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UMI®

Bridging Undergraduate Medical Education in Autism Spectrum Disorder (ASD) To Physicians' Early Detection Practices

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ABSTRACT

Health care providers, parents, and educators are calling for earlier diagnosis and treatment of Autism Spectrum Disorder (ASD). ASD is a devastating, life-long disorder that puzzles and even paralyzes both parents and professionals. Delayed diagnosis of ASD and constrained developmental surveillance is a critical issue because of physicians' variable detection practices and the increasing prevalence of ASD. The premise of this inquiry was to discover if the variability in physicians' practices also exists in undergraduate medical education, because once physicians leave medical education, continuing medical education has limited effect on practice behavior. Therefore, the rationale of this study was this: medical school is the best setting--and where there is the greatest opportunity--to teach physicians about ASD and early detection practices.

Borrowing from an ethnographic perspective, this study investigated curricula and education practices used in an undergraduate medical school for identifying and treating children with ASD. Rich descriptions of these curricula, along with common themes emerged from the data which included telephone interview transcripts from 13 participants (2 medical school administrators, 7 fourth year medical students, and 4 instructors), curricula syllabi, and in some instances curricula content. The analysis of the findings followed Miles & Huberman's Interactive Model and the Six-Step Approach to Curriculum Development for Medical Education. Methods such as triangulation, respondent validation, and member checking confirmed the findings. This needs assessment of undergraduate medical education provides a framework for the content and structure of ASD curricula in order to understand and to change the underpinnings of physician detection practices.

Three factors delay ASD diagnosis until late preschool: physician detection practices, misinterpreted and inaccurate parent reports, and the symptomatic nature of ASD. The findings suggest all the factors that delay diagnosis in clinical practice are present in current practices in undergraduate medical education. Four major themes emerged: (1) Curricula structure and medical education's current pressures affect child development and ASD integration in the curricula; (2) Students learn basic developmental milestones as a method to detect ASD and other developmental disorders; (3) Clinical guidance is constrained for detection practices of ASD and other developmental disorders, and (4) Students experience limited ASD patient contact and do not have the skills for early detection practice. These findings provide opportunities and have implications for learning and teaching ASD curricula in undergraduate medical school.

This study offers insight to the practice gap in early child health surveillance and provides educational goals and teaching strategies for medical students on early detection practices. The findings provide curriculum planners with a baseline for evaluating the impact of ASD curricula. The long-term goal of this research is to ensure ASD curricula is relevant and succinctly comprehensive. The anticipated long-term outcome is to prepare medical students for their future practices so they have a positive impact on the health of children with ASD and their families.

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CHAPTER 1

1.0 *Introduction: An Overview of the Health Care Gap*

When a child is born, the family waits with bated breath to hear the words, "It's a healthy baby." Once they've heard them, they relax and begin the journey of raising their child. During the child's early years, when parents begin to have concerns about their child's development, they continue to cling to the words they first heard. What they may not know and what physicians may not identify is that their child has some form of developmental delay or Autism Spectrum Disorder (hereafter ASD). ASD is a devastating, life-long disorder that puzzles and even paralyzes both parents and professionals. Governing health care providers, parents, and educators are calling for solutions that lead to earlier diagnosis and treatment of ASD (Feinberg & Vacca, 2000; Filipek et al., 1999). This study examines one aspect in the complex set of factors related to early detection: the degree to which curricula related to ASD are found in current medical education.

Delayed diagnosis of Autism Spectrum Disorder (ASD) and constrained developmental surveillance is a critical issue in medical education because of physicians' variable detection practices and the increasing prevalence of ASD (Chakrabarti & Fombonne, 2001; Sices, Feudtner, McLaughlin, Drotar, & Williams, 2003). According to recently published data, one child in two hundred fifty (1/250) has Autism Spectrum Disorder (ASD), a chronic condition (Chakrabarti & Fombonne, 2005). The average age for a diagnosis of ASD is four years (Charman et al., 2001; Howlin & Moore, 1997; Palfrey, Singer, Walker, & Butler, 1987). According to child development and early intervention research, a diagnosis at four years is late, but explicable: ASD is a puzzling disorder, and difficult to detect (Bryson, Zwaigenbaum, &

Roberts, in press; Filipek et al., 1999). Often parents' and physicians' beliefs, fears, and uncertainties delay the diagnosis of ASD (Nissenbaum, Tollefson, & Reese, 2002; Sices et al., 2003). Three factors delay ASD diagnosis until late preschool: physician detection practices, misinterpreted and inaccurate parent reports, and the symptomatic nature of ASD (Bryson et al., in press; Sices et al., 2003).

Parents report that physicians and other health care professionals have difficulty detecting ASD (Avdi, Griffin, & Brough, 2000; Howlin & Moore, 1997; Midence & O'Neill, 1999). Some parents believe physicians act as barriers to receiving an appropriate referral (Howlin & Moore, 1997). However, parents often play a role in the delay of diagnosis, either through ignorance (they may not report symptoms) or through opposition (they deny the possibility of a developmental concern) (Nissenbaum et al., 2002). Despite the role they may play in the delay of diagnosis, parents blame their physicians for not detecting their child's ASD (Nissenbaum et al., 2002). Because parents experience tremendous stress and grief when their child is diagnosed with ASD, a late diagnosis intensifies their pain, especially, when they learn that early detection and early treatment of ASD may have improved their child's developmental outcomes (Gray, 1994; McEachin, Smith, & Lovaas, 1993; Rogers, 1998). That they may have missed a critical developmental window is heartbreaking and only intensifies parents' call for immediate intervention services (Nissenbaum et al., 2002). In Nova Scotia, it is largely children under six who receive funding for early intervention and health services (psychological assessment, occupational therapy and speech language therapy, for example) (McSorley, 2005). Children who are over six years old must be referred to their school's services. Therefore, the later the diagnosis of ASD, the less chance a family has of accessing early intervention resources and the greater the burden on the

family and educators as the child enters the school system where resources and expertise related to ASD are scarce (MacLeod, 2001).

Family physicians are often the first contact for parents of developmentally delayed children (Howlin & Moore, 1997; Sices et al., 2003). They play a critical role in identifying developmental delays and ASD (Glascoe, 1999). Presently, most physicians are not using objective or systematic tools for detecting ASD (Sices et al., 2003). They are primarily using "eyeballing", parent and child interviews, and their own adapted version of developmental assessment tools (Sices et al., 2003). Health care professionals admit they experience difficulty, fear, and uncertainty when detecting ASD (Nissenbaum et al., 2002). Evidently there is need for physician education on ASD detection and treatment practices. However, Davis et al. (1999) found continuing medical education has limited effect on changing physicians' practice behavior. Therefore, the premise of this study is this: medical school is the best setting--and where there is the greatest opportunity--to teach physicians about ASD and early detection practices.

1.1 Statement *of Purpose*

The purpose of this study is to identify the scope and nature of curricula and education practices used in an undergraduate medical school for identifying and treating children with ASD. This study uses a qualitative approach to an examination of the undergraduate medical curricula at a Canadian medical school. The inquiry takes the form of an educational needs assessment and borrows from the conceptual framework of the six-step approach to curriculum development authored by Kern, Thomas, Howard, and Bass (1998). The objective of this approach and this study is to link medical

education to the health care needs of children and families who live with ASD. This study will be based generally on the first 4 steps:

- Step 1: A general needs assessment of the health care gap provided in the review of the research literature.
- Step 2: Learning needs assessment with the 4th year medical students.
- Step 3 : Recommendations for curricula objectives, and
- Step 4: Proposed educational strategies.

The expected outcome is to provide information and insight for curriculum planners of pediatric medical education and a provision for Steps 5 & 6: implementing and evaluating the curricula objectives and educational strategies (Kern et al., 1998).

1.2 The *Research Questions*

This study uses a qualitative approach to inquiry, in which I will provide a description and then an interpretation of an undergraduate medical school's human development and ASD curricula objectives, contexts, and educational methods. This inductive approach to research (Creswell, 2005; Denzin & Lincoln, 2000) has become a standard methodology in education and the social sciences and is most suited to an examination of curricula. This exploration of the curricula materials and individual interviews with students and instructors will provide an understanding of the ASD curricula by asking the following questions:

1. What are students learning about ASD and by which educational methods?
2. What are students' experiences, interpretations, and understandings regarding detection, and diagnosis of children with ASD for future clinical practice?

1.3 Definition *of Terms*

The following terms and their definitions are used for this study:

ASD describes all the Autism Spectrum Disorders which include Autistic Disorder, Asperger's Disorder, Pervasive Developmental Disorder–Not Otherwise Specified (PDD-NOS), Childhood Disintegrative Disorder, and Rett's Disorder (American Psychological Association [APA], 1994).

Parents are all caregivers who care for children with ASD. This term is meant to be inclusive of different types of families which include biological parents, adoptive parents, grandparents, and same sex parents.

Physicians are representative of general and family physicians who are likely to be the frontline health care providers and gatekeepers for children and their families.

Health care professionals are speech language pathologists, psychologists, psychiatrists, and occupational therapists.

Students and clerks are undergraduate medical students in their first four years of medical education.

Residents have graduated from the four year undergraduate medical program and have been matched to their medical discipline or specialty (e.g., family medicine, pediatrics). This residency program is two years in duration.

Instructors are medical doctors, faculty and invited experts such as psychologists who teach undergraduate medical students about child development and ASD.

These terms are used throughout the ASD research literature and this study. The following chapter provides a foundation for the exploration of the curricula and informs the interview protocols.

CHAPTER 2

2.0 *Identification and Diagnosis of ASD: Current Understandings from the Research Literature*

Currently, no research literature explores ASD in undergraduate medical education. Therefore, this section will provide a review of the literature related to aspects of ASD identification, diagnosis, and physicians' practices. This chapter will also provide an overview of undergraduate medical education to show the context for pediatrics and ASD in the curricula.

2.01 Defining *Autism/ASD.* Autism Spectrum Disorders (ASD) is an umbrella term for several pervasive developmental disorders which vary in appearance and severity of symptoms. According to the *Diagnostic and Statistical Manual of Mental Disorders*, 4th edition (DSM-IV), five types of disorders fall within the spectrum (APA, 1994): Autistic Disorder, Asperger's Disorder, Pervasive Developmental Disorder–Not Otherwise Specified (PDD-NOS), Childhood Disintegrative Disorder, and Rett's Disorder (APA, 1994).

Autism spectrum disorders are characterized by developmental variances in social development and communication (APA, 1994). Social deficits in the child present with the child's lack of eye contact, inability to share interests with others, and a lack of emotional reciprocity. The child's communication issues are apparent in language delays, repetitive use of language, and a lack of functional play skills. Affected individuals have a high need for rigid routines, display a restricted range of interests, and engage in self-stimulatory behaviors (Charman & Baird, 2002).

The DSM-IV distinguishes ASD in three ways: (1) age at which symptoms

become noticeable; (2) number of autistic symptoms present; and (3) types of symptoms present. Autism disorder (classic autism) presents with a significant cognitive delay (APA, 1994). Asperger Disorder does not involve a delay or disruption in early language development and no significant delay in cognitive function or self-help skills. PDD-NOS is described as "atypical autism" and does not meet the criteria for Autism disorder because of the late age of onset, atypical behaviors, or mild presentation of symptoms. Childhood Disintegrative Disorder is a severe regression of developmental milestones in several areas, which follows at least 2 years of typical development. Rett's Disorder, mainly diagnosed in females, is associated with slow head growth, characteristic hand movements (wringing hands), and gross motor issues (walking and body). ASD presents with a significant range and intensity of symptoms with or without cognitive impairment. Individuals with ASD are often different from one another. Therefore, this disorder is often symbolized as a puzzle by families and health care professionals.

ASD is the most common of the severe disorders of development (Bryson & Smith, 1998; Chakrabarti & Fombonne, 2001; Filipek et al., 1999). There is significant evidence the prevalence of ASD is increasing (Bryson & Smith, 1998; Filipek et al., 1999 (Rutter, 2005). In the past, autism was thought to be rare (1/1000), but now, with recent estimates (1/166; Rutter, 2005), ASD appears to be more common a condition in the pediatric population than cancer, diabetes, spina bifida, and Down's syndrome (Filipek et al., 1999).

Males are more likely to be born with ASD than females (4:1) (APA, 1994). Therefore, researchers hypothesize there is a strong genetic component in autism, yet current research does not support a genetic link and no known physiological or biological cause has been found (Rutter, 2005). This difficulty in understanding the

causes of ASD has significantly contributed to the difficulty in identifying and diagnosing it, especially in the early years of development (Bryson & Smith, 1998; (Bryson, Rogers, & Fombonne, 2003). Known physiological or biological markers for ASD would guide physicians in their identification process and provide definitive evidence for referrals, especially in the early years, when it is difficult to identify ASD and when families are likely to be resistant or find it difficult to receive a referral (Bryson, Rogers, & Fombonne, 2003).

It is important to detect autism in the early years (Filipek et al., 1999) as there is significant evidence that early intervention and treatment can improve long-term outcomes for children with ASD (Guralnick, 1998; McEachin et al., 1993). Programs such as Applied Behavioral Analysis (ABA) and TEACCH (Training and Education of Autistic and related Communication Handicapped CHildren) have improved the quality of the lives of people who live with ASD. Research on brain plasticity in the early years and the media buzz around this issue has also spurred clinicians and families to detect developmental issues early (Thompson & Nelson, 2002). These findings are fueling the debate on the merits of screening for ASD in the general population, with which instrument, when, and by whom (Bryson & Smith, 1998; Bryson, Rogers, & Fombonne, 2003; Charman & Baird, 2002).

2.02 The *early signs of ASD.* Adrien, Lenoir, Martineau, Perrot, Hameury, Larmande et al. (1993) have documented the early signs of ASD by analyzing home videotapes of children later diagnosed with ASD. They found that children with ASD differed from their typically developing peers and focused on five developmental inconsistencies (Adrien et al., 1993; Zwaigenbaum et al., 2005). These inconsistencies are "poor social interaction or joint attention, absence of social smile, inappropriate

facial expressions, unstable attention, and hypotonia" (Adrien et al., 1993). These markers are stable indicators and are predictors of ASD in later years of development.

The symptoms of ASD become more obvious as development unfolds. Children with ASD show differences in their development, not necessarily failures to meet developmental milestones. In the second year of development the signs of ASD become "red flags". Zwaigenbaum et al., (2005) has reported the following clinical descriptors of ASD signs:

> Several specific behavioral markers, including atypicalities in eye contact, visual tracking, disengagement of visual attention, orienting to name, imitation, social smiling, reactivity, social interest and affect, and sensory-oriented behaviors; (2) prolonged latency to disengage visual attention; (3) a characteristic pattern of early temperament, with marked passivity and decreased activity level at 6 months, followed by extreme distress reactions, a tendency to fixate on particular objects in the environment, and decreased expression of positive affect by 12 months; and (4) delayed expressive and receptive language.

All of these early signs are more noticeable in the second year of development when developmental expectations increase (Adrien et al., 1993). For example, in the first year, lack of eye contact describes children's social deficits and in the second year, lack of eye contact expands to ignoring people. Children appear to shut down and use strategies such as turning away and covering their eyes to avoid social contact. They do not show the usual interest in toys or play with them appropriately. In the second year, stereotypical behaviors emerge (for example, a fascination with light or objects that move in a repetitive motion such as ceiling fans). Some children play with their hands by twisting them or tapping them on objects. Parents may note increased sensitivity to sensory stimuli, such as sound. For instance, children may become upset when the vacuum or dishwasher is on. They may oscillate between appearing not to hear your voice and to covering their ears when a sound bothers them. All of these behaviors are

clearly definable but some families see these behaviors as typical development. *However, it is the quality, intensity, and number of behavioral occurrences that distinguish them from typical development* (Zwaigenbaum et al., 2005).

Malvy, Barthelemy, Damie, Lenoir, Bodier, and Roux (2004) found four behavior profiles of ASD symptoms: Children in group A have substantial appearances of all symptoms. Group B have most symptoms but no auditory perception disorder. Group C have moderate scores in all items and conclusive scores for auditory disorder, eye contact and use of objects. Children in group D have no stereotyped behaviors or hypo activity. The findings of Malvy et al. (2004) show the complexity and variability of symptoms physicians and parents grapple with when they try to detect children with ASD. Physicians fail to detect ASD when clinical descriptors differ with parents descriptors of ASD (Glascoe, 2001). For example, clinicians describe children with ASD as lacking social reciprocity and parents report their children do not play "peek-a-boo". It is important for physicians to know the clinical signs and how parents report those signs (Glascoe, 2001).

2.03 ***Parents' report: "Something is not right with my child."*** Early identification of ASD typically occurs when parents voice their concern to a health care professional (Glascoe, 1997a). If the physician considers the concern valid, the child is referred to a developmental specialist for assessment (Howlin & Moore, 1997). Parents may describe the stereotypical symptoms of autistic disorder (hand-flapping and social unresponsiveness) or describe symptoms that are not exclusive to ASD (Glascoe, 1997a). Parents may also report deafness, lack of play skills, disinterest in other children, tantrums, language delays, and various hypersensitivities to sound or touch (Filipek et al., 1999). Parents relay their concerns in different ways depending on their

level of suspicion. According to Nissenbaum et al., (2002) parents' fall into three groups before diagnosis. Parents in group one suspect their child has ASD. Group two suspect some form of developmental delay but not ASD. Parents in group three have no suspicions or concerns about their child's development. Parents' suspicion level affects how they report symptoms and to what extent they accept the referral and diagnosis (Nissenbaum et al, 2002). Physicians respond to parents in different ways based on their level of suspicion (Sices et al., 2003).

Nissenbaum et al., (2002) found that few parents suspect their child has ASD. Typically, those parents who do suspect ASD describe symptoms definitively and seek a referral. They report a sense of relief when they receive a diagnosis. However, it is important to stress that although these parents expected the diagnosis it did not diminish their pain and grief. Parents who suspect a delay but not ASD may describe symptoms in a more general way (Nissenbaum et al., 2002). They typically describe their child as language delayed, hearing impaired, or as having behavioral difficulties. This scenario leads to multiple referrals to rule out possible physiological health concerns. Howlin and Moore (1997) found the referral process convoluted and significantly delayed a diagnosis. Families also reported that referred specialists, told them "not to worry" or referred them to another specialist. Some families received referral to two or three different specialists before they received a diagnosis (Howlin & Asgharian, 1999). Parents who experience multiple referrals have a mixed response to the diagnosis. Some parents experience relief while others are angry with the professionals who failed to identify their child's disorder earlier (Nissenbaum et al., 2002).

Parents who are unaware of their child's disorder are negatively affected by the diagnosis (De Giacomo & Fombonne, 1998; Nissenbaum et al., 2002). Most of these

parents had never heard of ASD and usually made excuses for their child's autistic behaviors. They typically explained the ASD behaviors as eccentric family traits, or traits caused by circumstances within or outside their child's control (Midence & O'Neill, 1999). They also believe their child could grow out of their symptoms or that once he or she went to school, the child's behaviors would improve (Howlin & Moore, 1997). Professionals report that they would be more likely to take a "wait and see approach" with this group: they wait until the parents are ready for the referral. Physicians find it difficult to identify children whose parents have no suspicion of a developmental irregularity because they are afraid of breaking the bad news. These groups of parents respond to voiced concerns with denial, anger, grief, and shock (Nissenbaum et al., 2002). Until parents are ready to receive the diagnosis it is difficult to provide support to them or their child, so until parents ask for help, none is provided (Midence & O'Neill, 1999). These families are typically at a crisis point when they ask for assistance. A diagnosis of ASD adds to the crisis load and can be detrimental to the health of the entire family (Nissenbaum et al., 2002). However, although parents in this group meet identification with resistance, retrospectively they report it is better to know before they reach a crisis point (Nursey, Rohde, & Farmer, 1991). If they receive a late diagnosis (for example school-age) parents often experienced guilt for obstructing the diagnosis and angry toward the professionals who did not have the courage to refer them for a diagnosis (Nissenbaum et al., 2002).

The impact of a diagnosis is great for all family members (Gray, 1994). There are significant health, social, career, and education implications for parents and their children with ASD (Gray, 2002). This is most likely why professionals view ASD as a "heavy-duty" diagnosis and parents view it as a "death sentence" (Nissenbaum et al.,

2002). Although it is difficult to identify autism early, the long-term benefits to families outweigh the difficulty.

2.04 The *importance of early identification of ASD.* All parents report benefits from receiving an early diagnosis (Gray, 2002; Nissenbaum et al., 2002; Nursey et al., 1991). After receiving a diagnosis, parents felt that they were no longer to blame for their child's behavior. They also felt they could finally help their child. Parents still felt overwhelmed by the diagnosis but it gave them a context in which to explain their child's behavior and possible intervention strategies to follow. Parents felt more proactive, and better equipped to seek information, education, and treatment services (Nissenbaum et al., 2002).

The age at which a child is identified influences the decisions and actions of both parents and physicians (Nissenbaum et al., 2002). Physicians report that it is easier to discuss a positive prognosis when a child is identified early and receives early intervention. Parents also believe that an early diagnosis increases the likelihood of progress. Evidently, for both physicians and parents, early diagnosis is directly correlated to a more hopeful future for the child (Nissenbaum et al., 2002). For families who have a child with autism, hope is the reason why they seek intervention and face the challenges of raising a child with autism. Hope provides them with the courage to advocate for their child (Nissenbaum et al., 2002). Although hope spurs families on, there is also well confirmed evidence that proves early diagnosis of ASD and intervention can make a difference in the lives of people with autism (Guralnick, 1998; McEachin et al., 1993; Rogers, 1998).

Once a child receives a diagnosis, families receive funding, information, and support. The system that provides these services is best described as having a "pull

from" not a "push at" mode of delivery. "Pull from" services put the onus on the family: if families are not actively seeking services they will not receive services. This mode of delivery is particularly difficult when a child has been diagnosed with ASD, in large part because families must seek help from a range of professional services that play a role in treatment: psychology, speech language pathology, occupational therapy, and early intervention. Each discipline and professional has a waiting list and each discipline not only provides assessment, but also is a gatekeeper for some form of treatment. Parents must not only seek out the services, but integrate the various forms of information and intervention strategies into one approach, a process that can be overwhelming and difficult.

Research on ASD indicates the earlier families receive the diagnosis, the better (Rogers, 1998). Parents need time to adjust and learn about the diagnosis, specifically how ASD affects their child (Gray, 2002). This time is especially important because once their child enters school; these services are no longer available. Three months after school entry early intervention services are discontinued by health services and are transferred to school services. Most parents have fewer than two years to benefit from early intervention and services because the average age of diagnosis is 4 years. During this time, parents gather information on intervention services, learn new parenting skills, learn what autism means for their child, and cope with their own feelings of stress and grief before they lose service and support. Once children reach school age they enter an education system that is significantly under-resourced (MacLeod, 2001).

Children with ASD have unique learning styles (Rogers, 1998). The term "spectrum" conveys the variability in the symptoms and educational needs of ASD (Rogers, 1998). Consequently, it is important parents receive child-specific early

intervention and information: a "one size fits all" approach does not work. Long-term adjustment and coping is enhanced when parents are educated about their child's abilities and needs (Gray, 2002). Providing families with intervention skills will allow them to share these skills with others. Parents report an improvement in their quality of life when they have the ability to interpret their child's needs for others (e.g., school, friends, and family) (Gray, 2002). These skills decrease the isolation that families often experience with this disorder and increases families' ability to be a part of the community (Gray, 2002). Early identification is crucial to provide parents with the time necessary to educate parents and provide intervention for their children.

When ASD is not identified early, it places an unnecessary strain on the entire community; families, interventionists, health care providers, and educators. As a result, professionals and educators are calling for earlier identification and diagnosis of autism/ASD (Filipek et al., 1999). Many believe that implementing developmental screening in the general population is a necessary step in achieving this goal; (Baron-Cohen, Allen, & Gillberg, 1992; Bryson & Smith, 1998; Charman & Baird, 2002; Filipek et al., 1999; Howlin & Moore, 1997). The quality of parents' reports and physicians' experience with ASD can result in incorrect referrals or a "wait and see" approach, thus delaying diagnosis. However, when physicians use a validated instrument to assess children, rather than rely on "eyeballing" or parent reports alone, they are more likely to detect ASD and give the proper referral (Klin, Lang, Cicchetti, & Volkmar, 2000).

2.05 Diagnostic *instruments: Identifying, screening, and diagnosing ASD.*

Three categories of developmental diagnostic instruments exist: identifying, screening and diagnosing (Filipek et al., 1999). Developmental screening instruments have two

potential uses in clinical practice. First, they are useful as a general screen for identifying developmental disorders; and second, as a screening or part of the differential process to identify a specific developmental disorder (for example, ASD). In primary health care practices, screening for developmental disorders is typically performed at well-child visits and their purpose is to identify developmental irregularities that may need follow-up. Several screening instruments have been validated over the past 10 years (Baron-Cohen et al., 1992; Charman & Baird, 2002; Glascoe, 2001). They range from parent questionnaires, which are completed in the waiting room, to structured interview instruments that are implemented by health care staff (Bristol-Power & Spinella, 1999).

There are two levels of instruments (Filipek et al., 1999). A Level 1 instrument is designed to detect for suspected developmental concerns. This screening can be administered quickly (less than 5 minutes). It can be administered by both untrained laypersons and health care practitioners (Squires, Potter, Bricker, & Lamorey, 1998). Level 2 screening instruments require more training and take more time to administer (from 15 minutes to over 1 hour). They are used when a developmental issue has been identified and clinicians want to specifically screen for ASD (Charman, 2003).

Three examples of Level 1 screening tools are parent questionnaires such as, *The Parents' Evaluations of Developmental Status* (Glascoe, 1998), the *Ages and Stages Questionnaires* (ASQ, Bricker & Squires, 1999) and the Denver Developmental Screening Test II (Denver II) (Frankenburg, Dodds, Archer, Shapiro, & Bresnick, 1992). The first example is the PEDS questionnaire which consists of 10 questions to elicit parents' concerns. It is written at a grade five level in English, Spanish, and Vietnamese. Its standardization was determined by multistate centers with a sample population of 771

given diagnostic measures. The PEDS has a sensitivity (ability to detect developmental delay) of 74% - 80% and a specificity (ability to detect typically developing children) of 70% - 80% for children ages birth to 9 years. It can be completed in 2 minutes (Glascoe & Frankenburg, 2002).

Another example is the ASQ which provides clear drawings and simple directions to help parents measure children's skills (Bricker & Squires, 1999). There are 25 to 35 items for each age range, which follow the recommended well-child visit schedule. Its standardization was determined by multi-state centers with a sample population of 538 given diagnostic measures. The ASQ has a combined sensitivity and specificity of 70% - 90% except at the 4-month level which is 76% - 91%. It is appropriate for children ages birth to 6 years and can be completed in 5 minutes (Glascoe & Frankenburg, 2002). The ASQ is also appropriate as a screening tool for older children with a sensitivity of 96% and a specificity of 80% (Berument, Rutter, Lord, Pickles, & Bailey, 1999).

The Denver II is mainly used in primary care practices and is recommended by the *Canadian Guide to Clinical Preventative Health Care* for use by family physicians (Feightner, 1994). It is easy to give, takes 15-20 minutes to complete and is designed for children from birth to 6 years-old. Through parent interviews, it measures language, fine and gross motor, and social abilities. No studies have tested the validity of the Denver II. Consequently, this instrument is controversial. Glascoe et al. (1992) found the Denver II had low sensitivity and therefore missed children with developmental delay. As well, it was found the Denver II lacked specificity and identified typically developing children as delayed. Based on current research, the PEDS and ASQ may be more suitable for use in a busy family physician practice (Charman, 2003). However, until the *Canadian*

Guide to Clinical Preventative Health Care guidelines are updated and physicians are provided with continuing medical education, the Denver II will continue to be used in general medical practice (Canadian Task Force on the Periodic Health Examination, 1994).

Level 2 instruments are specific screens for ASD. These instruments require training and are recommended for use by ASD specialists. Such screens include the Checklist for Autism in Toddlers ([CHAT]; Baron-Cohen, Allen, & Gillberg, 1992), the Childhood Autism Rating Scale ([CARS]; Schopler, Reichler, & Rochen-Renner, 1988), and the Autism Diagnostic Interview-Revised ([ADR-R]; Lord, Rutter, & LeCoutour, 1994)). The DSM-IV is also considered a level 2 instrument and may be used by physicians. However, if a physician does suspect ASD in a very young child and consults to the *DSM-IV*, it is highly likely to mislead the diagnosis.

The reported *DSM-IV* diagnostic symptoms are rarely found in a 2- or 3-year-old child (Charman et al., 2001). Children of this age have emergent language and are in the early learning phase of social reciprocity. The symptoms that are described in the *DSM-IV* such as irregularities in social language abilities and stereotypical behavior may not be evident. Very young children may not use language for social communication. It is more likely that young children will use pointing and eye gaze to share attention. These age- appropriate deficits make it difficult to judge the qualitative nature of the symptoms described. Charman et al. (2001) found when analyzing home video of children with ASD in the first year of development, that they were more likely to lack appropriate facial expressions (social smile) and have poor joint attention skills. They also found that in the second year, children with ASD have added social differences such as ignoring people, not responding to their name, choosing to be alone, lack of eye contact,

and lack of social gestures (pointing). These symptoms are not clearly reported in the *DSM-IV* as possible developmental criteria for autism and known only by practitioners who have experience in ASD. Therefore, because of the variability and sometimes subtlety in the presentation of symptoms, a skilled and experienced practitioner is needed to diagnose and perhaps detect a developmental delay or ASD in a child under the age of 4-years-old. This strongly supports a possible reason why, children are diagnosed with ASD after the age of 4 years for that is when it is more likely that *DSM-IV* symptoms are present. At this age of development, the lack of social communication is more obvious and it is also more likely that stereotypical behavior will be present which provides a basis for a stronger cue for ASD (Charman & Baird, 2002). Consequently, level 2 screens are not recommended for general practice as they are more difficult to administer and are not suitable for a busy practice than perhaps a level 1 screen would be.

Physicians show considerable variability in adopting level 1 instruments for detecting ASD and other delays into their practices. These instruments are largely viewed as the purview of the psychologist or developmental pediatrician and not the domain of family practitioners (Sices et al., 2003). Physicians find these instruments are too time consuming or labor intensive to administer in a typical office visit. As well there is no clear direction as to which one is the best one to adopt for the general population (Bryson et al., in press). These practice issues are evident in the practices of physicians in Nova Scotia.

2.06 Physicians' *assessment practices of ASD in Nova Scotia.* In Nova Scotia, family practices pair well baby care visits with the immunization schedule (Nova Scotia Medical Services Insurance, 1996). The purpose of well-care visits is to record

physiological and cognitive development. Physicians use the Rourke Baby Record: Evidence Based Infant/Child Health Maintenance Guide III ([Rourke]; Rourke, Rourke, & Leduc, 2000) to record development during each visit. It is important to note this instrument is a developmental growth chart not a screening tool for cognitive developmental disorders. Rourke et al. (2000) place a disclaimer at the bottom of the instrument which states: "Given the constantly evolving nature of evidence and changing recommendations, The Rourke Baby Record: EB is meant to be used as a guide only." The Rourke is administered to record achieved developmental milestones not to probe for developmental inconsistencies. So, for example, if a physician used the Rourke guide to interview a parent about their child's development, the guide's focus and measure is the number of words not the quality or social features of language. This protocol is unlikely to detect the symptoms which lead to ASD detection and an appropriate referral.

Although, level 1 screening instruments such as the PEDS and ASQ identify developmental concerns and research has shown they are well suited for family practice as a general screen, they are not used in Nova Scotia's family practices. Presently, physicians receive practice recommendations from the *Canadian Guide to Clinical Preventive Health Care* (Canadian Task Force on the Periodic Health Examination, 1994) which suggest administering the Denver II. Unfortunately, physicians report that this test is too onerous to use in an office visit but The College of Family Physicians of Canada has not recommended any other developmental tool.

If a developmental concern arises, the *Canadian Guide to Clinical Preventive Health Care* guidelines recommend a referral for physiological tests. For example, tests for auditory function, blood lead levels, chromosomal abnormalities, and other

biological markers that suggest a physiological abnormality. Once possible physiological issues are ruled out, the next step is to administer the Denver II. As stated earlier, the Denver II lacks the sensitivity and specificity to assess developmental difficulties (Glascoe et al., 1992). This situation may account for the significant variability found in physicians' referral practices because they have reported limited or inconsistent use of screening instruments (Sices et al., 2003). Physicians do not have the tools to collect sufficient evidence to make a referral. Without the benefit of experience with ASD or a valid screening instrument to target symptoms, physicians will start the differential process by eliminating suspected causal possibilities. This process will include referrals to audiologists, speech language pathologists, or occupational therapists which further delays the diagnosis (Howlin & Moore, 1997). Unfortunately, this process is time consuming and stressful for families. With each referral a new possible diagnosis looms and valuable intervention time is lost.

As well as, lack of screening for ASD, there are other possible barriers to early detection. In Nova Scotia, physicians combine developmental assessment with the immunization schedule (Nova Scotia Medical Services Insurance, 1996). This protocol has inherent flaws. The immunization procedure is stressful for parents and their children. Combining immunization and developmental assessment may mask development concerns, especially when information gathering is unstructured and informal. Research has shown that without the aid of a screening instrument to focus parents and physicians on the necessary developmental indicators, the likelihood of detection is significantly diminished (Glascoe, 1997a).

Possibly the biggest drawback for detecting children with developmental issues is the system that supports family physicians' practice. MSI does not pay physicians for

well-care visits after the age of 12 months plus one day (Nova Scotia Medical Services Insurance, 1996). This age cut off constrains and restricts early screening and detection during the preschool years. The fee schedule limits physician visits to immunization and illness for children past the age of one year. Health care visits for immunization and illness mask developmental disorders, as children do not acting typically when they are stressed or sick. As well, research suggests that detecting ASD in children who are under the age of 18 months is very difficult for physicians who are not using screening tools (Glascoe, 1997a; Klin et al., 2000; Sices et al., 2003)

The next reimbursed well-care visit is for the school entry immunization (children range in age from 4-5 years) (Nova Scotia Medical Services Insurance, 1996). Children who are detected at this age are unable to benefit from early intervention. To receive funding for early intervention a child must have a diagnosis. The waiting period for diagnosis in Nova Scotia is one year. The cut off for early intervention services and funding is three months after school entry (McSorley, 2005). Consequently, if a child is detected at the school entry immunization it is too late for early intervention services.

Nursey and Rohde (1991) found that a late identification of ASD has other ramifications as well. They found physicians' attitudes and beliefs about early detection influenced their screening behavior. Some physicians were reluctant to identify children early. They believed there was a lack of intervention services available or the family was not ready to undertake the challenge of a child with a developmental disorder (Nursey et al., 1991). Nissenbaum et al., (2002) had similar findings. They found health care professionals experience fear and feelings of incompetence when giving a diagnosis of autism. Physicians also admitted that they would be devastated if their own child was diagnosed with autism and they believed that parents were too positive about potential

outcomes for their child with autism. This reflects physicians' lack of understanding of families and the importance of early diagnosis.

Kennedy, Regehr, Rosenfield, and Roberts, (2004) found physicians need a sense of urgency and certainty to act on a suspicion of ASD. They asserted a sense of urgency arises from knowing a diagnosis can make a difference in a child's life and using a screening tool increases their certainty there is a difficulty and they are not alarming families unnecessarily. Glascoe et al. (1992) found family physicians show great variability in practice patterns when screening for developmental disorders. Research has found there are many confounds that prevent early detection of ASD. Among them are the variability in of the symptoms of ASD, coexisting disorders, parent report issues, and physicians' lack of ability to detect. As well, the lack of systems to support detection also contributes, such as the inconsistent use of valid screening tools. This situation weakens the capacity to detect developmental problems especially in young children or in mild cases of ASD (Bryson & Smith, 1998; Charman et al., 2001; Glascoe & Frankenburg, 2002; Howlin & Moore, 1997; Nissenbaum et al., 2002).

Governing bodies of health policy such as the U.S. Academies of Pediatrics, Neurology and Child and Adolescent Psychiatry, and the National Institutes of Health also recommend performing routine surveillance for developmental disabilities in child healthcare management (Filipek et al. 1999). As well, over 10 years ago, The Canadian Guide to Clinical Preventive Health Care recommended an evaluation of developmental screening instruments as a research priority to provide direction for change in practice guidelines (Feightner, 1994). All of these factors are fueling the debate on how and when to carry out early developmental screening in the general population to ensure early detection.

To move forward and address these needs, we need a better understanding of the gaps in our present system. A search of Pub Med, Medline, and PsycINFO databases (1980-2005) revealed current and past research has addressed the following topics related to developmental disorders: pediatricians' practices, family physician referral patterns, costs of screening, attitudes toward people with disability, and disclosure of developmental concerns to families. Only two studies focused on developmental screening and the practices of family physicians (Glascoe & VanDervoort, 1985; Sices et al., 2003). These studies concluded most physicians support early diagnosis of developmental issues but only half use a developmental screening tool and of this portion fewer still use the instrument as intended. Consequently there is significant variability in the effectiveness, use, and choice of instrument for screening and identifying ASD and other developmental disorders. Studies have shown it is difficult to change physicians' behavior once they leave medical school and start their own practices (Davis et al., 1999). Therefore, an assessment of medical students' pediatric curricula are relevant to discover if the variability in detection practices is traceable to undergraduate medical education.

2.1 *ASD in Undergraduate Medical Education*

Pediatric curricula are spread across the years. Where ASD can be found in the pediatric curricula is not well-known. Therefore, the question that guides this research will address this gap: "What are the current curricula practices for ASD from the perspectives of medical students and instructors? The research goal and focus of this study is to discover what medical students are taught about ASD: in what settings and by which methods. In effect, I would like to trace the issue of early identification of ASD from the beginning stages of the medical school educational process.

In conclusion, this research amounts to a qualitative needs assessment of medical students' pediatric curricula to discover if the variability that Sices et al. (2003) reported in physicians' practices also exists in undergraduate medical education. The findings from this study will provide direction about curricula content with instructors and curriculum planners to promote evaluation of curricula regarding ASD. The long-term goal of this research is to ensure ASD curricula are relevant and succinctly comprehensive so when medical students are in their future practices they may have a positive impact on the health of children with ASD and their families.

CHAPTER 3

3.0 Methodology

This study will borrow from the qualitative tradition of ethnography to provide a thorough exploration and a detailed understanding of the curricula (Creswell, 2005). Qualitative inquiry is a preferred method when little is known about the topic. Presently, no published research has explored the experiences and phenomena related to ASD in undergraduate medical education. Therefore, I have used the qualitative methods of interviewing, content and descriptive analysis (Creswell, 2005; Kvale, 1996; Maxwell, 1996) within the framework of the six-step approach to curriculum development (Kern et al., 1998) to provide a comprehensive needs assessment. This approach provides a rich description of ASD curricula (content and contexts) through the lens of medical students and instructors (Maxwell, 1996). For purposes of situating this methodology, I consider this approach a form of qualitative evaluation in the tradition of Lincoln and Guba (1985) whose naturalistic and inductive approaches are widely used in health and education research.

I chose to use elements from ethnographic methodology and Kern et al.'s (1998) method of the six-step approach to curriculum because they ground my research and research position. When researching medical students and instructors it is important to consider their culture of "knowing" (Regan-Smith, 1992), and to address this, I borrow from an ethnographic approach (Schram, 2003). I am a constructivist inquirer who is researching with medical participants and audiences (e.g., Kern et al., 1998) whose perspective might be characterized as post-positivist. Constructivists situate knowing from "people's meanings and constructs within and amid specific social, political, cultural, economic, ethnic and other contextual factors" (Schram, 2003, p.33).

Alternatively, post-positivists believe that knowledge is imperfectly and probabilistically known through falsification of hypotheses (Guba & Lincoln, 1994). As a researcher, I am mindful of the different research traditions (for example traditions grounded in qualitative or quantitative) that each of these worldviews may adopt. MacCleave (2005) likens the different research traditions to different cultures; researchers who combine approaches are aptly named cultural negotiators. In this way I view research as a negotiation and collaboration between me --the information gatherer-- and the research participants.

Creswell (2005) defines ethnographic researchers as those who "look for shared patterns of behavior, beliefs, and language the culture-sharing group adopts overtime" (p. 444). Culturally-shared patterns are developed and constructed through exposure to tacit group rules and expectations which influence individuals' interactions in a cultural setting. Medical culture influences members' perspectives, understandings, and declared needs (Bennett et al., 2004). Most importantly the culture defines for participants who they are willing to share with; those who share their culturally shared patterns (Bennett et al., 2004).

I am a member of the medical culture by association. Member-by-association stems from Junker's (1960) conceptualization of observer-as-participant. A member-by-association has in-depth experience over time and contexts, as well as multiple points of association which enable them to understand the behaviors, beliefs, and language of the culture under study. I have twenty-five years of experience in special needs (8 of those years were spent in the medical community) as an administrator, service provider, educator, and as a parent of a child with ASD. I have collaborated with many health care professionals from various disciplines in various settings. As a result, I am in a unique

position to study the issue of undergraduate medical curricula regarding ASD.

In keeping with Junker's (1960) original intent of transparency and collaboration, my presence was known to the participants and my participation was secondary to my role as information gatherer (Adler & Adler, 1998; Merriam, 1988). As well, I was invited to this research project by a medical instructor within the undergraduate medical program and therefore, was "more or less publicly sponsored by people in the situation studied" (Junker, 1960, p.37); as a result, I was granted access to the students, instructors, and the information they chose to share. Following Maxwell (1996), Coffey and Atkinson (1996), Neilsen (2001), among others, I see my 'insider knowledge' affording me a seasoned perspective as member-by-association and a depth of insight into the issues of this study that I otherwise would not have. Rather than consider my insider knowledge to taint the research (a threat to objectivity that is the keystone to early positivist work, for example), I consider my knowledge to enhance my understanding of contextual forces, issues, and educational and discursive practices; my insider knowledge affords me a nuanced perspective I would otherwise not have.

My experience as an interviewer played a role in this research. I explored the medical school community by interviewing all the people who play a role in the medical school pediatric curricula. I tailored my interview questions and approach to the medical culture of "experts" to determine their experiences of the ASD curricula. Rossman and Rallis (2003) suggest interviewing experts places increased demand on the interviewer. Fortunately, I have many years experience interviewing physicians, nurses, pharmacists, laboratory personnel, and hospital administrators to discover their needs. During those years I learned about the form and type of questions that are well received by members of medical culture. For example, inappropriate questions are closed-ended or ask

generally about knowledge. Alternatively, well received questions ask for an opinion or behavioral responses based on a particular case example. When interviewing "experts" it is important to either, "establish competence by displaying a thorough knowledge of the topic or, lacking such knowledge, by projecting an accurate conceptualization of the problem through shrewd questioning" (Rossman & Rallis, 2003, p. 134). Although I am not an expert on medical education, I consider myself an expert on ASD. The research questions were open-ended and often the interview direction depended on the experiences of the participants. During the interviews I drew on my knowledge of ASD to ask meaningful questions about participants' experiences of the curricula. Thus, as the researcher I engaged in what Haraway (1989) calls "power-sensitive conversations" with medical students and instructors.

The interview method I chose was sensitive to the schedules of the participants. Considering the taxing schedules of medical students and medical instructors, I chose the method of semi-structured telephone interviews as a means to collect data. I chose telephone interviewing because the medical community has large demands on their time and in some cases, engaged in clerkships outside of Nova Scotia. I interviewed administration participants on site and in person because the information I requested from them was best delivered by hand (e.g., curricula materials).

My analysis of the interview transcripts and curricula materials was facilitated by the Miles & Huberman's Interactive Model (Huberman & Miles, 1994; 1984). Kern et al.'s (1998) framework for a curriculum needs assessment was used as a model for the findings. This model is well-known to the medical education community and will ensure the research outcomes are presented in an established format. Kern et al.'s (1998) underlying assumptions are as follows:

- educational programs have aims or goals, whether or not they are clearly articulated
- medical educators have a professional and ethical obligation to meet the needs of their learners, patients, and society
- medical educators should be held accountable for the outcomes of their interventions
- a logical, systematic approach to curriculum development will help achieve these ends. (p. 4)

I reviewed recursively the data from my field research with medical school administrators, interview transcripts from the students and instructors, curricula syllabi, and in some instances curricula content. This approach is marked by systematically and analytically reading and rereading the data to ensure the participants' voices and intentions are represented in the interpretation of the data (Strauss & Corbin, 1998). As well, I explored the contextualization of the connections between parts, and between parts and the whole of ASD curricula to provide a comprehensive Needs Assessment (Agar, 1996; Wolcott, 1999, as cited in Schram, 2003).

In summary, borrowing from an ethnographic perspective, I explored a medical school's culture of knowledge (behavior and beliefs) (Maxwell, 1996). I explored the link between the present health care gap in early identification of ASD and how physicians are trained to detect and treat ASD (Sices et al., 2003). I classified the content and form of ASD undergraduate medical education in order to understand the underpinnings of physician detection practices. The descriptions of these curricula experiences and understandings, along with common themes that emerged provide a Needs Assessment of ASD in undergraduate medical education. The methods I used are

described below.

3.1 Methods

The following is an explanation of the procedures used for this research, steps in data management and analysis, as well as, threats to the trustworthiness of the study.

3.11 ***Participants and recruitment.*** I invited 2 medical school administrators by email to participate in a personal interview to gather medical curricula syllabi and course content. One administrator was in the department of Undergraduate Medical Education and the other was in the department of Pediatric Undergraduate Medical Education (Appendix A).

I interviewed by telephone 7 students to discover students' perceptions and understandings about ASD curricula in undergraduate medical school. I chose students who were in their fourth and final year of undergraduate medical education to gain a full picture of the four year programs' curricula. All the students had received notice of their future medical discipline (e.g., pediatrics, general medicine) which creates a sense of closure on the undergraduate years. I contacted the Head of the Division of Developmental Pediatrics, Department of Pediatrics for Undergraduate Medical Education to seek permission to send an invitation, requesting student volunteers' participation (Appendix B and C). A letter of invitation was sent by e-mail to 91 students asking for student volunteers to contact me by e-mail or phone. I encouraged potential volunteers to contact me by phone or e-mail for clarification of the research topic, purpose, and interview questions. Five students responded, subsequently contacted, and interviewed. Two weeks later a fourth year medical student offered to send a reminder e-mail inviting more participants. I specifically requested student volunteers who had experience with ASD. At this point in the data collection, I had

saturated the category of 'no direct experience with ASD' with only one student who had experience. Three students responded, but only 2 met the criteria of experience with ASD in the curricula and telephone interviewed.

I contacted and telephone interviewed 4 instructors who teach about ASD to discover instructors' perceptions and understandings about ASD curricula in undergraduate medical school. I delivered all letters of invitation and consent forms by hand to the instructors' offices (Appendix E). I arranged the appointments for telephone interviews by e-mail. All 4 instructors agreed to participate.

In summary, I interviewed by telephone, 13 participants for this study: 2 medical school administrators, 7 students, and 4 instructors. I informed all participants that this research fulfilled the thesis requirement for my Master of Arts degree in Education. I gave all of the participants an opportunity to fill out a consent form ensuring confidentiality and assuring the resulting thesis would not reveal any identifying information (Appendix D).

3.12 ***The interview protocol.*** The first draft of the interview protocol was based on relevant research literature and the curricula syllabi analysis. Using this first draft, I consulted with two experienced qualitative researchers and one medical education instructor. In these meetings, I asked the consultants to provide comments on the clarity, content, and perceived intent of the open-ended questions. Their feedback aided me in tailoring the questions in the interview schedule to the culture of the medical community in order not to offend but to stimulate the descriptive responses I was seeking. I also made changes to the sequence of the questions as well as, added questions that enriched my inquiry. The key considerations were question clarity, flow, and efficiency (completing the interview in 30 minutes). The final interview protocol comprises core

open-ended questions and follow-up questions for clarification. An example of a core question is: "Where is ASD taught in the undergraduate medical school curricula?" An example of a follow-up question is: "Was ASD mostly taught for pediatrics or was it mentioned in other areas of the curricula?" I piloted the final draft with a willing volunteer who was not a study participant (Appendix F and G).

3.13 ***Design.*** The study was undertaken in ***three phases*** and over the course of one year.

Phase one:

- I contacted the Coordinator of Undergraduate Curriculum and requested a meeting to obtain curricula syllabi and handouts that included course content on ASD. As well, I requested the names, emails and addressed of pediatric curricula instructors. I sent a follow-up e-mail outlining my request (Appendix A). We agreed on a convenient appointment time and I obtained the necessary information.
- I contacted the Administrative Assistant in the Department of Pediatrics, Undergraduate Medical Education. I requested a meeting to obtain curricula syllabi and handouts that included course content on ASD and any additional names, emails and addressed of pediatric curricula instructors. As well, I requested help in contacting the students who were in the fourth year of their undergraduate medical program. I sent a follow-up e-mail outlining my request (Appendix A). We agreed on a convenient appointment time. I obtained the necessary information.
- I developed the interview protocol by analyzing the curricula syllabi and handouts for course content on ASD (Appendix F and G).

Phase two:

- I contacted the Head of Developmental Pediatrics by email requesting interviews with fourth year medical students who are graduating in 2005 (Appendix B). The letter included:

  a) An attachment which provided an explanation of the purpose of the research;

  b) A brief outline of participant responsibilities and informed consent;

  c) A request to contact me by email or telephone (Appendix C and D).

- Seven student participants provided rich description through semi-structured telephone interviews about their learning experiences around ASD in the curricula.
- Two weeks later, an interview participant volunteered to contact non-responders by email because the Head of Developmental Pediatrics was away. The email included all the information from the first e-mail and an assurance the interview would be "no trouble" (Dillman, 2000).
- The telephone interviews were 30-45 minutes in length. Interviews were audio-taped, transcribed, and rendered confidential by assigning a letter to ensure confidentiality when reporting findings. Participants were given a choice to review their interview transcripts and verify that the content reflected their intended message. As a follow up and at the request of the participants I will send a summary of the results.

Phase three:

- I telephone interviewed 4 instructors who provided rich description through semi-structured telephone interviews about their teaching experiences on ASD in the curricula.
- I hand delivered the packages which requested the instructors' participation. The

packages included:

(a) An explanation of the purpose of the research;

(b) A brief outline of participant responsibilities and consent form;

(c) A request to contact the researcher by telephone or e-mail (Appendix D and E).

- The telephone interviews were 30-45 minutes in length. Interviews were audio-taped, transcribed, and rendered confidential by assigning a letter. Participants were given a choice to review their interview transcripts and corroborate the content reflected their intended message. At the request of the participants and as a follow up, a summary of the results will be sent at a later date.

3.14 ***Analysis.*** I borrowed from the inductive and descriptive methods of Miles and Huberman's (1984) Interactive Model of Data Analysis, and analyzed the data throughout the research process, including; the planning, development, data collection, and data interpretation. As well, I used Kirby and McKenna's (1989) adaptation of the constant comparison method to manage and analyze the data. I reviewed curricula syllabi data for themes and categories to assist in developing the telephone interview questionnaire. I recorded field notes to capture the informal data collection. The interview transcripts were reviewed and analyzed throughout the study to provide a rich description of the participants' experiences and understandings of ASD in undergraduate medical curricula.

I transcribed the telephone interviews verbatim and assigned a number to each interview as one of the ways to protect confidentiality (for example, P1, P2, etc.) The data management and organization included consecutively numbering pages of transcripts and maintaining filing systems of all original transcripts (Kirby & McKenna,

1989). I made 2 copies of each transcript. One copy was cut into sections of single thought. I placed these sections into files of emerging categories to facilitate data selection and condensation. These categories were flexible and their patterns changed during analysis. I used the constant comparative method, within and between categories, to compare and contrast the data until no new categories emerged (Kirby & McKenna, 1989). Once the categories were saturated and stabilized, I explored the relationships and interrelationships of the categories. In the final analysis, I contextualized the findings into Kern et al.'s (1998) framework of curriculum development and developed a "lessons learned" section for the findings that did not fit into the framework.

3.15 ***Trustworthiness of the data analysis.*** I used several methods that converge to ensure the trustworthiness of this research. I recorded in a journal; an "audit trail" of the inquiry process decisions. This included my grappling with the rationale for the research design, methods, and analysis (Creswell, 1998; Huberman & Miles, 1994; Kirby & McKenna, 1989; Lincoln & Guba, 1985). The contents of this journal reflect the growth I have experienced as a researcher and a scholar.

For credibility, I used triangulation of data sources which allowed for corroboration of the findings and provided broad and in-depth reporting of the subject matter than any one source may have given (Lincoln & Guba, 1985; Strauss & Corbin, 1998). I carefully decided which stakeholders (populations) were best to provide information and insight for my research question. The interviews were transcribed verbatim which provided "rich" data. "By "rich" data, I mean "data that are detailed and complete enough that they provide a full and revealing picture of what is going on" (Maxwell, 1996, p. 95). I also debriefed with a researcher who was both my peer and mentor. I was able to discuss issues as they occurred and increase my understanding of

the research process. A member check for category verification was conducted. I asked an independent researcher to review a transcribed and coded interview to ensure the categories reflected the data. All of these steps increased the dependability of the categories that emerged from the data and thus findings of this research (Lincoln & Guba, 1985).

3.16 ***Ethical considerations.*** I followed the ethical conduct outlined by the TriCouncil policy statement on Ethical Conduct for Research Involving Humans for this study. I took the following steps to ensure I conducted the research ethically:

- I gained ethics approval from Mount Saint Vincent University's Review Ethics Board for research.
- I provided all participants with the purpose of the research and the time their participation would require.
- I assured all the participants that their participation was voluntary and they were free to stop the interview.
- I asked permission to record the interview before each interview began and I told participants when I turned it on. One participant requested I turn the recorder off at the end of the interview to continue our discussion and I did not include the rest of the conversation in the findings.

I protected participants' confidentiality in several ways:

- I removed all identifying names and events that could identify the participants from the transcripts and the findings. I assigned numbers to the transcripts (for example, P1, P2, etc.)
- In the findings I reported all the findings from the administrators', students', and

instructors' interview together rather than separately to ensure participant confidentiality in a medium size medical school.

In the next chapter, I will convey the participants' voices and report the study's findings.

CHAPTER 4

4.0 Findings

The purpose of this study is to identify the scope and nature of curricula and education practices used in an undergraduate medical school for identifying and treating children with ASD. As I explored the curricula and spoke with the participants I discovered several factors that significantly influence the teaching and learning about ASD and developmental disorders in medical school. I was primarily interested in ASD curricula but as the study progressed it became clear developmental curricula in general are foundational to ASD curricula. I decided to include developmental curricula as a context for ASD curricula. As well, I included the participants' concerns about the pressures on the curricula which also influence ASD medical education. These inclusions expand the research questions and I have organized the findings accordingly. They are as follows:

4.0; 4.1: *What are the effects of curricula structure and medical educations' current pressures on learning ASD curricula?*

4.2: *What do students learn about ASD and child development in undergraduate medical education?*

4.3: *What are students' experiences learning about ASD in medical school?*

4.4: *What do students learn about ASD for future medical practice?*

4.5: *Do instructors and students want ASD curricula to change and if so, in what ways?*

I will begin this chapter with a description of findings about curricula structure and context, followed by findings related to medical students learning ASD curricula. I will finish with participants' suggestions to enrich ASD curricula (see Figure 1 for overview).

This study was carried out in a medium size medical school with 91 fourth year medical students. I chose to report all the findings from the administrators', students', and instructors' interviews together rather than separately to ensure participant confidentiality. I have not differentiated the voices because there are significantly fewer instructors and administrators than students and by identifying the groups individually, I may have breeched confidentiality. However, I have assigned identifiers to participant quotes (for example, P1, P2, etc.) to ensure confidentiality and blend the voices of the students and instructors to create a rich depiction of the curricula's ASD content and context.

My goal for this study is to provide a collective understanding and recommendations for the curricula on ASD. The students and instructors gave different perspectives of the curricula. I found overall, students' talked about their educational experiences and curricula content and instructors talked about the curricula context and medical school structure. Figure 1 is a guide and a map of the studies' categories and themes, thus, a structural organization of the findings.

Figure 1

Map of the Questions, Categories, and Themes

Questions, Categories, and Themes				
4.1 What are the Effects of Curricula Structure and Medical Education's Current Pressures on Learning ASD Curricula?	**4.2 What do Students Learn About ASD and Child Development in Undergraduate Medical Education?**	**4.3 What are Students' Experiences Learning About ASD in Medical Education?**	**4.4 What do Students Learn about ASD for Future Medical Practice?**	**4.5 Participants' Recommendations for Change in ASD Curricula**
4.11 Curricula Structure	4.21 Nowhere to Call Home	4.31 Independent Learning and ASD Learning Gaps	4.41 Relevant Curricula are Tested	4.51 Participants' Suggestions for ASD Curricula
4.11.1 Years 1 and 2	4.22 Just the Basics	4.32 Clinical Leadership in Year 1 and 2	4.42 ASD Learning Experiences in Clerkship	
4.11.2 Years 3 and 4		4.33 Clinical Leadership in Clerkship	4.43 Teaching Early Detection of ASD and Developmental Disorders	
4.11.3 Administering Curricula Content		4.34 ASD Patient Interviews are too Hard to Teach	4.44 Teaching ASD Relevance for Future Medical Practice	
4.11.4 Integrating Curricula Content				

4.1 ***What are the Effects of Curricula Structure and Medical Educations' Current Pressures on Learning ASD Curricula?***

Participants report the structure of undergraduate medical education and the curricula context play a significant role in ASD education. All participants convey a commitment to "best practice" in medical school education. They also talk about students' learning, practice and time constraints. Relating some of their descriptions here will put the rest of the findings into a broader context. Instructors report external and internal pressures influence undergraduate medical educations' delivery and students' learning opportunities. The pressures are described as thus:

> There are a number of pressures right now. There are all kinds of pressure depending what aspects you look at. There is the increasing class size. There is a change in health care delivery patterns. Over the last 10 years we are unable to rely on the old stand by of all the people who were in hospital that we could teach around and from. There used to be kids in hospital that weren't that sick. They were available for doing all sorts [of teaching], for students to takes histories from or do physicals on. Now that doesn't work because there are very few people in hospital and when they are in, they are pretty sick. We have a mismatch for the number of learners and number of patients on the inpatient service. Where are the patients who are out in the community, in the ambulatory setting? That is a much harder way to organize teaching. You need a lot more teachers. Much harder to standardize what people are going to learn. You can't assume everybody is going to be available for any seminar or anything else. Now preceptors [Doctors] in communities say it costs money to have student here, it slows you down in a clinical setting. What are you going to offer as remuneration? That is becoming a problem. There are pressures. (P8)

This participant has summarized aptly all participants' reports of pressures and influences on the medical school to provide medical education. This is a list of the medical education curricula context factors:

- increasing class size
- fewer patients in hospital to teach from
- clinicians treat patients in out-patient settings and are not as available to teach

students

- preceptors (Doctors) in community settings want compensation for teaching
- adjusting curricula to the changes in health care delivery patterns

Finding for 4.1: Instructors report teaching challenges in undergraduate medical education such as large classes; too few, patients' in-hospital to teach from and too few clinical instructors to provide teaching.

4.11 ***Curricula Structure in Undergraduate Medical Education***

Undergraduate medical education is divided into two programs. Years 1 and 2 are basic science and case-oriented, problem-stimulated curricula (COPS): Years 3 and 4 are clerkship apprenticeships and tutorials. The following is a description of the curricula structure.

4.11.1 ***Years 1 and 2: Basic science and case-oriented, problem-stimulated curricula.***

The setting for this study of ASD curricula is a four-year undergraduate medical education program. Within this program, the structure and delivery of the medical curricula continues to evolve. I found external forces such as societies' health practices and health policy spark change in medical school curricula. For example, one participant said, "Patients' complementary medicine practices prompted a recent change in the curricula because physicians need to know how to treat patients who are using traditional medicine with homeopathic treatments". (P11) Participants also discussed how the delivery of curricula has changed over the years, from a traditional science or body-system based program to a more patient-centered integrated curricula.

> The traditional model which did have many faults was departmentally based. Anatomy, physiology, internal medicine, and ophthalmology, etc., they would all

> teach their own thing and fight over curriculum and there really was no integration whatsoever. Somewhere along the line, with curriculum reform, came about around the globe. Which is probably the most common reform that happened was the problem based format [Case-Oriented, Problem-Stimulated (COPS) Curriculum].... clinical units where.... the clinical piece moved into the early years.... students would do physical exams and see patients in first and second year. (P9)

The first two years of undergraduate medical school consist of units which include basic medical science courses with some opportunities for patient-doctor interaction. The instructors and students found applying early theoretical learning to medical practice in COPS curricula, helped students to learn less material by rote and develop skills for the "real world of clinical practice". For example, Brain & Behavior is a basic medical science unit in the curricula and the corresponding COPS component is a case on Tourette's syndrome, a neurological disorder. The cases within the units promote a deeper understanding of the material and allow students to apply what they learn in the classroom to problem-based cases that simulate practice to promote critical thinking (for example, a case involving a patient with Tourette's). Participants report the purpose of the program is to help students learn the medical curricula and make the transition from student to skilled practitioner:

> ... To help students to acquire the appropriate knowledge, skills, attitudes and values which will prepare students for a professional lifetime in Medicine. The curriculum recognizes that no one individual can know everything for the practice of Medicine, and that knowledge is continually changing. Medicine is also changing, as the emphasis on promotion of health and prevention grows. (P9)

The overarching educational goal is to teach undergraduate medical students to learn independently, identify their own learning gaps, as well as critically analyze and reason when solving problems. In years 1 & 2, the COPS Curriculum begins by assigning students into groups of seven or eight. The groups work through a weekly succession of

cases that make up a "unit". The units can last from 4-10 weeks and run concurrently or successively depending on the topic; a typical week in year 1 and year 2 includes a minimum of 25-30 hours of course work. Groups rotate through 15 units in years 1 and 2. Thus, one student may start with a unit or topic that another student ends with. The expectations for the groups are as follows:

> The tutorial groups generally complete one case per week. Effective group learning requires active participation from everyone. The unit objectives in the first year place an emphasis on uncovering issues in a particular case, and understanding "why" and "how" they occur. Cases are used as a vehicle for students to learn in a clinical context and to apply the first steps of a clinical reasoning which will be defined and further developed over the four years of undergraduate medical education. In later years, a shift in emphasis for the unit objectives will occur, which will center around "solving the mystery" and deciding upon a management plan. (www.dal.ca/medical/curriculum)

Tutors and course instructors provide academic support for the unit's educational goals. Students receive a Pass-Fail within each unit. There are several sources of remedial measures for poor academic performance: tutors, course instructors and the Learning Resource Centre (LRC). The LRC provides an enriched opportunity for students to put medical theory into practice by providing a "Simulated Patient Program". Participants report simulation-based teaching is effective and students report high learning satisfaction from this educational format. However, this format is expensive to carry out broadly in medical education and students' access this format after exhausting the other remedial measures.

> They go.... [Not sure how often]. [There are] scheduled specific cases but I don't know how often. Access at an ad hoc basis is limited. Access cases if they want to. It's cost prohibitive. (P8)

Once students successfully complete the COPS curriculum they begin the clerkship program in Year 3 and 4.

Finding for 4.11.1: Students state they did not encounter ASD in the first and second year of the Case-Oriented, Problem-Stimulated (COPS) Curricula.

4.11.2 ***Years 3 and 4: Clerkships.*** Clerkships are practical experiences or apprenticeships in health care settings and signify a transition from the COPS curriculum, body-system and problem based learning, to a patient based disease-process method of learning.

> I think they work in teams, in their COPS program very well.... It does start them off on a good footing.... COPS is problem based and it gets lost in clerkship, because clerkship is on the disease process basis. I don't want it to be like that. I want it to be more rounded; more on, "let's see if I can talk to you and identify problems with the infant".... "What problems did the infant come in with?"... "What are the things to think about?" (P13)

The last two years consist of clerkships in multiple medical settings and medical disciplines. The clerkship program is delivered in two phases:

Phase 1 is 55 weeks and consists of a 4-week Introduction to the Clerkship Unit, followed by a maximum of 20 shifts in Emergency Medicine and 12-week blocks in each of the following disciplines:

- Medical
- Family Medicine and Psychiatry
- Surgical
- Women, Children and Youth's Health.

Students are assessed by:

- a multiple-choice question exam at the end of each 12-week unit
- Objective Structured Clinical Examinations (OSCE) both at the midpoint (24 weeks) and end of Phase 1 (48 weeks).

Phase 2 is 32 weeks with a focus on ambulatory patients and community

involvement. Phase 2 is composed of:

- 12-weeks for Electives
- 12-week unit entitled Continuing and Preventive Care
- 4-weeks vacation
- 4-weeks for engaging in the Canadian Resident Matching Service (CaRMS).

CaRMS is external to the university and provides a computer matching service that aids residency program directors and students with entry into postgraduate medical training. All the students talked about engaging in the selection procedure of CaRMS and their future residency program. At this point in the program students reflect on specific skills they will need for their residency and prepare to address learning gaps for topics they may have missed in the undergraduate program. There are many pressures on the curricula, on the instructors, and on the medical students as learners to fit all the necessary knowledge and skills into the four-year program.

Finding for 4.11.2: Students evaluate their knowledge gaps when they engage in the Canadian Resident Matching Service (CaRMS). Students matched to family practice and pediatrics acknowledged a knowledge gap for ASD and other developmental disorders.

4.11.3 ***Administering curricula content.*** Curriculum committees decide curricula content. The amount of content exceeds the four-year allotment for undergraduate medical education. Students feel overwhelmed by the amount of information in the curricula.

> Funny when I started I was like, "Why do they need four years for this?", but at the end of my four years, I was like I can't believe there's only four years for this. (P4)

The participants expressed strong feelings about finding space for curricula content, *"We battled this for many, many years."* (P9) and competition for which topics are covered.

> [The] Associate Dean always said... I don't really like this parallel but he always said put more steps in the curriculum and it's like a bunch of penguins on an iceberg and if you want to put on another penguin you have to kick another off of (sic) the iceberg so basically it's sort of just tight, how much space there is in the curriculum. But I don't actually subscribe to that. I think if there's something missing then you put it in regardless of how you do it. Yah, so that's the job of the curriculum committee.... the curriculum committee makes decisions based on what students and faculty as well as National bodies in Canada recommend or demand so ..... (P3)

Instructors report a vested interest in their area of expertise; Women, Children and Youth's Health, Psychiatry, Medical, Family Medicine, Surgical, and Emergency Medicine. Instructors also say when the COPS curriculum (problem-based learning) was introduced in the first two years of the undergraduate program, it was no longer departmentally-based but administered by the Undergraduate Medical Education administration. *"The faculty, if you like, took much more control over it and created a much more unified program so that exams and the issue of this stuff being looked at and distributed was system wide."* (P9) This shift in the medical school structure allowed curricula to be more integrated but it also created difficulties in administering curricula. As a result, instructors' report individual departments compete for curricula space.

> So departments created their own parallel education outfit if you like, with the university medical undergraduate program.... We try to keep an eye on it; we in fact, do cover everything. (P9)

The curriculum planners and developers use several rigorous strategies to determine curricula content within the COPS units and Clerkship blocks, such as:

> [We decide by] reviewing certain standard texts available to students. Looking at what other universities across the countries are doing. I belong to a Canadian

> [professional body] and American Directors of ..... Hitting reality, what time is available in the schedule. (P9)

Participants talk with pride about course curricula they developed. *"We researched it, we validated our course, [and] we did a reasonable job of it."* (P13) However, once developed, curricula are informally administered with a "try to keep an eye on it" approach.

Finding for 4.11.3: Curricula are informally administered and monitored with a "try to keep an eye on it" approach; therefore, if there is a gap in the curricula it is difficult to find and fix.

4.11.4 ***Integrating curricula content.*** Participants express dissatisfaction with the absence of information on curricula content:

> There is information available through the undergrad medical office. More or less what the curricula are in other areas. That's less than perfect. It's supposed to be a data base system where you basically punch in a topic or an issue or treatment and supposed to be able to get the answer. But there's actually a lot of work involved to try and get that. (P9)

This participant is referring to a database called Curmit which is an internet database for North American medical school curricula. Administrator report course instructors have not provided "Mesh terms" for their course content but because of time constraints. Hence this important curricula database is not available to provide reliable information and there are no other formal methods for communicating, coordinating or integrating curricula. Therefore, instructors rely on informal methods for communicating curricula with one another.

> Coordination isn't always an active process, it happens passively. Someone may know that something is going on. One of the challenges we have discussed in.... We think we know most, but perhaps not all, generally speaking. What we don't know is the details of what one individual faculty may teach in a group setting. A ball park is there are at least ten who teach. One predicts that a little bit will be

> about development, part of what you have to take a history on. I don't know what they are actually teaching and neither would .... At the next level we have a limited idea what might be taught by Family Medicine and Psychiatry. (P8)

> I have certain awareness. I would not be aware necessarily on a year to year basis what adjustments have been made in that program. (P9)

Participants say curricula content integration is deficient. One participant said, *"I don't have a sense of a program. I don't have a sense of a coordinated program."* (P12) Another said, *"...hope that overtime – that curricula, child and family project, overtime they will develop some knowledge. Hope through exposure to experience [they] will pick up along the way."* (P8) The first two years provide a concentrated foundation of basic science and the second two years provide both theoretical and practical knowledge for medical practice. However, participants report trying to ensure foundational knowledge in the curricula for a specific disorder or specific health topic is difficult. Topics appear across the units and blocks. Curricula appear disjointed and unorganized. Participants say there is no system in place to track where or when a particular disorder will appear and so there is overlap for some disorders and absence for others. This randomness occurs because individual instructors decide which disorders and health issues are present in the curricula. The undergraduate medical education department does not coordinate the content with or among the instructors. This instructor had a broader concern about communication and the lack of coordination for curricula objectives among the various settings and instructors.

> Do we talk enough across the department lines in particular, from the ... [teaching hospital] out to the community? We have so many other players with the education process, all the community preceptors – hundreds. We have a lot of acknowledged or unacknowledged, that we are not doing anything with. I couldn't tell you what they are teaching or modeling – which is very important. (P8)

From the students' perspective curricula coordination is informal and in some cases absent.

> Very informal. Mostly sent out into the hospitals in third year and we never really came back. I haven't been with my whole class as a group, except for exams, since the beginning of my third year. So there is not a forum to consolidate that which is too bad. People all over the place and been through rotations and other responsibilities and can't really do it. (P2)

The perceived goal for undergraduate medical education curricula is expressed by this participant, *"You can't specifically pick a disease process. You got to do things more all round."* (P13) However, departments and patients are vested in disease processes. They hold a stake in how much and how well the foundational curricula cover these processes in cases, lectures, and clerkship tutorials. Participants find *"its part of the problem with the design that the undergraduate medical education has been designed into certain silos...."* (P9)

Participants also say, *"The advocacy for certain aspects of the human body, human mind and human behavior were lost in the new system and didn't have a stand."* (P9) One participant articulates the implications for ASD in the undergraduate medical curricula:

> Jockey for position with other topics. One positive counter pressure is the currently high public profile of autism. There is a recognition that autism exists. There is a reason why people should be thinking about it. That is a good counter pressure, when the public are talking about something. It is a little bit easier to say, "What are we doing about it?" the medical school and faculty. Development in general and autism specifically, it doesn't currently fit into one specific block so it doesn't have a specific place there. We're trying to get it to fit in the first two years, little a bit about what is normal. The gap for autism has been part of the whole gap, not gap, area, of abnormal child development, when things are not going right, issues for delay and disorders. A few years ago we put this seminar in clerkship about language delay, language disorder and autistic disorder to try to get at that. (P8)

The structure of the curricula on child development and ASD in pediatrics

illustrates these concerns and highlights instructors' expectations of medical students' learning.

Finding for 4.11.4: The structure of undergraduate medical curricula forces child development and ASD curricula to jockey for position with no formal method for communicating or integrating curricula across the 4 year program.

4.2 ***What do students learn about ASD and child development in undergraduate medical education?***

4.21 ***Nowhere to call home.*** Participants report children' health and development is spread across the COPS curricula in the first two years of the undergraduate program, "It doesn't have a specific home that says pediatrics." (P8) For example, students who attend a lecture on kidneys will learn about issues related to adult kidneys and the lecture will include a section unique to pediatric kidneys.

> I found the teaching in peds through the first two years pretty, pretty – just sporadic. It was just spread out all over the place. You would be doing CV and then throw in a 15-minute lecture on congenital heart disease on children....(P4)

Participants said the coverage of pediatrics as a whole is sparse and random in the COPS curriculum of year 1 and 2. Student's say, *"They kinda leave the whole children, youth thing out of the first two preclinical years, altogether."* (P2) Specifically, The Life Cycle, as part of the Patient-Doctor Unit provides an introduction to pediatrics through the Child and Family Project.

The Child and Family Project involve pairs of students who follow an infant's progress through the first and second year of life through home visits. The home visits follow a set structure. Students conduct the Rourke inventory and the Denver II assessments with the children and their families. Instructors caution students not to

provide medical advice but to refer questions to the families' doctor. Students also receive a preparatory lecture and complete a take-home exam to report their learned experiences. This unit is teaching students about child development and provides them with an applied learning opportunity.

> Then there is pediatrics in child and family project. Student placed in pairs are to follow a recently born baby and his/her parents for the first 2 years. A meeting to go over what the project is, what we are doing, orient them to the guide book that goes along with it. A little bit of teaching specifically around some of the things they are going to do. Introduce how to measure a child using a doll. It is in a lecture format. We go over how to do the relevant early bits out of the Denver. We go over the things that are in the book. There's growth charts. They have to learn the Rourke, a section on temperament. I think there was 2 or 2 ½ hours didactic teaching. I did a whirl wind exposure to themes of looking at the developing child. It is very basic. It is about what are the kinds of things when you think about development. It wasn't on any disorders. [Teaching] the concept that you might look at age referencing as a way to understand it. The idea of very briefly what were Freud and Erickson. What kinds of things they were looking at to orienting those who never had that background. What stages of development are and what are the different frameworks people might use. [It's] very broad and very general and short. (P8)

Students say they appreciate the Child and Family Project. This project offers an opportunity for students to experience children in their home environment and learn first-hand the important developmental milestones and how to measure them.

> I don't know if it was useful for everyone but I honestly, growing up, somehow managed to avoid babies and infants altogether. I thought it was interesting and I definitely learned some of the major screening aspects.... how many words and when you expect them to be able to sit on their own... I honestly would have had no appreciation of that.... I thought it was useful going to do that and its fun too! (P4)

The Child and Family Project is the foundation for learning normal development in year 1 and 2. In Phase 1 of the third and fourth year, Pediatrics has a home in the Women, Children and Youth's Health block. This participant talks about the learning expectations for child development in pediatrics.

> In terms of normal development, I think they should come out with what the normal is. I personally I don't think that the abnormal is something to learn. It's something to be aware of but you learn that through your residency program. What they need to come out with is a very solid knowledge base of normal interview, interview techniques, communication skills and gathering the information and then they can work on the abnormal and they will get that through lots and lots of faces, they should be getting through residency.... We get them taking histories and writing them up in essentially year one and two because by the time they get to year three they are ready for more pathology and they are ready to see things more in depth. It would be absolutely wonderful if each one of them could see a real patient with autism or even a patient with anything, cystic fibrosis. (P13)

Some instructors believe third year students are *"ready for more pathology and they are ready to see things more in depth"* (P13) but the curricula in the first 2 years may not prepare some students for this level of practice.

Finding for 4.21: Students report the developmental curricula in the first 2 years do not prepare them for treating patients with ASD in clerkship years 3 and 4.

4.22 *Just the basics.* Instructors express concern that some curricula content is too advanced for some students. *"I think the trouble is you try and teach over people's heads most of the time. You've got to teach them the basics, try to teach and try to get the basics."* (P13) Participants believe students must have a good understanding of the developmental milestones before they are ready for developmental pathology (for example, ASD). *"I mean half the time as long they come out knowing that there are four basic milestones and they've got to think about language, they've got to think about vocalization and hearing and stuff like that."* (P13)

The pediatric undergraduate program is introductory and covers general health concepts on infants, children, and adolescents. Instructors understand undergraduate students grapple with straightforward patient interviews and find it difficult to deal with more complex patient cases.

> Students who are in pediatrics do a lot. You can't specifically pick a disease process-- you've got to do things more all round.... make sure they see and interview an adolescent patient that can be tricky for a lot of them. If you could imagine that is a tricky aspect for them to do, to actually face, see, and write up one adolescent face in 6 weeks of pediatrics, you can see there is no way they are going to see all disease processes. So you pick something extremely, I wouldn't say minor, I have a lot of respect for all of the developmental disabilities. (P13)

Instructors report they cover child development in the curricula. Child development curricula serve as a foundation to learning developmental disorders. As this participant indicates *"They actually get taught development from year one all the way through, but they don't know they are being taught it."* (P13) Students report they learn some aspects of development but experience barriers to learning about developmental disorders.

Finding for 4.22: The syllabi state learning objectives for developmental disorders but instructors informally communicate the learning priority is basic developmental milestones.

The next section of my findings will focus on one of the disorders: Autism Spectrum Disorder (ASD).

4.3 ***What are Students' Experiences Learning about ASD in Medical School?***

The ways medical students' learn and instructors' teach contextualize the findings on ASD in undergraduate medical education. I consistently heard from participants that if a student did not learn a topic they independently sought the material or experience to fill their knowledge gap. The following describes how medical students achieve this goal for ASD.

4.31 ***Independent learning and ASD gaps.*** Students do not report a learning gap for child development, but students report a significant learning gap for ASD. The cohort

of students graduating in 2005 relay that ASD was present in the Brain and Behavior, Genetics, Embryology & Reproduction Unit, a one-hour clerkship pediatric lecture and some exposure in the Psychiatry block. Students' mostly report no or vague recollections of ASD curricula for example, "*never had a clear objective to know about autism*" and "*I think it's so hard to remember where you remembered everything. I did learn during pediatrics.*" (P2); "*I can't recall the specific lecture in the first two years. I assume we had one but I don't recall one. We definitely had one in the third year, so besides that I don't remember any other teaching around it.*" (P4). One participant clearly remembered the ASD teaching:

> It was taught during the Brain and Behavior Unit of the second year and that was our first exposure to it - a series of lectures on it over about a week. And then there was another lecture series in Pediatrics and another lecture series in our Psychiatry component clerkship and Pediatrics in clerkship as well and both of those would be third year. (P5)

All participants talked about medical students as independent learners who can identify learning gaps. Students report that test scores measure their gaps with no other formal measures between. "*I didn't get really [any] feedback what I was doing right or wrong.*" (P2) The stakes are high for students because there is no middle ground for formal assessment. Given the scale of the curricula and the various topics covered in medical school, students may not identify their gaps and learning needs. This happens because no formal assessment practices or procedures are in place to help students identify their gaps and learning needs

> But there is (sic) no formal procedures where we give feedback to them on things we are missing, skills we didn't have or knowledge we didn't have in our clerkship rotations that should have been included in the second year or first year unless you take initiative until the graduation survey which I just filled out now and that is not specific and is sort of general. (P3)

These words describe what most students expressed: "no one is watching". All the participants except one said the teaching in development is adequate for students but because "no one is watching" they also report learning is inadequate for 50% of medical students who will practice in primary care and pediatrics. This student's report exemplifies this finding.

> I'd say that I feel reasonably comfortable with developmental stages and the teaching we had. The reason I feel comfortable with this is because a lot of us.... I don't think that a lot of us will have involvement with that in the later stages in our career. If that makes any sense? The amount of teaching that we did get is appropriate for most people who are going through medical school. I don't think it is appropriate for people who are going into pediatrics for instance or people who are going into primary care settings where they will be dealing with a lot of younger children and these sorts of things. But in a general sort of background I think it was fine. But those people who would do those sorts of things would take a special interest and take on more self directed learning in that way. Does that make any sense? (P1)

The premise in medical school which permeates participants' reports is that students as independent learners will recognize learning gaps and gain knowledge and clinical experience in areas where the curricula is weak. So the expectation for 50% of medical students, who go on to practice in primary care and pediatrics, is they will identify their knowledge gaps in child development without procedures to assist them in this task. Participants report, students rely on clinical leadership as a source of support to help identify gaps in curricula content for future practice.

Finding for 4.31: Students convey an ASD knowledge gap but receive little guidance or strategies for evaluating or addressing knowledge gaps during the four-year program.

4.32 ***Clinical leadership in years 1 and 2.*** The curricula instructors in years 1 and 2 are science faculty and clinicians. They teach the courses which include ASD curricula

(for example COPS cases and Child and Family project).

Tutors lead the COPS cases that contextualize the curricula content and prepare students to think about how the theoretical relates to the practical. Tutors are *"supposed to be members of the faculty; they might be basic scientists; they could be clinicians; they could be at any academic level."* (P8) facilitate the COPS cases.

> Those [Tutors] are the individuals, who will show up to the small group of learning, on Monday, Wednesday, Friday, for example. Going through the case based learning with the group, leading and monitoring the group. (P8)

Participants report the tutor is not an expert in the case content as there are other faculty members who are available as experts. The tutors ask "what are the questions we should be thinking about" rather than "these are the answers". Participants expressed concern about "non-expert" facilitators leading the group. They believe students do need constructive feedback on what they are learning as well as support in how to practice in the first two years of their medical training.

> There has been an endorsement over the years of the non expert tutor to facilitate the group of learning [and] making sure they are on track and participating, they are coming back to the case, sticking with the approach that is needed. The expert versus non expert tutor has come into challenge. I can't be successful with the group unless I know the subject enough to know if they are on track or not. If I tutor something, I study at night, not to become an expert but to know what they are talking about. (P8)

This participant describes how to prepare for the role of tutor. Often the cases are not from the tutor's area of expertise or discipline and they sacrifice at least 8 hours of medical practice to participate. As a result, participants say it is difficult to recruit clinicians for the role of tutor and so, non-clinicians facilitate students' problem solving of COPS cases. The foundational premise of COPS is to provide preparatory practice skills in the first two years with the goal of generalizing these skills to clinical clerkship

in year three and four. Participants relay that non-clinicians may not be the best choice to facilitate pre-clinical skills for ASD and prepare students for patient contact.

In the Child and Family project students learn about basic child development and measurement instruments such as the Rourke and Denver II. Participants report clinical teaching support for this project is a brief lecture and students are given the option to contact an experienced clinician if they need guidance. Clinical teaching and guidance is sparse in the first two years for students who may face ASD in medical practice.

Finding 4.32: Students receive minimal ASD clinical guidance in the first two years from "non-expert" tutors and a brief lecture from a developmental clinician on typical development.

4.33 ***Clinical leadership in clerkship.*** Participants report in years 3 and 4 students learn on-site and off-site in clinical settings and attend clerkship seminars on various health issues. Preceptors (teaching physicians), who are on and off-site provide clinical education experiences for third and fourth year medical students in all disciplines of medical practice (for example, Family Medicine, Pediatrics, and Psychiatry). Participants say it is challenging for preceptors to balance patient and teaching responsibilities. Students report a high-level of learning satisfaction in the clerkship years.

> The real life application I have gotten outside of school [classroom]. Always the way, academia is never real world. That is just the way things work. I learned more, probably in everything in medicine in the last two years than I did during the first two years. You learn three or four times as much in clinical experience than you do in the classroom. (P2)

In clerkship, students apply and practice what they learned in year 1 and 2 with practicing clinicians (preceptors). Students say residents typically guide clerks in the hospital not clinicians. Residents play a key role in guiding clerks in clinical rotations.

Residents have graduated from the four-year undergraduate program and are undertaking their graduate work in an area of specialty (for example, Emergency Medicine or Family Medicine). Essentially they are students who are learning too. Participants perceive resident teaching as a "watering down" of clinical expertise and education.

> Well the odd thing about it is.... We have six weeks of pediatric rotation, 3 of them are on the ward. During that time you actually have very little contact with staff except for teaching. Almost exclusively with the resident and then the staff person might just come by and, I mean depending on who the staff person, is sometimes they are very hands on but that's exceptional. Then the other 3 weeks you are in the clinic. Spend a day or two in each type of clinic. There is no continuous staff person contact unless you happen to have someone with for your time on the wards that are present frequently. (P3)

Preceptors, who take on the role, add an additional responsibility to a demanding practice. One participant describes the teaching challenges for preceptors who provide an educational opportunity for clerks in community clinical settings.

> .... rotations outside the area are more difficult to guarantee good supervision for because of the dearth of [clinicians].... they are very busy with clinical rotations. They often can't do the academic stuff. They provide the student with clinic experience but things like the seminar series, history reviews, and guiding their readings, etc., they kind of find that hard to do. The other thing, they find hard to do, is not having students all of the time. They can get a clinic geared up for seeing students all the time, but if they see students some times and the next rotation they don't and two rotations after that they do again, they find that very difficult. (P9)

Clinical instructors try to provide a learning environment for the students without compromising their patient's care. In the context of a busy practice, instructors are sensitive to students and try to provide *"constructive feedback on how to make little changes"*. (P13)

> [What] they find very hard is accepting critical feedback, telling them, "Now let's try and improve on this. You have to be so careful. You have to be careful with every body when you do that. It's very, very, tricky when they have always scored A+ and nineties and you're now telling them you can try and do this a bit better. (P13)

The experience of "being wrong" in medical school is common. This articulates the culture and structure of medical school teaching and *"how we set them up"* (P13) as learners and practitioners. In the clinical setting, instructors give feedback on students' performance without providing a lot of modeling and practice.

> I pop in and out. I observe them doing bits and pieces. They report back to me. I go back in there and they check on a few more things.... The teaching in med 1 and med 2 is specific hours .... Teaching in med 3 is more of a [apprenticeship].... (P13)

However, participants talk about clinical practice as a high risk setting for learning errors. Students are more likely to make errors and need correcting. It also speaks of more checking and correcting than preparing or teaching. Medical students perform and then, are measured. There is no room for error in clinical practice settings which serve as the treatment room and classroom for instructors and students. Students learn while "on-the-job" and clinicians teach while practicing medicine. The participants spoke about the constraints on teaching time and placing the needs of patients over the learning needs of the students.

> One of the biggest problems, if you want to know the bottom line, is that clinical work and research come first and teaching comes last. You are expected to fit the teaching in with all the other stuff that you are doing.... I wish the teaching got its fair share of the time with everything. (P13)

The expectation for medical students is to learn independently to compensate for instructors' time constraints and the demands on the medical system. One of the participants voiced concern about the lack of support students receive in medical education.

> .... essentially what should be happening is that there should be a huge, much, much, much, much, more observation and much more feedback and much more of the students watching us and us watching the students and its not getting done. (P13)

The instructors agreed students need more observation and guidance. Students report they want to learn clinical practice skills using standardized tools, with relevant instruction, and expert guidance.

Finding for 4.33: In clerkship years 3 and 4, students receive clinical guidance from residents who may lack practice experience in ASD, and clinicians, who juggle patient responsibilities, so teaching is placed last.

4.34 ASD patient interviews are too hard to teach. Clinical instructors report they choose patients from their practice for students to learn from. They base decisions on the complexity of the patient's needs and the ability of the student. This instructor shared the decision process for choosing patients to teach clerks about ASD in clinical practice.

> If you think of taking a student in with you.... I can think of a case not so long ago and I said to the student well you go in to see the patient with the reflux, that's a pretty basic thing that is what we need to teach you. I went in and saw the patient with the autism. Essentially there were two patients to choose from, I didn't send my student in to meet the parents, the social worker and the worker from the home with the patient with autism because essentially they would be lost on their own. They could start of course, they could start. (P13)

This participant explains ASD is too difficult for clerks to learn about in the clinical setting and too demanding. The goal for clerks is introductory concepts and patient cases.

> They could be there with me and I could guide them. Working in clinic you can't do that. Third years, they see patients on their own. (Where do they get their mentoring and modeling?) They are getting a bit of both. They are getting some of both. At that level, you want them to be taking their own histories and doing their own physical, with some of it observed. (P13)

Consequently, 25% of the medical students from this study met a patient with ASD in clerkship. However, as this participant shares, there is no clinical leadership for a patient contact with a person who has ASD and it is not required.

> Encountering a patient with autism is not a required encountered. What they are required to encounter is that they learn from terminology and something about it which they do through tutorial which is given to the whole class. If they don't get it through tutorial it is on video if they want it. I'm not sure if there's something specific to autism there is a web based computer based case. We have a number of cases which covers the whole of the curriculum. There will be something about autism in one of those cases and there is certainly quite a bit on development in a number of those cases. So they will cover it in that but there is no way you are going to get every student to see an autistic patient or have an encounter with an autistic patient. (P13)

Participants acknowledge students learn best from patient contact. "What they are going to remember is patient contact and they are not going to have that much patient contact with an autistic person so it's going be vague recollections for most of it." (P13) However, for ASD, patient contact is one part of the learning equation: knowledge and clinical teaching support are the other parts of the equation.

The two participants who had direct contact with ASD report they received guidance by an instructor or supervisor. Some instructors have experience with ASD and some have none. Although students had clinical guidance, they talk about their experiences with ASD and patient contact in clerkship as overwhelming and frustrating.

> I had contact with families and children. I did an elective in adolescent psychiatry and there was a small child component to that. Other than that, I would think if you wouldn't have had that, you wouldn't have been exposed.... It was just for an assessment with my supervisor. My impression was that the child was relatively debilitated compared to other children his age. Just as far as his communication skills. And that was the most striking feature that I noticed. It was extremely difficult to communicate with him with any interaction with a goal in mind. The child's parents were there and it was a joint effort compared to the many other experiences and other children we saw and compared to the other average assessments that we were doing. (P1)

Participants report patient contact is overwhelming because of the complexity of ASD and frustrating because the student did not have the skills to conduct the patient interview. This finding represents the preparation students receive in undergraduate

medical education on ASD and the expertise in the clinical settings. This student shared an experience with a patient who had ASD in the hospital. The participant expressed frustration with the lack of support and knowledge of the teaching clinicians.

> Patients in emergency that had other problems and they were coming into emerg for this specific problem with the co morbidity of autism. Quite often they found they were not listened to, that they weren't given the right care. And when I went into see them and I said ok I understand and I can see your child is in an extreme amount of pain, when you strip away the self stimulatory behavior and all that. You could see this person is in a lot of distress. And they went, "exactly". We took the work up from there. This is informal teaching but whereas some of the emerg Docs didn't have a clue what to do and they even said, "How am I supposed to figure out this kid has pain?" Well it's not very hard if you look at it and find out from the parents. (P5)

The lack of ASD clinical knowledge and leadership confounds the pervading notion that students are likely to learn about ASD on their own, through clerkship seminars or electives.

> So I guess cause you run the risk of having people not go out and learn it better on their own and then also run the risk because of that, these kids not being identified as early as they could be and my understanding is that the earlier they are identified the better off it is for them. I mean obviously it doesn't really affect the life of the physician in any way but the better off it is for them. (P4)

Participants spoke about early identification of ASD and thought it was relevant to learn. This participant wonders if students will understand knowing about ASD is important for practice when they have limited clinical knowledge and no patient contact. *"The big idea that anybody in medicine needs to be a self-motivated learner, it also has to set up situations to tune people into things."* (P8) This lack of exposure and clinical leadership creates doubt about students' knowledge on ASD and capacity to help children based on the education they received in undergraduate medical education.

> I'm frightened because I'm just graduating and I don't know anything yet and I am going to be a family doctor and I am going to the first line for all of this stuff.

> But.... ummm I hope that I'm gonna be at least attentive enough, and be able to spend enough time with my patients to listen to their concerns. You know always hear about first time parents being overly cautious and overly anxious and concerned about things, but you know sometimes they're right. They're experts in their own children. Sometimes what they are worrying about is actually something worth worrying about. I hoping I'm going to take their concerns seriously enough and have enough knowledge and background so that I can apply that and see enough kids that I know what is normal and what's not and when to refer, have the knowledge. Maybe it's better to refer when you're wrong then not to refer, and be wrong. (P2)

Participants talk about fear of making the wrong decision, *"Afraid of scaring them. You don't want to make someone anxious for no reason, if you're wrong, (pause) worse consequences."* (P2) Students and instructors prefer patient contact for teaching purposes only. This format is low-risk and a rich learning opportunity that is rare and expensive to implement in medical school. Participants say they are better supported in this learning environment and the feedback is more instructive and constructive because as this participant shares, there is more time to do it properly.

> What I am trying to do for next year is to have proper teaching clinics. We do that for cardiology. That is rated highly. One of the retired cardiologists.... It's been going for about 4 years... 2 children just for teaching. Four of them [students] gather round and they thoroughly enjoy it. We just don't do enough. (P13)

This participant speaks to the call for more clinical guidance and learning guidance in the undergraduate medical education program.

Findings for 4.34: Instructors report ASD is either too hard to teach or it is too hard for students to learn. Few clinical instructors have the time to teach students about ASD and so students report minimal or unsuccessful experiences with ASD patients.

4.4 ***What do Students Learn About ASD for Future Medical Practice?***

Students' report they judge and select curricula for relevance. Relevant curricula

are on exams and communicated in clinical practice. Participants think it is important to learn about ASD. *"I think learning about autism is important both in terms of being able to recognize people who are potentially autistic and then also to be able to reassure parents who are concerned about autism."* (P3) However, this participant wonders if it would make a difference if students learn to recognize ASD, when the referral process for diagnosis is so convoluted. Consequently, what students experience about ASD referral from their clinical clerkships in medical practice is frustration with the system.

> Knowing they don't know all of the areas of development particularly pertained to autism or how to diagnose autism.... Where to go for the help is half the problem. So once you have a feeling something is going on, where do you go to even in my clinic and pick up something? I think something is going on here, its language based. We'll get a hearing test or a vision test. Do you know how long it is... to get a referral to psychology or anybody? Sometimes I say to them look, I am going to put down with autistic characteristics, at least you will get a good screening with the autism team. So you know what? You are trying to jump through loops half the time because there isn't actually anybody out there you can make a referral to. There isn't anybody who can do a quick .... I always tell people then use your speech language pathology. That may be one of the real drawbacks because they don't see people working in teams enough other than with other doctors. (P13)

The referral system is difficult and the waiting lists are long. Other participants thought this is a problem which is fed by outdated information and mitigated by earlier detection of ASD.

> I have to talk to them about where to refer them. I have to talk to them about that too. But I also have to spend time convincing them, that they get a lot of outdated information, convincing them an 18 month old [child] who doesn't have any words, you don't wait. You get them to speech and language. (P12)

Students report instructors should stress the significance of ASD in the population and provide a succinct strategy for detection in the curricula.

> Everyone thinks this is a 1/1000 disorder because that is the figure that is quoted.

> People need to realize that it's roughly 1 in 150 that are afflicted by ASD. I say 1/150 and people say "oh my God"! That's the main thing. It could be a bigger part of pediatrics, the pediatrics course rotation. Juvenile diabetes gets a hell of lot more attention but I don't think the prevalence is as great as autism. That should be a big focus in the message. Were looking for things, when a parent says my child just doesn't seem right. We are testing them for vitamin deficiency and all sorts of things. But if we have no test, and no screen and it is not on our radar to test them for a developmental disorder then these kids run around getting all sorts of bazaar tests and delaying diagnosis. That is so far from what is going on. One lecture on it, and maybe we should get 2 or 3. We do get a lecture about it. The instructor needs to talk clinically. You need to go in and give a facts presentation. Say look these are the signs, these are things we know. The prevalence and are there any risk factors and then say ok now, what are the things you would look for and with this screen and this is how you give it. It just seems to be, it needs to be more direct, instead of ..... Nobody ever says this is how you administer this test, nobody administers a test. (P5)

Students are frustrated with the lack of clear direction for ASD detection and treatment.

Finding for 4.4: Participants report learning about ASD is important but students say instructors do not communicate this in the curricula. Instructors convey ASD requires low suspicion and referring children with suspected ASD is futile because of the long waiting lists.

4.41 ***Relevant curricula are tested.*** Students' learn curricula instructors convey as important health issues and relevant to their success in medical school and future clinical practice. Participants talk about medical students actively using various skills to navigate medical school and view learning curricula as an act of endurance. Students report they are selective about the curricula content they study. Students screen curricula material for relevance to reduce the information to learn and use curricula syllabi as guides only. Medical school students are selective and savvy learners and they confess the bottom line is passing the exams. Students are finely tuned to how they are measured and the

knowledge they need for entry to the next level. All of the students said untested material is not actively learned because going on to the next level is dependant on test scores. Students describe testing in medical school as a series of choices about relevant curricula content.

> So you're encouraged to study a wide variety of topics.... it's the nature of our program. It's actually quite scary at times when they don't test you on each component... they test you on groups of subjects. So you'd be tested at the end of second year. There's a test on gastro... kidneys, [etc.]... that's okay, so to pass you only need a 60. So you're being tested on three or four different areas, so you know you play your odds and you go well, can I study everything, no! So.... you could theoretically not study anything with respect to the kidneys.... you're still gonna pick up some things, just through passive learning, while you're sitting in class and on the floor. But you could, if you knew the other topics very well, you could get 75% without knowing anything on the kidneys. It's a problem you know with the way we're tested.... I guess you run the risk of showing up and the whole exam being on the kidneys and then you're in trouble but that would never happen right?... you can get away with completely avoiding entire areas just because their not the main sort of topics that come up on the exams.... you know that from speaking with the people that come before you and the lists of questions that are put around before exams. (P4)

Students report topics that are not explored in depth are not typically on the exam and if they are, will not significantly alter their test scores. One of the students indicates testing also highlights areas that require more study. *"When it comes to writing your exams and you're asked about it then, maybe you realize that you didn't read as much of it as you could have."* (P2) The perception is if the topic is important enough to be on the exam, then I should learn about it. In medical school, if a student does not learn, the only way it will be noticed is through poor test scores because no one is following the individual student's progress in any other formal way.

> It's easy to not listen because as a student you are the lowest person on the rung. You choose not to listen at rounds and you don't read up about what you saw in rounds later that day. Then you don't learn. (P2)

Throughout the interviews, I found myself saying, "This is not a test".

Participants struggled to provide me with the right answers, *"Are you looking for something specific for autism? Just say a word..."*. (P2) One participant had delayed studying about development to participate in the study. I clearly said, "I want to understand your experiences and educational process." but they continued to try and get it right. I tried to convey to the participants there is no right or wrong way to express personal experiences. The unfortunate consequence of medical schools' emphasis on testing is clearly voiced by this participant,

> If it's not on the exam you don't learn it?! What is on the exam.... It's not your life skills. It's not what you are going into life using or needing, because that is never on the exam. (P13)

The participants' reported that students' hyper-sensitivity to testing increase the likelihood they will participate in learning for tested curricula. I asked participants if they were tested on ASD. Most said they were not tested; however there are a few questions on the exams throughout the four year program. One student remembered, *"It was clear. We were tested on the material."* (P5) Most students did not remember ASD on the exams or more importantly, ASD was not clearly earmarked for exams.

> Well I mean theoretically I guess there could have been a question on one of our psych exams or our pediatric exam. I don't recall a question specifically, not autism, you will have a test on autism, no. (P4)

There is no specific objective for ASD. There is little measurement of ASD curricula and consequently no motivation to learn about ASD. When ASD is rarely tested, the tacit message is that the topic is unimportant.

Finding for 4.41: Students are rarely tested on ASD and testing is important to ensure students learn about ASD so they will apply their knowledge in future medical practice.

4.42 ***ASD learning experiences in clerkship.*** The majority of participants discuss

students' diverse backgrounds and learning needs. "Students have different minds about [curricula]; they have different backgrounds and so on." (P9) Participants discussed the difficulty of teaching to a diverse student audience. The students often express differing opinions on relevant curricula content. Some students start medical school with a lot of experience in certain areas and some start with none. So there is a sense of a baseline but the uniqueness of the individual students also influences the types of learning experiences they need to learn about developmental disorders.

> What I realized over the years is we have a very mixed bunch in every class. We have some individuals who have a lot of background in child development – Masters' in psychology, teachers, [and those who] worked with kids in other kinds of capacities. Then we have people who haven't taken a very basic psychology class and no exposure to kids. They are all over the map. I am going from the very basic and hope that over time – that curricula, child and family project, over time they will develop some knowledge. Hope through exposure to experience [they] will pick up along the way. (P8)

Clerkships offer students core learning opportunities in practice, seminars, and electives which build on the learning in the first two years. The instructors and students have mixed opinions about their ASD experiences in the clerkship settings and seminars.

ASD is taught in a third year clerkship seminar. In one hour students learn about ASD signs and pathology. The instructor explains the curricula content.

> You know when I get to the students we just work hard for our whole hour on me trying to help them understand autism, the spectrum of autism placing it in the broader spectrum of developmental disorders and then focusing in very quickly on a case and helping them learn what the early signs of autism are. I present them the data. I say these kids are getting diagnosed too late. This is horrendously upsetting for families. All families wait for two years to get a proper diagnosis and we have to change this and then we get right down to talking about the signs and I make sure they understand them. (P12)

Although students receive this hour of ASD information they mostly report no recollection of the experience. The clerkship structure provides context for their vague

learning on this topic. This student talks about the experience while trying to remember the seminar.

> I'm trying to remember if .... we had a lecture on it. We may have had one but I don't remember having one. But because I was here, I didn't make it to all the lectures cause... when I was, here I was ... it was a little bit more difficult for me to go to the lectures, but when I did go to the lectures I was just listening on the phone so like there was no visual component so I'm trying to remember. (P4)

Some students report they missed the lecture because they were off-site. Students' value clerkship experiences outside the universities' teaching hospital because they are able to do more. Participants report more frontline patient contact and more independence in their clerkships but they miss or are unable to fully participate in the clerkship seminars.

> I did mine away so I didn't get the lectures they were doing in ..... I was in a typically non teaching hospital. I liked going away for my rotations because I got to do more but it also meant that everything was a little less structured and makes the whole experience, less standard. What my classmate may have seen in ...., all this big fancy stuff is completely different from what I saw. Everything that is big and fancy gets sent to ..... So you know I don't see this. (P2)

Twenty-five percent of the students go off-site for clerkships and the other portion stay in the teaching hospital near the university. Those who are off-site and those who experience demand in their clerkship placements find it challenging to attend the third year clerkship tutorials. The ASD seminar is 1 of 21 pediatric tutorials in the third year which cover a number of disorders and child development. This difficulty is recognized by the instructors and they provide video tapes for students who miss the tutorials.

> .... that is why we have the videotapes. On the whole, listening or watching on video tape or even listening by phone is not the ideal way of being taught. [It would be better] if in the off-site places, if they could actually try and give those who miss the lectures here, to be given, by the people who are actually there. (P13)

Participants felt the speed and volume of the curricula coupled with the constant time demands restricts "catch up". I found clerkship tutorials are the only place in the curricula where disorders and specific health topics receive comprehensive teaching. Participants report clerkship seminars and tutorials are underutilized. This participant describes the concern for curriculum planners and students who miss relevant curricula.

> What I am increasingly realizing is that is going to help to get to see them. Any given time a significant number of times they are not here they are elsewhere that is not going to happen. There is the issue whether they will get it and if they don't get do they recognize they should read about it. The big idea that anybody in medicine needs to be a self motivated learner, it also have to set up situations to tune people into things so the clerk who doesn't get that seminar they should look at a list of seminars – I didn't get to that I should read about it. (P8)

Students report ASD knowledge gaps. Most students talk about identifying gaps in the fourth year after the opportunity for learning a topic in undergraduate medical education had passed.

Finding for 4.42: A one hour tutorial on ASD is delivered in the third year of clerkship when students' are either off-site or have competing patient responsibilities. Lack of ASD information and patient contact creates knowledge gaps which students do not identify in or through undergraduate medical education.

4.43 ***Teaching early detection of ASD and other developmental disorders.***

Students report they learn two developmental assessment instruments. They shared their knowledge and opinions on the tool they thought was best for detecting ASD.

> You know I might have been able to detect some types of developmental delay. I mean, can I say that we would have been able to identify all forms of autism, no. I think that the other thing about the Denver is I mean we were seeing kids every 3 months or something along those lines. Every 2 or 3 months and so you show up and it depends on the mood the child is in and you only see them a couple of times and uh it's hard to tell cause you mean you're a stranger to this family and under that environment. I think that the Denver is more limited under that environment. As a family doctor or a pediatrician who is seeing someone more

> regularly whether I might have a different level of comfort not only with the family but also with the child, it might be a little bit better there but under that particular environment with the baby project, I think you'd be pretty lucky unless it was really pretty obvious. I'm not, I mean unless it was a very a more significant or a more prevalent form of it. I mean we would have. I don't know if there's an answer in there for you or not, no. (P4)

This student thought the Denver's ineffectiveness was related to the home environment but a more experienced practitioner said, *"In the office they are not going to perform very well for you anyway, so an assessment in the office is probably, doesn't ...."* (P13) The Denver is cited by the participants as *"the best generalized screen looking for any kind of developmental, social, motor, fine and gross motor, and language"*. (P2) But students did not view this tool as useful for practice, *"We do the Denver every time we visit them and things. I mean, I can't see doing that every single time you see a kid in the office"*. (P2) The Denver is the only tool taught in undergraduate medical education for measuring development and the only tool recommended for family physicians in clinical practice. I asked students if they observed an assessment of ASD in the pediatric clinical clerkship and this student shared the experience.

> I guess when you see an assessment that is that detailed one of the first things that comes to mind is its something that you need a lot of training to be able to do and it's something that you go and you know this detailed of an assessment to decide how it, this sort of thing to can be done by a family doctor and how would a family doctor ever be able to do that is something that came to mind. (P4)

This student is overwhelmed by the experience and another student supports this impression from the family physician perspective.

> The problem is there are so many things you have to go through. Every single system that you have to make sure is working and function and going well. Yes your worried about social language and cognition and that kind of thing but that is one, of a huge list of things you have to do and so making sure. If you have a screening tool for absolutely every disease the kid could have then the kid would

be there all day. That's the problem. (P2)

ASD is one of many health issues family physicians are expected to detect in children. Participants suggest that physicians report they are screening for ASD but it is not happening.

> There are instruments we have looked at whether there are instruments that are advised regarding autism, that are actually used by primary care physicians and discovered that while the literature says so it is simply not happening. There is a sense it can be done but its not happening. People use a scale like the Denver which very broadly looks at overall kinds of development and that might be useful but a scale that identifies autism, a condition much less common, it simply is not used by primary care physicians. (P9)

These findings suggest students will not use the Denver in practice and consequently, when they are practicing physicians they will not use an instrument to detect ASD. Participants said that another effective way of detecting a developmental disorder is to ask the parent if they have concerns about their child's development.

> What is normal for kids and they should be developing awareness for when should I get worried. What is the most efficient "I should be worried tool". In fact they some of them will carry around something in their pockets. The Rourke has red flags, and general question do you have any questions about your child's development – surprisingly effective. Remind them to ask parents if they have concerned in those two domains. Whether they need something specific for autism it would have be very, very simple, if it's complicated then they won't use it or use it well. (P8)

However, other participants' report that parents do not feel physicians listen to their concerns and this is a barrier for detecting ASD.

> There is a bit of a barrier, young parents are often nervous, calling their doctor about problems, well I am a worried Mom, or I'm an inexperienced Mom, or by the time I bring the kid to the office what I see at home doesn't happen. They are apprehensive of presenting something where the physicians won't take them fully seriously and doesn't validate their concerns. In turn the physicians are not well enough trained with the little time we give them.... to do a more thorough assessment so they use opinions rather than the scientific approach. (P9)

Some believe physicians do not listen because they have no time to listen.

> A good family physician, will listen to the parent, hear what the parent has to say and work with the parent on their issues, even if they haven't a clue about what they are talking about…..you work with your family. I don't think they have enough time to work with the families or their patients. They are gatekeepers, they gotta say, yes hiccups is normal, colic is normal, this is okay. I am very, very sympathetic to what they do. I think they are amazing people doing what they have to do…. You are not going to get family physicians knowing much more about autism. What they really need is the time to work with families about the things they are bringing into them. There is no time for discussion, preventative care instruction, there's no time for all of that stuff. That's probably more of the problem than anything else. (P13)

If physicians lack time to detect then the Denver will not be useful because it takes 20 minutes or more to administer. If students are not taught a time efficient, "scientific approach" for detecting ASD, then as physicians, they will rely on "eyeballing" children for developmental disorders. Students reflect on how they would assess children without an instrument.

> Well, I know things like the social aspects. You find there is a kid that is 18 months, he's not looking at you eye contact, not pointing, trying to get you involved with themselves, focused with you and mom looking at the same object. That is a red flag that rises up to look further into it….I mean, when you look at a kid; you kinda get a feel for the kid. It's the art of medicine. Feel whether or not this kid is normal and whether they are developing the same way as other kids their age are. I don't know that, I don't think they told us any one thing. (P2)

Other students talk about the danger of physicians using this approach. This approach may not provide physicians with the certainty they need to identify a child with ASD. Participants report identifying a developmental disorder without a screening instrument is risky. As a result they may not alert parents and they may choose to not to identify a child with ASD until they are positive about their suspicions.

> I think like you know there are certain conditions where you go on a really low

> index suspicion, like you know, let's say child abuse. You're supposed to go on a really low index suspicion before you would do something about it and I think with something like autism or yeah where there's a high stake to tell a parent, "I'm concerned about your child's development". I think that probably physicians would be reluctant to do that unless they had a really compelling you know sort of something you wouldn't ignore, not that they would do it willingly like that but um ya, just knowing that it's hard, hard news to give but like a hard, like a hard reality to recognize. It would be easy to not recognize it if you didn't have to. (P3)

As this participant shares, receiving a diagnosis of ASD is "hard news". A participant shared a first experience of suspected ASD with me.

> I think that one of my friend's sons is autistic. Ya. And when she realized, when she voiced it the first time, her fear. I actually happened to be with her at the time. That is the closest I have ever come. It was first year. Ummm, she was telling me about her son, he was almost two and he hadn't spoken yet. Her concerns, I was sitting there thinking, ohhhh….. He's autistic but I didn't want to say that. So I was like, oh okay, I was trying to you know be nice and she kinda like looked at me and she said, "You're thinking he's autistic aren't you?" Yes, I was like, well yes, but I didn't want to say anything. She said, "I have been playing with that in the back of my head." ….later…. the diagnosis came. You know what the two of us…, we're sort of in different places, but whenever we see each other, like you know. (P2)

This was an intense encounter and conveys how emotionally laden this experience is for both sides. Participants talk about a sense of urgency to identify developmental disorders like ASD because "the earlier they are identified the better". (P4) They also think about the importance of knowing how to identify a child with ASD and how that may affect them in their medical practice.

> Being able to identify red flags in children's development um but I think that there is, sort of like, urgency cause these are things you really need to know cause if you miss it this kid's in trouble and maybe you're in trouble too. (P3)

Finding for 4.43: Students are not taught effective or useful developmental measurement instruments for detecting ASD or other developmental disorders.

4.44 ***Teaching ASD Relevance for Future Medical Practice.*** Participants report

the breadth and the density of medical curricula creates difficulty for most students to remember specific details of their undergraduate learning experience. They are more likely to remember the context or the instructor, than curricula content.

> Vague recollection for any subject. It just shows you that if you get a vague recollection than it is better than nothing at all. I'm absolutely sure that when we are teaching in a lecture format or tutorial format, they hardly remember anything. What they are going to remember is patient contact .... The stuff they will remember is the stuff they have done more in depth. A student as a whole will remember their electives or they will probably remember the teacher more than anything else, if you .... said "tell me about a teacher", they remember the teacher. They remember her, more than what she is teaching. That's what is surprising. (P13)

Students report they remember what is important for their present and future success. Instructors communicate the relevance of curricula. Participants share that instructors infer a separation of body and mind in the curricula. This separation is the perception of a division between physiological and psychological findings in medicine. Traditionally, physicians treated physiological ailments by investigating physical findings and students are still taught traditionally in some areas of the curricula, *"Because there are a lot of physical findings, so they're big, they're big on teaching us physical findings"*. (P4) This instructor believes stressing physical findings is cause for concern,

> ... It's how old fashioned we are. Yes 50 years ago, 100 years ago, physical findings, your liver, your spleen, infectious diseases but what we should be big on is preventative medicine. I think we still teach to a very old fashioned model. (P13)

One participant thought medical students may perceive psychological findings as less relevant than physical findings for their future practice, particularly when instructors stress physical findings in their lectures.

> .... another thing is that I think there tends to be a real separation in medicine and it is a somewhat artificial separation between things of the body and things of the

> mind and even though cognition or you know personality or communication, however you classify that, they are all very much brain, which is the body. I think they that they tend to be really separated so unless you are going into something very specific and you know that, like developmental medicine or psychiatry, I think people tend to feel somewhat removed from those kinds of issues... like this would be something that you'd refer early on because you might not have those competencies. (P3)

Another participant spoke about the students' experience of the mind-body separation in the curricula and how instructors apply counter pressure in the curricula.

> .... the second year... unit called Brain and Behavior. A few years back when a particular [instructor] who was open to behavior issues, mental health issues, underpinnings to health like sociological issues and so on, allowed a broader and more sensible integration with the psychiatry mental health topics, with the neurological science based topics. So that we proceeded in an anatomic kind of way until we got from the peripheral nervous system into certain parts of the brain where on a biological basis, mental health issues become important and it became possible to anticipate that with peripheral nerve diseases, because people's behaviors might lead to acquiring peripheral nerve diseases and then it became more biological as hit the mid part of the brain and as it hit the cortex of the brain it became quite open again. (P9)

This instructor clearly explains the mind interrelates with physical health. This is a good example of a clear connection between mental health and neurology. Another mind-body example is the connection between child development and neurology (for example, developmental disorders). Students actively evaluate curricula for relevant information. If they discount development because they think it is not relevant they will be less likely to create that connection in future practice. Participants relay integrating the mind and body in curricula is important for integrated health issues which have implications for multiple health systems. A clear understanding of how behavior impacts health and how health impacts behavior is the cornerstone of integrated curricula that reflects practice and preventive health practices.

> .... a unit where the students could see at all levels some sort of integration, the cases were integrated, biologically it was integrated, in terms of health issues it

was more integrated, it made more sense. (P9)

The notion of a mind-body separation in medical school may stem from a lack of integration or a failure to make the connection, in the curricula. Instructors and students may fail to make the connection between the systems and understand the impact of the lack of integration between the units because the curricula in the first two years are taught one system at a time.

> When another [instructor] took over that particular Brain and Behavior.... a lot of the integrating components in the cases were basically removed and then we ended up with two silos again. And then the students objected. Some of the students who would like to see it more integrated said this is terrible .... Other students who didn't quite care said we don't like .....students are not of one mind about things like that. (P9)

The students *"who didn't quite care"* are the students who did not perceive a need for this type of integration and additional information. Students are expected to gain the basics in all of the medical disciplines before selecting their postgraduate discipline (CaRMS). They are discouraged from deciding their post graduate discipline too early in the four year program. However, once medical students decide their postgraduate destination they can also select curricula content relevant for their future practice.

> The question is how much more time does this particular topic need to explored with an entire class versus just be applied toward people who would be dealing with these issues on a more regular basis, for instance psychiatry or pediatric residents. These types of people who would have much more interaction with that population, the teaching would be much better there than to teach everyone, when a lot of people may not actually encounter those clinical populations all that often. (P1)

Participants had a sense students may deselect important information before learning the basics in all the medical disciplines. Deselecting parts of the curricula is a barrier to learning relevant material but is also a strategy for making the curricula more manageable.

> ... Reported that students get their priority list wrong, a tendency to down-weight certain types of learning. I always suspected that development is put in that category. What practicing physicians and pediatricians need more on is developmental types of things. (So in practice it's more important). If you end up in general practice, pediatrics, and psychiatry. You need it. (P8)

I reviewed the graduation list and almost fifty percent of the students chose general practice and pediatric residency program positions. Consequently, those who did not focus on human development will discover they will need this information for future practice and need more training in this area. The participants had different opinions on what should be taught and how students address the gaps in their undergraduate learning. No one wants to repeat or revisit curricula content. However, the instructors thought some overlap is important in the curricula; *".... you build on building blocks, that needs then to be built upon, you fine tune yourself...."* (P13), and students want to avoid it. Students deselect material they know and select curricula based on it's relevance for this level or the next level.

> I think to focus the teaching in areas where people would be exposed to an identification situation, family practice or whatever. In our undergrad I can understand why there isn't a whole lot of teaching in this area. Because it is focused in a sense, a lot of us actually probably won't be encountering that on a regular basis and there are a lot more topics we need to cover and be more comfortable because we would see it more often. At this point in our careers and as we move on [to residency] it becomes more obvious which patient populations will be involved.... I think focusing teaching there.... will be much more valuable than having it at this stage of the game, because we are struggling with a lot of other material. (P1)

Based on the residency programs students are selected for, pediatrics is a significant component of future medical practice for almost half of the students in medical education. Students who do not attend to child development in their undergraduate training will not have the knowledge to build on in future residency and

practice. This is important as students go on in leadership roles as tutors and practitioners who treat children in medical practice and foster other students' ideas about curricula relevancy.

> I know that kids with developmental disorders are going to be coming into [my practice] even if I do emergency, they're going to be coming in. I know those are areas I'm weak in and if I don't get teaching around it, I know for the next three years I will teach myself about it the best I can cause that's how I operate. I don't know I don't know of all the people in my class really work that way I'm not sure they will take the time to go out and learn... learn about the different developmental disorders... so I don't know if everyone else would do that and maybe. (P4)

And so the curricula continue to evolve. Instructors continue to change curricula to meet the needs of the patients and students. Students continue to request more streamlined, relevant medical education for their future clinical practices.

Finding for 4.44: Students do not learn the relevance of ASD for future medical practice. Almost half of the students in medical education choose family medicine and pediatric residency programs. These students may not graduate from undergraduate medical school with the knowledge to assess and detect ASD and other developmental disorders.

4.5 ***Participants' Recommendations for Change in ASD Curricula***

Participants suggest curricula planners may change the curricula if the findings of ASD and developmental curricula are deficient and this deficiency impacts children lives.

> I guess if you could show that the teaching was limited and that because the teaching is limited these people would be identified 6 months, 12 months, 24 months later and that will have a significant impact on the lives of these children. Then you might be able to convince them to do more teaching around that. (P4)

All participants gave suggestions for enriching ASD curricula. No one thought the content or teaching on ASD is satisfactory. The most frequently suggested changes are

organized into 7 key areas in the following section.

Finding for 4.5: All participants gave suggestions for enriching ASD curricula.

4.51 ***Participants suggestions for ASD curricula.*** All students report they need more training on ASD.

> Autism and the whole spectrum is very interesting and I'm sure I'm going to get a lot more training than I have right now. I hope to. I expect to and if not I'm going to be disappointed. (P4)

1. Students suggest a clear objective to learn about ASD, *"You've got to present it as a much more urging issue than I think it comes across."* (P4) As well as, test students' knowledge to increase the relevance of ASD curricula.

> I think it [ASD] definitely should be addressed at least with the basis of one lecture during some point, which you are going to be tested on, because if people aren't tested on the lecture, they won't go to the lecture. (P4)

2. Students want integrated curricula across the four years that includes a foundational and in-depth knowledge of communication and developmental disorders.

> I think having it at several points in the curriculum particularly because it's not something that... for example I haven't seen autism in general practice like in my family medicine rotation, so presumably it's either not common enough or at least not present enough in those rotations so that you see it. So I think that it's a condition that's important to diagnosis early and be able to intervene early. If you're not going to be exposed to it in terms of patients then they need to have tools with clinical teaching on it to make sure you understand it or know something about it. (P3)

Instructors suggest placing ASD and developmental delay curricula in the following units and blocks:

> I think we could load in a bit more in the family & child project time, maybe the second year. If it is a didactic milestone or something like that – everyone will go to sleep who are awake will think of something else. Autism wise I think it would be possible to increase their tuning into what should be in there. Clerkship is the time to think of it. I think the pediatric clerkship is a time when everybody gets back to thinking about it in a way that is motivating for them. (P8)

And,

> There are elective experiences. One of the interesting things about the curriculum is that it has huge amounts of times for electives. They are sometimes called something else. Preventive and Continuing Care unit where one can elect, select huge tracks of time in doing various things and to work with mentally handicapped people or people who have been brain damaged or people who have learning disability or chronic disability of any sort. (P9)

3. Student state they need to learn an efficient screening tool for detecting ASD.

> [Learn] a screening tool that would be useful for us to become familiar with this area. I think that would be a good way to spend some of the time in undergraduate teaching and to have the tools or just become introduced to some of the tools that they use on a more regular basis or practical level that you can apply in your clinical experience. (P1)

> As far as a screening tool.... Something with no more than 10 questions. A quick questionnaire, does your child have trouble making eye contact when he communicates, does he point at things, or does he grab you hand over hand to get something for him. Does he not use any words or is he just repeating, echolalia. It's not that hard to use a specific scale, absolutely. (P5)

4. Students want information for where to direct a referral for ASD diagnosis and treatment.

> Its' [screening tool] got to be quick and its' got to be something that that can give and easily interpretable and provide some sort of outcome where you can go with this information. (P1)

Instructors believe students should learn about potential collaborative partners and to work with others in the community.

> I think the education regarding the identification of developmental disorders and those kinds of disorders... is one where you wonder whether its best done in isolation for physicians... or whether we should really train... to work more collaboratively with other organizations like the schools and preschool settings and maybe parenting outfits.... We have so many physicians when they refer things to us who are saying the school told me to assess this kid and make a referral to you. They haven't assessed the kid themselves, they are just acting as middle men and they don't know how to work with the schools. I think maybe there is an opportunity.... to get together with other people and not expect family physicians to do that completely by themselves. (P9)

5. Instructors want to provide students with clinical teaching and modeling for ASD detection in a clinical setting.

> A family physician who is modeling the practice. If you were to go train in a clinical practice that was using a particular tool, I would predict it would influence what you would do. (P8)

6. Instructors suggest students learn communication and interview strategies for children with ASD.

> I think in general needing more exposure in a clinical sense. I don't think we had a strong background with an approach to dealing with these children, as far as diagnosis and just communication strategies. I don't think we were taught enough about that and any time I had an interaction, only a few times, with these children, that was the most striking feature for me. I found it difficult to communicate with them. I think that further experience with other children who have these types of disorders and trying to develop communication strategies along with their families to serve their needs whatever that might be. (P1)

7. Student suggested they should have more opportunities to experience patients with ASD.

> I guess just from talking to you like it seems like a glaring discrepancy to not have interacted with any patients who have autism or any parents who have children with autism or whatever would somehow make it less of a text book condition and make it more of a real life condition so to have that integrated either into the second year brain and behavior, psychiatry and Baby project.... (P3)

Instructors and students suggest developing video tapes of children with ASD in a variety of settings or providing experience children with ASD in early intervention centres.

> [Instructor] showed us videotapes of kids. This kid in school; you got to see what it was like to be an EA in school with the teacher and the full class. Sometimes you can see it is unfair for everybody. You get a real sense this is a hard problem to deal with. (P5)
>
> And,
>
> I thought what I would move to is a video tape. I can't have 8 of them around a young child, it's not fair and I can't always arrange that because to arrange it at

> their convenience not the families' convenience [is difficult]. So what I am going do is make a video tape. The other thing I do is present in the form of a case. (P12)

And,

> Lining up a bunch of kids who have autism because as soon as you get to see these kids it's very easy to recognize, once you've seen this. We need actual patient contact. That's the biggest thing. [Instructor] has tried to do that with other kids who have problems and that was great. First and second year they brought kids into talk to us and that sticks out in my mind. We got to meet them, we got to have them tells us about their disease. What they eat and drink, kids with PKU. We got to see all these things, so not that bad of a disorder if you catch it early. Now these kids have these life long treatments they have to go through and it was quite extreme. If we saw a kid with autism, so they could find what a kid with autism was like. How do they appear when you first meet them? Because when you first meet them you don't know that there is anything wrong. Everybody goes he looks perfectly normal. Then all of a sudden you go, you start to see, and start to see how they interact. (P5)

There are many implications in these findings and to adopt them all is very time consuming for everyone. This participant sums up with these final words,

> I'm fully aware. What to do about it is very hard. You can chip at it little by little. I mean if I had someone who wanted to come along and put a big emphasis on not autism but say development and look at the whole how we are teaching development and childhood development in years 1 through year 4 and put a whole emphasis on that, great. If you're going to give me somebody who is going to work on it a couple of days a week for the next couple of years. I have no problem with that they can have a whole new program. They can find little areas, it's bits and pieces. (P13)

Finding for 4.51: No one thought the content or teaching on ASD is satisfactory. Students do not graduate from undergraduate medical school with the knowledge to assess and detect ASD and other developmental disorders.

4.6 A Summary of the Findings.

4.0 – What are the Effects of Curricula Structure and Medical Educations' Current Pressures on Learning ASD Curricula?

Instructors report challenges in teaching undergraduate medical education such

as large classes, too few patients' in-hospital to teach from and too few clinical instructors to provide teaching.

4.1 - **CURRICULA STRUCTURE IN UNDERGRADUATE MEDICAL EDUCATION**

4.11.1 – **Years 1 and 2: Basic Science and Case Oriented Problem Stimulated Curricula (COPS)**

Students state they did not encounter ASD in the first and second year of the Case-Oriented, Problem-Stimulated (COPS) Curricula.

4.11.2 – **Years 3 and 4: Clerkships**

At the end of year 4, students evaluate knowledge gaps when they engage in the Canadian Resident Matching Service (CaRMS). Students matched to family practice and pediatrics acknowledged a knowledge gap for ASD and other developmental disorders.

4.11.3 - **Administering Curricula Content**

Curricula are informally administered and monitored with a "try to keep an eye on it" approach therefore if there is a gap in the curricula it is difficult to find and fix.

4.12.4 - **Integrating Curricula Content**

The structure of undergraduate medical curricula forces child development and ASD curricula to jockey for position with no method for communicating or integrating curricula across the 4 year program.

4.2 **WHAT DO STUDENTS LEARN ABOUT ASD AND CHILD DEVELOPMENT IN UNDERGRADUATE MEDICAL EDUCATION?**

4.21 **Nowhere to call Home**

Students report the developmental curricula in the first 2 years do not prepare them for treating patients with ASD in clerkship years 3 and 4.

4.22 Just the Basics

The syllabi state learning objectives for developmental disorders but instructors informally communicate the learning priority is basic developmental milestones.

4.3 What are Students' Experiences Learning About ASD in Medical School?

4.31 Independent Learning and Identifying ASD Learning Gaps

Students convey an ASD knowledge gap but receive little guidance or strategies for evaluating or addressing knowledge gaps during the four-year program.

4.32 Clinical Leadership in Year 1 and 2

Students receive minimal ASD clinical guidance in the first two years from "non-expert" tutors and a brief lecture from a developmental clinician on typical development.

4.33 Clinical Leadership in Clerkship

In clerkship years 3 and 4, students receive clinical guidance from residents who may lack practice experience in ASD, and clinicians, place patient responsibilities first and teaching last.

4.34 ASD Patient Interviews are "too hard" to Teach

Instructors report ASD is either too hard to teach or it is too hard for students to learn. Few clinical instructors have the time to teach students about ASD and so students report minimal or unsuccessful experiences with ASD patients.

4.4 What do Students Learn About ASD for Future Medical Practice?

Participants report learning about ASD is important but students say instructors do not communicate this in the curricula. Instructors convey ASD requires low suspicion and referring children with suspected ASD is futile because of long waiting lists.

4.41 Relevant Curricula are tested

Students are rarely tested on ASD and testing is important to ensure students learn about ASD so they will apply their knowledge in future medical practice.

4.42 ASD Learning Experiences in Clerkship

A one hour tutorial on ASD is delivered in the third year of clerkship when students' are either off-site or have competing patient responsibilities. Lack of ASD information and patient contact creates knowledge gaps which students do not identify in or through undergraduate medical education.

4.43 Teaching Early Detection of ASD and other Developmental Disorders

Students are not taught effective or useful developmental measurement instruments for detecting ASD or other developmental disorders.

4.44 Teaching ASD Relevance for Future Medical Practice

Instructors do not teach the relevance of ASD for future medical practice. Almost half of the students in medical education choose family medicine and pediatrics residency programs. Students who do not attend to child development and ASD in their undergraduate training will not have the knowledge to build on in future residency and practice.

4.5: Do Instructors and Students Want to Make Changes in the ASD Curricula and if so, in What Ways?

All participants gave suggestions for enriching ASD curricula.

4.51 Participants suggestions for ASD Curricula Goal and Teaching Strategies

No one thought the content or teaching on ASD is satisfactory. Students do not

graduate from undergraduate medical school with the knowledge to assess and detect ASD and other developmental disorders.

In the following discussion of the findings, I will contextualize the findings with the body of research literature which influenced the undertaking of this work.

CHAPTER 5

5.0 A *Discussion of the Findings*

Physicians are gatekeepers for a child's diagnosis of ASD. Physicians want and need to identify children with ASD earlier because early diagnosis and treatment mitigates several lifelong difficulties for children and their families (Rogers, 1998). Three factors delay the diagnosis until late preschool: physician detection practices, misinterpreted and inaccurate parent reports, and the symptomatic nature of ASD (Bryson et al., in press; Sices et al., 2003). The three factors intertwine in the experience of a diagnosis of ASD and this study suggests: *all the factors that delay diagnosis in clinical practice can be traced to undergraduate medical education.*

The premise of this inquiry was to discover if the variability in physicians' practices also exists in undergraduate medical education for once physicians leave medical education, continuing medical education has limited effect on practice behavior (Davis et al., 1999). Therefore, the rationale of this study was this: medical school is the best setting--and where there is the greatest opportunity--to teach physicians about ASD and early detection practices. *Medical students, in this study, report they do not graduate with the knowledge to assess and detect ASD and other developmental disorders.*

The findings from this study offer insights to the early identification health care practice gap, as well as, provide educational goals and teaching strategies for medical students on early detection practices. This study gives curriculum planners a baseline for evaluating the impact of ASD curricula they choose to put into practice. The long-term goal of this research is to ensure ASD curricula are relevant and succinctly comprehensive. The hope is to prepare medical students for their future practices so they

have a positive impact on the health of children with ASD and their families.

Four major themes emerged:

1. Curricula structure and medical educations' current pressures affect child development and ASD integration in the curricula.
2. Students learn basic developmental milestones as a method to detect ASD and other developmental disorders.
3. Clinical guidance is constrained for detection practices of ASD and other developmental disorders.
4. Student experience limited ASD patient contact and do not have the skills for early detection practice.

These findings offer promising solutions for learning and teaching ASD curricula in undergraduate medical school. The following discussion of the findings will describe the medical education gaps; connect the gaps to present clinical practice, and recommend curricula changes (see Figure 2).

Figure 2

Intervening Factors for Learning and Teaching ASD in Undergraduate Medical Education

Summary of the Findings				
5.1 The Impact of Curricula Structure and Medical Education's Current Pressures on Learning ASD Curricula	**5.2: What Students Learn About ASD and Child Development in Undergraduate Medical Education**	**5.3 Students' Experiences Learning About ASD in Medical Education**	**5.4 What Students Learn about ASD for Future Medical Practice**	**5.5 Provisions for Change in ASD and Child Development Curricula**
5.11 Finite Resources Affect ASD Curricula	5.21 Learning Typical Child Development as a Method to Detect ASD	5.31 Independent Learning and Identifying ASD Learning Gaps	5.41 Hidden Curriculum	Goal 1: Clear objective to learn about ASD. Goal 2: Integrate curricula across the four years.
5.12 Curricula Structure Affects ASD Curricula Content	5.22 Vague Recollection for ASD	5.32 Clinical Leadership in Year 1 and 2	5.42 ASD Learning Experiences in Clerkship	Goal 3: Teach an efficient surveillance tool. Goal 4: Provide clear referral paths.
5.13 Administering ASD Curricula Content		5.33 Clinical Leadership in Clerkship	5.43 Teaching Early Detection of ASD and Developmental Disorders	Goal 5: Model developmental surveillance in a clinical setting.
5.14 Integrating ASD Curricula to Improve the Quality of Medical Education		5.34 ASD Patient Interviews are too Hard to Teach and too Hard to Learn	5.44 Students' Understandings for Future Medical Practice	Goal 6: Teach interview skills for patients with cognitive impairment. Goal 7: More clinical exposure to patients with ASD.

The factors in Figure 2 have implications for learning and teaching ASD curricula in undergraduate medical school. In this chapter I will explore these factors which provide a clear direction for ASD medical education.

5.1 *The Impact of Curricula Structure and Medical Education's Current Pressures on Learning ASD Curricula.*

Current pressures influence students' learning about ASD and other developmental disorders such as finite resources (5.11), curricula structure (5.12), ASD curricula administration (5.13), and ASD integration in the curricula (5.14).

5.11 ***Finite resources affect ASD curricula.*** This study found *"Instructors report challenges in teaching undergraduate medical education such as large classes, too few patients' in-hospital to teach from and too few clinical instructors to provide teaching."* (Finding 4.0)

Medical schools need adequate resources to provide students with applied learning experiences. Students learn less material by rote and develop skills for the *"real world of clinical practice"* when they apply early theoretical learning to medical practice (Regan-Smith, 1992; Weller, 2004). They include sufficient patients' in-hospital to teach from, skilled clinical instructors, and placements with preceptors in clinical practice (Hopkins & Chandarana, 2002). Students and instructors report they struggle within the context of finite resources to provide ASD education. Other Canadian medical schools share the challenge of managing finite resources (Hopkins & Chandarana, 2002). This study describes finite resources as pressures on medical education. The implications of finite resources for learning about ASD are that students have minimal contact with ASD patients. The result is students do not translate lectures into clinical practice. Thus, they

lack the experience with the complexity of ASD which does not enhance their understanding for later clinical practice.

5.12 ***Curricula structure affects ASD curricula content.*** The findings suggest in years 1 and 2, *"Students did not encounter ASD in the first and second year of the Case-Oriented, Problem-Stimulated (COPS) Curricula."* (Finding 4.11.1) and in years 3 and 4, *"Students matched to family practice and pediatrics acknowledged a knowledge gap for ASD and other developmental disorders."* (Finding 4.11.2) The overarching focus in undergraduate medical education is on general foundational skills for medical practice. Hence, the teaching objectives for specific disease or disorders such as ASD are present but not communicated. Participants explain in medical school *"You can't specifically pick a disease process."* (P13) The pathology or in this case, ASD and other developmental disorders are briefly and randomly interwoven in the four-year curricula to provide some exposure but not an in-depth understanding. This explains students' fragmented recollections of ASD in the curricula. They receive an introductory exposure which acclimatizes them to the basic facts of ASD and this is insufficient to prepare students for clinical practice (Alexander, 1997; 1998 as cited in Ormrod, 2004).

5.13 ***Administering ASD curricula content.*** In medical school, curriculum planners and developers use several rigorous strategies to determine curricular content within the COPS units and Clerkship blocks. The instructors I interviewed carefully plan and develop curricula, *"We researched it, we validated our course, [and] we did a reasonable job of it."* (P13) However, once developed, curricula administration is informal with a *"try to keep an eye on it"* (P13) approach and so students and instructors report a lack of curricula integration for ASD and other health topics across the units and

blocks. (Finding 4.11.3)

For this medical school under study there is no curricula database or other formal methods for communicating, coordinating or integrating ASD curricula. The instructors' observations of undergraduate medical curricula are, *"I don't have a sense of a program. I don't have a sense of a coordinated program." (P12) and "...hope that overtime – that curricula, child and family project, overtime they will develop some knowledge. Hope through exposure to experience [they] will pick up along the way."* (P8) The findings convey no integration of ASD and child development curricula across the units and blocks; therefore curricula content overlaps for some disorders and is absent for others.

Presenting topics with stepwise continuity and integrating them across multiple relevant subjects strengthens students' knowledge and prepares students for clinical practice. Students learn more effectively when curricula build on students' prior learning (Ormrod, 2004). An instructor shares the teaching thought process in medical education, *"You build on building blocks that then need to be built upon, [and] you fine tune yourself. These are the things you need to pull out."* (P13) Thus, to learn skills for ASD, students benefit from integrated curricula that build on their knowledge and abilities (Ormrod, 2004). By integration, I mean curricula which target a health topic and provide carefully planned associations within and across the relevant units and blocks. For example, integrated curricula for ASD would associate atypical neurophysiology in the Brain and Behavior Unit with the early signs of ASD in the Pediatric Clerkship Block, therefore improving the quality of the curricula content. Most topics receive limited time and exposure, so for ASD and other developmental disorders, the quality of curricula integration and content is an important focus.

5.14 *Integrating ASD curricula to improve the quality of medical education.*

"The structure of undergraduate medical curricula forces child development and ASD curricula to jockey for position with no method for communicating or integrating curricula across the four- year program." (Finding 4.12.4) Health care providers, parents, and educators are calling for earlier diagnosis and treatment of ASD (Filipek et al., 1999). They hold a stake in how much and how well foundational curricula cover ASD in cases, lectures, and clerkship tutorials. Participants found *"Its part of the problem with the design. The undergraduate medical education has been designed into certain silos...."* (P9)

The silos in the first two years are body-system based science units (for example, Metabolism and Function Unit, Brain and Behavior Unit). In the last two years, silos are clinical blocks in patient settings and specific patient populations (for example, Family Medicine and Psychiatry Block; and Women, Children and Youth's Health Block). The curricula silos are fifteen units, six blocks and multiple electives. The teaching silos comprise hundreds of faculty instructors, clinical instructors, and community-based preceptors. All the silos create organization challenges for curriculum planners and instructors. Communicating and integrating curricula are difficult across the many educational settings and hundreds of instructors.

Without formal methods such as a database to simplify planning and governing the curricula, participants' report topics like ASD *"jockey for position"* (P9) in a zero-sum medical program. One participant describes curricula content as *"a bunch of penguins on an iceberg and if you want to put on another penguin you have to kick another off the iceberg"*. (P3) Therefore, participants say ASD, like other curricula topics

in undergraduate medical education, need champions; medical educators who adopt a topic and ensure curricula integration to provide greater learning opportunities for medical students in the areas of child development, early signs and detection of ASD.

5.2 *What Students Learn About ASD and Child Development in Undergraduate Medical Education*

In undergraduate medical school, students learn typical child development as a method to detect ASD (5.21) and report vague recollections for ASD curricula (5.22).

5.21 Learning typical child development as a method to detect ASD. Exploring the curricular content is important to understanding the educational message student receive and their knowledge for clinical practice. "*Students report the developmental curricula in the first two years do not prepare them for treating patients with ASD in clerkship years 3 and 4.*" (Finding 4.21) and "*The syllabi state learning objectives for developmental disorders but instructors informally communicate the learning priority is basic developmental milestones.*" (Finding 4.22)

Instructors claim child development curricula serve as a foundation to learning about child health. This instructor points out, "*They actually get taught development from year one all the way through, but they don't know they are being taught it.*" (P13) Instructors say that, as they teach students about pediatric medicine, they often use child development as a way to explain health concerns. Participants explain how learning child developmental milestones apply to ASD detection practices: knowing "*what is normal and what's not and when to refer*". (P8) Therefore, undergraduate medical education teaches students that knowing "normal" developmental milestones is a precursor for knowing ASD. This is the only strategy students learn for early detection of ASD.

Students learn about developmental milestones in the first two years of the undergraduate program. Instructors and students report children's health and development is spread across the curricula. Participants explain, *"It doesn't have a specific home that says pediatrics."* (P8) For example, students who attend a lecture on kidneys will learn about issues related to adult kidneys and the lecture will include a section on pediatric kidneys. The coverage of pediatrics as a whole is sparse and random in the COPS curriculum of year 1 and 2. Students report, *"They kind of leave the whole children, youth thing out of the first two preclinical years, altogether."* (P2) However, in year 1 and 2, there is a specific focus on child development in the Patient-Doctor Unit; The Life Cycle provides an introduction to child development through the Child and Family Project.

In the Child and Family Project, pairs of students, follow an infant's progress in the first and second year of life through home visits. Students receive a brief lecture on child development and students seek clinical support for the visits if they need it. Instructors caution students not to provide medical advice to parents but to refer questions to the families' doctor. Students conduct the Rourke inventory and the Denver II assessment with the infants and their families. Students report this learning experience is a meaningful introduction to basic developmental assessment. The program's limited effectiveness for detecting ASD and other developmental disorders is evident in physicians' present practices (Sices et al., 2003). Students do not learn to detect developmental disorders and this finding is evident in physicians' practices on detection.

5.22 *Vague recollections for ASD.* Students report no learning gap for child development; however, the findings reveal students have a significant learning gap for

ASD. For this studies' cohort of students, ASD was present in the Brain and Behavior Unit, Genetics, Embryology & Reproduction Unit, a one-hour clerkship pediatric lecture and some exposure in the Psychiatry block. However, the participants' memories for ASD curricula are "vague recollections". For example, "I can't recall the specific lecture in the first two years. I assume we had one but I don't recall one. We definitely had one in the third year, so besides that I don't remember any other teaching around it." (P4)

Instructors suggest they expect students will be "ready for more pathology and they are ready to see things more in-depth" (P13) in year 3 and 4, but the curricula in the first 2 years may not prepare some students for applying their knowledge to practice. Students in this study discuss the "red flags" of atypical development but not the ability to apply this concept in practice. So, students report capacity to assess typical development but report they are not prepared to assess developmental disorders such as ASD. Physicians also experience discomfort with assessing children with developmental delay (Sices et al., 2003). Students assess "normal" development because typical development is the focus of undergraduate medical education and ASD is "too advanced" with the limited amount of normal development they learn. (P13)

5.3 ***Students Experiences Learning About ASD in Undergraduate Medical Education***

Undergraduate medical education purports to provide independent learning and identification of knowledge gaps (5.31). However, clinical instructors, for Year 1 and 2 (5.32) and clerkship years 3 and 4 (5.33), relay ASD patient interviews are too hard to teach and too hard for medical students to learn (5.34).

5.31 ***Independent learning and identifying ASD learning gaps.*** All the participants talked about medical students as independent learners. Medical education

provides postgraduate training with no assigned academic supervisor or committee to guide the students' academic progress. The participants talk about medical school as a challenging academic environment that influences how medical students learn. The breadth of medical school curricula and the lack of individual academic support require students to compensate for curricula and knowledge gaps. The findings suggest "*Students convey an ASD knowledge gap but receive little guidance or strategies for evaluating or addressing knowledge gaps during the four-year program.*" (Finding 4.31)

An independent learner is a student who does not require monitoring, will identify learning gaps and actively address the gaps by seeking knowledge to fill those gaps. Students report, *"I didn't get really any feedback on what I was doing right or wrong."* (P2) Students report exams are the critical measure for going on to the next level. The stakes are high for students because there is no middle ground for assessing knowledge gaps prior to exams and clinical practice. Participants say poor tests scores measure knowledge gaps because no one is following the individual student's progress in any other formal way. Students report, *"It's easy to not listen because as a student you are the lowest person on the rung."* (P2)

Given the scale of the curricula and the various topics covered in medical school, students may not identify their gaps and learning needs. Especially when no formal practice is in place to help students learn to identify their gaps and learning needs. This finding has important implications for continuing medical education and the difficulty medical educators experience in changing physicians practice behaviors (Davis et al., 1999). Physicians in practice also need to identify knowledge gaps to embrace education and change outdated practice patterns (Bennett et al., 2004).

In this study the graduating students did identify learning gaps for ASD and other developmental disorders. Students' report they are actively seeking ways to learn more about ASD in residency for future clinical practice. The curricula syllabi state written objectives for child development and ASD. Nevertheless, students' suggest they *"never had a clear objective to know about autism"*. (P2) Participants point to the informal curriculum as an explanation for this gap.

The findings replicate Hafferty's (1998) description of the informal curriculum found in undergraduate medical education. Bennett et al., (2004) provides this definition for informal curriculum, *"an unscripted, predominantly ad hoc and interpersonal form of teaching and learning that takes place between and among faculty and students."* Participants said the informal curriculum affects students' learning on ASD and is conveyed through clinical leadership and teaching decisions.

5.32 *Clinical Leadership for ASD in Year 1 and 2.* Students believe that strong and experienced clinical leadership is important for developing clinical skills. Other undergraduate medical students in Canada share this belief (Hopkins & Chandarana, 2002). The participants report "*Students receive minimal ASD clinical guidance in the first two years from "non-expert" tutors and a clinician who gives a brief lecture on typical development."* (Finding 4.32)

The curricula instructors in years 1 and 2 are science faculty and clinicians. They teach courses which may include ASD curricula. These courses contain assigned COPS cases designed to prepare students to apply the theoretical to the practical. Tutors facilitate the COPS cases and participants describe tutors' expertise as, *"[They are] supposed to be members of the faculty; they might be basic scientists; they could be*

clinicians; they could be at any academic level." (P8) For example, last year, a newly graduated undergraduate medical student was tutor for the year. Hence, 'tutor' does not mean 'expert' in the case content as there are other faculty members who are available as experts.

The tutor's role is to guide students' critical thinking. Participants describe the COPS case rationale as a *"what are the questions we should be thinking about"* versus a *"these are the answers"* approach (A8). This approach supports the "independent learner" assumption which permeates medical school culture: the students are responsible for the content and the tutor is responsible for the process. However, participants express concern about "non-experts" or "non-clinicians" tutors leading groups with case content on assessing and treating patients with complex disorders. Students report no COPS cases for ASD and instructors found students unprepared for complex cases like ASD in clinical practice. In fact, they report students found basic developmental assessments challenging.

Educators assert students' learning is more "meaningful" if the tutor is an expert in the case content and also supports the critical thinking process (Ormrod, 2004). However, participants suggest it is difficult to solicit a clinician for two primary reasons. Often the cases are not from the tutor's area of expertise or discipline and tutoring requires at least 8 hours to participate. As a result, it is difficult to recruit clinicians for the role of tutor and so, non-clinicians facilitate students' problem solving of COPS cases.

However, if lead by experienced clinicians, COPS cases have significant benefits for learning about complex disorders like ASD. Introducing critical thinking for detecting

developmental disorders may increase students' ability to apply this skill in clerkship. The findings show students master only the basic developmental knowledge in clerkship years 3 and 4. Instructors report they will not support students to stretch past the point of competency, so it is unlikely they will engage in more challenging practice assessments (for example, early identification of ASD) before they graduate.

5.33 *Clinical leadership for ASD in clerkship.* This study finds, "*In clerkship years 3 and 4, students receive clinical guidance from residents who may lack practice experience in ASD, and from clinicians, who place patient responsibilities first and teaching last.*" (Finding 4.33) In years 3 and 4, students learn on-site and off-site in urban and rural, hospitals and clinical practices. Instructors are clinicians in all disciplines of medical practice (for example, Family Medicine, Pediatrics, and Psychiatry). With the increasing demand on physicians in health care settings, the time they give clerkship students is finite. All the instructors express enormous dedication and commitment to providing quality undergraduate medical education. Students report a high-level of learning satisfaction in the clerkship years.

In clerkship, students apply and practice what they learned in years 1and 2, with practicing clinicians (preceptors) and other health care professionals. Students are keen to learn practice skills from experienced clinicians. Participants report clinical instructors are stretched between patients and students responsibilities. Therefore, when clinicians have pressing patient responsibilities, residents fill the teaching gap. Residents frequently guide clerks in the hospital settings. Residents have graduated from the four-year undergraduate program and are undertaking their graduate work in an area of specialty (for example, Emergency Medicine, Family Medicine, or Internal Medicine). Essentially

they are students who are learning too.

Participants report preceptors in the community face challenges when they add a teaching responsibility to a demanding practice. Preceptors try to provide a learning environment for students without compromising their patient's care. Clinical instructors chose patients from their practice for students to learn from. They base decisions on the complexity of the patient's needs and the ability of the student.

The findings suggest instructors may not choose patients with ASD as teaching opportunities for clerks in clinical practice. Consequently, only 25% of the medical students from this study experienced a patient with ASD in clerkship. Participants explain that *"Encountering a patient with autism is not a required encountered"* in clerkship. (P13) However, given medical students learn from tutors, residents, and busy clinicians, it may be difficult to take advantage of clinical opportunities: particularly, when students require significant clinical support to interview patients with ASD.

5.34 *ASD patient interviews are too hard to teach and too hard to learn.*

Participants explain ASD is too difficult and too demanding for clerks to learn about in a clinical setting. The goal for clerks is introductory patient interviews because they see patients independently. Instructors report *"ASD is either too hard to teach or it is too hard for students to learn. Few clinical instructors have the time to teach students about ASD and so students report minimal or unsuccessful learning experiences with ASD patients."* (Finding 4.34) Participants assert clerkship is an apprenticeship for patient care in clinical practice. In parallel with Collins (as cited in Osmond, 2004) the ideal form of clerkship apprenticeship should include:

- Instructor modeling and coaching,

- Scaffolding of students' knowledge,
- Articulation of problem solving reasoning,
- Reflection and comparison of students' practice with clinicians,
- Increasing the complexity of clinical demand,
- Experiencing and exploring the clinical interview independently.

A learning experience with all of these rudiments is the ideal and therefore is not practical in many educational settings. However this model highlights the gap between the ideal and the apprenticeship experience medical students report. The findings show students interview the patient independently and clinical feedback follows. Therefore students display the skill before receiving any of the preceding learning support suggested for apprenticeships. The findings suggest there are adverse learning effects for understanding ASD using this method of teaching.

Students talk about fear of making the wrong decision in ASD clinical practice, *"Afraid of scaring them. You don't want to make someone anxious for no reason, if you're wrong, (pause) worse consequences."* (P3) The experience of "being wrong" in medical school is common. This voices the culture and structure of medical school teaching and *"how we set them up"* as learners and practitioners (P13). In the clinical setting, instructors give feedback on students' performance without providing modeling and practice. Nevertheless, for a busy practice, instructors are sensitive to students and try to provide *"more constructive feedback on how to make little changes"*. (P13) Instructors report students are sensitive to critical teaching and credit this sensitivity to the students' dislike of criticism, not the teaching strategy.

Participants speak about clinical practice as a high risk setting for learning errors.

The medical teaching model guarantees students are more likely to make errors and require correction. Students learn while "on-the-job" and clinicians teach while practicing medicine. There is no room for error in clinical practice settings which serve as both treatment room and classroom for instructors and students. The participants spoke about the constraints on teaching time and placing the needs of patients over the learning needs of the students. Instructors regretfully share the *"teaching comes last".* (P13)

However, students and instructors report they prefer patient contact for teaching purposes only. This format is a rich learning opportunity that is rare and expensive to carry out in medical school (Weller, 2004). Participants say they prefer this learning environment because the teaching is more instructive and productive. Given the complexity of ASD this approach would provide a supportive environment for the student, patient, and instructor.

In spite of the constraints on clinican teaching time, participants report students learn best from supported clinical patient contact. For ASD this is a challenge, *"What they are going to remember is patient contact and they are not going to have that much patient contact with an autistic person so it's going be vague recollections for most of it."* (P13) However, the findings suggest for ASD, patient contact is only one part of the learning equation: knowledge and clinical teaching are also important for learning about ASD. The findings suggest the informal curriculum on ASD is opposing the written curricula.

The few participants who experienced ASD patients report they received instructor guidance in the patient interview. The findings suggested only experienced instructors guide students in these patient encounters. Although students received clinical

guidance, students describe patient experiences as overwhelming because of the complexity of ASD and frustrating because they did not have the skills to conduct the patient interview. This finding represents most students' ASD experiences in undergraduate medical education.

Instructors report pathology like ASD is *"too advanced"* for students in clerkship years 3 and 4. Pediatric clerkship is the opportunity to apply years 1 and 2 child development curricula, to patients' development in clinical practice. Instructors report modest expectations for the basics: *"As long as they come out knowing there are four basic milestones."* (P13) This expectation is modest but also realistic, as instructors watch undergraduate students grapple with straightforward patient interviews. Instructors say students find it difficult to deal with more complex cases like ASD. Instructors report *"it's too hard to teach"*. Other studies show that ASD is a challenging and complex disorder that requires experienced clinical support and teaching for students to gain a full understanding (Bryson et al., in press; Kennedy et al., 2004). Therefore not all instructors can teach ASD and not all students are prepared to learn about ASD. This education gap requires a structured training strategy specifically teaching the skills students will need in future practice for patients with ASD and developmental disorders.

5.4 What Students Learn About ASD for Future Medical Practice

Participants report both students and clinicians grapple with treating ASD patients. A student, who sought clinical guidance for a patient with ASD in the hospital, expressed frustration with the lack of support and knowledge of the teaching clinicians. This student also reported the teaching clinician expressed similar frustration in treating the patient with ASD, *"How am I supposed to figure out this kid has pain?"* (P5) This

experience is common among other physicians in clinical practice who also report difficulties in treating patients with ASD (Sices et al., 2003). The findings suggest, "*Participants report learning about ASD is important but students say instructors do not communicate this in the curricula. Instructors convey ASD requires low suspicion and referring children with suspected ASD is futile because of long waiting lists.*" (Finding 4.4)

In this study, Hafferty's (1998) concept of hidden curriculum influences medical school culture for learning ASD curricula. Bennett et al., (2004) describe hidden curriculum as a "set of (sometime unwritten) rules, routines, and regulations" which may support the curriculum or "exert a powerful countervailing influence". The findings show hidden curriculum (5.41) is present in the lack of ASD curricula testing and the division between physiological and psychological findings in medicine. This section will also explore students' ASD learning experiences in clerkship (5.42), ASD early detection practices, and students' learning about ASD for future practice.

5.41 *Hidden Curriculum.* Students report *"no testing on ASD and testing is important to ensure they learn about ASD and apply their knowledge in future medical practice."* (Finding 4.41) Students say all relevant curricula are on exams and communicated in clinical practice. Participants talk about medical students actively using various skills to navigate medical school and view learning curricula as an act of endurance. Students report they are selective about the curricular content they study. Students use curricula syllabi as guides only and screen curricula material for relevance to reduce the information to learn.

All the students said they do not focus on untested material because going on to

the next level depends on test scores. Students report topics which are explored in-depth are typically on the exams. ASD and other developmental disorders receive brief attention in the curricula. Participants also suggest testing highlights areas that require more study. *"When it comes to writing your exams and you're asked about it then, maybe you realize that you didn't read as much of it as you could have."* (P2) The opinion is if the topic is important enough to be on the exam, then I should learn about it.

The participants' report that students' hypersensitivity to testing increases the likelihood they will learn tested curricula. Most participants' state there is no specific objective for ASD on exams; however one student reports questions on exams throughout the four-year program. Educators claim students will not identify information as important if there is no specific objective to learn about it (Ormrod, 2004). Students say they will have to be tested for ASD, to learn about ASD for future medical practice.

Students remember what is important for their present and future success and instructors provide the cues. Instructors communicate relevant curricula. Participants share that instructors imply a separation of body and mind in the (hidden) curricula (Hafferty, 1998). This separation is a perceived division between physiological and psychological findings in medicine. Traditionally, physicians treated all ailments by investigating physical findings and students report traditional teaching in some areas of the curricula, *"Because there are a lot of physical findings, so they're big, they're big on teaching us physical findings"*. (P4) Instructors believe stressing physical findings is cause for concern, *"... it's how old fashioned we are. I think we still teach to a very old fashioned model."* (P13) Therefore, when instructors stress physical findings in their lectures, medical students may perceive psychological findings as less relevant than

physical findings for future practice. Early detection of ASD is based on mostly developmental, psychological, and behavioral findings.

Instructors say, *"Students get their priority list wrong, a tendency to down weight certain types of learning. I always suspected that development is put in that category."* (P8) If students' discount developmental curricula, they are less likely to identity ASD and other developmental disorders in future practice.

A review of the graduation list indicates almost fifty percent of the students choose general practice and pediatric residency program positions. Therefore, child development is a significant component of future medical practice for almost half of the students in medical education. Students who do not attend to child development in their undergraduate training will not have the knowledge to build on in future residency and practice. Residency programs report undergraduate medical students have clinical gaps in many areas (Langdale et al., 2003; Paolo & Bonaminio, 2003). So, those students who do not focus on human development will discover they need this information for future practice and need more training in residency. But studies show this is not happening at any level of post undergraduate education so the hidden curricula pervades present and future medical education (Bennett et al., 2004; Sices et al., 2003). Therefore, integrating child development and ASD curricula and underscoring the mind-body connection is important to make ASD curricula relevant for students. For students will eventually take leadership roles as instructors and physicians who treat children with ASD in medical practice and foster other students' ideas about curricula relevancy.

5.42 *ASD Learning Experiences in Clerkship*. Students report *"a one hour tutorial on ASD is delivered in the third year of clerkship when they are either off-site or*

have competing patient responsibilities. Minimal ASD information and patient contact creates knowledge gaps which students do not identify in or through undergraduate medical education." (Finding 4.42)

ASD is taught in a third year clerkship seminar. In one hour students learn about ASD signs, pathology and how important early detection is for families. Although students receive this hour of ASD information they mostly report no recollection of the experience. The clerkship structure provides context for their vague learning on this topic. Student talk about the difficulty of balancing clerkship clinical responsibilities with the lectures offered in third year. Some students they were off-site for their clerkship experiences, *"when I did go to the lectures I was just listening on the phone so like there was no visual component so I'm trying to remember."* (P4) Students' value clerkship experiences outside the universities' teaching hospital because they are able to do more. Students report more frontline patient contact and more independence in their clerkship. This student suggests that in off-site clerkships, *"Everything was a little less structured and makes the whole experience, less standard."* (P2) Students say off-site clerkship settings refer complex cases like ASD to the on-site clinical settings, *"What my classmate may have seen in ...., all this big fancy stuff is completely different from what I saw. Everything that is big and fancy gets sent to ..... So you know I don't see this."* (P2) ASD is referred to the on-site clinical setting and so this student did not experience ASD in clerkship.

In this studies' cohort of students, twenty-five percent went off-site for clerkships and the other portion stayed in the teaching hospital near the university. Students report they did not attend all of the third year clerkship tutorials. The ASD seminar is 1 of 21

pediatric tutorials in the third year which cover several disorders and child development. The instructors recognize these attendance difficulties and provide videotapes of the lectures for students who miss the tutorials.

However, students relay the speed and volume of the curricula coupled with the constant time demands restricts "catching up". Participants report clerkship seminars are the only place in the curricula where disorders and specific health topics receive comprehensive teaching. Therefore, clerkship seminars and tutorials may not have the intended nor needed educational effect.

Every year more students go off-site for clerkships and miss the learning potential of the clerkship seminars. The medical school is relying heavily on the notion that medical students are independent learners who will recognize these missed opportunities as learning gaps while in continuing medical educators grapple with the same issue (Bennett et al., 2004). In this study, most students identified gaps in the fourth year after the opportunity for learning a topic in undergraduate medical education had passed. Students' report to avoid an ASD knowledge gap, medical curricula should stress the prevalence and significance of ASD, provide patient contact and a strategy for early detection.

5.43 Teaching early detection of ASD and other developmental disorders. Participants say patient contact *"tunes them in"* to necessary clinical skills (A9). Students report they learn two developmental assessment instruments to record child development: the Denver II and the Rourke Baby Record: Evidence Based Infant/Child Health Maintenance Guide III ([Rourke]; Rourke et al., 2000). The Rourke records developmental milestones but has limited results for developmental disorders. This

protocol is unlikely to detect the symptoms which lead to ASD detection and an appropriate referral for children with ASD. However, the Rourke does include a question that instructors encourage medical students to ask their patients' parents, *"Do you have any concerns about your child?"* (P8) The Denver II is taught for assessing developmental delay and disorders.

The *Canadian Guide to Clinical Preventative Health Care* recommends the Denver II for family physicians' clinical practices (Feightner, 1994). This instrument is controversial. Glascoe et al. (1992) found the Denver II had low sensitivity and therefore missed children with developmental delay. As well, Glascoe et al. (1992) found the Denver II lacked specificity and identified typically developing children as delayed. However, Feightner (1994) reports it is easy to give, takes 15-20 minutes to complete and is designed for children from birth to 6 years-old.

Participants cite The Denver II as *"the best generalized screen looking for any kind of developmental - both social, motor, fine and gross motor, and language"*. (P2) In the Child and Family project, students report the Denver II was difficult to give and blamed its ineffectiveness on the home environment. However, a more experienced practitioner said, *"In the office they are not going to perform very well for you anyway, so an assessment in the office is probably, doesn't ...."* (P13) Both instructors and students did not view this tool as useful for practice, *"We do the Denver every time we visit them and things. I mean, I can't see doing that every single time you see a kid in the office"*. (P2) These findings suggest students will not use the Denver II when they are practicing physicians. Sices et al., (2003) finds physicians do not use the Denver II or any other instrument to detect developmental disorders.

ASD is one of many health issues family physicians expect to detect in children (Filipek et al., 1999). Participants report that physicians say they are screening for ASD but they are not using *"a scale that identifies autism, a condition much less common, it simply is not used by primary care physicians."* (P9) The findings of this study reveal students use the Denver II in the same manner as practicing physicians. They only use the relevant parts of the instrument which reduces the efficacy of the tool. Physicians cite time and practice constraints as reasons for not using the Denver II properly (Glascoe, 1998). Participants said informal assessment is another effective way of detecting a developmental disorder.

Informal assessment involves asking parents if they have concerns about their child's development; observations in the office; experience with the child overtime and experience with many children in general. Students report they lack the communication skills to interview patients with ASD. Therefore, informal assessment has negative implications for physician practice and early identification of ASD. Participants' in this study and others say physicians do not listen to parents and act on their concerns; this is a barrier for detecting ASD (Glascoe, 1997a; Howlin & Moore, 1997). However, some believe physicians do not listen to parents because they have no time to listen; therefore they do not have time for informal or formal developmental screening. This suggests a health care system issue that allows little time for informal or formal detection practices (Nova Scotia Medical Services Insurance, 1996). Given the time constraints and interview difficulties, studies suggest physicians need but lack a quick and easy screening tool to guide patient interviews and confirm parents' reports (Bryson et al., in press; Filipek et al., 1999). Participants' predict students who do not learn a time efficient,

scientific approach for detecting ASD, will then as physicians rely on informal methods for assessing developmental disorders. Students talk about the danger of physicians using this approach. Studies have shown this approach may not provide physicians with the certainty they need to identify a child with ASD (Kennedy et al., 2004). Participants report identifying a developmental disorder without a screening instrument is risky. As a result physicians may not alert parents to their suspicions and they may not choose to identify a child with ASD until they are positive about their suspicions.

Participants confirm other research findings which report ASD is *"hard news"* to give and receive (A3; Nissenbaum et al., 2002). For a physician to suspect ASD, without an instrument to confirm those suspicions, will require courage and a sense of urgency to identify ASD and refer for diagnosis (Glascoe, 2001). Parents also need encouragement to ask a physician's opinion on their child's development (Nissenbaum et al., 2002). A parent expressing concerns about their child's development is an intense encounter. This conveys how emotionally laden this experience is for both sides of early detection of ASD (Nissenbaum et al., 2002). Participants talk about a sense of urgency to identify developmental disorders like ASD because *"the earlier they are identified the better"*. (P4) Students believe it is important to know how to identify children with ASD. They think about how it may affect them in medical practice, *"if you miss it this kid's in trouble and may be you're in trouble too"*. (P3) By not providing students with specific interview training, we are performing a disservice to them, as future physicians and to their patients. Many studies report physicians experience significant difficulty in the patient interview for ASD and developmental delay (Howlin & Asgharian, 1999; Howlin & Moore, 1997; Sices et al., 2003). Participants report difficulty with interpreting

parents' concerns, *"I'm a worried Mom"* (A9) and this difficulty often results in incorrect referrals or a "wait and see" approach (Howlin & Moore, 1997, Sices et al., 2003).

Participants think it is important to know about ASD. *"I think learning about autism is important both in terms of being able to recognize people who are potentially autistic and then also to be able to reassure parents who are concerned about autism."* (P3) However, this participant wonders if it would make a difference if students learn to recognize ASD, when the referral for diagnosis is so convoluted. Thus, students experience frustration with the system from their clinical clerkships in medical practice; ASD is difficult to detect and referral is not effective. Practitioners' sense of clinical efficacy mirrors the learning concept of self-efficacy (Bandura, 2000). Medical students who become future physicians need to learn their referral will make a difference in the lives of children who have ASD.

The referral system is difficult and the waiting lists are long in Nova Scotia (McSorley, 2005). However, participants thought outdated information perpetuated the problem. Regardless of the waiting list, when physicians identify ASD early, this helps the entire community; families, interventionists, health care providers, and educators. Based on current research, the PEDS and ASQ may be more suitable for use in a busy family physician practice (Charman, 2003). Supplementing the Denver II with an effective tool is a possible solution to practice efficacy. So, until the *Canadian Guide to Clinical Preventative Health Care* reforms clinical practice, general medical practice and medical schools will continue to use the Denver II as a method for detecting developmental disorders (Canadian Task Force on the Periodic Health Examination, 1994). Thus the educational messages students receive in clinical settings will not prepare

them to learn about treating and identifying ASD.

5.44 ***Students' understandings of ASD for future medical practice.*** The findings show, *"Instructors do not teach the relevance of ASD for future medical practice. Almost half of the students in medical education choose family medicine and pediatrics residency programs. Students who do not attend to child development and ASD in their undergraduate training may not have the knowledge to build on in future residency and practice."* (Finding 4.44) Limited ASD clinical knowledge and leadership confounds the pervading notion students are likely to learn about ASD on their own, or through clerkship seminars or electives. Participants doubt if students will understand the implications for ASD in future practice when they have limited clinical knowledge and no patient contact. *"The big idea that anybody in medicine needs to be a self-motivated learner, it also has to set up situations to tune people into things."* (P8) This overall lack of exposure in undergraduate medical education creates doubt about students' knowledge on ASD and capacity to treat patients in future practice. Research substantiates this concern; physicians experience difficulty when assessing and treating ASD.

Medical educators logically assume students will learn ASD in residency or continuing medical education but studies show this is not happening (Kennedy et al., 2004; Sices et al., 2003). The findings support there is sparse knowledge across the continuum of medical education on ASD: undergraduate, residency, and continuing medical education (Kennedy et al., 2004; Sices et al., 2003). And yet participants from this study and others, report physicians are the gatekeepers for ASD identification and treatment (Howlin & Moore, 1997): *"They haven't assessed the kid themselves; they are just acting as middlemen".* (P9) The findings of this study agree with the overwhelming

converging evidence that family physicians need support to treat children with ASD (Bryson, et al., in press). Physicians need support and education on proper screening instruments, clear referral plans, and relevant patient information (Bryson, et al., in press; Sices et al., 2003).

5.5 *Provisions for change in child development and ASD curricula.*

The findings of this study suggest teaching is limited on ASD in undergraduate medical education and "*All participants gave suggestions for enriching ASD curricula.*" (Finding 4.5) Instructors believe undergraduate curricula goals should be inclusive of all developmental disorders (for example, communication and cognitive). Therefore, I recommend specifically teaching ASD curricula in some areas of the curricula and as part of a larger goal for detecting developmental disorders in other areas of the curricula. All of the participants had suggestions for curricula change which I have organized into curricula goals and teaching strategies.

Goal 1: Provide students with a clear objective to learn about ASD. "You've got to present it as a much more urging issue than I think it comes across." (P3)

Teaching for Goal 1: Test students' knowledge to increase relevance for ASD curricula (for example, take-home exam, or assign a computer-based case).

Goal 2: Create integrated curricula across the four years that includes a foundational and in-depth knowledge of communication and developmental disorders.

Teaching for Goal 2: Place ASD and developmental delay curricula in any or all the following teaching entry points with relevant curricular content.

- Brain and Behavior Unit – neurology of ASD in lectures and a case on ASD led by a specialist,

- Patient-Doctor Unit: Family and Child Project – introduce a screening tool for developmental disorders to administer with families,
- Pediatric Block – patient or patient-simulated interview skills for children with ASD and developmental disorders; videotape of several children with ASD,
- Family Medicine Block – patient contact and clinical experience with using a developmental screening tool,
- Psychiatry Block– patient contact with a focus on the chronic difficulties associated with ASD,
- Continuing and Preventive Care – early screening as prevention for all developmental disorders, and
- Electives – a comprehensive course on referrals and collaboration with other organizations (for example, preschool, early intervention centres, and schools) and other treatment disciplines (for example, psychology, speech language pathology, and occupational therapy).

Goal 3: Teach an efficient screening tool for detecting ASD.

Teaching Goal 3: Introduce a screening tool for developmental disorders to administer with families in the Family and Child Project.

Goal 4: Provide students with information of where to direct a referral for ASD diagnosis and treatment.

Teaching Goal 4: Teach students about potential collaborative partners and to work with others in the community.

Goal 5: Provide students with clinical teaching and modeling for ASD detection

in a clinical setting.

Teaching Goal 5: Placing students with clinicians who have experience with ASD and a structured method for early detection of developmental disorders. Allow students to first watch and then gain clinical experience with a development screening tool for developmental disorders.

Goal 6: Give students communication and interview strategies for children with ASD, developmental delays, and developmental disorders.

Teaching Goal 6: Teach students interview guidelines for children with ASD and their families. Expose students to patient-simulated interview experiences. Develop a pocket-size cue card for key points.

Goal 7: Create more opportunities to experience patients with ASD.

Teaching Goal 7a: Develop videotapes of multiple children with ASD in various settings.

Teaching Goal 7b: Organize an opportunity to experience children with ASD in an early intervention centre.

In summary, the findings suggest all the factors that delay diagnosis in clinical practice are present in undergraduate medical education. The next step is to implement participants' suggestions to change the curricula and measure the resulting progress. However, the participants also said ASD curricula will need champions; medical educators who adopt this topic and want to make a difference for physicians and families with ASD. Medical school curricula changes because of external and internal influences. A participant explains:

> "A positive counter pressure is the currently high public profile of autism. There is a recognition that autism exists. There is a reason why people should be

> thinking about it. That is a good counter pressure, when the public are talking about something. It is a little bit easier to say, "What are we doing about it?" the medical school and faculty. (P8)

The external influence then creates an internal influence for curricula change. This participant suggests curriculum planners may change the curricula if the findings of ASD and developmental curricula are deficient and this impacts children's lives.

> I guess if you could show the teaching was limited and that because the teaching is limited these people would be identified 6 months, 12 months, 24 months, later and that will have a significant impact on the lives of these children. Then you might be able to convince them to do more teaching around that. (P4)

This study provides the catalyst and supporting educational baseline to inspire change in ASD undergraduate medical curricula.

CHAPTER 6

6.0 Implications of this Research

From this study four major themes emerged about ASD curricula in undergraduate medical education:

1. Curricula structure and medical educations' current pressures affect child development and ASD integration in the curricula.
2. Students learn basic developmental milestones as a method to detect ASD and other developmental disorders.
3. Clinical guidance is constrained for detection practices of ASD and other developmental disorders.
4. Student experience limited ASD patient contact and do not have the skills for early detection practice.

These findings have major implications and promising solutions for learning and teaching ASD curricula in undergraduate medical school.

This study traces the gap in present medical practice for ASD to undergraduate medical education. The information gained from this study provides a foundation for educating physicians in present and future practice about early detection of ASD. The findings also stress the importance of collaborating across the disciplines associated with ASD to establish a community of support for health care professionals and the families they pledge to support.

6.1 Possibilities for Further Research

1. Implementation and Evaluation. This study completes steps 1 through 4 of Kern et al.'s (1998) six-step approach. I recommend completing the last 2 steps: step 5 is

implementation and step 6 is evaluation of the implemented curricula. A replication of this study will serve as a measure for the impact of the curricula changes.

2. Needs Assessment of Nova Scotia Family Physicians. The findings of this study and others suggest physicians require more support and education for detecting children with ASD. Therefore, it is important to conduct a Needs Assessment to target learning gaps and provide continuing medical education. Educating physicians will benefit children with ASD and their families, as well as, provide stronger clinical leadership for students in clinical placements.

Appendix A

Letter to Administrators

Dear (Name of Administrator),

My name is Paula Hutchinson and I am conducting research for my Master's thesis in the Department of Education at Mount Saint Vincent University. The focus of this research is to examine autism and developmental delay in pediatric undergraduate medical curricula. The expected outcome of this study is to provide information and insight for curriculum planners of pediatric medical education on autism and developmental delay.

I would sincerely appreciate your voluntary participation in providing me with a list of the pediatric curricula instructors. Specifically, I am interested in faculty and visiting clinicians who teach any component of the pediatric undergraduate program. Would it be possible to include in the list the following information: instructors' names, email addresses, and topic or course they teach? I am also interested in these instructors' pediatric curricula syllabi and course content on human development and developmental disorders.

I would like to arrange a time to meet with you to collect this information. If you have any questions or concerns, please contact me by phone at (902) XXX-XXXX or by email address. You may also contact my supervisor, Dr. Lorri Neilsen (902) 457-6700. Should you have any questions regarding the conduct of this research you may contact Dr. Anthony Davis, Associate Vice-President Research, MSVU, who is at arms length from this study, at (902) 457-6350.

Thank you in advance for your time and assistance.
Paula Hutchinson

Appendix B

Letter to Head of Developmental Pediatrics

Dear Letter to Head of Developmental Pediatrics,

My name is Paula Hutchinson and I am currently a Masters' student in Department of Education at Mount Saint Vincent University conducting research for my Masters' thesis. The purpose of this research is to identify curricula and education practices used in undergraduate medical education for detecting children with autism and developmental delay. The expected outcome is to provide information and insight for curriculum planners of pediatric medical education.

I would sincerely appreciate your voluntary participation in assisting me by sending an email to fourth year undergraduate medical students inviting their voluntary participation in a 20-minute audio-taped telephone interview. I have attached the letter outlining their time commitment and ways they can contact me.

Strict measures are employed to protect the identity of all participants. No identifying information will be released in the Thesis report, and all audiotapes will be destroyed on the completion of the Thesis. Participants may withdraw at any time without any consequence.

If you have any questions or concerns, please contact me at (902) XXX-XXXX or email address. You may also contact my Supervisor, Dr. Lorri Neilsen (902) 457-6700. Should you have any questions regarding the conduct of the research, you may contact Dr. Anthony Davis, Acting Chair of the University Research Ethics Board, at 457-6350.

Thank you for your time and consideration.

Sincerely yours,

Paula Hutchinson
Masters Student
Department of Education
Mount Saint Vincent University

Dr. Lorri Neilsen
Professor
Department of Education
Mount Saint Vincent University

Appendix C

Letter to Students

Dear (Student's name),

My name is Paula Hutchinson and I am currently a Masters' student in Department of Education at Mount Saint Vincent University conducting research for my Masters' thesis. The purpose of this research is to identify curricula and education practices used in undergraduate medical education for detecting children with autism and developmental delay. The expected outcome is to provide information and insight for curriculum planners of pediatric medical education.

I would sincerely appreciate your voluntary participation in a 30-minute audio-taped telephone interview. I have attached the proposed questions for your information. Your responses are vital to a deeper understanding of the curricula material. Should you decide to participate, you will need to complete the enclosed consent form and return it in the enclosed self-addressed envelope. I will contact you by phone to arrange for a convenient time.

Strict measures are employed to protect the identity of all participants. No identifying information will be released in the Thesis report, and all audiotapes will be destroyed on the completion of the Thesis. Participants may withdraw at any time without any consequence.

If you have any questions or concerns, please contact me at (902) XXX-XXXX. You may also contact my Supervisor, Dr. Lorri Neilsen (902) 457-6700. Should you have any questions regarding the conduct of the research, you may contact Dr. Anthony Davis, Acting Chair of the University Research Ethics Board, at 457-6350.

Thank you for your time and consideration.

Sincerely yours,

Paula Hutchinson
Masters Student
Department of Education
Mount Saint Vincent University

Dr. Lorri Neilsen
Professor
Department of Education
Mount Saint Vincent University

Appendix D

Interview Consent Form

I, _____, agree to participate in the research entitled Autism
(please print name)
and Developmental Delay Curricula in Undergraduate Medical School. The purpose of this research is to identify the scope and nature of curricula and education practices used in an undergraduate medical school for detecting children with autism and developmental delay. The participants are selected because of their unique perspective of the curricula.

I understand that telephone interview with Paula Hutchinson, Masters student in the Department of Education, at Mount Saint Vincent University, will last approximately 30 minutes, and it will be audio taped.

I understand that my participation is voluntary. I have the right to refuse to answer any questions and/or to be audio taped at any time. I may withdraw at any time without negative consequence.

I understand that strict measures are in place to protect my identity. No identifying information will be released in the Thesis report. I understand that the audiotape of my interview, which will be stored in a research office at Mount Saint Vincent University, will be destroyed upon completion of the Thesis.

I understand there is no anticipated harm or risk related to my participation, and that an Ethics committee at Mount Saint Vincent University approved this research.

I understand that a final copy of the report will be available for participants to view.

I give my free and informed consent.

Date: _____

Participant Signature: _____

Interviewer Signature: _____

If you have any questions about how this study is being conducted, you may contact Dr. Anthony Davis, Acting Chair of the University Research Ethics Board, c/o MSVU Research and International Office, who is not directly involved in the study, at 457-6350 or via e-mail at research@msvu.ca.

Phone number where I can be contacted to arrange for an interview: _____
The best time to call me is: _____
I would like to view a final summary of the thesis report. Yes _____ No _____

Appendix E

Letter to Instructors

Dear (Instructor's name),

My name is Paula Hutchinson and I am currently a Masters' student in Department of Education at Mount Saint Vincent University conducting research for my Masters' thesis. The purpose of this research is to identify curricula and education practices used in undergraduate medical education for detecting children with autism and developmental delay. The expected outcome is to provide information and insight for curriculum planners of pediatric medical education.

I would sincerely appreciate your voluntary participation in a 30-minute audio-taped telephone interview. I have attached the proposed questions for your information. Your responses are vital to a deeper understanding of the curricula material. Should you decide to participate, you will need to complete the enclosed consent form and return it in the enclosed self-addressed envelope. I will contact you by phone to arrange for a convenient time.

Strict measures are employed to protect the identity of all participants. No identifying information will be released in the Thesis report, and all audiotapes will be destroyed on the completion of the Thesis. Participants may withdraw at any time without any consequence.

If you have any questions or concerns, please contact me at (902) XXX-XXXX. You may also contact my Supervisor, Dr. Lorri Neilsen (902) 457-6700. Should you have any questions regarding the conduct of the research, you may contact Dr. Anthony Davis, Acting Chair of the University Research Ethics Board, at 457-6350.

Thank you for your time and consideration.

Sincerely yours,

Paula Hutchinson
Masters Student
Department of Education
Mount Saint Vincent University

Dr. Lorri Neilsen
Professor
Department of Education
Mount Saint Vincent University

Appendix F

Students' Interview Protocol

1. I understand this is your last year of undergraduate studies. What residency program have you been matched to?

2. I'm looking at autism in the undergraduate medical school curricula. My understanding is that it is mostly in the pediatric curriculum? Is that right?

3. Where did you do your pediatric rotation? Location and person?

4. In what ways did your instructors help you to understand the relevance of autism to your future practice?

5. Was there a strategy that stood out for you?

6. Were you taught any instruments (screening or assessment) to detect autism?

7. Did you have any exams or papers, observations, on autism?

8. What types of direct, hands on, experiences did you have with families and children who have autism during your program? Did you have any outside of your program?

   If no, is this something you were interested in doing?
   If no, was the absence of this opportunity mentioned in the program?
   If yes, Tell me about the experience(s)?
   What will you take from your hands on experience that will help you in your clinical practice?

9. Was there anything that wasn't included in the hands on experience, that you thought should have been included?

10. How much time did you have to discuss your experience with your clinical instructor? With your curriculum instructor?

11. How about pediatric electives, did you take any?

12. Where do you think autism fits as priority for students in the pediatric curriculum? Why?

13. What would you suggest to pediatric curriculum planners to help students learn about early detection of autism?

14. Is there anything else that you would like to add or discuss that was not touched on in the interview?

Appendix G

Instructors' Interview Protocol

1. Tell me a little about your teaching role in the university and at the hospital? Clarifying, Courses, areas of specialty.

2. When you address autism with your students, what approaches do you use?

3. Are you aware of other areas in the curriculum where autism is taught?

4. How is the curriculum coordinated between the courses?

5. Do undergraduate students have direct contact with families and children who have autism and other developmental disorders?

   Clarifying,
   What does this look like? Is it structured or unstructured? Types of settings?
   If yes, how is it measured?
   If not, are there reasons for not offering such opportunities?

6. In what ways do you communicate curricula objectives with the clinical instructors?

7. How do clinical instructors communicate clinical objectives with you?

8. My understanding is that the Denver II and Rourke are taught. Are there any other screening instruments taught that I haven't mentioned?
   Clinical practice?

9. Are there any screening instruments for development that you would like to introduce to undergraduates? that are not presently taught?
   If yes, are they in the process of being introduced? Are there barriers?

10. I have interviewed some of the students from your program and it was mentioned that the curriculum was used as a guideline only. Can you comment on that?

11. The students have reported that they did their clerkships in PEI and St. Johns? How well do think that is working?

12. Where do you think autism and developmental disorders fit as a priority for students in the pediatric curriculum? Why do you think that?

13. Is there anything else that you would like to add or discuss that was not touched on in the interview?

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