

12-31-2014

## Risk and Protective Factors for the Safety of Children with Autism: A Qualitative Study of Caregivers' Perspectives

Rebecca Pfeffer

University of Houston-Downtown, pfefferr@uhd.edu

Follow this and additional works at: <http://digitalcommons.library.tmc.edu/jfs>

---

### Recommended Citation

Pfeffer, Rebecca (2014) "Risk and Protective Factors for the Safety of Children with Autism: A Qualitative Study of Caregivers' Perspectives," *Journal of Family Strengths*: Vol. 14: Iss. 1, Article 21.

Available at: <http://digitalcommons.library.tmc.edu/jfs/vol14/iss1/21>

The Journal of Family Strengths is brought to you for free and open access by CHILDREN AT RISK at DigitalCommons@The Texas Medical Center. It has a "cc by-nc-nd" Creative Commons license (Attribution Non-Commercial No Derivatives) For more information, please contact [digitalcommons@exch.library.tmc.edu](mailto:digitalcommons@exch.library.tmc.edu)

---

# Risk and Protective Factors for the Safety of Children with Autism: A Qualitative Study of Caregivers' Perspectives

## **Acknowledgements**

The author would like to thank Dr. Nicole Rafter, Dr. Carlos Cuevas, and Dr. Amy Farrell for their support and guidance throughout this research process.

## Introduction

As of 2014, it is estimated that 1 in 68 children born in the United States have been diagnosed with an autism spectrum disorder (ASD). Although these disorders affect children of every ethnicity and socioeconomic group, prevalence of these disorders is more common among males; it is estimated that 1 in 42 boys born in the United States will be diagnosed with an ASD (Baio, 2014). While it is unknown whether there are actually more children born with these disorders or if practitioners are more adept at identifying and diagnosing autism spectrum disorders, the fact that the prevalence rate of cases of autism in the United States has rapidly increased during the last decade is undeniable. The number of children with ASDs receiving services in American public schools increased by more than 400% in the ten years between 2001 - 2011 (U.S. Department of Education, 2013).

Previous research investigating correlations between autism and crime has mostly focused on the potential for offending among this population (Baron-Cohen, 1988; Stokes, Newton & Kaur, 2007; Langstrom et al., 2009; Allen et al., 2008). Yet, prior research focusing more broadly on people with intellectual and developmental disabilities indicates that there are certain characteristics that elevate risk of victimization for these people. Chief among these characteristics are impaired social skills and a deficit in communicative ability, which are two of the defining features of autism spectrum disorders. This suggests that individuals with such diagnoses may be exceptionally vulnerable to exploitation. Indeed, previous research has found that people with autism spectrum disorders report higher rates of victimization than people with other types of disabilities or those without disabilities (Pfeffer, 2013). Prior criminological research supports the notion that children with autism are at increased risk for victimization, as we know that children are more prone to victimization than any other segment of the population (Finkelhor & Asdigian, 1996) and that children with disabilities are at particular risk when compared to their typically-developing peers (Nettleback & Wilson, 2002; Turner et al., 2011).

It has been well established that victimization among any group of people does not occur uniformly (Hindelang, Gottfredson & Garofalo, 1978; Sampson & Lauretson, 1994). Within certain populations, there exist salient predictors of victimization (Schreck, Miller & Gibson, 2003). We know little about the specific risk factors that contribute to the vulnerability of autistic youth to maltreatment, neglect, and criminal victimization. Even less research has explored the protective factors that work to prevent such victimization. For the purposes of this paper, a risk factor is defined as a

characteristic, experience, or event that is associated with an increase in the probability of victimization. Risk factors generally refer to antecedent conditions associated with an increase in the likelihood of adverse outcomes, while protective factors are antecedent conditions associated with a decrease in the likelihood of negative or undesirable outcomes (Kazdin et al., 1997). A comprehensive understanding of risk and protective factors is critical to the prevention of crime (Farrington & Welsh, 2008).

To understand the risk and protective factors that contribute to the safety of children with autism, this study utilizes data collected as part of a project that examined the victimization rates and experiences of a national sample of children with ASDs in the United States (Pfeffer, 2013). Though the study sample was not nationally representative, it includes children from a diverse range of backgrounds ( $n = 262$ ). For the present study, data from in-depth follow-up interviews conducted with 40 caretakers of autistic children are used to understand personal and situational characteristics that caretakers believe function as either risk or protective factors for their child's safety at home, at school, and in the community.

### **Autism**

Autism is a complex neurological disorder that affects social interaction and communication. ASDs are characterized by a triad of (a) impairments in reciprocal social interaction; (b) difficulties with both verbal and nonverbal communication; and (c) displays of restricted, stereotypic activities and interests (American Psychiatric Association, 2013; Oellette-Kuntz et al., 2007).

A key feature of ASDs is a lack of "theory-of-mind," which is defined as the ability to predict and explain the behavior and feelings of others based on reference to mental states such as beliefs and desires (Slaughter, Dennis & Pritchard, 2002). Theory-of-mind is an important aspect of social skills as it indicates the ability to understand that other people know, want, feel, or believe things (Premack & Woodruff, 1978). Lower levels of theory-of-mind have been correlated with reduced ability to build and maintain peer relationships (Slaughter, Dennis & Pritchard, 2002), which is relevant to the present discussion because research specifically investigating rates of bullying among children with ASDs finds that lack of friends is an important risk factor for peer victimization among this population (van Roekel, Scholte & Didden, 2009).

### **Disability and Victimization**

A substantial body of literature has accumulated on the association between disability and victimization. Results from the 2007 National Crime Victimization Survey (NCVS) reveal that Americans with disabilities have a victimization rate higher than non-disabled Americans. Further, results indicate that people with cognitive disabilities experience crime at a rate higher than people with other types of disabilities (Rand & Harrell, 2009). Similarly, a 2012 meta-analysis funded by the World Health Organization surveyed the results of 26 studies of violence against people with disabilities and concluded that not only are people with disabilities at a higher risk of violence than non-disabled adults, but people with mental health or intellectual disabilities are at particular risk (Hughes et al., 2012).

Studies focusing specifically on the victimization of individuals with Intellectual and Developmental Disabilities (IDDs) confirm that these people are among the most vulnerable in our society, experiencing disproportionate rates of abuse and criminal victimization (Reiter, Bryen & Schachar, 2007; Wilson & Brewer, 1992). Disability researchers have estimated that people with developmental disabilities are four to ten times more likely to be victims of crime than their non-disabled counterparts (Sobsey, Lucardie and Mansell, 1995). Women seem to be at particular risk; Sobsey and Doe (1991) concluded that more than 70% of women with developmental disabilities are sexually assaulted in their lifetime, which is a rate 50% higher than for women without disabilities. Precise estimates of victimization are hard to formulate due to the issues of under- and differential reporting. For instance, it has been estimated that only about 10% of actual incidents of sexual abuse of people with developmental disabilities are ever reported (Ryerson, 1984).

### **Risk Factors**

Although no research has looked specifically at the risk factors for victimization among children with autism, researchers have identified multiple risk factors associated with the elevated rates of victimization among the broader population with intellectual and developmental disabilities. First, it has been suggested that people with IDDs are more susceptible to exploitation because they are often completely dependent on others for their well-being (Furey, Granfield & Karan, 1994). Caregivers include parents, bus drivers, teachers, therapists, babysitters, and any other people who are trusted with the care of persons with disabilities. Research suggests that people with intellectual disabilities are conditioned to respond passively to caregivers—to comply with and not challenge them (Walmsley, 1989). Conversely, perpetrators, specifically of sexual

abuse, often victimize those they perceive to be weaker, unable to defend themselves, and unlikely to be considered credible if accusations of abuse are made (Furey, Granfield & Karan, 1994; Nettleback & Wilson, 2002).

In a study focusing on the maltreatment of children with IDD, Vig and Kaminer (2002) reported that on top of certain environmental and familial risk factors that can increase the likelihood of abuse or other forms of maltreatment for all children (such as poverty, educational deprivation, social isolation, or parental substance abuse), families of children with disabilities face additional stressors. Parents of children with disabilities, particularly parents who have one or more autistic child, experience a great deal more stress than other parents (Rodrigue, Morgan & Geffken, 1990; Lessenberry & Rehfeldt, 2004).

A study of children with Asperger's syndrome and non-verbal learning disorders cited lack of social skills as a significant risk factor for physical abuse and emotional bullying. According to caregiver reports, 94% of the children in this sample had been victimized by their peers; these children were described as "perfect victims" because of their profound deficit in social skills (Little, 2002). This lack of social skills has significant consequences; deficits in self-protective skills, social skills, and supportive peer networks can increase a child's risk for peer bullying and assault (Little, 2002; Turner et al., 2011). While many children with intellectual disabilities are still socially capable, communication and social deficits are central to autism spectrum disorders, rendering these children particularly vulnerable to peer victimization.

Wilson, Seaman & Nettlebeck (1996) specifically investigated whether interpersonal competence impacts an individual's vulnerability to criminal exploitation. This research involved a sample of people with IDDs to see if those who had been criminally victimized were distinct from those not victimized in terms of social competence. The results indicated that the group of victims indeed showed poorer social competence, regardless of IQ, again indicating that lack of social understanding among youth with autism may increase vulnerability to victimization.

### **Current Study**

The current study addresses the following research questions:

Q1: What are the personal and situational risk factors for maltreatment and criminal victimization of children with ASDs, as identified by their caretakers?

Q2: What are the personal and situational protective factors that function to help prevent the maltreatment and criminal victimization of children with ASDs, as identified by their caretakers?

Answering these questions adds to the existing literature and extends our current understanding of the risk factors contributing to the vulnerability of people with disabilities to victimization, by focusing specifically on individuals with autism spectrum disorders. While many previous studies on risk factors have been quantitative in nature, this study uses a qualitative design to assess the risk and protective factors that caretakers of children with ASDs believe contribute to the safety of their children at home, at school, and in the community. The survey component of this project largely focused on quantifying specific forms of victimization, including maltreatment, neglect, bullying, and criminal victimization. However, the supplemental open-ended survey questions and follow-up interviews, from which the data for the current study is drawn, focused on victimization more generally and as defined by caretakers based on the experience of their children.

## **Design and Methods**

### **Sample**

The data utilized in this analysis was collected as part of a larger project that aimed to understand and quantify the victimization experiences of children with autism spectrum disorders in the United States (Pfeffer, 2013). Subject recruitment was facilitated by the Interactive Autism Network (IAN) Project at the Kennedy Krieger Institute, Baltimore, Maryland. IAN is an online collaboration that links tens of thousands of families affected by autism with hundreds of researchers involved in autism research. Participants recruited for this study were parents or caretakers of children with ASDs between ages 5 and 18.

Most survey respondents were the biological parents of the autistic child whose experiences they were reporting (95%). Five percent of participants were either adoptive parents (2.5%) or other related guardians (2.5%). These respondents ranged in age from 26-71, but the mean age of respondents was 42.8 years old. Of participants who reported their gender (n=246), 96% were female. Reported annual household incomes ranged from less than \$10,000 to \$125,000 or more, with the majority of respondents reporting an income of at least \$40,000 per year.

Participants were contacted using the subject recruitment services of IAN. A recruitment letter describing the study was emailed to IAN participants who were the parent or guardian of a child between the ages of 5-18 diagnosed with an ASD. Potential participants were then directed to the study survey website, where consent for participation was obtained prior to administration of the online survey. The survey itself consisted of three components: 1) a series of nine open-ended questions, 2) the 34-

question caretaker version of the Juvenile Victimization Questionnaire (JVQ), and 3) nineteen measures of child and caregiver demographics. Caregiver responses from the open-ended questions on the survey are included in the present analysis.

Respondents were promised confidentiality and were given the chance to win a \$50 amazon.com gift card for their participation. All participants were provided with a number of resources for stress management, parenting support for children with disabilities, and a hotline number to call if their children were being mistreated. All procedures were authorized the Institutional Review Board of Northeastern University.

At the conclusion of the online survey, participants were asked whether they would be amenable to participate in an interview to further extrapolate on their child's experiences with victimization and safety in their communities. Participants were instructed to provide their contact information if they were willing to further share their experiences. At this point, participants were also asked for basic demographic information about their child including their age, gender, autism diagnosis, and the state in which they lived. Subjects' contact information was collected separately from their survey responses in order to guarantee the anonymity of their survey responses. Of the 262 participants who completed the survey, 148 indicated their interest in following up with an in-depth interview. Of these 148 participants, 69 continued forward with the study by, in a separate survey so that anonymity in the victimization survey could be maintained, provided demographic information about their children as well as participant contact information. Each of these 69 individuals was contacted at least once for follow-up interviews, and ultimately follow-up interviews were completed with 40 of the original survey respondents.

### **Interviews**

In-depth interviews were conducted with 40 respondents from within the original study population. As described above, these respondents were the primary caregivers of autistic children. The qualitative strategy of the follow-up interviews was designed to conduct phenomenological research through interviews focusing on specific cases of children who had experienced victimization (n=40). Phenomenological approaches are most appropriate for learning about a small group of individuals who have experienced a similar phenomenon (Creswell, 2007). In this case, the phenomenon is the experience of caring for a child with an autism spectrum disorder and considering their public and personal safety. A phenomenological procedure consists of identifying a phenomenon to



study, collecting data from various people who have experienced the phenomenon, and then analyzing that data by breaking text into quotes and combining meaningful text into themes. This text was organized and analyzed using QSR-NVivo software, which will be described in more detail below. Rather than focus on individuals who are victims of crime, the goal of the qualitative component of this study was to understand the phenomenon of this particular type of victimization.

Since a participant's interview could not be linked to their anonymous survey data, the interviews were necessarily exploratory and followed a semi-structured format. Because the survey was available to respondents across the country, interviews necessarily took place over the telephone. Although it is best to conduct interviews in person, research indicates that telephone interviews are the next best approach (Weiss, 1994), especially when respondents are confident in the identity of the researcher and in the confidentiality of the study (Tausig & Freeman, 1988).

With participant consent, most interviews were recorded using the services of Google Voice. Although no parents objected to the recording of phone calls, for various reasons (for example, when a parent did not want to call the Boston-based phone number or if a research assistant was simultaneously conducting a second interview when an interview was already being conducted on the Google Voice call line) some interviews were not recorded; during these interviews, in-depth notes were taken.

The interviews, conducted between July 2011 and February 2012, ranged in length from twenty minutes to an hour and gave parents and caretakers the opportunity to provide details about their children's victimization experiences that either were not captured by the survey or could not be explained adequately in the limited survey format.

### **Analysis**

Interviews were transcribed and the transcripts were verified against the audio recordings (n=40). The interview text was then uploaded into QSR-NVivo 9, a qualitative data analysis software package for coding and preliminary analysis. Additionally, survey data, in the form of textual responses to open-ended survey questions, were also imported into the software for analysis (n=262). Thematic codes were developed representing themes derived from the overarching research questions and emerging concepts from interviews.

## Findings

### **Risk Factors that May Increase Victimization among Autistic Youth**

Parents identified four main risk factors that they felt contributed to their children's vulnerability to abuse, neglect, maltreatment, or criminal victimization. These risk factors include 1) dependence on others for safety and well-being, 2) a lack of trustworthy friends despite strong desire for social acceptance, 3) a lack of a sense of danger, often manifesting in trust of strangers, and 4) little or no verbal proficiency. While some of these risk factors, discussed in greater detail below, overlap with what has been discussed in the broader literature on vulnerability of people with disabilities to victimization, all of these risk factors are inherent to autism spectrum disorders and therefore warrant careful consideration in terms of preventing the victimization of this special population.

### ***Dependence on Others for Care and Well-Being***

Many caregivers reported that their children were always under adult supervision. It was common for parents to report that the child was never without the supervision of a family member, with the exception of when their child was at school. As one caretaker reported, "He is with me when he is not in school, so I watch him all the time. I stopped blinking over four years ago," (Survey 7). Many parents reported that this level of vigilance was necessary to protect their child from potential victimization, but of equal concern for parents was the chance that the child would bolt, or suddenly run away. This problem, referred to in the autism community as elopement, constituted a major safety concern for the parents of autistic children in this study sample, exacerbated by the fact that parents had major fears about the ways their children's social deficits could lead to victimization.

Caretakers also recognized that whenever their children were out of the home and under the care of somebody else, they were at risk of victimization due to their extreme level of dependence on that other caretaker, whether a teacher, classroom aide, bus driver, or other service provider. Sometimes parents feared victimization by those entrusted with the care of their children. One parent even recognized how her son's acceptance of having caregivers could be a risk factor for abuse.

Well he's always had to have a caregiver. So he is used to somebody pretty close. And he is nonverbal. He's not going to tell you what hurts. He's not going to tell you what happened. And he's um, you know, his first reaction might not be one of crying or of fear, so it might take some time to realize if there was a place he

was afraid of, or crying, or that upset him. And also, you know, he would easily be, if someone could isolate him...I'm sure he could be sexually abused easily. (Interview 19)

Many parents expressed particular concern with the care their children received in school settings, often the only place where children were regularly out of their parents' supervision. Two major concerns were commonly discussed by parents relevant to their trust in school-based caretakers. First, parents often worried that the caretakers themselves, whether teachers, aides, or other school-based practitioners, might directly victimize their children. For many parents, this fear was not unfounded; several reported gross maltreatment and abuse of their children by school-based caretakers. A secondary concern was that these school-based caretakers would not supervise the children well enough to prevent their children from being bullied or mistreated by other children at school. One parent reported that due to insufficient caretaking, both of these problems had been a reality for her son. Similar experiences were reported by multiple survey and interview participants.

My child was bullied throughout his 4th grade year by his peers, through typical students harassing him by taking advantage of his processing and expressive disabilities to ridicule him, and by his classmates, through verbally abusing him and excluding him. He was also physically and emotionally abused by his teachers through inappropriate restraint and seclusion. He was put in a seclusion room several times that school year, with horrible results...one time when I arrived to pick him up, he was having a complete panic attack in the seclusion room, where he had been put by himself, and the aide was holding the door closed, while he was crying and begging to be let out. (Survey 2)

In situations in which students with ASDs are mainstreamed with typically-developing children for part of the school day, they may be dependent upon teachers who may be well intentioned but do not have the capacity to observe and supervise their student with special needs every minute of the day. One parent reported one such situation:

“My son was taunted and physically abused in math class in 7th grade, age 12. The teacher was monitoring the passing period outside her classroom door and did not see the abuse. Another

student stood up for him and the teacher handled it well when she found out,” (Survey 198).

Many children with ASDs are dependent upon trusted and caring service providers and caregivers to ensure their safety, whether at home, at school, or elsewhere in the community. Parents commonly felt that this dependence resulted in vulnerability, as many had experiences in which caretakers had proved to be untrustworthy or unable to provide adequate supervision to protect their children.

### ***Lack of Trustworthy Friends Despite a Strong Desire for Social Acceptance***

Another commonly reported risk factor for victimization was a strong desire to have friends without the capacity to understand and participate in healthy, reciprocal social interaction. It is important to note that difficulty with reciprocal social behavior is a problem inherent to autism spectrum disorders, making this risk factor particularly problematic and rather unique to the autistic population. Parents frequently noted that their children had few or no true friends. As one mother said of her daughter, “She tries so hard to fit in but can’t because she is so socially awkward. She only wants to be accepted by her peers but they want nothing to do with her,” (Survey 54). This problem was reiterated by another parent who attributed the problem directly to her son’s social skills deficit. “My son seems to always have been an easy target because he wants friends so bad but doesn’t have the appropriate social skills to “keep” friends, especially at that age,” (Survey 46). Another parent gave a more colorful description of her son’s social difficulties.

He’s ten years old. He basically has no friends, because he ...he talks above them, and he doesn’t know how to communicate with kids his own age. I mean, first he gets stuck on a subject and doesn’t want to get off of it. And you know...there’s only so much you want to talk about Legos before you really don’t want to talk about it anymore. (Interview 14)

While these parents express that their children cannot forge typical social relationships with their peers, other parents spoke more directly about how this difficulty was a risk factor for victimization. Some parents believe that a child without friends is a natural target for bullying. One parent explained that her son’s “lack of friends and the mean spiritedness of other children makes him a target for abuse,” (Survey 198). Another

parent expressed this same concern, saying, “[My son] is very trusting and wants friends so badly that he can't see that others might want to harm him,” (Survey 163).

Other parents confirmed that a lack of interpersonal competence was a risk factor for their child, as many were exploited for their inability to gauge the intentions of their peers, who took advantage of their desire for friendship and their social naïveté. One respondent explained that in his son's desire for social belonging, he was often drawn to peers who did not have kind intentions. “He tends to make (not keep) ‘friends’ who are more likely to get into trouble. One child once said he had a gun and was going to bring it to school and shoot my son,” (Survey 44).

Many parents described situations in which their children were coerced into engaging in harmful or disruptive behavior in the hopes of social acceptance. As one parent relayed,

A group of boys taunted him and told him that if he was cool, he would go up to a girl at school and touch her inappropriately. Of course he wanted to be friends with the boys and included in the cool group so he did (even though on several occasions my husband and I talked to him and explained appropriate behavior) and was caught. Thankfully, while we were in the principal's office one of his teachers over heard the boys bragging about it, and brought them to the office, or my son would have been expelled from school. (Survey 1)

Some of the children in this study engaged in potentially dangerous behaviors in the hopes of gaining social acceptance. One respondent reported the ways in which her son had been manipulated by his peers in the hope of increased social belonging. “My child was encouraged to (and did) eat grass, sand and trash on the playground when in 2nd and 4th grade,” (Survey 114). Another parent reported that her child was suspended from school following one of many incidents in which he was manipulated by another student.

My son is in the 5th grade and while he generally has had a good experience in school, he is sometimes goaded into doing inappropriate things...He was told to pull the fire alarm at school during lunch this year, 5th grade, 10 years old. The whole school had to be evacuated and the fire department had to come. He was suspended, but could not remember who it was that told him to do it. We had to come to a re-instatement hearing before they would

let him back in school and of course, the other student is off Scott free! (Survey 233)

The desire to belong, combined with a lack of understanding about how reciprocal interpersonal relationships work, constituted a major vulnerability for many of the children in this study.

### ***Trust of Strangers***

Due to deficits in social understanding, many parents expressed concern that their children demonstrated a trust of strangers or an inability to differentiate between strangers and trusted acquaintances. Some parents reported that their child did not understand that not all people are inherently good. One parent described their child's trust of strangers, saying, "At times he does not understand that all people are not nice," (Survey 215). Another parent echoed this sentiment, describing her child's social vulnerability in the following terms, "My son does not know any better, and does not understand there are good and bad people in the world. He has the biggest heart you will ever meet," (Survey 64). Another parent echoed the sentiment that her child could not distinguish between friends and strangers. Questioned about her biggest concern for her son's safety, she answered, "His inability to tell a friend from a stranger. He likes everyone. Wandering off by himself, letting strangers get too close to him because he does not realize that not all people are friendly," (Survey 16).

Other parents did not assume that their children were inherently trusting of strangers, but rather did not have the wherewithal to protect themselves from individuals that they do not know. One parent described her child's difficulty as: "He is too trusting of anyone, will start up a conversation with strangers. He has no fear, has no sense of 'stranger danger'," (Survey 69). Another parent described her child's inability to tell the difference between a stranger and an acquaintance. "He's very trusting and still thinks, at almost 11, that if he knows your name, you are not a stranger to him. He will walk up to anyone and start talking and find out their name. Now they aren't a stranger to him. That scares me," (Survey 141). In an interview, one mother described this vulnerability in more depth:

They [children with ASDs] can tend to be more naïve. Like really believing in the best of people, like not understanding that there's bad people... It's like other kids get that sense of toughness or that sense of irony or sarcasm, kind of looking out for yourself and seeing the dark side of people and seeing that people have bad

intentions sometimes. You kind of look for that to protect yourself. And I don't know if [my son] will ever evolve and do that. You know, I just don't think that will come naturally to him. I don't know if he'll ever teach himself that or if we're going to have to keep driving it home for him, but I just don't think it's a natural part of who he is. He won't do that like most kids do. And I wonder if they will get abducted, because they're just such friendly and naïve kids, and they trust people. And then they find out too late that they trusted the wrong person. (Interview 2)

Indeed, many parents told of incidents in which their children approached strangers with no hesitation. One parent said, "He will talk to everyone, [or] walk off with strangers if he's interested in something they have or say," (Survey 108).

Navigating these social boundaries is difficult for many children with autism spectrum disorders, regardless of functioning level or intellectual ability. One parent of a child with Asperger's Syndrome, an autism diagnosis typically characterized by above average intelligence, expressed that despite her son's high IQ, he still struggles with understanding and abiding by social boundaries, which may put him at risk for victimization. "My son Reece is very high functioning. The only challenge is that sometimes he will walk up to complete strangers and talk to them as if he knows them. That scares me that he might be easily led away. I never let him out of my sight," (Survey 13).

Prior research focused on teaching safety skills to individuals with intellectual disabilities finds that teaching people with disabilities to protect themselves from the lure of strangers is an important area of social skill instruction (Akmanoglu & Tekin-Iftar, 2011). Previous research has concluded that children with disabilities often have difficulty with communication and proper judgment, making it easier for perpetrators to coerce them into dangerous situations (Matson, 1984). The current study finds that children with autism are no exception; however, children with ASDs may require specialized social skill instruction, as these problems are definitional of their autism diagnosis and children with autism often have trouble generalizing social lessons in terms of their application in varied environments.

### ***Limited or No Verbal Proficiency***

While not all individuals with autism have a speech deficit, it is common for youth with ASDs to have limited, or sometimes no verbal ability. In the survey sample of the present study, 9.4% of children in the sample were

able to speak no or a few consistent words, 9% could speak words but not sentences, 20.8% were able to use sentences but did not have fluent speech, and 60.8% had fluent speech and the ability to construct complex sentences.

A lack of proficient verbal ability was considered by many parents to be a risk factor for victimization. Parents of children with limited or no speech commonly expressed fear that perpetrators might target their children specifically because they would not easily be able to report their victimization to parents, other caregivers, or other authority figures. In the words of one study participant, "the fact that [my son] doesn't speak makes him vulnerable," (Survey 4). Expressing this same concern, one parent said, "If [my son] didn't have autism, he may be able to speak and I would be able to better protect him. Right now I don't know what happens to him," (Survey 142). Similarly, another parent lamented that, "[my son] could be hurt and will not be able to clearly tell us what happened, or may not tell us anything at all," (Survey 169). In an interview, one parent expressed this problem based on her experience of observing bruises on her son without being able to ascertain how he had obtained them. This observation led to the realization that if he was being abused in other ways that did not leave physical evidence, she might never know.

That's the real pain. The real gut-wrencher. Unless he presents with a bruise or a cut, I'm not going to know...A couple of times he'd come home with a very round bruise. But we never know what he's doing in his own room...that he could've bumped into something. And you don't know how long it takes bruises to come up. So it's...I worry about that kind of stuff. I worry about him being sexually abused somewhere, because I would never know. (Interview 27)

While for some parents, this fear was unrealized, other caretakers reported that this fear is warranted, based on previous experiences in which they knew that their child had been victimized but, due to their child's inability to speak, they could never figure out exactly what happened. For example, one parent reported that she only figured out that her son was being mistreated by his classroom teacher's aide when she forgot to remove the evidence.

My child's shoes were taped to his ankles at school by his teacher's aide. My son was in third grade at this time, and is non verbal so he couldn't communicate to us that this was happening to him. The



teacher forgot to remove the tape from his ankles this day due to his wearing jeans. (Survey 34)

Another parent discussed a time when she believes her young daughter was victimized, though she still doesn't know exactly what happened. "About seven years ago she was on a school bus and her whereabouts were unknown for an hour. The school was only a five-minute bus ride from our residence. To this day I still don't know what happened due to the fact that she was not very verbal at that time," (Survey 145).

This fear was almost universal among parents of children with very limited speech. Even if parents had not had an incident of suspected victimization, the fear remained very real. One parent describes her anxiety about her son's vulnerability due to his lack of speech.

If I feel something is happening, Connor can't confirm that it happened. It's always going to be other people's word against mine. Connor is unable to communicate that anything is happening. Makes me very angry. The preschool that specialized in treating kids with autism that Connor attended is now under investigation for possible abuse of children. Several county child welfare agencies are investigating the preschool. What if they did something to him??? How will I ever know? (Survey 47)

Quantitative analysis of responses to the survey measures in this study indicate that parents of children with fluent verbal ability reported more victimization incidents than parents of children with limited or no speech (Pfeffer, 2013). However, based on the information gleaned from interviews and open-ended survey responses, it seems likely that children with limited speech are probably victimized at greater rates than parents were able to report on the survey, because they often do not know about the victimization faced by their children.

### **Protective Factors that May Decrease Risk of Victimization**

Caretakers identified several strategies that they believe help to diminish the likelihood that their children will face victimization. Each of the strategies described by parents involves some form of supervision, but the methods of supervision vary widely and include supervision by protective peers or siblings, supervision by adults/caretakers, virtual supervision using GPS or other technology, and supervision by service dogs.

### ***Protective Peers and Siblings***

Some parents expressed belief that the presence of protective peers, whether good-intentioned schoolmates or siblings, could help to decrease the chance that their children would be victimized. However, this seems to be highly dependent on individual personalities—both of the child with autism and his or her classmates, who may or may not have the child's best interest in mind when initiating social contact. An interviewee explained how her son's personality seemed to influence the level of protection he received from his peers.

Right now the kids are great. Right now the kids...especially girls, because right now he's like a walking doll and he likes it when girls hug him and take him by the hand and dragging him around everywhere and right now he loves the hand-holding thing and they love it. So they do look out for him and I have seen kids, like in the grocery store, I have seen kids that are not in the autism class say, "Oh, that's Kyle from my school. Hi Kyle." And it's amazing that they...they don't get offended if Kyle doesn't look in their face or say hi because they're too young. You know? So lots of kids at this age, they're very...they seem to be very in tune and willing to help or mentor because of his nature. (Interview 17)

Reliance on peers for protection can be fickle, as many peer relationships throughout childhood are tumultuous. One survey respondent, for example, discussed that although her son was currently popular with the other students, she had no assurance that his popularity among his classmates would remain consistent over time.

My son is 13, and I have received a few calls from school about bullying by other students. Luckily, my son is popular and the kids in his class are very protective. They tell on the bullies who are then reprimanded. However, as he gets older, I don't know how much longer he will maintain his "popularity" and worry that there will be no one to "have his back." (Survey 13)

Another parent expressed her belief that a sense of belonging among a group of friends would serve as a protective factor for her child. She said, "I think the buddy thing, if it works, will be really great at school. Because if you belong to a group it's harder to be victimized and stuff," (Interview 16).

Considered slightly more reliable than peers at school is the supervision of siblings. Siblings can also be counted on in many different

environmental contexts while the protective power of kind classmates is limited to school settings. One interviewee discussed how one of her children looked out for her autistic son. “I feel like my older son Jack spends a lot of time sort of looking out for him,” (Interview 25). Although it is helpful to parents to know that siblings could be relied on many different environments, not all parents expressed confidence in siblings. While most had kind intentions, some siblings were reported to instigate peer victimization.

### ***Supervision by Trusted Adults***

As has been discussed, many caretakers reported that in an attempt to protect their children, they do not entrust them to the care of other adults outside of school providers. The pressure for one or both parents to be home to personally supervise the autistic child can put great strain on interfamily relationships, effects can even be financial as this strain may influence a parent’s ability to employment. A survey respondent discussed the way that her child’s need for supervision impacts their family. “When the kids aren’t at school, they are always with my husband or myself. We have no one nearby who we would trust to babysit, which causes many problems, [such as] scheduling doctor appointments, trying to work during summer months, etc.”(Survey 196).

Another parent expressed concern with hiring a trusted babysitter for her child, even going so far as to conduct criminal background checks on potential babysitters before hiring them and leaving the children in their care (Survey 161). While out of the ordinary for many parents, a vigilant and careful selection of trusted caretakers is an essential component of ensuring the safety of their children.

### ***Virtual Supervision***

In addition to supervision by other individuals, parents often also relied upon technology to keep track of their children’s whereabouts, further ensuring their children’s safety. Most common among parents in this study sample was utilization of a program called Project Lifesaver, in which children with autism are outfitted with a GPS tracking device that is worn as a bracelet on their wrist. This bracelet, which cannot be removed, emits an individualized tracking signal. If the child goes missing, or is not where they should be at any given time, parents can call the local law enforcement agency that manages the Project Lifesaver Program, and they can identify the child’s location right away and send law enforcement to find and secure the child.

A secondary benefit of this program is that, since the batteries in the bracelets must be changed monthly, children with autism and their families have frequent exposure to law enforcement officers, who get to know their children and their individual traits. At least one parent found this to be beneficial when her child went missing.

My child wears a project lifesaver monitor, and a police officer comes to our house every month to change out the battery. There was one incident where my son escaped and we had to call the police to get them to look for him. Fortunately, he went to the door of a house in my neighborhood, the neighbor did not know my son (they don't live very close to us), but realized that my son was "different" and called 911. The officer that had been coming to change the battery in my son's monitor heard the 911 call, and was able to give information about him to the responding officers. This all happened about the same time as we were calling to have them look for him, so the project lifesaver equipment wasn't necessary. (Survey 184)

Unfortunately, while available in many municipalities nationwide, Project Lifesaver is not available in all parts of the United States, and many parents desire such a program but do not have access to it.

Parents have creatively utilized the latest cell phone technology to track their children. As one survey participant reported, "[My daughter] is oblivious to dangers. She will wander or talk herself into dangerous situations. We have her keep a GPS equipped cell phone on her at all times to assist if she ever wanders or gets lost," (Survey 54). Similarly, another parent utilizes an application on her son's iPhone to locate him when he is away from home.

There's no doubt I'm a mother hen type. I'm keeping a pretty close eye on him and he has an iPhone now. And there's this thing called "Find My iPhone", which has turned out to be incredibly convenient. It means that if he has his phone and it's turned on, I can, on my phone, find his phone. I can find Paul. Because if you lose your phone it tells you where your phone is. But it also means that I can know where he's at. So if I open up my phone and find my iPhone for Paul's iPhone, it tells me where Paul is. I can locate him. (Interview 18)

Caretakers utilize technology to extend their limited capacity to personally supervise their children. These tools are especially useful for autistic children who wander or elope, a common behavior among autistic youth, which places these children at special risk (Anderson, et al., 2012).

### ***Supervision by Service Dogs***

A final method of supervision that parents commonly mentioned in the current study that is believed to protect children against potential victimization was the use of specially trained service dogs. There are many potential ways that a service dog may protect an autistic child from victimization. At a basic level, they act as a physical barrier between the child and any potential perpetrators. Research also finds that service dogs help protect autistic children from environmental dangers in places such as in the home, walking outside, in cars, and in shopping centers (Burgoyne et al., 2014). Additionally, it is common for caretakers to use a lead and belt to tether their child to the service dog, binding them physically. The dogs are then trained to sit or lie down and remain in place if the child tries to bolt. If children are successful in wandering or are led away from where they should be, the dogs are trained to lead them back to a familiar place (Burgoyne, et al., 2014).

## **Discussion**

This study identified factors that caregivers of children with autism perceived as affecting children's safety in their homes, in their school settings, and in the community. Many factors are consistent with those found in the broader literature concerning risk factors for the victimization of people with disabilities more generally. However, some factors have not been previously identified, or have not been identified as having particular importance for this specific population. For example, this study finds that one manifestation of the social deficits inherent to autism spectrum disorders is that children with autism frequently do not display a natural distrust of strangers, which may place them at particular risk of victimization. This study also finds that the inability to speak fluently may place children with autism at risk for victimization, as perpetrators may understand that these children have difficulty reporting victimization.

A significant limitation of this study is that caregivers were not likely to report on familial risk factors or risk factors originating in the home. There were additional limitations to the subject recruitment strategy, namely that participating caretakers were self-selected. Although the invitation to participate in the survey was distributed to all IAN participants who are caretakers of autistic children, only the potential respondents

interested in the survey completed it. In addition, the pool of potential caretaker respondents was limited to those who had elected to participate in IAN research in the first place. Caretakers who did not have access to the Internet or who did not have the time or interest to participate in such research are absent from the sample. Parents of autistic children who register to be part of IAN research are not necessarily representative of all parents of autistic children.

This is the first qualitative study of factors that may affect an autistic child's risk of victimization. The findings of this study point to several recommendations that may decrease the risk of victimization for these children. One strategy that may reduce bullying in particular is the implementation of structured mentorship or buddy systems in schools that pair autistic and typically functioning children at schools, which may increase the presence of capable guardianship for autistic children in schools.

Another recommendation would be to implement social skills training to increase the children's awareness of strangers and proper social boundaries, focusing on preventive safety skills. Preventive safety skills serve to avoid potentially dangerous prior to their occurrence (Akmanoglu & Tekin-Iftar, 2011).

This study also finds that there should be specialized training and technology for autistic children with limited verbal ability to report their victimization to parents or other caretakers. School and law enforcement authorities should be trained to interact with and question children with limited or no speech, using whatever communicative technology the child prefers.

However, this study finds that there are patterns in both the risk and protective factors identified by caretakers of autistic children. Many of the risk factors are directly related to problems inherent to autism spectrum disorders, while all of the protective factors that parents identified involved either direct supervision by trusted individuals or the utilization of tools to increase the ability of trusted individuals (such as parents or law enforcement) to supervise the children. Considered through the perspective of theories of crime prevention, this suggests that the most effective way to prevent the victimization of children with autism might be to assign more responsibility for the prevention of crime against people with autism to others who are capable of providing this protection, rather than relying on individual lessons of safety. Theories of crime prevention may provide more systematic methods for considering the safety of autistic children. Future research should consider the application of situational crime prevention methods, such as target hardening, to prevent

crimes against children with autism, as this study finds that these individuals face victimization risk for reasons beyond their control.

## References

- Akmanoglu, N. & Tekin-Iftar, E. (2011). Teaching children with autism how to respond to the lures of strangers. *Autism, 15*(2), 205-222. doi:10.1177/1362361309352180
- Allen, D., Evans, C., Hider, A., Hawkins, S., Peckett, H. & Morgan, H. (2008). Offending behaviour in adults with Asperger Syndrome. *Journal of Autism and Developmental Disorders, 38*(4), 748-758. doi:10.1007/s10803-007-0442-9
- American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders* (5<sup>th</sup> ed.). Washington, DC: American Psychiatric Association.
- Anderson, C., Law, J. K., Daniels, A., Rice, Catherine, Mandell, D.S., Hagopian, L., & Law, P.A. (2012). Occurrence and family impact of elopement in children with autism spectrum disorders. *Pediatrics, 130*(5), 870-877. doi:10.1542/peds.2012-0762
- Baio, J. (2014). Prevalence of Autism Spectrum Disorders Among Children Aged 8 Years—*Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010*. Atlanta, GA: Centers for Disease Control. Retrieved from <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm>.
- Baron-Cohen, S. S. (1988) An assessment of violence in a young man with Asperger's syndrome. *Journal of Child Psychology & Psychiatry and Allied Disciplines, 29*(3), 351-360. doi:10.1111/j.1469-7610.1988.tb00723.x
- Burgoyne, L., Dowling, L., Fitzgerald, A., Connolly, M., Browne, J.P., & Perry, I.J. (2014). Parents' perspectives on the value of assistance dogs for children with autism spectrum disorder: A cross-sectional study. *BMJ Open, 4*(6), e004786. doi:10.1136/bmjopen-2014-004786
- Creswell, J. W. (2007). *Qualitative Inquiry & Research Design: Choosing Among Five Approaches*. Thousand Oaks, CA: Sage.
- Farrington, D. P. & Welsh, B. C. (2008). *Saving Children from a Life of Crime: Early Risk Factors and Effective Interventions*. New York: Oxford University Press.
- Finkelhor, D. & Asdigian, N. L. (1996). Risk factors for youth victimization: Beyond a lifestyles/routine activities theory approach. *Violence and Victims, 11*(1), 3-19.
- Furey, K., Granfield, J. M. & Karan, O. C. (1994). Sexual abuse and neglect of adults with mental retardation: A comparison of victim characteristics. *Behavioral Interventions, 9*(2), 75-86. doi:10.1002/bin.2360090202



- Hindelang, M. J., Gottfredson, M. R. & Garofalo, J. (1978). *Victims of Personal Crime: An Empirical Foundation for a Theory of Personal Victimization*. Cambridge, MA: Ballinger.
- Hughes, K., Bellis, M. A., Jones, L., Wood, S., Bates, G., Eckley, L., McCoy, E., Mikton, C., Shakespeare, T., & Officer, A. (2012). Prevalence and risk of violence against adults with disabilities: A systematic review and meta-analysis of observational studies. *The Lancet*, 380(9845), 899-907. doi:10.1016/S0140-6736(12)60692-8
- Kazdin, A. E., Kraemer, H. C., Kessler, R. C., Kupfer, D. J., & Offord, D. R. (1997). Contributions of risk-factor research to developmental psychopathology. *Clinical Psychology Review*, 17(4), 375-406. doi:10.1016/S0272-7358(97)00012-3
- Langstrom, N., Grann, M., Ruchkin, V., Sjostedt, G. & Fazel, S. (2009). Risk factors for violent offending in autism spectrum disorder: A national study of hospitalized individuals. *Journal of Interpersonal Violence*, 24(8), 1358-1370. doi:10.1177/0886260508322195
- Little, L. (2002). Middle-class mothers' perceptions of peer and sibling victimization among children with Asperger's syndrome and non-verbal learning disorders. *Issues in Comprehensive Pediatric Nursing*, 25: 43-57.
- Matson, J.L. (1984). Talking about the best kept secret: Sexual abuse and children with disabilities. *The Exceptional Parent*, 14(6), 15-20.
- Nettleback, T. & Wilson, C. (2002). Personal vulnerability to victimization of people with mental retardation. *Trauma, Violence, & Abuse*, 3(4), 286-306. doi:10.1177/1524838002237331
- Oellette-Kuntz, H., Coe, H., Lloyd, J. E. V., Kasmara, L., Holden, J. J. A. & Lewis, M. E. S. (2007). Trends in special education code assignment for autism: Implications for prevalence estimates. *Journal of Autism and Developmental Disorders*, 37(10), 1941-1948. doi:10.1007/s10803-006-0326-4
- Pfeffer, R. (2013). "Autistic and at-risk: the public and personal safety of children with autism spectrum disorders" *Criminology and Justice Policy Dissertations*. Paper 15.
- Premack, D., & Woodruff, G. (1978) Does the chimpanzee have a 'theory of mind'? *Behavioral and Brain Sciences*, 1(4), 515-526.
- Rand, M. & Harrell, E. (2009). *National Crime Victimization Survey: Crime Against People with Disabilities*. Washington, DC: Office of Justice Programs, U.S. Department of Justice.
- Reiter, S., Bryen, D. N., & Shachar, I. (2007). Adolescents with intellectual disabilities as victims of abuse. *Journal of Intellectual Disabilities*, 11(4), 371-387. doi:10.1177/1744629507084602

- Ryerson, E. (1984). Sexual abuse and self-education for developmentally disabled youth: A priority need. *SIECUS Report*, 13, 1-3.
- Sampson, R. & Lauritsen, J.L. (1994). Violent victimization and offending: Individual-, situational-, and community-level risk factors. In A. J. Reiss & J. A. Roth (Eds.), *Understanding and Preventing Violence*, Vol. 3. Washington, DC: National Academy Press.
- Schreck, C. J., Miller, J. M. & Gibson, C. L. (2003). Trouble in the school yard: A study of the risk factors of victimization at school. *Crime & Delinquency*, 49(3), 460-484. doi:10.1177/001128703049003006
- Slaughter, V., Dennis, M.J. & Pitchard, M. (2002). Theory of mind and peer acceptance in preschool children. *British Journal of Developmental Psychology*, 20(4), 545-564. doi:10.1348/026151002760390945
- Sobsey, D. & Doe, T. (1991). Patterns of sexual abuse and assault. *Journal of Sexuality and Disability*, 9(3), 243-259. doi:10.1007/BF01102395
- Sobsey, D., Lucardie, R. & Mansell, S. (1995). *Violence and Disability: An Annotated Bibliography*. Baltimore, MD: Paul H. Brooks.
- Stokes, M., Newton, N. & Kaur, A. (2007). Stalking, and social and romantic functioning among adolescents and adults with autistic spectrum disorder. *Journal of Autism and Developmental Disorders*, 37(10), 1969-1986. doi:10.1007/s10803-006-0344-2
- Tausig, J.E. & Freeman, E.W. (1988). The next best thing to being there: Conducting clinical research interview by telephone. *American Journal of Orthopsychiatry*, 58(3), 418-427.
- Turner, H. A., Vanderminden, J., Finkelhor, D., Hamby, S. & Shattuck, A. (2011). Disability and victimization in a national sample of children and youth. *Child Maltreatment*, 16(4), 275-286. doi:10.1177/1077559511427178
- U.S. Department of Education. (2013). *Digest of Education Statistics, 2012*. U.S. Department of Education, National Center for Education Statistics. Retrieved from <http://nces.ed.gov/pubsearch/pubsinfo.asp?pubid=2014015>. Published December 31, 2013.
- Van Roekel, E., Scholte, R. H. J., & Didden, R. (2009). Bullying among adolescents with autism spectrum disorders: Prevalence and perception. *Journal of Autism and Developmental Disorders*, 40(1), 63-73. doi:10.1007/s10803-009-0832-2
- Walmsley, S. (1989). The Need for Safeguards. In H. Brown & A. Craft (Eds.), *Thinking the unthinkable: Papers on Sexual Abuse and People with Learning Difficulties*. London: FPA Educational Unit.

- Weiss, R. S. (1994). *Learning from Strangers: The Art and Method of Qualitative Interview Studies*. New York, NY: The Free Press.
- Wilson, C. & Brewer, N. (1992). The incidence of criminal victimization of individuals with an intellectual disability. *Australian Psychologist*, 27(2), 114-117. doi:10.1080/00050069208257591