

**CARING FOR THE AUTISTIC CHILD: A RESOURCE MANUAL FOR HEALTH CARE  
PROVIDERS**

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## **Abstract**

**Background:** Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that affects approximately 1 in 68 children (CDC, 2014). Comorbid medical conditions and psychiatric disorders increase the likelihood that these children will require acute care services more often than their neurotypical peers (McDermott, Zhou, & Mann, 2008; Simonoff et al., 2008). The evidence suggests that most health care providers are unprepared for the complexity of the interactions with these children during an acute care episode (McGongile, Migyanka, et al., 2014; McGongile, Venkat, et al., 2014; Muskat et al., 2015). Currently, there are no formalized training programs for acute health care workers in Regina Qu'Appelle Health Region (RQHR).

**Purpose:** The purpose of this practicum project was to use the best available evidence on the care needs of children with Autism Spectrum Disorder (ASD) and effective interaction strategies to guide development of a resource manual for acute care health workers, especially registered nurses (RNs), working in the RQHR.

**Methods:** Initial steps involved planning for and conducting a needs assessment. The resulting database emerged from a critical review of relevant literature, an environmental scan of resources within RQHR, and informal consultations with parents and caregivers of children with ASD, acute care nurses and nurse managers and experts in the field of ASD. Following analysis and collation of all data into major themes, a draft blueprint guided development of a resource manual for health care providers interacting with and providing care to children with ASD.

**Results:** The needs assessment data informed development of an educational resource manual appropriate for all health care providers who encounter children with ASD and their parents and/or caregivers within acute care environments. The *Caring for the Autistic Child: A Guide for Health Care Providers in Acute Care* provides insightful information on the disorder and associated comorbid conditions, as well as effective approaches to care delivery with this priority population.

Implementation and evaluation plans will guide distribution of the resource manual within the RQHR.

**Conclusion:** The sequential and interdependent steps taken in this practicum project led to the development of a resource manual comprised of simple, easy to implement strategies capable of assisting nurses and all healthcare providers in providing care tailored to the autistic child's unique needs and challenges.

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## **Introduction**

The past decade evidenced a marked increase in the number of children diagnosed with Autism Spectrum Disorder (ASD). According to the Centers for Disease Control (2014), this number has increased to a staggering 1 in 68 children. Common to children with ASD are comorbid conditions that affect overall physical and mental health states. Comorbidities are the primary reason that many of these children present to emergent care areas. Because of the increasing volume of children with ASD seeking acute care services, it is imperative that frontline nursing staff become aware of and proficient in interventions designed to reduce stimuli, increase communication success, and decrease stress for these children and their families.

## **Background**

While there is a growing body of literature and research on care of the autistic child in acute care, it is still very limited. Much of the knowledge in this area focuses on the manifestations of ASD and the lived experience of raising a child on the autism spectrum. What is missing or present in a rather restrictive sense is effective strategies to help minimize stress and distract these children during the performance of assessments and procedures when presenting to acute care settings like emergency departments.

Research findings also suggest that frontline nurses working in acute care require advanced education to help them deal with the speech and developmental delays typical of autistic children. One study in particular studied nurses comfort levels in providing care to individuals with ASD (McGonigle et al., 2014). Using a pre-test post-test design, McGonigle et al. (2014) found that nurses did not feel as comfortable providing care to individuals with developmental delays such as ASD as typically developing children who



present to acute care with other types of chronic or complex conditions. Other authors concur with these findings (Bultas, 2012; Landa, Holman, O'Neill, & Stuart, 2011; McGonigle, Migyanka, et al., 2014; Scarpinato, Bradley, Kurbjun, et al., 2010; Will et al., 2013).

## **Purpose**

Based on informal conversations with nursing colleagues and interventionists at the Child and Youth Autism Center in Regina during appointments with my daughter, I became aware of an important need for advanced nursing education on how to care for children with ASD. Nursing colleagues voiced feeling unprepared and uncomfortable when providing care to children with speech and developmental delay. During an informal conversation with the manager of the Child and Youth Autism Center, she revealed that she was unaware of any type of resource manual on how to care for the autistic child within the Regina Qu'Appelle Health Region (RQHR).

There are several reasons for choosing this topic for my practicum project. First, I chose this area because of personal experiences as a parent of an autistic child who required emergency services on a couple of different occasions. During each emergency department visit, I encountered health care providers who were not only uninterested in the fact that my daughter had been diagnosed with ASD but dismissed it as having any relevancy for the situation at hand. Consequently, these clinical encounters proved to be very traumatic for both of us. The use of different triaging approaches coupled with a few minor modifications to my daughter's care would have improved things considerably and resulted in very different outcomes. The second reason is a direct consequence of the first. On a personal level, I want to learn more about ASD and ways to prevent sensory

overload and/or counteract its negative impact, especially when my daughter requires emergency room care. It is my hope that in doing so, I will affect the lives of other families dealing with ASD. Finally, it is my expectation that by compiling the new knowledge gained from the literature and consultations with key stakeholders into a resource manual for all health care providers, the RQHR will be receptive to adopting its use in staff orientations and in-servicing. With advanced education in this area, nurses will not only experience increased comfort during interactions with children with ASD but also greater feelings of competency.

### **Significance**

This project is important for several reasons. First, a resource manual will augment existing knowledge on effective care strategies for children with developmental and speech delays. There are many useful resources available for instructing parents on how to communicate effectively and manage behaviors associated with ASD.

Unfortunately, there are no comparable educational tools available to health care providers to assist them during clinical encounters with these children and their families.

Secondly, the development of a resource manual for health care providers has the potential to have a positive impact on children with ASD and their families.

Implementing measures to decrease the stress associated with emergency room visits will facilitate the delivery of care in a calm, professional manner while respecting the unique qualities of each child. Nurses and all health care providers must be comfortable implementing techniques to reduce anxiety and behavioral flair ups in order for the child to have positive experiences during emergency room visits and future care requirements in other acute care settings. Finally, when care helps reduce the child's stress, parents

will also experience less stress and worry when accessing health care services.

Confidence in the health care team begins with properly educated nurses who are sensitive to the needs of children and their parents.

## **Objectives**

The overall mission of the current project was to use the best available evidence to inform the development and implementation of an education program focused on effective care strategies for health care providers, especially nurses, when caring for children with ASD. The project goal was to develop a resource manual capable of increasing the knowledge, confidence and comfort levels, skills and abilities and overall competence of frontline providers involved in caring for children diagnosed with Autism Spectrum Disorder who access acute care services within the Regina Qu'Appelle Health Region (RQHR). A second goal was to demonstrate the Advanced Nursing Practice competencies of research, leadership, consultation, and collaboration during the development of the resource manual. The expectation is that this manual, or a modified version of it, will become part of the orientation package in clinical areas frequented by pediatric clients with ASD within the RQHR.

The specific practicum objectives were:

1. Develop a resource manual to guide care of the child with ASD in acute care.
2. Perform a needs assessment to develop insight into the advanced education requirements of healthcare providers, especially nurses working in acute care settings caring for children with ASD.

3. Develop an implementation plan for promoting the incorporation of the resource manual as part of the orientation package in clinical areas frequented by pediatric clients with ASD within the RQHR.
4. Demonstrate Advanced Nursing Practice competencies of clinical, research, leadership, consultation and collaboration.

### **Overview of Methods & Conceptual Model**

#### **Methods**

A needs assessment comprised of several key activities helped meet project goals. A literature review assessed the current body of research evidence and the availability of educational resources to form the basis for training manuals appropriate for use within the region. A detailed overview of the literature review results is in Appendix A. Consultations with key stakeholders within RQHR, including health care providers, regional managers, ASD experts and parents of children with ASD, augmented the information gathered from a critical review of the literature. In addition, an environmental scan of resources within the region failed to identify a formal process for educating nurses or other health care providers. There was also no comprehensive resource manual available to guide care of children with ASD in the acute care setting. Appendix B contains a summary of the consultations and environmental scan.

Analysis and integration of data generated by the needs assessment informed development of a resource manual for health care providers involved in caring for children with ASD. This manual incorporates practical methods of stress reduction,

communication modalities, and a toolkit of items to help calm and distract the child during clinical encounters. Appendix C presents the resource manual in its entirety.

### **Conceptual Model**

Similar and disparate conceptual models and theoretical frameworks exist to guide development and implementation of health promotion programs. Because of the nature of this practicum project, the Generalized Model for Program Planning seemed the most logical choice (McKenzie, Neiger, & Thakeray, 2009). The Generalized Model is a basic model capable of providing a template for most program planning models. Key steps involved in the process include a needs assessment, establishing goals and objectives, and developing, implementing and evaluating a program (McKenzie et al., 2009).

The three F's of program planning were very important for this project (McKenzie et al., 2009). *Fluidity of the process* refers to the sequential and comprehensive steps involved in project planning (McKenzie et al.). Incorporating a needs assessment as a preliminary step in developing the resource manual ensured that its content was reflective of the target population's needs. *Flexibility* refers to openness to change at each stage of the planning process in response to the ongoing collection of new and evolving information from key stakeholders. While considering the views and perceptions of each priority population participating in the current project, unanticipated new information often surfaced especially in the beginning phases. *Functionality* refers to targeting improved health outcomes as the primary goal behind the planning of any type of health promotion activity or

program. This was true for this project as well, where the ultimate goal of developing a manual for health care providers was to provide a resource to assist them in caring for and interacting with children with ASD, and, ultimately, to increase positive outcomes for these children within the acute care setting.

## **Summary of the Literature Review**

### **Methods**

The focus of the literature review was to determine acute care providers', especially nurses, perceptions of how prepared they are for clinical encounters with children diagnosed with ASD, and the kind of educational supports needed to increase their knowledge, confidence and comfort levels, skills and abilities and overall competence. A comprehensive search of MEDLINE, CINAHL plus with full text and Cochrane Libraries, with limiters added to compile results from 2005 to 2015, used the following search terms: 'autism', 'autistic disorder', 'autism spectrum disorder', 'ASD', 'nursing', 'nurse', 'education', 'comfort level', 'acute care', 'emergency', and 'hospital.' Various combinations of these terms resulted in a very small number of articles with little relevance to the topic. The decision to broaden the search with the phrase 'autism spectrum disorder' returned 1514 articles. The search was subsequently limited to articles dealing with children age 2 to 12, resulting in a return rate of 876 articles. A cursory review of article titles and abstracts led to the selection of twenty-three articles for more in-depth review. Three additional articles not identified from the search results came from an alternate source.

The Public Health Agency of Canada's Toolkit (PHAC) (2014) guided the critical appraisal of the final set of selected articles but only nine were relevant to the current study. A comprehensive overview of the final set of articles and their ratings can be found in Appendix A.

### **Literature Summary**

The purpose of conducting a literature review was to determine the effects of caring for a child with ASD on the family unit, the quality and quantity of data on the educational needs of nurses in acute care who care for children with ASD, and nurses' perceptions of their comfort levels while providing care. While the body of literature surrounding ASD is growing, few articles focus specifically on nursing care of children with ASD, nurses' educational needs, and the challenges faced by families experiencing ASD. Most articles report on common comorbidities associated with ASD, and effective instructional strategies for teaching these children in the classroom.

The critical analysis of selected articles resulted in two substantive themes that form the basis of the discussion in this section of the report. The first theme focuses on the lived experience of raising a child with ASD and some of the difficulties that can arise in everyday life, including gaining access to health care services. The second theme addresses health care provider experiences and education needs.

## **The Lived Experience**

It is very important to develop some understanding of the lived experience of families dealing with the challenges of ASD on a daily basis. By developing insight into the struggles and triumphs faced by these families, health care providers will be better equipped to care for these children and their families in acute care settings.

Every child with ASD is unique and presents similar and disparate challenges to family members. However, one constant is that most parents assume the caregiver role. Because mothers tend to take on multiple roles as they try to cope with caring for a child with special needs (Lutz, Patterson, & Klein, 2012) this may increase the burden of care for them. With little respite from caregiver demands, role strain can create increased stress (Lutz et al., 2012; Swinth, Tomlin, & Luthman, 2015).

It is common for many children with ASD to have comorbidities. These may include, but are not limited to, gastrointestinal disorders, language deficits, delayed gross and fine motor control, sleep disturbances, lack of social awareness, and impaired problem solving. Because many of these health issues require intensive therapies to improve function, the additional strain placed on the family unit can alter family dynamics (Swinth et al., 2015) and lead to relationship breakdown (Lutz et al., 2012).

Following a diagnosis, many parents describe grieving about the uncertainty that may lie ahead. Grieving is ongoing and relived each time the child fails to meet



developmental milestones. By immersing themselves in the role of expert, parents try to manage feelings of grief and anger (Lutz et. al., 2012).

Many parents are of the opinion that practitioners are underprepared to provide the level of care needed for their children with ASD (McGonigle et al., 2014; Lutz et al., 2012). This leaves families feeling dissatisfied with the level of care received when accessing acute care services. An example of dissatisfaction voiced by parents is the tendency for health care providers to rely on chemical and/or physical restraints to calm the child and make care delivery possible (McGonigle, et al.). What this approach does is enhance parental stress and nurses discomfort levels, and ultimately, makes future encounters stressful and full of negativity for the child.

### **Health Care Provider Experiences and Education Needs**

Much of the literature describes a multifactorial association between nurses' confidence and comfort levels while providing care to children with ASD, and the provision of skilled, competent nursing care. Many nurses feel inadequately prepared to care for children with complex needs. In addition, nurse participants report encountering such barriers as inadequate care coordination, family skepticism of vaccines, and time to adequate care provision (Bultas, 2012; Landa, Holman, O'Neill, & Stuart, 2011; McGonigle, Migyanka, Glor-Scheib, et al., 2014; Will et al., 2013).

On the positive side, the literature identifies several strategies for improving care and increasing positive outcomes for children and families affected by ASD.

One effective strategy is providing health care providers with education sessions that focus on ways to minimize sensory overload by engaging in more focused triage procedures and removing unnecessary equipment from treatment rooms (Giarelli, Nocera, Turchi, et al., 2014). A second recommended strategy involves using different forms of distraction (Drake, Johnson, Stoneck, Martinex, & Massey, 2012) to help reduce stress by having the autistic child focus on something other than the procedure at hand. Another useful strategy is communication techniques like the Picture Exchange Communication System (PECS), visual schedules, and social stories. Each of these techniques has the ability to prepare the child for what is coming, allowing the child to make choices and determine what is expected (Drake et al., 2012). Finally, collaboration between parents and health care personnel is especially important with children who have special needs and are unable to communicate their fears, wants, and needs. Parents and formal caregivers are often the best resource when dealing with new or stressful situations (Bultas, 2012).

### **Strengths and Limitations of Research**

Unfortunately, the current literature evidences more limitations than strengths. Only one study of health care personnel by McGonigle et al. (2014) used a pre-test post-test design to investigate the effects of education on health care personnel's comfort levels while providing care to individuals with ASD. Most of the findings are from research studies with cross-sectional designs and convenient, small samples. More research studies with longitudinal designs are needed with larger, geographically diverse samples. Furthermore, given the limited research

literature in this area, it is apparent that greater information dissemination requires a wider variety and range of media possibilities, like webinar or online learning modules. For a complete discussion of the literature review, please refer to Appendix A.

### **Summary of Consultations**

Development of a resource manual grounded in real world issues and the needs of priority populations requires the collection of primary data. For the purpose of the current study, it was important to consult with experts in ASD, nurses working in the acute care areas where children with ASD come for treatment, and parents and caregivers of children with ASD who have experienced accessing the healthcare system.

The consultation findings suggest that nurses in acute care receive limited education on how to care for children with ASD. Furthermore, there is no readily available reference resource for nurses. The information obtained from the various consultations was invaluable and helped inform development of a resource manual that aims to increase nurses' knowledge about ASD, while providing practical examples of ways to reduce stress and promote positive outcomes. The long-term goal is to present the manual developed to the RQHR for distribution to all health care personnel. This report presents a brief summary of the consultations.

Appendix B contains a comprehensive overview of the consultation findings.

## **Staff Nurses**

The focus of the informal consultations with nurses working in the RQHR was on how they perceived their interactions with children with ASD in terms of their comfort level and areas where they struggled or excelled, and how well they engaged parents during clinical encounters and sought their input on the best approach to take with their children. An additional focus was on determining how willing nurses are to participate in an education module designed specifically to improve interactions with children with ASD. Consenting nurses completed a questionnaire comprised of questions addressing this content. Briefly, most of the nurse participants felt that their current knowledge level about ASD and care requirements was inadequate, did not feel comfortable providing care to children with ASD, and desired further education on the disorder, especially regarding effective care strategies. Appendix B contains the health care provider questionnaire as well as a detailed summary of the findings for each item.

## **Parents and Guardians**

Informal consultations with parents focused on obtaining their ratings of the care received by their children with ASDs while accessing health care services within the RQHR. A social media support group, the Saskatchewan Parents of Children with an Autism Spectrum Disorder, provided the medium for subject recruitment. Consenting parents received questionnaires via the online Survey Monkey program. Overall, parents rated the care received during clinical encounters with health care providers as being only fair to poor. Most parents were

of the opinion that health care providers do not have sufficient education and training in how to effectively interact with children with ASD, fail to acknowledge parents or caregivers as experts in their child's care and consult with them accordingly, and rarely implement special precautions to help reduce environmental stimuli. Significantly, the majority of parents surveyed felt that all health care providers could benefit from further education to increase their understanding of the disorder and the care requirements of these children.

### **ASD Expert and Nurse Managers**

The focus of informal interviews with the manager of the Child and Youth Services Autism Center and several managers of acute care nursing units was on identifying current resources available for educating health care providers and determining the need for a comprehensive resource manual for nurses on how to care for children with ASD who present to acute care settings. Appendix B lists the questions guiding the interviews.

The outcome of those consultations revealed that no provincial resources are currently available anywhere in Canada. While educational opportunities are available to nurses through the University of New Brunswick, through national conferences on ASD, and through expert presentations throughout the region, the limited financial resources prevent nurses from accessing these resources. The manager of the Child and Youth Services Autism Center also noted that overtures to provide in-service education sessions to help nurses care for children with ASD have not been accepted by system managers mainly due to the logistics of freeing nurses

from duty. It is not surprising then that all of the managers supported the benefits from having a resource manual for acute care nurses.

### **Summary of Manual Development**

A resource manual for healthcare providers in acute care who care for children with ASD does not exist within the RQHR. The literature review and consultation components of the needs assessment support the need for such a manual. In response to this identified need, the long-term goal of the current project is to develop and implement a comprehensive manual outlining the disorder and some of the commonly associated deficits and comorbid medical conditions.

Besides providing health care providers with basic information on ASD, the needs assessment findings stressed the importance of educating them about effective intervention strategies that could help improve the quality of clinical encounters experienced by children with ASD and their parents when accessing acute care settings. The literature review identified a variety of strategies related to reducing extraneous stimuli, engaging with parents as experts, using different types of communication modalities and distraction techniques, using a common care plan document, and developing unit specific autism resource kits.

The content of the resource manual developed for this practicum attempts to adhere to the recommendations of the needs assessment. The manual is comprised of eight chapters. Learning checkpoints follow each chapter. This strategy helps encourage readers to engage in critical reflection upon the content of each chapter before moving on to the next one. Appendix C contains the resource manual, *Caring*

*for the Autistic Child: A Guide to Health Care Providers in Acute Care*, developed for this practicum. Chapters 1 and 2 discuss what ASD is, the diagnostic approach taken to determine its presence, and the wide range of deficits commonly seen in children with ASD. Because of the nature of the disorder, it is important that healthcare providers understand that while many children have marked difficulties in communication, behavior, and socialization, others may excel in intellectual ability or demonstrate exceptional mathematical, artistic or music skills (Autism Speaks Canada, 2015). These chapters also highlight the importance of early interventions to improve functionality and overall positive outcomes (Autism Speaks Canada, 2015; Hutchins & Prelock, 2013; Landa et al., 2011; Lunskey, Paquette-Smith, Weiss, & Lee, 2015; Reichow, Barton, Boyd, & Hume, 2012; Rogers, Dawson, & Vismara, 2012; Schreibman & Stahmer, 2014; Sussman, 2012; Swinth et al., 2015).

The content of Chapters 3 and 4 illustrate different methods of stimuli reduction, and possible ways to involve parents as experts in the care of their children. For instance, research has shown that when clinical areas are noisy, negative health effects are seen even in people without underlying sensory issues (Potter & Perry, 2014; Muskat et al., 2015). Reduction of noise and other stimuli is important in maintaining a calming environment for children with ASD who are ill and confronting a new setting different from the familiar home environment. Best results occur following the initiation of stimuli reduction strategies soon after the child enters the acute care area. The focus should be on swift triage to a quiet, low stimulus area. Reliance on parents as experts in their child's care is also very

important as it builds trust between nurses and parents. Research findings suggest that when parents receive a diagnosis on their child's condition, they often become motivated to learn more about available treatments to ensure that their child is not disadvantaged in any way. When driven to be as informed as possible in the various strategies to help children with ASD, parents often become experts in the disorder (Appleton, & Minchom, 1991; de Geeter, Poppes, & Vlaskamp, 2002; Fowler, Rossiter, Bigsby, Hopwood, Lee, & Dunston, 2012; Lutz, Patterson, & Klein, 2012). Many nurses forget that parents can be a very valuable resource. Alternately, they may feel that asking parents for help suggests that they are not knowledgeable caregivers.

Chapter 5 discusses the importance of learning how to assess how a child with ASD communicates with unfamiliar others, while also offering suggestions on strategies to improve communication between the nurse and child. Visual tools such as Social Stories, the Picture Exchange Communication System (PECS), visual schedules, and video based modelling, are examples of useful methods for promoting positive communication outcomes. It is possible to modify highlighted templates to capture specific occurrences within a particular clinical area. Furthermore, adjustments can be made in visual tools to highlight expected behaviours of children with ASD while receiving treatment or undergoing specific procedure, and ways to help these children understand objects and events present in variant contexts (Ganz, Goodwyn, Boles, Hong, Rispoli, Lund, & Kite, 2013; Ganz, Parker, & Benson, 2009; Schreibman, & Stahmer, 2014).



Chapter 6, 7 and 8 highlight additional tools for use in acute care environments. Distraction is a useful technique for all children and works by taking the child's mind off the procedure at hand. A second useful technique is having regionally accepted documents, such as health care plans, which are given to parents to present at all appointments and exchanges with health care providers working within the system. Individualized care plans can also promote interdisciplinary teamwork while also removing reliance on guesswork regarding effective strategies to use with particular children. By keeping health care plans updated, each time the child presents to any clinical setting (s) he is receiving care tailored to his or her needs via intervention strategies developed collaboratively by the entire health care team. The final illustrated technique, the *Autism Resource Kit*, is an example of how unit-specific kits can be developed and used anytime a child with ASD presents to that particular area. Filled with sensory toys, communication tools, and social stories, it is possible to make adjustments at a moment's notice to tailor the experience to the child and foster positive outcomes.

All of the noted interventions are examples of recommended strategies for helping ensure that any child who enters the acute care setting receives competent care from confident health care providers. As many of the participating nurses from the RQHR noted in their responses, advanced education in this area would certainly benefit their practice. Comments received from participating parents also highlight the importance of ensuring that all health care providers have the requisite knowledge and skills to interact with and provide care to children with ASD. Many

parents voiced concerns about not only the communication difficulties displayed by many health care providers but also inadequate attempts to reduce environmental stimuli. As well, many parents noted that they would like to be involved in their child's care, especially by being asked about useful ways to provide care that is less traumatic for their child. In short, the hope is that the manual developed for this practicum contains information that will not only help nurses provide more effective care but also benefit children by making visits to acute care settings less traumatic.

### **Advanced Nursing Practice Competencies**

The Canadian Nurses Association (2008) identified four advanced practice competencies expected of nurses participating in nursing graduate programs. Graduate nursing students should understand how their work helps contribute to the advancement of nursing knowledge. The advanced nursing practice (ANP) competencies comprise four distinct areas: clinical competencies, research competencies, leadership competencies, and consultation and collaboration competencies. This practicum project has provided me with many opportunities to address each of these competencies. The content of the following sections will illustrate how my work demonstrates each of the required competencies.

#### **Clinical Competencies**

According to the ANP National Framework, clinical competency in advanced nursing practice involves demonstrating an ability to use clinical experience and expertise in conjunction with research knowledge to cultivate assessment skills while maintaining a client centered focus that empowers individuals, families and

communities to live healthy enriched lives. This may be accomplished through advanced research techniques that enhance a nurse's ability to analyze how the lived experience effects everyday functioning. Nurses who develop an expertise in a specific field are able to use advanced knowledge to inform their practice by identifying the impact of determinants of health on the health status of similar and different target populations.

During this practicum, I have been able to demonstrate on multiple levels the clinical competency requirement of an advanced practice nurse. Clinical insights from personal encounters with the health care system as the parent of a child diagnosed with ASD coupled with new information from research and theoretical literatures helped enhance my clinical practice and understanding of the implications for these children and their parents when nurses do not possess the necessary knowledge to provide effective care. From a more practical perspective, the activities and knowledge that guided me while developing this resource manual have far-reaching health implications for families, groups, and communities beyond the initial local target group. For example, during the development of a nursing resource manual, I had to plan, initiate contact with key stakeholders in the region, and coordinate and collaborate with members of the healthcare team as well as parents of children with ASD. All of these activities facilitated the incorporation of relevant and timely information into the manual. Besides giving me greater insight into how to enhance nursing care of children with ASD, this practicum has helped increase my personal competence in caring for these children.

## **Research Competencies**

Knowledge of research methodologies provides nurses with the necessary tools to engage in critical appraisal of studies for relevant findings to guide and inform clinical practice. It is also extremely important that advanced practice nurses are capable of conducting research to generate information that will help them more effectively care for their clients. During the current practicum, multiple opportunities surfaced to help improve my research skills. For example, I conducted a literature review on the educational needs of nurses working with children with ASD. Critical analysis of this literature supported the need for further education of nurses working in clinical areas frequented by children with ASD. In collaboration with key stakeholders in the RQHR, I was able to plan and actually conduct a needs assessment that has helped advance my nursing knowledge. I will also be disseminating these findings through the formal process of this practicum report, as well as informally through conversations with colleagues on the issues surrounding care of children with ASD.

## **Leadership Competencies**

According to the Canadian Nurses Association (2008), advanced practice nurses demonstrate leadership skills in their areas of practice. As leaders, advanced practice nurses possess high level problem solving skills, use research findings to inform practice, engage in shared decision-making, and have well-developed interpersonal and communication skills, among other things. Working from the premise of evidence informed practice (EIP), leaders advocate on behalf of patients

and their families by using knowledge from research findings to help change how others view health issues such as ASD. By developing a resource manual for health care providers, I am promoting EBP while advocating for children and families with ASD living in Saskatchewan and across Canada. The review of relevant literature and consultations with nurses and other key stakeholders in the RQHR highlighted learning needs of all health care providers that require attention. In particular, the needs assessment data revealed gaps in nursing knowledge surrounding ASD and care of these children within acute care settings. The resource manual developed for this practicum is one useful approach for increasing nursing knowledge in this area. Finally, from my role as a health educator in Saskatchewan, this project provides me with a forum for teaching and mentoring upcoming nurses about ASD, especially in effective strategies for ensuring the delivery of quality care to this very vulnerable population.

### **Consultation and Collaboration Competencies**

Consultation and collaboration competencies support and overlap with leadership clinical and research competencies. Advanced practice nurses are expected to communicate and collaborate with key stakeholders and become members of interdisciplinary teams. With extensive knowledge of targeted subject areas, advanced practice nurses partner with other member of the health care team, as well as patients and families, to influence the delivery of care directed toward achieving positive outcomes. During this practicum project, I engaged in consultations with parents of children with ASD, nurses working in the frontline of

nursing care, and experts in the field of autism. The resource manual developed for this project is an important outcome of these collaborative efforts. Significantly, the themes emerging from the survey results guided development of a resource manual intended to inform nursing practice. Without consultations and collaborative efforts, it would be impossible to develop a resource intended to improve the quality of care provided to children with ASD and their families.

### **Next Steps: Implementation and Evaluation**

#### **Implementation**

A significant shortcoming of the current project is that insufficient time was available to implement the resource manual in the target area. Nevertheless, involving regional administration representatives from acute care nursing and the Child and Youth Services Autism Center during the planning and developmental stages was an important strategic step toward achieving broader system support for adopting the resource manual in targeted acute care areas. It is important to note that participating administrative representatives supported, in principle, the objectives for the project and the proposed route via a resource manual to meet them.

The next logical step is to present the manual to the Child and Youth Services Autism Center and administration of the RQHR, especially managers responsible for pediatric clinical settings frequented by children with ASD. Key regional stakeholders must provide tangible support to achieve successful implementation of the manual. The proposed approach to implementation will include distribution of

the manual to each nursing unit and their associated clinical educators. What would also work well, depending upon the availability of necessary resources, is in-service education opportunities offered during lunch breaks. By using such an approach, coverage for nursing staff and hence system costs will be kept at a minimum.

### **Evaluation**

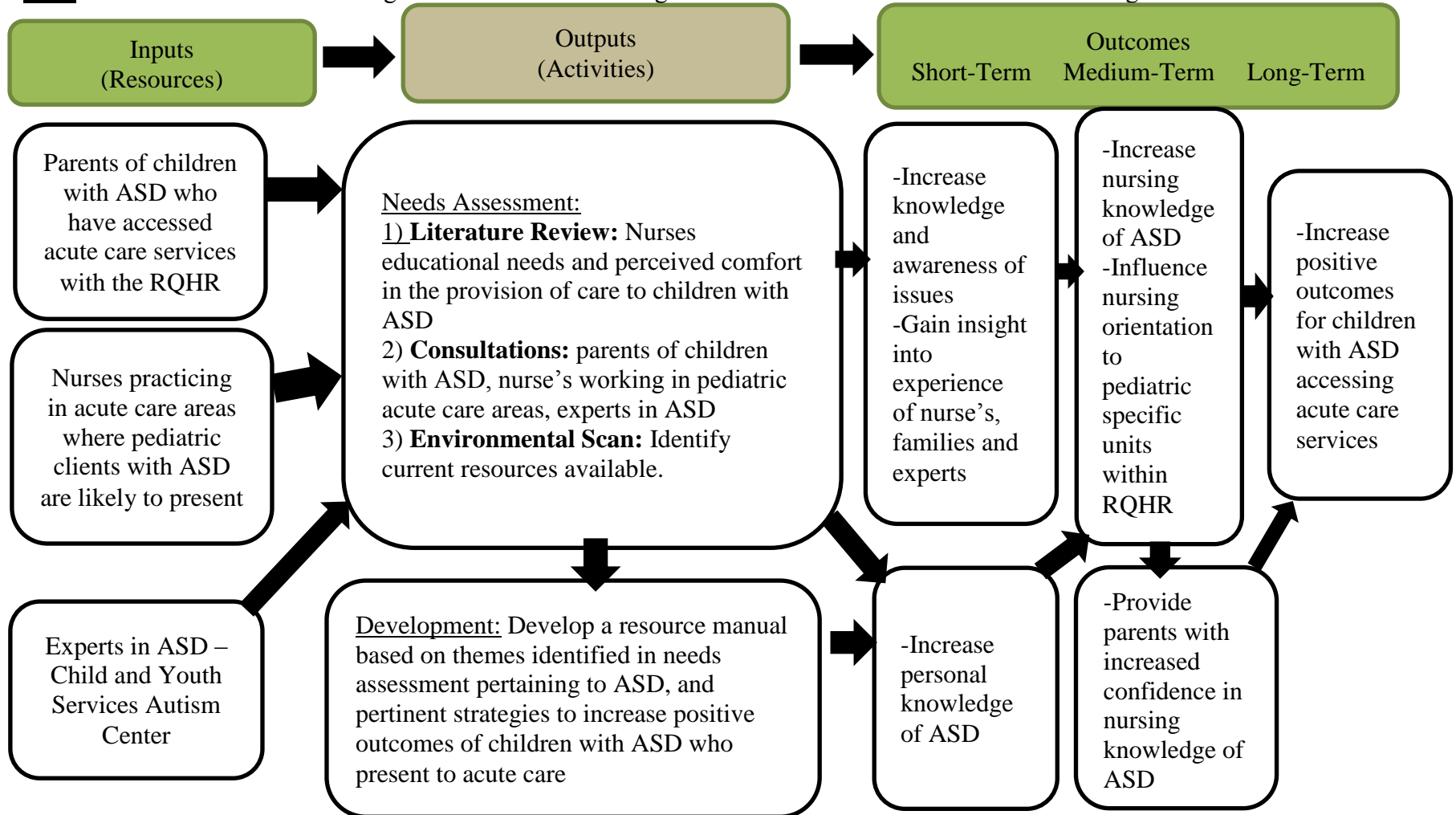
Many approaches exist to evaluate the impact of the resource manual upon the nursing staff and the standard of care provided to children with ASD and their families. One useful approach is to assess the change in nursing knowledge prior to and following implementation of the manual. In this particular situation, administration of a pre-test questionnaire prior to introducing the resource manual and conducting luncheon sessions will be followed by post-test evaluation sessions at different intervals (i.e., immediately after the teaching session, three and six months post, and finally at one year). Additional measures to evaluate the impact of the resource manual could involve asking families of children with ASD to rate their perception of any changes, if any, in the quality of nursing care observed over the past six- months to one year post intervention.

The following page outlines a Logic Model that describes the project and some of the intended outcomes. The inputs relate to the priority populations who, in this instance, were the targets for the primary data during the needs assessment phase. The outputs refer to the activities completed during this practicum project. The outcomes are divided into short-, medium- and long-term.

### Logic Model

**Situation Statement:** Nurse's in acute care settings require additional education pertaining to Autism Spectrum Disorder (ASD) to increase competency and confidence in caring for children with ASD.

**Goal:** To increase nurse's knowledge and confidence in caring for a child with ASD in the acute care setting.





## **Conclusion**

During the current practicum, I engaged in conducting research on nurses' comfort level and educational needs in caring for children with ASD. The need for conducting such research arose from personal experiences accessing acute care services for a child with ASD. I have seen firsthand the impact of nursing care not tailored to the unique needs of the child with ASD. The range of deficits associated with ASD makes it imperative that nurses and other healthcare providers receive the education and knowledge to improve their practice, as each child is unique and presents with their own unique set of challenges.

Through consultations with parents, nurses and experts in the area of ASD, it was determined that all parties supported the importance of advanced education on this disorder, as well as effective intervention strategies. Data were collected via questionnaires distributed via Survey Monkey and face-to-face, as well as email correspondence. The themes identified from the data analysis suggested that parents were not satisfied with the level of care received when accessing acute care services, nurses felt uncomfortable during care provision, and that experts were unable to identify a comprehensive manual that could guide nursing care.

A manual was developed using information gathered from the survey results that included not only background information into the disorder, signs and symptoms, and co-morbid conditions that are prevalent in this population, but also practical strategies that can be implemented within the acute care setting to improve care. Most of these strategies are relatively easy to implement, do not cost

very much, and are based on research with positive results. It is hoped that the implementation of this manual into acute care within the RQHR, will increase nursing knowledge, increase nurse's perception of competence in provision of care, and promote positive outcomes for children with ASD and their families.

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**Appendix A**  
**Review of Literature**

Caring for the Autistic Child: A Resource Manual for Healthcare Providers

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**Caring for the Autistic Child: A Resource Manual for Healthcare Providers****Abstract**

Autism Spectrum Disorder (ASD) is one of the most common neurodevelopmental disorders affecting Canadians, with one in 68 children diagnosed yearly (Autism Society Canada, 2015; Center for Disease Control, 2014). This increase in diagnoses equates to an increase in the presentation of children with ASD and their families to acute care services in urgent or emergency situations (Giarelli et al., 2014; Muskat et al., 2015). Because of the characteristic deficits in speech and communication, social interaction, repetitive rigid behaviours, and learning, many nurses feel underprepared and under educated to provide the specialized care required of children on the autism spectrum (Autism Society Canada, 2014; Will, Barnfather, & Lesley, 2013). The purpose of this paper is to examine the literature on existing resources available for nurses caring for children with autism spectrum disorder. A second purpose is to determine the quality of available evidence in terms of its ability to support development of a resource manual for possible introduction into nursing curricula or orientation programs to nursing units frequented by children with ASD. To date there has been minimal research that focuses solely on the educational needs of nurses. Most of the studies found in the literature document the behaviours associated with the disorder and the lived experience of families dealing with a diagnosis of ASD. It is proposed that development of a comprehensive resource manual designed specifically for nurses is a practical first step in addressing the educational needs of all health care providers.

## Introduction

Autism Spectrum Disorder (ASD) is an umbrella term that encompasses several disorders of early childhood: autistic disorder, pervasive developmental disorder not otherwise specified, and Asperger's syndrome (Autism Society Canada, 2015). Each individual presents with a slightly different variation of the disorder, making it very difficult to diagnose definitively (Will, Barnfather, & Lesley, 2013). Because of the range of disability ASD is rated on a spectrum from mild to severe (Autism Society Canada, 2015). As severity increases, functionality decreases often manifesting as marked decreases in social ability, language acquisition, and repetitive self-injurious behaviors. Characterized by lack of functional speech, rigid, repetitive behaviours and sensory disturbances, ASD affects every aspect of life (Will et al., 2013).

Definitive diagnosis of ASD in early childhood requires collaboration from a clinical psychologist with expert knowledge in the area. Diagnosis is obtained by using the DSM-V to rate language acquisition, social functioning and restrictive behaviours (Center for Disease Control, 2015a). Although current medical treatment modalities are inadequate to address the multifactorial nature of ASD, promising new programs and therapies are emerging that support early development. The clinical evidence suggests that early diagnosis followed by a structured program of interventions designed to increase functional speech, decrease unwanted behaviours, and minimize the effect of sensory disturbance facilitates positive outcomes (Rogers, Dawson, and Vismara, 2012) According to Reichow, Barton, Boyd, and Hume (2012), although not every child will benefit from early intervention the greatest gains seem to occur during peak brain growth and development.

According to the Center for Disease Control (CDC) approximately one in 68 children are diagnosed with this pervasive disorder of normal development (2014). Significantly, ASD is reported more often in males than females with approximately one in 42 boys diagnosed with ASD compared to one in 189 girls (CDC, 2015). These statistics are staggering and highlight the importance of conducting further investigation into the health care requirements of individuals with ASD. More importantly, the steady increase in the incidence and prevalence of ASD over the past decade (CDC, 2014) is concerning when coupled with the limited research exploring the quality and quantity of health care supports needed to address the needs of these children and their families and caregivers (Giarelli et al., 2014; McGonigle, Migyanka, et al., 2014; Muskat et al., 2015). Research findings suggest that children with ASD present to emergency services 20% more often than neurotypical children (McDermott, Zhou, & Mann, 2008). This situation is attributed, in part, to the child's lack of safety awareness coupled with many co-morbid conditions such as seizure disorders, gastrointestinal disturbances, and depression and anxiety (McDermott et al., 2008). Unfortunately, a large proportion of children with ASD who present to acute care require treatment due to acute agitation, aggression, or other mental health crisis (McGonigle, Venkat, Beresford, Campbell, & Gabriels, 2014). In a study by Simonoff et al., (2008), 70% of children diagnosed with ASD had at least one comorbid psychiatric disorder and 41% had two mental health conditions.

It stands to reason that nurses working in acute care will see an increasing number of autistic children. All health care providers, including nurses require specialized education to effectively care for these children and their families. However, research studies investigating the advanced education needs of acute care nurses in relation to effective care strategies is minimal (Giarelli et al., 2014; McGonigle, Migyanka, et al., 2014; Muskat et al., 2015). Much of

the existing literature focuses on the lived experience of ASD and how families cope with the challenges of raising a child on the autism spectrum. While this content is very important for enhancing understanding of how to provide care to individuals and their families, more methodological sound studies are needed on the education requirements of health care providers. In particular, more evidence-based information is needed on how to provide safe, competent, and compassionate care. Interventions based on sound evidence has the ability to reduce stress experienced by children with ASD and increase positive experiences in acute care.

The overall objective of the current project is to use the best available evidence to inform the development and implementation of an education program targeted to increase the knowledge, confidence and comfort levels, skills and abilities and overall competence of health care providers, specifically nurses, involved in caring for children diagnosed with ASD who access acute care services within the Regina Qu'Appelle Health Region (RQHR).

An important step in this process involved consulting with key stakeholders within the region. Informal consultations were held with frontline nursing staff, the Child and Youth Services Autism Center staff, and parents/caregivers of children with ASD. The overall goal of these consultations was to determine what resources are currently available to help guide health care providers in caring for to children with ASD. A secondary aim of these consultations was to accomplish the following: a) determine which resources were currently available to guide health care providers in providing care to children with ASD, b) determine the depth of knowledge on ASD received by nurses during their basic education programs, c) identify nurses working within RQHR who have had clinical encounters with children with ASD and inquire about how they experienced these interactions including comfort level and

areas where they excelled or struggled, d) determine the extent to which nurses engaged parents during these interactions and sought their input on the best approach to take with their children, e) determine how interested nurses are in participating in an education module designed to improve interactions with children with ASD, f) determine nurses perceptions of the difference in caring for child with ASD as compared to neurotypical children, g) determine the perceptions of the manager of the Child and Youth Services Autism Center on the need to develop a comprehensive resource manual for nurses in the acute care setting, and h) determine parents' perceptions of care received by their children with ASD within the RQHR.

The following paper provides a discussion on the literature review component of the needs assessment. The first section presents an overview of the methodological approach to the search strategy, article selection, and critical appraisal of article quality. The second section presents an integrated synthesis of findings from the review of literature. The presentation of findings is divided into two major subsections according to target substantive content areas – Living with ASD and family challenges and Health care provider experiences and education needs. A summary table of included studies is presented in Appendix A. The third section presents a brief discussion on common themes emerging from the analysis of findings. An attempt is made to synthesize the findings and determine their significance for informing development of the proposed resource manual for nurses working in RQHR.

### **Critical Appraisal**

#### **Methods**

In reviewing the literature MEDLINE, CINAHL plus with full text and Cochrane Libraries were utilized with limiters added to compile results from 2005 to 2015. Search terms included 'autism', 'autistic disorder', 'autism spectrum disorder', 'ASD', 'nursing', 'nurse', 'education',

'comfort level', 'acute care', 'emergency', and 'hospital' as well as a combination of each. Variable combinations of these terms only yielded a very small number of articles with little relevance to the topic. When the more restrictive terms were removed and the search focused on 'autism spectrum disorder', the result was 1514 articles. The search was subsequently limited to articles relevant to children age 2 to 12, with full text access, to ensure a more manageable number of articles. A total of 876 results were returned. These articles were first analyzed by title alone to determine their possible relevance for inclusion. Articles selected for abstract read generated twenty-six articles for further review. Two articles that did not surface during the search were identified from an alternate search conducted by a colleague. A search of agency sites provided two additional documents that were used as supporting evidence (CIHI, 2008; CIHI 2012).

Following critical appraisal of the 26 articles with the Public Health Agency of Canada's Toolkit (PHAC) (2014), only 10 articles were judged to be of sufficient quality for the current study. The articles selected were appraised to have moderate to strong research evidence according to the PHAC criteria. Only four articles were deemed specific to the educational needs of front line nursing staff, with the remaining articles used as supportive evidence. Three of the selected articles were phenomenological studies, with the remaining seven having a variety of research designs such as cross sectional post-test survey, observational, randomized controlled trial, descriptive narrative, causal comparative study, pre- and post-test study, and quantitative descriptive study. The remaining sixteen articles were either too broad in their focus, or had significant methodological flaws.

### **Integrated Literature Review**

The purpose for conducting a literature review was twofold. The first was to determine the effects of caring for a child with ASD on the family unit, and the challenges that this poses. The second was to determine the quality and quantity of the existing literature on the educational needs of nurses in acute care who care for children with ASD, as well as nurses' perceptions of their comfort level in the provision of that care. However, literature specific to these factors is very limited, with the majority of research focusing on the specific characteristics of ASD and treatment modalities. Exploring the literature provides the reader with an inside look at some of the difficulties that can arise in everyday life and when accessing health care services, while remaining cognizant of the fact that each child is unique and can present with different challenges than the next.

A summary table was created for articles selected for inclusion in the literature review (Appendix A). The table provides an overview of the articles' objectives, methodology, theoretical backgrounds, key findings, strengths and limitations, and conclusions and overall ratings.

### **Living with ASD and Family Challenges**

**The Lived Experience.** As with any condition, it is important to understand the lived experience of children and families affected by ASD. The unique challenges that the disorder presents to families range from mild to severe. This can lead to caregiver role strain and increased stress for both children and parents. Language deficits, delayed gross and fine motor skills, sleeping abnormalities, gastrointestinal issues, lack of social awareness, and impaired problem solving capacity are just a few of the issues seen in children with the disorder. These deficits require intensive therapies to improve functioning of the child and can place great

strain on families. Acquiring and maintaining services is a full time job, and places a large financial burden on families and caregivers of children with ASD.

While there are medications available to help with attention deficits, and the psychological issues accompanying ASD, none are available to treat the core deficits of this disorder (Will et al., 2013). Behavior modification and education are the two main strategies used to improve functioning of children with ASD (Will et al.). These techniques show promise in helping children achieve maximum potential but there is a time commitment that many families find extremely difficult to manage (Lutz, Patterson, & Klein, 2012).

After diagnosis is achieved, many parents describe experiencing a type of grieving. Dreams of having a 'normal' child are shattered. The unending nature of the disorder places an additional burden, where parents are unable to look to the future and anticipate what their child will become. The ongoing burden of care places strain on personal as well as family functioning and often leads to relationship breakdown (Lutz et al., 2012). Mothers often take on multiple roles as they try to cope with the addition of a child with special needs (Lutz et al.). Being caregiver, advocate, therapist, and support person is often described as the normal functioning of the new role of the mother. This level of burden can add stress and often leads to physical health ailments, as well as caregiver burnout.

Searching for answers is a logical outcome of the grieving process. Parents try to become experts in dealing with the condition and are constantly searching for ways to help alleviate some of the burden of finding and maintaining services. Grief is an ongoing process that is relived each time the child does not meet the milestones of their typically developing peers. Anger often accompanies the grieving process leading parents to question why they were chosen to deal with the challenges of caring for a child with ASD (Lutz et al., 2012).



Parents try to manage feelings of grief and anger by seeking answers and methods to help their children (Lutz et al.).

Lutz et al. (2012) describe a concept known as dis-ease where parents feel that they are in a constant state of psychological, physiologic, and social uncertainty as they live with the anxiety, physical manifestations of stress, and stigmatization of the diagnosis. Anxiety stems from a variety of issues, including the tendency of children with ASD to be often unaware of physical safety and as a result put themselves in dangerous situations. This could manifest as wandering or running from caregivers. Behaviour problems like these leads parents to modify their children's activities further which may actually increase their burden with some of them finding it difficult to balance job and child care demands (Lutz et al.).

Parents identify the need to seek out support through socialization and spirituality as coping mechanisms (Lutz et al, 2012). Being with other people who understand the struggles of raising a child with ASD is a means of decreasing the stress of always being on guard and fearing the manifestation of typical behaviors (Lutz et al.). This form of support may also give parents hope as they network with other families who have been through the same developmental stages. Faith gives recognition of the important aspects of life; learning to live within the disability and taking solace in things that many parents of typical children may take for granted. According to Swinth, Tomlin, and Luthman (2015), many parents in their sample were surprised at how well they were able to cope even in adversity, making even the smallest achievements a source of pride.

Raising a child with a diagnosis of ASD can be life altering. Oftentimes, day-to-day functioning and routines are altered to accommodate the child with ASD which not only impacts family dynamics but also the way the family socializes with others (Swinth et al.,

2015). Caregiver stress and burnout is a major factor to consider as parents struggle to obtain and maintain services needed to promote language acquisition, socialization, and deter unwanted repetitive behaviours. Acquiring services often places strain on the family structure due, in part, to the financial demands of maintaining intensive therapies (Swinth et. al.) This can lead to further stress when levels are already at their maximum. Exploration of parental coping mechanisms can provide nurses and other healthcare workers with insight into the everyday lives of families with ASD, as parents often become experts in their children's care. Unfortunately, many nurses and other healthcare providers are underprepared and undereducated on the special needs of a child with ASD. This leads us to question how parents/caregivers experience the care provided by nurses and other healthcare providers.

### **Health Care Provider Experiences and Education Needs**

The literature on health care workers caregiving experiences with children with ASD reveals a multifactorial association between confidence and comfort levels and the provision of skilled, competent care. There is some literature detailing the barriers perceived by nurses during care provision, as well as examples of specific interventions to help reduce those barriers. Notably, collaboration among healthcare providers and clients and families is discussed as a priority strategy in providing care that reduces stress for everyone involved.

**Health care workers caregiving experiences.** A large amount of research pertains to the comfort level of health care personnel while caring for individuals with ASD. Research findings suggest that health care providers feel unprepared for the complex care needs of children with ASD as compared to children with other chronic and complex conditions (Bultas, 2012; Landa, Holman, O'Neill, & Stuart, 2011; McGonigle, Migyanka, et al., 2014; Will et al., 2013).

Similar observations have been made by parents. Practitioners are often viewed as being unable to provide a level of care that reflects adequate knowledge and understanding of the disorder (Lutz et al., 2012). McGonigle, Migyanka et al. (2014) report that families of autistic individuals are often dissatisfied with the level of care received from health care providers working in emergency departments. Parents' dissatisfaction stems from health care providers lack of understanding of the condition, especially regarding communication difficulties and typical behaviors. As a result, children may experience overwhelming sensory overload with care only capable of being provided under aggressive sedation or physical restraint (McGonigle, Migyanka et al.). Unfortunately, this adds to an already stressful situation, and increases the child's fear of future health care encounters.

Many children with ASD have multiple co-morbidities making access to the health care system a necessity. Co-morbidities increase the complexity of care needed, adding to the discomfort felt by nurses. McGonigle, Migyanka et al. (2014) conducted a needs assessment of medical personnel in emergency departments and found that education was needed on the clinical presentation of ASD, myths surrounding behaviors and language deficits, concurrent medical issues that are commonly seen in clients with ASD, and how to approach care in a manner that minimizes stressors. The authors administered a questionnaire to participants using a Likert 5-point scale to determine the impact of an education module. Using a paired t-test to determine change, these authors found that practitioners' confidence level and comfort in providing care to individuals in the emergency setting was increased from baseline results.

For many children with ASD, a trip to the emergency room (ER) can be a traumatic experience. Sensory overload and change in routine, in addition to health crisis, can result in agitation behaviours, including self-harm and meltdowns (CIHI, 2008; McGonigle, Venkat et al.,

2014). This type of behavior can also impact nurses comfort level in providing care, as de-escalation of agitation and aggression in children with ASD can be difficult. The proposed development and implementation of an education module similar to one used in the McGonigle, Migyanka et al. (2014) study supports the goal of the current project because of the similarity of setting and participants.

**Barriers.** Health care personnel have described several barriers to providing care to autistic individuals in the acute care setting. According to Will et al. (2013), the greatest barrier is lack of coordination of care services, with family skepticism of vaccines, and time listed in the top three. It is also noted that lack of provider education about the disorder is a major barrier to care for these children (Will et al.). Because this is a common theme throughout the literature further research is warranted in this area (Bultas, 2012; Lutz et al., 2012; McGonigle, Migyanka et al., 2014; and Muskat et al., 2015).

**Interventions.** Several themes have emerged in the literature as possible strategic measures for improving health care and increasing positive outcomes for children and families affected by ASD. One common theme is that health care providers require education on how to minimize sensory input to reduce overload. This could be achieved through a quicker triage process that minimizes the amount of time the individual spends in areas known to have higher levels of stimuli, such as the waiting room, and instituting measures to help reduce the presence of unnecessary extraneous equipment in treatment rooms (Giarelli et al., 2014).

Another useful intervention involves introducing distraction tools such as a coping kit (Drake, Johnson, Stoneck, Martinez, & Massey, 2012). Distraction is an intervention that is beneficial for a couple of reasons. First, toys and other sensory devices can help children focus on something other than the task at hand which facilitates relaxation (Drake et al., 2012). The

use of communication cards similar to those used in the Picture Exchange Communication System (PECS), a therapy designed to help children articulate their wants, needs and fears, would also help practitioners prepare the child for targeted procedures (Drake et al.).

Social stories have also been identified as helpful tools for children with ASD (Sussman, 2012). According to Drake et al. (2012), the use of stories helps to break down tasks and procedures into smaller more manageable chunks of information for processing. It helps the child see how a particular situation will unfold and prepare him/her for that situation. This can be beneficial in reducing anxiety from not understanding what will happen next.

It is important that interventions designed to reduce anxiety are used effectively because even the simplest of tasks can provoke sensory overload and meltdown. As mentioned previously, ASD is characterized by repetitive behavior. As such any deviation from the normal routine is cause for alarm and anxiety.

**Collaboration.** Collaboration between family care givers and health care personnel, while important for all caregiving situations, is even more important when a child is unable to communicate effectively or has sensory impairments. According to Bultas (2012), parents and formal caregivers of children with ASD are often the best resource when dealing with new or stressful situations. When parents/caregivers are included as key members of the health care team, they are able to advise the health care personnel on strategies that work well for their particular children. It is important that this partnership is fostered to ensure optimal health outcomes. Unfortunately, nurses sometimes do not take the time to utilize this resource while providing care, especially in urgent or emergent situations, leading to unnecessary trauma and stress for the child, and their parents. It is imperative that nursing staff are educated on the

importance of incorporating the family into client care, as families have expert knowledge of their child's behavior and communication difficulties.

The provision of competent, compassionate care is the ultimate goal of nursing practice. Unfortunately, many nurses feel underprepared to provide care to children with ASD. The literature supports the view that practitioners' confidence levels are lower when caring for children with ASD than when caring for other neurotypical children or those with complex health care needs. Research findings suggest that education pertaining to reduction of stimuli, methods of distraction, and the introduction of social stories in the context of care, can reduce stress for everyone involved. Perceived barriers to care include lack of coordination of services, skepticism of vaccine efficacy, lack of time, and lack of provider education. While collaboration with families and other members of the healthcare team is one way to counter these barriers, education for nurses and other health care providers remains a very important action in increasing practitioner comfort and competence levels.

### **Discussion**

With the increasing incidence and prevalence of ASD, it is logical to assume that an increasing number of children with this disorder will be accessing acute care services. The reasons for this are multifactorial with the concurrent co-morbidities (e.g., gastrointestinal functioning, seizures, sleeping disorders, and psychiatric disorders such as depression and anxiety) topping the list of contributing factors (CIHI, 2008; McGonigle, Migyanka et al., 2014). Health care providers practicing in emergency medicine are the usual first point of contact for children with ASD and their families.

The increasing need for services equates to billions of dollars in health care spending per year with this amount expected to rise in the future (McGonigle, Migyanka et al., 2014). When care is provided in a manner that creates anxiety and sensory overload for the autistic child, research findings suggest that this may result in longer length of stay within health care facilities and poorer patient outcomes (Landa, Holman, O'Neill, & Stuart, 2011; Giarelli et al, 2014). It is therefore imperative that health care providers are able to engage in positive interactions with the autistic individual. The negative effects of improper care can be long lasting for the child with ASD.

Education is one of the most promising means of ensuring that the health care provided fosters positive experiences for children with ASD and their parents. Nurses are especially vulnerable because the special needs and complex care requirements of children with ASD are only given brief coverage in basic nursing curricula. This leaves nurses inadequately equipped to provide care. For this reason, the development of a resource manual targeted towards nurses and other healthcare providers in the acute care setting is a logical first step towards increasing family confidence in having access to competent and skilled nurses. Having a resource that highlights strategies to reduce stimuli, increase positive communication techniques, and reduce overall stress for children with ASD and their families, will also increase the comfort level of nurses providing care.

**Strengths of current research.** Several studies have shown promising results. The McGonigle, Migyanka et al. (2014) is one of a very limited number of medium quality studies (pre/post-test design) that investigates the effects of education on health care personnel's level of comfort while caring for individuals with ASD.

**Limitations of current research and recommendations for future research.**

Several limitations were noted with current research findings. First, most of the studies used a small number of participants. For example, studies of medical personnel were primarily based on convenience sampling from a single source. To ensure generalizability of the findings these studies need to be replicated using larger samples, across a variety of care settings and in different geographical locale.

The second limitation identified was the absence of longitudinal data. All of the studies included consisted of a data collected at a single point in time, without follow-up. It would be pertinent then to study the long-term effects of education on comfort and competence levels several months or years after the education intervention. It would also be pertinent to evaluate if a change in practice occurred following the education intervention.

A third limitation is that the sole focus has been primarily on the comfort levels of medical personnel. That is, no attempt was made to determine families' perspectives of the effectiveness of education interventions on providers caring abilities. In order to ensure that study findings are reliable and valid, it is important to also collect data on the perceptions of parents and caregivers of children with ASD.

A fourth limitation identified relates to limited dissemination of information. . McGonigal, Migyanka et al. (2014) recommend using different types of electronic media such as webinar. It may also be pertinent to include this type of education in the curricula of nursing education programs, ensuring that new practitioners have the basic knowledge to deal with the complexities of care of a child with ASD.

The results of this literature review will help guide development of a resource manual to be presented to the RQHR. Gaining a greater understanding of nurses' perceptions of



quality of care provided, as well as relying upon the expert opinions of parents and caregivers, will ensure that barriers to care can be addressed. The development of such an educational resource will provide nurses with a means of increasing their knowledge, confidence, and competence in the provision of care to children with ASD and their families.

### **Conclusion**

As the prevalence of ASD rises, the number of children presenting to acute care for treatment will also rise. This leaves front line nursing staff to deal with behaviours and communication difficulties associated with ASD while attempting to provide holistic nursing care. Unfortunately, there is little education provided to nurses either from their educational program, the licensing body, or the employer, on effective strategies to employ while caring for individuals with ASD. Nurses feel underprepared and stressed at the idea of providing care to individuals with neurodevelopmental disorders. It is imperative that education is provided on how to deal with sensory issues, communication difficulties, and social interaction, to ensure that the care provided is done so in a calm reassuring manner, rather than under physical or chemical restraint.

The literature to date provides very little information on the positive effects of education on provision of care to individuals with ASD. Most of the focus is on the lived experiences of parents/caregivers, health care workers' perception of care provided, barriers to care for individuals with ASD, possible interventions and the importance of collaboration among members of the healthcare team providing care. While these topics are definitely important and aid in the understanding of the bigger picture of ASD, effective education programs for front line nursing staff is not readily available documented. It is this writer's opinion that change cannot occur in the provision of quality care without education, and it is

the responsibility of the healthcare community as a whole to embrace educational experiences that will improve care outcomes, and ultimately the lives of those affected by ASD.

## Appendix A

Literature Summary Table

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results/Findings	Strengths/ Limitations	Conclusion and Rating
<p><i>The health care experiences of the preschool child with autism.</i> Bultas (2012).</p> <p>Study Objective: to gain a better understanding of the experiences of mothers accessing healthcare services for their autistic children</p>	<ul style="list-style-type: none"> <li>11 mothers with preschool children with ASD</li> <li>recruitment took place through a parent resource group</li> <li>mothers older than 18 years with a child with a confirmed diagnosis of ASD between the ages of 36 months to 72 months</li> </ul>	<ul style="list-style-type: none"> <li>interpretive phenomenology</li> <li>interviewed 3 times over a 2 to 4 week period</li> <li>interviews lasted between 1-2 hours</li> <li>semi-structured interview</li> </ul>	<ul style="list-style-type: none"> <li>themes include: they just don't get it, and marginalized by those who should care</li> <li>Mothers felt they were dismissed and their expertise in knowing their child was not used</li> <li>Healthcare providers didn't understand the mother's need to seek out alternative therapies and treatments</li> <li>Healthcare providers tended to dismiss mothers' concerns</li> </ul>	<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>Qualitative, inductive, interpretive study</li> <li>Selective research on the topic</li> <li>Research cited is current to the study</li> <li>Gaps in current knowledge discussed</li> <li>Critical thinking about issue evident</li> <li>Primary sources used</li> <li>Inclusion/exclusion criteria discussed</li> <li>Use of validated screening tools</li> </ul> <p><b>Limitations</b></p> <ul style="list-style-type: none"> <li>Small sample size</li> <li>Participant recall could be altered/ inaccurate</li> <li>Full disclosure may not have been present</li> <li>Only mothers perceptions were studied – not generalizable beyond the sample provided</li> </ul>	<p>Based on design of research this study is of medium quality.</p> <p>Conclusion: Mothers of preschool children with ASD serve as a valuable resource for the healthcare provider that is rarely used to its full potential. Increased collaboration between parent and health care provider can increase the positive outcomes associated with accessing health care services.</p>

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results/Findings	Strengths/ Limitations	Conclusion and Rating
<p><i>Evaluation of a coping kit for children with challenging behaviors in a pediatric hospital.</i> Drake, Johnson, Stoneck, Martinez and Massey( 2012).</p> <p>Study Objective: to determine nurses perception of the effectiveness of a coping kit as an intervention for challenging behavior.</p>	<ul style="list-style-type: none"> <li>• 24 registered nurses</li> <li>• US Midwestern pediatric hospital</li> <li>• Convenience sample</li> </ul>	<ul style="list-style-type: none"> <li>• Cross sectional post test survey study</li> <li>• A coping kit with tools to improve communication and provide distraction was developed and administered to children with developmental disabilities</li> <li>• Modified Hudson's intervention effectiveness survey was used to measure nurses perception of effectiveness</li> </ul>	<ul style="list-style-type: none"> <li>• Nurses perceived the coping kits to be effective</li> <li>• Decreased anxiety, calmed unwanted behavior, and increased cooperation</li> </ul>	<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>• Research cited is current to the study</li> <li>• Gaps in current knowledge discussed</li> <li>• Critical thinking about issue evident</li> <li>• Primary sources used</li> </ul> <p><b>Limitations</b></p> <ul style="list-style-type: none"> <li>• Convenience sample in only one setting limits generalizability</li> <li>• Anxiety and behaviors were not measured using a quantitative tool</li> <li>• Diagnosis of ASD was not verified</li> <li>• Parents perceptions of effectiveness of coping kit not addressed</li> </ul>	<p>Based on design of research this study is of moderate quality</p> <p>Conclusion: Nurses perceived a decrease in unwanted behavior and anxiety, and an increase in cooperation during procedures when the coping kit was used, as compared to data before implementation of the coping kit.</p>

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results/Findings	Strengths/ Limitations	Conclusion and Rating
<p><i>Sensory stimuli as obstacles to emergency care for children with autism spectrum disorder.</i> Giarelli et al.( 2014)</p> <p>Study Objective: to describe the amount of sensory stimuli present in emergency departments that act as barriers to care of children with ASD.</p>	<ul style="list-style-type: none"> <li>• Large metropolitan teaching hospital</li> <li>• Measured over 4 - 5days</li> </ul>	<ul style="list-style-type: none"> <li>• Observational study</li> <li>• Data was collected in 4 different areas: hallway, doorway of waiting room, chair in waiting room, and treatment room over a variety of times throughout the day</li> <li>• Instruments used to measure sound and light intensity</li> </ul>	<ul style="list-style-type: none"> <li>• Light intensity varies across areas in the ED with highest levels in the waiting room</li> <li>• Noise levels exceeded both the EPA and WHO recommendations in all areas with highest levels of noise in the waiting room</li> </ul>	<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>• Research cited is current to the study</li> <li>• Gaps in current knowledge discussed</li> <li>• Critical thinking about issue evident</li> <li>• Primary sources used</li> </ul> <p><b>Limitations</b></p> <ul style="list-style-type: none"> <li>• Accuracy of instruments – purchase price \$100; battery operated</li> <li>• Limited to one hospital – cannot be generalized</li> <li>• Visual clutter scale – subjective measurement</li> <li>• Only measured over 4 - 5 days – may not be representative of normal ED functioning</li> </ul>	<p>Based on design of research this study is of moderate quality</p> <p>Conclusion: While it is not possible to completely remove noise and light stimuli, the quick assessment and triage of patients with ASD into treatment rooms where noise is less would facilitate a more therapeutic encounter</p>

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results/Findings	Strengths/ Limitations	Conclusion and Rating
<p><i>Intervention targeting development of socially synchronous engagement in toddlers with autism spectrum disorder: a randomized controlled trial.</i> Landa, Holman, O'Neill, and Stuart (2011).</p> <p>Study Objective: to examine the effects of a hypothesized active intervention program that targeted social development in toddlers.</p>	<ul style="list-style-type: none"> <li>50 toddlers with ASD</li> <li>aged 21 to 33 months</li> <li>randomly assigned to one of two intervention programs with one having a social component; both programs were identical in intensity</li> </ul>	<ul style="list-style-type: none"> <li>randomized controlled trial</li> <li>toddlers randomized into one of two 6 month interventions</li> <li>the experimental group were provided a supplementary curriculum targeting social imitation, joint attention, and affect sharing</li> </ul>	<ul style="list-style-type: none"> <li>a significant treatment effect was noted in the group receiving the social component with socially engaged imitation and eye contact more than doubling (17% to 42%) after intervention.</li> <li>Toddlers were able to generalize this skill to other areas and contexts at follow-up</li> <li>Similar gains were noted for joint attention and shared positive effect</li> </ul>	<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>Quantitative, randomized controlled trial</li> <li>Selective research on the topic</li> <li>Research cited is current to the study</li> <li>Gaps in current knowledge discussed</li> <li>Critical thinking about issue evident</li> <li>Primary sources used</li> <li>Inclusion/exclusion criteria discussed</li> <li>Control group</li> <li>Random assignment</li> </ul> <p><b>Limitations</b></p> <ul style="list-style-type: none"> <li>None noted</li> </ul>	<p>Based on design of research this study is of high quality.</p> <p>Conclusion: Toddlers in the intervention group with social programming improves short term outcomes without additional cost. These toddlers showed social, language, and cognitive gains compared to the control group</p>

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results/Findings	Strengths/ Limitations	Conclusion and Rating
<p><i>Coping with autism: A journey toward adaptation.</i> Lutz, Patterson, and Klein (2012).</p> <p>Study Objective: to explore the experiences of families of individuals with autism as perceived by the mother</p>	<ul style="list-style-type: none"> <li>16 mothers of children and/or adults with autism spectrum disorder</li> <li>invited to participate via a posting on AutismLink an electronic mail server</li> <li>participants age ranged from 30 – 54 years</li> <li>childrens ages ranged from 2 – 31 years</li> </ul>	<ul style="list-style-type: none"> <li>Descriptive narrative study</li> <li>Personal interviews</li> <li>Interviews lasting 1-3 hours</li> <li>Option of face-to-face or telephone interview</li> </ul>	<ul style="list-style-type: none"> <li>Initial diagnosis was a stressor that initiated feelings of grief and anger</li> <li>Coping strategies were employed</li> <li>Mothers found comfort in searching for information about the disorder and gaining knowledge</li> <li>Mothers tended to take on multiple roles – parent, advocate etc.</li> <li>Adaptation to the diagnosis described as personal growth and focusing on what is important in life</li> </ul>	<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>Selective research on the topic</li> <li>Research cited is current to the study</li> <li>Gaps in current knowledge discussed</li> <li>Primary sources used</li> <li>Inclusion/exclusion criteria discussed</li> </ul> <p><b>Limitations</b></p> <ul style="list-style-type: none"> <li>Possible bias with all interviews conducted by researcher with child with autism</li> <li>Participants were not studied longitudinally</li> <li>Only mothers perceptions taken into account, not generalizable to other members of the family</li> <li>no saturation of data suggested</li> </ul>	<p>Based on the design of research this study is of moderate quality.</p> <p>Conclusion: the autism diagnosis was the initial stressor that led mothers to find different ways to cope and adapt. This study may lend merit to the understanding of nurses and other health care providers can assist families to enjoy a life that doesn't dwell on the autism diagnosis but rather move past it to adaptations</p>

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results/Findings	Strengths/ Limitations	Conclusion and Rating
<p><i>Injury treatment among children with autism or pervasive developmental disorder.</i> McDermott, Zhou, and Mann (2008).</p> <p>Study Objective: to determine the differences in frequency or type of injury based on wheather diagnosis of ASD vs typically developing children.</p>	<ul style="list-style-type: none"> <li>138,111 children were measured for injury frequency who were insured with Medicaid during 2003</li> <li>focused on more severe injuries that required hospital admission or emergency department visits</li> <li>46000 children with diagnosis of disability (broad)</li> <li>92000 children without diagnosis</li> </ul>	<ul style="list-style-type: none"> <li>causal-comparative research</li> <li>comparison of injury report of children with ASD/PDD vs children without diagnosis</li> </ul>	<ul style="list-style-type: none"> <li>children with ASD/PDD were 20% more likely to require treatment in hospital for injury</li> <li>Those with different insurance coverage/no insurance coverage may not present as often as those with insurance</li> <li>Children with ASD/PDD presented with sprain strain injuries less often than their control peers</li> <li></li> </ul>	<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>Age matched sample at 2:1 ratio</li> <li>Selective research on the topic</li> <li>Research cited is current to the study</li> <li>Gaps in current knowledge discussed</li> <li>Critical thinking about issue evident</li> <li>Primary sources used</li> <li>Inclusion/exclusion criteria discussed</li> </ul> <p><b>Limitations</b></p> <ul style="list-style-type: none"> <li>Results were obtained using computerized Medicaid reimbursement files so results may not be generalizable to other insurance carriers</li> <li>Age range of participants was based on insurance coverage by age</li> <li>Study is only generalizable in South Carolina as insurance carriage may be different in other states</li> </ul>	<p>Based on design of research this study is of moderate quality.</p> <p>Conclusion: While this study showed that from the sample selected there was a 20% increase in prevalence of injury in children with ASD/PDD the study should be replicated in other states with other insurers/ uninsured</p>



Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results/Findings	Strengths/ Limitations	Conclusion and Rating
<p><i>Development and evaluation of educational materials for pre-hospital and emergency department personnel on the care of patients with autism spectrum disorder.</i> McGonigle, Migyanka, et al. (2014).</p> <p>Study Objective: To describe the steps in developing educational materials for health care workers in the provision of care to individuals with ASD and evaluating comfort levels of knowledge obtained from the education presented.</p>	<ul style="list-style-type: none"> <li>Team of specialists brought together to plan and produce an educational module based on a needs assessment</li> <li>110 emergency medical services personnel</li> <li>3 training sessions</li> </ul>	<ul style="list-style-type: none"> <li>quantitative, pre and post test single group design</li> <li>survey: likert response scale</li> </ul>	<ul style="list-style-type: none"> <li>Need assessment themes: need to impart knowledge, need to dispel myths, education surrounding co-morbidities such as psychiatric disorders, GI issues, seizures, and self-injury, and ways to streamline basic nursing care and treatments</li> <li>Knowledge increase noted through survey responses</li> <li>Increase in comfort level of assessing and triaging patients with ASD</li> </ul>	<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>Pre and post test design</li> <li>The first study of its kind</li> <li>Selective research on the topic</li> <li>Research cited is current to the study</li> <li>Gaps in current knowledge discussed</li> <li>Critical thinking about issue evident</li> <li>Primary sources used</li> </ul> <p><b>Limitations</b></p> <ul style="list-style-type: none"> <li>No control group</li> <li>Relatively small sample</li> <li>No long term evaluation of knowledge retained</li> <li>No saturation of data suggested</li> </ul>	<p>Based on design of research this study is of moderate quality.</p> <p>Conclusion: the provision and use of training materials about ASD and effective ways to manage care is effective in teaching medical personnel and increasing comfort level.</p>

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results/Findings	Strengths/ Limitations	Conclusion and Rating
<p><i>Autism comes to the hospital: The experiences of patients with autism spectrum disorder, their parents and health care providers at two Canadian paediatric hospitals.</i> Muskat, et al. (2015).</p> <p>Study Objective: to understand the experiences of children and families while in hospital as well as health care providers experience of providing care to individuals with ASD.</p>	<ul style="list-style-type: none"> <li>42 participants (youth with autism spectrum disorder, their parents and health care providers)</li> <li>20 distinct cases</li> </ul>	<ul style="list-style-type: none"> <li>qualitative descriptive</li> <li>semi structured interviews</li> </ul>	<ul style="list-style-type: none"> <li>themes include difficulties with communication, heightened sensory sensitivities and waiting/transiting within the hospital; recognizing parents as experts, knowing the child and preparing</li> <li>suggested changes include using a resource kit, better communication, and staff education and training</li> </ul>	<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>Qualitative, inductive, interpretive study</li> <li>Selective research on the topic</li> <li>Research cited is current to the study</li> <li>Gaps in current knowledge discussed</li> <li>Critical thinking about issue evident</li> <li>Primary sources used</li> <li>Inclusion/exclusion criteria discussed</li> <li>Use of validated screening tools</li> <li>Consultation groups used to ensure accuracy of data</li> <li>A variety of techniques used to ensure rigor</li> </ul> <p><b>Limitations</b></p> <ul style="list-style-type: none"> <li>Two specialized pediatric health care settings – not generalizable to other non specialized institutes</li> <li>A large majority of participants had severe social impairments – given spectrum of symptoms of ASD this is not generalizable to all children with ASD</li> <li>Parents disclosed diagnosis to HCPs- not generalizable to those who chose not to disclose</li> </ul>	<p>Based on design of research this study is of medium quality.</p> <p>Conclusion: patients with ASD face multiple challenges when accessing health care services. Those practitioners who acknowledged parents as experts in their child's care were described as the most supportive and improved the experience of contact with the health care system.</p>

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results/Findings	Strengths/Limitations	Conclusion and Rating
<p><i>Content analysis of qualitative research on children and youth with autism, 1993-2011: Considerations for occupational therapy services.</i> Swinth, Tomlin, and Luthman (2015).</p> <p>Study Objective: to determine how qualitative research over a specified time period can influence clinical interventions based on evidence based practice within the occupational health service for children and youth with ASD and their families</p>	<ul style="list-style-type: none"> <li>• 2 independent searches</li> <li>• 125 articles; 110 articles met inclusion criteria; 79 included for coding</li> <li>• Journals from Occupational therapy as well as outside professions</li> <li>• Topline research databases utilized</li> </ul>	<ul style="list-style-type: none"> <li>• Qualitative literature review</li> </ul>	<ul style="list-style-type: none"> <li>• Three themes identified: 1. Service challenges for the family; 2. Day-to-day experience of autism; 3. Reframing family</li> <li>• </li> </ul>	<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>• Two independent searches conducted at different points in time</li> <li>• Both searches analyzed</li> <li>• Articles were all read a minimum of 2 times before analysis</li> <li>• Peer review of coding</li> <li>• Researchers met regularly to ensure consistency of data</li> <li>• Trustworthiness of designs analyzed</li> </ul> <p><b>Limitations</b></p> <ul style="list-style-type: none"> <li>• Random selection of 30 out of 76 articles chosen for review</li> <li>• Review only includes up to 2011 more information may be available at this time</li> </ul>	<p>Based on design of research this study is of medium quality.</p> <p>Conclusion: content analysis of qualitative data ensures that the lived experience of children with ASD and their families is considered when determining appropriate measures are in place for care.</p>

Name, Author, Date, Study Objective	Sample/Groups (Size, Setting, Characteristics)	Design and Methodology	Key Results/Findings	Strengths/ Limitations	Conclusion and Rating
<p><i>Self-perceived autism competency of primary care nurse practitioners.</i> Will, Barnfather and Lesley (2013).</p> <p>Study Objective: to examine the self-perceived autism competency and barriers to care of primary care nurse practitioners</p>	<ul style="list-style-type: none"> <li>• 126 nurse practitioners attending a national NP conference</li> <li>• NPs provided care to children and adolescents under the age of 18 years</li> <li>• Convenience sample</li> </ul>	<ul style="list-style-type: none"> <li>• Quantitative descriptive</li> <li>• Self-report survey</li> <li>• Validated survey from previous work by Gulnik et al. (as cited in Will, Barnfather and Lesley)</li> <li>• Likert 7 point scale</li> </ul>	<ul style="list-style-type: none"> <li>• NPs rated their competency as significantly lower when providing care to children with ASD as compared to children with other chronic or complex medical conditions</li> <li>• top four barriers to care were listed as lack of care coordination, skepticism of vaccines, lack of time, and lack of provider education</li> </ul>	<p><b>Strengths</b></p> <ul style="list-style-type: none"> <li>• Selective research on the topic</li> <li>• Research cited is current to the study</li> <li>• Gaps in current knowledge discussed</li> <li>• Critical thinking about issue evident</li> <li>• Primary sources used</li> <li>• Inclusion/exclusion criteria discussed</li> <li>• Use of validated study instrument</li> </ul> <p><b>Limitations</b></p> <ul style="list-style-type: none"> <li>• Small convenience sample – cannot be generalized outside of the conference participants</li> <li>• Low response rate (126 NPs at a conference with 5000 attendees)</li> </ul>	<p>Based on design of research this study is of medium quality.</p> <p>Conclusion: NPs did not feel prepared to provide care to children with ASD and a desire for more education was requested.</p>

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**Appendix B**  
**Consultation Report**

**Memorial University of Newfoundland  
School of Nursing  
Master of Nursing Program**

**PRACTICUM: CONSULTATION REPORT**

**Student's Name:** Sherrilee Rudolph

**Student ID #:** 200345759

**Course Names and Numbers:** Nurs 6660 MN Practicum I

**Supervisor:** Dr. Christine Way

**Title:** Caring for the Autistic Child: A Resource Manual for Healthcare Providers

**Date:** August 23, 2015

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**1. Brief overview of the project**

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As a result of personal experience raising a child with autism spectrum disorder (ASD), I have had to bring my daughter to the emergency room during an acute illness. The care provided was often inadequate, inducing stress for something that should have been relatively noninvasive. From the perspective of a nurse with extensive acquired knowledge of ASD, there were many things that could have been done differently to help alleviate much of the stress of the situation. From the perspective of a parent who has only her child's best interest at heart, the resulting care was unnecessarily traumatic. All of this could have been avoided if these nurses had received appropriate education on expected behaviors of children with ASD, proper techniques for reducing stimuli, and effective communication techniques.

To date limited research has been completed on the effects of advanced education programs on improving health care providers' abilities to identify and implement effective

strategic approaches when caring for individuals with ASD. Most of the research has focused on the lived experience, specific interventions, the importance of collaboration among team members, and perceived comfort levels of front line health care workers providing care to individuals with neurodevelopmental disorders. More importantly, no single comprehensive document was identified from a search of multiple databases and review of relevant literature which could provide a useful resource for educating and guiding nurses in the care of individuals with ASD.

For this practicum project I will develop a resource manual that will be presented to the Regina Qu'Appelle Health Region (RQHR) for distribution to nurses who provide care to children with ASD. Preliminary consultations with colleagues in the region suggest that this type of resource is currently absent but would be beneficial for all health care providers. The overall objective for this project is to use the best available evidence to inform the development and implementation of an education program targeted to increase the knowledge, confidence and comfort levels, skills and abilities and overall competence of health care providers, specifically nurses, involved in caring for children diagnosed with (ASD who access acute care services within the RQHR.

By developing a resource manual, I hope to improve the health outcomes of children with ASD and their families who present to the acute care setting for urgent and emergent care. The long-term goal is to ensure that this resource will be part of the fundamental hiring practices of RQHR, as well as other regions throughout Canada. Through such education practices, competence can be built and, ultimately improve the quality of care provided to children with ASD.

## **2. Specific objective(s) for the consultation**

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The specific objectives for the consultation were:

- To determine the resources currently available to guide health care providers in providing care to children with ASD;
- To determine the depth of education received during the basic educational preparation of nurses;
- To identify nurses working within the RQHR who have had encounters with children with ASD and describe their perceptions of these interactions their comfort level while providing care and areas where they struggled during interactions;
- To describe how well nurses engaged parents during clinical encounters and sought their input on the best approach to take with their children;
- To determine how willing nurses are to receive in-service education on a resource manual designed specifically to improve interactions with children with ASD;
- To gather information on areas where nurses felt they struggled or excelled in providing care;
- To determine nurses' perceptions of the difference in caring for children with ASD as compared to neurotypical children;
- To determine the perceptions of speech language pathologists, social workers, and psychologists at the Child and Youth Services Autism Center on the need to develop a comprehensive resource manual for nurses in the acute care setting on how to care for children with ASD.
- To determine parents' perceptions of care received by their children with ASDs within the RQHR

### 3. Setting and Sample

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#### ***Setting:***

The setting for the consultations was relevant departments of the RQHR most likely involved in the care of children with ASD presenting with urgent and emergent issues. Possible sites included the Child and Youth Services Autism Center, the Regina General Hospital Emergency Department, the Regina General Hospital Pediatric Unit, the Regina General Hospital Youth Mental Health and Addictions Unit, and the Pasqua Hospital Emergency Department. A second consultation was planned for parents of children with ASD who had accessed acute care services within the RQHR. This sample was recruited from the social media group Saskatchewan Parents of Children with an Autism Spectrum Disorder.

#### ***Sample:***

The final sample consisted of managers and nurses from the target sites. Because of the nature of the Child and Youth Services Autism Center, informal consultations were held with the manager only as all other team members were involved with appointments. The overall focus of the consultations was on identifying resources available for educating health care team members outside of this setting.

Registered nurses were the primary focus of the consultation component. The major rationale for developing the resource manual was to identify strategies to help minimize the stress experienced by nurses during interactions with children with ASD and, ultimately, improve the quality of care provided to these children in acute care settings. In the acute care areas identified above I was able to conduct informal interviews with a total of 17 nurses, 3 nurses from the Regina General Hospital Youth Mental Health and

Addictions Unit, 5 nurses from the Regina General Hospital Pediatric Unit, and 8 nurses from the Regina General Hospital Emergency Department. No nurses participated from the Pasqua Hospital Emergency due to problems contacting the unit manager related to scheduling difficulties as a result of holidays over the summer months. The consultations were kept very informal and data were collected by an anonymous self-administered survey. Unit managers were mostly unavailable for fact-to face consultations but were contacted for feedback on the need for such a resource manual via emails. While face-to-face meetings would have been preferred, the responses received answered all of my questions regarding the need for such a resource.

I also consulted with parents and caregivers of children with ASD who were members of the Saskatchewan Parents of Children with an Autism Spectrum Disorder and had previously interacted or were currently interacting with the acute care system. The primary focus of these consultations was to develop insight into their perceptions of the care provided during these interactions. A secondary focus was to document any suggestions that they might have concerning the educational needs of nurses working in acute care settings. Again these consultations were informal in nature. I extended an invitation to all parents and caregivers to share any thoughts about how they experienced nursing care while accessing acute care resources within the RQHR via survey monkey. I decided that this would be the best way to maintain anonymity and ensure that everyone who wished to participate would have the opportunity to do so.

A formal letter of recruitment was not necessary due to the informal nature of the consultations.

#### 4. Data Collection

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Data were collected from the manager of the Child and Youth Services Autism Center through verbal dialogue. The question content guiding the informal interview focused on describing current resources available within the region, identifying suggestions for manual development, and determining the value placed on the need for such a resource. Information obtained during the interview was recorded in a notebook for later reference. See Appendix A for a list of questions guiding the consultation.

Data collected from acute care nurses were by self-report to a questionnaire (see Appendix -B). Once the manager introduced the project to staff members and solicited their agreement to being contacted I visited each targeted unit and explained the project in greater detail. Staff nurses who expressed an interest in participating were then asked to complete the questionnaire. My original plan was to have a maximum of ten nurses from each unit. This proved to be unrealistic. For example, one unit only has three nurses per shift with all of them agreeing to fill out the questionnaire. With regards to the other two units, only five nurses per unit agreed to participate. All participants completed the questionnaire relatively quickly, so I remained on the unit until they were finished. No identifying data were collected. As well, all of the data were combined to give an overall picture of the findings while maintaining individual and unit anonymity.

The parental and caregiver consultation was in the form of a questionnaire delivered through the Survey Monkey program (see Appendix C). An invitation was extended to members of a social media group, the Saskatchewan Parents of Children with an Autism Spectrum Disorder. Members expressing an interest in participating in the project were provided with a brief description of the project and a link to the survey. No

identifying data was collected, maintaining anonymity of the sample. Data were accessed through the Survey Monkey platform.

The questionnaires were specific to nurses and parents/caregivers. Because of the informal nature of these consultations, confidentiality of the data was ensured with only the primary investigator having access to information provided.

## **5. Data Management and Analysis**

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The data from the questionnaires were analyzed for relevant themes which formed the basis of the content of the resource manual. Numerical data from the questionnaires were entered into a data management file in Excel, collated and then analyzed for major themes. For example, with the parental questionnaire, the percentage of individuals who accessed emergency care for their child with ASD was tabulated. Analysis of all data helped identify specific priority areas for inclusion in the resource manual.

## **6. Ethical Considerations**

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Because of the informal nature of the consultation process and the target objective (i.e., determine the need for and possible content areas to be included in a resource manual), ethical permission was not a requirement. After completion of the Health Research Ethics Authority Screening Tool, it was determined that approval from the Research Ethics Board was not necessary (see Appendix D).

All questionnaires were free of identifying information and were submitted in a plain non-descript envelope to ensure confidentiality. These questionnaires were viewed only by the primary investigator and stored in a locked filing cabinet in the primary investigator's home.

Responses to the online questionnaire through Survey Monkey are also free of



identifying information. No IP addresses were collected. Data from those questionnaires are stored on an external data storage device that has been placed in a locked filing cabinet in the primary investigators home.

## **7. Consultation Results**

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Results were compiled into three separate categories: Parental Questionnaires, Health Care Questionnaires, and Expert Consultations. By comparing and contrasting the major themes emerging from separate sources, it was possible to prioritize content areas for inclusion in a resource manual focused on providing health care to children with ASD.

### ***Parental Questionnaires***

A total of 27 participants agreed to complete the questionnaire. There were no skipped questions. Twenty-six of the participants were the parent or guardian of a child with ASD. One participant was a grandparent. All 26 parents and/or guardians had accessed health care services for their child in the past. These services included emergency and urgent care, surgery, dental care, and regular doctor checkups.

Five main themes emerged from the data analysis: education needs of health care providers, parents/caregivers as experts, effective strategies for reducing extraneous stimuli, ratings of experiences with health care providers, and -communication difficulties during clinical encounters. Most respondents (70.37%) felt that the medical staff involved in their child's care was not adequately prepared for that encounter. The data also revealed that healthcare providers needed to focus more on ensuring that parents are included as experts in the care process. Many respondents also noted that no special precautions were implemented to reduce stimuli and decrease overstimulation (66.67%). While most participants were triaged relatively quickly, only 25.93% rated their overall experience as

good or great. These findings suggest that health care providers working in acute care require greater insight and understanding of the care requirements of children with special needs. Comments reflecting this include: “My son had to get his throat swabbed. He is three. The doctor in emergency gave no direction on how we could achieve this. Simply stared at me until I asked if I was expected to hold him down and pry his mouth open. Useless!!!!”; “The lack of awareness amongst the staff on needing to wait for my daughter to process the info given was disappointing”. When respondents were asked if they felt an educational manual pertaining to ASD would be beneficial for healthcare professionals in the region, a resounding 92.59% said yes. For complete questionnaire results see Appendix E.

### ***Health Care Questionnaire***

A total of 17 participants from different nursing units at the Regina General Hospital were given a short questionnaire asking about their experiences working with children with ASD.

Four main themes emerged from the data: educational preparation for working with children with ASD, perception of competency in caring for children with ASD, and perception of need for further education. While most of the nurse participants were aware of the disorder and the different types of common deficits, there was conflicting data on comfort levels in caring for these children and knowledge adequacy. Although only 17.6% of survey respondents felt comfortable providing care to children with ASD, only 29.4% felt that their current knowledge was inadequate. Considering the low percentage of satisfied parents, this is significant and provides further support for the importance of developing an educational resource for nurses. This type of resource would need to be primarily directed at increasing nurse’s comfort and overall competency in of providing care to children with

ASD. Participants were also asked how well they were able to reduce extraneous stimuli while providing care. Although 41.2% indicated that they were able to minimize overstimulation parents consulted for this project perceived things rather differently. However, 64.7% of the nurse respondents noted that they experienced difficulty in communication with the child with ASD. This suggests that these nurses do require more information and guidance on effective strategies for improving communication with these children. Even though the results were mixed with regards to the need for further education, 88.3% supported the benefits of receiving additional education. For complete questionnaire results see Appendix F.

***Expert Consultation:***

Through conversations and correspondence with several managers of nursing units and Child and Youth Services Autism Center, it is clear that 100% of managers supported the benefits of additional information for nurses and health care providers. While there are a multitude of resources currently available through third party advocates, there is no current comprehensive manual that focuses on the care of children with ASD. Some of the resources that were highlighted include national conferences, and courses offered by the University of New Brunswick for health care professionals and parents. The main barrier to providing nurses with additional education in this area is the costs involved in first sending nurses to conferences and second accessing extra nursing resources to cover staffing requirements in their absence. It was also mentioned that many of the nursing units had been offered in-services from the Child and Youth Services Autism Center. It is interesting that all of them declined requesting a pamphlet instead that could guide the nurses. Each of the managers I talked with were very supportive of the idea of a manual,

and offered to help in any way needed. A list of questions used to guide the one-on-one interviews and email consultations is provided in Appendix A.

## **8. Conclusion**

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Results from the consultation with parents of children with ASD, nurses working in the acute care setting where children with ASD are most likely to present, and managers of the acute care units and Child and Youth Services Autism Center provide an important part of the database used to inform development of the resource manual. The overarching theme from the data analysis was that while some nurses feel that their knowledge level is adequate, parents feel that this is not the case. The proposed resource manual will be based on the themes that emerged from the different data sets and will include not only background information pertaining to ASD, but also strategies to reduce stimuli and communicate more effectively autistic children. It is also important to develop a resource kit that can be accessed by all nurses on the unit and that includes information about items that can be used to assist in distraction, and how to develop a comprehensive care plan that facilitates continuity of care. Both parents and nurses identified all of these content areas as areas of care needing improvement. Both groups noted that the development of a comprehensive resource manual such as this, will increase nurse confidence and competency in the provision of care, as well as increase positive outcomes for the children receiving care.

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**Appendix A**  
**Interview Guide for Expert Consultations**

### **Nurse Managers in Acute Care Settings:**

1. What is your role in the health care system?
2. Do you oversee the day- today functioning of the units under your jurisdiction?
3. Thinking about the area that you are responsible for, how often do you see pediatric patients?
4. Do you see children diagnosed with Autism Spectrum Disorder? If so, is this a common occurrence?
5. What kind of educational preparation do the nursing staff receive during orientation on Autism Spectrum Disorder?
6. To your knowledge, is there any resource currently available that you or your staff would be able to access within RQHR to guide the care of children with ASD?
7. Have you ever requested information from the Child and Youth Services Autism Center to help in the care of children with ASD on your unit?
8. What are some of the barriers to implementing educational opportunities for nurses in your area?
9. Would a resource manual explaining ASD, its characteristics, and useful strategies for improving communication and reducing overstimulation be beneficial to the nurses practicing on your unit?

### **Manager of Child and Youth Services Autism Center:**

1. What is your role within Child and Youth Services?
2. What kind of services do you provide here?
3. Do you provide nurses and other healthcare providers with information about ASD?
4. Have you ever been asked to provide information to nurses working with this population?
5. In your opinion, what have been the biggest barriers to educating nurses within the RQHR about ASD?
6. To your knowledge, is there any resource currently available within the RQHR acute care settings to guide the care of children with ASD?
7. Outside of the RQHR and Child and Youth Services, are there educational programs available to nurses in Canada to guide care of children with ASD? How accessible are these programs? What barriers exist that discourage nurses from accessing these resources?
8. Would a comprehensive resource manual be beneficial to nurses and other healthcare providers within the RQHR?

**Appendix B**  
**Nursing Staff Questionnaire**

## Questionnaire – Nursing Staff

	Strongly Agree	Agree	Undecided/ NA	Disagree	Strongly Disagree
1. I am aware of the condition known as Autism Spectrum Disorder (ASD)	1	2	3	4	5
2. I am aware of the types of deficits that commonly present with ASD	1	2	3	4	5
3. I received adequate training related to ASD as part of my educational program	1	2	3	4	5
4. I received training on ASD as part of my orientation to the nursing unit where I currently work	1	2	3	4	5
5. Training related to ASD would be beneficial to me in my current position	1	2	3	4	5
6. I have experience providing care to children with a diagnosis of ASD	1	2	3	4	5
7. I feel comfortable providing care to children with a diagnosis of ASD	1	2	3	4	5
8. While providing care I did not experience any difficulties communicating with children with a diagnosis of ASD	1	2	3	4	5
9. While providing care to a child with ASD I was able to minimize overstimulation	1	2	3	4	5
10. While providing care to a child with ASD I was able to perform noninvasive procedures without using chemical or physical	1	2	3	4	5



restraints					
11. While providing care to a child with ASD I was able to perform invasive procedures without the use of chemical or physical restraints	1	2	3	4	5
12. My current knowledge level is adequate for providing care to children with a diagnosis of ASD	1	2	3	4	5
13. I would like to have further information on ASD and strategies to improve the care that I provide	1	2	3	4	5
14. Do you have any suggestions for content that could/should be included in a resource manual for the care of children with ASD? If yes, please specify areas that you consider to be essential for such a manual.					
Further comments:					

Thank you for your time and valuable contribution to research in the care of children with ASD.

**Appendix C**  
**Parental/Caregiver Survey**

Parental Survey – Care of Children with ASD in Acute Care

1. I am the parent/guardian of a child with a diagnosis of Autism Spectrum Disorder (ASD)
  - ☐ Yes
  - ☐ No
  - ☐ Other (please specify)
  
2. In the past, I have had to access health care services for my child with ASD
  - ☐ Yes
  - ☐ No
  - ☐ Other (please specify)
  
3. If you answered YES to question #2, were those services urgent or emergency?
  - ☐ Urgent care
  - ☐ Emergency care
  - ☐ Other (please specify)
  
4. Do you feel that the medical staff that were involved in your child's care were adequately prepared to deal with the special needs of your child?
  - ☐ Yes
  - ☐ No
  - ☐ Other (please specify)
  
5. Were you asked for information on how to best deal with your child's special needs?
  - ☐ Yes
  - ☐ No
  - ☐ Other (please specify)
  
6. Was care provided in a manner that reduced extraneous stimuli?
  - ☐ Yes
  - ☐ No
  - ☐ Other (please specify)

7. How long did you wait in the waiting room?
- ☐ 0-30 mins
  - ☐ 30 mins – 1 hour
  - ☐ Greater than 1 hour
  - ☐ Other (please specify)
8. Was the waiting room...
- ☐ Quiet
  - ☐ Somewhat noisy
  - ☐ Extremely noisy
  - ☐ Other (please specify)
9. Overall how would you rate your experience? Please give comments.
- ☐ Great
  - ☐ Good
  - ☐ Neutral
  - ☐ Poor
  - ☐ Horrible
  - ☐ Other (please specify)
10. Do you think a resource manual for healthcare providers educating them on ASD and how to provide care in a manner that reduces stress would be beneficial? Why or why not? (Please comment below)
- ☐ Absolutely
  - ☐ Yes
  - ☐ Neutral
  - ☐ No
  - ☐ Absolutely not
  - ☐ Other (please specify)

**Appendix D**  
**Ethical Review Requirements**

### Health Research Ethics Authority Screening Tool

	Question	Yes	No
1.	Is the project funded by, or being submitted to, a research funding agency for a research grant or award that requires research ethics review	<input type="checkbox"/>	<input checked="" type="checkbox"/>
2.	Are there any local policies which require this project to undergo review by a Research Ethics Board?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
	<b>IF YES</b> to either of the above, the project should be submitted to a Research Ethics Board. <b>IF NO</b> to both questions, continue to complete the checklist.	<input type="checkbox"/>	<input type="checkbox"/>
3.	Is the primary purpose of the project to contribute to the growing body of knowledge regarding health and/or health systems that are generally accessible through academic literature?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
4.	Is the project designed to answer a specific research question or to test an explicit hypothesis?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
5.	Does the project involve a comparison of multiple sites, control sites, and/or control groups?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
6.	Is the project design and methodology adequate to support generalizations that go beyond the particular population the sample is being drawn from?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
7.	Does the project impose any additional burdens on participants beyond what would be expected through a typically expected course of care or role expectations?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>LINE A: SUBTOTAL Questions 3 through 7 = (Count the # of Yes responses)</b>		<b>1</b>	<b>4</b>
8.	Are many of the participants in the project also likely to be among those who might potentially benefit from the result of the project as it proceeds?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
9.	Is the project intended to define a best practice within your organization or practice?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
10.	Would the project still be done at your site, even if there were no opportunity to publish the results or if the results might not be applicable anywhere else?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
11.	Does the statement of purpose of the project refer explicitly to the features of a particular program, Organization, or region, rather than using more general terminology such as rural vs. urban populations?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
12.	Is the current project part of a continuous process of gathering or monitoring data within an organization?		<input checked="" type="checkbox"/>
<b>LINE B: SUBTOTAL Questions 8 through 12 = (Count the # of Yes responses)</b>		<b>4</b>	<b>1</b>
	<b>SUMMARY</b> <b>See Interpretation Below</b>		

**Interpretation:**

- If the sum of Line A is greater than Line B, the most probable purpose is **research**. The project should be submitted to an REB.
- If the sum of Line B is greater than Line A, the most probable purpose is **quality/evaluation**. Proceed with locally relevant process for ethics review (may not necessarily involve an REB).
- If the sums are equal, seek a second opinion to further explore whether the project should be classified as Research or as Quality and Evaluation.

**These guidelines are used at Memorial University of Newfoundland and were adapted from ALBERTA RESEARCH ETHICS COMMUNITY CONSENSUS INITIATIVE (ARECCI). Further information can be found at: <http://www.hrea.ca/Ethics-Review-Required.aspx>.**

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**Appendix E**  
**Parental/Guardian Findings**



### Parental/Guardian Survey Results

1. I am the parent/guardian of a child with a diagnosis of Autism Spectrum Disorder (ASD)

- ☐ Yes
- ☐ No
- ☐ Other (please specify)

<b>Answered 27</b>	<b>Skipped 0</b>
<b>Answer Choice</b>	<b>Response</b>
Yes	96.30% 26
No	3.70% 1
Other (please specify)	0.00%
Total	27

2. In the past, I have had to access health care services for my child with ASD

- ☐ Yes
- ☐ No
- ☐ Other (please specify)

<b>Answered 27</b>	<b>Skipped 0</b>
<b>Answer Choice</b>	<b>Response</b>
Yes	96.30% 26
No	3.70% 1
Other (please specify)	0.00%
Total	27

3. If you answered YES to question #2, were those services urgent or emergency
- Urgent care
  - Emergency care
  - Other (please specify)

<b>Answered 26</b>	<b>Skipped 1</b>
<b>Answer Choice</b>	<b>Response</b>
Yes	23.08% 6
No	50.00% 13
Other (please specify)	26.92% 7
Total	26
Comments: <ul style="list-style-type: none"> <li>• Aside from numerous surgeries (tubes in ears or dental), we wen to ER once for blood tests.</li> <li>• He has had Dental surgery and had blood drawn twice.</li> <li>• Office visit</li> <li>• Regular doctor checkups</li> <li>• Went to the Meadows after an accident to get checked over</li> <li>• Both</li> <li>• Both</li> </ul>	

4. Do you feel that the medical staff that were involved in your child's care were adequately prepared to deal with the special needs of your child?
- Yes
  - No
  - Other (please specify)

<b>Answered 27</b>	<b>Skipped 0</b>
<b>Answer Choice</b>	<b>Response</b>
Yes	25.93% 7
No	70.37% 19
Other (please specify)	3.70% 1
Total	27
Comments: <ul style="list-style-type: none"> <li>• I explained how to interact with my child and they were able to do so.</li> </ul>	

5. Were you asked for information on how to best deal with your child's special needs?

- ☐ Yes
- ☐ No
- ☐ Other (please specify)

<b>Answered 27</b>	<b>Skipped 0</b>
<b>Answer Choice</b>	<b>Response</b>
Yes	18.52% 5
No	77.78% 21
Other (please specify)	3.70% 1
Total	27
Comments: <ul style="list-style-type: none"> <li>In last few years, awareness has increased and nursing staff try to consult with us to find out best way to make things work</li> </ul>	

6. Was care provided in a manner that reduced extraneous stimuli?

- ☐ Yes
- ☐ No
- ☐ Other (please specify)

<b>Answered 27</b>	<b>Skipped 0</b>
<b>Answer Choice</b>	<b>Response</b>
Yes	25.93% 7
No	66.67% 18
Other (please specify)	7.41% 2
Total	27
Comments: <ul style="list-style-type: none"> <li>There is still much to improve in that respect but I find there is a genuine will to help make things easier for everyone</li> <li>We were fast tracked through</li> </ul>	

7. How long did you wait in the waiting room?

- 0-30 mins
- 30 mins – 1 hour
- Greater than 1 hour
- Other (please specify)

<b>Answered 27</b>	<b>Skipped 0</b>
<b>Answer Choice</b>	<b>Response</b>
0-30 mins	29.63% 8
30 mins -1 hour	25.93% 21
Greater than 1 hour	40.74% 11
Other (please specify)	3.70% 1
<b>Total</b>	<b>27</b>
Comments: <ul style="list-style-type: none"> <li>• We ended up leaving ER without getting results because it was taking too long and our son was too agitated</li> </ul>	

8. Was the waiting room...

- Quiet
- Somewhat noisy
- Extremely noisy
- Other (please specify)

<b>Answered 27</b>	<b>Skipped 0</b>
<b>Answer Choice</b>	<b>Response</b>
Quiet	25.93% 7
Somewhat noisy	48.15% 13
Extremely noisy	18.52% 5
Other (please specify)	7.41% 2
<b>Total</b>	<b>27</b>
Comments: <ul style="list-style-type: none"> <li>• Entirely too stressful</li> <li>• Z</li> </ul>	

9. Overall how would you rate your experience? Please give comments.

- Great
- Good
- Neutral
- Poor
- Horrible
- Other (please specify)

<b>Answered 27</b>	<b>Skipped 0</b>
<b>Answer Choice</b>	<b>Response</b>
Great	18.52% 5
Good	7.41% 2
Neutral	44.44% 12
Poor	33.33% 9
Horrible	7.41% 2
Total	27
Comments: <ul style="list-style-type: none"> <li>• Having to visit ER is our worst fear! In any circumstances, kids with ASD have difficulty with medical visits so adding an emergency factor makes it that much more of a nightmare</li> <li>• When been in emergency has never waited went straight through either to be treated immediately or sent directly to ward</li> <li>• My daughter has a hard time waiting in the emerg dept and it is hard to keep her calm at times. I work in the district as a paramedic so I know a lot of the nurses, because of this they usually are better with her but it's still no easy</li> <li>• I live in a small town so the service is different. But we have always been treated well.</li> <li>• We were very clear about the fact that we were bringing a child on the spectrum into the emergency. We bypassed triage, and we walked immediately into a curtained area, and a nurse who was clearly very experienced with children came in and talked to her son, almost magically calming him, and the staff was able to treat our son's injury</li> <li>• My son had to get his throat swabbed. He is three. The doctor in emergency gave no direction on how we could achieve this. Simply stared at me until I asked if I was expected to hold him down and pry his mouth open. Useless!!!!</li> <li>• Having to explain to each healthcare provider how to best interact with my child to make the experience less traumatic got to be frustrating.</li> <li>• The lack of awareness amongst the staff on needing to wait for my daughter</li> </ul>	

to process the info given was disappointing

10. Do you think a resource manual for healthcare providers educating them on ASD and how to provide care in a manner that reduces stress would be beneficial? Why or why not? (Please comment below)

- Absolutely
- Yes
- Neutral
- No
- Absolutely not
- Other (please specify)

<b>Answered 27</b>	<b>Skipped 0</b>
<b>Answer Choice</b>	<b>Response</b>
Absolutely	70.37% 19
Yes	22.22% 6
Neutral	14.81% 4
No	3.70 1
Absolutely not	0.00% 0
Total	27
Comments: <ul style="list-style-type: none"> <li>• Knowledge is power. When are kiddos are clam they are set up for success which I turn makes it easier for everyone trying to work with them in any situation</li> <li>• Reducing lights and noise would be a great start. He is non verbal so we would as parents have to be with him always</li> <li>• Each autistic person is unique – some talk some don't – different tools to communicate and or help with behaviour etc</li> <li>• I think that if people understand what is going on with your child and why they may be acting the way they are it would help with the care that they provide. People with obvious disabilities get treated differently. Because this is a disability that is not seen physically I think that we need more understanding</li> <li>• They don't understand that all kids are different and they all have different needs</li> <li>• It would be... I have 2 kids with ASD and they are totally different...but quiet and explaining..low lights. That would all be helpful</li> <li>• Not all nurses are magical, and know intuitively how to calm a very</li> </ul>	

frightened and over-stimulated child on the spectrum. We have dealt with hospital staff who were much less familiar with our son's needs, in such stressful circumstances. A manual explaining what is happening for a child on the spectrum who is encountering strange, transition heavy environments like the ER, and detailing strategies to manage the environment and head off meltdowns would be great

- I think it would be beneficial, however they would have to actually read it. As well, drop their assumptions that they know "all about autism because they treated one child with it". ALL ASD children are different and have different needs.

## **Appendix F**

### **Health Care Provider Survey Results**



### Health Care Provider Survey Results

I am aware of the condition known as Autism Spectrum Disorder (ASD)

Answer Choice	Responses (out of 17)
1 Strongly Agree	8 (47.1%)
2 Agree	9 (52.9%)
3 Undecided/NA	0
4 Disagree	0
5 Strongly Disagree	0

I am aware of the types of deficits that commonly present with ASD

Answer Choice	Responses (out of 17)
1 Strongly Agree	3 (17.6%)
2 Agree	13 (76.5%)
3 Undecided/NA	1 (5.9%)
4 Disagree	0
5 Strongly Disagree	0

I received adequate training related to ASD as part of my educational program

Answer Choice	Responses (out of 17)
1 Strongly Agree	0
2 Agree	3 (17.6%)
3 Undecided/NA	4 (23.5%)
4 Disagree	9 (52.9%)
5 Strongly Disagree	1 (5.9%)

I received training related to ASD as part of my orientation to the nursing unit that I work

Answer Choice	Responses (out of 17)
1 Strongly Agree	0
2 Agree	2 (11.8%)
3 Undecided/NA	1 (5.9%)
4 Disagree	10 (58.8%)
5 Strongly Disagree	4 (23.5%)

Training related to ASD would be beneficial to me in my current position

Answer Choice	Responses (out of 17)
1 Strongly Agree	7 (41.2%)
2 Agree	9 (52.9%)
3 Undecided/NA	0
4 Disagree	1 (5.9%)
5 Strongly Disagree	0

I have had to provide care to children with a diagnosis of ASD

Answer Choice	Responses (out of 17)
1 Strongly Agree	7 (41.2%)
2 Agree	9 (52.9%)
3 Undecided/NA	1 (5.9%)
4 Disagree	0
5 Strongly Disagree	0

I felt comfortable in providing care to children with a diagnosis of ASD

Answer Choice	Responses (out of 17)
1 Strongly Agree	0
2 Agree	3 (17.6%)
3 Undecided/NA	8 (47.1%)
4 Disagree	5 (29.4%)
5 Strongly Disagree	1 (5.9%)

I have provided care and I did not have any difficulty in communicating with those children with a diagnosis of ASD

Answer Choice	Responses (out of 17)
1 Strongly Agree	0
2 Agree	1 (5.9%)
3 Undecided/NA	5 (29.4%)
4 Disagree	10 (58.8%)
5 Strongly Disagree	1 (5.9%)

I have provided care to a child with ASD and I was able to minimize overstimulation

Answer Choice	Responses (out of 17)
1 Strongly Agree	0
2 Agree	7 (41.2%)
3 Undecided/NA	6 (35.3%)
4 Disagree	4 (23.5%)
5 Strongly Disagree	0

I have provided care to a child with ASD and I was able to perform noninvasive procedures without the use of chemical or physical restraint

Answer Choice	Responses (out of 17)
1 Strongly Agree	0
2 Agree	7 (41.2%)
3 Undecided/NA	5 (29.4%)
4 Disagree	5 (29.4%)
5 Strongly Disagree	0

I have provided care to a child with ASD and I was able to perform invasive procedures without the use of chemical or physical restraint

Answer Choice	Responses (out of 17)
1 Strongly Agree	0
2 Agree	2 (11.8%)
3 Undecided/NA	4 (23.5%)
4 Disagree	6 (35.3%)
5 Strongly Disagree	5 (29.4%)

My current knowledge level is adequate to provide care to children with a diagnosis of ASD

Answer Choice	Responses (out of 17)
1 Strongly Agree	0
2 Agree	6 (35.3%)
3 Undecided/NA	6 (35.3%)
4 Disagree	5 (29.4%)
5 Strongly Disagree	0

I would like to have further information regarding ASD and strategies to improve the care I provide

Answer Choice	Responses (out of 17)
1 Strongly Agree	14 (82.4%)
2 Agree	1 (5.9%)
3 Undecided/NA	1 (5.9%)
4 Disagree	0
5 Strongly Disagree	1 (5.9%)

Do you have any suggestions for content that could/should be included in a resource manual for the care of children with ASD? If yes please describe.

- working together as a team, making sure what everyone can do & make sure everyone is aware of ASD & how to deal
- how to prevent overstimulation
- how to appropriately explain procedures
- ways to decrease stimulation on a busy unit
- if possible have staff go to their environment/place of residence
- tools to decrease stimuli, lighting, noise
- ongoing information sessions for nursing staff related to best practice when nursing pts with ASD

Further Comments:

- Training is important to become more aware of the spectrum

**Appendix C**  
**Resource Manual**

Caring for the Autistic Child:  
A Guide for Healthcare Providers  
In Acute Care

© Sherrilee P. Rudolph, BN, RN

## Abstract

..... Autism Spectrum Disorder (ASD) is one of the most common neurodevelopmental disorders affecting Canadians, with one in 68 children diagnosed yearly (Autism Society Canada, 2015; Center for Disease Control, 2014). This increase in diagnoses equates to an increase in the presentation of children with ASD and their families to acute care services in urgent or emergency situations (Giarelli et al., 2014; Muskat et al., 2015). Because of the characteristic deficits in speech and communication, social interaction, repetitive rigid behaviours, and learning, many nurses feel underprepared and under educated to provide the specialized care required of children on the autism spectrum (Autism Society Canada, 2014; Will, Barnfather, & Lesley, 2013).

..... The purpose of this manual is to provide nurses and other healthcare providers with the necessary information to understand the disorder, apply effective practical strategies to help reduce the level of stimuli present in all clinical situations, engage in positive interactions, and become competent and confident caregivers of children with ASD. The content of this manual highlights different communication, distraction, and collaboration strategies to use with the child, family and interdisciplinary team. The ultimate goal is to increase positive health encounters for children with ASD.

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## **Chapter 1**

### **Introduction**

Healthcare providers working in today's fast-paced system must become knowledgeable about clinical disorders commonly encountered in acute care and proficient in treatment strategies. Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that you will see more and more often in your practice. Recent statistics show that one in 189 girls have a diagnosis of ASD, compared to one in 42 boys, making it 4 to 5 times more common in boys (CDC, 2014). Overall, ASD is present in one in 68 children, with the numbers continuing to rise every year (CDC, 2014). This increasing trend is significant because with each diagnosis, there is a greater likelihood that all health care providers will be required to provide care to this vulnerable population.

ASD is comprised of unique traits known to influence behaviour, language and socialization. There are also common co-morbidities associated with ASD that may require healthcare treatment. Recent findings suggest that children with ASD are 20 times more likely to access emergency services than their neurotypical peers (McDermott, Zhou, & Mann, 2008). This increased emergency room visitation may be due to the child's lack of safety awareness coupled with many co-morbid conditions such as seizure disorders, gastrointestinal disturbances, sleep disorders, hearing and vision impairments, and mental health issues like anxiety and depression (McDermott et al., 2008; Muskat et al., 2015). In a study of 112 children and adolescents with ASD, Simonoff et al. (2008) found that 70% had at least one psychiatric comorbid condition and 41% had two psychiatric disorders. These results lend merit to the need for further education regarding possible interventions to use in acute care settings.

Furthermore, studies have shown that many healthcare providers feel underequipped to care for children with neurodevelopmental disorders such as ASD when compared to children with other chronic and complex conditions (Bultas, 2012; Landa, Holman, O'Neill, & Stuart, 2011; McGonigle, Migyanka, et al., 2014; Muskat et al., 2015; Weill et al., 2013). Parents of children with ASD have made similar observations. Many parents are of the opinion that practitioners do not have sufficient knowledge and understanding of the condition to be capable of providing the level of care that reflects knowledge and understanding of the disorder (Lutz et al., 2012). For these reasons, it is imperative that nurses and other caregivers working in acute care receive quality education to augment existing communication and relation-building skills if they are to more effectively interact with this special population.

This manual will present background information on ASD with the target goal of helping health care providers better understand the special needs of these children and their families. Consideration will also be given to practical strategies that may help improve the quality of care received by this population in acute care settings. Specifically, intervention strategies will be highlighted that may help ensure that these children and their families are received and cared for in a manner that reduces sensory overload, and promotes health in a holistic manner. Nurses will be better equipped to tailor care to the specific needs of their clients by using evidence-based techniques capable of reducing sensory overstimulation, enhancing communication, building trust, and decreasing unwanted behaviour.

## **Chapter 2**

### **What is Autism Spectrum Disorder?**

### ***What is Autism Spectrum Disorder?***

Autism Spectrum Disorder (ASD) is an umbrella term that encompasses several developmental disorders, including Asperger's Syndrome, Autistic Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS) (Autism Speaks Canada, 2015). ASD is usually diagnosed in early childhood around the age of 18 months when developmental milestones are at their greatest, but can occur at any time from early childhood to adulthood. A formal diagnosis is obtained when a clinical psychologist, educated in the use of the DSM-5 (Diagnostic and Statistical Manual – 5<sup>th</sup> Ed), performs an assessment focusing on language use and acquisition, social interaction, restrictive and repetitive behaviours, and sensory disturbances (CDC, 2015).

There is a wide range of deficits associated with ASD, which is consistent with its spectrum description. Typical deficits may include the following:

- repetitive, restrictive behaviours such as flapping of hands (stimming) or head banging;
- inability to transition from one task to the next; little to no eye contact; preference for solitary individual play;
- unusual reactions to noise, taste, or smell;
- difficulty with language acquisition and use (ranges from completely non-verbal with only utterances of sound to very echolalic with repetition of words, phrases, and sentences, over and over again) (Autism Speaks Canada, 2015).

Box 2.1 presents a more comprehensive list of common deficits associated with ASD.

While many children with ASD show marked behavioral, communication, and social difficulties, others may have minor deficits in one or more areas. For example, some children may not display language deficits but may be socially awkward, and unaware of the social cues around them. Still other children may have reduced perception of safety hazards and consequently place themselves in dangerous situations. These children are often at increased risk for injury (Lunsky, Paquette-Smith, Weiss, & Lee, 2015). While these challenges exist in many children with ASD, the disorder does not necessarily correlate with decreased intellectual ability. Approximately 40% of children with ASD have normal to increased intellectual ability, and many excel in math, art, music, and visual skills (Autism Speaks Canada, 2015).

The scope and variability of deficits may pose challenges to parents and caregivers because of the child's reduced ability to express needs appropriately, leading to frustration and meltdown. This can make treating a child with ASD difficult because of individual uniqueness and challenges. Nevertheless, there is a growing body of literature that supports the idea that early intervention and treatments tailored to each child's specific needs, leads to positive outcomes (Autism Speaks Canada, 2015; Hutchins & Prelock, 2013; Landa et al., 2011; Reichow, Barton, Boyd, & Hume, 2012; Rogers, Dawson, & Vismara, 2012; Schreibman & Stahmer, 2014; Sussman, 2012; Swinth, Tomlin, & Luthman, 2015).

It is important for health care providers to remember that each child needs care, respect, and dignity despite the many challenges. Families often struggle with the challenge of caring for a child with special needs and as such require supportive care. The onus rests with health care providers to ensure that both the child and the family have



a team of knowledgeable, caring, and empathetic individuals who will advocate not only for the rights of the child but also the parent/caregiver.

### Box 2.1 Common Deficits Associated with ASD

- Stimming - Repetitive, restrictive behaviours (flapping of hands, head banging)
- Difficulty transitioning from one activity to the next
- Little to no eye contact
- Preference for solitary individual play
- Unusual reactions to noise, lighting, taste, smell, and touch
- Difficulty with language acquisition and use (completely non-verbal with utterance of sounds, screaming, yelling, or echolalia)
- Inability to use reciprocal communication
- Anxiety
- Self-injurious behavior
- Aggression, irritability and tantrums
- Meltdowns
- Impaired social interaction
- Inattention or hyperactivity
- Sensory overload/Sensory deficit
- Restricted interests
- Sleep deficits
- Immune dysfunction

(Autism Speaks, 2015; Cohen-Silver et al., 2014; Lunksy et al., 2014; McGonigal, Magyanka, et al., 2014 ; Muskat et al., 2014)

## **Learning Checkpoint**

### **Questions for Reflection:**

- 1. What is Autism Spectrum Disorder?**
- 2. What is the prevalence of Autism Spectrum Disorder?**
- 3. What are the diagnostic criteria for Autism Spectrum Disorder?**
- 4. What are the most common deficits associated with Autism Spectrum Disorder?**

**“’Normal’ is a dryer setting!”**

Emily Moon

**Chapter 3**  
**Comorbid Conditions**

## **Comorbid Conditions**

Many children with ASD also experience disturbances related to other areas of health and well-being. Common comorbid conditions include depression, anxiety, schizophrenia, bipolar disorder, seizure disorders, sleep disturbances, sensory processing disorders, pica, and gastrointestinal problems (Autism Speaks Canada, 2015; Lunsky et al., 2014). Because of associated comorbid conditions facing children with ASD, there is an increased chance of health challenges and the need to access acute care services. The evidence suggests that children with ASD are more likely to access health care services than their peers. Estimates are that nearly 13% of emergency department visits by these children are due to mental health issues and 10% face acute psychiatric difficulties requiring hospitalization before adulthood (Lunsky et al.).

Unfortunately, a large proportion of children with ASD who present to acute care, require treatment due to acute agitation, aggression, or other mental health crisis (McGonigle, Venkat, Beresford, Campbell, & Gabriels, 2014). Because of the similarity between some symptoms of acute mental health crisis and the underlying deficits of ASD, it is often very difficult to separate the two for appropriate treatment (McGonigle, Venkat et al., 2014). However, it is a much easier task when practitioners are well educated.

It is imperative that health care providers learn how to best promote positive experiences for these children and their families. The sections that follow provide examples of possible intervention strategies that could help improve care and reduce stress for everyone involved in the clinical encounter.

## Learning Checkpoint

### Questions for Reflection:

1. What are some common comorbidities associated with Autism Spectrum Disorder?
2. What is the prevalence of mental health disturbances in children with Autism Spectrum Disorder?
3. What is the first step in understanding Autism Spectrum Disorder?

Always  
Unique  
Totally  
Interesting  
Sometimes  
Mysterious

Author Unknown

**Chapter 4**  
**Reduction of Stimuli**

## **Reduction of Stimuli**

The first step to having a successful experience in hospitals or acute care settings is to reduce the possibility for negative experience occurrences. For autistic children who experience marked perceptual changes in their sense of light, sound, smell, and taste, it is extremely important for health care providers to be cognizant of the need to reduce the amount of external stimuli. To illustrate, some children with ASD describe excessive noise as painful or fearful, and experience relief when the excess noise is reduced (Kirby, Dickie, & Baranek, 2015).

Research has shown that noise levels exceeding recommended guidelines can negatively impact health outcomes of all patients (Muskat et al., 2015). Increased blood pressure, sleep disturbances, and decreased healing are a few documented negative consequences of increased noise levels (Potter & Perry, 2014). This is true regardless of the presence of developmental disorders such as ASD.

A key step in developing this resource manual involved recruiting a provincial sample of parents and caregivers of children with ASD from the social media group, Saskatchewan Parents of Children with an Autism Spectrum Disorder, who had accessed acute care resources within the RQHR. Parents and caregivers were invited to share their perceptions of the care provided during these interactions anonymously via survey monkey. When asked about strategies used by health care providers to help reduce sensory stimulus, 80% of parents and caregivers responded that no measures had been taken. Approximately 90% of parents and caregivers also said that, in their opinion, health care providers required additional education to help them more effectively meet the health care needs of this special population. According to Bultas (2012), healthcare



personnel feel unprepared to care for the complex needs of children with ASD as compared to children with other chronic and complex conditions. This lends merit to the need for health care providers to have access to an educational resource when the need arises.

Children with ASD often have difficulty with sensory overload. The senses of many children are so acute that they may become overwhelmed with what many neurotypical children are able to handle quite readily. This is especially true in the hospital or acute care setting where the environment is one of efficiency and time restraint. Healthcare personnel are buzzing around clinical units populated by raised voices and machines that beep and emit bright lights. All of these conditions can spell disaster for a child who is already on high alert when experiencing significant changes in surroundings different from the familiar home environment. Strange noises couple with odd smells can be overwhelming for even neurotypical children. So imagine the impact of this on a child with an enhanced sense of hearing and smell.

Surprisingly, the solution to this problem is relatively simple; remove the child from a high stimulus environment. You may question, “How is it possible to do this in a hospital emergency room?” Obviously, it is not possible to completely eliminate the normal sounds that accompany the busyness of this type of setting. Nevertheless, measures should be taken to reduce noise to acceptable levels.

Effective treatment of children with ASD requires that assessment begin when a child registers for care. Asking parents/guardians if their child has ASD can trigger a focused assessment and expedite the triage process. The waiting room is one of the

noisiest areas of an emergency department. Moving the child to a quieter area facilitates transition to an unfamiliar environment and sets the stage for more positive encounters.

Because bright lights can also be bothersome for children with ASD, placing the child in a room where it is possible to dim lights is optimal. Of course, it is sometimes necessary to have bright lighting for assessment. What is important is to warn the child before turning on lights. Providing the child with sunglasses is also something to consider.

Following triaging and the child is placed in a suitable waiting room it is very important to consider a private as opposed to a semi-private room or ward, if possible. The sensory stimulation from the close proximity of other patients with varying health conditions and environmental noises can be very bothersome, and lead to sensory overload.

Interventions for a child with ASD experiencing sensory overload are comparable to those required by any patient experiencing sensory overload. Reducing unwanted noise is as easy as removing unnecessary equipment from the room (Potter & Perry, 2014). Additional strategies include setting alarms on monitoring equipment to silent or low, when appropriate, or taking an extra few minutes to set up the parameters on equipment to reflect the pediatric population to minimize the alarms on many monitoring systems.

While not necessarily practical for all emergency departments, choosing a room that has minimal supplies, adjustable lighting, and neutral warm colors, could be an option. The use of proper acoustical construction materials can reduce the amount of noise that is heard when room doors are closed (Joseph & Ulrich, 2007). Removing all

unnecessary equipment can reduce anxieties, making the area more inviting and less institutional. Keeping in mind that not all visits to the emergency department are for life threatening illnesses or conditions, much of the urgent care required could be performed in this type of setting. To illustrate, many visits to the ER for children with ASD are due to mental health crisis such as anxiety (McGonigle, Venkat et al., 2014).

Continuity of care is important regardless of the situation. It is especially crucial for children with ASD who may experience difficulty building trust with new people. When a multitude of healthcare providers are providing care the therapeutic relationship may be in jeopardy due to the child's need for routine and similarity (McGonigle, Venkat et al., 2014). Being unable to predict who the next person will be to walk into the room can be both unsettling and anxiety producing for the autistic child, leading to sensory overload and possible emotional melt down.

Although not an exhaustive list of possible interventions for effectively reducing stimuli in acute care settings, these practical and easily implemented interventions can ease the sensory stimulation of children with ASD, resulting in less stress and anxiety (see Box 4.1). Working to create a conducive environment is a necessary pre-requisite for achieving positive health outcomes.

**Box 4.1 Stimuli Reduction Strategies**

- Focused triage assessment
- Triage quickly to quiet area away from waiting room
- Sensory reduced room
- Private room

- Adjustable lighting
- Acoustical ceiling tiles
- Removal of unnecessary equipment /supplies
- Silencing or lowering of equipment alarms
- Continuity of healthcare provider if possible

## **Learning Checkpoint**

### **Questions for Reflection:**

1. What is the first step to having a successful experience within the acute care setting?
2. What are some stimulation reduction strategies? Why would these be beneficial to a child with Autism Spectrum Disorder?
3. True or False: It is much too difficult to reduce stimuli in a busy acute care setting.

**"What lies behind us, and lies before us are small matters compared to what lies within us"**

Ralph Waldo Emerson

**Chapter 5**  
**Parent/Guardian as Expert**

### **Parent/Guardian as Expert**

Most parents and caregivers are eager to learn more about ASD and any interventions that will help make life easier for their child and themselves. Information derived from searching relevant literature and conducting informal consultations with parents/guardians suggest that most are acutely aware of areas their child struggles with and what works best to help make things better. More importantly, most parents have researched different treatment modalities and experimented with every available resource. As noted by several authors many parents are not only proactive but have become experts in their child's care (Appleton, & Minchom, 1991; de Geeter, Poppes, & Vlaskamp, 2002; Fowler et al., 2012; Lutz, Patterson, & Klein, 2012).

Asking a parent what can help to reduce an already stressful situation helps build therapeutic relationships and trust. This approach can also have a ripple effect and facilitate development of trustful relations with the child who is already familiar with the techniques used by parents and caregivers. Frustration may surface when parents feel dismissed rather than included in their child's care.

Although it is not always possible or safe to assign or delegate certain tasks and procedures in urgent or emergent situations, it is important to take the time to assess every situation to determine if the parent could deliver the treatment. For example, parents and caregivers could administer oral medications with proper instruction. Involving parents/caregivers could be the difference between the child taking the medication or not. Another example might involve teaching parents how to perform minor procedures such as administering medication via nebulizer mask. It is important to assess any task allocation on a situation-by-situation basis. The child may be more accepting of this type

of procedure if it is possible to deliver by someone s (he) trusts (Appleton & Minchom, 1991; de Geeter et al., 2002). Obviously, if preliminary assessment suggests the parent very stressed or the task is beyond parental learning capacity then this approach may not be feasible.



## **Learning Checkpoint**

### **Questions for Reflection:**

1. When assessing children with ASD, parents can be a valuable. What are some ways you can include parents in care?
2. Keeping in mind the need to assess every child and his/her family, what are some routine tasks in your practice area that parents could be taught to reduce their child's stress?
3. True or False: Family centered care can only be implemented in areas with a slow pace of care.

**"I Am An Autism Parent,**  
**They have taught me how to**  
**Truly and deeply see,**  
**They have opened my eyes, ears, and especially**  
**My Heart"**

Tim Tucker

Chapter 6  
Communication

## **Communication**

Many children with autism have communication difficulties. These may range from complete inability to communicate verbally to use of repetitive words or phrases to communicate to slight impediments in communication. Because of the wide range in abilities, it is sometimes difficult to identify the most effective communication methods for healthcare providers to use in urgent or emergent situations. All recommended communication strategies have some degree of merit and rest on the simplistic approach premise.

Subsequent sections will highlight a variety of communication modalities for use with children on the spectrum. Social stories, the picture exchange communication system, and visual schedules are given special consideration. All of these treatments have gained the attention of researchers around the world. As a result, there is a growing body of evidence supporting the utility of each one on different levels and in similar and different contexts (Cihak, Smith, Cornett, & Coleman, 2012; Ganz et al., 2013; Ganz, Parker, & Benson, 2009; Greenberg, Erikson Tomaino, & Charlop, 2014; Hutchins& Prelock, 2013; Schreivman, &Stahmer, 2014)

## **Social Stories**

Social stories are useful techniques for helping children with ASD to understand expectations, behaviours and outcomes. These stories address a specific activity and expected behaviour while participating (Croizer & Tincani, 2007). Because it is possible to personalize social stories, the child has a vested interest in its outcome. Of course, it is not realistic to develop a fully personalized story suitable for every child with ASD that presents to acute care. What is possible though is to develop a template of pre-scripted social stories with blanks left for the presenting child's personal information. This type of template can form part of the ASD toolkit present on specific units. Stories depicting the most common treatments and procedures are a great resource that can be accessed immediately and require no preparation by the healthcare worker.

However, making a good social story requires specific techniques to realize targeted behavioral change. The following section focuses on how to develop a social story for use across diverse situations.

**Making a social story.** The first step in preparing a good social story is to think about its purpose. If the goal is to teach the child not to move while having blood drawn, then it is important to determine what is required to help the child understand this. For example, the child needs to understand that any movement could cause more hurt. If the child could be encouraged to remain as still as possible, it will be possible to complete the procedure quickly and with minimal pain.

To personalize the social story more, it is important to determine the child's likes, dislikes, and any fears to incorporate into the story line. Personalization of the text gives

the child a frame of reference for desired behaviours and, as such, helps script the process.

A social story is composed of different types of sentences presented in a specific order to achieve the intended goal. There are seven types of sentences including:

- ✓ *descriptive sentences* that answer ‘wh’ questions (who, what, when, where, & why);
- ✓ *perspective sentences* that refer to feelings, opinions, and ideas;
- ✓ *directive sentences* that offer suggestions regarding the specific behaviour (s) to be modified;
- ✓ *affirmative sentences* that lets the child know that feeling a certain way is okay and not something to be ashamed of;
- ✓ *co-operative sentences* that show how others can help the child achieve set goals;
- ✓ *control sentences* that are written from the perspective of the autistic child (e.g., “I need to make sure I don’t move because...”); and,
- ✓ *partial sentences* that allow the reader to insert information into the story to allow personalization (Sadeghi, Mohammadi, Shamshiri, Baghrzadeh, & Hossinkhani, 2013).

All of these sentence types must be presented in a positive manner and describe what should be done to accomplish the goal rather than what should not be done (Sadeghi et al., 2013). As well, graphics and/or photographs can facilitate understanding since many of these children are visual learners. In addition, if the outcome is not definitive it is best to use language such as ‘sometimes’ and ‘usually’ (Sadeghi et al.). Box 6.1 illustrates the application of some of these principles during a blood test.

It is also possible to use social stories to help the child cope with an unfamiliar situation. While the preparation time is short, the benefits for children with ASD presenting to acute care can be monumental and may mean the difference between a positive or negative healthcare experience.

### Box 6.1 Social Story Example

\_\_\_\_\_ (Child's name) Has A Blood Test

My name is \_\_\_\_\_ (child's name). I am not feeling well today. My mommy/daddy/guardian brought me to the hospital. While at the hospital, I need to have a blood test done to check to see if I am healthy.

To do the blood test the nurse or doctor sometimes puts a cream on my arm. This cream feels cold. The nurse or doctor will then put a big rubber band around my arm. This will be tight and might feel like someone is squeezing my arm. This is ok. The nurse or doctor will then clean a small patch of skin and this will feel cold. The nurse or doctor will then put a needle into the skin. I will feel a pinch or prick that can hurt a little. I may not feel anything at all. I can hold mommy/daddy/guardian's hand if it makes me feel better. This is ok.

It is important that I keep very still when the nurse uses the needle. Moving can cause it to hurt. If I am able to stay still, it will be over in just a minute. I will see blood go up a tube and this is okay. This is how the nurse or doctor gets enough blood to test. When the nurse or doctor is finished, the needle comes out and a small bandage is put there. Sometimes I get a sticker or another small treat for keeping still and mommy/daddy/ guardian will be very proud of me.

## **Picture Exchange Communication System**






















The Picture Exchange Communication System (PECS) is a system of communication used for children and adults with ASD who are non-verbal or have great difficulty with spoken language. Developed in 1984 by Lori Frost, MS, CCC/SLP and Dr. Andrew Bondy, it provides a medium to help children communicate non-verbally by using descriptive pictures. This system is widely used in the autistic community. It has undergone significant modifications over time to include computerized application systems, making it very accessible to potential users. The premise behind the PECS system is that when a child needs or wants something, (s) he brings a small picture token to the caregiver. For many children with ASD who struggle with verbal communication, this can alleviate stress, and improve day-to-day functioning (Greenberg et al., 2014).

According to Tager-Flusberg, Paul, and Lord (2005), 20-50% of children diagnosed with autism spectrum disorder are non-verbal. This is significant information for nurses because if these children are unable to express their needs, caring for them is going to be very difficult. Evaluative studies conducting on the overall effectiveness of the PECS program show promising results. Children involved in these studies have demonstrated greater ability to communicate, with some showing beginning verbal abilities (Ganz et al., 2013; Ganz et al., 2009; Schreivman, & Stahmer, 2014)

It is possible to incorporate the PECS tools into *Autism Resource Kits* present in acute care settings. Several sources offer these tools for purchase. Your local Autism Resource Center can facilitate access to any of these resources.

Examples of the PECS visual cards are for your consideration in this manual.



 I WANT		 I SEE		 THANK YOU	
 JUICE	 COOKIE	 APPLE	 CAKE	 CHIPS	 BANANA
 BOOK	 COLORING	 TABLET	 PENS	 DOLL	 PUZZLE
 SNEAKERS	 SWEATER	 PANTS	 COAT	 SOCKS	 HAT

(Rudolph, 2015a)

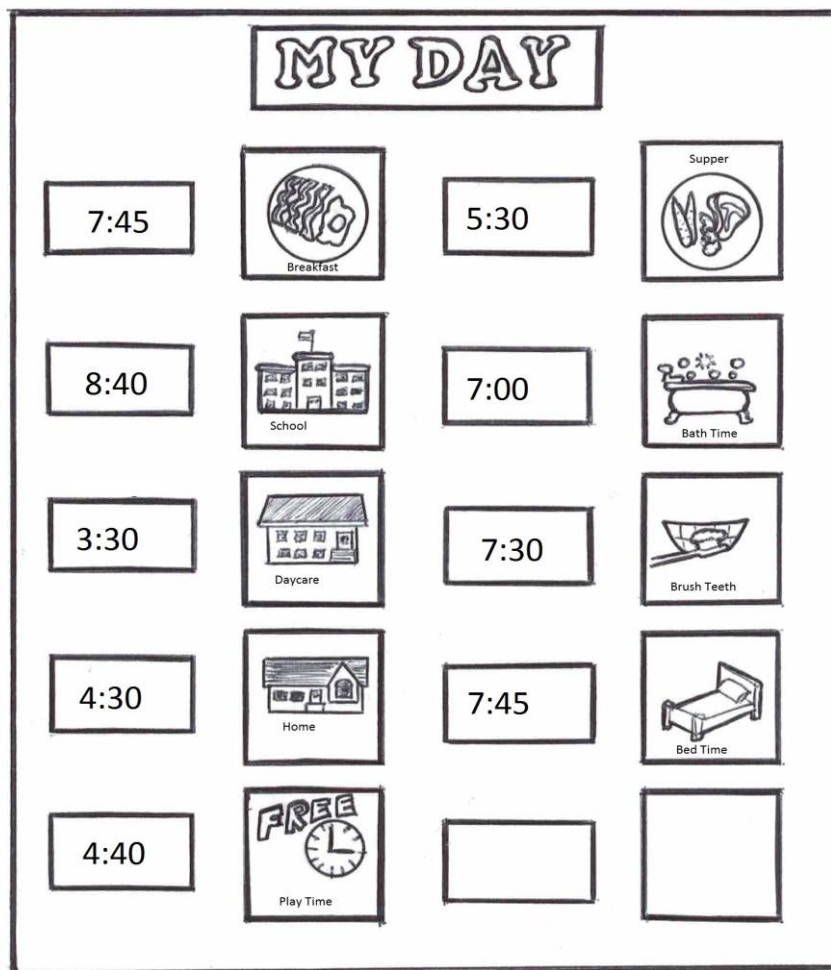


(Rudolph, 2015a)

It is possible to explain the most common medical procedures with pictures rather than words. All that is required is a little creativity and time. Visual representations give children sufficient time to internalize the information and prepare for the procedure.

## Visual Schedules

Visual schedules are similar to the PECS system with both resting on the premise that visual representation of an idea can facilitate communication. Many children with ASD are visual learners and so having a visual schedule of the day's events or sequence of events can facilitate understanding and reduce the chance of fear associated with the unknown. Being able to see what comes next can alleviate stress and increase the child's comfort level with the presenting task. An example is presented of a visual schedule.



(Rudolph, 2015b)

Development of visual schedules is easily accomplished by using a white board, Velcro, and laminated pictures. It is possible to customize visual schedules to reflect the normal routines of the pediatric unit or the sequence of events that the child will encounter while in the acute care setting. Additional examples of visual schedules are located at the following website:

<https://www.autismspeaks.org/family-services/resource-library/visual-tools>

This website presents a variety of tools that can be used to communicate with children with ASD, as well as decrease anxiety and meltdowns before they begin.

## **Learning Checkpoint**

### **Questions for Reflection:**

1. What is the function of a social story?
2. Using the guidelines presented, develop a simple social story that could be beneficial for your particular unit.
3. What is the function of the PECS system?
4. Thinking about the unit where you work, is it possible to identify some symbols to use with the PECS system?
5. What is the function of a visual schedule?
6. Reflecting upon where you work, develop a visual schedule based on the routine and structure of a typical workday.
7. What is the function of video-based modeling?
8. Thinking about the unit where you work, can you think of a possible situation to use as a video model for children with autism?

**"If you've met ONE child with Autism, you've met ONE child with Autism"**

Author Unknown

## **Chapter 7**

### **Distraction**

## **Distraction**

Distraction is another technique that can be used alone or in combination with other techniques. Distraction is not a new concept. Nevertheless, it is often underutilized with children with ASD. Through discussions with parents/caregivers, it is possible to modify care to include things that the child enjoys such as coloring or bubbles. This approach will provide much needed distraction from tests, procedures, or assessments.

Distraction is a common strategy used in the care of children, regardless of diagnosis, especially when performing potentially painful treatments. One useful strategy is to have the child focus on external stimuli such as a stuffed animal or bubbles. Alternatively, the child can be helped to perform certain tasks alone. For example, having the child inflate a balloon, or sing a song allows him/her to focus on the task rather than the intervention being performed (Mutlu & Balci, 2015). Success with this approach requires the collection of assessment data from parents/guardians to ensure that the reward or distraction is specific to the child's likes and dislikes.

## **Learning Checkpoint**

### **Questions for Reflection:**

1. What is the first step for the child with ASD to have a successful experience within the acute care setting?
2. What are some common distraction strategies? Why would these benefit a child with Autism Spectrum Disorder?
3. True or False: It is difficult to use distraction techniques in a busy acute care setting.

**"What lies behind us, and lies before us are small matters compared to what lies within us"**

Ralph Waldo Emerson



## **Chapter 8**

### **Care Plans**

## **Care Plans**

Individualized care plans are not a new concept in health care, and are something routinely used within most health regions. The premise behind creating a care plan in healthcare is to tailor care according to the needs of the client and foster continuity of care.

According to Gulliford, Naithani, and Morgan (2006), continuity of care is more than just having the same healthcare provider over the course of being treated for a specific health threat or illness episode. These authors propose that continuity of care also embodies quality assurance and cost effectiveness. Furthermore, continuity of care is concerned with reducing fragmentation. The Institute of Medicine (2001) described the importance of remaining patient centered while providing care: “[Patient- centered care is] providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions” (p6). When dealing with families and children with ASD, this is very important because of the wide variability in the spectrum of abilities. However, care plans are generally not shared with anyone outside of the immediate care team for confidentiality reasons.

In the case of families with a child with ASD, care plans could be given to parents or caregivers to present when accessing all healthcare services. Portable care plans will help remove guess work and enhance quality care (Lunsky et al., 2015). It will also promote parental involvement by equipping parents with the information needed to assist in the care of their child while empowering them in the process. At each clinical encounter, parents could present this care plan, making collaboration efforts among all members of the health care team effortless.

This approach may not be necessary in instances when a team of pediatric specialists is responsible for healthcare delivery at one facility. However, without a specialized pediatric hospital in Regina, personalized care plans could prove to be a valuable tool. With portable care plans, successful interventions could be recorded and updated regularly. By using a more tailored approach to care delivery, positive outcomes are more readily attainable.

### **Learning Checkpoint**

#### **Questions for Reflection:**

1. What is the purpose of a care plan for children and families with ASD?
2. What information would you like to see as part of the ASD care plan?

**"I am different...not less"**

Dr. Temple Grandin

**Chapter 9**  
**Autism Resource Kit**

## Autism Resource Kit

To ensure that all recommended tools are available to healthcare providers, it is a good idea to develop an 'Autism Resource Kit'. This kit should include social stories, visual schedules, and PECS cards on the most common medical treatments in your area. This kit can also include sensory stimulation toys and activities, such as spin tops, stress balls, chew pendants, weighted blankets or vests, and easy to make sensory bottles. Sensory items promote distraction and work to calm the child experiencing stress. Another great tool for a resource kit is ear defenders or other noise cancelling earmuffs for use in situations where it is difficult to control noise. Examples of common sensory items are presented here.



(Rudolph, 2015c)

The following websites provides additional examples of items for an Autism

Resource Kit:

- ✓ <http://www.nationalautismresources.com/sensory-integration.html>
- ✓ <http://www.autism-products.com/>

Each of website shows a variety of products that can be useful in any Autism Resource Kit. Products range from weighted blankets, safe and durable chew toys, as well as ear defenders for those children who cannot tolerate loud noises.

### **Learning Checkpoint**

#### **Questions for Reflection:**

1. Using the information presented in this manual, make a list of items that could be placed in your autism resource kit?
2. What benefit do these items play in the care of a child with ASD?

**"Autism isn't contagious,  
But ignorance is!"**

Author Unknown



## **Chapter 10**

## **Conclusion**

## **Conclusion**

Quality care starts with qualified and highly educated healthcare workers. It is a realistic expectation that everyone regardless of ability, intellect, social class, or race, receives quality care when accessing health care services. This is also true of children and their families who are dealing with ASD. Unfortunately, limited efforts have focused on identifying strategies to help make the provision of health care a positive experience for children with sensory issues and developmental delay. Each person is treated the same as the next regardless of their diagnosis, and while this is great for promoting equality, it can be detrimental to how a child with ASD perceives the health care environment.

The first step towards ensuring that children with ASD and their families receive care tailored to the special needs of the child is by educating health care providers on effective interventions. What is important to remember is that interventions designed to reduce stress and sensory overload will have a positive impact on these children and the entire family. It is the responsibility of all health care providers to identify ways to care for this special population. The tools and strategies outlined in this manual can help make health care a less scary place for children with ASD.

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