yes ◯ No
Do you think your child has any knowledge of the concept of sexuality?	◯ Yes ◯ No
Is your child aware of the physical changes that occur during puberty?	◯ Yes ◯ No
Do you think your child is aware of different romantic relationships (dating, marriage, etc)?	◯ Yes ◯ No
Does your child know about sexual intercourse?	◯ Yes ◯ No
Does your child understand the concept of contraception (e.g. birth control pills, condoms, etc)?	◯ Yes ◯ No
Does your child know about sexually transmitted diseases?	◯ Yes ◯ No
Does your child understand what is and what is not acceptable behavior towards someone they are romantically interested in?	◯ Yes ◯ No
Does your child know how to decline sexual advances by someone who is interested in them?	◯ Yes ◯ No
Does your child understand that intercourse can lead to pregnancy/baby?	◯ Yes ◯ No

Has your child participated in any of the following dating behavior?	Yes	No
Supervised group dates	◯	◯
Unsupervised group dates	◯	◯
Supervised one-on-one dates	◯	◯
Unsupervised one-on-one dates	◯	◯
Exclusive romantic relationship	◯	◯
Multiple dating partners	◯	◯
Exclusive sexually active relationship	◯	◯
Multiple sexual partners	◯	◯

What is your child's current relationship status?	◯ Single ◯ Dating, not-exclusive ◯ Exclusive relationship ◯ Engaged ◯ Married ◯ Divorced (Please choose one from the drop-down menu.)
Has your child been in love or said that he or she is in love?	◯ Yes ◯ No
To your knowledge, has your child been sexually intimate with another person?	◯ Yes ◯ No

To your knowledge, does your child do any of the following?	Yes	No
Masturbate	◯	◯
Use contraception	◯	◯
Have sexual intercourse	◯	◯

If your child has dated in the past or is currently dating, did his or her partner also have Down syndrome?	◯ Yes ◯ No ◯ My child has not dated
Does your child's current or past partner have a learning difference, developmental disability, or other special need?	◯ Yes ◯ No
What is the diagnosis of your child's current or past partner?	_____

Please answer the following questions regarding your child's developmental history and social behavior.	
What is your child with Down syndrome's verbal language ability?	◯ Non-verbal ◯ Single words, e.g. "ball" or "mom" ◯ 2-5 word phrases, e.g. "I want the ball" ◯ Fluent speech
Does your child use sign language?	◯ Yes ◯ No
Does your child use assisted technologies for communication? e.g. iPad, proloquo, etc.	◯ Yes ◯ No
What is your child's current reading ability?	◯ Does not read ◯ Knows alphabet ◯ Reads at a 1st-2nd grade reading level ◯ Reads at a 3rd-4th grade reading level ◯ Reads at a 5th-6th grade reading level ◯ Reads at a 7th grade reading level or higher (Please choose one from the drop-down menu.)

Has your child received any of the following therapies?		
	Yes	No
ABA therapy	◯	◯
Speech therapy	◯	◯
Occupational therapy	◯	◯
Physical therapy	◯	◯

Who does your child with Down syndrome currently live with?	◯ Lives with parents/family ◯ Lives in a community/group home ◯ Lives with a roommate ◯ Lives with a partner/spouse ◯ Lives independently ◯ None of these (Please choose one from the drop-down menu.)

Does your child use any of the following social media websites?		
	Yes	No
Facebook	○	○
Twitter	○	○
Instagram	○	○
Snapchat	○	○
YouTube	○	○
Tumblr	○	○

Appendix B:

Confirmation of self determination of exempt research by UCI Institutional Review Board.

SECTION 10: LEAD RESEARCHER ASSURANCE

The Lead Researcher (and Faculty Sponsor – if applicable) assure the following.	
As Primary Lead Researcher and Faculty Sponsor, we have ultimate responsibility for the performance of this study, the protection of the rights and welfare of the human subjects, and applicable UCI policies, as well as state statutes for research involving human subjects. **We hereby assure or acknowledge the following:** 1. The information provided in this application is accurate to the best of my knowledge. 2. All named individuals on this project have read and understand the procedures outlined in the protocol and their role on the study. 3. All named individuals on this project have completed the required electronic educational research tutorials and have been made aware of the "Common Rule" (45 CFR Part 46) and acknowledge the importance of the Belmont Principles - Respect for Persons, Beneficence and Justice in conducting research involving human participants. Also UCI has signed the Federalwide Assurance (FWA) that is available for review on the Human Research Protections (HRP) website. 4. Minor changes to the research that do not increase risk to participants, or significantly alter the study aims or procedures, such as the addition or removal of students researchers, do not require additional self-confirmation of exemption or approval from the IRB. Major changes that increase risk or constitute substantive revisions to the research including procedural changes will require a new self-confirmation of exemption or approval from the IRB. 5. When conducting research off-site or collaborating with an investigator at another institution (e.g., another UC, CHOC, CSUF, or a local school district), Lead Researchers must comply with the requirements and policies of the site, including securing Confirmation of Exempt Status from the IRB. 6. The Self-Determination of Exemption, consent documents including recruitment materials and data collection materials will be maintained by the Lead Researcher or Faculty Sponsor for 10 years beyond the completion of the research. 7. This research study is subject to routine monitoring by the Human Research Protections (HRP) unit of the Office of Research. Through the Education Quality and Improvement Program (EQUIP) program, HRP staff conduct periodic quality improvement monitoring and educational outreach.	
Please sign below, indicating that you agree with the above.	
Digitally signed by Jessica Greenwood, BS Date: 2018.3.12 9:40:42 **Lead Researcher's Signature**	December 3, 2018 **Date**
Maureen Bocian, MD, FAAP, FACMG Digitally signed by Maureen Bocian, MD, FAAP, FACMG Date: 2018.11.11 14:50:03 -08'00' **Faculty Sponsor's Signature (if applicable)**	November 11, 2018 **Date**

HUMAN RESEARCH PROTECTIONS CONFIRMATION OF EXEMPTION (OPTIONAL)

Researchers: You may request that the HRP staff review and confirm the self-determination of exemption. You may submit a completed Self Determination Tool signed by the LR / FS and any relevant supporting documents (i.e., grant, consent forms, study materials) to the HRP staff at IRB@research.uci.edu. You should receive a response within 10 business days.

FOR IRB ONLY – researchers do not complete this section.

☑ The proposed activity is exempt research. IRB review is not required.

This determination only applies to the activities described in this request. Please review Item #4 under Section 10: Lead Researcher Assurance. If there are any changes that may alter this determination the investigator may request another written determination.

* Note: Section 9(2) should note identifiers retained (even temporarily)

☐ The proposed activity does not qualify as exempt research. Submission of an IRB Application IS REQUIRED.

IRB Approval must be obtained before the research can begin. Please complete and submit an IRB Application with the appropriate Protocol Narrative. All forms are available on the Applications & Forms web page under Human Research Protections.

Benemy Acevedo HRP Staff or IRB Member	12.20.2018 Date

Appendix C: Responses of survey questions by gender of parent

Table 9: Responses of survey questions by gender of parent

Question	Parent Gender				
	Female		Male		P value
	N	Yes (%)	N	Yes (%)	
Do you have concerns with your child being in a romantic relationship?	95	66.30 %	12	50.00 %	0.340
Do you believe your child is interested in romance?	95	83.20 %	12	83.30 %	1.000
Do you or would you allow your child to participate in dating?	95	97.90 %	12	83.30 %	0.061
Do you or would you allow your child to participate in a sexually active relationship, now or in the future? Parent	88	81.80 %	12	66.70 %	0.251
Do you believe that your child understands consent?	91	46.20 %	12	50.00 %	1.000
Do you believe your child has the ability to consent to kiss another person?	93	75.30 %	12	75.00 %	1.000
Is your child allowed to be alone with a romantic partner or interest?	92	33.70 %	12	41.70 %	0.748
Has your child expressed desire to be alone with a romantic partner?	94	29.80 %	12	25.00 %	1.000
Are you worried that another person might misinterpret your child's behavior as having sexual content that was not intended?	93	59.10 %	12	50.00 %	0.552
Are you concerned that your child has misconceptions about sex?	94	63.80 %	12	50.00 %	0.362

Table 9 (Continued): Responses of survey questions by gender of parent

Question	Parent Gender				
	Female		Male		P value
	N	Yes (%)	N	Yes (%)	
Do you want your child to find a life partner?	94	56.40 %	12	75.00 %	0.352
Do you have concerns for your child with respect to sexual abuse?	94	79.80 %	12	50.00 %	0.033
Do you have concerns for your child with respect to pregnancy?	94	45.70 %	12	25.00 %	0.224
Do you have concerns for your child with respect to sexually transmitted diseases?	93	54.80 %	12	33.30 %	0.222
Do you have concerns for your child with respect to happiness?	93	69.90 %	12	66.10 %	1.000
Have you received any specialized parent education/training for educating your child about sexual behavior and romance?	95	40.00 %	12	16.70 %	0.204
Has your child received sexuality education from you?	94	77.70 %	12	58.30 %	0.162
Has your child received sexuality education from his or her other parent?	92	37.00 %	12	33.30 %	1.000
Has your child received sexuality education from a male sibling?	91	7.70 %	12	0.00 %	1.000
Has your child received sexuality education from a female sibling?	92	20.70 %	12	0.00 %	0.117

Table 9 (Continued): Responses of survey questions by gender of parent

Question	Parent Gender				
	Female		Male		P value
	N	Yes (%)	N	Yes (%)	
Has your child received sexuality education from another family member?	92	9.80 %	12	8.30 %	1.000
Has your child received sexuality education from a teacher?	91	53.80 %	12	33.30 %	0.227
Has your child received sexuality education from a therapist?	90	17.80 %	12	16.70 %	1.000
Has your child received sexuality education from his or her peers?	84	26.20 %	11	9.10 %	0.286
Has your child received sexuality education from pictures?	89	52.80 %	12	33.30 %	0.234
Do you think your child has any knowledge of the concept of sexuality?	95	60.00 %	11	54.50 %	0.754
Is your child aware of the physical changes that occur during puberty?	95	87.40 %	12	66.70 %	0.079
Do you think your child is aware of different romantic relationships (dating, marriage, etc)?	94	81.90 %	11	72.70 %	0.435
Does your child know about sexual intercourse?	92	46.70 %	12	33.30 %	0.540

Table 9 (Continued): Responses of survey questions by gender of parent

Question	Parent Gender				P value
	Female		Male		
	N	Yes (%)	N	Yes (%)	
Does your child know how to decline sexual advances by someone who is interested in them?	91	49.50 %	12	50.00 %	1.000
Does your child understand that intercourse can lead to pregnancy/baby?	91	44.00 %	12	33.30 %	0.550
Has your child participated in supervised group dates?	93	51.60 %	12	25.00 %	0.124
Has your child participated in unsupervised group dates?	95	15.80 %	12	16.70 %	1.000
Has your child participated in supervised one-on-one dates?	94	45.70 %	12	33.30 %	0.542
Has your child participated in unsupervised one-on-one dates?	95	15.80 %	12	16.70 %	1.000
Has your child participated in an exclusive romantic relationship?	92	22.80 %	12	25.00 %	1.000
Has your child participated in dating multiple partners?	92	7.60 %	12	0.00 %	1.000
Has your child been in love or said that he or she is in love?	95	54.70 %	11	45.50 %	0.751
To your knowledge, has your child been sexually intimate with another person?	95	4.20 %	12	0.00 %	1.000
To your knowledge, does your child masturbate?	93	53.80 %	12	50.00 %	1.000
To your knowledge, does your child use contraception?	93	9.70 %	12	16.70 %	0.611

Table 9 (Continued): Responses of survey questions by gender of parent

Question	Parent Gender				
	Female		Male		P value
	N	Yes (%)	N	Yes (%)	
Does your child use sign language?	94	14.90 %	12	25.00 %	0.404
Does your child use assisted technologies for communication? e.g. iPad, proloquo, etc.	95	10.50 %	12	41.70 %	0.012
Does your child use Facebook?	95	37.90 %	12	25.00 %	0.530
Does your child use Twitter?	95	11.60 %	12	16.70 %	0.638
Does your child use Instagram?	94	28.70 %	11	27.30 %	1.000
Does your child use Snapchat?	93	22.60 %	12	16.70 %	1.000
Does your child use YouTube?	95	78.90 %	12	75.00 %	0.718

Appendix D: Comparison of linked survey responders

Table 10: Comparison of linked survey responders

Question	Linked parents: female (f); male (m)					
	f/m	f/m	f/m	f/f	f/m	f/m
	Pair 1	Pair 2	Pair 3	Pair 4	Pair 5	Pair 6
Do you have concerns with your child being in a romantic relationship?	0	1	1	1	1	1
Do you believe your child is interested in romance?	1	1	1	1	1	1
Do you or would you allow your child to participate in dating?	1	1	1	1	1	1
Do you or would you allow your child to participate in a sexually active relationship, now or in the future?	1	1	1	1	1	0
Do you believe that your child understands consent?	1	1	1	1	1	1
Do you believe your child has the ability to consent to kiss another person?	1	1	1	0	1	1
Is your child allowed to be alone with a romantic partner or interest?	1	1	0	1	0	1
Has your child expressed desire to be alone with a romantic partner?	1	1	1	1	1	1
Are you worried that another person might misinterpret your child's behavior as having sexual content that was not intended?	1	1	0	1	0	1
Are you concerned that your child has misconceptions about sex?	0	1	1	0	0	1
Do you want your child to find a life partner?	0	1	0	0	1	1
Do you have concerns for your child with respect to sexual abuse?	1	1	1	1	0	1
Do you have concerns for your child with respect to pregnancy?	1	1	1	1	1	1
Do you have concerns for your child with respect to sexually transmitted diseases?	1	1	0	1	0	0
Do you have concerns for your child with respect to happiness?	1	0	0	1	0	1
Have you received any specialized parent education/training for educating your child about sexual behavior and romance?	0	1	1	1	1	1
Has your child received sexuality education from you?	1	1	1	1	1	1
Has your child received sexuality education from his or her other parent?	0	1	1	0	1	1

* Couples' answers match (1) vs Couples' answers do not match (0)

Table 10 (continued): Comparison of linked survey responders

Question	Linked parents: female (f); male (m)					
	f/m	f/m	f/m	f/f	f/m	f/m
	Pair 1	Pair 2	Pair 3	Pair 4	Pair 5	Pair 6
Has your child received sexuality education from a male sibling?	0	1	1	1	1	1
Has your child received sexuality education from a female sibling?	1	0	1	1	1	0
Has your child received sexuality education from another family member?	1	0	1	1	1	1
Has your child received sexuality education from a teacher?	1	1	1	1	0	1
Has your child received sexuality education from a therapist?	0	1	1	1	1	1
Has your child received sexuality education from his or her peers?	1	1	0	1	1	0
Has your child received sexuality education from pictures?	1	1	1	0	0	0
Has your child received sexuality education from pornographic media?	1	1	1	1	1	0
Do you think your child would benefit from appropriate sex education?	1	1	1	1	1	1
Do you think your child has any knowledge of the concept of sexuality?	1	1	0	0	1	0
Is your child aware of the physical changes that occur during puberty?	0	1	1	1	1	1
Do you think your child is aware of different romantic relationships (dating, marriage, etc)?	1	1	1	1	1	1
Does your child know about sexual intercourse?	1	1	1	0	1	1
Does your child understand what is and what is not acceptable behavior towards someone they are romantically interested in?	1	1	1	0	1	1
Does your child know how to decline sexual advances by someone who is interested in them?	1	1	1	0	0	0
Does your child understand that intercourse can lead to pregnancy/baby?	1	1	1	1	0	1
Has your child participated in supervised group dates?	1	0	1	0	1	0
Has your child participated in unsupervised group dates?	0	0	1	0	1	1

* Couples' answers match (1) vs Couples' answers do not match (0)

Table 10 (continued): Comparison of linked survey responders

Question	Linked parents: female (f); male (m)					
	f/m	f/m	f/m	f/f	f/m	f/m
	Pair 1	Pair 2	Pair 3	Pair 4	Pair 5	Pair 6
Has your child participated in supervised one-on-one dates?	1	0	1	1	1	0
Has your child participated in unsupervised one-on-one dates?	1	1	0	0	1	1
Has your child participated in an exclusive romantic relationship?	0	1	1	1	1	1
Has your child participated in dating multiple partners?	1	1	0	1	1	1
Has your child been in love or said that he or she is in love?	1	0	1	1	1	1
To your knowledge, has your child been sexually intimate with another person?	1	1	1	1	1	1
To your knowledge, does your child masturbate?	1	1	0	1	1	1
To your knowledge, does your child use contraception?	1	1	1	1	1	1
Does your child use sign language?	1	1	1	1	1	1
Does your child use assisted technologies for communication? e.g. iPad, proloquo, etc.	0	1	1	1	1	1
Does your child use Facebook?	1	1	1	1	1	1
Does your child use Twitter?	0	1	1	1	1	1
Does your child use Instagram?	1	1	1	1	1	1
Does your child use Snapchat?	1	1	1	1	0	1
Does your child use YouTube?	1	1	1	1	0	1

* Couples' answers match (1) vs Couples' answers do not match (0)

	Linked parents: female (f); male (m)					
	f/m	f/m	f/m	f/f	f/m	f/m
	Pair 1	Pair 2	Pair 3	Pair 4	Pair 5	Pair 6
Percent match	76%	86%	80%	76%	76%	80%

Appendix E:

Limited demographics of respondents who did not complete the survey

Table 11:
Limited demographics of respondents who did not complete the survey

Age	N	Mean	SD
Age of parent	24	49	12.59
About Excluded participants	N	(%)	
Parent Race			
White	19	83	
Hispanic	4	17	
Asian	0	0	
Total	23	100	
Parent is female (1) vs male (0)	21	88	
Parent education			
Graduate degree	4	17	
Four-year degree	5	21	
Technical school	0	0	
Two-year degree	5	21	
High school diploma	10	37	
None of these	1	4	
Total	24	100	
Family Composition	N	Yes (#)	Yes (%)
Do you have any other children?	23	15	65

Appendix F:

Limited responses from respondents who did not complete the survey

Table 12: Limited responses from respondents who did not complete the survey

Question	Survey completion				
	Completed survey		Not Complete		p value
	N	Yes (%)	N	Yes (%)	
Do you have concerns with your child being in a romantic relationship?	107	57	14	7	1
Do you believe your child is interested in romance?	107	73	14	7	0.033
Do you or would you allow your child to participate in dating?	107	85	14	9	0.033
Do you or would you allow your child to participate in a sexually active relationship, now or in the future? Parent	100	71	13	8	0.469
Do you believe that your child understands consent?	103	41	14	3	0.09
Does your child understand what is and what is not acceptable behavior towards someone they are romantically interested in?	105	54	4	0	0.041