

The Pennsylvania State University

The Graduate School

College of Health and Human Development

**“IF YOU USE YOUR AAC FROM THE BEGINNING OF A RELATIONSHIP, IT
WILL BE NORMAL FOR YOU AND YOUR PARTNER, EVEN DURING SEX”:
PEOPLE WHO USE AUGMENTATIVE AND ALTERNATIVE
COMMUNICATION AND THEIR EXPERIENCES WITH SEXUALITY**

A Thesis in

Communication Sciences and Disorders

by

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ABSTRACT

Existing research within the field of augmentative and alternative communication documents aspects of sexuality such as preventing abuse, assessing capacity to consent, and providing education and opportunities (Hingsburger, 2010). Although these are all important areas of sexuality for discussion, research documenting sexual experiences, perspectives, needs, and priorities, of individuals who actually use augmentative and alternative communication as their primary communication modality is virtually nonexistent. This qualitative, phenomenological research study explored the experiences and recommendations of four individuals with complex communication needs who used AAC as their primary communication modality. The four participants completed semi-structured interviews via email. The interviews addressed the following topics: sexuality education, sexual experiences, relationship experiences, and communication. The results of this study were coded into five different themes: sexuality education, sex and sexuality specifically, communication during and about sex, barriers to sexuality, supports for sexuality, and recommendations. The clinical implications of this study are best described by the participants in their recommendations for professionals. Providing individuals with the supports that they need for communication in order to achieve their own goals and dreams includes providing supports for communicating about sexuality and relationships.

Keywords: sexuality, sex, AAC, augmentative and alternative communication, complex communication needs, speech-language pathology, disability, relationships

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DESCRIPTION OF LANGUAGE USE

The language used to describe groups of people is often strongly impactful, and everyone has a different preference. It is understood that across the disability community there are strong personal expectations for language. A combination of people-first language and identity first language has been used. Both have been included in order to represent and respect individuals who prefer people first language, as well as disabled people who prefer to use identity first language. Any quotations from participants replicate the language that they used, and have not been modified or changed to reflect the authors' word choice preferences or expectations.

'They' and 'their' have been used as singular, gender neutral pronouns throughout this paper whenever possible. This is in an attempt to further maintain anonymity of participants, as well as to minimize gender role assumptions made by the reader. Gendered pronouns (he/she, him/her, etc.) are used only if the use of the pronoun is inherently necessary for meaning, or if they were used in quotes from participants or other references.

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CHAPTER I: INTRODUCTION

“Providing disabled adults with access to sexual lives is not just crucial for a life with dignity. It is an issue of fundamental social justice with far reaching consequences for everyone” (Külick & Rydstrom, 2015, back cover).

Sexuality plays an intrinsic role in what it means to be human, and has an intricate connection within and throughout our lives (Pownall, Jahoda, & Hastings, 2012; Bernert & Ogletree, 2013). “Sexuality is an ever-present, ever-evolving, multifaceted resource of every human being” (Levine, 1992, p. 1). Sexual health, as an important aspect of sexuality, has been defined by the World Health Organization as “a state of physical, mental, and social well-being in relation to sexuality. It requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination, and violence” (WHO, 2015). As such, access to sexuality for all individuals is key, especially for individuals who may require additional support.

All individuals, including individuals with disabilities are sexual beings (Hingsburger, 2002). Inherently communication is imperative for developing sexuality. Davis et al. (2006) found that the strongest predictor of sexual dissatisfaction was poor communication. In a study completed by Friedman, Arnold, Owen, and Sandman (2014), self-advocates with intellectual and developmental disabilities identified communication as a crucial aspect of practicing sexual self-advocacy, especially in terms of speaking up, accessing information, and building healthy and positive relationships.

Some individuals with disabilities have significant communication impairments, whereby they are unable to express their thoughts and feelings by using verbal speech.

These individuals require the supports of augmentative and/or alternative communication (AAC). The American Speech-Language-Hearing Association (2005) defines AAC as:

...an area of research, clinical, and educational practice. AAC involves attempts to study and when necessary compensate for temporary or permanent impairments, activity limitations, and participation restrictions of individuals with severe disorders of speech-language production and/or comprehension including spoken and written modes of communication (p. 1).

Research documents many aspects of disability and sexuality, however very limited research investigates how communication disabilities, requiring the use of AAC, impact sexuality in the development and maintenance of intimate relationships.

AAC may consist of aided or unaided devices, strategies, or techniques that allow individuals to communicate with the people around them (ASHA, 2017). Mainstream technology such as smart phones, tablets, touch screens, wearable technology and more are now commonplace among nondisabled individuals. This increasing reliance and acceptance of technology to support everyday needs across many populations has helped AAC to also become more accepted in recent years. Not only does AAC allow individuals to interact with others face-to-face, it can often be used in conjunction with more mainstream technology such as social media, email, text messages, instant messaging, and even online dating applications and websites (Hynan, Murray, & Goldbart, 2014). Having such extensive access to many different supports allows people with CCN to communicate about a broad range of topics and in a broad variety of contexts with both familiar and unfamiliar partners.

These forms of communication, while necessary and helpful for individuals with CCN, may still result in stigma and negative connotations from the eyes of a nondisabled world. Using AAC to compose messages is often time consuming and may be difficult for quick, immediate responses. Unfortunately, stigma around both disability and assistive technology (including alternative forms of communication) persists (Parette & Scherer, 2004). Even when using AAC supports, individuals may not have access to the vocabulary required to communicate about sexuality. If individuals do not have literacy skills, particularly encoding skills, they are limited to the vocabulary that has been programmed into an AAC device for them, or must individually program vocabulary pages, which is often quite time consuming, and still somewhat limiting in terms of the quality and variety of vocabulary available (Fallon, Light, & Paige, 2001).

Sexuality education for individuals with disabilities is often inadequate if it occurs at all. While this is not a challenge inherent to people who use AAC alone, it is important to consider. If an individual who uses AAC lacks literacy skills, and does not have access to sexual vocabulary on their AAC device, how much and to what extent could they communicate with a sexual partner?¹ Shuttleworth (2003) addressed the importance of ensuring access to sexuality and information about sexuality, identifying the need for a research focus on sexual access for individuals with disabilities.

Because of the importance of communication in developing and maintaining sexuality, this study sought to understand the experiences and perspectives of individuals who primarily use AAC to communicate. These perspectives of individuals who use AAC may help to inform professionals in the fields of communication sciences and

¹ Details regarding use of the singular they/them gender neutral pronoun can be found in The Description of Language Use in the Front Matter of this paper.

disorders and AAC, as well as help to identify best practices for ensuring that individuals have the support that they need to develop, maintain, and communicate about sexuality. Further, because this study explored the experiences and opinions of individuals who use AAC, it aims to provide other individuals who use AAC with insight and information on this topic. Through a qualitative, phenomenological research design, this study sought to understand intimate relationships from the perspectives of individuals who use augmentative communication modes.

Literature Review

Research literature in the fields of AAC, AAC and sexuality, disability and sexuality, cerebral palsy and sexuality, and communication and sexuality were reviewed. These areas, while all distinct, had many overlapping themes and objectives with each other, as well as with the current study. Each of the above areas was reviewed in order to provide a base of knowledge around the current research available, in order to better establish a rationale and approach for the current study. The intersection between disability and sexuality has been studied (Wiegerink et al., 2006, 2010, 2010; Shuttleworth, 2000; Tepper, 2000; Küllick & Rydstrom, 2015; McRuer & Mollow, 2012; McCabe et al., 2000, 2003; Hingsburger, 2002). Less research is available on the role of AAC and sexuality, perhaps because this technology and field have only begun to develop within the past few decades or perhaps because of the discomfort around disability and sexuality (Hingsburger, 2010). People with disabilities do have and desire sexual lives and feelings. However, complex communication needs (CCN) add a layer of intricacy because communication plays such an important role in sexuality and relationship development (Byers, 2011; Byers & MacNeil, 1997; Litzinger & Coop

Gordon, 2005; Timm & Keiley, 2011). The current literature focuses on different themes of sexuality including issues of sexual abuse, capacity to consent, and access (Bryen & Bornman, 2014; Bryen, 2008; Bryen, Chung, & Lever, 2010; Bryen, Carey, & Frantz, 2003; Bryen & Wickman, 2011; Collier, McGhie-Richmond, & Odette, 2004, 2006). In addition to these different themes and approaches to research about individuals who use AAC and sexuality, literature has also begun to document the experiences of individuals who use AAC around sexuality, as well as sexuality and cerebral palsy, and the importance of communication for sexuality and relationships.

Cerebral Palsy and Sexuality

Research has shown that individuals with cerebral palsy (CP) do have and desire romantic, intimate, and sexual relationships (Wiegerink et al. 2006, 2010, 2010). Despite social perceptions of asexuality, people with disabilities (including CP) may identify themselves anywhere on the spectrum of sexuality. The assumption that individuals with disabilities are asexual has been widely documented (Kattari, 2015; Kulick & Rydström, 2015; Tepper, 2000), and these same resources have explained the errors behind this societal perception. Nonetheless this assumption persists, and only recently has sexuality and disability become more prevalent in the research literature and in society more broadly. McCabe (2003) found that people with more severe physical disabilities engage in sexual activity with another person less frequently than people with mild physical disabilities or the able-bodied population. Wiegerink (2010, 2010, 2006) completed several studies that looked at the challenges that arise for adolescents and young adults with cerebral palsy specifically. In 2006, in a review of the literature, Wiegerink found that spontaneous social activities for adolescents with CP occurred less frequently than

with their nondisabled peers. They also found that people with physical disabilities had lower levels of sexual knowledge and experience than their nondisabled peers. In 2010, Wiegerink also found that young adults with CP between the ages of 20 and 24 had comparable sexual interest with their nondisabled peers, but had less experience in both romantic relationships and sexual experiences. Additional factors may also affect relationships and sexuality, including education, environment, family, personality, etc. There is a continued need for research that is sex neutral and discusses sex and sexuality from a social framework (Kattari, 2015). Kattari (2015) stated that individuals should have “unfettered access to information around sexuality and disability” (p. 883), however access is often still limited. Wiegerink et al. (2010) also found that young adults with cerebral palsy who had a lower education level tended to date later than those with a higher education level. They suggested that this could be due to limited access to information and opportunities for sexuality.

Sexual Abuse

Some individuals with CP have significant speech impairments and require AAC. What limited research is currently available regarding individuals who use AAC and sexuality focuses on preventing sexual abuse and determining capacity to consent (Bryen & Bornman, 2014; Bryen, Carey, & Frantz, 2003; Bryen & Wickman, 2011; Burke, Bedard, & Ludwig, 1998; Collier, McGhie-Richmond, & Odette, 2004, 2006). Overall this research focuses on the negative aspects of sexuality for individuals with CCN. Many researchers have documented the high rates of sexual abuse among individuals with disabilities, especially individuals with communication disabilities, and examined ways to prevent sexual abuse toward these individuals. Individuals with communication

disabilities are at a higher risk for abuse, including sexual abuse, because they may be viewed as being unable to report crimes committed against them (Bryen & Bornman, 2014; Bryen, Carey, & Frantz, 2014; Bryen & Wickman, 2011; Burke, Bedard, & Ludwig, 1998; Collier, McGhie-Richmond, & Odette, 2004, 2006). While these are indeed crucial issues, studies addressing development and positive aspects of sexuality (e.g., relationship building, intimacy, and consensual, successful, sexual relationships) are much more limited.

Access to Sexuality: Education, Vocabulary, and Experiences

AAC research also discusses the importance of addressing sexuality in transition plans, the types of vocabulary that are needed to communicate about sexuality, and the importance of education and capacity to consent (Ziff, 1986; Hingsburger, 2010; Friedman, Arnold, Owe, & Sandman, 2014; Bryen, Chung, & Lever, 2010; & Bryen, 2008). The topics addressed in the literature thus far are absolutely necessary to ensure that individuals with CCN have access to sexuality vocabulary, education, and an understanding of consent. Discussing sexuality in these contexts is necessary. However, conversations must be ongoing and progressively more inclusive of individuals who use AAC, both at the participant and research levels.

Communication and Sexuality

Regardless of disability status, communication is an important aspect of developing positive relationships with others (Cupach & Comstock, 1990; MacNeil & Byers, 1997, 2005; Metts & Cupach, 1989). According to MacNeil and Byers (2005), communication about sexuality is crucial to the “development and maintenance of satisfying sexual relationships” (p. 170). In 1997, MacNeil and Byers found that better

communication, in general, as well as communication about sexuality were associated with increased sexual satisfaction. Again in 2005, they found that communication about sexuality is crucial for sexual satisfaction (MacNeil & Byers, 2005). However, Cupach and Metts (1989) also found that communicating about sexuality is generally uncomfortable for many people. Adding any sort of complex communication need further complicates the importance of using strong communication skills to develop and maintain successful, sexually intimate relationships. Regardless, Montesi et al. (2010) found that sexual satisfaction relies, in part, on effective communication.

AAC, Sexuality, and Acquired Communication Disorders

Leigh (2010) completed a study in which they investigated the experiences of intimacy for adults with acquired communication disorders who use AAC. Ten individuals were interviewed, five with an acquired communication disorder, and five partners. Interviews were completed individually and jointly with their partners. Leigh identified several themes across both people who use AAC and their partners, including: the effort needed to communicate; reprioritization of the importance of different values and life experiences; the many new emotions experienced following an acquired communication disorder; changes in identity; changes and generally a decrease in privacy; the time needed to maintain adequate communication within relationships; the role of physical and emotional closeness; and the importance of adaptation. Many of these themes discussed the impact of the acquired communication disorder and the changes that impacted their intimate relationships (Leigh, 2010). This study focused on the experiences of sexuality for people who had acquired communication disorders.

However, the experiences of these individuals may differ from the experiences of people who have had communication disorders for most of their lives.

AAC and Sexuality

David Hingsburger (2010) discussed sexuality and the use of AAC. This chapter is currently the most comprehensive work on AAC and sexuality available. Hingsburger discusses several case studies of individuals who use AAC, and then discusses the attitudes and issues around the topic. Some of these included: prejudiced attitudes toward sexuality for individuals who use AAC, attitudes based on fear, assessing consent, confronting fear, assessment and instruction in boundaries and consent, and limited opportunities for relationships to develop. Hingsburger discussed the importance of language and communication in developing sexuality; they argue that, without sex education, it is impossible to add meaningful language around sexuality to an AAC system. Providing both education and language for sexuality gives individuals power to communicate about these topics. Likewise, not having access to education and/or language for sexuality may limit power for individuals with CCN. Despite the many concerns and issues around sexuality for individuals who use AAC, relationships can and do work. Many individuals who use AAC develop positive, loving, sexual relationships. Hingsburger demonstrates through case studies the limited progress that has been made, though did not directly share the perspectives of individuals who use AAC to communicate.

Rationale for the Study

Given the importance of sexuality and the lack of research to date, the purpose of this qualitative study was to explore the experiences and perspectives of individuals with

CCN regarding sexuality and AAC use. The goal was to explore and specifically discuss experiences related to education, sexual experiences, communication, and recommendations. These discussion topics were chosen in order to gain insight and perspective from participants across broad fields of experience. Further, the study investigated access to appropriate and necessary vocabulary, education, and opportunities to develop positive sexual experiences.

This research was driven by the perspectives of individuals with CCN who use AAC, supporting the principle, well-known within the disability rights movement, of “nothing about us without us” (Charlton, 1998). Individuals who use AAC can, and should, have the strongest impact upon discussions about their own sexuality. If people who use AAC are to be fully and truly included in society, these conversations must include them, and value their perspectives, experiences, and opinions. Too often, nondisabled individuals provide the framework, the structure, and the stories to drive the lives of disabled individuals. However, the experts on disability, in this case navigating the experience of sexuality and disability while using AAC, are individuals who actually use AAC and have firsthand experiences. The goals of this study were to explore the perspectives of individuals with cerebral palsy who used AAC on the following issues: (a) sexuality education; (b) experiences with sex and sexuality; (c) communication during sexual experiences; (d) recommendations for professionals; and (e) recommendations for other people who use AAC. The results have the potential to guide the fields of communication sciences and disorders and AAC to better understand the requirements, benefits, and limitations of AAC as it pertains to this aspect of individuals’ lives. This information will allow professionals to create better AAC systems, opportunities, and

intervention that support sexuality, and will provide professionals with information about the impact of AAC on developing and maintaining positive intimate relationships.

Clinicians, individuals who use AAC, and their families will gain greater knowledge and understanding to develop AAC strategies, supports, education, and intervention that may enhance access and reduce barriers to building and maintaining intimate and/or sexual relationships. This study will, finally, help to build a knowledge base about how using AAC may (or may not) impact sexuality.

CHAPTER II: METHODOLOGY

Research Design

A qualitative, semi-structured interview design was chosen for this study in order to better understand experiences of sexuality for individuals who use AAC as their primary communication modality. This study was reviewed and approved by the Pennsylvania State University Institutional Review Board. Qualitative, phenomenological research designs allow for an in-depth approach to explore and understand the lived experiences of others, and the interpretations that others make about those experiences (Seidman, 2013). One-on-one interviews completed via email provided a comfortable environment, and best protected the privacy of the participants. Semi-structured interviews were chosen as the primary methodology so that participants had the opportunity to expand upon their answers, and interviews could be customized and personalized to their individual experiences. Broad questions and topics were introduced, and then probes were used in order to obtain further information (see Appendix A). The use of qualitative, phenomenological practices has important implications and uses in research. The study of lived experiences of individuals with communication disorders, specifically individuals with CCN who use AAC systems, allows for researchers and clinicians to explore how individuals adapt and live, and in what areas additional support may be necessary (Hinckley, Ball, Müller, & Nelson, 2014). Qualitative research “is what it is; the most appropriate way to examine the subjective and individual experiences of what it means to be a person who has a communication disorder” (Guendouzi, Ball, Müller, & Nelson, 2013, p. 340). Semi-structured interviews have also been used as a

qualitative methodology across previous research studies in the AAC field (Balandin, Hemsley, Sigafoos, & Green, 2007; Hodge, 2007; Leigh, 2010).

Participants

The study involved four individuals. Inclusion criteria for participation included the following: (a) were age 18 or older; (b) had a diagnosis of cerebral palsy; (c) had functional vision and hearing to participate in this study; (d) had access to the internet; (e) had CCN whereby their speech is inadequate to meet their daily communication needs and alternative methods are used; (f) could independently construct a written paragraph (3-5 sentences); (g) reported that they had had at least one sexual experience and/or intimate relationship; and (h) were willing to participate in an interview with the primary researcher. The inclusion criteria were developed according to the recommendations made by Higginbotham and Bedrosian (1995).

Participants were recruited through researchers' personal contacts, social media groups which self-identify as serving the needs and interests of individuals with CCN, and support groups for individuals with CNN in different regions of the United States. Private practice and school personnel (e.g., teachers and speech-language pathologists) were contacted and invited to distribute information about the study. Emails, listserv postings, and social media messages were the primary means of contacting potential participants. A flyer was provided with basic information and any interested participants contacted the researcher directly via email. All four participants were recruited through emails and personal connections with the research team or other participants. Only the primary researcher was associated with the process of obtaining consent. The sole role of

outside parties was to distribute recruitment materials. Pseudonyms have been used throughout to protect the confidentiality of the participants in the study.

Participants first completed a screening questionnaire to determine if they met the inclusion criteria for the study (see Appendix B). Three of the participants identified as male, and one identified as female. Three identified as heterosexual, and one identified as homosexual. All participants had completed high school, and three completed some college. The ages of the participants ranged from 35 to 60 years. All participants were Caucasian. The participants were from different geographic areas. In terms of communication, the participants used a wide variety of both aided and unaided supports. The demographics of the participants are summarized further in Table 1.

TABLE 1: Participant Demographics

Participant	1-Lee	2- Sam	3- Pat	4- Jesse
Gender	Cisgender, Male	Cisgender, Male	Cisgender, Male	Cisgender, Female
Sexual Identity	Heterosexual	Heterosexual	Heterosexual	Lesbian
Education	2 years college	High school certificate, Trade school	Bachelor's degree	Bachelor's degree
Means of communication	Spelling letters with head, some verbal speech, iPad with Speak for Yourself app ^a , language board, computer	Limited, unclear speech, iPad with Proloquo2Go ^b app. Limited hand sign vocabulary for use in shower, bath, or pool	ECO-2 ^c	Speech with close friends/family. Sign language, iPad ^d with Speak for Yourself app ^a or "notes", pen and paper
Relationship status	Single	Yes, 6 th year of second marriage	Married, 3 years	Engaged
Age	47	56	46	38
Race	Caucasian	Caucasian	Caucasian	Caucasian

^a Speak for Yourself app: Speak for Yourself, LLC. <http://www.speakforyourself.org/>

^b Proloquo2Go: AssistiveWare. <http://www.assistiveware.com/product/proloquo2go>

^c ECO-2: Prentke Romich Company. <https://www.prentrom.com/>

^d iPad: Apple, Inc. <http://www.apple.com/ipad/>

Materials - Interview Protocol Development

The interview questions covered a variety of topics relevant to sexuality, particularly the development of intimate relationships and the role of AAC (see Appendix A). These topics included (a) sexuality education; (b) experiences with sex and sexuality; (c) communication during sexual experiences; (d) recommendations for professionals; and (e) recommendations for other people who use AAC. Questions were designed in a semi-structured fashion, so that individuals could respond to a broad topic in whichever way they chose, making it appropriate and relevant to them individually (Seidman, 2013). Because of the time and effort that individuals required to construct answers using AAC,

questions were limited in number. The validity of the interview questions was established and verified with participants in the research study following the transcription of the interviews via a member check (Lincoln & Guba, 1985). Current qualitative research in the field of physical disability and sexuality verified the validity of the questions (Wiegerink et al., 2010). It ensured essential topics were covered, questions were worded appropriately, and the breadth of questions was sufficient. The topics and areas of sex and sexuality that have been discussed and used in surveys and interviews in previous research were used as a shell to compose the interview questions for this study. Experts in the field of AAC also reviewed and validated the interview questions. In a follow-up email, the participants in the study validated the questions *post hoc*. The interview questions were organized in such a way as to begin the interviews with topics that were more comfortable and neutral to discuss, and then, as rapport was built with the interviewer, additional and more personal topics were introduced via the interview questions. The protocol for the interviews was developed before the interviews occurred to provide a structure and format for the emails that was consistent across all participants. A shell of this interview protocol is available in Appendix C.

Interview Procedures

All participants completed the interview via email. This modality was chosen in order to allow individuals from many different geographical locations to participate. This also allowed the participants and the researcher to develop responses and questions given their own availability and timelines. Using email was more realistic than face to face interactions because of the depth of the interview questions, and the reality that using AAC can be a very time consuming process,. Though email was perhaps not the ideal

way to complete the interviews, as Seidman (2013) discusses, “it is better to conduct a long-distance interview than to not interview at all” (p.113). Interviews completed via email had both advantages and disadvantages for this study. Completing interviews via email did not allow for the same level of rapport building as in person interviews, and they did not support the spontaneity of face-to-face communication. Further, completing interviews via email can make it more difficult to develop an equitable relationship between the interviewer and interviewee (Seidman, 2013). Despite these challenges, there were also advantages to using email to complete the interviews. The participants in this study were from disparate geographical areas. It would not have been possible to conduct the interviews with these participants face-to-face because of limitations on time, travel, and funding. Email interviews may have been beneficial, given the sensitive nature of the topic, because they placed a distance between the researcher and the participants. This may have encouraged participants to share more details than they might in person, or it may have resulted in participants being more comfortable throughout the interviewing process. What email interviews may lack in spontaneity, they may gain in thoughtful, written responses. Finally, given the nature of the population for this study, having the time and space to compose responses allowed participants to complete the longer interview questions within their own time frame, without the time pressure that face-to-face interviewing can impose.

The primary researcher reviewed study procedures and the topics to be covered before beginning interviews with the participants. Throughout the interview process, participants were reminded that they could choose not to answer any interview questions that made them uncomfortable. Interviews were semi-structured, with open-ended

questions in order to allow for participants to take any direction that they wanted, with the intention of building an understanding of the participants' subjective experiences (Seidman, 2013). The semi-structured questions were developed with a list of topics and questions, but with the understanding that participants could elaborate on any area and that the researcher could follow up with additional questions to clarify a participants' responses (Seidman, 2013; Penn, Ball, Müller, & Nelson, 2014).

The entire interview process varied in length across participants. After responding to recruitment materials, participants received a brief introduction to the study and a screening questionnaire via email. Once the participants had completed the screening questionnaires, the primary researcher began asking interview questions throughout a series of emails (see Appendix C). Once a participant answered a question, they received feedback, any follow up questions, and the next question for the interview. This resulted in approximately 13 emails sent by the researcher and approximately 13 emails received from the participants. Each participant varied in the time needed to complete their responses. The full interview process ranged from a minimum of 31 days to a maximum of 99 days. Approximately four to six months later participants received a follow-up email containing their transcripts and coding themes.

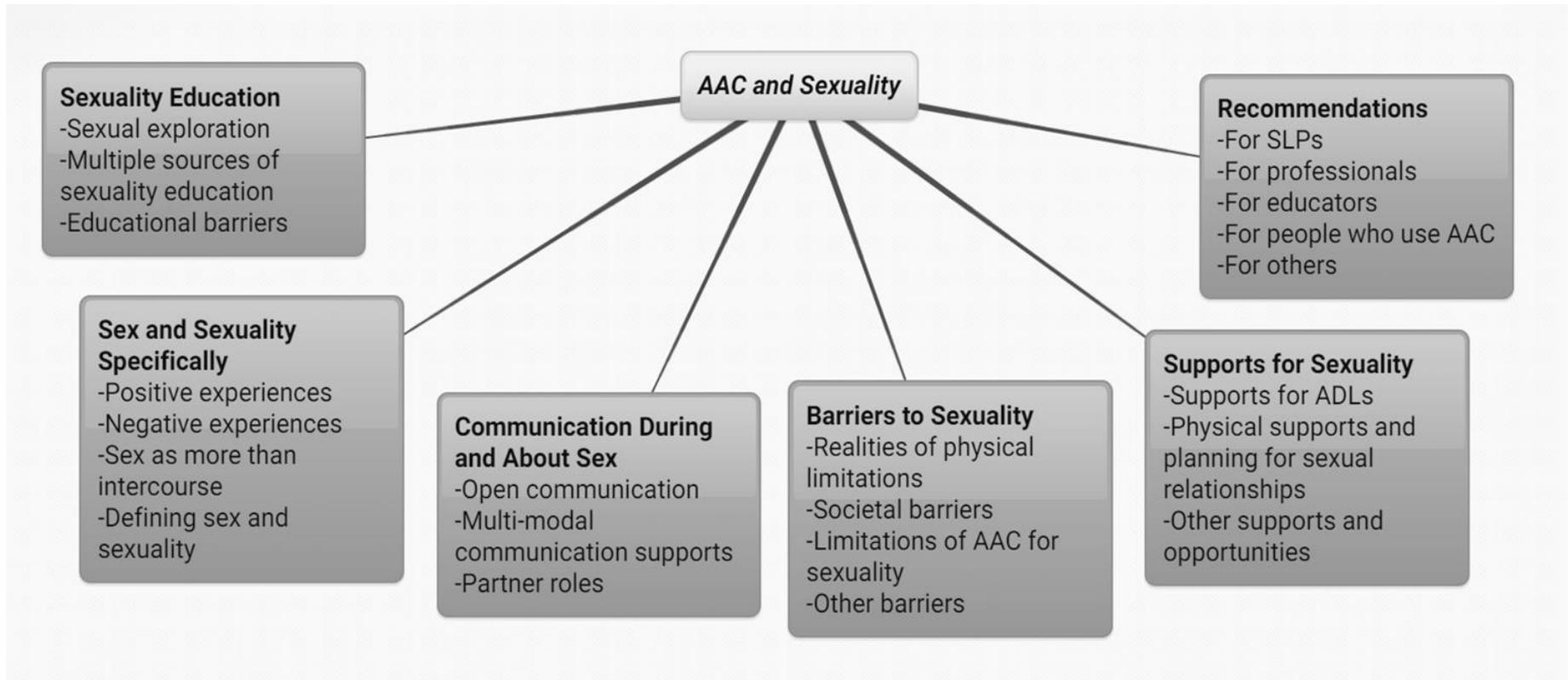
Data Analysis

Upon completion, all interviews were transcribed, and then coded for themes. Analysis procedures followed this process, adapted from Saldaña (2016) and Miles, Huberman, and Saldaña (2014). This process included: (1) data unitizing; (2) pre-coding of the data (3) preliminary-coding of the data (4) final coding of the data; (5) negotiating

agreement; (6) calculating agreement and reliability; and (7) confirming the summary with the corresponding participant.

The participants' responses to the interview questions were unitized per Lincoln and Guba's (1985) definition of a unit as the "smallest piece of information about something that can stand by itself... interpretable in the absence of any additional information other than a broad understanding of the context in which the inquiry is carried out" (p. 345). As done in Rackensperger et al. (2005), the unitized data were arranged in a table containing the participants' identification code, the question, numeric code (for the coding themes), and unitized data. Coding themes were developed *post hoc* based on a review of the participants' contributions (See Figure 1). Pre-coding was completed by highlighting and identifying potentially meaningful quotes (Saldaña, 2016). Preliminary coding was completed by labeling each thought unit with one word (Saldaña, 2016). The list of words was then grouped into categories and final codes were developed from the categories. The primary researcher completed the final coding process and developed operational definitions of the themes (see Appendix D).

FIGURE 1: Themes and Subthemes



The completion of a peer review and a member check ensured validity and reliability. This determined if the themes and information presented were rigorous and representative of the participants involved in the project (Balandin & Goldbart, 2011; Creswell & Miller, 2000, Lincoln & Guba, 1985). A peer review of codes determined the reliability of the interview responses and the coding themes. A doctoral student studying communication sciences and disorders coded 20%, or a minimum of 10 randomly selected lines, for each participant. The main themes were coded with 97% accuracy. The subthemes were coded with 93% accuracy. Across participants, reliability ranged from 95% to 100%. Reliability for subthemes across participants ranged from 90% to 100%.

All participants completed a member check. The researcher sent a summarized copy of the results via email to each participant. Summaries included the participant's transcript, as well as broad summaries of the main themes that were identified. The researcher asked participants to comment on the accuracy and presentation of the findings (McNaughton, Light, & Groszyk, 2001; Rackensperger et al., 2005).

Member checking allowed the four individuals to confirm the credibility of the information and themes as well as confirm that the conclusions and themes identified from the participants' responses were appropriate and agreed upon by the participants themselves (Lincoln & Guba, 1985; Rackensperger et al., 2005; Creswell & Miller, 2000). Member checking is the best validity procedure to use in a study where validity should be confirmed through the lens of study participants (Creswell & Miller, 2000). Each participant individually received an emailed transcript of their full interview responses, as well as a summary of how their responses were coded into the various themes. This member check allowed participants a final opportunity to ask any questions.

If the researcher needed any clarification or final thoughts from participants, they requested them at this time. All four participants responded to the member check emails and verified that the transcripts of their responses, as well as the summary of themes and subthemes, were appropriate, valid, and consistent with their responses to the interview questions. Three of the participants added follow-up statements. These additions are included in the discussion section.

CHAPTER III: RESULTS

All four participants answered all of the interview questions posed. A total of 11,200 words by four participants were obtained in response to the interview questions, with participants' responses ranging from 940 words to 5,650 words. The responses included a total of 401 thought units. A summary of the themes and subthemes is provided in Figure 1. The results are presented according to the six main themes that arose in participant's responses: sexuality education; sex and sexuality specifically; communication during and about sex; barriers to sexuality; supports for sexuality; and recommendations. Figure 1 includes a graphic describing the different themes and subthemes. Additional information about the frequency and prevalence of each of the themes and subthemes is presented in Table 2.

TABLE 2: Frequency and Prevalence of Themes and Subthemes

Themes	Subthemes	Prevalence^a	Frequency^b
Sexuality Education	Sexual exploration	3/4 = 75%	16
	Multiple sources of sexuality education	4/4 = 100%	27
	Educational barriers	2/4 = 50%	3
Sex and Sexuality Specifically	Defining sex and sexuality	4/4 = 100%	25
	Positive experiences	4/4 = 100%	47
	Negative experiences	2/4 = 50%	8
	Sex as more than intercourse	4/4 = 100%	22
	Other	3/4 = 75%	12
Communication During and About Sex	Open communication	2/4 = 50%	13
	Multimodal communication supports	4/4 = 100%	30
	Partner roles	3/4 = 75%	12
Barriers to Sexuality	Realities of physical limitations	3/4 = 75%	21
	Societal barriers	4/4 = 100%	30
	Limitations of AAC for sexuality	4/4 = 100%	11
Supports to Sexuality	Supports for ADLs	2/4 = 50%	14
	Physical supports and planning for sexual relationships	3/4 = 75%	28
	Other	2/4 = 50%	4
Recommendations	For people who use AAC	4/4 = 100%	19
	For SLPs	3/4 = 75%	3
	For professionals	3/4 = 75%	6
	For educators	3/4 = 75%	4
	For others	3/4 = 75%	5

Note:

- a. The percentage of participants who had at least one thought unit identified in that theme/subtheme.
- b. The total number of thought units that were identified in that theme/subtheme.

Sexuality Education

All participants identified the importance of sexuality education. Specifically, they discussed sexual exploration as education; having had multiple sources of sexuality education; and barriers to their sexuality education. All participants mentioned the importance of sexual exploration and experience in their education. “I learned the

‘physical act of sex’ mostly by experience,” said Jesse. Sam shared his experience at a sex and disability conference saying, “We were also told if we were still solo, it was encouraged to self-explore one’s own body, even if we had to use one or two mirrors to do so.” Sam added later, “Taking time to explore your own body and find your own sexual freedom/pleasures will often help you to build a good stable relationship that has more meaning.”

Jesse shared, “I learned about sex a few different ways.” Sam, Lee, and Pat all made similar statements, and shared the various ways that they learned about sexuality. They identified their main sources of sexuality education as high school, college, friends, media, porn, parents, the family farm, and more.

Although all participants did learn about sexuality through a variety of means, they also identified some barriers to their sexuality education. Specifically, Lee mentioned, “I was in a special school for the disabled until I was 14, so they really taught us very little about sex.” They went on to say that they learned the proper names and terms, and received formal sex education in high school. They also mentioned, “I think today in ‘regular’ school, kids learn sex ed much earlier. I hope kids in a special education school also learn earlier.” Sam explained that “It wasn’t until my early 20s that my [general practitioner] had a chat with me...” Sam also described the impact of having had such a delayed introduction to a thorough sexuality education saying, “growing up with a body that often didn’t do what I wanted to do, got my head thinking... could I even manage to have sex at all?”

Sex and Sexuality Specifically

In addition to discussing the importance of education, all participants also shared specific sexual experiences. They shared how they define sex and sexuality, as well as specific positive and/or negative sexual experiences. All participants elaborated on their definitions as well, saying that sex is more than just intercourse, highlighting the importance of intimacy in sexual relationships.

No two definitions of sex and sexuality were the same across the four participants. Sam defined sex and sexuality saying, “To me, sex and being sexual is a large part of my physical and emotional being... Like most other humans, I too enjoy being with a partner; sharing our intimacy, body touch, warmth of being skin-to-skin, romance and imagination.” Pat described sexuality as “... the desire to be with another person intimately.” Jesse shared:

I think sex is 2 things; first it’s how society defines a male & female from the time of birth, which might not be a good thing, 2nd it’s a physical thing people do, mainly between 2 or more people but a person can have it by their self. People have sex either to have babies or for pleasing their partner & or their self.

Sexuality is about how you feel & define yourself. I’ve learn your sexuality can change & you can’t fight your sexuality & truly be happy.

Lee defined sex as

... the way we define a male & female. Sex is the way life is created & it’s when 2 or more people become intimate for love, creating life or sometimes just for pleasure. I really shouldn’t say it’s for 2 or more people because 1 person...can have sex by their self for strictly pleasure.

In terms of specific sex and sexuality experiences, Lee shared that they had not had what they would consider to be a “real” sexual relationship. Sam shared that the first time the doctor brought up sexuality was in their early 20’s. Jesse shared that they learned the most about sexuality through experience as well as courses when they were in college.

All four participants shared their positive experiences with sex and sexuality. Lee shared their experiences at a topless bar. Jesse shared their experience with meeting their partner saying, “We go have a few drinks, and I knew [they were] special, she starts rubbing my arm & back, I lean over & kiss her then she asks me back to her house so we went back to her house...” Pat and Sam shared details of their relationships with their partners, talking about positive sexual experiences as well as positive intimacy and relationship experiences. Pat said:

Sometimes my wife and I sit in bed and cuddle and watch tv and I have my communication device then. We are usually naked and sometimes she rubs my penis. During those times, I am able to tell her how good it feels and that I love her.

Sam elaborated on their experiences with sexuality, saying:

Most of my sexual experiences have been quite positive as I try to prepare my partner with good communication using my AAC, well before we get ready for time together. Explaining what I need, how these will help, what we wish to achieve while we are together, plus go through some basic hand and body gestures that can be handy if I need to communicate.

Pat and Sam, who were the only married couples at the time of the interviews, both also discussed the difficulty that can come with being in long-term relationships such as their own.

Pat and Sam both referred to the importance of working to maintain a positive relationship. Pat said, "...being in a romantic relationship is a lot of work..." and Sam explained, "being in a happy and healthy relationship takes time and good communication, plus there will be challenges along the journey."

Both Jesse and Sam shared specifically negative experiences with sexuality and relationships. Jesse discussed a previous relationship saying, "we fought, we'd have sex, then he'd go sleep in the living room & take my iPad. He said he got tired of my disability." Jesse was very open, sharing this experience that was negative both in terms of sexuality, but also in terms of the relationship and communication. Sam described their first attempt at intercourse saying, "But my first attempt at intercourse wasn't pleasurable at all; in fact, it hurt like hell. Because of CP my whole body went into full spasm from head to toe; something I've had to work on..."

When defining sex and sexuality, all of the participants mentioned how sex is more than just intercourse. Pat said, "...it is more than just lust; it is the feeling of tenderness and love." Sam explained:

...sex is also the simple things as well; giving my partner a beautiful flower, sharing chocolates or a nice warm drink, holding hands while watching a DVD/Movie, enjoying a good meal, even just holding each other while listening to favourite music; these may be simple to most people, but to me these simple things are still very pleasurable and sexual as well.

Communication During and About Sex

All of the participants shared their experiences using multimodal communication supports. Strategies for communication, as well as a variety of aided and unaided communication supports, were identified. All participants emphasized open communication as a crucial piece of developing and maintaining sexual relationships. Several participants identified their partners as playing important roles in their communication, either as a support, as a ‘translator’, or by improving communication with familiarity.

Three of the four participants shared that they used multiple different modes of communication beyond their primary AAC technology devices during sexual experiences. All of the participants described the supports that they used in addition to, or instead of their primary AAC devices (See Table 3).

TABLE 3: Communication Modes Used During Sexual Experiences

Participant	1-Lee	2-Sam	3-Pat	4-Jesse
Primary AAC system	Spelling letters with head Some verbal speech iPad with Speak for Yourself app ^a Language board Computer	Limited, unclear speech iPad with Proloquo2Go ^b	ECO-2 ^c	Speech with close friends/family Sign language iPad ^d with Speak for Yourself app ^a or “notes” Pen and paper
AAC system(s) used during sexual experiences	Partner supports Same as primary	Communication boards Body touch signals Same as primary	Head gestures Verbal sounds Spelling letters with nose “Happy sounds” Yes/No	Same as primary

^a Speak for Yourself app: Speak for Yourself, LLC. <http://www.speakforyourself.org/>

^b Proloquo2Go: AssistiveWare. <http://www.assistiveware.com/product/proloquo2go>

^c ECO-2: Prentke Romich Company. <https://www.prentrom.com/>

^d iPad: Apple, Inc. <http://www.apple.com/ipad/>

Lee discussed how in different situations they used any combination of the following: switches with their iPad, a head pointer with their iPad, head spelling, and/or having a familiar partner translate. Sam also used a variety of techniques including using their primary AAC device, using signs and/or gestures, or using what they called “body touch signals.” Sam explained a few of the body touch signals that they use with their partner, “Body touches for: Stop, slower, faster, tighter, that’s better/Ok, and wait - are usually the only communication signals/hand touches I use when in intercourse” (See Table 4). Sam also described visual supports that they and their partner have used specifically to support communication during and about sexual experiences if other AAC systems are unavailable. These may take the form of a grid-based low-tech support using symbols or photos and can make communication options during sexual experiences more easily accessible.

TABLE 4: Examples of Body Touch Signals*

Examples of Body Touch Signals	I can only manage intercourse with my partner in the ‘doggy’ position, so these touches only work in this situation/pose*
Stop	2 fists pressing onto my partner’s butt firmly
Slower	1 (right) hand palm moving from my partner’s butt down her right outside thigh
Faster	2 fists on my partner’s hips/outer thighs, squeezing them together
Lower down (move to downward dog)	1 right hand on my partner’s butt moving up her spine/back towards her neck
Tighter (asking to squeeze me more)	2 fists on my partner’s butt, moving them down the outside of each thigh
To lower or raise her bottom	Both arms around my partner’s abdomen (like a cuddle) then either lifting her up or lying her back to lower her down.

*Note: Table contents provided by Sam, a participant in this study. They came up with the signals on their own, and continues to adapt them as needed over time (personal communication, 2016).

Sam also elaborated on how other forms of intimacy can be communicative as well, such as picking a flower, holding hands, just laying together, and more. Pat discussed how they did not use their communication device during sexual intercourse, saying, “Fortunately I have known my partners very well and we always had a way of communicating without my device with head gestures and verbal sounds.” Jesse, who typically used their aided AAC system during sexual experiences said, “The benefits of using my AAC is I can clearly ask my partner to do certain positions or ask her what she wants while we’re having sex, we can still talk while being intimate.” Though Jesse generally used their iPad during sexual experiences they also stated that if the iPad needed to be charged or was unavailable, that they sometimes used a simple pen and paper if they needed to communicate with their partner during these times.

Beyond the explanations of various communication supports that the participants used, they also discussed the importance of open communication with their partners as being crucial for positive sexuality experiences. Sam and Jesse both shared how they told their partners about cerebral palsy and how they explained the impact on their communication and mobility. Sam said, “I was open with her when we first made contact; explaining all about my CP and poor mobility, plus my lack of oral communication skills.”

Communication inherently requires at least two people, one sending a message and one receiving. Thus, it is logical that participants identified their communication partners as playing an important role in their communication during and about sexuality. Luke, Jesse, and Sam all discussed how their communication partners played a role in interactions. Jesse discussed how their partner ensured that they had physical access to

their iPad. Sam shared how their partner knew them so well that they could often predict their thoughts when talking with less familiar partners. Sam always had their AAC device during these interactions, and could clarify if there were misunderstandings, but their partner had a significant role in these situations. Lee discussed how very few of their communication partners understand their spelling with their head, so they required familiar partners to help with translating if they met or talked with someone new, especially if they did not have their aided communication system with them.

Barriers to Sexuality

All participants identified barriers to sexuality that were experienced in a variety of ways. Specifically, these barriers were related to the realities of physical limitations as well as broad societal and attitudinal barriers that had impacted their development of sexual relationships. In addition, three of the four participants reported that AAC systems can be a barrier for sexuality.

Three participants mentioned the physical limitations and reality of a disability like CP. While they experienced success developing relationships, they acknowledged that the realities of their physical limitations did impact sexuality. When Sam was defining sex and sexuality, they brought up how, “At times it [sex and sexuality] has been a huge hurdle, even to the point of downright embarrassing; more so when medications and physical restrictions make being sexual extremely challenging.” Pat discussed how, “It is very hard to find the right person especially if you have a disability of any kind.” Their statement provided insight into two of the barriers identified, the reality of physical limitations, but also the impact of social expectations and norms, and the impact of the view of disability more broadly.

The social model of disability suggests that disability is often a result of the culture and society in which it is positioned, not necessarily inherent to specific physical impairments. All four participants discussed the impact of social and attitudinal barriers.

Jesse said:

I just feel, in today's world even though the way people think about disabled people have come so far, there's still this stigma that moderate to severe handicapped don't have sexual desires.

Lee also said, "People almost act like we don't have sexual desires." Further, Sam stated:

Until we have all our universities and their teaching faculty educated on sexuality needs for people living with disabilities/CP and the high need for advancement in AAC communication; our society will still hold great prejudice on disability mixing with sexuality and relationships.

Pat described this barrier in a very positive way, saying, "Everybody has sexual desires and even if you have a severe disability we should be able to fulfil those desires." Three participants acknowledged that progress has been made, however they also were very realistic regarding the amount of additional progress required before true acceptance can be achieved.

While AAC was undoubtedly an important tool for all four of the participants, they also all identified the limitations of using AAC to communicate during and/or about sexuality. Pat explained:

During a sexual experience, I usually do not have my communication device because it is difficult to position while I am usually lying down and my partner is

either on top of me or we are on our sides... Plus, my device is large and it would be quite awkward and cumbersome having it in bed during sex.

Pat, Lee, and Sam opt to not use the AAC devices that they use during day-to-day interactions during sexual experiences, as Pat explained above. Jesse, however, did choose to use their communication device in bed with them during sexual experiences and still experiences some difficulty, explaining “The challenge is keeping my iPad near me during sex but not having it get in the way or laying on it.” Sam keeps their primary AAC system nearby with a folder of sex talk that they put together, but went on to say:

...using AAC can get rather messy and sticky, especially if we use foreplay and my hands and fingers are covered in mucky body fluids. I’ve tried on occasions covering the AAC with a plastic bag, cling-film, and other transparent forms of protection, but this makes the touch pad very difficult to manipulate with slippery fingers.

While some situations allowed for individuals to use their primary communication systems, the communication supports that the participants employed specifically for sex and sexuality were varied and often did not include their primary AAC system (See Table 1 and Table 4).

Supports for Sexuality

Three of the four participants identified different supports that had played a role in their sexuality. They discussed the importance of supports for activities of daily living, and the support and planning needed in order for sexual relationships to be successful.

Although three of the participants identified the realities of physical limitations as a potential barrier to sexuality, they also discussed the many supports that were in place

in order to work around the barriers. Support for activities of daily living was mentioned by two of the participants, and while it might not seem directly related to sexuality, these supports were crucial for daily life. Sam discussed the role of carers in helping them to shower daily. Lee discussed the need for support for drinking, bathing, and dressing.

Because of their physical limitations, all four participants discussed the supports necessary for a sexual experience to occur. They talked about the need for support for activities of daily living, but also their physical support needs specific to sexuality. Sam talked about how they plan for sexual time, saying:

We had 'date nights' as we called them (big red hearts marked on our calendar).

This was to help my carer team so they could make sure I was looking special, plus, they would help prepare our bed with towels and extra pillows.

Jesse discussed their partners' role in preparing for sexual experiences, how a partner helped remove clothing, or assisted them into bed, or made sure their iPad was within easy reach. Lee, who was not in a relationship at the time of this study, discussed how they would need assistance with undressing and washing before having sex. Sam also shared how coordinating time for sexual experiences differs for individuals who have disabilities as compared to nondisabled individuals:

More people with disabilities, in my case CP, timing and assistants/supports from care teams are important to make a 'big moment' happen. Sometimes having more than your partner involved, can in itself take the 'surprise'/spontaneous moment away; but with careful planning and sensitivity on the care team preparations, time being together with my partner is well worth the waiting.

Other supports that participants used in order for sexual intercourse to be a physical reality included books on body positioning, pillows to help with positioning, different sex aids or toys, timing medications correctly, or using self-exploration to support body awareness and understanding. Sam discussed the benefits of talking with other people with similar difficulties to learn new methods and techniques for positioning and logistics for sexual intercourse.

Recommendations

Participants were asked to provide recommendations for professionals as well as for individuals who use AAC. Each participant responded to this question in their own way, making recommendations for people who use AAC, educators, SLPs, other professionals, and society.

One participant shared their recommendations for people who work with individuals who use AAC in informal ways (such as personal carers, family, etc.) saying, “This group would probably be the best to help educate, (along with persons that have a disability/CP) our universities, medical schools, sex therapists and our government funders.” Lee shared that, “First, I would make the sex topic less of a taboo situation especially for disabled people that use AAC devices. People almost act like we don’t have sexual desires.” When asked to provide recommendations for educators Jesse suggested:

People who work with people that use AAC should talk to them about sexual feelings & say it’s normal to have sexual desires & use your device to express your feelings if you & your special person are in the right situation.

Jesse added that, “Maybe school teachers & college professors could teach also, that just because somebody is disabled doesn’t mean they can’t have sex.” Lee explained that professionals can “Try to educate people including parents, some disabled people have sexual needs & wants.” Both Lee and Jesse also mentioned the importance of representing disability (including people who use AAC devices) in more mainstream media in romantic roles.

All four participants made recommendations for other people who use AAC. Pat said, “My only recommendation is to try to find the right person and don’t jump into things just because a person shows interest in you.” They also added:

I highly recommend counseling for anybody in a long-term relationship. It has helped me to see my wife’s view of things and be more caring. We were very lucky to get a counselor who is so patient and understanding of our communication difficulties.

Jesse shared, “I would recommend to others, don’t be afraid to express your feelings just because you use an AAC, plus, if you use your AAC from the beginning of a relationship it will be normal for you & your partner even during sex.” Lee expressed, “I would tell someone use your AAC just like you would verbally communicate. If you feel like cursing, then curse. If you’re mad with someone, tell them off. If you’re out and meet a hot girl or guy and have the courage to strike up a conversation, do it.” Sam shared:

I’d recommend to anyone younger with a disability and can use AAC, especially an electronic speech device, not to be shy, and get out with your friends in your community and live life. With the advancement in technology today, mobility and electronic speech devices/text-to-speech apps (AAC), most of our younger

population are far more accepting of their peers with complex disabilities being out and about in the community. To people with disabilities (and using AAC) just new to or thinking of being in a relationship, be open and have good honest communication, plus not to rush things. I've seen too many people in this situation rush into a poor relationship, get their hearts broken, then lost their confidence. It's so sad to listen to their unhappy experience... Communicate well and tell your partner about anything that they need to do to help you, this would also apply to people just dating.

Sam shared many recommendations, but ended by saying, "Above all, be honest to yourself and be open and honest with your partner."

CHAPTER IV: DISCUSSION

The small number of participants involved in this study may result in poor generalization to other individuals who use AAC, as each individual who uses AAC may have their own unique experiences with sexuality. The four participants in this study varied significantly in terms of their gender, sexual orientation, age, geographic location, and sexuality experiences. Three of the participants reported that they did not use their AAC technology during sexual experiences because of difficulties with access, positioning, and technology. Yet, all participants had more than one way in which they communicated with their partners during intimate situations. Each individual had very different experiences in terms of their dating, sexual, and romantic lives. Although these participants were each completely unique in terms of their style of communication, experiences, age, and gender identity, they shared some similarities in terms of how their CCN impacted sex and sexuality. All four participants were passionate about sharing their experiences, in the hope that they could initiate positive change and spark conversations both in professional fields such as speech-language pathology, but also among other people who use AAC.

Sexuality Education

All the participants described the importance of access to sexuality education, which is consistent with other research and literature regarding disability and sexuality (Shuttleworth, 2003). The participants in this study all completed high school diplomas and some college. Because of their educational experiences, these individuals likely had more thorough and positive sexuality education than others. It is crucial that research be conducted with individuals who use AAC who are parts of different educational

demographics, so that areas for intervention can be identified. While all individuals shared that they learned about sex and sexuality, they did not identify professionals as their primary educators. In fact, they often cited experience, conversations with peers, and mainstream media as their educational sources. Media, however, often does not portray individuals with disabilities in positive sexual relationships, and further do not represent individuals with CCN who use AAC in this way. Clearly, additional education can and should be implemented by professionals, parents, and organizations in order to ensure that the sexuality education that people receive is realistic, appropriate, and sufficient.

Sex and Sexuality Specifically

Previous research suggests that sex and sexuality are important to adults with disabilities (Kulick & Rydstrom, 2015). People with disabilities, including those with communication disabilities value sexuality. The participants in this study certainly confirmed this, and mentioned that there is, unfortunately, still an assumption that people with disabilities do not have sexual desires. The most significant difference between research about sexuality and people with disabilities and this research about sexuality and people who use AAC is that the communicative aspects of relationship and intimacy dynamics are changed. High-tech AAC systems and devices generally consist of a relatively large piece of technology, that may require specific positioning and additional hardware, which may not be ideal for sexually intimate situations.

Wiegerink et al. (2010) found that young adults (20-24 years of age) with CP had similar sexual interest as nondisabled peers, but had less experiences with romantic relationships and sexual activity. This supports the results of this study in that education

and sexual experiences were more common for the participants in this study once they were a bit older (generally beyond high school). It is interesting to note that the participants in this study were older. While the inclusion criteria stated that participants must be 18 years or older, the youngest participant in this study was 38 years old.

The following sections discuss communication as well as various supports and barriers that the participants faced in terms of developing intimate relationships. The sexual experiences shared by the participants in this study suggested consistency with the research on disability and sexuality as well as CP and sexuality. The participants in this study suggested that, because of their disabilities, it may be harder to find sexual partners, which resulted in them having sexual experiences later in young adulthood than perhaps nondisabled peers.

The descriptions of negative experiences presented one major difference between the research literature and this study. There has been extensive literature documenting the prevalence of abuse and victimization of individuals with CCN (Bryen & Bornman, 2014; Bryen, Carey, & Frantz, 2003; Bryen & Wickman, 2011; Burke, Bedard, & Ludwig, 1998; Collier, McGhie-Richmond, & Odette, 2004, 2006). However, none of the participants in this study shared about experiences with abuse or victimization. Jesse shared an experience they had with a partner in which their device was taken away and they were disrespected. Sam shared about a physically painful experience. Neither of these were categorized as abusive by the participants. Participants may have been less likely to share negative experiences because this study was focused more on positive and successful experiences. Later, Sam discussed how they have seen many relationships fail because of the disability dynamic within the relationship. However, each relationship is

incredibly individualized, and it is difficult to draw conclusions about positive and/or negative experiences of sexuality with only four participants.

The positive experiences shared by the participants, however, were more consistent with the research literature. Similar to conclusions drawn by Kulick and Rydström (2015), the participants emphasized their sexual desires and interests. Both Pat and Sam wrote about how imagination played a role in their sexual lives, as they needed to be creative to coordinate the logistics of positioning, communication, and comfort during a sexual experience. The positive experiences shared by Lee, Pat, Sam, and Jesse were also consistent with Hingsburger's (2010) conclusions in that these relationships can, and do, work. As evidenced by the participants in this study, individuals who use AAC can and do develop positive, loving, sexual relationships.

Communication During and About Sex

Though prior research has emphasized the importance of communication in building relationships and supporting sexuality (Cupach & Comstock, 1990), the group of participants in this study truly emphasized the importance of not only good, open communication, but also the need for multimodal communication supports for all of the different aspects of a relational and/or sexual experience. All four participants shared how they communicated during sexual experiences, and while Jesse did use their high-tech system, Pat, Lee, and Sam all discussed ways that they communicated with sexual partners using other, multimodal, creative solutions and supports. The participants appreciated the complexity of communication, and also acknowledged the great importance to their relationships. The theme of open communication from this study is compatible with previous research. Communication about sexuality is crucial for sexual

satisfaction (MacNeil & Byers, 2005). The acknowledgement of the participants in this study of the role of open communication in their relationships further emphasized the need for access to communication about sexuality for individuals who use AAC. The participants discussed how, for them, having a strong form of communication in their relationships was important, especially as it grew stronger over time with increased familiarity and intimacy. The creative variety of ways that this group of four individuals communicated only reinforced the importance of ensuring that AAC is individualized on a case-by-case basis.

The five principles of AAC identified by Williams, Krezman, and McNaughton (2008) include the following: the time for AAC is now; one is never enough; my AAC must fit my life; AAC must support full participation in all aspects of 21st century life; and “nothing about me without me.” These principles apply to using AAC broadly, but are also applicable for communication specific to sex and sexuality. One is never enough is perhaps the most salient, especially with the individuals that participated in this study. They all used multiple different forms of communication dependent upon their environment, activity, partner(s), and abilities. The importance of fully participating in all aspects of life was also obvious throughout the interviews. The participants all accessed email, accessed online dating, and participated fully in many aspects of 21st century technology and media. However, many individuals who use AAC may not have the same levels of access as this group did. Finally, this research aimed to include the participants as much as possible, reinforcing the goal of “nothing about us without us.” The participants were involved as much as possible, and their words and explanations have

been used to the extent possible in order to ensure that they were included throughout the research process.

Barriers to Sexuality

Wiegerink (2011) identified several aspects of sexuality that present barriers to individuals with cerebral palsy, particularly adolescents and young adults. The participants in this study did not identify as many barriers as Wiegerink, however the ones that they did identify were consistent with the suggestions and conclusions made by previous researchers. In 2010, Wiegerink found that there are potentially many factors that account for less sexual experience in young adults with CP. Some of the factors identified were education, environment, family, and personality. Additional research is required in order to determine the specific issues and how they may impact skills and/or opportunities for individuals with CP (or other disabilities) to establish and maintain romantic and/or intimate relationships. For instance, three of the four participants identified their physical limitations as being challenging for sexuality. The need for specific positioning, the set-up needed for sex to occur, and communication support from close partners in the early stages of dating were all identified as challenges they had faced. Participants also identified societal roles as playing a large role in their own sexual experiences. They indicated that they were often assumed to be asexual because of their disabilities. This is something that arises often in research about disability and sexuality (Kattari, 2015; Kulick & Rydström, 2015; & Tepper, 2000). This assumption was only one example of a socially based barrier for sexuality. This barrier is not something that is inherent to the individuals themselves, but is instead problematic because of how they have been ideologically constructed by the majority, non-disabled population. One

participant discussed how people with disabilities, especially more complex disabilities, have a hard time finding and maintaining positive relationships. This is a barrier that is much more difficult to overcome on an individual and personal level, because it is external to the individual and is caused by a broader systemic barrier.

Finally, participants identified how their high-tech AAC systems were often inadequate for many different romantic, intimate, or sexual situations. The devices may be too bulky and/or too difficult to position. They may not be fast enough. They may get broken. These were only a few of the potential problems that were identified. Because of this, it is crucial that people working with individuals who use AAC acknowledge these difficulties, and work with the individual who uses AAC and their partners, to establish other types of AAC supports to use during these types of experiences. This barrier is specific to people who use AAC. Hingsburger (2010) discussed several of the potential barriers to sexuality for individuals who use AAC such as prejudiced attitudes and/or fear, issues of consent, assessment and instruction in boundaries and consent, and limited opportunities for relationships to develop. However, limitations of AAC was not something mentioned. This has the potential to be a difficulty only experienced by some people who use AAC. Multiple forms of communication are necessary for different situations and must be considered, including sexual situations (Williams, Krezman, & McNaughton, 2008).

Supports for Sexuality

Despite the barriers that were identified by participants, they also identified the supports that were in place in order for them to have positive sexual experiences and lives. One of these was simply the physical support needed to complete activities of daily

living such as showering, brushing teeth, combing hair, dressing, etc. These types of activities, while not directly related to sexuality, do play a role. If someone is not clean, dressed (or undressed), this may impact their opportunities for sexual experiences and without these supports, could be a barrier to sexuality. In addition to the supports and carer teams that were in place for activities of daily living, the supports needed specifically for sexual experiences were identified. Sam, Jesse, and Lee all discussed pieces of the process that must occur in order for sexual experiences to happen. These supports included the following: preparation of beds, pillows, and blankets; assistance with undressing; and assistance with physical positioning. These supports are unique to the disabled population and the participants in this study readily acknowledged the importance of these supports.

Recommendations

The recommendations for other people who use AAC regarding sexuality were honest, open, and insightful. These recommendations suggested the importance of mentoring relationships between and among people who use AAC (Light, et al., 2007). Information sharing among individuals who use AAC, in a mentoring relationship or through more formal or academic means, can help to build a larger network of supports and information sharing regarding sexuality. The insights that the participants in this study shared are powerful, and should be shared with many others who use AAC. Their positive attitudes, advice, and genuine desire to make a difference in the lives of others was obvious throughout the completion of the interviews. Ideally, these recommendations should be shared not only in this paper, but in an informal way with other people who use AAC.

The recommendations made for SLPs and other professionals consisted mainly of being open to having discussions and providing education about sexuality to individuals who use AAC. While this may seem to be outside the scope of practice for some professionals, there are currently no designated professionals who assume responsibility for discussions about sexuality. This means that there is a need for all professionals to increase their involvement, and address sexuality in whatever way it does fit within their scope of practice. For example, speech-language pathologists need to ensure that the individual using AAC has access to all the vocabulary that they want, including vocabulary for sexuality. They may need to provide intervention addressing the communication skills necessary for developing sexual and/or intimate relationships. A physical therapist should be ensuring that the individual knows positioning for sex, physical limitations or strengths, and where to go if they need additional supports. General practitioners should be discussing sexuality with people who use AAC at around the same time that they would begin discussing it with nondisabled people. Because such limited supports are currently available, the people who provide services must ensure that the individual does have access to this aspect of life. Bryen (2010, 2008, 2003) has completed much research on sexuality for people who use AAC, specifically in terms of violence, sexual abuse or assault, and ensuring that the legal safeguards are present for this population. Bryen and Ziff (2008, 1986) have each created lists of important sexual vocabulary to be included in AAC systems for people who do not use speech to communicate. Too often the contributions of professionals to discussions about sexuality with individuals who use AAC are limited, and many of the participants in this study identified the need for professionals to be more involved in sexuality education and

discussions. The participants also identified the need for continued advocacy at a broad systemic level. The stigma that is still present has played a role in all of their lives, and they all recommended the importance of continued advocacy. While disability rights has come a long way, there is still much work to be done at a social justice level to ensure that individuals with disabilities (including those with CCN who use AAC) have the same opportunities to meet their life goals and dreams as the majority nondisabled population.

Implications for Practice

The clinical implications of this study are best described by the participants in their comments about recommendations for professionals. More than one participant stated that speech-language pathologists as well as other professionals working with individuals who use AAC should be discussing the topic of sexuality with their clients. When determining the types of AAC systems that may be implemented with an individual, multimodal systems that can be used across different environments and activities, including sexuality, must be considered. When determining the vocabulary of a system, access to vocabulary about sexuality needs to be available to the individual, including anatomical and physiological vocabulary. Additionally vocabulary and communication skills relevant to flirting, dating, sexuality, relationships, intimacy, sexual experiences, ‘pillow talk’ and more, must be addressed, especially if a symbol-based AAC system is being considered. Finally, ensuring that individuals have access to the skills and opportunities to develop positive, meaningful relationships is crucial.

While this may seem like an area that is outside the scope of practice for an SLP, indeed it is well within the scope of practice. Providing individuals with access to the

supports that they need for communication across contexts in order to achieve their own goals and dreams includes providing supports for communicating about sexuality and relationships. Speech-language pathologists as well as other professionals must begin to acknowledge this aspect of life for the people with whom they work, and must be aware of the research and information around the topic. Though sexuality may be uncomfortable to discuss, it is important that they are comfortable supporting the communication of people who use AAC about any and all meaningful topics, including sex, sexuality, and relationships.

Limitations of the Study

This study is one of the first to investigate the sexuality experiences of individuals who use AAC. Despite the contribution, there are some limitations that should be considered in interpreting the results. This study examined the perspectives of only four participants. One significant limitation of this study is that because of the small sample size, the results of this study may not easily generalize to other individuals with CCN who use AAC. Interviews completed via email may have limitations in comparison to face-to-face interviews. They lack the benefits of meeting and interviewing participants in person, and may make it more difficult to build rapport between the researcher and participant. Email is much more indirect. Further, because the interviews were conducted via email, communication modalities had to be explained in text, whereas in-person interviews would have allowed for communication modalities to be observed. Participants reported that they all completed the interviews independently; however, because they were completed via email, there is no way of guaranteeing if additional supports were needed or used. One limitation of this study, as well as most studies

involving people who use AAC, is the heterogeneity of the group. This is difficult to avoid because of the very limited number of people who were interested in completing the study and who met the inclusion criteria (Higginbotham & Bedrosian, 1995). Because the primary researcher does not identify as a disabled person, nor as someone who uses AAC, there are biases and differences of experience and background inherent to this type of research. (Linton, 1998). Ideally, future research will include at least one individual who uses AAC as a member or leader of a research team in order to even better ensure reliability and validity for this population. Including a member of the population as a lead author on a future project such as this one would also ensure that research is completed in a way that ensures that there is no additional marginalization of disabled people as “objects of inquiry” (Linton, 1998, p. 74). Though this paper is not written through the lens of an individual who uses AAC, the results were presented through the words of the participants to the extent possible.

Directions for Future Research

This study has only been a brief introduction to this topic, but should begin many more conversations about the experiences, perspectives, and recommendations about sexuality by and for individuals who use AAC. The results of this study and the recommendations made for individuals who use AAC as well as for professionals working with people with CCN should be shared. Further, more research must be done in this area. This study is only an initial step. Research is needed to investigate how to best support individuals with CCN in developing relationships and sexuality. Ensuring that professionals have access to research about people with CCN is necessary if this group is to receive valuable information and support from educators, medical professionals,

counselors, and SLPs. Many questions remain unanswered and should be addressed in future research studies. For individuals who use AAC to access all aspects of socially valued adult roles, sexuality must be discussed. How should individuals with CCN receive sexuality education? Who is responsible for providing a relevant and quality sexuality education? What are the priorities of individuals who use AAC when it comes to discussions about sexuality? What are the experiences and perspectives of individuals who use AAC who have different disabilities impacting their communication, such as autism, or an intellectual disability? What roles do various professionals play in terms of providing access to and supports for sexuality? What are the barriers and supports available to professionals regarding discussions about sexuality across multiple disciplines and populations? Further research and ongoing conversations about these topics are crucial in order to guarantee that individuals with CCN who use AAC have equal access to sexuality. Professionals working with people with disabilities have an important role, in that they should be ensuring that the individuals they work with have access to communication across environments and situations, including sex and sexuality.

Conclusion

When responding to member check emails participants were given an opportunity to share any final thoughts for the study. This study was intended, from its inception, to be a conversation with people who use AAC about their own experiences. Keeping that objective at the forefront, this paper concludes with the final thoughts shared by Pat, Sam, Jesse, and Lee.

Sam

The only other input/comment I'd like to mention: is it possible to get speech therapists to work with Electronic (AAC) text-to-speech programmers; to put more thought into age related files, especially for adults with more emphasis on 'pillow talk' / sexuality and relationships plus intercourse...? The programme/iPad app I'm using at present is very orientated towards the younger (4-8 y/o) ... child. It had a major update 12 months ago to supposedly make it more age related for all users globally, but I still have to build my own folders to suit my own places/the community where I need to use AAC/talk with different people. It takes me many hours to build and fine tune each folder... (Sam, personal communication, 2016).

Jesse

I'm doing fabulous, a month ago out of the blue [my partner] said why are we waiting to get married, I said I have no idea. I go online saw cheap flights to Vegas & booked them. We flew on a Sunday & the next day got married, the officiant said we were his 1st wedding that used a device. we had a wonderful night in a suite, it was ironic this was the last suite opened & it had a big handicapped accessible shower, we sure enjoyed it (Jesse, personal communication, 2016).

Lee

Well family members especially parents and guardians of disabled people should know or be advised disabled people still have sexual desires... (Lee, personal communication, 2016).

Pat

Everybody needs to remember people with disabilities have sexual desires but they might think "out of the box" when it comes to performance. Don't be afraid to ask questions to help each other to understand what would work best for the individual. Experimentation is always fun (Pat, personal communication, 2016).

REFERENCES

- ASHA (2017) Augmentative and Alternative Communication: Introduction to AAC. *National Joint Committee for the Communication Needs of Persons with Severe Disabilities*. Retrieved from <http://www.asha.org/NJC/AAC/>
- ASHA (2005). Roles and responsibilities of speech-language pathologists with respect to augmentative and alternative communication: Position statement. Retrieved from <http://www.asha.org/policy/PS2005-00113/>
- Balandin, S., & Goldbart, J. (2011). Qualitative research and AAC: Strong methods and new topics. *Augmentative and Alternative Communication*, 27(4), 227-228. doi:10.3109/07434618.2011.630409.
- Balandin, S., Hemsley, B., Sigafoos, J., & Green, V. (2007). Communicating with nurses: The experiences of 10 adults with cerebral palsy and complex communication needs. *Applied Nursing Research* 20, 56-62. doi:10.1016/j.apnr.2006.03.001.
- Bernert, D.J. & Ogletree, R.J. (2013). Women with intellectual disabilities talk about their perceptions of sex. *Journal of Intellectual Disability Research*, 57(3), 240-249. doi:10.1111/j.1365-2788.2011.01529.x.
- Bryen, D.N. & Bornman, J. (2014). *Stop Violence Against People with Disabilities: An International Resource*. University of Pretoria, South Africa: Pretoria University Law Press.
- Bryen, D.N., Carey, A., & Frantz, B. (2003). Ending the silence: Adults who use augmentative communication and their experiences as victims of crimes. *Augmentative and Alternative Communication*, 19(2), 125-134. doi:10.1080/0743461031000080625.

- Bryen, D.N., Chung, Y., & Lever, S. (2010). What you might not find in a typical transition plan! Some important lessons from adults who rely on augmentative and alternative communication. *Sig 12 Perspectives on Augmentative and Alternative Communication*, 19, 32-40. doi:10.1044/aac19.2.32.
- Bryen, D.N. (2008). Vocabulary to support socially-valued adult roles. *Augmentative and Alternative Communication*, 24(4), 294-301. doi:10.1080/07434610802467354.
- Bryen, D.N., & Wickman, C.H. (2011). Ending the silence of people with little or no functional speech: Testifying in court. *Disability Studies Quarterly*, 31(4). Retrieved from: <http://dsq-sds.org/article/view/11711/1759>.
- Burke, L., Bedard, C., & Ludwig, S. (1998). Dealing with sexual abuse of adults with a developmental disability who also have impaired communication: Supportive procedures for detection, disclosure, and follow-up. *The Canadian Journal of Human Sexuality*, 7(1), 79-91. Retrieved from ProQuest.
- Byers, E.S. (2011). Beyond the birds and the bees and was it good for you?: Thirty years of research on sexual communication. *Canadian Psychology*, 52(1), 20-28. doi:10.1037/a0022048.
- Byers, E.S. & MacNeil, S. (1997). The relationships between sexual problems, communication, and sexual satisfaction. *The Canadian Journal of Human Sexuality*, 6(4), 277-291.
- Charlton, J. I. (1998). *Nothing About Us Without Us: Disability Oppression and Empowerment*. Berkeley and Los Angeles, CA. University of California Press.
- Collier, B., McGhie-Richmond, D., & Odette, F. (2004). *Reducing the Risk of Sexual Abuse for People who use Augmentative Communication: A Community Response*. The Speak Up

Project: Safeguarding people who use augmentative communication from sexual abuse/victimization. Toronto, ON.

Collier, B., McGhie-Richmond, D., Odette, F., & Pyne, J. (2006). Reducing the risk of sexual abuse for people who use augmentative and alternative communication. *Augmentative and Alternative Communication, 22*(1), 62-75. doi:10.1080/07434610500387490.

Creswell, J.W. & Miller, D.L. (2000). Determining validity in qualitative inquiry. *Theory into Practice, 39*(3), 124-130.

Cupach, W.R. & Coustock, J. (1990). Satisfaction with sexual communication in marriage: Links to sexual satisfaction and dyadic adjustment. *Journal of Social and Personal Relationships, 7*, 179-186.

Cupach, W.R. & Metts, S. (1989). Sexuality and Communication in Close Relationships. In McKinney, K., & Sprecher, S. (Eds.), *Sexuality in Close Relationships* (pp. 93-110). New York, NY. Psychology Press.

Davis, D., Shaver, P., Widaman, K., Vernon, M., Follette, W., & Beitz, K. (2006). "I can't get no satisfaction": Insecure attachment, inhibited sexual communication, and sexual dissatisfaction. *Personal Relationships 13*, 465-483.

Fallon, K.A., Light, J.C., & Paige, T.K. (2001). Enhancing vocabulary selection for preschoolers who require augmentative and alternative communication (AAC). *American Journal of Speech-Language Pathology, 10*, 81-94.

Friedman, C., Arnold, C.K., Owen, A.L., & Sandman, L. (2014). "Remember our voices are our tools": Sexual self-advocacy as defined by people with intellectual and developmental disabilities. *Sexuality and Disability, 32*, 515-532. doi:10.1007/s11195-014-9377-1.

- Guendouzi, J. (2014). Qualitative Research Revisited. In Ball, M., Müller, N., and Nelson, R. (Eds.), *Handbook of Qualitative Research in Communication Disorders* (pp. 331-342). New York, NY: Psychology Press.
- Higginbotham, D.J., & Bedrosian, J. (1995). Subject selection in AAC research: Decision points. *Augmentative and Alternative Communication, 11*(1), 11-13.
- Hingsburger, D (2010). The Language of Love. In McNaughton, D., & Beukelman, D. (Eds.), *Transition Strategies for Adolescents and Young Adults who use AAC. AAC Series* (pp. 145-160). Baltimore, MD: Brookes Publishing Company.
- Hingsburger, D. & Touch, S. (2002). Healthy sexuality: Attitudes, systems, and policies. *Research and Practice for Persons with Severe Disabilities, 27*(1), 8-17.
- Hinckley, J.J. (2014). Phenomenology. In Ball, M., Müller, N., and Nelson, R. (Eds.), *Handbook of Qualitative Research in Communication Disorders* (pp. 93-111). New York, NY: Psychology Press.
- Hodge, S. (2007). Why is the potential of augmentative and alternative communication not being realized? Exploring the experiences of people who use communication aids. *Disability and Society, 22*(5), 457-471. doi:10.1080/09687590701427552.
- Hynan, A., Murray, J., & Goldbart, J. (2014). 'Happy and excited': Perceptions of using digital technology and social media by young people who use AAC. *Child Language Teaching and Therapy, 30*(2), 175-186. doi:10.1177/0265659013519258.
- Kattari, S.K. (2015). "Getting it": Identity and sexual communication for sexual and gender minorities with physical disabilities. *Sexuality and Culture, 19*(8), 882-899. doi:10.1007/s12119-015-92298-x.

- Kulick, D. & Rydström, J. (2015). *Loneliness and Its Opposite: Sex, Disability, and the Ethics of Engagement*. Durham and London: Duke University Press.
- Leigh, A. (2010). *The experiences of intimacy for adults with acquired communication disorders using augmentative and alternative communication (AAC)*. (Unpublished master's thesis). University of Canterbury: Christchurch, New Zealand.
- Levine, S. B. (1992). *Sexual Life: A Clinician's Guide*. New York: Plenum Press.
- Light, J., McNaughton, D., Krezman, C., Williams, M., Gulens, M., Galskoy, A., & Umpleby, M. (2007). The AAC mentor project: Web-based instruction in socio-relational skills and collaborative problem solving for adults who use augmentative and alternative communication. *Augmentative and Alternative Communication, 23*(1), 56-75.
- Lincoln, Y.S. & Guba, E.G. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications.
- Linton, S. (1998). *Claiming Disability: Knowledge and Identity*. New York, NY: New York University Press.
- Litzinger, S. & Coop Gordon, K. (2005). Exploring relationships among communication, sexual satisfaction, and marital satisfaction. *Journal of Sex and Marital Therapy, 31*(5), 409-424. doi:10.1080/00926230591006719.
- MacNeil, S. & Byers, E.S. (2005). Dyadic assessment of sexual self-disclosure and sexual satisfaction in heterosexual dating couples. *Journal of Social and Personal Relationships, 22*, 169-181.
- McCabe, M.P., Cummins, R.A., & Deeks, A.A. (2000). Sexuality and quality of life among people with physical disability. *Sexuality and Disability, 18*(2), 115-123.
- McCabe, M.P. & Taleporos, G. (2003). Sexual esteem, sexual satisfaction, and sexual behavior among people with physical disability. *Archives of Sexual Behavior, 32*(4), 359-369.

- McNaughton, D., Light, J., & Groszyk, L. (2001). 'Don't give up': The employment experiences of adults with amyotrophic lateral sclerosis who use augmentative and alternative communication. *Augmentative and Alternative Communication, 17*, 179-195.
- McRuer, R., & Mollow, A. (2012). *Sex and Disability*. Durham and London. Duke University Press.
- Miles, M.B., Huberman, A.M., & Saldaña, J. (2014). *Qualitative Data Analysis: A Methods Sourcebook*. Thousand Oaks, CA. Sage Publications.
- Montesi, J.L., Fauber, R.L., Gordon, E.A., & Heimberg, R.G. (2010). The specific importance of communicating about sex to couples' sexual and overall relationship satisfaction. *Journal of Social and Personal Relationships, 28*(5), 591-609. doi:10.1177/0265407510386833.
- Parette, P., & Scherer, M. (2004). Assistive technology use and stigma. *Special Education and Training in Developmental Disabilities, 39*(3), 217-226.
- Penn, C. (2014). Intercultural Health Communication. In Ball, M., Müller, N., and Nelson, R. (Eds.), *Handbook of Qualitative Research in Communication Disorders* (pp. 219-224). New York, NY. Psychology Press.
- Pownall, J.D., Jahoda, A., & Hastings, R.P. (2012). Sexuality and sex education of adolescents with intellectual disability: Mothers' attitudes, experiences, and support needs. *Intellectual and Developmental Disabilities, 50*(2), 140-154. doi:10.1352/1934-9556-50.2.140.
- Rackensperger, T., McNaughton, D., Krezman, C., & Williams, M. (2005). 'When I first got it, I wanted to throw it over a cliff': The challenges and benefits of learning technology as described by individuals who use AAC. *Augmentative and Alternative Communication, 21*, 165-186.

- Saldaña, J. (2016). *The Coding Manual for Qualitative Researchers*. Thousand Oaks, CA. Sage Publications.
- Seidman, I. (2013). *Interviewing as Qualitative Research*. New York, NY. Teachers College Press.
- Shuttleworth, R.P. (2000). The search for sexual intimacy for men with cerebral palsy. *Sexuality and Disability, 18*(4), 263-282.
- Shuttleworth, R.P. (2003, September). *The case for a focus on sexual access in a critical approach to disability and sexuality research*. Paper presented at the meeting of the 1st Annual Disability Studies Association, Lancaster, England.
- Tepper, M.S. (2000). Sexuality and disability: The missing discourse of pleasure. *Sexuality and Disability, 18*(4), 283-290.
- Timm, T.M. & Keiley, M.K. (2011). The effects of differentiation of self, adult attachment, and sexual communication on sexual and marital satisfaction: A path analysis. *Journal of Sex and Marital Therapy, 37*, 206-223. doi:10.1080/0092623x.2011.564513.
- World Health Organization. (2015). *Sexual Health*. World Health Organizations, Geneva. Retrieved from http://www.who.int/topics/sexual_health/en/.
- Wiegerink, D., Roebroek, M., Bender, J., Stam, H., & Cohen-Kettenis, P. (2011). Sexuality of young adults with cerebral palsy: Experienced limitations and needs. *Sex and Disability, 29*, 119-128. doi:10.1007/s11195-010-9180-6.
- Wiegerink, D., Roebroek, M., Donkervoort, M., Stam, H., & Cohen-Kettenis, P. (2006). Social and sexual relationships of adolescents and young adults with cerebral palsy: A review. *Clinical Rehabilitation, 20*, 1023-1031.

- Wiegerink, D., Roebroek, M., Van Der Slot, W., Stam, H., & Cohen-Kettenis, P. (2010). Importance of peers and dating in the development of romantic relationships and sexual activity of young adults with cerebral palsy. *Developmental Medicine and Child Neurology*, 52, 576-582. doi:10.1111/j.1469-8749.2010.03620.x.
- Wiegerink, D., Stam, H., Gorter, J., Cohen-Kettenis, P., & Roebroek, M. (2010). Development of romantic relationships and sexual activity in young adults with cerebral palsy: A longitudinal study. *Arch Physical Medicine and Rehabilitation*, 91, 1423-1428.
- Williams, M.B., Krezman, C., & McNaughton, D. (2008). 'Reach for the stars': Five principles for the next 25 years of AAC. *Augmentative and Alternative Communication*, 24(3), 1194-206. doi:10.1080/08990220802387851.
- Ziff, S.F. (1986). Symbolic sexual vocabulary for the severely speech impaired. *Sexuality and Disability*, 7(1/2), 3-14. doi:10.1007/BF01101825.

APPENDIX A: Interview Questions

1. I would like to start by talking about how you define sex and sexuality. The first question addresses how you personally think about and talk about these topics.
 - a. Tell me about sexuality. Define sex and sexuality.
 - b. Probes: 1a. How did you learn about sex/sexuality?
2. The next questions asks about your sexual experiences. Please feel free to include as much or as little detail as you are comfortable with. Communication is considered an important part of relationships and sexuality. This question will help to explain the types of experiences you have had, as well as how you communicate in these situations. This can provide information to other people who use AAC on how to communicate in similar situations.
 - a. Tell me about a sexual experience (positive, negative, or both). How do you communicate in these situations?
 - b. Probes: Do you? With whom? When? How did you learn? If not, why not?
3. Everyone's goals and dreams for their present and future relationships vary. What is your dream for yourself in terms of relationships and sexuality?
 - a. How could support from professionals help you achieve that goal?
 - b. What recommendations do you have for professionals?
 - c. What recommendations do you have for other individuals who use AAC?
 - d. Additional probes as needed/appropriate.
4. If there is anything you would like to tell me about that was not addressed in the previous questions, please feel free to add it now.
 - a. Additional probes as needed/appropriate.

APPENDIX B: Screening Questions

Name:

Date of Birth:

Age:

Race:

Gender:

Sexual Orientation:

Disability/Diagnosis:

Education:

Location (country, state):

How do you communicate? (you can describe your AAC system, speech, gestures/signs, low-tech systems, mobile technology, etc.)

How would you describe your literacy skills?

Can you independently write a paragraph of 3-5 sentences?

Are you currently in a relationship?

How many relationships have you had in the past?

How long have your relationships typically lasted?

Tell me about your experiences with relationships. Have any of your relationships included physical intimacy? Have those experiences been positive, negative, or both?

(Please answer in at least 3-5 sentences).

APPENDIX C: Interview Protocol Shell

1. Hi _____, Thank you again for your interest in participating in this study. The next step is for you to answer the lengthier interview questions. There are 5 main questions that I would like you to answer. Depending on your answers I may follow up with additional questions. I will let you know each time we move on to the next main question. Please use at least 3-5 sentences to answer the main questions. Longer answers are fine as well. Please respond within 1 week.

2. I would like to start by talking about how you define sex and sexuality. The first question addresses how you personally think about and talk about these topics. Tell me about sexuality. Define sex and sexuality.
[participant responds]
Probes:
 How did you learn about sex/sexuality?
 Additional probes as needed/appropriate.
[participant responds]

3. 2. The next question asks about your sexual experiences. Please feel free to include as much or as little detail as you are comfortable with. Communication is considered an important part of relationships and sexuality. This question will help to explain the types of experiences you have had, as well as how you communicate in these situations. This can provide information to other people who use AAC on how to communicate in similar situations. Tell me about a sexual experience (positive, negative, or both). How do you communicate in these situations?
[participant responds]
Probes:
 Can you? do you? With whom? When? How did you learn? If not, why not?
 What are benefits of using AAC when communicating about this? Challenges?
 Additional probes as needed/appropriate.
[participant responds]

4. Everyone's goals and dreams for their present and future relationships vary. What is your dream for yourself in terms of relationships and/or sexuality?
[participant responds]
Probes:
 How could support from professionals help you achieve that goal?
 Recommendations for professionals.
 Additional probes as needed/appropriate.
[participant responds]

5. If there is anything you would like to tell me about that was not addressed in the previous questions, please feel free to add it now.
[participant responds]
 Additional probes as needed/appropriate.
[participant responds]

APPENDIX D: Operational Definitions of Coding Themes

0.0-Uncoded: Includes conversational messages (e.g. “It’s nice to talk to you again”) and filler statements (“that’s an interesting question”). Statements that do not appear to fit into any established category yet and are not filler/unrelated statements. This will not be a final coding category.

1.0 Main Theme: Sexuality Education: This main theme refers to statements around how people learned about sex, sexuality, and relationships. The below subthemes are broken up into some of the main topics that commonly arose during the discussion around education.

- 1.1 Subtheme: Sexual Exploration: These are descriptions of masturbatory experiences, experience as a means of education, and exploration sexually in terms of trying new positions, watching adult videos, or exploring with toys. This excludes experiences with communication during these experiences, as this will be addressed in another section.
- 1.2 Subtheme: Multiple sources of sexuality education: These are descriptions of educational experiences that have occurred and are described by participants. It could include school, parents, peers, media, etc. It excludes experiences with communication or sexual exploration during these experiences, as this will be addressed in another section.
- 1.3 Subtheme Educational barriers: These include any discussions of sexuality education that were negative, unhelpful, or actually limited the acquisition of knowledge about sex and sexuality. These exclude descriptions of specific negative sexual experience or descriptions of societal barriers as these are included in other coding themes.
- 2.0 **Sex and sexuality specifically:** This theme category refers to information that was shared about sex and sexuality generally. This excludes information about communication, AAC, or supports for these relationships. This includes definitions, descriptions of experiences, etc.
 - 2.1 Subtheme Defining sex and sexuality: These refer to specific definitions of how people define sex and/or sexuality. These exclude definitions that refer to how sex is more than just intercourse as that is covered in a different coding theme.
 - 2.2 Subtheme Positive experiences: These refer to descriptions of specific sexual experiences that have been positive and were described in a positive light. These exclude sexual experiences that were negative.
 - 2.3 Subtheme Negative experiences: These refer to descriptions of specific sexual experiences that were negative and described as such. This excludes negative experiences with AAC specifically.
 - 2.4 Subtheme Sex as more than intercourse: These are statements that discuss how sex and sexuality refer to much more than just intercourse. These may include descriptions of non-intercourse interactions that are still defined as sex or descriptions of sex as intimacy. This excludes statements about communication, intercourse, or specific experiential descriptions.

2.5 Subtheme Other: These are statements that do not fit into one of the above coding themes regarding sex and sexuality specifically.

3.0 Main Theme: Communication during and about sex: This main theme refers to how, why, and when people are communicating during and/or about sexual experiences. The subthemes refer to areas of communication that multiple participants discussed.

3.1 Subtheme Open Communication: These include descriptions about the importance of maintaining communication with your partner throughout relationships. This may include descriptions of building relationships through communication, discussing the importance of communication throughout relationships, etc.

3.2 Subtheme Multimodal Communication Supports: These include descriptions of the variety of types of communication that people use in the different stages of relationships/intimacy/sexuality. These may include descriptions of high-tech, low-tech, or unaided AAC systems, speech, writing, symbols, etc. This also includes descriptions of the benefits of using AAC and how using multimodal communication has had a positive impact on individuals as it relates to the development of their relationships and/or sexuality.

3.3 These include descriptions of the types of strategies that individuals have used to support their communication. This may include strategies used when building relationships, with partners, during sexual experiences etc. .

3.4 Partner roles: These are statements that specifically refer to the role of a partner as a communication support. This may include statements about how they “translate”, how communication has improved over time, etc. This excludes any communication supports outside of the partner.

4.0 Barriers: This theme includes any barriers that people reported in terms of sexuality. These could be physical, environmental, societal, etc.

4.1 Subtheme Realities of Physical Limitations: These include descriptions of how cerebral palsy and the physical impairments associated with it can impact relationships. Specifically barriers.

4.2 Subtheme Societal Barriers: These include descriptions of how societal expectations, stigma, media, etc. impact the development and maintenance of relationships, intimacy, and sexuality for people who use AAC. These also includes attitudes and stigma around disability specifically.

4.3 Subtheme Limitations of AAC for sexuality: These include descriptions of how AAC devices or supports may not be ideal for sexual situations. This may include difficulties with access, difficulty using a device in bed, etc.

4.4 Subtheme Other Barriers: These include descriptions of any barriers to sex/sexuality that do not fit into one of the above subtheme categories.

5.0 Main Theme: Supports for sexuality: This main theme refers to the different types of opportunities and supports that people who use AAC described as important and necessary to them.

- 5.1 Subtheme Supports for ADLs: These are descriptions of the types of supports that are needed for activities of daily living. This could include needs such as eating, toileting, dressing, mobility, etc. This excludes descriptions of supports needed specifically for romantic/intimate/sexual experiences. This also excludes descriptions about how physical realities may be a barrier to sexuality. Supports in this category, barriers in 4.1.
- 5.2 Subtheme Physical supports and planning for sexual relationships: These are descriptions of the types of physical supports that are needed for romantic/intimate/sexual relationships. This could include things to support masturbation, dating, kissing, sexual intercourse, oral, anal, etc. These also include descriptions of the planning and logistical arrangements for romantic/intimate/sexual activity. This may include arrangements in terms of time, transportation, support staff, etc.
- 5.3 Subtheme Other supports/opportunities: These are any descriptions of supports/opportunities that do not fit well into any of the above subtheme categories.
- 6.0 Main Theme: Recommendations:** Participants were asked to share any recommendations that they have in regards to sexuality and AAC. The below subthemes are broken up based on who the recommendations are for.
- 6.1 Subtheme Recommendations for people who use AAC: These are recommendations that are made specifically for other individuals who have complex communication needs and use augmentative and alternative communication as their primary mode of communication.
- 6.2 Subtheme Recommendations for SLPs: These are recommendations that are made specifically for individuals who are SLPs, specifically those working with people who use AAC.
- 6.3 Subtheme Recommendations for Educators: These are recommendations that are made specifically for individuals who are in an educational role. This may include teachers in primary, secondary, or higher education positions.
- 6.4 Subtheme Recommendations for Professionals: These are recommendations that are made specifically for professionals who may be working with people who use AAC, these made include doctors, counselors, therapists, government officials, etc. This excludes educators and SLPs as these groups are addressed in another section.
- 6.5 Subtheme Recommendations for Others: These are recommendations for individuals who do not fit into one of the above categories.