Perspectives and Learning Needs Assessment of Pediatric Residents Across Medical Schools in Canada: A Qualitative Study of Autism Care and Education

by

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Abstract

Autism is a neurodevelopmental condition characterized by social communication differences and the presence of restricted, repetitive interests and patterns of behaviour. Despite its 2% prevalence rate in Canada, many pediatricians miss cases of autism due to a lack of knowledge of screening tools. Knowledge about resources and approaches to the management of co-occurring conditions is also variable. Currently, there is no literature on the evaluation of autism in the medical education system in both medical school and in pediatric residency in Canada. The overarching objectives were to assess the perceived needs and opportunities for improvement related to Canadian pediatric residents' educational experiences with regards to autism care, and to determine residents' perspectives on providing best practice care for autistic patients. Pediatric residents (n=12) from medical schools in Alberta and British Columbia, Canada participated in interviews, which focused on two main areas: best practice care and learning needs regarding autism. The interviews were conducted using Thorne's Interpretive Description phenomenological methodology, and analysis was conducted using a reflexive thematic approach to encapsulate best practice perspectives and a summative content approach to determine barriers to providing best practice care and gaps to mitigate the gaps. This qualitative study provides insight on the critical issues surrounding residency education regarding care for autism. Addressing learning needs and areas of improvement identified by pediatric residents could lead to better outcomes for autistic individuals and their families. By providing pediatric residents with more comprehensive training and resources, we can work towards reducing missed cases of autism and enhancing the quality of care for autistic patients.

Preface

This thesis is an original work by Nicholas Piroddi. The study was a qualitative study which required informed consent from twelve participants, who were pediatric residents at the University of Alberta and University of British Columbia. The study received research ethics approval from the University of Alberta Ethics Board 1 project titled "Perspectives and Learning Needs Assessment of Pediatric Residents Across Medical Schools in Canada: A Qualitative Study Regarding Autism Care and Education" (Pro00132919). The ethics approval was used for only the study presented in this thesis.

The study was designed in collaboration with Dr. Lonnie Zwaigenbaum and Dr. Lori-Ann Sacrey. I was responsible for its conduct - I conducted all the interviews, carried out the data analysis, and wrote up the dissertation, with guidance from Dr. Zwaigenbaum and Dr. Sacrey, as well as from committee members Dr. Sandra Thompson-Hodgetts and Dr. Heather Brown. My work has been supported by the Stollery Children's Hospital Foundation Chair in Autism, and the 2023-2024 Autism Research Centre / Autism Edmonton Graduate Student Grant. Funders had no role in study design, data collection, analysis, manuscript preparation, or the decision to submit any results for publication. No part of this thesis has been previously published, but there is intent to publish in the future.

Dedication

To my family,

Thank you for your unwavering support, encouragement, and love throughout this journey. You’ve been there for me through so many struggles in life, which ultimately inspired me taking on this thesis project, and completing it.

And to the autistic community and their families,

I am grateful to be a part of your community. Our voices, experiences, and resilience inspire and guide this work.

This thesis is dedicated to you.

Acknowledgements

The last two years have been a journey, to say the least – in terms of personal and professional growth. I want to acknowledge many individuals who have supported, guided, and cared for me while I have worked on this thesis – you are all amazing people, and I am forever grateful for the opportunity to have learned from you.

Firstly, to my supervisor, Dr. Lonnie Zwaigenbaum, I want to extend my thank you to taking a chance on a graduate student who had lost his way. I started graduate school in another department, and, due to ableist bullying, I left the program. I reached out to Dr. Zwaigenbaum, and he took me in as his own graduate student, and has shown incredible patience, passion, and support over the past few years. Dr. Zwaigenbaum, not only have you been a wonderful supervisor and an inspirational leader, but you have also helped me discover my self-worth, and for that, I am incredibly indebted to you.

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To my committee members – Dr. Sandy Thompson-Hodgetts and Dr. Heather Brown – thank you for your support, guidance, and care you have provided to me throughout my graduate journey. I truly am grateful for the feedback you have provided, and your willingness to check in on my wellbeing. And thank you to Dr. Emily Hotez for graciously agreeing to serve as the external member of my committee.

To my family, I love you so much. Mom and Dad, thank you for advocating for me my whole life, and never giving up on me. Your dedication to me has inspired me to do the work that I am doing now and will continue to do for the rest of my life. You've been there for me through all the successes, the challenges and struggles, and everything in between. To my siblings Lucas and Emily, you have encouraged me not to give up when times were tough countless times, and it's because of your faith in me that I've been able to accomplish writing a thesis. I love our family so much, and it's because of us as a family unit that I am able to follow my dreams.

To my friends, I also have immense love for you. In particular, I want to acknowledge three friends who have been there for me through hardships in my academic journey, both when I was just starting out as a graduate student, and as I was working through writing this thesis. Thank you to my friends Dr. Dylan Ziegler and Marissa Yoneda, and my cousin Dr. Austin Pietramala for your incredible support throughout my Master's degree; for helping me demonstrate resilience, follow my passions, take care of my mental health, and being such an optimistic presence in my life. It is thanks to your support that I had the drive to finish my thesis.

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CHAPTER 1. Introduction

1.1. Thesis Introduction and Rationale for the Research

Autism is perceived to be complex neurodevelopmental condition by healthcare providers, particularly those in pediatric settings. As the prevalence of autism continued to rise, there is an increasing need for pediatricians who are well-equipped to provide comprehensive, compassionate, and evidence-based care to autistic children. However, despite the growing recognition of autism's importance in pediatric care, significant gaps remain in the training and education of pediatric residents regarding autism diagnosis, management, and long-term care.

The goal of this thesis is to explore the current state of autism education within pediatric residency programs in Canada, focusing specifically on residents from the University of Alberta and University of British Columbia's pediatric residency programs. Thorne's Interpretive Description methodology was used for interviews, and through a combination of reflexive thematic analysis and summative content analysis, this study aims to identify the key factors that influence best practice care for autistic children and their families, as well as the gaps in training that hinder residents' ability to provide such care. Additionally, I will propose some practical recommendations for enhancing autism education in residency programs, with the goal of better preparing the next generation of pediatricians to adequately meet the needs of the autistic community.

The research questions guiding this study are twofold. First, what are the current learning needs of Canadian pediatric residents with regards to autism care, and what potential areas for improvement exist in their training experiences? Second, what are pediatric residents' perspectives on providing best practice care for autistic patients, including the role of the pediatrician on the care team? By addressing these questions, this thesis aims to contribute to the ongoing efforts to improve autism care in Canada, and to ensure that the next generation of pediatricians are well-equipped to provide high-quality, patient-centered care to autistic children and their families.

The following chapters will provide a comprehensive overview of the literature on autism, detailing its history, prevalence, diagnostic procedures, and the current landscape of autism care in Canada. The methods chapter will outline the research design and analytical approaches used in this study, followed by the presentation of findings from the interviews with pediatric residents. The discussion will contextualize these findings within the broader field of pediatric education, offering practical recommendations and highlighting areas for future research. Ultimately, this thesis aims to bridge the gap between autism education in residency programs and the real-world needs of autistic patients, contributing to the development of a more inclusive and effective healthcare system.

1.2. Positionality Statement

As the primary investigator of this research, I, Nicholas Piroddi, bring a unique perspective shaped by my personal journey growing up on the autism spectrum. My experience as an autistic individual has led me to face barriers in the healthcare system, particularly with regards to communication. I have also experienced ableism in an academic setting prior to starting my Masters in Pediatric Medicine. These lived experiences have significantly influenced my current academic pursuits and research interests. As an autistic researcher, I am committed to dedicating my career to unravelling the complexities of autism education and care in medical settings, drawing not only from scholarly literature, but also from the intimate knowledge gained through my own encounters with the healthcare system, and discussions with healthcare providers who are experienced in the field of autism care.

I was diagnosed with autism shortly after my sixth birthday in 2004, and my journey with autism has been marked by challenges and triumphs. Upon my initial diagnosis, the greatest challenge I faced was the ambiguity surrounding language that was used. Navigating these intricacies has emphasized the importance of tailored, informed, and empathetic care for autistic individuals. My experiences fuel my dedication to contributing to the enhancement of medical education programs, particularly in the realm of pediatric residency training, ensuring that future healthcare providers are better equipped to address the diverse needs of autistic individuals.

While I do believe my personal lived experiences provide valuable insight in conjunction with my academic experience throughout my Masters, I am cognizant of the need to approach this research with academic rigor and impartiality. As an autistic researcher and advocate, one of my goals is to bridge the gap between lived experience and scholarly inquiry, offering a nuanced perspective that enriches the overall understanding of autism, and autism education. I acknowledge that my positionality may shape the research process and interpretation of findings, especially in a qualitative context (Rowe, 2014; Shaw et al., 2019; Darwin Holmes, 2020). I am therefore committed to maintaining transparency and reflexivity throughout the study.

It is imperative to recognize that my experiences as an autistic individual is not universally representative. Autism is a spectrum, and individual experiences will vary widely. Thus, my aim is to amplify diverse voices within both the autistic and medical communities by capturing a range of perspectives through qualitative research methods. My positionality as an autistic researcher studying autism is an asset that enriches the research process. I approach this study with a commitment to balance lived experiences with scholarly inquiry, fostering a deeper understanding of the challenges and opportunities in pediatric residency training related to autism care.

CHAPTER 2. Literature Review

2.1. Chapter Introduction

Understanding the landscape of autism care is crucial for addressing the complex challenges faced by individuals with autism, their families, and healthcare providers. The purpose of this “background” chapter is to provide an overview of the current state of knowledge on autism care, focusing on the Canadian context. Through a critical analysis of relevant studies, theoretical frameworks, and empirical evidence, this chapter examines the key themes, trends, and gaps in the existing literature to inform and contextualize the research undertaken in this thesis, ultimately contributing to the advancement of knowledge in the field of autism care in Canada.

The chapter begins with a discussion of autism prevalence in Canada, then the overarching challenge in pediatrics regarding autism care; the need to increase community capacity. After describing the problem at a community level, barriers are explored within the autism healthcare landscape, followed by discussions of what autism is from a medical model, and the historical context of autism. The Canadian Pediatric Society (CPS) statements on standard practice of autism care are then introduced, with a focus on diagnostic and long-term health care needs. The general pediatric residency program and curricular objectives are then outlined with a focus on developmental pediatrics learning objectives, and an analysis of what has been investigated in the literature regarding autism care in residency is highlighted. Finally, the chapter concludes with a statement of the problem leading to this thesis’s objectives, and the research questions that have therefore been posed.

2.2. Prevalence of Autism in Canada

Understanding the prevalence of autism is crucial for informed healthcare planning, resource allocation, and determining public policy (Zeidan et al., 2022). The Centres for Disease Control and Prevention (CDC) reported 1 in 36 American children are diagnosed with autism as of 2020, an increase from the 2018 report of 1 in 44 children (Maenner, 2023). In Canada, a slightly lower prevalence rate of 2% was observed in children aged 1 to 17 in 2022 (Public Health Agency of Canada, 2022). An increased awareness of features of autism, changes in diagnostic criteria, improved recognition by health care professionals, and increased research in genetic and environmental studies all contribute to the increasing prevalence rate of autism (Lyall et al., 2019).

It is also important to note general and mental health and co-occurring long-term health conditions in Canada. Among youth, there was a statistically significant difference in those with autism who reported excellent/very good general health (59.3%) and excellent/very good mental health (39.0%) compared to those without autism (89.5% and 84.1% respectively) as of the 2022 Public Health Agency of Canada report. Similarly, 68.7% of youth with autism had another long-term co-occurring condition, compared 21.9% without autism, where ADHD, anxiety, and learning disabilities were among the most common, though other statistically significant conditions include asthma and epilepsy (Public Health Agency of Canada 2022).

The prevalence rates for developmental conditions, such as autism, can vary across regions in Canada, and demographic factors, such as geography, socioeconomic status, and cultural diversity, may influence variation in prevalence rates (Fombonne, 2018). For example, British Columbia's prevalence rate of autism is 2.2%, slightly above the national average whereas Alberta's prevalence rate is 2.0%. Saskatchewan, by contrast, has the lowest prevalence rate, at

0.8%. In addition, the prevalence rate of autism by sex differs and is estimated to be a 4-to-1 ratio of male-to-female children diagnosed with autism. The literature suggests that the sex difference in diagnosis may result from a gender bias in diagnosis (e.g., the diagnostic criteria reflect a male-centric phenotype) and that females may have better adaptation and compensation strategies due to gender stereotypes (Dworzynski et al., 2012; Milner et al., 2019). Understanding how such demographic factors affect variation in prevalence rate is important to elucidate unique resources needed to improve community capacity (Andermann, 2016). In building community capacity, diagnostic wait times can be reduced (Guan et al., 2022; Penner et al., 2018) and ongoing research is needed to monitor trends, identify factors that lead to an increased likelihood of autism, and address resultant changes in autism prevalence (Zeidan et al., 2022).

2.3. The Overarching Challenge: The Need to Increase Community Capacity in Canada

The prevalence of autism has been steadily increasing in Canada from 1.5% in 2018 to 2% in the 2022 report (Public Health Agency of Canada, 2022). Despite this, we have not seen a parallel growth in trained clinicians with expertise in autism to match the prevalence rate (Bridgemohan et al. 2018). This poses challenges in Canada with respect to the landscape of autism care, there may not be a sufficient number of trained clinicians to support (i) the changing landscape of autism with respect to diagnosis, (ii) the high prevalence of co-occurring conditions, (iii) transitioning into adulthood, and (iv) caring for autistic individuals in rural communities (Malik-Soni et al., 2021; Das et al., 2022; Guan et al., 2022). A 2022 Canadian Academy of Health Sciences (CAHS) report on public policy development considerations in Canada for autism care emphasized building capacity for a diverse and skilled autism workforce across the country with the aim of addressing barriers in delays of diagnosis and care disparities (Canadian Academy of Health Sciences, 2022).

To address the scarcity of professionals with autism expertise, there is a need to expand the workforce by extensive capacity building of clinicians. In Canada, there are typically a multitude of practitioners caring for autistic patients, including primary care physicians, consultant pediatricians, subspecialists (such as developmental pediatricians), and allied health care workers (i.e. psychologists and speech language pathologists) (Young et al., 2020). Community providers, however, have reported a lack of expertise, including a lack of knowledge, comfort, and competence in providing best practice care for autistic patients (Carbone et al., 2020; Golnik et al., 2009; Kearny et al., 2024). Educational programs, such as the Extension of Community Healthcare Outcomes (ECHO) Autism model, in which community physicians and allied health care professionals can access learning based on complex cases and didactic teachings provided by autism experts in the community, are in practice in Alberta, Ontario, and Quebec (Sohl et al. 2022; Jane et al. 2023). A limitation of the ECHO model however, is that participants self-select to attend and as such may have a higher level of interest in autism education. Therefore, ECHO may not be widespread enough to reach the majority of physicians who care for autistic patients.

One way to improve the reach of autism education is to introduce more training on care in medical schools and residency training programs (Canadian Academy of Health Sciences, 2022; Clarke & Fung, 2022). At present, a knowledge gap exists regarding an evaluation of the medical education surrounding autism. A first step in building capacity, including pediatricians who can support timely diagnosis, assessments, and supports and services, is gathering information on how professionals are being trained, as well as their experiences working in the medical field with respect to experienced mentors, patients on the autism spectrum and their families.

By training more physicians to be competent in autism knowledge and care through residency training, some of the challenges surrounding autism care in Canada can be addressed (Jane et al., 2023).

2.4. Barriers in the Autism Care Landscape

One of the primary barriers that many families face in Canada regarding autism care is access to a timely diagnosis (Malik-Soni et al., 2022). Long wait times for diagnostic assessments and limited availability of physicians and allied healthcare professionals contribute to delays in accessing crucial supports and intervention in a timely manner (Government of Canada, 2019). The waitlists for an autism diagnosis following initial query were reported to be upwards of 19 months prior to the COVID-19 pandemic, however, this has likely gone up in a post COVID-19 era, based on patterns from other countries such as the United Kingdom (Zwaigenbaum et al., 2019; Penner et al., 2018; Haden, 2023; Children of the North Campaign, 2024). The longer the waitlist times, the longer the delays in accessing evidence-based resources and interventions during critical development periods (Zwaigenbaum et al., 2015; Warren at al., 2011). Recently, the Government of Canada assented Bill S-203, "An Act representing a federal framework on autism spectrum disorder," which was deemed concurred by the House of Commons on March 28, 2023. Some highlights of the bill include provided measures to timely and equitable access to autism screening and diagnosis, a national research network to promote research and improve data collection on autism, and sustained, accessible, and culturally relevant resources on evidence-based information to support autistic individuals in Canada (Parliament of Canada, 2023).

Another barrier in Canada regarding autism care is the variability in the quality of care. There are different *best practice guidelines* and standards for autism diagnosis and long-term care across Canada (Yaholkoski et al., 2021; Smith et al., 2021; Brian et al. 2019; Ip et al., 2019). Several factors influence quality of care, including the availability of evidence-based interventions, the expertise of healthcare providers, and the coordination of services across healthcare and community settings. Further, factors such as race, ethnicity, culture, socioeconomic status, sex, and gender identity also contribute to health disparities regarding quality of autism care (Bishop-Fitzpatrick & Kind, 2018). For example, Tint et al. (2017) highlights how females with autism are more likely to report psychiatric emergencies compared to males with autism, despite males having more externalizing features, such as self-aggression. A potential reason for this is because females with autism are more likely to receive a late diagnosis of autism or are misdiagnosed with other conditions, such as co-occurring anxiety and depression (internalizing features) being more prominent (Werling & Geschwind, 2014). There are also disparities related to race regarding autism care. For example, Liu et al., (2023) highlight the disparities that Black and Hispanic children face regarding both access to timely diagnosis and access to services post diagnosis across the United States. Further, lack of access to healthcare providers is impacted by geographic location, such as rural communities, where an Ontario-based study found that community pediatricians see diagnosis as a part of their practice, without additional training in autism education (Das et al., 2022). This variability highlights the need for standardized practices and quality assurance mechanisms to ensure individuals with autism receive optimal support and treatment.

Addressing the challenges in the autism care landscape in Canada requires a multifaceted approach, emphasizing the importance of having community capacity for diagnosis and care.

Strengthening community-based services, enhancing the training and expertise of healthcare providers, and promoting collaboration between healthcare professionals and community organizations are essential steps toward improving access to timely and high-quality care for individuals with autism (Zwaigenbaum et al., 2015; Penner & Lai 2023; Zwaigenbaum & Penner 2018).

2.5. History of Autism

Autism (referred to as autism spectrum disorder in diagnostic and best practice documents) is a complex neurodevelopmental condition characterized by challenges in social interaction and communication, as well as the presence of repetitive behaviours in the DSM-5 (American Psychiatric Association, 2013). The concept of autism has evolved significantly since first being identified in 1943 by Leo Kanner as a lack of affective contact and an intense desire for sameness (Kanner, 1943). Notably, the word "autism" was used to describe the pronounced self-isolation observed by the 11 children in his case series. The following year, a study was published identifying a similar condition, which was later known as Asperger's Syndrome (Asperger, 1944). Some key difference between Kanner and Asperger's work is that Kanner described autism as a developmental condition, while Asperger described Asperger's Syndrome as a personality disorder. Further, Kanner's work focused on children who had a co-occuring intellectual disability while Asperger's work highlighted a broader spectrum of abilities, including those with average or above-average intelligence quotients (Mirkovic & Gerardin, 2019).

Autism was officially recognized as a diagnosis in the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM), published in 1980, under the newly formed "Pervasive Developmental Disorders" (PDD) category (APA, 1980). The criteria for diagnosis of "Infantile Autism" were rigid and focused on the childhood period (Rosen et al., 2021). The DSM-IV, published in 1994, elaborated the three domains of the diagnostic criteria for autism, reciprocal social interaction, communication, and restricted or repetitive behaviours that were first introduced in DMS-III-R, and officially introduced Asperger's disorder (also referred to as Asperger's Syndrome), Rett syndrome, and childhood disintegrative disorder (CDD), while also keeping pervasive developmental disorder not otherwise specified (PDD-NOS) (APA, 1994). The DSM-5 consolidated previous pervasive developmental disorders (autistic disorder, Asperger's syndrome, CDD, and PDD-NOS) into a single category: autism spectrum disorder.

The DSM-5[1] aims to provide standardized criteria for psychiatric conditions. To meet criteria for an autism diagnosis, the person must have persistent deficits in all areas of social communication and interaction (criterion A), and at least two of the four types of restricted, repetitive behaviours (criterion B). Criterion A's social communication challenges require (1) deficits in social-emotional reciprocity, (2) deficits in nonverbal communicative behaviours, and (3) deficits in developing, maintaining, and understanding relationships. Criterion B's restricted, repetitive patterns of behaviours include (1) stereotyped or repetitive motor movements, object usage, or speech patterns, (2) inflexible adherence to routines or ritualized patterns of behaviour, (3) highly restricted and fixated interests in intensity or focus on unusual objects or perseverative

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[1] The language used in this subsection is the language used in the DSM-5, and is not consistent with self-advocate and the author's current perspectives on language, labelling, and negative connotation surrounding certain words (i.e. "deficit"; "disorder", "stereotype")

interests, and (4) hyper- or hypo-reactivity to sensory input in the environment. Table 2.1 provides some examples of how criteria A and B may present in autistic individuals. In addition to criteria A and B, (i) symptoms must be present in the early developmental period (even if not fully manifested), (ii) symptoms must cause clinically significant impairment in function, and (iii) the disturbances are not better explained by intellectual disability disorder (IDD), though the two can cooccur (Criteria C – E). The severity of autism is qualified using levels of support needed, with level 1 requiring support, level 2 requiring substantial support, and level 3 requiring very substantial support.

Table 2.1. Examples of presentation of diagnostic criteria A and B in autistic individuals

A1 - Deficits in social emotional reciprocity	Criteria A1 means one is struggling with the back-and-forth nature of neurotypical conversation. Examples include info dumping, answering questions bluntly, interrupting others in conversation, and not initiating conversation with others.
A2 - Deficits in non-verbal communication behaviors	Criteria A2 means one is struggling to understand and use non-verbal communications according to neurotypical norms. Examples include lack of eye contact, or intense eye contact, masking, and struggling with other's facial expressions or gestures.
A3 - Deficits in the development, maintenance, and	Criteria A3 means one is struggling to make, keep and understand relationships with neurotypicals. Examples include struggling to make friends and maintain friendships, feeling like an "outcast" of a social group, or not understanding the point of a friendship.

comprehension of relationships	
B1 - Stereotyped or repetitive speech, motor movements or use of objects	Criteria B1 means that one may repeat words or noises, movements, or repetitively use objects. This is sometimes known as “stimming”. Stimming can be verbal (noises, including echolalia), or with the body (flapping hands, or body rocking).
B2 - Excessive adherence to routines, patterns, or resistance to change	Criteria B2 means that one may rely on patterns and routines and getting distressed when these are not changed or not able to be followed. (i.e. struggles with change). These changes can include major life events, day-to-day tasks, or even conversational norms.
B3 - Highly restricted, fixated interests that are abnormal in intensity or focus	Criteria B3 means having interests that are more intense and more focused than how neurotypicals would experience interests. Examples include having the constant urge to talk about one’s interests and spending lots of time thinking about and researching one’s interest.
B4 - Hyper or hypo reactivity to sensory input or unusual interest in sensory aspects	Criteria B4 means being over or under sensitive to sensory input. Examples of presentation include struggling with the feeling of clothes, seeming to be overwhelmed in loud/busy environments, bumping into objects, struggling with certain food textures or tastes, or seeking sensory input, such as wanting constant hugs and going under heavy objects.

The diagnostician must specify if there is the presence or absence of accompanied intellectual disability, language impairment, or associated genetic conditions (APA, 2013; Baker, 2013).

These changes reflect the current understanding that autism is continually evolving, with ongoing research exploring the genetic, neurological, and environmental contributing factors (Lord et al, 2018) to better capture the heterogeneity of symptoms and the spectrum's diverse presentations (Halfon & Kuo, 2013). Research and clinical needs of note include more timely diagnosis, earlier detection of autism symptoms, and earlier access to intervention (Zwaigenbaum et al., 2015; Sandbank et al., 2023).

2.6. Standard Practice for Autism Care in Canada

The diagnostic process for autism in Canada involves a comprehensive and typically multidisciplinary approach to ensure an accurate diagnosis. The Canadian Paediatric Society (CPS) provides guidelines for diagnosis, though it is important to note that there are regional differences in diagnostic processes across Canada (Brian et al., 2019; Yaholkoski et al., 2021). The standard approaches to diagnosis and components of a comprehensive autism assessment, as defined by the CPS, are highlighted below.

There are three pathways for diagnosing autism: sole pediatric care provider (approach 1), shared care model (approach 2), and a team-based approach (approach 3). In approach 1, an experienced pediatric care provider can make an autism diagnosis when the child's symptoms clearly indicate autism based on DSM-5 criteria and clinical judgement. In approach 2, a clinician shares joint responsibility with an allied health care provider (i.e., a psychologist) for more "complex" cases, or if the child is under 2 years of age. In approach 3, an interdisciplinary or multidisciplinary team works together to provide an autism diagnosis. In some parts of Canada, only approach 3 is used for children to access specialized services. Unsurprisingly, approach 3 is associated with longer waitlist times due the constraints on availability of team members (Penner et al., 2018).

There are no biomarkers for diagnostic purposes of autism; autism must be diagnosed from behavioural and clinical observation. CPS highlights three objectives critical to autism diagnostic assessment, including (1) providing a definitive diagnosis of autism, (2) exploring conditions that mimic autism features and identify co-occurring conditions, and (3) determine the child's overall level of adaptive functioning. The steps for an autism diagnostic assessment begin with a review of the patient's records, including medical records and assessments from allied healthcare professionals. The next step involves interviewing primary caregivers, which may be semi-structured and include questionnaires, such as the Autism Diagnostic Interview-Revised (ADI-R) (Lord et al., 1994). The third step involves observing core features of autism; this is typically done through direct interactions with the child (using behavioural observation diagnostic tools such as the Autism Diagnostic Observation Schedule – 2nd edition (ADOS-2) (Lord et al., 2012) or the Childhood Autism Rating Scale – 2nd edition (CARS-2) (Schopler et al., 2010). Caregiver interviews are also utilized in this step to ensure sensitivity and specificity (Randall et al., 2018). Next, a physical examination is used to investigate any medical causes or associations with behavioural presentation (for example, vision and hearing assessments, neurological examination, or laboratory testing). It is critical to consider other conditions that may overlap or mimic autism features, including neurodevelopmental conditions, such as attention-deficit hyperactivity disorder (ADHD), mental health conditions, such as anxiety and depressive disorders, genetic conditions, such as Fragile X syndrome, and neurological conditions, such as cerebral palsy (Al-Beltagi et al., 2021). The final step involves making a clinical judgement to establish an autism diagnosis and communicating comprehensively with both the caregiver and the child, where appropriate.

Despite established diagnostic procedures, there are challenges and criticisms that persist. For example, that the diagnostic criteria may not capture the full autism spectrum, leading to potential underdiagnosis biases (Hodges et al., 2020). Further, there are debates about the cultural sensitivity in the diagnostic process and the need for ongoing training for professionals (Samadi & McConkey , 2011, Yang et al., 2023). Finally, differences in how diagnostic criteria may manifest across cultures, as well as socioeconomic disparities, should be considered when assessing for autism and communicating a diagnosis to promote health equity (Mandell et al., 2002; Wiggins et al., 2020; Aylward et al., 2021).

2.7. Pediatric Residency Training Programs in Canada

In Canada, a general pediatric residency program is typically four years long after completion of medical school (Canadian Medical Association, 2019). Within those four years, only one four-week rotation of developmental pediatrics is required, depending on the medical school. For example, in Western Canada, the University of British Columbia and University of Calgary only require one rotation in developmental pediatrics in the senior years (PGY-2/3) and junior years (PGY-1) respectively, while the University of Alberta requires two developmental pediatrics rotations – one in the junior years (PGY-1/2) and one in the senior years (PGY-3/4). Across Canada, there are 163 spots in pediatric residency annually. In Western Canada, there are 17 spots offered at the University of British Columbia and 12 spots each offered at the University of Alberta and University of Calgary.

After completing the general pediatrics residency, physicians have the option to apply to a subspecialty through the Canadian Resident Matching Service (CaRMS) organization (Canadian Pediatric Society, 2004). There is a very limited number of spots in the developmental pediatrics rotations, with 10 spots per year Canada-wide, including two spots at the University of British Columbia and two spots at the University of Alberta. The developmental pediatrics subspecialty program curriculum includes inpatient and outpatient rotations in neuromotor disorders, brain injury and rehabilitation, autism, and other developmental and behavioural conditions (University of British Columbia; University of Alberta program description websites).

2.8. CanMEDS Curriculum Design and Developmental Pediatrics Objectives

The Royal College of Physicians and Surgeons of Canada have defined the physician competency framework for medical schools across Canada, named CanMEDS, in an effort to provide a comprehensive definition of the domains of medical practice in medical education (Frank et al., 2015). There are seven competencies, with medical expert being the central, integrating the other six roles: communicator, collaborator, leader, health advocate, scholar, and professional. As of 2017, thirteen medical schools in Canada have adapted the CanMEDS framework, and as of 2021, CanMEDS also provides the foundational structure for residency education in Canada, an initiative known as competence by design (Karpinski et al., 2021). These competencies are revised every ten years, with the next revision scheduled to be published in 2025.

Residency training for developmental pediatrics includes specific goals and objectives outlined by the medical schools that follow the CanMEDS framework guidelines, providing specific learning objectives for the developmental pediatrics rotation in residency. The rotation specific goals, as outlined by the University of British Columbia, are summarized in Table 2.2.

To our knowledge, there is no publication on a pediatric approach to autism spectrum disorder that uses the CanMEDS framework. There is, however, a case study in family medicine (CanMEDS-FM) that utilizes the competencies concurrently with the DSM-5 criteria to develop an approach to managing autism for follow-up care (Lee et al., 2015).

Table 2.2. Rotation-specific goals and objectives for the developmental pediatrics rotation as defined by the University of British Columbia.

Competency	**Goals and Objectives**
Medical Expert	1. Elicit a comprehensive developmental history from patients and families, that includes a functional review and perform a mental status examination 2. Elicit a substance exposure history from a birth mother when appropriate 3. Measure facial features accurately when evaluating a patient for a possible Fetal Alcohol Spectrum Disorder diagnosis 4. Demonstrate the ability to elicit minor neurologic indicators from physical examination (such as overflow movements, mirror movements, finger agnosia, etc.) in the context of specific developmental conditions 5. Perform a functional developmental assessment appropriate to the child’s developmental and chronological age 6. At the level of a general pediatrician, describe the clinical presentation, differential diagnosis, evaluation, and management of children with some of the following developmental conditions: a. Global Developmental Delay/Intellectual Disability b. Language delay/disorder

	c. Autism Spectrum Disorder d. Learning Disorders e. Attention Deficit Hyperactivity Disorder f. Neuromotor conditions: Cerebral Palsy, other motor impairments, Developmental Coordination Disorder g. Sensory impairments (Vision/Hearing) h. In utero substance exposure with emphasis on Fetal Alcohol Spectrum Disorders i. Behavioral phenotypes associated with underlying genetic conditions/syndromes
Professional	1. Discuss patient issues while considering issues of confidentiality 2. Demonstrate an awareness of how issues involving disability, gender, race, religion, and culture may impact the patient and families' experience with health care 3. Demonstrate a sense of responsibility by adequately preparing for clinics and ensuring all tasks are completed by the end of the rotation (reports, follow up, etc.)
Collaborator	1. Describe the role of the multidisciplinary team, and demonstrate respect for allied health care team members, community providers and translators in all interactions
Advocate	1. Demonstrate an awareness of local services and resources available to support children with developmental disabilities in the community

Communicator	1. Demonstrate sensitivity to the emotional state of the child, parents and caregivers when communicating with patients and families 2. Synthesize all aspects of patient encounter (including observation) to clearly communicate a differential diagnosis to the supervising developmental pediatrician 3. Create a consultative report for complex conditions at the level expected of a general pediatrician
Scholar	1. Prepare an evidence based personal learning project on a developmental topic of choice which will enhance their knowledge in: Child development, the assessment of developmental conditions, or the management of developmental conditions in the community.
Leader	*No learning objectives set.*

The Royal College of Physicians and Surgeons of Canada also defines Entrustable Professional Activities (EPAs) for medical training. EPAs are actions or tasks defined by the competencies a physician should have upon completing training. In pediatrics, autism is covered under the Core EPA #7: assessing and managing patients with developmental, behavioural, and school issues (Royal College of Physicians and Surgeons of Canada, 2020). The CanMEDS milestones associated with EPA #7 are listed in table 2.3 in the order they are presented by the Royal College of Physicians and Surgeons of Canada.

Table 2.3. CanMEDS milestones defined by the Royal College of Physicians and Surgeons of Canada for Pediatrics Core EPA #7: Assessing and managing patients with developmental, behavioural, and school issues.

Competency Category	**Milestones**
ME 1.3	Apply knowledge of normal and abnormal physical, cognitive, emotional, social, and behavioural development
ME 1.4	Perform a clinical assessment that addresses all relevant issues
ME 2.2	Use screening tools and validated questionnaires, as applicable
ME 2.2	Adapt the clinical assessment to the child's age and developmental stage
ME 2.2	Synthesize biological, psychological, and social information to determine a diagnosis
ME 2.4	Develop and implement a management plan that considers all of the patient's health problems and context
ME 4.1	Determine the need for and timing of referral to another health care professional
ME 4.1	Develop a plan for ongoing management and follow-up
COL 1.3	Support and educate professionals in other sectors, including daycare and school teachers, in their interactions with the patient and family
COM 1.1	Communicate using a patient-centred approach that facilitates trust and autonomy and is characterized by empathy, respect, and compassion

COM 5.1	Document clinical encounters to adequately convey clinical reasoning and the rationale for decisions
HA 1.1	Facilitate timely access to services and resources in the health and/or social system(s).

2.9. Literature on Residency Training Surrounding Autism Care

There is a dearth of literature on residency training regarding autism care on both a national and global scale. A recent systematic review that studied pediatric medical training programs for autism-related training found that only 12% of programs studied accounted for medical students and residents (Clarke & Fung, 2022). Newly graduated pediatricians typically report inadequate training regarding developmental and behavioural health in residency and feel unprepared to diagnose and manage autism (Major, 2015; Major et al., 2012). One path forward is to incorporate more training on autism care into medical education, particularly at the residency stage. To our knowledge, no study has evaluated the pediatric residency training programs in Canada to determine where the learning needs and gaps are in autism care.

Some studies in Canada have explored other residency training programs. O'Flanagan & Nicholson (2023) investigated psychiatric residency training related todevelopmental conditions in Canada, though the article seldom touched on autism, and focused on prevalence (mentioning ADOS-2 as a diagnostic tool), as opposed to diagnosis and long-term care. Other studies, such as Das et al. (2022) and Kearney et al., (2024) investigated community pediatrician perspectives on aspects related to autism care, with rural communities and learning health networks being the focal points of discussion respectively. Interestingly, results of Project ECHO Autism in Ontario suggests that ongoing education is necessary for pediatricians to improve their competencies on developmental and behavioural conditions in the earlier years of their career (Jane et al., 2023).

Globally, autism care in residency training has also been looked at with regards to curricula. For example, family medicine programs were recently evaluated in the US, with one study focusing on a program to improve healthcare providers' knowledge on autistic individuals' transitions to adulthood (Fernandes et al., 2022). Another American study looked at a particular curriculum of pediatric residency training involving web-based learning and supervised autism evaluations and found that 95% of the residents' confidence and comfort significantly increased (Hine et al., 2021). Despite the studies being far and few between, there is evidence that better training programs lead to better outcomes for autistic children, and there seems to be a desire for pediatric residents to learn more about autism.

2.10. Statement of the Problem and Research Questions

This chapter highlighted an examination of the current state of autism care in Canada, and the dearth of literature regarding autism training in residency. The overarching lack of adequate community capacity is the root of the challenges and barriers faced in autism care, leading to unmet needs related to access to diagnostic assessment and ongoing health care for individuals with autism. Through an analysis of key themes and trends in the literature, it is evident that disparities in access to timely diagnosis, interventions, and specialized resources across Canada exist. Though the CPS statements provide guidelines, there is no standardized approach to best practice care regarding autism in Canada. The CAHS states that a way to increase community capacity to overall improve best practice care is to incorporate more training in the residency stages of medical training. Though there are curricular objectives, to our knowledge, they have not been properly evaluated in terms of the perspectives and learning needs of residents who are currently in pediatric training or have recently graduated and are now practicing in the community.

Considering these challenges, the central focus of this thesis emerges: to explore the learning needs and perspectives of pediatric residents to provide best practice care for autistic patients in Canada. The specific research questions are:

1. What are the current learning needs and areas of improvement of Canadian pediatric residents with regards to autism care?
2. What are the pediatric residents’ perspectives on providing best practice care for autistic patients, including the role of the pediatrician on the care team?

By addressing the research questions posed in this thesis, I aim to contribute to the ongoing efforts to enhance autism education and healthcare delivery practices, with the ultimate goal of improved outcomes and quality of life for children with autism and their families in Canada. Understanding the perspectives and learning needs of pediatric residents is an essential first step prior to making curricular and policy changes on how autism is taught in medical training.

CHAPTER 3. Methodology

3.1. Chapter Introduction

Exploring the experiences of pediatric residents to understand their perspectives about working with children with autism is a topic well aligned to qualitative methodology. As my research questions are exploratory, prompted by a real-world clinical challenge, I utilized an interpretive description (ID) methodology that is clinically oriented with the aims to directly impact practice. ID undergirds a co-construction of knowledge generation between the researcher and participant, thus providing in-depth analysis of complex systemic issues while recognizing the influence of context (Crotty, 2020). Further, reflexive thematic analysis (RTA) was used as an analytic approach to investigate the findings of the conversations.

The research questions for this study are reiterated here:

1. What are the perceived learning needs and areas of improvement of Canadian pediatric residents with regards to autism care?
2. What are the pediatric residents' perspectives on providing best practice care for autistic patients, including the role of the pediatrician on the care team?

The purpose of this chapter is to present an overview of the study design and procedures. A description of ID is provided first, followed by the ontological and epistemological theoretical frameworks that guide the research. Then, ID is further discussed with regards to how it is used in medical practice. The inspiration for the study is then detailed, followed by a description of the methods used for the interview development, participants selection, and data collection. RTA is then discussed as a method for data analysis. Finally, strategies towards achieving methodological rigor and trustworthiness are described to maximize the validity of the findings throughout the data collection and analysis processes.

3.2. Interpretive Description

ID is a non-categorical qualitative research method with roots in nursing science that focuses on incorporating the holistic experience of healthcare professionals (Thorne et al., 1997; Thorne, 2016). The aim of ID is to collect participant perspectives and prior information on a topic with the aim of deriving newer, practical insights based on the interpretive mind of a researcher (Thorne, 2016).

The overarching goal of ID is to identify themes and patterns from subjective perspectives, whilst recognizing a variety of experiences from interviewees. As such, ID is not intended to be completely objective, but instead functions to serve as a framework for practical and clinically relevant research (Thorne et al, 1997). The research team has flexibility to explore clinically relevant topics based on the research questions being investigated. For this reason, ID offers flexibility to explore the participants' experiences from a constructivist and naturalistic orientation, free from any predetermined theoretical mandate to examine a choice from particular world viewpoints, thus ensuring data collection is ultimately relevant to clinical best practice and patient care (Hunt, 2009; Thorne, 2016).

ID has been used in clinical disciplines outside nursing, including pharmacy (Murphy et al., 2016), physiotherapy (Atkinston & McElroy, 2016), and physician education (Chan et al., 2017). Regarding autism care, ID has been used in two theses to investigate the perspectives of Montessori teachers (Lane-Barmapov, 2016) and parent perspectives of children diagnosed with Asperger's Syndrome (York, 2011). Only one study has used ID to explore healthcare professionals' experiences with autism - regarding the surgical experiences of autistic children (Snow et al., 2022). Although a recent study investigated medical students' perceptions of feedback from residents using ID at the University of British Columbia (Wong et al., 2022), this is the first study to our knowledge that explores medical residents' perspectives on autism care.

The goal of this research was to gain insight into pediatric residents' perspectives on autism care, as well as the learning needs and gaps involved care for autistic patients. As such, use of ID methodology allows us to focus on the residents' experiences in training, emphasizing the individuals' experiential knowledge and perspectives, with the understanding that individuals' experiences can be varied, and at times, contradictory (Thorne, 2016).

3.3. Theoretical Frameworks – Ontology and Epistemology

Ontological Perspective

The ontological perspective of this research is grounded in constructivism, which posits that reality is socially constructed and is dependent on the researcher, thus can vary across individuals and contexts (Guba & Lincoln, 1994). In the context of autism education in medical training, this recognizes that the experiences of pediatric residents in Canada, individuals on the autism spectrum, and advocates (such as family members) are shaped by their unique perspectives and interpretations of reality. The adoption of a constructivist ontological stance aligns with ID methodology (Thorne, 2016) as it emphasizes the significance of socially constructed meanings and the subjective nature of individuals' experiences in the context of medical education (Mann & MacLeod, 2015; Rees et al., 2020). Within autism education, acknowledging the socially constructed nature of knowledge is essential for capturing the complexity of pediatric residents' learning needs and perspectives, and recognizing the diverse health care needs within the broader autistic community.

Adopting a constructivist perspective is advantageous for a variety of reasons. Firstly, constructivism recognizes the subjectivity inherent in an individual's experiences and perspectives. That is, individual experiences are shaped by unique sociocultural, personal, and contextual factors (Rillo et al., 2020) for both pediatric residents and autistic individuals. These differences were highlighted in Milton (2012), who coined the “double empathy problem” from his studies of the mutual understanding between autistic and neurotypical individuals. Milton noted that although autistic individuals can experience a lack of insight into neurotypical culture and perspectives, neurotypical individuals also experience a similar lack of insight into autistic culture and perspectives. Milton’s thesis challenges a deficit-oriented view of autism, highlighting the importance of understanding the social construction of individual experiences through a constructivist approach to qualitative research.

Secondly, this research focuses on the socially constructed nature of resident’s perspectives on the healthcare system, derived from their personal experiences with the environment and materials shared in medical school. As such, constructivism lends itself as an ontological approach for understanding the learning needs of residents, as their experiences in autism care are contingent with educational curricula, cultural factors, and individual understanding of autism, which will influence the learning needs and perspectives given in the interviews.

Epistemological Perspective

The epistemological perspective guiding this research is rooted in subjectivism, which implies that knowledge is not universal or objective, but contingent upon the perspectives of those involved (Guba & Lincoln, 1994). In the context of education in a medical setting, this means acknowledging the multiplicity of perspectives of the residents and other involved parties. By embracing a subjective approach, this research recognizes that there is no single objective truth regarding the learning needs and perspectives of pediatric residents. Instead, a multifaceted approach based on the experiences of those involved can be interpreted to contribute a more fulsome understanding of autism care in a medical education setting.

There are several advantages to the epistemological perspective of subjectivism. A subjectivist stance aligns with the understanding that knowledge is situated within specific sociocultural contexts (Ratner, 1997; Ratner, 2002). Similar to constructivism, subjectivism emphasizes the contextual nature of knowledge, which can demonstrate experiential teaching method effectiveness, communication strategies, and healthcare practices that may be traditionally used. These factors can be influenced by cultural factors, socioeconomic status, and regional healthcare policies (Delisa & Lindenthal, 2012; Verbree et al., 2023). Secondly, the subjectivist perspective acknowledges the multiplicity of perspectives (Salgado & Hermans, 2009). This is beneficial in two ways. Autism is a spectrum and as such, the experiences of each individual with autism will vary. An understanding of this is relevant as the residents' perspectives will be shaped by the preferences and needs of individuals with whom they worked. Likewise, healthcare professionals will have varied experiences with autism, based on sociocultural factors, personal experience, and exposure to autism in training. A subjectivist approach promotes a more comprehensive understanding of the learning needs and perspectives of pediatric residents by gathering and embracing diverse experiences.

3.4. Suitability of ID in Clinical Research

The methodological framework of ID was used to provide a robust and contextually sensitive approach to exploring complexities of pediatric residency training regarding autism care. ID is systematic, yet flexible, with several tenets that are central to its methodology. Below I describe how we embraced each tenet of ID with the aim to understand the learning needs and perspectives of the residents on providing best practice care for autistic patients during their training and in their future practice.

First, ID emphasizes the importance of context in shaping an individuals' experiences in practice (Thorne et al., 2004; Hunt, 2009). In the context of this study, the unique sociocultural and institutional factors influencing the residency training in autism care were carefully considered. That is, interview questions were poised to attend to the specificities of the Canadian pediatric healthcare landscape, where information on regional policies, resources, and guidelines were taken into consideration and specifically inquired (Ocean et al., 2022).

Second, the nature of ID is iterative, allowing for an ongoing dialogue between data collection and analysis (Thorne et al., 2004). Within this dialogue, the researcher locates findings within the existing body of knowledge, which, in the context of this research, comes from the literature, regional policy, and curriculum guidelines, to identify factors that may arise from the data analysis. Throughout the data collection process, the research team actively investigated factors that may influence interviewee responses and preliminary results were continuously refined and compared to influence subsequent data collection efforts. Thus, the iterative nature of ID facilitated a deeper understanding of the nuances within the data, allowing for the exploration of emergent themes throughout data collection to help inform future interviews.

Third, ID encourages the integration of theoretical insights with practical knowledge obtained from interviewees with the overarching goal of bridging the gap between academia and clinical practice (Burdine et al., 2021). For this study, theoretical frameworks from the fields of medical education, autism research, and healthcare delivery were considered to inform the interpretation of data to offer practical recommendations for enhancing pediatric residency training regarding autism care by grounding the findings in relevant theoretical perspectives.

Fourth, central to ID is recognizing the researcher's subjectivity and positionality and the importance of reflexivity throughout the research process (Kearney, 2001; Hunt, 2009). Reflexive thematic analysis, as described later in this chapter, provides a means of navigating the data analysis while attending to biases and lived experiences of the research team and the participants. By engaging in continuous reflection, the researcher aimed to enhance transparency and methodological rigor (Johnson et al., 2020).

Fifth, a strength of ID is that the approach prioritizes the generation of knowledge that is directly applicable to practice and policy (Thorne, 2016; Hunt, 2009). This findings of this research will help guide future studies that explore education, policymaking, and healthcare practice surrounding autism care. By using ID to emphasize practical utility, our findings could facilitate the initial steps to positive change in pediatric residency training programs to prepare the next generation of pediatricians to better improve quality of life for autistic patients.

Throughout the application of ID, this research adopted a nuanced and contextually sensitive approach to explore pediatric residency training regarding autism care in Canada. The strengths of using ID lie in attending to the specificities of local context, integration of theory with practical knowledge, and prioritizing reflexivity and practical utility to generate meaningful insights and contribute to the enhancement of autism education, ultimately leading to better healthcare delivery practices for the next generation of pediatricians in Canada.

Limitations of ID

While ID offers valuable insights into complex phenomena, taking nuanced perspectives into consideration throughout data collection and analysis, there are challenges associated with the methodological approach. As with many qualitative methods, ID acknowledges subjectivity, including that of the research team's perspectives, biases, and preconceptions (Hunt, 2009). Although a reflexive thematic approach was used to mitigate bias, there is still a risk that subjective interpretation influenced data analysis. Second, ID emphasizes contextual specificity; as a result, there may be limitations in the generalizability of findings to other populations or contexts. For example, participants were recruited based on their interest in the study and most of the participants had some interest in improving autism education (see Table 3.2 in the Participants section). While this provided rich, in-depth insights which are encouraged in ID, the results may not be easily transferable to other settings or populations (for example, residents who are not interested in autism care; Thorne, 2016). Future work may be needed to make the findings more generalizable to implement change into the curriculum and policymaking. Third, ID lacks specific guidelines for data analysis, leading to variability in the analytical approach across studies. This flexibility allows a research team to adapt methodologies specific to research questions and contexts, though it may also result in ambiguity in data reporting and interpretation. Further, incorporating diverse perspectives into interpretive processes can be a challenge. By balancing perspectives while maintaining methodological rigor, tension or conflicts of interest may arise during data analysis (Thorne et al., 2004).

Despite these limitations, ID remains a valuable approach for generating rich and contextually situated insights into complex phenomena, as poised by the research questions in this study. By addressing these challenges, the research team can enhance the validity and rigor of data interpretation and use the findings to guide future studies to implement policy and curricular changes.

3.5. Study Background

The roots of this research were planted from a study I participated in, led by the research team at Holland Bloorview Kids Rehabilitation Hospital in Toronto, Canada. That study interviewed community pediatricians to determine the collection practices, learning needs, capacity, and overall interest in an autism learning health network, and to identify the perspectives of engagement with a potential learning health network for implementation (Kearney et al., 2024). Twenty-nine participants from three sites were interviewed – Ontario, Alberta, and Missouri - and I interviewed all the participants from the Alberta site. At the same time, I engaged in several public speaking opportunities early in my Master's and realized there was a lack of education on autism care, and a desire to learn more, both from newly graduated doctors and those who have been in practice for many years. This led to conversations among the research team, involving myself (NP, graduate student), research associate (LS), and developmental pediatrician/ researcher (LZ, project supervisor), ultimately generating the current thesis research questions.

3.6. Semi Structured Interviews

The development of the interview guide occurred from June to August 2023, and underwent multiple revisions to best address the research study questions. The interview guide was primarily created by NP, with input from study team members LZ and LS. Prior to data collection, a pilot interview was completed with a pediatrician who was not involved in this study. The purpose of the interview was two-fold. Firstly, the pilot interview was used to test the technological parts of the interview; for example, confirming that the connection to the Zoom platform, visual and sound quality, and audio recording were adequate. Secondly, the pilot interview allowed the research team to assess how well the interview guide covered the research questions and generated data that addressed the aims of the study.

As interviews progressed, the interview guide was refined to capture some of the recurring initial themes of prior interviews, and to accommodate for a more natural conversational flow. The guide was organized into four subsections (see Table 3.1 and Appendix E).

Table 3.1. Subsections of questions in the semi-structured interview guide, and their purpose

Question Subsection	**Purpose of Questions**
Introduction Questions	To gain a sense of the resident's overall understanding of autism, and their experiences with autism within and outside the educational environment.
Perspectives Questions	To define best practice care in a community context applied to autism, to determine factors most important to best practice care, and to identify who should be involved in best practice care.
Learning Needs Questions	To determine what residents have learned regarding autism care, to identify strengths and gaps in autism training, and gain a sense of resident's comfort with autism care in a pediatric setting.
Concluding Questions	To inquire about future roles in providing healthcare to autistic patients and to give residents an opportunity to mention anything they feel was not queried in the interview.

3.7. Ethical Consideration and Approval

Ethical approval was approved by the Health Research Ethics Board 1 through the University of Alberta (Pro00132919). The ethical application included considerations to maintain confidentiality of participants, risks and benefits assessments associated with the study, and how the data would be protected. Participants were given a consent form via email and completed an informed written consent on the University of Alberta's Redcap platform prior to participating in the study. The consent form explained the rationale for the study, the expectations of participants, and the participants' right to confidentiality, compensation, and to withdraw from the study at any point. Participants were also reminded of their rights prior to beginning the interview, including that audio recordings would be made and sent to a transcription service, who had signed a data confidentiality agreement.

3.8. Procedure

This research was conducted from the University of Alberta. Interviews were conducted using the virtual platform Zoom with the intent of including participants outside of the University of Alberta to maximize our sample size. A University of Alberta developmental pediatrician (LZ) sent recruitment posters and information to colleagues affiliated schools in Western Canada – University of Alberta, University of Calgary, and University of British Columbia. The pediatric residency department leads at these respective centres circulated the recruitment information, initially to senior (third and fourth year) residents as well as developmental fellows and recent graduates. Additional emails were sent to a broader sample to include junior (first and second) residents. The recruitment emails included information on the study philosophy, time commitment, and modest stipend to acknowledge the residents' time and contributions. Potential participants then emailed NP directly, stating their interest in the study.

Data were collected from September 2023 to January 2024. Upon signing a consent form, participants filled out an online demographic questionnaire through the University of Alberta's REDCap platform. Then, NP scheduled an interview through the Zoom platform. The interviews were 30 to 60 minutes in duration. The twelve interviews were audio recorded and sent to *The Comma Police*, a transcription service, where they were transcribed verbatim. The transcripts were deidentified, and sent back to the research team, where they were uploaded to NVivo 14 software. Participants received a $25 Indigo gift card as a token of appreciation for participating in the study.

3.9. Participants

To apply ID methodology, participants are needed who have lived experience that aligns with the research aims (Thorne, 2016). We sought to recruit pediatric residents and developmental fellows who had recently completed a general pediatric residency, thus participation was opportunistic rather than selected sampling (King & Hugh-Jones, 2019).

Twelve residents participated in the interviews. All participants were female and from a variety of educational backgrounds prior to undergraduate medical education. Eight of the participants were affiliated with University of Alberta, and four were affiliated with University of British Columbia. Table 3.2 summarizes information on each of the participants.

Table 3.2. Relevant demographic information from the demographic questionnaire

Participant	**Residency Status**	**Do they plan on doing a subspecialty?**	**Have they had additional training?**	**Have they had personal experience with autism?**
1	Senior Resident at University of Alberta	Yes, in Developmental Pediatrics	Yes, Developmental Pediatrics elective	No
2	Recent Graduate from University of Alberta	No	No	No
3	Recent Graduate from University of Alberta	No	No	Yes, an extended family member with autism
4	Senior Resident at University of Alberta	Yes, in Pediatric Emergency Medicine	No	Yes, a friend with autism
5	Developmental Subspecialty Fellow at University of Alberta	Yes, currently in Developmental Pediatrics	Yes, several Developmental Pediatrics electives	Yes, a friend with autism, and through volunteer experiences
6	Junior Resident at University of Alberta	Unsure	Yes, electives and selective in medical school	Yes, through volunteer and employment experiences
7	Neonatology Subspecialty Fellow at University of Alberta	Yes, currently in Neonatology	No	Yes, through volunteer experiences
8	Recent Graduate (Developmental Subspecialty) from University of Alberta	Yes, finished Developmental Pediatrics	Yes, several Developmental Pediatrics electives	Yes, an immediate family member with autism
9	Developmental Subspecialty Fellow	Yes, currently in Developmental Pediatrics	Yes, an elective specifically on autism	Yes, a friend with autism

	at University of British Columbia			
10	Recent Graduate (Developmental Subspecialty) from University of British Columbia	Yes, finished Developmental Pediatrics	Yes, several Developmental Pediatrics electives	Yes, an extended family member with autism
11	Developmental Subspecialty Fellow at University of British Columbia	Yes, currently in Developmental Pediatrics	No	No
12	Junior Resident at University of British Columbia	No	No	Yes, an extended family member with autism

3.10. Reflexive Thematic Analysis

The methodological approach I used to analyze the qualitative data regarding best practice care is reflexive thematic analysis (RTA), which offers a nuanced and reflective lens to explore and interpret the rich and complex narratives that are inherent with the data (Braun & Clarke, 2006; Braun & Clarke, 2022). This analytic approach aligns with pragmatic qualitative methods designed for applied research, such as ID (Campbell et al., 2021). RTA allows for an exploration of the intricate details of the learning needs and perspectives of pediatric residents on providing best practice care for autistic patients.

RTA is a dynamic six phase process (as outlined below), in which the researcher plays an active role in shaping the data interpretation (Braun & Clarke, 2022). The reflexive element emphasizes the researcher's position and engagement with their own knowledge and preconceptions, biases, and assumptions throughout the analytic process. This thematic approach allows for identification and exploration of patterns, commonalities, and variation within the data collected. The themes emerge from the narratives of the pediatric residents, which are essential to understanding nuances of learning needs and perspectives to better the education system regarding autism care, ultimately to deliver care to autistic patients.

Subjectivity is inherent in qualitative research and RTA not only recognizes but appreciates this (Breuer et al., 2002). RTA allows the researcher to go beyond surface-level interpretations, and provide deeper understandings embedded in the narratives as it allows for data analysis to be guided by the perspectives of the participants and the research team. The iterative nature of RTA aligns with the iterative cycle of the ID method, reinforcing our commitment to capturing the complexity surrounding training in autism care in residency. Moreover, RTA provides a robust framework for bridging the gap between theoretical frameworks and actual data, facilitating a coherent and meaningful interpretation of findings (Nowell et al, 2017). The researcher is positioned to navigate the analysis by reflexively processing transparency and accountability, allowing the readers to understand the influence of the researcher's background and positionality on the interpretation of data, codes, and themes presented (Holmes, 2020).

The Six Phases of RTA

As mentioned, RTA is a six-phase process that are not designed to be followed linearly; rather, the researcher goes back and forth between phases while doing data analysis (Braun & Clarke, 2022).

Step 1. Familiarization with the Data. The initial phase involved familiarizing myself with the data to become engaged with the content of the interviews. For this study, I became familiar immediately, as I created the semi-structured interview and conducted the interviews independently. While interviewing, I made sure to ask relevant follow-up questions to get clarification as needed, with the aim of being less subjective during data analysis by obtaining as complete a story as I could from each interviewee. I continued to immerse myself in the data following the transcription process, where I read each transcript over at least twice, and made annotations on a copy of the transcripts to highlight points I thought relevant, or that I wanted to investigate further in the coding process. As the interviewer, I was cognizant to look for emergent themes that arose during the interviews and I also annotated insights that I would be likely to code in step 2.

Step 2. Generating Initial Codes. The second phase of RTA involves coding, described as identifying the building blocks that will eventually be used to generate themes (Braun & Clarke, 2022). Code labels were used to capture relevant meanings and ideas, then were grouped together across interviews. I began the coding process by using semantic coding (or more "explicit, surface level" codes), and then explored latent coding (or more "implicit, beyond-the-text level" codes) on a second readthrough. The latent coding drew heavily on preconceived knowledge of the medical system and autism care in Canada and applying theoretical perspectives to that knowledge. I used the qualitative software program NVivo 14 for coding of the transcripts. As is considered good practice for RTA, I was the primary coder for this study, though when I had questions or wanted a second opinion on the latent coding, I worked with study team member LS to come to an agreement on the implicit meanings.

Step 3. Generating Initial Themes. The third phase of RTA involved the clustering of codes generated in step 2 into more broad themes and subthemes related to the research questions. Demographic data was also considered here, including ethnicity and gender, and previous exposure to autism and autism-related topics, as asked in the demographic questionnaire prior to the interview.

Step 4. Developing and Reviewing Potential Themes. The fourth phase of RTA involved an assessment of the themes. The codes collected from step 3 were compiled and grouped together to initiate the process of creating larger themes. Then, I, alongside research team member LS, hand-drew visual thematic maps to aid in theme generation, and to explore how codes and potential themes may be correlated to one another (see Appendix F for the final diagram). During this phase we also determinined how well the codes represented the initial themes, and supported exploring for nuances as well as patterns across participants.

Step 5. Defining and Naming Themes. The fifth phase of RTA involved defining what the themes were and refining which codes would be considered under each theme. The essence of each theme was articulated through a reflexive dialogue between myself, LS, and supervisor LZ to provide a clear label that encapsulated the meaning with regards to the research questions poised.

Step 6. Writing the Analysis. The final phase of RTA involved writing up the analysis and findings for the thesis, in preparation for dissemination.

3.11. Summative Content Analysis

To thoroughly examine the gaps in medical training and some of the solutions proposed to mitigate these gaps by pediatric residents regarding autism care, I employed content analysis approach. Content analysis, compared to thematic analysis, is a systematic method for analyzing qualitative data, allowing for the identification, coding, and categorization of patterns within textual data (Humble & Mozelius, 2022). The specific approach utilized was a summative content analysis, in which keywords are identified before and during data analysis, and keywords are derived from the interest of researchers and a review of the literature prior to data collection.

Summative content analysis is an analytical technique to analyze qualitative data by quantifying certain words or content within textual data followed by an interpretation of the underlying context (Hseih & Shannon, 2005). This method is useful for identifying patterns and trends in data, and to highlight more of the content said by the residents in the interviews, without having to conform to thematic patterns. There is a five-step process to summative content analysis which, unlike RTA, is designed to be followed in a more linear fashion.

Step 1. Keyword Identification. After familiarizing myself with the data for both thematic and content analysis (see Step 1 of Section 10), and identified initial codes (see Step 2 of Section 10), I identified key terms and phrases relevant to the research question of gaps and solutions. Specifically, I looked for codes that related to potential gaps (for example, lack of education on long-term care), and solutions (for example, the addition of continuity clinics).

Step 2. Keyword Frequency Count. Once the key terms and phrases were identified, I then systematically analyzed the interview transcripts to count the occurrences of the identified keywords to provide an overview of the most frequently mentioned barriers and solutions related to autism training needs.

Step 3. Contextual Analysis. The third step in summative content analysis involves analyzing the context in which the key terms and phrases appear. I analyzed the surrounding text to understand the meaning and implications of the keywords within their broader narrative to help identify nuances in the residents' discussions about training gaps and solutions. The purpose of this contextual analysis step was to ensure that findings were not just based on quantitative frequency, but also with regards to their significance in the narratives.

Step 4. Categorization and Pattern Recognition. The fourth step in summative content analysis involves categorizing the keywords and their contextual meanings into broader categories to help in pattern recognition and drawing connections between different parts of the data. For this step, major categories were grouped into patterns that reflected specific training needs and gaps. For example, “training gaps” were categorized into specific areas such as “lack of practical experience,” and “insufficient multidisciplinary training.” This process was conducted as a collaboration between me and team member LS to ensure that as many ideas from the interviews as possible were captured in the content analysis, and that the context in which they were analyzed under made sense to both of us.

Step 5. Interpretation of Findings. The final step involved interpreting the categorized data to draw meaningful conclusions that answer the research questions in preparation to write up the analysis and findings for the thesis, in preparation for dissemination. This step goes beyond identifying what is frequently mentioned to understanding why it is significant, and how it relates to a broader research context. Part of this step is also conducted in the discussion of the thesis.

3.12. Methodological Rigor and Trustworthiness

Methodological rigor was paramount to ensure the trustworthiness and validity of research findings. We drew apon Lincoln and Guba’s model of trustworthiness (1985). Their model contains four tenants – credibility, transferability, dependability, and confirmability – which were addressed throughout the data collection and analyses of this thesis project.

1. Credibility. Credibility refers to the extent to which the findings accurately represent the experiences and perspectives of the participants. To enhance credibility, follow-up questions were asked in the interviews to ensure an accurate understanding of concepts and themes were being addressed. Additionally, prolonged engagement with data, including discussion groups with the study team, facilitated a deeper understanding of the nuances within the narratives. The study team brings many years of autism research, clinical experience, and life experience together, which further enhances the credibility of the findings.

2. Transferability. Transferability pertains to the extent of which findings can be applied or transferred to other contexts. Transferability was fostered by obtaining a purposeful sample to identify key informants who could actively contribute to the topics of the research study. Thick description of the data, including extensive quotes and contextual details in the coding and thematic analysis processes, further support transferability of the findings by facilitating understandings and comparisons across the sample.

3. Dependability. Dependability refers to the consistency and stability of findings over time and across different research teams. Dependability was ensured through the maintenance of an audit trail, where all decisions and changes made throughout the research process were documented to enable study replication. Coding was checked by study team member LS in discussion groups, which also contributed to the study's dependability.

4. Confirmability. Finally, confirmability refers to the objectivity of the findings, indicating that they are shaped by the data rather than the researcher's biases or preconceptions. Reflexivity was integrated into the research process, where lead researcher NP continuously reflected on his positionality, biases, and influences during data interpretation. Peer debriefing and checking of codes were utilized to solicit feedback from external sources, ensuring that the interpretations remained grounded within the data.

Lincoln and Guba’s aspects of trustworthiness enhanced the validity and the quality of the research, ultimately contributing to the advancement of knowledge regarding pediatric residency training in autism care in Canada.

In addition to Lincoln and Guba’s model, I also employed Braun and Clarke’s “15-point Checklist for Good Reflexive TA (2022; p. 269) to allow for reflection about my positionality, biases, assumptions, and values. The checklist is summarized in Table 3.3 and are categorized based on the processes to which they correspond (item 1, transcription, items 2-6, coding and theme development, etc.). The relevant criteria were considered at each point in the RTA process.

Table 3.3. Braun and Clarke's 15-point Checklist for Good Reflexive TA – adapted from Braun & Clarke (2022, p. 269).

Process	**Item No.**	**Criteria**
Transcription	1	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the recordings for accuracy.
Coding and Theme Development	2	Each data item has been given equal attention in the coding process.
	3	Themes have not been generated from a few vivid examples, but instead, the coding process has been thorough, inclusive, and comprehensive.
	4	All relevant extracts for each theme have been collated.
	5	Themes have been checked against each other and back to the original data set.
	6	Themes are internally coherent, consistent, and distinctive.
Analysis and Interpretation	7	Data have been analyzed rather than simply paraphrased or described.
	8	Analysis and data match each other, and the extracts illustrate the analytic claims.
	9	Analysis tells a convincing and well-organized story about the data and topic/research questions.
	10	A good balance between the analytic narrative and illustrative extracts is provided.
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.
Written Report	12	The assumptions about thematic analysis are clearly explicated.
	13	There is a good fit between what is claimed to be done, and what is shown to have done – i.e. describing the method and the reported analysis are consistent.
	14	The language and concepts used in the report are consistent with the ontological and epistemological position of the analysis.
	15	The researcher is positioned as *active* in the research process, and themes do not just emerge.

CHAPTER 4. Findings – Reflexive Thematic Analysis

4.1. Chapter Introduction

The purpose of this chapter, named “Findings” as opposed to “Results” due to the constructivist ontological perspective and subjectivist epistemological perspective of this study, is to present the data collected from the interviews. Building upon the literature, theoretical framework, and methodological approach outlined previously, this chapter offers a detailed examination of the learning needs of pediatric residents and their perspectives on providing best practice care for autistic patients. Through reflexive thematic analysis of the qualitative data obtained from the interviews, this chapter aims to delve into the rich narratives and insights shared by the 12 participating residents to create a narrative of the challenges, experiences, and opportunities inherent in autism education and healthcare delivery from the context of pediatric residency training. The overarching goal is to answer the research question, “what are pediatric residents’ perspectives on providing best practice care for autistic patients, including the role of the pediatrician on the care team?”

The chapter begins with a summary table of the demographic data collected from participating residents. Then, an infographic is presented, which summarizes the categories and themes that will be narratively described in the chapter. The subsequent sections will follow a framework based on the categories and themes found from the reflexive thematic analysis. This will include a narrative with direct quotations embedded into the findings for each subtheme. The subsequent chapter will continue the findings and focus on content analysis of the interviews.

4.2. Demographic Information

Twelve participating residents were interviewed for this study, as described in the “Participants” section of the “Methodology” chapter. The participants ethnicity, medical school background, and experiences with autism are provided in Table 4.1.

Table 4.1. Relevant demographic information and experiences with autism from participants.

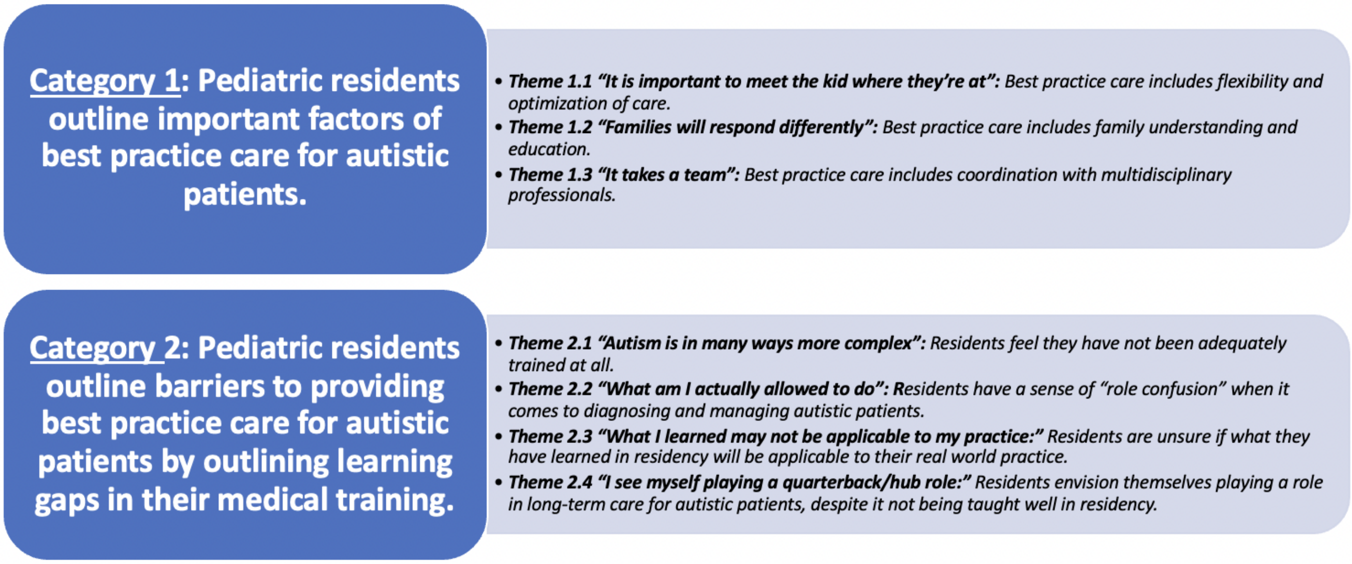
Participant	Ethnicity/Race	Medical School Attended	Year Graduated Medical School	Experiences with Autism
1	South East Asian	University of Manitoba	2021	***Personal:*** Through summer camps as an educational aide ***Medical School:*** Development in clerkship through neurology ***Residency:*** Exposure in developmental and general pediatrics blocks, sought out additional experiences
2	Caucasian/White	University of Alberta	2018	***Personal:*** Volunteer experiences at recreational organizations, working one-on-one with a child in need of supports ***Medical School:*** Saw children with autism in an integrated community clerkship in rural communities ***Residency:*** Exposure in developmental pediatrics blocks in first and third year of residency
3	Caucasian/White	McMaster	2019	***Personal:*** Acquaintances with autism, including a brother-in-law ***Medical School:*** Limited exposure, recalls a lecture in pre-clerkship ***Residency:*** Exposure in developmental pediatrics blocks in first and third year of residency; academic half day lecture; attended community pediatrics events focusing on autism; limited exposure in community blocks
4	Caucasian/White	University of Alberta	2021	***Personal:*** Worked at a summer camp for children with developmental delays ***Medical School:*** Participated in a "developmental disabilities" elective; some exposure in pediatrics rotation in clerkship

				Residency: Limited exposure in 1st year developmental rotation
5	Caucasian/White; South Asian	University of Manitoba	2019	***Personal:*** Friends with autism in childhood ***Medical School:*** One lecture on autism in pediatrics, elective in developmental pediatrics, limited exposure in pediatrics in clerkship. ***Residency:*** Exposure in a single developmental pediatrics block; diagnostic care in developmental subspecialty; limited out-patient experience (even in subspecialty)
6	Caucasian/White	University of Ottawa	2022	***Personal:*** Volunteer experience for children with developmental delays in school, hospital, and day program; friends with autism in childhood ***Medical School:*** Lecture in psychiatry block; pursued electives in developmental pediatrics in pre-clerkship and clerkship ***Residency:*** Saw autistic children in outpatient clinics; some exposure in psychiatry
7	Caucasian/White	University of Calgary	2017	***Personal:*** Volunteered with a respite group ***Medical School:*** Group project in pediatrics rotation; textbook exposure ***Residency:*** Some clinical exposure in community pediatrics and developmental pediatrics rotations
8	Caucasian/White	Memorial University	2018	***Personal:*** Family member with autism, involved with Special Olympics and Autism Society ***Medical School:*** One lecture in pre-clerkship and one lecture in clerkship, very limited clerkship "hands-on" exposure ***Residency:*** Exposure in developmental pediatrics blocks; two additional developmental electives; diagnostic care in developmental subspecialty

9	Latin American	Universidad Industrial de Santander (Colombia)	2005	***Personal:*** Extended family members, friends, and community members with autism ***Medical School:*** No exposure in medical school ***Residency:*** Some exposure in psychiatry; diagnostic care and long-term care in developmental subspecialty
10	South Asian	University of Manitoba	2012	***Personal:*** Extended family member has autism ***Medical School:*** A lecture on child development in pre-clerkship; no exposure in clerkship ***Residency:*** Exposure in a single developmental pediatrics block, of which there was minimal autism, diagnostic care in developmental subspecialty.
11	Caucasian/White	Western University of Health Sciences (United States)	2013	***Personal:*** Friends and colleagues with autism, acquaintances in childhood ***Medical School:*** Minimal in pre-clerkship or clerkship ***Residency:*** Some exposure in developmental and behavioural pediatrics rotations, diagnostic and long-term care in developmental subspecialty
12	Caucasian/White	University of British Columbia	2022	***Personal:*** Acquaintances with autism, including a brother-in-law; worked as a support worker in camps ***Medical School:*** One lecture, no exposure in clerkship ***Residency:*** Didactic sessions on autism, some observation during assessments in developmental rotation

4.3. Summary of Categories and Themes

Seven prominent themes were developed through reflexive thematic analysis that fit best into two categories: (1) important factors contributing to best practice care, and (2) barriers in providing best practice care due to learning gaps. Three themes fell under category one, and four themes fell under category two, which are summarized in Figure 4.1. The remainder of this chapter will elaborate on each theme, using direct quotes from the interviews with commentary on how they fit into the greater narrative, as guided by the initial research questions.



Category 1: Pediatric residents outline important factors of best practice care for autistic patients.

- ***Theme 1.1 "It is important to meet the kid where they're at":*** *Best practice care includes flexibility and optimization of care.*
- ***Theme 1.2 "Families will respond differently":*** *Best practice care includes family understanding and education.*
- ***Theme 1.3 "It takes a team":*** *Best practice care includes coordination with multidisciplinary professionals.*

Category 2: Pediatric residents outline barriers to providing best practice care for autistic patients by outlining learning gaps in their medical training.

- ***Theme 2.1 "Autism is in many ways more complex":*** *Residents feel they have not been adequately trained at all.*
- ***Theme 2.2 "What am I actually allowed to do":*** *Residents have a sense of "role confusion" when it comes to diagnosing and managing autistic patients.*
- ***Theme 2.3 "What I learned may not be applicable to my practice:"*** *Residents are unsure if what they have learned in residency will be applicable to their real world practice.*
- ***Theme 2.4 "I see myself playing a quarterback/hub role:"*** *Residents envision themselves playing a role in long-term care for autistic patients, despite it not being taught well in residency.*

Figure 4.1. A summary of the categories and themes identified in the reflexive thematic analysis.

4.4. Category 1: Pediatric Residents Outline Important Factors of Best Practice Care for Autistic Patients

Several key themes were developed from the data when exploring the perspectives of pediatric residents on providing best practice care for autistic patients. These themes highlight the nuanced understanding, as well as misconceptions, that residents have developed through medical training and their experiences in autism care. The three primary themes identified include: The necessity of flexibility and optimization of care; the importance of family understanding and education; and the critical role of coordinated care with other professionals. It is commonly stated that best practice care was similar for neurotypical patients and autistic patients, yet there are considerations that need to be taken to enhance the child's experience in a clinical setting. The themes, developed from the interviews with pediatric residents, collectively underscore the multifaceted nature of best practice care for autistic patients.

Theme 1.1 "It is important to meet the kid where they're at": Best practice care includes flexibility and optimization of care.

One of the most prominent themes identified by pediatric residents is the importance of flexibility and optimization in the care of autistic patients. Residents consistently emphasized that best practice care involves adapting to the unique needs, strengths, and challenges of each child, rather than adhering to a rigid, 'one-size-fits-all' approach.

A recurring comment that came up in the interviews was that standardized care procedures, such as components of a physical exam, may need to be modified to tailor clinical approaches to the individual child. This was well described in this quote from Resident 7, which highlights the necessity of flexibility and optimization of care in best practice:

> "Now on the child's side of things, I think it's important to meet the kid where they're at. I mean we're very used to, in pediatrics, dealing with toddlers that don't want their lungs checked, their blood pressure checked, their ears checked, and so a kid that has different sensory needs, again you figure out what is truly important. If there's a question of if this kid has an ear infection, then yeah, you might actually need the parent to help hold the child down to be able to check their ear to be able to diagnose them and treat them appropriately. But if there's no concerns with their ear and that's something that is only going to cause trauma and harm to the kid then it's probably not the most appropriate time when they came in for a completely different concern to proceed with checking their ear."

Pediatric residents highlighted the need for a deep understanding of the spectrum nature of autism, which necessitates a flexible approach to care. This was alluded to in the previous quote by Resident 7, and also highlighted by Resident 10:

> "But also understanding that one child with autism is not the same as another child with autism right, it's not a check box, and presentations are different, needs are different, behaviors are different and that you have to manage the child that's in front of you and not a child with autism."

Flexibility in clinical practice may involve modifications to appointment schedules, allowing for longer or more frequent visits, or incorporating alternative communication methods. Resident 12 illustrates this point:

> "Ideally with some flexibility around accessing services and offering combinations of in-person and virtual appointments and ideally too at hours that work for families and the practitioner"

Adopting a flexible approach also extends to the families and their goals for a clinical visit. As noted by Resident 11:

> "I think it sort of depends on the family, like I think a lot of times families will bring up concerns or like certain like behavioral concerns will often be how things are brought up. Or they, often the children will have like some type of speech or communication delay and just like get really easily frustrated or just kind of acting different than some of their peers. So, I think each family is kind of unique in that what their biggest concern is and then going from there."

Flexibility and care optimization is central to best practice care for autistic patients. Pediatric residents underscored the importance of meeting each child (and their families) where they are, personalizing care, and maintaining flexibility in clinical practice to address the needs of autistic individuals. Frequently, residents noted that fostering therapeutic environments that are both effective and empathetic were important aspects of providing flexible care. The insights provided by the residents highlight the critical need for a nuanced and individualized approach to autism care, which is essential for promoting positive outcomes for not only children, but their families as well.

Theme 1.2 "Families will respond differently": Best practice care includes family understanding and education.

Residents identified that the role of families in the care of autistic children cannot be overstated, particularly in the initial discussions regarding diagnosis. The residents frequently discussed the importance of engaging with families, understanding their unique perspectives, and providing them with the kindness needed to navigate the complexities of an autism diagnosis. This theme highlights the importance of family-centered care approaches that recognize and respect the diverse responses, needs, and dynamics of families when managing an autism diagnosis. Families are the primary caregivers, and often take on an advocacy role for their children. Residents agreed that family involvement is crucial in the care process. Resident 6 used her training experiences with diagnosis to exemplify this point, in the context of a family being upset over an autism diagnosis:

> "Some families will respond differently to a diagnosis. I've seen families be really, really upset with having the diagnosis because they're worried about the child's future and of course it's really important to communicate that we actually don't know how this child is going to progress through life."

She then continued to discuss a strategy that can be used to support the family, noting:

> "Always checking the family's understanding and not using jargon to … support the family in the understanding of why we think the child has autism and what are of course the areas of strengths and areas where they can grow."

As the residents noted, families respond differently to an autism diagnosis. Resident 10 elaborated on this, emphasizing the importance of approaching families with kindness:

> "I think kindness towards the family because most families, they go through almost this grieving process of my child isn't neurotypical and then coming through that acceptance of okay now we need supports for my child so just empathy and kindness towards the family."

Resident 3 elaborated on an approach they use to help educate families:

> " I think I take the approach of trying to be really encouraging and trying to give them the outlook that even if your child's different, it doesn't mean that they can't learn. It doesn't mean that they won't grow. It doesn't mean that they can't have educational attainment or friends or relationships. It will change their lives, but a lot of their hopes for their kid are still possible. And so, I think I try to take that positive approach of even though you have this diagnosis, your hopes and dreams for your child, and their hopes and dreams are still possible."

This comment accentuates a commonality that many residents noted- that kindness to the child and family are among the most important factors in providing effective care in pediatrics as a whole.

Alongside kindness is the family's understanding of autism. Education and support for families are key components in providing best practice care. Residents often highlighted the need to provide tailored information and resources that address specific concerns and questions for each family. Resident 8 noted:

> "So, I would say like again kind of therapeutic lines with the parents is key. So, like making sure the parents, caregivers are on the same page and same with the child too, right? Like making sure we're kind of all like what's our understanding of this. Like why are we here?"

Resident 8 highlights the importance of providing families with comprehensive but understandable information about autism not only for the parents to best support their child's development, but also for the child's comfort in participation in assessments and evidence-based interventions. It was noted that this education piece should be ongoing and responsive to the evolving needs of the child and family.

Family understanding and support extends to the environment surrounding the child. Resident 1 noted how family and caregiver support is intertwined with environmental support – from extended family, the education system, and social networks. In turn, the child reciprocally influences the environment and caregivers. She stated:

> "And I see this in like, if we're seeing a preschooler with a new diagnosis of autism especially but I guess it can expand on when they're older to. It's just so important to have that support coming from your environment. Like you know like you give a child with a diagnosis of like a lifelong diagnosis essentially, it effects not just the child but everyone else around that child. So, I think it's such a huge factor and like now having seen like different cases of children with autism, seeing one with you know like a stable, like a someone who lives in a stable environment versus someone who maybe not have that, objectively seeing the outcomes of like a child with quote unquote, the same diagnosis really, it's striking, right."

This quote supports the interconnected relationships between parents and caregivers, the child, and their surrounding environment. By prioritizing family-centric care approaches, physicians can support families in their role of primary caregivers, ultimately promoting better outcomes in terms of quality of life for autistic children. The residents highlight the importance of an empathetic approach to family engagement as an essential component of best practice care in medicine.

Theme 1.3 "It takes a team": Best practice care includes coordination with multidisciplinary professionals.

Pediatric residents emphasized the necessity of a collaborative approach in providing best practice care for autistic patients, specifically noting the importance of coordinated care involving a multidisciplinary team of professionals.

As part of the interviews, residents were asked to list who is involved in the care of autistic patients. All residents noted more than just a physician is needed, with the most common healthcare professionals being speech language pathologists and occupational therapists, followed by behavioural therapists and pediatricians. Figure 4.2 summarizes the data collected in response to this question.

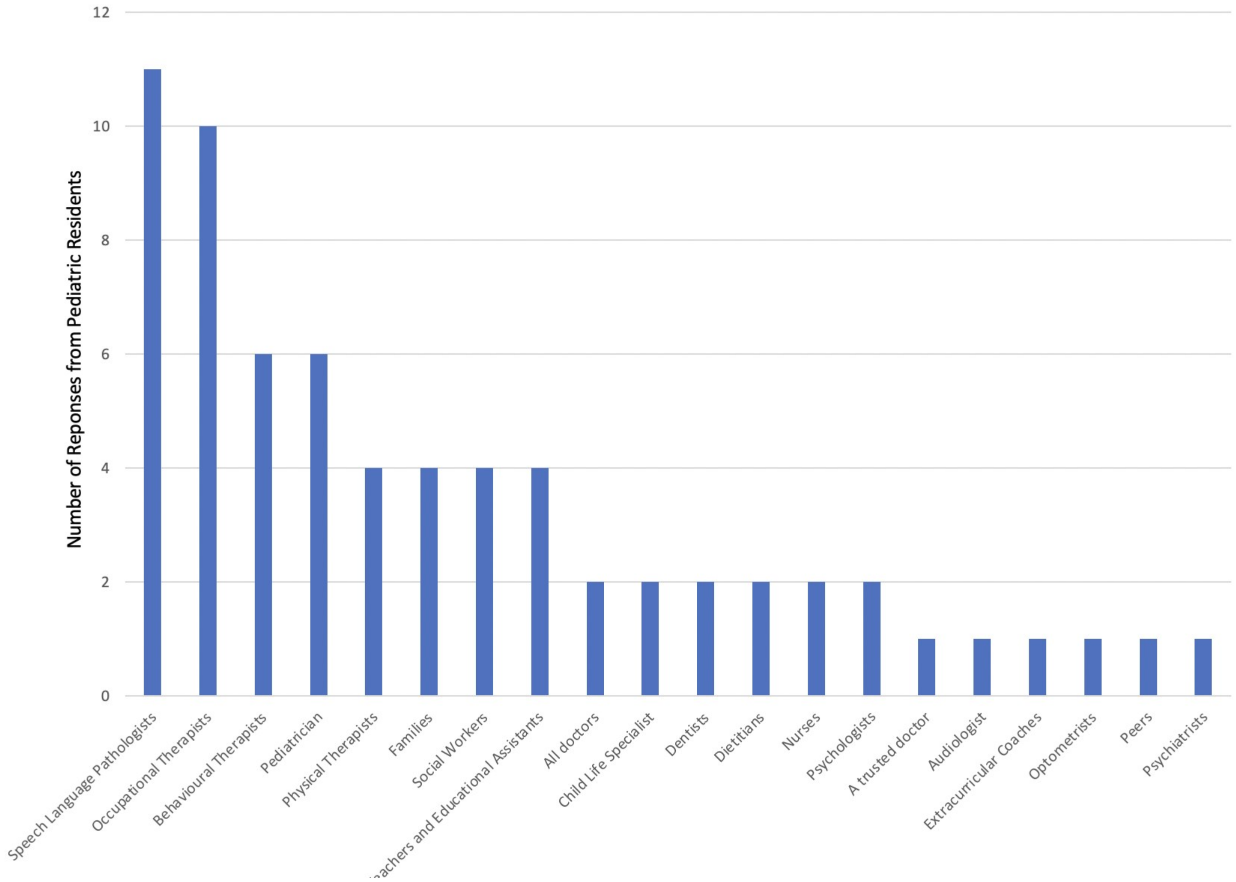


Figure 4.2. Healthcare professionals involved in the care for autistic children, according to pediatric residents interviewed (n=12)

That it takes more than just a physician is described by Resident 6:

> “The other piece, I’m not sure if you’re alluding to this but from the autism assessments that I have seen they’re not just done by a physician one on one, they’re often done with a resource teacher or a resource person or an occupational therapist or a speech language pathologist and they’re all doing the diagnosis together and doing the ADOS together and then having face-to-face communication to determine is there a diagnosis of autism and what allied healthcare resources should be used.”

The interviews suggested that collaboration among healthcare professionals streamlines the diagnostic proceedings. By working together, multidisciplinary teams can more effectively identify and address both the strengths and needs of autistic children, allowing for an integrated approach for best practice care.

As displayed in Figure 4.2, only half of the residents explicitly listed a pediatrician as involved in care for autistic children (note that some residents opted to say “all doctors,” which may include pediatricians and family physicians). Resident 7, who noted that pediatricians play a “quarterback” role, stated:

> “I think patients with autism definitely need a multidisciplinary team and the extent of the different members of that team I think again is very personalized to the patient. Everything comes through one person then it’s not going to be lost, the child won’t be lost to care and they get the supports they need so hearing from the school and being able to make sure that they can communicate directly with, you know, if there’s an SLP in the community that’s taking care of the kid and can help tell the school what the child needs.”

Resident 7’s comments stress that, while a multidisciplinary team may be necessary, the team needs to be personalized to the patient, with the physician playing an integral role within the team. This role of pediatrician as a quarterback will be further explored in theme 2.4. Residents identified challenges in the community with respect to communication among members of a child’s health care team, especially outside of specialty sites where residents had trained, such as the Glenrose Rehabilitation Hospital in Edmonton or the Sunny Hill Health

Centre in Vancouver. Some of the challenges noted included logistical difficulties in schedule coordination and differences in professional perspectives across healthcare professionals who are caring for the autistic patient. Resident 3 discusses the applied community practice context, stating that there is a lack of communication between professionals:

> "But I think more likely in applied community practice it's quite siloed, so you send a referral to the speech therapist, and they see the child totally separate from the pediatrician, they write a report, the pediatrician reads that report then. But usually there's not a lot of back and forth between the pediatrician and the speech therapist similar to the OT, similar to all those other services, so often there's a lack of, like, communication between the two in an ongoing way."

Resident 12 elaborated on this point, noting that communication between healthcare professionals in the community is not great regarding ongoing care:

> "Yeah, I don't think it's great. I think if you're working in like a private pediatrics office, like your own office, like a community office, I guess, I think your notes can be sent to them and then obviously they can send your notes to your clinic and they show up in your EMR but I don't think there's generally great ways for it."

Addressing these challenges requires deliberate strategies to foster a team culture that values diversity of thought and collaborative problem-solving. Coordinated care between multidisciplinary professionals was reported as important for best practice care for autistic patients, highlighting the value of a teams that provides comprehensive, coordinated care that addresses the diverse needs of autistic patients. Effective communication among healthcare professionals and families, role clarity, and respect for the expertise of each team member were identified as critical components of this collaborative approach.

4.5. Category 2: Pediatric Residents Outline Barriers To Providing Best Practice Care for Autistic Patients and Gaps in their Learning

Pediatric residents identify numerous potential barriers in providing best practice care for autistic patients. These barriers impact their confidence and effectiveness in diagnosing autism and in managing the long-term care and co-occurring conditions associated with autism. This category explores the specific challenges identified by residents, revealing critical areas where their training falls short. Through the analysis of interview data, four themes emerged: The perceived complexity of autism, role confusion, uncertainty about the adequacy and applicability of their training, and the vision of their future roles in long-term care for autistic patients. Each theme highlights a distinct aspect of the learning gaps that pediatric residents described as hindering them from delivering optimal care to autistic patients.

Theme 2.1 "Autism is in many ways more complex": Residents feel they have not been adequately trained.

Pediatric residents frequently expressed concerns about the adequacy of their training in the realm of autism. They noted that autism is more complex than most pediatric conditions due to the wide range of presentations and co-occurring conditions, which pose significant challenges that many residents feel unprepared to address effectively.

When asked directly if they have been trained adequately in autism care, all twelve residents stated they did not feel their training was adequate. Some residents even brought statistics into the conversation, saying that the number of children coming in for developmental and mental health concerns is disproportionate to the amount of time they spend on developmental health in medical training. Resident 10 bluntly stated:

> "No. My general pediatrics residency was not adequate. I just didn't learn enough. I mean for the average general pediatrician, 60% of your practice is child development and we do one, maybe two, rotations in all of our general pediatric residency and you know I didn't have a continuity clinic just the way that my residency was structured."

Autism is a highly heterogenous condition, characterized by a variety of features that range in their presentation. Many residents felt the more nuanced aspects of autism care, such as managing certain behavioural features, or knowing about certain pharmaceuticals, was not adequate, with Resident 7 stating:

> "And then in terms of direct care for autism, I don't actually feel like I got the best education, to be honest, for managing some of the ongoing or nuanced pieces"

Resident 5 made a similar comment, reflecting on her time before entering a developmental subspecialty, providing a specific example of aggression:

> "I would have been really unsure what to do with some of them in terms of like say they need medication help for like aggression. Like I wouldn't have been comfortable prescribing that or like knowing where to go with that."

The residents were also asked how their knowledge base for other developmental conditions, such as ADHD and anxiety, compared to their knowledge of autism. Most of the residents agreed that their knowledge of ADHD and anxiety was better due to the more streamlined approach of assessment and management of those conditions. Resident 6 commented on neurodevelopmental conditions in general being overlooked in medical education, stating:

> “I would say that at the medical school level medical students are not provided necessarily adequate teaching on how to interact with patients with autism and other neurodevelopmental disabilities.”

Resident 3 provided her perspective regarding what community providers should be able to do based on their title as a medical doctor and how this may lead to a gap in training.:

> “I think many general pediatricians aren’t comfortable making a diagnosis about autism, which I think is something that many community providers should be able to do. And so, I think that’s a big deficit even in the diagnostic skills or comfort. And some of it comes from the presumption that you need to be either a developmental pediatrician or have like a table filled with all the allied health specialists every day that like is able to make that. So, I think there’s still a commonly held view in the community that people need to be referred to [a multidisciplinary site] to have a diagnosis. Like even if in your clinic you are certain the child has autism, they meet all the criteria, most community pediatricians won’t say it. They say I suspect this but I’m going to send you there for the final diagnosis.

This comment was in reference to practicing preceptors in the community not teaching residents skills regarding diagnosis, likely due a lack of comfort on their end. Resident 3 continued to talk about her experience in training, and where certain aspects of care need to be better addressed, again, using pharmaceuticals as an example when discussing regulation of sleep and behaviour:

> “So, I think that’s like, I don’t even as much as we’ve been taught, I don’t think we’ve been adequately trained or have the confidence to actually provide the diagnosis, which I think can be important for many families and for funding and for resources. And then I

> think, I don’t think we’re adequately trained in addressing some of the specific even pharmacologic needs of some children with autism. So, thinking about when there’s dysregulation and like how do we, is there a role for pharmaceuticals in some degree of like helping with emotional regulation or sleep regulation like those sorts of things. I don’t think we’ve been adequately taught to think about like if a child with autism comes in and is awake at 1 a.m. every day for 3 hours like, is it appropriate to use trazadone or something else and if so yes, why, what’s the impact on this child’s brain from that med? I don’t think we’ve been trained adequately at all.”

The medical curriculum typically includes only a brief overview of autism mixed in with a lecture on typical development, and the learning objectives regarding autism at the medical school level focus on basic diagnostic criteria. Residents noted that this limited exposure is inadequate for developing a deep, practical understanding of autism. Resident 2 commented on this, as she felt that medical education focuses more on physical diagnoses:

> “I think there’s greater expectation for general ... like we should make those [physical] diagnoses and manage them, whereas for autism I almost feel like there is this expectation from, and I’m not sure if it’s from the medical communities…”

Resident 2 further described how she felt about her knowledge base for physical conditions in pediatrics compared to autism:

> “You know I think, and I think this is just based on the nature of our training, I think I probably would feel more confident with some of those physical diagnoses because things that we are exposed to more repetitively throughout residency.”

Resident 5 corroborated this, stating from both a didactic and clinical perspective, physical conditions are focused on more in pediatric training, despite a large proportion of a pediatric practice being developmental health. She stated:

> "I think probably we definitely got a lot more exposure both like teaching-wise and clinically to the physical conditions such as asthma, diabetes; Autism is a little more wishy-washy. I think we have a few things we always think about like oh like maybe they'll flap, like I feel like that's the common one. I flap just in general, I flap when I'm excited but anyway."

In addition to describing how stereotyped behaviours are focused on in training rather than the more nuanced features of autism, Resident 5 elaborated that physical conditions may be more easily managed, despite seeking extra training in developmental health:

> "Yeah and you'd only send the ones that like for asthma, like a pediatrician could easily manage asthma and if it gets really severe and it's not you know being managed well on the common medications, then they get sent to like a specialist. So, yeah I think there's a little bit of a lack of comfort there from a general pediatrician perspective."

This sentiment that autism is seemingly more difficult to diagnose extends beyond physical conditions and into other neurodevelopmental conditions. For example, Resident 7 said:

> "I think autism is just in many ways a little bit more complex so community pediatricians feel a lot more comfortable diagnosing ADHD, anxiety, depression, for example, 'cause the criteria is quite clear and it doesn't always require a multidisciplinary team to make the diagnosis so I think simply just based on complexity, I think my understanding of some of the other things is better but that's not because of more teaching in one area or the other."

Interestingly, Resident 7 discussed how teaching in autism is not necessarily lacking, in contrast to what the majority of residents stated (see the previous comment from Resident 3 for an example). It should be noted that Resident 7 is doing a subspecialty in neonatal care, so her experiences with autism may be different than the majority of residents, who plan on having a community practice or doing developmental pediatrics.

Resident 9 provided an interesting perspective, saying that she felt, in the community, that she did not require a deep understanding of conditions such as autism, as she would only need to know enough to make a referral to subspecialist:

> "So, I don't need to be super related to those conditions, I just need to have a good suspicion of them and then have a great deal of understanding for a referral and that's it."

She clarified that this perspective was related to her training before additional training in developmental pediatrics, as she was reflecting on her time as a practicing pediatrician before doing a subspecialty.

Significant gaps in training regarding autism were identified, emphasizing the need for more comprehensive and practical education. The nuanced pieces to working with autistic children require a deep understanding and a flexible, personalized approach to care, which many residents stated they feel unprepared to provide, whether that be for lack of didactic teaching, or lack of hands-on experience. Addressing these educational gaps through enhanced curriculum coverage, practical experience, specialized training, and interdisciplinary collaboration opportunities is essential for empowering pediatric residents to deliver best practice care to autistic patients. The insights from residents therefore highlight the critical need for a responsive educational framework that supports the evolving field of autism research and therefore what constitutes best practice care for autistic patients.

Theme 2.2 "What am I actually allowed to do": Residents have a sense of "role confusion" when it comes to diagnosing autism.

A theme that emerged from the interviews was the sense of role confusion residents experience in diagnosing autism. Role confusion stemmed from ambiguous guidelines and a lack of clear protocols within their training programs. Without a well-defined understanding of their role, residents may hesitate to take necessary actions, potentially delaying diagnosis, thus impacting the timeline for interventions.

Resident 2 described the uncertainty of one's responsibilities and the scope of practice:

> "So that is kind of a gap where I'm like okay what can I actually do and can I make this diagnosis to get funding or to get resources."

This sentiment was common among residents. Resident 4's comments elaborated this point, noting that vocabulary can be confusing, such as giving a "tentative" diagnosis. She states:

> "And I guess the other thing is that I'm still kind of confused about what it means to have a tentative diagnosis by a pediatrician who's experienced in autism care versus that quote unquote formal diagnosis that you need for FSCD and AISH and all that stuff ."

Resident 4 further described a common perception among pediatric residents, stating:

> "My perception is that it's almost like community pediatricians aren't like allowed to make a formal diagnosis."

Role confusion can significantly impact the diagnostic process for autism by slowing the process down. Pediatric residents often find themselves uncertain about the extent of their role in diagnosis, as multidisciplinary sites are seemingly the gold standard for diagnosing autism. Resident 3 shared a potential reason for this:

> “Some of it comes from the presumption that you need to be either a developmental pediatrician or have like a table filled with all the allied health specialists every day that like is able to make that. So, I think there’s still a commonly held view in the community that people need to be referred to the [specialty centre] to have a diagnosis.”

Confusion about the boundaries of a pediatrician’s role can hinder residents from taking proactive steps in the care management of autistic children, affecting the child’s quality of care.

Role confusion around diagnosis extended beyond community pediatrics and include the emergency room. Concerns about overstepping boundaries or making decisions that fall out of their scope of practice creates additional hesitation. Resident 5 (who had completed special training for autism) stated:

> “I remember being in the emergency room and there was a child who was there because they were refusing to eat. And I went to see them and maybe they had a cold or something, but like the child had autism and never were diagnosed. And since they weren’t dehydrated and they weren’t losing weight, we discharged them but like we, I was like do we refer them? Like what do we do? Like they probably have autism. But, of course I didn’t do a long assessment because it was emergency room.”

Role confusion appeared to be a significant barrier for pediatric residents in providing diagnosis as a part of best practice care for autistic patients. The ambiguity in training programs and clinical guidelines, coupled with uncertainties about their scope of practice, contributes to this role confusion.

Theme 2.3 “What I learned may not be applicable to my practice:” Residents are unsure if what they have learned in residency will be applicable to their real-world practice.

Pediatric residents frequently expressed concerns about the relevance and applicability of their training to their real-world practice. This theme highlights the disconnect between theoretical knowledge acquired during residency and the practical challenges faced in clinical settings. For example, residents wondered over if what they’ve learned from specialty sites will be applicable in rural communities.

Resident 2 identified this concern when discussing how she was working with autistic children in rural communities during her training. She discussed wanting to have a practice in a rural community where she could see children with autism, but disclosed that what she learned may not be applicable to her future practice:

> “But it wasn’t always necessarily practical or realistic for what I saw myself doing in the future, so sometimes I struggled with what I was learning in terms of how am I actually going to implement this in my practice in the future, knowing that, I am hoping to work in rural communities where it might just be me and maybe I can get like a speech assessment but, I just struggled with you know being exposed to that resource-rich setting and thinking how am I gonna actually do this in the future when I don’t have those resources at my fingertips.”

The disconnect between theoretical assessments and practical aspects in communities where a multidisciplinary team may not be an adequate approach may lead residents to feel unprepared and anxious about their ability to effectively diagnose and provide long-term care in their future practices. Resident 4 made a similar comment, though focused on community pediatrics in general, stating:

> “I think I would love a little bit more almost from a community provider perspective because to be honest going to the [speciality site] and participating in a day-long assessment just doesn’t really feel that relevant to my daily practice if that makes sense.”

Residents reported that their training was lacking in relevancy with respect to autism. Resident 10 gave a candid response as to why autism gets missed in the community:

> “And I see that in referrals that I get now as well is that like these amazing community pediatricians are missing sort of clear signs of autism and I know it’s simply because it just wasn’t taught in residency”

When asked to elaborate, Resident 10 mentioned the disconnect between the children seen for developmental concerns in practice compared to how much they see in residency training, stating:

> “I just didn’t learn enough... Some residents will have a continuity clinic but you don’t necessarily capture the amount of child development that you see through a continuity clinic and you know generally pediatric residencies are focused on inpatient care, not outpatient care, so I think you just truly don’t get the experience.”

Resident 10 practiced as a pediatrician for a few years before doing a subspecialty fellowship in developmental pediatrics. She provided an interesting perspective that ongoing professional development is a vital component of being a pediatrician in the realm of developmental pediatrics, and that learning does not end in residency. She stated:

> “I actually learned more about autism while I was a practicing pediatrician from attending conferences and chatting with colleagues and sort of doing my own continuing

> medical education simply because I then saw so many kids walk through my door where I was like I don't even know what to do for these kids, like I don't know how to screen for them, I don't know how to do anything."

Residents also questioned the relevance of some of the training content to their future practice. They noted that certain topics covered during residency, such as diagnostic care, is focused on too heavily in residency, whereas topics such as providing long term quality care and managing co-occurring conditions are not covered sufficiently. Resident 9 elaborated on this point, discussing the scope of her program:

> "So, the scope of my program is basically diagnostic; So, I have no exposure to any of the interventions. Other fellows and residents have tried to connect with people who are providing therapies, providing occupational therapy, language therapy, psychology support, and behavioral support. But because it's not addressed in the program, it's kind of difficult to get teaching time from these professionals. So it's mostly diagnostic"

Resident 9's comment highlight a concern and need for more tailored and context-specific curricula that aligns with the diverse settings in which residents will see children in practice. These comments on the uncertainty about the applicability of residency training to real world practice is a significant concern among the resident's interviewed. The disconnect between theoretical knowledge and practical skills, limited exposure to diverse cases, and the need for more relevant, skills-based training all contribute to this uncertainty.

Theme 2.4 "I see myself playing a quarterback/hub role:" Residents envision themselves playing a role in long-term care for autistic patients, despite it not being taught well in residency.

Many pediatric residents envision themselves playing a central, coordinating role in the long-term care of autistic children in their practice, often likening this role to that of a quarterback or hub role. Despite this aspiration, they frequently expressed concern at the lack of emphasis on this aspect of care within their medical training. This theme explores the residents' vision for their future roles, the gaps in their current training, and the need for enhanced education on long-term care coordination for autistic patients.

Pediatric residents recognize the importance of continuous, coordinated care for autistic children. They often see themselves as central figures who integrate various aspects of care, from initial diagnosis to long-term management. This concept came up with many residents, who discussed the ideal role they would like to play on the care team for their autistic patients. Resident 2 first brought up this concept, stating:

> "Ideally general pediatricians should be like sometimes they call them the quarterbacks of kids with complex care. Just to be able to ensure that they're plugged in with the other right services and that we're not missing something else that's underlying. And so yeah, I think that's an important role."

Resident 2 then proceeded to circle back to an important point of best practice care regarding family support, stating:

> "And then I think checking in on the family too. Like I think there's so much caregiver burnout and whatnot, and I think as a community pediatrician having that long-term relationship with the family you get a unique perspective in terms of being able to follow that."

Other pediatric residents shared this sentiment, adding that the family care component is also important. As Resident 7 stated:

> "If I'm practicing as a pediatrician, … the quarterback role is definitely kind of where I see myself, so making sure that all of those resources are available, making sure they're being accessed, and then there is definitely a role for medical treatment in certain kids' cases so also being able to support the family through that. And then there are also some other resources like behavioral specialists and different things that sometimes are of benefit to you and just even being able to provide resources to access those things as a pediatrician is huge."

The ideal role was different across residents who were interviewed, but most wanted to play a prominent role in autism care. Resident 9 noted her ideal role in her community regarding autism care, stating:

> "I hope 90% of my practice becomes autism; I hope that everyone who has an autistic patient refers him or her to me."

Despite their aspirations, residents report significant gaps in their training regarding long-term care coordination. The current residency curriculum and teachings in medical education tend to focus more on diagnosis and immediate clinical management, and less on the broader ongoing needs of autistic children. When asked to elaborate on the experience she had regarding her clinical exposure and teaching, Resident 7 stated:

> "And then on my developmental rotation as well; definitely more from a diagnostic setting so during my developmental rotations. Some long-term care learning but honestly that was a little bit more minimal and that was probably because of the structure of our longitudinal clinics at the time but when you saw a patient for the first time then you would follow them so unless there was a new consult that came in for a child with autism it wasn't really the patients that I was seeing as frequently in terms of that longitudinal care and being the one to really help take over and manage that care."

Resident 8 also stated similar concerns; she completed additional training in autism care and gave lectures and seminars on autism both from a clinical and personal experience. She stated that:

> "I actually probably didn't learn quite as much during residency as it did from real life to be honest. Like in terms of like what autism is, how like, what life is like for an autistic individual 'cause that was more of my own personal background with my family."

She then described the co-occurring conditions to be aware of both in terms of physical health and mental health when working with autistic patients:

> "In terms of the long term follow up it was a lot around the comorbidity stuff like the other things that go along with being autistic. Like that was kind of the big things that I learned a lot about in residency. Like the other things to monitor for, recognizing that like other medical comorbidities are higher. Like all the like the GI side like issues. The sleep

> stuff, epilepsy like all of that stuff that was higher that was what I remember learning about that you needed to screen for a lot more of that. Then I think we like people give credit for so that was something I remember picking up. It's like you know gotta watch everything else"

Resident 7 (and many other residents) shared a similar sentiment by concluding her interview stating:

> "And then in terms of direct care for autism, I don't actually feel like I got the best education, to be honest, for managing some of the ongoing or nuanced pieces"

Pediatric residents therefore envision themselves playing a central, coordinating role in the long-term care of autistic children, akin to a "quarterback" or "hub". However, they felt their training often fell short in preparing them for this role, with gaps in education on long-term care coordination and management of co-occurring conditions, navigation of healthcare systems, and advocacy roles.

4.6. Chapter Summary

This chapter reflects on the experience and viewpoints of the twelve participating residents who took part in this research study. The analysis of the interviews with pediatric residents revealed critical insights into both the factors that constitute best practice care for autistic patients, and the significant training gaps that hinder the provision of such care. Category 1 summarized the residents perspectives on valuing flexibility and optimization in care delivery, emphasizing the importance of family understanding and education, and recognizing the necessity of coordinated, multidisciplinary approaches. These elements collectively form the foundation of best practice care for autistic patients. From category 2, the pervasive challenges faced by residents in providing best practice care were highlighted, including inadequate training on the perceived complexities of autism, role confusion in diagnosis, and uncertainty about the applicability of their training in their real-world practice. Despite these challenges, residents envision a central, coordinating role for themselves in long-term autism care, akin to a quarterback or a hub. Addressing these identified training gaps through curriculum enhancements and more practical training opportunities is essential to equip future pediatricians with the skills and knowledge necessary to provide comprehensive, coordinated care for autistic patients and their families.

The next chapter will continue to explore the interviews from a summative content analysis perspective, in which identified gaps in the education system will be highlighted, as well as solutions that residents have provided in the interviews to mitigate these challenges.

CHAPTER 5. Findings – Summative Content Analysis

5.1. Chapter Introduction

The purpose of this chapter is to present the data collected from residents' interviews about their perspectives regarding specific gaps in their training in autism care and potential mitigating solutions . Upon doing the reflexive thematic analysis, there were a variety of gaps and solutions that came up that did not fit neatly into a "themed" approach, but instead made more sense to be included in a content analysis, to best capture all the ideas that were shared in the interviews. While the previous chapter focused on gaps in providing best practice care, the primary goal of this analysis is to identify and understand specific areas where current training programs fall short according to residents, and to highlight actionable recommendations from the residents' perspectives. It is important to note that there is some overlap between the gaps in providing best practice care and specific gaps to the training programs. This chapter aims to systematically quantify and interpret the content of the interview data to provide an overview of the residents' experiences, challenges, and suggestions for improving autism care education.

The analysis is structured around two main categories: the gaps identified in the existing medical education related to autism, and the potential solutions to mitigate these barriers. The first category explores what residents feel are core gaps in their medical education to prepare them to provide optimal care to autistic children, and the second category delves into the solutions proposed by residents to overcome these challenges. By addressing these challenges residents believe that training programs can be improved to better equip the next generation of pediatricians for real-world clinical practice regarding autism care.

The chapter will include a summary table that summarizes the gaps and solutions presented in more than one interview and a brief description of the codes with an example quote embedded in each subsection.

5.2. Summary Table of the Gaps and Solutions

Gaps and solutions that were mentioned more than once are summarized in Table 5.1, and are ordered by the frequency in which they were brought up by different participants (*Code n represents the number of participants who brought up the topic, not the total number of codes in the database.)

Table 5.1. Codes within the categories for the gaps found in autism education and solutions to mitigate the gaps based on the interviews that were mentioned more than once.

Category	**Codes within category**	**Code n***
Gaps in Medical Education Training	Lack of clarity on their role in autism related care	5
	Lack of focus on long-term care for autistic patients	5
	Lack of exposure/teaching of autism in residency	4
	Lack of knowledge on pharmaceuticals associated with autism care	4
	Timely diagnosis to both patient and physician	4
	More exposure to assessments in training	3
	Communication concerns in the community	3
	Lack of focus on community diagnostics in practice (general pediatrics and community rotations)	2
	Lack of knowledge on community services	2
	Lack of perceived support systems in the community	2
	Lack of knowledge on the management of co-occurring conditions	2

	Unclear on the practicality of what is learned in the real world	2
Solutions to Mitigate Gaps	More teaching on autism outside the development block	8
	Expansion of the development rotation in residency	5
	Seeing autistic patients in a continuity clinic	4
	More teaching on long-term care management	4
	Clearer directions on community guidelines from community providers	4
	More skills in diagnostic delivery	4
	Autism should be more prominent earlier on (in undergraduate medical education)	3
	Learning activities better integrated in the community (both urban and non-urban)	3
	Learning activities on autonomy from program providers to allow for a more hands-on approach	2
	Teaching on interventions and services recommended to patients	2
	Training time with allied healthcare professionals	2

5.3. Category 1: Gaps in Medical Education

The first category of findings pertains to the significant gaps in autism education and training identified by pediatric residents. These gaps encompass many aspects of autism care, ranging from a lack of clarity regarding their roles in autism-related care to insufficient focus on long-term management strategies for autistic patients. Residents also highlighted a general lack of exposure to autistic children and teaching opportunities during residency, inadequate knowledge of pharmaceuticals and community resources, and challenges in timely diagnosis. The gaps identified collectively indicate a need for improvement in the residency curriculum to better prepare future pediatricians for comprehensive autism care. Each identified gap is elaborated on in the following paragraphs, with direct quotes from residents illustrating their experiences and perspectives.

1.1 Lack of clarity on their role in autism-related care. Residents frequently mentioned confusion about their specific role in the care of autistic patients. This lack of clarity impacted their confidence in working with these children. As resident 2 noted, there were gaps on the autonomy of diagnosis, stating:

> "I think a gap that I still feel is yeah kind of that like okay what can I actually do as a community pediatrician, in terms of can I actually make this diagnosis, or do I have to send everyone to the [specialty center]? And like that's something where I kind of feel like what can I do, and what are the expectations of me as a community pediatrician?"

1.2 Lack of focus on long-term care for autistic patients. There was a significant gap in training related to the long-term management of autistic patients. Residents expressed a need for more comprehensive education for ongoing care strategies. Resident 7 provided some insight into this, stating:

> "Yeah and I think that's the biggest thing, to be honest, is some of that follow up care. I also think there's some degree of gaps in knowledge with managing some of the medical conditions that stem from sensory difficulties. So for example constipation can be quite severe in kids with autism that are unable to eat certain foods or drink certain amounts of water or take medications."

1.3 Lack of exposure/teaching of autism in residency. Residents noted insufficient exposure to autism-related cases and inadequate teaching during their residency programs. Resident 10 noted this, by stating:

> "I mean enough exposure right, exposure and understanding that the red flags that we look for capture a small subset of people but that other things that are concerning are not always captured and I think that pediatricians don't always know those other things."

1.4 Lack of knowledge on pharmaceuticals associated with autism care. A lack of detailed education on pharmaceuticals that may be used in autism care, and how they may help or harm autistic patients, was identified as a gap. Resident 5 discussed this with the example of aggression, and compared her experiences with autism to that of working with asthma, stating:

> "Yeah and you'd only send the ones that like for asthma, like a pediatrician could easily manage asthma and if it gets really severe and it's not you know being managed well on the common medications, then they get sent to like a specialist. So yeah I think there's a little bit of a lack of comfort there from a general pediatrician perspective."

1.5 Timely diagnosis to both patient and physician. The process of diagnosing autism in a timely manner was perceived to be a challenge for both patients and physicians. Concerns related to, and the time it takes to do an autism assessment as a limitation to autism training, largely due to the length of the waitlists. As stated by resident 1 when asked about gaps:

> "[A gap is] timely diagnosis to autism. Which I guess like ties in with like what acts, sorry, timely diagnosis and then therefore access to interventions. So in Manitoba for example, their developmental program, their facility, they predominantly see

> preschoolers and the funding there, like there's funding for preschoolers and if you've graduated from that kind of age group you lose that funding. But if there's a delay in diagnosis then you lose out on those opportunities to access those interventions and so really like that timely diagnosis is just key."

1.6 More exposure to assessments in training. Residents expressed the desire for more hands-on experiences and exposure to autism assessments during their training. For example, Resident 3 stated:

> "We are not taught to do the APPLES or ADOS, so we're not taught to do any sort of play-based or observational-based interview with the child. We may if you're lucky like observe one or two in a clinic, but it's not part of our residency training to go through like AAPLES training or ADOS training or something. Which I think is a deficit because I can read the diagnostic checklist to a parent and I can probably do the diagnostic interview, but I can't do the like physical exam assessment itself."

1.7 Communication concerns in the community. Effective communication with healthcare professionals in the community was identified as an area needing improvement, including skill-building of how residents can effectively communicate with others. When asked about communication in the community, Resident 11 noted it's strong at the multidisciplinary site, but in the community, there are challenges. She noted:

> "I think sometimes in the community sometimes they're not as well trained, it depends sort of on where they are. You know I'm sure Alberta's the same, you have some people in really remote communities where you're just really limited. And so they might be more limited in their practice if they're even able to see somebody, so I think it varies,

> there's a lot of variation like out in the community. But like at the hospital they're really, have been really wonderful."

1.8 Lack of focus on community diagnostics in practice. Residents reported that their training lacked a focus on community-based diagnostic practices, including general pediatrics and community rotations. Resident 3 called this a deficit, stating:

> "I think many general pediatricians aren't comfortable making a diagnosis about autism, which I think is something that many community providers should be able to do. And so I think that's a big deficit even in the diagnostic skills or comfort."

1.9 Lack of knowledge on community services. There was noted to be a gap in knowledge about the available community services and how to access them, including what they entail, which affect the residents' abilities to provide comprehensive care and make meaningful suggestions to families. Resident 9 noted this, by stating:

> "Yeah. Well, I would have loved to have been exposed to therapies, to all the things that I would love to have followed a few patients after they are diagnosed and understand what's their path after Sunny Hill. I mean Sunny Hill is the part of the hospital that diagnose autism."

1.10 Lack of perceived support systems in the community. Residents perceived a lack of adequate support systems within the community to assist with providing best practice care for autistic patients. This extends to autism advocacy for patients, which Resident 8 noted:

> "I did not, I feel like as a fellow and as a resident I did not do much autistic advocacy. Boy I feel like I've been doing a lot more now. It's like okay like schools are struggling like I've had four conversations with the Autism Society in the past 2 months where I'm like okay I need you to like contact the school and go in and do your presentation"

1.11 Lack of knowledge on the management of co-occurring conditions. Managing co-occurring conditions is an area where a few residents stated they felt underprepared. Resident 11 noted the nuanced pieces of working with co-occuring conditions and autism, by stating:

> "Yeah I mean there's definitely like you said and I feel sometimes that's tricky to tease out like ADHD, anxiety, I've seen Tourette's in two kids last year, depression. There's definitely a lot of mental health concerns, there can be some GI, like reflux and that type of thing. Do you see it, fair amount of gender diverse youth as well I think overrepresented in the kids that I've seen in my time last, over the last year and a half. So yeah but definitely lots of like mental health types of conditions, and I think that's why some of them, like the kids who we see later are usually higher functioning and more verbal and so it's been trickier I think for them to get the referral sooner."

1.12 Unclear on the practicality of what is learned in the real world. Residents often found a disconnect between what they learned during training and its practical application in real-world cases. Resident 4 noted this indirectly, by stating that what is learned in residency is not what happens on the job in general pediatrics:

> "I think like one kind of weakness of our program is that we actually don't do a lot of clinic General Pediatrics. And we spend a lot of time in our program in the hospital on subspecialty rotations where you're not making autism diagnoses. So I think that just generally we don't have a lot of community rotations."

5.4. Category 2: Solutions to Mitigate Gaps

The second category of findings in this content analysis focuses on the solutions proposed by pediatric residents to address the identified gaps in autism education. Residents suggested a range of strategies aimed at enhancing their training and better equipping them to provide comprehensive care for autistic children. These solutions include incorporating more autism-related teaching outside the traditional development block, expanding the development rotation, and introducing continuity clinics where residents can gain regular, hands-on experience with autistic patients. Additionally, residents called for clearer practice guidelines, increased focus on long-term care management, and more skills in delivering diagnoses. They also emphasized the importance of introducing autism education earlier in medical training, integrating learning activities within diverse community settings, and providing more autonomous, hands-on learning opportunities. Each proposed solution is elaborated on in the following paragraphs, with direct quotes from residents to provide context.

2.1 More teaching on autism outside the development block. Residents suggested incorporating some autism-related teaching throughout the residency program would be beneficial, including outside of the the developmental pediatrics block. Resident 4 provided her perspective on this, saying that she could learn a lot more practical skills for her practice from community providers:

> "I think like my personal perspective is it would be really helpful if we had more experiences with community providers who are making autism diagnoses, and as much as the [specialty centre] is a great place like personally I found my experiences there weren't super helpful for my learning. For example watching an autism diagnosis, I was given a script where I was reading questions off and then that was the extent of my participation. So I didn't really get a lot of experience or practice with actually making a diagnosis myself. It was like here's how we make the diagnosis. You can read off this script and then the team would all discuss and they would make the diagnosis. It wouldn't be me. So if we got to go with more general pediatricians or people who do those more simple autism assessments I think that would probably be like more helpful for my learning versus doing the complex like a full-day autism assessment kind of thing"

2.2 Expansion of the development rotation in residency. Expanding the development rotation to include more focused training on autism was recommended. Resident 8 gave some examples of how this could be done in the developmental rotation, stating:

> "I think one thing the residents really need is the academic half day. They need to practice some skills with it. So not just hearing about autism I think like potentially having lived experience like of someone coming in and talking to them about autism

> would be helpful. The other thing that we thought would be helpful is like actually teaching them how to do elements of the APPLES or the mini ADOS so they get some time to practice that and become a bit more comfortable. So I think like the teaching opportunities there need to change."

2.3 Seeing autistic patients in a continuity clinic. Introducing a continuity clinic where residents can regularly see and work with autistic patients and continue to learn from them was proposed as a potential solution. Resident 5 provided an example of how a continuity clinic would benefit pediatric residents even beyond autism care, stating:

> "I think it would be helpful to be able to follow, maybe as part of like a continuity clinic, to be able to have a couple of kids with autism in your roster so that you can actually follow them over time and see the different things that come up for them and how to manage them. Because I think that's really realistic as to what your practice could look like as a general pediatrician. And I'd probably say the same like for instance for cerebral palsy or just a few kids that aren't neurotypical or maybe have different areas of development that they are struggling with or working on, to kind of incorporate that in addition to a couple of kids with autism."

2.4 More teaching on long-term care management. Increased emphasis within the curriculum on the long-term management of autistic children within the curriculum was suggested by residents. Resident 8, who is now a practicing developmental pediatrician in Canada, noted long-term care teaching is necessary, stating:

> "In terms of the long term follow up it was a lot around the comorbidity stuff like the other things that go along with being autistic. Like that was kind of the big things that I learned a lot about in residency. Like the other things to monitor for, recognizing that like other medical comorbidities are higher. Like all the like the GI side like issues. The sleep stuff, epilepsy like all of that stuff that was higher that was what I remember learning about that you needed to screen for a lot more of that. Then I think we like people give credit for so that was something I remember picking up. It's like you know got to watch everything else."

2.5 Clearer directions on community guidelines from community providers. Residents called for clearer guidelines on community-based autism care to enhance their understanding and application of these practices. One such solution, as mentioned by Resident 2, was to have increased opportunities to learn about autism in a community setting, where practitioners may not have access to specialists.

> "I think they've been huge yeah. I can think in particular there's been a couple of pediatricians that I've worked with quite closely who work outside of Edmonton and do general pediatrics but also have a ton of experience with development. It's been really valuable working with them and learning more of that community-based approach from them.

2.6 More skills in diagnostic delivery. Improving residents' skills in delivering autism diagnoses was highlighted as a key component to add to the residency training curriculum. Resident 12 noted this gap, and suggested more skills are necessary:

> "Yeah well I think just having some focus on sort of what that diagnostics should look like and in a way that's maybe a little, just like delivered in a way that's a bit more standardized. 'Cause I think that I've had good experiences from it because I've worked with staff that have had a good approach to what they do for autistic kids but if you haven't worked with that staff then you might not have that, so I don't know if there's a way to have some formal teaching around that."

2.7 Autism should be more prominent earlier on (in undergraduate medical education). Residents recommended that there should be more than just a lecture on autism in the medical school years; in preclerkship and clerkship. Resident 1 brought this up when discussing her experiences in medical school, and implied that child development should be more of a focus in the earlier years of training, stating:

> "My exposure to developmental pediatrics I was actually under my neurology block so there was not like a developmental behavioral block per se, it was just neuro and then there's maybe like one class on, like one presentation on development. So it definitely, I think that's where like the gap starts, like medical school and pre-clerkship. And then you move into clerkship and there's, so development is not like a core block in clerkship, it actually was not again, like until l did like my neuro block"

2.8 Learning activities better integrated in the community (both urban and non-urban). Integrating learning activities within both urban and rural community settings was seen as essential for providing diverse training experiences in providing autism care. Resident 2, who wanted to work in rural communities, stated:

> "And then I think it would have been helpful to actually like I said have more exposure to making the diagnoses for autism in the community rather than just at the [specialty center] you know where it might just be you in kind of figuring out initial management plan."

2.9 Learning activities on autonomy from program providers to allow for a more hands-on approach. Residents advocated for more autonomous, hands-on learning opportunities provided by the residency programs. Resident 3 provided an example of the lack of clarity of her role led to wanting autonomy and more hands-on learning, stating:

> "I would recommend that the community itself figure out who's allowed to diagnose autism so that the residents are more clear. Because I think many residents have had experiences in the community where they're like I really think this child has autism. And I will go through my best developmental history thing, I'll take 2 hours, but then they go to the preceptor and the preceptor says oh, you're probably right but we can't make the diagnosis. We've got to send them to the [specialty center]. And so I think that as a resident that's confusing and then as a new grad you're like well am I allowed to make this diagnosis? I would recommend that the community itself figure out who's allowed to diagnose autism so that the residents are more clear. Because I think many residents have had experiences in the community where they're like I really think this child has autism… And so I think that as a resident that's confusing and then as a new grad you're like well am I allowed to make this diagnosis?"

2.10 Teaching on interventions and services recommended to patients. Education on the various interventions and services recommended to the autistic patients was highlighted as a necessity. Resident 9 stated that she would not want to remove anything from the program, but would include intervention knowledge to the program:

> “Letting go, probably nothing, and including interventions. Like exposure to interventions.”

2.11 Training time with allied healthcare professionals. Spending more training time with allied healthcare professionals to understand other facets of autism care, and to gain insightful perspectives from other angles, was suggested. Resident 2 commented on this, by stating:

> “I think it’s good to be exposed to some of the multidisciplinary teams and I think that’s an area that we actually could get a little bit more exposure you know. I would have loved to have actually spent more time with like a speech and language pathologist or a dietician or like I mentioned this the feeding and swallowing clinic. I think those would have been really valuable things to learn. Particularly for a community pediatrician when you, you know, sometimes you’re trying to do more alone.”

5.5. Chapter Summary

The summative content analysis from the interviews with pediatric residents has provided a comprehensive understanding of the existing gaps in autism education, and some ideas for solutions to address these deficiencies. In Category 1, residents highlighted significant gaps, such as unclear roles in autism care, insufficient focus on long-term management, and a lack of practical, hands-on experiences. These gaps underscore the need for a more robust and well-rounded curriculum that can better prepare residents for autism care in their future practices. In Category 2, residents proposed a variety of solutions to mitigate these gaps, emphasizing the need for more integrated and continuous autism education throughout their residency. Key suggestions include expanding upon the developmental rotation, introducing continuity clinics with autistic patients, providing clearer community guidelines, and enhancing training on long-term care management and diagnostic skills. The residents also stressed the importance of early and diverse exposure to autism education, integration of learning activities in communities, and fostering interdisciplinary collaboration with allied healthcare professionals.

Together, these findings highlight the critical areas where improvements can be made to enhance the training of pediatric residents with regards to autism care. Addressing these gaps and implementing the proposed solutions will be crucial in equipping future pediatricians with the knowledge, skills, and confidence necessary to provide high-quality, comprehensive care for autistic patients and their families. This chapter has laid the groundwork for the current state of autism education in pediatric residency programs, and begins to offer some insight into curriculum enhancements and future training innovations.

CHAPTER 6. Discussion

6.1. Chapter Introduction

The purpose of the “Discussion” chapter is to integrate and contextualize the findings of the reflexive thematic analysis and the summative content analysis with to the broader landscape of pediatric residency education and autism care that is in the literature. By analyzing the perspectives of pediatric residents on best practice care in autism and identifying gaps in their training this study sheds light on the complexities and challenges associated with preparing future pediatricians to provide high-quality care to autistic children in their future practice. This chapter explores the implications of these findings and offers practical recommendations for enhancing autism education in residency programs. Through this discussion, the thesis project aims to contribute to the ongoing efforts to improve autism care in Canada and to ensure that the next generation of pediatricians are well-equipped to meet the needs of autistic children and their families.

The chapter begins with a figure that provides a high-level overview of the themes that were presented in Chapter 4, with connections to the gaps presented in Chapter 5, which are discussed briefly before going into a lengthier discussion of the thematic analysis, with all seven themes being discussed in the order presented in Chapter 4. Themes 1.1 to 1.3 are focused on outlining important factors of best practice care for autistic patients, while themes 2.1 to 2.4 are focused on outlining the barriers to provide best practice care for autistic patients based on the gaps in medical training. Then, there is a discussion of the summative content analysis, which focuses on two categories – gaps in medical education training, and solutions to mitigate gaps. While there is some overlap between category 2 of the thematic analysis and category 1 of the content analysis, the goal of the latter is to list all the areas where pediatric residency training programs are lacking with regards to training, without considering what constitutes best practice care in a clinical context. After the findings from the analysis are discussed, some practical recommendations are provided for medical schools and community physicians to consider, and future directions of research are provided based on these recommendations. Finally, limitations to the study are also discussed in this chapter.

6.2. Integrated Overview of Findings

Figure 6.1 provides a visual representation of the key themes identified in the thesis regarding the factors influencing best practice care for autistic patients and the gaps in autism education identified by pediatric residents. The figure is divided into two primary sections, with the factors essential for best practice care being depicted in blue, and the challenges in providing best practice care depicted in green. The figure illustrates how the themes are interconnected by the gaps that were identified by the content analysis, with specific challenges in education directly impacting the ability of residents to provide optimal care.

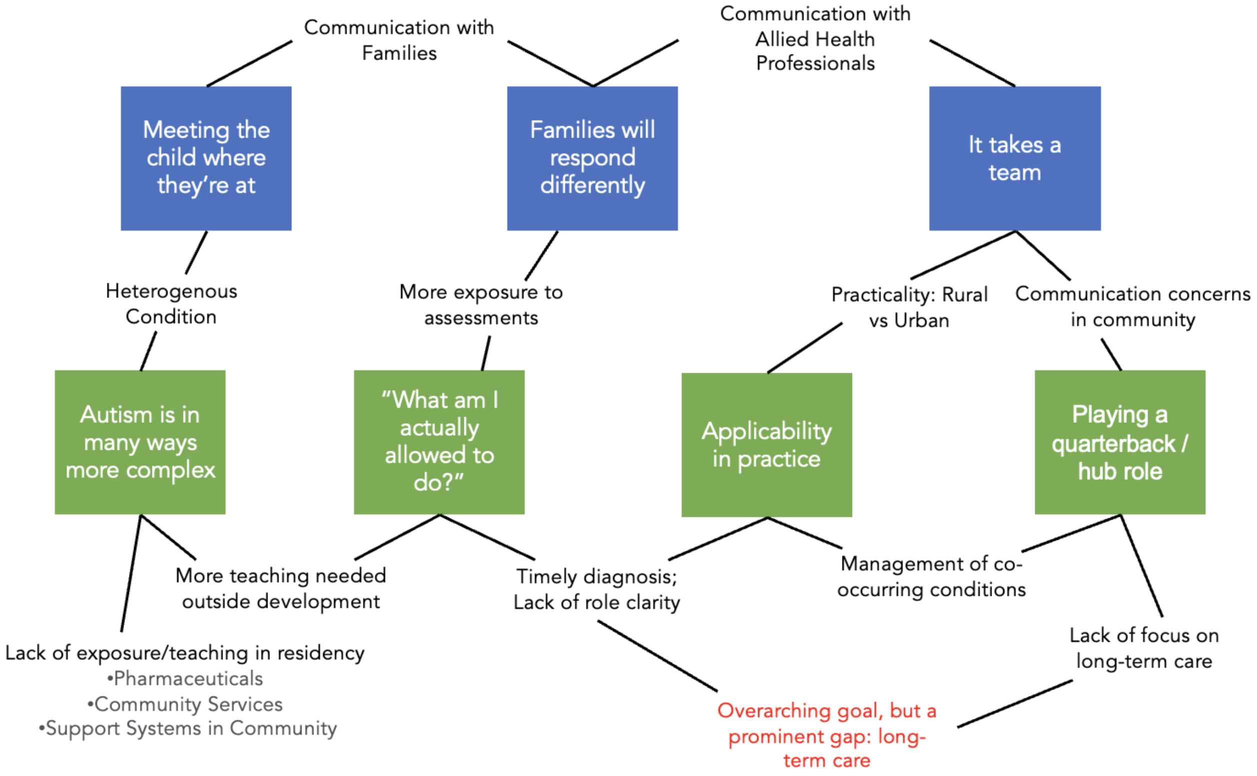


Figure 6.1. Conceptual diagram showing the interconnected nature of the themes regarding best practice care and the gaps in medical training surrounding autism care.

The theme "meeting a child where they're at" emphasizes the importance of flexibility and individualized care when working with autistic patients. Residents noted that because autism is a heterogenous condition, best practice care requires healthcare providers to adapt their approach based on the specific needs and abilities of each child. Figure 6.1 suggests that residents understand the complexity of autism, connecting this theme to "autism is in many ways more complex," but also identify a lack of exposure to teaching on the diverse aspects of autism, which include the use of pharmaceuticals, knowledge of community services and support systems available in the community.

The theme of “meeting a child where they’re at” also connects to “families will respond differently,” with residents noting communication with families as a crucial component of best practice care that is not necessarily emphasized in training. Residents recognize that families have varied responses and needs, necessitating a personalized approach to family education and support. Figure 6.1 underscores the importance of providing residents with more exposure to assessments and real-world interactions with autistic patients and their families during their training, which they currently noted was inadequate.

Communication with allied healthcare professionals is another key gap identified, which aligns with the theme of “it takes a team.” This theme reflects the importance of multidisciplinary care in working with autistic children. Residents acknowledge that effective autism care involves collaboration with allied healthcare professionals, such as psychologists, speech therapists, and occupational therapists. Figure 6.1 also points to practical challenges, such as the differences in care coordination between rural and urban settings (connecting this theme to “applicability in practice), and communication concerns in the community (connecting this theme to “playing a quarterback/hub role”).

Figure 6.1 also highlights residents’ perception that autism is a multifaceted condition that is not sufficiently covered in training, leading them to believe that “autism is in many ways more complex.” They identify a need for more comprehensive teaching outside the developmental block, connecting this theme to the theme of “What am I actually allowed to do?” This theme reflects the role confusion residents face in diagnosing and working with autistic children. This figure suggests that timely diagnosis and lack of clarity on their role are significant concerns, indicating that residents call for clearer guidance and more structured opportunities to practice in the community regarding autism care. The management of co-occurring conditions is another significant gap that connects the theme of "applicability of practice," in which residents express uncertainty about whether the skills and knowledge they acquire during residency will be applicable in real-world practice, with the theme of "playing a quarterback/hub role," in which residents noted their aspirations to play a central role in the long-term care of autistic patients. This was an overarching goal for a majority of the residents, but providing long-term care was also highlighted as one of the most prominent gaps in medical training surrounding autism care.

6.3. Detailed Discussion on the Thematic Analysis: Best Practice Care Components

Theme 1.1 "It is important to meet the kid where they're at"

One of the most prominent themes that emerged from the interviews with pediatric residents was the importance of meeting autistic children where they are in terms of their developmental, communicative, and behavioural needs. This theme underscores the necessity for flexibility and individualized care in working with autistic children, highlighting a critical aspect of best practice care.

Pediatric residents emphasized that autism is a spectrum, and that healthcare providers should adapt their approaches based on the individual needs of each child. This sentiment aligns with the principle of patient-centred care in medicine, which advocates for tailoring healthcare to the individual characteristics, needs, and preferences of each patient (Epstein & Street, 2011). Residents provided examples of providing best practice care to autistic patients in the emergency room, for example, which aligns with qualitative research suggesting that patient (and family) centred care is integral to serving autistic children (Nicholas et al., 2020; Kouo et al., 2022). By “meeting the kid where they’re at,” residents acknowledge the diversity within the autism spectrum and the importance of flexible care strategies that can accommodate a wide range of strengths and challenges.

The residents noted the heterogeneity of autism, reflecting that the understanding of a “one-size-fits-all” approach is inadequate in autism care. This perspective is supported by research indicating that individualized interventions and medical visits are a factor that contribute to more positive outcomes for autistic children, and if not individualized, can lead to variable outcomes (Lord et al. 2022; Vivanti et al. 2014; Ip et al., 2019). By recognizing and responding to specific needs of each child, residents noted that healthcare providers can facilitate more effective care to their autistic patients.

The theme of individualized care has significant implications for the training and practice of pediatric residents. It suggests that residency programs should place a stronger emphasis on teaching flexibility and adaptability in clinical practice, as opposed to the rigid diagnostic criteria and standardized methodologies that residents feel are currently focused on. Residents thus need to be equipped with skills to assess and respond to varying needs of autistic children, including an understanding of different communication styles, sensory sensitivities, and behavioural patterns. Training programs should therefore incorporate case-based learning exercises related to autism that present a range of scenarios, allowing residents to practice adaptability in a controlled environment (Major et al., 2015).

The emphasis on individualized care is well supported by existing autism literature. Studies have consistently shown that personalized interventions tailored to the specific needs of the child lead to better developmental and behavioural outcomes (Zwaigenbaum et al., 2015). Some examples of flexibility in the context of clinical practice include flexibility in appointment scheduling, accessing services, and standardized procedures (Brian et al., 2019; Hyman et al., 2020). This approach not only enhances the effectiveness of care, but can also help in building rapport with the child and family, which is crucial for successful long-term management, another area residents noted they wanted more autonomy in.

Theme 1.2 "Families will respond differently"

Another crucial theme that emerged from the interviews with pediatric residents is the recognition that families of autistic patients respond differently to diagnosis, services, and care strategies, and how families' understanding of autism may differ. This theme highlights the importance of family understanding and education in providing best practice care to autistic children. The diverse responses of families necessitate a tailored approach to communication, education, and support, ensuring that each family's perspectives are addressed.

The pediatric residents emphasized that effective autism care extends beyond the patient to include the family unit, which includes kindness towards the family in response to diagnosis and care strategies. The perspective that family-centric care is essential in working with autistic children in terms of the diagnostic process and long-term care is supported by the literature. A mixed methods study concluded that high levels of parental stress during the diagnostic process are associated with negative experiences with healthcare providers, including dismissive nature and little time spent on parent concerns (Myers et al., 2021). This sentiment ties in to what residents stated, including the kindness and educating components of best practice care.

The varying responses of families can significantly impact patient outcomes and family dynamics, as alluded to by the residents. Residents noted that families may be overwhelmed by an autism diagnosis, and, depending on their education level, may even struggle to accept the diagnosis, while other families may actively seek information and become strong advocates. A review article highlighted that tailored family education and support programs can lead to better coping mechanisms, reduced parental stress, and overall improvement in family functioning amidst an autism diagnosis (Karst & Van Hecke, 2012). For example, a study by Tarver et al., (2019) found that parent training programs tailored to the specific needs of families resulted in significant improvements in parent-child interactions, and ultimately led to reduction in disruptive behaviours, hyperactivity, and parental stress. This underscores various points made by the residents, in which tailoring the diagnostic approach and next steps are essential in providing best practice care.

Residents noted effective communication to be a critical component of providing family-centered care, which includes clear, compassionate, and culturally sensitive communication strategies. This is particularly important in multicultural settings where families may have different perspectives and cultural beliefs related to autism. Culturally sensitive communication helps build rapport and ensures that families feel respected and understood, which is essential for effective collaboration and care (Kwame & Petrucka, 2021). This relates to the residents' statements on empathy, and understanding the interconnected relationships between the caregivers and environment with the child.

The recognition of diverse family responses and the need for tailored education is well-supported in the literature. Studies have consistently shown that family-centric approaches improve care outcomes for autistic children. Hodgetts et al. (2015) looked at the overall, best, and worst met service needs and predictors of those needs for families of autistic children, and found that determining the services that best need the needs of families identified by the families is an important step to improve quality of life for autistic individuals.

Moreover, the importance of family education is emphasized in the guidelines of major health organizations. For example, the CPS statement on autism diagnosis recommends a family-centered approach, which involves listening and talking to family members, understanding the family history, and taking family goals into account (Brian et al., 2019). Planning for interventions and further assessments should take family concerns, priorities, and resources into consideration.

The theme of family understanding and education is a critical component of best practice care for autistic children. Pediatric residents emphasized the need to engage with families, provide tailored educational resources, and building strong, collaborative relationships that respect diverse responses and family dynamics. This finding aligns with existing literature and Canadian best practice guidelines, highlighting the need for residency programs to incorporate training beyond just child interactions, but also family dynamics and communication strategies.

Theme 1.3 "It takes a team"

The theme "it takes a team" reflects pediatric residents' recognition of the importance of coordinated, multidisciplinary care in working with autistic children. This theme emphasizes the importance of involving various healthcare professionals beyond a pediatrician, including speech and language therapists, occupational therapists, behavioural therapists, and social workers, to provide comprehensive and effective care for autistic children. Residents acknowledged that team-based care can streamline both diagnostic proceedings and long-term care.

Autism presents as a heterogenous condition, with a wide range of communication, social, and sensory processing differences, and high rates co-occurring conditions such as anxiety, ADHD, and epilepsy (Lord et al., 2020). Due to this diversity in presentation, residents noted they welcomed the expertise of various specialists to address the individual needs of each child effectively. A multidisciplinary team approach ensures that all aspects of a child's developmental trajectory are considered, and that care is coordinated across different domains (Fulceri et al. 2023). Residents highlighted the value of working within a multidisciplinary team, with the residents' perspectives aligning with evidence suggesting that integrated care models, where professionals from different disciplines collaborate closely, lead to better outcomes and quality of life for children with autism. Such models facilitate comprehensive assessments, individualized treatment plans, and cohesive support strategies that address core features of autism, as well as any associated co-occurring conditions (Dosreis et al., 2006).

While the residents did agree there are benefits to multidisciplinary care, they also noted challenges associated in the implementation of such models. These include logistical issues such as schedule coordination, ensuring consistent communication, and aligning goals. Residents noted that communication is strong in specialty sites, but not as strong in the community setting. Therefore, communication strategies with allied healthcare professionals should be included in professional development modules of medical training when discussing autism. This will allow for the next generation of pediatricians to not only communicate effectively with the child and their families, but also with healthcare professionals, fostering a collaborative mindset that allows for an integrated approach in providing best practice care.

While multidisciplinary collaboration is typically recommended for autism care, in which healthcare professionals primarily work in parallel and communication is minimal, interdisciplinary collaboration refers to healthcare worker communicating more with shared goals and responsibilities, while maintaining disciplined roles (Bowman et al., 2021; Kunze & Machalicek, 2021). With some residents noting that they would value time with allied healthcare professionals, and would like a more integrated approach to diagnostic proceedings in the community, perhaps teaching and practicing interdisciplinary models in a community setting alongside a multidisciplinary model in specialty sites would allow for various care models to allow residents to understand the roles and contributions of different professionals in the care of autistic children more clearly.

The CPS also advocates for both multidisciplinary and interdisciplinary care as a standard practice in working with children with autism, recommending that pediatricians work closely with other specialists to ensure that all aspects of the child's health and development are addressed (Brian et al., 2019). By prioritizing multidisciplinary care both in multidisciplinary sites and in the community, healthcare providers can ensure that autistic children receive the highest quality of care, ultimately improving outcomes and quality of life.

Theme 2.1 "Autism is in many ways more complex"

The theme "Autism is in many ways more complex" emerged from pediatric residents' reflections on their training and clinical exposure to autism. This theme underscores the perceived inadequacy of their training to fully equip them to handle discerned complexities of providing best practice care to autistic children. Throughout the interviews, residents expressed that their medical education often failed to capture the full spectrum of autism's manifestations, co-occurring conditions, and the nuanced needs of patients and their families. This insight is critical, as it highlights the necessity for more comprehensive and in-depth training in autism care within pediatric residency program.

As a few residents noted, upwards of 60% of a community pediatricians' practice is developmental and behavioural health. The WHO notes development is among the most prevalent reasons for families to visit a pediatrician (World Health Organization, 2013). Though the number is not explicitly stated in Canadian literature, Canadian studies have concluded there is a disproportionate gap in how much time is spent on developmental pediatrics in medical training, compared to the quantity of children seen in practice for development and behavioural concerns (Tassone et al., 2018; McLeod et al., 2022). All twelve interviewed residents noted they did not feel adequately prepared to work with children with autism in the community while doing or after completing a general, four-year residency program in pediatrics, though the interviewees who went on to do additional training in development felt more prepared. This aligns with theme 4 from Tassone et al. (2018), in which 93% of pediatric residents and 100% of family medicine residents suggested additional training in developmental pediatrics would be beneficial.

Residents noted specific areas in the care of autistic patients they felt most uncomfortable working with. The areas that were noted the most frequently regarding long-term care were regarding pharmaceuticals, community services, and aggression. A recent study conducted by Hamp et al. (2023) synthesized primary care provider's top perceived challenges in autism care, and stated the top two are lack of knowledge on community services and working with parents who get emotional during the process. There is no mention of pharmaceuticals or dealing with aggression in this study. To our knowledge, no study has investigated resident's perspectives on the most challenging parts of autism care. Pharmacologic interventions for behavioural conditions and mental health conditions are among the RCPSC competencies for developmental pediatrics, and they are explicitly stated as entrustable professional activities (EPAs) in the developmental rotation curricula for the University of Alberta and University of British Columbia pediatrics programs. Therefore, based on resident statements and the curricular objectives set out by residency programs, long-term care for autistic children should be focused on more in developmental pediatrics concurrently with diagnosis – perhaps focusing different rotations on developmental diagnosis, and on developmental and behavioural care.

Another sentiment that was frequently discussed in the interviews was that pediatric residents felt significantly more comfortable with physical diagnoses such as diabetes and asthma, noting that there was more exposure to them during residency, and the guidelines on how to proceed with physical conditions were more streamlined. This extended to other neurodevelopmental conditions such as ADHD, where residents felt their knowledge on diagnosis and long-term care was better, due to assessment protocols and medications being more streamlined. Residents noted autism is more complex, and the complexity is compounded by co-occurring conditions such as anxiety, ADHD, gastrointestinal and sleep challenges, and epilepsy (Tye et al., 2019). The diversity in presentation is what likely makes it challenging for healthcare providers to offer standardized care, requiring a personalized approach to diagnosis and long-term care.

The theme “autism is in many ways more complex” underscores a critical gap in pediatric residency training. A question to pose is if autism even *is* more complex, or if the lack of comprehensive skills-based training leads residents to perceive autism as more complex. There are nuanced pieces, such as varied presentations and frequent co-occurring conditions, which require a deeper understanding than what participating residents feel they got in training. Addressing this gap is essential for preparing pediatricians to provide high-quality, personalized care for autistic children and their families. Enhancing training to include more detailed and practical education on autism can lead to better diagnostic accuracy, more effective management of co-occurring conditions, and improved outcomes for the children (Clarke & Fung, 2022).

Theme 2.2 "What am I actually allowed to do"

The theme of "What am I actually allowed to do?" reflects the uncertainty and role confusion experienced by pediatric residents regarding their responsibilities and scope of practice and diagnosing and caring for children with autism. This uncertainty often stems from inadequate training and a lack of clear guidelines, leading to hesitation and a lack of confidence in providing best practice care, as highlighted in the interviews. Addressing the sense of "role confusion" is crucial for ensuring that the next generation of pediatricians are well-prepared to meet the needs of autistic individuals and their families.

Throughout the interviews, pediatric residents often reported feeling uncertain about their role in the diagnosis and care of autism, in terms of where to get resources, the vocabulary used by specialty sites, and perceptions that pediatricians are not allowed to make a diagnosis. This uncertainty can be attributed to several factors, including limited exposure to autism during training, inconsistent guidance from mentors and supervisors who may not be as comfortable with autism, and a lack of comprehensive education on the subject. As a result, residents noted they feel unsure about the extent of their responsibilities in community practice, particularly in areas such as early diagnosis, referral processes, and long-term care management.

This sense of role confusion is not unique to just residents. It is also reported among practicing pediatricians who may struggle with determining the appropriate level of involvement in the care of autistic patients (Golnik et al., 2009; Young et al., 2020; Hamp et al., 2022). This confusion can also be exacerbated by the overlapping responsibilities of different healthcare professionals, including developmental pediatrician specialists, psychologists, and speech therapists. Residents noted this as well, with one resident noting she would like more time with allied healthcare professionals in training to better understand other perspectives of autism care that are not necessarily taught in medical training.

Role confusion can have significant implications for patient care. When healthcare providers are unsure of their responsibilities, it can lead to delays in diagnosis, inconsistent care practices, and insufficient support systems. Early and accurate diagnosis is crucial for initiating timely and relevant supports that can improve outcomes for autistic children, however, if residents are hesitant to make diagnostic decisions or even initiate referrals due to role uncertainty, it can impede this process (Zwaigenbaum et al. 2015). Furthermore, a lack of clarity regarding the scope of practice can lead to variability in quality of care provided. Residents noted that they are afraid to overstep their boundaries, leading them to believe they need to be overly cautious, ultimately resulting in suboptimal care. Providing residents with training on the ethical aspects of autism care can help alleviate concerns addressed by the residents, ensuring that they can practice within an appropriate framework while delivering high-quality care.

To address these issues, clear protocols, structured training, interprofessional collaboration, and education on ethical considerations are all examples of how the medical education system can educate residents to fulfil their roles in autism care effectively. Studies have shown that targeted educational interventions can improve pediatricians' knowledge base and confidence in working with autism, leading to more consistent and effective care (Carbone et al., 2010). By enhancing role clarity, training programs can ensure that pediatric residents are better equipped to diagnose autism, support long-term care, and manage co-occurring conditions, ultimately improving the quality of life and care for the children.

Theme 2.3 "What I learned may not be applicable to my practice"

The theme "what I learned may not be applicable to my practice" reflects the concerns expressed by pediatric residents about the relevance and applicability of their training in real-world clinical settings. This sentiment arises from the residents' perceived disconnect between what is taught in residency compared to the practical applications faced when working with autistic children in the community. For example, residents noted how the specialty sites' multidisciplinary teams are not always feasible, especially when considering rural community practice. A study conducted by Das et al. (2022) noted that rural community pediatricians in Ontario, Canada all consider autism diagnosis to be in their scope of practice. Beyond rural communities, community pediatricians in urban environments could be used as a resource to shorten diagnostic waitlists. Penner et al. (2017) described community pediatrician's perspectives on their willingness to provide diagnostic and long-term care, which was followed by a study by Penner et al. (2023), which showed high accuracy with general pediatricians making the diagnosis, suggesting children with co-occurring developmental delays may be suitable candidates for community assessment.

The interviews showed that pediatric residents often encounter a discrepancy between what is taught in training and the realities of clinical practice. As discussed in Penner et al. (2023), diverse presentations of autism and the wide range of needs among autistic individuals complicate matters, especially in terms of ruling out an autism diagnosis. Studies have shown that healthcare professionals, including pediatricians, often feel underprepared to address the unique challenges associated with autism, such as managing co-occurring conditions, communicating effectively, and navigating the healthcare system (Rhoades et al., 2007; Carbone et al., 2010).

To address this gap, practical training opportunities and a re-evaluation of the curriculum for developmental pediatrics, as well as through ongoing professional development. Realigning the developmental pediatrics rotations to be better in line with the curriculum objectives surrounding diagnostic and long-term care, exposure to different approaches to diagnosis (team based versus community pediatrician based), and opportunities for residents to engage with autistic patients and their families in a variety of settings are ways to make the autism training more applicable. Research supports the importance of experiential learning in medical education as well. For instance, studies have found that clinical exposure to autism can significantly enhance medical students' and residents' competence and confidence in diagnosing and managing autism (Major et al., 2013; Citil et al., 2021; Taslibeyaz et al., 2017).

One resident noted that, as a practicing pediatrician before going into a subspecialty in developmental pediatrics, she learned more as a practicing pediatrician than in residency. The comment emphasized the importance of staying updated with best practices in autism care. Ongoing professional development ensures that pediatricians remain informed about the latest advancements and can adapt new research findings into their practice. Ongoing learning projects such as Project ECHO Autism allow for practicing pediatricians to learn through case-based scenarios in an "all teach all learn" format, with a group of multidisciplinary experts in the field of autism (Sohl et al. 2022). Projects such as ECHO Autism also have been shown to be successful in increasing capacity for community-based care through its use of case discussions with allied healthcare professionals, and didactic teachings (Jane et al., 2023). One recommendation would be to incorporate Project ECHO Autism-like cases and didactic teachings in developmental pediatrics rotations in residency to see a greater breadth of cases and related topics to autism.

Theme 2.4 "I see myself playing a quarterback/hub role"

Another prominent theme that came up reflected pediatric residents' aspirations to serve as central coordinators in the care of autistic children. This vision aligns with the concept of the "medical home model," where pediatricians act as the primary point of contact and coordination for a child's healthcare needs, particularly for multifaceted conditions such as autism (American Academy of Pediatrics, 1967; Todorow et al., 2018). The theme of residents seeing themselves as playing a "quarterback" or "hub" role underscores the importance of comprehensive training and support in medical training to enable pediatric residents to effectively fulfil this role.

Pediatric residents often envision themselves as key coordinators or "quarterbacks" / "hubs" in the care of autistic children, managing various aspects of care and facilitating communication between different healthcare providers and services. Residents noted that in the community, they envision their roles in ensuring that autistic children within their practice receive holistic and continuous care, addressing their medical, developmental, and psychosocial needs. This concept is supported as the medical home model, as described in the literature, which is particularly beneficial for conditions such as autism where multiple disciplines, such as developmental pediatrics, psychology, speech and language therapy, occupational therapy, and behavioural therapy among others are required (Todorow et al. 2018). The medical home model helps to decrease unmet health needs as reported by parents, where a study conducted by Strickland et al., (2011) showed that only 8.1% of children with special healthcare needs have unmet health needs, compared to 22.55% who lack a medical home.

While residents noted that the vision of serving as a central coordinator is appealing, there are significant challenges in realization of this role. One major barrier is the lack of specific training in care coordination and management of multidisciplinary teams. Based on the interviews, pediatric residency programs may not provide sufficient opportunities for residents to develop these skills, leading to uncertainty and a lack of preparedness. This sentiment is supported by Golnik et al. (2009), which stated that more pediatricians gained skills related to being the medical home coordinator for their autistic patients throughout practice compared to in medical school or residency.

Additionally, systemic issues such as fragmented healthcare issues and insufficient resources can impede the ability of pediatricians to effectively coordinate care. Mazurek et al. (2022) highlighted that pediatricians often struggle with coordinating care due to time and resource constraints, lack of access to care coordination, and shortages of autism specialists. These challenges can be particularly pronounced in rural communities, where residents noted resources are scarcer.

To support pediatric residents in fulfilling the quarterback or hub role several strategies may be implemented. Firstly, residency programs should incorporate training modules that focus on care coordination, team management, and interprofessional collaboration. These modules can include simulated case scenarios and didactics, similar to ECHO Autism sessions, and rotations in clinics that exemplify the medical home model. Furthermore, mentorship from pediatricians who can successfully fulfill the coordinator role can provide valuable guidance and support.

Unsurprisingly, residents noted they learned most about autism when they had preceptors comfortable in working with autistic children, both in a diagnostic and long-term care capacity. Preceptors can share best practices, offer insights into navigating systemic barriers, and help residents build confidence in their ability to manage more complex care needs residents noted, such as pharmaceuticals (Johnson & Myers, 2007; Penner et al., 2022). Health systems also need to invest in infrastructure that supports care coordination. Residents noted electronic health records and care coordination teams to be among the most helpful infrastructure supports; electronic health records can facilitate better communication and information sharing among providers, while care coordination teams can assist pediatricians and allied healthcare professionals in managing referrals, follow-ups, and effective communication with the families (Gimm et al., 2016).

The vision of pediatricians as quarterbacks in autism care is aligned with the goals of the medical home model, which seeks to provide continuous, comprehensive, and family-centered care. Residents feel, however, that they lack the training in providing long-term care while doing residency or just finishing residency to best provide this service for autistic children. By equipping pediatric residents with the necessary skills and support, residency programs can better help realize this vision, ultimately benefiting the broader healthcare system and the autistic community.

6.4. Detailed Discussion on the Content Analysis: Gaps & Solutions in Medical Training

Category 1. Gaps in Autism Education

While the thematic analysis focused on detailing gaps related to providing best practice care, the summative content analysis focused on revealing critical gaps specifically in autism education based on the interviews with pediatric residents. These gaps, encompassing various aspects of their training and preparedness, highlight areas that require significant improvements to better equip the next generation of pediatricians for the perceived complexities of autism care.

The two most frequently mentioned gaps in medical education training that were mentioned were a lack of clarity on the pediatrician's role in autism related care activities, and the lack of focus on long-term care for autistic patients in training. In terms of the lack of clarity, the ambiguity can lead to uncertainty and hesitance in taking on responsibilities related to diagnosing and managing long-term care of autism. The literature supports this concern, with studies indicating that many healthcare providers feel unclear about their roles in autism care, which includes their role in a multidisciplinary care team when that is the typical standard used, which can lead to fragmented care for autistic children (Carbone et al. 2010). Parents also noted that fragmented care leads to confusion in obtaining best practice care for their children, which leads to decreased parent education and resources, as noted by the residents (Brewer, 2018). Residents also noted a deficiency in training focused on the long-term care of autistic patients, an objective that is only briefly mentioned in the developmental pediatrics-specific objectives by University of Alberta and University of British Columbia's curriculum. This is a concerning gap, as long-term care planning is critical in improving outcomes for autistic individuals (Lord et al., 2020). Residents noted the focus on diagnostics in residency is not always proportional to the children they will see in their real world practice; while some residents note that they would like to be involved in diagnostic care, many of them envision themselves in following children more long-term in practice.

Another significant gap is a lack of exposure to autism-related cases and inadequate teaching on autism during residency. Research studies have shown that increased clinical exposure to autism can enhance healthcare providers' competence and confidence in providing more robust care (Citil et al., 2021). Further, training programs like Project ECHO Autism report that clinicians who participate feel better equipped to work with autistic individuals because of the training (Dreiling et al., 2022). Therefore, more hands-on experience and case-based learning akin to what is taught in Project ECHO Autism may be crucial for developing practical skills and knowledge.

Residents also noted pharmacological management of co-occurring conditions in autism, such as anxiety, ADHD, or aggression, is a critical aspect in which they feel they lack knowledge in. This gap can ultimately lead to suboptimal management of co-occurring conditions, thus negatively impacting the overall well-being of the autistic patients. Houghton et al. (2017) demonstrated the need for more comprehensive training on the use of medication surrounding psychotropic medications in autism care, as some patients are getting prescribed certain medications for co-occurring conditions even without the co-occurring diagnosis. While residents called for more training in pharmaceuticals, it should be noted that more research is needed on medications and how they affect autistic patients with co-occurring conditions compared to patients who do not have autism (Hellings, 2023).

Another gap identified is with regards to the timely diagnosis, which is crucial for early intervention and significantly improving outcomes for autistic children (Zwaigenbaum et al., 2015). Residents expressed concerns about their ability to diagnose autism promptly and accurately. Residents noted that the time it takes to do an assessment is a limitation to training as well, because they get less exposure to assessments. These residents indicated a need for more training in conducting and interpreting assessments for autism. The literature supports this sentiment, with research showing that there is need for more exposure to training in the medical field (Johnson et al., 2007; Gallaher et al., 2023).

Effective communication with autistic patients and their families, as well as with allied healthcare providers, is another area where residents noted they felt underprepared, Developing strong communication skills is important in trust building, understanding the needs of patients and other healthcare providers, and providing overall appropriate support. The literature emphasizes the importance of tailored communication strategized to improve patient-provider interactions in autism care (Araujo et al., 2022; Clark et al., 2019).

The other five gaps that were noted included a lack of focus on community diagnostics in practice, a lack of knowledge on community services, a lack of perceived support systems in the community, a lack of knowledge on the management of co-occurring conditions, and a lack of clarity on the practicality of what is learned in the real world. All five of these gaps represent an elaboration on previous discussion points, in which a call to action of curricular objectives of residency training programs in developmental pediatrics should be more aligned to better meet the needs of autistic children in the community. It should be noted that the lack of knowledge on management of co-occurring conditions, community services, and community diagnostics are not mentioned in the developmental pediatrics curriculum, and could potentially be integrated into community practice, or long-term continuity clinics with developmental objectives.

Category 2. Solutions to Mitigate Gaps

The analysis of the interviews with pediatric residents also identified a range of solutions to address the gaps in autism education within their training programs. These solutions, derived from the lived experiences and suggestions of residents, provide a potential roadmap for enhancing autism education to ultimately improve care for autistic patients, leading to improved quality of life for the children.

The most frequently suggested solution was the need for more comprehensive teaching on autism beyond the confines of the developmental block in residency programs. Integration of autism education throughout residency can ensure continuous learning and reinforce the importance of autism care in general pediatric practice. This approach aligns with the recommendations of the Royal College of Physicians and Surgeons of Canada (RCPSC), which emphasizes the need for a well-rounded curriculum that addresses the diverse needs of pediatric patients, including those with developmental conditions like autism (RCPSC Pediatrics Competencies, 2021). This aligns with another solution given by residents, which was to see autistic children in a continuity clinic. A continuity clinic would provide residents with ongoing, hands-on experience in working with autistic children over time, facilitating a deeper understanding of the long-term care needs, which was highlighted as a goal that residents stated they had in their future practices. Continuity clinics have been shown to improve residents' skills and knowledge by providing consistent, real-world practice (Walker et al., 2018). Bahrami et al. (2024) found a significant increase in autism-related follow-up visits and best practice care for autistic children with the implementation of a continuity clinic with autistic patients.

Residents also called for an expansion to the developmental pediatrics rotation to provide more in-depth training and exposure to autism care. Some suggestions that residents gave on ways to expand on the developmental rotation are by adding lived experience panels, academic half days with didactic teaching, training on diagnostic tools, and other teaching opportunities. Residents also noted potentially more time in developmental pediatrics if it was a feasible option. An expansion of the developmental pediatrics rotation would allow residents to gain a better understanding of the complexities of autism and develop more robust diagnostic and long-term care skills. A study conducted by Stein et al., (2017) showed that a longer, expanded developmental pediatrics rotation leads to fewer perceived barriers and more long-term care knowledge, showing that the length of developmental pediatrics training is proportionate with skills associated in the field. Residency programs can also take inspiration from Project ECHO Autism to incorporate case-based learning and didactic teaching into the developmental pediatrics rotation with allied healthcare professionals to address another gap prominently mentioned – a lack of time with allied healthcare professionals (Jane et al., 2023). Having an expanded residency with a Project ECHO Autism-like framework would also address the gaps of more teaching on long-term care management being needed, a solution mentioned by four pediatric residents.

Providing clearer directions on community guidelines and resources from community providers was another solution that was proposed by the residents. This includes better education on the systems in place to diagnose and manage autism, how to navigate and utilize community services, both essential components of providing comprehensive care. Clearer guidelines and knowledge of community resources are vital for effective care coordination and support (Thomas et al., 2007). Integrating learning activities in community settings, both urban and non-urban, was another potential solution identified by residents. This approach can provide diverse clinical experiences and expose residents to varied contexts in which autism care can be delivered, providing more robust care for the autistic children. Community-based training has been shown to enhance residents' understanding of the social determinants of health and improve their ability to provide patient-centered care (Carbone et al., 2010).

Residents also recommended that autism education should be introduced earlier in their medical training, starting as early as the pre-clerkship years. Early exposure can lay a strong foundation for understanding autism and its accompanying nuances. A model developed in medical education in the United Kingdom entitled "Time for Autism" contains lived experience as a core component in the pre-clerkship years, a program which is being evaluated currently (Dhuga et al., 2022; Gallaher et al., 2023). Incorporating programs with lived experience panels and activities earlier on in medical training can lead to more competence and willingness to learn about autism in the later years of training, including in residency.

Another skill that residents wanted more training in was in diagnostic delivery, including using diagnostic tools more effectively. Proficiency in diagnostic delivery can significantly impact how parents handle the diagnosis and partake in the next steps for their children (Smith-Young et al., 2020).

The other suggestions that were mentioned include learning activities on autonomy from providers to foster hands-on and practical skills, teachings on interventions and services that physicians recommend to autistic patients, and spending time with interdisciplinary allied healthcare professionals to improve teamwork in healthcare. The suggestions discussed by the twelve residents all would all play a role in an enhanced curriculum in autism education, and ultimately help provide the next generation of pediatricians with the expertise needed to provide competent healthcare to autistic children, therefore improving their quality of life.

6.5. Practical Recommendations

Based on the findings of this study, several practical recommendations are discussed here to improve autism education within pediatric residency programs. These recommendations aim to enhance the knowledge, skills, and confidence of pediatric residents in providing high-quality care to autistic patients in their future practice. Additionally, suggestions for policy changed and institutional support are provided to facilitate the implementation of these improvements.

Suggestion 1. Integrating Autism Education Throughout the Pediatric Residency Program. A key recommendation is to integrate autism education across multiple stages of the residency curriculum rather than confining it to a specific rotation, such as the developmental pediatrics block. Continuous exposure to autism-related content, including didactics, case discussions, and clinical experiences, can help reinforce the importance of autism care in general community pediatrics. Since developmental and behavioural health is approximately 50-60% of a pediatrician's practice, residents noted that the teachings in residency should be proportionate to what is seen in the community. This approach ensures that residents understand a more comprehensive understanding as a lifelong condition that requires ongoing support in different facets of healthcare.

Suggestion 2. Expanding the Developmental Pediatrics Rotation. The expansion of the developmental pediatrics rotation is a crucial suggestion to provide residents with more in-depth training on autism. Extending the duration of this rotation and incorporating more hands-on experiences with autistic patients either through a continuity clinic or with learning objectives such as mini ADOS competencies and participation in multidisciplinary team meetings can significantly enhance skills related to autism diagnosis and long-term care. In addition, a better selection of elective opportunities in specialized autism clinics should be offered for residents to gain additional exposure to best practices in autism care. This focused training can equip residents with the knowledge and skills necessary to provide comprehensive, evidence-based care to autistic children.

Suggestion 3. Establishing Continuity Clinics that Include Autistic Patients. Continuity clinics are a component of some pediatrics rotations across Canada, and incorporating autistic patients in these clinics is another practical recommendation that would allow residents the opportunity to follow autistic patients over time, gaining valuable insights into the long-term care needs of the children. Continuity clinics can also foster strong relationships between residents, children, their families, and other allied healthcare professionals, thus enhancing skills on effective care coordination and communication. These clinics could also serve as a hub for interdisciplinary collaboration, allowing residents to work in a “hub” role, as they stated they are interested in doing so, allowing residents to work closely with allied healthcare professionals such as speech therapists, psychologists, and occupational therapists.

Suggestion 4. Strengthening Community-Based Learning Opportunities. Strengthening community-based learning opportunities is essential for preparing residents to provide autism care in a diversity of settings, including urban, rural, and underserved regions. Community-based training can expose residents to the social determinants of health and the unique challenges that may be faced by autistic children and their families in different communities. Residency programs should consider incorporating rotations in community health centers and schools to help foster a deeper understanding of resources available in the community, and to learn how to effectively collaborate and utilize community service and providers to support autistic patients and their families.

Suggestion 5. Policy Changes and Institutional Support. To implement these recommendations effectively, some policy changes and institutional support are necessary. Medical schools, residency programs, and healthcare institutions should place more emphasis on autism education and allocate resources to support the proposed changes. These may include revising accreditation standards, increasing funding for autism-related training, and incentivizing faculty and physician training in autism care. Moreover, national and provincial healthcare organizations should advocate for policies that promote comprehensive autism education in medical training. This could involve the establishment of training in the national autism strategy, supporting research on best practices in autism care, and development of resources for educations and trainees. Institutional support is also crucial for creating an environment conductive to learning and professional development; residency programs sould provide mentorship and supervision from experienced clinicians in autism care, as well as opportunities for residents to engage in research, advocacy, and community outreach activities.

6.6. Future Directions of Study

The findings from this thesis highlight several areas where further research and educational development are needed to improve autism care within pediatric residency programs. Future work could focus on implementation and evaluation of proposed solutions presented in this discussion, such as the incorporation of Project ECHO Autism-like teachings and more lived experience components integrated throughout medical education in residency programs. Additionally, future research could explore the long-term impacts of the newly proposed solutions in terms of how it impacts quality of care provided to autistic children and families. A future longitudinal study could assess how changes in residency affect pediatricians' practices and patient outcomes over time. Furthermore, there is a need for more in-depth exploration of the role of community-based learning activities and interdisciplinary training in enhancing pediatric residents' competencies in autism care.

Another important future direction involved examining the broader system-level changes necessary to support these educational improvements. This includes addressing potential barriers to implementing these solutions, such as resource limitations, faculty training, and curricular restructuring. Collaborative efforts between medical schools and community healthcare providers will be essential to successfully integrate these changes and ensure that they lead to meaningful improvements in autism care nationally.

Finally, engaging autistic children and their families in the development and evaluation of educational programs could provide valuable insights and help ensure that the training is aligned with the needs and preferences of the autistic community. Community based participatory research approaches could foster a more inclusive and patient-centered perspective in medical education, ultimately leading to better care for autistic patients.

6.7. Research Limitations

Amidst the crucial findings and contributions, and the various strengths employed by the qualitative methodology and ontological and epistemological perspectives, there are several limitations evident to address in future research to foster more knowledge on the topic of autism training in medical education. The purpose of documenting study limitations aids in transparency and is an important in the reflective piece of RTA. Macleod (2019) highlights this, stating that qualitative research methodologies can lead to an “elite bias,” in which the most articulate members of a group are represented. This is evident in this study, as the participants were recruited based on their interest in the study, and most participants had some interest in autism to begin with. Individuals who are not as focused on autism training may have different opinions and experiences than the participants recruited in this study, thus would have altered the themes and content of the data.

Another limitation of the study is that all participants identified as female. While there is a higher proportion of females in the field of general pediatrics (Canadian Medical Association, 2019), there are male participants in the potential pool that were missed. It is not known if male participants would have had any differing opinions to female participants with regards to the questions posed in the interviews. Likewise, none of the participants identified as autistic, and it is unclear if autistic doctors would have differing opinions on the medical education system surrounding autism care. While some participants had family members with autism, such as Resident 8, who had some strong opinions on the education system, and also took an active advocacy role in her training, others had little exposure to autism beyond work and school. More diversity in the participant sample would broaden the results to a more generalizable audience.

Further, despite two schools participating in the study, there are regional contexts and healthcare structures that differ across Canada, which may introduce nuances that are not represented in this study, despite the overarching question asking about Canadian residents. Despite the factors listed in this section, the overarching themes and content identified here provide a foundation for addressing how pediatric residents currently view best practice care regarding autism in community practice, what the current gaps in training are as perceived by pediatric residents, and what the next steps are for curriculum reform in terms of the pediatric residency training programs. Future studies may incorporate a larger participant sample with greater geographic width and more diversity in the study sample.

6.8. Summary of Discussion and Concluding Remarks

The discussion of this thesis has explored resident's perceptions on best practice care related to autism, and the critical gaps in autism education within pediatric residency programs. By examining the perspectives of pediatric residents, it is evident that there is a strong desire to provide best practice care to autistic patients, but there are significant challenges that must be overcome to achieve this goal. The recommendations outlined in this chapter offer first steps towards practical solutions to enhance the training of future pediatricians.

This chapter highlighted the need for interdisciplinary collaboration, community-based learning opportunities, and a greater focus on long-term care planning as essential components to a comprehensive curriculum regarding autism. Institutional support and policy changes are crucial to the successful implementation of these recommendations, ensuring that all pediatric residents receive the education and training necessary to provide effective patient-centered care for autistic children.

Ultimately, this thesis underscores the importance of ongoing efforts to improve autism care in Canada by looking at pediatric residency programs and training the next generation of pediatricians to be competent in autism care. By recognizing that well-trained pediatricians are vital to the long-term health and well-being of autistic patients, residency programs can work to better prepare their trainees to meet the needs of autistic patients, and provide care to them in a more timely manner, thus leading to improved outcomes and a more inclusive healthcare system.

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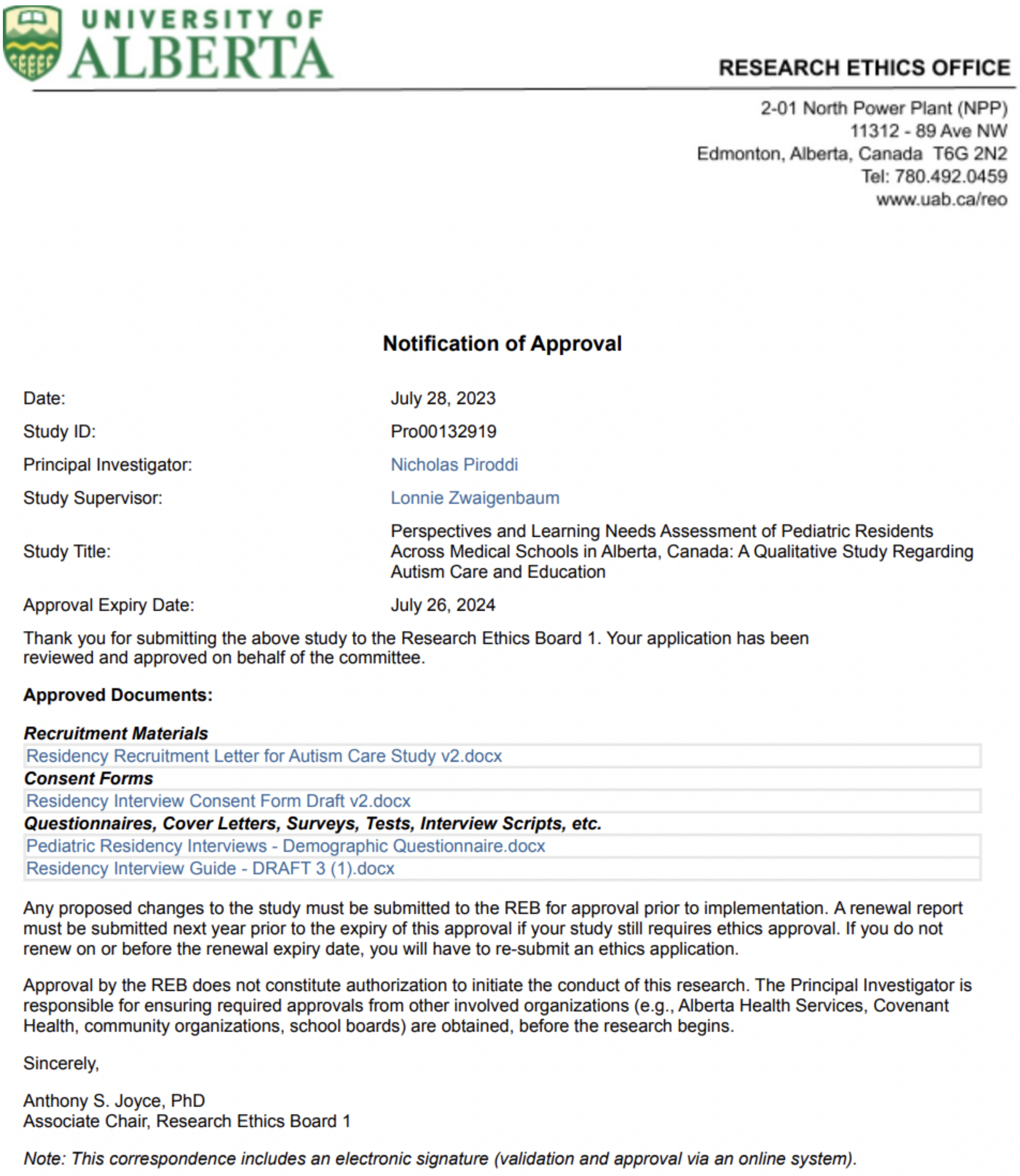
APPENDIX A. Certificate of Institutional Ethics Review Board



UNIVERSITY OF
ALBERTA

RESEARCH ETHICS OFFICE

2-01 North Power Plant (NPP)
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Edmonton, Alberta, Canada T6G 2N2
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Notification of Approval

Date:	July 28, 2023
Study ID:	Pro00132919
Principal Investigator:	Nicholas Piroddi
Study Supervisor:	Lonnie Zwaigenbaum
Study Title:	Perspectives and Learning Needs Assessment of Pediatric Residents Across Medical Schools in Alberta, Canada: A Qualitative Study Regarding Autism Care and Education
Approval Expiry Date:	July 26, 2024

Thank you for submitting the above study to the Research Ethics Board 1. Your application has been reviewed and approved on behalf of the committee.

Approved Documents:

Recruitment Materials

Residency Recruitment Letter for Autism Care Study v2.docx

Consent Forms

Residency Interview Consent Form Draft v2.docx

Questionnaires, Cover Letters, Surveys, Tests, Interview Scripts, etc.

Pediatric Residency Interviews - Demographic Questionnaire.docx
Residency Interview Guide - DRAFT 3 (1).docx

Any proposed changes to the study must be submitted to the REB for approval prior to implementation. A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the REB does not constitute authorization to initiate the conduct of this research. The Principal Investigator is responsible for ensuring required approvals from other involved organizations (e.g., Alberta Health Services, Covenant Health, community organizations, school boards) are obtained, before the research begins.

Sincerely,

Anthony S. Joyce, PhD
Associate Chair, Research Ethics Board 1

Note: This correspondence includes an electronic signature (validation and approval via an online system).

APPENDIX B. Informed Consent Form

Research Consent Form for Pediatric Residency Interviews

Title of Study: Perspectives and Learning Needs Assessment of Pediatric Residents Across Medical Schools in Western Canada: A Qualitative Study Regarding Autism Care and Education

Ethics ID: Pro00132919

Primary Investigator, Graduate Student: Nicholas Piroddi, BSc, MSc candidate. University of Alberta; 780-735-6273; piroddi@ualberta.ca

Research Supervisor: Dr. Lonnie Zwaigenbaum, MD. University of Alberta, Faculty of Medicine and Dentistry, Department of Pediatrics; 780-735-8280; lonniez@ualberta.ca

Why am I being asked to take part in this research study?

We are investigating the perspectives and learning needs regarding autism care in medical training. Our team is interested in gaining insight into autism care with respect to the CanMEDS framework guidelines, and how senior resident's perspectives can be used to inform learning objectives on developmental rotations (and other applicable rotations) regarding autism diagnosis and long-term care. We would like to invite you to take part in this research study. Before agreeing to take part in the study it is important to understand how you will be involved. This form contains information about the study. If you have any questions, please feel free to ask questions to Nicholas Piroddi by telephone or email. You will be given a copy of this form for your records.

What is the reason for doing this study?

The study is being conducted as part of Nicholas Piroddi's MSc thesis. Despite autism being a prominent condition, research has shown that pediatricians typically lack confidence in their ability to diagnose and provide long-term care for children with autism, citing a lack of knowledge in assessment/screening tools, effectiveness in tools, and lack of knowledge on resource access. To our knowledge, pediatric residents have not given insight as to their perspectives and learning needs with regards to autism care, including what they perceive their role to be in autism care, and inquiring about their experiences in medical training.

This overarching goal of Nicholas' thesis and career is to improve autism care in Canada. To do this, it is important to understand the learning needs and perspectives of residents to inform curriculum developers and program directors of residents' needs, strengths and limitations of the current training system, and overall interest in more education with regards to autism. We plan to obtain this information through one-on-one interviews with senior residents (PGY3 and PGY4) at the University of Alberta, University of Calgary, and University of British Columbia. We are looking to recruit at least 12 senior residents to provide adequacy of data.

What will I be asked to do?

If you decide to participate in this study, you will be involved in the following:

- Sign the consent form to be involved in the study
- Fill out a demographic survey with information on general demographics, your education, and experience (approximately 5 minutes to complete via RedCAP)
- Participate in a 30-45 minute one-on-one interview with a research staff member (i.e., a graduate student at the University of Alberta). Please note that having your camera on is optional, and you may choose to keep your camera off during the interview.

How long will I be in the study?

Participation will take a total of about 1 hour to 1.5 hours.

What are the risks and discomforts?

Potential Risks: There should be no risk to you participating in this study. If you feel uncomfortable at any time during the interview, you can request that we stop the interview, or take a break.

Inconvenience of Time: There is an inconvenience of time, as the interview will take about 30 - 45 minutes.

It is not possible to know all the risks that may happen in a study, but the researchers have taken all reasonable safeguards to minimize any known risks to a study participant.

What are the benefits to me?

There are no known benefits to participating in the study. Some people feel satisfaction from knowing they are sharing their experience that could improve curriculum development and the overall education regarding autism in Canada.

The study will lead to a better understanding of the perspectives and learning needs of pediatric residents to inform future program delivery.

Do I have to take part in the study?

It is your choice to take part in the study; participation is voluntary. You can change your mind at any time during the interview. The study team may ask why you are withdrawing for reporting purposes, but you do not need to give a reason to withdraw from the study if you do not want to. This decision will not affect your residency training or relationships with the Glenrose Rehabilitation Hospital, and if you choose to participate, you may stop at any point. If you decide to leave the study, you can contact the Principal Investigator or a member of the study team to let them know. You can withdraw your data prior to anonymization of the transcript of their interview, which will take place two weeks after the interview is conducted.

Will I be paid to be in the research?
You will receive a $25 Indigo gift card for participation in this study, which will be received over email upon completion of the interview. The gift card will be retained if the participant chooses to withdraw after the interview

Will my information be kept private?
During the study we will be collecting data about you. We will do everything we can to make sure that this data is kept private. No data relating to this study that includes your name will be released outside of the researcher's office or published by the researchers. Sometimes, by law, we may have to release your information with your name so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your information is kept private.

During research studies it is important that the data we get is accurate. For this reason, your health data, including your name, may be looked at by people from the University of Alberta, and/or members of the Research Ethics Board.

We will collect some personal information about you (name, age, gender) and information about your practice/career (years of service, education) so that we can describe the group of people we interview. If you would like to receive a paper copy of the consent form, you have the option of providing us with your address. This personal information will not be shared outside of the Glenrose Rehabilitation Hospital Autism Research Centre team. All information collected about you will be "de-identified" by replacing your identifiable information (i.e., name) with a "study number". We will do this as soon as we check that the interview was successfully recorded and before we send it for transcription.

Even though your name will not be part of the audio recording or the transcription, your voice may still be identifiable as your voice. If you mention identifiers (e.g., your name, location), during the recording, we will remove them from the transcript. We may use direct quotations from your interview without any identifying information when we share the results of this study in papers and presentations.

The audio recordings and de-identified transcripts will be kept for 7 years after study closure as required by University of Alberta policy. De-identified information will be available to the Glenrose Rehabilitation Hospital Autism Research Centre team and may be accessed for the purpose of quality improvement work.

What if I have questions?
If you have any questions during your participation in this research study, you can contact the Primary Investigator (Nicholas Piroddi) or the Research Supervisor (Dr. Zwaigenbaum), who will be happy to answer any questions that you may have. If you have any questions regarding your rights as a research participant, you may contact the University of Alberta Research Ethics Office at reoffice@ualberta.ca. This office has no affiliation with the study investigators.

How do I indicate my agreement to be in this study?

By signing below, you understand:

- That you have read the above information and have had anything that you do not understand explained to you to your satisfaction
- That you will be taking part in a research study
- That you may freely leave the research study at any time
- That you do not waive your legal rights by being in the study
- That the legal and professional obligations of the investigators and involved institutions are not changed by your taking part in this study.

SIGNATURE OF STUDY PARTICIPANT

Name of Participant

____

Signature of Participant Date

__________________________________ __________________________________

SIGNATURE OF PERSON OBTAINING CONSENT

Name of Person Obtaining Consent Contact Number

__________________________________ __________________________________

Signature Date

__________________________________ ______________________

SIGNATURE OF THE WITNESS

Name of Witness

____

Signature of Witness Date

__________________________________ ______________________

A copy of this consent form has been given to you to keep for your records and reference.

APPENDIX C. Recruitment Documents

Initial Recruitment E-Mail

Subject Line: Research Study: Pediatric Residency Interviews Regarding Autism Care in Western Canada

Email Text:

Dear Resident,

Graduate student Nicholas Piroddi is looking for participants for his thesis project regarding autism care in Western Canada. (supervisor: Dr. Lonnie Zwaigenbaum) at the University of Alberta in the Department of Pediatrics.

The main goal of the thesis project is to better understand the perspectives of senior pediatric residents (defined as PGY3 and PGY4, as well as recent grads) in Western Canada with regards to how their learning needs and priorities are being met with regards to autism care during their training. The hope is that perspectives can be used to inform learning objectives and curriculum for pediatric residents regarding autism diagnosis and ongoing health care, and potentially in medical school as well.

We would like to invite you to be a part of this research study. Please note that participation is voluntary, and you will receive a $25 Indigo Gift Card for your time.

If you are interested in participating, please email Nicholas at piroddi@ualberta.ca stating your interest in the study.

After an initial email, Nicholas will contact you, and the next steps, which involve:

- Sign the consent form to be involved in the study
- Fill out a demographic survey (approximately 5 minutes to complete via RedCAP)
- Participate in a 30-60 minute one-on-one interview (virtually, over Zoom)

If you are interested in participating, please let Nicholas know so we can set up an interview time over Zoom this fall. Please note that you can have your camera off if you choose during the interview.

The next steps following involve the study team sending you a consent form, and you filling out a short demographic questionnaire on the RedCAP platform.

Thank you for your time and consideration, and we look forward to hearing from you. Please feel free to contact Nicholas at piroddi@ualberta.ca, or at his office phone number (780-735-6273) if you have any questions!

Ethics ID: Pro00132919

Nicholas Piroddi, BSc

Masters Student / Research Assistant

Department of Pediatrics, University of Alberta

Autism Research Centre (E209)

10230 - 111 Avenue

Glenrose Rehabilitation Hospital

Edmonton, Alberta

Second Recruitment E-Mail

Subject Line: NOW OPEN TO PGY1 AND PGY2 RESIDENTS - Research Study: Pediatric Residency Interviews Regarding Autism Care in Alberta (Participation still needed!!)

Email Text:

Dear residents,

This is a followup to the email sent earlier this fall. University of Alberta graduate student Nicholas Piroddi (supervisor: Dr. Lonnie Zwaigenbaum, Department of Pediatrics) is continuing to look for participants for his thesis project regarding autism care in Western Canada, **and is now opening up the project to all residents - meaning first and second year residents can participate if interested!** It is important for us to understand all perspectives from a variety of backgrounds with regards to autism care. The hope is that perspectives can be used to inform learning objectives and curriculum for pediatric residents regarding autism diagnosis and ongoing health care, and potentially in medical school as well.

If you are interested in participating, please email Nicholas at piroddi@ualberta.ca stating your interest in the study. He will be in touch with the next steps, which include filling out a consent form and demographic questionnaire, and setting up a 30-60 minute Zoom interview. You will be compensated with a $25 gift card for your time following the completion of the interview process.

Thank you for your continued support, and consideration! We look forward to hearing from you. Please contact Nicholas at piroddi@ualberta.ca if you have any questions!

Ethics ID: Pro00132919

Nicholas Piroddi, BSc

Masters Student / Research Assistant

Department of Pediatrics, University of Alberta

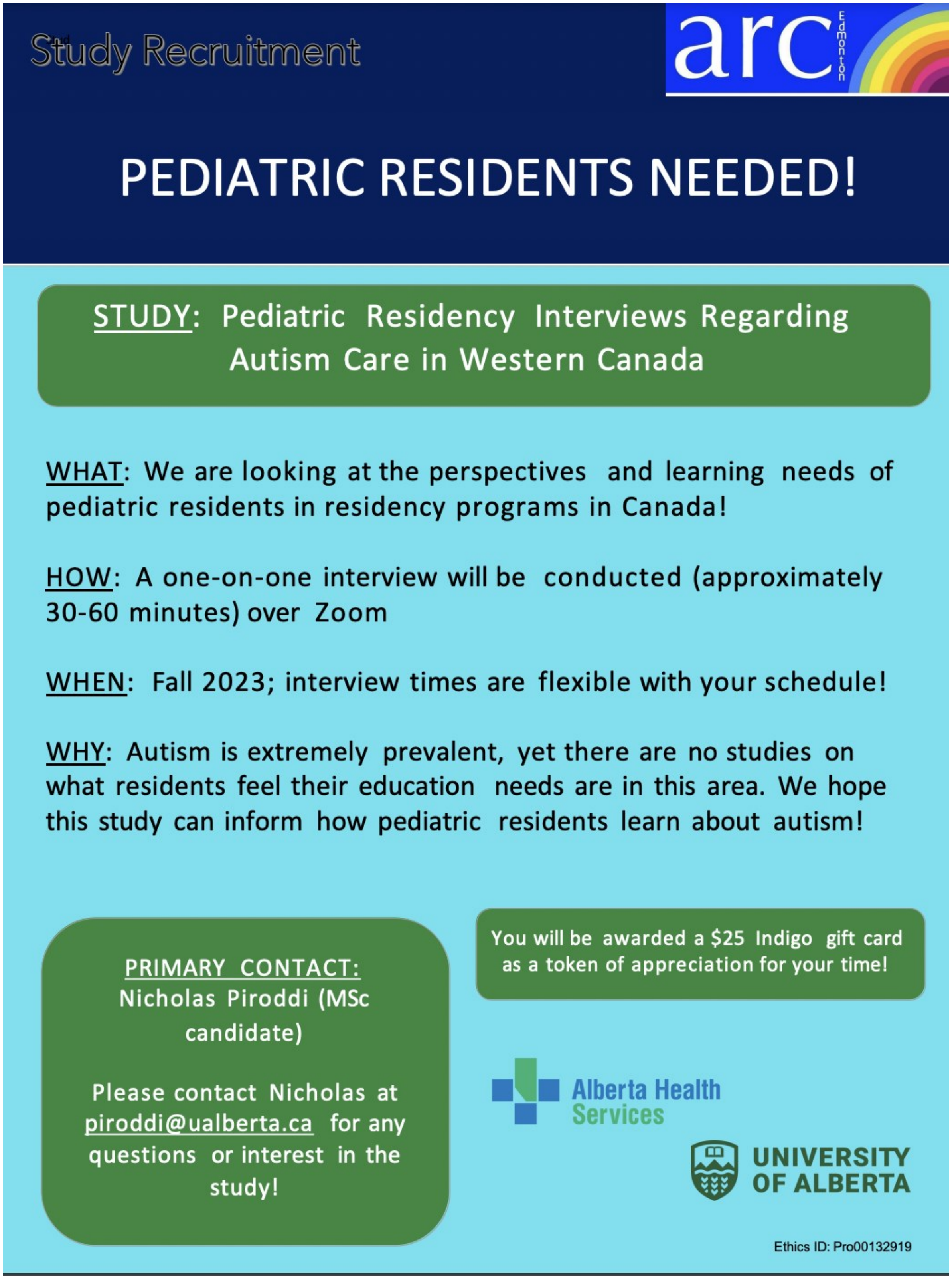
Autism Research Centre (E209)

10230 - 111 Avenue

Glenrose Rehabilitation Hospital

Edmonton, Alberta

Recruitment Poster



Study Recruitment

arc Edmonton

PEDIATRIC RESIDENTS NEEDED!

STUDY: Pediatric Residency Interviews Regarding Autism Care in Western Canada

WHAT: We are looking at the perspectives and learning needs of pediatric residents in residency programs in Canada!

HOW: A one-on-one interview will be conducted (approximately 30-60 minutes) over Zoom

WHEN: Fall 2023; interview times are flexible with your schedule!

WHY: Autism is extremely prevalent, yet there are no studies on what residents feel their education needs are in this area. We hope this study can inform how pediatric residents learn about autism!

PRIMARY CONTACT:
Nicholas Piroddi (MSc candidate)

Please contact Nicholas at piroddi@ualberta.ca for any questions or interest in the study!

You will be awarded a $25 Indigo gift card as a token of appreciation for your time!

Alberta Health Services

UNIVERSITY OF ALBERTA

Ethics ID: Pro00132919

APPENDIX D. Demographic Questionnaire

Pediatric Residency Interviews - Demographic Questionnaire

Title of Study: Perspectives and Learning Needs Assessment of Pediatric Residents Across Medical Schools in Western Canada: A Qualitative Study Regarding Autism Care and Education

Ethics ID: Pro00132919

Primary Investigator: Nicholas Piroddi, BSc, MSc candidate. University of Alberta; 780-735-6273; piroddi@ualberta.ca
Research Supervisor: Dr. Lonnie Zwaigenbaum, MD. Glenrose Rehabilitation Hospital; 780-735-8280; lonniez@ualberta.ca

Note: The survey will be conducted via RedCAP. The purpose of this document is for Ethics approval.

Your Gender Identity:

- Woman
- Man
- Non-binary
- Gender fluid
- Two spirit
- Trans Male
- Trans Female
- Androgynous
- Prefer Not To Say
- Identity not listed (specify below)

If Not Listed, Specify Here:

Ethnicity (please check all that apply)

- Arab
- Asian - East (e.g., Chinese, Japanese, Korean)
- Asian - South (e.g., Indian, Pakistani, Sri Lankan, Indo-Caribbean)
- Asian - South East (e.g., Malaysian, Filipino, Vietnamese)
- Asian - West (e.g., Iranian, Afghan)
- Black or African American [Africa (e.g., Ghanaian, Kenyan, Somali)]
- Black or African American [Caribbean Region (e.g., Barbadian, Jamaican)]
- Black or African American [North America]
- Caucasian/White (e.g., English, Italian, Portuguese, Russian)
- Hispanic or Latino origin [Mexican, Mexican American, Chicano/a]
- Hispanic or Latino origin [Puerto Rican]
- Hispanic or Latino origin [Cuban]
- Hispanic or Latino origin [Another Hispanic, Latino/a or Spanish origin]
- Indigenous/First Nations/Aboriginal [North America]
- Jewish
- Latin American (e.g. Argentinean, Chilean, Salvadoran)
- Middle Eastern (e.g., Armenian, Iraqi, Lebanese)
- Native Hawaiian or Other Pacific Islander
- North African (e.g., Egyptian, Moroccan)
- Other group - specify
- Unknown
- Do not wish to provide

If Not Listed, Specify Here:

Optional - Country of Origin:

What Country Did You Graduate Medical School From?

Which Medical School Did You Graduate From?:

What Year Did You Graduate Medical School?:

What Year Of Your Residency Are You In?:

What School Are You Currently Doing Your Residency Through?
- University of Alberta
- University of Calgary
- University of British Columbia

Do You Plan On Doing A Pediatric Subspecialty Residency?:

If Yes, Which One?:

Have You Taken Any Electives/Additional Training In Child Development?
- Yes
- No
- Don't Know

If yes, please specify:

Have you had personal experience with autism?
- Yes, I have autism
- Yes, I have an immediate family member with autism
- Yes, I have an extended family member with autism
- Yes, I have a friend with autism
- No

Briefly explain your experience with autism in an academic setting:

In your medical training thus far, what tools or strategies have you been exposed to when you are presented with cases of developmental concerns? (Check all that apply)

- History
- TELE-ASD-PEDS
- CARS
- Diagnostic Criteria
- RITA-T
- Video Recording
- Informal Observation/Interaction
- Autism Questionnaires
- School Questionnaires
- ADOS
- Developmental Questionnaires
- Developmental Assessments
- School Report
- Mini-ADOS
- MCHAT
- AAPLES
- Other

If Other, Specify Here:

APPENDIX E. Semi-Structured Interview Guide

As part of my Masters of Science thesis, I am asking pediatric residents either as they are completing or after they have completing their training about their perspectives about their learning needs related to assessment and the ongoing care of children and youth on the autism spectrum. Our hope is that this will inform curriculum development for pediatric training to support clinical practice that improves quality of life for autistic children in Alberta.

Primary Research Questions:

(1) What are the current learning needs of Alberta Pediatric Residents with regards to autism care and potential areas for improvement in terms of their training experiences?

(2) What are pediatric residents' perspectives on providing best practice care for autistic patients, including the role of the pediatrician on the care team?

Introduction Questions

(1) How do you define autism?

(2) What is your personal experience working with people with autism, outside of the educational environment (i.e. from life experience)?

(3) How much exposure did you have to autism-related topics in preclerkship years in medical school? Clerkship years? In residency so far?
    (a) Undergrad?

(4) What learning experiences have you had during residency related to providing care to people with autism?

Perspectives Questions

(1) How do you define 'best practice care' in a community context? How would you apply this definition to autism care specifically?

(2) What factors do you perceive as being most important when working with a patient you suspect may have autism? How about if they've already been diagnosed with autism?

(3) From your perspective, who should be involved in care for autistic patients?

    (a) (Probe: Among these professionals, what do you see your role being in providing best practice care?)
    (b) (Probe: How have you seen, or how do you foresee, allied healthcare professionals communicating to promote best practice care for autistic patients?)

Learning Needs Questions

(1) What have you learned in your training regarding autism care? Do you think that what you've learned is adequate? Why or why not?
    (a) (Probe: ask about diagnostics, long term care, and co-occurring conditions)

(2) What are some gaps you have found in your training regarding autism care?
    (a) (Probe: ask about diagnostics, long term care, and co-occurring conditions)

(3) In comparison to other pediatric conditions and disorders, such as asthma and diabetes how do you feel your knowledge base compares with regards to autism?
    (a) (Also probe to other developmental conditions)

(4) What strategies do you use or envision using when discussing an autism diagnosis and management plan to a patient and/or family?
    (a) (Probe: Incorporate into future practice; would you involve any other allied healthcare professionals?)
    (b) (Have the residents shared a diagnosis? (Probe))

(5) Taking your current experiences into account, what would you recommend keeping and/or changing to residency training related to autism?
    (a) (Probe: developmental pediatrics rotation vs other rotations?)

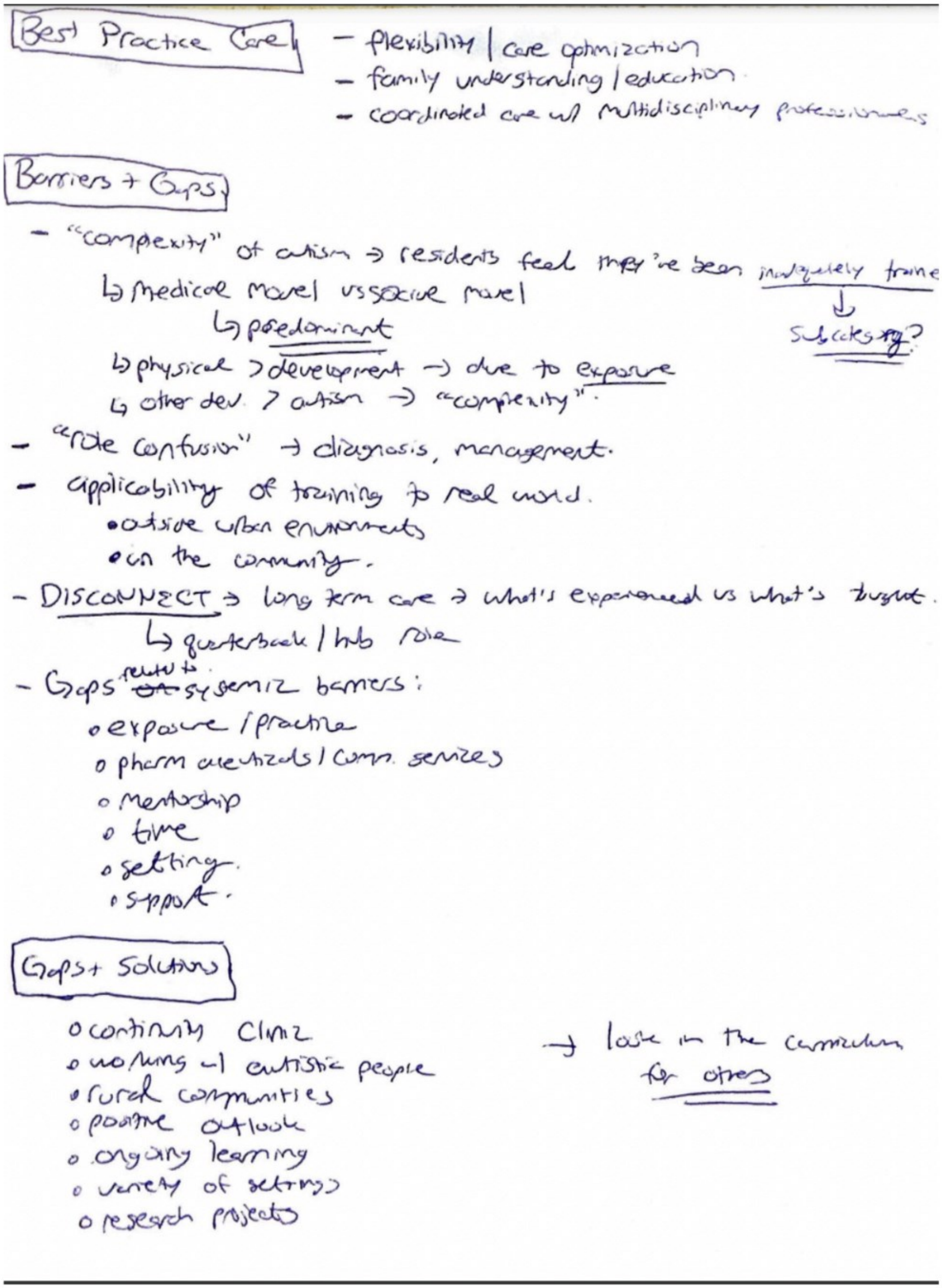
(6) How have your preceptors contributed to your knowledge of working in autism care in a pediatric setting?

Concluding Questions

(1) What roles do you anticipate in providing healthcare to autistic patients in your future practice?

(2) Is there anything else that these questions did not cover regarding your education and perspectives on autism care that you would like to discuss?

APPENDIX F. Visual Schematic of Thematic Analysis Planning



Best Practice Care
- flexibility | care optimization
- family understanding | education.
- coordinated care w/ multidisciplinary professionals

Barriers + Gaps

- "complexity" of autism → residents feel they've been inadequately traine
  ↳ Subcategory?
  - ↳ medical model vs social model
    - ↳ predominant
  - ↳ physical > development → due to exposure
  - ↳ other dev. > autism → "complexity".
- "role confusion" → diagnosis, management.
- applicability of training to real world.
  - outside urban environments
  - in the community.
- DISCONNECT → long term care → what's experienced vs what's taught.
  - ↳ quarterback / hub role
- Gaps ~~on~~ related to systemic barriers:
  - exposure / practice
  - pharm electives / comm. services
  - mentorship
  - time
  - setting.
  - support.

Gaps + Solutions

- continuity clinic
- working w/ autistic people
- rural communities
- positive outlook
- ongoing learning
- variety of settings
- research projects

→ lack in the curriculum for others

APPENDIX G. Codebook Summary

Research Question 1. Perspectives

1.1 Autism Definitions

- 11 out of 12 participants gave the DSM-5 criteria of autism when asked, focusing on the medical model
- 4 of the 12 participants also discussed the social model of autism when asked about a definition of autism.
- A few other codes:
    - "Don't know the origins of" - 2
    - "Spectrum condition" - 2 / "Multifaceted condition" - 2

1.2 Experiences with Autism

- Lived experience:
    - 6 participants have had volunteer experiences with autistic people prior to medical school
    - 5 participants noted a friend with autism
    - 4 participants had work experiences with autistic people prior to medical school
    - 3 participants had an extended family member with autism
    - 2 participants noted little personal experience
- 9 of the 12 participants stated that there is VERY little exposure to autism in medical school.
- 8 participants noted gaps in the clerkship years of medical school (UGME Years 3 and 4).
- 6 of the 12 participants took optional electives or shadowing experiences in medical school years.
- 5 of the participants noted that this occurred in the pediatrics rotation
- Residency:
    - 9 participants noted autism experiences in developmental pediatrics blocks, and 8 participants noted autism experiences in other pediatrics blocks (not development)
    - 3 participants noted that there was little exposure to autism in residency even
    - There are lectures in residency, as noted by 3 participants
    - 3 participants noted that there is not a focus on long-term care, and another 3 participants noted that there is not a focus on outpatient care.
        - 7 participants noted a focus on diagnostics in residency when doing developmental pediatrics.
- 7 participants stated that specific people are needed to guide autism-related training, and some also noted that there aren't a lot of these specific people.

1.3 Best Practice Care

- 9 of the 12 participants noted that the criteria best practice care for general pediatrics does not change for those with autism compared to neurotypical
- 5 participants noted "optimizing care" for the patient is important in best practice care, with another 2 talking about taking a holistic approach (biopsychosocial model)
- 3 participants noted access to a primary care provider is considered best practice care; and 3 participants noted that access to needed/necessary services is considered best practice care
- 3 participants noted that "actualizing gold standard practices" is considered best practice care.
- 3 participants noted a family centered care approach to providing best practice care
- 3 participants noted in depth assessment is necessary for best practice care
- 2 participants noted that making the correct diagnosis and evaluating for co-occurring conditions is important
- 2 participants noted teamwork support for best practice care
- 2 participants noted timely access and care for best practices

1.4 Factors Important in Care

- 7 participants noted flexibility/optimizing care is important when considering factors involved in autism care. On top of that, 6 participants stated that the patient is #1 when looking at important factors associated with autism.
- 6 participants noted parental understanding is important, and 5 participants noted supports and resources at home are important factors to consider. 1 participant noted kindness to family
- 4 participants noted taking a developmental history
- 4 participants noted that the important factors do not change before and after diagnosis of autism.
- A few other codes:
    - "After diagnosis - looking at connected resources the family may have" - 2
    - "Factors associated with the context of safety" - 2
    - "Continue to do functional assessments even after diagnosis" - 2
    - "Functioning piece (of the child)"" - 2

1.5 Professionals Involved

- 7 participants noted communication is strong at multidisciplinary sites such as the Glenrose or Sunny Side, with 2 participants noting that in the community there is not a lot of back and forth communication. 3 participants noted communication is good, but not strong.
- 6 participants explicitly stated that more than a physician is needed to provide best practice care for autistic patients
- 6 participants noted a pediatrician is important in autism care; 3 participants noted family physicians should be involved in autism-related care if they are comfortable doing so
- 2 participants noted that the role of a developmental pediatrician varies across Canada

- *Who all is involved in autism care?*
    - 11 - Speech Language Pathologist therapy
    - 10 - Occupational therapy
    - 6 - Behavioural therapist
    - 6 - Pediatrician
    - 6 - Physical Therapy
    - 4 - Family
    - 4 - Social Work
    - 4 - Teachers and EAs
    - 2 - All doctors
    - 2 - Child life specialist
    - 2 - Dentists
    - 2 - Dietitian
    - 2 - Nursing
    - 2 - Psychologists
    - 1 - A trusted doctor
    - 1 - Audiologist
    - 1 - Extracurricular Coaches
    - 1 - Optometrist
    - 1 - Peers
    - 1 - Psychiatrist

1.6 Future Roles

- 7 participants noted that they envision themselves playing a role in long term care for autistic patients
- 6 participants noted that they envision themselves playing a "hub/quarterback" role, and 4 participants noted that they want to be the primary care provider for the child.
- 6 participants noted that they envision themselves doing at least some diagnostic work
- 4 participants stated a desire to play a role in autism care explicitly
- 3 participants noted that they want to "help change the system such that pediatricians can diagnose autism," and potentially play a role in education and advocacy.
- 3 participants see themselves doing the initial assessment of autism, even if that doesn't mean being in the diagnosis part.
- 2 participants noted they will be cognitive of autism when conducting physical exams
- 2 participants noted they want to be able to do "obvious case diagnosis"

Research Question 2. Learning Needs

2.1 What's Been Learned

- 10 of the participants stated that what they learned regarding autism is *not adequate*, and 2 participants noted that what they've learned is adequate, but are focusing on subspecialties where autism is not as much of a priority.
- 2 participants noted that they've learned more about autism from real life than from medical school
- *Things that have been learned:*
    - 6 - Autism is a "wide spectrum"
    - 5 - CPS statements
    - 3 - Autism Diagnosis and tools
    - 3 - DSM-5 criteria
    - 3 - Long term management care and co-occurring conditions
    - 3 - Team approach to diagnostics
    - 2 - Assessing for co-occurring conditions
    - 2 - Care is multifaceted
    - 2 - Differences in care
    - 2 - external factors/environment is important

2.2 Gaps Found

- 5 participants noted they have a lack of clarity on their role in autism-related care
- 5 participants noted that in training, there was a lack of focus on long-term care for autistic patients
- 4 participants stated they want more exposure and teaching in residency, and 4 participants stated that they want/need more practice with autism-related care activities.
- 4 participants noted a lack of knowledge on pharmaceuticals associated with autism care
- 4 participants noted that timely diagnosis is a gap to both patients and to doctors.
- 3 participants stated that they wanted more exposure to assessments in residency training
- 3 participants noted there were gaps regarding skills in communication in the community
- 2 participants noted that community diagnostics were lacking in general pediatrics
- 2 participants noted a lack of knowledge on services in residency training
- 2 participants noted a lack of perceived support systems for kids in residency training
- 2 participants noted the management of co-occurring conditions was a gap found
- 2 participants stated that what they've learned in residency is not really practical/applicable to the real world outside of major urban centers (i.e. rural communities). 1 participant noted that what they've learned is not proportional to the real world.

2.3 Comparing to Other Conditions

- 10 participants noted they are more comfortable with physical conditions than they are mental/developmental conditions. 2 participants noted equivocal knowledge
- 9 participants noted they are more comfortable with other developmental conditions (i.e. ADHD) compared to autism
    - 2 participants stated a potential reason for autism being less focused on is because it is "more subjective" compared to other developmental concerns. 2 participants even noted that there is a lack of clarity of what autism even is sometimes
    - 2 participants noted they are comfortable managing co-occurring conditions such as ADHD with medication, but not autism specifically
- 3 participants stated that sometimes developmental concerns are ignored, and 2 participants said that training in development compared to other conditions is "terrible"
- 3 participants noted that they are more comfortable with autism than physical conditions only after a developmental pediatrics subspecialty.

2.4 Strategies Involved

- 9 participants noted that they want to have a positive outlook when diagnosing a child with autism; 2 participants noted that diagnostic delivery must be approached in an empathetic manner
- 8 participants noted that parental readiness is an important factor when disclosing a diagnosis, and 7 participants
- 8 participants noted a case-by-case approach in diagnostic delivery
- 4 participants noted it is important to read the room when giving an autism diagnosis
- 4 participants noted they would get allied healthcare professionals involved, with some noting it is due to them having more skills in diagnostic delivery.
- 3 participants noted they give examples of what was seen in the assessment as a strategy for disclosing a diagnosis
- 3 participants noted that they would offer support immediately to patients
- 3 participants stated that their approach to delivering a diagnosis would depend on the complexity of the case
- *Important to note that many seemed to dance around the question - skill issue?*

2.5 Changes to Program

- 5 participants stated that they want more teaching on autism, and 5 participants stated that there should be more teaching outside of the developmental block.
- 5 participants said that the developmental rotation should be kept, and expanded upon.
- 4 participants stated they would like autistic patients in an additional continuity clinic
- 4 participants stated they wanted more teaching on long-term care management
- 4 participants stated they want clearer direction on community guidelines
- 4 participants noted they want more skills in diagnostic delivery, and 2 participants noted more skills in general
- 3 participants noted that experiences with autism should be more prominent earlier on in medical training (UGME)

- 2 participants noted they would like the autism related learning to be better applicable to non-urban centers, and another 2 participants noted that they wish what they've learned could be better integrated into the community
- 2 participants said they wanted to learn more autonomy from program providers, allowing the residents to have a more hands-on approach
- 2 participants noted they would like to be taught on interventions and services they are recommending to patients.
- 2 participants noted that they would like training time with allied health care professionals and staff to learn more about autism, not just from doctors.

2.6 Preceptors

- 4 participants said that they've adopted strategies from their preceptors
    - Interacting with families (2)
    - Multidisciplinary teamwork (1)
- 4 participants stated there was not a lot of conversation regarding autism in the community from preceptors, with 2 participants stating they are only taught what they are comfortable with
- 4 participants said that community preceptors were valuable in the community, with 2 saying that the specialists have been great. 4 participants also said there was thoroughness in discussions in developmental pediatrics rotation. (2 said willing to have conversations in the community)
- 2 participants noted that the preceptors had a hands-on approach to autism-related learning activities