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INCREASING SELF-DETERMINATION SKILLS THROUGH BEHAVIORAL
SKILLS TRAINING FOR INDIVIDUALS WITH EXTENSIVE SUPPORT NEEDS TO
EXAMINE REVERSIBLE CONTRACEPTIVE CHOICES

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A Dissertation

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A Dissertation Approved on

September 26, 2022

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DEDICATION

This dissertation is dedicated to my parents

Dr. Stephen Pollard

and

Mrs. Mary Ann Pollard

for their constant love and support

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First and foremost, I would like to thank my family and friends, especially Leo and Sally, for supporting me during this program and making sure I stayed sane and fed. I would also like to thank my advisor, Dr. Ginevra Courtade, for her guidance during my program as well as my committee members for their feedback and support during this process. I want to thank Erica McClure, Mary Elliot, Tara Harmon, and Caroline Fitchett for their assistance in completing this study. Thank you to my dear friends, Dr. Neetu Jose and Dr. Lakshmi Kartha for assisting in the generalization probes of this study and giving up time on their Saturdays. Lastly, I want to thank myself for not giving up.

ABSTRACT

INCREASING SELF-DETERMINATION SKILLS THROUGH BEHAVIORAL SKILLS TRAINING FOR INDIVIDUALS WITH EXTENSIVE SUPPORT NEEDS TO EXAMINE REVERSIBLE CONTRACEPTIVE CHOICES

Jennifer Pollard

September 26, 2022

There is a long history of individuals with extensive support needs (ESN) being sterilized without their knowledge and consent. Students with ESN are defined as individuals who need continuous and widespread supports necessary for academic, communication, and/or daily living skills. These individuals typically have more than one diagnosis including a developmental disability (DD), intellectual disability (ID), and/or traumatic brain injury (Kurth et al., 2019; Taub et al., 2017). Part of the reason this is able to occur is due to a lack of education about sexual development and a lack of interventions to build skills related to self-determination or informed decision-making. This dissertation aimed to increase these skills for participants with ESN related to their choices in reversible contraceptives.

Three participants were first taught about their menstrual cycles and given preference assessments about reversible birth control options. Participants then created individualized graphic organizers to help guide them through the process of asking about choices and recording the information given from doctors. A single-case multiple probe design was used to examine the effectiveness of using behavioral skills training to

increase the skills of asking a doctor about choices and recording the information. All three participants were able to reach mastery level within three to four probes. Two participants stayed at mastery level for their generalization and maintenance probes. One participant did not stay at mastery level for their generalization and maintenance probe but was only 3 points away from mastery level, and 29 points above their baseline level. Social validity results were positive and participants reported that they liked being able to talk to a doctor themselves. Future researchers should focus on increasing self-determination skills in other areas related to sex education and breaking down barriers to access education and care centered around dignity for the individual with ESN.

This dissertation is divided into five chapters. Chapter One gives an overview of the history of sex education and health care services for individuals with ESN. Chapter Two is a review of literature related to sex education and self-determination skill building for individuals with ESN. This chapter also includes evidence that informed the decisions to include the different study components. Chapter Three details the methodology of the study and Chapter Four details the results for all three participants. Chapter Five explains the results related to previous literature and considerations for future research

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CHAPTER ONE: INTRODUCTION

This chapter describes the background and need for this study. The role and current state of comprehensive sex education, need for more resources and access to education for all students, especially students with extensive support needs. The consequences for lack of education and interventions for comprehensive sex education (CSE) and menstrual management, specifically, are highlighted. The relationship between CSE and self-determination (SD) skills is also highlighted as well as the lack of resources and regulation for the development of these skills for students with extensive support needs (ESN). At the end of the chapter, the purpose of this study, research questions, and definition of terms is included.

Comprehensive Sex Education

Learning about, understanding, and enjoying our bodies is a basic part of life and is a necessary part of having a high quality of life (World Health Organization, 2012). Flynn et al. (2016) found adults who were sexually healthy and satisfied had better overall health outcomes than those who did not. To achieve sexual health and understanding of your own body in adulthood, it is imperative to receive quality CSE. The United Nations Educational, Scientific, and Cultural Organization (2018) states that CSE is a basic human right and necessary for gender equality throughout the world. The American Public Health Association (2014) states that all students in kindergarten to 12th grade should learn about their bodies, sexuality, contraception, and disease prevention to become happy and healthy adults.

However, there appears to be a lack of access to CSE in the United States (U.S.) despite top health organizations supporting the need for this content in schools. According to The Guttmacher Institute (2021) only 28 states (out of 50) and the District of Columbia (DC) require CSE and human immunodeficiency virus (HIV) education, 2 states only require CSE, and 9 states require only HIV education. Out of these states, only 18 states require the content to be medically accurate and 26 states require that content be age appropriate. Thirty-nine states require that abstinence education be stressed and 19 states require sex only within marriage be stressed. It should be noted that abstinence only education has been found by multiple studies to be less effective at preventing unwanted pregnancy and the spreading of sexually transmitted infections (STI) than CSE, especially for marginalized students (Hoefler & Hoefler, 2017). Yet only 19 states require education about contraception and STI prevention methods (Guttmacher Institute, 2021).

The Center for Disease Control and Prevention (CDC; 2019) identified 20 key areas that should be taught in schools related to CSE. Advocates for Youth, Sex Ed for Social Change (SIECUS; 2021) surveyed the 50 states in the U.S. to find how many states are teaching students the CDC key areas. For grades 6-8, Utah was the lowest with 0% and California was the highest with 39.9% of students taught this content. The average for grades 6-8 is 18.1%. For grades 9-12, Utah was the lowest with 3.9% and New Jersey was the highest with 86.8% of students taught this content. The average for grades 9-12 is 40.4%.

The Future of Sex Education Initiative (FoSE) is an organization that works in conjunction with SIECUS and Answer Sex Ed Honestly. These organizations have been working for decades, some starting in 1964, to address the lack of CSE and the long

terms effects on adults and our population as a whole. FoSE (2021) developed standards based on 30 years of research, in association with their partners, to align with the National Health Education Standards (2007), specifically related to students learning about core concepts of promoting health and disease prevention, analyzing influences from their environment, accessing information, interpersonal communication, decision-making, goal setting, self-management, and advocacy. The FoSE (2021) standards have been organized in to seven categories: (1) consent and healthy relationships, (2) anatomy and physiology, (3) puberty and adolescent sexual development, (4) gender identity and expression, (5) sexual orientation and identity, (6) sexual health, and (7) interpersonal violence.

Students with Extensive Support Needs

Students with ESN are defined as individuals who need continuous and widespread supports necessary for academic, communication, and/or daily living skills. These individuals typically have more than one diagnosis including a developmental disability (DD), intellectual disability (ID), and/or traumatic brain injury (Kurth et al., 2019; Taub et al., 2017). Since there is an overall lack of curricula and access to CSE and the FoSE (2021) standards for the general school population, there are some students who have even more barriers to receiving this education. Multiple researchers found that CSE curricula were developed without accommodations or adaptations necessary for comprehension and incorporated biases with a lack of dignity for students with ESN (Barger et al., 2009; Blanchett & Wolfe, 2002; Coutoure & Daigle, 2011; Jung et al., 2019).

The American Association on Intellectual and Developmental Disabilities (AAIDD; 2013) states that individuals with IDD have the same sexual rights as neuro-typical individuals, including access to quality CSE. The Individuals with Disabilities Education Act (IDEA; 2004) requires that all students with disabilities have access to and make progress in the general curriculum in the least restrictive environment. Therefore, students with ESN should be given access to CSE in schools like their peers.

The largest barrier for this population is the stereotype and bias that students with ESN do not develop sexually or have sexual feelings (Barnard-Brak, 2014; Medina-Rico et al., 2008). Also, some teachers and/or caregivers do not believe that CSE is appropriate for this population despite reporting higher stress levels dealing with issues related to puberty and natural human development, like menstrual management (MM), masturbation, body odor, and respecting social boundaries (Barnard-Brak, 2014; Cummins et al., 2020; Curtiss, 2018). The National Longitudinal Transition Survey-2 (NLTS2; SRI International, 2002) found that 56% of students with mild IDD did not have access to CSE and 84% with ESN did not have access to CSE. Barnard-Brak (2014) surveyed teachers and results indicated these teachers believed 75% of their students with ESN would not benefit from CSE. And Howard-Barr et al. (2005) found that only about 7% of 494 special education teachers in Florida received formal training in teaching CSE which impacts access for students with ESN.

The lack of access to CSE for students with ESN can have a lasting and devastating effect on life development and quality of life. Quality of life is defined as feeling included in a society, higher rates of emotional and physical well-being, and reaching personal potential in different areas (Turnbull et al., 2003). Tamas et al. (2020)

found that stress levels for adults with ESN had the highest correlation with negative interpersonal relationships due to lack of social and communication skills. The ability to identify, develop, and maintain interpersonal relationships depends on skills often not taught to students with ESN (e.g., reading social cues, identifying and expressing emotions, identifying abusive relationships) which results in a lack of lasting and important relationships into adulthood. The development of different types of relationships is also impacted by the lack of education around sexuality for individuals with ESN due to biases against these individuals (Medina-Rico et al., 2018).

This lack of education and acceptance of sexuality for students with ESN can result in inappropriate sexual behaviors (e.g., public masturbation, self-harm for pleasure, speaking about body parts or sexual acts in public places without consent) that roughly 6-28% of this population at risk of abuse, legal consequences, and/or strained relationships (Falligant & Pence, 2020). The development of inappropriate sexual behaviors may have an impact on the fact that individuals with IDD are four to eight times more likely than the general population to experience sexual abuse and are at increased risk at experiencing repeated abuse (Barnard-Brak, 2014; McDaniels & Fleming, 2016). Part of this is impacted, again, by lack of social and communication skills, not being able to identify social or danger cues, not being able to report incidents, and not being able to say “no” which can lead to 17.1% higher probability of dating violence (Mitra et al., 2013; Quint, 2014).

Many individuals with ESN also rely on others for their care and the maintenance of their bodies. This causes an increased risk of abuse as well as increased rate of cancer, urinary tract infections, and other health related issues, especially for individuals who do

not have the knowledge or skills to care for their penis. Lack of these skills can also create foul odor or other issues that can negatively impact interpersonal relationships (Wilson et al., 2009). This can be the same for individuals who have a uterus and vagina and require assistance with skills related to handling their menstrual cycle and keeping their vagina clean (Quint, 2014).

Menstrual Management

Some caregivers of children with ESN have gone to extreme lengths to severely limit their physical growth to curb the above issues. The “Ashley Treatment” first occurred in 2007 to a young girl with ESN. She was given extensive estrogen medication to stunt her growth, had her uterus removed, and her breast buds removed at the age of nine. This treatment was approved by a team of doctors, her parents, and a hospital’s ethics committee. There have been doctors, scientists, and researchers who agree with this treatment because they do not feel this individual would have been able to care for herself nor that she would have been able to form an opinion about the topic, therefore, she was not invited or allowed to be part of the decision-making process for her surgeries and treatment (Diekema & Fost, 2010; Spriggs, 2010).

“Ashley” is not the only patient to be put in this position. Li et al. (2018) found that women with disabilities are 7.3%-9.8% in the US are more likely to be sterilized or given a hysterectomy than women without disabilities and at a younger age. Wu et al. (2019) found that women with ESN are much more likely to have a sterilization procedure performed as opposed to long-lasting but reversible contraceptives like their same age peers. Countries other the U.S. have experienced similar circumstances, for example, in Belgium, Servais et al. (2004) found that women with ESN are three times

more likely to be sterilized than their same age peers. It is believed that a lack of education for the patient, their caregivers, and their healthcare providers add to the above results (Verlenden et al., 2020).

In the U.S., there are also many laws supporting forced or uninformed sterilization. According to a report by the National Women's Law Center (2021), 31 states in the U.S. and Washington, DC have laws allowing forced sterilization of disabled people and 17 states allow forced sterilization of disabled minors. These laws are also enforced at the federal level in the U.S. by *Buck vs. Bell (1927)* which was the first Supreme Court decision allowing forced sterilization of a young woman named Carrie Buck based on her classifications, including, "imbecility" and "feeble-mindedness" (terms historically used to describe individuals with IDD). This ruling was part of the eugenics movement in the U.S. and has never been overturned.

However, many practitioners and researchers do not believe this form of treatment and highly invasive procedures are ethical (Lantos, 2010). The completion of hysterectomies may occur to make caregivers' lives easier, avoid uncomfortable situations for caregivers, and the individuals are often not given the dignity of being part of making an informed decision (Lantos, 2010; Liao et al., 2007). Stefánsdóttir (2014) found that women with ESN who were subjected to sterilization faced mental health and depression issues afterward, especially for those who were not informed of what was happening or involved in the decision-making process.

While reviewing case notes, Roy (2010) found that women with ESN, who were given access to information and to different contraceptives and birth control, could avoid STIs and unwanted pregnancies so should be given the option of other treatments before

sterilization. The American College of Obstetricians and Gynecologists' Committee on Adolescent Health Care (2016) published an official opinion that women with ESN must be offered the same "dignity and respect" as other women and offered informed choices about their health care and reproductive rights in response to this controversy and lack of consistent practice.

A study by Retznick et al. (2021) revealed that out of 42 participants with IDD, the majority took a reversible long acting birth control yet there was a need for more education that includes graphics and clear language. McCarthy (2009) found that 21 of the 23 women with ESN, who took reversible contraceptives, did not know why or what they were taking. Even though the participants in these studies were given other options besides sterilization, they were not educated on these options nor given the opportunity to learn and participate in making an informed decision about which medication they would take. Two different studies concluded that the largest gaps in CSE knowledge for individuals with ESN is information about contraceptives and that young adults with ESN were not able to use contraceptives effectively due to lack of education on use and options available (Dekker et al., 2014; Schmidt, 2019). This is a concern that can lead to greater consequences, like unwanted pregnancy or STIs, Brkić-Jovanović et al. (2021) found that 84% of participants in their study (adults with ESN living in residential facilities) were sexually active but did not have knowledge about contraceptives.

The lack of education in this area is compounded by the fact that women with ESN may use different forms of communication and have additional needs for their education and in developing their own opinions. Many doctors are not fully trained on these needs or how to educate or communicate with these women. Women with ESN are

not taught about their bodies, menstrual cycles, and/or options for care as stated above due to many systemic barriers. Without full CSE in school, women with ESN are also not taught the tools to self-advocate or use self-determination (SD) skills needed to be part of the decisions made about their bodies and healthcare (Agaronnik, 2020; Gilmore & Malcolm, 2014).

Self-Determination

Self-determination (SD) involves skills related to making informed decisions, setting goals, self-learning, self-advocacy (SA), and more. However, building these skills relies on consistent opportunities within an individual's environment. Building SD skills also greatly depends on a person's self-perception which is influenced by their environment (Taylor et al., 2005; Wehmeyer & Garner, 2003). Although practitioners value these skills and their importance in the lives of students with ESN, there is inconsistent instruction and fostering of SA and SD skills in classrooms and school systems (Carter et al., 2008; Sagen & Ytterhus, 2014; Test et al., 2003).

Self-advocacy (SA) is the ability to speak up for one's self and ask for what you need when you are not being treated equitably in your environment (Van-Belle et al., 2006). In the late 1900s practitioners accepted and realized that individuals with ESN could and should be part of the decision-making about their life and care which lead to the development of a movement toward SA. Tools needed to truly advocate for one's self include understanding your rights and options in life, communicating your needs, and identifying who to communicate those needs with (Van-Belle et al., 2006; Wehmeyer et al., 2000). Kim et al. (2020) found that students with ESN reported feeling more accepted

and were happier in their environments when they learned SA skills. SA skills are a piece of a broader set of skills known as SD.

Self-Determination Skills and Comprehensive Sex Education

Travers et al. (2014) showed significant overlap in teaching SD skills and CSE to students with ESN and Höglund & Larsson (2019) found that midwives in Sweden working with and supporting women with ESN were very aware of the right to be self-determined. In fact, the goal of some FoSE (2021) standards reflect the school creating a community that supports and teaches all students, including those with ESN, to learn to advocate for themselves in all situations related to CSE. Part of developing and implementing this plan is teaching and allowing students to use SA/SD skills related to CSE to make informed decisions about how they want to handle different aspects of puberty and human development, like MM and making informed decisions about contraceptive use based on individual needs. An important aspect to learning how to make these decisions is the need to educate teachers, caregivers, and administrators about evidence-based practices (EBPs) to disseminate knowledge and teach skills effectively to individuals with ESN to allow them to make informed decisions about their care.

Behavioral Skills Training

Behavioral skills training (BST) is an EBP that has been effectively used to increase SD skills in different areas of the lives of individuals with ESN, for example, choosing a residential facility and being an active member of their individualized education program (IEP) meeting (Faw 1996; Hammer, 2004; Schaefer & Andzik, 2021). Similar to MM, these are both areas of the lives of individuals with ESN which they are not a part of the decision-making process. BST is an EBP used to teach new skills. BST

consists of the following: (1) educate about a skill, (2) model the skill, (3) the learner tries the skill, (4) specific feedback is given about the learner's try, (5) repeat until a pre-determined level of mastery is met (Schaefer & Andzik, 2021; Ward-Horner & Sturmey, 2012). As the use of BST is effective in increasing SD skills, this could also be a promising intervention used to increase SD skills related to MM.

Purpose of the Study

The purpose of this study is to add to previous research aimed at increasing EBPs related to CSE and SD for students with ESN. Specifically, for individuals who menstruate to learn to be an active participant in their care by learning to gain knowledge to inform their choices on medical interventions related to their menstrual management.

Research Questions

1. Does behavioral skills training increase the skill of stating needs and asking questions, measured by a score on a task analysis, about medical interventions related to menstrual management for individuals with extensive support needs?

2. Does behavioral skills training increase the skill of completing a graphic organizer to record information (circle and/or write answers) related to individual preferences about menstrual management for individuals with extensive support needs?

Definition of Terms

Students with Extensive Support Needs means students with ESN are defined as individuals who need continuous and widespread supports necessary for academic, communication, and/or daily living skills. These individuals typically have more than one diagnosis including a developmental disability (DD), intellectual disability (ID), and/or traumatic brain injury (Kurth et al., 2019; Taub et al., 2017).

Comprehensive Sex Education means education that is developed on evidence and research based information that incorporates the National Health Standards (2007) about core concepts of promoting health and disease prevention, analyzing influences from their environment, accessing information, interpersonal communication, decision-making, goal setting, self-management, and advocacy (FoSE, 2021).

Menstrual Management means the ability to manage symptoms related to menstruation and/or the ability to complete daily living tasks related to menstruation care.

Self-determination Skills means skills necessary to make informed decision and set goals based about one's life trajectory and care (Deci & Ryan, 1985; Taylor et al., 2005; Wehmeyer & Garner, 2003).

Antecedent Intervention means an intervention or learning strategy utilized before a problem or issue occurs (Cooper, Heron, & Heward, 2007; Wilder & Carr, 1998).

Evidenced-Based Practices means interventions and/or teaching strategies that have been studied multiple times showing a positive effect on the participants (Council for Exceptional Children, 2014)

Behavioral Skills Training means an educational training that combines an instructional component, modeling of the skill, role play and/or rehearsal of the skill, and feedback (Ward-Horner & Sturmey, 2012).

Visual Supports means adding a photographic or picture icon (can be realistic, cartoon, or somewhere in between) to a word or phrase to help with comprehension (Jaime and Knowlton, 2007; Tissot & Evans, 2003).

Graphic Organizer means a visual tool used for individuals with IDD to organize information in a meaningful way (Behtune & Wood, 2013; Bishop et al., 2015; Douglas et al., 2011; Hall et al., 2013).

CHAPTER TWO: REVIEW OF LITERATURE

This chapter outlines the literature reviewed while designing this study and the supports used within the study. There were five systematic literature reviews conducted to determine what is currently available regarding comprehensive sex education, contraceptive use, and self-determination skills for individuals with extensive support needs. The methods used and information gathered is detailed as well as four specific articles that helped to design this specific study. Following the literature is information about the different components of this study: behavioral skills training, task analysis, graphic organizers, and visual supports.

Systematic Literature Reviews

There were five systematic literature reviews conducted to investigate the information related to the content of this study: (1) comprehensive sex education (CSE), (2) status of use and knowledge of contraceptives, (3) contraceptive interventions and education, (4) self-determination (SD), and (5) SD and contraceptive use. All searches were initially conducted in Fall 2021 and then again in Summer 2022. I also met with a research librarian to ensure that all relevant literature was searched accurately. The databases used for the searches included educational, behavioral, and medical databases: academic search complete, CINAHL, EBSCOhost, education full text, education administration abstracts, ERIC, health source, MEDLINE, open dissertations, psychology and behavioral health, APA psychinfo, teacher reference center, and consumer health reference ebook.

All searches included these terms as one of the themes: developmental disabilities or intellectual disability or mental retardation or special needs or idd or i/dd or extensive support needs or moderate severe disability. These terms were chosen based on current and past terms used to describe the population of individuals with extensive support needs (ESN). Searches one, three, and four also included these terms as one theme: interventions or strategies or best practices or teaching or learning or applied behavior analysis or aba. These terms were chosen for the searches examining behavioral and educational interventions. Searches two, three, and five also included these terms as one of the themes: contraception or birth control or family planning or menstrual management or menarche or birth control options. These terms were chosen because these searches were examining information specific to contraceptive use, knowledge, or skills. Searches four and five included these terms as one of the themes: self-advocacy skills or self-advocacy or self-determination or self-determination skills. These terms were chosen for these searches because they were examining specifics about self-determination skills. Search one included these terms as one of the themes: puberty or menarche or menstrual cycle or anatomy or consent or sexuality or masturbation or healthy relationships or dating violence or contraception or sexually transmitted infection or STIs or HIV or STI prevention or healthy boundaries or self-defense or sexual abuse consent and healthy relationships OR anatomy and physiology OR puberty and adolescent sexual development OR gender identity and expression OR sexual orientation and identity OR sexual health OR interpersonal violence. These terms were used to encompass the terms used in FoSE (2020) standards and other related terms. These terms were also used for search two as a theme: women or female or woman or females. These were chosen to

ensure the information reviewed contained perspectives, knowledge, and skills related only to individuals who menstruate.

For articles to be included in the searches, they had to meet all the following criteria:

1. Related to CSE and/or SD
2. include participants with extensive support needs (ESN) or participants described using a previously used term for individuals with ESN [e.g. moderate-severe disability (MSD), Intellectual and developmental disability (IDD)]
3. be an antecedent intervention
4. could be a single-case study, group design study, meta-analysis, literature review, curriculum/program review (for search 1 only), or qualitative study (for search 1 and 2 only).

Antecedent is defined as an intervention or information taught prior to problem behaviors, abuse, development, menstruation, etc. occurring as a prevention or teaching strategy. Participants with ESN is defined as individuals who need continuous and widespread supports necessary for academic, communication, and/or daily living skills. These individuals typically have multiple diagnoses including a developmental disability (DD), intellectual disability (ID), and/or traumatic brain injury (Kurth et al., 2019; Taub et al., 2017). Criteria one was chosen as this is the content and skills focused on in this study. Criteria two was chosen as this is the participant population of this study. Criteria three and four were chosen as these are components of this study (an antecedent intervention in a single-case study). Curriculum and program reviews were allowed for search one as this search was trying to establish the current state of CSE for individuals

with ESN while the other searchers were looking for more specific interventions as opposed to an entire curriculum. Qualitative studies were included for search one and two only to help give information about the knowledge and perspectives of contraceptive use as background information for the content of this study. Other requirements for the searches were: (a) it had to be in English, (b) had to be a in peer-reviewed journal, and (c) the full text had to be available. These requirements were chosen based on my ability to read and access the article as well as making sure studies met minimum quality indicators in a peer-reviewed journal.

For articles to be excluded from the search, they had to meet one or more of the following criteria:

1. qualitative research (for searches 3-5)
2. practitioner pieces
3. interventions or curriculums that had not been studied with participants with ESN
4. reviews (for searches 2-5)
5. participants described as having mild disabilities and/or other related terms (e.g. “high-functioning autism”, “educable intellectual disability”), physical disability, learning differences, mental health issues, neuro-typical individuals
6. interventions determined to be ineffective or lacking in adaptations for individuals with ESN (for searches 3-5)
7. interventions implemented without the participants’ consent
8. studies that were not accessible
9. studies that examined reactive interventions or strategies

Reactive is defined as an intervention or teaching strategy that is taught after a problem behavior, abuse, development, menstruation, etc. occurs to stop the problem from continuing. Criteria one was chosen due to the fact information about interviews were conducted using necessary adaptations for individuals with different communication needs was not included or discussed in qualitative studies found. Criteria two was chosen as these are typically suggestions but not based on a research study with data. Criteria three was chosen since individuals with ESN have specific needs (e.g. visual supports) that need to be met for effective interventions, therefore, interventions that do not meet their needs does not add to the research benefitting this population. Criteria four was chosen for searches 3-5 as these searches were looking for specific interventions as opposed to entire curriculums. Criteria five was chosen since individuals with those descriptors are not part of the ESN population which was the population targeted in this study. Criteria six was chosen for searches 2-5 as these interventions are shown to not serve the population targeted in this study. Criteria seven was chosen as these are unethical practices (this was only seen in older studies). Criteria eight was chosen since it is hard to get all the information and data when the article is not accessible. Criteria nine was chosen since this study is focusing on an antecedent intervention as opposed to a reactive intervention.

Search One: Comprehensive Sex Education

The literature search came back with 3,856 results and 3,321 after duplicates were removed. After reviewing the 3,321 abstracts, 63 were kept for further review. Out of the 63 articles, 38 were determined to meet inclusion criteria: one meta-analysis, 13 literature reviews, six program or curriculum reviews, 11 group design studies, and eight single

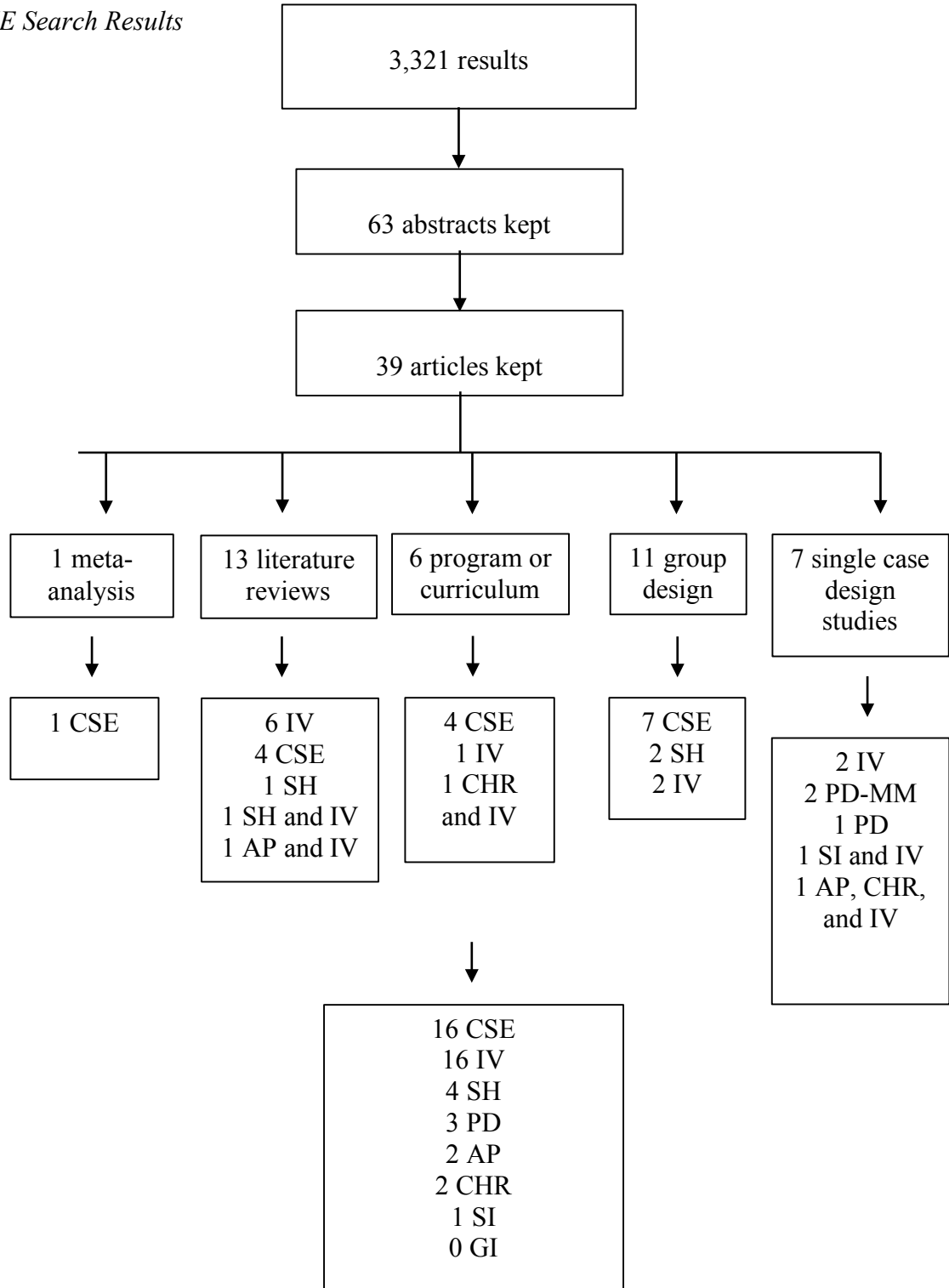
case design studies. Sixteen of the abstracts kept examined CSE. The prevalence of the FoSE (2020) standards examined were: 17 interpersonal violence (IV), four sexual health (SH), three puberty and adolescent sexual development (PD), two anatomy and physiology (AP), two consent and healthy relationships (CHR), one sexual orientation and identity (SI), and zero gender identity and expression (GI; see Figure 1).

Comprehensive Sex Education

The 16 pieces of literature that examined CSE, meaning they should involve all the FoSE (2020) standards, were one meta-analysis, four literature reviews, four program or curriculum reviews, and seven group design studies (see Figure 1). Out of this literature, seven pieces reported an increase in sexual education knowledge (Caspar & Glidden, 2005; Graff et al., 2018; Jurkowski, 1994; Lindsay et al., 2008; McDermott et al., 1999; Murray, 2019; Schaafsma et al., 2015). However, nine pieces of literature (included some that reported increase in knowledge of some or all participants) stated that there needs to be more research in modifications and/or adaptations necessary for individuals with ESN, found the interventions to be ineffective for individuals with ESN, and/or found a need for more training and education for implementation (Blanchett & Wolfe, 2002; Couture & Daigle, 2011; Graff et al., 2018; Murray, 2019; Schaafsma et al., 2013; Schmidt et al., 2020; Sobsey & Mansell, 1990; Whitehouse & McCabe, 1997; Wu & Zeng, 2020). Five pieces of literature specified needing to examine maintenance and generalization of interventions and/or validity of the measures used (Blanchett & Wolfe, 2002; Graff et al., 2018, Sala et al., 2019; Schaafsma et al., 2015; Schaafsma et al., 2013). Four pieces of literature also reported a lack of dignity and respect for individuals with ESN, their want and needs for relationships, and/or found restrictive views of sexuality

Figure 1

CSE Search Results



Note. This figure is an overview of the search results.

AP=anatomy and physiology, CHR= consent and healthy relationships, GI=gender identity and expression, ID= identity, IV= interpersonal violence, MM= menstrual management, PD= puberty and adolescent sexual development, SH= sexual health, SI= sexual orientation and identity

*based on FoSE (2020) standards

and identity (Couture & Daigle, 2011; Lofgren- Martenson, 2012; Whitehouse & McCabe, 1997; Wings-Nanez, 2014). One specified using single sex groups in conjunction with intensive training for teachers increases effectiveness (Gonzalvez et al., 2018; see Appendix A).

Interpersonal Violence

The sixteen pieces of literature examining IV, included eight literature reviews, one program or curriculum review, two group design studies, and four single case design studies (see Figure 1). Seven of these pieces of literature reported positive gains in developing skills, especially decision making skills, but not all skills related to PS (Dukes & McGuire, 2009; Egemo-Helm et al., 2007; Hickson et al., 2015; Khemka et al., 2005; Kim, 2016; Lumley et al., 1998; Ward et al., 2012). However, nine pieces of literature reported issues with maintenance and generalization, lack of validity, and/or poor research methodology (Bruder & Kroese, 2005; Chrastina & Vecerova, 2020; Doughty & Kane, 2010; Dukes & McGuire, 2009; Egemo-Helm et al., 2007; Hickson et al., 2015; Kim, 2010; Lumley & Miltenberger, 1997; Lumley et al., 1998). Four pieces of literature reported needing a better understanding of individuals with ESN, decreasing bias of

curriculum developers and teachers or staff implementing the interventions, and a need for more adaptations or modifications specific for individuals with ESN (Barger et al., 2009; Jung et al., 2019; Kim, 2010; Lumley & Miltenberger, 1997; see Appendix A).

Puberty and Adolescent Sexual Development

Out of the three pieces of literature concerning PD, two were specific to menstrual management (MM), and both were single case design studies (see Figure 1). The two pieces of literature examining MM, all focused on teaching females with different diagnoses to use sanitary napkins and used different interventions. While both were successful, the participants were not given a choice of MM products and neither were replicated (Ersoy et al., 2009; Veazey et al., 2016). One piece of literature involved five young adults with DD and found a functional relationship between self-monitoring and increased hygiene skills (Gushanas & Thompson, 2019). While these pieces of literature found successful results, and most found maintenance and generalization of skills, all implemented different interventions and none were repeated so it is unknown if results can be replicated (see Appendix A).

Anatomy and Physiology

There was one literature review and one single case design study examining AP (see Figure 1). The single case study involved three children with mild to moderate disabilities (MMD) who increased skills of tacting or labeling body parts (Kim, 2016). While the study found positive results, it has not been replicated. The literature review stated that all 33 studies included in the review involved had multiple methodological issues and were therefore invalid (Sala et al., 2019; see Appendix A).

Sexual Health

There were four pieces of literature examining SH: two group design studies and two literature reviews (see Figure 1). Both group design studies examined the same computer-based intervention program, one involved women with MMD and one involved men with MMD. Both studies had positive results of increasing tacting and skills related to sexually transmitted infections and human immunodeficiency virus. However, it should be noted that both studies were implemented by the same researchers so replication of results in other environments is unknown (Wells et al., 2012; Wells et al., 2014). There was also one literature review concerning SH, that concluded, out of 32 documents, there was a lack of understanding of individuals ESN and a need for more research to create effective CSE (Jung et al., 2019). One literature review examined pregnancy and reproduction with women with intellectual and developmental disabilities (IDD). It found that even in 37 articles, these women were not actively involved in the decisions related to the contraception methods used for their MM. It was also reported that these women were not involved in most conversations with their health care providers and should be given dignity to be part of the conversation (Verlenden et al.; 2019; see Appendix A).

Sexual Orientation and Identity and Consent and Healthy Relationships

SI and CHR were not studied on their own and the results of the literature examining these results have been discussed above (Dukes & McGuire, 2009; Kim, 2016; Ward et al., 2012; see Figure 1; see Appendix A).

Gender Identity and Expression

There were no studies that examined GI (see Figure 1).

Participants

Out of the 38 pieces of literature kept, only eight specified involving minors, defined as individuals under the age of 18 years old. Out of those eight, four also involved adults, and three involved minors between 15-17 years old. Therefore, there has been very little research involving minors who are the ages mainly found in schools who would have more possibility of access to CSE curriculum. Only 13 pieces of literature specified gender of participants (11 with females and two with males). Most participants were labeled as IDD, DD, ID, mental retardation (MR), or MMD which does not necessarily mean that these participants would be in an individual with ESN. Only two pieces of literature specified participants with either MSD or moderate severe mental retardation (MSMR) and three specified participants with ASD and ID or IDD. Therefore, only five out of 38 pieces of literature most likely included individuals with ESN while studying the effectiveness of interventions (see Appendix A).

Excluded Literature

There were some themes found within the literature that met exclusion criteria that are important to note to show that there is a large amount of literature either focusing on reactive strategies and/or giving credence to the need for more effective CSE for individuals with ESN. Six-hundred twenty pieces of excluded literature examined the attitudes, bias, and/or perspectives of teachers, staff, and/or caregivers about sex and sexuality related to individuals with ESN. Of those, 59 focused on most effective strategies for changing these bias. Three-hundred two pieces of excluded literature examined forced sterilization and/or MM, 271 examined sexual abuse and/or sexual abuse survivors with IDD, and 111 examined inappropriate sexual behaviors and/or public masturbation.

Search Two: Status of Use and Knowledge of Contraceptives

The first step of understanding the importance and need for more education about contraceptives for students with ESN is to understand if this population is actually using contraceptives and the level these individuals understand why they are using the contraceptives. One-hundred-nine articles came back, 86 once duplicates were removed. Six of these abstracts and articles met inclusion criteria. An ancestral search was completed and 37 more articles were found to meet inclusion criteria, with a total of 43 articles in this analysis. This literature consisted of 19 qualitative studies or questionnaires, 13 group studies, three mixed methods studies, three literature reviews, two medical record reviews, one intervention evaluation, and one case study. In these articles, at least 9,193 women with ESN, aged 15 and older, were included in different studies and reviews. Out of the participants in these 43 articles, 13.52% were using contraceptives, 0.38% had used an emergency contraceptive in the last twelve months, and 3.47% reported sexual relationships (Bernert, 2011; Brown et al., 2018; Burke et al., 2010; Chamberlain et al., 1984; Dotson et al., 2003; Egan et al., 1993; Gil-Llario, 2018; Grover, 2002; Hamilton et al., 2011; Hamilton et al., 2012; Hillard, 2012; Huovinen, 1993; Kaskowitz et al., 2016; Kijak, 2013; Kirkham et al., 2013; McCarthy, 2009; Mosher et al., 2018; Pownall et al., 2020; Quint et al., 2006; Schaafsma et al., 2017; Servais et al., 2002; van Schrijnstein et al., 2011; Tenenbaum et al., 2011; Timmer et al., 1981; Wu et al., 2017; Wu et al., 2018). Out of all the participants, only 5 women were identified who were part of the decision-making process about which contraceptive they would use (McCarthy, 2009). Most participants reported that they had either not been given information or the decision was made by a caregiver or physician and they were

unsure why they were taking one contraceptive over another (e.g. Bernert, 2011; Brown et al., 2018; Dotson et al., 2003; Egan et al., 1993; Hamilton et al., 2012; Hillard, 2012; Jahoda & Pownall, 2014; Kaskowitz et al., 2016; see Appendix B). Although Brown et al. (2018) found that women with ESN are 3.7% more likely to have rapid repeated pregnancy, Mosher et al. (2018) found that women with ESN are also 4.7% less likely to receive services, 2.8% less likely to get birth control counseling, and 3.8% less likely for a check up on their birth control.

Women with ESN need more access to informed care in the medical setting but also are not getting adequate background knowledge from CSE. While in 3 studies women with ESN could name 3 contraceptives (the pill and condom being the most generally discussed), it was also found that, 50% of participants in one study reported that contraceptives were not addressed in their CSE curriculum (Leuter & Mihokovic, 2007; Kijak, 2013; Schaafsma et al., 2017). Edmonson et al. (1979) found that on a CSE test, women with ESN scored 28% lower on contraceptive questions compared to 12 other CSE topics. This type of scoring was found again by Galea et al. (2004) with contraceptive questions having the 2nd lowest scores. Women with ESN scored 19.3 points lower than women without ESN on one questionnaire about contraceptives and 7.19 points lower on another (Jahoda & Pownall, 2014; McCabe, 1999).

Dotson et al. (2003) reported that half of the women with ESN in their study were not sure if they were even able to get pregnant and one participant had never heard of contraceptives. Women with ESN also reported that romantic relationships were important to them and that contraceptives prevented pregnancy but only 59% of participants in one study could recognize a picture of a condom (Sieblink et al., 2006).

The information regarding education is inconsistent but also clearly shows that women with ESN need more appropriate education surrounding this topic. The focus of studies has also concentrated on preventing pregnancy although many women with ESN are referred by their physicians and/or caregivers for contraceptives to help regulate menses, regulate blood flow during menses, and help stabilizing moods during menses (Burke et al., 2010; Hamilton et al., 2011; Hamilton et al., 2012; Kaskowitz et al., 2016). All authors in this review concluded that more education for women with ESN as well as providers is needed as well as needing more appropriate education materials and resources to meet this population's needs. Most participants indicated that they wanted to be more educated and involved in the decision-making process (see Appendix B).

Search Three: Contraceptive Interventions and Education

This search resulted in 441 results, 295 when duplicates were removed. There were no abstracts or articles that met inclusion criteria.

Search Four: Self-Determination

The second piece of this study is teaching the participants how to be part of the decision-making process involved in choosing an appropriate contraceptive for themselves. This is something that many neuro-typical individuals take for granted and many of the participants in the first search indicated that they would like to increase in their lives. This literature search came back with 954 results and 647 after copies were removed. Following the abstract review, 21 articles were kept for further review. After reviewing these articles, 13 were determined to meet inclusion criteria. Five of these articles resulted in increased SD skills and/or knowledge. However, eight included interventions specific to increasing individuals with ESN ability to be part of the

decision-making process related to their academic placement, residential placement, leisure activities, job placement, communication devices, and in health settings. The following EBPs were used to teach SD skills to the participants (listed in order of how often utilized in the studies): modeling, visuals, prompting, preference assessment, scripts, errorless teaching, constant time delay, role play, reinforcement fading, tangible reinforcement, and a graphic organizer. All studies found success (Faw et al., 1996; Hammer, 2004; Palmer & Wehmeyer, 2003; Sigafos et al., 2005; Singh et al., 2003; Test & Neale, 2004; Torres, et. al., 2021; see Appendix C).

Four Studies

There were four studies that stood out for their design and respect toward students with ESN as individuals that helped guide the design of this study.

1. Faw et al. (1996) used a multiple probe (MP) study to increase SA in adults with IDD regarding choosing their own residential facility. The authors used three preference assessments to increase reliability and assess participants' preferences for different rules, settings, etc. in their residences. After this was conducted and their answers analyzed, the authors created graphic organizers specific to each participant to help them ask or find information about what was important to them (i.e. smoking allowed, visiting hours, how many people live there). Visuals were also incorporated in to any pamphlet or questionnaire used. Through modeling and role play, the participants learned how to gain this information using their specific graphic organizer and informational pamphlets so that they could find information about different residential facilities and be an active part of making this decision. The authors also used a pre-and post-questionnaire to measure increase in this skill.

2. Hammer (2004) used a multiple baseline across participants (MBAP) study to increase students' active engagement in their individualized education plan (IEP) meetings. The author used an interview as baseline to measure how active the participants could engage in the IEP conversations. The participants then viewed a computer program that taught what an IEP meeting was for and the different parts. After the educational piece, participants used role play with prompting to work on skills of SA while in an IEP meeting so that they could ask questions and let others know what they wanted in their educational experience.

3. Bollman and Davis (2009) used a MP study to increase women with IDD's ability to report inappropriate staff interactions. The authors used a panel of different professionals to create videos of inappropriate staff interactions with examples and non-examples of how to respond. The authors then used role play with the participants on how to respond in different scenarios with scripts. Social reinforcement was used for responding correctly with corrective feedback as needed. The authors used generalization probes with other trained people who would initiate an inappropriate interaction.

4. Torres, et. al. (2021) used a MP study to increase individuals with ESN's ability to evaluate possible job offers and decide which one best suits their needs and interests. The authors used remote video coaching or teaching that included a visual graphic organizer for participants to circle "yes" or "no" to different aspects of the job placement. A task analysis (TA) was created to score how many steps the participants could complete on their own as well as score intervention fidelity data. All three participants could meet mastery and keep their skills at mastery level at generalization and maintenance probes.

Search Five: Self-Determination and Contraceptive Use

This search yielded seven results, four were new and had not been found in other searches. However, zero met inclusion criteria.

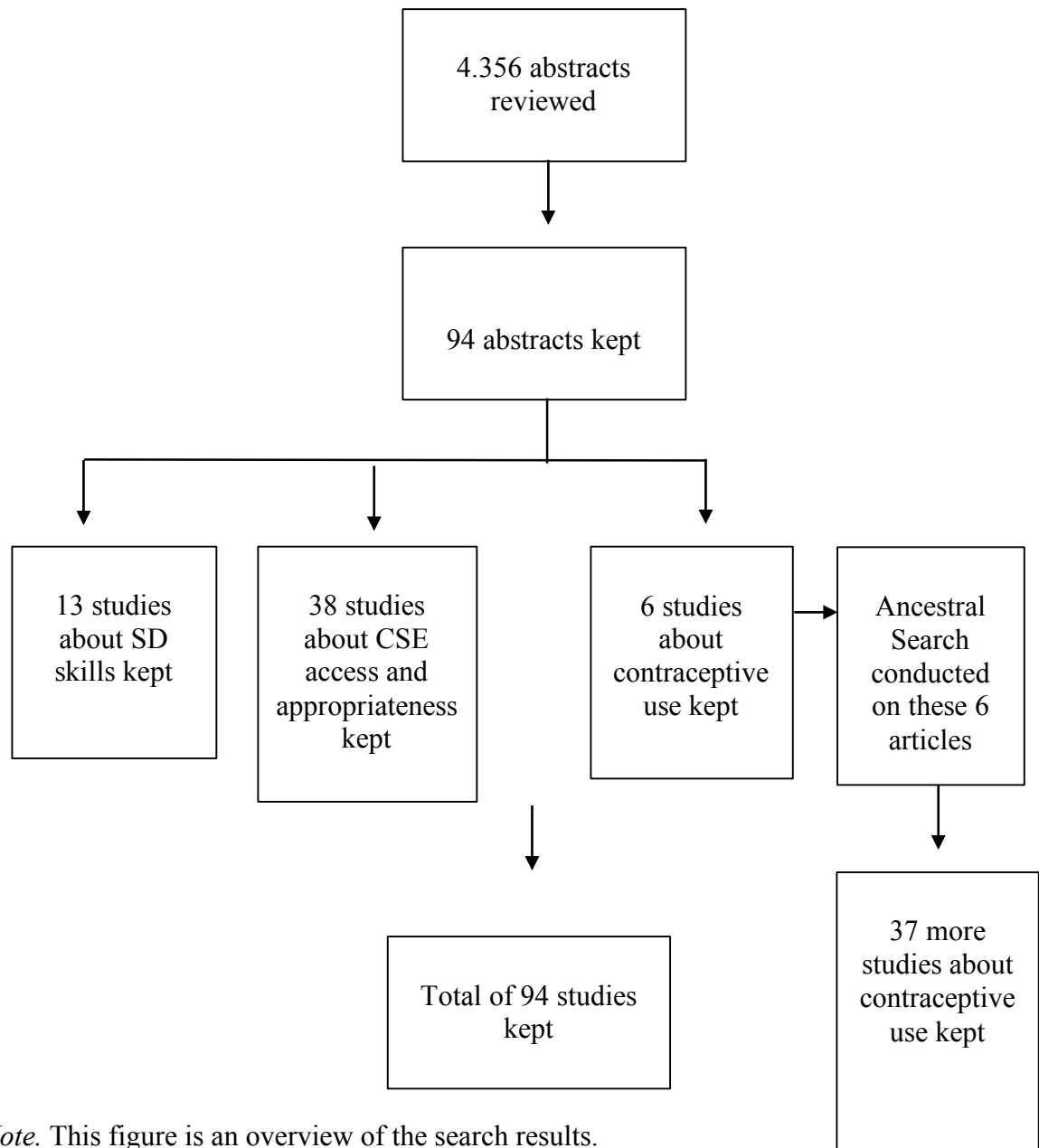
Overview of Five Searches

Overall, 4,356 abstracts were reviewed. Ninety-four of these abstracts were kept for further review. Following an ancestral search that yielded 37 more articles, a total of 94 articles were examined related to contraceptive use, CSE, SD skills, and interventions for women with ESN (see Figure 2). The literature related to contraceptive use and education shows that women with ESN do use contraceptives yet there is inconsistency in their understanding of the contraceptives and most are unaware of other choices. Choices were made by caregivers and physicians without appropriately educating the patients. The women were already at a deficit prior to seeking care without having access to this information and/or education in their schooling which is directed by law.

While there are interventions related to CSE, almost all were not found appropriate to students with ESN and need more modifications and accommodations to truly teach students with ESN. There is not any current literature related specifically to contraceptive use and increasing this knowledge and decision-making. There is promising research for teaching SA/SD skills yet not related to contraceptive use and choices. There is a clear deficit in research to support women with ESN to be an active part of their healthcare as adults and to be treated to same as their peers. The next chapter outlines the methodology used to help promote SD skills for individuals with ESN related to MM.

Figure 2

Outline of Search Results



Note. This figure is an overview of the search results.

CSE=comprehensive sex education, SD= self-determination

Study Components

Behavioral Skills Training

Behavioral skills training (BST) is a widely-used and effective intervention to increase skills or skills set (behavior chains) that contains four main components: (1) instruction, (2) model of the skill, (3) role play or rehearsal, and (4) feedback (Leaf et al., 2016; Ward-Horner & Sturmey, 2012). This system or package has been used since the 1970s at least to teach social skills (e.g. Bornstein et al., 1977; Turner et al., 1978). Briedenbach (1984) was the first to use the term BST when 34 school-aged children were taught anger management skills with the intervention package. Since then BST has been used to teach neuro-typical and neuro-diverse children and young adults to complete different skill sets from interview skills, using a picture exchange system, asking for help when lost, learning to ride a skateboard, and more (e.g. Edgemon et al., 2020; Leaf et al., 2016; Pan-Skadden et al., 2009; Rosales et al., 2009; Thomas et al., 2016).

BST has also been found an effective intervention for teaching pre-service teachers and board certified behavior analysts (BCBAs) different skill sets and interventions to use in their practice with individuals with ESN (e.g. Hogan et al., 2015; Kirkpatrick et al., 2019; Sarokoff & Sturmey, 2004). There has even been success of increasing parents' skills of implementing interventions and supports in their homes with their children with ESN (Schaefer & Andzik, 2021). Due to the large evidence base of the effectiveness of BST and its use in the four articles outlined above, it was chosen as the intervention package used in this study to teach the behavior chain of asking about choices in contraceptive care.

Task Analysis

A task analysis (TA) is a tool and intervention that break a behavior chain down in to different steps. A behavior chain is a complex skill that is made up of many small

skills. For example, brushing your teeth begins with gathering the materials you need (i.e. toothbrush, toothpaste, mouthwash), then you brush your teeth (front side, back), then you rinse, then you spit, then you wipe your mouth, then you put your materials away. A TA would display each small skill inside this complex skill or behavior chain for a person to follow (Cooper et al., 2007; Steege et al., 2007). TAs have long been found an effective intervention for teaching behavior chains or complex skill sets. TAs have been used to successfully teach and monitor a variety of skills to individuals with IDD such as sewing, social skills, janitorial skills, yoga and hygiene skills. The TAs are first used to teach behavior chains and then used to monitor progress in learning and maintaining these behaviors chains. Sometimes the learner tracks the TA and sometimes the teacher tracks the TA (e.g., Cronin & Cuvo, 1979; Cuvo et al., 1978; Parker & Kamps, 2011; Stokes et al., 2004; Torres et al., 2018). TAs were chosen to be part of this study due to the evidence base supporting their effectiveness in teaching and monitoring behavior chains. This study is focusing on the large behavior chain of talking to a doctor about choices in contraceptive care which is a large and complex behavior chain. A TA helped to organize the steps necessary to effectively asking questions of a doctor.

Graphic Organizer

Graphic organizers are tools used for individuals with IDD to organize information in a meaningful way. They can include visuals, sentence starters, fill ins, and more. These organizers give visual element to connect information that increases comprehension and memory of content. These organizers can be set up in a variety of ways (e.g., Venn diagram, mind map, flow chart) and have been effective tools to increase comprehension of material read or heard about a variety of content from

functional skills, social studies content, reading comprehension, and more (e.g. Behtune & Wood, 2013; Bishop et al., 2015; Douglas et al., 2011; Hall et al., 2013). Due to the goal of participants being able to record information from a doctor about contraceptive content in hopes of using this information to make an informed decision later, graphic organizers were chosen to help participants with managing and comprehending the information given to them.

Visual Supports

Visual supports consist of adding a photographic or picture icon (can be realistic, cartoon, or somewhere in between) to a word or phrase to help with comprehension. Comprehension of the word or phrase is increased by connecting it to something that learner has seen or knows what it is already. For example, using a picture of an apple above the word apple so a learner can select it to ask for an apple, understand what the word apple says while reading, and more (Jaime and Knowlton, 2007; Tissot & Evans, 2003). Visuals were implemented in two different parts of this study due to their effectiveness at increasing comprehension. Visuals were used in the educational packet (described in Chapter Three; see Appendix H, I) to increase content knowledge and comprehension of participants about their menstrual cycle and contraceptive choices. Visuals were also used in the participants' graphic organizers (described in Chapter Four, see Tables 3, 4, 5) to assist them in completing their behavior chain.

All Components

The above components were chosen for this study based on the evidence base for them in increasing content knowledge and/or skills for individuals with ESN. It was believed that the evidence base gave promise to the effectiveness of these interventions for

building self-determination skills related to menstrual management for individuals with ESN.

CHAPTER THREE: METHODOLOGY

This chapter outlines the methods used in this study including purpose of the study, research questions, information about participant inclusion criteria, setting of the study, and materials used. Details about the study design, pre-baseline measures, the independent variable, the dependent variable, validity data, and reliability data are also included.

Purpose of the Study

The purpose of this study is to add to previous research aimed at increasing evidenced-based practices (EBPs) related to comprehensive sex education (CSE) and self-determination (SD) skills for students with extensive support needs (ESN). Students with ESN are defined as individuals who need continuous and widespread supports necessary for academic, communication, and/or daily living skills. These individuals typically have multiple diagnoses including a developmental disability (DD), intellectual disability (ID), and/or traumatic brain injury (Kurth et al., 2019; Taub et al., 2017). Specifically, the purpose of this research is for individuals with ESN who menstruate to learn to be an active participant in decision-making about their care by asking questions to inform their choices on medical interventions related to their menstrual management (MM). This study was approved by the Institutional Review Board (IRB) at the University of Louisville (U of L; see Appendix D).

Research Questions

1. Does behavioral skills training increase the skill of stating needs and asking questions, measured by a score on a task analysis, about medical interventions related to menstrual management for individuals with extensive support needs?
2. Does behavioral skills training increase the skill of completing a graphic organizer to record information (circle and/or write answers) related to individual preferences about menstrual management for individuals with extensive support needs?

Methodology

Study Design

A single case multiple-probe (MP) design was used to evaluate the acquisition of skills to ask and evaluate choices related to individual preferences for contraceptive choices. MP designs are a variation on multiple baseline across participant (MBAP) design and used to determine the effect of an independent variable on the acquisition of skills or a behavior chain (a skill that is made up of several smaller skills). MP designs are often used to measure successive approximations of a skill, meaning during each probe the participant performs a skill closer and closer to the desired outcome and used in these situations instead of MBAP (Horner & Baer, 1978). In this study, the goal was to have each participant reach mastery of the skill of asking questions to a doctor and then completing their graphic organizer. The goal was that after each behavioral skills training (BST) session with feedback and modeling the participant would be able to complete the skill or behavior chain closer to mastery on each probe which is the reason an MP design was determined to be the most appropriate.

Participants

To be eligible for the study, participants had to meet the following inclusion criteria: (a) presence of ESN [as reported by caregivers based on the diagnos(es) given to participants by medical professionals or school evaluations], (b) school aged (21 years old or younger), (c) had the biological ability to menstruate, (d) experienced at least one full menstrual cycle, (e) ability to write simple numbers and circle answers, (f) ability to communicate independently (e.g., vocalizations, gestures), (g) ability to attend to instruction/modeling procedures for at least 10 minutes. Inclusion criteria a and b were chosen due to the lack of research and resources available for individuals in these populations in this subject area. This information was gained from report by the primary caregivers. Inclusion criteria c and d were chosen because of the subject matter (MM) and the fact that every individual with a menstrual cycle has different needs and concerns based on how their body operates so it was important each participant had personally experienced a menstrual. This information was also obtained by report from the primary caregiver. Inclusion criteria e, f, and g were reported by the participants' primary caregivers and were necessary to make sure each participant could participate in the intervention procedures as designed.

Participants were all under the age of 18; therefore, they required a legal guardian's consent to participate in the study. When caregivers filled out the informed consent form, they were also asked to fill out a brief demographic survey. All participants were asked to assent to participate in the study as well when their caregivers were asked for informed consent. Informed consent and assent forms were reviewed and signed at the first meeting. The forms were approved by the IRB and signed forms are secured in a

locked drawer inside a home office that also locks (see Appendix E, F). All participants' names have been changed to protect their identity.

Setting

Due to global pandemic, school visits were still restricted. Participants were given the choice of participating at their home in person, in a classroom at the University of Louisville in person, or via an online video platform. These options were given for all sessions and probes.

Materials

In Person

For participants who chose to participate in person, we used the following: (a) a printed educational packet, (b) a printed preference assessment, (c) a computer/ printer to design and print an individual graphic organizer, (d) an individualized printed graphic organizer, (e) a writing utensil, (f) the participant's augmentative and alternative communication (AAC) device (if applicable), (g) task analysis (TA) for monitoring steps completed, and (h) an iPad for video recording.

Online

For the participants who chose to participate via an online video platform, we used the following: (a) a computer for the participant, (b) a computer for the researcher, (c) a computer for the doctor, (d) Zoom app for video conferencing and recording, (e) the PowerPoint slides of the educational packet, (f) the PowerPoint slides of the preference assessment, (g) a computer/ printer to design and print an individual graphic organizer, (h)an individualized graphic organizer (printed for the participant and researcher and

emailed to the doctor, (i) a writing utensil, (j) the participant's AAC (if applicable), (k) TA for monitoring steps completed.

Pre-Baseline

Pre-Baseline included four different components: (1) vocabulary probe, (2) an educational packet, (3) three preference assessments, and (4) the development of a graphic organizer. The pre-baseline sessions lasted 30-40 min and sometimes included multiple of the following components. All pre-baseline sessions occurred in person at the participant's home either on the living room couch or at the kitchen table, based on the participant's choice. Other family members, pets, and multiple stimuli (stimuli expected to be present in typical family homes in the U.S.) were present for each session. Each session was conducted and all components were implemented by myself (see Table 1).

Vocabulary Probe

First, a vocabulary probe was conducted to determine if each participant knew and could identify the visual representation of the basic vocabulary that was used in the educational packet. Nine terms were used in this probe: menstrual blood or period, vagina, breasts, shot, pill, patch, cramps or pain, sad, and angry. Each term had three visual representations (one correct and two that were not) for the participant to choose from to demonstrate comprehension. These terms were chosen based on the information in the educational packet that would impact the participants' ability to comprehend their choices and preferences. This was used to determine how much pre-teaching each participant needed to fully understand the options for MM and develop informed choices and preferences (see Appendix G).

Educational Packet

After the vocabulary probe was conducted and the participant scored 80% or higher, then the educational packet was used to aid participants in creating informed preferences and increase their knowledge on all aspects on medical MM (e.g., side effects, symptoms that can be reduced). All educational materials presented to the participants were designed using educational best practices based on interactive read-aloud events during which a text is presented to a student with ESN, read aloud with a professional, and then discussed with the support of a visual representation or picture of certain objects or ideas above the words. During the read-aloud event, the participants were asked questions to check for comprehension. Questions were posed verbally with the support of written words and visuals. These techniques have been found an effective way of teaching different subject matter through reading comprehension for students with ESN (Browder et al., 2007; Browder et al., 2017; Browder et al., 2020; Hudson et al., 2014).

Two different educational packets were created, one including more detail and specifics to use if a participant was not able to answer comprehension questions correctly on the first packet. The more detailed packet gave detail of each MM option (e.g., shots are taken at the doctor's office every 3 months) as opposed to the other educational packet that included an overview of options (e.g., MM can be taken at home or the doctor's office, MM can be a shot, pill, etc.) The packet(s) included: (a) information about the menstrual cycle, (b) symptoms of menstrual cycles that can be problematic or uncomfortable (e.g. pain, excessive bleeding, acne), (c) choices for where to receive MM (e.g. the doctor's office or home), (d) how often different MM needs to be taken (e.g.,

every day, once a month, once a year), (e) how often a period would occur on different MM (e.g. once a month, three time a year), (f) how different MM is taken/ received (e.g. swallowing a pill, getting a shot), and (g) different side effects that have occurred with different MM (e.g. spotting, pain at injection site). Information for the educational packets was taken from the American Academy of Obstetrics and Gynecology (n.d.) and Planned Parenthood (n.d.; see Appendix H, I). After the vocabulary probe and educational packet were reviewed with the participant and they scored at least 80% on all comprehension questions, each participant was given two preference assessments, one was administered prior to the educational packet.

Preference Assessments

A paired-stimulus preference assessment based on the information in the educational packet (listed above) was created and given to each participant three times. The purpose of the preference assessment was to help determine the following information for each participant: (1) which symptoms of their menstrual cycle is most concerning, (2) preferences on how MM is taken, (3) preferences on how often MM is taken, (4) preferences on where MM is taken, (5) preference on how often a period occurs, and (6) concerns about side effects. Paired- stimulus preference assessments are designed to rank an individual's preferences by presenting two different stimuli at one time. The stimuli here were presented with the words and visual supports used in the educational packet. For example, the choices of "swallow a pill" or "get a shot" would be presented and the participant would make a choice. If they chose "swallow a pill", then they would be presented with "swallow a pill" or "get a patch" and so forth. This happened for the categories two through five listed above. For categories one and six,

participants were presented with a list of all possible symptoms and side effects to indicate which were most concerning to them (Carr et al., 2000; see Appendix J).

Individuals with ESN often will make choices when asked but that is not always indicative of what choice they want to make, just that the individual is completing the action of making a choice. Past researchers have given preference assessments to individuals with ESN three times to validate the choices of participants (Faw et al., 1996). Participants were given the preference assessment once before the educational packet and twice after reviewing the educational packet. More detail about the preference assessment. The decision to complete one before the educational packet was to observe if the educational packet made a difference in the participants' opinions because they had more information about the different components of MM. These preference assessments were video recorded to obtain inter-observer agreement (IOA) for reliability. An independent researcher and I watched the video recordings of the preference assessments and would mark which choice the participant chose. Then I would look at both IOA forms and determine if the independent researcher and I marked yes and no on the same choices. If there was ever a discrepancy, the plan was to watch the video together and discuss what we were seeing. This did not have to happen during this study (see Appendix K).

Caregivers were also given a preference assessment to determine if their preferences and/or what they assumed their child would prefer would match. These answered were compared to the preferences chosen by the participants to examine if caregivers' choices would align with what each participant wanted (see Appendix L).

Graphic Organizers

Following the preference assessments, each participant created an individualized graphic organizer based on their preferences with the assistance from myself. Graphic organizers have been found to be an effective way to help students with ESN to connect information, record information, and assist in asking questions (Dieruf et al, 2020; Shogren et al, 2015). Participants chose the following to include in their graphic organizers: (a) how they wanted to greet the doctor, (b) how they wanted to phrase what they were concerned about related to their specific menstrual cycle, (c) what questions they wanted to ask about MM and how to phrase them, (d) what side effects they were concerned about related to MM, (e) visuals to accompany their words, and (f) how the information on graphic organizer was ordered (see Figures 3,4,5 in Chapter Four).

Baseline

Baseline probes were conducted by myself and took place after the completion of the graphic organizer. All participants chose to meet in person at their homes. Caregivers, for each participant, gave the choice of the living room couch or the kitchen table. Participants were asked to choose where they wanted to sit each time. Other family members, pets, and multiple stimuli (stimuli expected to be present inside typical family homes in the U.S.) were present for each probe. Participants were prompted “pretend that the doctor just walked in” and were asked to use their graphic organizer to ask questions and record the information. No other prompts were given but I did answer the questions as if I was the doctor (e.g., “you take the pill at home”). All forms of communication were accepted (e.g. vocalizations, vocal approximations, gestures, American sign language [ASL]). Only social reinforcement was given at the end of the probe (e.g. “good

job”). Baseline probes lasted between zero to three minutes and were video recorded on an iPad to obtain IOA.

The aim was to obtain at least three to five baseline probes per participant. However, two participants independently communicated that they did not want to try to ask the questions or complete the graphic organizer without help from myself. The participants started engaging in some mild tantrum and elopement behaviors clearly communicating that they were stressed about having to try something they could not do. This made the primary caregivers start to get frustrated with their child and try to intervene, also communicating a level of stress. Research should not cause undue stress on the participants or their caregivers, as an ethical issue. Therefore, the ethical decision to respect the participants’ decision and reinforce their communication for help was made to move on to the intervention (Grady et al., 2014; Hill, 2006; see Table 1).

Independent Variable

The independent variable (IV) was the use of BST to increase SD skills of asking questions and recording information pertaining to preferences on MM. BST is an EBP that has been successfully and effectively used to increase new skills for individuals with ESN (e.g., self-determination skills). BST consists of the following: (1) educate about a skill, (2) model the skill, (3) the learner tries the skill, (4) specific feedback is given about the learner’s try, (5) repeat until a pre-determined level of mastery is met (Schaefer & Andzik, 2021; Ward-Horner & Sturmey, 2012). In this study, the first step of BST was me modeling how to use the graphic organizer to communicate with the doctor (ask questions, state preferences) and fill in the graphic organizer with the correct answers. I explained to the participants about how asking the questions would help them get

answers about their preferences and filling it in would help them remember the answers. The participant then attempted to independently complete the skills (ask the questions and fill in the graphic organizer). After the participant attempted to complete the skills I modeled, I gave feedback based on the specific participant's performance and modeled, again, how to improve their skill acquisition. The model-role play-feedback cycle continued until the participant reached the pre-determined mastery level (Ward-Horner & Sturmey, 2012).

These sessions lasted between 30 – 60 minutes and included probes to track the participants' progress of skill acquisition and different aspects of BST, like modeling and feedback. The number of sessions and probes was different for each participant and depended on when they each reached mastery which was defined as a score of 80% (on the TA, discussed below) for three consecutive probes and completing the graphic organizer without prompts for at least three consecutive probes. The probes were all video recorded on an iPad to obtain prompting fidelity data (the prompting given to the participants during probes) and IOA on TA scores. Probes lasted between 1 to 6 mins, depending on how much the participant could complete on the graphic organizer. After the completion of the graphic organizer and implementation of BST, sessions would include more than one probe with feedback and a break of at least 5 min was given to the participant between probes where they could listen to a song, get a snack, or just relax. Sessions sometimes included more than one probe so that the study could keep moving along as opposed to taking several more weeks with only one probe each session (see Table 1).

Generalization and Maintenance Probes

Generalization probes are important to determine if skills and/or knowledge gained in a study will also occur in a different environment (Cooper et al., 2007; van den Pol et al., 1981). This study was designed to build SD skills to speak to a doctor about options for reversible birth control. It was important to measure whether participants could use the skills built in their home when working with myself while speaking with a doctor they had not met before. The generalization probes occurred after each participant reached mastery and lasted between 5 to 7 min and only included the prompting procedures and redirections (detailed below), no other aspects of BST were used because these were only probes to observe if the skills remained at mastery level in a different environment and/or after several weeks. BST was only used to build the skills.

The generalization probes included a doctor present; all participants chose to meet with the doctor via video conferencing. I sat with the participants at their kitchen table while we signed on to the video conferencing app to speak with the doctor. Female doctors were asked to take part in the generalization probes to provide a level of comfort for the participants. It became clear that this was the correct choice as two of the participants expressed that they hoped the doctor was a “girl” before signing on to the video conferencing app. I sent the specific participant’s graphic organizer to the doctor ahead of time. This decision was made since the graphic organizers were supports and aided in communication; if the probes had been in person, the doctor would have seen the graphic organizer. It can be difficult to see documents via video conferencing so the doctors were sent the graphic organizers so they would have access to the communication supports and see what they would have seen if it was in person. At times, during the

generalization probe, I would repeat what the participant communicated due to audio issues with video conferencing; however, it was only after the participant communicated the idea first.

Maintenance probes are used to determine if skills and/or knowledge gained stayed with the participants and can be measured later (Cooper et al., 2007). The maintenance probes occurred in person 6 to 10 weeks after the generalization probe, based on scheduling availability of the participant. All maintenance probes occurred in participants' homes at their kitchen tables. These probes lasted 4 to 6 min. Only the prompting procedures and redirections were used for these probes, no other aspects of BST were used because these were probes to observe if the skills remained at mastery level in a different environment and/or after several weeks. BST was only used to build the skills. For one participant, their first generalization probe was unable to occur due to the doctor having a last-minute emergency so the participant's generalization and maintenance probes were conducted together. The generalization and maintenance probes were video recorded on the video conferencing software to obtain IOA for the TA and prompting fidelity data (see Table 1).

Table 1

Timeline of Sessions

Session	Activities
One	Sign Informed Consent and Assent Forms Explain Study
Two	Complete Vocabulary Probe Complete First Preference Assessment Caregivers Fill Out Their Preferences
Three	Complete Education Packet Complete 2 nd and 3 rd Preference Assessments

Four	Create Graphic Organizer Baseline Probe(s)
Five +	BST: Modeling, Role Play, Training Repeat
Six	Generalization Probe Social Validity Probe
Seven	Maintenance Probe

Note. This table explains the timeline of the study.

Prompting Procedures

Least to most prompting was used with participants. This is a strategy that allows the learner time to show what they know and began with the least intrusive prompt (e.g. asking the participant to communicate their concerns) and built to more intrusive prompts (e.g. saying the entire word or sentence to be repeated; Cooper et al., 2007). There were three levels of prompts used: (1) a verbal prompt to talk to the doctor, (2) a gestural prompt of pointing to the specific step they were on on the graphic organizer, (3) a full verbal prompt of modeling how to complete the step they were on response prompts have long been found effective for teaching behavior chains of different skills (Cooper et al., 2007, Cuvo et al., 1978). Prompts were faded to help with generalizing skills and reducing the possibility of prompt dependence (Libby et al., 2008; see Appendix M).

Reinforcement

Only social reinforcement was utilized in all phases of the study. Reinforcement is what causes a behavior or skill to be repeated in the future as it gives some benefit to the learner. Social reinforcement is saying something like “good job”, “way to go”, or “nice job”. It could also be a fist bump or high five as well (Eby & Greer, 2017; Hammond, 1980).

Dependent Variable

Task Analysis

A TA was created to score the behavior chain of asking the questions to the doctor, with guidance from the graphic organizer, during each probe. Participants also saw the TA but were focused on the graphic organizer during the probes, focusing on both documents would have been overwhelming. The TA included the following steps in the graphic organizer (a) expressing why they were at the appointment, (b) asking for help, (c) asking questions about three different options, and (d) asking about side effects. There were 8 redirections that could be given to indicate time to start the next step in the behavior chain. Since participants asked about three choices, some redirections had the chance to be given more than once resulting in the possibility of 20 redirections total. A redirection is defined as a verbal prompt to call the participant back to the task at hand when distracted by environmental stimuli. It also included a place to record the prompting level needed to complete the different steps of the behavior chain. There were three prompting levels (least to most) used: (1) a verbal prompt to talk to the doctor, (2) a gestural prompt of pointing to the specific step they were on for the graphic organizer, (3) a full verbal prompt of modeling how to complete the step they were on. The maximum score was 40, mastery (at least 80%) was a score of 32-40. This score of 80% or higher was chosen to show mastery as this has been a long-accepted rule in behavior analysis and special education (Leaf & McEachin, 1999; Pitts & Hoerger, 2021). There was a space to record if the prompting procedures were completed with fidelity by the member of the research team. There was also a list of eight redirections that were given, as

necessary, for the participant to move on to the next step of the behavior chain and the number of redirections needed was recorded on the TA as well (see Appendix M).

These data were collected to answer the first research question: Does behavioral skills training increase the skill of stating needs and asking questions, measured by a score on a task analysis, about medical interventions related to menstrual management for individuals with extensive support needs?

Permanent Product

For the completion of the graphic organizer, permanent product recording data was taken (Kelly, 1976). These data reflect that participants completed the graphic organizer or did not. The completion of the graphic organizer was defined as a participant recording the information they received by either circling the answer to a question or writing what was said by the doctor without prompting (see Figures 3,4,5 in Chapter Four). The participants were not trained to mark or record information as the ability to write and record simple information was a requirement to be included in the study.

These data were collected to answer the second research question: Does behavioral skills training increase the skill of completing a graphic organizer to record information (circle and/or write answers) related to individual preferences about menstrual management for individuals with extensive support needs?

Validity and Reliability

Social Validity

Social validity is an important aspect of determining if an intervention is useful and important to the individuals who may use it in the future; something is not seen as

useful, efficient, and important then the intervention will most likely not be employed (Wolf, 1978).

Social validity measures were incorporated with a short questionnaire for the participants completed after the generalization probe. It was given at this time in case an event occurred that prevented the participant from meeting for the maintenance probe. This questionnaire had six questions that were answered by selecting “yes”, “no”, or “maybe” with visuals consistent with the materials used during the study. The questions asked about the experience of the participants, if they found the intervention helpful, if they liked getting to interact with a doctor, and if they would like to do it again. It also included a prompt to “tell me anything else” to allow participants a chance to communicate any other thoughts or concerns not asked within the survey. The survey was read out loud to participants who needed this support (see Appendix N).

A second survey was given to each participant’s caregiver about their thoughts on the intervention, if their opinions of their child’s skills changed, if they would recommend the intervention to other caregivers, and if they wish that these skills were taught in schools more. This survey had six questions that were answered by selecting “strongly agree”, “agree”, “neither agree or disagree”, “disagree”, or “strongly disagree”. It also contained one open ended question for caregivers to express any other thoughts or comments about the study (see Appendix O).

IOA and Fidelity

Consent was given to video record all sessions for an independent reviewer to view and fill out the TA to get IOA and prompting fidelity data. I trained the independent reviewer was on the intervention and the TA, their answers were correlated to mine to

determine a percentage. Both myself and the independent reviewer would watch the probe via video and each would fill out the TA. The total score for the probe is calculated at the bottom of the TA. The smaller number of the two answers (if there was a smaller number) was divided by the larger number (if there was a larger number) and then multiplied by 100 (Gast & Ledford, 2014). If IOA was less than 80% at any point (baseline, preference assessment, probes) then the session would be repeated until IOA was at least 80%; however, this never occurred during the study. The independent reviewers were also trained on the prompting procedures to record if prompting procedures were implemented with fidelity. If fidelity measures fell below 90% at any point during the study then the session would be repeated; however, this did not occur during the study (Burns, 2012; Maggin et al., 2013).

IOA and fidelity data were collected via video recording for the following reasons: (1) the participants may feel less awkward with only one person instead of two due to sensitive subject matter, (2) participants may be more inclined to be in person with one person instead of two due to concerns with COVID-19, (3) it is easier to coordinate two schedules instead of three.

The three independent reviewers were doctoral students the University of Louisville and had previous experience and knowledge about single case research design.

Data Analysis

Descriptive Statistics

Descriptive statistics were also used to analyze data in this study. The frequency of the skill occurring was recorded on the TA along with the prompting level necessary. These numbers together were then divided by the highest number possible to give the

range. This information was used to determine mastery level (80%) and then put into a graph (Gay et al., 2012).

Visual Inspection

A visual line graph was created of the data obtained from the study. This analysis technique is commonly used to determine when increases or decreases of skills or knowledge have been obtained. The trend and variability of the lines helped to determine when skills increased and/or decreased. The lines that are sloping upwards indicate an increase in the skills while a line sloping downward indicate a decrease in a skill (Cooper et al., 2007; Gay et al., 2012).

CHAPTER FOUR: RESULTS

This chapter details the participants that agreed to take part in this study. It also discusses each participants' preferences, their scores and results during each probe, and their social validity responses. The IOA and fidelity data is also reported for each participant. At the end, the research questions are answered based on the data collected and presented.

Participants

Three participants and their caregivers agreed to join the study. The first participant, Hope, was a 14-year-old White female of Armenian descent with Down syndrome (DS). Her doctors believed she may have poly-cystic ovarian syndrome (PCOS) which often causes pain during the menstrual cycle. Hope communicated through a mixture of vocalizations and American Sign Language (ASL). She was adopted into her family through private adoption and had seven brothers and sisters, five were adopted. Five of her siblings had different levels of support needs (e.g., blindness, autism spectrum disorder). While her siblings were from various ethnic, racial, and cultural backgrounds, English was the primary language spoken at home. She lived in a suburban area outside of a medium size city. Hope chose to meet at their home for baseline, intervention, and maintenance sessions/probes. She met with a doctor via video conferencing for the generalization probe.

The second participant asked to be referred to as Carly Brewster and was an 11-year-old White autistic female with Shaken Baby Syndrome. She was adopted in to her family through foster care. Her mother reported that it is still unclear the severity of the abuse and neglect she endured as an infant before going in to foster care and long term effects on Carly Brewster's development are unknown. She communicated through vocalizations and had one older brother who was typically developing. English was the only language spoken in their home. She lived in a rural community where the closest city was 73 miles away and the community was mainly in low socio-economic status. She chose to meet at their home for baseline, intervention, and maintenance sessions. She met with a doctor via video conferencing for the generalization probe.

The third participant was Meera, a 12-year-old biracial female with DS. She lived with her biological parents who were both dependent on wheelchairs and was an only child. Meera communicated through a mixture of vocalizations, ASL, and gestures. The more time she spent with someone, the more she used vocalizations. English was the primary language spoken in her home and she lived in a suburban area outside a medium sized city. She chose to meet at their home for baseline, intervention, and maintenance sessions. She met with a doctor via video conferencing for the generalization probe.

Hope

Vocabulary Probe and Preference Assessments

Hope scored 100% on her vocabulary probe indicating that she could identify the vocabulary used in the study and what the different words meant (see Appendix G). Hope currently received 100% on the comprehension questions with the first educational

packet, indicating she understood the information without needing more supports from the second educational packet (see Appendix I).

Across the three preference assessments, Hope indicated: (a) she was concerned with her bleeding, acne, pain, and sleepiness during her period, (b) she would prefer a shot or arm implant, (c) swallowing a pill was the third most attractive option for her, (d) she would like to take her medicine every four months, (e) she preferred a doctor administer the medication at an office, (f) she only wants to get her period four times a year, and (g) she is concerned about having a sore arm and ovarian cysts as side effects. On the two preference assessments given after the educational packet, Hope indicated she was concerned with sadness and anger during her menstrual cycle. On the preference assessment given prior to the educational packet, she also indicated she was concerned with spotting and having a sore back as side effects. All preference assessment data had 100% IOA. Hope's results indicated strong validity in her choices due to the consistency between her answers. It was noted that she became more concerned about symptoms after the educational packet and was more concerned about side effects before the educational packet.

Hope's caregiver communicated that they believed she would most like to swallow a pill at home and have her period 1 to 4 times a year. Her caregiver also communicated she believed that Hope was concerned about bleeding, acne, and pain during her menstrual cycle. They did not communicate any side effects that they thought Hope would be concerned with. They were most concerned with being able to manage her pain during her period, especially with the possible PCOS diagnosis. This information indicated that the caregiver's thoughts do align with how often Hope wanted to get her

period and what Hope was concerned about but not how often she wants to receive MM and/or how she would prefer to receive the MM (see Table 2, Appendix J, L).

Table 2

Hope's Preference Assessment Results

Preference Assessment #/ Preference Item	Preference Assessment #1 (prior to EP)	Preference Assessment #2 (post EP)	Preference Assessment #3 (post EP)	Caregiver Preference Assessment
Concerned with excessive bleeding	X	X	X	X
Concerned with acne	X	X	X	X
Concerned with pain	X	X	X	X
Concerned with sleepiness	X	X	X	
Concerned with sadness		X	X	
Concerned with anger		X	X	
Receiving a shot is her 1 st preference	X	X		
Receiving an implant in her arm is her 2 nd preference	X	X		
Swallowing a pill is her 3 rd preference	X	X		
Swallowing a pill is her 1 st preference	X			X
Prefer to take her MM every four months	X	X	X	
Prefer her period 1-4 times a year	X	X	X	X
Wants a doctor to administer	X	X	X	

FIGURE 3










Hope's Graphic Organizer

“My blood”    

hurts gives me bumps makes me sad makes me sleepy

“What can help?”   

a shot a pill put something in my arm

 <p>“I prefer to take it at the doctor’s office, where is this one taken?”</p>	 <p>“I want my blood 1 time a year, how often do I get my blood with this??”</p>	<p>“How do I take it?”</p>	 <p>“How often do I take it?”</p>
  <p>Home Doctor’s Office</p>	 <p>I would get my blood _____ times a year.</p>	   <p>swallow arm get a shot put in</p>	<p>_____ times a day</p> <p>_____ times a month</p> <p>_____ times a year</p>

 “Will this hurt my arm?”

Baseline Probe

Hope completed one baseline probe. She looked over and refused to open her mouth, then asked for help. She indicated she could not nor would she try to complete the graphic organizer or ask questions without support. Hope asked for help to complete the behavior chain and graphic organizer. She said, “I cannot do it” and started asking to go upstairs to her room and her voice level was rising. Her primary caregiver also started becoming upset at Hope’s reaction to baseline. Due to the undue stress of being asked to complete a skill she did not know how to complete, the ethical decision to move on to intervention was made. She scored zero on her baseline probe with 100% IOA (see Figure 6).

Intervention Probes

Hope completed seven intervention probes, reaching mastery level for the last four probes. For the first three probes, she was only able to complete asking about one option on her graphic organizer and required six-seven redirections. For the last four probes, she could ask about all three options on her graphic organizer and required 10-14 redirections. She could complete the graphic organizer independently for the last three probes. Her scores during her seven probes were the following: 1/40, 2.5/40, 17.5/40, 34/40, 33/40, 38/40, 36/40). Her data had 96% IOA and the prompting procedures were implemented with 100% fidelity. It should be noted that Hope required more redirections than other participants. However, she lived in a very busy house with many stimuli and activities going on around where the probes were conducted in the home. Therefore, the fact that she was still able to reach mastery in a real-world situation which is the opposite

of a sterile or clinical situation gave credence to the effectiveness of the intervention (see Figure 6).

Generalization Probe and Maintenance Probe

Hope's first scheduled generalization probe did not occur because the physician having a last-minute emergency. Her generalization probe and maintenance probe occurred at the same time with a doctor, 10 weeks after concluding the intervention probes. I went to Hope's house in person and together we called the physician via video conferencing. Prior to meeting with her, the physician received Hope's graphic organizer via email. She could complete the graphic organizer independently, scored a 29.5/40 on the TA, and needed 9 redirections indicating that, while she did not meet mastery, she was still able to complete the behavior chain 29.5 points higher than baseline and only 2.5 points away from mastery level (at least 32), with a new person, and in a new environment. It should be noted, the physician's audio kept cutting out and communications needed to be repeated multiple times during this probe which was frustrating to the participant and may have impacted the completion of her skills (see Figure 6).

Social Validity

Hope answered "yes" to all six Likert scale questions on her survey indicating that she enjoyed the study, liked to advocate for herself, found the graphic organizer helpful, and liked talking to doctors. She did not want to answer the open-ended question (see Appendix N).

Hope's caregiver answered, "strongly agree" too all six Likert scale questions on her survey as well indicating that she believes Hope is more capable of helping to make

decisions for herself, has more skills to advocate for herself, and she wishes that these skills were taught in schools. She did answer the open-ended question by saying “now that she’s done this I know how to prepare her for doctor’s visits... thank you for that” (see Appendix O).

While the doctor involved in the generalization probe did not complete an official social validity survey, she stated: “I love hearing a patient voice what they want and what they are nervous about, it helps me care for them in a more individualized manner. I wish we had been taught how to communicate with patients who do not speak like we are used to.”

Carly Brewster

Vocabulary Probe and Preference Assessments

Carly Brewster scored 100% on her vocabulary probe indicating that she could identify the vocabulary used in the study and what the different words mean (see Appendix G). She also scored 100% on the comprehension questions with the first educational packet, indicating she understood the material without needing more supports from the second educational packet (see Appendix I).

Across all three preference assessments, Carly Brewster communicated she (a) was concerned about bleeding too much, pain, and nervousness (she independently added this option for herself) with her period, (b) she preferred to either have a shot, implant in her arm, or swallow a pill, (c) preferred to take her medicine at home, (d) wanted to get her period 1 to 4 times a year, and (e) was concerned about the side effects of spotting, ovarian cysts, sore breasts, and pain. On the two preference assessments after the educational packet, she communicated: (a) she was concerned with anger while on her

period, (b) preferred the shot or implant over taking the pill, and (c) preferred to take her MM 1 to 3 times a year. On the first preference assessment, prior to the educational packet, she communicated: (a) she preferred the pill and (b) preferred to take her MM every day. For Carly Brewster, the educational packet influenced her decision about preferred method of receiving MM and how often she wanted to take MM. The consistency across her answers indicated validity in her choices overall. These preference assessments had 100% IOA (see Table 3; Appendix J).

Table 3

Carly Brewster's Preference Assessment Results

Preference Assessment #/ Preference Item	Preference Assessment #1 (prior to EP)	Preference Assessment #2 (post EP)	Preference Assessment #3 (post EP)	Caregiver Preference Assessment
Concerned with excessive bleeding	X	X	X	X
Concerned with pain	X	X	X	
Concerned with nervousness	X	X	X	
Concerned with anger		X	X	
Receiving a shot is her 1 st preference	X	X		
Receiving an implant in her arm is her 2 nd preference	X	X		
Swallowing a pill is her 3 rd preference	X	X		
Swallowing a pill is her 1 st preference	X			X

Prefer to take her MM everyday	X			X
Prefer to take her MM 1-4 times a year		X	X	
Prefer her period 1-4 times a year	X	X	X	X
Preferred to take her MM at home	X	X	X	X
Concerned about having sore breasts	X	X	X	
Concerned about ovarian cysts	X	X	X	
Concerned about spotting	X	X	X	
Concerned about pain	X	X	X	

Note. This figure outlines Carly Brewster’s and her caregiver’s responses on the preference assessments. EP=educational packet; MM= menstrual management

Carly Brewster’s caregiver communicated she thought she would prefer to swallow a pill at home every day and get her period 1 to 4 times a year. She also indicated that she is concerned with Carly Brewster’s ability to comprehend her menstrual cycle and medication. Her caregiver did align with Carly Brewster’s own preferences prior to the educational packet but these changed after the educational packet and were different from what her caregiver thought she would choose (see Table 2; see Appendix L).

Creating the Graphic Organizer.

While creating the graphic organizer, Carly Brewster wanted to start out by stating that she had some questions and then explaining she is concerned about being

nervous, pain, anger, sleepiness, and bleeding too much. She wanted to ask about all medicinal options. She chose to ask these four questions: (1) where the medication is taken (indicating she prefers at the doctor's office), (2) how often she would get her period (indicating she only wants it four times a year or less), (3) how the medicine is taken (indicating she preferred a shot), and (4) how often the medicine is taken. Lastly, she wanted to indicate she was concerned about the following side effects: stomach ache, headache, sore breasts, wet vagina, spotting, and ovarian cysts. Carly Brewster also chose the visuals used and wanted to change some that were consistent with the education packet (see Figure 4).

FIGURE 4

Carly Brewster's Graphic Organizer



Say: " Hello, I have some questions."

Say: "I want help with



being nervous,



angry,



pain,



















sleepiness,



and bleeding too much"

"Can you tell me about a kind of medicine"

Name _____

 <p>“I prefer to take it at the doctor’s office, where is this one taken?”</p>	 <p>“I prefer to have my period 4 times a year or less, is this possible?”</p>	 <p>“I like to get a shot, how do I take this?”</p>	 <p>“How often do I take it?”</p>
 <p>Home Office</p>  <p>Doctor’s Office</p>	 <p>Yes</p>  <p>No</p>  <p>Maybe</p>  <p>I would get my period _____ times a year.</p>	 <p>swallow</p>  <p>put on body</p>  <p>in vagina</p>  <p>get a shot</p>  <p>Dr. put in vagina</p>  <p>Dr. put in arm</p>	<p>_____ times a day</p> <p>_____ times a month</p> <p>_____ times a year</p>

Say “I want to know about these side effects



stomach ache



headache



sore breasts



wet vagina



spotting



ovarian cysts

Baseline Probes

Carly Brewster completed two baseline probes and scored an 8 on both. These had 100% IOA. After the two baseline probes, she asked to not complete the graphic organizer or questions again without support. Carly Brewster began whining and hitting her graphic organizer on the table indicating stress. Her caregiver then became upset with her and asked her to stop and apologized to myself. Due to the undue stress of being asked to perform skills she did not know how to complete, the ethical decision to move on to the intervention probes was made (see Figure 6).

Intervention Probes

Carly Brewster completed four intervention probes, reaching mastery in the last three. She was only able to ask about one option on the first intervention probe scoring a 16/40 and needing two redirections. During the last three probes, she could ask about three different options scoring 36/40, 40/40, then 40/40 and needing between 0 to 3 redirections. She could independently complete the graphic organizer in the last three probes. This data had 100% IOA and the prompting procedures were implemented with 100% fidelity (see Figure 6).

Generalization Probe

Carly Brewster completed her generalization probe with a doctor via video conferencing. I went to her home and sat with her at her kitchen table, we called the doctor together on a video conferencing app. The doctor received the graphic organizer prior to the probe as it was a support for Carly Brewster's communication. She could ask about three different options, received a score of 40/40, and needed three redirections, and could complete the graphic organizer independently. This data had 100% IOA and

was completed with 100% fidelity of prompting procedures indicating that Carly Brewster could use the skills she learned in a new environment with a new person (see Figure 6).

Maintenance Probe

Carly Brewster completed the maintenance probe in person at her kitchen table seven weeks after the conclusion of the generalization probe. She scored a 40/40, needed 1 directive, and could complete the graphic organizer independently indicating she has been able to maintain her skills after several weeks. IOA was 100% and prompting procedures were completed with 100% fidelity (see Figure 6).

Social Validity

Carly Brewster answered “yes” to all six of her Likert scale questions indicating that she liked the study, advocating for herself, found the graphic organizer helpful, and wants to ask more doctors questions. She answered her open-ended question: “you are the best” (see Appendix N).

Carly Brewster’s caregiver answered, “strongly agree” to five of her Likert scale questions and “agree” to one of them. This indicated that she feels her daughter is more prepared for doctors’ visits and advocating for herself, wishes this was taught in schools, and thinks other caregivers could benefit from this. She answered her open-ended question: “I really appreciate the time and effort of this program and the patience you had with Carly Brewster” (see Appendix O).

The doctor involved in the generalization probe did not answer an official social validity survey but independently responded: “Carly Brewster did so well, I wish my other patients came so prepared for their visits, this is something needed.”

Meera

Vocabulary Probe and Preference Assessments

Meera scored 95% on her vocabulary probe indicating that she could identify the vocabulary used in the study and what the different words mean. The only question she got wrong was one asking what period blood looked like. Afterward, her mother reported she likes to call her period “period” and says “blood” comes from a cut. Moving forward, I used the word “period” only with her to make sure there was not any confusion (see Appendix G). Meera also scored 100% on the comprehension questions on the first educational packet indicating she understood the material without needing more specific information from the second educational packet (see Appendix I).

Across all three preference assessments, Meera communicated she: (a) was concerned about acne and sleepiness during her period, (b) preferred a shot, a patch, or swallowing a pill, (c) preferred to get her MM at the doctor’s office, (d) preferred to take her MM 1 to 3 times a month, (e) preferred to get her period 1 to 4 times a year, and (f) was concerned about the side effect of spotting. On the two preference assessments after reviewing the educational packet, Meera communicated: she (a) was concerned about excessive bleeding during her period and (b) swallowing the pill was her first choice and a shot was her second preferred. On the preference assessment prior to the educational packet Meera communicated that getting a shot and swallowing a pill were both her first choice. All preference assessments had 100% IOA. The consistency between the preference assessments indicated validity in her choices (see Table 3; Appendix J).

Meera’s caregiver communicated that she believed Meera preferred to swallow a pill, take her MM 1 to 3 times a month, get her period 1 to 4 times a year, and would be

concerned with bleeding and acne. The caregiver was concerned about Meera's comprehension of her menstrual cycle and how to manage it. Meera's caregiver did report similar preferences to Meera except did not report any side effects she thought would concern Meera. (see Table 4; Appendix J).

Table 4

Meera's Preference Assessment Results

Preference Assessment #/ Preference Item	Preference Assessment #1 (prior to EP)	Preference Assessment #2 (post EP)	Preference Assessment #3 (post EP)	Caregiver Preference Assessment
Concerned with acne	X	X	X	X
Concerned with sleepiness	X	X	X	
Concerned with excessive bleeding		X	X	X
Receiving a shot and swallowing a pill are her 1 st preference	X			
Swallowing a pill is her 1 st preference		X	X	X
Getting a shot is her 2 nd preference		X	X	
Using a patch is 3 rd preference	X	X	X	
Prefer to take her MM 1-3 times a month	X	X	X	X
Prefer her period 1-4 times a year	X	X	X	X
Preferred to take her MM at home	X	X	X	X

Concerned about spotting	X	X	X
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Note. This figure outlines Meera’s and her caregiver’s responses on the preference assessments. EP=educational packet; MM= menstrual management

Creating the Graphic Organizer.

Meera chose to first let the doctor know that she did not like the blood, sleepiness, or bumps (acne) during her period. Meera chose to only ask about getting a shot, swallowing a pill, or using a patch. She chose to ask these four questions about the options: (1) if it can be taken at home, (2) if she can get her period four times a year, (3) how it is taken (only asking about swallowing, putting it on her body, or getting a shot), and (4) if it can be taken once a month. Meera then wanted to ask about the side effect of spotting and wanted to write the name of the MM at the end. Meera chose the visuals used and wanted to change some of the ones that were consistent with the educational packet (see Figure 5).















FIGURE 5

Meera's Graphic Organizer

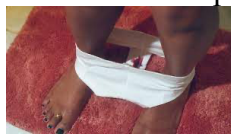


“I don’t like my period blood sleepiness and bumps”

“I want to know about medicine”

 “can I take it at home?”	 “Can I get my period only 4 times a year”	“How do I take it?”	“Can I take it once a month”
  Home Doctor's Office	   Yes No Maybe  I would get my period _____ times a year.	    swallow put on body get a shot	  Yes No

“Does it make me have spotting?”



It is _____

Baseline Probes

Meera completed three baseline probes. She scored 12/40, 14/40, then 14/40 on these probes. This data had 100% IOA (see Figure 6).

Intervention Probes

Meera completed five intervention probes, reaching mastery on the last three. She was also able to independently fill out her graphic organizer in the last three probes. On the first two intervention probes, Meera was only able to ask about one option of MM and scored 9.5/40 on each, she needed five or six redirections for each probe. It should be noted that during these probes one of her primary caregivers was present and kept saying “use your words” indicating he wanted Meera to only vocalize as opposed to using other modes of communication. This caused Meera to stick her tongue out at him and need some reassurance to keep communicating how she wanted. The last three probes, Meera could ask about all three MM options, scored 37/40, 39/40, then 38/40 and required 9-14 redirections. This data all had 100% IOA and the prompting procedures were implemented with 100% fidelity (see Figure 6).

Generalization Probe

Meera met with a doctor via video conferencing for her generalization probe. I went to her home and sat with her at her kitchen table, we called the doctor together on the video conferencing app. The doctor received her graphic organizer via email prior to the session as it was a support for Meera’s communication. Meera asked about all three options, scored 35/40, and required 10 redirections indicating that she could use her skills in a different environment with a different person. It should be noted that while Meera was able to ask the questions to the doctor, she used more gestural communication than

the vocalizations she used in her intervention probes. This data had 100% IOA and the prompting procedures were implemented with 95% fidelity (see Figure 6).

Maintenance Probe

Meera completed her maintenance probe six weeks after the completion of her generalization probe in person at her kitchen table. She scored 40/40, completed her graphic organizer independently, and needed three redirections. This was Meera's most successful completion of the behavior chain. It should be noted that during this probe neither of her primary caregivers was in the room and Meera communicated with gestures almost exclusively. This probe had 100% IOA and prompting procedures were completed with 100% fidelity (see Figure 6).

Social Validity

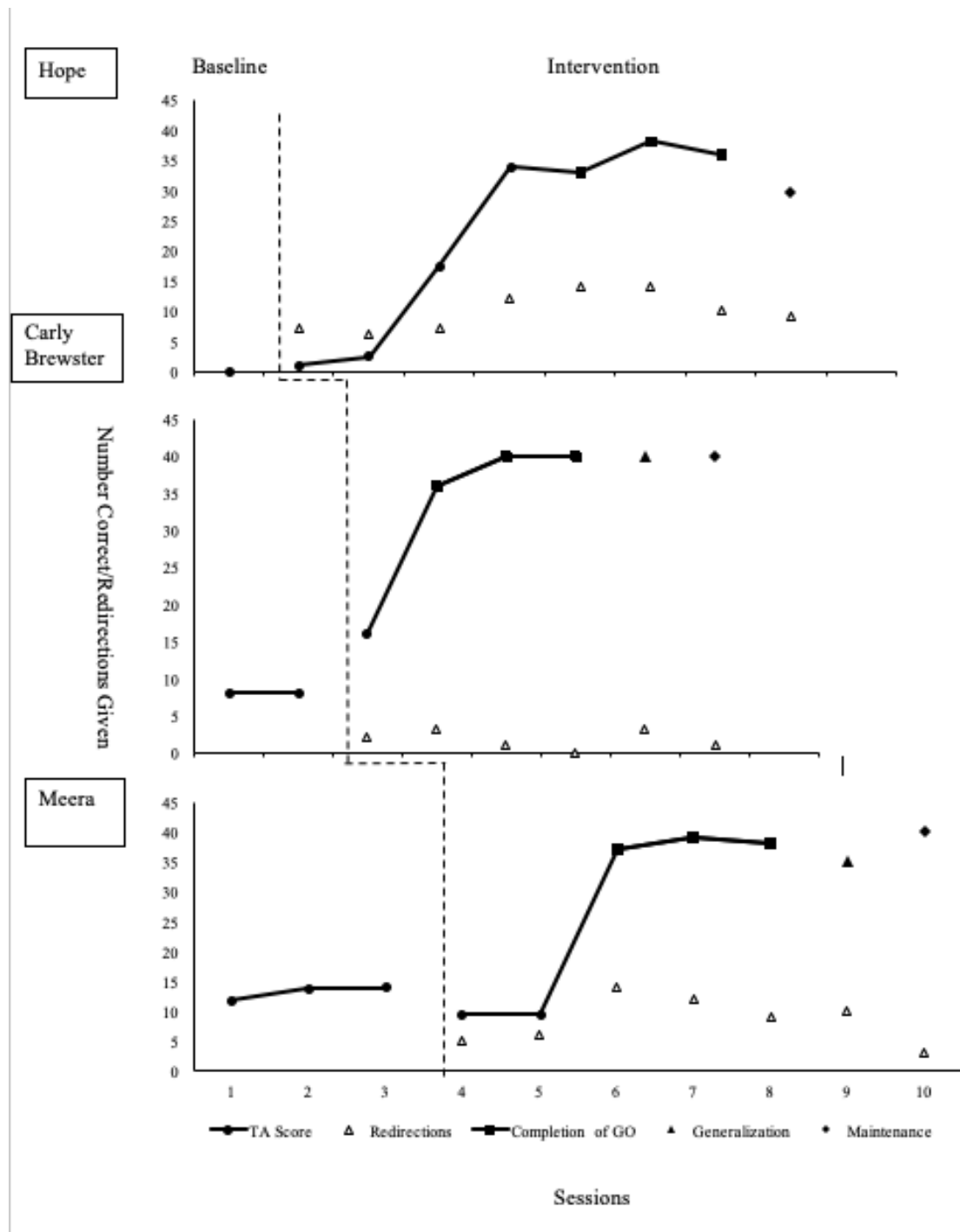
Meera answered "yes" to five of her six Likert scale questions indicating she liked asking questions, enjoyed the study, and found the graphic organizer helpful. While she answered "yes" that she liked asking this doctor questions she answered "no" that she would not like to ask other doctors questions. She did not choose to answer the open-ended question (see Appendix N).

Meera's caregiver answered, "strongly agree" to two of her Likert scale questions and "agree" to four of the Likert scale questions indicating that she felt Meera was now more capable of making decisions, thought other caregivers should have access to this intervention, and wished schools would teach these skills. She answered the open-ended question stating: "(this) helped her be more aware and accepting of her cycle" (see Appendix O).

The doctor involved in the generalization probe did not complete an official social validity survey but independently responded: “I was glad to see a patient with different communication feel like they can ask questions for themselves, all doctors need to work on how to support patients in this way.”

Figure 6

Results



Note. This figure depicts the results of the study, showing the individual participants' scores on the task analysis in baseline, intervention, generalization, and maintenance probes. Also shown is when each participant could complete the graphic organizer independently and how many redirections they required on each probe.

GO= graphic organizer; TA= task analysis

CHAPTER FIVE: DISCUSSION

This chapter discusses the results of the study and the interpretation of them in to practice while also finding some limitations. Secondary data and its impact on policy, access to information, caregiver bias, and physician training are also discussed.

Effectiveness of the Intervention

The answer to the research questions are:

1. Does behavioral skills training increase the skill of stating needs and asking questions, measured by a score on a task analysis, about medical interventions related to menstrual management for individuals with extensive support needs?

All three participants could create an individualized graphic organizer about their concerns with MM and reached the pre-determined mastery level of advocating for themselves within four to seven intervention probes. Results indicate behavioral skills training may have increased these skills. Also, all participants could generalize these skills to a new person and environment during a generalization probe and maintained skills at or close to mastery level six to ten weeks later.

2. Does behavioral skills training increase the skill of completing a graphic organizer to record information (circle and/or write answers) related to individual preferences about menstrual management for individuals with extensive support needs?

Yes, all three participants could independently fill out their individualized graphic organizer within two to five intervention probes.

The results of this study indicate that with adequate support, individuals with ESN can understand their options for MM, express their preferences, speak to doctors about those preferences, and record the information related to their questions. This study adds to previous research suggesting behavior skills training (BST) in building different behavior chains and skill sets. The results suggest that BST is an intervention that can help to develop self-determination (SD) skills related to menstrual management (MM) for individuals with extensive support needs (ESN). All the participants completed the different phases of the study in their homes with many other stimuli and activities present yet all could reach mastery level indicating this intervention does not need to be implemented in a sterile or very controlled environment for effective results. Also, all participants communicated in a different way, of their choice and within their skill repertoire, indicating that BST may be an effective intervention for increasing SD skills regardless of mode of communication. It is important to note that one of Meera's caregivers encouraged her to vocalize and her scores were lower during these probes as opposed to the probes where she could communicate in a way comfortable for her. It is an important note to let caregivers, teachers, and researchers recognize that when communicating needs and wants, we all need to give the respect to each individual to choose how they want to communicate.

However, there were multiple pre-baseline measures implemented prior to beginning BST that are also necessary to ensure the dignity and respect of individuals with ESN and may have impacted the effectiveness of the results. This included educating individuals about their body and options and taking the time to validate preferences related to MM. All the participants could successfully answer comprehension

questions with supports indicating that each participant could comprehend the different aspects of their menstrual cycle and care. This was something that all three caregivers were concerned about and possibly why caregivers think they need to make decisions about medical care without consulting their children with ESN. There is an ethical concern of not including these and only focusing on the skill building that the information would not be relevant to the participants' needs and unhelpful in making individual decisions.

Caregiver Bias

Researchers have determined there are existing bias of caregivers (parents, teachers, guardians, etc.) about sexuality, natural development, and ability to make decisions for individuals with ESN (e.g. Barnard-Brak, 2014). This bias was present in this study, especially during recruitment. After reaching out to 15 teachers, 7 BCBA's, and 4 clinics, with a potential to recruit between 100-450 participants, only three individuals and their families agreed to be part of this study. Below is listed some feedback from recruitment:

- From a teacher “I have five students who need this support but only one still has a uterus.”
- From a parent: “I discussed the study with my daughter and she started telling me her opinions and I don’t want to deal with that so we are not going to participate”. This child was 17 years-old.
- From a parent: “Oh I have already made those decisions and we are not going to change them.”

Of the participants who did take part in the study, two were adopted by caregivers aware of their ESN prior to adoption and one was born in to a family where everyone has a disability. These families already were used to disability advocacy by education and/or experience. Even with these backgrounds, all three caregivers reported in the social validity survey that this changed their own perceptions of what their child was capable of comprehending and expressing. Also, only Meera's caregiver indicated preferences that were almost the same as Meera while the other two indicated preferences different from what their child wanted in their MM. In this particular study, this information suggests that parents will only know what their child wanted some of the time.

How can we educate families and caregivers to stop under-estimating their children and respect their rights to express their opinions and have opinions? One way is to involve caregivers in the research process in some way, even having them see the result when individuals reach mastery or have them see their children answering comprehension questions correctly. This can be done in person or through video recording. This is what changed the caregivers' perceptions in this study.

Another interesting aspect of the families that chose to participate in this study is that they were all contacted by a community organization they belong to for support on resources and similar families. These organizations may be places to begin reaching out to caregivers and places to utilize training on breaking down bias and building skills. Also, all caregivers involved in this study were already interested in disability advocacy. It is unclear if this study would be as effective with participants who come from households that are described below and/or if these caregivers' perceptions of their

children would be changed as they were in this study. The above evidence of caregiver bias, influenced the limitations of this study.

Limitations

While the results of this study were positive, there were several limitations. The first limitation is that while three to five baseline data points is suggested for research, I was only able to obtain 1-3 for my participants. However, due to the behaviors elicited when asked to complete a skill they had not mastered, there was clear undue stress communicated from the participants. This, in turn, caused undue stress to their caregivers who became frustrated and/or upset with their child's behavior. Research is meant to inform the world of benefits to interventions but should not cause undue stress to participants. This is why Institutional Review Boards were created: to protect participants. It felt the most ethical decision was to carry on with the study and respect the participants' request for help and clear dislike of being asked to do something they could not do. After all, this study was designed to increase participants' communication skills so reinforcing this was also important; therefore, the decision was made to move forward without more baseline data.

Another limitation is the small number of participants. This may have been impacted by COVID-19 because research was still not allowed to happen in schools so the families had to be comfortable and open to someone coming in to their homes. The results to this study may not replicate with other participants who have different diagnoses and/or communication skills. Also, all participants chose to complete the study at their homes and on zoom for the generalization probes. Replication of the results may not occur in other environments.

A third limitation is the fact that all the participants were younger. It is unclear if this study would be as effective with participants who are older and may have already had a decision made for them regarding MM and have grown accustomed to their MM. Also, if participants had been even younger and not experienced a menstrual cycle then they may have required more pre-teaching and support. Despite these limitations, there are some interesting findings and recommendations for future researchers, discussed below.

Breaking Barriers

All caregivers expressed the fact that they wished schools would address MM and similar topics in schools as well as teach students with ESN how to advocate for themselves and make informed choices. While reviewing the educational packet, all the participants expressed that a lot of the information was new for them and they were not aware of the specific information about their menstrual cycle before. Why was this the first time these individuals were taught about a natural function in their bodies? Why are these skills and this information not being taught?

Implications for Policy

In the United States (U.S.) a lot of what is taught in school is related to laws and policy at both the federal and state levels. We know that only 28 states have laws requiring some sort of comprehensive sex education (CSE) but every state is different and it is often not an area that is enforced or evaluated by testing measures so gets pushed aside (Guttmacher, 2020; SIECUS, 2021). We know many professional organizations like the Center for Disease Control (2019) and World Health Organization (2012) consider these skills and this education to be paramount to equal rights and full quality of

life. This means that individuals need to start advocating for more comprehensive laws about CSE, including MM, for all students to lawmakers and school boards. This education will not be implemented for students with ESN until it is implemented for all students (Hoefler & Hoefler, 2017).

Implications for Practice

All teachers, board-certified behavior analysts (BCBAs), and other professionals contacted for recruitment during this study, felt this was a great need and could think of many individuals who needed these supports. Many of these professionals reported wanting to work on this topic and these skills as menstrual cycles and periods do not exclusively occur within private homes but occur wherever an individual with a menstrual cycle may go. However, many are not trained to work on these in an explicit way and most programs only lightly touch on CSE in pre-service training, making these professionals unsure of the best way to proceed especially with lack of policy. The intervention supports used are evidenced-based practices (EBPs) and/or considered best practice in education and applied behavior analysis (ABA) so the argument that professionals already know how to design and implement these interventions can be made.

While this may be true, we do not expect these same professionals to develop every single intervention they utilize from scratch and they often have validated resources to turn to for different content area and skill building. However, there is little to none related to MM and teaching how to make informed decisions. The information that is available, has been found to lack dignity and respect for individuals with ESN (e.g. Barger et al., 2009). Researchers need to support professionals and individuals by

developing more interventions and supports to be used in schools and clinics. Research on interventions, supports, and curricula are needed in CSE.

Implications for Physician Training

The physicians who agreed to be part of the generalization probes reported that they were taught in their residencies (both at large and well-known medical schools) that it was the norm to perform hysterectomies for patients with ESN if their caregivers requested and/or when receiving other MM became too “cumbersome” for the family to manage. They both recognize that this is something that needs to change and a large part of this is a lack in training for physicians in different areas. Training and resources are needed for doctors to learn to effectively communicate with all their patients with dignity and respect.

Conclusion

Despite some limitations, this study indicated that educational supports and BST are an effective intervention package to increase SD skills related to MM. The results were at or close to mastery level for generalization and maintenance probes indicating that once the skills are taught, the participants could use them in different environments and at a later date without practicing in between. Interesting findings were also brought to the researcher’s attention related to access to information and skill-building, bias from caregivers, and lack of training and support for teachers, BCBAs, and physicians related to this content area and skill-building. Changes need to be made in policy to help to advocate and ensure meaningful change for individuals with ESN to have the respect and dignity to be part of the decision-making process related to their medical needs.

Considerations for Future Research

There are several areas of research that have come to light due to this study and the content examined. Here are some suggestions for future studies for building skills and knowledge related to CSE and SD/SA: (a) utilizing BST with other skill building related to making informed decisions, self-advocacy (SA), and/or SD, to build on research determining the effectiveness of this intervention for these behavior chains/complex skills, (b) including more participants to determine the effectiveness of the intervention across ages, diagnoses, races/ethnicities, and/or individuals who speak English as a second language or not at all, (c) including participants who use AAC devices or other modes of communication to determine the effectiveness of the intervention with a different population, (d) utilizing this intervention in other environments (i.e., only online, in schools, in clinics) to determine the generalizability of the intervention, (e) utilizing this intervention in a small group settings as opposed to one on one to determine the generalizability of the intervention, (f) utilizing graphic organizers for other SA and SD needs to determine the effectiveness of this intervention related to these behavior chains/complex skills, (g) in an urban area to determine the generalizability of the intervention, (h) different cultural or ethnic backgrounds to determine the generalizability of the intervention, (i) in a small group setting to determine the generalizability of the intervention, (j) use the same participants to discuss other medical needs to determine the generalizability of skills, (k) all content area of CSE due to lack of appropriate content, (l) options related to menstrual care (pads, tampons, period underwear, etc.) to determine interventions appropriate for these skills., (m) comprehension of the menstrual cycle to determine generalizability of the educational component, (n) how to ask questions about

the menstrual cycle to determine best interventions for this skill set, and (o) consequences of the menstrual cycle to determine best interventions for this skill set.

Here are some suggestions for future research related to breaking down barriers to access of this information and opportunities: (a) measuring perceptions of caregivers pre- and post in studies related to building self-advocacy and SD skills for individuals with ESN to determine best methods of breaking caregiver bias, (b) training caregivers to train other caregivers how to build these skills to determine best interventions for this to cast a wider net on breaking down barriers, (c) determine areas where caregivers are hesitant to let their children with ESN make decisions for themselves to determine areas for future research, (d) measure caregivers' perceptions about their children's ability to comprehend complex subject matter to determine areas of future research, (e) education on different modes of communication for medical professionals to increase likelihood of individuals engaging in SA/SD skills in a natural setting, (f) practice communicating with patients who communicate in different ways for medical professionals to increase likelihood of individuals engaging in SA/SD skills in a natural setting, (g) training and practice on advocating for these patients and asking caregivers to be partners in decision-making for medical professionals to increase likelihood of individuals engaging in SA/SD skills in a natural setting, (h) pamphlets and literature with EBPs/academic supports (like visuals) to give to patients in medical offices to increase likelihood of individuals engaging in SA/SD skills in a natural setting, and (i) resources with EBPs/academic supports available to help patients make choices and understand their choices to increase likelihood of individuals engaging in SA/SD skills in a natural setting.

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APPENDIX A

INCLUDED STUDIES FOR CSE LITERATURE SEARCH

Authors, year	Design	FoSE (2012) standard addressed	Participants	Intervention(s)	Conclusions
Blanchett, W. J., & Wolfe, P. S. (2002)	Curriculum Review- 12 curriculums	CSE	Individuals with MSD	Multiple	Need more modifications, teaching in naturalistic environments, and more access
Caspar, L. A., & Glidden, L. M. (2001)	Group Design	CSE	Individuals with DD aged 28-62	New Program	Found increase in knowledge and attitudes
Couture, G., & Daigle, M. S. (2011)	Group Design	CSE	Individuals with IDD	EVAAS	Not effective with MSD population-need more adaptations, training, and research

Graff, H. J., Moyher, R. E., Bair, J., Foster, C., Gorden, M. E., & Clem, J. (2018)	Experimental Group design Pre-test, Post-test study over 3 years	CSE	53 participants with IDD, mean age 20 years old	Multiple	Found statistically significant increases in the post-test for experimental group with positive social validity interviews, need more research on accurate assessments and maintenance of knowledge and skills
González Carolina, Fernández-Sogorb Aitana, Sanmartín Ricardo, Vicent María, Granados Lucía, & García-Fernández José M. (2018)	Meta-Analysis- 31 studies included from 8 reports	CSE	Individuals with ID	Multiple	Found single sex groups, high degree of training and experience to deliver programs are most effective
Jurkowski, E. (1994).	Group Design	CSE	107 individuals with moderate ID	Life Journeys	“good results” with an increase in knowledge

Lindsay, W. R., Bellshaw, E., Culross, G., Staines, C., & Michie, A. (2008)	Group Design- pretest- posttest	CSE	46 adults with MMD aged 17- 49	New Curriculum	Increase in knowledge
Löfgren-Mårtenson, L. (2012)	Curriculum review: social validity	CSE	16 Individuals with IDD aged 16-21	Multiple	Restrictive views on sexuality and scripts to talk about it, want to know how to build intimacy and relationships
McDermott, S., Martin, M., Weinrich, M., & Kelly, M. (1999)	Group Design	CSE	252 women with MR	Multiple	Hygiene, social interaction, and experience affected sexual knowledge and ability to learn
Murray, B. L. (2019)	Group Design	CSE	101 Individuals with DD aged 16-24	Adaptation of Canadian Red Cross RespectEd	Reported high social validity and need of sex education but did not specify effectiveness of adaptations and interventions

Schaafsma, D., Kok, G., Stoffelen, J. M., & Curfs, L. M. (2015)	Literature Review- 20 articles included	CSE	Individuals with IDD	Multiple	Studies found gains but were not specific enough to describe under which contexts they were effective and maintenance and generalization data was missing or ineffective
Schaafsma, D., Stoffelen, J. M. T., Kok, G., & Curfs, L. M. G. (2013)	Program evaluations: interviews with developers of 5 sex education programs	CSE	Individuals with IDD	Multiple	Programs are unlikely to be effective, more valid assessments methods need to be developed, and interventions specific to individuals with IDD need to be implemented
Schmidt, E. K., Brown, C., & Darragh, A. (2020)	Literature Review- 6	CSE	Individuals with ASD and	Multiple: illustrations, adapted texts,	Need for more research in to the

	studies included		IDD, aged 15-24 years old	activity based learning. Measured both education and behavioral outcomes	effectiveness of interventions.
Whitehouse, M. A., & McCabe, M. P. (1997)	Literature Review	CSE	Individuals with IDD	Multiple	Most programs ineffective with individuals with IDD and more on prevention rather than intervention or healthy promotion of identity and sexuality.
Winges-Yanez, N. (2014)	Curriculum Review: Discourse Analysis of FLASH	CSE	N/A	Multiple	Did not find the curriculum comprehensive or promoting dignity of individuals with IDD, relationships, or proactive interventions

Wu, J., & Zeng, S. (2020)	Literature Review over 30 years	CSE	Individuals with IDD in grades K-12	Multiple	Has not been implemented well over past 30 years, need for more research on interventions effective for students with IDD as well as changes in laws and policies
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Note. This figure gives details of the CSE literature search.

ASD= autism spectrum disorder, DD=developmental disabilities, ID= intellectual disability, IDD= intellectual and developmental disabilities MR= mental retardation, MMD= mild or moderate disabilities, MSD= moderate or severe disabilities, MSMR= moderate or severe mental retardation, N/A=not applicable, PDD-NOS= pervasive developmental disorder not otherwise specified

APPENDIX B

INCLUDED STUDIES FOR CONTRACEPTIVE USE LITERATURE SEARCH

Authors, year	Country	Design	Participants	Results
Abells, D., Kirkham, Y. A., & Ornstein, M. P. (2016)	USA	Literature Review	Women with DD	-Need education
Anderson, P., & Kitchin, R. (2000)	Northern Ireland	Qualitative	Women with disabilities	-women with disabilities feel unwelcome in health clinics and some cannot physically access the spaces -nor are they given education on services that makes sense
Bernert, D.J. (2011)	USA	Group Design	14 women with ID	-10 women accurately talked about methods (e.g. “pills”, “shots”, “condoms”) to prevent pregnancy -Five women were on contraception administered by agencies or families but still chose abstinence. Not reported whether other women in the

<p>Bratkovic D, Teodorovic B (2000)</p>	<p>Russia</p>	<p>Group</p>	<p>Individuals with MSD</p>	<p>sample were using contraception -Used condom when had vaginal sex in last 30 days (p < .01): No disabilities: 74.9% One disability: 72.1% 2 disabilities: 69.9% -Used emergency contraception in last 12 months (p < .01): No disabilities: 15.5% One disability: 16.1% 2 disabilities: 17.8% -Had or caused unintentionally pregnancy, last 12 mo. (p < .01): No disabilities: 2.1% One disability: 2.2% 2 disabilities: 3.2%</p> <p>Significant improvement in sexual knowledge (p < .001), with largest improvement seen in knowledge about contraception.</p>
<p>Brown, H. K., Kirkham, Y. A., Lunsky, Y., Cobigo,</p>	<p>USA</p>	<p>Mixed Methods</p>	<p>Women with ID Comparison Group</p>	<p>-Contraception postpartum 1:3 -Nonsurgical 1:2</p>

V., & Vigod, S. N. (2018)				<ul style="list-style-type: none"> -Surgical 1:8 -Injectables 1:9 although more complications -Why do women with ID more likely to have irreversible surgery or more risky birth control and why not involved in decision-making?
Brown, H. K., Ray, J. G., Liu, N., Lunsy, Y., & Vigod, S. N. (2018)	Canada	Group Design	Women with IDD	<ul style="list-style-type: none"> -Women with IDD more likely for rapid repeated pregnancy (3.7% more likely than women without IDD) -need more access to care and education
Burke, L. M., Kalpakjian, C. Z., Smith, Y. R., & Quint, E. H. (2010)	USA	Qualitative	44 Adolescent females with DS, ASD, and, CP	<ul style="list-style-type: none"> -biggest complaints irregular bleeding and behavioral/mood changes. -Individuals with ASD had more behavioral changes -Used oral contraceptives and anti-inflammatories -more education needed
Chamberlain, A., Rauh, J., Passer, A.,	USA	Questionnaire	Female adolescents with MR	25% of girls with ID used contraception at

McGrath, M., &
Burket, R. (1984)

both first and most
recent intercourse, vs.
49.3% of girls without
ID (p .001)

Dotson, L. A.,
Stinson, J., &
Christian, L. (2003)

USA

Qualitative

7 women with IDD

- One woman had never heard of birth control.
- Half of the women were unsure about whether or not they could become pregnant
- Six women reported current or past use of contraception;
- birth control pills were mentioned by 3 women, methods used by other women were not reported.
- One woman was sterilized.
- Five women said they were sexually active, including one not using contraception because her boyfriend was “fixed”
- Gynecologists use language women don't understand
- Discomfort with asking doctors about

Edmonson, B., McCombs, K., & Wish, J. (1979)	USA	Group	Women with MR aged 18-41	<p>contraception or reproductive issues -No opportunity to choose type of contraception to use - Lack of info about risks and side effects</p> <p>Contraception was topic on which women scored lowest (49e50% correct responses) vs. 50e78% correct in 12 other topics</p>
Egan, T. M., Siegert, R. J., & Fairley, N. A. (1993)	New Zealand	Mixed Methods	23 women with ID in an institution	<p>-Eight women were prescribed contraceptives to control menstruation, 13 to control fertility and 1 for both reasons. Methods included: DMPA (n ¼ 18); OCP (n ¼ 4) -Unilateral contraceptive decisions by hospital staff -46% of women said they were given no info about the contraceptives they were prescribed - Consent not</p>

				sought/obtained for 74% of women with ID
Galea, J., Butler, J., Iacono, T., & Leighton, D. (2004)	USA	Group	Women with ID	-Assessment of sexual knowledge -Of 15 topics, contraception knowledge had 2nd lowest scores
Gil-Llario, M. D., Morell-Mengual, V., Ballester-Arnal, R., & Díaz-Rodríguez, I. (2018)	USA	Mixed Methods	180 men and women with ID	-84.2% sexual relationships -76.5% on contraceptive -9.4% of women reported abuse -Need education on related to each person and their lives
Grant, T., Huggins, J., Connor, P., Pedersen, J. Y., Whitney, N., & Streissguth, A. (2004)	USA	Group	Women with fetal alcohol spectrum disorder	Worked with providers over 12 months to work on all needs of these women but did increase those on contraceptives due to provider training that did include communicating with women with ID more effectively.
Grover, S. R. (2002)	Australia	Survey	107 women with ID	-2 out of 107 needed surgical intervention

					<ul style="list-style-type: none"> -others could use other contraceptives -should be treated like other women -Contraception prescribed for 22 women currently or potentially sexually active or deemed at risk of sexual abuse. - Of these, 6 also presented with menorrhagia and 4 with irregular menses.
Hamilton, A., Marshal, M. P., Sucato, G. S., & Murray, P. J. (2012)	USA	Qualitative	Females with Rett Syndrome	<ul style="list-style-type: none"> -Contraception used for heavy bleeding and mood changes - based on mothers' needs and wants 	
Haynes, R. M., Boulet, S. L., Fox, M. H., Carroll, D. D., Courtney-Long, E., & Warner, L. (2018)	USA	Group	Women with disabilities	<ul style="list-style-type: none"> -Why correlation between contraception and disability 	
Hillard, P. J. (2012)	USA	Group	Women with DD	<ul style="list-style-type: none"> -Historically it is based on family needs, not patient centered 	

				-21 insertions of IUD, anesthesia required for 20 -results promising
Horner-Johnson, W., Moe, E. L., Stoner, R. C., Klein, K. A., Edelman, A. B., Eden, K. B., Andresen, E. M., Caughey, A. B., & Guise, J.-M. (2019)	USA	Literature Review	Women with ESN	-Need to increase contraceptive knowledge, often used mixed use of contraception
Huovinen, K. J. L. (1993)	Finland	Medical Records Review	256 women with MR	Reason for consultation for women with vs. without ID: Contraception: 2.7% vs. 23.1% (p < .05) Therapeutic amenorrhea (TA): 48.2% vs. 0.4% (p < .001) Methods used by women with vs. without ID: Oral lynestrenol for TA (current): 53.3% vs. 0.4% (p < .001) Oral lynestrenol for TA (history): 67.5% vs. 0.4% (p < .001) Oral progestin in cyclic manner: 0% vs. 1.6%

				DMPA for TA: 0.8% vs. 0% Combined oral contraceptive: 0% vs. 19.6% (p < .05) Progestin only mini pills: 0% vs. 3.1% All pregnancies in ID group (n = 3) ended in induced abortion
Jahoda, A., & Pownall, J. (2014)	USA	Questionnaire	30 women with ID with comparison group	-Mean contraception knowledge scores for women with ID versus without ID: 7.43 (SD = 4.03) vs. 26.73 (SD = 7.56). -Few sources of sexual health information (median = 6 vs. 10 for people without ID) -Few sources of sexual health information (median = 6 vs. 10 for people without ID) Less likely to talk with friends (11 vs. 26), family (8 vs. 20), or doctors (3 vs. 16) about sexual health
Kaskowitz, A. P., Dendrinis, M., Murray, P. J., Quint,	USA	Qualitative	Women with Angelman Syndrome	-Heavy bleeding and seizures a concern

E. H., & Ernst, S. (2016)				-Hormones used to suppress by less than half -Caregivers make the decisions
Kijak, R. (2013)	Poland	Questionnaire	133 participants with ID	-Only 10% of cohort could name at least 3 methods of contraception. - Condoms and pills were mentioned most often. -In full sample, 18 were sexually active; 7 of these (39%) used any method of contraception
Kirkham, Y. A., Allen, L., Kives, S., Caccia, N., Spitzer, R. F., & Ornstein, M. P. (2013)	USA	Qualitative	Caregivers of women with DD	-Based on caregiver satisfaction
Leutar, Z., & Mihoković Marija. (2007)	USA	Questionnaire	24 participants with ID	-79.2% of respondents knew purpose of contraception. -Specific methods were recognized by differing percentages of respondents: birth control pill (54.2%),

				condom (87.5%), IUD (58.3)
Lindsay WR, Bellshaw E, Culross G, Staines C, Michie A (1992)	USA	Group	Individuals with ID	3 months, substantial gains in all areas including contraception
McCabe, M. (1999)	USA	Questionnaire	Individuals with disability With Comparison Group	Average contraception knowledge scores (out of 18 possible): 6.28 (SD: 3.72) for intellectual disability group 10.81 (SD: 4.27) for physical disability group 13.47 (SD 1.92) for non-disabled group
McCarthy, M. (2009)	England	Qualitative	23 women with ID	-14 did not know how their contraception worked -5 decided which kind on their own -all said they could not remember or were not asked questions by the doctor during consultations -17 said contraception was to avoid pregnancy -6 reported being sexually active -1 expressed she was vulnerable

					<p>-2/3 could name a contraceptive method in addition to ones they had used</p> <p>-61% did not know how contraception worked or why a particular method had been suggested for them</p> <p>-2 women only learned about contraception after they got pregnant.</p> <p>-need more education materials</p>
McCarthy, M. (2014)	USA	Qualitative	17 women with ID	- women want greater control over sexual lives and decisions	
McDermott, S., Kelly, M., & Spearman, J. (1994)	USA	Intervention Evaluation	Individuals with MR	Were not given choice After 1 year, proportion of intervention group using birth control increased from 68.1% to 80.9% (p < .05). Control group showed minimal change (67.3% e68.0%).	
Mosher, W., Hughes, R. B., Bloom, T., Horton, L., Mojtabai, R., & Alhusen, J. L. (2018)	USA	Group Statistical Analysis	data from National survey of family growth 7505 at risk of unintended	-women with cognitive and physical disability 94% higher chance of sterilization	

			<p>pregnancy from 2011-2015 for women between 15-44 with a disability status</p>	<p>-Need education and take in to account disability -Family planning received by women w/ vs. w/o disabilities: Any service: 37.7% vs. 42.4% (p < .01) Birth control method: 29.2% vs. 33.8% (p < .01) Birth control counseling: 16.6% vs. 19.2% (p < .01) Birth control checkup: 21.9% vs. 25.7% (p < .01) Adjusted analyses: women with any disability, physical/ sensory disability only, and both physical/sensory and cognitive disabilities less likely to receive any service</p>
<p>Pownall, J., Wilson, S., & Jahoda, A. (2020)</p>	<p>USA</p>	<p>Questionnaire</p>	<p>Individuals with ID</p>	<p>-42 had used contraception (29 were at time of study), and 12 had used two methods. Methods included: DMPA (n ¼ 28); OCP (n ¼ 19); IUD (n ¼ 7)</p>

				-Median pregnancy/contraception knowledge scores (max ¼ 9): 6 (range: 3e9; SD: 1.6) for intellectual disability group 7 (range: 4e9; SD: 1.4) for physical disability group 9 (range; 6e9; SD: 0.9) for non-disabled group
Quint, E. H., Breech, L., Bacon, J., & Schwandt, A. (2006)	USA	Case Study	1 teenager with DD	Tried multiple options to decrease irregular bleeding and considered a complicated medical history. Reported education of the patient and not just caregivers are important as well as understanding the patient must be given information before sterilization as well as understanding that all other options must be used first to work on problems of menstrual cycle
Schaafsma, D., Kok, G., Stoffelen, J. M.	USA	Questionnaire	Individuals with ID	-All knew condoms prevent pregnancies and diseases. Some

T., & Curfs, L. M.
G. (2017)

participants (across genders) also mentioned the pill (n ¼ 6), IUD (3), injection (n ¼ 2), or female condom (n ¼ 2).
-Half of those who reported sexual activity had used condoms; 4 women had not because on prescription birth control.
-Sex education 1-2x rather than ongoing
50% said contraception was not addressed in sex ed
-Education may lack depth or be too complex, resulting in superficial knowledge -
Minimal conversation about reproductive health with family and friends

Servais, L., Jacques, D., Leach, R., Conod, L., Hoyois, P., Dan, B., & Roussaux, J. P. (2002)

USA

Group Design

397 women control group and women with ID

Contraception use of women with ID vs. general population:
Overall: 59.2% vs. 68%
Sterilized: 22.2% vs. 7%
- Influences not medically based for women with ID but on

Siebelink, E. M., de, J. M. D., Taal, E., & Roelvink, L. (2006)	USA	Questionnaire	76 individual with ID	<p>living arrangement and contraceptive policy there, having a boyfriend, and severity of ID</p> <p>-Romantic relationships important -93% knew that a woman could get pregnant from sexual intercourse - 59% recognized a picture of a condom</p>
Tenenbaum A, Fuchs B, Raskas M, Carmeli E, Aspler S, Merrick J (2011)	Israel	Medical Records Review	Individuals with ID in residential facilities	Total proportion receiving contraception in a given year (1999e2009) ranged from 11.42% to 15.77%.
Timmers, R., DuCharme, P., & Jacob, G. (1981)	USA	Qualitative	10 women with DD living in apartment setting	<p>-All participants knew how to prevent pregnancy through abstinence, sterilization, or an effective form of contraception -10 women had had intercourse, 5 were sexually active on a frequent basis</p>

				-7 used contraceptives to prevent pregnancy. -- Overlap of sexual activity and contraception use not specified
van Schroyen Lantman, de V. H. M. J., Rook, F., & Maaskant, M. A. (2011)	Holland	Qualitative	234 women with ID in residential facilities	78% took medicine 20% surgical contraceptive 2% both -started because parent or physician asked -need more health promotion material
Verlenden, J. V., Bertolli, J., & Warner, L. (2019)	USA	Literature Review	N/A	-need to work on decision-making and education for patient and practitioner
Wu, J. P., McKee, M. M., Mckee, K. S., Meade, M. A., Plegue, M., & Sen, A. (2017)	USA	Group Statistical Analysis	Women with at least one reported IDD on national survey for growth 2011-2013	-Physical or sensory dis 9.3% of those 28.2% had been sterilized -3.9% less likely to have LARC - Highly effective: 13.3% vs. 18.8% (ns) Moderately effective: 25.6% vs. 37.9% (p < .001) Less effective: 34.4% vs. 28.0% (ns)

				No method: 26.7% vs. 15.3% (p < .001) In adjusted analyses, women with disabilities were: Less likely to use highly effective or moderately effective methods
Wu, J., Zhang, J., Mitra, M., Parish, S. L., & Minama, R. G. K. (2018)	USA	Group Statistical Analysis	13,059 women with at least one reported IDD on National survey for growth 2009-2011	-2.1% less likely to be provided LARC and --- 8.8% less likely to be provided options except for progesterone shot was 10.4% more likely -Women with physical or sensory disabilities vs. no disability: Sterilized: 28.2% vs. 15.0% (p < .001) LARC: 5.4% vs. 9.3% (p ¼ .005) Adjusted odds of sterilization: 1.36 (1.03e1.29)

Note. This figure gives details of the CSE literature search.

DD=developmental disabilities, ID= intellectual disability, IDD= intellectual and developmental disabilities MR= mental retardation, MMD= mild or moderate disabilities, MSD= moderate or severe disabilities,

APPENDIX C

INCLUDED STUDIES FOR SELF-DETERMINATION LITERATURE SEARCH

Authors, year	Design	Reliability and Validity	Assessments	Intervention
Bollman, J. R., & Davis, P. K. (2009)	MP	IOA	Generalization	Video Model
				Probe
				Role Play
				Feedback
Browder, D. M., Cooper, K. J., & Lim, L. (1998)	MBAP	IOA	Observation	Reinforcement
				Errorless Teaching
Chao, P.-C. (2020)	Group	Statistics	Pre-and Post-Test	Time Delay
				Visuals
				Stories
				Reinforcement
Faw, G. D., Davis, P. K., & Peck, C. (1996)	MBAP	Social Validity	3 Preference Assessments	Role Play
				Visual Questionnaire
				Graphic Organizer
				Modeling

Feldman, M. A., Owen, F., Andrews, A., Hamelin, J., Barber, R., & Griffiths, D. (2012)	Group	Statistics Social Validity	Pre-and Post-Test	Prompting Visuals Game PPT Video Modeling
Hammer, M. R. (2004)	MBAP	IOA	Interview Pre-and Post-Test	Computer Program with Visuals Role Play
Knowles, C., Blakely, A., Hansen, S., & Machalicek, W. (2017)	MBAP	IOA Social Validity Fidelity Checklists	Maintenance Probes	Prompting Example and Non-Example Modeling Goal Setting Self-Monitoring with Fidelity Checklists

				Graphic Organizers
McPherson, L., Ware, R. S., Carrington, S., & Lennox, N. (2017)	Group	Statistics	N/A	Diaries Self-Monitoring Task Analysis
Palmer, S. B., & Wehmeyer, M. L. (2003)	Group	Statistics Social Validity	Pre-and Post-Test	Graphic Organizers
Sigafoos, J., O'Reilly, M., Ganz, J. B., Lancioni, G. E., & Schlosser, R. W. (2005)	MBAP	IOA Social Validity	Generalization Probes Preference Assessment	Visuals Modeling Least to Most Prompting Tangible Reinforcement
Singh, N., Lancioni, G., O'Reilly, M., Molina, E., Adkins, A., & Oliva, D. (2003)	Changing Criterion	N/A	Maintenance Probes	Modeling Physical Prompting Reinforcement with Fading

Test, D. W., & Neale, M. (2004)	MP	Fidelity Checklist	Generalization Probes	Modeling
		IOA		Scripts
		Social Validity		Visuals
Torres, A., Kearney, K.B., Berlingo, L., & Brady, M.P. (2021)	MP	TA/Fidelity Checklist	Generalization Probes	Visuals
		IOA	Maintenance Probes	Graphic Organizer
		Social Validity		Remote Coaching

Note. This Figure gives details of designs and interventions for the studies found in the self-determination search.

CC = changing criterion; IOA= inter-observer agreement; MBAP = multiple baseline across participants; MBAR = multiple baseline across response, MP = multiple probe; N/A = not applicable

APPENDIX D

IRB APPROVAL LETTER

Human Subjects Protection Program Office
300 E. Market Street, Suite 380
University of Louisville
Louisville, KY 40202



DATE: February 04, 2022
TO: Ginevra R Courtade, Ph.D.
FROM: The University of Louisville Institutional Review Board
IRB NUMBER: 21.1077
STUDY TITLE: Increasing self-determination skills in medical settings for women with extensive support needs
REFERENCE #: 738486
DATE OF REVIEW: 02/04/2022
CONTACT FOR QUESTIONS: Jackie Powell 852-4101 jspowe01@louisville.edu

This study was reviewed on 02/04/2022 by the Chair of the Institutional Review Board and approved through Expedited Review Procedure, according to 45 CFR 46.110(b), since this study falls under Category 7: Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies

This study now has final IRB approval from 02/04/2022 through 02/03/2025. The following items have been approved:

Submission Components
Form Name Version Outcome
Submit for Initial Review Version 1.1 Approved as Submitted

Review Response Submission Form Version 1.0 Approved as Submitted
IRB Study Application Version 1.1 Approved as Submitted
Study Document
Title Version # Version Date Outcome
Demographic Survey Version 1.0 01/31/2022 Approved
Recruitment Email/Script Version 2.0 01/28/2022 Approved
Study Protocol Version 2.0 01/28/2022 Approved
Sample Graphic Organizer Version 1.0 12/27/2021 Approved
Caregiver Social Validity Survey Version 1.0 12/27/2021 Approved
Participant Social Validity Version 1.0 12/27/2021 Approved
Educational Packet 2 Version 1.0 12/27/2021 Approved
Educational Packet Version 1.0 12/27/2021 Approved
Caregiver Preference Version 1.0 12/27/2021 Approved
Preference Assessment Version 1.0 12/27/2021 Approved
Preference Assessment IOA Version 1.0 12/27/2021 Approved
Data Form/IOA Form Version 1.0 12/27/2021 Approved
Vocabulary Probe Version 1.0 12/27/2021 Approved
Informed Consent Caregivers Clean Version 2.1 01/28/2022 Approved
Subject Assent Form Version 2.0 01/28/2022 Approved

IRB policy requires that investigators use the IRB “stamped” approved version of informed consents, assents, and other materials given to research participants. For instructions on locating the IRB stamped documents in iRIS visit:
<https://louisville.edu/research/humansubjects/iRISSubmissionManual.pdf>

Your study does not require continuing review per federal regulations. Your study has been set with a three-year expiration date following UofL local policy. If your study is still ongoing at that time, you will receive automated reminders to submit a continuing review form prior to the expiration date. If you complete your study prior to the

expiration date, please submit a study closure amendment.

All other IRB requirements are still applicable. You are still required to submit amendments, personnel changes, deviations, etc... to the IRB for review. Please submit a closure amendment to close out your study with the IRB if it ends prior to the three year expiration date.

Human Subjects & HIPAA Research training are required for all study personnel. It is the responsibility of the investigator to ensure that all study personnel maintain current Human Subjects & HIPAA Research training while the study is ongoing.

Site Approval Permission from the institution or organization where this research will be conducted **must** be obtained before the research can begin. For example, site approval is required for research conducted in UofL Hospital/UofL Health, Norton Healthcare, and Jefferson County Public Schools, etc...

Privacy & Encryption Statement

The University of Louisville's Privacy and Encryption Policy requires identifiable medical and health records; credit card, bank account and other personal financial information; social security numbers; proprietary research data; and dates of birth (when combined with name, address and/or phone numbers) to be encrypted. For additional information: <http://louisville.edu/security/policies>.

Implementation of Changes to Previously Approved Research

Prior to the implementation of any changes in the approved research, the investigator must submit modifications to the IRB and await approval before implementing the changes, unless the change is being made to ensure the safety and welfare of the subjects enrolled in the research. If such occurs, a Protocol Deviation/Violation should be submitted within five days of the occurrence indicating what safety measures were taken, along with an amendment to revise the protocol.

Unanticipated Problems Involving Risks to Subjects or Others (UPIRTSOs)

A UPIRTSO is any incident, experience, or outcome, which has been associated with an unexpected event(s), related or possibly related to participation in the research, and suggests that the research places subjects or others at a greater risk of harm than was previously known or suspected. The investigator is responsible for reporting UPIRTSOs to the IRB within 5 working days. Use the UPIRTSO form located within the iRIS system. Event reporting requirements can be found

at: <http://louisville.edu/research/humansubjects/lifecycle/event-reporting>.

Payments to Subjects

In compliance with University policies and Internal Revenue Service code, payments to research subjects from University of Louisville funds, must be reported to the University Controller's Office. For additional information, please call 852-8237 or email controll@louisville.edu. For additional information: <http://louisville.edu/research/humansubjects/policies/PayingHumanSubjectsPolicy201412.pdf>

The committee will be advised of this action at a regularly scheduled meeting. We value your feedback; let us know how we are doing: <https://www.surveymonkey.com/r/CCLHXP>

Peter M. Quesada, Ph.D., Chair Social/Behavioral/Educational Institutional Review Board PMQ/jsp

APPENDIX E

CAREGIVER CONSENT FORM AND DEMOGRAPHIC SURVEY

Subject Informed Consent Form

Investigator(s) name & address:

Ginevra Courtade, Ph.D.
College of Education and Human Development
University of Louisville
Louisville, KY 40292
502-852-2144
g.courtade@louisville.edu

Jennifer Pollard, M.Ed. BCBA LBA
College of Education and Human Development
University of Louisville
Louisville, KY 40292
502-592-4167
jmpoll01@louisville.edu

Choice of site(s) where study is to be conducted:

1. Your Residence
2. University of Louisville

Phone number for subjects to call for questions: 502-852-2144 or 502-592-4167

Introduction and Background Information

You and your child or ward is invited to participate in a research study through the University of Louisville's Department of Special Education, Early Childhood, & Prevention Sciences. This is because they experience a menstrual cycle and have extensive support needs (i.e. an intellectual disability, developmental disability). They may benefit from learning skills to ask questions to medical professionals and record information to help them be part of the decision-making process about their menstrual care. The study is being conducted by Dr. Ginevra Courtade, Ph.D., a faculty member in the College of Education and Human Development; and Jennifer Pollard, M.Ed. BCBA LBA, a doctoral student in the College of Education and Human Development. During the study, they will only meet with the research team and one session they will meet with a member of the medical community to see if they are able to use the skills learned while speaking with a physician. You can choose for your child/ward and yourself can choose to be part of the study in person or online. We will collect some demographic information for background data as well.

Purpose

The purpose of this study is to teach females with extensive support needs to better understand what their menstrual cycle is, what happens in their body, the reason people use contraceptives (pregnancy prevention, reducing blood flow, minimizing mood changes, and more), the different choices, and how to ask about these choices with a medical professional. There is little to no appropriate education materials that meets the needs of this population about this subject matter. There is promising research about interventions that teach appropriate skills about gaining information to be part of the decision-making process. Every person deserves to be part of the decision-making process related to their medical care. This intervention will help your participant learn how to be a more active participant in choosing their care by understanding choices and how to speak to professionals about these choices.

Procedures

First, participants will be asked if they know specific vocabulary related to their menstrual cycle and care. If they are unaware of these terms, we will teach them the vocabulary terms. Participants will be asked to make choices about medical care that are important to them, they will be asked three different times to make sure to get accurate responses. We will also ask for your input about their preferences based on your observations of them in daily life. Then an educational packet with information about the menstrual cycle, reasons people ask about contraceptives, and those choices that includes typed words and visuals to help promote understanding. After reviewing this packet, each participant will be prompted to ask questions about the choices of interest to them to get a baseline level of their ability to ask these questions. Following this baseline level, a preference assessment will be given to each participant to better understand what is important to them related to contraceptive use (i.e. how often it is taken, where it is taken, how often they would get their period, the side effects, etc.). After this preference assessment, an individualized graphic organizer/worksheet will be created specific to their needs. Each participant will then be taught how to use this to ask questions about their choices and record that information for later use, the goal will be to ask about three different choices. We will practice these skills together until each participant is able to do so independently. A generalization probe will occur with a medical professional to assess how well the intervention prepared participants to ask these questions with a doctor. Roughly, six weeks later a maintenance probe will happen where each participant is asked to complete the task again to assess how well the skills stayed with the individuals. You will have a choice to choose these sessions to take place in person either at your residence or in a small classroom at the University of Louisville. Each session will last between 30-60 minutes and the number of sessions will depend on how quickly your participant gains the skills. Sessions can take place every week or every other week depending on your schedule. You also have a choice to attend all sessions online via an a video conference platform. In each session only your participant and a member of the research team will be present. Session will be video recorded. These videos will only be used for a separate member of the research team to review to measure that the sessions are being conducted accurately.

Video Share

We hope to present the results of this study at a professional conference. Please indicate below if you agree to let the videos of your participant's sessions to be viewed at this conference as part of the presentation. The videos will not be distributed to the audience but only small clips may be shown as part of the presentation. People who attend this conference are other researchers and university professors from around the world who respect the rights and privacy of participants in research studies.

I agree to let videos of my participant's sessions be viewed at professional conferences.

Signature

Date

I DO NOT agree to let videos of my participant's sessions be viewed at professional conferences.

Signature

Date

Potential Risks

There are no foreseeable risks, although there may be unforeseen risks.

Benefits

The possible benefits of this study include improvement in your participant's ability to have a more active role in making decisions that affect their life and care. The information collected may not benefit your participant directly. However, the information learned in this study may be helpful to others, by providing new knowledge on how to improve working with students with disabilities in the educational setting.

Payment

You will not be compensated for your time, inconvenience, or expenses while your participant participates in this study.

Confidentiality

Total privacy cannot be guaranteed. We will protect your participant's privacy to the extent permitted by law. If the results from this study are published, your participant's name will not be made public. Once your participant's information leaves our institution, we cannot promise that others will keep it private.

Your information may be shared with the following:

- The University of Louisville Institutional Review Board, Human Subjects Protection Program Office, Privacy Office, others involved in research administration and compliance at the University, and others contracted by the University for ensuring human subjects safety or research compliance
- The local research team
- People who are responsible for research, compliance and HIPAA oversight at the institutions where the research is conducted
- Government agencies, such as:
- Office for Human Research Protections

All data collected in this study will be stored on a secured server. Only members of the research team will have access to the server.

Security

Your participant's information will be kept private by ensuring that all personal information and data collected will be stored on a secured server.

Voluntary Participation

Taking part in this study is voluntary. You and your participant may choose not to take part at all. If you and your participant decide to be in this study, you may stop taking part at any time. If you and your participant decide not to be in this study or if you stop taking part at any time, you will not lose any benefits for which you may qualify.

You will be told about any changes that may affect your decision to continue in the study.

Alternative

The alternative is not participate in the study.

Contact Persons

If you have any questions, concerns, or complaints about the research study, please contact Dr. Ginevra Courtade at 502-852-2144 or Jennifer Pollard at 502-592-4167

Research Subject's Rights

If you have any questions about your participant's rights as a research subject, you may call the Human Subjects Protection Program Office at 502-852-5188. You may discuss any questions about your participant's rights as a research subject, in private, with a member of the Institutional Review Board (IRB). You may also call this number if you have other questions about the research, and you cannot reach the study investigators, or want to talk to someone else. The IRB is an independent committee made up of people from the University community, staff of the institutions, as well as people from the

community not connected with these institutions. The IRB has approved the participation of human subjects in this research study.

Concerns and Complaints

If you have concerns or complaints about the research or research staff and you do not wish to give your name, you may call the toll free number 1-877-852-1167. This is a 24 hour hot line answered by people who do not work at the University of Louisville.

Acknowledgment and Signatures

This informed consent document is not a contract. This document tells you what will happen during the study if you choose to take part. Your signature indicates that this study has been explained to you, that your questions have been answered, and that you agree to take part in the study and permit your child or ward to participate. You are not giving up any legal rights to which you are entitled by signing this informed consent document. You will be given a copy of this consent form to keep for your records.

Subject Name (Please Print) Signed	Signature of Subject	Date
---------------------------------------	----------------------	------

Signature of Legally Authorized Representative (if applicable)	Date Signed	Printed Name of Legally Authorized Representative
---	-------------	--

Authority of Legally Authorized Representative to act on behalf of Subject

*Authority to act on behalf of another includes, but is not limited to parent, guardian, or durable power of attorney for health care

Printed Name of Investigator Signed	Signature of Investigator	Date
--	---------------------------	------

List of Investigators:

Phone Numbers:

Ginevra Courtade, Ph.D.

502-852-2144

Jennifer Pollard, M.Ed. BCBA LBA

502-592-4167

Demographic Survey

Subject Name:

Age:

Diagnoses:

Race:

Ethnicity:

Nationality:

APPENDIX F

PARTICIPANT ASSENT FORM

INCREASING SELF-DETERMINATION SKILLS FOR INDIVIDUALS WITH EXTENSIVE SUPPORT NEEDS TO EXAMINE REVERSIBLE CONTRACEPTIVE CHOICES

Investigator(s) name & address:

Ginevra Courtade, Ph.D.
College of Education and Human Development
University of Louisville
Louisville, KY 40292
502-852-2144
g.courtade@louisville.edu

Jennifer Pollard, M.Ed. BCBA LBA
College of Education and Human Development
University of Louisville
Louisville, KY 40292
502-592-4167
jmpoll01@louisville.edu

Choice of site(s) where study is to be conducted:

1. Your Residence
2. Via Zoom
3. University of Louisville

Phone number for subjects to call for questions: 502-852-2144 or 502-592-4167

You are invited to participate in a research study through the University of Louisville's Department of Special Education, Early Childhood, & Prevention Sciences. This is because you have a period and may need help with some medication

Purpose

We want to help you learn more about your period and different ways to help with different parts of your period like getting upset easily, cramps or pain, and acne or pimples. We want you to learn how to ask about choices for medicine and talk to a doctor so you can make a choice of what is right for you.

Procedures

You can participate in person at your house or a small classroom at U of L or we can meet online through Zoom. We will review a quick packet about your period and options for medicines. Then I will ask you to pretend like you are talking to a doctor. I will ask you what you think is most important when talking to a doctor then we will practice that. When you are ready, we will talk to a real doctor so you can ask them questions. Each session will last about 30-60 minutes and will be videotaped so that other researchers can see what we are doing. Only researchers will see these videos.

Video Share

We hope to present the results of this study at a professional conference. Please indicate below if you agree to let the videos of your participant's sessions to be viewed at this conference as part of the presentation. The videos will not be distributed to the audience but only small clips may be shown as part of the presentation. People who attend this conference are other researchers and university professors from around the world who respect the rights and privacy of participants in research studies.

I agree to let videos of my sessions be viewed at professional conferences.

I DO NOT agree to let videos of my sessions be viewed at professional conferences.

Potential Risks

There are no foreseeable risks, although there may be unforeseen risks.

Benefits

The possible benefit is that you will learn more about your period and learn to be more comfortable talking to your doctor about medicine.

Payment

You will not be paid to do this.

Confidentiality

We will protect your privacy as much as we can and information will only be given to other researchers listed below:

Your information may be shared with the following:

- The University of Louisville Institutional Review Board, Human Subjects Protection Program Office, Privacy Office, others involved in research administration and compliance at the University, and others contracted by the University for ensuring human subjects safety or research compliance

- The local research team
- People who are responsible for research, compliance and HIPAA oversight at the institutions where the research is conducted
- Government agencies, such as:
- Office for Human Research Protections

Security

Your information will be kept private by ensuring that all personal information and data collected will be stored on a secured server.

Voluntary Participation

Taking part in this study is voluntary. You get to choose if you want to do this and can stop at any time.

You will be told about any changes that may affect your decision to continue in the study.

Alternative

The alternative is to not participate in the study.

Contact Persons

If you have any questions, concerns, or complaints about the research study, please contact Dr. Ginevra Courtade at 502-852-2144 or Jennifer Pollard at 502-592-4167

Research Subject's Rights

If you have any questions about your rights as a research subject, you may call the Human Subjects Protection Program Office at 502-852-5188.

Concerns and Complaints

If you have concerns or complaints about the research or research staff and you do not wish to give your name, you may call the toll free number 1-877-852-1167. This is a 24 hour hot line answered by people who do not work at the University of Louisville.

Acknowledgment and Signatures

This informed consent document is not a contract. This document tells you what will happen during the study if you choose to take part. Your signature indicates that this study has been explained to you, that your questions have been answered, and that you agree to take part in the study. You are not giving up any legal rights to which you are

entitled by signing this informed consent document. You will be given a copy of this consent form to keep for your records.

Subject Name (Please Print) Signe	Signature of Subject	Date
--------------------------------------	----------------------	------

Printed Name of Investigator Signed	Signature of Investigator	Date
--	---------------------------	------

List of Investigators:	Phone Numbers:
Ginevra Courtade, Ph.D.	502-852-2144
Jennifer Pollard, M.Ed. BCBA LBA	502-592-4167

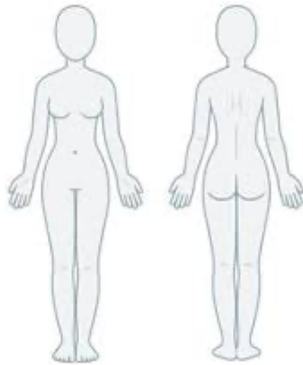
APPENDIX G

VOCABULARY PROBE

1. Which one shows menstrual blood or your period?



2. Where is your vagina? Where are your breasts or boobs?



shutterstock.com · 761158138

3. Which one is a shot?



4. Which one is a pill?



5. Which one is a patch?



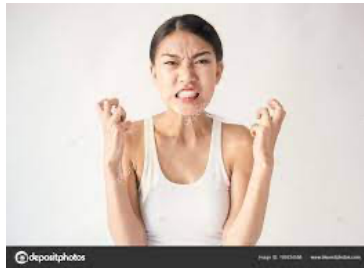
6. Who has period cramps or pain?



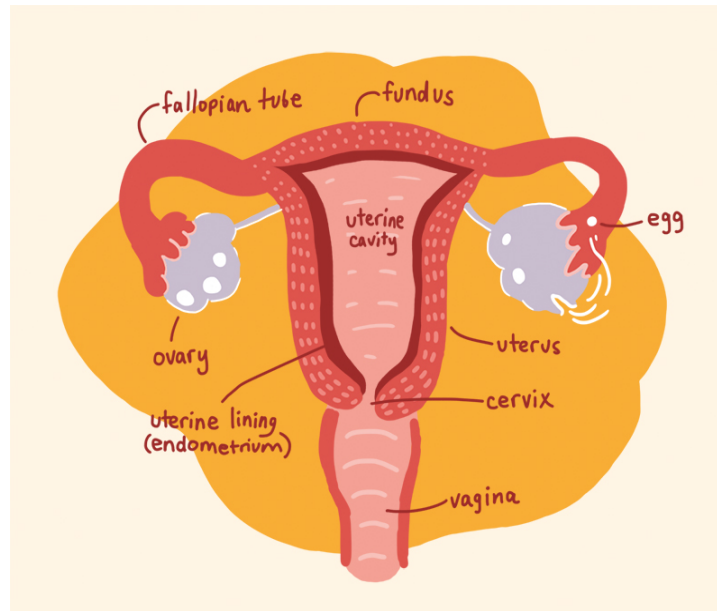
7. Who is sad?



8. Who is angry?



APPENDIX H
EDUCATIONAL PACKET
OPTION A

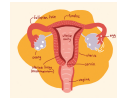


Managing your Period

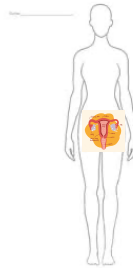
*image from firstperiod.org



What is your period or menstrual cycle?



- Your period comes from your reproductive organs.



- They are in your body.



- Your body sends hormones, they are inside, you cannot see them.



What does your body send for your period?



1. Energy



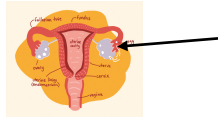
2. Eggs



3. Hormones



- Hormones make your body get ready for pregnancy.



- An ovary releases an egg.



- If it becomes fertilized with sperm then you become pregnant.

Your ovary releases an...



1. Chicken



2. Egg



3. Sperm



- Sperm comes from a man.



- This should only happen with your consent.

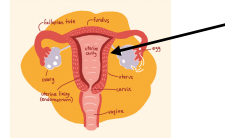
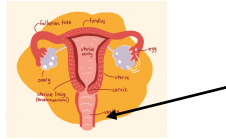


- If you do not get pregnant, then your body gets rid of the egg.

What does your body do with the egg if you do not get pregnant?



1. Keeps it
2. Cooks it
3. Gets rid of it



- It comes out of your vagina with blood from your uterus.



- You can see blood in your underwear when it comes out.



- This can be scary but it is normal.



What can you see in your underwear?



1. Blood



2. Dirt



3. Eggs



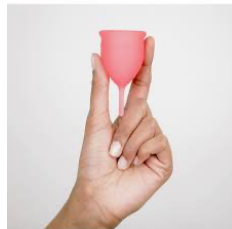
- You can use these options to help with the bleeding



Pads



Tampons



Menstrual Cups



Period Underwear

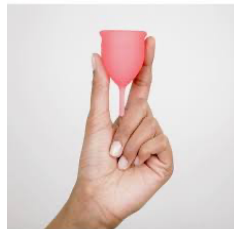
- Which do you prefer?



Pads



Tampons



Menstrual Cups



Period Underwear



- Besides bleeding, periods can cause:



Pain



Acne



Sadness



Sleepiness



Anger

- Do you ever feel these?



Pain



Acne



Sadness



Sleepiness



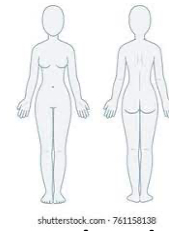
Anger



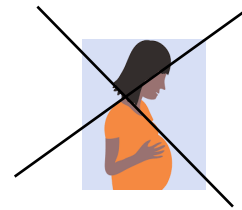
Is there anything that can help?



Reversible Contraceptives or Birth Control Options



- Reversible means it will not cause permanent change to your body.



- Birth Control means it helps to stop pregnancy from happening.

- Birth Control also helps with:



Pain



Acne



Bleeding Too Much



Sadness

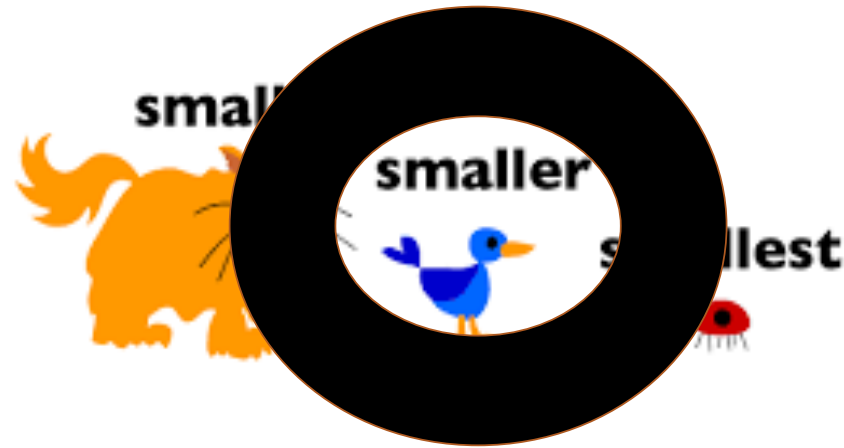


Sleepiness



Anger

Birth Control makes all those things



Birth Control Pills



How take them?



Swallow

How often?



MON	TUE	WED	THU	FRI	SAT	SUN
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WWW.CALENDARWART.COM

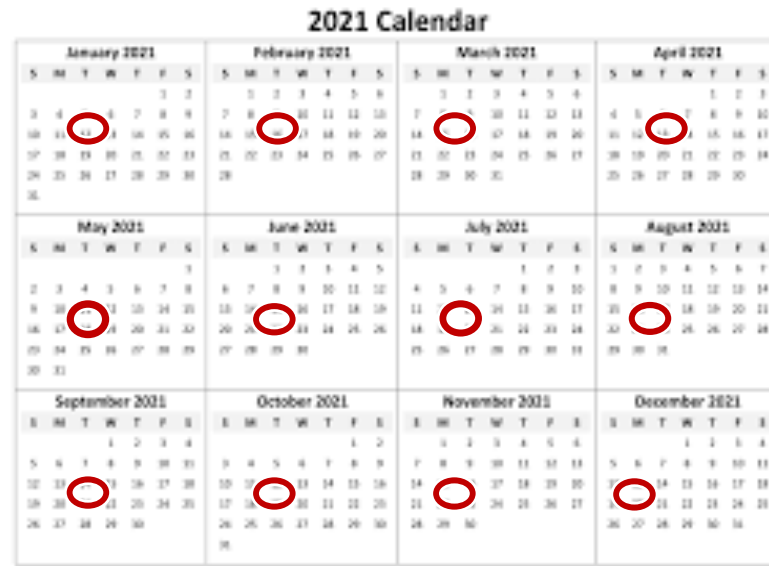
Every Day

Where?



At Home

How often get period?



12 Times a Year

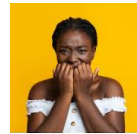
Side Effects?



A side effect is something unpleasant or bad that can happen from medicine.

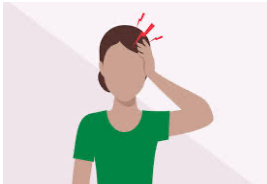


Usually they are small and not a big deal.



The doctor will tell you if you need to be concerned with any big side effect.

Side Effects?



Headache



Stomach Ache



Sore Breasts



Little Chance

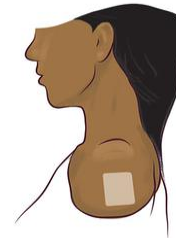
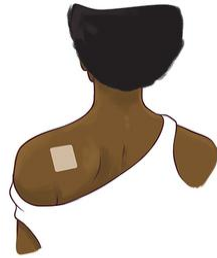
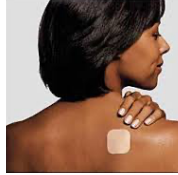
Possibly More



Birth Control Patch

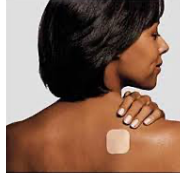


How take them?



Put on your Body

How often?

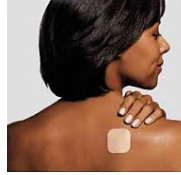


MON	TUE	WED	THU	FRI	SAT	SUN
○						
○						
○						

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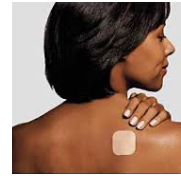
(3) Three Weeks a Month

Where?



At Home

How often get period?



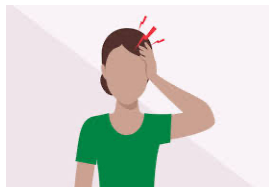
2021 Calendar

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May 2021	June 2021	July 2021	August 2021
S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31
September 2021	October 2021	November 2021	December 2021
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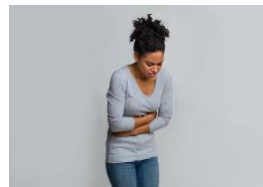
www.horikalendar.com

12 Times a Year

Side Effects?



Headache



Stomach Ache



Sore Breasts



Itchy Skin



Little Chance

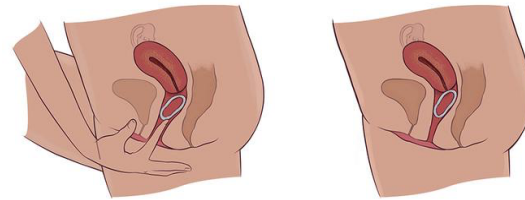


Possibly More

Birth Control Ring



How take them?



Put it inside your Vagina

How often?



MON	TUE	WED	THU	FRI	SAT	SUN
○						

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(1) Once a Month

Where?



At Home

How often get period?

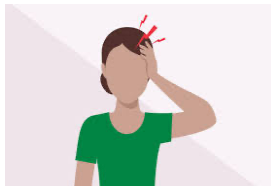


2021 Calendar

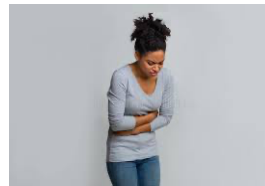
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12 Times a Year or Less

Side Effects?



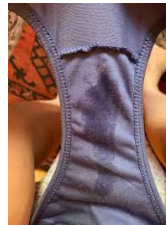
Headache



Stomach Ache



Sore Breasts



Wet Vagina and Underwear



Little Chance



Possibly More

Birth Control Shot



How take them?



Getting a Shot

How often?



2021 Calendar

January 2021	February 2021	March 2021	April 2021
S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30
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www.month-calendar.com

Every (3) Three Months

Where?



Doctor's Office

How often get period?

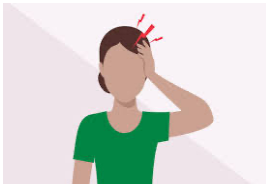


2021 Calendar

January 2021	February 2021	March 2021	April 2021
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4 Times a Year

Side Effects?



Headache



Stomach Ache



Sore Breasts



Sadness



Weight Gain



Sore Arm



Little Chance

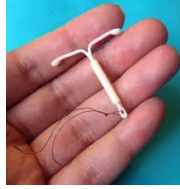


Possibly More

IUD



How take them?



Doctor puts it inside you Uterus

How often?



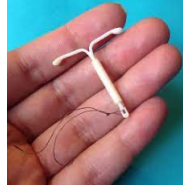
2021 Calendar

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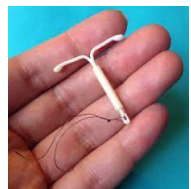
www.bank-holidays.com

0-1 Times a Year

Where?



Doctor's Office



How often get period?

2021 Calendar

January 2021	February 2021	March 2021	April 2021
S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30
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www.time-calendars.com

0-12 Times a Year

Side Effects?



Back Ache



Pain in Lower Belly



Some Blood in Underwear



Little Chance



Possibly More

Arm Implant



How take them?



Doctor puts it inside your Arm

How often?



2021 Calendar

January 2021	February 2021	March 2021	April 2021
S M T W T F S 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	S M T W T F S 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28	S M T W T F S 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30
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www.html-calendar.com

0-1 Times a Year

Where?



Doctor's Office

How often get period?  

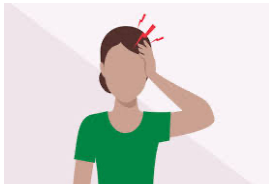
2021 Calendar

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0-12 Times a Year

Side Effects?



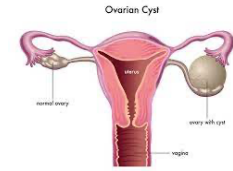
Headache



Stomach Ache



Sore Breasts



Ovarian Cyst



Weight Gain



Sore Arm



Little Chance



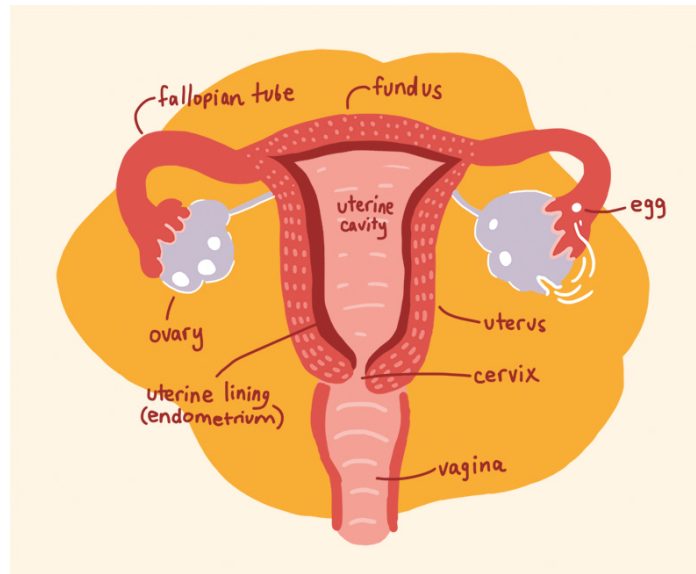
Possibly More

Information From...

[American College of
Obstetrics and Gynecology](#)

[Planned Parenthood](#)

APPENIX I
EDUCATIONAL PACKET
OPTION B



Managing your Period

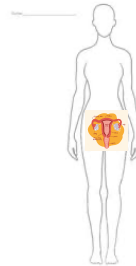
*image from firstperiod.org



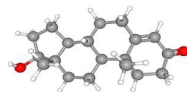
What is your period or menstrual cycle?



- Your period comes from your reproductive organs.



- They are in your body.



- Your body sends hormones, they are inside, you cannot see them.



What does your body send for your period?



1. Energy



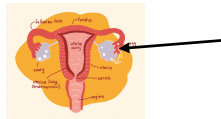
2. Eggs



3. Hormones



- Hormones make your body get ready for pregnancy.



- An ovary releases an egg.



- If it becomes fertilized with sperm then you become pregnant.

Your ovary releases an...



1. Chicken



2. Egg



3. Sperm



- Sperm comes from a man.



- This should only happen with your consent.

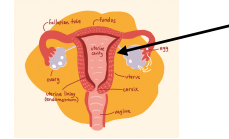
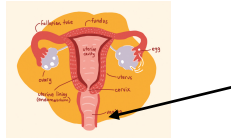


- If you do not get pregnant, then your body gets rid of the egg.

What does your body do with the egg if you do not get pregnant?



1. Keeps it
2. Cooks it
3. Gets rid of it



- It comes out of your vagina with blood from your uterus.



- You can see blood in your underwear when it comes out.



- This can be scary but it is normal.



What can you see in your underwear?



1. Blood



2. Dirt



3. Eggs



- You can use these options to help with the bleeding



Pads



Tampons



Menstrual Cups



Period Underwear

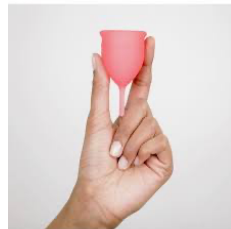
- Which do you prefer?



Pads



Tampons



Menstrual Cups



Period Underwear



- Besides bleeding, periods can cause:



Pain



Acne



Sadness



Sleepiness



Anger

- Do you ever feel these?



Pain



Acne



Sadness



Sleepiness



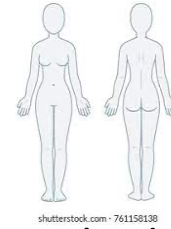
Anger



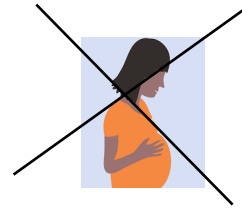
Is there anything that can help?



Reversible Contraceptives or Birth Control Options



- Reversible means it will not cause permanent change to your body.



- Birth Control means it helps to stop pregnancy from happening.

- Birth Control also helps with:



Pain



Acne



Bleeding Too Much



Sadness

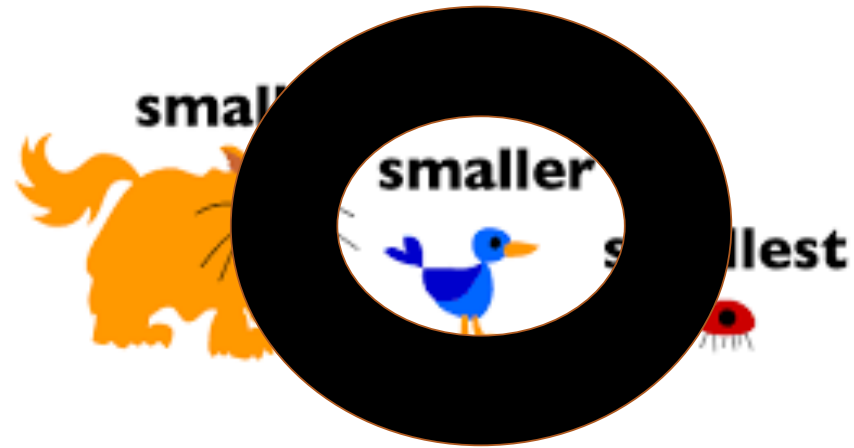


Sleepiness



Anger

Birth Control makes all those things



Options 



Pills



Patch



Ring



Shot



Vagina Implant

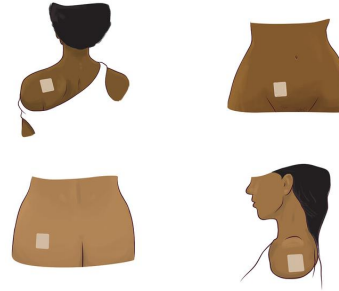


Arm Implant

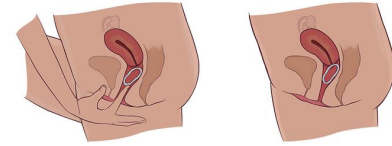
How take them?



Swallow



Put on Body



Put in Vagina

How take them?



Get a Shot



Doctor puts inside Uterus
through Vagina



Doctor puts inside Arm

How often?

MON	TUE	WED	THU	FRI	SAT	SUN
○	○	○	○	○	○	○
○	○	○	○	○	○	○
○	○	○	○	○	○	○
○	○	○	○	○	○	○
○	○	○	○	○	○	○

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Every Day

How often?

MON	TUE	WED	THU	FRI	SAT	SUN
○						
○						
○						

WWW.CALENDARWART.COM

(3) Three Weeks a Month

How often?

MON	TUE	WED	THU	FRI	SAT	SUN
○						

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(1) Once a Month

How often?



0-1 Times a Year

Where?



At Home

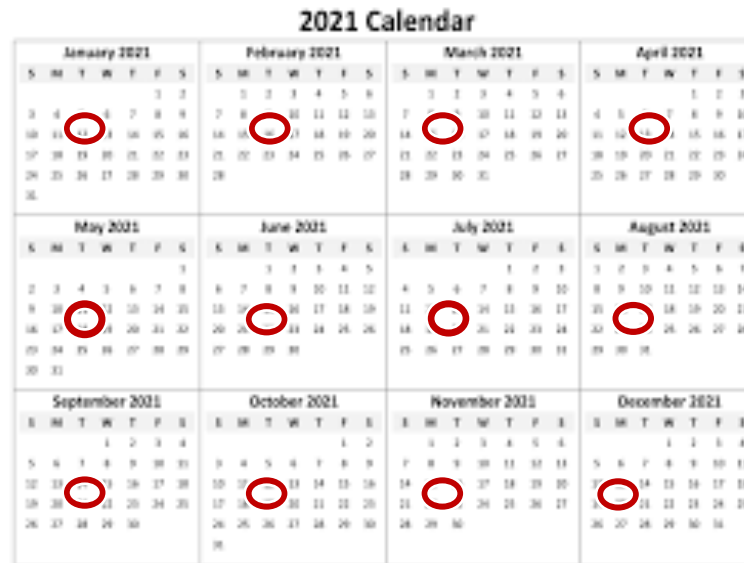
or



Doctor's Office



How often get period?



www.bahk-calendar.com

12 Times a Year



How often get period?

2021 Calendar

January 2021	February 2021	March 2021	April 2021
S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30
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4 Times a Year



How often get period?

2021 Calendar

January 2021	February 2021	March 2021	April 2021
S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30
May 2021	June 2021	July 2021	August 2021
S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31
September 2021	October 2021	November 2021	December 2021
S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31

www.html-calendar.com

0-12 Times a Year

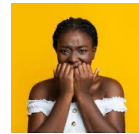
Side Effects?



A side effect is something unpleasant or bad that can happen from medicine.

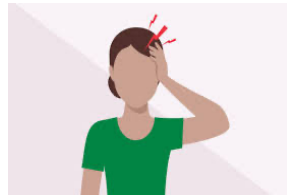


Usually they are small and not a big deal.



The doctor will tell you if you need to be concerned with any big side effect.

Side Effects?



Headache



Stomach Ache



Sore Breasts

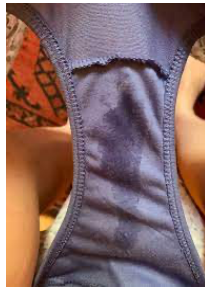
Side Effects?



shutterstock.com - 47673838



Itchy Skin



Wet Vagina
or Underwear



Sore Arm

Side Effects?



Weight Gain



Sadness

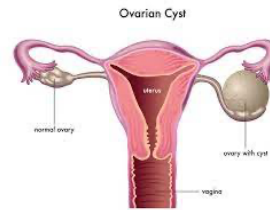


Pain in Lower Belly

Side Effects?



Back Pain



Ovarian Cyst



Blood in Underwear

Side Effects?



Information From...

[American College of
Obstetrics and Gynecology](#)

[Planned Parenthood](#)

APPENDIX J

PREFERENCE ASSESSMENT

Preference Assessment:

Order and images depend on answers by each participant. Participants will be asked to indicate their preferences

Not all slides/printed papers will be shown to each participant, it will be based on their answers

What do you want help with:



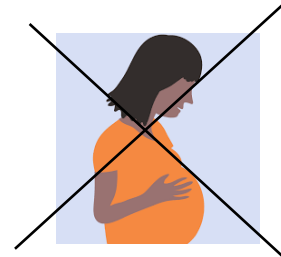
Pain



Acne



Bleeding



Pregnancy
Prevention



Sadness



Sleepiness



Anger

Where do you prefer to go to get your medicine?



At Home

or



Doctor's Office

Which do you prefer?

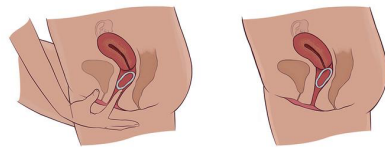


Swallow



Put on Body

Which do you prefer?



Put in Vagina



Swallow

Which do you prefer?



Swallow



Get a Shot

Which do you prefer?



Swallow



Doctor puts inside Uterus
through Vagina

Which do you prefer?

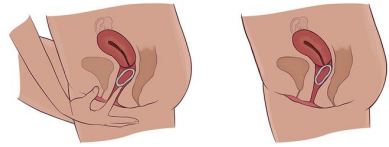


Doctor puts inside Arm

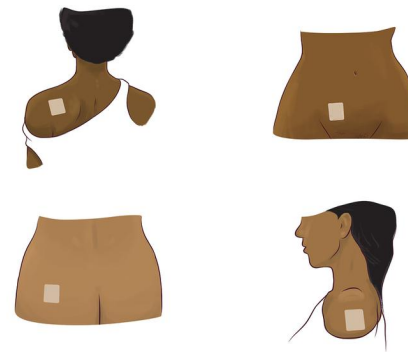


Swallow

Which do you prefer?



Put in Vagina



Put on Body

Which do you prefer?

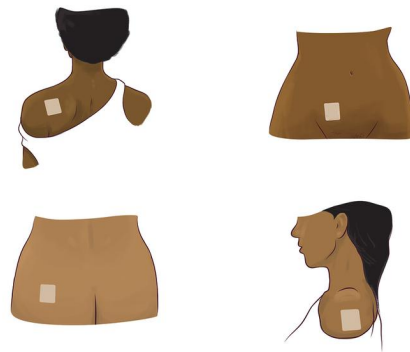


Get a Shot



Put on Body

Which do you prefer?

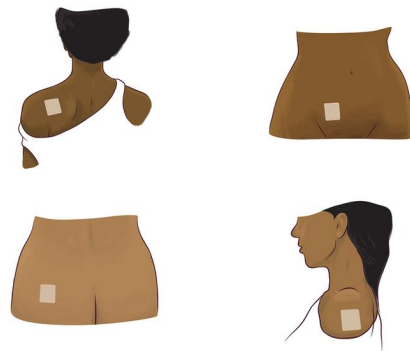


Get a Shot



Doctor puts inside Uterus
through Vagina

Which do you prefer?

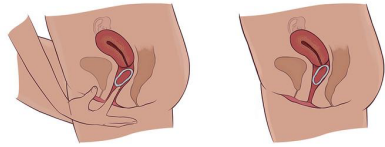


Get a Shot



Doctor puts inside Arm

Which do you prefer?



Put in Vagina

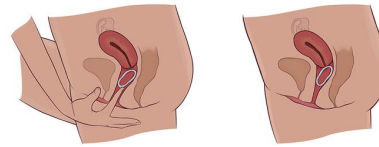


Get a Shot

Which do you prefer?



Doctor puts in Uterus
through Vagina

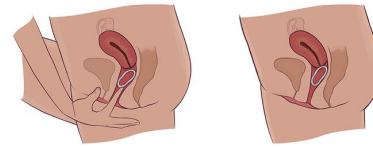


Put inside Vagina

Which do you prefer?



Doctor puts inside Arm



Put inside Vagina

Which do you prefer?



Doctor puts in Uterus
through Vagina



Get a Shot

Which do you prefer?



Doctor puts inside Arm



Doctor puts in Uterus
through Vagina

How often do you want to take them?

MON	TUE	WED	THU	FRI	SAT	SUN
○	○	○	○	○	○	○
○	○	○	○	○	○	○
○	○	○	○	○	○	○
○	○	○	○	○	○	○
○	○	○	○	○	○	○

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Every Day

MON	TUE	WED	THU	FRI	SAT	SUN
○						
○						
○						

WWW.CALENDARKART.COM




































(3) Three Times a Month

How often do you want to take them?

MON	TUE	WED	THU	FRI	SAT	SUN
						

WWW.CALENDARKART.COM

(1) Once a Month

MON	TUE	WED	THU	FRI	SAT	SUN
						
						
						
						
						

WWW.CALENDARKART.COM

Every Day

How often do you want to take them?

MON	TUE	WED	THU	FRI	SAT	SUN
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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Every Day



(1) Once a Year or Less

How often do you want to take them?

MON	TUE	WED	THU	FRI	SAT	SUN
○						

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(1) Once a Month

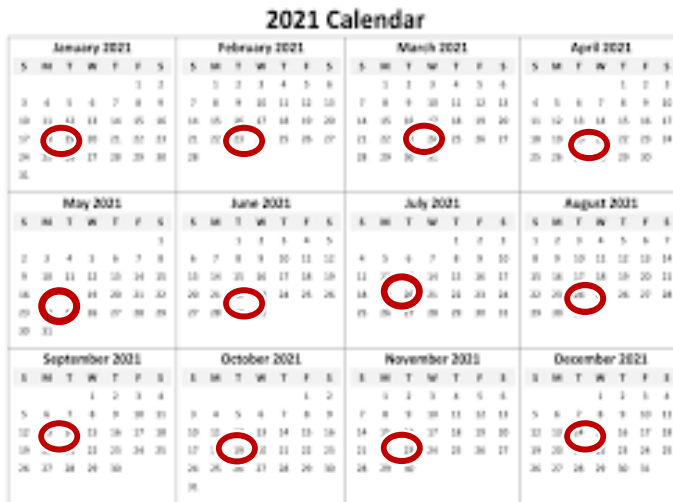
MON	TUE	WED	THU	FRI	SAT	SUN
○						
○						
○						

WWW.CALENDARART.COM

(3) Three Times a Month



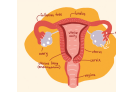
How often do you prefer to get your period?



12 times a year



4 times a year



How often do you prefer to get your period?

2021 Calendar

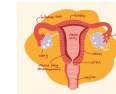
January 2021	February 2021	March 2021	April 2021
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May 2021	June 2021	July 2021	August 2021
S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31
September 2021	October 2021	November 2021	December 2021
S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31

1 time a year or less

2021 Calendar

January 2021	February 2021	March 2021	April 2021
S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30
May 2021	June 2021	July 2021	August 2021
S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31
September 2021	October 2021	November 2021	December 2021
S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31

12 times a year



How often do you prefer to get your period?

2021 Calendar

January 2021	February 2021	March 2021	April 2021
S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30
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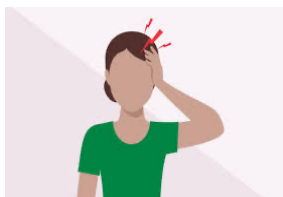
4 times a year

2021 Calendar

January 2021	February 2021	March 2021	April 2021
S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31	S M T W T F S 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30
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1 time a year or less

Which Side Effects Worry You?



Headache



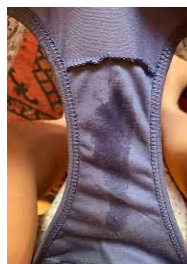
Stomach Ache



Sore Breasts



Itchy Skin



Wet Vagina or Underwear



Sore Arm

Which Side Effects Worry You?



Weight Gain



Sadness



Pain in Lower Belly



Sore Back



Ovarian Cysts



Spotting

There may not be one choice that meets all your preferences but it is important to ask about them

APPENDIX K

PREFERENCE ASSESSMENT IOA FORM

Directions: circle the preferences that the participant indicates independently

Areas of concern

Pain	Acne	Bleeding	Pregnancy Prevention
Sadness	Sleepiness	Anger	Other

Location of Receiving Medication

Home	Doctor's Office
------	-----------------

Method of Taking Medication

Swallow	Put on Body
Swallow	Put in Vagina
Swallow	Get a Shot
Swallow	Doctor Put Inside Uterus Through Vagina
Swallow	Doctor Puts Inside Arm
Put on Body	Put in Vagina
Put on Body	Get a Shot
Put on Body	Doctor Put Inside Uterus Through Vagina
Put in Vagina	Doctor Put Inside Arm
Get a Shot	Doctor Put Inside Uterus Through Vagina
Get a Shot	Doctor Put Inside Arm
Doctor Put Inside Arm	Doctor Put Inside Uterus Through Vagina

How Often to Take the Medication

Every Day	Three times a Month
-----------	---------------------

Every Day	Once a Month
Every Day	Once a Year or Less
Three times a Month	Once a Month
Three times a Month	Once a Year or Less
Once a Month	Once a Year or Less

How Often Get Period

12 times a year	4 times a year
12 times a year	1 time a year or less
4 times a year	1 time a year or less

Side Effects of Concern

Headache	Stomach Ache	Sore Breasts	Itchy Skin
Wet Vagina or Underwear		Sore Arm	Weight Gain
Sadness	Lower Belly Pain	Sore Back	Ovarian Cysts
Spotting			

APPENDIX L

CAREGIVER PREFERENCE ASSESSMENT

Directions: circle the preferences you believe your participant will indicate as important or a preference to them.

Areas of concern

Pain Acne Bleeding Pregnancy Prevention
Sadness Sleepiness Anger

Location of Receiving Medication

Home Doctor's Office

Method of Taking Medication

Swallow Put on Body Put in Vagina Get a Shot
Doctor Put Inside Uterus Through Vagina Doctor Puts Inside Arm

How Often to Take the Medication

Every Day Three times a Month
Once a Month Once a Year or Less

How Often Get Period

12 times a year 4 times a year
1 time a year or less

Side Effects of Concern

Headache Stomach Ache Sore Breasts Itchy Skin
Wet Vagina or Underwear Sore Arm Weight Gain

Sadness

Lower Belly Pain

Sore Back

Ovarian Cysts

Spotting

What are your concerns?

Is there any other information we should know?

APPENDIX M

TASK ANALYSIS

Date: _____ Participant: _____
 Scorer: _____ Session Observation: _____ Baseline # _____ Intervention # _____
 # _____ Generalization _____ Maintenance _____

Directions: Put a \checkmark next to tasks that are completed independently
 Put a P1 next to tasks that are completed with the first level of prompting (see back for details)
 Put a P2 next to tasks that are completed with partial prompting (see back for details)
 Put a P3 next to tasks that are completed with full prompting (see back for details)
 In the circle next to every task that included prompting please put a + if the researcher completed prompting procedures with fidelity and a - if it was not (see back for details)

- 1. Explain why they are at the appointment: "to learn about birth control options"
- 2. Explain why they need help and what they are concerned about
- 3. Ask for options (Goal is 3 options)
- 4. State preferences/ask about and record specifics for each option (prompted from personalized worksheet, there are 4 categories) (participant only has to state preferences once)
- 5. Ask about side effects for each option

Score: \checkmark = 2 _____
 P1 = 1 _____
 P2 = 0.5 _____
 P3 = 0 _____
 Total: _____/40

6. Number of redirections needed: _____

Prompting Procedures

1. Gain attention
2. Give directive (listed below). Wait 5 seconds.
3. If the participant completes the first step, give social praise.
4. If the participant does not start, remind them to start the directive (i.e. “you need to tell the doctor what you want to learn about” “you need to tell the doctor what you need help with”). Wait 5 seconds. (Mark P1)
4. If the participant completes the first step then give social praise.
5. If the participant does not start, give a gestural prompt by pointing the place on the graphic organizer where the directive starts and give the verbal directive again. Wait 5 seconds (Mark P2)
6. If the participant completes the step then give verbal praise.
7. If the participant does not start, give a full verbal prompt by modeling the step. Wait 5 seconds (Mark P3).
8. Repeat 2-7 until complete.

*Social praise examples: “good job”, high five, etc.

- 1st redirection: “start the conversation with the doctor”
- 2nd redirection: “tell the doctor what you need help with”
- 3rd redirection: “ask for a name of a medication”
- 4th redirection: “ask your first question”
- 5th redirection: “ask your second question”
- 6th redirection: “ask your third question”
- 7th redirection: “ask your fourth question”
- 8th redirection: “ask about side effects”

*If a participant does not require verbal redirections to begin each step of the graphic organizer then verbal redirections will not be given. Each participant will be given 30 seconds to begin steps independently before being given a verbal redirection. Some will be repeated over the three different choices so there is a total possibility of 20

APPENDIX N

PARTICIPANT SOCIAL VALIDITY SURVEY



1. I enjoyed being part of this study. myself.

YES NO MAYBE



4. I like being able to ask things

YES NO MAYBE



2. I found the information helpful. helpful.

YES NO MAYBE



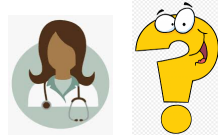
5. I found the graphic organizer

YES NO MAYBE



3. I liked asking a doctor questions. doctors.

YES NO MAYBE



6. I would try this with other

YES NO MAYBE

7. Anything else you want to say?

APPENDIX O

CAREGIVER SOCIAL VALIDITY SURVEY

1. I found the interventions in this study to be useful for my child to gain knowledge about their healthcare options.

Strongly Agree *Agree* *Neither Agree or Disagree* *Disagree* *Strongly Disagree*

2. I think my child is more capable of being part of the decisions made about their healthcare after taking part in this study.

Strongly Agree *Agree* *Neither Agree or Disagree* *Disagree* *Strongly Disagree*

3. I think my child will be able to use the skills learned at a later time.

Strongly Agree *Agree* *Neither Agree or Disagree* *Disagree* *Strongly Disagree*

4. I would recommend other parents or guardians use these interventions with their children.

Strongly Agree *Agree* *Neither Agree or Disagree* *Disagree* *Strongly Disagree*

5. I wish that these skills were taught more in schools to prepare children with extensive support needs to be successful later in life.

Strongly Agree *Agree* *Neither Agree or Disagree* *Disagree* *Strongly Disagree*

6. I think my child liked being part of this study.

Strongly Agree *Agree* *Neither Agree or Disagree* *Disagree* *Strongly Disagree*

7. Please share any other thoughts or comments about this study:

CURRICULUM VITA

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EDUCATION AND PROFESSIONAL CREDENTIALS

Degrees

- Ph.D. 2022 University of Louisville Curriculum and Instruction in Special Education
(Expected)
- M.A. 2015 Ball State University Applied Behavior Analysis with an Emphasis in
Autism
- M.Ed. 2013 University of Louisville Counseling and Personnel Services with an
Emphasis in School Counseling, Art Therapy
- M.A.T. 2008 Rhode Island School of Design Teaching and Learning Art and Design
Education
- B.A. 2005 George Washington University Art History and Fine Arts

Licenses

Board Certified Behavior Analyst, International (1-16-23597)
Licensed Behavior Analyst, Kentucky (171380)

Previously Held Licenses

Art Education Pre-K-12, Kentucky
Art Education Pre-K-12, Rhode Island

PROFESSIONAL EXPERIENCE

- 2020-2021 Zoom Group, Behavior Department Head
Board Certified Behavior Analyst
Support to Behavior Support Professionals
Review FBAs and BSPs

- 2017-present Princecare Group, Mariposa Place
Board Certified Behavior Analyst
- 2015-2018 Social Development, LLC
Board Certified Behavior Analyst (2017-2018)
Behavior Intern (2015)
- 2015-2017 Down Syndrome of Louisville
Board Certified Behavior Analyst (2015-2017)
Behavior intern (2015)
- 2010-2015 St. Francis School, Art Department
Art Teacher Pre-K- 4th Grade (2010-2015)
Department Chair (2011-2015)
School Counseling Intern (2013)
Chair of Junior National Arts Honor Society (2011-2012)
International Chaperone (2011)
- 2008-2010 Mercy Academy, Art Department
Art Teacher, 9th-12th Grade (2008-2010)
Chair of National Arts Honor Society (2009-2010)
Kentucky Teacher Internship Program (2008-2009)
- 2008 Rhode Island School of Design Museum of Art
Curriculum Development Intern
- 2007 Rhode Island School of Design, Young Artist's Program
Teaching Assistant
- 2005-2007 Carriage House Services and Preschool
One on One Aide (2006-2007)
Teaching Assistant (2005-2006)

PUBLICATIONS

Manuscripts In Preparation

Pollard, J. & Courtade, G. (2022). *Increasing Engagement in Students with Down Syndrome using the High-Probability Request Sequence*. In preparation

Long, A., Elliot, M., Pollard, J., Fitchett, C., & Courtade, G. (2022). *What's working in an alternative teacher preparation program? Survey results and next steps for program development*. In preparation.

Fitchett, C., Pollard, J., Elliot, M., Long, A., & Courtade, G. (2022). *Mentorship models: Helping alternative certification teachers be successful*. In preparation.

Curricula

Pollard, J. (2012) *Arts Education 2nd-4th grade*, St Francis School: Goshen, KY.

Pollard, J. (2010) *Arts Education Pre-K- 1st grade*, St. Francis School: Goshen, KY.

Pollard, J. (2008) *Arts Education for 9th- 12th grade*, Mercy Academy: Louisville, KY

Gagnon, A., Lefas-Tetenes, M., Pollard, J. (2008). *Dig the museum!: Building cultural connections*. Rhode Island School of Design Museum of Art: Rhode Island

PRESENTATIONS

Presentations

Pollard, J. & McClure, E. (2022, September). *Antecedent interventions for sex education: a systematic literature review*. Applied Behavior Analysis- International Conference. Dublin, Ireland.

McClure, E. & Pollard, J. (2022, September). *A systematic literature review of research-based behavior analytic interventions for inappropriate sexual behaviors*. Applied Behavior Analysis-International Conference. Dublin, Ireland.

Pollard, J., (2022, June). *Increasing self-determination skills in a medical setting- preliminary results*. Kentucky Council for Children with Behavior Disorders Behavior Institute. Louisville, KY (poster).

Elliot, M., Long, A., Fitchett, C., Pollard, J., & Courtade, G. (2022, April). *What's working in alternative teacher prep: Survey results and next steps for program development: HLPs, cultural competencies, mentoring, and more*. Kentucky Excellence in Educator Preparation Conference. Virtual.

Fitchett, C., Elliot, M., Pollard, J. (2022, March). *What's working in an atp program? Survey results and next steps for program development*. American Council on Rural Special Education Conference. Myrtle Beach, SC. (roundtable).

Courtade, G., Elliot, M., Long, A., Fitchett, C., & Pollard, J. (2022, January). *Ready or Not? Feedback From Teachers of Students with ESN in an Alternative Teacher Preparation Program on Their Preparedness for Implementing HLPs*. Council for Exceptional Children Conference, Orlando, FL. (poster).

Pollard, J. (2022, January). *Self-Determination and Comprehensive Sex Education for Individuals with Extensive Support Needs*. Teacher Education Division Kaliedoscope Poster Session. Council for Exceptional Children Conference, Orlando, FL.

Norton-Meier, L., Courtade, G., Andris, J., Sivira-Gonzalez, Y., & Pollard, J. (2021, August). *Resisting fragility: A group of early childhood teachers emerge from uncertain times leaning into relationships to renew innovative practices*. Association for Teacher Educators Summer Conference. Virtual.

Norton-Meier, L., Courtade, G., Andris, J., Sivira-Gonzalez, Y., Pollard, J. & Hattab, K. (2021, February). *It is so hard to work on my practice when the ground keeps shifting under my feet”: How one group of urban early childhood teachers continued to transform their practice amidst administrative changes and a global pandemic while working in diverse, high poverty neighborhoods*. Association for Teacher Educators Conference. Virtual.

Pollard, J. (2020, February). *Effects of High-Probability Request Sequence*. Graduate Student Regional Research Conference, Louisville, KY. (poster)

Pollard, J. (2020, August). *Effects of High-Probability Request Sequence*. Women in Behavior Analysis Conference. Virtual. (poster)

Invited Presentations

Pollard, J. (2022, June) *Understanding Behavior*. Workshop for Staff. Down Syndrome of Louisville. Louisville, KY.

Pollard, J. (2019, August) *Behavior Support Plan Training*. Workshop for Staff. Down Syndrome of Louisville. Louisville, KY.

Pollard, J. (2019, May) *Behavior Support Plan Training*. Workshop for Staff. Mariposa Place. Louisville, KY.

Pollard, J. (2019, April) *Behavior Support Plan Training*. Workshop for Staff. Kentuckiana Nursing Services. Louisville, KY.

Pollard, J. (2018, November) *Behavior Support Plan Training*. Workshop for Staff. Kentuckiana Nursing Services. Louisville, KY.

Pollard, J. (2016, June) *Applied Behavior Analysis*. Professional Development for Staff. Down Syndrome of Louisville. Louisville, KY.

Pollard, J. (2016, October) *Applied Behavior Analysis*. Workshop for Parents and Caregivers. Down Syndrome of Louisville. Louisville, KY

Kirkham, E. & Pollard, J. (2015, June). *Applied Behavior Analysis*. Professional Development for Staff. Down Syndrome of Louisville. Louisville, KY.

Pollard, J., Duechle, N., Yenawine, N. (2012, April) *Working with other professionals to design education experiences for students*. Professional Development for Staff. St. Francis School. Goshen, K

TEACHING

Teaching Assignments:

University of Louisville

EDSP 546 Behavioral Approach to Communication (Co-Teacher)

EDSP 650 Advanced ABA (guest lecture)

EDSP 440 MSD Curriculum and Methods II (Co-Teacher)

EDSP 650 Advanced ABA (Co-Teacher)

SERVICE

State and Local Service

2022- present Rural Special Education Quarterly, Reviewer

2022-present Kentucky Behavior Analysis Licensing Board, Secretary

2022- present Kentucky Behavior Analysis Licensing Board, Regulations Committee

2021-present Kentucky Behavior Analysis Licensing Board

2021-present Kentucky Behavior Analysis Licensing Board, Application Committee

2021 Search Committee for Head of the Early Childhood Research Center, University of Louisville.

2020-2021 Mentor to Alternative Certification Teaching Candidates, University of Louisville

2019-present Regional Interagency Transition Team, Louisville Kentucky

2016-2017 Human Rights Committee, Down Syndrome of Louisville

2014-2015 St. Francis School Grievance Committee

2011-2015 Community Outreach Education, St. Francis School

2011-2012 St. Francis School Junior National Arts Honor Society

2010-2015 Behavior Committee, St. Francis School

2009-2010 Mercy Academy National Arts Honor Society

AWARDS

2022- Admission to Higher Education for Special Education (HECSE) Consortium Short Course and Summit

2022- Student Travel Award- American Council on Rural Special Education
Conference
2008- Initiation to Kentucky Colonels

PROFESSIONAL AFFILIATIONS

Association for Behavior Analysis International (ABAI)

Association of Applied Behavior Analysts (APBA)

Kentucky Association for Behavior Analysts (KYABA)

Council for Exceptional Children (CEC)

Kentucky Art Education Association

National Art Education Association