

EXPLORING THE LEARNING EXPERIENCES OF REGISTERED NURSES WHO ARE
ACTIVELY WORKING WITH CHILDREN WITH INTELLECTUAL DISABILITIES

by

Emma Vanderlee

Submitted in partial fulfillment of the requirements
for the degree of Master of Science

at

Dalhousie University
Halifax, Nova Scotia
August 2020

© Copyright by Emma Vanderlee, 2020

Table of Contents

ABSTRACT	IV
LIST OF ABBREVIATIONS USED.....	V
ACKNOWLEDGEMENTS.....	VI
CHAPTER 1: INTRODUCTION AND RESEARCH PURPOSE	1
RESEARCH PURPOSE AND RESEARCH QUESTIONS	5
CHAPTER 2: LITERATURE REVIEW	6
HEALTHCARE EXPERIENCES OF CHILDREN WITH INTELLECTUAL DISABILITIES	6
NURSES' BELIEFS AND ATTITUDES	10
NURSING COMPETENCIES.....	12
NURSING UNDERGRADUATE AND CONTINUED EDUCATION ON CHILDREN WITH INTELLECTUAL DISABILITIES	13
CHAPTER 3: METHODOLOGY AND RESEARCH DESIGN.....	18
METHODOLOGY	18
FEMINIST POSTSTRUCTURALISM UNDERPINNINGS	18
KNOWLEDGE	20
POWER AND BINARY OPPOSITES.....	20
LANGUAGE AND MEANING	21
DISCOURSES	21
SUBJECTIVITY AND AGENCY.....	22
RESEARCH DESIGN.....	23
SAMPLING AND RECRUITMENT	23
RECRUITMENT STRATEGIES	23
DATA COLLECTION.....	24
REFLEXIVITY.....	27
DATA STORAGE.....	28
DATA ANALYSIS.....	28
TRUSTWORTHINESS.....	30
ETHICS	31
KNOWLEDGE TRANSLATION	32
CHAPTER 4: FINDINGS	33
LEARNING FROM OTHERS	34
LEARNING FROM EXPERIENCE	52
LEARNING FROM TOOLS AND RESOURCES	63
CONSTANT LEARNING PROCESS AND UNIQUE LEARNING CURVE	75
CHAPTER 5: DISCUSSION AND CONCLUSION	81
DISCUSSION	81
FORMAL/EXPLICIT AND INFORMAL/TACIT LEARNING DISCOURSES AND KNOWLEDGE	82
LEARNING FROM OTHERS	85
LEARNING FROM EXPERIENCE	87
LEARNING FROM TOOLS AND RESOURCES.....	89
CONSTANT LEARNING PROCESS AND UNIQUE LEARNING CURVE	91
RECOMMENDATIONS TO NURSES WORKING WITH CHILDREN WITH IDS	93

STRENGTHS AND LIMITATIONS OF THE STUDY AND RECOMMENDATIONS FOR FUTURE STUDIES	94
CONCLUSION	95
REFERENCES	98
APPENDIX A	103
APPENDIX B	104
APPENDIX C	105
APPENDIX D	109

Abstract

This study explored the learning experiences of registered nurses when caring for children with intellectual disabilities (IDs), how they provided best and evidence-based care to children with IDs and any recommendations they had to improve nurses' learning. To explore the learning experiences of registered nurses, the lens of feminist poststructuralism was used to understand how learning experiences were personally, socially, and institutionally constructed through discourse analysis and semi-structured interviews. This study found four themes; learning from others, learning from experience, learning from tools and resources, and constant learning process and unique learning curve. The nurses interviewed experienced informal and formal learning moments and opportunities that they turned into tacit and explicit knowledge. The process of learning to care for children with IDs is a unique and lifelong process that involves learning as you go and different learning processes because of the complexities and unique needs of children with IDs.

List of Abbreviations Used

ID	Intellectual disability
IDs	Intellectual disabilities
FPS	Feminist Poststructuralism
NP	Nurse Practitioner

Acknowledgements

I would like to first thank my supervisor and express my sincerest appreciation to Dr. Megan Aston, for her guidance and encouragement through each stage of the Masters and Thesis process especially when the road got tough. I am very thankful for the hours she has spent on the phone or skyping me to help me through brainstorming and realizing my work, coaching me through the whole process, and then hours editing my proposal, ethics, and thesis. Without her constant support this thesis would not have been realized.

I would like to thank my committee members, Dr. Sheri Price and Dr. Debra Sheppard-LeMoine, for their contribution to this thesis, their input has greatly improved the overall work and without the thesis would not be what it is today.

Lastly, I wish to acknowledge the support and great love of my father, Rick, my mother, Darlene, my brother, Keats and my partner, Guillaume. Their patience, kindness, and support have helped me through all stages of my Masters.

Chapter 1: Introduction and Research Purpose

Nurses are often the first line of care when children and families with intellectual disabilities (IDs) enter healthcare settings (Aston, 2014a; Aston, 2014b; Aston, Breau, MacLeod, 2016). Nurses must negotiate and navigate their ability to provide effective and competent care to children with IDs and this process sometimes includes a steep learning curve for nurses. Becoming a registered nurse in Canada requires the completion of a University degree of a Bachelor of Science in Nursing or Bachelor of Nursing Science that includes a generalist focus in order to prepare students for a generalist practice of nursing. Graduate nurses will then specialize and continue their own learning after graduation to provide effective care for all populations. This may include reflecting on personal or professional experiences, formal continued education, orientation, mentors, online searches, reading and more. This research aims to understand how nurses negotiate and navigate their learning to feel prepared and confident caring for children and families with intellectual disabilities.

The term intellectual disabilities can be defined in different ways depending on the context and country in which it is being used (Brown, 2007). In North America, it is often used within the term intellectual and developmental disabilities. However, internationally intellectual disabilities has become the widely accepted terminology (Brown, 2007) and will be used in this proposal with the following definition: An intellectual disability (ID) is defined in the ‘Diagnostic and statistical manual of mental disorders – 5th edition’ (DSM-5) as an impairment of general mental abilities that impact adaptive functioning in three domains; conceptual domain, social, domain, and practical domain (American Psychiatric Association, 2013). These domains determine how well an individual copes with everyday tasks. An ID is characterized by an onset in childhood, before the age of 18, and significant limitations in adaptive behaviour and

intellectual functioning (American Psychiatric Association, 2013; American Association of Intellectual and Developmental Disabilities, 2019; Schalock R.L. et al., 2011). Children with IDs are a heterogeneous group and their characteristics may vary greatly due to different factors. One determining factor is that IDs are often co-occurring with other conditions such as, but not limited to, autism spectrum disorders, cerebral palsy, down syndrome, fetal alcohol syndrome, attention-deficit disorder, and more (American Psychiatric Association, 2013). A meta-analysis of the international prevalence of IDs in children estimated that about 1.8% of all children and young people globally have an intellectual disability (Maulik, et al., 2011).

For children with IDs, they do not act, participate, and communicate within society the way typically developing children do; and therefore, they are considered a vulnerable population (Brown, 2007). Due to unequal power relations, discrimination and exclusion, people with IDs are also considered a marginalized population (Brown, 2007). Children with IDs face higher rates of mental and physical health problems than the general population (Walsh, et al., 2000). Studies have also shown that children with IDs tend to spend more time in healthcare systems and have longer admission stays (Brown & Guvenir, 2009; Walsh, et al., 2000). The marginalization of this population can create challenges and stigmatization for children and their families in society, specifically when they require help within our healthcare systems.

As a newly graduated registered nurse, I spent a few months working on a generalist pediatric unit in Northern Ontario. Based on my personal experience I felt unprepared and sometimes uncomfortable working with new patients and their families who had intellectual disabilities because I had no previous knowledge of the disability or ways to provide safe, effective, evidenced-based care. I spent extra time reading and researching the disability and watching experienced nurses interact with patients before I felt confident and capable of caring

for families on my own. It is my belief today that my lack of knowledge affected the care I was able to give.

In terms of providing quality effective nursing care to children with IDs, it is important to note that some empirical studies have shown that nurses, at any stage in their career, may feel unprepared, uncomfortable, and unequipped to be working with children with IDs (Aston, Breau, & MacLeod, 2014; Avis & Reardon, 2008; Brown & Guvenir, 2009; Lewis, & Stenfert-Kroese, 2010; Matziou, Galanis, Tsoumakas, Gymnopoulou Perdikaris & Brokalaki, 2009). Fear, negative attitudes, stereotypes and lack of education are some of the reasons that parents and nurses provide when referring to nurses' discomfort and inability to provide necessary competent and safe care for children with intellectual disabilities (Avis & Reardon, 2008; Breau, Aston, & MacLeod, 2016; Brown & Guvenir, 2009; Lewis & Stenfert-Kroese, 2010; Matziou, et al. 2009). However, there are few studies that have identified clear solutions to improving nursing care for children with intellectual disabilities for nurses that focus on learning. There is also a lack of research on the type of learning that helps nurses provide competent care for children with intellectual disabilities. Because children with ID spend more time in the health care system than typically developing children, they have more co-morbidities, and experience stigma and stereotypes (Brown, et al. 2009; Walsh, et al. 2000). It is important to examine the type of care provided by nurses, what best care should be, and what type of learning could improve care for children with ID. In this research study, the purpose is to uncover a deeper understanding of strategies to improve the learning of nurses who work with this population. Learning may include education programs, mentoring by others or personal online searches to name a few. By examining the learning experiences of nurses working with children with IDs in healthcare settings, it is anticipated that a deeper understanding of the learning needs of nurses working

with children with IDs will be gained and may lead to recommendations of best learning practices.

A study completed by Breau, Aston, and MacLeod in 2016 explored to better understand the complex factors that can impact the hospital experiences of children with IDs and their families. Overall the study found four main themes; diagnoses, labels and stereotypes, building relationships, reducing stigma through education and knowledge, and ID information sharing. Within these themes, they specifically discussed the importance of reducing stigma through education and knowledge. They created recommendations for improving future practice, including the need to conduct further research to understand the educational and learning experiences of nurses as it would be beneficial in improving the experiences of children with IDs in healthcare settings.

Therefore, this study conducted built on the previous study to address a gap in understanding the learning experiences of registered nurses at any stage in their nursing career who work with children with IDs with the intent of improving care and supporting nurses to feel better prepared and able to practice competently and safely with this population of children and their families. This included (but was not limited to) learning in undergraduate programs, personal experiences, continuing education, orientation, mentors, work seminars, hospital based programs, and online searches and resources. Understanding the learning experiences of nurses at all levels will help to close the gap on why education is an issue for nurses working with children with IDs by looking beyond formal education of nurses and examining all possible areas of learning registered nurses may attempt during practice.

Research Purpose and Research Questions

The purpose of this study was to explore the learning experiences of registered nurses when caring for children with intellectual disabilities, how they provided optimal care to children with IDs and any recommendations they had to improve learning. To explore the learning experiences, the lens of feminist poststructuralism (FPS) was used with discourse analysis to understand how experiences were personally, socially and institutionally constructed through discourse analysis. Therefore, the research questions were 1) How do registered nurses experience learning how to care for children with intellectual disabilities? 2) How do registered nurses experience social and institutional constructions of learning? 3) What recommendations do registered nurses have to improve learning?

Chapter 2: Literature Review

Nurses are often the front line of care within many healthcare settings and spend a significant amount of time caring for children with IDs and their families (Aston, 2014a; Aston, 2014b; Aston, Breau, MacLeod, 2016). It is important they possess the necessary evidence-based competencies and skills to promote health and well-being for this marginalized population. Past and present literature sheds light on the health disparities that children with IDs face, through examining their healthcare experiences from the perspectives of parents and nurses. There is also a small body of literature that examines the attitudes of nurses towards caring for this population. There is a lack of research-based information on what specific competencies are required by nurses to provide optimal care to children with IDs. There is also a lack of evidence on how nurses are best educated on those competencies that in turn would provide quality effective nursing care for all children with IDs. Throughout all the literature no study focused specifically on the clinical and educational learning experiences of nurses working with children with IDs in healthcare settings in Canada.

Healthcare Experiences of Children with Intellectual Disabilities

Studies have been conducted on the experiences of children with IDs in healthcare settings through a variety of perspectives such as parents, caregivers, and nurses, with only a few including the experience of the children (Aston, 2014a; Aston, 2014b; Aston, Breau, MacLeod, 2016; Avis & Reardon, 2008; Brown & Guvenir, 2009). This literature has found that the experiences of children and families with IDs in healthcare settings are generally negative (Barr & Sowney, 2007; Iacono & Davis, 2003).

In 1998, Hart completed 13 interviews of people with learning disabilities on their experiences with general hospital services. Grounded theory was the underpinning of this study

and the study found several areas where the needs of people with learning disabilities were not met or considered in their care. Five key themes were identified within this study; fear, general nursing care, communication about treatment, consent to treatment, and doctors. Only the first three themes were discussed in detail in the article. The patients identified being fearful of treatments and medical services which resulted in a number of reactions from the patients that they were often unable to control. Of all the patients, only one described an interaction with a nurse that demonstrated high levels of care, most were unsatisfied with their nursing care. Communication was very important for the patients and they found the nurses often spoke to others in the room before them, which was described as negative. The participants in the study wished to be spoken to first. The themes identified in this article are continuously identified in more recent literature discussed throughout this review because they are often the underlying aspects to general feelings and attitudes of negativity.

A study on the experiences of people with developmental disabilities in emergency departments in Australia was conducted by Iacono and Davis (2003). A questionnaire was created to learn whether patients' needs during hospital stays were met. A total of 328 questionnaires were completed, and of those 328, 119 had attended an emergency department. The respondents mostly felt that their needs for hydration and nutrition, medication, mobility and discharge were met. The authors conducted follow-up interviews with 11 respondents or their care givers. In these interviews the themes that emerged were an excessive reliance on care givers from the hospital staff, negative attitudes by hospital staff, and a lack of knowledge and skills in developmental disabilities. The article goes on to make suggestions for improving the issues that arose in the interview which included more exposure in nursing undergrad curriculum

and more time spent working with patients with developmental disabilities during nursing education.

One study by Avis and Reardon (2008) examined the views of parents of children with intellectual disabilities. They conducted a qualitative study to learn how parents felt about the nursing care their child received in hospital by interviewing 12 parents. This study found that parents' perceptions of nurses was that they were not always trusting of the nurses' capabilities and that the nurses would have caring attitudes. Parents were often concerned about the approach nurses take to care for their children and to recognize the needs of the parents. The concern from the parents often reflected negative relationships between nurses and parents. The parents voiced a distrust for nurses because the parents believed the nurses were unable to meet the needs of both child and parent, in particular the needs of the child without the help of the parent. The study suggests that there is a gap between theory and practice relating to family-centred care. In this article parents of children with IDs are deemed 'experts' in their childcare, the parents in this study found this contributed to a decrease in quality nursing care. The findings of this study lend weight to the need to develop an educational model for improving communication between nurses, families, and children.

Brown and Guvenir (2009) interviewed 13 carers of children with IDs who were in hospital for a period longer than 24 hours, nurses and two children with IDs using a semi-structured interview format. Carers, children and nurses all reported feeling anxious about the admission. Many carers believed nurses were often unprepared for their child's needs on admission. Nurses also stated that if a carer was not present during admission it was extremely difficult to meet the children's needs. The nurses' shared that they often lacked the confidence, skills, and experience to work with this marginalized population. Suggestions for improving

admission and stays of children with IDs from this British study include having specialist learning disability nurses present, having children with IDs in a private room, and clarifying carer and staff roles during admission.

Barr and Sowney (2007) wrote a paper on the current literature regarding the challenges and barriers often faced by people with IDs who seek out urology services. They attempted to identify key areas where challenges may arise for both the patients and the nurses caring for the patients; these areas include establishing effective communication, assessing abilities and needs, promoting decision-making for the patient, obtaining informed consent, and working collaboratively with patients and with other healthcare services. The literature showed that patients and nurses face challenges and barriers to care in all of these areas during a healthcare admission or visit.

A systematic literature review was conducted in Germany in 2013 by Doerschlen, Lachetta, Schulz, and Tacke on patients with learning and physical disabilities in hospital settings. 17 relevant publications were found. The article identifies communication barriers between patients and nurses. They also identified a lack of emphasis on the emotional stress of patients by nurses. Both communication barriers and emotional stress can be affected by time, continuity of care, professional competencies, and attitudes towards disabled people. The suggestion this article gives for improving these issues of communication and emotional stress is increase in family involvement during admissions.

Many of these articles identified that increased or improved education and learning for nurses are needed but none have a focus on how the nurses learned about children with IDs and how this in turn affects the experiences of children and families with IDs in a healthcare setting.

Nurses' Beliefs and Attitudes

It has been suggested that inequalities in the health care of children and people with IDs can be partly related to the attitudes of health care professionals, specifically nurses. It has also been suggested that nurses have the ability to change institutional and societal beliefs and attitudes towards children with IDs through education and caring actions (Matziou, et al., 2009). Many of the articles in this section found a link between education and learning of nurses and their attitudes towards children and families with IDs.

Lewis and Stenfert-Kroese (2010) conducted a study to measure the attitudes and emotional reactions of nurses towards caring for patients with an ID in general hospitals. This was done using a self-report, vignette style questionnaire. Attitudes towards physical disabilities were also tested as a comparison. Lewis and Stenfert-Kroese (2010) found overall less positive attitudes by nurses towards patients with an ID compared to a physical disability and that they reported their skills and training were insufficient to provide proper care for these patients. They then split the population of nurses into three groups; registered general nurse, student nurse, and nurse assistant, and found no statistical difference in attitudes or emotions towards caring for patients with IDs. This study suggests that less positive attitudes and emotions towards this population amongst nursing staff may negatively affect the quality of care. Suggestions made by Lewis and Stenfert-Kroese (2010) include improving attitudes through increased training, and increased partnerships among nursing staff and community services from people with IDs.

Matziou, et al. (2009) also suggests that health professionals, specifically nurses, do not exhibit the appropriate sensitivity and attitudes towards children with disabilities, resulting in decreased quality of care in health care settings. This study was conducted in Greece surveyed 228 first-year nursing students, 90 post-diploma nurses doing a Master degree, and 123 pediatric

nurses. They found all nurses included in the study generally had a negative view of children with a disability. Post-diploma nurses showed the best attitudes and the pediatric nurses attitudes were significantly the lowest. It was also found that females held significantly more positive attitudes than males. The study suggests that this finding may reflect a lack of nursing education to prepare nursing students for treating children with disabilities. Suggestions from this study include special courses for caring for disabled children to be incorporated into basic nursing studies and/or continuing education in the hospital setting.

Nurses and therapists are two of the largest groupings of healthcare professionals and may spend significant amounts of time with people with learning disabilities. Therefore, McConkey and Truesdale (2000) compared the reactions of nurses and therapists, to those of staff working in specialist services for people with learning disabilities and students not involved in health care services. 1008 questionnaires were completed of 269 nurses, 169 therapists, 270 staff working in learning disability services, and 261 undergraduate students who were not taking health science courses. Nurses and therapists scored their confidence with working with people with learning disabilities significantly lower than staff working in specialist disability areas. Nurses and therapists reported not knowing what to say and that they often had to seek advice for caring for patients with learning disabilities. This all suggests the need for both more education and more contact with people with disabilities in a work setting. The nurses and therapists welcomed both an increase in education and exposure.

The most recent found literature was done by Noronha and Pawlyn (2019) who completed a literature review of articles published between 2006 and 2016 looking at the experiences of general nurses caring for people with learning disabilities. It is suggested in the literature that this population experiences high levels of unmet healthcare needs and poor care

compared to the general population. This is often correlated with general nurses having poorer attitudes and knowledge regarding care for people with learning disabilities. Poor attitudes and a lack of knowledge for caring for people with learning disabilities were identified as the two major themes throughout the literature review. The article explains how these two aspects negatively affect nursing competencies and confidence surrounding care for people with learning disabilities. Noronha and Pawlyn (2019) make the suggestion that increased education, training, and awareness could help address the issue of decreased levels of care for people with learning disabilities.

The literature shows that the importance of education is widely accepted, however there is a gap on how nurses best learn about caring for children and families with IDs. There is also a lack of research on different types of learning nurses may encounter. None of this research looks at relations of power and FPS. FPS will provide a new lens on nurses' learning that includes beliefs, values and practices as well as how personal, social, and institutional discourses are constructed.

Nursing Competencies

One qualitative study was done in the United Kingdom by Lovell, Bailey, Kingdon, and Gentile (2014) on the specific competencies required by nurses to care for people with an intellectual disability, with an offending or criminal background. The study included four focus groups across four settings in which nurses care for people with IDs with offending backgrounds; low, medium, high security, and community settings. They also conducted thirty-nine interviews. This was analyzed using thematic analysis. The findings produced four over-arching competencies required by the nurses; knowledge assimilation and application, team-work, communication skills, and decision-making. All four themes are easily incorporated into each setting when working with people with IDs. The nurses' perceptions of these competencies were

that they could be taught or learnt through proper education and/or work experience. Nurses in this study believe that although the competencies were created for the settings from the study they are transferable to all healthcare settings caring for people with IDs.

As part of the above study, Lovell and Bailey (2017) shared an article discussing the individual or personal attributes required of nurses to work with patients with IDs and an offending background as there are few studies looking at individual competencies. This study identified three personal attributes required by nurses to build effective relationships and provide quality care to patients with IDs with an offending background; these three attributes were looking deeper, achieving balance, and connecting. Looking deeper meant seeing beyond the diagnosis of an ID and offending background and seeing what else makes the patient. Achieving balance in the workplace and at home was considered important for nurses to provide optimal care. Connecting included insight into the patient, empathy and compassion for the patient from the nurses.

A review of the literature reveals an overall lack of research regarding what specific competencies are required by newly graduated nurses to provide quality and effective care to children with IDs and a lack of information regarding how to incorporate teaching and learning of these competencies to nurses.

Nursing Undergraduate and Continued Education on Children with Intellectual Disabilities

Current Canadian Nursing undergraduate programs primarily provide generalist curriculums where they are expected to meet the entry level competencies for a beginning baccalaureate graduate (Silva & Sena, 2006). There are competencies provided at the provincial, national and international levels (Silva & Sena, 2006). Each individual school develops their

curriculum which is then accredited by the National Nursing organization, the Canadian Association of Schools of Nursing (CASN), as well as a provincial nursing body, in Nova Scotia that is the Nova Scotia College of Nursing (NSCN). These competencies are to help prepare nurses to be ready to enter the work force with a beginning confidence and self-awareness, as well as the ability to identify what they know and may not know and where they have learning gaps (Nova Scotia College of Nursing, 2013). Generalist and entry level competencies are provided by the Canadian Association of Schools of Nursing (CASN), as well as the International Family Nursing Association (IFNA) which have competencies more specific to family and pediatric nursing care. The IFNA provides five generalist family nursing competencies that are available in a document on their site for nurses and nurse educators (International Family Nursing Association, 2015).

One Canadian study by Temple and Mordoch (2012) looked at nursing students' perceptions of IDs and their preparation to care for this population. They surveyed 119 fourth-year nursing students and 155 second-year nursing students. 98% of the students felt nurses play an important role in meeting the health needs of people with IDs but that it was a specialized area and 96% did not believe people with IDs should be a lower priority for healthcare. In regard to their education, 82% of second year students and 63% of fourth year students had not received any education on how to interact and care for people with IDs. This study shows that nurses recognize the importance of care for children with IDs but do not receive adequate education.

The existing literature indicates that nurses believe their undergraduate education is not adequate to care for patients with IDs. One recent study conducted in Australia on the intellectual disability content within nursing curriculae in their Universities, specifically how it is taught (Trollor, Eagleson, Turner, Salomon, Cashin, Iacono, Goddard, & Lennox, 2018). Of 31

universities included in the study only half provide any ID content within nursing courses. Within the schools that did include ID content the methods for teaching the content varied greatly, with the most common being lectures, followed by tutorials, workshops, and e-learning. In only five of the schools, the nurses had direct contact with people with IDs, six schools had staff who specialise in IDs, and seven had a staff with a declared interest in IDs. This study suggested to improve education through using multiple methods to teach intellectual disability content, with an emphasis on involving people with IDs in teaching. Not being diverse in the teaching of ID content may result in nursing students continuing the inequalities faced by people with IDs in healthcare settings.

Another article developed from the above study looked at what exactly was included in the ID curriculae provided to students in Australia (Trollor, Eagleson, Turner, Salomon, Cashin, Iacono, Goddard, & Lennox, 2016). For courses or study that included ID content on average 3.6 hours were spent on ID content. The most common content included clinical assessment skills and ethical or legal issues. Human right issues and preventative health was underrepresented. Finally, only one school included a person with an ID in the content development or delivery. There is a high variability in the content taught and many gaps were found relating to important information for nursing students regarding ID content.

Only one study asked about pre-employment education, education before starting their nursing career, or continued education of nursing after their undergraduate education. In New Jersey, Walsh et al. (2000) surveyed 642 nurses on their pre-employment education related to developmental disabilities. Of the nurses surveyed 24% had no exposure to developmental disabilities during their education and 65.7% had little to no education on infants or adolescents with developmental disabilities. After their nursing education, only 17.9% took further education

regarding children with IDs, and 3.5% received on the job training. The majority of nurses indicated some need for further education related to disabilities.

Finally, one study employed a feminist poststructural perspective to better understand the complex factors that impact the hospital experiences of children with IDs and their families (Breau, Aston, & MacLeod, 2016). The analysis revealed four common themes, one of the themes was 'education and training.' The researchers interviewed 17 mothers of children with IDs, 12 nurses who have cared for children with IDs and 8 children with IDs, however the children did not speak about education and training. The nurses and mothers spoke to a lack of education and training, a devaluation of education, what type of education was needed, and the impact of this lack of education. Nurses spoke about how most of their knowledge on IDs was derived from experience rather than education. The nurses and mothers felt that more learning was required beyond what was on the internet, and that it needed to include practical, clinical, and sensitive information focused on families. The nurses had to seek out innovative ways to gain knowledge on IDs because they had received insufficient training in the past. Both nurses and mothers agreed that a lack of education impacts comfort and sensitivity of the nurses, as well as, their knowledge and skills to effectively communicate. In general, a lack of education interferes with a nurses' ability to provide a family with optimal care.

The body of literature that exists and the perspective of children, parents, caregivers, and nurses identified a lack of and importance of education and learning for nurses on the topic of children with IDs. This research aims to provide a more in-depth understanding of how to improve nurses learning to provide nurses with the confidence and abilities required to give optimal care to all children with an ID. This study will explore what type of learning done by nurses led to increased confidence and abilities. The types of learning will be examined through

nurses' personal experiences, insights, and recommendations that incorporates relations of power and discourses.

Chapter 3: Methodology and Research Design

Methodology

Feminist poststructuralism and discourse analysis was used to explore the learning experiences of registered nurses who are actively working with children with intellectual disabilities (Cheek, 2000; Foucault, 1983; Weedon, 1987). This methodology and method helped to understand the beliefs, values, and practices of nurses through the use of interviews. FPS also highlighted the personal, institutional, and social constructs that play a role on their personal practices and attitudes towards working with children with IDs, as well as, their clinical and learning experiences with intellectual disabilities. A feminist approach to the methodology provides a way of examining disabilities, gender, race, culture, and other constructs that may be important to participants (Weedon, 1987). Participants' experiences provided evidence on how they felt, questioned, and understood practices, discourses, and interactions and how nurses may challenge or accept them. This methodology helps to look beyond the fact that more education and learning is needed by nurses and offer unique recommendations and perspectives on how learning is being done by nurses on children and families with IDs.

Feminist Poststructuralism Underpinnings

FPS is the combination of feminist theory and poststructuralism because they draw on many of the same concepts (Barrett, 2005). Both of these ways of thinking work to re-construct the self, gender, knowledge, social relations, and culture without resorting to linear, hierarchical, holistic, or binary ways of thinking and being (Flax, 1987). This way of thinking will provide a lens for the researchers and participants to re-construct their clinical and educational learning experiences with children with IDs.

Originally, feminist theory was created with the fundamental goal of analyzing gender relations, specifically how the gender relations are constituted and experienced (Flax, 1987; Weedon, 1987). It was created alongside of the Women's Liberation Movement in the 1960s (Weedon, 1987). Today, feminist theory is no longer used solely for studies that have gender as a central focus, but rather the concepts can be applied to how all people appropriate and internalize, or conversely, resist and struggle against social, cultural, and economic power relations (Aston, 2016). Feminist theory is especially relevant for any marginalized and vulnerable populations and children with IDs is considered a marginalized and vulnerable population due to stigmatization, stereotypes, and exclusion (Aston, Breau, & MacLeod, 2014). This is seen in healthcare settings for children and families with IDs and affects their quality of care.

Poststructuralism challenges ways in which dominant discourses can trap us in conventional meanings and modes of being (Cheek, 2000; Barrett, 2005). It enables us to look at the social, cultural, and institutional constructs that act on our everyday discourses and the way people negotiate these relations (Cheek, 2000; Weedon, 1987). Using this approach, researchers will be able to analyze the discourses and power relations that play a role on the experiences of nurses working with children with IDs. Children with IDs often fall outside of the dominant discourses in society, and culture and therefore require a lens such as FPS to better understand both their experiences and the experiences of those working with them.

When the concepts of feminist and poststructuralist theories are combined, FPS is produced. Weedon (1987) described feminist poststructuralism as “a mode of knowledge production which uses poststructuralist theories of language, subjectivity, social processes and institutions to understand existing power relations and to identify areas and strategies for

change” (p. 40-41). FPS is a critical social philosophy, theory and methodology (Aston, 2016) that guided this research. It was used to critically examine and understand the clinical and educational learning experiences of nurses working with children and families with IDs.

To better understand how FPS and discourse analysis were conducted in this study, the following concepts were utilized to best understand the learning experiences of registered nurses on caring for children with IDs. The following headings describe the relevant concepts and how they were incorporated in this study.

Knowledge

To understand FPS theory, it is important to understand the approaches to knowledge. FPS rejects the possibility of one reality and one truth (Cheek, 2000; Weedon, 1987). The feminist view challenges male dominant discourses and patriarchal Western society, therefore casting suspicion on the idea of an absolute truth and the poststructural view constructs knowledge through social and institutional relations (Gavey, 1989). Knowledge is transient, inherently unstable and not neutral. Knowledge and knowledge generation is always associated with power and power relations through discursive fields (Gavey, 1989). Participants in the research had the opportunity to share their own truths with the researchers who interpreted the meanings from the participants using their exact words.

Power and Binary Opposites

Power is a central concept of FPS (Foucault, 1982; Weedon, 1987). It looks at how people are influenced by social and institutional constructs but more importantly how people challenge and/or accept power. The theory does not see power as simply a confrontation between two people but rather always dependent upon individual situations because power is relational (Foucault, 1982). People continuously negotiate power in everyday practice and are affected by

social, institutional, and cultural constructs (Foucault, 1982). This concept is also related to binary opposites. Binary opposites lock people into stereotypical thinking and positions such as man and woman, or doctor and nurse (Aston, 2016). FPS challenges this way of thinking and acknowledges how power is linked with knowledge, competence and qualifications as well as individual interactions (Aston, 2016; Weedon, 1987). I attended to relations of power that sometimes began as binary opposites that were evident in the participant interviews that played a role in their clinical and educational learning experiences.

Language and Meaning

Language is a crucial starting point for FPS (Aston, 2016, Gavey, 1989; Weedon, 1987). All meaning and knowledge is discursively constituted through language and practice (Gavey, 1989). The theory analyzes everyday language that interprets our feelings, thoughts, and experiences and the social and institutional constructs that play a part on our language and meaning. Meanings are constructed out of difference and distinctions, not out of direct and immediate essences and substances (Gavey, 1989).

Discourses

Language is believed to always be located in discourses (Foucault, 1982; Weedon, 1987). Weedon (1987) describes discourses as a structuring principle of society that constitutes and is reproduced in social institutions, modes of thought, and individual subjectivity. Discourses affect where and how people act and there are often competing discourses acting upon one person. Discourses have the potential to govern the unconscious and conscious minds and emotions of people as meaning is only created within discourses through a network of power relations (Aston, 2016). “It is through discourses that material power is exercised and that power relations are established and perpetuated” (Gavey, 1989, p. 464). Individuals are active and have a choice

in positioning themselves within these competing and varying discourses. Discourses are analyzed using discourse analysis which is discussed further in this proposal.

Subjectivity and Agency

Subjectivity and agency are constructed through language and discourse (Aston, 2016; Gavey, 1989). “Subjectivity refers to a person’s ability to be conscious of self as well as self-reflexive and able to work with, through and against social discourses that are believed to influence all of us” (Aston, 2016, p. 2258). Western society assumes that there is one essential and unique subjectivity, and FPS rejects this assumption (Gavey, 1989). Subjectivity can be reconstructed through the process of reflective practice and this type of reflection has also been referred to as “agency” (Aston, 2016). Agency is how a person chooses to act in each situation by fitting in or challenging. Registered nurses had the opportunity to discuss their own subjectivity and agency through the use of semi-structured interviews that reflected on their clinical and educational learning experiences.

Although there are many concepts they are all related and create the underpinnings and assumptions of FPS. FPS has the ability to analyze and explore the relations of power that construct the experiences of nurses and patients and uncover the intricacies within healthcare systems that offer meaningful direction for social, institutional, and healthcare changes (Aston, 2016). This theory will enable the newly graduated nurses to examine social justice issues within the healthcare system through relations of power. It is a critical, social analysis that can bring new meaning to their clinical and educational experiences. FPS provides a lens to examine the social, institutional, and cultural constructs and power relations that play a role on the clinical and educational experiences of registered nurses working with children with IDs. It can help uncover the reasons why children with IDs face health disparities and negative healthcare

experiences, as well as, what education is needed by nurses to improve care for children with IDs and how nurses can best conduct this learning.

Research Design

Sampling and Recruitment

To explore the learning experiences of registered nurses who are actively working with children with IDs, registered nurses with varying years of practice experience working at a hospital in Halifax, Nova Scotia were interviewed. Five nurses participated in the interview process. The goal of employing an FPS approach is not to generalize but to gain rich data from individual experiences in a small sample size and identify common themes. Purposive sampling strategy was used in this study as a specific experience was being researched; participants had worked with a child previously diagnosed with an ID (Creswell & Poth, 2017). The inclusion criteria for this study was bachelor prepared registered nurses who are actively working in a hospital setting, in-patient or out-patient, and have provided care to a child identified with an intellectual disability within the past two years. All the nurses who participated had completed a Bachelor of Science in Nursing degree and were currently working in a setting where they saw children with intellectual disabilities. This ensured that the nurses shared a similar educational background and allowed the interview to focus on their learning process working with children with IDs. The nurses were able to fluently read, write and speak English.

Recruitment Strategies

Recruitment strategies included the use of flyers, posters and snowball sampling. Flyers were distributed on different units of the IWK Health Center in Halifax, Nova Scotia that cared for children with IDs after ethics approval had been obtained from the IWK Health Center research ethics board. Snowball or chain sampling identified people of interest from other

participants. This allowed me to find more participants through word-of-mouth and sharing of the recruitment poster. The flyers and recruitment posters included a phone number and email address to contact me with any questions related to the study, or if they were interested in participating. Consistent with snowball sampling, participants who initially agreed to participate in the study were given a flyer with information to pass on to encourage others to join. Emails were sent to floor managers with the recruitment poster and explanation of the study to be shared by them to the nurses on their units. Participants were given gift cards of \$25 to a local store to reimburse their time.

Data Collection

Data on the experiences of nurses actively working with children with IDs was gathered through face-to-face in-depth, semi-structured interviews (Appendix A). Qualitative interviews “attempt to understand the world from the subjects’ point of view, to unfold the meaning of their experience, to uncover their lived world” (Creswell & Poth, 2017, p. 164). Semi-structured interviews are designed to gain subjective knowledge from participants of the study regarding a particular situation they have experienced (Mcintosh & Morse, 2015). In this study nurses were asked about their educational, clinical, and personal learning experiences with children with IDs. This means the participants were asked about all learning they have done regarding IDs including undergraduate educational experiences, prior knowledge and personal experiences, and any continued education done by employers or themselves. Participants were asked to discuss any way they felt they learned or did not learn about IDs.

The use of semi-structured interviews was chosen because they employ a relatively detailed interview guide that is used when there is sufficient objective knowledge about an experience but a lack of subjective knowledge (Mcintosh & Morse, 2015). This is the case for

nurses working with children with IDs. The results of semi-structured interviews create descriptive summaries from participants that are valuable for end-products as well as for entry points for future research studies (Mcintosh & Morse, 2015). The interviews were done face-to-face in a private place of the participants' choosing, this included either a private room in the IWK Health Center or a private room in Dalhousie University. Telephone interviews were also utilized for participants who were unable to meet in person.

Face-to-face interviews yield many advantages. The presence of the interviewer allows communication to be optimized because both verbal and non-verbal communication occurs. It also gives more structure to the interview and allows for easier and unscheduled prompting of the interviewee (Mcintosh & Morse, 2015). As well, the presence of the interviewer may lower discomfort or unease of the participant and can offer a break or emotional support (Mcintosh & Morse, 2015).

Telephone interviews are often used as an alternative to face-to-face but it should be acknowledged that this prevented the researcher from observing non-verbal cues of the participant (Creswell & Poth, 2017). However, the advantages of telephone interviews include; enhanced accessibility, auditory communication, which may remove preconceived ideas about the interviewed based on appearance, and they are often less costly in terms of time and labor for the researcher and participant (Mcintosh & Morse, 2015).

The interviews were implemented to be non-hierarchical. FPS research attempts to uncover personal stories and experiences of participants and to do this a relationship must be developed during an interview that is non-hierarchical (Roberts, 1981). Feminist scholars have often focused on the powerlessness of interviewees, but in 1981 Ann Oakley, argued that an interview must not be viewed as simply an exercise but rather an empowerment process for both

interviewee and interviewer. She argued that maintaining objectivity in interviewing is not only impossible but also overlooks the emotional role of interviewing and presents a ‘masculine paradigm.’ Today, feminist scholars focus on non-hierarchical interviewing with an intention to reduce power imbalances between interviewer and interviewee, including care, and empowering interviewees, in hopes of enabling social change through research (Boucher, 2017). Power relations between interviewer and interviewee are often inevitable, therefore, the researcher positioned herself with the interviewees to attempt to provide a positive and comfortable environment for the interviewee. I, the researcher, positioned myself as a Caucasian Canadian female from Ontario, who is a newly graduated registered nurse with experience on a general pediatric unit and with working with children and families with IDs. It is my opinion that being a registered nurse may have positioned me to have some similar experiences as the interviewees. Having similarities in professional position and experience may have helped to reduce some power imbalances that can be perceived between myself and an interviewee.

Interviews were arranged at the participant’s convenience. The interviews lasted between 30 minutes to an hour. A semi-structured interview guide was developed for the interviews (Appendix A). The guide included open-ended questions and probes to facilitate conversation. The semi-structured interview guide was reviewed by all members of the committee. The interview guide was updated and edited after interviews, as I noticed reactions to questions.

Participants also completed a demographic questionnaire. Demographic questions helped to determine factors that could influence the respondent’s answers. This questionnaire included questions of gender, race, age, education, and employment, specifically what unit they were employed by and the length of time on the unit, as well as other employment experience. This allowed the interviewer to better understand their professional and educational backgrounds that

affected their learning experiences. All interviews were audio recorded and transcribed by the researcher verbatim. Language and word-for-word transcriptions are important in FPS research to ensure the analyses of the interviews understands the participants' point of view, from their perspective and not the perspective of the researchers (Aston, 2016).

Reflexivity

In qualitative research, it is believed that how we write is a reflection of our own interpretation based on cultural, social, gender, class, and personal politics (Creswell & Poth, 2017). To ensure reflexivity the researcher is expected to reflect on their own position and personal politics in relation to those they are interviewing. I am a newly graduated registered nurse with experience on a general pediatric unit and working with children and families with IDs, therefore I was conscious of not assuming the participant had similar views and experiences as myself. Extra prompts and questions were included in the interview guide to use during the interview process to ensure I understood the perspective of the interviewee. I also took into consideration power relations between myself and an interviewee as being an interviewer may be seen as a place of power. I attempted to reduce power relations by positioning myself, as stated before. I actively considered any influences I may have upon the interview process and the data generated as a result of my role, beliefs, gender, class, and culture. I considered my position as a Caucasian female, newly graduated registered nurse in Nova Scotia, as well as any previous beliefs and knowledge on the subject. I was conscious of these aspects and the role they may play on my interpretations. In feminist research, one cannot look at data with an unprejudiced view (Oakley, 1981), therefore I considered their affect and actively worked to see the view of the participants.

In this study reflexivity was accomplished by the researcher keeping a record of thoughts and ideas during planning and carrying out of the interviews, during transcription, and during data analysis (Creswell & Poth, 2017). These thoughts and ideas were written electronically. All notes were discussed throughout analysis by myself and my supervisor in an effort to recognize any assumptions, correct misapprehensions and avoid premature interpretations of the data (Avis & Reardon, 2008).

Data Storage

All data was stored based on ethical suggestions and suggestions from Creswell and Poth (2017). Data collected included audio recorded interviews on a recording device, transcriptions of interviews, and electronic notes from interviews and analysis. Data was protected by using purchased, not shared, high quality recorders, all data with participant names and affiliations was kept confidential by the use of pseudonyms, and all data was backed up on an external hard drive (Creswell & Poth, 2017). All electronic data was kept password protected including, password locked hard drive and password locked computer files using Word documents. Recorders and hard drives were kept in separate locked cabinets or drawers in the supervisor's office at Dalhousie university and the primary researchers home office. Only researchers involved directly in the study had access to any of the data, this included myself, my supervisor, and two committee members.

Data Analysis

Data analysis of the transcribed interviews was done through a deconstructive process using discourse analysis. Discourse analysis is often used with FPS. Weedon (1987) stated that "social structures and processes are organized through institutions and practices such as the law, the political system, the church, the family, the education system and the media, each of which is

located in and structured by a particular discursive field” (p. 35). Discursive fields helped me to understand how discourses competed with one another and how a person experienced power (Weedon, 1987). Using discourses ensured that no matter whom the person is, the focus is always on their voice, their experience, their meaning and how they want to tell it. Discourse analysis allowed me to examine the dominant and external discourses playing a role on the learning experiences of nurses when working with children with IDs. This is why many people who use FPS also use discourse analysis (Aston, 2016).

Discourse analysis involves the analysis of texts such as transcripts from focus groups or individual interviews, or existing documents or records, followed by finding emerging themes within the texts (Gavey, 1989). In this study, transcribed individual interviews were analyzed. It is important to stay true to the experience of the participants so therefore close attention was paid to the beliefs, values, and practices of each individual on the important clinical and educational issues they identified. From there, social, institutional, and cultural discourses that played a role on the individual were identified, as well as, the relations of power. Lastly, a person’s subjectivity and agency were analyzed (Aston, 2016). Discourse analysis allowed me to understand the experiences of individuals as they negotiated power within social, institutional and cultural discourses.

Analysis was an ongoing process that began after the first interview was completed. Emerging findings helped inform the semi-structured interview guide by shedding light on minor modifications or clarifications as needed. The analysis of each transcript was shared with my supervisor and themes were identified. After discourses and themes were identified in each interview, comparisons between interviews occurred to discover overall themes. These themes led to a discussion of recommendations for future nursing education, learning, and practice. NVivo

and Atlas.ti are not conducive to FPS research as they do not support a discourse analysis and therefore neither were used during analysis. Only the software Word was used.

Trustworthiness

Trustworthiness in a study refers to the degree of confidence in the data, the interpretation, and the methods used (Connelly, 2016). In this FPS research study trustworthiness was established through strategies suggested by Creswell and Poth (2017) and by Lincoln and Guba (1985) to ensure the study is worthy of consideration by readers. This included methods to establish credibility, dependability, confirmability, and transferability.

Credibility is the confidence in the truth of the study as the findings are the most importance criterion for credibility (Connelly, 2016). Strategies used in this research study to establish credibility or validity included clarifying research bias, engaging in reflexivity, and debriefing the data and research process with my supervisor and committee members who are familiar with this type of research (Creswell & Poth, 2017). Clarifying research bias and reflexivity was previously described in this proposal under ‘reflexivity.’ I debriefed all steps of the analysis process with my supervisor who is an expert in feminist poststructuralism. This helped to remove any bias unnoticed by the researcher.

Dependability is the stability of the data over time and conditions of the study (Connelly, 2016). Dependability in this study was accomplished by keeping detailed process logs, notes and documents of each step of the research process so future researchers can follow the same research design (Creswell & Poth, 2017, Lincoln & Guba, 1985). These documents were kept locked and will only be shared for auditing purposes from the IWK research ethics board.

Confirmability refers to the degree in which the findings are consistent or can be repeated in future studies (Connelly, 2016). This was done by discussing my field notes and analysis with

my supervisor. These debriefing sessions were helpful as it enabled me to pay attention to having only one perspective on the research findings (Lincoln & Guba, 1985).

Transferability is the fourth component of the research study that helped ensure trustworthiness of the research. Transferability is the extent in which the findings are useful to persons in other settings (Connelly, 2016). Transferability of this study was established by having rich, detailed descriptions of the stories shared by the nurse participants and by being transparent about analysis (Connelly, 2016).

Ethics

Ethics approval was obtained through the IWK Health Center Research Ethics Board prior to starting the study. The FPS research of the learning experiences of nurses involved human participants. Therefore, written and verbal consent was obtained by each participant prior to the interview process. They were not pressured or coerced into participation (Creswell & Poth, 2017). Participants were given a consent form to sign prior to the start of the interview. Consent forms were then kept separate from all data to maintain confidentiality. Consent forms will be kept 3 years after publication of the research. Consent forms included information on the study and what was expected of the participants, how and when they could opt out of the study, contact information, information on confidentiality and more.

Participants were given an electronic gift card of 25 dollars for participating regardless of length or content of the interview. The participants were fully informed of the purpose of the research and no deception occurred in this study. Participants were informed that they could stop the interview at any time and could refuse to answer any questions, including answering any demographic questions. Participants were informed that they could opt out of the study up until two months after their interview. After two months, removal of the data would not be possible as

analysis required comparison and inclusion of all participant transcripts. If they chose to opt out before two months, all data obtained from the participant could be destroyed. However, no participants withdrew.

There were no anticipated physical or psychological risks for the participants in this study. There were no anticipated direct benefits of the study to the participants. The only possible benefits might be enjoyment and learning during the interview, as well as knowing their participation could lead to improving learning experiences of future nurses and nursing students.

Confidentiality was ensured by removing all identifying names, organizations, and other information by the use of pseudonyms during the analysis process. The recordings with any names were kept in a separate locked cabinet from the analyses to ensure confidentiality was not broken. All interviews will be deleted permanently 3 years after publication. No identifiers are used in the findings. The researcher, research team, and funding agencies have no conflict of interests and have no invested interests in the results of the study. The study was feasible.

Knowledge Translation

The findings of this research provided invaluable information about the learning experiences of nurses who were actively working with children and families with IDs. The results will be disseminated through presentations, published articles in journals, a published lay-person report that may be posted on a website and shared with health care professionals at the IWK health centre and Universities, and a manuscript. The results will also be shared, once published, with all participants if it was requested during the initial interview and any other person involved in the research. The information produced through this study will hopefully provide evidence for nursing practice and future nursing research. As well, in the future to have an impact on nursing education and nurses learning around children with IDs.

Chapter 4: Findings

In this study, I used the methodology of feminist poststructuralism to empirically understand how nurses negotiate and navigate their learning to become prepared and confident when caring for children with IDs and their families. Registered nurses first study nursing in a generic and generalist nursing education program where each student is not able to experience the full range or continuum of nursing care they might need in their future nursing practice. This is a primary reason why studies noted that nurses must engage in continuous learning to fully educate themselves after graduation from a basic baccalaureate program and through-out their nursing career (Walsh, et al., 2000; Manias & Bullock, 2002). Almost all studies in the literature review noted the need and importance of continuing education and life-long learning for nurses to provide optimal nursing care to any population of clients, especially populations that are not or are less covered during their undergraduate education. For this study I specifically looked beyond the formal and basic education of registered nurses and examined all possible areas of learning registered nurses attempt and utilize during their practice to provide optimal care to children with IDs. This included informal and formal learning experiences of nurses caring for children with IDs after graduating from their undergraduate programs.

To answer the research questions 1) How do registered nurses experience learning how to care for children with intellectual disabilities? 2) How do registered nurse experience social and institutional constructions of learning? 3) What recommendations do registered nurses have to improve learning?, five nurses were interviewed using individual semi-structured interviews. Their insights provided four major themes around learning that included subthemes. The first and most prevalent theme was ‘learning from others’. The subthemes within this theme were learning from children with IDs, learning from families, and learning from healthcare professionals. The

second theme was ‘learning from experience’ and this includes learning from personal and professional experience. The third theme is ‘learning from tools and resources’. The tools and resources that were consistently identified include hospital-based educational programs, extended formal education, and other learning tools. Lastly, the fourth theme is a ‘constant learning process and unique learning curve’. These four themes were consistently identified by the research participants in each of the five interviews. The four major themes highlight how each nurse informally learned to provide optimal nursing care to children with IDs in their own practice setting. Even though the research participants worked across a range of hospital settings such as acute inpatient pediatric floors, operating room (OR) units, outpatient clinics, and in managerial positions, how they learned to care for children with IDs seemed to be consistent and highlighted in each nurse’s practice experience.

Learning From Others

The first, most discussed, and prevalent theme in all interviews was the notion of ‘learning from others’. This theme included experiential learning from caring for children with IDs, learning from families, and learning from other healthcare professionals. Learning from others created informal learning discourses that the nurses utilized to create tacit knowledge on caring for children with IDs. To best understand this theme, I would like to first highlight *how* these nurses learned from others. Their way of learning from others mostly began with learning through observation but also included curiously asking questions, listening, watching, and having the ability to adapt and in turn, incorporate what they learned through this purposeful reflection on their own practice. Reflecting on their observations, questions, listening and watching helped the nurses in the study turn their learning moments into knowledge gained.

It was never formalized, definitely it's more so just watching people and families care for the kids and then stealing their tricks and tips along the way. It's a lot of just observational. – Nurse 4

Most of the nurses stated their learning around children with ID was never formalized, it was not part of their undergraduate education and their most important learning tool was direct observation. They purposefully utilized observation and reflection as a means to gain skills, including 'tips and tricks' to improve their nursing care and practice.

So there's a lot of that observation but on top of that you know clinicians need to not be afraid to ask the family, to ask questions and I've had to do that and I sometimes earlier in my career hesitated. I still do sometimes depending on the situation but just to say what's the best way to communicate or does she like touch, or can she hear me or can she see me or do I need to be so close for her to see me or how does she react to new people, new caregivers, how does she react to being moved around physically. Any part of the care like just asking those questions or just tell me about your kid, what's important to know about your kid and when you kind of gather all that information some by asking and some by observing then you can really often identify some really important components to include in the care plan. – Nurse 2

This nurse believes, values and practices observational learning and furthering her learning through asking questions and recognizing the family as experts. She recognizes that recently graduated or less experienced nurses may feel less agency in asking questions and that it may take more time for less experienced nurses to negotiate and navigate the ability to ask the family questions, and feel confident in their care. She uses the skills and information she learns from reflecting on her observations of both the child and the family to improve therapeutic

relationships and break down power imbalances between families and nurses. She believes observation and asking questions can lead to more open and effective communication. She believes a combination of observation and asking questions, including active listening can improve a nurse's direct care and learning more about how to care for children with IDs.

I think most of my learning has honestly come from the families and the patients themselves and just me building up enough confidence as a nurse to kind of ask those important questions about how to best care for the child. Another great source of information I've learned from is other nurses and health professionals, multidisciplinary health professionals so I can think of some physios and dieticians, physicians, who've all you know just in the way that they interact I've kind of learned by observing or I might have asked a question and said you know how do you find is the best way to do this intervention with this kid and they'll give me some tips and stuff. – Nurse 2

Most of the learning for the nurses interviewed in this study came from observation, asking questions, and listening to children with ID, their families, and other HCPs. The nurses turned this learning into knowledge by reflecting on their moments of observation, asking questions, and active listening. This nurse has utilized this form of learning because she feels she had no formal education or prior personal experience. She had to gain confidence and professional experience to ask questions and to learn the right questions to ask to gain more complex information about children with ID. Improving her learning and overall knowledge comes with confidence, observation and reflection.

I think it's just trying to be non-judgemental, be open, and saying you don't know this, you've never encountered this and asking for help especially if they are non-verbal and that. Yeah, you're getting in there, there is a lot of knowledge out there. – Nurse 1

...it's not going to be as good at first but that's how you learn. – Nurse 4

Gaining skills as a newly graduated nurse was an important part of observational learning that was raised by almost all the nurses interviewed. The nurses described how gaining the skills to care for children with IDs leads to competent care with this population that in turn led to confidence as a nurse. Observation and asking questions was very important, but so was the ability to ask them and to be confident. Confidence came with gained skills and the feeling of providing competent care as a nurse to children with IDs.

I would say be a really good listener and observer, listening to the family and to those who know the kid, the child well. I'm now thinking of something else maybe I could have said earlier, sometimes at the IWK the family has caregivers that help the child at home that actually come into the hospital with them. So those caregivers as well that are not like hospital employees are really good sources of information too. But as a new nurse really, really just listening and observing and respecting. Showing respect for the patient as a person and really focusing on them and getting to know them and their preferences and their likes and dislikes. But also just really respecting the family and not assuming that because you figure out something that works in one situation or for one kid that that's going to work for everybody or in all situations with that one kid. – Nurse 2

Many of the nurses challenged societal expectations of nurses that nurses are expected to know everything right away. Benner (1984) addressed this unreasonable expectation of nurses in her early work which has since been supported in literature focused on the transition of nurses from student to registered nurse (Cubit & Lopez, 2012; Manias & Bullock, 2002). Expecting new graduates and nurses transferring to new areas to know everything is not feasible as demonstrated by the nurses in this study. We can see how the nurse values having opportunities

to observe, ask questions, and listen. She believes nurses should not be afraid to ask questions and this will lead to better care through reflection and gaining skills or new knowledge on caring for children with IDs. The nurses interviewed described questions such as; how do the children communicate, what are the likes and dislikes of child, how does the family care for the child? The questions described by the nurses are used to create learning moments on the complex care of caring for children with IDs. They use tools of observation, reflection, questioning, and listening to create new knowledge.

Ask lots of questions. The parents don't mind answering questions, I think they would rather know that you've got a full sense of understanding when working with their child. And be adaptable and fun. – Nurse 5

Asking questions was a vital aspect of observational learning for the nurses interviewed. Nurses in this study navigated the use of observation but it was also important to utilize their agency in asking questions and listening to families, the children, and other healthcare professionals to gain the most insight into providing the children and families with optimal nursing care.

All the nurses spoke about ways to conduct observational learning from the children with IDs, their families and other healthcare professionals. This included direct observation, asking questions, listening, being curious and inquisitive, reflection, having confidence, and continuously learning more about the complexities involved in caring for children with IDs. It is important to highlight how the nurses navigated and negotiated learning from others and their experiences using observation, asking questions, listening and reflection to understand how they learned to gain knowledge, competence and confidence in caring for the complexities of children with IDs so this can be repeated by other registered nurses.

Learning from children

The first sub-theme under the theme of learning from others is learning from children with IDs. All the nurses stated learning from the children was significant to their nursing care and abilities. They utilized what they learned from children with IDs through observation, asking questions and reflection to improve their learning over time on nursing care. Some nurses even felt they learned to improve their personal life through working with children with ID.

I've learnt more, I tell people, you know I have been blessed to have my daughter, and anyone in the intellectual community that I have had a relationship with has enriched my life and taught me to be a better person. – Nurse 1

This is an example of a nurse who has a daughter with an ID and believed her life was enriched through what she had learned from caring for her daughter. She negotiated with the parent child hierarchy, that a parent is expected to do the teaching and a child only learns from the parents and believes she has learned a lot from her daughter, and not just her daughter learning from her.

Because they have strengths and are just amazing. I think the world would be a better place if people were recognized for these things and recognized for their strengths. – Nurse 1

All the nurses recognized that you can learn from children diagnosed with IDs. This next nurse challenged societal stigmas on children with IDs by noting that the world could be a better place if people were recognized for their strengths rather than their weaknesses. All of the nurses were supportive and kind towards their care for children with ID and challenged stigmas and stereotypes surrounding this population in both institutional and societal settings.

Well I think everybody is unique and I think that the thing that I find the best when I'm dealing with kids with intellectual disabilities is they really teach you so much. – Nurse 5
For repeated admissions and things like that so it's nice to kind of learn from them and learn about them and work with them so I think all around it makes you a better person anyway. – Nurse 5

All the nurses in the study believed that everybody is unique. They believed children with ID can teach you so much and they try to incorporate what they've been taught into their nursing practice. They also believed what you learn can pour into your personal beliefs and values by making you a better person. The nurses chose to use their agency to acknowledge the strengths of children with IDs and emphasized what they can do for you rather than just speak about what a nurse can do for them. This is a challenge of institutional and societal norms of nursing care and how it isn't always the nurses who are helping the patients but rather how patients can help nurses in their practice and personal life.

I think nurses and student nurses that get involved in working with people with intellectual disabilities they will learn a great deal. – Nurse 1

The nurses in this study challenged a normative hierarchy of knowledge by saying nurses and adults can learn a lot from children with ID. This nurse believed in a constant learning process regarding children with IDs and she practiced that in her personal life and in her nursing career.

You have to be certainly willing to learn from them. – Nurse 5

All of the nurses believed that in order to change norms and hierarchies, nurses needed to be open and willing to learn from the children with IDs to have the best possible healthcare outcomes in practice and in society.

Each child is very, very individual. I also recognize that it's person first and who they are. I don't like the word disability, I never have but it's the current word. Everyone has ability levels and so I always believe and always strive to find out what their strengths are. – Nurse 1

...each child, they're you know you can't put them in a box, no intellectual disability, they are in and out of different boxes. – Nurse 1

This nurse emphasized the importance of remembering individuality and uniqueness in children with ID and how that can affect learning and caring for children with ID. All nurses in the study believed each child or person was central to their care, and that everyone has abilities. This nurse challenged the word disability and how it can create stereotypes and stigma within nursing and society. All nurses believed it was important to believe and value individuality and uniqueness within each child with IDs because of its positive impact on practice and caring for children with IDs.

To me just starting with the word 'dis' is a negative connotation so you know, I have a daughter. A beautiful thirty-year-old daughter. Who happens to have Down Syndrome, but I first have a beautiful daughter and so it's looking at those, some people don't like to be identified by their diagnosis. In some cases, having a diagnosis helps for getting support, getting treatment and that so but I think just looking at their abilities. I don't know that I have a word for it. There's just not a word I've liked. – Nurse 1

I don't necessarily like labels. – Nurse 1

This nurse both supported and challenged the importance of a diagnoses but did not value the use of labels. She values that a diagnosis can get children support but challenges the meaning of a diagnosis and the power of language. She negotiates with negative labels such as 'dis' at the

beginning of ‘disability’ as it can be a negative connotation. This has been something she has learned from her own daughter with ID and something she challenges in institutional norms and practices and their use of language. As the only mother of a child with ID, this was not something that came up in interviews with the four other nurses, but it holds value when learning from children and how nurses can improve their practice based on what they intimately learn from children with IDs.

And you know what some of these kids will tell you themselves as well. So you have to remember to ask them and certainly ask their permission before you listen to them and touch them and what not, which I think you should do with everybody anyways. But yeah, so I think that's probably the biggest information source and impact. – Nurse 5

Finally, all nurses seemed to speak about and believe that children with IDs were valuable sources of information and you can learn the complexities and nuances about caring for them from the child directly. The children’s experiences cannot be found in a textbook and is rarely found in an undergraduate nursing curriculum. The nurses interviewed used their critical thinking and reflection skills to utilize the children as a learning resource to impact their beliefs, values and practices around caring for children with IDs. This in turn helped the nurses to challenge negative discourses including stigmas and stereotypes surrounding children with IDs. The nurses felt learning from children with IDs gave them a changed worldview that helped them to improve care and negative attitudes that may exist societally and institutionally.

Learning from families

Learning from families is another important and valuable source of information and resource for nurses to learn how to care for children with IDs. All five nurses spoke about the importance of families as a resource for their learning in terms of how they have learned from

families, what they've learned from families, why they chose to learn from families, and the positive outcome-based impact this learning had on their nursing practice. All the nurses believed utilizing families' knowledge and skills improved their care for children with ID, with the child of the family, and with children they may care for in future practice.

When asked what had the biggest impact on their learning when caring for children with IDs, one nurse responded with:

Probably working with the families, I guess, learning from the families. – Nurse 5

The nurses recognized and valued the knowledge the family had on how best to care for their child and what they can learn from them to improve their own learning and provide better care.

Yeah. I agree that was what popped into my head, the family is definitely number one. Nobody knows their own kid like their family. So they are number one for sure. And spending time with them and with the child, with the family of the child and just really having eyes open to observe the little subtle things that you might not think are that important but often end up being. So yeah, I would say working with the family.

Learning how to ask questions and how to listen to the family. And then spending time and observing and trying to interact with the patient with ID. – Nurse 2

Another nurse agreed that the family had a significant impact on her learning more about caring for children with ID. She utilized observational learning by noticing subtle things that may not be spoken about. She also used her agency to ask questions and listened to learn the most she could from families. This nurse believed it was important to spend time and interact with the patient and the families. Part of observational learning is taking the time to do it and spending time with the families.

One of the biggest things I will say with working with all families is that know their children and there are many things with many children with intellectual disabilities that are not textbook but the family know, listen to what they say on the cues for upsetting their child, or just the things that work. Never underestimate what the family says, sometimes it doesn't make any sense what they said and there's no logical reason for it but I have learned that what they say is true. – Nurse 1

It's very hard when you work with non-verbal which we do a lot of. So you have to really, that's where family input becomes important, that's where your observational skills become extremely important, you just recognize them because if they're non-verbal, non-touch child, how are you going to know. Looking at those clues. – Nurse 1

...it would just be more like when we would check in our patients we were bringing them in the room and getting the feedback from the parents and trusting what the parents were saying, more or less. Like taking their suggestions, like they know their child the best right. So they would just say like oh you know so and so doesn't communicate through words but is really great at this gesture means this and when he does this it means that. Like if you cover your ears then it's too loud or whatever. So we basically went to parents... - Nurse 3

These are examples of how nurses in this study utilized information provided by families about the child. They valued the opinions of the family and used this information to provide more personalized, effective, and meaningful care. They regarded what the family told them as the 'truth' about the child. They negotiated between their own personal experience, professional experience and shared knowledge from families to provide the best care to a child. They valued families and created relationships that would enable parents and children to also use their power.

The nurses indicated that they did not believe that they knew more than the families about their child, and therefore they worked at shifting power imbalances between family and nurse to create a better environment for learning and optimal care for the child. In this way, they were negotiating and navigating power relations that were often seen between families and nurses. In one example, the nurse with a child of her own with an ID, demonstrated that an understanding of trust and reliance on family may have come from being a family member to a child with ID herself. The nurses in this study believed and spoke about how they were constantly learning from families. They also learned about new tools and how to use them with children with ID. It is also noted that they sometimes valued family even more when a child had a more debilitating condition or severe symptoms and effects due to their ID. The example the nurse gave was when she cared for a non-verbal child she would rely on the parents more than a higher functioning child with ID or a neurotypical child. The nurses in the study described varying degrees of dependence on family.

... and certainly in Pediatrics I'm definitely used to having the family contribute to what their child's care needs are and that becomes that much more important when it's a child with ID and so but I also didn't want to assume that just by asking the parents the question that I was eliciting enough information that would reflect that child's preferences because she still very much has her own personality and has her own wishes and she makes her likes and dislikes of situations known. – Nurse 2

I really was able to learn a lot about how to include that child and that had to do with asking really specific questions to her parents about how do you think she would react in this situation and what do you think she would want in this situation or what are your concerns for her. So yeah just that, A) I wish there was more guidance and training and

information for clinicians but yet at the same time the family was such a rich source of information that I really felt that the child's needs were included in care planning. – Nurse

2

This nurse established and utilized a relationship with the parents to ensure she was meeting the specific needs of the child. She recognized families don't always know everything a child wants but that they are still an important resource to help understand the child better. Using a pre-established set of questions, she had learned over time that her questioning approach can reveal a child's 'likes and dislikes'. She believed all children were unique and have their own personalities that should be recognized and included in a care plan. As a nurse, currently in a managing role, she utilized her power as nurse manager, to encourage all children to have a voice and be involved in their care. This was done by utilizing the family as a learning resource to gain insight and information and as a learning resource for herself and on the child. This nurse utilized the family's knowledge and child's knowledge to make sure the child was receiving the optimal care.

Which is really scary for them. So you try to learn as much as you can about them and use those tools. If they love Paw Patrol, we're going to watch Paw Patrol, if you like sports, let's talk about sports while we walked down the hall. And it is definitely a high degree of distraction. But when they have intellectual delay you can't really rely on all those conversations and things as much so you really have to learn from the family what they like and if they like a certain ball or something that we can bring with them so to keep them calm and then sometimes there's nothing you can do 'cause they just they don't do much. So you just kind of talk in a nice calm voice and take them down there hall, yeah. – Nurse 4

Similar to the last nurse, the next nurse used the family as a resource to learn the likes and dislikes of a child when needing a distraction in an Operating Room (OR) setting where there is less time spent with the child. This nurse recognized that in some cases the child could not tell her everything, therefore she had to utilize the parents' knowledge on the child by asking questions on the likes and dislikes of the child and to try to give the child the best experience and care possible.

And then families. I find a lot of families, once you speak to enough of them, they all have very different ways of going about it but there's an underlying theme to kind of the care and just being patient and yeah, treating them like a kid with ID, like you would anyone else. Like be nice and ask permission before you touch them even though you don't really know if their understanding what you're saying, you know. – Nurse 4

This nurse spoke about how you can learn to care for future children with IDs in practice by utilizing previous knowledge, including 'tips and tricks' given by other families. This nurse used her critical thinking to create underlying themes of ways to care for all children with IDs. The nurses gathered individualized experiential knowledge about the likes of each child with an ID that they then used to develop more effective, individualized, complex nursing care.

But I love trying to win them over. To present yourself in a way that makes them feel comfortable and I also love working with the families. And I know some people are cautious about asking parents about their needs and things like that but I think that the only way you're ever going to find out is to be honest and open with the family and get their involvement and their input so I have no problem asking them you know upfront can they understand, can they talk and stuff like that. – Nurse 5

The nurses overall spoke highly of learning from the children and their families. They challenged the discourse that nurses should know everything about their patients. They chose to be open, honest and upfront with the children and their families about their own knowledge and understanding of what they knew or didn't know of the child's care and utilized the process of asking questions, observation and reflection to improve their own knowledge. They recognized the information families had and related to them as the experts who knew their children best. All the nurses learned from families, through observation, asking questions and reflecting on the shared information that improved their care by creating new beliefs, values, and practices on the complex care of children with IDs. The nurses navigated and negotiated the current institutional and societal discourses by learning from families of children with IDs.

Learning from healthcare professionals

Learning from healthcare professionals was the third and final subtheme in 'learning from others'. This included learning from other nurses, especially more experienced nurses, specialized hospital teams who cared for children with IDs regularly, and any other healthcare professionals that may have specialized knowledge on caring for children with IDs.

I might highlight again just the importance of learning from other health professionals too I didn't talk about that as much. But other nurses and multidisciplinary health professionals who have worked with that population for a long period of time. I think observing and learning from them and talking to them was really important as well. –
Nurse 2

The nurses in this study learned from other health professionals through inter-professional dialogue, direct observation, and reflection on their own practice. They all considered and viewed other healthcare professionals who had worked with children with IDs for

a long time, usually longer than themselves, as rich and valuable sources of information that can contribute to their on-going learning.

I'm going to say the other health care professionals I work with. Because a lot of people I work with have kids with different delays and problems and that's probably what led them to our job. So they have so much knowledge. And then just nurses working there for so long bring so much to the table. – Nurse 4

The nurses stated other healthcare professionals had a large impact on their learning around children with IDs. They believed that having high amounts of professional experience and also personal experience gave them more insight that they could learn from as newer or less experienced nurses. This was spoken about by all the nurses who participated in the study, whether they were newly graduated or more experienced, they noticed that they had and continued to learn from other seasoned and experienced healthcare professionals. They noticed they learned from other nurses because that is who they spent the most time observing and interacting with. They believed other experienced nurses had large amounts of experiential knowledge to share that was missing from their own practice.

Absolutely. Yeah and you find, well I find that I'm almost intimidated by the nurses that are so strong in those areas. Cause you always think that they can do better than you. But I sat back for a long time and always thought, you know, you're going to do a better job than me so you should do this but if you just watch them you can learn what they do. You can learn everything. You don't need to have personal experiences to be good with kids. – Nurse 4

This nurse struggled with power imbalances between herself as a new nurse and more experienced nurses. She believed for a long time that a more experienced nurse would do a better

job than her. This belief may have come from institutional practices and hierarchies between senior nurses and new nurses. She challenged and changed this belief through the use of observational learning and expanding her personal and experiential knowledge.

...other thing that I am very interested in is the hospital has a team called PACT which you used to be the palliative team but now they go by PACT. I forget what it stands for, P-A-C-T. And they have been a huge resource, you know because they deal with complex patients and they are very good and many of them are complex care and many may have an intellectual disability so they've been a wealth of knowledge in how to help in learning to recognize some triggers that I might not have even known. – Nurse 1

The use of hospital teams that specialized in complex patients was brought up by multiple nurses. This nurse recognized the complexity of caring for children with IDs and utilized the help of other team members with more knowledge. She was willing and able to share her care and power with other hospital staff in order to provide children with IDs with the best possible care. She considered the hospital team called PACT to be a 'wealth of knowledge' and learned from them.

We have Child Life specialists and so their trained you know in their education and they can come and help work with the children because sometimes we don't have the time to spend with the children 'cause we process other patients as they arrive. So Child Life can certainly you know get them toys. We've got special needs toys or like you know we got this Snoezelen cart and things like that that can also help them settle down or settle in sort of thing. So involving Child Life is a great asset that we have. – Nurse 5

The nurses appreciated and consciously took advantage of informal learning opportunities and practice-based situations to learn more about the complexities of providing

better nursing care to children with IDs. They chose to learn from specialized teams and incorporate this learning into their own practices, by reflecting on the learning opportunities and situations to create new knowledge about children with IDs.

I would probably say just watch and kind of listening and I often tell them like you know what you can learn so much from other people, maybe ask them to spend the day with Child Life or something like that, if not a day but maybe an hour or so. – Nurse 5

All the nurses spoke about inter-professional knowledge as a valuable resource for learning about children with IDs. This nurse in particular mentored many new students and oriented nurses and if she felt they struggled when caring for children with ID she would have them spend time observing and working with different hospital specialists who had experience working with children with IDs. She recognized how much knowledge can be gained and learned through observing specialized hospital teams and care providers.

‘Learning from others’ was a theme woven through all five interviews. It was identified that the nurses in this study learned a great deal about caring for children with IDs from three primary resources; in their direct care with children, their interactions and time spent with the families, and in their interactions with other healthcare professionals. Each nurse described their way of learning from others as mostly observation such as watching, asking questions, listening, spending time with, and reflecting. They believed that as nurses we do not know everything right after graduation and that there is little formal education on children with IDs. They all believed nurses must continuously learn from others and to seek out and reflect on informal learning experiences in order to provide the best complex care to children with IDs and their families.

Learning From Experience

The nurses interviewed in this study noted that they felt unprepared and uncomfortable at times when caring for children with IDs, at the start of their careers and even after years of experience if they had not cared for children with ID. The feeling of being unprepared and uncomfortable was also highlighted in the literature. All five nurses stated that they either recalled receiving minimal education on children with IDs or they had no undergraduate education at all on IDs so they recognized that they needed to learn from other sources while in practice. All five nurses noted their current knowledge and learning came through personal and professional informal/experiential learning discourses. Informal/experiential learning provided the nurses experiences to create tacit knowledge on caring for children with IDs. A nurse with many years of experience working in a health care setting that cares for children with IDs stated:

I would say if you're brand new just sit back at first and really watch. The good situations and the bad. And try to learn from them. And just have confidence in yourself and know that it will come, you're not going to be an expert when you start off but all the skills will pile up and you'll get there. – Nurse 4

All the nurses believed you could learn from positive and negative situations you encounter in nursing. Expert level nursing takes time and learning but the nurses recognized all nurses can reach an expert level with confidence and patience. They believed the best way to become an expert nurse was through observation and through reflective practice. Over time with reflective learning nurses will accumulate the skills to provide optimal care.

Learning from personal experience

In the interviews, it was revealed that two of the nurses had close personal experiences that-played a role in their learning and practice for children with IDs. One nurse had a daughter

with down syndrome and another nurse had a godson with autism. Both nurses spoke of them frequently in the interviews and how they had learned from their personal experiences caring for these children. The other three nurses had little to no personal experience with children diagnosed with a significant ID, but spoke about how they recognized nurses who had personal experience often incorporated these experiences into learning and knowledge on their own practice and how they believed it improved overall learning and care from children with IDs. The nurses without personal experience found they could learn from nurses who had more personal experience and also drew on their professional experiences which will be discussed in the next sub-theme.

And you know, for my daughter personally if she has to go for her blood test, then it's like we gonna go in the car, we gotta go now, because if I tell her ahead of time I'm not gonna get her in there. So they need to have as much control in any situation that they can, so you know, I've seen that. The thing I do with all children when I am going into work with them and this is mostly younger children, probably kids under 5 and I do it with many people with intellectual disabilities because I don't know necessarily where they are cognitively so I will, generally people have something of comfort with them so it be a bear, whatever or it can be a book, I'll make a joke out of it and I always introduce myself, I always get down to their level and I ask permission if I can listen to their bears heart, check their temperature, those kind of things and by then they become involved and then I'm just establishing trust so that they can then, and it gives them control so they can help with these things too. A book becomes a funny object but then they're more willing to let me touch them. – Nurse 1

Many of this nurse's beliefs and values are based on her experiences with her daughter with down syndrome. She is able to 'practice' her beliefs because she values them and is able to do this in the hospital environment where she works by challenging institutional norms and discourse to fit what she believes works best. Her personal and professional value system guides her practice in terms of developing more complex skills, improving her knowledge base and adjusting her attitude to provide effective and positive care to children with IDs. She practices her nursing in a way that is aligned with her beliefs and values. She is considered an expert nurse in the hospital. She purposefully navigates institutional practices of hospital protocol that supports caring for children that is aligned with her personal and professional beliefs and values. An example of this is that she tries to ensure that the child attains some power, by feeling in control.

You learn to maybe divert to different things and then you get at their level. You learn to see what they can know. – Nurse 1

You just have to learn where they are at so that when you talk to that child, you are talking to them at a level that they can understand, using words that they understand. First finding out what their understanding is and then correcting in simple terms. – Nurse 1

She has learned to use distracting techniques from personal experience. She also believed it is important to understand their level of knowledge and used that in her care, teachings and vocabulary when speaking to the child. She has learned from her personal experiences in terms of valuing and adapting to the child's developmental level.

Like I use music a lot if I can. I sing a lot. You know, I can be the clown on my floor. But I find music, whether it's me signing or whatever helps. There are many things and with many conditions routine is so vital, so any change in routine which may be coming into

the hospital is loss of control which is so stressful. And this is a really big thing for me 'cause I see it not just there, I see it with all the young adults that I'm in contact with now, the change in routine is extremely hard on them. So, learning what their routines are, you know as much as you can and as much as you can, adapt it into the hospital situation. – Nurse 1

This nurse learned about the importance of routine and self-control through interacting with people with ID in her personal life at special Olympics. Her daughter had also opened her up to other personal experiences by involving her in Special Olympics and other groups. These opportunities had given her the chance to spend additional time with children with other IDs outside of a hospital environment. She had learned to utilize her personal experiences into her nursing care on the unit despite hospital expectations and negotiations with hospital protocol to create an environment where patients have routine and feel in control.

So I do, like my godchild is autistic and I mean he's been part of my life so yeah. All the time I guess you could say, from a personal level with him. – Nurse 3

Sure, like I mean you try to treat everyone kind of you know the same but yeah for sure. Like I try to go up and above to like make sure it's not as scary. – Nurse 3

Like try to get that trust in the relationship. Instead of just being like two seconds before you go in the room and are like, hi my name is *NAME* and away you go, right. Like you try to do that so I guess kind of, like I do try to do little different things with them.

Distract them more with like the lights and all the toys and stuff like that a little more than I would say a quote unquote normal child if you will. But like you know you have to roll with the punches if you wanted to be successful going in with them and have a good experience you have to give them time. – Nurse 3

This nurse was learning to be more expert and purposeful with her nursing care to children with IDs. She negotiated and challenged institutional expectations and discourses by adding extra time and ‘doing different things’ such as distraction techniques with children with ID to improve their hospital experiences. She learned to use her personal experiences to guide her current nursing practice to find more innovative and effective ways to care for children with IDs. She has learned more complex nursing techniques that she can use in her current practice through caring for her godson outside of the hospital.

One-hundred percent, yeah, one-hundred percent. Because I know a couple of my colleagues didn't really do much paediatrics in the OR before they came to the IWK with us and said like some of the things that they struggle with say in the dental room or some other rooms with the kiddos with disabilities and they found it challenging for them to get them in the OR, to come with them, to like they didn't know how to react with them, like to get them to lay on the bed still. Like how to distract them, they found it super challenging. And I was in there like I found it super easy but I do find things that make me a little more easy going with them I guess right because of experience and the time and patience to do things with them. So yeah for sure if you have something to go by, it makes it easier at work. – Nurse 3

When asked if she believed having personal experience makes it easier for her to care for children with IDs, she agreed. She had learned from her personal experience and gained additional insights, shifted her attitudes, and improved her knowledge base, which in turn impacted her practice with children with ID. She stated that she was more easy-going and able to have ‘something to go by’ as a framework for providing nursing care. She felt she had more patience than some nurses because of her personal experiences. She noticed that nurses with no

personal, educational, or professional experience may struggle with basic skills for the children with IDs.

I think it would certainly make you a little bit more empathetic and understanding. I really do believe that. I think if you know whether it be personal or friends' children or something like that certainly I think it would make a difference. – Nurse 5

This nurse believed you can learn from and consciously utilize personal experience to improve one's nursing skills, attitudes and knowledge. Even the nurses who had no personal experience recognized the advantage personal experience may give a nurse, and the role it can have on a nurse's learning, agency, and power relations when caring for children with ID. Personal experience played a significant role on the two nurses who had significant personal experience and was recognized as an advantage to learning by the other nurses in this study.

Learning from professional experience

Learning from professional experience was described differently by each nurse, depending on years of experience. However, it was highlighted in all five interviews as significant to their learning and how they have learned to provide better care for children with IDs. Some of the ways the nurses found they learned from professional experience was through negative and positive experiences, trial and error, past mistakes, home visits, and just learning-as-you-go. One nurse noted how her professional experience had affected her personal experiences to date.

I had a time when I did not recognize, there was a moment when I did not recognize that this young adult was completely overwhelmed because I did not recognize their cues and this was someone who family weren't there, they were a foster child and I did not recognize and then that child became a bit aggressive and I realized afterwards this wasn't

their fault this was my fault because it was too much stimulation, it was too much, and for many, especially if they are non-verbal, they will act out with aggression because it is the only control they have. So it's you know recognizing that it is their body and they have the right to allow touch and not so it's finding ways to work with that. – Nurse 1

This nurse learned from her mistakes and negotiated with techniques and experiences she used in the past to gain new knowledge and insight on care for the children with IDs. She did not help the child feel in control, something she said she valued. She contributed to the child feeling overwhelmed and not in control. The practice techniques she used were not based on her beliefs and values. All of the younger nurses and nurses with less experience, under 15 years of experience, noted learning from mistakes and negative experiences were valuable to learning more and were a way to improve their professional experiences and knowledge on how to care for children with IDs. They learned from the negative experiences by using critical thinking and reflection on the situation. One nurse spoke about how she wrote a paper on the situation and analyzed different approaches for the next time she encountered something similar.

I've had positive experiences too. I just think the negative sticks out in your mind more, right. – Nurse 4

The newer nurses spoke often about the negative experiences that led to a learning experience. They found negative experiences were more impactful and memorable than positive experiences. And fortunately, they found they were able to translate negative experiences into positive learning moments through reflection and critical analysis.

Okay so she's nonverbal and she had something stuck in her throat, so she was coming in for a removal of foreign body and I didn't, it was really hard to connect with her because she was obviously panicked, even though she was stable. And she was nonverbal so to

get her into the OR was a challenge and I think we could have done it better but it's a struggle to figure out how exactly we could have done that. Especially when you work with the team and you can't control every member of your team, right. Everyone goes about things differently so I felt like we rushed her and we didn't do the best thing. Like we definitely took care of her body but I don't think we took care of her emotions and her processing of the situation. – Nurse 4

...it was also change of shift so I went in and I felt like we had a little bit of a connection and understanding. And I felt her relax around me some. And so I kind of built her trust but then unfortunately I wasn't there to bring her in the OR. So but I did see and it was very forced kind of. Like we need to put her to sleep to take out the object that's obstructing her breathing and I don't really know how to have made that better. I don't know, maybe you just need to have that connection and that person needs to bring her in no matter if it's shift change or not. But you couldn't have given her any pre-op sedation because of the nature of her airway issue. – Nurse 4

It was a good learning experience yes. Yeah, to advocate for patients more and advocate if you have a connection to stay the extra 15 minutes to bring them in the OR for their sake type thing. I'm not saying like I'm the savior in this situation I just think whoever builds that connection maybe should bring that person in. Because it's so stressful. – Nurse 4

This nurse struggled with the care given to this patient and was able to analyze afterwards through reflection that this patient did not receive the best emotional care. She challenged the mentality and norm of the team, rushing the patient into the OR. She negotiated and challenged a lack of knowledge around how to improve the situation, as well as the hospital protocol at shift

change. She believed that this population of children needed a trusting relationship and to take the extra time, despite a shift change, may help her patients better. She seemed to conceptually struggle with the institutional norm and discourse of leaving patients immediately after your shift. This new nurse experienced a negative situation and used it as an opportunity to reflect and learn how to provide this child with better care in the future. She used a negative situation to learn from her mistakes and turn it into a positive or meaningful learning experience for future practice. She recognized that not all situations align with the time of your shift and to advocate for patients and be adaptable with your time for the sake of the patients, especially for children with IDs.

And always asking permission, but you can't always say is it OK if I touch you because a lot of times they're gonna say no, so it's giving a choice I need to do this so we can check a temperature first or we can use the stethoscope. But you know, there are things we have to do but building trust. And that comes with anyone. – Nurse 1

Asking permission and gaining trust are examples of the way this nurse practiced based on her personal beliefs and professional value system. She did this as a way of negotiating power between herself and her patient. Giving choice recognizes that the child has power. She negotiates with hospital protocol to improve successful completion of tasks with children with IDs based on past experience. Hospital protocol included an order to do periodic vitals on children, least invasive to most invasive. This nurse used her power, knowledge, and past learning experiences to make professional choices. For example, she stated, “We can check a temperature first or we can use the stethoscope.” She still completed her vitals while using her own power to change the protocol for children with ID. This is something she learned through her professional experiences caring for children with IDs, and as an experienced nurse she used

her agency to put that experience into practice. Using agency in this way was noted by the more experienced nurses with 20+ years of experience who were interviewed.

Well I mean we touched on it probably, like in nursing school way back when, about the conditions and what they are right. Not so much how to care and treat for them but like you certainly probably learned what is ADHD, what is anxiety, what is you know all these different types of disabilities. So yeah I'm sure there was probably like school taught about the disease if you want to call it that. – Nurse 3

We don't touch on it like at hospital orientation or like orientation in the OR, like nothing really specific but you learn it as you kind of have to go in my job. – Nurse 3

Some of the nurses navigated a lack of educational and direct nursing experience focused on children with IDs, by informally 'learning on the job', and 'learning as you go' through the professional experiences in a hospital setting. 'Learning as you go' is how these nurses explain their learning through professional experiences.

But when I've done home visits they're more for my learning as opposed to me being a direct care provider because I use what I learn during home visits and observing the patient and family in their own environment. Them telling me about their experiences receiving Home Care Services. I use that to inform what I do at the hospital. – Nurse 2

Home visits were a part of one of the nurse's regular practice. She used this professional experience to learn about how to improve her nursing practice in a hospital, especially with children with IDs. The responsibility to do home visits gave her more time to learn about children with IDs and their home life, which in turn she believed improved how she cared for children with IDs in hospital. She appeared to reflect and learn from her professional experiences to improve her knowledge.

And so I think that my professional experience has certainly helped me not to feel intimidated to communicate with people and even if they have different levels of ability to just you know sometimes they're trying to communicate something or you even just to say hello to them or you know to make eye contact and smile. And you know those little things or to feel able to try and communicate with them. I think my professional experiences helped with that. And I know that I've helped people in my life. – Nurse 2

This nurse had not had any personal experience with children with IDs but believed her professional experiences had a positive impact on her personal interactions outside of work. She challenged societal norms, stigmas and stereotypes around children and adults with ID using her professional experience and personal agency. She also used her knowledge and power to teach others in her life.

I do find though that and also with my experience in emerge with families coming in, I think just through experience and stuff like that you kind of learn how to work with those children, like you know initially you don't approach them right away, just try to earn their trust and things like that. – Nurse 5

Overall, the nurses utilized their experiences as learning moments and resources to learn how to provide quality effective nursing care for children with IDs. The nurses in this study generally believed experience and 'learning as you go' were significant learning resources and a credible way for nurses to care for children with IDs. Whether they were learning from negative or positive experiences, past mistakes, home visits, or just learning as you go, their experiences played a big role on their learning to care for children with IDs as registered nurses at all stages of their career. The key seems to be there are little to no formal educative programs to teach nurses to care for children with IDs. Nurses need to rely on informal learning opportunities, both

personal and professional experiences, and informal learning methods like ‘learning as you go’ methods to become better nurses who try to provide quality care for the complex needs of children with IDs.

Learning From Tools and Resources

The theme of learning from tools and resources could be separated into three subthemes; hospital programs, extended formal education, and other learning tools. This theme explores and identifies some of the ways nurses furthered their learning on children with IDs through formal learning discourses, whether that was in formal educational programs, personal readings, webinars, or hospital-based educational programs. The way each nurse learned varied from nurse to nurse. However, continuing to learn through the use of different formal learning discourses was brought up in all five nurses experiences when learning to care for children and families with IDs. These formal learning discourses allowed the nurses to create explicit knowledge on how to provide best care or evidence-based care for children with IDs

Hospital programs

The hospital in Halifax, Nova Scotia, that all five nurses were recruited from, offered a program called Building Alliances for Autism Needs in Clinical Encounters (BALANCE). It is an interactive program that teaches healthcare professionals about autism and ways to provide best care to children and families with autism. It is primarily an online program, however the hospital set up day programs in which nurses and other healthcare professionals could voluntarily participate to learn about caring for people with autism in a hospital setting. Four out of five of the nurses interviewed participated in the program and spoke highly about what they learned from the program and how it could apply to caring for all children with IDs. The fifth nurse stated having hospital programs was beneficial to nurses’ learning.

...great program at the hospital now it's called BALANCE for autism. – Nurse 1

...it is a learning module and there were many things I didn't know, it is a condition where there was very little known when I started. – Nurse 1

I feel like I've learned a lot there, learned a lot about not touching you know, unless it's something that they can handle, noises, light, those are thing I never knew before but I have learned. – Nurse 1

Well what has been established at the hospital is the BALANCE program which I think is great for everybody. – Nurse 5

Some of the nurses negotiated with a former lack of knowledge on autism and how to incorporate this new knowledge from BALANCE into everyday care for children with autism. They utilized the power and knowledge learned by participating in the BALANCE program to improve their practice around children with ID, especially autism.

I don't know if you are familiar with it, it's called the BALANCE program. – Nurse 3

But it's basically a tool that they developed with like Child Life and a couple other people. It's called a take a sec checklist. And basically, if the kiddos are autistic or have developmental delay or any kind of mental health, intellectual disability issue then they'll go through this little checklist. So, you can pinpoint when you check in the patient like what triggers them, what helps them, what's, you know, gonna help them when they wake up from an anesthetic, that kind of stuff. What words don't they like, what sounds don't they like or like a box that has like stuff in it for them, like the fancy lights and just different things so that is like implemented in the OR which makes it easier to work with the children because you can just look at the checklist and be like oh they don't like bright lights let's turn the OR lights down before they come in. So that's helped us like

learn how to deal with them so to speak. Deal with them, right. But certainly, in the OR if you don't do those couple little things it's not very happy time because they just don't cooperate the way they should, you know. Because their triggers are still there. – Nurse 3

This nurse has learned how to use the 'take-a-sec' checklist that BALANCE created and presented in the program. It has helped her work better with children with IDs, to get more or better cooperation from the children. She utilized the institutional provided checklist because it was designed to help create more positive outcomes for children with IDs. She was supportive of the institutional discourse around the program and its learning tools.

And then when the BALANCE program came it was completely voluntary. You don't have to do it to work there, you don't have to do it for anything but they were looking for people to do the program and about, if not all are nurses in the OR did do the program. Because we deal with it every single day so it was like a no brainer. Why wouldn't you. Right, so we were very, very receptive. Because it was a hospital wide program, so like some PMU nurses, some MSNU nurses would do it but like honestly the OR everyone did it. Even some anesthesia, some of those doctors, like a lot of people. – Nurse 3

The program was voluntary but the nurses interviewed recognized that it could be a valuable learning tool for them when learning to care for children with autism and other IDs. This nurse recognized the receptivity of the healthcare providers to a hospital program that could improve their overall learning and create a better environment for children with IDs. All the nurses were appreciative and thankful for this institutional program and way of working with children with ID. The program contributed to an institutional discourse at the IWK Health Centre that created learning opportunities to the nurses in that institution. The program also provided

regulations in which the nurses could all follow and be able to work together through this discourse using the expected institutional practices.

Well, because you have the nurses saying a bunch of stuff, like we did the program and we always did A, B, C and D and then a surgeon says well I don't believe in A and B or A and D like blah, blah, blah. But a lot of them were on board to try it out and so now were all on the same page. Like hey you did BALANCE right like why don't we try doing this, this and this. Yeah, okay we get it, right. So it made our team a little more stronger together when dealing with these kiddos. Right. – Nurse 3

This nurse utilized her learning within the hospital program to improve care for children with IDs. She believed and valued a team that was on the same page and could work towards a similar goal. She valued efficient care for children with IDs in the hospital setting. This program was a learning tool that allowed nurses and other healthcare professionals to all be on the same team and work together towards the best care for children with IDs because the nurse stated that they all were using the same knowledge and skills created by the hospital program on what was best practice. She stated how one professional could quickly reference a part of the program they wished to incorporate in the practice setting and they all knew what that professional was speaking about. Rather than drawing on all different learning experiences and resources to provide the best care, they were all drawing on the same learning experience in practice.

I guess probably the one that mainly sticks out right now is the BALANCE program once it was developed. – Nurse 5

It kind of, it's a program that involves children with autism and their families and then physicians. So people are interviewed and they're saying what makes things better and then there's a whole checklist that we can give to the families for like sensory needs,

hearing needs and like you know how to approach them, what things might trigger them to make things worse, how they might present themselves if they're starting to get a little bit agitated. So it is something that we go over with the family, we actually do involve Child Life a lot with that 'cause it can take you know maybe 10-15 minutes to go over it with the family so sometimes time is a bit of an issue with us when dealing with the families but it is something we keep it on the chart so that we can share the information with everybody that's involved with that patient and family and then it just kind of directs us and guides us in how to approach and how to better care for the patient. – Nurse 5

The four nurses saw this assessment tool as helpful to their overall learning more about children with IDs, which in turn improved their care. The nurses believed in this formal institutional discourse of learning, because it provided them with expected institutional practices they understood and could follow and provided the opportunity to gain new knowledge. They incorporated this institutional discourse into their practice and advised others to utilize it as well. This program was a positive learning experience around caring for children with IDs for all four nurses involved.

No. I think there should be. It would be nice to have, mini programs for so many things, it's just unfortunately they don't have the resources to do that. – Nurse 4

The nurse who did not know about the BALANCE program felt she had never had formal educational learning around children with ID in the hospital setting. However, she stated that she believed hospital programs could be beneficial to nurses learning and caring for children with IDs. She stated she wished she had that sort of learning experience during her nursing practice or before. She recognized the benefits they could serve without having ever participated in one.

The hospital program the nurses participated in created new learning opportunities for the nurses with a variety of backgrounds and years of experience. They all agreed hospital programs were valuable and useful learning resources and led to better experiences for children and families with IDs. Significant learning occurred during the program and it was brought up often when nurses explained how they learned to care for children with IDs. They all highlighted this program as a positive experience for their learning how to nurse children with IDs. This was one of the most important formal learning discourses described by the nurses. The formal learning discourse of hospital-based programs was described as beneficial to their care for children with IDs.

Extended formal education

Two out of five of the nurses who participated in this study had done or were currently engaged in more formal education after completing their Bachelor of Science in Nursing undergraduate program. One nurse had completed her Masters of Nursing program where she did projects and had classes on children with IDs. The other nurse was currently completing her Nurse Practitioner program. Both nurses noted that their passion was pediatrics, specifically children with IDs.

And then just in my own studies when I was doing my final project for my Master's degree. ... So I did a survey of nurses that work in the home in Nova Scotia and just said you know what do you want to learn about when you're caring for kids in the home? What do you want to learn about? A lot of their learning needs were around kids that would have ID. And one of the big needs that came out was like how do I communicate with them and how do I make sure that their needs are included in the care plan. And when I went to do my own research of what's out there, I couldn't find anything pretty

much which is maybe why you're doing this project too. You know I searched hospital websites and just Google and the literature and lots of different sources and there just doesn't seem to be a lot out there. And so I ended up, between the little bits and pieces that I could pull from different resources and talking to other clinicians that have worked with this population for a long time, kind of putting together a list of tips and tricks for professionals that in the case of my project you know they predominantly work with adults and predominantly older adults in the home, so when they're working with child and particularly child with ID they just needed like you know a quick reference kind of resource. So they also were voicing to me we can't find educational resources on this population so and I couldn't find any, so I had to make my own. So yeah there's not a lot out there that I found that's formal education on that population. – Nurse 2

This nurse recognized a need for nurses to learn more around caring for children with IDs because of the lack of formal learning opportunities and information specific to this unique patient population. Her final project focused on how to communicate and care for children with IDs as a nurse. This project was a valuable learning opportunity for this nurse. She was able to better understand and challenge societal, institutional and even research discourses around children with IDs. Given the recognized lack of information in the literature about children with IDs, she was able to build her own resources and tools for herself and other nurses. She used her subject position as a Masters graduate student and agency to create more learning for her and other nurses caring for children with IDs. This was a unique learning experience for this nurse. Her formal education gave her an opportunity to learn about this population and therefore improve her own practice and care.

but to actually like know the definition of intellectual delay, it maybe was covered in undergrad but I can't remember that. Just recently for our project that I did, I realized that like global developmental delay is under 5 and then usually it moves to ID. – Nurse 4

This nurse was speaking about her classroom learning during her Nurse Practitioner program. Prior to completing more formal education, she felt she had little knowledge and was appreciative of the knowledge she had learned through her advanced education. She seemed to utilize this learning in her own practice of nursing well.

Both nurses felt that their extended formal education had led them to new knowledge about children with IDs. Without this formal learning experience, they felt they would have less knowledge that in turn impacted their practice and care. They both negotiated and navigated ways to utilize their learning experiences and advanced knowledge around children with IDs through extended formal education. This is another formal learning discourse experienced by two of the nurses but was important and relevant to the nurses that did participate in it. They put weight on this formal learning discourse and what it taught them around caring for children with IDs.

Other learning tools

All nurse participants believed that some of their learning came from learning opportunities outside of a hospital program and formal education. Some of the learning opportunities and tools discussed by the nurses were readings of interest, presentations, webinars, short academic resources, and conferences all of which they read, attended or participated in on their own personal time to learn more about how to nurse children with IDs. Many of the nurses also spoke about a lack of extra resources available for nurses and other clinicians. It is also important to note that the nurses who spoke about conferences or webinars

did not find any that were directly about IDs and/or children with IDs, but rather were on other general topics that reviewed IDs in an indirect way. Utilizing these informal learning experiences and tools outside of more formal learning and experiential learning at work was a way for these nurses to address their gap in knowledge and challenge the lack of learning opportunities available to them. This might also be seen as a challenge to perceived institutional and societal expectations regarding nursing knowledge, that nurses from a generalist educational program should be prepared for everything including how to care for children with ID. This supports what is discussed in the literature on how best to challenge this expectation, by having the ability to utilize tools to improve overall knowledge (Manias & Bullock, 2002). These nurses were resourceful, reflective and critical thinkers evidenced by their abilities to take on opportunities that expanded their knowledge about IDs and possibly improve their nursing care for children with IDs.

I'm often reading if I see something that comes up that is of interest. – Nurse 1

Like I do a lot of reading at home if something interests me then I will go for that. –

Nurse 2

The nurses often read independently based on their professional interests, which usually included children with IDs. They believed reading could help increase their depth and breadth of knowledge, and act as a good learning resource or tool.

How we're doing it right now in this class is it goes by life stages. So we did kind of like a fertility/prenatal and then we did newborn/peds and now we're moving to the older adult but basically there's so much reading. It's a lot of independent reading and just because that's my interest, I read more on that. So yeah, a lot of articles provided and our prof is a pediatric NP so she speaks a lot about kids. – Nurse 4

This nurse is utilizing her extended formal education to read more and to add to her learning. She recognized she had an interest and passion for pediatrics and children with ID so she chose to read articles about children with IDs to increase her knowledge base. She believed utilizing informal learning tools gave her more knowledge and expertise.

More recently I've been noting I guess a little bit more content about working with this population in the work that I do 'cause it's often dealing with respite for kids that have complex medical needs and many of those kids have ID as well. So in presentations and webinars and things like that. Then sometimes there's principles of working with those patients and families, everything from you know assessment tools for assessing pain in nonverbal kids to you know different feeding machines that you know you could try in this population but I guess that's not so much ID. Some that have talked about communication aids and different options like that that are available. So it's more of like indirectly touching on some of the ID components of a larger picture of care. I can't think of any that were specifically on ID. – Nurse 2

This nurse was in a managerial role and she had noticed other information and learning opportunities such as participating in conferences and webinars that could help provide her with more specific information and more learning opportunities than when she was a direct care nurse. She valued incorporating her learning from webinars and presentations into her current role and in teachings for other nurses because she had noticed a lack of information and learning for clinicians who cared for children with IDs in society, textbooks, and undergraduate education. She used her agency and power in a managerial role to try and teach other nurses about children with IDs and act as a learning resource herself.

And some general communication principles that you know kind of apply in any situation but yeah. I really, like I said like some formal webinars that there were principles of interacting with kids with ID but it was only part of discussing many different parts of their care, it wasn't focused on that. – Nurse 2

Yeah like there's a series of webinars from an organization called Children's Health Care Canada and it used to be Canadian Association for Pediatric Health Centers. So they do webinars just like on a regular basis. So, the ones I'm thinking of I think were in 2018-2019 as I've had that happen a couple times like a couple different webinars had those little kinds of tidbits of information in them. – Nurse 2

The nurses felt there were formal webinars that informed them indirectly on different aspects of care for children with IDs but had not participated in any webinars that were directly focused on how to nurse children with IDs. The nurses used their own critical thinking and subjectivity to create new knowledge from the information in the webinars and to learn how to better care for children with IDs.

No. No. Not that I can recall. Nothing specific for children with special needs or anything. Certainly, I think some of the conferences I've attended which might be like either on, like I do endocrine, so some like endocrine needs but nothing that there might be children with special needs or intellectual disabilities that you know have certain conditions but there's nothing specific for intellectual disabilities. – Nurse 5

This nurse believed some conferences she had attended peripherally discussed children with ID or special needs. She and other nurses recognized that no conferences or further education had been directly on children with ID. They challenged this institutional and societal lack of information.

...really realizing that there is no guideline, there's no information out there for clinicians in terms of how do you include that patients' preferences in care planning if they can't speak for themselves. – Nurse 2

I wish there was more guidance and training and information for clinicians.

I've never you know as a direct care nurse when I was in those roles I don't ever recall any you know education sessions or formal opportunities like that. – Nurse 2

Many of the nurses negotiated with a lack of guidelines and specific nursing knowledge and information on children with IDs. They chose to navigate a lack of information by informally learning through experience and recognized where their own knowledge might be lacking. They tried to fill this gap in learning by any available learning experience they could find such as webinars and conferences to provide some much-needed learning.

I guess like one thing would be like not kind of being afraid of them right, cause it's hard sometimes we put a stigma on them and that kind of thing. And the other thing is too is like just reach out to other ways to communicate and how to communicate with them. Find different programs like the BALANCE program or different other short resources, do you know what I mean? That someone can refer them too if they were having difficulty with them. – Nurse 3

The nurses challenged societal discourses of stigma and fear around children with IDs. They advised others to also challenge this norm. They believed learning might play a role in reducing stigma by improving communication and learning through the use of tools, programs and other resources. This was reiterated in all five interviews that utilizing formal learning experiences and creating informal learning opportunities could reduce stigma and fear around

children with IDs, both in society and institutions. This was a primary reason why many of these nurses chose to participate in the use of other learning tools on their personal time.

Constant Learning Process and Unique Learning Curve

Recognizing that caring for children with IDs is a constant learning process and a unique learning curve was an important part of all the nurses' learning that was woven through all the interviews and really tied into and reiterated why learning about how to care for children with IDs was unique and important. It demonstrates why learning to care for children with IDs varies from care of typically developing children. Each nurse spoke about how learning to care for children with IDs was a constant learning process and was needed over their nursing careers. Many of the nurses described this learning process as a steep learning curve because of the complexity of caring for children with IDs. The nurses felt it was important to note that nurses would learn to care for children with IDs at different paces depending on their ability to learn from others, their learning preferences, nursing experience, and the learning resources available. The nurses spoke often about being kind and patient with themselves while going through a steep learning curve and recognizing this learning as a constant process.

So I think that it's more of a learning experience, you keep learning things as you're going along and interacting with different families and different children. – Nurse 5

...well I guess it's kinda been like a learning curve in the OR – Nurse 3

...then the nursing have to become creative. – Nurse 3

All the nurses recognized learning to care for children with IDs as a learning curve and valued and believed in a constant and unique learning process. They believed nurses were always 'learning as they go' in their practice. They valued using creativity and learning to navigate lack of formal education and the informal learning processes that were available to them.

So, I'm constantly learning. And so, there's not specifics, taking time and listening.

Involving them as much as you can. Learning to use different tools. – Nurse 1

Most of the nurses recommended the use of different learning experiences to engage in informal, available, and effective learning experiences that helped them nurse children with IDs. They negotiated with what information was scattered in informal learning opportunities available institutionally. One nurse described the process as lifelong learning and one of the most experienced nurses said she was constantly learning.

But I think open mindedness is really the big thing and patience with yourself because I think it can be easy as a new nurse no matter where you work but with a population like this that presents a lot of unique challenges just by virtue of their having an ID, it can be easy to feel like you messed up or you missed the mark or you know I thought I was doing something that would you know, give comfort to this patient but then they got really agitated, so I screwed up you know. Just to be kind to yourself and to know that I definitely have had situations or even the families like oh my gosh like I don't know my child is really you know she's really upset, I'm not sure why. I feel like there is sometimes uncertainty and it's a really unique learning curve and it's a really unique learning process, so just to be kind to yourself and allow yourself to learn and grow and not beat yourself up when things don't go the way that you might have hoped they would. So yeah that's probably the biggest thing. – Nurse 2

While the nurse described the process as a 'unique learning curve and really unique learning process' she also said that messing up was part of the learning process and she needed to remember this and be open minded to these moments. Open-minded meant being kind to oneself for making mistakes so that you could take the difficult situation and 'learn and grow'

from it. Open mindedness was a very purposeful practice that helped her deal with uncertainty and shift her thinking about what was best when caring for a child with an ID. She also believed and valued being patient and kind to themselves throughout the process, especially as a new nurse who may be more inclined to feel discouraged when not knowing how to care for children with IDs. She recognized how children with IDs can present unique challenges and this contributes stress to the learning curve and process of caring for this population. She also challenged others to grow and learn.

And it was kind of nerve wracking to care for them because yeah, I didn't feel like I had a lot of experience knowing how to communicate. – Nurse 2

According to the nurses in this study, their University education provided little to no formal education on children and people with ID with minimal or no direct clinical experience with children with ID in the curriculum. This then created situations where they had to figure out ways to learn on their own after graduation. One nurse struggled with a lack of formal education including clinical, that left her feeling nervous and unsure of her ability to care for children with ID.

Maybe in nursing this is just the way it has to be. You have to learn a lot as you go because there's so much to know. But it would be nice to have opportunities to go learn more about this care, like specialized care for kids with ID and autism. – Nurse 4

We can see that this nurse is questioning the way learning has been organized both at the university and after graduation. ‘Maybe in nursing this is just the way it has to be’ is evidence that there is a discourse of learning that is perpetuated by everyday practices within nursing education. If we examine this nurse’s statement further, she is critically questioning and perhaps giving into a ‘way of learning’ that includes the understanding that one cannot be taught or learn

everything in school because there is simply too much to learn. Rather, continuing education is expected. She also points out that opportunities are not readily available after graduation, that contradicts the expectation or belief that nurses need to continue their education. All of the nurses in this study struggled to find ways to learn about children with ID, as stigma and stereotypes continued to be perpetuated through a discourse of disability, that created marginalized spaces for children with disabilities. This ultimately created a lack of learning opportunities for nurses.

It is important to note that nurses in this study challenged the lack of institutional and educational learning about children with ID by stating it would be nice to have more formal opportunities to learn about caring for children with IDs. While caring for children with IDs is a specialized field, it does not mean there should be a lack of evidenced-based information and formal learning opportunities. A lack of educational discourse at the university level and a lack of formal institutional discourses at the hospital level perpetuates stigmatization of children with IDs because of the invisibility in educational curriculum and hospital provided programs, guidelines and protocols. Many of the nurses negotiated and navigated this lack of societal and institutional information around children with IDs through reflection on their current practice, questioning, and seeking out their own resources and continuing education through mainly informal learning experiences such as learning from others and learning through experience.

Oh yeah, like laughter is the best medicine. And like making them laugh and smile I think would really put them at ease. You can't be too intense, like not all business. And you have to, you know what if it makes them upset to do a temperature then you don't do a temperature, like you have to kind of use your common sense. – Nurse 5

Another nurse challenged an institutional discourse of learning that she believed was too intense and serious by incorporating fun, laughter and smiles into her practice and care for children with IDs. She believed common sense was an important aspect of the learning curve and care for children with IDs.

Well I think it's important to know intellectual disabilities come in all sorts of like varieties, you know whether it be age related or you know they may be dyslexic or they could have autism and things like that. I think just having a good sense of knowledge of all the potential intellectual disabilities out there and just being you know receptive to it and non-judgmental. – Nurse 5

This nurse believes that there is judgement towards children with intellectual disabilities. This perpetuation of stigmas adds to the meaning that is created about caring for children with IDs and ultimately contributes to the construction of barriers to learning about children with IDs. The nurses in this study shared over and over again that stigma was perpetuated through a lack of education because of the invisibility and marginalization of children with IDs. The nurses were left to find information on their own because children with IDs were a ‘specialty group’.

In all the nurses’ experiences, they found being receptive to learning and being non-judgmental about children and families with IDs was a key part of the learning process. This supported the practice of being open-minded in their nursing care of children with IDs that was part of the discourse of constant learning. The nurses utilized open-mindedness to challenge their own beliefs and practices that ultimately demonstrated a type of learning that could challenge more authoritarian ways of caring. They recognized that each child was unique and all cases varied. They utilized basic knowledge and definitions of different intellectual disabilities and continued to learn more based on that foundation of information provided during undergraduate

nursing programs. They all saw this learning process over time as constant and unique. Each child is unique and each nurse is unique. The learning process around children with IDs varies from typically developing children due to a lack of formal education and the unique way all IDs can present in children and with their underlying health conditions. Communication patterns and techniques, likes and dislikes, and skills to providing care may vary in every single case a nurse encounters over their career. Nurses are expected to navigate and negotiate this reality by using reflection and critical analysis of sought out learning opportunities to create new knowledge.

Chapter 5: Discussion and Conclusion

Discussion

FPS and discourse analysis provided the lens to understand the experiences of the nurses interviewed by examining how nurses navigated and negotiated their learning experiences to create new knowledge, skills, and confidence when caring for children with IDs. This methodology helped me to deconstruct and reconstruct the nurses' experiences and understand how the nurses learned through observation, questioning, reflection, and engagement. I was also able to demonstrate how relations of power were negotiated by the nurses in different ways as they learned how to care for children with IDs and their families. Examining the nurses' beliefs, values and practices through discourse analysis allowed for their experiences to be understood through different discourses of learning. The nurses had a changed worldview from working with and learning from the children and their families including changed beliefs, values, and practices in both institutional, societal, educational, and personal discourses that in turn helped them to challenge norms, stigmas, and stereotypes on children with IDs. There was a lack of formal institutional educational learning discourses available to the nurses in this study both at the hospital and in previous undergraduate programs. This perpetuated the marginalization and stigmatization of children with IDs. The nurses challenged this marginalization and stigmatization by seeking out and creating informal learning discourses through learning from others and experience and spending personal time and extended education to find new formal learning discourse after completing their undergraduate education. Formal learning discourses allowed nurses to create explicit knowledge and informal learning discourses allowed nurses to create tacit knowledge that they can incorporate into their beliefs, values and practices on children with IDs.

Formal/Explicit and Informal/Tacit Learning Discourses and Knowledge

The nurses interviewed utilized both formal and informal learning discourses; however, most of their learning was through informal methods. The nurses interviewed felt they had little to no undergraduate education on children with IDs and therefore felt they needed to incorporate informal methods of learning to create new knowledge and skills for caring for children with IDs. The informal learning discourses included learning from others, such as children with IDs, their families, and other healthcare professionals, and learning from professional and personal experiences. Informal learning discourses created tacit knowledge. The formal learning discourses the nurses shared was through readings and aspects of webinars they participated in on their own time. Formal learning discourses created explicit knowledge for the nurses. The nurses found it hard to find formal resources directly on children with IDs. The marginalization that is perpetuated through social discourses of children with IDs may have played a role in making it difficult to find resources. Two of the nurses had participated in extended formal education including a nurse practitioner and a Master of Nursing program. These two nurses experienced learning opportunities in a formal education setting that helped them gain explicit knowledge. The nurses found their extended education was more focused and provided more information and learning opportunities on marginalized populations such as children with IDs. They also noted this group to be an interest of theirs and spent extra time learning during their extended education on children with IDs. As well, four nurses participated voluntarily in a hospital based program on caring for children with autism that they felt improved their explicit knowledge and care for all children with IDs. Nurses sought out formal learning discourses and explicit knowledge because they all noted a lack of formal educational discourses on children

with IDs and believed improving their explicit knowledge would lead to better care for children with IDs and in turn lower stigmatization and marginalization.

Learning around children with IDs is a complex, unique, and lifelong learning process. The nurses can learn new information and skills from each patient they encounter if they incorporate critical thinking and reflection techniques; however, it does not mean they will know exactly what to do for the next child with ID they care for as they are individual and unique (Brown & Guvenir, 2009). Each child may require unique and special care to provide the best care possible and nurses must be willing to constantly learn. The nurses can learn communication skills and patterns, individual child preferences, and more from each case which can in turn help in caring for future children with IDs. Children with IDs have a large range of signs and symptoms and nurses must use their critical thinking on what knowledge and skills to apply with what child with IDs and their family. Children with IDs have been labelled as ‘unique’ in a particular way (Brown & Guvenir, 2009). The meaning of ‘unique’ as it is applied to IDs is attached to an understanding of ‘difference’, ‘stigma’, ‘fear’, ‘other’, and ‘unknown’. The nurses in this study have demonstrated this. The discourse of disability incorporates a particular meaning or understanding of ‘uniqueness’ that requires nurses to ‘seek out’ different kinds of learning and ways of knowing. If the diversity and ‘uniqueness’ of children with ID sets them apart in a way that cannot be easily taught or learning in certain settings such as an undergraduate program, then ‘other’ discourses of learning will need to be developed. This is what the nurses had to do and why they sought out primarily informal learning discourses and opportunities.

In undergraduate schooling, nurses are taught to provide evidence-based practice to all patients. Evidence-based practice is a holistic approach that involves clinical decision making

that incorporates the best and latest evidence, clinical expertise, clinical assessment, and patient preference and values during care (Mackey & Bassendowski, 2017). The nurses in this study spoke about learning from four major areas that incorporated some formal learning but mostly informal learning to try and provide the best evidence-based practice possible and create new knowledge and ways of knowing. Evidence-based practice includes the incorporation of tacit and explicit knowledge to provide the best outcomes possible (Mackey & Bassendowski, 2017).

Tacit knowledge relates to experience-guided working, which is what the nurses describe in the first two themes through their informal learning (Zander, 2007). Explicit knowledge is gained from formal learning experience described in the third theme. In this study, the nurses' learning experiences emphasized the gaining of tacit knowledge over explicit knowledge. They put more weight to their learning from others and learning from experience and therefore it can be difficult to unpack these learning experiences. This is why FPS and discourse analysis become so important to provide the methodology to understand the nurses' learning experiences from their own perspectives. The incorporation of both formal learning discourses and explicit knowledge with informal learning discourses and tacit knowledge leads to evidence-based practice as the nurses learn from different discourses to challenge and navigate a lack of educational and institutional discourses on children with IDs.

Tacit and explicit knowledge are characteristic in nurses' ways of knowing. Knowing means that a nurse has a base on which to structure an action or way of being or caring. That base is also known as knowledge but in order for a nurse to gain or create knowledge they must first employ a learning process that may differ in each individual (Zander, 2007). In the nurses interviewed the themes that emerged describe the nurses' informal and formal learning processes and learning discourses that developed or created tacit and explicit knowledge on caring for

children with IDs. Explicit knowledge is formal information gained through written words, maps, or symbols while tacit knowledge is knowledge gained through experience, interaction, and the gaining of skills (Zander, 2007). The nurses created explicit knowledge while learning from formal learning discourses such as webinars, readings, extended education, and hospital based programs. As the nurses created and sought out informal learning discourses through personal and professional experience by interacting and engaging with children, their families, and other healthcare professionals they were gaining tacit knowledge that allowed them to have less reliance on explicit knowledge such as rules and facts. This permitted the nurses to use their agency and power to challenge and negotiate institutional and societal discourse on children with IDs. Tacit knowledge is strongly linked to ‘nurses’ intuition’ (Herbig, Bussing, & Ewert, 2001). In the care of children with IDs the intuition and tacit knowledge is harder to gain and find because tacit knowledge and expert level nursing is created through experiencing and reflecting on incidents that follow the same structure, children with IDs can present in many different variations and the same structure is uncommon (Herbig, Bussing, & Ewert, 2001; Brown & Guvenir, 2009). In order for the nurses to continuously learn about caring for children with IDs and to improve their care and confidence they incorporated both informal and formal learning discourses that created new explicit and tacit knowledge on caring for children with IDs to provide evidence-based care.

Learning from others

Learning from others was experienced by all nurses in the study and was the primary way that these nurses learned about children with ID. This type of learning was constructed through informal learning discourses and tacit methods and ultimately created particular ways of knowing and knowledge for the nurses interviewed. Two different theories of nursing; Carper’s

(1978) 'Fundamental patterns of knowing' and Benner's (1982) 'From novice to expert' theories support my findings of learning from others. By learning from others, the nurses were utilizing informal learning methods to create and gain tacit knowledge or 'knowing' from children with IDs, families, and other healthcare professionals. They spent time reflecting on interactions and time spent engaging by asking questions, observing, mentoring, and listening. Knowing means the nurse has extensive understanding and skills on the subject such as caring for children with IDs (Zander, 2007). By learning from others such as the children, families and other healthcare professionals the nurses are creating 'personal knowing' that is a type of evidence based practice. They are creating knowledge through observation, reflection, and self-actualization of things they have seen and experienced (Carper, 1978). This is similar to findings in this study. New knowledge and skills help nurses go from novice to expert level nursing in the field of children with IDs (Benner, 1982; Cubit & Lopez, 2012). Therefore, it is important to understand the therapeutic relationships in which they learn from and create personal knowing. In this study, the unique finding is understanding how the nurses specifically negotiated and challenged the different learning discourses (formal and informal) in order to finally gain the required evidence based explicit and tacit knowledge to help them care for children with ID.

Novice to expert level nursing theory challenges the societal expectation of nurses knowing everything about their patient (Benner, 1982). It supports nurses in utilizing mentorship and experience to learn as they progress through each stage of nursing. This is also supported in most literature on a nurse's transition from student to nurse (Cubit & Lopez, 2012; Manias & Bullock, 2002). Societal and sometimes institutional expectations of a nurse caring for patients and their families is that they know everything on how to best care for that patient. This is challenged by stating that nurses do not know everything, what is important is that they have the

ability and know how to learn and find information on best practice (Manias & Bullock, 2002). The nurses interviewed had a variety of years of experience and they all spoke about how they have been mentored by children with IDs, their families, and other healthcare professionals or how they are currently mentoring others to provide best care to children with IDs. Mentorship is in the literature as a common way for nurses to create informal learning discourses that lead to best practice and evidence based practice (Gentry & Johnson, 2019). This mentorship and ability to learn from others highlights the relational power of the nurses. The nurses challenge binary opposites of nurse to patient, parent to child, nurse to family and even experienced nurse to novice nurse. The nurses share how they feel all members utilize their power and how a nurse can learn from a child with ID, their family, experienced and non-experience nurses or other healthcare professionals. They challenge a hierarchical health care or institutional discourse of nurse over patient and family and feel learning comes from observation, engagement and reflection with all members involved in the care of children with IDs.

Learning from experience

Participants in this study learned through both professional and personal experiences. Experiences that are either professional or personal can be seen as practices that inform an informal learning discourse that create tacit knowledge by the nurses in this study. Experiential learning as a form of informal learning also created tacit knowledge for the nurses in this study especially through the use of reflection. Experiential learning originated in nursing from Kolb's (1984) theory of experiential learning. Experiential learning is implemented in nursing school and in nursing practice. Kolb's theory explains how individuals or nurses construct abstract representations from actual experiences which direct following actions in similar situations (Kolb, 1984). Students often need to practice the knowledge gained from classroom lectures and

readings in actual or concrete situations with patients. In the case of nurses working with children with IDs they were not given the base knowledge from classroom lectures or readings and therefore, have to build abstract meaning from experience with no prior knowledge creating a more difficult and complex learning process. Kolb (1984) described the experiential learning as the process where knowledge is constructed through the transformation of experience, resulting from continuous person-environment interaction and involves feeling, perceiving, thinking, and behaving. Kolb (1984) described a four-step cyclic learning process; concrete experience, reflective observation, abstract conceptualization, and active experimentation. These steps were experienced by the nurses in this study evidenced by their descriptions of personal and professional experiences that led to informal learning moments and discourses for them while caring for children with IDs and their families. Some nurses had actual experiences in their personal life with their own children or children of friends and family that created reflection, learning, and experimentation in care. All five nurses had experiences in their professional care that facilitated the learning process to generate new knowledge. Kolb (1984) recognizes that all people have different learning styles but possess the ability to complete the learning cycle just in different manners. This process is lifelong and constant when nurses care for children with IDs and have more and more actual or concrete experiences. While there are similarities to Kolb's experiential learning model, what is unique about the findings in my study is the way the nurses had to negotiate an informal learning discourse to create tacit knowledge. Experiential learning is a recognized way to obtain knowledge and implement evidence-based practice; however, this type of learning was not clearly offered or suggested to the nurses as a possible learning style. The nurses in this study chose to find many of these experiential/informal opportunities on their own, often without guidance from educational or health care institutions.

Reflective learning is an approach adopted by nursing education institutions to assist nursing student in learning to adapt in fast-paced dynamic and complex healthcare environments (Naicker & van Rensburg, 2018). It helps nurses effectively review and evaluate their actions with the aim of learning from their own experiences. The reflective process is often taught to nurses through their education and over the last 20 years the nursing profession has widely accepted reflective practice and reflective learning as effective measures to help students and nurses develop competencies and provide best patient care. Particularly in frequently changing contexts such as children with IDs who have a range of signs and symptoms to all diagnoses (Naicker & van Rensburg, 2018). Despite the fact that nurses in this study shared having little to no education regarding children or people with IDs, their nursing education gave them the foundation to lifelong learning, including how to reflect on experiences to create new knowledge and knowing including tacit and explicit knowledge. The nurses in this study used their agency and demonstrated their ability to identify gaps in learning opportunities and then choosing to use informal learning discourses that may often be seen by others as less rigorous when compared to more formal education discourses.

Learning from tools and resources

Learning from tools and resources was the way the nurses in this study described gaining and creating explicit knowledge through formal learning discourses on caring for children with IDs because it was not provided or taught during their undergraduate educations. The nurses in this study challenged the generalist educational nursing discourse (a type of formal learning discourse) by incorporating informal and formal discourses of learning to create tacit and explicit knowledge and ways of knowing. The nurses chose to find formal learning opportunities through other educational tools on children with IDs. They sought out tools such as hospital based

programs and readings or webinars. Two of the nurses went on to complete extended formal education. The use of learning tools are known to improve evidence-based practice (Palese, et al., 2018); however all the nurses described having a hard time accessing and finding tools directly on caring for children with IDs. Formal learning tools are recognized as a strategy to deliver high quality care to patients. The nurses who did participate in formal learning opportunities spoke highly of the new knowledge gained and the impact it had on their practice. The incorporation of formal learning aids nurses in providing best care and best evidence-based practice (Palese, et al., 2018).

Despite this the nurses spoke more about and based more of their learning on informal methods of learning from others including experiences through observation, engagement, and reflection. As we can see from the participants' experiences it was not a simple decision to choose informal over formal. In fact, informal learning was often the only choice. I would like to point out that while these two different discourses may be positioned as binary on a superficial level (Foucault, 1983; Weedon, 1987) it is not that simple. We need to look at the practices of the nurses and how they negotiated their learning. For example, relations of power that operate when one speaks or thinks about each discourse, can often create oppositions whereby formal education is seen to be better than informal education. Clearly the nurses in this study spoke highly about their informal learning opportunities including learning from others. The construction of discourses and how they are taken up through institutions and society create meaning and hegemonic ideologies. These nurses challenged these meanings and have brought positive meaning to personal learning that builds on the work of Benner, Carper, and Kolb.

Constant learning process and unique learning curve

Lifelong learning is a theme in nursing; however, when caring for children with IDs it is vital to provide children with IDs with the best care and evidence-based care as the nurses in the study reported little to no undergraduate education on children with IDs or people with IDs. Lifelong learning in nursing shifts the societal and sometimes institutional discourse that perpetuates the belief that registered nurses are expected to know everything about caring for patients to the discourse that nurses engage in professional learning continuously throughout their careers to keep their knowledge and skills current, growing, and in best practice (Gopee, 2005; Manias & Bullock, 2002). Historically in nursing the societal and institutional discourse was that nurses implemented and followed the orders of others rather than gathering and analyzing information and utilizing their own knowledge (Gaberson & Langston, 2017). Since the mid to late 1990's societal and institutional discourse on nursing expectations have moved to encourage and welcome nursing knowledge and information and give nurses the ability to create orders to produce optimal outcomes (Gaberson & Langston, 2017). The expectations and power between nurses and doctors is also shifting to less of a hierarchy, challenging the doctor-nurse binary opposite and discourse in institutional settings and in society (Gaberson & Langston, 2017). This in turn has increased the expectation and accountability of nurses to engage in educational and lifelong learning to prepare for the complex role of a 'knowledge worker'. This ability and accountability should be facilitated by institutions and the nurses in this study challenged institutional norms and discourses that hinder their ability to be a 'knowledge worker'. The process of lifelong learning is especially important and vital in the care of children with IDs because there is a significant lack of educational discourses and institutional and societal information.

Lifelong learning is a complex and dynamic learning process that encompasses both personal and professional life. It includes informal and formal processes, such as those described by the nurses in this study. Lifelong learning involves seeking and appreciating new world views or ideas in order to gain new perspectives as well as questioning one's environment, knowledge, skills, and interactions (Davis, Tayle, & Reyes, 2014). In research, the most essential characteristics of lifelong learning are reflection, questioning, enjoying learning, understanding the dynamic nature of knowledge, and engaging in learning by actively seeing learning opportunities (Davis, Tayle, & Reyes, 2014; Qalehsari, Khaghanizadeh, & Ebadi, 2017). These characteristics came out in all five interviews done with the nurses. The nurses used these characteristics to be able to translate informal and formal learning discourses into tacit and explicit knowledge that provides nurses with the capacity to deliver high quality and best nursing care to children with IDs.

The nurses in the study challenged a lack of learning opportunities that had been created by formal and informal educational discourses regarding children with IDs by incorporating lifelong learning and learning skills from undergraduate education, to learn and create knowledge about caring for children with IDs. All of the learning tools and types exist in the literature but none of them focus on nurses' learning around children with IDs. The nurses in the study utilized both formal and informal learning discourses to gain tacit and explicit knowledge on children with IDs. The ways in which the nurses described their learning may come from undergraduate discourses; however, the process of learning about children with IDs is unique and highly complex. It can change case to case with the individuality of each child and their family. Each child with an ID can be completely different and IDs can encompass a variety of levels of ability. Nurses working with children with IDs must be easily adaptable, confident and kind to

themselves through their lifelong learning process, just because something worked once does not mean it will work with the next child. The nurses spoke about how it is important to see the child first but then you must recognize their diagnosis and ID and that will in turn affect how a nurse approaches care. The way in which nurses provide best care to children with IDs takes constant reflection and ‘learning as you go.’

Recommendations To Nurses Working with Children with IDs

As the final question of the semi-structured interview the nurses were asked “do you have any advice for nurses who are starting to work with children with intellectual disabilities?” The following list summarizes the advice and recommendations given by the nurses who participated in this study. You will notice that the advice given by the nurses in this study are in align with the themes that emerged throughout the analysis and include informal/tacit/experiential, formal/explicit and lifelong learning.

- Be open and willing to learn from children with IDs, on their likes and dislikes, their communication style, and their skills in order to provide the best care.
- Engage, ask questions, and observe families while they care for their children with IDs.
- Engage, ask questions, and observe other healthcare professionals working with children with IDs. Utilize mentors.
- Take time to reflect on both positive and negative experiences had in personal and professional life. Reflect on what you can learn from experiences.
- Participate in any formal education that you may encounter both in hospital, in school and on personal time to help enhance overall learning.
- Be willing to constantly learn more. Be open to new information and reflect on new practices. Pick up tips and tricks in all your experiences and from many sources.

- Be confident and kind to yourself through the learning process. Understand no one knows everything.
- Have fun with your care and with the children, this may include but not limited to smiling, laughing and singing with and for the children.

Similarly to the recommendations given directly from the nurses, the recommendations that emerged through the analysis of this study include the following:

- Use purposeful reflection to reflect on any experiential learning and learning from other moments that occur throughout a nursing career, this may include writing experiences down, talking among colleagues, and spending time alone to reflect on learning discourses.
- Use your power and agency as a nurse to challenge institutional and societal stigmas and stereotypes around children with IDs, including a lack of information by continuously learning and seeking out formal and informal learning experiences and discourses.
- Be open-minded and non-judgmental in your care towards children with IDs and their families. This also includes being non-judgmental and kind to yourself through the learning process of caring for children with IDs.
- Remember that caring for children with IDs is a lifelong learning process, all nurses are continuously learning to improve care and provide evidence based care to children with IDs and their family.

Strengths and Limitations of the Study and Recommendations For Future Studies

All nurses were recruited from one hospital in Halifax, the IWK Health Centre, and this may have limited the diversity of the views obtained. Race and gender were not addressed in this study. All nurses interviewed were female and Caucasian. If there was gendered or racial

learning it did not emerge in the shared experiences of the nurses interviewed. FPS can provide a gendered lens and the discourse of nursing is predominantly female, however for this study FPS was used to focus on how all people appropriate and internalize, or conversely, resist and struggle against societal, cultural, and economic power relations and how they re-construct their learning experiences. This study is limited to only the voices of registered nurses and not those of other nurses or the children with IDs and their families. FPS and discourse analysis are considered a strength as it offered an in-depth analysis of the interviews conducted to yield rich and detailed data from a small sample.

It is suggested that further research be conducted to explore the relations of power and discourses that play a role on the care of children with IDs and the learning of nurses from the perspective of the children and their family and not just the perspective of the nurse. Another recommendations would be to interview a variety of nursing positions, including nurse practitioners, and registered practical nurses. Final recommendation for future studies is to conduct a quantitative study to build on the findings of this qualitative study.

Conclusion

The literature sheds light on a gap in research on how to improve nursing care of children with IDs by nurses in healthcare settings. The literature also has a gap in the best type of learning for nurses to be prepared and confident in caring for children and families with IDs. Due to these gaps, previous research done by Breau, Aston, and MacLeod (2016), and my own personal experience as a nurse working with children and families with IDs, the aim of this study was to explore the learning experiences of registered nurses when caring for children with intellectual disabilities, how they provided optimal care to children with IDs and any recommendations they had to improve learning. This study aimed to close a gap in research looking at nurses' learning

experiences working with children with IDs. The study looked at any learning experiences had by nurses that in turn improved their knowledge, competence, and confidence surrounding children and families with IDs, including educational, professional and personal experiences.

The nurses interviewed in this study found informal learning discourses and opportunities while observing, asking questions, engaging, and listening to others, such as the children with IDs, their families or other healthcare professionals. They also found informal learning discourses when reflecting on past professional and personal experiences, and constructing experiential learning. These informal learning discourses provided the nurses with the opportunities to create and gain tacit knowledge on caring for children with IDs. The five nurses also created formal learning discourses by participating in formal learning resources such as extended education, hospital programs, webinars, readings and more. This learning created explicit knowledge that in turn improved their competence and confidence when caring for children with IDs. The process of learning to care for children with IDs is recognized as a unique lifelong process that varies from caring for typically developing children because of the complexities and unique needs of children with IDs and the lack of educational discourses in undergraduate and institutional discourses. The learning moments of the nurses turned into knowledge and new skills when the nurses reflected on and incorporated critical analysis of the situations. The nurses were constantly navigating and negotiating their learning to improve their care of children with IDs. They navigated power relations between themselves, the children, families, and other healthcare professionals. They challenged institutional and societal norms, stigmas, and stereotypes on children with IDs in both their professional and personal beliefs, values, and practices. They changed their worldviews on children with IDs by challenging and navigating a lack of educational and hospital/institutional discourses that perpetuates the

stigmatization and marginalization of children with IDs as 'other'. This thesis provides insight into how the nurses interviewed learned to care for children with IDs through informal and formal learning discourses and created new tacit and explicit knowledge and insights on children with IDs and their families. It also gives recommendations to new or novice nurses beginning to work with children with IDs and how all nurses can participate in lifelong learning.

References

- American Association of Intellectual and Developmental Disabilities (2019). Retrieved June 18, 2019 <https://aaidd.org/home>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Aston, M. (2016). Teaching feminist poststructuralism: Founding scholars are still relevant today. *Creative Education*, 7(15), 2251-2267. Retrieved from <http://www.scirp.org/journal/CE/>
- Aston, M., Breau, L., & Macleod, E. (2014). Diagnoses, labels and stereotypes: Supporting children with intellectual disabilities in the hospital. *Journal of Intellectual Disabilities*, 18(4), 291-304.
- Avis, M., & Reardon, R. (2008). Understanding the views of parents of children with special needs about the nursing care their child receives when in hospital: a qualitative study. *Journal of Child Health Care*, 12(1), 7–17. <https://doi.org/10.1177/1367493507085615>
- Barr O, & Sowney M. (2007). Inclusive nursing care for people with intellectual disabilities using urology services. *International Journal of Urological Nursing*, 1(3), 138–145. Retrieved from <http://search.ebscohost.com.ezproxy.library.dal.ca/login.aspx?direct=true&db=c8h&AN=105962285&site=ehost-live>
- Barrett, M. J. (2005). Making (Some) Sense of Feminist Poststructuralism in Environmental Education Research and Practice. *Canadian Journal of Environmental Education*, 10(1), 79-93.
- Boucher, A. (2017). Power in elite interviewing: Lessons from feminist studies for political science. *Women's Studies International Forum*, 62, 99-106.
- Breau, L., Aston, M., & MacLeod, E. (2016). Education Creates Comfort and Challenges Stigma towards Children with Intellectual Disabilities. *Journal of Intellectual Disabilities*, 22(1), 18-32.
- Brown I. (2007). What is meant by intellectual and developmental disabilities? In: Brown I, Percy M, (eds), *A Comprehensive Guide to Intellectual and Developmental Disabilities*. Baltimore: Paul Brookes; 3–16.
- Brown, F., & Guvenir, J. (2009). The experiences of children with learning disabilities, their carers and staff during a hospital admission. *British Journal of Learning Disabilities*, 37(2), 110-115.

- Carper, B. A. (1978). Fundamental patterns of knowing in nursing. *ANS Advances in Nursing Science(1)* 1, 13-23.
- Cheek J (2000) Postmodern and Poststructural Approaches to Nursing Research . Thousand Oaks: Sage Publications.
- Connelly, L. (2016). Trustworthiness in Qualitative Research. *Medsurg Nursing : Official Journal of the Academy of Medical-Surgical Nurses*, 25(6), 435-436.
- Creswell, J. & Poth, C. (2017). *Qualitative Inquiry & Research Design. Choosing among five approaches* (4th ed). Thousand Oaks, CA: Sage.
- Cubit, K., & Lopez, V. (2012). Qualitative study of enrolled nurses transition to registered nurses. *Journal of Advanced Nursing*, 68(1), 206-211.
- Davis, L., Taylor, H., & Reyes, H. (2014). Lifelong learning in nursing: A Delhi study. *Nurse Education Today*, 34(3), 441-445.
- Doerschleln, I., Lachetta, R., Schulz, Mi., & Tacke, D. (2013). Nursing patients with learning and physical disabilities in hospitals -- a systematic literature review. *Pflege*, 26(1), 42–54. <https://doi-org.ezproxy.library.dal.ca/1012-5302/a000262>
- Flax, J. (1987). Postmodernism and gender relations in feminist theory. *Signs*, 12(4), 621.
Retrieved from
<http://ezproxy.library.dal.ca/login?url=https://search.proquest.com/docview/1300109601?accountid=10406>
- Foucault, M. (1982). The Subject and Power. *Critical Inquiry*, 8(4), 777-795.
- Foucault, M. (1983) The subject and power. In: Dreyfus HL and Rainbow P (eds) Michel Foucault, Beyond Structuralism and Hermeneutics . 2nd ed. Chicago: University of Chicago Press.
- Gaberson, K. B., & Langston, N. F. (2017). Nursing as knowledge work: The imperative for lifelong learning: Guest editorial the official voice of perioperative nursing the official voice of perioperative nursing. *AORN Journal*, 106(2), 96-98.
- Gavey, N. (1989). Feminist Poststructuralism and Discourse Analysis: Contributions to Feminist Psychology. *Psychology of Women Quarterly*, 13(4), 459–475.
- Gentry, J., & Johnson, K. V. (2019). Importance of and Satisfaction With Characteristics of Mentoring Among Nursing Faculty. *Journal of Nursing Education*, 58(10), 595-598.
- Gopee, N. (2005). Facilitating the implementation of lifelong learning in nursing. *British Journal of Nursing*, 14(14), 761-767.

- Hart, S. L. (1998). Learning disabilities. Learning-disabled people's experience of general hospitals. *British Journal of Nursing*, 7(8), 470–477. Retrieved from <http://search.ebscohost.com.ezproxy.library.dal.ca/login.aspx?direct=true&db=c8h&AN=107298103&site=ehost-live>
- Herbig, B., Bussing, A., & Ewert, T. (2001). The role of tacit knowledge in the work context of nursing. *Journal of Advanced Nursing (Wiley-Blackwell)*, 34(5), 687-695.
- Iacono, & Davis. (2003). The experiences of people with developmental disability in Emergency Departments and hospital wards. *Research in Developmental Disabilities*, 24(4), 247-264.
- International Family Nursing Association (IFNA). (2015). *IFNA Position Statement on Generalist Competencies for Family Nursing Practice*. Retrieved from <https://internationalfamilynursing.org/wordpress/wp-content/uploads/2015/07/GC-Complete-PDF-document-in-color-with-photos-English-language.pdf>
- Kolb D (1984) *Experiential Learning Experience as the Source of Learning and Development* Prenhce Hali, Englewood Cliffs, New Jersey
- Lewis, S., & Stenfert-Kroese, B. (2010). An Investigation of Nursing Staff Attitudes and Emotional Reactions towards Patients with Intellectual Disability in a General Hospital Setting. *Journal of Applied Research in Intellectual Disabilities*, 23(4), 355-365.
- Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.
- Lovell, A., & Bailey, J. (2017). Nurses' perceptions of personal attributes required when working with people with a learning disability and an offending background: A qualitative study. *Journal of Psychiatric and Mental Health Nursing*, 24(1), 4-14.
- Lovell, A., Bailey, J., Kingdon, A., & Gentile, D. (2014). Working with people with learning disabilities in varying degrees of security: Nurses' perceptions of competencies. *Journal of Advanced Nursing*, 70(9), 2041-2050.
- Mackey, A., & Bassendowski, S. (2017). The history of evidence-based practice in nursing education and practice. *Journal of Professional Nursing*, 33(1), 51-55.
- Manias, E., & Bullock, S. (2002). The educational preparation of undergraduate nursing students in pharmacology: clinical nurses' perceptions and experiences of graduate nurses' medication knowledge. *International Journal of Nursing Studies*, 39(8), 773-784.
- Matziou, V., Galanis, P., Tsoumakas, C., Gymnopoulou, E., Perdikaris, P., & Brokalaki, H. (2009). Attitudes of nurse professionals and nursing students towards children with disabilities. Do nurses really overcome children's physical and mental handicaps? *International Nursing Review*, 56(4), 456-460.

- Maulik, Pallab K., Mascarenhas, Maya N., Mathers, Colin D., Dua, Tarun, & Saxena, Shekhar. (2011). Prevalence of Intellectual Disability: A Meta-Analysis of Population-Based Studies. *Research in Developmental Disabilities: A Multidisciplinary Journal*, 32(2), 419-436.
- McConkey, R., & Truesdale, M. (2000). Reactions of nurses and therapists in mainstream health services to contact with people who have learning disabilities. *Journal of Advanced Nursing*, 32(1), 158-163.
- Mcintosh, M., & Morse, J. (2015). Situating and Constructing Diversity in Semi-Structured Interviews. *Global Qualitative Nursing Research*, 2, 2333393615597674.
- Naicker, K., & van Rensburg, G. H. (2018). Facilitation of Reflective Learning in Nursing: Reflective Teaching Practices of Educators. *Africe Journal of Nursing & Midwifery*, 20(2), 1-15.
- Noronha, M., & Pawlyn, J. (2019). Caring for people with learning disabilities: the attitudes and perceptions of general nurses. *Learning Disability Practice*, 22(3), 25–32. <https://doi-org.ezproxy.library.dal.ca/10.7748/ldp.2019.e1970>
- Nova Scotia College of Nursing. (2013). *Entry-level competencies for registered nurses in Nova Scotia*. <https://cdn1.nscn.ca/sites/default/files/documents/resources/EntryLevelCompetenciesRN.pdf>
- Oakley, A. (1981). Interviewing women: A contradiction in terms. In H. Roberts (Ed.), *Doing feminist research*. London: Routledge.
- Orb, A., Eisenhauer, L., & Wynaden, D. (2001). Ethics in Qualitative Research. *Journal of Nursing Scholarship*, 33(1), 93-96.
- Palese, A., Gonella, S., Grasseti, L., Destrebecq, A., Mansutti, I., Terzoni, S., Zannini, L., Altini, P., Bevilacqua, A., Brugnolli, A., Dal Ponte, A., De Biasio, L., Fasci, A., Grosso, S., Mantovan, F., Marognolli, O., Nicotera, R., Randon, G., Tollini, M., & Canzan, F. (2018). Multilevel National Analysis of Nursing Students' Perceived Opportunity to Access Evidence- Based Tools During Their Clinical Learning Experience. *Worldviews on Evidence-Based Nursing*, 15(6), 480–490. <https://doi-org.ezproxy.library.dal.ca/10.1111/wvn.12328>
- Pålsson, Y., Engström, M., Leo Swenne, C., & Mårtensson, G. (2018). A peer learning intervention targeting newly graduated nurses: A feasibility study with a descriptive design based on the Medical Research Council framework. *Journal of Advanced Nursing*, 74(5), 1127-1138.
- Qalehsari, M. Q., Khaghanizadeh, M., & Ebadi, A. (2017). Lifelong learning strategies in nursing: A systematic review. *Electronic physician*, 9(10), 5541.

- Roberts, H. (1981). *Doing Feminist Research*. London: Routledge & Kegan Paul.
- Schalock R.L. et al (2011). *Intellectual Disability: Definition, classification, and systems of support* (11th Edition) American Association of Intellectual and Developmental Disabilities.
- Silva, K. L., & Sena, R. R. D. (2006). Nursing education: seeking critical-reflexive education and professional competencies. *Revista latino-americana de enfermagem*, 14(5), 755-761.
- Spence Laschinger, H. K. (1990). Review of experiential learning theory research in the nursing profession. *Journal of Advanced Nursing*, 15(8), 985-993.
- Temple, B., & Mordoch, E. (2012). Nursing student perceptions of disability and preparation to care for people with intellectual disabilities. *Journal of Nursing Education* 51(7): 407–410.
- Trollor, Eagleson, Turner, Salomon, Cashin, Iacono, . . . Lennox. (2016). Intellectual disability health content within nursing curriculum: An audit of what our future nurses are taught. *Nurse Education Today*, 45, 72-79.
- Trollor, J. N., Eagleson, C., Turner, B., Salomon, C., Cashin, A., Iacono, T., . . . Lennox, N. (2018). Intellectual disability content within pre-registration nursing curriculum: How is it taught? *Nurse Education Today*, 69, 48–52. <https://doi.org/10.1016/j.nedt.2018.07.002>
- Walsh, K., Hammerman, S., Josephson, F., et al., (2000) Caring for people with developmental disabilities: survey of nurses about their education and experience. *Mental Retardation* 38: 33–41.
- Weedon, C. (1987). *Feminist Practice and Poststructuralist Theory*. New York.
- Zander, P. E. (2007). Ways of knowing in nursing: the historical evolution of a concept. *Journal of Theory Construction & Testing*, 11(1), 7-11.

Appendix A

Semi-Structured Interview Guide for Nurses

Title: Exploring the learning experiences of registered nurses who are actively working with children with intellectual disabilities

Thank you for agreeing to participate in my research study. I am interested to hear about your experiences as a nurse working with children with intellectual disabilities. As well as your learning experiences around children with intellectual disabilities. This is an exploratory study and there are no right or wrong answers. We want you to feel comfortable sharing your experiences in whatever way you feel you want to tell your story. This style of interviewing is very open and will be more like a conversation so that we can really understand your experience and explore how you care for and learn about children with intellectual disabilities. I would like to begin with a very broad question so that you can start with what you feel is important.

1. Tell me about any experiences you had caring for a child with an intellectual disability that may have stood out to you.
2. Tell me about any experiences you had caring for a child with an intellectual disability in your current healthcare setting.
3. How do you feel when caring for children with IDs?
4. How do you feel nursing care for children with IDs compares to neurotypical children?
5. Did you have any experiences caring for children with intellectual disabilities as a student nurse, if so can you tell me about it?
6. Do you have any personal experiences with children with intellectual disabilities?
7. Tell me about your learning experiences around caring for children with intellectual disabilities.
8. What has had the most impact on your knowledge and skills when working with children with IDs.
9. Tell me about any educational experiences you've had learning about intellectual disabilities.
10. Is there anything else you think was important to your learning that I did not ask about?
11. Do you have any advice for nurses who are starting to work with children with intellectual disabilities?
 - a. Possible Probes for all questions: How did this affect you personally? How did this experience make you feel? Can you give me a specific example? Tell me about your personal experiences, beliefs, and values.

Appendix B

Demographic Information of Nurses

You are being asked these questions as part of my study: Exploring the learning experiences of registered nurses who are actively working with children with intellectual disabilities

I am asking these questions so that I will be able to describe the characteristics of the registered nurses involved in the study as a whole. This will enable readers to have a better understanding of the study results.

Feel free to decline answering any questions with which you are not comfortable.

Name _____ Identification # for study _____

Age _____

Race _____ Ethnicity _____

Presenting gender _____

Length of time being a Registered Nurse _____

Employment at IWK _____

Length of time working at IWK _____

Previous nursing positions _____

Educational History:

Undergraduate Degree and Place _____

Any additional education _____

Appendix C

Consent Form

Research Title: Exploring the learning experiences of registered nurses who are actively working with children with intellectual disabilities

Researcher(s)

Principal Investigator:

Emma Vanderlee, BScN, MScN-year 2 student Dalhousie University

Supervising Investigator:

Dr. Megan Aston, School of Nursing Dalhousie University

Committee Team Members:

Dr. Sheri Price, School of Nursing Dalhousie University

Dr. Debra Sheppard-Lemoine, School of Nursing Saint Francis Xavier University

Introduction and Purpose

You are being invited to take part in a research study as part of my Master's Thesis. It is expected that 8-12 participants will be enrolled in this study. Before you decide if you want to take part, it is important that you understand the purpose of the study, the risks and benefits, and what you will be asked to do.

You do not have to take part in this study. Taking part is entirely voluntary (your choice).

You may decide not to take part or you may leave the study at any time, up to two months after completing the interview.

Purpose:

The purpose of this study is to explore the learning experiences of registered nurses on children with intellectual disabilities, through the lens of feminist poststructuralism. This study is important to help examine the type of nursing care children with intellectual disabilities are receiving during their hospital stays and what learning experiences help nurses provide optimal care to children with intellectual disabilities. Nurses working with children with intellectual disabilities can give personal insight on their clinical and educational learning experiences that they believe works best when working with children with intellectual disabilities. It asks the questions of what are the learning experiences of registered nurses on children with intellectual disabilities and what recommendations do nurses have to improve this learning?

How will the researchers do the study?

This research will examine the experiences of nurses who currently work with children with intellectual disabilities in a healthcare setting. I will collect data/information through semi-structured interviews face to face or by telephone.

What will I be asked to do?

You will be asked to participate in an interview, either face to face or by telephone with the Principal Investigator, Emma Vanderlee. The interview will be an open-ended discussion that will be audio taped and last 60-90 minutes. The interview will take place in a private room in the IWK health centre or Dalhousie University, you may choose which location you prefer. You will be asked to talk about your personal experiences working with children with intellectual disabilities. No names will be asked as to maintain confidentiality. Audiotapes will then be transcribed word for word.

What are the burdens, harms, and potential harms?

We do not anticipate that you will experience any potential harm. However, if you do become emotionally or psychologically upset while answering any questions we would suggest you follow up with a health care provider with whom you are comfortable speaking to discuss this issue. If you require assistance finding a health care provider, we will provide you with a list of local options.

What are the possible benefits?

There are no direct benefits to you from participating, but we hope the experience will be enjoyable and your ideas will benefit future registered nurses as well as children with intellectual disabilities in healthcare settings.

Can I withdraw from the study?

You can withdraw from the study at any time before, during or up to two months after the interview. All of your contact and demographic information and, if applicable, any recording or transcript of the interview will be destroyed. Withdrawal from the study will not affect your relationship with any health care facility, personnel or community agency.

Will the study cost me anything and, if so, how will I be reimbursed?

You will be given a \$25 gift certificate to a local store of your choosing to thank you for your time. If there are further costs, they will not be covered.

What about possible profit from commercialization of the study results?

The research team will not profit from any commercialization of the results of the research. We will openly and freely share research results and send you a copy of the final report if you want a copy.

Are there any conflicts of interest?

There are no actual, perceived or potential conflicts of interest on the part of the researchers and/or the institutions.

How will my privacy be protected?

Your consent form and demographic information will be locked in a filing cabinet in Dr. Aston's office at Dalhousie University and will be destroyed 5 years after publication of study results.

Original audio recordings will be stored on a password protected flash drive in a separate locked cabinet in Dr. Aston's office until 5 years after publication of results. Any sharing of information between the Principal Investigator and Supervising Investigator will be done using *send.nshealth.ca*, an encrypted email file transfer service approved by the Nova Scotia Health Authority for emailing confidential patient information. Only the Principal Investigator and Supervising Investigator will have access to the original audio recordings.

All names and identifying information will be removed from written transcripts. Location names (e.g. units or clinics) will be replaced with pseudonyms (made-up names). De-identified written transcripts will be used for analysis. All research team members will sign a confidentiality form. No names or other identifiable information will be included in any publications or presentations.

The IWK REB Audit committee may have access to study records for audit purposes.

What if I have study questions or problems?

If you have any questions or concerns please contact Emma Vanderlee at e.vanderlee@dal.ca or 705-499-5250.

What are my Research Rights?

Participating in the interview indicates that you have agreed to take part in this research and for your responses to be used. In no way does this waive your legal rights nor release the investigator(s), or involved institution(s) from their legal and professional responsibilities. Nothing written here about treatment or compensation in any way alters your right to claim damages. Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigator(s), sponsors, or involved institution(s) from their legal and professional responsibilities. If you become ill or injured as a direct result of participating in the study, necessary medical treatment will be available at no additional cost to you. You are free to withdraw from the study at any time without jeopardizing the health care you are entitled to receive. If you have any questions at any time during or after the study about research in general you may contact the Research Office of the IWK Health Centre at (902) 470-7879, Monday to Friday between 8:00 a.m. and 4:00 p.m.

How will I be informed of study results?

If you would like a copy of the final research report you sign the consent form indicating you would like an electronic copy emailed to you. Study results are expected between July and August 2020.

Study Title: Exploring the learning experiences of registered nurses who are actively working with children with intellectual disabilities

Participant Consent

I have read or had read to me this Information and Consent Form and have had the chance to ask questions which have been answered to my satisfaction before deciding whether to take part. I understand the nature of the study and I understand the potential risks. I understand that I have the right to withdraw from the study before, during or up to 2 months after the interview. I agree to have my words from the interview used in reports, publications, and conferences. I have received a copy of the Information and Consent Form for future reference. I freely agree to participate in this research study.

[For telephone consent Research Staff asks: “Do you wish to take part in this study?”]

[If YES, staff completes information below. If NO, thanks person and ends call.]

Name of Participant: (Print) _____

Participant Signature: _____

Date: _____ Time: _____

Statement by person providing information on study and obtaining consent

I have explained the nature and demands of the research study and judge that the participant named above understands the nature and demands of the study. I have explained the nature of the consent process to the participant and judge that they understand that participation is voluntary and that they may withdraw before, during or up to 2 months after the interview.

Name of person obtaining consent: (Print) _____

Signature: _____ Position: _____

Date: _____ Time: _____

How will I be informed of study results?

Would you like to receive an electronic copy of the final research report?

Yes _____ No _____

If you indicated yes to an electronic copy, please provide your email address:

Appendix D

TELEPHONE SCRIPT – INFORMED CONSENT

*Hello, [nurses name]. This is Emma Vanderlee calling from a **recorded line** at Dalhousie University. I am calling to go over the Consent Form for the interview on your experiences working with children with intellectual disabilities. Is this still a good time to talk?*

After reviewing the Consent Form, if you agree to take part and you still have time, we can also complete the interview during this call.

Did you receive your email copy of the Consent Form?

*If **NO**: The email address we have for you is: [verify/update address]. I can send you another copy **right now** for us to go over together, or I can send it to you and we can **reschedule** this call.*

*If **NOW**: [email a copy to parent and when they receive it **GO TO Review Consent Form, below**]:*

*If **LATER**: I will send you another copy of the Consent Form. When would you like me to call you back? [reschedule consent call/interview]*

*If **YES**: [GO TO Review Consent Form, below.]*

Review Consent Form: *Great. I will read over the form with you which will take about 10 minutes and then you can decide if you'd like to complete the interview. Please feel free to stop me if you have questions at any time.*

[Read Consent Form]

Emma Vanderlee: Do you have any questions about the study or what you will be asked to do?
[Answer all questions]

[Read signature page to obtain verbal consent if parent agrees.]

[Start interview or schedule a separate call, as per nurse's wish.]

*If **No** *Thank you for the time. Taking part in this study is completely voluntary. Have a nice day. [End call.]*