

Running head: AUTISM EMERGENCIES

Best Practices for Autism during Emergencies

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**Certification Statement**

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### **Abstract**

The chance of an emergency responder being called to help an individual with autism is becoming more likely with each passing day. Not only is the number of identified cases of autism on the rise worldwide, but studies show that those with autism are more likely to need emergency care than more neurotypical populations. An emergency incident involving autism has great opportunity for error on the part of the responder that could endanger the autistic individual, the responder, and the community as a whole. The problem was that Halifax Community College had no formal best practices documented for autism response to teach area responders. It is imperative that courses be taught with the use of researched practices so that the information given to students can be as sound and relevant as possible. The purpose of this research project was to examine and determine best practices in which to incorporate into future emergency response classes. This descriptive study used information from fire service personnel, healthcare personnel, and parents to examine best practices in emergency incidents involving individuals with autism. The results of each of the three components of the research were combined to answer two major questions. The first, what is being done currently in fire departments to prepare responders and the second question, what are the best practices when dealing with autistic individuals in times of emergencies? The study identified several best practices such as being patient, interacting with caregivers, training for responders, and more. From the study, a summary list of best practices was formed to help responders. Recommendations were made for future actions which included more formalized training with responders, more interaction between caregivers and responders, and more research.

## Table of Contents

Certification Statement.....	2
Abstract.....	3
Table of Contents.....	4
Introduction .....	6
Background and Significance .....	8
Literature Review .....	12
Introduction .....	12
Autism .....	16
General Emergency Response .....	19
Medical Treatment.....	21
Elopement.....	23
Drowning.....	26
Fire .....	28
Disaster Response .....	31
Prevention Efforts .....	32
Summary .....	34
Procedures .....	36
Assumptions.....	40
Limitations.....	40
Results.....	41
Fire Service Results .....	41
Health Care Survey Instrument.....	45

Parent Interviews..... 51

Discussion..... 55

Recommendations ..... 59

    Recommendations for Halifax Community College ..... 60

    Recommendations for the Fire Service..... 61

    Recommended Research ..... 61

    Conclusion..... 63

References ..... 64

Appendix A Fire Service Survey Instrument..... 72

Appendix B Healthcare Survey Instrument..... 76

Appendix C Interview Questions for Parents..... 81

Appendix D Fire Service Invitation Letter ..... 82

Appendix E Healthcare Providers Invitation Letter..... 83

Appendix F Fire Service Study Results ..... 84

Appendix G Healthcare Providers Study Results ..... 90

Appendix H Summary List: Best Practices Autism in Emergencies ..... 97

## **Best Practices for Autism during Emergencies**

### **Introduction**

In the world of emergency response it is easy to become confused between the world of fact and myth. For example, myth: All autistic individuals can be treated the same. Fact: Autistic individuals' needs and abilities vary greatly to each individual (Vaz, 2010). Myth: Talking sternly with an autistic individual will cause them to obey. Fact: Calming, nonthreatening tones generally work better when communicating with an autistic individual (Debbaudt, 2002). Myth: Autistic children are attracted to sirens and lights of emergency vehicles. Fact: Some autistic individuals are attracted by flashing lights while others are repelled by them and many are repelled by loud noises due to sensory issues (Rzucidlo, 2003).

Dealing with autistic individuals can be a challenge under normal circumstances but can seem to be almost impossible in an emergency situation for responders that are unfamiliar with the spectrum (Martin & Mims, 2009). With the number of those diagnosed with Autism in America climbing to 1.5 million it is becoming more likely with every passing day that each emergency responder will have interactions with autistic individuals (Martin & Mims, 2009; Russell, 2009). The preparation that the responder puts forth towards these anticipated incidents could spell success, or lack of preparation could spell disaster. It is the responsibility of the emergency service educators to ensure that responders are prepared for the tasks and challenges that they will face as they go forward to protect and serve their community (IFSTA, 2006). This includes being armed with the knowledge to help those with Autism.

The problem is that Halifax Community College has no formal best practices documented for teaching area responders how to best deal with autistic individuals in times of emergency. It

is imperative that courses be taught with the use of researched best practices so that the information given to students can be as sound and relevant as possible. If classes do not impart factual information the significance of the problem could be misrepresented, the derived policies could be flawed, and the services that are required for these individuals could be ineffective or even problematic causing harm to the individual, the department, and the community.

The purpose of this research project was to examine different practices in dealing with autistic individuals to determine a set of best practices to teach to area responders. Armed with best practices the college will be able to develop and present a research based program to benefit area responders and the communities that they protect. With these best practices described it is hoped that area departments and others will look at their policies for dealing with autistic individuals and adjust response, prevention, and training programs accordingly.

This descriptive study was divided into three separate components. Component one used an electronically administered survey asking fire department personnel from across the country quantitative and qualitative questions about their department's efforts in helping autistic individuals. The second component of this research used a different electronic survey presented to healthcare professionals that treated autistic individuals in order to gain their perspective on the issue. This health care electronic survey also used both quantitative and qualitative questions. It was also national in scope. The third component of this project consisted of personal interviews with parents/caregivers of autistic individuals in order to gain their perspective. The results of each of the three components of the research were combined to answer two major questions for the research. First, what is being done currently in fire departments to prepare responders for incidents involving autistic individuals? Second, what are the best practices when dealing with autistic individuals in times of emergency?

## **Background and Significance**

Joseph Swigart, a twelve year old autistic child warned his family of the smell of smoke and helped them to escape only to run back into the fire to die after it is believed he became confused by the noise outside the house (Evans, 2011). Mason Medlam, a 10 year old autistic child left his home through a partially open window only to die in a nearby pond (Porter, 2011). James Delorey, a seven year old autistic child, succumbed to hypothermia after following his dog into the woods (Pate, 2007). Hansel Cunningham, a 30 year old Autistic patient in a group home, died of mechanical asphyxiation when law enforcement officers tried to restrain the patient with a taser, pepper spray, sedatives, and hand cuffs (Reynolds, 2006). These are a few of the many stories that can be told of autistic individuals' lives coming to tragic ends. As sad as these stories are, they can and should serve as inspiration for emergency responders to not only understand the complex condition known as autism but also to know the best practices to be more efficient and successful in their endeavors of saving others.

Autism is a disorder of the brain that affects cognitive functions (Martin & Mims, 2009). The disorder has no outward physical appearance that one may identify the condition with (Debbaudt & Rothman, 2001). Autism is one of a group of commonly typed disorders that make up Autistic Spectrum Disorder, also known as ASD, which affects over 1.5 million Americans (Ratajczak, 2011). Autistic individuals can often have secondary medical issues to contend with that can further complicate the individuals' needs (Autism Society, 2012). This disorder and its effects place the autistic individual into a special needs category for responders as often the normal protocols do not fit the requirements of the individual anymore (Russell, 2009). Responders can be called on any given day to help autistic individuals for numerous reasons

from medical reasons, to wandering, to behavioral issues that may be overwhelming for care givers.

The Autism Society (2012) estimates that there are approximately 1.5 million individuals with Autism in America of all ages. A 2006 study estimated that Autism Spectrum Disorder has a 9.0 per 1000 prevalence rate in the American population. This is considered to be an increase of 57% from the previous study conducted in 2002 (Rice, 2009). It is estimated that approximately 2% of all healthcare patients have a learning disability and that 26% of those with learning disabilities are admitted into the hospital annually compared to only 14% of the general population (Vaz, 2010). It is reported that children with autism are more likely to elope than other children of similar age (Law & Anderson, 2011). Statistically an autistic individual is seven times more likely to need the service of responders than non-autistic individuals (McDermott, Zhou & Mann, 2008). Dawson (2011) also reported that autistic individuals have a mortality rate of 5.6 times higher than the average population.

A large population, increasing numbers, and a greater need for services results in an increased likelihood of responders being called to help an autistic individual. The recognition and proper response to an autistic patient by emergency responders could mean success or failure during an incident (Rzucidlo, 2003). Proper emergency response comes from preparation and training (IFSTA, 2006).

Often responders indicate they are familiar with autistic behaviors but this may not always be true. For example, Vaz (2010) reported findings that 83% of emergency room staff self reported as having a reasonable understanding of ASD. The study also reported though that 50% of the participants did not realize that sensory overload could occur in the emergency room causing undesirable behavior from the autistic individual. A parallel could be drawn between

hospital responders and pre-hospital responders through similar training suggesting possibly a similar lack of understanding by fire, emergency medical, and law enforcement crews.

It is hoped that this study will provide insight into emergency responses involving autistic individuals. The primary purpose of this paper is to establish best practices for dealing with emergencies involving autistic individuals. With this information gathered it is hoped that an accurate and up to date program can be developed by Halifax Community College for its local responder students. It is further hoped that other organizations will be able to enhance their own programs based off of the information found in this study.

Halifax Community College is a rural two year college in Northeastern North Carolina. The school services approximately 1,700 curriculum students and 3,000 continuing education students including emergency responders from over thirty different organizations (Temple & Carter, 2012). The college services a population of approximately 70,000 citizens from two economically rated tier I counties (Temple, 2008). The Occupational Extension Office of the continuing education department of the college is tasked with providing initial and continuing education for all area responders.

The Halifax area is not without its own history of dealing with autistic individuals. July, 15, 2011 a three year old girl, April Eubanks, who was participating in a family reunion with her parents went missing that morning (abc local, 2011). She was fortunately found alive and well later that day. The girl was found near the river bank almost four and half hours after her disappearance. This situation could have easily had a tragic ending rather than a cheerful reunion that. This event helped to show the local area need for better training efforts for responders in the area of autism and other special needs.

This paper will not only provide insight into the best practices of dealing with autistic individuals during emergencies, but it will also meet the requirements of the applied research program for the National Fire Academy's Executive Fire Officer Executive Analysis of the National Incident Management System and addresses the United States Fire Administrations five operational objectives as the paper explores the best practices in responses with autistic individuals (FEMA, 2011). By exploring best practices and understanding the needs better plans, policies, and training can be developed (IFSTA, 2006). With better plans and training in place efficient exercises can be developed to increase the cooperation and efficiency of multiple agencies and organizations working towards successful conclusions to incidents (FEMA, 2011). In dealing with incidents and autistic individuals there is often the need for numerous organizations to work together to best serve the needs of the community and the individual (FEMA, 2011). All of these results will help improve the community's ability to respond, recover, prepare for, and mitigate incidents, large and small, involving autistic individuals. In addition the information found in this study can be used to promote the dynamics and professionalism of the fire service as it provides information to help responders better serve the customers it protects (FEMA, 2012).

It is hoped that the information gleaned from this study will not only help Halifax Community College train responders on proper practices to use with emergencies, but that other organizations will use the material as well. The study used a national population for each phase to allow for a reliability of information that could be assimilated by other organizations across the country.

## Literature Review

### Introduction

Studies report that autistic individuals are seven times more likely to need emergency medical care than non-autistic individuals (McDermott, Zhou & Mann, 2008). Studies suggest that autistic individuals are more likely to be involved in self-inflicted injuries at a rate of 20-71% depending on age and IQ level of the individual (Bright Tots, 2012). These studies also conclude that autistic individuals with a lower IQ or diagnosed with mental retardation in addition have a higher rate of self-injury. A Swedish survey found similar results with respect to lower IQ but found the risk curve being more horseshoe shaped with the lower IQ and higher IQ both to be at a higher risk (Torben, Mouridsen & Rich, 1999).

Standardized mortality ratios for autism can range between 1.9 and 5.61 (Myers, 2012). A standardized mortality ratio value greater than 1.0 for a group indicates a higher than expected value. These numbers vary on the location of the study but more importantly on the coexisting medical factors that may accompany the autism. For example, a study from the Autism Tissue Program concluded that the mortality rate increases by 800% for a person with autism and epilepsy (Pickett, Xiu, Tuchman, Dawson & Lajonchere, 2011).

Accidental death for individuals with autism tends to be higher than non-autism groups as well. For example, many autistic individuals have an affinity to water. A study of drowning victims in California found that autistic children were at a higher risk of drowning than non-autistic and that drowning accounted for 5% of the all of the autism deaths in the state (Myers, 2012). The standardized mortality ratio for autism victims with mild or no intellectual disabilities was 3.9, but for those with intellectual disabilities the ratio rose to 13.71 (Myers, 2012).

Accidental deaths are often controllable through prevention and mitigation techniques (Martin & Mims, 2009). With the mortality rate more than five times the normal for autistic individuals more research is needed to understand causal effects and prevention options (Dawson, 2011). Accidental deaths can be a broad category encompassing many different causes that can affect responders. For example, elopement or wandering issues have long been identified as an autistic tendency especially in young children that results in accidental death (Law & Anderson, 2011). Wandering is a medical condition that can affect even the most prudent and safety conscious of caregivers (AWAARE, 2012). Those that wander are in high risk of injury from the environment, other people, and existing medical conditions (Law & Anderson, 2011). An autistic individual may not react as a normal lost child might (12). For example, they often will not answer responder's calls, do not seek help, and often will hide (12).

Fire is another example of accidental death that affects autistic individuals. While exact numbers affected are not known case history shows a serious issue (Russell, 2009). There are many recorded cases of autistic individuals being evacuated from a fire only to run back in amidst the confusion (Russell, 2009). There have also been documented events of autistic children not evacuating or hiding presumably due to the anxiety of the situation (Martin & Mims, 2009; Russell, 2009).

In some instances even the responders and caregivers are responsible for the accidental deaths for autistic individuals. There are multiple cases of caregivers contributing to the death of an ASD individual as they try to control them. For example, a 14 year old boy died of mechanical asphyxiation while being held down by healthcare workers so the boy could be chemically restrained to keep him from hurting himself (Schreiber, 2000). Responders have also had a hand in autistic deaths from not realizing the full situation and misreading the response

required (Rain, 2012). This is exemplified by multiple mechanical asphyxiation deaths documented while in responders care.

While responders typically think of children having autism it has to be remembered that these children become adults. Numbers show that soon a half- million young adults with some form of ASD will be leaving high school. Often the transitional pieces to help them into adulthood are not in place (Dawson, 2011). While some with ASD can be functioning adults in modern society many will always need supervision. There are only approximately 25 care facilities in America that highly specialize in the placement and care of ASD adults (Sullivan, 2007). Sullivan (2007) reported a national crisis in the lack of residential care for those autistic individuals above the age of 22 years old that are not able to live fully on their own. Esbensen, Bishop, Seltzer, Greenberg & Taylor, (2010) concluded similarly in their paper and added that in comparison to other adult disabilities those with ASD have fewer services available and more unmet needs.

Mims (2008) concluded that autistic individuals present to emergency services as a high risk customer that needs additional consideration and training for response situations. The responses for which emergency service may be called to help an autistic individual are vast and becoming more frequent. The consequences for a botched response are high to the individual, to the department, and to the community as a whole. Responders can and should learn from past events, scientific research, and from the experts/caregivers the best practices when dealing with autistic individuals.

Information from this literature was located from multiple sources including the National Fire Academy Resource Center, local libraries, the NC Live online library service, the internet,

and other sources. Key words used in the search included but were not limited to Autism, ASD, Learning disabilities, emergency actions, elopement, and others.

The review of the literature found a substantial amount of information on Autism with regards to the medical issues concerned with the condition. In the realm of dealing with autistic individuals during times of emergencies literature was found to be more limited including only two prior National Fire Academy applied research papers at the time. Both of these papers dealt with the awareness issue to autism more than then the focus of this paper in finding best practices. Furthermore, there was little research found on the actual risks, prevention, and response to autistic individuals in emergencies for responders to utilize.

The review of literature found several gaps in published information, research, and knowledge. For example, Autism Spectrum Disorder is increasing in America with no known reason for the increase (Herbert & Kouloglioti, 2010; Ratajczak, 2011; Brasic, 2012). Significant numbers of autistic individuals require emergency responses every year but little research is available in these areas as well. Wandering or elopement habits can be considered a fairly common issue in autistic children yet there is little to no research on why this occurs (Law & Anderson, 2011). It is estimated that approximately 1% of the child population in America is affected by ASD, but yet there is relatively little known about risk factors, cause, biology, treatments or interventions concerning the issue (HHS, 2011).

There was enough information and sources for a few themes to emerge during the literature review. One predominant theme was that of diversity among those that contend with the issues of autism. While there are generalities of the syndrome these generalities cannot accurately be applied across every individual (Herbert & Kouloglioti, 2010). This could result in a challenge to apply best practices. Another theme to emerge was that responders were more

likely to have encounters with autistic individuals as the numbers of autistic individuals have increased by more than 54% in the past decade (Martin & Mims, 2009). With a higher frequency of an event and the high severity that the event can have for the customer and the responder traditional training models would indicate this as a high need for training (IFSTA, 2006). The third theme that was gleaned from the literature review was the need for responders and their agencies to become more progressive in preparing for emergencies with autistic individuals.

### **Autism**

Merriam-Webster dictionary (2011) describes autism as an impairment marked by social interaction and communications issues with possible stereotypical behavior. Leo Kanner in 1943 first identified a pattern that he had been noticing in children that were previously diagnosed as mentally retarded (Ratajczak, 2011). Kanner noticed that the children being observed were not just slow learners and their patterns did not reflect those of emotionally disturbed individuals so he began a new classification originally referred to as early infantile autism (Kanner, 1943). Independently, Hans Asperger came to a similar conclusion with children with the notable difference that they were verbal. This group later became known as Asperger's Syndrome (19). By first estimates the occurrence of autism was to occur in only 1 in 10,000 children (Ratajczak, 2011).

In the early 1990's the rate of autism births was documented at approximately 1 for every 2500 births in America (Sullivan, 2007). With recent reports the rate of autism appears to be growing. Some estimate at a rate of 10 – 17 percent a year being found (Martin & Mims, 2009). The Center for Disease Control (2012) estimated one out of every 150 births in America was prone to Autistic characteristics in a 2007 report. A renewed in 2009 estimated approximately 1 out of every 110 births was prone to ASD. The most recent study released in 2012 concluded that

the autism birth rate has moved up to 1 in every 88 births (CDC, 2012). There is no perfect explanation concerning this recent jump in ASD. One explanation may be in the use of the word autism. For example, Kanner originally only used the term for non-mentally retarded students (Kanner, 1943). Later observations showed that some mentally retarded diagnosed children also exhibited autistic signs (Ratajczak, 2011). Another explanation may be the stigma that went with autism for both the individual and the parents. In the mid-twentieth century autism was thought by Freudian thinkers to be the result of parenting (Rain, 2012). This thinking tended to shy physicians and parents from utilizing the term.

As the rise is not totally understood the cause or causes of autism also are not fully understood. There are several beliefs as to the cause though (Brasic, 2012; Hebert & Koulouglioti, 2010). At one time some groups suggested that vaccines may contribute to autism in children but there has been no scientific evidence to support such a claim (O'Neill, 2011). The federal vaccine injury compensation program has granted compensation to 83 autistic individuals for vaccine-induced brain injury (Holland, Conte, Krakow & Colin, 2011). Holland, Conte, Krakow & Colin (2011) remind readers of their report that the compensation in these cases does not show or represent a scientific causation from vaccines to autism but merely the need for more scientific research into the issue and into how compensation determinations are applied to cases. Recent research has challenged and tested claims that vaccines were a cause for autism and have shown no link to causation and have recommended for parents to continue vaccination programs (Brasic, 2012; Ratajczak, 2011).

In the mid-twentieth century some researchers suggested that autism was a psychological condition caused by distant parenting techniques, often referred to as the refrigerator mother syndrome (Rain, 2012). These early ideas have also been debunked through scientific research

(Brasic, 2012). The current mainstream thought is that autism is caused by a gene(s) that is being triggered more frequently by environmental influence(s). The environmental influence(s) has not been identified though (Hebert & Koulouglioti, 2010). Other causation beliefs are being followed with research. For example, there is hypothesis that maternal rubella may have a higher risk for autism (Brasic, 2012). Another thought is that there is a sugar issue in the form of Glutamatergic signaling blockage (Mehta, Gandal & Siegel, 2011).

The term Autistic Spectrum Disorder commonly refers to one of three conditions, classic autism, aspergers syndrome, and pervasive development disorder also called PDD (Ratajczac, 2011). In some writings childhood disintegrative disorder and Rhett syndrome will also be included in the ASD spectrum (Autism Speaks, 2012). Autism is diagnosed based on behavioral characteristics of the individual (Ratajczac, 2011). The most common of these characteristics are communication abilities, social skills, and repetitive patterns of behavior (HHS, 2011).

Classic autism is often generalized by a set of behaviors. Underdeveloped communication ability is often viewed as a key indicator of autism (Brasic, 2012). Communications within the autistic individual may be found in various conditions. Communication skills may be slow in development or the individual may remain nonverbal (Sullivan, 2008). Some will be able to comprehend better than they are able to respond back. Some will have a limited communication ability, which may include taking communications very literally. Others may find it easier to communicate in other ways such as with picture graphs or sign language (Debbaudt, 2002).

A lack of social interaction is often viewed as an indicator of autism (Brasic, 2012). That is to say the individual seems self occupied rather than interested in the events around them. This is often described as a need based system. Meaning individuals have little reaction with those around them until they need something that they cannot provide for themselves.

Behavioral patterns or repetition can be viewed as an indicator of Autism (Rzcucidlo, 2007). Hand flapping, for example, is often thought to be a classic sign. This is a habit where the individual flaps their hands, normally around their face area. Repetitious motions such as this can often be observed during anxious situations for the individual as a coping mechanism (Brasic, 2012). The repetition of behavior may contribute to the need for a consistent routine. Many autistic individuals are reliant on a set routine and find change to that routine stressful (Debbaudt, 2002).

Detection of ASD is a critical step as the earlier the individual can be properly diagnosed the earlier interventions can be applied that positively influence the future of the individual (HHS, 2011). There are tools available that can reliably diagnose ASD by the age of 3 (White, 2012). In some studies high risk children have been able to be correctly diagnosed by 12 months of age (Landa, Holman & Garrett-Mayer, 2007).

Currently there are no medical options to overcome the core issues associated with autism (Mehta, Gandal & Siegel, 2011). Some experiments have been conducted with mice. The mice are treated prenatally with a Valproic Acid to give them repetitive tendencies such as marble burying and grooming tendencies. Through these experiments it is thought that there is an issue in the Glutamatergic signaling receptors may be the problem. In preliminary trials receptor antagonists have reduced the repetitive behaviors in the mice but not the locomotor activities (Mehta, Gandal & Siegel, 2011).

### **General Emergency Response**

An emergency experience can often be a terrifying ordeal to an autistic individual due to the change in environment and their inability to process what is happening (Vaz, 2010). This may cause the patient to be problematic possibly causing harm to himself/herself or even the

responder if the situation is not appropriately dealt with. It is imperative that first responders be able to identify indicators that a victim may be autistic in order to provide the best possible care and attention for the individual and the family (Rzucidlo, 2003). Responders should be alert for indications of the patient having special needs such as medical tags, unusual behavior, etc.

Individuals with ASD are at higher risk of needing responder aide due to issues such as concurrent medical problems, atypical responses, and behavioral interpretation (Mimms, 2008). Responders must consider all possibilities when dealing with an autistic individual as they may have done something unexpected without their parent or caregiver being aware (Rzucidlo, 2003). Their behavior may seem strange or bizarre to the responder but to the individual seem perfectly normal. For example, episodes of pica have been observed with some autistic individuals (Rzucidlo, 2003). The individual may have been compelled to consume something that seems impossible by the responder.

Communications will often be one of the biggest challenges for the responder with the autistic individual (Mims, 2008). Responders must remember to be patient and talk slowly, clearly, and literally (Autism Society, 2012). Often responders joke with victims to ease their anxiety but the autistic individual may not understand the humor that the responder uses (Debbaudt, 2001). Speaking slowly and clearly will give the individual a chance to evaluate and interpret the responder's message. Yelling or being authoritative in tone often does not result in compliance but causes more anxiety (Rzucidlo, 2003). Being visual can be helpful. Often autistic individuals will be more likely to comprehend visual or modeling clues than verbal explanations (Vaz, 2010).

## Medical Treatment

Research shows that autistic individuals are more likely to need emergency medical care than non autistic. For example, one study conducted of Autism and Pervasive Development Disorder, also known as PDD, found that these children were 7.6 times more likely to be medically treated for poisoning and self inflicted injury than other children their age (McDermott, Zhou & Mann, 2007). The mortality rate for autistic individuals has been found to be as much as 5.6 times higher than that of the average mortality rate (Dawson, 2011). A high percentage of autistic individuals have been found to have coexisting medical problems that even further increase their need for emergency medical interventions (Vaz, 2010). With a higher demand on the emergency medical system responders need to be prepared to deal with these individuals (Mims, 2008).

While demand on the system is a concern the responder also needs to be aware that the autistic patient may not be a cooperative patient (Vaz, 2010). Autistic individuals often will not understand the emergency situation that they are in as it is out of their normal routine (Mims, 2008). By being out of the standard routine the stress for the individual can be severe (Good, 2011). The responder needs to be alert to things that may agitate the patient. Many autistic individuals have tactile sensory issues that can be exacerbated with the use of bandages or other sticky type of products (Rzucidlo, 2003). Anti-agitation is an important concept in treating an autistic individual and there are several techniques that can be used to minimize agitation (Cannata & Rzucidlo, 2003). For example, performing physical exams from the distal or feet to the proximal or head/chest area can put the patient more at ease (Rzucidlo, 2003). Individuals with autism may not like to be touched and doing so may evoke aggression (Debbaudt, 2001). Demonstrating procedures on self or the caregiver can help to put the autistic individual at ease

as well (Vaz, 2010). Patience is a key to medical treatment for these individuals. Responders can often help to defuse an anxious environment by ignoring the individual's anxious behavioral traits and using positive reinforcement for cooperative behavior (Vaz, 2010). Responders need to remember to look for medical alert jewelry or cards to help communicate information that could be crucial in the care (AWAARE, 2012). For example, if the patient is non-verbal with allergies this could be a significant issue that the responder could mistakenly aggravate endangering the patient.

Autistic patients do not have the normal threshold for pain or discomfort as that of other people (Rzucidlo, 2003). This could present as improper behavior or a minor situation when in fact there is a more serious medical issue occurring. This can also be an issue if the individual becomes anxious and begins to act out. If a responder tries to hold or restrain the individual the pressure needed to do so could be so great that manual asphyxia or other injuries could occur (Debbaudt, 2002).

The thoracic muscles can frequently be underdeveloped in autistic individuals (Rzucidlo, 2003). This can lead to difficulty breathing or inefficient breathing under physical external pressure. This can and has resulted in injury and death of the autistic individual that responders and caregivers were trying to help. Restraint in any form can be dangerous to an autistic individual and actually increase the anxiety to a harmful level.

The inability to communicate combined with a higher level of pain threshold may allow what may be normal conditions to progress without the caregivers' knowledge to the point that it becomes an emergency later. Even things as simple as a toothache could cause an autistic individual to act out or become hostile due to the pain and anxiety. This may be a legitimate concern as some worry that with repetitious behaviors such as teeth grinding or pica that damage

to the teeth could occur. A Turkish study reported that while the occurrence of traumatic dental injuries was higher in the Autistic test group than the neurotypical group, it was not a significant difference (Altun, Guven, Yorbik & Acikel, 2010). It should be pointed out that this study was limited in scope with only 183 total participants all residing in Turkey.

## **Elopement**

Early reports from a 2007 online poll taken by the National Autism Association reported that 92% of the participants reported wandering issues (AWAARE, 2012). A more comprehensive study involving 800 participants nationally has preliminarily reported that nearly half of all children with ASD between the ages of 4 and 10 engage in elopement behavior (Law & Anderson, 2011). Despite the large number of autistic children that wander from their caregivers annually and the dire consequences that this behavior can bring there is virtually no research on the issue (Law & Anderson, 2011). One survey indicates that wandering is not only a health concern for the child but also for the caregiver. The study concluded the stress to mothers of wandering autistic children was comparable to soldiers in a combat zone (McIlwain, 2012).

Law and Anderson (2011) defined elopement simply as an individual exiting a safe area which in turn puts them in harm's way. In their study they suggest children with ASD are four times more likely to wander than other children. Couple this with the study result that 35% of those reported to wander were reported to never or rarely able to communicate their name or other vital information and the results could be disastrous. An interesting result of the survey is that the top reasons identified for elopement with ASD children are they enjoy exploring at 54% and the child heads for a favorite place indicated by 36% of the respondents. It is important to know 33% reported that their child does often elope to avoid anxiety and 27% reported they wander to escape sensory discomfort (Law & Anderson, 2011). The study reported that 51% of

the parents claimed the child was happy when he/she eloped and 51% reported the child was focused when eloping. Autistic children hold a serious focus on escaping when they elope. A wandering autistic child is not typically a case of neglect or poor parenting (Rzucidlo, 2003). Anecdotal evidence may suggest wandering is a warm weather event, but the study found that the majority of parents, 67%, reported that there was no seasonal pattern associated with elopement.

Those parents that reported wandering incidents by their child reported that the situation concerned them enough to call emergency services 32% of the time. Out of those two thirds reported a close call to an injurious event occurring (law & Anderson, 2011). Although some have pointed out that wandering can occur in large groups when one is feeling the child is safe from wandering. Overconfidence in safety measures can be misleading and even if the individual has never wandered before it is still a possibility (AWAARE, 2012). With strong determination autistic children have been reported to get out of or get into areas that were not thought possible by the caregiver. Children have been reported to wander from large family or social gatherings where several sets of eyes were looking out for the child. This may suggest that caregivers of wandering children need to be given positive wandering prevention help from the stakeholders for the community's welfare (Rzucidlo, 2003).

Prevention methods may include locks on doors including interior doors. Some caregivers have reported the only locks that will stop their charge from wandering are the ones that can be locked from both sides with a key (AWAARE, 2012). It needs to be pointed out that this often becomes a fire safety concern and caregivers and fire personnel need to work together to find the safest and best plans possible. Nanny cams or baby monitors have been found useful by some caregivers to keep them informed on the whereabouts and actions of their charge

(AWAARE, 2012). Some caregivers have reported success at placing red stop signs on windows to prevent their autistic charge from exiting the window (AWAARE, 2012).

Door alarms or alarm systems can be useful to monitor people leaving the home or the area (Landau, 2011). New tracking systems allow caregivers to set a safe zone with the system that will send an alert to the caregiver's smart phone if the boundaries of the zone are crossed by the tracking system (Schechtman, 2011). The zones can be changed making these devices especially helpful while traveling where the normal household security is not in place.

Tracking systems come in a wide variety of abilities. Some systems as mentioned previously work in cooperation of the caregiver's cell phone. These systems typically use a global positioning system (Schechtman, 2011). Others such as the Project Lifesaver program consist normally of a radio frequency tracking band that can be used by trained personnel to more efficiently find the individual than more traditional methods (Project Lifesaver, 2012). Other systems may use cell phone towers or a combination of technologies. Tracking systems can have an initial cost of a few dollars to a couple hundred dollars. Some systems will have monthly service costs and may have upkeep costs as well such as battery expenses. Each system has strengths and weaknesses, and it is strongly recommended that caregivers research each system carefully before making a choice (AWAARE, 2012).

Medical alert bracelets can be very helpful in alerting others on the condition of the wandering autistic person especially if they are non-verbal (Debbaudt, 2002). Neighbors and responders should be made aware of the individual's needs so that if they spot something they will follow up rather than ignore the situation (AWAARE, 2012). Another identification marker is the use of long lasting temporary tattoos. These tattoos can last for a week, cost around ten dollars for a kit and can give vital information to would be rescuers (Schechtman, 2011). These

solutions may be a problem for some caregivers as they try to treat their charge as close to normal as possible. They may not want to draw undue attention to their family. Information filed with local responders can be used to help them in the event of an emergency to respond quicker and better prepared. Forms and suggestions for talking with neighbors and responders can be found online (AWAARE, 2012).

Service dogs have been found to be helpful with the safety of some autistic individuals (AWAARE, 2012). Blessings Unleashed website (2012) reports that service dogs can increase the independence of an autistic patient as well as help to calm them in stressful situations. While contributions help to defray costs a typical price for a service dog is above ten thousand dollars. Caregivers also must consider the service dog's needs in both normal activities and those of emergencies. For example, if placed in a disaster shelter what special needs will the dog have such as food and space.

### **Drowning**

There were many cases found involving autistic individuals and drowning during the literature review. Children with autism often exhibit an attraction for water even when they cannot swim (Rzucidlo, 2003). The fearlessness that many with autism display expound this problem as it removes a natural barrier from the water that other children may have (Anderson-Lee, 2012). There is also some evidence that suggests that autistic individuals do not exhibit the same physical characteristics as a non-autistic person does in water. While a non autistic individual goes into the water the natural instinct is to close the mouth to keep the water from entering the system some believe that this may not be the instinct of an autistic child (45 ). This may mean that in bad water conditions the autistic individual even knowing how to swim may

still be in danger. Drowning is a major cause of deaths in individuals with autism (Shavelle, Strauss & Pickett, 2001).

It is an important safety consideration that autistic children not only are taught to swim but to be able to swim with their clothes on (AWAARE, 2012). This may be a key in saving their life if they are overcome by the draw of water and fall into water that they cannot walk out of. Teaching a child with communication difficulties to swim can be a challenge in itself (Rain, 2012). Some local pools may have swim instructors with special training or experience in teaching autistic children to swim but these are few. Parents are encouraged to teach their children to swim though some parents may be reluctant as the idea of placing the child in the water may signal to the child it is an acceptable thing to do and they may attempt it more freely when they are alone.

Swimming can be a great outlet for an autistic child for enjoyment, sensory issues and developing gross motor skills and muscle strength (Rain, 2012). Autism is a spectrum and it should be remembered that while some may be attracted to the water others may actually be repelled by it and will have sensory issues with water contact. These children may take time and positive coaching just to get used to the feel of water on their feet.

There are programs to help teach children with autism how to swim such as the one offered by the National Center on Physical Activity and Disability (NCPAD, 2012). A starting point to begin swim lessons for an autistic child is to evaluate where they are in development, sensory, and communication in order to set goals and the best methods to use in teaching the individual to swim (Rain, 2012). Different techniques can be used to teach those with challenges such as the use of a mat next to the pool to show swim strokes out of the water or the use of floatation devices to help the student build familiarity and comfort in the water (NCPAD, 2012).

Teaching a child with autism to swim can be a life saver, especially if the child is attracted to the water but should not be the only line of defense utilized for the child's safety (Rzucidlo, 2003). Other methods can be employed such as letting any neighbors that have pools or ponds know of the child's issues so they can help keep their area safe and be vigilant on the need for things such as closed gates (Debbaudt, 2002). If the child lives in a house with a pool a secure fence and/or safety cover can be used to keep the child out of the water (AWAARE, 2012). For areas that cannot be easily secured floatation alarms can be utilized that sound an audible alarm if the water surface is broken. These alarms can be set up to alarm at the pool and in remote locations such as in the house as well.

## **Fire**

Fire can be a deadly event for anyone. In 2010 reports show that fire departments responded to over 380,000 house fires in America that resulted in more than 2600 civilian deaths and over 13,000 injuries (Karter, 2011). It is unknown how many fire deaths include individuals with autism as the number is not tracked. An internet search can easily find several cases such as the 12 year old boy that died in his house fire after he hid under the bed (Pryor, 2011). The National Fire Protection Association (NFPA) (2012) recognizes that individuals with autism may be less able to help themselves than more neurotypical individuals. Complications may arise from their communication abilities or their comprehension on what is happening outside of their normal routine which can cause fear and anxiety.

Anxiety is a leading factor for issues with an autistic individual in the event of a fire (Russell, 2009). Anxiety can be inspired by a number of things in a fire, even things as common as a smoke detector activation meant to save lives. One survey reported that the auditory sound of an activated smoke detector actually placed one third of the autistic occupants into sensory

overload (Good, 2011). In the same survey another third of the parents of autistic children reported that they did not believe their child would respond to the smoke detector sound and half of the respondents indicated concern that their child would run and hide in the event of a fire.

The actions that autistic individuals take during a fire are important to their survival. Most children in America are taught proper fire evacuation techniques in school and by their local fire department. Autistic children can receive similar training but it may take longer to take hold and it may need to be done differently. Good (2011) describes his observations of a special needs class practicing evacuation drills more intensely than normal. He reported that while the students were able to evacuate orderly with assistance there was doubt whether all of the children would have responded properly without assistance. If this is a problem in a school program with structure and professional teachers the problem at home may be even more significant.

Russell (2009) points out study results that showed parents of autistic children self reported that only 53% of the participants stated they had a fire escape plan and only 67% of those had never practiced the plan. This can be an issue with neurotypical occupants but even more dangerous to an individual with autism that may go into sensory overload during an evacuation event. Without recognizing a plan and what to do in the chaos of a fire, autistic individuals may choose to hide or run without a set destination causing harm to themselves (Good, 2012).

The very precautions that parents/caregivers use to help maintain safety can be a hindrance in fire situations. For example, often double keyed deadbolts can be used on exterior and interior doors to prevent wandering and access to areas of danger (Rzucidlo, 2003). A survey conducted with the parents of children with autism reported that nearly 75% of the respondents indicated they used alternative locking device to prevent wandering and other dangerous

activities by their children (Russell, 2009). This can create evacuation problems in the event of a fire as well as cause forcible entry issues for firefighters trying to gain access to the home (Good, 2012).

There are options that can be utilized to help improve the survivability rate of an individual with autism in the event of a fire. An important concept is the familiarization with the autistic individual and the responders. Many jurisdictions have registry systems in place where the address and exact information can be placed into a dispatch or other type of database to be used to inform responders prior to their arrival at the home (Debbaudt, 2002). Visual markers can be used on homes and vehicles. Stickers to readily recognize the home or vehicle of an autistic individual are available with a universal warning symbol at [www.Autism-society.org](http://www.Autism-society.org) (Shore, 2011). Exposure to responders can help the autistic individual feel like they are more of the routine than a disturbance but this may take time. Good (2012) relates his story of working with special needs children to familiarize them with firefighters in turnout gear. He points out that where other classes may need to be visited annually for the message to take hold the special needs program may need monthly interaction for obtain a familiarity with the children.

For children that do not react or react adversely to traditional fire alarms, alternatives may be considered. For example, instead of a traditional beeping type of smoke detector the family may find the autistic individual reacts better to a voice smoke detector that records the parent's voice message and plays it back in a loop upon activation. This type of detector is not as auditory obtrusive and may prevent sensory overload as well as it gives the individual simple directions to be followed. While no studies were found with these smoke detectors involving autistic children a general study found the voice recorded alarm had better results than traditional alarms. The study conducted of 25 children between the ages of 6 and 11 found the voice

activated alarm awoke 96% of the children and of them 83% were able to successfully self rescue. The traditional alarm sound only awoke 58% of the children and of them only 38% were able to self evacuate (Smith, Splaingard, Hayes & Xiang, 2006).

### **Disaster Response**

With the event of several devastating disasters in the past years a new light has been brought on the preparedness for the autistic individual (Shore, 2011). The needs of a family affected by autism during a disaster exceed the basics of survival that other families may be able get by with (Autism Speaks, 2005). Individuals with autism will often need ways to cope with the interruption in the normal routine that he/she has become accustomed to. Without this familiarization the individual may become problematic for self, family, and those trying to help. Though major disasters are infrequent in most people's lives it should be remembered that these events can cause a sensory overload to the autistic individual causing response issues from locating to sheltering for responders (Shore, 2011).

An autistic individual affected by a sudden disaster and fueled by the ensuing chaos is likely to shutdown totally or possibly go into self-stimulatory behavior. This may make it hard for responders to know where to look or find these individuals (Shore, 2011). A solution to this may be the use of identifying markers on the exterior of house or a note being tied into the computer aided dispatch system alerting responders. This may at least give responders the advanced notice that special precautions and tactics may be needed to help the family best deal with the disaster.

Many of the same principles for disaster preparedness apply to the general population and ASD individuals. Which means that many of the techniques used for ASD preparedness can cross to other groups with or without disabilities (Shore, 2011). Common practices used for

disaster preparedness such as they use of pre-packed go bags, emergency contacts setup out of state, and even a backup supply of medications recommended for all of the population can be transferred to the family affected by autism.

The safety of a shelter may be the only refuge available to a family affected by autism. This could represent a tremendous change in the routine and safety accommodations of the autistic individual. Problems may come in forms of behavioral issues based on the change of venue to sleep disruptions and elopement. For example, it is common for autistic individuals to have disrupted sleep patterns that can cause wandering and other issues at night. This often leads to sleep deprivation issues in care givers which can be chronic and problematic (Rzucidlo, 2003). This could be compounded in a shelter leading to a dangerous situation.

While it is known that Autistic individuals are more likely to need emergency services than other individuals there is little known about specific injury patterns (McDermott, Zhou & Mann, 2007). Meaning that there is no one common answer to expect when sheltering an autistic individual but there is a potential for a wide variety of things to occur. This is a large gap in the literature review on how to best shelter autistic individuals during an emergency.

### **Prevention Efforts**

Prevention efforts are probably the greatest method that responders have to save lives, limb and property (Giesler, 2011). Much of the literature review pointed to the same idea for safety issues and autism. Helping autistic individuals and their caregivers with preventative information for emergencies is a key factor to the success for a positive outcome during an emergency incident involving an ASD individual (Mims, 2008). Russell (2009) concluded that two of the most important prevention techniques were the use of a smoke detector that worked for the individual and the efficient use of a safety evacuation plan. Through prevention efforts

fire safety programs can be taught, water safety programs can be delivered, caregivers can be educated and responders better prepared. The issue then becomes how best to present prevention programs to autistic individuals and/or their caregiver.

An autistic individual can usually be taught any activity that a neurotypical child can be taught with the proper considerations (Rain, 2012). Most of the literature agrees with the idea that prevention training can have a positive effect with autistic individuals. However, there are varying ideas as to what extra effort will be needed and how effective the training actually can be in the event of an emergency. Knudson, Miltenberger, Bosch, Gross, Brower-Breitwieser, & Tarasenko, (2009) questioned this with their study of mentally retarded group home occupants. Their study questioned the testing of cognitive knowledge and psychomotor testing as evaluation methods of how well the mentally handicapped were prepared for an emergency after prevention training. Post fire prevention training they observed the participants in unannounced and non-proctored fire drills. They concluded that only one of the seven participants was able to self evacuate within the allotted time.

Training for children with autism has to be geared differently to meet the learning style and the sensory issues of the individual (Good, 2012). Patience has to be exhibited and lessons have to be taught in small literal pieces (Rain, 2012). Often visual cues will be more receptive to those with autism than traditional lecture modes. For example, family members in one study indicated that their autistic child responded better to pictures than video or other forms of communications (Russell, 2009). The belief in the literature review is though that prevention training is an important concept in the safety of those with autism.

The literature review did uncover training tips and materials that can be used in the training of the individual with autism, the caregiver, and the responder. Some of the programs

that were found required a fee to use them and others were free. An example of a free source is the NFPA's online resource involving a short social story aimed at high functioning children with autism between the ages of 6 to 9 to help communicate fire safety (NFPA, 2012).

There are several organizations that are able to help responders in their prevention efforts with information and resources such as the Autism and Law enforcement Coalition (ALEC) founded in 2003 in Massachusetts (White, 2012). There are websites such as the Autism of America site which has valuable information (Debbaudt, 2002). There are experts in the field that can be consulted such as Susan Rzucidlo who has written papers and helped provide emergency service checklists for use (Cannata & Rzucidlo 2003).

### **Summary**

The review of the literature was able to not only help influence the study but also illuminated information that was already available on the matter of autism and emergencies. The literature review found that while there is a lot of information concerning autism, safety for autism, and even ideas for responders to use as best practices there is still much that is not known. The risk factors and biological causes are unknown (Dawson, 2011). Little is understood about the reactions of autistic individuals in regards to why they do what they do (Ratajczak, 2010). Information has been collected from a few sources on how responders can better recognize and respond to individuals with autism but more information is needed (Russell, 2009). The gaps in knowledge did influence this project to seek some of the missing answers. For example, there was little information found on the topic of emergency sheltering of individuals with autism so a section was added into the questions for respondents to get their opinions.

The literature review did identify best practices in several different realms of emergency response when dealing with individuals with autism. Probably the most notable issue was the understanding of the autism disorder in general. Material echoed over and over again that while certain generalities can be applied to autism the disorder is a spectrum with a great deal of diversity that affects the way each individual will react to a situation differently from others. This diversity can affect everything that this study examines.

There were some very specific areas that the literature review shed light on. For example, teaching methods were examined as needing to be slow, simple, and broken down into smaller components once an evaluation of the individual's needs and learning styles had been conducted (Rain, 2012). The need to address certain issues as high frequency, high severity issues such as elopement of autistic children were identified during the review of the literature (Law & Anderson, 2011). Even something as simple as conducting a medical exam was explored as a possible stressor to the individual with autism.

The gaps in knowledge from the literature review were found to be substantial. While experts in the field of emergency response with autism are available they are not numerous. There was little information offered on many response specific topics such as how to best provide emergency shelter, why a child runs back into a burning house, how to overcome the high pain thresholds in medical examinations, etc. Much of the information found was not scientific in nature but based on observational data from parents and care givers. Many blogs and posts were noted on the internet of parents sharing experiences with others and often asking for solutions to problems they were having indicating more research needed in several different areas. These parent posts and articles found influenced the study from a simple questionnaire for

the parents to a free flowing interview that allowed the parents to discuss their observations and what they thought was important on the topics.

### **Procedures**

This descriptive study examined the best practices in dealing with autistic individuals during emergencies in three parts. In the first part the study used an electronic questionnaire using both quantitative and qualitative questions to examine the issue from the fire service's point of view. The second portion of the study used an electronic questionnaire consisting of qualitative and quantitative questions administered to healthcare providers to obtain their perspective on the issue. The third part of the study consisted of interviews with individual parents/caregivers of autistic individuals to obtain information from their vantage point.

Several different research methods were considered for this study. For example, the use of case studies was considered as an option. A case study examines an issue by reviewing specific events over a period of time (Creswell, 2009). This option was considered using different incidents that the fire service responded to involving autistic individuals. This method was not chosen due to the narrow focus perspective if only the documentation of an incident was to be examined. A more comprehensive examination of case studies would be difficult within the scope of this project's time frame as it would require the researcher to track down and obtain perspectives from the fire service, the healthcare professionals, and parents of each case for a holistic view of the issue.

Another research method explored for this study was the experimental or quasi experimental method. An experimental or quasi experimental method would focus very narrowly on only one or two variables rather than the large scale of the problem. True experimental or even quasi experimental would require contact and involvement of autistic individuals, a

protected class from a research perspective (HHS, 1993). This would require a lengthy internal review board approval process, which would be beyond the scope of this project's time and monetary resources. It was decided that these methods and others considered would not give the direct and holistic perspective on the research questions desired within the scope of the project.

Ultimately a three part mixed method study was decided upon as the best choice to answer the research questions for this study. A mixed method study combines quantitative and qualitative components together to give a holistic vision of the research question (Creswell, 2009). Quantitative studies can be effective at finding answers to social and behavioral questions by giving an insight into the issues (Beauchamp & Childress, 2009). Qualitative research can be useful in exploring a more in-depth view of a research question (Creswell, 2007). By combining the quantitative and qualitative together in a mixed study a more complete answer to the research question is liable to emerge (Creswell, 2009).

Participation in each phase of the study was totally voluntary. There were no repercussions for not participating and no financial rewards for participating. Study participants' identities were kept totally anonymous. Participants were not required or asked for any personal information while responding to questionnaires. Some participants did leave phone numbers for the researcher to contact them to complete the individual caregiver's interview. These numbers were not recorded or tracked in anyway. The researcher is the only person that had access to any responses that could be used to identify participants. Any information that could be viewed as personal has been and is still protected for the confidentiality of all involved.

In January 2012, a survey tool was developed to meet the needs of the study for the first part of the study dealing with fire departments. During the same month a survey tool was developed to be administered to the healthcare professions for the second phase of the study.

These two survey tools were given to five academics with either fire service or healthcare backgrounds to field test. A field test utilizes experts to gauge a survey tool for validity as well as visual appearance prior to the tools use (Espisto, 2009). Field testers were purposely chosen based off of their academic abilities as well as their relationship with either the fire service or the healthcare field. The field testers made very minor comments on the survey tools. Minor modifications were made in the format of grammar and the tools were sent to be pilot tested.

The use of a pilot test can be used to add to the reliability as well as the validity of a study if conducted (Valdez, 2008). Pilot tests for this study were conducted in March of 2012 for both the fire service and healthcare survey instruments. Non-probability sampling was used to select the sample for the pilot test. Students at HCC were purposely chosen based on their background and convenience to participate in the pilot test. A pilot test is a useful tool in that it allows for a test run of a new survey tool to identify problems prior to the official study (Leedy & Ormrod, 2005). The fire service tool was found to have no glitches. The healthcare provider instrument though was found to contain too many qualitative questions with very few quantitative questions. It was noted in the review of the pilot test that the majority of participants did not complete all of the short answer questions leaving a poor completion rate and a lack of information in order to reliably come to any conclusions in that part of the study. More quantitative questions were added to the healthcare provider instrument to overcome the issue found in the pilot testing. Corrected questionnaires were completed based on the results of the field and pilot tests. The electronic survey for the fire service can be seen as Appendix A. The electronic survey form used for the healthcare professionals that work with autism can be seen in Appendix B.

The third part of the study was designed as interviews conducted with the caregivers of autistic individuals. These interviews while using seven general questions were meant to be free flowing to allow a free path of information unimpeded by any research bias. The seven questions, Appendix C, were field tested by academics for validity in regards to the study. No actions were suggested by field testers for the seven questions.

During the months of April and May 2012 firefighters, healthcare workers, and parents were recruited and asked to participate in their respective part of the study. Approximately one thousand fire service personnel from across the United States were contacted via email and asked to participate in the study. The invitation email can be seen in Appendix D. The emails were obtained from established email lists. This sampling pool was a non-probability convenience sampling method. It was believed that with such a large national cross section that a relatively stratified sample of the demographics would emerge. The diversity of the fire service combined with access made random, stratified or even clustered sampling problematic within the constraints of this project.

An internet search was conducted using the key words autism and healthcare to find twenty-five health care organizations that specialized in autism care. Each care organization was sent an email, as seen in Appendix E, to the contact email address given asking for their participation in the study as well to pass the study on to other healthcare providers that may be interested in participating. Where multiple contact email points were given often more than one email was sent to the organization. The letter also asked the organizations that if they had any parents that would be willing to participate in an interview on the matter to contact the researcher. After two weeks it was noted that the response level for the emails sent was very low.

A second internet search was done using the same search criteria and a different group of twenty-five providers were contacted via email with the same invitation letter as the first group.

Statistically a sample size of 278 fire service participants would be required from 1,000 invites with a confidence level of 95% and confidence interval of 5% (Macorr, 2012). The healthcare providers email invitation was sent to the organization to be passed along to others. It is impractical to attempt to assume how many individuals were invited to participate in order to determine an appropriate sample pool size.

### **Assumptions**

This study made the following assumptions. The first assumption made was that all participants would answer the questions they were asked in a sincere and truthful manner as it applied to their unique perspective. It was also assumed that there would be differences in perspectives and areas of interest between the fire service, healthcare, and parent/caregiver therefore three different survey methods/tools were devised.

Just as the individual is diverse from others with the disorder the emergency and the responding agencies are diverse as well. These differences can be seen in geographical, policy, and even perceptions. It is believed though that even with these differences that with the scope of this study that information gleaned from it can be useful to responders, healthcare professionals, and parents/caregivers of autistic individuals across the United States.

### **Limitations**

This study, like others has limitations. For example, random probability sampling would have been a more desirable sampling pool for purer results over the non-random convenience sampling that was used. Despite the sampling method chosen it is believed the sample pools were diverse given their numbers and the wide variety of participants.

The use of new survey instruments can cause skepticism about the reliability and validity of the instruments (Creswell, 2009). All survey tools were field tested to help show validity. The fire service and healthcare provider tools were pilot tested to help verify the reliability of them with the main study.

The scale of the study is another limitation. Due to available time and resources this study was fairly small with respect to participants. The study does represent a diverse group from across the country in the hope that it will translate accurately across the nation. It is believed that with an internal review board, IRB, approval process in place for this study that more professional doors may have been opened allowing greater access to participants especially in the area of healthcare workers and parent/caregivers of autistic individuals. Unfortunately time and resources did not provide an opportunity for this project to seek IRB approval.

## **Results**

Results were recorded from each of the three phases of the research. The first phase consisted of an electronic questionnaire sent to firefighters. The second part of the study consisted of an electronic survey sent to healthcare providers that have experience with autistic patients. The third part of the study used face to face and telephone interview with the parent(s) of autistic children to gain their perspective on the issue.

### **Fire Service Results**

There were 63 responses to the fire service survey tool that was distributed to fire service personnel across America via email invitation. The survey tool was posted on the electronic survey site, Survey Monkey. Appendix F contains a complete copy of the quantitative information from the fire service survey instrument.

The sample pool for the fire service survey tool was noted to be diverse in the career departments, which was comprised of paid firefighters. The combination departments comprised of volunteer and paid firefighters also showed a diverse representation. No participants indicated that they were from a strictly voluntary department. At 52% the majority of the respondents were from the Eastern Time zone but all four continental time zones were represented.

Approximately 30% of the participants responded that they felt that their fire department was partially to completely prepared for an emergency involving an autistic individual. The most popular answer at 46% was that the department would be able to make do with a situation.

Respondents indicated that training requirements ranged from 1.8% indicating mandatory training for initial hires with routine updates to almost 44% of the respondents indicating that members are not trained in autism response. A few of the respondents indicated that autism was covered as part of their Emergency Medical Technician continuing education training. One respondent indicated members received training through their state fire marshal's office.

Almost 89% of the respondents indicated that their department has no procedures, policies, or best practices neither written nor verbal for dealing with autistic emergencies. Almost 5% indicated that their department had written policies and 6% indicated they had verbal direction. A few of the participants indicated that their procedures for autism fell under their procedures for special needs or mental emergencies protocols. One respondent indicated that their department partnered strongly with the local mental health agency and have found success in their response system.

Nearly 67% of the respondents indicated that they typically do not target autistic individuals or their caregivers for prevention training. A small percentage of respondents did target the caregivers and almost 24% of the respondents indicated that they offer classes as

requested by groups. Some respondents stated that they do have contact with special needs children during their normal elementary school programs but there is nothing specific to address special needs. Other respondents indicated steps to teach programs geared to the learning styles of autistic children. Some respondents also included special medical care classes offered to the caregivers of autistic individuals. One respondent indicated that due to budget cuts the prevention specialist position that normally dealt with special needs had been cut. A respondent indicated that his/her local county and state provide excellent training to all stakeholders including the autistic individual, caregiver and responders. A couple of the respondents discussed that their organizations custom make programs, as requested, taking into account the learning style and mental age instead of gauging the program to the traditional biological age. Another respondent discussed a local program that organizations use to invite autistic individuals and their caregivers in to meet the area responders. They also then register the individuals with their address in the computer aided dispatch system along with any other important information.

Fire service participants were asked about the number and types of autistic responses to which their organization has responded. A common answer by most was that the numbers of autistic individual responses was not tracked so quantitative information was not available to them. Many of the respondents did answer anecdotally based on their experiences and these responses ranged from a few a year to a few a week with a few respondents indicating they were not aware of any responses involving autistic individuals. The type of calls varied as well by the respondents. Many of the recited calls were medical without mishap. Some were more serious. For example, one response noted the physical restraint of an anxious autistic teenager by law enforcement. A paramedic recognized the problem and helped to calm the victim down. Another respondent indicated an autistic individual that has a habit of jumping out of windows with no

fear of heights when he becomes stressed. The respondent indicated that they work with other organizations such as the school system to keep him from second floor or higher situations. Other responses indicated issues with autistic individuals running away from responders without regard to personal safety.

The final question asked the fire service participants if they had any additional thoughts or comments with regards to dealing with autistic individuals in emergencies. This question generated several responses. The most common response given was the fire service or the organization in general was not as prepared as they could be for dealing with autistic emergencies. Proactive versus reactive was mentioned by some participants. Several participants stated that this survey had them wanting to take a closer look at their departments abilities and needs with regard to autism. A few respondents even noted particular resources in their jurisdictions that could help in this regard that they had not approached previously just because they simply had not thought of the need. One respondent pointed out the need but also pointed out the difficulty in making the time to focus on it with all of the other priorities placed on the modern fire department. One participant questioned whether it was a matter of time and resources or a cultural issue with change. Some of the respondents even indicated the need for more research in the area of emergency response and care for special needs victims.

Several of the participants mentioned the need to concentrate education on caregivers so that they can help prepare the autistic individual for an emergency as well as help the responder during the emergency. Several participants pointed out the importance of the caregiver in any activity involving a special needs person and how his/her presence and experience can be very beneficial to the responders having a successful conclusion to the incident.

Some participants discussed different things that they have noticed as far as increasing or decreasing the stress level of the autistic individual. For example, one respondent noted the importance of examining how difference response habits affect each individual differently. The respondent pointed out how lights and sirens may scare some individuals but not others. Another participant described the length of time that a traumatic event could disrupt the autistic individuals' routine and how that cause other related issues mentally and physically.

### **Health Care Survey Instrument**

There were 25 responses to the healthcare survey instrument. Healthcare workers that specialized with autistic patients were solicited to participate in this study through an email invitation. The invitation led them to a link to the survey instrument located in electronic format in Survey Monkey. Appendix G contains a complete copy of the quantitative information from the healthcare survey instrument.

The group had a fairly diverse mix. The experience level of working with autistic individuals was very good with 56% of the participants reporting greater than 15 years of experience working with autistic patients. More than 61% of the respondents had advanced training in autistic or ASD subjects. Other participants reported special concentrations in college programs, special certifications with autistic patients and other training for special needs patients. Participants consisted of nurses, doctors, psychiatrist, psychologists, and other medical professionals. While all four continental time zones were represented by participants, the majority of participants, 64%, indicated being in the Eastern Time Zone.

The quantitative section of the healthcare questionnaire asked the participants to indicate how important they thought individual response issues were when dealing with autistic individuals. Each item was asked to be graded on a scale of 1 as not being important to a 5 as

being very important. An average score of 80% equates to a 4.0 or higher. Items averaging higher than a 4.0 were viewed as significant issues.

There were several issues identified in the survey by the participants that were of significance. The highest scoring issue with an average score of 4.92 was that when autistic individuals are placed in an emergency shelter the family needs to be assigned an area that can be as calm as possible. The next highest score of 4.88 was the need for responders to be patient with the individual. Other top issues identified were the need for responders to be calm around the individual and speak explicitly using simple language.

The only item that had any participants indicate as not important was for autistic individuals to be given a tour of the emergency shelter when arriving. The majority of respondents still thought it was important enough that the issue still was found to be significant with an average score of 4.17. The only response issue that was not found to be significant by the participants was the responder removing hats or other distracting items prior to talking with the autistic individual. This issue scored a 3.68, but it should be noted that 28% of the participants did indicate the issue as very important in their response.

The qualitative questions from the healthcare providers generated some great information. The most obvious trend recognized in the question asking for general considerations or tactics for responders to consider in all emergencies was that autism is a spectrum disorder, and that it is hard to generalize the condition or the responses that each individual may exhibit. One respondent gave the example that while some with autism may flee from sirens and uniforms others may very well be attracted by them. Only experience with the individual will clue responders as to which is going to yield the best result for the individual. As in the fire service survey the importance of utilizing the parent or caregiver for information on the

individual's reactions and calming mechanisms was stressed by many of the healthcare providers.

Communication issues were stressed by many of the participants. It was noted by several that the emergency will take the individual out of their normal routine and can be frightening to the individual. Combined with the inability to communicate this fright or anxiety can make the condition even worse causing outbursts or other inappropriate behaviors. Several participants pointed out the importance to communicate responder's actions to the individual in terms that the individual will understand. This was pointed out as slow and simple words giving the individual extra time to absorb and understand the message. A few pointed out the need to communicate at the developmental age rather than biological. Some noted to consider using visual cues or pictures as a form of communication rather than or in conjunction with verbal cues. It was pointed out by one response that often autistic individuals respond to pictures or a demonstration method better than they might with verbal communications.

The respondents gave 18 specific responses to the survey question asking for care tips in dealing with an autistic individual that has become injured and in need of emergency medical attention. Many of the comments reinforced the qualitative comments such as the use of patience by the responder, simple language, etc. There were several new ideas and concepts that were brought out in this question as well though. For example, several participants noted that autistic individuals are known to have high thresholds for pain. This characteristic can lead to the individual masking symptoms or the responder not understanding the seriousness of the situation based on the reaction of the individual. This characteristic may also make it hard for the responder to determine the injury's or illness's root cause. One respondent gave the example of a patient that had stepped on a nail. The only way the parents knew there was a problem was by

the bloody sock which prompted them to conduct a more thorough examination and care.

Another participant echoed this thought with the story of a child who burnt his hand but acted as if nothing had happened. Other participants pointed out that the high threshold of pain can be misleading to responders due to the general characteristic of tactile simulation issues. One participant gave the example of the individual showing no signs of pain for the application of alcohol or the administration of a vaccine but then having a totally different reaction to the placement of a bandage on the wound.

Many participants commented on the importance of a caretaker present to help not only relieve the anxiety of the individual but also to communicate for him/her as the individual may not be able to communicate or the stress of the situation may make communication difficult. Several noted that even though communication may be difficult the responder still needs to explain all actions in simple to understand terms. Demonstrating procedures on others first may help. Allowing the individual to touch and hold the procedure equipment when possible may help. Allowing the individual to hold something of interest may help reduce the anxiety of the patient as well. The tip was given to start exams at the feet and work up to the head may work well as it is less threatening to the individual. One participant did specifically mention splints and back boarding autistic individuals. The participants' point was that some patients may resist what they perceive as restraint causing them more damage while others may take it better as a swaddling type of care that can reduce anxiety in some autistic individuals.

A question on the healthcare questionnaire asked the participants to discuss any additional considerations that may be used by responders if the caregiver of the autistic individual is the one that is injured. Out of the 15 participants that responded to this question the most repeated answer was to make contact with a backup caregiver or family member as soon as

possible. One participant noted that this might be done by using the caregiver's cellular phone and looking for emergency contacts or family members. Several participants pointed out that the separation of the ASD individual from the caregiver may make the situation worse than to leave them together including through transportation if a backup caregiver is not present. Again the need for communications to the autistic individual was stressed by many of the participants even though he/she is not the patient because this event is out of the normal routine for the individual and needs to be explained.

Question 10 of the healthcare survey asked participants about special considerations that may need to be taken into account when placing an autistic individual in a public shelter following a disaster of some type. Seventeen responses were collected for this question. The most common answer given was the need for personal space for the individual. It was pointed out that while a room would be nice if that is not possible a chair or even lines on a floor depicting boundaries may allow the individual to feel more secure and better able to cope. Several of the participants noted the importance of creating a routine that resembles their normal as soon as possible. This may involve favorite past times, meal times, personal space etc. Several participants suggested the use of a favorite toy and mentioned that video games for older children or adults may help keep their attention away from the activities going on around them. A few participants even mentioned the use of earphones and turning the individual away from others to minimize the impact of the shelter on the anxiety level of the individual. Some of the participants pointed out the need to prevent wandering from what may be a stressful environment for the individual. Watches may need to be stationed, alarms used, or secure areas found for the autistic individual to prevent wandering from the shelter. Visual communications means were mentioned again in this question. An example was given using a first and then card to

demonstrate an action and reward system for the individual. Another example given was a 5 minute card to give the individual a visual cue of changing activities to establish a routine while in the shelter.

Wandering can be an issue with autistic individuals especially at younger ages. The healthcare participants were asked about any special considerations that responders should take with incidents involving wandering. This question elicited 19 responses. Many of the responses discussed the importance of utilizing the parent/caregiver for information that may give insight as to where the individual may have gone such as favorite activities but also the need for the caregiver to help contain and reduce the stress of the individual once found. Several of the participants pointed out that a characteristic of autism is the attraction to water. With this in mind they point out the need for any water system in the area to be checked and secured to prevent the individual from entering the water and possibly drowning. Participants warned that often wandering autistic individuals will not answer to their name and those areas must be thoroughly searched including small areas as often the ASD individual will find comfort in tight spaces. A few participants suggested carrying the individuals' favorite food or drink to help attract them to the responder. Some pointed out the need of a picture of the caregiver so that it can be shown to the individual to gain their trust and help reduce anxiety. Prevention methods such as additional locks and tracking devices were mentioned. An important point mentioned by participants was to not blame the parents/caregivers in any way as often the autistic child can be very determined when he/she want to accomplish a goal. Often the parents already have taken extraordinary measures to keep the child from wandering but total confinement is often elusive.

The final question for healthcare providers was a general question for any other comments that they thought may be relevant to dealing with autistic individuals in emergencies.

This question generated 13 responses. Many of the responses echoed comments from before to reinforce their importance. For example, the diversity of autism was brought out as well as the importance of caregivers, simple communication and patience in dealing with the individual. Some new ideas brought out included the utilizing local responder registry systems for the autistic individual and caregivers. The use of resource material from organizations such as the Autism Society and the UNC School of Medicine TEACCH Program was suggested. Participants pointed out that autistic individuals could be smart, determined and have no fear, which could be dangerous for them. It was also pointed out that a change in their routine from an emergency could cause individuals to act out, meltdown, shutdown, or any combination of the above. Several of the participants commented on the need for the type of work and research that this study represented.

### **Parent Interviews**

The third part of this study examined the issue from the parent/caregiver's perspective. This information was collected in five different interviews with one or more of the autistic individual's parents/caregivers. These interviews represented three of the continental time zones. All of the parents represented minors of ages from toddlers to teenagers. Two of the parents were emergency responders, the other three were not. Each parent(s) were asked seven general questions and allowed to expand on the question as thought relevant.

The first question asked of parents was what concerns would there be if their autistic child was involved in a singular emergency incident involving their child's care such as a motor vehicle accident or a house fire and what could responders do to best deal with their child. Each parent indicated the need for patients and to work with the communications issues of their child. For example, one parent identified her child as nonverbal but that his level of comprehension of

speech was very good. This meant that the child understood but often did not give feedback as to the level of understanding. Another parent commented that picture cards work much better with their child than did verbal conversation. Another parent stated that her child would ask a lot of questions and the simple truth was important to the child. Communication seemed to be a resonating theme through the responses to all seven questions with each parent.

The response to lights and sirens ran the gamut. Some stated it would scare their child while others said it would not bother the child. Some said they were not sure but it made them curious to know the answer. As far as dealing with the responders the response was varied as well with some parents stating it depended on the mood of the child and the approach of the responders. Others indicated that a stranger is normally a distracter to the child causing some anxiety on its own. A couple of the parents were concerned that the anxiety could cause aggressive behavior by the child or cause the responder to take an action such as restraint that would elicit an aggressive behavior. All mentioned the higher tolerance of pain and the problems that it could cause. Some mentioned tactile issues and that the child would not deal well with bandages or other medical treatment. They did indicate that with patience, communication, and/or demonstration the anxiety of tactile issues could be overcome.

The second question asked was what the parent(s) thought the child would do if he/she were with the care giver and the caregiver needed emergency medical help. This question split the parents with some saying the child would be indifferent and others believing their child may become protective if he/she thought the care giver was in harm. Again communication with the child was indicated by several of the parents to help keep the child at ease. Some parents did indicate that they did have emergency contacts listed in their cellular phone for such events though this question was not specifically asked in the interviews.

The third question asked of the parents was what problems they might expect if they were forced to stay in a shelter for a matter of days or longer due to a disaster. Many of the parents stated that it was a terrible thought and would cause many issues. All of the parents mentioned the interruption of the daily life and how important it would be for them to find some kind of routine while in the shelter to offer a resemblance of normalcy to the child. Some parents indicated that their child would do better with distracters such as video games, movies, and toys. Others stated concern for the child wandering and having issues with not having his/her own space. Some of the parents recognized a need for headphones to try to isolate the child from the noise of the crowd. All of the parents at one point indicated the need for a space that the child could identify as his/hers. This may represent a safe or familiar spot that helps to soothe or calm the child. Some parents indicated this might be as simple as a box drawn on the ground, a chair, or a small room to which the child could escape.

The fourth question asked the parents what special precautions they take with their autistic child that they normally would not have taken with a non-autistic child. All of them claimed to be much more watchful of the autistic child. Many of them commenting that their child could be doing something wrong very quickly and some of these actions could be very dangerous. The majority of parents discussed wandering issues with their children. These parents had taken precautionary steps to prevent the child from escaping the house through the use of things such as, child protective door knob covers and installing of keyed deadbolt locks even on interior doors in the house. Some parents use a home alarm system to help keep their child indoors while others have moved locking methods to a higher elevation out of the child's reach. One parent commented on the reduction of lightweight chairs because her child was fond of moving the chair to climb to reach things of interest. Climbing issues were mentioned by a few

parents. Some had to strap down heavy items such as televisions to keep the child from pulling it down on themselves. One parent commented that they put locks on the dryer and other confined spaces after they caught their child climbing into the refrigerator. Some of the parents talked about their concerns with their child and water. They discussed how hard it was to isolate all of the water sources because there were so many and often out of their control. Some parents did mention using identification bracelets and/or information cards for responder use.

The fifth question asked the parents to discuss if they had any concerns calling emergency responders for help. All of the parents responded that if the situation warranted it they would certainly call emergency responders for help with their child. A few of the parents did comment on the hope that responders would not be judgmental and understand some of the things they saw that might be out of the norm. For example, one parent commented that the fire department may not like the idea that the home had keyed deadbolts on the interior doors. Another parent was concerned that the child may be reported for aggressive actions and the problems that it might create. A few of the parents were more concerned with implications that would come about once social services were notified of the incident and what might transpire from that encounter. Each of the parents that mentioned this though did state the need for responders would outweigh the issues that may come about from social services after the incident.

The sixth question asked what the parents would like to see from the emergency responders to help their autistic child in time of need. All of the parents again mentioned the patience, understanding and communication points as they had in earlier questions. A few of the parents mentioned they would like responders to have good training on how to deal with autism. Some of the parents mentioned they would like the local responders to actually know their child

and condition. They did not know that they could go and visit the responders with their child to introduce them. Other parents did not know there was a way to identify their child in the dispatch process to emergency responders. A couple of parents did mention the need for other organizations to understand autism as well as responders. For example, a few of the parents did not think that their town was child and certainly not autistic friendly in design or activities. Some felt that social services did not understand the issue of autism and were not able to give effective help for the actual problem encountered. One parent even commented on the insurance system and the coding issues for autism and how that could be problematic in getting the help they needed for their child.

The last question asked the parents whether their child had been involved in an incident requiring emergency responders. A few of the children had been and in each case it had been wandering. Luckily, each case had a safe conclusion but caused a great deal of stress during and after the incident to the parent.

### **Discussion**

The purpose of this research project was to identify best practices to be used when dealing with autistic individuals during times of emergencies. It is hoped that the information found in this study will assist course developers at Halifax Community College develop material to educate area responders on the best practices to incorporate when dealing with autistic individuals. It is also hoped that the information found in this study will be useful to other organizations in their preparation and training of responders for emergencies involving autistic individuals. A summary list of best practices was put together from this study for this purpose. See Appendix H to see the summary list.

This descriptive study was conducted using three different sources of information for a holistic approach to the problem. With the use of quantitative and qualitative tools a more rounded answer can be determined for the research questions being asked (Creswell, 2009). An electronic survey tool was used for fire service participants while a different electronic survey tool was used for the healthcare provider participants. Both questionnaires were field and pilot tested prior to being utilized to help ensure reliability and validity. Fire service participants were recruited through email invitation via pre-developed email mailing lists. The healthcare providers were recruited via email through a search for addresses on the internet. The surveys were open for more than one month. Even though this was longer than initially anticipated the sample size for both groups was smaller than anticipated. The third part of the study included interviews with parents of autistic children to gain their perspective. The seven general questions asked of the parents were field tested.

There were several areas where similarities were found between the different study parts and the literature review that can be utilized as best practices for dealing with autistic individuals during emergencies. For example, autistic individuals are just as diverse as the rest of the population (Debbaudt, 2002). The diversity of the individual and the reaction the individual may have was a consistent theme in each study part as well as the literature review. That is to say that while there are generalities that may be assigned to autism they are not guaranteed. Not every child will run from lights and sirens of emergency vehicles but some may (Rzucidlo, 2003). This means that while policies and procedures are important to develop for responses, the responder needs to stay cognitive that not every tactic may work with every individual. Tactics will need to be evaluated during their application to determine success or if redirection will be needed. Some of the parents emphasized this when they spoke about their children's expected behavior. Often

they commented on their mood and or their anxiety level being an influence. With this in mind patience may be needed by the responder to determine which tactic will breed success over others.

One of the most important tools that a responder can use when dealing with an autistic child is patience (Vaz, 2010; Rzucidlo, 2003; Debbaudt, 2001). This sentiment was brought forward in all three parts of the study especially in the healthcare survey and the interviews with the parents. In fact the healthcare providers ranked patience as number two in importance when dealing with autistic individuals. Patience pertains to issues in communication, assessment, behavior, and even for the responder to be accepted by the autistic individual.

Several participants in the study discussed the need for training of responders in dealing with autistic individuals. Mims (2008) and Russell (2009) both found in their research that training was needed of responders in this area as well. There are some training tools and options already available for responders interested in learning more about autism response (Good, 2011). For example, there are expert speakers that will come to sites and lecture (Debbaudt, 2012). There are websites with information for responders (Autism Speaks, 2012; Autism Society, 2012). There are even advanced degree programs at different universities that can help people understand autism better (Blessing, 2012). The research is still lacking in many of the fields of autism (Dawson, 2011). There is enough out there to give responders a starting point to move forward with though. In fact some states such as North Carolina have even begun to legislate mandates for autism response training for emergency services (Debbaudt, 2007).

Though there may not be a lot of research presently on why communication is an issue with autistic individuals there is information that can help the responder. For example, many autistic individuals deal better with pictures than they do verbal or written words (Rzucidlo,

2003; Debbaudt, 2002). The study results echoed this thought. Even though communication may be an issue, if responders understand the visual concepts of autism better they may be able to use a picture book or a quick drawing to get their point across with less stress and anxiety to the patient than traditional means may do. Some participants mentioned the use of flash cards, or simple easy wording to help facilitate the communication process. This may be something to help responders with not only autism issues but other special needs candidates or possibly even those patients that do not speak English.

The study reconfirmed several traditional practices with autistic individuals as best practices. For example, the Autism Society (2012) recommends for people to stay calm around those with autism even when they are upset. To confront anger or aggression from autistic individual will only evoke a higher level of response. A much better response is to have a calming demeanor (Rzucidlo, 2003; Debbaudt, 2002). By modeling a calm manner this may calm or place the aggressor at ease. This was a main and consistent point by many of the study respondents. Especially the parents stressed the importance of remaining calm with their children and not letting their behavior become frustrating.

Some areas of the study pointed to experiences that left lasting impressions. Several of the parents discussed the issues and the fear that they had of their children wandering or eloping. This was confirmed in the recent study done by Law & Anderson (2011) reporting that many children with autism wander. The good news is that often the children outgrow this behavior (Tilton, 2012). This did not always curve the precautions that the parents took though as the children became adolescents and teens. In fact some parents stated they had even taken more precautions because the older children had overcome the original precautions. In one case a

parent talked about installing deadbolts on interior doors that required a key on both sides of the door to keep the child safe.

A parent's beliefs and experiences can be crucial for understanding the actions that they take for their children. These beliefs can range from anti-wandering steps to healthcare. For example, Hebert & Koulouglioti (2010) point out in their research parents' views towards vaccinations and causal effects to autism can affect how they interact with healthcare issues and their children later. Vaccines have been proven unrelated to autism in several different studies (Miller-Watson, 2012). Regardless of these studies those with the fear of vaccines and the misinformation can still be found. It is the misinformation that was a cause of concern for several of the respondents. All seemed to have very open minds but there was some confusion at times as to what was available to individuals with autism and what was factual. This is understandable when yet so little is actually known about the condition (Dawson, 2011).

The respondents provided some wonderful new ideas to consider in the arena of emergency response. They also gave credence to several ideas that were found in the literature review. Furthermore, several of the respondents brought up more questions than what was within the scope of this project. The study was able to answer the questions that it set out to solve, but there is much work left to be done on the topic of autism and emergencies.

### **Recommendations**

This study was able to reinforce several traditional ideas and concepts for dealing with autistic individuals as well as shedding light on some newer ideas to be considered best practices. The study brought forth several opportunities for Halifax Community College to improve on its training practices for area emergency responders in how to best deal with emergencies involving

individuals with autism. Hopefully others will find useful information within this study to help better prepare other area emergency responders as well.

### **Recommendations for Halifax Community College**

This study found through the literature review and the three part study a great deal of information that can be used to develop up to date training for area responders providing each with a myriad of best practices to put in their tool box to use when dealing with those that have ASD. This study found that in general there is a weakness in the responders' training base for understanding autism and how to best respond to situations involving autism indicating a need for further training. The study pointed out a fairly comprehensive list of best practices that was validated and strengthened by the literature review to share with responders.

As an aside this study has also found information and a need for developing training for members of the public on issues of autism as well. A lack of local resources and/or collaboration for those autistic individuals and parents was found in the area. Public service training provided by the college to interested groups could be the beginning of a more aware and responsive community to the autism issues.

It is recommended that Halifax Community College use the information from this study to update and expand training being done with emergency responders. It is further recommended that Halifax Community College organize in a simpler format the information found in this study and disseminate it to other relevant curriculums on campus such as the nursing, dental, social services, and others that may come across individuals with autism in times of emergencies. A further recommendation is for the college to partner with other groups such as the Child Protection Team to provide community training on autism issues in order to raise the awareness level of the community to gain a more thorough network of support for those affected by autism.

## **Recommendations for the Fire Service**

This study purposely recruited participants from across the country to increase the reliability of the study in hopes the information it collected could be used by others. While the problem of autism is often diverse among individuals it is a common problem across the country affecting virtually every group in the country regardless of social, racial, or other classes. While this study used only participants from the four continental time zones the autism problem including numbers found in the literature review' to be a worldwide issue. That is to say that an argument could be made that the results from this study could be validly used in most places around the world with a good degree of reliability.

The literature review found several programs that were available for training in autism issues though the study showed a majority of the fire service were untrained and/or unprepared to efficiently deal with an autistic event. It is recommended that other members of the fire service incorporate the information learned in this study and apply it to their training program as well. It is further recommended for the fire service, as well as other responders, to elevate autism response training to a higher priority level for it to be more of a mainstream idea rather than a sidelined event. It is further recommended that the fire service make a more concerted effort to create uniform public education geared towards individuals with autism to help them and their caregivers prepare for emergencies more efficiently.

## **Recommended Research**

Research is an important responsibility for every profession's growth and development (Neuman, 2006). The literature review found several gaps in the knowledge concerning autism as a disorder, behaviors, corrective actions, and even in response methods to emergencies. It is

strongly recommended that continued research not only occur in the realm of ASD in the medical arena but also from the social and emergency arenas as well.

A continuation of this study would be recommended. The study proved to have some very enlightening responses from the fire service, the healthcare profession, and the parents. The same project on a larger scale may evoke even more great ideas or, at the very least, help prove the reliability of this study. It is thought that the use of an internal review board process would help legitimize the study and allow more professionals to take part as participants.

The study showed a gap in the training being offered and the number of responders taking the autism courses. It would be interesting to conduct a survey on the affective learning domain of responders to see if there is a reason why more responders do not take part in provided training. Such a study may also help indicate why other areas of emergency response training are not viewed as critical as others.

Knudson et al. (2009) questioned the effectiveness of traditional prevention training and evaluation methods for those with special needs. It would be interesting to do more experimental or quasi experimental types of studies, which were safe for individuals with autism, but would give researchers a clearer picture of what the anticipated reactions, may be and how more favorable reactions in emergencies, could be fostered.

Through the course of this study a small pool of individuals with advanced experience and writings in the field of autism and emergencies was identified. It may prove beneficial to utilize such a pool in a Delphi style study in order to come to a consensus on best practices to be used in the event of an emergency affecting an individual with autism. A Delphi study can be a useful tool in answering questions in social research (Valdez, 2008).

## **Conclusion**

Autism is an issue that is growing in large numbers and an issue of high severity for responders. This study suggests that traditionally responders have not thought a great deal of a response with an autistic individual as anything different or unique with which to contend. The literature review and the study both show a need for responders to take the issue more seriously and to do anything otherwise can be tragic to the autistic individual, to the responder, and to the community. Through training, education, and further research though emergency responders can step to up to the plate and hit a home run being heroes in their community for their compassion and for thought.

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## Appendix A Fire Service Survey Instrument

Emergency Response with Autistic Individuals – Fire Service
<b>Informed Consent</b>
<p><b>INFORMED CONSENT</b></p> <p>Thank you for your expressed interest in participating in a research study that is investigating best practices when dealing with autistic individuals during times of emergencies. Participants for this survey have been selected based on their involvement in the fire service.</p> <p><b>Research Purpose:</b> This portion of this descriptive study will be using a survey tool to explore the best practices when dealing with autistic individuals during times of emergencies from a fire department perspective. This knowledge will allow for more effective emergency response practices to be developed when dealing with autistic individuals.</p> <p><b>Research Process:</b> Each participant will be asked to voluntarily and anonymously complete a web based survey that will collect demographic information and information about the participant's department in regards to response considerations to autistic individuals.</p> <p><b>Confidentiality:</b> Anonymity is preserved between participants, as participants do not have interaction with anyone except the researcher. Interaction with the researcher is primarily through providing and receiving survey responses, although participants are able to contact the researcher if they have questions. Participant responses are completely anonymous; at no time will participants be asked any information that could identify them. All participant documentation will be held in strict confidence. No one except the researcher will have access to the data.</p> <p><b>Risks and Benefits to the Participant:</b> There are no known psychological or physical risks to individuals who participate in this study.</p> <p><b>Voluntary Participation:</b> Participation is voluntary and participants are able to stop participation at any time, without penalty. There are no associated risks or consequences in withdrawing from the study at any point in the process.</p> <p><b>Compensation:</b> There is no compensation provided for individuals participating in this study.</p> <p><b>Contact Information:</b> The researcher conducting this study is Dr. Kevin Kupietz, the Fire / EMS Coordinator for Halifax Community College and National Fire Academy Executive Fire Officer student. At any point in this process, you may contact the researcher if you have questions or concerns about any aspect of this study.</p> <p>Kevin Kupietz Fire/EMS Coordinator Halifax Community College Kupietzk@halifaxcc.edu (W) 252 536 7293 (C) 252 532 1242</p> <p><b>*1. I voluntarily consent to participate in this study.</b></p> <p><b>NOTE: If you do not consent to participate in this survey you will not be able to continue in the study.</b></p> <p><input type="radio"/> Yes</p> <p><input type="radio"/> No</p>

**Emergency Response with Autistic Individuals - Fire Service**

**2. For demographic purposes please indicate the response that best describes your department.**

- Volunteer < 50 members
- Volunteer > 50 members
- Paid < 50 members
- Paid 50 - 150 members
- Paid > 150 members
- Combination < 100
- Combination > 100

Other (please specify)

**3. For demographic information please indicate the time zone that best describes the geographical location of your department.**

- Eastern
- Central
- Mountain
- Pacific

Other (please specify)

**4. Do you feel that your agency is prepared to for an incident or emergency dealing with an autistic individual?**

- Completely ready
- Partially prepared
- Able to make due
- Not prepared at all

Other (please specify)

**Emergency Response with Autistic Individuals - Fire Service**

**5. Does your agency participate in autism awareness training for responders?**

- Mandatory for all initial employees
- Mandatory for all initial employees and routine update training
- The department offers Autism training routinely
- The department offers Autism training occasionally
- The department offered Autism training once
- Some members have obtained training on their own
- Members are not trained in Autism issues

Other (please specify)

**6. Does your department have specific policies, procedures, or best practices for dealing with autistic individuals during emergencies?**

- Written policies/procedures
- Written best practices
- Verbal directions
- None

Other (please specify)

**7. Please describe any policies, procedures, and/or best practices that your department has for dealing with autistic individuals.**

**Emergency Response with Autistic Individuals - Fire Service**

**8. Does your agency's public education purposefully target autistic individuals and/or their caregivers.**

- Our agency specifically targets autistic individuals
- Our agency specifically targets caregivers of autistic individuals
- Our agency specifically targets both autistic individuals and their caregivers
- We combine this group with other special needs groups
- Public education is offered to this group when requested by individuals or groups
- Our agency does not offer public education to autistic individuals or their care givers

Other (please specify)

**9. Please describe your agencies public education program(s) for autistic individuals and their care givers.**

**10. Please describe number and types of incidents your department may have responded to involving autistic individuals.**

**11. Please describe your thoughts/concerns/comments to responding to emergencies involving autistic individuals that may not have been listed above.**

## Appendix B Healthcare Survey Instrument

Best Practices for Emergency Response with Autistic Individuals - Health
<b>Informed Consent</b>
<p><b>INFORMED CONSENT</b></p> <p>Thank you for your expressed interest in participating in a research study that is investigating best practices when dealing with autistic individuals during times of emergencies. Participants for this survey have been selected based on their involvement in the Health care profession with ASD / autistic individuals.</p> <p><b>Research Purpose:</b> This portion of this descriptive study will be using a survey tool to explore the best practices when dealing with autistic individuals during times of emergencies from a health care perspective. This knowledge will allow for more effective emergency response practices to be developed when dealing with autistic individuals.</p> <p><b>Research Process:</b> Each participant will be asked to voluntarily and anonymously complete a web based survey that will collect demographic information and information about the participant's knowledge/beliefs in regards to response considerations to autistic individuals.</p> <p><b>Confidentiality:</b> Anonymity is preserved for all participants, as participants do not have interaction with anyone except the researcher. Interaction with the researcher is primarily through providing and receiving survey responses, although participants are able to contact the researcher if they have questions. Participant responses are completely anonymous; at no time will participants be asked any information that could identify them. All participant documentation will be held in strict confidence. No one except the researcher will have access to the data.</p> <p><b>Risks and Benefits to the Participant:</b> There are no known psychological or physical risks to individuals who participate in this study.</p> <p><b>Voluntary Participation:</b> Participation is voluntary and participants are able to stop participation at any time, without penalty. There are no associated risks or consequences in withdrawing from the study at any point in the process.</p> <p><b>Compensation:</b> There is no compensation provided for individuals participating in this study.</p> <p><b>Contact Information:</b> The researcher conducting this study is Dr. Kevin Kupletz, the Fire / EMS Coordinator for Halifax Community College and National Fire Academy Executive Fire Officer Program student. At any point in this process, you may contact the researcher if you have questions or concerns about any aspect of this study.</p> <p>Kevin Kupletz PhD            Fire/EMS Coordinator            Halifax Community College            Kupletzk@halifaxcc.edu            (W) 252 536 7293            (C) 252 532 1242</p> <p><b>*1. I voluntarily consent to participate in this study.</b></p> <p><b>NOTE: If you do not consent to participate in this survey you will not be able to continue in the study.</b></p> <p><input type="radio"/> Yes</p> <p><input type="radio"/> No</p>

**Best Practices for Emergency Response with Autistic Individuals - Health**

**2. How many years have you worked with ASD / Autistic individuals?**

0-5 years  
 5-10 years  
 10-15 years  
 > 15 years

**3. What is your primary role in the health care field? You may choose more than 1**

Physician  
 Nurse  
 Psychiatrist  
 psychologist  
 Emergency personnel  
 Counselor  
 Other

**4. Do you have special education or certifications for in autism or ASD? Please check all that apply.**

Special concentration in college degree  
 Special certifications for autism/ASD  
 Advanced training in autism/ASD  
 Emergency response training  
 Other

**5. For demographic information please indicate the time zone that best describes the geographical location of where you practice.**

Eastern  
 Central  
 Mountain  
 Pacific

Other (please specify)

**Best Practices for Emergency Response with Autistic Individuals - Health**

**6. Please rate the following items as how important you feel each may be in the handling of an autistic individual in a time of emergency. 1 is least important 5 is very important.**

	Not important at all	Slightly important	Moderately important	Important	Very important
Minimize the use of flashing lights or strobes	<input type="radio"/>				
Minimize the use of sirens and horns	<input type="radio"/>				
Use soft / low tones when speaking to the individual	<input type="radio"/>				
Avoid confrontational behaviors such as commands and stern tones	<input type="radio"/>				
Be calm around the individual	<input type="radio"/>				
Remove hats or other distracting articles when able prior to talking to the individual	<input type="radio"/>				
Minimize physical contact with the individual	<input type="radio"/>				
Be patient with individual	<input type="radio"/>				
Use simple language	<input type="radio"/>				
Be explicit (direct) when speaking	<input type="radio"/>				
Use visual aides when communicating with the individual	<input type="radio"/>				
In an emergency shelter environment allow the individual to tour the facility	<input type="radio"/>				
In an emergency shelter environment provide the family with as calm an area as possible	<input type="radio"/>				
In an emergency shelter environment provide the family with extra support for the care of the individual	<input type="radio"/>				
Look for lost victims in locations that they enjoy or are attracted to	<input type="radio"/>				

**Best Practices for Emergency Response with Autistic Individuals - Health**

**7. What do you feel are general considerations/tactics that responders should consider when dealing with an autistic individual in any emergency situation that was not discussed above?**

**8. What do you feel are specific considerations/tactics that responders should consider when dealing with an injury to an autistic individual that was not discussed above?**

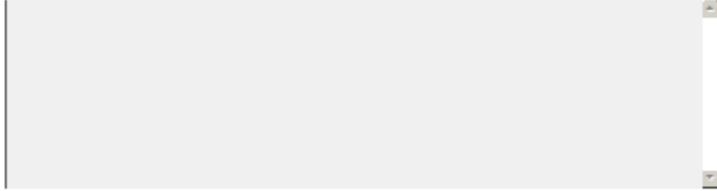
**9. What do you feel are special considerations/tactics that responders should consider when dealing with an injury to an autistic individual's caregiver that was not discussed above?**

**10. What do you feel are specific considerations/tactics that responders should consider when having to provide sheltering care for an autistic individual that was not discussed above? (i.e. a hurricane and the individual has been placed in a local shelter facility for the night or longer)**

**11. What do you feel are specific considerations/tactics that responders should consider when dealing with an autistic individual that has wandered off and responders are in search mode that was not discussed above?**

**Best Practices for Emergency Response with Autistic Individuals - Health**

**12. Is there anything thing else that you think is important for responders to consider when dealing with autistic individuals that was not discussed above?**



## Appendix C Interview Questions for Parents

### EFO ARP Autism Questions for Parents

1. What are your concerns for your child with autism in the event of an emergency that directly affects him/her, such as a motor vehicle accident, fire or medical emergency such as a broken arm?
2. How do you think your child (autistic) would react to you being injured and needing treatment from emergency responders in his/her presence?
3. What problems would you expect if you and your family were required to be sheltered for days in a public shelter following a disaster such as a tornado, hurricane etc.?
4. What special precautions (preventions) do you take to maintain the safety of your child with autism that you may not have taken with other children?
5. Do you have any concerns with calling 911/emergency responders in time of need with your autistic child?
6. What would you like to see from responders that come to help your child in the event of an emergency?
7. Have you and/or your child been involved in an emergency incident involving emergency responders?

## Appendix D Fire Service Invitation Letter

Best Practices for dealing with autistic individuals during emergencies

I am currently working on an applied research project for the National Fire Academy's Executive Fire Officer Program in which I am currently enrolled. This year my applied research project will be examining the best practices for responders to follow when dealing with autistic individuals in times of emergencies. The research will look at the issue from three different perspectives: that of the responders, that of healthcare personnel that deal with autism regularly, and that of the parent/care giver of autistic individuals.

At its completion this project will be available through the National Fire Academy library for the benefit of all responders in their effort to help autistic individuals in time of need. Please help in this project by taking a few minutes to complete the fire service survey part of this research project. The link to the survey can be found at the bottom of this e mail. The survey will remain open until April 30, 2012.

If you are a care giver/parent or health care provider of an autistic individual and would like to participate in the other two parts of this study please contact me.

Thank you for your time and if you have any question please feel free to contact me.

Survey link: <https://www.surveymonkey.com/s/L5TDPZL>

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## Appendix E Healthcare Providers Invitation Letter

Best Practices for dealing with autistic individuals during emergencies

I am currently working on an applied research project for the National Fire Academy's Executive Fire Officer Program in which I am currently enrolled. This project will be examining the best practices for responders to follow when dealing with autistic individuals in times of emergencies. The research will look at the issue from three different perspectives: that of the responders, that of healthcare personnel that deal with autism regularly, and that of the parent/care giver of autistic individuals.

At its completion this project will be available through the National Fire Academy library for the benefit of all responders in their effort to help autistic individuals in time of need. Please help in this project by taking a few minutes to complete the Health care provider survey part of this research project. The link to the survey can be found at the bottom of this e mail. The survey will remain open until April 30, 2012.

Please share this survey with other health care providers for Autistic individuals.

If you are a parent of an autistic individual and would like to participate in a short telephone interview for the parent perspectives of this study please contact me by email.

Thank you for your time and if you have any question please feel free to contact me.

Survey link: <https://www.surveymonkey.com/s/VJY8NSS>

<https://www.surveymonkey.com/s/VJY8NSS>

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### Appendix F Fire Service Study Results

Note: Qualitative responses were not included in order to maintain the confidentiality of the respondents.

Emergency Response with Autistic Individuals -  SurveyMonkey  
Fire Service

1. I voluntarily consent to participate in this study. NOTE: If you do not consent to participate in this survey you will not be able to continue in the study.

	Response Percent	Response Count
Yes	88.4%	83
No	1.6%	1
answered question		84
skipped question		0

2. For demographic purposes please indicate the response that best describes your department.

	Response Percent	Response Count
Volunteer < 50 members	0.0%	0
Volunteer > 50 members	0.0%	0
Paid < 50 members	14.3%	9
Paid 60 - 160 members	33.3%	21
Paid > 150 members	17.5%	11
Combination < 100	25.4%	16
Combination > 100	9.5%	6
Other (please specify)		0
answered question		83
skipped question		1

**3. For demographic information please indicate the time zone that best describes the geographical location of your department.**

		Response Percent	Response Count
Eastern		62.4%	33
Central		23.8%	15
Mountain		14.3%	9
Pacific		9.5%	6
Other (please specify)			0
answered question			83
skipped question			1

**4. Do you feel that your agency is prepared to for an incident or emergency dealing with an autistic individual?**

		Response Percent	Response Count
Completely ready		4.8%	3
Partially prepared		25.4%	16
Able to make due		48.0%	29
Not prepared at all		23.8%	15
Other (please specify)			0
answered question			83
skipped question			1

5. Does your agency participate in autism awareness training for responders?		
	Response Percent	Response Count
Mandatory for all initial employees	0.0%	0
Mandatory for all initial employees and routine update training	1.8%	1
The department offers Autism training routinely	7.0%	4
The department offers Autism training occasionally	15.8%	9
The department offered Autism training once	3.5%	2
Some members have obtained training on their own	28.1%	16
<b>Members are not trained in Autism Issues</b>	<b>43.8%</b>	<b>26</b>
Other (please specify)		9
<b>answered question</b>		<b>67</b>
<b>skipped question</b>		<b>7</b>

**6. Does your department have specific policies, procedures, or best practices for dealing with autistic individuals during emergencies?**

	Response Percent	Response Count
Written policies/procedures	4.8%	3
Written best practices	0.0%	0
Verbal directions	6.5%	4
None	88.7%	66
Other (please specify)		2
answered question		82
skipped question		2

**7. Please describe any policies, procedures, and/or best practices that your department has for dealing with autistic individuals.**

	Response Count
	20
answered question	20
skipped question	44

**8. Does your agency's public education purposefully target autistic individuals and/or their caregivers.**

	Response Percent	Response Count
Our agency specifically targets autistic individuals	0.0%	0
Our agency specifically targets caregivers of autistic individuals	0.0%	0
Our agency specifically targets both autistic individuals and their caregivers	3.2%	2
We combine this group with other special needs groups	6.3%	4
Public education is offered to this group when requested by individuals or groups	23.8%	15
Our agency does not offer public education to autistic individuals or their caregivers	66.7%	42
Other (please specify)		1
answered question		63
skipped question		1

**9. Please describe your agencies public education program(s) for autistic individuals and their care givers.**

	Response Count
	25
answered question	26
skipped question	38

**10. Please describe number and types of incidents your department may have responded to involving autistic individuals.**

	Response Count
	37
answered question	37
skipped question	27

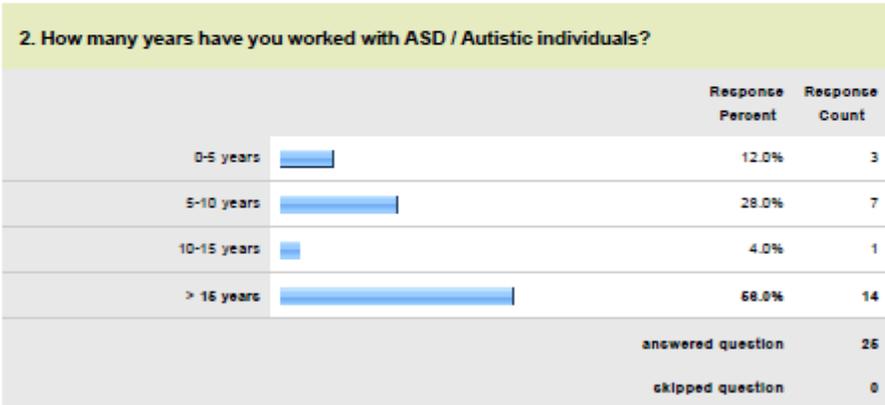
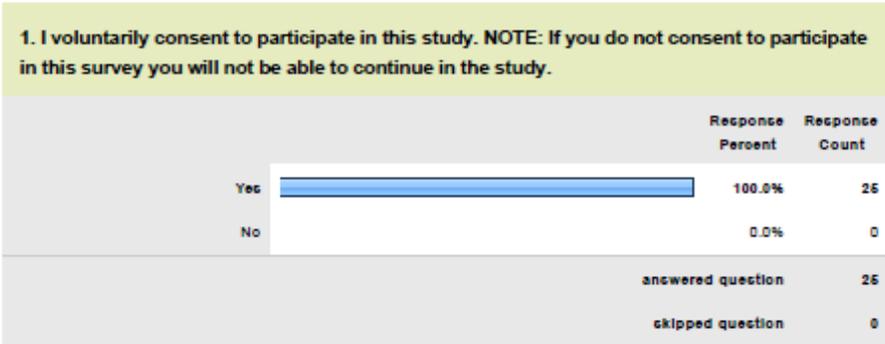
**11. Please describe your thoughts/concerns/comments to responding to emergencies involving autistic individuals that may not have been listed above.**

	Response Count
	32
answered question	32
skipped question	32

## Appendix G Healthcare Providers Study Results

Note: Qualitative responses were not included in order to maintain the confidentiality of the respondents.

### Best Practices for Emergency Response with Autistic Individuals - Health care



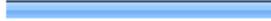
**3. What is your primary role in the health care field? You may choose more than 1**

		Response Percent	Response Count
Physician		4.0%	1
Nurse		4.0%	1
Psychiatrist		8.0%	2
psychologist		32.0%	8
Emergency personnel		0.0%	0
Counselor		4.0%	1
Other		62.0%	13
		answered question	26
		skipped question	0

**4. Do you have special education or certifications for in autism or ASD? Please check all that apply.**

		Response Percent	Response Count
Special concentration in college degree		19.0%	4
Special certifications for autism/ASD		14.3%	3
Advanced training in autism/ASD		61.8%	13
Emergency response training		9.5%	2
Other		33.3%	7
		answered question	21
		skipped question	4

5. For demographic information please indicate the time zone that best describes the geographical location of where you practice.

		Response Percent	Response Count
Eastern		84.0%	18
Central		4.0%	1
Mountain		16.0%	4
Pacific		16.0%	4
	Other (please specify)		0
		answered question	25
		skipped question	0

**6. Please rate the following items as how important you feel each may be in the handling of an autistic individual in a time of emergency. 1 is least important 5 is very important.**

	Not Important at all	Slightly Important	Moderately Important	Important	Very Important	Rating Average	Response Count
Minimize the use of flashing lights or strobes	0.0% (0)	8.0% (2)	20.0% (5)	24.0% (6)	48.0% (12)	4.12	25
Minimize the use of sirens and horns	0.0% (0)	4.0% (1)	4.0% (1)	20.0% (5)	72.0% (18)	4.60	25
Use soft / low tones when speaking to the individual	0.0% (0)	4.0% (1)	12.0% (3)	32.0% (8)	62.0% (13)	4.32	25
Avoid confrontational behaviors such as commands and stern tones	0.0% (0)	4.0% (1)	20.0% (5)	28.0% (7)	48.0% (12)	4.20	25
Be calm around the individual	0.0% (0)	0.0% (0)	4.0% (1)	8.0% (2)	88.0% (22)	4.84	25
Remove hats or other distracting articles when able prior to talking to the individual	0.0% (0)	16.0% (4)	28.0% (7)	28.0% (7)	28.0% (7)	3.68	25
Minimize physical contact with the individual	0.0% (0)	4.2% (1)	16.7% (4)	29.2% (7)	60.0% (12)	4.25	24
Be patient with individual	0.0% (0)	0.0% (0)	4.0% (1)	4.0% (1)	92.0% (23)	4.88	25
Use simple language	0.0% (0)	0.0% (0)	16.0% (4)	12.0% (3)	72.0% (18)	4.56	25
Be explicit (direct) when speaking	0.0% (0)	0.0% (0)	4.0% (1)	12.0% (3)	84.0% (21)	4.80	25
Use visual aides when communicating with the individual	0.0% (0)	12.0% (3)	12.0% (3)	24.0% (6)	62.0% (13)	4.16	25
In an emergency shelter environment allow the individual to tour the facility	4.2% (1)	0.0% (0)	12.5% (3)	41.7% (10)	41.7% (10)	4.17	24
In an emergency shelter environment provide the family with as calm an area as possible	0.0% (0)	0.0% (0)	0.0% (0)	8.0% (2)	92.0% (23)	4.92	25
In an emergency shelter							

environment provide the family with extra support for the care of the individual	0.0% (0)	4.0% (1)	4.0% (1)	28.0% (7)	<b>64.0% (16)</b>	4.52	25
Look for lost victims in locations that they enjoy or are attracted to	0.0% (0)	0.0% (0)	4.0% (1)	20.0% (5)	<b>76.0% (19)</b>	4.72	25
<b>answered question</b>							<b>26</b>
<b>skipped question</b>							<b>0</b>

**7. What do you feel are general considerations/tactics that responders should consider when dealing with an autistic individual in any emergency situation that was not discussed above?**

<b>Response Count</b>	
21	
<b>answered question</b>	<b>21</b>
<b>skipped question</b>	<b>4</b>

**8. What do you feel are specific considerations/tactics that responders should consider when dealing with an injury to an autistic individual that was not discussed above?**

<b>Response Count</b>	
18	
<b>answered question</b>	<b>18</b>
<b>skipped question</b>	<b>7</b>

9. What do you feel are special considerations/tactics that responders should consider when dealing with an injury to an autistic individual's caregiver that was not discussed above?

	Response Count
	15
answered question	16
skipped question	10

10. What do you feel are specific considerations/tactics that responders should consider when having to provide sheltering care for an autistic individual that was not discussed above? (i.e. a hurricane and the individual has been placed in a local shelter facility for the night or longer)

	Response Count
	17
answered question	17
skipped question	8

11. What do you feel are specific considerations/tactics that responders should consider when dealing with an autistic individual that has wandered off and responders are in search mode that was not discussed above?

	Response Count
	19
answered question	19
skipped question	8

12. Is there anything thing else that you think is important for responders to consider when dealing with autistic individuals that was not discussed above?

	Response Count
	13
answered question	13
skipped question	12

## **Appendix H Summary List: Best Practices Autism in Emergencies**

### **Organizational**

- Emergency responders should work in advance with individuals with autism and their caregivers.
- Responders should work in advance with other community stakeholders concerning autism such as mental health, social services, hospitals, schools, and others that could be helpful in emergencies.
- Responder organizations should conduct drills with their personnel to help reinforce proper techniques and strategies concerning a response to an autistic person.
- Develop written policies, procedures, and/or best practices for responders to follow during emergencies.
- Track types and numbers of incidents involving autism to be able to better plan and prepare for community needs.
- Create/publicize a way to allow for the registration of individuals with autism into the dispatch system to alert responders enroute to an incident.
- Set a policy or procedure for the quick notification of a lost child with autism whether the amber alert system is appropriate or if another mechanism needs to be in place.
- Examine the local community. Is it friendly to special needs? Does it offer support systems, outlets for activities, specialized events etc.?
- Understand the laws and rules governing autism for the area. There may be programs or benefits that autistic individuals qualify for in the area that the parents are not aware of such as tracking devices for those that wander.

**General**

- Remember that Autism is a spectrum. Individuals are diverse and while there are some generalities that can be applied, each individual will react differently.
- Do not underestimate the abilities of an autistic individual they can be smart, strong, and very determined.
- All responders should be trained initially and with updates on how to recognize and deal with an individual with autism.
- Keep the added stimulation as low as possible in the response i.e. only the number of responders needed around individual, less noise, calm manner, etc.
- Minimize the use of lights and especially sirens and horns around autistic individuals.
- Use soft calming tones when speaking. Speak slow, distinct, and literally. Allow the individual time to process and answer. Some individuals may be able to comprehend better than they can verbally respond. Their response may be nonverbal.
- Consider the use of nonverbal communications such as visual aids, demonstrating or modeling.
- Keep picture books on emergency vehicles to help communicate with autistic individuals.
- Explain to the autistic individual what is going on. Communicate with them even if they are not appearing to respond back. Lack of eye contact does not mean they are not paying attention.
- Be calm around the individual, avoid confrontational behaviors such as commands and stern tones.
- Be patient with the individual and pay attention to their behavior changes to gauge what is working and what is not.
- Be prepared for outbursts or what may be perceived as improper behavior. Do not react similarly.

- Do not take words or actions from the individual personally. Often they do not have the ability to understand the responder's perspective or express themselves better.
- Remember the individual may become aggressive depending on the situation and the individual. Often this aggression can be aimed at themselves. Watch for clues of this in their behavior as their anxiety level rises. Attempt to calm the situation before it escalates.
- Look for tags or other emergency information devices on the individual. This could be jewelry, tattoos, card, electronic device, or tags stitched in clothing.
- Typical signs of abuse may not be signs of abuse with autism individuals.
- Remember to use compassion and empathy in dealing with autism cases.

### **Medical**

- Individuals with autism may have a higher than normal threshold for pain. This can mask or mislead from serious medical problems.
- Often individuals with autism will have other medical conditions which can complicate a response.
- Minimize unsolicited physical contact as much as possible. Work into their trust if time permits.
- Be mindful of sensory issues including tactile for things such as bandages, blood pressure cuff, etc.
- Try to have them hold their favorite toy or item that may comfort them during the care.
- Allow the individual to see and feel the equipment or supply before using it if they want to.
- Conduct physical exams at extremities and work towards the trunk and head to gain trust.
- When possible avoid restraints or items that will be perceived as restraining, as this may make the autistic patient struggle more, complicating their situation.

- Remember that physical restraints medical, law enforcement, or others could cause mechanical asphyxiation of the autistic patient. If this must occur monitor the patient very closely.

### **If the Caregiver is the One Injured**

- Contact backup caregiver as soon as possible.
- Look for emergency contact information on card, caregivers cell phone (i.e. emergency, ICE etc.), jewelry, etc.
- Explain to autistic individual what is being done to the caregiver and why.
- Try not to separate the two unless necessary or unless backup caregiver is present.
- Monitor the behavior of the autistic individual, some may be indifferent to the care being given some may try to defend or protect the caregiver.
- Reassure caregiver that their charge will be constantly monitored until backup caregiver arrives if they need to be separated.

### **Fire**

- Use good prevention techniques designed for the needs of the individual.
- Conduct frequent fire drills with the individual with autism to make evacuation a routine.
- Once the autistic individual is evacuated from a fire restrict them to a safe, monitored spot.
- Traditional smoke alarms may not work with autism. Experiment with different types of smoke alarms such as voice recorded or strobes to determine the most efficient type for the individual.
- Be prepared to have to search for the child in a fire as they may hide and not respond to calls or commands.
- Be alert for additional locking mechanisms on the exterior and interior of the house meant to protect the child.
- Furniture and household items may be secured in place for the safety of the autistic individual.

**Wandering**

- Do not blame the parent or suggest/hint that the incident is due to poor parenting.
- Consider the use of a community alerting system such as amber alert.
- Leave no place unchecked, they often can get into small places looking for the comfort or warmth provided by the confined area.
- May seek area of calm during over stimulation period.
- Protect nearby water sources especially if the child is known to have an attraction to water.
- check areas of interest to the individual.
- Before a wandering incident introduce the child that wanders to neighbors and ask for their help if they should see him/her away from home alone.
- Search parties without caregivers should carry picture(s) of caregivers(s) to help win the trust of individual when found.
- Carrying a favorite toy, item, or food by the search party may help reassure and calm the individual when found.
- Search parties can call the child's name but should not be surprised if the child does not respond back.
- The use of a favorite sound may attract the wandering child such as song, movie or video game.
- Consider the use of electronic tracking devices if the child is equipped with one.
- Consider the use of more traditional tracking techniques such as scent dogs or tracking teams if available.
- When finding the victim approach slowly and calmly, chasing the child may make them run away without regard for the dangers around them.

- Children that wander can be equipped with tags, electronic tracking devices, and/or devices that alarm when a child leaves an area. The family can also put together lost packs with pictures of the child, answers to questions that responders will need, even frozen scent pads of the child for the dogs to use.

### **Emergency Shelter**

- Allow the individual to be shown around the shelter site.
- Show the individual a place that is their private space for them to use. This could be a room, a chair, or even a box drawn on the floor.
- Keep familiar people and items around the individual.
- Ask the caregiver(s) what can help the autistic individual with the given circumstances i.e. he/she may need special food.
- Try to create a routine for the autistic individual as close to what he/she is used to as possible.
- Use systems such as first-then to establish a reward system for desired behavior.
- Older autistic individuals may be occupied with video games or movies.
- Sound cancelling headphones or earplugs may help calm exterior stressors from the noise of a shelter.
- Provide an outlet for repetitive behaviors such as a walking route, sorting or lining up items depending on the individual and the behavior(s).
- Alert shelter workers of the individual and his/her characteristics so they can be observant for problems before they arise.
- Conduct a safety check of the shelter for anything that could be a danger for the autistic individual such as unsecured doors, swimming pool or ponds, etc.

### **Prevention**

- Provide prevention programs targeted at the individual with autism and the caregivers.
- Target specific programs for specific autism issues such as water safety, wandering, etc.
- Prevention programs should be geared to developmental age not biological age.
- Integrate visuals into training as well as verbal. Social stories may work well.
- Provide opportunities for the responders and autistic individual to meet and become familiar with each other.
- Encourage caregivers to have identification for their charge and themselves including emergency information such as alternate caregiver(s), contacts, medications, issues, etc.
- Individuals with autism may need refresher prevention training more often to become more at ease during an emergency.
- Teach Autistic children to swim at an early age.
- Teach children with autism to be able to hand alert cards to responders when stopped.
- Consider a special training program for babysitters, child care professionals, and teachers to better be able to deal with autism.
- Prepare educational safety programs for adults with autism to prepare them for life away from home.