HOW PRIMARY CARE PROVIDERS RECOMMEND AND COMPLETE CERVICAL CANCER SCREENING IN WOMEN WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

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ABSTRACT

HOW PRIMARY CARE PROVIDERS RECOMMEND AND COMPLETE CERVICAL CANCER SCREENING IN WOMEN WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

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Abstract: Cervical cancer screening (CCS) is one of the most effective forms of cancer screening. However, women with intellectual and developmental disabilities (I/DD) are less likely to be screened for cervical cancer compared to women without disabilities. A scoping review was conducted to identify the barriers and facilitators to CCS for women with I/DD, which revealed that type of health care provider was associated with women with I/DD participating in CCS. Results of the scoping review informed the subsequent phase of research. An exploratory sequential mixed method study was designed with the overall research objective of identifying how primary care providers (PCPs) recommend and perform CCS in women with I/DD. This study also implemented a community engaged approach, where a community advisory board of PCPs assisted in developing research materials. In the first study, interviews were conducted with 13 PCPs to identify how they recommended and performed CCS in women with I/DD. All PCPs recommended CCS to women with I/DD while they acknowledged the challenges in performing CCS in this population. Interview results were used to develop clinical vignettes for a questionnaire. In the second study, ninety-eight PCPs participated in an online questionnaire. PCPs were presented with three clinical vignettes, each clinical vignette had two conditions, PCPs were randomly presented with one of the two conditions. Based on the clinical vignette, PCPs were asked if they would continue to perform CCS. The clinical vignettes described a woman with I/DD with the following conditions: participating or not participating in sexual activity, comfort or discomfort prior to CCS, and low or high support needs.

Questionnaire results were consistent with the qualitative study, the majority of PCPs reported performing CCS. Clinical vignette scenario conditions that elicited fewer PCPs reporting performing CCS included the conditions where a woman with I/DD was not participating in sexual activity and patient discomfort prior to CCS. Both studies demonstrated that PCPs consider several factors prior to performing CCS in women with I/DD.

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Finally, a thank you to my partner, Jordan Wilkins for your love and support during this journey, there is no one else I'd rather have by my side.

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DEDICATION

I would like to dedicate this dissertation to my parents, Yoon Lee and Sylvia Curiel.

My father is from Daegu, South Korea and my mother is from Mexico City, Mexico. My parents immigrated to the United States as children, their parents left behind their homes and anything familiar in the hope of providing a better life for their children. Once my parents had a family of their own, they centered their entire lives around my sisters and I, making countless sacrifices to provide my sisters and I with a better life. This milestone is just as much theirs as it is mine.

PREFACE

The first chapter of this dissertation provides an overview of the literature related to cervical cancer screening (CCS) in women with intellectual and developmental disabilities (I/DD). The subsequent chapters are written as articles to appear in peer-reviewed journals. The second chapter is a scoping review article that is currently (November 2023) under review at *The Journal of Social Work in Public Health,* at the time of the writing of this dissertation defense. This journal was chosen as the social work profession can apply some of the lessons learned in the scoping review. Chapters three and four report on the results of the mixed method study, chapter three presents the data and findings from the qualitative study and will be submitted for publication to *The Journal of Cancer Education*. Chapter four reports on the quantitative questionnaire findings and will be submitted for publication to *Intellectual and Developmental Disabilities*. Chapter 5, the final dissertation chapter, will provide an overall summary of the results, implications and a summary of the study's strengths and limitations.

The author of this work recognizes the different language preferences amongst those who live with disabilities. Some prefer identity-first and others prefer person first language. In this dissertation, person first language will be used.

CHAPTER 1

Introduction and Comprehensive Literature Review

Cervical cancer screening (CCS) is one of the most effective forms of cancer screening.[1] However, women with intellectual and developmental disabilities (I/DD) do not get screened for cervical cancer at the same rates as women without disabilities or women with different types of disabilities.[2–4] There are many factors contributing to why women with I/DD have lower rates of CCS compared to women without disabilities, including not receiving a recommendation from their provider. Up-to-date Pap testing within the previous three years was higher among women with disabilities who reported receiving a recommendation for a Pap test from their provider than those who did not receive a recommendation (94.7% vs. 84.1%).[5] Physician type was also associated with participation in CCS in women with I/DD. In one study, women with I/DD who had a general practitioner (e.g., family practice, internal medicine, residential provider, health department, or rural health clinician) as their primary physician were less likely to receive CCS (Odds Ratio= 0.13, 95% CI [0.02-0.81]) compared to a woman who had an obstetrician/gynecologist (OB-GYN) as their primary physician.[6]

Researchers in Canada conducted two studies related to how primary care providers recommend cancer screening to individuals with I/DD.[7,8] In the first study, using clinical vignettes, the authors examined whether attitudes toward community inclusion of individuals with I/DD were related to PCP and trainees' recommendations for cancer screening to patients with I/DD. The authors found mixed results; attitudes were associated with recommending breast cancer screening but not CCS.[8] In the second study, interviews were conducted with majority family physician trainees, who reported that recommending cancer screening for individuals with

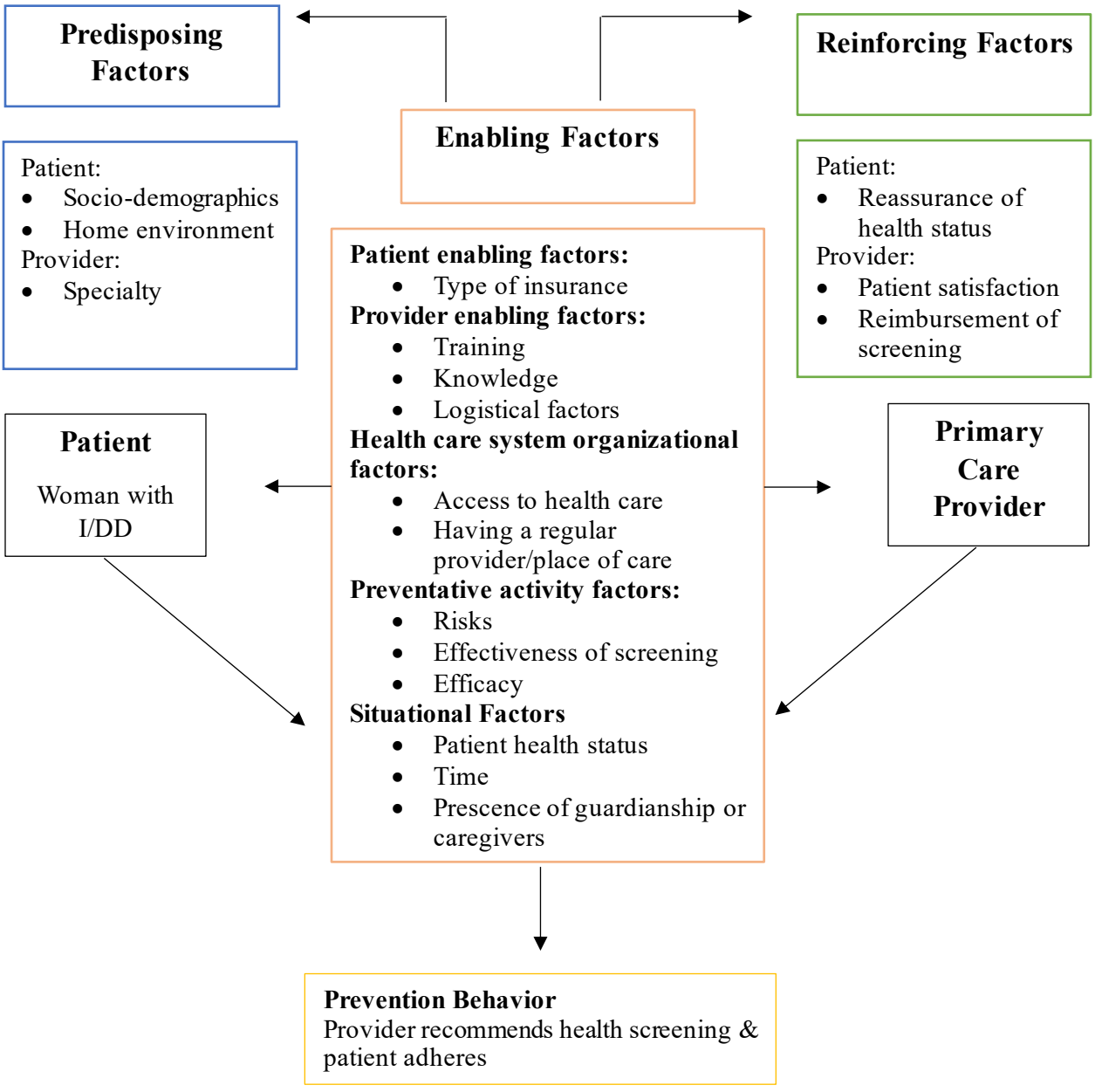
I/DD was complex, where multiple factors were considered including the patient' judgment, the patient's eligibility for screening, patients' autonomy, and the larger medical system.[7]

Theories of Provider Recommendations for Cancer Screening

Primary care providers (PCPs) are health care providers that serve as the main point of access to care in the United States health care system. PCPs often facilitate preventative health care activities, including CCS. Examples of PCPs include physicians, physician assistants, nurse practitioners or midwives trained in family medicine, internal medicine, OB-GYN, or midwifery. PCPs consider a variety of factors when recommending and completing preventative care such as cancer screening due to time constraints, awareness/training, agreement with preventative health testing guidelines, and self-efficacy.[9,10]

The Systems Model of Clinical Preventive Care[11] focuses on the interaction between patient and provider in addition to the factors that the patient and the provider contribute to the promotion or inhibition of preventive health care (See Figure 1). There are three major categories, predisposing, enabling, and reinforcing factors, that a provider and patient contribute to related to this interaction. The Systems Model of Clinical Preventive Care has been used to assess other preventative care contexts, including CCS,[12] breast cancer screening in elderly women,[13] and hypertension interventions.[14]

Figure 1. The Systems Model of Clinical Preventive Care



Motivation to participate in a health behavior or motivation to perform a health screening are examples of predisposing factors. For patients, predisposing factors include demographics such as education, income, as well as beliefs and attitudes (i.e., anxiety) that are related to participation in health behavior. Predisposing factors for providers may include what their specialty is. Enabling factors include the skills and or resources needed to participate in a health behavior or motivation to perform a health screening. For patients, enabling factors include health knowledge and logistical factors (e.g., transportation). Enabling factors from a provider includes their training in preventative medicine.

Other relevant factors that impact the interaction include health care system related organizational factors, preventative activity factors, and situational factors. Health care system related organizational factors include access to care, availability of personnel, cost of health care and organizational priorities. Preventative activity factors are aspects related to the preventative activities themselves and include risks, effectiveness, and efficacy of CCS. Situational factors include triggers to health behavior, such as time and the patient's current health status. Patient reinforcing factors may include social support or reassurance of health status (CCS comes back negative). Provider reinforcing factors include patient satisfaction or reimbursement from screening.

Current Study

First, a scoping review was conducted to identify the barriers and facilitators to CCS in women with I/DD. The results from the scoping review informed the development of the larger research study as research demonstrated lower rates CCS in women with I/DD by type of provider. Guided by previous research and the Systems Model of Clinical Preventive Care, the current study's overall aim was to examine how PCPs in the United States recommend and

perform CCS in women with I/DD. This research study utilized a sequential mixed method study design.

In **study 1**, PCPs (N=13) were interviewed to identify what factors were considered when recommending and performing CCS in women with I/DD. The proposed journal to submit this manuscript to is the *Journal of Cancer Education*. Interview data from study 1, were analyzed and used to inform the development of clinical vignettes for a questionnaire for study 2. The purpose of **study 2**, was to identify the degree to which sexual activity, patient discomfort, and level of supports were related to PCP's performing CCS in women with I/DD. PCPs (N=98) participated in study 2, an online questionnaire. Participants were randomly presented with one of two conditions based on a fictitious patient, a woman with I/DD. The three clinical vignettes topics were on sexual activity, patient discomfort, level of supports; participants were asked if they would perform CCS in women with I/DD. Participants were also presented with two scales related to attitudes towards individuals with I/DD and self-efficacy in providing care to people with I/DD. The proposed journal to submit the second study to is the *Journal of Intellectual and Developmental Disability*.

CHAPTER 2: Scoping Review

Background

Forty-two years ago, cervical cancer was one of the leading causes of death among women in the United States.[15] Cervical cancer screening (CCS) has been highly effective in reducing mortality rates associated with cervical cancer.[1] For early detection of cervical cancer, the U.S. Preventive Services Task Force (USPSTF) recommends that: (1) all women aged 21 to 29 years receive screening using cervical cytology (i.e., looking for abnormal cellular change) every three years; and (2) women aged 30 to 65 years receive screenings every three years using cervical cytology, every five years using testing for high-risk human papillomavirus (hrHPV), or every five years with hrHPV testing in combination with cervical cytology.[16] Despite CCS guidelines being applicable to all women, women with disabilities experience disparities in receiving CCS.[17–19] According to Medical Expenditure Panel Survey (MEPS) data, there is also evidence that women with more complex disabilities are less likely to be up-to-date on CCS compared to women with less complex health and behavioral health needs.[3]

Included in the disability group experiencing disparities in CCS are individuals with intellectual and/or developmental disabilities (I/DD), which include disabilities such as intellectual disability, developmental disability, autism spectrum disorder (ASD), and Down syndrome. Recent literature has highlighted cancer screening inequities for all adults with I/DD.[20,21] Chan and colleagues (2022) published a global systematic review on barriers (e.g., co-morbid conditions, fear, embarrassment) and facilitators (e.g., ability to provide consent to screening, mobility status) across a variety of cancer screenings in adults with I/DD. However, women with I/DD experience a particularly unique set of barriers to CCS due to challenges with communication, transportation barriers, limited access to accessible equipment, bias about sexual

activity informing the perceived need for screening, and guardianship-related decision making issues.[17–19,22] Additionally, more information is needed to understand the challenges faced in receiving primary care, such as CCS, among women with I/DD within the unique context of the U.S. health and social care systems.

The Profession of Social Work and Individuals with Disabilities

Social workers have long played an important role in the field of disability.[23,24] With disability estimated to impact approximately 15% of the global population, social workers in a variety of practice settings (e.g., health care, education, child welfare, aging services) encounter and support individuals with disabilities in their daily work (International Federation of Social Workers, 2010). Social workers' responsibility within the field of disability has also been well-established. For example, the most recent Council on Social Work Education Educational Policy and Accreditation Standards[25] recognizes disability as one of the intersecting dimensions of diversity and directs social workers to understand how it shapes lived experiences and informs equity and inclusion. Further, the profession's ethical principles, as outlined in the National Association of Social Workers Code of Ethics, articulate a commitment to both individuals and the larger society, implying an obligation to assess and intervene at all levels (e.g., micro, mezzo, macro) when the needs of a marginalized community are left unmet.[26]

Social workers can play an essential role within the field of I/DD, often sitting at the intersection of policy and practice.[27] Dating back to the early-mid 1900s, social workers were among those advocating for disability rights legislation and working across systems to coordinate community-based care for people with I/DD and their families.[28] Although very few I/DD professionals carry the title of social worker today, opportunities persist for social workers to exercise their unique scope of practice on multidisciplinary teams within this field.[27,28]

In the context of health care, social workers have been found to support self-determination by utilizing shared decision-making models to empower people with I/DD, among others, to discuss plans of care and explore treatment alternatives with their providers.[29] Social workers have also played an integral role in facilitating the assessments and interventions necessary for successful discharge planning. In this role, they can support individuals, caregivers, and providers to navigate complex community-based service systems toward successful outcomes.[30,31] In addition, social workers have utilized an empowerment framework to support individuals in advocating for the removal of barriers that impact their ability to access care, for screenings and/or treatments essential to high quality care, and for policy change within the complex health care systems they frequently navigate.[27]

The purpose of this paper is to present the results of a scoping review designed to: (1) describe the barriers and facilitators that women with I/DD living in the United States experience in relation to CCS, and (2) provide recommendations as to how social workers can assist this group through education, advocacy, and interprofessional practice.

Method

Study Selection

Inclusion criteria included original research articles that: (1) were published in peer-reviewed journals; (2) were conducted in the United States; (3) were published after 1990; (4) reported results of data collection from females with an I/DD diagnosis documented prior to age 18 and not due to an injury (this included women with intellectual disabilities, autism, Down syndrome, and developmental disabilities); (5) involved study participants who were older than 21 but younger than 65 years old; and (6) focused on CCS. Literature was selected after 1990 because the Americans with Disabilities Act and Section 504 of the Rehabilitation Act required

that health care providers afford individuals with disabilities full and equal access to their health care services and facilities. As there were evolving guidelines for CCS during the years covered in this scoping review and to ensure readers are aware of the CCS guidelines during the year in which each article of this scoping review was published, the different guidelines are included in Table 1.

Search Strategy

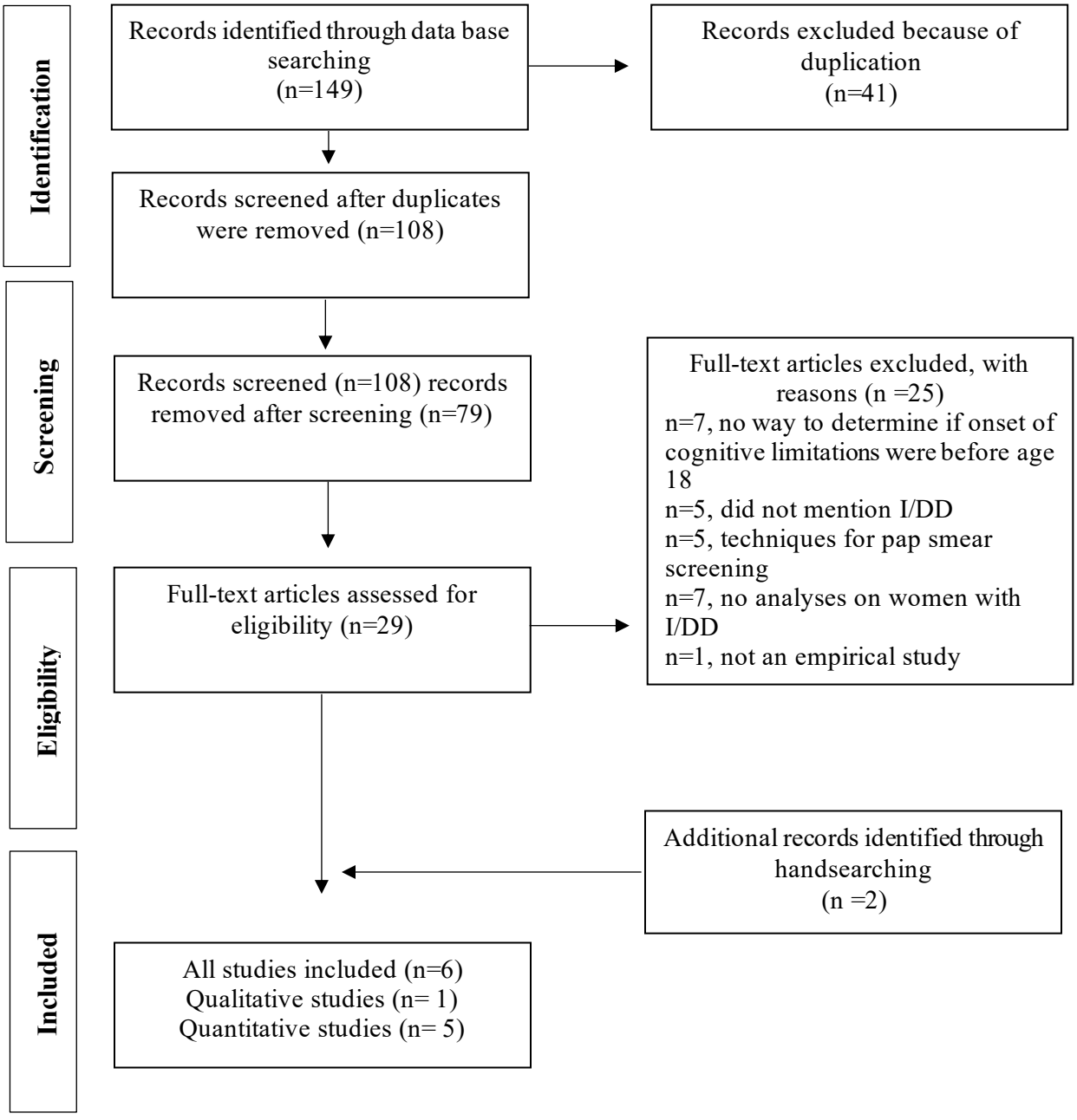
A health sciences librarian was consulted and acted as a search coordinator. The librarian worked with the first and senior author to formulate keywords, select databases, and conduct a trial search of PubMed (MEDLINE) on June 17, 2020. The search strategy followed the PRESS 2015 Guidelines for Recommendations for Librarian Practice and involved translation of the original research question, "*What are the facilitators and barriers to CCS in women with I/DD*?" into a search string that could be replicated across the following databases: CINAHL, PsycINFO, and PubMed (MEDLINE).

The initial search was designed to include case reports, clinical studies, clinical trials, observational studies, peer-reviewed clinical trials, and randomized controlled trials measuring outcomes in women ages 21-65 years. The search was limited to English-language publications, and studies published outside the United States were included in the search results but removed during screening. The search team strategy is available in Appendix A. Following best practices, hand searching was also used as a method to ensure all appropriate literature was included.[32]

A total of 149 results were retrieved across databases. All records identified through databases were exported to the reference management software Zotero. After deduplication, the final search included 108 results. Three reviewers (ML, CB, SS) independently screened the 108 titles and abstracts of the studies for relevance based on the inclusion criteria. In the case of

disagreements, after discussing the rationale for including or excluding an article, an additional reviewer (HW) determined whether an article should be included. Twenty-nine articles were retrieved for full text review and an additional two articles were identified via handsearching, resulting in 32 articles that were assessed for full-text review. In total, six articles met the inclusion criteria after full-text review (Figure 2).

Figure 2. PRISMA Chart Showing Review Process of Article Elimination



Data Extraction Method

The research team (ML, CB, SS, HW) assembled a data extraction sheet to organize and classify article information, such as: study samples, demographics, type of disability, research design, methodological approach, and major findings. CB and SS conducted the first extraction of the articles, subsequently ML reviewed the data extraction sheet to verify the information pulled. If there were any article discrepancies, research team members (ML, CB, SS, HW) met to discuss these articles.

Results

Six articles met full inclusion criteria.[6,33–37] For a description of the study designs reviewed for this project see Table 1. For a more detailed description of the analyses, please reference the appendix. As most of the included studies are population-based correlational studies, we list the studies below as indicating potential barriers and facilitators.

Table 1. Summary of the Scoping Review Literature

Article Authors and Year	Study Design	Setting of Data Collection	Analyses	Year(s) of Data Collection	Cervical Cancer Screening Guidelines at Time of Study	Sample Size of those with CD	Disability Type
(Parish & Saville 2006)	Quantitative Cross-sectional Secondary data analysis	Medical Expenditure Panel Survey (MEPS)	Logistic regression	2000 and 2002	2000-2002: Pap testing at least every 3 years for women 18-65 years of age	296	Cognitive impairment/ disabilities
(Parish et al., 2012)	Qualitative Interviews	North Carolina Computer assisted and face to face interviews	Descriptive Summary Statistics	Late 2009-early 2010	2003-2010: Pap testing at least every 3 years for women 21-65 years of age	202	Mild to moderate (91%) Severe or profound (9%)
(Parish et al., 2012)	Quantitative Randomized control trial	North Carolina Computer assisted and face to face interviews	Compared Women's Correct Knowledge indicator responses from baseline to post test in treatment (WBH) group	Late 2009-early 2010	2003-2010: Pap testing at least every 3 years for women 21-65 years of age	175	Mild and moderate DD
(Parish et al., 2013)	Quantitative Cross-sectional Secondary data analysis	Medical care records	Multiple logistic regression (w/ Pap test within a three-year period as predictor variable)	2006-2010	2000-2002: Pap testing at least every 3 years for women 18-65 years of age. 2003-2010: Pap testing at least every 3 years for women 21-65 years of age	163	Women with intellectual disabilities Primarily mild/ moderate

Article Authors and Year	Study Design	Setting of Data Collection	Analyses	Year(s) of Data Collection	Cervical Cancer Screening Guidelines at Time of Study	Sample Size of those with CD	Disability Type
Swaine et al., 2014	Quantitative Randomized control trial	North Carolina Computer assisted and face to face interviews	Compared Women's Correct Responses at Baseline to Post test in Treatment Groups and logistic regression models	Late 2009-early 2010	2003-2010: Pap testing at least every 3 years for women 21-65 years of age	198	Women with DD Mild to moderate (91%) Severe (9%)
Xu et al., 2017	Quantitative Secondary Data analysis	N/A South Carolina Medicaid claims	Multinomial logistic regression for Pap testing: Adjusted for covariates (mean age, squared term of mean age, eligibility years, squared eligibility of years and residential neighborhood category	2000 and 2010	2000-2002: Pap testing at least every 3 years for women 18-65 years of age. 2003-2010: Pap testing at least every 3 years for women 21-65 years of age	5,490	Mild intellectual disability, moderate intellectual disability, and unspecified intellectual disability

DD=Developmental Disabilities

Potential Barriers

Education

One article highlighted the lack of knowledge among women with I/DD about breast and cervical cancer screenings.[34] As there were no breast and cervical cancer screening knowledge measures in existence at the time, the authors first reviewed National Core Indicators and other measurement tools to develop their interview instrument. After pilot testing with two women with developmental disabilities and the measurement tool was refined, the final tool developed to assess the participants' knowledge took 15-20 minutes to complete and was administered in one-on-one interviews with 202 women with developmental disabilities. Knowledge of Pap testing was assessed with four items (Pap test definition, Pap test frequency, Pap test picture identification, and identified ways to decrease anxiety related to pelvic exam), where low mean composite scores (M=1.5, SD=1.2) were noted. Answers were handed coded by a research team using a binary scale (correct or incorrect answers) where slang terms were accepted as correct.

Home Environnent

In the same article, Parish and colleagues (2012) also identified the proportion of CCS knowledge based on participants' home environment. Limited knowledge about CCS was most acute for women living with family caregivers (M=1.2, SD=1.2) compared to women living in residential settings (M=1.7, SD=1.2) or alone/with a spouse (M=2.4, SD=1.3). Other research, utilizing medical records data from 2006-2010 for women with intellectual disabilities, found that CCS outcomes were associated with a woman's home environment.[6] Women with I/DD who lived with their family caregivers were less likely to receive Pap testing (OR=0.21, 95% CI [0.08-0.52]) than women living in residential settings or alone/with a partner (OR=0.60, 95% CI [0.14-2.51]). Similarly, marriage status was a factor that also impacted participation in CCS.

Data from the Medical Expenditure Panel Survey for 2000 and 2002 comparing women with and without disabilities that were the same ages indicated that women with I/DD were less likely to have had a Pap test in the last year if they were married (OR=0.68, 95% CI [0.62-0.74].[35]

Type of Health Care Provider

Researchers also found that health care provider type had an impact on CCS. Women with I/DD who had a general practitioner (e.g., family practice, internal medicine, residential provider, health department, or rural health clinician) as their primary physician were less likely to receive CCS (OR= 0.13, 95% CI [0.02-0.81]) compared to woman who had an obstetrician/gynecologist (OB-GYN) as their primary physician (reference group).[6]

Potential Facilitators

Education

Education was found to be related to Pap testing; women with higher educational attainment were more likely to have a Pap test in the last year (OR 1.09, 95% *CI* [1.08-1.11]).[35] Interventions to address cancer screening education gaps among women with I/DD have also been conducted. Researchers conducted a randomized control trial to test the efficacy of a cervical and breast cancer screening education intervention, *Women Be Healthy*.[38] Women assigned to the experimental group participated in this health education program for eight weeks, while the control group participated in their regular vocational training or educational activities. Women participating in the *Women Be Healthy* program demonstrated knowledge gains in three of the four Pap testing measures, showing statistically significant knowledge gains from baseline to posttest: (1) frequency of Pap test (OR= .97, X^2= 10.67); (2) Pap test picture identification (OR=.99, X^2= 5.00); and, (3) identified ways to decrease anxiety (OR=.99, X^2= 6.26). However,

after controlling for baseline knowledge, these knowledge gains were not statistically significant in logistic regression models.

Swaine et al. (2014) built off *Women Be Healthy* to create *Women Be Healthy 2.* The major differences between these interventions included extending the class duration from 8 to 11 weeks and spending more time on CCSs. This randomized control trial had participants assigned to either *Women Be Healthy, Women Be Healthy 2,* or a control group. Of the *Women Be Healthy 2* group, two of the measures were statistically significant in knowledge gains: (1) Pap test definition; and (2) Pap test picture identification. However, no statistically significant differences between the *Women Be Healthy* and *Women Be Healthy 2* posttest knowledge item (Pap test picture identification) were found in logistic regression models that controlled for baseline scores, knowledge, type of site, and living arrangement.

Home Environment

One article discussed how Pap testing was associated with location. Women who lived in a rural setting had a greater likelihood of receiving a Pap test (OR=3.43, 95% CI [1.40-8.40]) than women who lived in urban settings ("reference group").[6] Pap testing was also associated with income levels, where the higher a women with I/DD's income was, the more likely she was to have had a Pap test in the last year (OR=1.05, 95% CI [1.00-1.09]).[35]

Xu et al. (2017) found that, after adjusting for covariates, women with intellectual disabilities who lived in a group home, medical facility, or supervised community living setting were more likely to be fully adherent with Pap testing recommendations compared to those who lived alone or with family. Community living settings had the highest adjusted rates of odds of full adherence for women who were Medicaid eligible (AOR= 4.14, 95% CI [3.24-5.29]) and for women with dual insurance (AOR= 27.30, 95% CI [11.97-62.63]).[37]

Health Care Access

Insurance type was also associated with CCS participation, where insurance category (i.e., Medicaid only, Medicare only, Medicare and Medicaid) was significantly associated with Pap testing adherence. After adjusting for covariates (mean age, squared term of mean age, eligibility years, squared term of eligibility years, and residential neighborhood category), women with intellectual disabilities who were dually insured by Medicare or Medicaid had a 4.70-fold (95% CI [3.64- 6.08]) odds of full adherence and 3.01-fold (95% CI [2.34-3.86]) odds of partial adherence to Pap testing.[37] In this paper, full adherence was defined as a woman having received all screening tests in adherence with USPSTF recommendations across all year of eligible enrollment, while partial adherence was defined as a woman having at least one screening test but less than the number recommended for full adherence. Women with I/DD were also more likely to have had a Pap test in the last year the more often they had visited their doctor (OR=1.13, 95% CI [1.10-1.15]).[35]

Discussion

Most of the studies examined only the associations between variables; additional research is needed to understand *how* these factors directly and indirectly impact women with I/DD participating in CCS. Articles that described the CCS experiences of women with I/DD from their own perspectives were expected, but not found. Individual demographic variables (e.g., socioeconomic status, marriage status, living situation) were associated with participation in CCS by women with I/DD. Finally, some articles described organizational influences (e.g., insurance status, number of doctor visits, and type of provider) on CCS in women with I/DD. These findings align with research conducted in the general population of women.[39,40]

The Role of Social Workers in Educating Women with I/DD

Education and health knowledge are associated with positive health outcomes for people with disabilities.[41] Populations with low socioeconomic status experience additional barriers to participating in cancer screenings.[42,43] We found that women with I/DD were less likely to have knowledge about CCS or participate in CCS. Like other minoritized groups, women with I/DD inhabit categories (e.g., higher rates of poverty) that consistently put them at greater risk for not participating in cancer screenings.[44] Higher education and income have also been noted as facilitators to cancer screening in adults with I/DD.[20]

Home environments were noted by multiple articles to be associated with cancer screening, which is unsurprising due to the active role caregivers play in influencing health care decisions among adults with disabilities.[45] Higher rates of CCS were noted for women who did not live at home with family. This may be due to congregate living facilities having policies regarding regular provider health checks, including cancer screenings.[46] The association between type of residence and Pap testing among women with I/DD is also noted in other literature.[47]

Educational programs and opportunities intentionally designed for women with I/DD are essential in supporting increased knowledge about CCS in this population. Curricula, such as *Women Be Healthy* and *Women Be Healthy 2,*[34,36] have demonstrated encouraging results. Social workers within or adjacent to the field of I/DD can provide information about and refer women to appropriate health education resources, such as the *Women Be Healthy* series. Social workers are also being integrated as allied health professionals in primary and specialized care settings.[48] In these roles, social workers may be well-suited to empower women with I/DD to discuss CCS in the context of their daily lives, offering education on how to ask questions of their health care providers, raise concerns regarding their care, and address barriers to accessing routine CCS.[49] To the latter, a social worker might offer training and support to women with I/DD who wish to

request medical transport services and request extended appointment times when scheduling with a provider's office.[49] Social workers can also encourage family members or caregivers to participate in education programs, as many do not receive formal guidance or training about cancer screening for women. Yet, they often play important roles in assisting women with I/DD in making health care decisions.[50,51]

The Role of Social Workers in Promoting Self-Advocacy Among Women with I/DD

There were no articles that discussed how attitudinal influences impact women with I/DD participating in CCS. However, given the extensive literature that indicates how impactful biases are[52] and how they can affect behavior,[53] it is necessary to discuss how biases might impact cancer screening recommendations. Women with I/DD potentially face two unique barriers to CCS compared to other populations: their caregivers and potential guardianship status. In many cases, caregivers act as "gatekeepers" to health care where they may not want their family member participating in certain health care services.[51,54] Some caregivers to women with I/DD believe that withholding information related to sexual health, such as CCS, protects against exploitation, or they believe that their children are uninterested in sex.[55] Depending on the type of guardianship arrangement, a guardian may further complicate the health choices of a woman with I/DD. As a specific example, some types of guardianship arrangements allow for the guardian to have full responsibility of health care decisions. Therefore, women with I/DD may not receive CCS because of guardian preferences, such as not wanting to distress the women with I/DD.[54]

Additionally, there were no articles that discussed the degree to which health care providers impact CCS in women with I/DD. However, there is extensive research among the general population describing how a provider's recommendations impact cancer screenings in

individuals without disabilities.[56] Recent literature has been published indicating only 40% of U.S. physicians reported feeling very confident in their ability to provide the same quality of care to individuals with a disability that they provide to individuals without disabilities.[57] Medical providers may not recommend CCS to women with I/DD due to their perceptions of low cervical cancer risk among women with I/DD.[58] However, women with I/DD are more likely to be victims of sexual abuse compared to women without disabilities,[59–61] and women with disabilities are less likely than other women to report sexual abuse.[62,63] Therefore, providers should consider the living environment of a woman with I/DD, as exposure to more individuals may lead to increased risk of sexual abuse and therefore increased risk of developing cervical cancer thus making them a high priority for participation in CCS.

Social workers can rely on evidence-based practices to empower women with I/DD to exercise their right to timely and effective health care, including CCS. Supported decision making, for example, has been endorsed by social workers as an alternative to guardianship due to its empowerment perspective.[64,65] In supported decision making, individuals with I/DD retain their decision-making capacity and choose someone to assist them in making decisions and communicating their choices to others, including around such topics as sex and sexual health.[66] Another way in which social workers may support women with I/DD is to advocate alongside them, particularly as it relates to the tension between safety and self-determination in the context of CCS. Specifically, social workers can advocate with family, caregivers, and health care providers for system changes that promote more frequent screenings for cervical cancer. They can also advocate for a sexual justice perspective, which recognizes the rights of women with I/DD to exercise their sexuality while also acknowledging the increased risk for sexual abuse that persists for many.[67]

The Role of Social Workers in Working with Other Health Care Professionals

This scoping review found that, as with women without disabilities,[39,40] insurance type and number of visits to the doctor were associated with participation in CCS among women with I/DD. Also, this scoping review found one study that demonstrated the association between CCS in women with I/DD and type of medical provider, where OB-GYNs were more likely to recommend CCS than general practitioners. This may be related to physicians recommending care that is within their specialty area. However, additional research is needed to better understand this relationship.

Although this scoping review did not include the perspectives of health care providers, some research indicates that providers have challenges in following preventative health care screening guidelines for patients with I/DD.[68] This is unsurprising, as physicians report having no formal training about their obligation to provide equitable treatment for individuals with disabilities despite a federal civil rights law (ADA) requiring them to provide inclusive care.[69] Adding to this challenge, providers report not having appropriate training, resources, time, and confidence in their ability to provide gynecological care to this population.[68,70,71]

Of all service professionals, social workers often have the most holistic and comprehensive perspective on women with I/DD, as their scope of practice tends to afford them the opportunity to thoroughly assess the day-to-day lives of their clients.[49] As such, social workers are increasingly asked to join and contribute to integrated health care teams.[72] On these teams, social workers have been found to provide other health care providers with important insights on how best to engage individuals with I/DD, their families, and their caregivers to elicit both important clinical information and ensure a person-centered approach to care.[28] Social workers also frequently function as health care system navigators, working collaboratively with

the team to rectify insurance challenges and other common barriers that could impact a woman's access to CCS.[27,46] Social workers have also joined with their interprofessional colleagues to advocate for macro-level change, including engaging in advocacy within their organizations, health care systems, and governmental organizations to promote and enforce policies related to disability and sexual health.[73,74]

Limitations

Limitations of this scoping review should be acknowledged. There has been limited research in this area, resulting in a small number of final articles meeting the inclusion criteria. The study team included literature based on I/DD diagnosis and status; however, there could be studies that used other diagnostic labels for their samples that were, therefore, not identified by our search strategy. Finally, three of the six articles were part of one study, indicating that half of the studies in the scoping review came from a similar data pool of participants, limiting generalizability.

Conclusion

This scoping review identified six articles over a period of 30 years in the United States, where most evidence highlighted the degree to which individual factors impact cervical cancer knowledge and screening in women with I/DD, particularly women's home environment. Like other woman, women with I/DD should receive CCS recommendations. Social workers can play an important role in providing resources to women with I/DD about CCS, including scheduling appointments for CCS. Social workers can also empower women with I/DD by educating them about options such as supportive decision making and facilitating their ability to self-advocate and self-determine. Social workers can also act as a support to women with I/DD, their family members, and health care providers in conversations around CCS. Finally, social workers on

interdisciplinary health care teams can assist clients in navigating barriers within the health care system, as well as to advocate for person-centered care.

CHAPTER 3: Interviews with Primary Care Providers

Background

Cervical cancer screening (CCS) is effective at detecting cervical cancer, as demonstrated in the reduced mortality rates due to cervical cancer screening.[1] Research has highlighted the lower rates of CCS in women with disabilities compared to women without disabilities.[5,17–19] According to Behavioral Risk Factor Surveillance System (BRFSS) 2020 data on up-to-date cervical cancer screening among females 21 to 65 years of age, the prevalence of CCS among women with cognitive disabilities was 77.4% compared to 84.2% of women without disabilities.[4]

Individuals with disabilities have not been viewed as a population engaging in sexual activity[75] despite evidence that this population does participate in sexual activity.[76] One consideration for lower rates of CCS in women with Intellectual and developmental disabilities (I/DD) may be related to physicians not recommending CCS. Historically, primary care providers questioned the need for CCS in women in I/DD due to concerns such as provoking anxiety or pain in women with I/DD.[77] Women with I/DD at the time were also not as integrated into the community as they are today.[78] As more women with I/DD participate more in their communities, their opportunities for relationships and sexual relations increases.[77] Women with I/DD are also more likely to be victims of sexual abuse compared to women without disabilities[59,61] and women with disabilities are less likely than other women to report sexual abuse.[63] In considering these risk factors as well as considerations for equitable health care for all, women with I/DD should participate in recommended CCS.

Primary care providers serve as the main point of contact in the United States health care system, where they provide preventive health and women's health care. Primary care physicians are trained in family medicine, general internal medicine, or general pediatrics and are

responsible for the patient's comprehensive care including preventive health care.[79] Nurse practitioners, also primary care providers trained in family medicine, provide a wide range of care, including diagnosing, treating, and managing acute and chronic diseases while emphasizing health promotion and disease prevention.[80] Obstetrician-gynecologists (OB-GYNs) are also critical to women's health as they provide medical and surgical care to women throughout their lifespan.[81] Midwives provide primary care for individuals from adolescence through the life span and provide care related to sexual and reproductive health, gynecological health, family planning, and pregnancy.[82]

Choosing which type of primary care provider a patient sees is based on insurance, availability of provider, and personal preference.[83] Having a primary care provider is associated with positive health outcomes (e.g., prevention of illness (e.g., lower mortality rates of cancer)[84] and reduced emergency visits in the general population including those with I/DD.[85] Having a recommendation for CCS is also associated with greater adherence to CCS. In one study, researchers used National Health Interview Survey (NHIS) data found that a lack of recommendations for CCS contributed to lower adherence to CCS.[86]

Health care providers play key roles in cancer screening including CCS, as they often perform or refer people to CCS. In women with disabilities, the prevalence of up-to-date Pap testing within the previous three years was higher among women with disabilities who reported receiving a recommendation for a Pap test from their provider than those who did not receive a recommendation from their provider (94.7% vs. 84.1%).[5] The type of primary care provider is also associated with CCS in women with I/DD. In one study, women with I/DD who had a general practitioner (e.g., family practice, internal medicine, residential provider, health department, or rural health clinician) as their primary physician were less likely to receive CCS

(OR= 0.13, 95% CI [0.02-0.81]) compared to woman who had an obstetrician/gynecologist (OB-GYN) as their primary physician (reference group).[6]

Research understanding how primary care providers recommend and perform CCS to women with disabilities is limited. Most research has been focused on the challenges that primary care providers, specifically, OB-GYNs have in providing women's health care to women with disabilities.[68,71] Other literature has identified barriers to cancer screening in adults with I/DD from the perspective of nurses.[87] Only one study to date has focused on Canadian family physician trainees and their experiences regarding cancer screening, including CCS in patients with I/DD. Breau and colleagues (2022) conducted a qualitative study of family physician trainees who reported that recommending cancer screening was complex such that they needed to consider multiple factors such as their own individual judgment, the patient's eligibility for screening, patients' autonomy, and the larger medical environment needed to occur.[7] However, no study has been conducted on practicing PCPs in the United States and how they recommend and perform CCS in women with I/DD. The primary objective of this paper was to explore and identify what factors primary care providers (PCPs) consider when recommending and performing cervical cancer screening in women with I/DD.

Method

Community Advisory Board and Semi-Structured Interview Guide

The researcher used the proposed theoretical framework, The Systems Model of Clinical Preventive Care[11] to help draft a semi-structured interview guide ensuring that the major areas from the framework were included (e.g., enabling, predisposing, and situational factors). These interview questions were first presented to a practicing family medicine physician who provided feedback on the questions, modifying the language to align it with language used by practitioners.

As this research study utilized a community engaged design, 4 PCPs (two family medicine physicians and two family nurse practitioners) sat on an advisory board to provide clinical expertise for the project. Including an advisory board in the research process was important as the researcher wanted to include the perspectives of the population being studied. Advisory board members reviewed the semi-structured interview guide, provided feedback regarding the questions, assisted with recruitment, and reviewed the findings from the interviews. See the Appendix for the semi-structured interview guide.

This five-member research team includes one team member sharing the focal characteristics of the target audiences: a PCP to individuals with I/DD. The first author was the primary researcher who collected and analyzed all data, is not a PCP, identifies as a biracial female without a disability and is a family member to an individual with a disability. The first author has over four years of conducting research in the disability field.

Participants

Eligible participants were self-identified primary care providers (PCPs), including physicians, physician assistants, nurse practitioners, and midwives practicing in the United States with specialties in the following areas: family medicine, internal medicine, OB-GYN, or midwifery. Purposive sampling was used to recruit participants and recruitment methods included sending the advertisement for the study to relevant contacts via email and through online social media advertisement. Participants who were interested in participating in the study contacted the first author, confirmed their eligibility to participate, then scheduled time for a Zoom interview.

Data Collection

One on one semi-structured interviews were held primarily over Zoom, with one interview that took place in person. The first author conducted all the interviews. An incentive of a $25 gift card was offered to each participant to thank them for their time. Interviews took place between December 2022 through April 2023. Institutional Review Board approval for the study was granted by [Northern Arizona University] and verbal consent was obtained from each participant.

Data Analysis

With permission from participants, recorded interviews were transcribed using the closed captioning function in Zoom then reviewed and edited by the first author. Interviews on average lasted 49 minutes and ranged from 26 to 60 minutes. An inductive approach[88] was used to code interviews. The first and second author independently read the transcripts and documented major themes represented in the interviews. Meetings to discuss consistency among the major themes found were held until major themes were agreed upon. Subsequently, a code book was used to organize codes, definitions, and examples of each code.[89] Revisions to the code book were made throughout the analysis stage. When coding differences were present, the two coders met and discussed differences until agreement was reached. Once agreement was reached, the first author coded all interviews in NVivo 12 and the other coder (AD) independently reviewed a random sample of interviews (n=6), where coding agreement was at 93%. Coding agreement was determined by reviewing consistency in coding in the interviews. The coding agreement percentage was calculated as the number of coding agreement in the interview text over the number of overall codes in the interviews. Data analysis also included triangulation of codes described by PCP type. Inductive thematic saturation[90] was met after 11 interviews were conducted where no additional codes or themes were found.

Results

A total of 13 PCPs including 9 physicians, two nurse practitioners, one physician assistant, and one midwife participated in the study. There was minor variation in specialization among the sample where the majority of PCPs were trained in family medicine. The majority of PCPS worked in Urban areas in a Southwestern state (84%). Years of practice ranged from 2-23 years with an average of 10 years. Participants in this study practiced at a variety of health care settings including Federally Qualified Health Center (FQHCs), non-profit health care system or other settings. See Table 2 for a description of participant characteristics.

No participants reported receiving any training in providing health care to individuals with I/DD. Four participants indicated that they had a family member or friend with a disability (n=4, 36%) and some participants indicated they had some experience related to individuals with disabilities in residency (n=3, 23%). Most participants reported seeing patients with I/DD in their practice occasionally. Interview analysis revealed the following themes including education and training gaps, CCS counseling, individualized risk benefit analysis of CCS, and future solutions to improving CCS in women with I/DD. These themes are described in detail in the following sections.

Table 2. Demographic Characteristics of Interview Study Participants (N=13)

Type of Primary Care Provider (PCP)	**Number of Participants (%)**
Physician (MD/DO)	9 (69%)
Nurse Practitioner	2 (15%)
Physician Assistant	1 (8%)
Midwife (CN/CNM)	1 (8%)
PCP Specialty	
Family Medicine	10 (76%)
Midwifery	1 (8%)
Internal Medicine/ Internal Medicine/Pediatrics	1 (8%)
OB-GYN	1 (8%)
Health Care Practice Setting	
Federally Qualified Health Center (FQHC)	4 (30%)

FQHC + Faculty at Medical School	3 (23%)
Non-profit Health Care Corporation	2 (15%)
Small Health Clinic/Community Clinic	2 (15%)
Outpatient Clinic	1 (8%)
Private Practice	1 (8%)

Education and Training

Most participants aimed to provide equitable health care to all their patients. Most physicians reported they had no education or training in working with individuals with I/DD or were not able to recall the education or training they received as part of their degree requirements. Participants reported being aware of factors related to their ability to perform CCS in women with I/DD including outdated attitudes and how guardianship status can impact a PCP's ability to perform CCS.

Participants used previous experiences with populations they considered women with I/DD similar to in order to reflect on how they would counsel and perform CCS with patients with I/DD. Participants were cognizant of negative attitudes toward the disability population. One participant describes how they considered their bias before providing health care to women with I/DD:

> "We all have implicit bias about almost anything. Our background, our framework that we grew up in will bias us in one way or another….by going into it [the interaction with patient], knowing that I have implicit bias, it helps me prevent my bias translating to their care by going in and just being more open-ended with my questions. I try to understand exactly where they are, instead of jumping to a conclusion."
>
> -Family Medicine Physician #7

In most cases, negative attitudes towards women with I/DD were related to them not being sexually active and therefore not needing CCS. Participants were aware of the concept of guardianship, however, did not express awareness of several types of guardianship that exist guardianship (e.g., full versus limited guardianship). Most reported that guardianship was the most challenging when women with I/DD were accompanied by group home or the state care

providers (direct support professionals) rather than a family member. Less frequently mentioned were PCP's having challenges in understanding the guardianship dynamics with a new patient. Some participants reported being aware of the guardianship status before entering into the patient exam room, however, this was not always the case. One participant describes their assumption of guardianship in a patient with I/DD,

> "I feel like I should, but I can't say that I check that [guardianship]. I've assumed that. I don't know if I've ever really confirmed or looked or said, 'oh, mom, are you the legal guardian?' I've assumed that if someone's living at home, they can't be independent. I'm assuming that the mom's the guardian, but I can't say that I've ever done some confirmatory research or checking or looking."
>
> -Family Medicine Physician #5

In this quote, the participant did not verify documentation related to medical decision-making authority, assuming that the parent had the medical making authority. Most participants reported following the guardian's decision regarding CCS completion though some participants mentioned incorporating shared decision making with women with I/DD when making decisions around CCS. Other participants discussed how they relied on tactics they used with similar populations to help them counsel and perform CCS in women with I/DD. Similar populations described included adolescents or a patient who had never had CCS or a pelvic exam before. A participant describes this comparison below:

> "I think there is a huge overlap with our adolescent population and our preteen population… someone who is like 8 years old. 9, 10, 14. So you're on this continuum of where's your patient? At what is their level of understanding? I think that's why it's not such a leap with my developmentally disabled patients is you're still doing that same assessment right?"
>
> –Nurse Practitioner #1

CCS Counseling in Women w/ I/DD

Participants reported having little difficulty in having discussions about CCS with patients and families about CCS. Participants first provided education around what CCS is then provided time for patients/families to consider CCS where often providers would need to revisit

the topic of CCS at a subsequent appointment. When discussing CCS with patients, providers described acknowledging discomfort around CCS, using patient-friendly language, communicating how quickly CCS could be done, using visuals to help explain CCS when counseling women with I/DD, engaging family members in the discussion of CCS, and implementing a gradual consent process when performing CCS. In the quote below, a participant attempts to understand the barrier to CCS to help direct their conversations around CCS education and counseling:

> "These are long conversations where I keep coming back to what does the patient perceive as a barrier, what are they worried about? You know, especially with intellectual disability. I think a lot of times there is difficulty understanding it, and it seems like a fearful thing to be on this table. So, I try to demystify the procedure, but also talk about how quickly usually I can get it done, and that it's helps protect them, you know for the future."
>
> -Family Medicine Physician #2

As PCP's need to understand their patient and their health needs. Some PCP's expressed needing extra time or assistance (e.g., information from a caregiver) to gauge the patient with I/DD and their willingness to participate in CCS. In some cases, participants expressed how if available they would attempt to build a patient's tolerance to performing CCS over multiple visits. A participant describes this in detail below:

> "I move very slow. I give people time to respond, and I stop. You know it is my responsibility as the provider. It is not the responsibility of the patient to make sure that there is informed consent both verbally and bodily, if there's not, I mean the other thing is that I've definitely done it for people with I/DD where we understand that it can be a process that it's like, hey, let's try. We will stop and I have people [for whom] that's all I can do. You say great. You did fantastic. Come back."
>
> -Nurse Practitioner *#3*

Family engagement and relationships among patients and PCPs were also a key factor for participants when counseling and performing CCS in women with I/DD. As many providers saw patients over time, participants described how important relationships and trust were to

successfully being able to perform CCS in women with I/DD. In most cases PCPs indicated how helpful family members were in discussing and performing CCS in women with I/DD. Family members often assisted the PCPs when they were performing CCS,

> "I'm relying on that person for any of these little cues [from the patient] that that caregiver person will pick up on, and they'll be able to communicate directly with the patient, and explain things, and pick up on things because I don't know this person like they do." -Nurse Practitioner #1

In some cases, family members did not think that women with I/DD needed CCS. In this case, PCPs would attempt to re-educate family members but also respected decisions when patients/families declined CCS. Below, a participant described the importance of buy in from family members to perform CCS:

> "If you don't have active family participation and buy in for the importance of screening it is considered, it's one more thing, you know…depending on this extent of disability. If you aren't able to get buy-in or feedback, you're potentially submitting your child or families to one more thing that feels very hard. And so that is a patient or family related factor that certainly would impact my desire for screening if I had a family who was like this isn't worth it to us."
>
> -Family Medicine Physician #2

Individualized Risk-Benefit Analysis of CCS

In alignment with the U.S. Preventative Services Task Force (USPSTF), all participants indicated that they would recommend CCS to women with I/DD. However, participants indicated several factors contributed to whether CCS was performed. Most participants described how completion of CCS for women with I/DD should consider a patient's individualized risk factors including participation in sexual activity, their ability to provide consent, and patient readiness. One participant expressed the balance of the USPSTF recommendations and individual risk in recommending CCS to women with I/DD,

> "That's the starting point of the conversation [US Preventative Services Task Force Recommendations], and that's where the personalized risk assessment comes into play. When I think about some of the patients depending on the degree of the disability. What

> we come to notice is that some patients don't have the same risk for cervical cancer due to potentially less sexual interactions. There are a number of patients for a variety of reasons, and may have never been sexually active, and so their risk is significantly lower. But the guidelines are the starting point of that conversation. And then the other part is the patient's ability to undergo the screening and willingness and the potential harm from undergoing the screening itself. It's a bit more of an invasive process that also plays a role in that sort of shared decision making for risk-benefits."
>
> -Family Medicine Physician #7

Sexual activity was the most frequently mentioned factor participants considered when determining a patient's CCS risk. Many participants emphasized how if women with I/DD were not sexually active, they were at a significantly lower risk of Human papillomavirus (HPV) and thus CCS. Sexual history documented in charts was reviewed or requested from women with I/DD. Additionally, some participants requested one-on-one time so that if a patient could have the opportunity to disclose any sexual activity history in private. Interestingly, most participants were aware of the high rates of sexual assault and abuse in women with I/DD, however, only one participant described in detail their assessment of the home environment and other relevant physical symptoms related to CCS:

> "So I talk with the patient and the guardian, and if they're not sexually active, and it seems like that's not in question at all, they live in like a safe environment where there's not other people coming in and out of that environment, or strangers that could put a risk at, you know, sexual abuse or things like that and the guardian is pretty confident.…And there's no other concerns of what the patient's experiencing like any abnormal discharge or odor, or other things that would lead me to thinking that there would be any other indication of sexual activity or infection."
>
> -OB-GYN Physician Assistant #1

Participants also expressed that challenges with consent were an important consideration in their ability to perform CCS in women with I/DD. Participants often referenced the severity of I/DD or communication challenges as complicating their ability to obtain an accurate sexual history and consent. Many participants referenced how the severity of a disability also impacted their decision of their CCS recommendations, where participants often wanted to ensure that a

patient was understanding CCS and the steps that were involved in CCS. Some participants expressed that recommending and performing CCS was easier when there was a family member or someone else with the patient with I/DD or that they expressed additional comfort in having that additional person. One physician describes this feeling below:

> "If I had a patient and they had I/DD I feel like I would have felt comfortable, but maybe more comfortable knowing that they had somebody with them to make sure that they understood or could consent in a way that I felt comfortable, that they didn't feel like violated or uncertain."
>
> -Family Medicine Physician #5

Nurse practitioner participants overtly stated that if they were uncertain that a patient with I/DD did not understand CCS or did not obtain proper consent, they were at risk of causing harm and would not perform CCS. Two participants described how barriers to consent contributed to their rationalization of being able to complete CCS:

> "Your patient has to consent right? I think the thing with developmental disabilities is depending on how impacted they are… Can you get consent? That is the biggest thing. Because if they're not understanding, then you're at risk for causing more harm."
>
> –Nurse Practitioner #1

> "Legally, we need the caregiver's consent. But I feel like just as a human being. We need the women's consent, you know. And so, if they are saying no…they're not a willing participant. I'm not trying to assault anyone."
>
> –Nurse Practitioner #2

Patient/family readiness was discussed less frequently but was discussed as a consideration for CCS completion. Participants assessed nervousness of women with I/DD around CCS, physical tolerance to participate in CCS, whether CCS may cause trauma or harm, and their patient's health status for why they might defer performing CCS. As a specific example, a participant mentioned one patient with Autism who had significant sensory barriers so severe she could not tolerate inserting tampons and thus the provider did not recommend or complete CCS to their patient.

Suggestions for Encouraging CCS in Women with I/DD

Participants were asked what would encourage CCS in women with I/DD. Most participants indicated additional training and new advances in CCS could be beneficial to encourage overall CCS in women with I/DD. When asked about their preparedness in providing CCS to women with I/DD post residency, physicians expressed overall discomfort in providing care to with women with I/DD. One participant describes that discomfort:

> "It probably would have been good to have had some more specific training, because although I might have felt comfortable, I might not have been presenting in a way that made sense, or was easy, understand, or like what I thought I knew. I don't really have any base that on except my own comfort but doesn't mean that I was like correct or right or doing it in the best way."
>
> -Family Medicine Physician #5

Other participants mentioned how information on positioning in regard to performing CCS in women with I/DD would be beneficial. In some cases, particularly more challenging cases, participants indicated referring the patient to ob-gyn if they felt the patient and their needs were out of the scope of their practice or if they were unable to perform CCS. Although participants acknowledged the need for additional training, participants acknowledged how challenging this would be due to an already extensive medical curriculum. Participants acknowledged that rather than attending a traditional lecture, participating in more hands-on activities such as volunteering with Special Olympics would likely be more beneficial to learning how to provide health care to individuals with I/DD.

Some participants mentioned Human papillomavirus (HPV) self-sampling as also being potentially helpful for encouraging CCS. Sedation was also mentioned as necessary or beneficial for CCS in women with I/DD, particularly for patients who had anxiety around the exam. One participant indicated observing providers working together to coordinate preventative screenings for a patient with I/DD during their training however does not know how they would coordinate that effort now if their patient needed CCS:

> "I feel a little unprepared to discuss how to move forward with it, especially because it's a very sensitive exam, and I don't know the resources around me to do this. I remember in medical school someone performed a pap smear while the patient was under anesthesia with, of course appropriate, informed consent from the guardian. I don't know if that's even available to me, and for a patient who would not be able to, you know safely, and both physically and psychologically, safely undergo a cervical cancer screening."
>
> -Family Medicine Physician #1

Discussion

The objective of this paper was to identify factors PCPs consider when recommending and performing CCS in women with I/DD. All PCP's reported recommended CCS, however, the performance of CCS was evaluated based on individual risk factors such as sexual history and tolerance to complete the exam. PCPs described receiving minimal education and training regarding providing health care to individuals with I/DD. As such, PCPs recommended that future PCPS would benefit from education and training opportunities that would assist their ability to perform CCS to woman with I/DD. PCPs also mentioned potential solutions that might aid in increasing CCS in this population.

This study provides support for The Systems Model of Clinical Preventive Care, this model considers the interactions among predisposing, enabling, and reinforcing factors from patients and PCPs. This qualitative study provided evidence around enabling factors, preventative activity factors, and situational factors that appear to influence PCPs reporting performing CCS in women with I/DD. Regarding enabling factors, some PCPs expressed having limited knowledge in being able to perform CCS in women with I/DD. Included in enabling factors, are preventative activity factors, where all PCPs described how they considered the effectiveness of CCS. PCPs often referenced USPSTF CCS recommendations and discussed how these guidelines should be followed for all patients, while simultaneously acknowledging consideration of individualized risk factors in this population (e.g., discomfort, severity of

disability).

PCPs also reported considering situational factors related to performing CCS in women with I/DD, specifically as it relates to families/guardians being present at health care appointments and their role in health care decision making related to CCS. Relatedly, PCPs referenced obtaining information related to the patient's predisposing factors, specifically around their home environment (e.g., are they in a safe environment), to better inform their decision around recommending and performing CCS in women with I/DD. In the current study, there was no direct evidence for reinforcing factors as it relates to CCS in women with I/DD.

PCP Education and Training

Most PCPs did not recall or report receiving any education or training on providing health care to people with disabilities. Further, some PCPs expressed uncertainty in providing health care to with women with I/DD. This is unsurprising, as disability is not integrated into medical education curriculum.[91–93] Discomfort in working with the disability population among health care providers has been documented. Iezonni and colleagues (2021) obtained a nationally representative of sample of physicians practicing in the United States and found that less than half (40.7%) of physicians reported feeling confident in their ability to provide quality care to individuals with disabilities and most physicians (80%) viewed the quality of life of an individual with a disability as worse compared to individuals without disabilities. Similar observations are also observed in OB-GYNs who reported not receiving proper training and having challenges with performing gynecological exams to adolescents with disabilities.[71]

Additional research should examine how PCPs understand guardianship and consent in women with I/DD, as this research found that many PCPs feel significantly more comfortable when caregivers/family members are present when counseling, recommending, and performing

CCS. One recent study found that in a sample of about 700 physicians who saw at least one patient with significant levels of intellectual disability, that 74% reported usually or always communicating with someone other than the patient.[94] Challenges in understanding guardianship have been also been noted in physicians who provide reproductive care for women with I/DD.[95,96]

PCPs also discussed not being aware of various positions or techniques for performing CCS for women with I/DD. Various positioning and techniques have been published in midwifery journals[97] however, integrating this content into a filled medical education curriculum is likely challenging. PCP's will likely encounter a situation where they need to recommend and perform cancer screening to a patient with I/DD, future research should examine how they would handle a situation where a patient with I/DD expresses discomfort during the CCS. Finally, many PCPs discussed that medical students would benefit from hands on training and experience with this population rather than lecture-based learning. These hands-on experiences have demonstrated immediate impacts on PCPs comfort and skills (e.g., communication) in working with patients with I/DD.

Considerations Prior to Completion of CCS

All participants referenced the USPSTF recommendations as they determined their recommendation for performing CCS. Unsurprisingly, most PCPs indicated that if a patient disclosed participation in sexual activity or there was documentation stating participation in sexual activity, which was associated with a CCS recommendation. PCPs in this study reported being mindful of assumptions about sexual activity in women with I/DD, a positive finding given that women with I/DD are sexually active.[98,99] Future research should assess the degree to which PCP's perform CCS in women with I/DD when participation in sexual activity is disclosed

compared to situations when women with I/DD do not disclose participating in sexual activity. Given the findings from this study, one would expect that all patients with I/DD would receive CCS if they were sexually active.

Most PCPs were expressed awareness that women with I/DD had high rates of sexual assault however, few PCPs indicated how they considered this knowledge into their recommendation and completion of CCS. Only one PCP reported assessing for signs and symptoms of abuse such as examining for sexually transmitted itching, bruises, or unexplained urinary tract infections, or consideration for how active the woman with I/DD was in the community and thus at an increased exposure for a relationship or sexual activity.[100] Additionally, given that CCS is an invasive procedure, surprisingly, most PCPs also did not report checking the patient's HPV vaccine history, this is surprising as many physicians in previous work have noted that importance of HPV vaccines due to this populations low rates of pap smears and high rates of sexual abuse.[101]

In addition to sexual activity, PCPs also reported assessing the patient's severity of disability as a factor prior to performing CCS. As a specific example, PCPs discussed sometimes they were not aware if the patient fully understood CCS after using plain language and other techniques to educate their patients about cervical cancer and CCS. Other PCPs reported having these same feelings about the history that was provided particularly if this was with a new patient or if there was poor documentation. Due to these factors' PCPs expressed discomfort and extra caution when recommending and performing CCS in women with I/DD. Future research should examine the degree to which PCP's report performing CCS in women with different severity levels of intellectual disabilities.

All participants referenced the USPSTF recommendations when discussing CCS while

simultaneously acknowledging the need for utilizing an individualized approach for women with I/DD and CCS. Breau and colleagues (2022) found similar findings where family physician trainees reported they attempted to follow the national cancer screening guidelines while also exercising their own clinical judgment in cancer screening for individuals with I/DD. Taking a more individualized approach to cancer screening acknowledges that the USPSTF guidelines were designed for women of average risk and how some women may have additional considerations.[102]

PCPs also considered guardianship status, consent from the patient, and collaborating with the patient's family members or caregivers when recommending and performing CCS. PCPs emphasized the importance of having relationships with patients, family members/guardians and emphasized the contributions that family members/guardians made to health discussions and procedures. In some cases, PCPs discussed how they occasionally mediated relations if there were differing opinions when discussing CCS. One strategy that might reduce these challenges might be implementing a shared decision-making model. Shared decision making is a multi-step process that includes obtaining information related to a patient's health situation, formulating a diagnosis and prognosis, verifying this information, then working with the patient and their supporters (e.g., caregivers) to determine the best medical interventions that align with the patient's goals.[103]

Encouraging CCS in Women with I/DD

PCPs also provided insight as to what would encourage CCS in women with I/DD. PCPs were excited for HPV self-sampling as some research has demonstrated the effectiveness of HPV self-sampling when compared to a physician-collected swab for HPV.[104] HPV self-sampling has been noted as an appropriate CCS alternative for particularly hard to reach populations and

women who have experienced trauma or sexual abuse.[105] Sedation was also discussed as a facilitator improve CCS in women with I/DD, where some PCP's discussed how women with I/DD could undergo CCS while having other procedures that require sedation at the same time such as dental work. However, sedation comes with associated risks of anesthesia (e.g., respiratory depression).[104] Additionally, sedation for patients with I/DD has long been controversial where there are case studies documenting some of the challenges (e.g., proxy consent).[106,107] One study found that 11% reported that physicians sedate at least one patient with intellectual disability with routine procedures, procedures most frequently associated with sedation were Pap tests and pelvic exams.[94]

Strengths and Limitations

The strengths of this study include obtaining perspectives from practicing PCPs on this topic, which differs from the most recent related study which primarily sampled family medicine trainees.[7] This study also included an advisory board of PCP's where these members reviewed the research materials for relevance. This study has several limitations. First, this study primarily included PCPs from a Southwestern state, limiting generalizability of results. PCPs opted into participating in this study and therefore likely had an interest in participating in the study, as some PCPs reported having relationships with individuals with disabilities. Although this study tried to recruit additional health care providers including PCPs that had ab ob-gyn specialty only one participant trained in OB-GYN was able to participate in this study.

Conclusion

The findings of this study suggest that PCPs recommend CCS to their patients with I/DD. However, performing CCS depended on several factors including a PCP's ability to counsel and educate a woman with I/DD about CCS and assessing for individualized risk factors of women

with I/DD when determining their recommendations and completion of CCS. PCPs reported how it would be beneficial to receive additional training and education to feel prepared to perform CCS in this population.

CHAPTER 4: Clinical Vignette Questionnaire

Background

Women with disabilities do not receive cervical cancer screening (CCS) at comparable rates to women without disabilities.[5,17–19] Precise estimates of CCS are challenging to obtain due to limitations with national health surveillance data collection in which women with intellectual or developmental disabilities (I/DD) are difficult to identify (e.g., I/DD is categorized with other types of disabilities such as those with dementia or Alzheimer's disease). In the most recent estimates, 2020 Center for Diseases Control and Prevention indicates that in females 21 to 65 years of age, prevalence of up-to-date cervical cancer screening in women with cognitive disabilities was slightly lower 77.4% compared to of women without a disability 84.2%.[4] One reason women with I/DD may have lower rates of CCS is due to a lack of a recommendation from a health care provider.

Primary care providers (PCPs) play important roles in recommending and performing CCS in women with I/DD in the United States. In one study, women with I/DD who had a general practitioner (e.g., family practice, internal medicine, residential provider, health department, or rural health clinician) as their primary physician were less likely to receive CCS (OR= 0.13, 95% CI [0.02-0.81]) compared to a woman who had an obstetrician/gynecologist (OB-GYN) as their primary physician.[6] PCPs often have an ongoing relationship with their patients and discuss preventative health measures including cancer screening and can perform CCS in patients. Research has also been conducted assessing the degree to which having a regular care provider is associated with an increased likelihood of being screened for cervical cancer[108] although other studies have found a null association.[109] Health care providers have

reported on challenges in providing women's health care to women with disabilities as specific training and education with this population is often limited.[68,71]

In the 19th and 20th centuries, individuals with disabilities in the United States were the target of the eugenics movement and were institutionalized and sterilized without their consent.[109] Currently, laws around forced sterilization still exist in 31 states and Washington DC.[110] This history, in addition to perceptions and attitudes about people with disabilities, is likely related to why the general population likely does not consider the disability population as sexually active.[55,75] However, many individuals with I/DD in the United States are integrated into communities, including engaging in romantic relations.[78] Sexual activity rates for individuals with I/DD in the United States are difficult to obtain, though literature conducted in European countries has presented evidence that individuals with I/DD engage in sexual activity.[76] Other negative perceptions of individuals with I/DD from health care providers may contribute to the type of health care received. For example, a secondary data analysis of National Survey of Family Growth (2011-2015) demonstrated that female sterilization is higher in women with disabilities (24.7%) and women with cognitive disabilities (22.1%) compared to women without disabilities (14.8%).[111] In a more recent qualitative study, some physicians reported recommending routine sterilization in women with I/DD.[95] Other research has reported that individuals with I/DD may not receive cancer screening because of their behavior or lack of cooperation where additional intervention such as sedation is needed.[87]

Fear and anxiety that women in I/DD have around CCS is another reason why providers may not recommend or complete CCS in this population.[112] Being fearful of a cancer screening exam[113] or having family express hesitation in participating in CCS[51] likely contributes to negative attitudes around CCS. Further, there could be a history of unsuccessful attempts with a

patient contributing to the provider thinking their next attempt will be unsuccessful.[87] Although many women have anxiety around getting a pelvic exam or cervical cancer screening, providers are extra cautious about performing CCS in women with I/DD if they are not confident about the individual's level of understanding of CCS or if they have challenges around communication. Providers often rely on others such as caregivers to overcome communication barriers.[114] Given these challenges and fear of not being able to provide adequate care to people with disabilities, physicians have reported referring out or discharging patients with disabilities.[114]

A provider's perception of independence and intellectual ability is another factor likely considered when deciding whether to complete CCS in women with I/DD. To obtain more thorough information, providers might ask women with I/DD additional questions about their day-to-day activities. It is likely that individuals with I/DD who attend doctor appointments with their families often are perceived as less independent. Multiple studies have determined that women with I/DD living at home with their caregivers/families had the most limited understanding of CCS[33] as well as Pap tests.[115,116]

Other factors that impact a provider's decision to recommend and perform CCS include attitudes towards disability, self-efficacy in one's ability to provide CCS to a woman with I/DD, and age. In one study, younger providers and trainees were more likely to believe that individuals with disabilities should feel empowered to take control of their lives compared to older providers.[117] A provider's self-efficacy may also contribute to a provider not performing CCS.[118] Self-efficacy has been also related to being able to provide care to individuals with disabilities in different provider groups.[95,119,120] Recent research has also found that physicians have negative attitudes towards individuals with disabilities.[114,121] It has also been speculated that residents,

trainees, and younger physicians also have more favorable opinions related to disability compared to older PCPs.[7]

In one recent study conducted in Canada, researchers using clinical vignettes evaluated the degree to which cancer screening for patients with I/DD was related to attitudes towards disability in family physicians and family physician trainees attitudes towards disability.[8] Provider attitudes towards community inclusion predicted some types of recommendations for cancer screening (breast cancer screening) but not others, including cervical cancer screening; no explanation as to why the researchers found a difference in recommending breast but not cervical cancer screening was documented. To date, no study has been conducted on how PCPs in the United States recommend and perform cervical cancer screening in women with I/DD. This study builds upon the work of Breau and colleagues (2020) with the aim of being able to identify the relationship between three clinical vignette scenarios and the likelihood of a PCP performing CCS. The objective of this exploratory study was to use clinical vignettes to examine the relationship between sexual activity, patient discomfort, and levels of support of a woman with I/DD are how these factors are related to PCP's performing CCS.

Method

Community Advisory Board

This research project utilized a community advisory board of PCPs to ensure perspectives from the population, were represented. The community advisory board included five PCPs (two family medicine physicians and three nurse practitioners in family medicine) who provided insight on the research project from their perspectives as clinicians. The community advisory group met quarterly and assisted reviewing all project materials, including the development of the questionnaire used in the current study.

Questionnaire Development

No single, validated questionnaire served the purpose of this study; therefore, existing scales and exploratory qualitative methods were utilized to inform data collection in the current study. This study is part of a larger sequential mixed-methods study. The development of the interview questions was informed by The Systems Model of Clinical Preventive Care.[11] Interview results from the first study informed the development of clinical vignette conditions used for the current study. Clinical vignette topics were chosen based on triangulation[122] of interview data where the researcher examined topics related to recommending and performing CCS in women with I/DD among the different types of PCPs. Interview findings and an initial draft of the questionnaire were presented to a practicing physician to individuals with I/DD. After the physician provided feedback, the feedback was incorporated into the questionnaire.

At an advisory board meeting, interview findings and draft clinical vignettes were presented to the advisory board for feedback. Clinical vignettes were aloud, followed by the researcher requesting advisory board members to consider how they would respond to the clinical vignette. Advisory board members took turns providing feedback and the researcher ensured that each advisory board member had the opportunity to provide feedback. The advisory board members brought up meaningful points, including explaining how including a scenario on guardianship might then detract a PCP from considering CCS because the PCP might focus on what the guardian's preferences were as it relates to performing CCS.

After revisions from the advisory board were made, the questionnaire was moved into Qualtrics, an online software platform and a cognitive interview took place over Zoom with a physician trained in family medicine. Using questions to guide the cognitive interview, the first author and the physician went through each item on the questionnaire. The researcher took

detailed notes during the cognitive interview, including noting of facial and body expressions. For example, the researched asked the participant to explain why they paused at a question, their interpretation of a clinical vignette, or why they chose to answer the questions out of order. Results of the cognitive interview informed, one revision, the order of two questions after the clinical vignette was presented. Subsequently, the questionnaire was piloted with two additional PCPs (one MD and one nurse practitioner) to ensure there were no other concerns.

Questionnaire

Two questions were used to ensure that participants met inclusion criteria. Once electronic consent was obtained, participants were directed to the questionnaire. The questionnaire had three major sections. The first section included three clinical vignettes with two randomized conditions. The three clinical vignettes were written in alignment with the USPSTF recommendations as most PCPs use USPSTF guidelines to make CCS recommendations. In each of the three clinical vignettes, a woman with moderate I/DD presents [to the provider] with similar attributes (e.g., age, never been screened for cervical cancer). See Appendix to see the questionnaire.

First Clinical Vignette

In the first clinical vignette, participants were randomly presented with one of two conditions: a woman with I/DD with a boyfriend reporting they were sexually active or a woman with I/DD with a boyfriend reporting they were not sexually active. Following the clinical vignette, participants were provided a space for their open-ended responses and asked to list out the factors they considered before performing CCS. Subsequently, they are asked if they "*Continue to perform the cervical cancer screening*?" The response options were 'yes' or 'no'.

Second Clinical Vignette

In the second clinical vignette, participants were randomly presented with one of two conditions: a woman with I/DD with a boyfriend reporting they were sexually active being uncomfortable prior to CCS or a woman with I/DD with a boyfriend reporting they were sexually active who is comfortable prior to CCS. The same follow-up questions that were presented in the first clinical vignette were asked.

Third Clinical Vignette

In the third clinical vignette, participants were randomly presented with one of two conditions: a woman with I/DD reporting previous sexual activity who had low level of supports and was relatively independent and participated in her community or a woman with I/DD reporting previous sexual activity with higher level of supports who lives at home with their family. The same follow up questions that were used in the previous clinical vignettes were asked.

Adapted Scales

The second section of the questionnaire included two short scales. The first scale was an adapted version of the Adult Autism Scale-Self-Efficacy Scale (AASPIRE).[123] The AAPSIRE scale was used to evaluate, self-efficacy in health care providers and was developed from prior work, including 129 surveys from PCPs and nine interviews with PCPS about their needs and preferences in caring for autistic adults. Assessment of the AASPIRE scale included 143 PCPS, where strong internal consistency was demonstrated (Cronbach's alpha of 0.87). This six-item scale with a 5-point Likert-type response options (1= *not at all confident* to 5= *very confident*) was adapted to replace the term "autism spectrum" with "intellectual and developmental disabilities (I/DD)."

The second scale used was an adapted version of Iezzoni's subscale focused on physician attitudes towards individuals with disabilities.[121] This subscale is five questions with Likert-type response options (1= *strongly disagree* to 5= *strongly agree*). One item is reverse coded. This sub-scale is part of a larger questionnaire that went through multiple phases of testing, including cognitive interviews with practicing physicians and pilot testing with 50 physicians.

The last section of the questionnaire included demographic questions. Demographic questions were included at the end of the survey as it is associated with preventing primacy effects and allows for rapport with participants.[124,125] Example demographic questions included questions about where participants practiced, number of years as a PCP, and their disability status.

Survey Participants

Eligible participants were self-identified primary care providers (PCPS) including physicians, physician assistants, nurse practitioners, and midwives practicing in the United States with specialties in family medicine, internal medicine, OB-GYN, or midwifery. Exclusion criteria included: residents, trainees, or PCPs not currently practicing in the United States.

This study utilized a descriptive cross-sectional study design with non-probability sampling methods. First, a partnership was established with two Federally Qualified Healthcare Centers (FQHCs) located in a Southwestern state to assist with disseminating the research study to PCPs through provider listservs. Second, the researcher created a list of PCP organizations across the United States with relevant contact organization information. Examples included official state academy of family physicians, physician assistant, nurse practitioner and midwife organizations.

Procedures

The research study was approved by Northern Arizona University's (NAU) Institutional Review Board (IRB Number:1847965). The researcher collaborated with the program coordinators at the FQHCs where the questionnaire was sent out once a month via email to a listserv to relevant PCPs. The researcher wrote emails to relevant organizations, describing the research study, asking if they would be willing to send out the research opportunity to the relevant organization via email listserv. If organizations replied, the researcher worked with the organization representative to send the relevant research study information.

The 34-item questionnaire was administered online using Qualtrics where it was estimated to take ten minutes to complete. Electronic consent was obtained from participants prior to them taking the questionnaire. An incentive of a $10 gift card was offered to each participant after completion of the questionnaire. Data collection occurred between July 2023 and September 2023.

Bot Attack

During data collection, the questionnaire was infiltrated by bots in attempts to receive the $10 gift card incentive for participating in research. Bots have been a frequently cited issue in online research.[126,127] Once this bot attack was identified, data collection was paused, and was reported to the NAU's Institutional Review Board. It is unclear what the source of the bot attack was. In response to the bot attack, the researcher examined literature related to best practices in identifying and preventing future bot attacks.[126,128] Additional security measures were implemented on the new online questionnaire including additional metrics that detect bots and a knowledge check question. Further, the researcher asked organizations specifically not to post the study advertisement on any social media websites to avoid future bot attacks.

Data Analysis

After the survey closed, questionnaires were reviewed to assess for completion and to ensure that each respondent was completed by a human. The researcher was able to identify 520 bots attacked the questionnaire within a two-hour time span determined by reviewing patterns in the data (Please see the Appendix). In reviewing the 520 responses, these were determined as bots and these responses were excluded from the analysis.

Data screening consisted of reviewing data to ensure participants finished over 80% of questionnaire and ensuring that participants filled out the knowledge check question correctly. The knowledge check question asked participants to answer the following question: "*What was the survey you just took about?*" with the following response options: 1) Attitudes that primary care providers have towards women with I/DD, 2) How primary care providers recommend cervical cancer screening to women with I/DD, 3) Pregnancy related care for women with I/DD, or 4) None of the above. Second, descriptive statistics were calculated for relevant variables where the researcher reviewed distributions of continuous variables, assessed for patterns of missing data, calculated means and standard deviations, and calculated frequencies/percentages for categorical variables.

Responses to the clinical vignettes (yes/no to continuing to perform CCS) were used to calculate odds ratios (OR) and 95% confidence intervals (95% CI) on each clinical vignette condition. R Studio specifically the package "epitools" was used to calculate odds ratios. Statistical significance of OR was evaluated by reviewing the confidence intervals, where if "1" was present in the 95% CI there was no effect on the odds of the outcome variable, and this was deemed not statistically significant.[129]

Open-ended questions collected information on participants' rationale for the factors they considered before performing CCS. Using the coding tree from the first study, the researcher

read and coded the open-ended responses. To assess for triangulation among codes between participant subgroups, the researcher evaluated for patterns across clinical vignettes responses. For instance, the researcher assessed if open ended responses varied among participants who reported "no" to performing CCS and looked to see if there were differences by type of PCP (Physician Assistant vs. Physician). NVivo 12 was used to code and examine patterns across open-ended responses.

Results

Based on the data screening procedures described above, 520 bots were removed, two participants were removed for only finishing about 30% of the questionnaire, and four participants were removed because of incorrect knowledge check responses. The final analytic sample size of this study was 98 participants, with 225 open-ended responses from the questionnaire.

Demographics

Descriptions of the sample of participants are described in Table 3. Most participants were physician assistants (37%), or physicians (MDs/DOs) (35%) trained in family medicine (73%). Most participants identified as being a woman (81%) and were between the ages of 30 and 70 years old with the average age being 42 years (SD 10.6). The average number of years participants had practiced was 15 years with a range of practicing from 1 to 33 years (SD 10.4). Most participants practiced in Arizona (56%), Illinois (24%) or Nevada (12%). Participants practiced in a variety of health care settings, including Federally Qualified Health Centers (FQHCs) (40%), group practices, (20%), and private practice (19%). Most participants did not report receiving any specific education or training related to individuals with I/DD (69%).

Table 3. Demographic Characteristics of Questionnaire Study Participants (N=98)

Type of Primary Care Provider	Number of Participants (%)
Physician (MD/DO)	34 (35%)
Physician Assistant	36 (37%)
Nurse Practitioner	16 (16%)
Midwife (CN/CNM)	12 (12%)
Primary Care Provider Specialty	
Family Medicine	72 (73%)
Midwifery	12 (12%)
Internal Med/Internal Med/Peds	9 (9%)
OB-GYN	5 (5%)
Gender Identity	
Woman	80 (81%)
Man	14 (14%)
Race/Ethnicity	
White	64 (65%)
Asian	12 (12%)
Hispanic	11 (11%)
African American	4 (4%)
Native American	2 (2%)
Other	1 (1%)
I prefer not to answer	4 (4%)
Practice Geography	
Urban	75 (75%)
Rural	25 (25%)
Health Care Practice Setting	
Federally Qualified Health Center (FQHC)	40 (40%)
Non-profit Health Care Corporation	12 (12%)
Private Practice	19 (19%)
Group Practice	20 (20%)
Community Clinic/Other	7 (7%)
Disability Status	
Does not have a disability	94 (95%)
Has a disability	4 (4%)
Family or Friend with a Disability	
Does not have a family/friend with disability	58 (58%)
Has a family/friend with disability	38 (38%)

Clinical Vignettes

Across the three clinical vignettes, regardless of conditions, most participants (85%) reported performing CCS. See Table 4 for a summary of participant responses by clinical vignette. In the first clinical vignette, the first condition described a woman with I/DD who was sexually active, and the second condition reported a woman with I/DD who was not sexually active. The odds of participants reporting performing CCS were 20.59 times greater in the condition where a woman with I/DD was sexually active than the other condition where a woman with I/DD was not sexually active (OR= 20.59, 95% CI [3.92-511.41]).

In the second clinical vignette, the first condition reported a woman with I/DD who was comfortable prior to CCS and the second condition reported a woman with I/DD expressing discomfort prior to CCS. The odds of participants performing CCS were 20.92 times greater in the condition where a woman with I/DD was comfortable compared to the condition where a woman with I/DD expressed discomfort prior to CCS, (OR=20.92, 95% CI [3.97-520.65]).

In the third clinical vignette, the first condition described a woman with I/DD who lived alone with little support and the second condition presented a woman with I/DD who had more support from their family. The odds of participants performing CCS were 1.75 times greater in the condition were a woman with I/DD with less supports compared to a woman with I/DD with higher levels of supports (women with I/DD was more dependent on family) (OR= 1.75, 95% CI [0.48, 7.38]).

Table 4. Frequencies of PCPs Reporting Performing Cervical Cancer Screening by Clinical Vignette Condition (N=98)

	Clinical Vignette #1		Clinical Vignette #2		Clinical Vignette #3	
	Sexual activity	No sexual activity	Patient is comfortable	Patient is uncomfortable	Patient is independent	Patient is dependent on family
Yes, continue to perform CCS	49	35	47	33	44	43
No, do not continue to perform CCS	1	17	1	17	4	7

Acronyms: Primary Care Providers = PCPs; Cervical Cancer Screening = CCS

Adapted AASPIRE *and Adapted Attitudes Towards Disability Scale*

The Adapted AASPIRE scale[123] examined health care providers self-efficacy in providing health care to individuals with I/DD. AASIPRE was scored by totaling the items, where higher scores demonstrate higher self-efficacy (max score of 30). In this sample, the total self-efficacy average score was 21.74 (SD 4.29). Table 5 provides a review of how participants responded to the adapted AASPIRE items, reporting of AASPIRE items correspond with how the authors of the scale presented their results.[123]

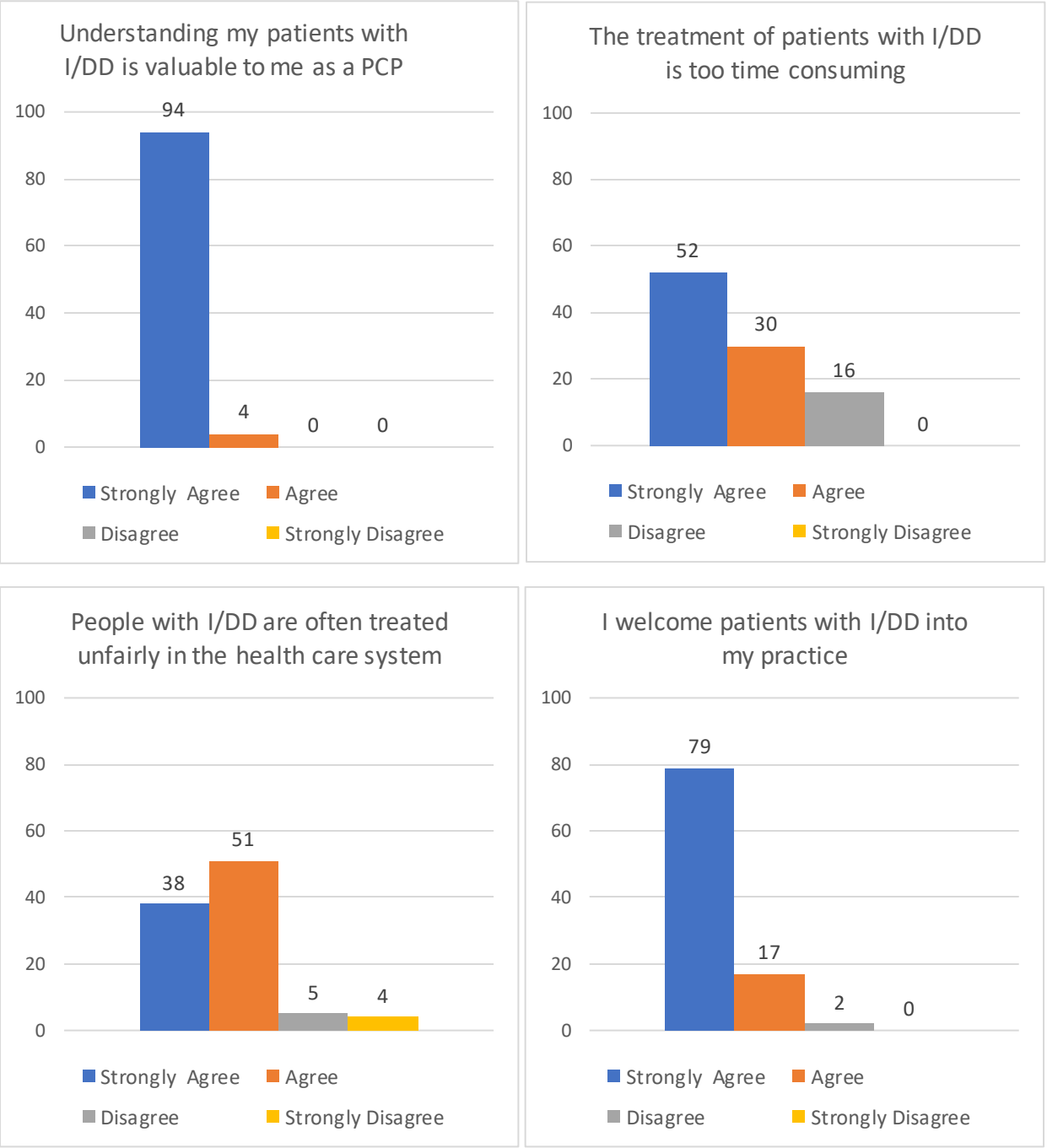
Table 5. Adapted AASPIRE Items and Related Descriptive Statistics

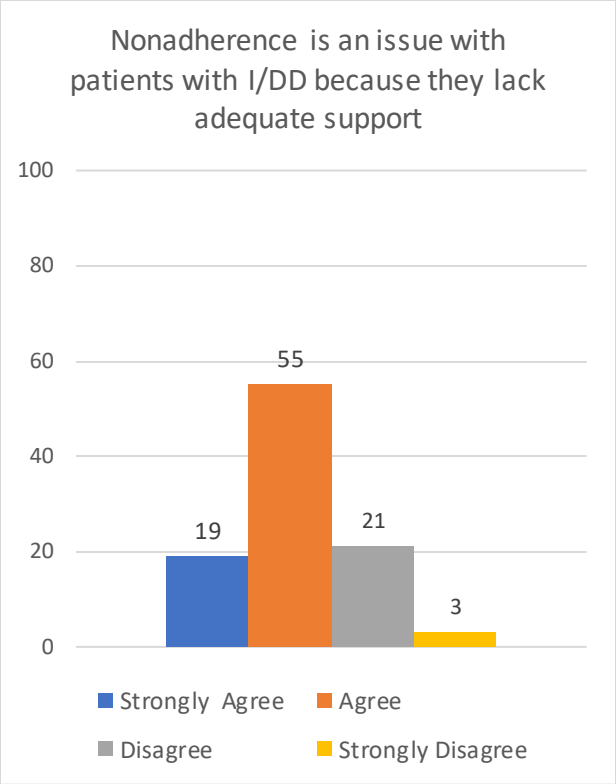
Adapted AASPIRE Items	Mean (SD)	PCPs who reported high confidence, N%
Successfully communicating with your patients with I/DD	3.81 (0.82)	24 (24.5%)
Successfully performing physical examinations or procedures on your patients with I/DD	3.93 (0.81)	25 (25.5%)
Accurately diagnosing and treating other medical issues in your patients with I/DD	3.90 (0.83)	24 (24.5%)
Helping your patients with I/DD stay calm and comfortable during a clinic visit	4.08 (0.80)	32 (32.7%)
Identifying what accommodations will help facilitate your patients with I/DD care	3.63 (0.93)	23 (23.5%)
Making the necessary accommodations to facilitate your patients with I/DD care	3.74 (0.96)	26 (26.5%)

Response options used a 5- point Likert-type scale 1= *Not at all confident* to 5= *Very Confident*.
Acronyms: Adult Autism Scale-Self-Efficacy Scale = AASPIRE; Standard Deviation = SD; Primary Care Providers = PCPs; Intellectual and Developmental Disabilities = I/DD

Iezzoni's attitudes sub-scale contained five questions.[121] See Figure 2 for a visual representation of how participants responded to the questions, this reporting corresponds with how Iezzoni and colleagues reported their results. Most participants (95%) 'strongly agreed' with valuing patients with I/DD and (80%) 'strongly agreed' in welcoming patients with I/DD into their practice. Regarding the item related to patients with I/DD being time consuming, 53% of participants 'strongly agreed' or 30% 'agreed' with this statement. Participants in the current study also indicated that people with I/DD are treated unfairly in the health care system, 38% 'strongly agreed' and 52% 'agreed' with the statement. Finally, the last statement was about nonadherence being related to lacking adequate support, 19% of participants 'strongly agreed' or 56% 'agreed' with this statement.

Figure 3. PCP Attitudes of Patients with I/DD in Health Care Settings (Iezzoni's Sub Scale)





I/DD= Intellectual and Developmental Disabilities

Clinical Vignette Open Ended Responses

Participants were asked to describe the factors they considered before performing CCS in women with I/DD. The most frequent open-ended responses included USPSTF CCS guidelines, participants referred to age, sexual activity, and the absence of CCS history. Three participants described how their rationale for recommending CCS below corresponds with the USPSTF guidelines:

> "Sexual activity is a huge consideration for me. HPV, which causes the majority of cervical cancer, is sexually transmitted. If she is sexually active, I would strongly encourage her to get a pap smear."
>
> -Family Medicine Physician

> "The woman's age and history of sexual activity. Her intellectual disability makes her at higher risk of assault. But based on her age and description of being sexually active that is enough to warrant screening."
>
> -Family Medicine Physician

> "She is 30. There is real risk of CIN in this age group."
>
> -Family Medicine Physician

Consent and assessing for capacity to consent were also mentioned where participants described assessing a patient's ability to communicate or evaluating the patient's education and understanding of sex, cervical cancer, and CCS.

> "Patient's ability to communicate during the exam/screening. I'd consider the possibility that even with consent, the patient may not fully understand what the screening entails. I would express to both mom and patient that I will stop at any point in time if either one of them asks me to. Depending on the patient's verbal abilities, I may suggest the patient raise her hand or another form of nonverbal communication to signal to me that she is ready. I'd narrate the procedure, so the patient and mother know exactly what's happening throughout. I'd consider showing the equipment to the patient if that seemed like it may help her understand."
>
> -Midwife

> "Does mother have medical power of attorney? Can patient understand the invasiveness and possible discomfort of procedure? Does patient understand/awareness of what sexual activity means? Does the family think she is emotionally ready for the procedure today?"
>
> -Family Medicine Physician Assistant

Consent was specifically mentioned in open-ended responses of the second clinical vignette where participants described how they would attempt to reeducate and or counsel to reconfirm consent prior to performing CCS.

> "I feel like I would first need to assess her understanding of the procedure. It seems like she may not have fully understood the process."
>
> -Family Medicine Physician

> "Can the patient explain what she is feeling/offer consent a second time? Her discomfort implies removing the first consent."
>
> -Family Medicine Physician Assistant

Of note was some participants described their consideration of mom in the interaction including the impact that mom in the room might have on the woman with I/DD disclosing participating in sexual activity and consent to perform CCS.

> "Had a boyfriend, so may be sexually active currently, but doesn't want to say in front of mom, perhaps isn't currently sexually active but has been in the past or doesn't define her current situation as sexually active but could still put her at risk of exposure to HPV. Might want to discuss this alone with patient. Make sure she knows all the steps of cervical cancer screening/PAP smear and make sure she is OK with it."
>
> -Family Medicine Physician Assistant

Less frequently, mentioned were other health factors including (Human papillomavirus) HPV vaccination status, family history of cervical cancer, and other health related symptoms.

Discussion

The aim of this exploratory study was to use clinical vignettes, to examine how PCPs consider sexual activity, patient discomfort, and levels of support of a woman with I/DD in relation performing CCS. The decision to perform CCS in clinical vignette appears straightforward, most PCPs reported they would perform CCS regardless of the clinical vignette condition. In two of the clinical vignettes, large odds ratio estimates were produced. The sexual activity and discomfort conditions elicited greater variability than the level of supports clinical

vignette conditions. It is unsurprising that PCPs reported performing CCS in the condition where sexual activity was present, as participation in sexual activity is associated with increased risk of HPV. This finding also aligns with previous related research where national guidelines of screening are often cited.[7]

Considering the clinical vignette condition where a woman with I/DD expressed discomfort prior to CCS, there was an expectation that *more* PCP's would have not continued to perform CCS. The proportion of PCPs who reported not performing CCS due to discomfort was (17/50) compared to the proportion of PCPs who said 'yes' to performing CCS despite a patient expressing discomfort (33/50). Though some research does report physicians insensitivity to discomfort or pain around gynecological exams.[130] Further, PCPs might not assume that this discomfort is greater than expected as many women find pelvic exams and other gynecological exams uncomfortable.[131] In the clinical vignette conditions around varying levels of support, most PCPs reported performing CCS in women with I/DD.

Breau and colleagues used clinical vignettes in their study, examining recommendations of cancer screening in individuals with I/DD. In one condition, a woman with mild I/DD with a boyfriend is described, this woman also reports being sexually active, relatively independent, with no history of a pap smear.[8] In the control condition, a woman with a chronic health condition was presented with the same attributes. The researchers found no differences in recommending CCS among these two conditions, these similar findings demonstrate the complications in identifying all factors that contribute to a PCP recommending and performing CCS. In the current study, there was no control condition and the patient's mom was present at the well woman exam in all clinical vignettes.

This study's sample included physician assistants and physicians trained in family medicine, which differs from Breau and colleagues who did not sample physician assistants. Examining the AASPIRE scores, the current study sample demonstrated higher AAPSIRE scores (21.74) compared to other research, where their sample of PCP's had lower AASPIRE scores (18.01).[123] Upon examination of the AASPIRE sample characteristics, a substantial proportion, approximately half, comprised of participants who were trained in internal medicine. Additionally, the gender composition differed, the AASPIRE study included a relatively equal distribution of male and female participants, while the current study primarily included participants that identified as women.

In the current study, most participants reported positive attitudes towards individuals with I/DD as it relates to health care which differs from Iezzoni's research, where less positive attitudes towards individuals with disabilities were observed.[121] As a specific example, in the following statement, "*Understanding my patients with disability is valuable to me as a physician*" Iezzoni found that 79% 'strongly agreed' with this statement compared 94% in the current study. Additionally, this study found higher levels of agreement (79%) of 'strongly agree' with the following statement, "*I welcome patients with disabilities into my practice*" compared to Iezzoni's study 56%. However, there were differences in the study samples, Iezzoni's study included a substantially larger sample size, a more sophisticated study design, and participants from a variety of specialties (e.g., family medicine, internal medicine, rheumatology, neurology, ophthalmology, and orthopedic surgery) where our study primarily focused on PCPs who predominantly specialized in family medicine. One reason why family medicine PCPs may have welcoming attitudes towards individuals with disabilities may be related to their training as well as their regular interactions with patients with disabilities compared to those in specialty

positions. Additionally, family medicine PCPs may be aware of issues related to individuals with disability and access to care, as recent literature has highlighted these issues.[114,121]

The current study's clinical vignettes included the woman with I/DD's mom who was present during the well woman exam. During advisory board meetings, the advisory board discussed including mom in the clinical vignettes in acknowledging the degree to which having a support person present is often beneficial to providing healthcare.[69] Nevertheless, including mom in the clinical vignette added complexity, represented in the open-ended responses, where some PCPs mentioned needing to obtain consent from the woman with I/DD, from mom, and or needing consent from both individuals. Few specifically mentioned determining who had guardianship or medical power of attorney, which highlights the need for PCPs to be cognizant of who has medical decision-making abilities in health care situations. In many cases, PCPs reported assessing if the patient was comfortable with mom being in the room and or providing an opportunity to have a private conversation without mom.

This study provides support for The Systems Model of Clinical Preventive Care.[11] This theoretical model considers interactions between PCPs and patients and the predisposing, enabling, and reinforcing factors that influence these interactions. In this study, there was evidence of preventative activity and situational factors that influenced the likelihood of PCPs reporting they would continue to complete CCS in a woman with I/DD. Preventative activity factors were noted in open ended responses in all clinical vignettes as most PCPs reported their consideration of the USPSTF CCS recommendations in their performance of CCS. PCPs also reported considering situational factors when performing CCS in women with I/DD, specifically as it relates to discomfort of a patient during CCS in the second clinical vignette condition.

The presence of mom in clinical vignettes was another individual that PCPs needed to

factor into their decision to perform CCS. Predisposing factors were considered where the PCP would attempt to gauge the patient's abilities, understanding of sex, cervical cancer, and CCS. Surprisingly, the home environment was brought up less in this study compared to study 1 though, some PCPs did gauge the relationship dynamics. Like the qualitative study, the current study found no direct evidence of reinforcing factors in the study. Though, it is plausible that PCPs consider the USPSTF recommendations for CCS which is associated with most insurance companies reimbursing for CCS.

Limitations and Strengths

This study had limitations. PCPs are a hard group to conduct research with, therefore, this study employed a convenience sampling technique however this sampling method introduces bias in the results.[132] Given the high scores in self-efficacy in providing care to individuals with I/DD and the positive attitudes related to individuals with I/DD in this study, speculation arises as research has demonstrated that providers do not report being comfortable providing health care to individuals with disabilities[58] and self-report not being biased about individuals with disability yet have demonstrated being implicitly biased towards individuals with disabilities.[133]

Additionally, although the study aimed to recruit a larger sample size, at the time of the dissertation defense only 98 participants were able to be used in the analysis. The calculated odds ratios produced substantially wide confidence intervals, therefore these estimates should be interpreted with severe caution as small sample sizes are associated with unstable estimates.[134] The strengths of this study include obtaining perspectives from practicing PCPs related to women with I/DD, a topic that has been understudied. This study also included an advisory board of PCPs contributing to the external validity.

CHAPTER 5

Discussion of Results

The aim of this study was to examine how PCPs in the United States recommend and perform CCS in women with I/DD as limited research has been conducted on this topic.[7,8,117] A scoping review was first conducted to identify the barriers and facilitators to CCS in women with I/DD. Three major categories of barriers education, the home environment, and provider type were identified from the scoping review. These barriers and facilitators also provided additional considerations for the researcher to consider related to the women with I/DD participating in CCS. Further, some of these factors were considered in the development of the clinical vignettes. One study from the scoping review revealed that women with I/DD who had a PCP as their primary physician were less likely to receive CCS (OR= 0.13, 95% CI [0.02-0.81]) compared to woman who had an OB-GYN as their primary physician.[6] This study influenced the aim of the next research project, where an exploratory sequential mixed method study was designed with the following objectives:

1) To identify what factors PCPs, consider when recommending and performing CCS in women with I/DD.
2) To use clinical vignettes to examine the relationship between sexual activity, patient discomfort, and levels of support of a woman with I/DD and how they are related to a PCP's decision to perform CCS.

The purpose of conducting a sequential mixed methods design was to draw upon the strengths of both types of research designs, as qualitative studies often explore how an experience occurs, whereas quantitative studies often address questions related to examining the relationship between variables.[135] A mixed method approach allows for research to be examined

from two perspectives, rather than a single qualitative or quantitative lens. In the current study, the findings and themes derived from the qualitative study in addition to the advisory board's feedback was used to develop the clinical vignettes for the questionnaire.

Overall, consistent patterns across study 1 and study 2 were found. In one-on-one interviews, thirteen PCPs reported they would recommend CCS, in alignment with the USPSTF CCS recommendations. The decision to recommend CCS was based on age and participation in sexual activity. Additionally, the complexity of performing CCS in women with I/DD was noted, where PCPs would often conduct an individualized risk-benefit analysis considering a patient's ability to provide consent, readiness, and input from their family members. The results of this study are similar to related research, which also acknowledges the complexity of performing CCS in this population.[7]

In study two, 98 PCPs participated in an online questionnaire that contained three clinical vignettes with two randomized conditions, two scales on self-efficacy and attitudes towards individuals with I/DD, and demographic questions. Regardless of the clinical vignette and conditions, most PCPs reported continuing to perform CCS in women with I/DD. However, PCPs acknowledged the additional factors that should be considered (e.g., ability to communicate, ability to provide consent). In this study, PCPs rated their ability to provide health care to individuals with I/DD as high and their attitudes towards to individuals with I/DD as non-stigmatizing. PCPs in this study acknowledged the need for women with I/DD to participate in CCS (non-stigmatizing attitudes towards I/DD) and confident in being able to perform CCS (high levels of self-efficacy). An additional investigation into the 'no' responses to performing CCS open-ended responses will take place and will be compared to the 'yes' responses to

performing CCS to observe if there are any differences in rationale or justification for performing CCS.

Theoretical Implications

This exploratory sequential mixed method study provides support for the Systems Model of Clinical Preventive Care[11] (See Figure 1). This model focuses on the interaction between patient and PCP and participation in preventive health care. Within the Systems Model of Clinical Preventive Care, there are three major categories, predisposing, enabling, and reinforcing factors that a PCP and patient contribute to. While this study did not address all factors that may be influencing the interaction between PCP and patient, both studies provide evidence for PCPs considering predisposing and enabling factors when reporting performing CCS in women with I/DD.

In the interviews and open-ended responses, PCPs considered USPSTF CCS recommendation or preventative activity factors which falls under enabling factors. Additionally, in both studies, PCPs reported evaluating situational factors which also falls under enabling factors, including the importance of obtaining consent for performing CCS as well as involving mom in the conversation around performing CCS. PCPs also often examine the patient's predisposing factors such as severity of a patient's disability and assess education and comprehension of sex, cervical cancer, and CCS. In study 1, some PCPs were less confident about their ability to perform CCS in a woman with I/DD, this was not observed in study 2. This may be due to the difference in study designs, where in the interviews, the participant and researcher were able to develop rapport, which is possibly why participants felt more comfortable sharing this information with the researcher.

Examples of stigmatizing attitudes towards individuals with disabilities were captured in study 1, where some PCPs acknowledged communicating to women with I/DD as if they were an adolescent or not checking who had decision making power before a visit with a patient with I/DD. However, stigmatizing attitudes towards this population as it relates to CCS were less present study 2. In both studies, reinforcing factors included the U.S. Preventative Services Task Force Recommendations.

Interdisciplinary Health Implications

Women with I/DD who do not receive CCS who have been sexually active are at risk for cervical cancer.[136] Participating in CCS involves a multitude of factors including behavioral, social, and environmental factors. One factor related to participating in CCS is receiving a recommendation by a health care provider; therefore, it is critical to understand how PCPs make decisions around recommending and performing CCS. When women with I/DD do not participate in CCS, it influences multiple disciplines, including disability, public health, social work, and primary care. Cervical cancer care has a substantial impact on the United States economy; in 2020, the cost of cervical cancer care amounted to 2.3 billion dollars.[137] Recognition for acknowledging individuals with disabilities as a population with health disparities has been established,[138] therefore it is imperative to focus on identifying how to support PCPs in being able to recommend and perform preventative health care including CCS in women with I/DD.

This exploratory research study highlights potential areas of further research. First, a study examining if there are differences in PCPs self-reported completion for CCS in women with I/DD and a chart audit would be beneficial, as there is likely self-reporting bias of overperforming CCS in this population. PCPs also expressed comfort in providing care to

women with I/DD with mom present, future research should examine the knowledge that PCPs have related to individuals with disabilities and health care decision making (e.g., guardianship). Finally, though this was not the focus of the current study, many PCPs described their awareness of women with I/DD being at risk for sexual assault though less is known how an assessment related to sexual assault or a trauma informed approach occurs in this population.

Limitations and Strengths

This study had limitations. As this research is cross-sectional in nature, one is unable to determine the direct relationship between the factors (sexual activity, discomfort, and levels of support) and their direct impact on PCPs performing CCS in women with I/DD. Both studies relied on convenience sampling to obtain participants as PCPs are a challenging group to motivate to participate in research. Therefore, self-reporting bias is likely present in this study.[132] Research studies have demonstrated implicit and explicit biases that health care providers have related to individuals with disabilities[114,121,133] in addition to the discomfort health care providers have around providing care to individuals with disabilities.[68,71,114]

In study 3, at the time of this dissertation defense, the analytical sample size was 98 participants, which was half of the intended participant count. The small sample size therefore impacted the odds ratio estimates and wide confidence intervals. As such, the quantitative results from study 3 should be interpreted with severe caution as smaller sample sizes are less stable and reliable.[134] While this study adopted an exploratory approach and a simplified analysis was chosen after reviewing similar work,[8] a reevaluation of the results initiated discussion of how to better articulate the findings of study 3. To enhance clarity and transparency, a more suitable method for reporting study 3 data is reporting proportions of CCS performance by clinical vignette in addition to supplementing this work with qualitative, open-ended responses.

This study also had several strengths. First, this study incorporated a mixed method approach, whereby using this approach allowed the researcher to draw upon two different methodologies to provide a comprehensive approach in examining the research objectives. Second, this project integrated an advisory board of PCPs to help develop and guide the development of this research. Third, the majority of study 2 and 3 participants were PCPs trained in family medicine, which allowed for a thorough assessment of how PCPs trained in family medicine PCPs approach recommending and performing CCS for women with I/DD. Finally, this project included a diverse group of two different health care professionals, physician assistants and physicians, representing a variety of health care settings, and a variety of states across the United States.

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APPENDIX

Consent for Interviews and Interview Questions

Thank you for taking the time to talk with me today. This purpose of this research is to understand how primary care providers make decisions to perform cervical cancer screening in women with Intellectual and/or Developmental Disabilities (I/DD). I/DD are disorders that occur prenatally, neonatally, or during the age of development (under 18 or 22 years of age) and affect the trajectory of an individual's physical, intellectual, and or emotional development. Examples of I/DD include autism spectrum disorder and Down Syndrome. This study is voluntary. You can choose not to talk to me today or skip any questions at any time. If you choose to participate today then change your mind, you can ask me to remove your information from the study. I'd like to start by having you provide oral consent to this interview. Do I have your consent?

**Wait for Response*

Additionally, I would like to both record our conversation and turn on the captioning. The recording will only be used to complete more thorough notes.
While completing our notes, all names will be removed, and any personal information will be de-identified.

Once the transcript is complete, we will delete the video, only keeping the transcript. Do I have your permission?

**Wait for Response*

If you do have any questions, concerns, or complaints about the study you may contact the NAU Human Research Protection Program at 928-523-9551.

Do you have any questions before we get started?

*Wait for Response

Demographic Questions:

1. Can you tell me what your highest degree is in? (MD, DO, NP, PA?)
2. What is your practice specialty? (Family Medicine, General Internal Medicine, OB-GYN, other?)
3. How many years have you been practicing?
4. What type of health care setting(s) do you practice in? (Small private practice, private group practice, employed in a health care system, academic health care system?)
5. Prior to the current health care setting you are practicing in, where else have you practiced?
6. Can you describe your patient panel? (Age, demographics, socio-economic status, rural or urban?)
7. Do you see individuals with I/DD in your practice?
8. Describe the training you have received regarding working with patients with disabilities and with I/DD specifically?
    a. If yes, what type of training was this?

Cancer Screening Questions:

1. What do you feel is your role in promoting cancer screening to your patients?
2. What do you feel your role is in promoting cervical cancer screening specifically?

Cancer Screening and I/DD Population Questions:

1. For your patients with I/DD, do you follow the same cancer screening guidelines as those without I/DD? (e.g., consideration of risk and guidelines)
2. Please tell me about a time you recommended or did not recommend cervical cancer screening to a patient with I/DD.
    - What specific factors did you consider when making your recommendation?
    - How did you talk to this patient about cervical cancer screening?

3. What factors do you consider that would encourage or make it easier for women with I/DD to get cervical cancer screening?

    First, I would like you to think about specific individual <u>provider factors</u> that would encourage or make it easier for women with I/DD to get cervical cancer screening.

    For example, think of your training, have you had any disability training, your confidence in being able to provide CCS to this population, or your attitudes/beliefs on whether or not this population needs CCS.

    Wait for response.

    Now, I'd like you to think of <u>patient factors</u> that would encourage or make it easier for women with I/DD to get cervical cancer screening.

    For example, think about their home environment, sociodemographic factors, barriers to consent, patient health status (age, sexual activity denoted or not), guardianship status, relationship with patient, if there someone that is advocating on behalf of the woman.

Wait for response.

What about environmental level factors?

These might include time for appointment, type of visit scheduled, busyness of clinic that day, other issues addressed at visit, is there someone to help support the woman with I/DD (support staff).

Wait for response.

Finally, one more level to discuss. What system level factors would make it easier for women with I/DD to get a cervical cancer screening?

System level factors include health care reimbursement, accessibility of facility, accessibility of follow up care, lack of knowing how to discuss cancer screening with this population.

*Repeat considering levels and what factors make it more challenging to get screened for CCS.

4. Do you have anything else you would like to share with us today about discussing CCS to women with I/DD?

Thank you for your time today. We will be in contact with you about receiving your gift card via email.

Questionnaire

Introduction and Screener

Thank you for your interest in this research study. You will be asked two short screener questions to ensure you meet inclusion criteria for the study. If you meet inclusion criteria, you will be directed to a consent form and then to the questionnaire. If you do not meet inclusion criteria, you will not be able to participate in this study, and the questionnaire will end.

Thank you!

Screener Q1: Are you a primary care provider (Physician, Physician Assistant, Nurse practitioner, or Midwife) in the United States?

- ○ Yes
- ○ No

Screener Q2: What is your area of specialty?

- ○ Family Medicine
- ○ Internal Medicine
- ○ Internal Medicine/Pediatrics
- ○ Midwifery
- ○ OB-GYN
- ○ None of the above

Consent

This research study is interested in understanding how primary care providers recommend and perform cervical cancer screening in women with Intellectual and developmental disabilities (I/DD). In this study, you will be asked to complete: 3 clinical vignettes, 2 short scales, and demographic questions. The study should take you around 10 minutes to complete.

Your participation in this survey is voluntary. You may choose to terminate your participation in this study for any reason. Your responses will be kept confidential. The only risk in participating in this research corresponds with your data. However, our team has taken steps to ensure your data remains secure. If you would like an incentive for your participation, you will receive a $10 gift card for your participation. If you have questions, you can reach out the Northern Arizona University (NAU) Institutional Review Board (IRB) office at 928-523-9551 or the Principal Investigator, Michele Lee of this study can be contacted at [Michele.lee@nau.edu or 847-651-7554]. By clicking the button below, you acknowledge: Your participation in the study is voluntary, that you are at least 18 years of age, and that you have read the information above.

○ I consent to participate in the study.

○ I do not consent, I do not wish to participate in this study.

Questionnaire

Instructions: You will be presented with 3 separate clinical vignettes. Please read the full description of the patient scenarios and answer the subsequent questions.

CV1A: Patient is a 30-year-old woman with a moderate intellectual disability who comes in for a well-woman exam with her mom. Patient lives at home with her mom, dad, and sister. Patient is a nonsmoker, overweight (20 pounds). Vitals are normal. Patient has a boyfriend and reports being sexually active. Patient has never had cervical cancer screening.

CV1B: Patient is a 30-year-old woman with a moderate intellectual disability who comes in for a well-woman exam with her mom. Patient lives at home with her mom, dad, and sister. Patient is a nonsmoker, overweight (20 pounds). Vitals are normal. Patient has a boyfriend and reports not being sexually active. Patient has never had cervical cancer screening.

CV_1_Factors Please describe the factors you consider before performing cervical cancer screening for this patient.

_____

_____

_____

CV_1_Response Do you perform the cervical cancer screening?

- ○ Yes
- ○ No

CV2A: Woman is 32 years old with a diagnosis of moderate intellectual disability. Patient is scheduled for her well-woman exam. Patient is with her mom. Patient lives with mom and rest of her family members. Patient is stable. Patient is a nonsmoker and is slightly overweight (16 pounds). Blood pressure is normal. Patient reports having been sexually active with her boyfriend. Patient has never been screened for cervical cancer. You explain what the steps of cervical cancer screening to patient and mom. The patient verbally consents to cervical cancer screening. You ask the patient to change and leave the room. Once you and mom come back in the room and get the patient ready for the lithotomy position, you look up and observe that the patient appears to be very uncomfortable. This is expressed in her facial expressions and tense body language.

CV2B: Woman is 32 years old with a diagnosis of moderate intellectual disability. Patient is scheduled for her well-woman exam. Patient is with her mom. Patient lives with mom and rest of her family members. Patient is stable. Patient is a nonsmoker and is slightly overweight (16 pounds). Blood pressure is normal. Patient reports having been sexually active with her boyfriend. Patient has never been screened for cervical cancer. You explain what the steps of cervical cancer screening to patient and mom. The patient verbally consents to cervical cancer screening. You ask the patient to change and leave the room. Once you and mom come back in the room and get the patient ready for the lithotomy position, you look up at the patient and obtain physical cues that the patient appears comfortable.

CV_2_Factors Please describe the factors you consider before performing cervical cancer screening for this patient.

_____

_____

_____

CV_2_Response Do you perform the cervical cancer screening?

- ○ Yes
- ○ No

CV_3A: Patient is a 33-year-old woman with moderate intellectual disability. Patient is at well-woman exam with her mom. Patient lives at home with her parents. Patient is stable and does not smoke. Patient is 25 pounds overweight. Patient works at local grocery store part time as a cashier. Patient gets to work by bus. Patient also takes attends a day program part time where she participants in life skills programming. Support needs for this patient includes financial assistance. Patient indicates she has been sexually active in the past. No record of cervical cancer screening is in the patient's file.

CV_3B: Patient is a 33-year-old woman with moderate intellectual disability. Patient is at well-woman exam with her mom. Patient lives at home with her parents. Patient is stable and does not smoke. Patient is 25 pounds overweight. Patient spends most of their time at home. Support needs for this patient include managing finances, medication management, and assistance with meal preparation and clean up. Patient indicates she has been sexually active in the past. No record of cervical cancer screening is in the patient's file.

CV_3_Factors Please describe the factors you consider before performing cervical cancer screening for this patient.

_____

_____

_____

CV_3_Response Do you perform the cervical cancer screening?

- ○ Yes
- ○ No

Adapted AASPIRE Scale

Instructions: Please rate your confidence in doing the following for your patients with intellectual and or developmental disabilities (I/DD).

	Not at all Confident 1	2	Somewhat confident 3	4	Very Confident 5
Successfully communicating with your patients with I/DD	○	○	○	○	○
Successfully performing physical examinations or procedures on your patients with I/DD	○	○	○	○	○
Accurately diagnosing and treating other medical issues in your patients with I/DD	○	○	○	○	○
Helping your patients with I/DD stay calm and comfortable during a visit	○	○	○	○	○
Identifying what accommodations will help facilitate your patients' with I/DD care	○	○	○	○	○
Making the necessary accommodations to facilitate your patients' with I/DD care	○	○	○	○	○

Attitudes towards Individuals with Disabilities Scale

Instructions: Please rate the extent to whether or not you agree with the following statements.

	Strongly disagree (1)	Somewhat disagree (2)	Somewhat agree (4)	Strongly agree (5)
Understanding my patients with I/DD is valuable to me as a physician	○	○	○	○
The treatment of patients with I/DD is too time consuming	○	○	○	○
People with I/DD are often treated unfairly in the health care system	○	○	○	○
I welcome patients with I/DD into my practice	○	○	○	○
Nonadherence is an issue with patients with I/DD because they lack adequate support	○	○	○	○

Demographics

Instructions: Please answer these questions based on your comfort level.

What type of health care provider are you?

- ○ Doctor or Osteopathic Medicine (DO)
- ○ Doctor or Allopathic Medicine (MD)
- ○ Certified Nurse Midwife (CNM) or Certified Midwife (CM)
- ○ Nurse Practitioner (NP)
- ○ Physician Assistant (PA)

What state do you live in?

_____

What is your age?

_____

What is your gender? Do you identify as:

- ○ A woman
- ○ A man
- ○ Transgender
- ○ Non-binary or genderqueer
- ○ I prefer not to answer

Please describe your race/ethnicity: (Please select all that apply)

- ○ African-American
- ○ Asian
- ○ Native American
- ○ Pacific Islander
- ○ Hispanic
- ○ White (non-Hispanic)
- ○ Other, Please describe: ____
- ○ I prefer not to answer

How many years have you been practicing in your profession? (Post-residency/training if applicable)

_____

What type of health care setting do you practice in?

- ○ Federally Qualified Health Center (FQHC)
- ○ Non profit health care corporation
- ○ Private practice
- ○ Group practice
- ○ Community Clinic
- ○ Long-term care facility
- ○ Other, please describe _____

What is the zip code of the area that you practice in?

_____

How would you describe the area that you practice in?

- ○ Urban
- ○ Rural

Do you have a disability?

- ○ Yes
- ○ No
- ○ I prefer not to answer

Do you or someone close to you have a disability?

- ○ Yes
- ○ No
- ○ I prefer not to answer

Do you have specific education or training related to working with people with Intellectual and developmental disabilities?

- ○ Yes
- ○ No

If yes, please describe the nature of the training and when it took place.

_____

Bot Management

Steps Taken to Confirm Bot Attack

- Reviewed dissemination of questionnaire for the past few days (e.g., who did you send the questionnaire to, how was the questionnaire was sent, how often were you receiving responses to your questionnaire prior to the attack, etc.).
- Paused data collection, informed dissertation advisors, reported to IRB, and others (e.g., community partners).
- Communicated to organizations that dissemination of study information must occur through listservs only.

Reviewing and Cleaning Data

- Reviewed meta data collected from Qualtrics
    - Did not include any responses from the day that the attack occurred
    - Reviewed the start and completion time of bot responses for patterns
        - Many bots took the exact same amount of time completing the questionnaire.
    - Reviewed illogical responses that did not make sense given the demographic sample.
        - Reviewed all open-ended responses. When bots filled out the open- ended responses from the questionnaire the open-ended responses didn't seem fully coherent.

Addition of Security Measures

- Created a new survey link.
- Did not allow for online social media dissemination (e.g., Facebook or Twitter).
- Added a knowledge check question to the questionnaire.
- Asked the same question at two separate times and checked for differences in responses.
- Enabled Qualtrics features (See: https://www.qualtrics.com/support/survey-platform/survey-module/survey-checker/fraud-detection/?utm_medium=product&utm_source=survey-builder#EmailScanRoadblock)
    - Prior to the attack, I had the default settings from NAU Qualtrics set
        i. Turned on 'Prevent multiple submissions' feature
        ii. Turned on 'Bot detection' feature
        iii. Turned on 'security scan monitor'
        iv. Turned on 'RelevantID'
        v. Turned on 'Prevent indexing'
- Reviewed embedded data
    - Reviewed Qualtrics guidance around the interpretation of these scores then made general rules with my data set.
    - Reviewed Q_Recaptcha Score
        - Lower scores meaning more likely respondent is bot. Range 0-1.
        - Excluded scores .25 or lower, scores from .26-.50 were individually reviewed.
    - Reviewed Q_RelvantIDDuplicate/BallotBoxStuffing Score

        - Higher scores associated with likelihood response is a duplicate. Range 0-1.
        - Excluded scores .75 to 1. Scores from 0-.76 were individually assessed.
    - Reviewed Q_RelevantIDDuplicate Score
        - Higher scores are associated with more confidence the respondent is not a bot. Range 0-100.
        - Excluded scores 0-25. Scores from 26-50 were individually assessed.
    - Reviewed Q_RelevantIDFraud Score
        - Higher scores are associated with more confidence. Range 0-130.
        - Excluded scores 0-50. Scores from 51-100 were individually assessed.

Other tips

- Security measures need to be added *before* people fill out your questionnaire.
- Add more than one open-ended response as this often allows you to be able to detect bot responses more so than if you had a questionnaire without open ended responses.
- Review academic journals and other platforms to learn best practices related to bots as this this problem is likely going to get worse as bots become more sophisticated.
- Ask others for guidance, this has likely happened to someone else that does online social science research.
- Target social media dissemination for study can likely still be used, with severe caution. Consider using groups to obtain your sample and taking another step to verify that the participant is a human.
- Consider turning on additional features such as the 'password protection' and 'survey access by 'invitation only' feature.