

Women's healthcare in women with developmental disabilities

Sarah Elizabeth Boerst

Follow this and additional works at: <http://utdr.utoledo.edu/graduate-projects>

This Scholarly Project is brought to you for free and open access by The University of Toledo Digital Repository. It has been accepted for inclusion in Master's and Doctoral Projects by an authorized administrator of The University of Toledo Digital Repository. For more information, please see the repository's [About page](#).

Women's Healthcare in Women with Developmental Disabilities

Sarah Elizabeth Boerst

Research Advisor: Alexia E. Metz, Ph.D., OTR/L

Occupational Therapy Doctorate Program

Department of Rehabilitation Sciences

The University of Toledo

This scholarly project reflects individualized, original research conducted in partial fulfillment of the requirements for the Occupational Therapy Doctorate Program,
The University of Toledo

Abstract

Although women with developmental disabilities have the same basic healthcare needs as other women, as a group, they are often neglected where women's healthcare needs are concerned. Women face the risk of female-oriented cancers, which can typically be detected through recommended screenings. Studies also indicate that individuals with developmental disabilities are at an increased risk for sexual abuse. Regular gynecological care is a service necessary to promote general physical wellbeing as well as positive emotional health. The American Occupational Therapy Association (AOTA) states in the *Occupational Therapy Practice Framework, 3rd Edition*, "Occupational therapy services are provided for habilitation, rehabilitation, and promotion of health and wellness for clients with disability—and non-disability-related needs" (AOTA, 2014, p. S1). This study used content derived from focus groups conducted with varied professionals with first-hand experience with the gynecological needs of women with developmental disabilities. Using multiple raters, themes were extrapolated from the transcribed content of the focus groups, analyzed, and supported with literature to identify implications for the profession of occupational therapy to advocate and provide for those affected by this issue. Ultimately, this study aimed to promote and encourage successful gynecological healthcare appointments for women with developmental disabilities, while setting out to identify the role and ethical responsibility of the profession of occupational therapy in the process.

Women's Healthcare in Women with Developmental Disabilities

The United States Department of Health and Human Services, Office on Women's Health (2013), provides a website (girlshealth.gov) for girls ages 10-16 years to access that provides information regarding issues pertaining to health and well-being. The content addresses nutrition and healthy living, social pressures, and human sexuality. There is also information that provides details of a visit to the gynecologist. In addition to a typical vitals-screening exam, it describes the more invasive aspects of the experience. The importance of breast health and regular exams is discussed as well and the differences between a pelvic exam and a Pap test. Girlshealth.gov (2013) recommends that girls should begin visiting an obstetrician/gynecologist (OB/GYN) between the ages of 13 and 15 years.

Although neither a pelvic exam nor Pap test is typical of these introductory visits, gaining an understanding of personal physiological changes and developing rapport with a specialist is an important step towards healthy habits. Open communication that is comfortable and familiar between an individual and her practitioner assists in developing a comfortable rapport allowing sensitive topics to be freely discussed without feelings of judgment or embarrassment. Another focus of these initial visits is in addressing general health issues such as immunizations and dietary habits. Finally, these initial visits should focus on issues pertaining to sexual health, including topics such as sexual activity, dating violence, and any additional problems that may result from heredity or unsafe behavioral practices (Sanfilippo & Lara-Torre, 2009).

The American Congress of Obstetrics and Gynecologists (ACOG, 2011) created a document to answer questions teen girls might have regarding their first gynecological visit. The first visit could be a consultation visit to introduce the patient to the concept of women's healthcare, why it is important, and what will take place during her exam. A typical first *clinical*

visit would involve a basic physical examination and an external genital check. The basic physical would include taking a medical history and measuring height, weight check, and blood pressure. After the physical exam, the physician would examine the patient's external vulva. Unless the patient is having problems with excessive bleeding, cramping, or some other problem that suggests there could be a problem, a pelvic exam is not recommended until she is 21 years of age. The pelvic exam involves three parts. First, the physician checks the external vulva for abnormalities. Second, the physician checks the vagina and, using a speculum, checks the cervix. Third, the doctor checks internal organs by palpating between a gloved hand from within the vagina and the other hand on the patient's abdomen (ACOG, 2011).

The United States Department of Health and Human Services, Office of Population Affairs, provides a Fact Sheet describing the recommended screenings used for early detection of cervical cancers, a form of cancer that can usually be controlled with early identification. Pap tests are used to detect cellular changes in a woman's cervix, and are performed vaginally. The Fact Sheet recommends women have a Pap test three years after a woman's first experience with sexual intercourse, or by the time she turns 21 years of age. Pap tests are then recommended every two years for women with results that are consistently normal. After the age of 30, with test results that are normal for three consecutive years, gynecological care practitioners may consider extending the interval between Pap tests to once every three years, and they are no longer recommended for women over the age of 65, who have had three consecutive normal test results (United States Department of Health and Human Services, 2013.).

In addition to pap and pelvic examinations, the American Cancer Society (2013) recommends breast self-examinations (BSE), clinical breast examinations (CBE), high quality mammograms, and in specific situations, magnetic resonance imaging (MRI) for early breast

cancer detection. Women in their 20s are encouraged to perform regular BSEs. In addition to finding a potential abnormality, this provides the opportunity for women to learn and develop knowledge of the detailed characteristics of their own breast tissue, thereby increasing success with self-detection of potential future problems. As women move through their 20s and 30s, a CBE is recommended every three years. After a woman turns 40 years old, it is recommended she have an annual CBE and a high-quality mammogram. Women who are considered at risk (greater than 20% according to criterion provided by American Cancer Society) should have a high-quality mammogram, a CBE, and an MRI every year after they turn 30, unless problems present themselves before then (American Cancer Society, 2013).

Womenshealth.gov is a website provided by the United States Department of Health and Human Services, Office on Women's Health that women can access to learn important health information specific to women. Among the many resources available, it provides a detailed description of the process of having a mammogram: "You stand in front of a special x-ray machine. The person who takes the x-rays, called a radiologic technician, places your breasts, one at a time, between an x-ray plate and a plastic plate. These plates are attached to the x-ray machine and compress the breasts to flatten them. This spreads the breast tissue out to obtain a clearer picture. You will feel pressure on your breast for a few seconds. It may cause you some discomfort; you might feel squeezed or pinched. This feeling only lasts for a few seconds, and the flatter your breast, the better the picture. Most often, two pictures are taken of each breast — one from the side and one from above. A screening mammogram takes about 20 minutes from start to finish" (United States Department of Health and Human Services, Office on Women's Health, 2010, para.4).

Women with Developmental Disabilities

The Center for Disease Control (CDC, 2012) reports 67.1% of women over the age of 40 were compliant with mammogram screening in 2010. Wilkinson, Lauer, Freund, and Rosen (2011) reported that women with developmental disabilities had the same rate of breast cancer as other women; however, they were less likely to have mammograms. Only 12% to 30% of women with developmental disabilities over the age of 40 had undergone a mammogram, and women with developmental disabilities were found to have had higher mortality rates from breast cancer than women without developmental disabilities (Wilkinson, Lauer, Freund, & Rosen, 2011).

In addition to cancer screenings, women with developmental disabilities should seek regular gynecological care given their vulnerability to sexual abuse. It is estimated that 68% to 83% of women with developmental disabilities will have been sexually abused at some point in their lives (Mahoney & Poling, 2011). Further, this population experiences revictimization more than any other; presumably by perpetrators who are familiar to them (Glover-Graf & Reed, 2006). A qualitative study conducted by Kopac and Fritz (2004) used surveys for the purpose of gaining an understanding from nursing professionals regarding the availability and accessibility of women's healthcare services for women with developmental disabilities. The most common barriers identified included emotional distress and increased incidences of abuse. Nearly half, 46%, of the returned surveys reported incidences of physical abuse in women with developmental disabilities and 49% identified reporting sexual abuse in women with developmental disabilities. Azikiwe and colleagues (2005) conducted survey research with healthcare practitioners in nationwide emergency rooms to identify incidences of sexually transmitted diseases (STDs) in individuals who experienced rape. Although the study had limitations with regards to surveys that were not returned, as well as the decreased validity often

found in self-reported data, the general conclusion was that the risk of contracting an STD from rape was a little over 26%.

Healthcare Barriers for Women with Developmental Disabilities

Past studies confirm that it is common for individuals with developmental disabilities to experience poor access to adequate healthcare (Kopac & Fritz, 2004; Parish & Sauville, 2006; Brown & Gill, 2009). Parish and Sauville (2006) discussed several barriers relating to adequate gynecological care for women with developmental disabilities. Specific training for healthcare practitioners during their formal education that addressed the unique needs of individuals with developmental disabilities was lacking. Healthcare practitioners were also found to demonstrate poor communication skills when delivering services to women with developmental disabilities, which produced feelings of emotional discomfort and lack of understanding with the invasive procedures being delivered. Stigma was also noted in healthcare practitioners with regards to the assumption that women with developmental disabilities were assumed to be lacking in quality of life. Reimbursement was also an area of frustration, particularly for individuals receiving managed care funds for services rendered. Women with developmental disabilities often required more time for services rendered, and the managed care systems reimbursed according to a fixed rate of specific services delivered. As a result, physicians were compensated for their individualized services, but not the extra time it took to deliver the services (Parish and Sauville, 2006).

Individuals with developmental disabilities lack accessibility to their own sexuality due to a stereotype that suggests that as a group, they are not sexual. They are often denied education explaining appropriate sexual practices, as well as privacy in which to engage in those sexual practices (DiGiulio, 2003). As a result of this general public denial regarding the sexuality of

individuals with developmental disabilities, it is suspected that women with developmental disabilities are frequently overlooked regarding reproductive healthcare (Parish, Moss & Richman, 2008).

Wilkinson, Dreyfus, Cerreto, and Bokhour (2012) examined the concerns of physicians working with people with cognitive impairments. The most reported concerns by the physicians in the study were feelings of lack of preparedness and increased anxiety due to unconventional behaviors that were sometimes part of treatments with individuals with developmental disabilities. Within the context of their formal training, healthcare practitioners are given many tools to be successful in their specialized field. However, the tools generally focus around the general public rather than individuals with specific disabilities. Providing a way for practitioners to provide patient-centered care, regardless of a disability, is a way to reduce general stereotypes that accompany disabilities, as well as a way to optimize relationships between patients and clinicians.

Brown and Gill (2009) used focus groups with women with developmental disabilities who had experienced a gynecological exam at least one time to examine barriers they personally faced in accessing gynecological care. The women in the focus groups communicated feeling misunderstood by medical personnel and that they did not understand the information given to them about their bodies. They also reported experiencing fear, anxiety, pain, and overall discomfort when going to the gynecologist, and as a result, they did not go back. The authors concluded that there are several aspects for improving patient/practitioner communication. Clinicians should develop awareness of behavioral reactions to pain or emotional discomfort exhibited by women with developmental disabilities within the context of gynecological care. They must also consider the cognitive level of functioning of women with developmental

disabilities. The authors recommended creative strategies for changing negative health-related experiences into positive experiences. For example, one of the women in the focus group reported an effective calming strategy her gynecologist used. She was encouraged to watch a movie that explained the upcoming procedure prior to her exam (Brown & Gill, 2009).

A study conducted by Parish and colleagues (2012), examined the level of knowledge regarding cervical and breast cancer screenings among women with developmental disabilities. Participants either lived with family caregivers in residential settings, lived alone, or lived with a spouse. They found that all participants had limited knowledge of both screenings; however, they had less knowledge of cervical cancer screenings. In addition, women who lived with family caregivers had a far less understanding of cervical cancer screening than women living independently or with a spouse. The study presented a number of limitations which included nervousness among the participants due to the nature of the questions asked. The authors also discussed how the questions asked may have required verbal capabilities the participants did not have. However, the questions asked were taken from an assessment created specifically for individuals with developmental disabilities. Nonetheless, the findings indicate the lack of resources available to individuals who have developmental disabilities, specifically with regards to their own medical care.

Women who have both developmental disabilities and physical disabilities experience additional barriers regarding environmental factors. Todd and Stuijbergen (2012) examined barriers experienced by women with physical disabilities with regards to breast cancer screening. Participants reported difficulties with transportation, long wait times, and poor equipment accessibility. The women in the study also reported that their clinicians demonstrated outward frustration. One woman with multiple sclerosis reported that the technician performing her

mammogram became frustrated with her as a result of her inability to “stand up and stay still” during her procedure (Todd & Stuijbergen, 2012, p. 76). When seeking medical attention, having access to clinicians who are understanding should be customary for all individuals.

Varied coping strategies encourage smoother interactions between people. However, Janseen, Schuengel, and Stolk (2002) remind readers that individuals with developmental disabilities are not always capable of applying an appropriate strategy to a specific situation. Women with developmental disabilities experience feelings of stress when placed in situations where they are misunderstood and/or they are unsure of what is happening. Consequently, these individuals are at risk for emotional stress due to the inability to process information, the need for an environment that is consistent and predictable, and the general lack of behavioral strategies implemented. Physiological responses may also surface as a result of stress, causing responses that are equally negative in all situations, regardless of context. Removing factors that threaten the psychosocial well-being of women with developmental disabilities is pivotal in creating a medical environment that is harmonious for everyone involved.

Client Factors and Individuals with Developmental Disabilities

The Occupational Therapy Practice Framework Domain and Process, 3rd Edition (2014) identifies the central objective of the profession of occupational therapy as “achieving health, well-being, and participation in life through engagement in occupation” (p. S4). Client factors are areas relevant to each individual person and guide participation in life, and include values, beliefs, spirituality, body functions, and body structures. Occupational therapy practice is designed to provide a holistic level of care regarding the comprehensive needs of individuals, specific groups of individuals, or specific populations to promote the engagement in a life that is healthy and fulfilling (AOTA, 2014).

Occupational justice is an expected outcome of occupational therapy-related services rendered. Occupational therapy practitioners have the professional responsibility to advocate for and empower clients by providing resources for access comparable to that of the general public in order “to satisfy personal, health and societal needs” (AOTA, 2014, p. S35). The presence of impairments does not invalidate the need for personal empowerment, nor does it eliminate the need for advocacy promoting personal empowerment. Shalock and colleagues (2002) analyzed concepts related to quality of life for individuals with developmental disabilities. Personal empowerment with a focus on individual differences was a significant indicator of enhancing the quality of life of individuals with developmental disabilities (Shalock, et al., 2002).

The Direct Role for Occupational Therapy

The centennial vision of occupational therapy places emphasis on meeting the occupational needs of society (AOTA, 2007). As noted by Kathleen Barker Schwartz in her 2009 Eleanor Clarke Slagle lecture, AOTA’s Centennial Vision resonates with the profession’s founding vision: “the successful promotion of occupation as a vital force to meet society’s needs” (p. 681). In the same lecture, Schwartz (2009) continued to discuss the role of modern occupational therapy as it relates to the needs of all people. She stated “Like the founders, we are confronted with inequities and disparities in society that affect people’s health, quality of life, and participation. Like the founders, we have a powerful tool—the use of engagement in occupation—as both a means and end to health” (Schwartz, 2009, p. 689).

Nelson (1988) defines *occupational form* as “an objective set of circumstances independent of, and external to a person”, and describes *occupational performance* as “human actions taken in response to an occupational form” (Nelson, 1988, p. 633). Using these concepts, it is reasonable to deduce that an individual’s success with occupational performance is

dependent on the occupational form. The Person-Environment-Occupation Model designed by Law and colleagues (1996) promotes an ever-changing, lifespan approach to occupational performance. The model defines *person* as “a unique being who assumes a variety of roles simultaneously” (p. 15). The model gives equal attention to cultural and socioeconomic aspects when examining an individual’s *environment*. A study (2011) examining the national trend of children with developmental disabilities living in the United States between 1997 and 2008 found a link between an increased prevalence of developmental disabilities in those from homes with incomes below the federal poverty level (Boyle et al., 2011). The creators of the Person-Environment-Occupation Model (1996) consider trends like these critical when examining an individual’s environment. These findings illustrate appropriate application of the model to the subject matter at hand; women with developmental disabilities and their poor access to healthcare. The model also recognizes, institutional, physical, and social factors of a person’s environment with the same regard, as they are also interrelated, significant facets in the environment of women with developmental disabilities. *Occupation* describes groups of functional tasks and activities that an individual does throughout the course of life. *Occupational performance* results from of the interaction between the person, environment and occupation and is impacted by how well each component coordinates within the others. The process is dynamic, and interactive. *Person, environment* and *occupation* are ever-changing components, and result in an *occupational performance* that also changes. The role of occupational therapy is to encourage balance within these components to optimize occupational performance (Law et al., 1996).

Law and colleagues continue with a problem solving process (Appendix E) for clinical application. It begins with identifying “strengths and problems” in occupational performance (p.

19). This is accomplished by assessing the intricate details that comprise the occupation, environment, and performance components (which include specific characteristics found within that person related to mind, body, and spirit). Although subjective to each person, problems for women with developmental disabilities, include the various components related to barriers to healthcare access previously described that contribute to poor compliance with recommended screenings. Strengths are subjective to each individual as well and are assessed using similar logic. From information gathered, an intervention is developed with the client, which includes all of the components previously discussed. The results are measured by the outcome; the balance between the three major components impacting occupational performance. In the circumstances surrounding our study, occupational performance would include positive, patient-centered, gynecological care for women with developmental disabilities (Law et al. 1996).

The literature referenced supports the role of occupational therapy in advocating for and supporting all people, populations, and communities in their pursuit to actively engage in occupations that promote health, wellbeing, and safety. This includes improving access to women's healthcare related services for women with developmental disabilities. We conducted a thematic analysis of content derived from focus groups with individuals personally invested in the care of women with developmental disabilities. In addition, we sought out to seek insight regarding the growing need for proactive initiatives by occupational therapy practitioners to advocate for empowerment and quality of life for women with developmental disabilities.

Method

This is a qualitative research study about the emotional and physical needs of individuals invested in the gynecological care of women with developmental disabilities. This study

employed focus groups in order to gain the perspectives of stakeholders invested in the care and well being of women with developmental disabilities.

Participants

After receiving approval from The University of Toledo Biomedical Institutional Review Board, the recruitment of participants began with the following methods: flyers, email, word-of-mouth, personal visits, telephone correspondence, and follow-up with all methods previously mentioned.

Service providers. Two Direct Support Professionals (DSPs) with significant experience working closely with women with developmental disabilities were recruited. Both had five or more years of experience working with individuals with developmental disabilities. Both were also directly involved in the process of taking women with developmental disabilities to appointments relating to gynecological care.

Women's healthcare providers. Three women's healthcare providers with credentials to perform gynecological and breast exams were recruited for the purpose of identifying the concerns and recommendations related to individual experiences had by healthcare providers regarding the reproductive health and wellness of women with developmental disabilities.

Procedures

On two separate dates, in two separate locations, focus groups were conducted, each with a specific protocol (See Appendices A and B). Each session was recorded using a digital audio recorder and later transcribed.

Focus groups. Informed consent was requested from all focus group participants. Participants were assigned to focus groups within their participant category upon enrolling in the study. Focus groups were facilitated by the student researcher. The focus group for service

providers began with the student researcher reviewing the recommendations and typical procedures of an initial clinical women's healthcare visit (Appendix C). The focus group with the women's healthcare providers began with the student researcher reviewing common characteristics of developmental disabilities and a brief overview of literature identifying statistical facts specific to women's healthcare services for women with developmental disabilities (Appendix D). After the introductions, each of the groups were encouraged to discuss topics and questions presented by the student researcher relating to their experiences with women with developmental disabilities on a women's healthcare setting (see Appendices A and B for focus group discussion content). The student researcher polled the focus group members for their agreement and disagreement with consensus views, and encouraged each member to contribute. The student researcher guarded against domination of the conversation by single members. Focus groups were recorded by audio devices for offline transcription and analysis.

Data Analysis. Focus groups were transcribed from the digital audio recordings. Transcriptions were independently analyzed by two raters for themes. The two raters discussed their differences and negotiated a set of themes. A third rater reviewed the transcriptions and themes to recommend clarification. When this rater agreed, this stage of analysis was considered complete. However, if this individual had disagreed, the analysis would have been started from the beginning and repeated until all raters agree on the theme classifications. Presentation of themes includes quotations and descriptive statistics.

Results

Common themes were identified and agreed upon between the two raters and verified by a third according to the transcribed content of the focus groups. The themes included:

communication, education, scheduling, time, changes in reimbursement and policy, ethics, and supportive resources for women.

Communication

All participants in both the practitioner group and the service provider group identified communication barriers that prevented adequate access to reproductive healthcare for women with developmental disabilities. The participants in the practitioner group identified experiences that involved poor communication from service providers and caregivers, and the service provider participants identified experiences with poor communication from practitioners. Other common themes discussed in both groups related to issues with scheduling and the lack of adequate past medical history records available for many women with developmental disabilities. One participant in the practitioner group discussed the benefit of knowing beforehand any behavioral concerns that might compromise the health and safety of all involved. The participant stated:

In the dialogue, one of the care giving people mentioned that if I was bitten... me as provider, it sort of took me back. Anticipating that I could be assaulted... because that seems stressful to me and kind of an odd thing to bring up, and it never crossed my mind that I would be bitten or assaulted.

In addition to the common themes between groups, the service provider group discussed general communication with others regarding the importance of gynecological care for women with developmental disabilities. A participant from the Service Provider group stated:

I think a lot of people are scared to talk about that stuff because they're afraid it's going to come back as sexual- harassment or

sexual abuse even though it was meant to be an educational conversation...I know a lot of times people are like 'you talk to her about that?' And I say 'yeah, I did, and I did in this way and in this place'.

Education

The members of each group suggested that some of the challenges in women's health care for women with developmental disability stem from issues presented by the counter-group. This included an overall lack of education and low awareness of the services provided by their own group. Participants discussed suggestion for possible educational opportunities to improve the experience for all involved. Participants in the practitioner group identified a gap in educational resources available to them, a "lack of clear guidelines" recommended by the American Congress for Obstetricians and Gynecologists, and noted that although a module created for the care of women with developmental disabilities was helpful, it was a general guideline, and did not address other issues such as educating caregivers and/or service providers regarding the benefits of cervical cancer screenings. As a result, women with developmental disabilities were not receiving adequate supports needed for successful examinations. One participant stated:

...often the people who accompanied the women with disabilities aren't really understanding the rationale behind the exam...It's a very challenging exam for all women.

The participants in the service provider group discussed successful exams that were conducted by understanding practitioners who communicated effectively with the caregivers and service providers, allowed support, were flexible with scheduling, were routine in their delivery,

(that is, they conducted the same procedure the same way each time it needed to be performed), and asked many questions regarding the specific challenges of the individual they were examining. The participants in the service provider group also described specific situations in which the practitioners did not have an awareness of the needs of individuals with developmental disabilities, and it was clear they had not received formal training. As a result, the exams that were attempted were unsuccessful. One service provider noted having a negative experience while taking a woman with developmental disabilities to her scheduled mammogram appointment. The technicians were negative towards the woman when the woman displayed anxiety with the machines; although they made no attempts to explain the procedure, or show her how the machine operated. They were also negative towards the service provider, refused to make accommodations, and suggested they return when the woman with developmental disabilities could “*take a pill*” before her mammogram. The service provider stated:

I think they need to sharpen their awareness of people with developmental disabilities. I'm sure she isn't the first or the last that they're going to see.

Scheduling

Scheduling was a common theme addressed by all participants in both focus groups. The practitioner group identified frustration with scheduling and the lack of flexibility available for necessary patient modifications; however, they also noted that those who call to schedule appointments for individuals with developmental disabilities should identify a need for extra time and recommended modified services. One participant from the practitioner group commented:

There is increasing pressure for providers in terms of productivity and often, at least in my practice, we have a same-day type of scheduling, and you have to know ahead of time that that woman is going to need a little bit longer and that perhaps somebody would be coming with her.

The service provider group commented on scheduling as well. The participant who had experienced positive healthcare experiences with women with developmental disabilities noted the addition of a medical information specialist to the care team with which that individual worked. The medical information specialist had recently been hired to address issues specifically related to the medical concerns of the individuals served. This participant commented:

She [the scheduler] does all of the appointments. Luckily, she is somebody who had worked with the women... for several years before taking the position.

Time

All of the participants from both groups discussed the importance of allowing extra time to provide quality care for women with developmental disabilities. The service providers identified that individuals they knew with disabilities needed time to process information. Healthcare practitioners identified that they appreciated extra time to provide quality, client-centered care to women with developmental disabilities. A participant from the practitioner group stated:

It would take a significant amount of time physically and mentally to go through the steps, and these people are so subjected to abuse,

and if there is any abuse in their history that presents additional challenges. I think just developing a trust that you're not going to hurt them is going to take time. So time is huge.

The service provider group identified successful outcomes when practitioners allowed extra time for accommodations. One service provider recalled the following experience:

We decided to take her... to a group I had heard good things about. So...she was able to do the breast exam and was...very slow and because she [the patient] is deaf...[the doctor said] 'tell me if I need to slow down, tell me if I need to do anything else... she got the breast exam done, and that went well.

Reimbursement and Policy

Both groups addressed the issues of reimbursement and policy that affected the level of care received by women with developmental disabilities. Two out of the three participants in the practitioner group commented on changes in policy that affected their abilities to provide patient-centered care – changes they felt would most benefit women with developmental disabilities. One practitioner emphatically communicated having dedicated staff personnel who deeply valued practitioner/patient rapport. The same practitioner also expressed frustration regarding changes in policy that challenged schedule flexibility:

Well, in my case, 'office' is not what office meant to me years ago, because years ago, 'office' meant my office, and we could work out whatever was necessary. But now, my office is a separate and disconnected scheduling system, and a separate, somewhat less disconnected, receptionist system... There would be no way I could

say we could make alterations, because the scheduling desk is not... there's no good feedback there, to even receive the information that may be heard or transmitted.

One of participants of the service provider group also discussed challenges with reimbursement and changes in policy. Medicaid is a primary payer source for many individuals with developmental disabilities; however, some of the policies in place are not conducive to suit the needs of the individuals it provides for. One participant in the service provider group discussed a woman with a family history of cervical cancer who required regular screenings. After many unsuccessful attempts in various clinical settings, one doctor recommended sedation in a hospital. After consulting with the woman's legal caregivers, an order was written, and the procedure was completed successfully in a way that was much less traumatic for all involved. Despite the favorable outcome, a barrier presented itself regarding reimbursement services. An unsuccessful visit was required to justify a hospital visit. The participant stated:

Medicaid wants them to prove that they still need the anesthesia before they'll pay for it. So, they want them to come in and get traumatized by trying to do the appointment, and failing and then get anesthesia.

Ethics

Ethical considerations were addressed by all participants in both groups. A participant in the practitioner group identified ethical issues with regards to sedation, and indicated there had been situations in which their input was not considered in the process. As a result, the practitioner felt uncomfortable not having the opportunity to communicate with the patient. A different practitioner discussed ethical issues with regards to those who schedule appointments

without effectively communicating the need for modified services at the time of scheduling on behalf of a patient with disabilities. The practitioner stated:

I think that we could do a better job then, knowing that there are either some physical limitations or some cognitive challenges in terms of spending a few extra minutes for the procedure. It's a very intimate exam and sometimes women leave feeling violated because they don't understand what's going to happen and then it happens and they leave and say what just happened?

The service provider group discussed ethical considerations as well, and described incidences in which women with disabilities were treated poorly in healthcare settings. One service provider described taking a woman for a mammogram:

...they were awful. They see this lady every year and so they said 'oh it's her'. They tried to get her to put her breast on [the machine] and she wouldn't, so they just gave up and that was it. They didn't try anymore....they were really rude, and not at all accommodating.

Supportive resources for women

All participants in both groups discussed supportive resources for women with developmental disabilities. Both groups introduced the idea of finding alternate locations that were less traumatic at which women's healthcare services could be provided. Participants from both groups discussed the need for personal advocates that could speak on a woman's behalf, and discussed the need for support, which included privacy and respect. A participant in the

practitioner group described a situation in which a patient was without an advocate. The practitioner recalled:

I remember having a patient, and I was asking the caregiver some questions and she said 'listen I'm just a driver', and I thought 'oh, okay, this woman has no relationship with this woman', and I thought it was inappropriate for her to be in the room and she seemed uncomfortable to be there as well.

Participants in the service provider group commented on possible supports for women as well, including supports that encouraged successful visits such as allowing the service provider to be in the room with the patient, and general communication with the patient, (descriptions of equipment, procedural events etc.). One participant described the differences in individuals and the varying levels of support they asked for regarding women's healthcare services. The participant stated:

...she completely understands what it is. She doesn't feel comfortable with it at all, but we prepared her for a whole month before. She'd only talk about it with me...and it would be in private because it is a private thing. She would ask me questions and we would talk about making sure that she was clean, making sure we showered every day because it's really important for the hygiene, and all of those things... and she did great. But I think just giving her that platform to talk with me...seemed to help her. [A different service provider] went with her and she did great. She sat through all of it but she did have [support]. She wanted

somebody to stay in the room with her.

Discussion

The main objective of this study was to gain practical insight from the perspectives of different professionals involved in the care of women with developmental disabilities in women's health-related situations. From this, we can explore the implications that relate to occupational therapy practice. The themes and their interrelationship provide direction to improve women's health services for women with developmental disabilities.

Communication and Education

Data gathered support a need for more effective communication between those involved in the care of women with developmental disabilities. Missing information in the health records of individuals with developmental disabilities impact effective communication between practitioners and service providers. The service providers commented on the lack of accurate histories of the women they accompanied on medical appointments, and the practitioners reported finding it difficult to treat women without some idea of their past medical history. Without accurate histories, practitioners expressed concerns about providing invasive procedures while knowing there were possible incidences of past sexual abuse. With the likelihood of 83%, according to Glover-Graf and Reed (2006), this could very well be the case.

The practitioners also commented that many of the service providers did not know how to accurately answer pertinent questions, to communicate potential problems, or provide other pieces of beneficial information. This group noted further, that service providers and caregivers were not knowledgeable in the reasoning behind invasive procedures such as cervical cancer screenings. Wilkinson and colleagues (2011) support these findings in their study addressing mammograms and the lack of compliance with recommended screenings in women with

developmental disabilities. Recommended initiatives to increase awareness included educating guardians and individuals with developmental disabilities (Wilkinson et al., 2011). Parish and colleagues (2012) emphasize the benefit of a wider knowledge base for service providers who work with women with developmental disabilities, by learning more about health-related issues and procedures so they can better prepare their clients for life-saving screenings. These authors also promote education for not only family members and caregivers but also women with developmental disabilities so they might exercise compliance with recommended screenings (Parish et al., 2012).

The service providers felt many of the healthcare practitioners they had encountered when supporting women with developmental disabilities lacked the altruism necessary to care for individuals with developmental disabilities. Wilkinson et al. (2012) found that primary care physicians acknowledged feeling uncomfortable when working with individuals with individuals with developmental disabilities. Their recommendations include changing the residency training for medical students to incorporate more experiences with individuals with disabilities. (Wilkinson et al., 2012).

Time, Scheduling, Reimbursement, and Policy

These themes were commonly addressed and interrelated. The data confirm that women with developmental disabilities require more time for procedures, and scheduling practices play a significant role in providing such accommodations. The challenge of reimbursement when extra time is allotted also addressed in the focus group content, reflecting the literature. Kopac and Fritz (2004) report that insurance companies often fail to compensate for extra time, a strategy that may help women with developmental disabilities better cope with the experiences of visits. Reimbursement itself can pose a challenge. Kopac and Fritz (2004) further report a limited

availability of providers willing to provide care to individuals receiving Medicare or Medicaid benefits.

Ethics and Supports for Women

Ethical considerations and supports for women were discussed in tandem. All participants expressed interest, and provided insight to help women have better experiences with women's healthcare. This supports recommendations from Brown and Gill (2009) who discuss benefits from a "collaborative approach" when addressing the needs of women with developmental disabilities. Their suggestions for supports include personal advocates and peers to empower women in receiving quality services (Brown & Gill, 2009).

Participants also revealed instances in which healthcare practices were not ethical. The verbiage used about and in front of individuals in healthcare settings did not support ethical guidelines that should be commonplace in healthcare professions. Parish and colleagues (2008) used focus groups with women with cognitive disabilities living in the community, and identified negative attitudes found in healthcare professionals did impact healthcare accessibility for women. Recommendations include advocacy training for individuals who are closely involved with women with developmental disabilities, in addition to a focus of care that is more client-centered in nature (Parish et al., 2008). Sexuality is another area discussed in our focus groups as well as the literature. In addition to the stereotype suggesting individuals with developmental disabilities are *asexual*, Di Giuolio (2003) further discusses the negative impact this stigma has on access to women's healthcare. The author emphasizes the value of discussing sexuality with women with developmental disabilities for the purpose of educating them about healthy and unhealthy practices (DiGiuolio, 2003).

Study Limitations

There are some factors that limit the broad applications of the findings of this study. The number of groups and participants are significant limitations to this study. More same-category groups recruited from various settings would have added a multidimensional component. Although they worked in different areas with different individuals of varied cognitive and functioning levels, the participants in the service provider group were employed by the same facility. Similarly, the participants from the women's healthcare practitioner group held credentials to treat women in different capacities, but were recruited from the same medical institution. Additionally, the voices of other stakeholders including but not limited to caregivers, schedulers, and women with developmental disabilities would have added more comprehensive content to this study.

It should be noted that all participants in the study were educated. All were high school graduates, and all but one participant had pursued and graduated with at least one college degree. Other individuals working with and caring for people with developmental disabilities may not have similar backgrounds, and as a result, may have different insight into the needs of women with developmental disabilities.

Future Research

Research endeavors should consider existing and potential advocacy and educational efforts for healthcare practitioners, service providers, schedulers, caregivers, and women with developmental disabilities. One possible theme might examine the defined roles of each of these various stakeholders related to services provided to women with developmental disabilities. Tangible modifications to the physical environment in addition to advanced planning strategies might be explored and implemented to successfully eradicate current barriers to healthcare for women with developmental disabilities. Studies that focus on scheduling practices for women

with developmental disabilities would be of benefit, as it was a conflict frequently discussed.

This necessary service is meant to be the initial liaison between patient-practitioner relations, and may be lacking in productivity due to a deficient support system. Research directed towards the investigation of these gaps would benefit all invested in the care of women with developmental disabilities.

Another possible aim could be directed towards a comprehensive focus of women with developmental disabilities to better individualize strategies to address the current set of issues. These studies might encompass demographic data collected at the international, national and local levels to identify cultural and socioeconomic differences within the population in different social constructs. Protocols could be developed for healthcare practitioners to better address this complex set of issues. Related, another research direction could address an insight into the differences within the population targeted here. Due to the array of diversity found within the group: “women with developmental disabilities”, studies that identify and embrace differences would be beneficial to promote empowerment for women with similar oppressive experiences. By directly focusing on peer relations within the group, the outcome of these studies could encourage self-advocacy and possibly address other issues relating to sexual abuse and circumstances of vulnerability. Finally, one more research aim could explore the accessibility and appropriateness of the governmental electronic resources available to women with varying levels of cognitive and physical abilities. These tools are available for adolescent girls and women across the lifespan to promote health, learning, and self-empowerment, however our findings indicate a lack of appropriateness for women with disabilities.

Implications for Occupational Therapy

The Occupational Therapy Practice Framework, 3rd Edition (2014) explains the structure of the profession by defining the conceptual elements, and thereby suggesting the roles of occupational therapy practitioners in appropriate settings. *Occupations* refer to specific pursuits of life, and are considered as broadly or intricately as necessary. The skill set of occupational therapy practitioners is designed to holistically evaluate the ability to participate in occupations, to recognize setbacks impeding function, and to make modifications accordingly (AOTA, 2014; Law et al., 1996).

Occupational therapy interventions are meant to foster participation in a life filled with good health and wellbeing. Interventions are client-centered and allocated for individuals, groups, or populations (AOTA, 2014). The professional scope of occupational therapy is broad, because it addresses and embraces all the components of an individual that makes them a unique being. People are comprised of a physical self, and there is significant focus on anatomical and physiological dysfunction, which certainly can impact an individual's participation in life. However, the mind and spiritual aspects of a person define them as well, and are also considered within the realm of the occupational therapy professional domain (AOTA, 2014).

This study illustrates a social injustice in a vulnerable population experiencing barriers to healthcare that impact their right to have life-saving procedures. There are a multitude of opportunities to utilize the expertise specific to the profession of occupational therapy to promote social justice and good health for women with developmental disabilities.

Advocacy. One significant implication for occupational therapy practice that will benefit women with developmental disabilities is advocacy. Advocacy is a significant component of the occupational therapeutic intervention process. It is implied in all practice settings, and promotes self-empowerment, encourages independence, and ideally, results in participation in life. Public

advocacy initiatives are needed to improve the quality of life for women with developmental disabilities with regards to gynecological care, and could be directed towards local, national, and international levels (AOTA, 2014). Examples of possible advocacy efforts that occupational therapy practitioners could initiate include: becoming involved as a board member that supports women with developmental disabilities, becoming a mentor for a woman with developmental disabilities, becoming a legal advocate for a woman with developmental disabilities, or simply being a positive example in a clinical setting by acting according to ethical principles when someone is being exploited.

Program Development. Programs designed for various stakeholders invested in the quality care for women with developmental disabilities would provide complementary frameworks to enhance collaboration. Practice skills within the occupational therapy domain would address many of the demands of such programs. First, occupational therapists are well versed in the delivery of mental-health services according to evidence-based models. Next, occupational therapists have an understanding of human anatomy and physiology which provides them with practical insight into the medical needs of women. Next, the profession's holistic view of people assists in identifying other factors that may be impacting access to women's health care. Finally, and most significantly, occupational therapy practitioners promote the value of engagement in occupations. Taken together, this demonstrates how the expertise of occupational therapy practitioners in recognizing individual differences, without limiting potential, supports full engagement in a quality life.

Women with developmental disabilities. Support groups using semi-structured peer groups to discuss barriers to healthcare within the context of scheduled meeting times would be beneficial. Mediation provided by a trained support professional, such as an occupational

therapist, would encourage all participants to have equal opportunities to “voice” concerns. The aim would be to encourage women to collaborate with one another, to help them feel empowered rather than oppressed, and provide opportunities to advocate for themselves and others.

Programs focusing on the educational aspect of women’s healthcare would also be beneficial for women with developmental disabilities. Creating materials specific to the needs of each woman might help her to understand the reasoning for invasive procedures such as mammograms and pelvic exams. The potential aim of this program is to increase awareness, understanding, and compliance with participation in recommended screenings.

Programs focusing on methods used for preparation for an exam might help women have experiences at the doctor that are more successful. These programs could be tailored to each woman to prepare her prior to her first and subsequent experiences. Tangible objects like speculums, exam tables, gowns etc.; learning resources such as books, social stories, pictures etc.; and peer supports from other women (with and without disabilities) could all be used as possible tools to make her experience less traumatic.

Caregivers. A program using support groups to provide emotional support to caregivers would give them the opportunity to collaborate with others to voice concerns regarding the anxiety that exists when caring for an individual with developmental disabilities. Knowing others have similar experiences would ideally validate feelings of guilt, anger, and resentment, and help caregivers move towards acceptance of their situation. The aim of this program is to encourage caregivers to use available supports.

Other elements of such programs for caregivers might include training modules to address issues related to the personal care of an individual with developmental disabilities.

Activities of daily living (ADLs). Activities of daily living are self-maintenance occupations individuals engage in each day (AOTA, 2014 p. S19). Some examples of ADLs relating to gynecological care and women with developmental disabilities include bathing, toileting, grooming, and dressing. Occupational therapy practitioners have specialized skills in addressing deficits related to this area, and are well equipped with tools to modify tasks considered to be overly challenging for any given population. Passing these tools on to caregivers allows for increased independence despite disability and encourages personal empowerment. When individuals are able to fully engage in these tasks with any amount of independence, an element of dignity is added to their life, and they become confident in other areas. This confidence ideally gives women with developmental disabilities a voice regarding the level of care they should expect, and in principle, decreases their vulnerability in healthcare settings. Further, increasing functional independence in women with developmental disabilities lessens the physical and emotional burdens experienced by caregivers. In addition to a programmatic plan of action, these services can be provided on a consultative basis through direct observation and demonstration, designed to specifically address the demands of each situation.

Instrumental activities of daily living (IADLs). Similar to ADLs, these occupations are personally relevant, however they are typically more broad-based, and require higher-level skills. Examples of IADLs include community-based experiences such as safety, mobility, and health-management maintenance (AOTA, 2014, p. S19). Women with developmental disabilities and their caregivers would benefit from client-centered strategies to improve their access to healthcare. These teaching and learning strategies are routine intervention tools used within the occupational therapy profession, and like ADLs, can be implemented using formal programmatic

and consultative services. Breaking down the intricate components of women's healthcare experienced by each woman with developmental disabilities, analyzing those components, and developing strategies to address the disparities found within, will encourage better experiences.

Environmental barriers. As previously discussed, significant emphasis is placed on the context of the environment because it impacts participation. Barriers within the context are evaluated further so problem-solving strategies can be developed. These barriers could include physical barriers, such as the poor design of a mammogram machine limiting access for a woman with physical disability. Ergonomic modifications can many times be made through occupational therapy practitioners specializing in this area. These specialists work closely with other disciplines such as biomedical engineers or architects to develop products and room designs appropriate to address the needs of individuals with varying needs.

Barriers could also include those challenging a person's internal structure. A woman with developmental disabilities may interpret components of the environment related to sensory input such as loud machines, bright lights, or irritating textures differently than the general population. Reactions to such stimuli could include fear, behavioral outbursts, and non-compliance with recommended screenings. The role of occupational therapy in helping caregivers prepare for these challenges for women with disabilities is broad, and again, can incorporate formal, programmatic structures, or consultative services. Educational materials such as handouts that are informational and interactive can be tailored, and distributed to caregivers to provide problem-solving strategies relevant to their specific situations. For example, a checklist designed for a caregiver can be sent to the clinic's scheduling department ahead of time. This allows the caregiver to communicate pertinent pieces of information related to their specific set of circumstances when scheduling appointments for their loved one. This

provides schedulers with accurate information that can be forwarded to healthcare practitioners who directly administer treatments to women with developmental disabilities. Strategies for caregivers that are client-centered and occupation-based may encourage better outcomes related to women's healthcare experiences for women with developmental disabilities.

Supports for women in healthcare setting. Programs focusing on ethical issues in healthcare are appropriate areas of content to address by occupational therapy. Literature previously discussed and findings from data collected both support ethical issues in healthcare settings as factors limiting full participation in life for women with developmental disabilities. Components of therapeutic communication including body language, voice control, and word choices that consider the cognitive and psychosocial aspects of clients and their caregivers should be emphasized and used to encourage rapport building between patients and those providing healthcare services.

Educational programs encouraging ethical and safe healthcare practices are appropriate to address as well and are supported by the occupational therapy domain. Education, used as an intervention provides knowledge to be gained for the purpose of developing positive changes. These positive changes become constant routines that benefit the specific set of circumstances (AOTA, 2014, p. S42). Lifelong education is critical for all individuals working with people who may be considered vulnerable. Advancements in medicine broaden the knowledge base and create changes in protocol that require consistency among professions. Changes in policies and procedures such as billing and documentation practices should be addressed to reflect current laws and guidelines. Compliance with general care practices such as universal precautions, fire and electrical safety, and disaster preparedness are typically mandated in healthcare settings. Regular training in these areas is meant to promote safety, as well as to prepare services

providers for unexpected situations. Educational foci also address unique aspects related to the care of specific populations for the purpose of providing healthcare practitioners a knowledge base to support appropriate treatment protocols, thereby encouraging a level of care that is patient-centered. Opportunities exist for occupational therapy services to address the current state of services delivered to women with developmental disabilities in terms of women's healthcare. The delivery of these could be through mandated in-services, continuing education courses (a requirement by many professions to uphold licensing credentials), or consultative services.

Strong support for service providers can indirectly promote participation in women's health care services by women with developmental disabilities. There is great variety in the background, knowledge and training among professionals who provide services to women with developmental disabilities. The supports provided to service providers should reflect their specific professional roles and responsibilities. Occupational therapy practitioners can analyze the needs of the service providers and develop programs to support them. The subsequent impact may translate to their care of women with developmental disabilities as related to women's health care.

Direct support professionals (DSPs). These individuals care for individuals in long-term settings and become intimately involved in the care of women with developmental disabilities. Consultative interventions such as ADL training will emphasize the positive role of independence for women with developmental disabilities. Structured supports for these individuals should include additional ethical components such as dignity with regards to modesty. Additional consultative efforts should address the physical demands on DSPs.

Strategies for body mechanics and client safety will promote feelings of emotional and physical security for women with developmental disabilities in women's health related settings.

Technologists. These service providers administer procedures such as mammograms. Supports for these service providers can include consultative efforts relating to advocacy for women with developmental disabilities. These professionals will benefit from learning strategies for possible outward behaviors sometimes displayed by individuals with developmental disabilities that are considered unconventional by the general public. Women with developmental disabilities may be more accepted in healthcare settings where individuals providing services such as mammograms have advanced knowledge of potential situations and who are comfortable implementing strategies to prevent or deescalate unusual behaviors.

Women's healthcare providers. The data collected from the participants of this study confirm a number of concerns for women with developmental disabilities that relate to communication barriers, education, and available supports for women. By providing consultative services to others involved in the care of women with developmental disabilities, women's healthcare providers stand to gain by the improvements made in the areas of communication, education, and the overall collaboration between all stakeholders invested in the care of women with developmental disabilities. As a result, women would have better experiences with women's healthcare services.

Conclusion

Although the themes identified support the findings in the literature relating to poor access to women's health care for women with developmental disabilities, they also illustrate a level of advocacy available to women with developmental disabilities by professionals invested in their care. Both groups of participants demonstrated strong support for quality care for

women with developmental disabilities. They further reported potential benefit from the improvement of existing conditions. The Occupational Therapy Practice Framework (2014) defines the professional responsibilities and obligations of the profession of occupational therapy. The framework also clearly illustrates an appropriate role for occupational therapy practitioners as active members of the team closely involved in the care of women with developmental disabilities. Providing positive supports for women with developmental disabilities and the stakeholders invested in their care will increase the likeliness of successful experiences had regarding women's healthcare. These experiences are important and will greatly contribute to their overall quality of life.

Acknowledgments

I would like to thank Dr. Metz for her guidance and support throughout this process. In addition to her clinical and research expertise, this qualitative study would not have been possible without her patience with me, her love and compassion for people, and her overall knowledge and dedication for the profession of occupational therapy.

I would also like to thank those individuals who agreed to participate in my focus groups. The insight they provided into the needs of women with developmental disabilities and the array of concerns surrounding their access to gynecological care were inspiring and allowed me to see first hand, advocates willing to come forth and make changes.

I would like to thank Sarah Bialecki for being a terrific interrater. I will always be grateful for all of the time she took away from her own projects and her personal life to make time to work with me to find themes.

I would like to thank the number of authors I grew to know throughout my literature review. There are many people from many disciplines who are active in the movement supporting better access to women's healthcare for women with developmental disabilities. It is incredibly inspiring.

Finally, I would like to thank every one of the women with developmental disabilities who I have had the pleasure of knowing. Each and every one of them has contributed something wonderful and special to my life in some way. My experiences with them have made me a better parent, a better spouse, a better friend, and an all around better person. These women are awesome people, and they are definitely worth advocating for.

References

- American Cancer Society (2013). *Breast cancer: Early detection*. Retrieved from <http://www.cancer.org/cancer/breastcancer/moreinformation/breastcancerearlydetection/breast-cancer-early-detection-ac-recs>
- American College of Obstetricians and Gynecologists. (2011). *Frequently asked questions, FAQ150, especially for teens, your first gynecologic visit* [Fact sheet]. Retrieved from http://www.acog.org/~media/For%20Patients/faq_150.pdf?dmc=1&ts=20140318T1259152522
- American Occupational Therapy Association. (2007). AOTA's centennial vision and executive summary. *American Journal of Occupational Therapy, 61*, 613-614. doi:10.5014/ajot.61.6.613
- American Occupational Therapy Association. (2014). Occupational therapy practice framework: Domain and process (3rd ed.). *American Journal of Occupational Therapy, 68*(Suppl. 1), S1– S48. <http://dx.doi.org/10.5014/ajot.2014.682006>
- Azikiwe, N., Wright, J., Cheng, T., & D'Angelo, L. J. (2005). Management of rape victims (regarding STD treatment and pregnancy prevention): Do academic emergency departments practice what they preach? *The Journal of Adolescent Health 36*, 446–448. doi:10.1016/j.jadohealth.2004.11.130
- Boyle, C.A., Boulet, S., Schieve, L.A., Cohen, R.A., Blumberg, S.J., Yeargin-Allsopp, M., Visser, S. & Kogan, M.D. (2011). Trends in the prevalence of developmental disabilities in US children, 1997-2008. *Pediatrics, 127*, 1034-1042. doi:10.1542/peds.2010-2989

- Brown, A.A., & Gill, C.J. (2009). New voices in women's health: Perceptions of women with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, 47, 337–347. doi:10.1352/1934-9556-47.5.337
- Di Giulio, G. (2003). Sexuality and people living with physical or developmental disabilities: A review of key issues. *Canadian Journal of Human Sexuality*, 12, 53-68. Retrieved from <http://web.a.ebscohost.com/ehost/detail?sid=220982fd-567d-40f0-a650-8091830daa91%40sessionmgr4003&vid=1&hid=4101&bdata=JnNpdGU9ZWZWhvc3QtbGl2ZQ%3d%3d#db=f5h&AN=11751137>
- Glover-Graf, N., & Reed, B. J. (2006). Abuse against women with disabilities. *Rehabilitation Education*, 20, 43–56. doi: <http://dx.doi.org/10.1891/08970106805065449>
- Janssen, C. G. C., Schuengel, C., & Stolk, J. (2002). Understanding challenging behaviour in people with severe and profound intellectual disability: A stress-attachment model. *Journal of Intellectual Disability Research* 46, 445–453. doi: 0.1046/j.1365-2788.2002.00430.x
- Kopac, C. A., & Fritz, J. (2004). The availability and accessibility of gynecological and reproductive services for women with developmental disabilities: A nursing perspective. *Clinical Excellence for Nurse Practitioners*, 8, 35-42. doi: <http://dx.doi.org/10.1352/1934-9556-50.2.79>
- Law, M., Cooper, B., Strong, S., Stewart, D., Rigby, P. & Letts, L. (1996). The person-environment-occupation model: A transactive approach to occupational performance. *Canadian Journal of Occupational Therapy*, 63, 9-23. doi:10.1177/000841749606300103

- Mahoney, A., & Poling, A. (2011). Sexual abuse prevention for people with severe developmental disabilities. *Journal of Developmental and Physical Disabilities*, 23, 369–376. doi:10.1007/s10882-011-9244-2
- Nelson, D. L. (1988). Occupation: Form and performance. *American Journal of Occupational Therapy* 42, 633-641. doi:10.5014/ajot.42.10.633
- Parish, S. L., Moss, K., Richman, E. L. (2008). Perspectives of healthcare of adults with developmental disabilities. *Intellectual and Developmental Disabilities* 46, 411- 426. doi: 10.1352/2008.46:411–426
- Parish, S. L., & Saville, A. W. (2006). Women with cognitive limitations living in the community: Evidence of disability-based disparities in health care. *Mental Retardation*, 44, 249–259. doi:10.1352/00476765(2006)44[249:WWCLLI]2.0.CO;2
- Parish, S. L., Swaine, J. G., Luken, K., Rose, R. A., & Dababnah, S. (2012). Cervical and breast cancer-screening knowledge of women with developmental disabilities. *Intellectual and Developmental Disabilities*, 50, 79–91. doi:10.1352/1934-9556-50.2.79
- Sanfilippo, J. S., & Lara-Torre, E. (2009). Clinical expert series, adolescent gynecology. *Obstetrics and Gynecology*, 113, 935–947. doi:10.1097/AOG.0b013e31819b6303
- Schalock, R. L., Brown, I., Brown, R., Cummins, R. A, Felce, D., Matikka, L., ... Parmener, T. (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Report of an international panel of experts. *Mental Retardation*, 40, 457–470. doi:10.1352/0047-6765(2002)040<0457: CMA AO Q>2.0.CO;2

Schwartz, K. B. (2009). Reclaiming our heritage: Connecting the founding vision to the centennial vision. *American Journal of Occupational Therapy* 63, 681–690. doi: 10.5014/ajot.63.6.681

Todd, A., & Stuijbergen, A. (2012). Breast cancer screening barriers and disability. *Rehabilitation Nursing*, 37, 74–79. doi:10.1002/RNJ.00013

United States Department of Health and Human Services, Centers for Disease Control (n.d.). *Developmental disabilities* [Key findings: Trends in prevalence of developmental disabilities in U.S. children 1997-2008]. Retrieved from <http://www.cdc.gov/ncbddd/developmentaldisabilities/features/birthdefects-dd-keyfindings.html>

United States Department of Health and Human Services, Centers for Disease Control and Prevention (2012). Health, United States, 2012: With special feature on emergency care. Retrieved from <http://www.cdc.gov/nchs/data/hus/12.pdf#082Hyattsville,MD>. 2013.

United States Department of Health and Human Services, Office of Population Affairs (2013). *Pap test* [Fact sheet]. Retrieved from <http://www.hhs.gov/opa/pdfs/pap-test-fact-sheet.pdf>.

United States Department of Health and Human Services, Office on Women's Health (2010). *Mammogram Fact Sheet*. Retrieved from <http://womenshealth.gov/publications/our-publications/fact-sheet/mammograms.cfm#c>

United States Department of Health and Human Services, Office on Women's Health (2013). Why see a gynecologist? Retrieved March 16, 2014, from http://www.girlshealth.gov/body/health_help/gynecologist.html

- Wilkinson, J. E., Dreyfus, D., Cerreto, M., & Bokhour, B. (2012). “Sometimes I feel overwhelmed”: Educational needs of family physicians caring for people with intellectual disability. *Intellectual and Developmental Disabilities, 50*, 243–250. doi:10.1352/1934-9556-50.3.243
- Wilkinson, J.E., Lauer, E., Freund, K. M., & Rosen, A. K. (2011). Determinants of mammography in women with intellectual disabilities. *Journal of the American Board of Family Medicine JABFM, 24*, 693–703. doi:10.3122 /jabfm. 2011.06. 110095

Appendix A

Service Provider Focus Groups

After they are informed of what typically happens during a first gynecological visit, as well as a brief summary of what happens in subsequent visits, the service providers will be asked to discuss the following questions.

- What challenges do you predict
- What information should be shared between all involved prior to the initial visit?
- What can caregivers/clients do to be prepared?
- What preparations/modifications can women's health providers make?

Appendix B

Women's Healthcare Provider Focus Groups

After they have a brief introduction to developmental disabilities, these professionals will be asked to discuss the following questions:

- What challenges do you predict?
- What questions should the caregivers be prepared to answer?
- What should the client/caregiver be prepared for?
- What kinds of preparations/modifications would your office be able/willing to make?
- How should caregivers go about requesting preparations/modifications?

Appendix C

Explanation of First Gynecological Exam and Subsequent Exams

The investigator will read:

The following information is found in a fact sheet for teens released from the American Congress of Obstetrics and Gynecology. It reads:

“The first visit may be just a talk between you and your doctor. You can find out what to expect at future visits and get information about how to stay healthy. You may have certain exams at the first visit. If you choose, a nurse or family member may join you for any part of the exam. Most often, the exams performed are a general physical exam, and an external genital exam. During the general exam, your height, weight, and blood pressure will be checked. You also will be examined for any health problems you may have. An external genital exam is when the doctor looks at the vulva. He or she may give you a mirror so that you can look at the vulva as well. This exam is a good way to learn about your body and the names for each part.” (ACOG, 2011)

- Girls should have their first gynecologic visit between the ages of 13 and 15
- For the purpose of establishing rapport and to avoid feelings of awkwardness or embarrassment, careful interviewing and counseling should precede an examination (Sanfilippo & Lara-Torre, 2009, p. 936).
- Thereafter, an external genital exam will be done. This is when the doctor looks at the vulva. He or she may give the patient a mirror so they can look at the vulva as well. (ACOG, 2011)

Next, a description of a typical Pap test and pelvic exam will be read to the participants:

- A pelvic exam is not typically necessary until a woman is 21 years of age, or three years following her first experience with sexual intercourse.
- A pelvic exam includes: Examining the vulva, using a speculum to examine the vagina and cervix, and using a gloved hand to examine the internal organs
- A Pap test involves a sample that is gathered with a small brush during the portion of the pelvic exam where the clinician uses a speculum to look at the vagina and cervix (ACOG, 2011)
- While the patient lies on an exam table, the healthcare practitioner puts an instrument called a speculum into their vagina, opening it to see the cervix.
- The healthcare practitioner will then use a special stick or brush to take a few cells from inside and around the cervix.
- The cells are placed on a glass slide and sent to a lab for examination.

(U.S. Department of Health and Human Services, 2013).

Appendix D

Brief Introduction to Developmental Disabilities

The following will be read to the Women's Healthcare Provider focus group.

A brief explanation will be given of developmental disabilities, and specific challenges faced by women with developmental disabilities according to the literature review.

A loose definition of developmental disabilities was retrieved from the Center for Disease Control's website. It reads:

- According to the Center for Disease Control, developmental disabilities are usually life long, and diagnosed before age 22. They are a group of chronic conditions resulting from mental impairments and/or physical impairments. Individuals with developmental disabilities demonstrate difficulties in basic independent living.
- Common developmental disabilities include autism spectrum disorders, cerebral palsy, and intellectual disabilities.

(CDC, n.d.)

Next, the investigator will read:

- Kopac and Fritz (2004)
 - Studied a nursing perspective on barriers to adequate gynecologic care for women with developmental disabilities.
 - Common barriers included lack of formal training that limited the number of clinicians willing to provide these services to women with developmental disabilities, and fearfulness in participants resulting from communication barriers between clinicians and patients

- Brown and Gill (2009)
 - Used focus groups with women with developmental disabilities who had experienced a gynecological exam at least one time
 - Women reported they felt misunderstood by medical personnel
 - Women reported they did not understand the information that was given to them about their bodies
 - Women reported experiencing fear, anxiety, pain, and overall discomfort when going to the gynecologist
 - Women reported not going back as a result of the barriers mentioned
- Parish, Swaine, Luken, Rose, and Dabanah (2012)
 - Looked at the level of knowledge women with developmental disabilities living with family caregivers in residential settings, and women with developmental disabilities who either lived alone, or with a spouse had regarding cervical and breast cancer screenings.
 - Found that all participants had limited knowledge of both screenings, however they had less knowledge of cervical cancer screenings.
 - Found women who lived with family caregivers had a far less understanding of cervical cancer screening than women living independently or with a spouse
 - Limitations of the study include nervousness among the participants and level of cognition required to respond, however, the questions asked were taken from an assessment created specifically for individuals with developmental disabilities

- Todd and Stuijbergen (2012)
 - Examined barriers experienced by women with physical disabilities with regards to breast cancer screening.
 - Participants reported difficulties with transportation, long wait times, and poor equipment accessibility
 - Participants reported outward frustration demonstrated by the clinicians involved. For example, one woman with multiple sclerosis reported that the technician performing her mammogram became frustrated with her as a result of her inability to “stand up and stay still” for her mammogram
- Wilkinson, Dreyfus, Cerreto, and Bokhour (2012)
 - Looked at the concerns of physicians working with people with cognitive impairments
 - The most reported concerns were the lack of knowledge felt when treating women with developmental disabilities. Participants also reported feelings of intimidation and anxiety resulting from challenging behaviors exhibited by individuals with intellectual impairments, and lack of appropriate resources and support

Appendix E

Person-Environment-Occupation Model of Occupational Performance: Occupational Therapy

Process, (Law et al., 1996, p. 19).

