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**Internet Use Among Parents of Children with
Autism Spectrum Disorders (ASD)**

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Dedication

To the parents in this study (and to my own)
Who gave so much to meet their children's needs
And to those who have kept their watch for me

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Internet Use Among Parents of Children with Autism Spectrum Disorders (ASD)

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Parents of children with autism spectrum disorders (ASD) are uniquely stressed by the difficult behaviors of their children which often result in isolation, depression and financial burden. The causes of ASD are not well-understood but are believed to result from a complex interplay between genetic and environmental factors. There is no standard treatment protocol for ASD. Since early intervention is associated with more favorable outcomes for the child, many parents search the Internet hoping to find effective therapies and treatments. This study employed Naturalistic Inquiry methodology, as described by Lincoln and Guba (1985), to explore how parents of children with ASD use the Internet, what kinds of information the parents were seeking and how they located, evaluated and chose to use ASD-related information. Twelve parents of children with ASD were interviewed for the study. Data consisted of bio-demographic information and transcribed interviews. Data was unitized and analyzed inductively; coded descriptively, topically and analytically (Morse & Richards, 2002) in a recursive manner using the constant comparative method (Glaser & Strauss, 1967). Rigor and data trustworthiness were enhanced by using data management and analysis strategies to ensure credibility, fittingness and auditability (Lincoln and Guba, 1985; Beck, 1993). Findings revealed that parents searched with intensity and urgency for

information about causes, treatments, how to interpret symptoms of ASD and to confirm their child's diagnosis. They searched in response to unsatisfactory experiences with the healthcare and educational systems. Parents reported that they would like more information online about strategies to handle difficult behaviors, respite care, encouragement for daily living and how to access direct services for their children.

Table of Contents

CHAPTER 1: INTRODUCTION	1
Overview of Autism Spectrum Disorders (ASDs).....	1
The Internet	6
Purpose of Study	8
Naturalistic Inquiry	9
Data Analysis and Management	9
Findings.....	10
Summary	10
CHAPTER 2: REVIEW OF LITERATURE	12
Introduction.....	12
Screening.....	15
History of Autism – 1940s to present	15
Prevalence of ASDs	16
Vaccine Controversy.....	18
Genetics.....	22
Twin studies	22
Genetic syndromes.....	23

Copy number variations.....	23
Linkage and association studies, genetic screens	24
Environmental and other risk factors	25
Educational and Clinical Interventions for ASDs.....	26
Applied Behavioral Analysis (ABA).....	26
TEACCH.....	27
Relationship-focused interventions.....	27
Speech and language therapy.....	28
Occupational therapy	28
Pharmacology	28
Complementary and alternative therapies.....	29
Parental Responses to Having a Child with ASD.....	33
The Internet	38
The Internet and Health.....	40
CHAPTER 3: METHODOLOGY	46
Introduction.....	46
Research Questions.....	46
Naturalistic Inquiry	47
Data Collection and Management.....	51
Interviews.....	51
Sampling strategies	51

Saturation	53
Inclusion criteria	53
Recruitment and informed consent	54
Confidentiality	56
Instruments and interviewing strategies.....	56
Software for data management	58
Software for coding support.....	59
Summary	63
Data analysis strategies	64
Coding strategies.....	67
Strategies to Ensure Rigor	68
Credibility	68
Fittingness	69
Auditability	69
Summary of Study Results.....	70
CHAPTER 4: FINDINGS	71
Introduction.....	71
Demographic Profile of Study Participants	72
Searching.....	73
Why They Searched.....	76
Healthcare system issues.....	76

Summary	85
Educational system issues.....	85
What They Searched For	91
Confirming diagnosis.....	92
Causes	93
Understanding symptoms.....	96
Therapies and treatments	98
Summary	104
How and Where They Searched	104
Methods of searching for information	104
Determining trustworthiness of information.....	105
Trusted Internet sources	109
Other Sources of Information	111
What They Did Not Find	114
Summary	117
What Else of Value They Found.....	118
Summary of Findings.....	123
CHAPTER 5: DISCUSSION, RECOMMENDATIONS & CONCLUSIONS	125
Comparison of Findings to the Literature.....	127
Implications of the Findings	137
Limitations	140

Recommendations for Further Research.....	141
Conclusions.....	145
Appendix A...List of Abbreviations.....	147
Appendix B...Recruitment Flyer.....	149
Appendix C...Recruitment Script.....	150
Appendix D...Subject Consent Form.....	152
Appendix E...Bio-demographic Survey.....	157
Appendix F...Interview Guide.....	159
Appendix G...Examples of Coding.....	161
Appendix H...Categories of Data.....	163
References.....	164
Vita	

Chapter 1: Introduction

This chapter provides a summary of the literature surrounding the issues related to the autism spectrum disorders (ASDs), their prevalence in the United States, and how they typically are diagnosed. Potential causes of ASDs and treatment options for children with ASDs are presented as well as a summary of the literature describing the unique stresses of parents of children with ASD and how they and others use the Internet in response to their needs for health-related information. The philosophical underpinnings and rationale for the use of the research methodology, naturalistic inquiry, is provided. This is followed by the findings of the study and how these findings answer the research questions about the context and motivation for Internet use among parents of children with ASDs. The chapter also will describe the use of qualitative research software, NVivo 7 (NVivo 7, 2007) to code and store interview data along with the methods that were utilized to ensure the rigor and trustworthiness of the findings. Finally, the chapter provides an overview of the study findings.

OVERVIEW OF AUTISM SPECTRUM DISORDERS (ASDs)

Autism spectrum disorders are neurodevelopmental disorders affecting 1:150 children in the United States (CDC, 2007). The ASDs include autism disorder (AD), Asperger's syndrome (AspS), and pervasive developmental disorder not-otherwise-specified (PDD-NOS). The ASDs are categorized as pervasive developmental disorders in the Diagnostic and Statistical Manual of Mental Disorders 4th edition (DSM-IV-TR) (APA, 2000). Rett syndrome and Childhood Disintegrative Disorder are the other two

pervasive developmental disorders. Rett syndrome and Childhood Disintegrative Disorder are relatively rare and not included in this discussion.

All of the ASDs are characterized by varying degrees of impairments in communication and social interactions and the presence of restricted, repetitive, and stereotyped patterns of behavior (Newschaffer et al., 2007). The most severe form of the three ASDs is autism disorder (AD); the least severe is Asperger's syndrome (AspS). If a child has symptoms of either AD or AspS, but does not meet the criteria for either, the diagnosis given is PDD-NOS (Newschaffer et al., 2007).

The United States prevalence of ASDs is estimated to be 60 per 10,000 or 1 in 150, based on summary prevalence data among 8-year-olds in multiple United States communities (CDC, 2007) in 2007. For decades, the best estimate for prevalence of autism was four to five per 10,000 (CDC). Many experts attribute the increased reported prevalence to broadened diagnostic criteria and improved awareness (Muhle, Trentecoste, & Rapin, 2004), but a real increase in incidence of ASD due to environmental and epigenetic factors acting upon a genetically vulnerable background is also likely (Lintas & Persico, 2009). Many parents suspect that childhood vaccines cause AD, but most studies do not support a causal connection between AD and vaccines (Offit, 2008).

There was no biological basis for understanding ASDs until 30 years ago. The psychoanalytic interpretation that autism is caused by cold and uncaring mothers (Bettelheim, 1967) lost credibility in 1977 when the first of several concordance studies of twins with ASD demonstrated a strong genetic and biological basis for AD (Folstein & Rutter, 1977, 1997). Monozygotic twins had a concordance rate of 60%; dizygotic had 0% concordance. Rare genetic disorders such as Fragile X and tuberous sclerosis are known causes of ASDs and are called syndromic autism and represent less than 1% of all

cases (Abrahams & Geschwind, 2008). Other causes of ASDs are unclear, but are most likely related to a complex interplay between environment and genetic make-up. Other possible causes include prenatal and perinatal complications (Glasson et al., 2004), viral exposures like rubella (Abrahams & Geschwind, 2008), and increased age of the father (Reichenberg et al., 2006) which may be related to *de novo* copy number variations (CNVs), which are spontaneous genetic mutations occurring in the sperm or egg before conception (Rapin & Tuchman, 2008). Despite recent advances in molecular genetics knowledge and technology, the promise of a “cure” or finding “the autism gene” seems unlikely given the genotypic and phenotypic heterogeneity of the disorder and the complexity of the genetics involved.

Parents of children with ASD and other advocates are frustrated that research has not yielded a better understanding of the causes of ASD and that there are very few documented optimal treatment strategies for ASDs. Some of the clinical and educational interventions include: Applied Behavioral Analysis (ABA) (Lovaas, 2003), Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH) (Mesibov, Shea, & Schopler, 2005), relationship-focused interventions such as Developmental, Individual-Relationship-based mode (DIR) (Greenspan & Wieder, 1997), Relationship-Development Intervention (RDI) (Gutstein & Sheehy, 2002), and Responsive-Teaching curriculum (RT) (Rogers, 1998). (A List of Abbreviations is provided in Appendix A.) There are also speech, language, and occupational therapies. The FDA recently approved the use of risperidone for irritability and aggression in children and adolescents with ASD; there is also some “off-label” (not FDA-approved) use of olanzapine for aggressive behaviors. Some of the SSRIs that have been approved

for obsessive compulsive disorder and depression may also be used to treat individuals with ASDs (NIMH, 2008).

The use of complementary therapies by parents for their children with ASDs is commonplace. Examples of non-biomedical complementary interventions include auditory integration training, behavioral optometry, craniosacral manipulation, dolphin-assisted therapy, music therapy, and facilitated communication (Levy & Hyman, 2005). Complementary biomedical interventions include dietary restrictions of food allergens, administration of antiviral agents, detoxification therapies, gastrointestinal treatments or diets such as the gluten-free casein free diet, dietary supplements such as vitamins or other compounds that are believed to modulate neurotransmission through immune factors or epigenetic mechanisms (Gupta, 2004; Levy & Hyman, 2005).

Many of the therapies used in the treatment of ASDs cannot be evaluated using evidence-based criteria because of methodological flaws, inadequate sample sizes or lack of replication of studies (Myers et al., 2007); however, as Levy and Hyman (2003) note, many commonly used medical treatments have not met standards of rigor. Parents might perceive it to be inconsistent or hypocritical to hold complementary therapies to a higher standard of evidence than are held conventional therapies. Nevertheless, even when certain studies failed to demonstrate the effectiveness of a therapy, some parents have continued to press for its use (Levy & Hyman, 2003).

Green et al. (2006) surveyed parents of children with ASD and found they were using an average of seven different unvalidated treatments. Similarly, the parents of children with ASD in the survey conducted by Goin-Kochel et al. (2006) were using, on average, between four and six treatments and had been previously been using between seven and nine complementary therapies. Parents revealed they were almost always on

the lookout for other therapies to try, not wanting to miss the one treatment that might help their child (Goin-Kochel et al., 2006).

Determining if any therapy, whether complementary or conventional, would have a therapeutic effect on a child with ASD is difficult, time-consuming, and expensive. Compounding the parents' pressure is a lack of standard treatment guidelines for ASD (Thorne, 2007). Many parents have taken matters into their own hands by researching on the Internet the potential causes of and treatments for ASD. These parents search assiduously for information about alternative and conventional therapies and other possible ways to ameliorate symptoms or improve their child's functioning, yet no one can tell them with certainty which therapies might be best for their child (Mackintosh et al., 2005).

It is not surprising that the families of ASD children suffer additional stress including less marital happiness and family adaptability and diminished parental earning potential (Dunn et al., 2001; Higgins et al., 2005; Hodapp, 2002). Parents are likely to score higher levels of aggravation than parents of children with other developmental problems (Schieve et al., 2007), while over half of mothers with children with ASDs screened positive for significant psychological stress (Bromley et al., 2004). Other studies report parental depression, anxiety, decreased family cohesion, and increased somatic complaints when compared to other parents of typically developing children (Higgins et al., 2005; Sivberg, 2006; Weiss, 2002). Still other studies reveal that families experience autism as an event that controls their lives (DeGrace, 2006), and that caring for children with an ASD can result in caregiver burden among parents (Bloch & Gardner, 2007) and a shift to emotion-based coping strategies from problem-based coping strategies (Gray, 2006). There is a concern that using clinic-based versus population-based sampling of

parents in these studies may have created biased results. Montes and Halterman (2007) found that mothers of children with ASD were indistinguishable from mothers in the general population with respect to having a close relationship with their child, feeling angry toward their child, and coping with parenting tasks.

THE INTERNET

The Internet was developed in the 1960s as a U.S. military communication system and later used exclusively by academic and research organizations. The Internet was made available for public use in 1995. The Internet is composed of many interconnected computer networks which allows anyone with Internet access to communicate with anyone else on-line, post information, retrieve information, use distant applications and services, and buy or sell products (Comer, 2000).

The 2006 Pew Internet and Life Project reported that 113 million, or 80% of U.S. Internet users, seek health information on line (Fox, 2006) and likely are relying more on the Internet for health information than they are relying on their physicians (Zaidman-Zait & Jamieson, 2007). Most seek information about specific diseases (65%), treatments (51%), and diet and nutrition (49%) (Fox, 2006). To cope with the uncertainty of illnesses or disturbing aspects of symptoms, many seek emotional support provided by online discussion groups, instant messaging and asynchronous modes, such as e-mail and blogging (Jones & Lewis, 2001; Wright, 2000, 2002). Parents of children with ASD have difficulty obtaining adequate information and support to guide them in the care of their children (Huws et al., 2001), hence, many use the Internet to get their information needs met.

People affected by many disorders, such as irritable bowel syndrome, breast, ovarian and prostate cancers, hysterectomy, and multiple sclerosis, use the Internet to obtain information and support about their health concerns, but very few studies exist about the use of online resources by parents of children with ASD (Bunde et al., 2006; Coulson, 2005; Weis et al., 2003; Winefield, 2006). Mackintosh et al. (2005) found that 86% of parents of children with ASD used websites, e-mail, and listserves as information sources; Huws et al. (2001) determined that parents used group e-mail as a social support mechanism to make sense of ASDs.

Bernhardt and Felter (2004) used focus groups to determine that mothers of typically developing children use the Internet to seek online health information and that these mothers evaluated the information's credibility by looking for replication among different sources and using websites ending in "edu" or "org" rather than the for-profit designation "com." One study has determined that very few Internet users check the source and date of information that they found on line and 66% of Internet users began their session using a search engine and 27% started at a website (Fox, 2006). Although many searchers felt confident of their findings, 25% said they felt overwhelmed, 22% felt frustrated, and 18% felt confused (Fox, 2006). Eysenbach and Kohler (2002) found that participants professed to check the accuracy of Internet information about health, but when observed in a computer lab they failed to check the "about us" or any disclaimer statements on the websites.

Parents of children with disabilities including ASD cited a number of advantages to using online information for information and support. These advantages include: the provision of anonymity, access to broad sources of information about obscure diseases and clinical trials and practical advice from other parent about potential treatments,

interactive educational tutorials, and videoconferencing (Zaidman-Zait & Jamieson, 2007). Disadvantages included feeling overwhelmed by the volume of information and a concern that Internet authors are not held accountable for the quality and accuracy of information posted (Zaidman-Zait & Jamieson, 2007).

The number of therapies parents seek and employ for their children with ASD (Goin-Kochel et al., 2006) speaks to the urgency with which parents are evaluating and choosing these therapies. Many parents feel that they do not have time to wait for data to confirm treatment effectiveness and must press ahead in hopes that the latest treatment will be effective. Hence, it was important to understand how parents use the Internet to find and choose therapies and treatments and how parents assess the credibility and adequacy of the information they find online.

PURPOSE OF STUDY

The purpose of this study was to improve understanding of how parents of children with ASD used the Internet to find information about ASD, how parents might have used this information to select therapies for their children, and how parents assessed the trustworthiness and viewed the adequacy of Internet-derived information and support.

The study used naturalistic inquiry to answer the following research questions:

1. How do parents of children with ASD use Internet resources in response to their needs as parents and caregivers?
2. How do parents evaluate the trustworthiness and describe the adequacy of information and support that they find on the Internet?

3. How do parents of children with ASD choose Internet-derived information and how does this information influence their decisions about their choice of treatments and therapies for their child?

NATURALISTIC INQUIRY

Naturalistic inquiry (NI) as described by Lincoln and Guba (1985) was used to guide this exploratory study. NI is an appropriate research paradigm or methodology for the study because it emphasizes the contextual and subjective aspects of inquiry that are necessary for understanding human behavior. Lincoln and Guba describe the interdependence of cause and effect and a mutual simultaneous shaping that occurs between researcher and participant during the research process. Hence, any solution or problem-solving that is concurrent with the research process must be holistic because one part of the problem or phenomenon will affect the other. Since being a parent of a child with a neurodevelopmental disability such as autism is not a single tangible reality that can be reduced and approximated, NI is an appropriate methodological approach for the study. NI allows for exploration and discovery of the multiple constructed realities held by individuals like these parents and the only way the researcher can know or understand the unknown (the parents' reality) is through sharing the beliefs or constructions of these parents (Pickard & Dixon, 2004).

DATA ANALYSIS AND MANAGEMENT

Twelve parents of children with ASDs participated in the study. All study procedures were approved by the Institutional Review Board (IRB) of the University of Texas Medical Branch (UTMB) and study participants gave written informed consent. Study data consisted of bio-demographic and interview data. All data, collected by the

investigator, was audio-recorded for later transcription. The recorded interviews were transcribed and stored on a notebook computer and an external hard drive. All identifying information was removed from the data and codes were assigned to each participant in order to maintain confidentiality. Data analysis was accomplished using the constant comparative method (Glaser & Strauss, 1967). NVivo 7, a qualitative research management software, was used for data management (QSR, 2006).

FINDINGS

Data analysis revealed that the parents of children with ASDs used the Internet to search with intensity and urgency about ASD-related information, especially right after receiving the diagnosis of ASD. They were motivated to search the Internet due to inadequate information and support received from healthcare and educational systems. Parents in the study searched to confirm their child's diagnosis, research possible causes of ASD, improve their understanding of symptoms, and to evaluate and locate practitioners, therapies and treatments. They used search engines and evaluated websites for credibility by assessing their professional appearance and sponsorship; some parents relied on their education and training to assess quality of online information. A few parents also reported using web-based wireless technologies in unexpected ways including monitoring the child's teacher, storing information about the child's educational development and helping the child communicate with an assistive device.

SUMMARY

This chapter has provided an overview of the description, prevalence, possible causes of ASDs and some of the unique stressors experienced by parents of children with ASD. The increasing use of the Internet among individuals seeking health information

online, that includes parents of children with developmental disabilities such as ASD, is described. Data analysis strategies as well as methods used to ensure trustworthiness have been detailed including the use of qualitative research software for data management and auditability. How parents used and evaluated online information was described along with the underlying principles of NI, the research questions used to guide this study, and the research methodology of the constant comparative method.

Chapter 2 provides a more complete review of the literature concerning ASDs, the Internet and the use of the Internet among parents of children with ASDs. Chapter 3 provides an in-depth discussion of the methodological aspects of the study, including data management, data analysis and a justification for the use of NI. The findings of the research are presented in detail in Chapter 4. Chapter 5 discusses the research findings in relation to extant literature, limitations of the study, recommendations for future research and the implications of the study findings.

Chapter 2: Review of the Literature

INTRODUCTION

This chapter reviews the literature describing ASDs, including their characteristics, prevalence, and causes, as well as findings in the area of molecular genetics research that help to elucidate heritability of ASDs. Some conventional and alternative therapies and educational interventions for children with ASD are reviewed. A brief description of the Internet is provided and how it has been used by a variety of individuals seeking health-related information. The chapter concludes with a description of the unique stresses of parents of children with ASD and why this study was undertaken to understand and explore the context and their motivation for Internet use.

The ASDs represent a wide range of neurodevelopmental conditions characterized by limitations in three core areas: 1) reciprocal social interactions and social functioning; 2) language and speech impairments; and 3) stereotypical repetitive behaviors (American Psychiatric Association [APA], 2000). ASDs correspond to three of the five pervasive developmental disorders defined in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (APA), and International Classification of Diseases (ICD-9) (WHO, 2000). The three pervasive disorders include: AD, AspS, and PDD-NOS. The term ASD does not include the two relatively rare pervasive developmental disorders included in the DSM-IV which are Rett syndrome and

childhood disintegrative disorder. Rett syndrome affects mostly females. It is characterized by an early loss of social engagement, a pattern of acquired microcephaly, loss of hand skills usually in the end of the first year of life, and progressive development of gait disturbance, and stereotypic hand movements (Freitag, 2007). Childhood disintegrative disorder is a rare disorder in which there is apparently normal development until two years of age followed by a significant loss of skills before aged 10 (Freitag, 2007).

There is no biologic diagnostic test for ASDs; the diagnostic criteria are behavioral and are specific to numbers and levels of impairment in the three core areas of language, social impairment, and repetitive behaviors (Newschaffer et al., 2007). AD, AspS, and PDD-NOS differ regarding symptom severity, early development of language, and cognitive and social behavior (Freitag, 2007). Individuals with AD show impairment in all three core areas (social, language, and repetitive behavior) and abnormal development before three years of age (Freitag, 2007). Asperger's Syndrome (AspS) is characterized by qualitative impairment in social interaction, restricted, repetitive, and stereotyped patterns of behavior, interests and activities with an apparently normal language and cognitive development before 3 years of age (Freitag, 2007). Individuals with AspS differ from those with AD because they do not experience language delays and consistently have average-to-above-average cognitive skills (Newschaffer et al., 2007). Individuals with PDD-NOS show impairment in the social domain, but their pattern or severity in the social domain or in the other two domains (language and repetitive behaviors) is insufficient to meet diagnostic criteria for AD (Newschaffer et al.,

2007).

Rapin and Tuchman (2008) offer a description of ASDs that is less illness-oriented than other definitions. They emphasize that autism is not a disease but rather a symptom of atypical development of the immature brain. They observe that children who have autism are not sick or fragile nor are they emotionally disturbed despite the behavioral nature of many of their symptoms (Rapin & Tuchman, 2008). Their description of the behavioral dimensions of autism is richer and perhaps easier to envision than the aforementioned diagnostic criteria. Rapin and Tuchman (2008) describe children with ASD as having impaired sociability and ability to read other people's moods and intentions, with resulting inadequate or inappropriate social interactions. Children with an ASD also exhibit rigidity and perseveration, including purposeless repetitive movements and activities. They often have the need for sameness and are resistant to change. They have impaired language, communication, and imaginative play. Speech is typically delayed or may regress and comprehension is impaired. Pretend play is delayed or absent. Speech may be abundant and rich but with an atypical vocabulary and clearly abnormal features such as echolalia, frequent verbatim use of scripts, and unusual prosody. The severity of autism's deficits is extremely variable. No single sign, symptom, clinical feature, associated handicap or diagnosis suffices for a diagnosis of autism or invalidates it, and no individual presents all the impairments listed (Rapin & Tuchman, 2008).

Professionals who specialize in autism have introduced the term *autism spectrum disorders* to reflect the broader spectrum of clinical characteristics that now defines

autism (Johnson et al., 2007). The spectrum nature of the symptoms of ASDs does not necessarily imply a single underlying etiology because the range of symptoms could be explained just as easily by multiple etiologies that result in overlapping or shared impairment profiles (Newschaffer et al., 2007). In other words, though some who are affected might share the same kind or level of impairment, the cause of the impairment could be different among affected individuals.

SCREENING

ASDs often can be reliably detected by 3 years of age, and in some cases, as early as 18 months (Filipek et al., 2000). Recognition of the early symptoms of ASDs has progressed significantly in recent years. Screening instruments like the Modified Checklist for Autism in Toddlers (Kleinman et al., 2008) use social behaviors to detect autism in toddlers and distinguish it from other developmental delays. The Quantitative Checklist for Autism in Toddlers (Allison et al., 2008) has also been developed recently and acknowledges the dimensional deficits of social behavior.

HISTORY OF AUTISM – 1940S TO PRESENT

The study of autism began in the early-1940s. It was first outlined in 1943 by Leo Kanner, an Austrian-born Professor of Child Psychiatry at Johns Hopkins. He described children with mental retardation and severe isolation that was not explained by the child's developmental level (Freitag, 2007), and named the syndrome Infantile Autism (Kanner, 1943). At the same time, Hans Asperger in Vienna, Austria, noticed similar patients who exhibited autistic symptoms and normal intellectual abilities (Asperger, 1944). Both

Kanner and Asperger suspected a biological or genetic basis for the disorder (Freitag, 2007); however, various psychoanalytic interpretations such as having an aloof mother were theorized as the cause of autism (Bettelheim, 1967). It was not until after the 1960s that Michael Rutter (1968) and Lorna Wing (1981), the parent of a child with autism, began discussing diagnostic concepts and etiology of autism that excluded psychodynamic interpretations (Freitag, 2007).

PREVALENCE OF ASDS

There is not much discussion in the literature about the incidence of ASDs. Most describe the prevalence of ASDs. One explanation has been offered for the relative absence of incidence reporting for ASD: “Not only is autism diagnosed distal to disease initiation but also the time between initiation and diagnosis is likely influenced by a wide range of other factors potentially unrelated to risk” (Newschaffer et al., 2007, p. 239).

Newschaffer et al. (2007) reviewed and summarized several studies citing prevalence trends of ASDs that have been conducted over the past 40 years to elucidate the reasons for the increased incidence of the disorders. They reported that AD prevalence was about 5 per 10,000 in the 1960s and 1970s, tended to be 10 per 10,000 in the 1980s, and has been highly variable since the 1990s with reported estimates as low as 5 per 10,000 and as high as 72 per 10,000 (Kadesjo et al., 1999; Sponheim & Skjeldal, 1998). Factors that created the variation in prevalence estimates may have included the size and composition of the populations studied, the means used to conduct initial screening, and the methods and criteria by which cases were confirmed (Fombonne,

2005; Karapurker et al., 2003; Wing & Potter, 2002). Most recent reviews of prevalence data have concluded that prevalence of AD is 10-20 per 10,000 (Newschaffer et al., 2007).

Prevalence data has shown ASDs overall have been surprisingly consistent compared to the prevalence data for AD (Newschaffer et al., 2007). The overall prevalence of ASDs is estimated to be about 60 per 10,000 (Baird, Charman et al., 2000), although one report from the United Kingdom gives a much higher prevalence of 110 per 10,000 (Baird, Simonoff et al., 2006). The Center for Disease Control (CDC) in February, 2007 released its largest summary data on ASD prevalence in the U.S. Based on health and school records of 8-year-olds in 14 communities, there was an average prevalence of 6.6-6.7 per 1,000 children (or 66-67 per 10,000). This rate translated into 1 in 150 children (CDC, 2007), much higher than the numbers shown in studies from the 1980s and early 1990s that reported a prevalence of 4-10 per 10,000 children (Yeargin-Allsopp et al., 2003). The prevalence of ASDs reported in 2001 and 2002 ranged from 30-50 per 10,000 children (Fombonne et al., 2001; Wing & Potter, 2002).

ASD prevalence is debated prominently both in lay and professional publications. There was a 556% reported increase in pediatric prevalence of ASD between 1991 and 1997. This prevalence is higher than the prevalence of spina bifida, cancer or Down syndrome (Muhle et al., 2004). The extent to which this increase reflects change in occurrence, case definition or referral patterns of ASD is the subject of vigorous debate (Schechter & Grether, 2008). Some parents of children with ASD and others suspect that a recent environmental or exogenous agent, such as a vaccine, is causing the increased

numbers of children with ASD. The cause for rising prevalence is still debated. Some assert that the jump in prevalence probably can be attributed to heightened awareness and changing diagnostic criteria rather than to new environmental influences (Muhle et al., 2004); however, most involved in the genetic research of ASD believe that at a real increase in incidence is due to environmental and epigenetic factors acting upon a genetically vulnerable background (Abrahams & Geschwind, 2008; Lintas & Persico, 2009).

Other researchers have attempted to explain the rising reported prevalence of ASD as being related to expansion of boundaries set for behaviors consistent with the autistic phenotype (Gernsbacher et al., 2005; Shattuck, 2006; Wing & Potter, 2002). Newschaffer et al. (2007) reported that the U.S. special education in the United States did not classify or diagnose AD until 1994 and some of the rise in ASD has occurred as a result of the educational system diagnosing cases. Using similar reasoning, Volkmar et al. (APA, 2000) retrospectively reviewed ASD cases and found that changes in the wording of the Diagnostic and Statistical Manual of Mental Disorders (DSM) inappropriately broadened the construct of PDD-NOS that could have resulted in inappropriate cases being diagnosed. The wording was subsequently corrected in the DSM-IV-TR (APA).

VACCINE CONTROVERSY

Childhood vaccines have been implicated as causes of the increased number of children diagnosed with ASDs from two perspectives or dimensions. One study hypothesized that the measles component of the measles, mumps, and rubella vaccine

(MMR) was responsible for ASD symptoms (Wakefield et al., 1998). It was theorized that measles caused enterocolitis that caused opioid production and symptoms of ASD. The other perspective is that thimerosal, a mercury-containing preservative used in diphtheria, tetanus and pertussis (DTP), hepatitis B, and haemophilus influenza type b vaccines (Ball et al., 2001) may somehow cause or trigger the symptoms of ASD. With the exception of one study (Geier & Geier, 2003), all studies investigating the role of vaccines in causing ASD failed to reject the null hypothesis of no association between vaccines and rise in autism rates (Doja & Roberts, 2006). A recent study in California discounted the role vaccines play in causing autism by demonstrating that the prevalence of ASD did not decrease over a period of years as one would have expected when all but a trace of mercury was removed from the vaccines (Schechter & Grether, 2008). Nevertheless, these and other findings have not quelled the debate about whether vaccines cause ASD.

In May, 2008 a pediatric neurologist announced on CNN that his daughter developed autism after receiving a vaccine (CNN). He said that he and his wife had sued the Vaccine Injury Compensation Program and won. The parents believed that five vaccines their child, Hannah Poling, had received when she was 19-months-old had triggered her autism. A commentary in the *New England Journal of Medicine* by a prominent pediatric infectious diseases specialist disagreed that the vaccine had caused the autism. Instead, his opinion was that a mitochondrial enzyme deficiency had caused Hannah Poling's encephalopathy. He said: "Those features of her condition considered autistic were part of a global encephalopathy caused by a mitochondrial enzyme deficit.

Indeed, features reminiscent of autism are evident in all children with profound impairments of cognition, but these similarities are superficial, and their causal mechanisms and genetic influences are different from classic autism” (Offit, 2008, p. 2091). The father, Dr. Poling, responded to Dr. Offit’s comments in a subsequent issue: “Offit’s remarks about my daughter’s case are not evidence-based. He has no access to my daughter’s personal medical records, legal records, or affidavits...In contrast, physicians [from government agencies] who studied this information recommended that the government concede Hannah’s case” (Poling, 2008, p. 1). Dr. Poling went on to write that clinical trials do not support the “the simultaneous administration of multiple vaccinations” as safe, much less in “potentially susceptible subpopulations” [such as children with autism who have mitochondrial enzyme deficiency] (Poling, p. 2). The matter was complicated when it was revealed Dr. Poling had submitted a manuscript to a professional publication about his daughter’s case but did not disclose, as a conflict of interest to the publication, that he was suing the Department of Health and Human Services because he believed that vaccines had caused his child to develop autism (Fombonne, 2008).

Confusion about what to believe about vaccine safety must have continued among parents of children with ASD when Bernadette Healy, former director of the National Institutes of Health, responded to the Poling vaccine safety controversy by saying on CBS News: “I don’t think you should ever turn your back on any scientific hypothesis just because you’re afraid of what it might show...If you know that susceptible group, you can save those children” (Healy, 2008). Hence, vaccine safety continues to be a

debated topic in the United States and it is not surprising that parents are confused about whether or not vaccines play a role.

Despite many well-reasoned explanations for the rising prevalence of ASDs, many still express their uncertainty about why the reported prevalence has increased. Newschaffer et al. (2007) questioned the actual impact of the explanations of expanded diagnostic criteria and improved awareness on the reported increases in prevalence of ASDs: “The question of whether this historical increase can be fully accounted for by these and other changes in diagnostic and classification remains open to debate, largely because it is very difficult to develop quantifiable estimates of diagnostic effects and impossible to prove or disprove changes in risk profiles given the condition’s unknown etiology” (p. 239). The lack of certainty about whether there is an increased prevalence of ASDs perhaps helps to fuel the debate among parents and advocacy groups concerning the causes of ASDs and whether government-sponsored vaccine programs or other exogenous factors are responsible for the increased rate of ASDs. Dr. Offit, who had commented on Hannah Poling’s case, said that much of the research funding had been for genetics because potential of a genetic link to ASDs seemed to be so promising, but as a result, there was not enough allocated to studying the prevalence of ASDs (Offit, 2008). Even if one finds only limited support in peer-refereed journals for exogenous or environmental causes of ASDs, one could understand how confusing the issue must seem to concerned parents of children with ASDs.

GENETICS

Advances in the field of molecular genetics in the last several years have resulted in a greatly improved understanding of the causes of ASDs. This is particularly the case when considering there was a complete absence of any biological understanding of ASDs until about thirty years ago (Abrahams & Geschwind, 2008). The possibility of a genetic link to ASDs has been explored through examination of twin studies, genetic syndromes, and copy number variations.

Twin studies

The first evidence that ASDs had a genetic component appeared in 1977 when Folstein and Rutter (1977) published findings comparing the rate of ASDs in 10 pairs of dizygotic (DZ, i.e. fraternal) twins and 11 pairs of monozygotic (MZ, i.e. identical) twins. Thirty six percent (36%) of MZ twins had concordance for ASD; 0% of DZ had concordance for ASD. In 1997, they repeated their study with a larger sample and found that 60% of MZ twins had concordance for ASD and 0% of DZ had concordance for ASD (Folstein & Rutter, 1997). Other studies of families support a genetic influence in autism. The relative risk of a child being diagnosed with ASD is increased at least 25-fold over the population prevalence in families in which a sibling is affected (Jorde et al., 1991). Siblings and parents of an affected child are more likely to show subtle cognitive or behavioral features that are qualitatively similar to those observed in probands or individuals with ASD. Individuals with these subtle autism-like features who are related to the individual with ASD are referred to as the broader autism phenotype (BAP)

(Bishop et al., 2004; Bolton et al., 1994). All of these studies point to the strong role played by genetics in ASD.

Genetic syndromes

Neurogeneticists have recently estimated that defined mutations, *de novo* copy number variations, and rare genetic syndromes account for 10 – 20 % of ASD cases (Abraham & Geschwind, 2008). Examples of these rare genetic syndromes include: Angelman syndrome, Fragile X, tuberous sclerosis, Rett syndrome, Joubert syndrome, and Timothy syndrome (Abrahams & Geschwind, 2008). These rare syndromes affect less than 1 to 2% of the people who have ASD, however, the copy number variations, discussed in more detail below, are estimated to be responsible for 2 to 10% of ASD cases, and the cytogenic lesions or mutations, are probably responsible for about 6 to 7% of ASD cases (Abraham & Geschwind, 2008).

Copy number variations

Although it had been generally thought that genes are almost always present in two copies in a genome, recent discoveries have revealed that large segments of DNA can vary in their number of copies, i.e., copy-number variation (CNV). The copy number variations (CNV) refer to the insertion or deletion of a relatively large DNA fragment on the chromosome, *de novo*, signifying a mutation that neither parent possessed nor transmitted. In other words, the mutation was spontaneous. Such differences in DNA sequence can enhance susceptibility to diseases or disorders such as ASDs (Redon et al., 2006). Sebat et al. (2007) compared the genes of children with autism with the genes of

their parents and found *de novo* CNVs. *De novo* CNVs are mutations in the child's genes that were not inherited from either parent; children with ASD were more likely to have these spontaneous mutations than other children. Sebat et al. (2007) believe that these sorts of mutation occur in the egg or sperm before conception or in the earliest stages of embryonic development. This theory would help explain why researchers have had difficulty identifying a candidate gene associated with autism. The presence of CNVs has important implications for genetic counseling because if mutations are spontaneous in nature, future children of a couple would not have a great risk of having ASD (Sebat, 2007).

Linkage and association studies, genetic screens

There are other genetic approaches being used to study autism. Linkage and association studies have identified various susceptibility genes, located on various chromosomes, especially 2q, 7q, 15q, and the X chromosome (Muhle et al., 2004; Persico & Bourgeron, 2006). Genetic screens have been powerful tools for monogenic disorders characterized by direct genotype-phenotype correlations, but have been less useful in the case of complex disorders like ASD (Persico & Bourgeron, 2006). The clinical heterogeneity of ASD probably reflects the complexity of its genetic underpinnings, involving multiple contributing loci, genetic heterogeneity, epistasis, and gene-environment interactions (Persico & Bourgeron, 2006). Broader diagnostic criteria and greater awareness of ASD have contributed to the increased prevalence of ASD, but those involved in genetics research have suggested that environmental and epigenetic factors

acting upon a genetically vulnerable background are also likely contributors (Abraham & Geschwind, 2008; Persico & Bourgeron, 2006). ASD research is reminiscent of research into mental retardation, an overlapping but distinct neurodevelopmental syndrome, in which many relatively rare genetic mutations rather than a single genetic cause are responsible for the disorder (Abraham & Geschwind, 2008).

Environmental and other risk factors

Abrahams and Geschwind (2008) observe that heightened awareness and broader diagnostic criteria do not exclude the potential for involvement of environmental factors in ASD risk. Increased incidence of prenatal and perinatal complications has been noted in cases of ASD (Glasson et al., 2004), and viral exposures, such as rubella, also may increase the risk (Abrahams & Geschwind, 2008). Other researchers have suggested that risk is increased with increased age of fathers of children with ASD (Reichenberg et al., 2006), that may be related to the previously described *de novo* copy variations found by Sebat et al. (2007). Although contributions of epigenetics, that is, molecular changes that are not related to DNA sequencing, have been promoted, the manner and extent of their involvement is unknown (Abrahams & Geschwind, 2008). ASDs are considered to be highly heritable conditions; it is likely that variations in many genes, influenced by environmental factors, interact during brain development causing vulnerability to ASD (National Institute of Mental Health [NIMH], 2007).

In summary, the ASDs are a complex, heterogeneous disorder. Many debate whether expanded diagnostic criteria and enhanced awareness are sufficient explanations

for the increased prevalence of ASDs. Neurogenetic research points to a multifactorial, genotypic heterogeneity interacting with the environment to cause ASDs in genetically vulnerable populations. Most studies have discounted vaccines as a cause of ASDs, but the issue about the safety of vaccines continues to crop up as even prominent healthcare publications and institutions apparently cannot escape the confusion arising from this issue. Much has been discovered about the molecular genetics of ASD and much work is left to be done. Parents and advocacy groups have funded some of the genetics research and helped to organize and fund the tissue sharing and data base development that will allow large population based-studies and genetics research to be more productive.

EDUCATIONAL AND CLINICAL INTERVENTIONS FOR ASDS

This section will review some of the educational and clinical interventions that have been applied in the care of children with ASDs. These interventions include Applied Behavioral Analysis, TEACCH, relationship-focused interventions, speech and language therapy, occupational therapy, drug therapy, and complementary and alternative therapies.

Applied Behavioral Analysis (ABA)

ABA uses the principles of operant conditioning to teach specific social, communicative, and behavioral skills to children with ASDs (Rogers, 1998). ABA involves teaching the child behavioral skills through repetition. Problem behaviors are addressed by analyzing triggers or antecedents to the behavior then eliminating those triggers in the environment (Lovaas, 2003). Recent studies suggest that ABA is superior to other interventions, however, an intense time commitment (i.e., a minimum of 20 hours per week) is essential (Howard et al., 2005; Rogers, 1998).

TEACCH

The Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH) is a teaching method emphasizing organization of the physical environment, predictable sequences of activities, visual schedules, routines with flexibility, structured work-activity systems, and visually-structured activities (Mesibov et al., 2005). TEACCH places emphasis on improving skills of the individual with an ASD and modifying the environment to accommodate the person's deficits (Myers et al., 2007).

Relationship-focused interventions

Relationship-focused interventions include the Developmental, Individual-difference, Relationship-based mode (DIR) (Greenspan & Wieder, 1997); Relationship Development Intervention (RDI) (Gutstein & Sheehy, 2002), and Responsive Teaching curriculum (RT) (Mahoney & McDonald, 2003). DIR focuses on floor-time play sessions and other strategies to enhance relationships and emotional and social interactions in order to facilitate emotional and cognitive growth and development. DIR also includes therapies to remediate processing and language, motor planning and sequencing, sensory modulation, and visual spatial processing (Greenspan & Wieder, 1997). RDI focuses on interactive activities to help the child discover the value of positive interpersonal activity and become more motivated to learn the skills necessary to sustain relationships (Gutstein & Sheehy, 2002). RT teaches parents to use strategies to encourage their children to acquire and use pivotal developmental behaviors such as attention, persistence, interest,

and cooperation (Mahoney & McDonald, 2003).

Speech and language therapy

A variety of approaches have been effective in improving communication skills of children with ASDs (Goldstein, 2002; Paul & Sutherland, 2005). These include Discrete Trial Teaching (DTT), verbal behavior, natural language paradigm, pivotal response training, and milieu teaching. There also has been support for developmental-pragmatic approaches such as the Social Communication Emotional Regulation Transactional Support (SCERTS) model, the Denver model, RDI and the Hanen model. Alternative communication modalities including gestures, sign language, and picture communication programs are also used to enhance communication (Goldstein, 2002; Paul & Sutherland, 2005).

Occupational therapy

Traditional occupational therapy (OT) often is used to help develop self-care skills such as dressing, using utensils and personal hygiene. OT also can assist in the area of sensory integration. The purpose of sensory integration is not to teach specific skills and behaviors, but to help remediate deficits in neurologic processing and integrate sensory information, allowing the child to interact with the environment in a more adaptive fashion (Myers et al., 2007).

Pharmacology

A variety of pharmacological options are used to address symptoms in children

with autism. The Federal Drug Administration (FDA) approved the use of risperidone (Risperdal) in October, 2006 for the symptomatic treatment of irritability in children and adolescents ages 5 to 16 with ASD (NIMH, 2008). Irritability associated with ASD includes aggression, deliberate self-injury, and temper tantrums (NIMH). Olanzapine (Zyprexa) and other antipsychotic medications are used “off-label,” or without FDA approval, for the treatment of aggression in children, including those with autism (NIMH). Fluoxetine (Prozac) and sertraline (Zoloft) are approved for children age 7 or older with obsessive-compulsive disorder. Fluoxetine also is approved for children age 8 and older for treatment of depression, although in 2007 the FDA issued a warning that their use increased risk of suicide (NIMH). Stimulant medications such as Methylphenidate (Ritalin) have been used to reduce impulsivity and hyperactivity in some children with ASD, especially those higher functioning children (NIMH). Seizures are found in one of four persons with ASD, most often in those who have low IQ or are mute (NIMH). These are treated with anticonvulsants such as carbamazepine (Tegretol) and valproic acid (Depakote) (NIMH, 2007).

Complementary and alternative therapies

Levy and Hyman (2005) observe that in no area of developmental pediatrics is there more controversy regarding treatment choice than the area related to children with ASD. Levy and Hyman offered several explanations to account for this phenomenon: 1) The natural history of the disorder involves regression of social and language skills in about one third of children (Tuchman & Rapin, 1997), so parents might hope that an

external event or exposure could reverse the disorder or return the child to a prior state of development; 2) there are many anecdotal descriptions of children who once fit diagnostic criteria for ASD, but who have matured or responded to treatment so they appear no longer to meet diagnostic criteria (Michelotti et al., 2002; Seroussi, 2000); 3) children with ASD may not have congenital anomalies or abnormalities in neuroimaging, which may be interpreted as evidence for absence of underlying neurological dysfunction; 4) the lack of identification of a specific cause accepted by the scientific and medical establishment allows for proliferation of multiple hypotheses that may not be compatible with current understanding of neuroscience; and 5) conventionally prescribed treatments for ASD address its symptoms, not the underlying causes. Complementary and alternative therapies purport to eradicate the cause of ASD (Levy & Hyman, 2005).

Many of the interventions lack empirical support and are diligently researched, pursued, and shared by parents in news and support groups on the Internet. The American Academy of Pediatrics (AAP)'s Committee on Childhood Disabilities reviewed many of the educational and behavioral interventions and have discovered a paucity of conclusive research about the effectiveness of interventions (Myers et al., 2007).

Complementary and alternative medicine (CAM) is described by the National Center for Complementary and Alternative Medicine (2000) as a group of diverse medical and healthcare systems, practices, and products that are not currently considered to be part of conventional medicine. The Cochrane Collaboration defines CAM as a broad domain of healing resources that encompasses all health systems, modalities, and practices and their accompanying theories and beliefs, other than those intrinsic to the

politically dominant health systems of a particular society or culture in a given historical period (Zollman & Vickers, 1999).

Complementary therapies used to treat ASDs have been categorized as biomedical or non-biomedical (Levy & Hyman, 2005). Non-biomedical interventions that have been used with ASD include auditory integration training, behavioral optometry, craniosacral manipulation, dolphin-assisted therapy, music therapy, and facilitated communication (Levy & Hyman, 2005).

Examples of biomedical interventions used in the treatment of ASDs include immunoregulatory interventions (e.g., dietary restrictions of food allergens or administration of immunoglobulin or antiviral agents), detoxification therapies (e.g., chelation), gastrointestinal treatments or diets (e.g., digestive enzymes, antifungal agents, probiotics, yeast-free diet, gluten-free casein free diet, and vancomycin), and dietary supplement regimens believed to act by modulating neurotransmission through immune factors or epigenetic mechanisms (e.g., vitamin A, vitamin C, vitamin B6, magnesium, folic acid, folinic acid, vitamin B12, dimethylglycine, trimethylglycine, carnosine, omega-3 fatty acids, inositol, various minerals and others) (Gupta, 2004; Levy & Hyman, 2005).

Many complementary therapies used in the treatment of ASD cannot be evaluated using evidence-based criteria due to methodological flaws, inadequate sample sizes or lack of replication in the studies (Myers et al., 2007). Some therapies, however, have been evaluated in randomized, double-blind, placebo-controlled trials to test their effectiveness. One such therapy is the use of secretin. Use of secretin for ASD has not

been supported in studies conducted by Sturney (2005) and Williams et al.(2005).

Similarly, facilitated communication, a technique in which a trained facilitator provides physical support to a nonverbal person's arm or hand while that person uses a keyboard to spell, was deemed ineffective as an intervention for ASD (Mostert, 2001).

Other therapies and intervention that have been shown to have no significant benefit included demethyclycine, vitamin B6 and magnesium, and auditory integrated training (Myers et al., 2007). Both positive (Gupta et al., 2006) and negative (DelGiudice-Asch et al., 1999) results have been described for studies of intravenous immunoglobulin. The use of omega-3 fatty acid has not been supported for ASD (Amminger et al., 2007). Studies examining the effectiveness of a gluten-free casein-free diet for ASD have had mixed results, although studies currently in progress will perhaps shed light on the diet's effectiveness (Myers et al., 2007). Chelation therapy to remove mercury has not been extensively studied; unfortunately, a boy died as a result of inappropriate administration of chelation therapy (Brown et al., 2006).

Barbaresi et al. (2006) noted that traditional medicine does not offer a cure for autism and, as a result, parents may provide their children with unproven biomedical interventions (Hyman & Levy, 2000). Barbaresi et al. (2006) also noted that patients with unclear pathophysiologic features, fluctuating courses and few available evidence-based treatments are most vulnerable to the placebo effect (Kaptchuk & Eisenberg, 1998). They also noted that, among cases most similar to autism, unproved explanations of causation and unproved therapies abound (Barbaresi et al., 2006).

Green et al. (2006) surveyed parents of children with ASD and found that they

were using an average of seven different treatments, most had no scientific support. Similarly, Goin-Kochel et al. (2006) found that parents of children with ASD were employing, on average, between four and six treatments and had previously been using between seven and nine complementary therapies. They noted that parents of children with ASD seemed to be trying treatment after treatment in an effort to find those most beneficial for their children (Goin-Kochel et al., 2006). Parents also revealed that they were constantly on the lookout for other therapies to try, not wanting to miss the one treatment that might help their child (Farmer et al., 2007; Goin-Kochel et al., 2006).

Levy and Hyman (2003) describe a hierarchy of evidence in which randomized controlled trials provided the best means to test whether an outcome is clearly due to the treatment. They admit that even some commonly used medical treatments have not met these standards of rigor, that makes criticizing untested complementary therapies somewhat hypocritical.

Determining if any therapy, whether complementary or conventional, will have a therapeutic effect on a child with ASD is difficult, time-consuming, and expensive. The amount of focus and perseverance needed to identify, understand and implement therapies, and manage a child's difficult behaviors is a difficult and complex task.

PARENTAL RESPONSES TO HAVING A CHILD WITH ASD

Having a child with ASD is stressful to parents and families. Families are exposed to internal stressors resulting from the child's difficult behaviors; these stressors continue to increase when it becomes necessary for the parents to advocate for health, social, and

educational services for the child (Twyo et al., 2007). Other stresses and challenges of raising a child with ASD are associated with receiving the child's diagnosis, the necessity of being constantly involved in education and therapy decision-making, increasing contacts with multidisciplinary professionals, scarcity of resources, and purchasing and using therapeutic or technological supports (Lord & McGee, 2001).

Parents of children with ASD are more likely to score high in the aggravation range (55%) than parents of children with developmental problems other than ASD (44%), parents of children with special healthcare needs with no developmental problems (12%), and parents of children without special health care needs (11%) (Schieve et al., 2007). The proportion of parents with high aggravation within the ASD group was 66% for those whose child recently needed special services and 28% for those whose child did not (Schieve et al., 2007).

Bromley et al., (2004) found that over half of mothers of children with ASD screened positive for significant psychological distress; this distress was associated with low levels of family support and bringing up a child with challenging behaviors. Mothers were more likely to report low levels of family support if they were a single parent, were living in poor housing or were the mother of a boy with ASD. Levels of reported distress were associated with high levels of child behavior problems and low levels of informal support in the family.

Several studies have reported increased psychological distress, including depression and anxiety among parents of children with ASD. Decreased family cohesion and increased somatic complaints and burnout have been reported among parents of

children with ASD when compared to parents of typically developing children (Higgins et al., 2005; Sivberg, 2006; Weiss, 2002; Yirmiya & Shaked, 2005). A study by Higgins et al. (2005) showed that families of children with ASD restricted contact with friends and family and became isolated due to a lack of understanding of other people regarding their children's repetitive and withdrawal behaviors, and misbehavior.

A phenomenological study of parents of children with ASD conducted by DeGrace (2006) revealed that families experienced autism as an entity that "controlled their lives" and daily routines centered on activities to "occupy and pacify" the child resulting in only "fleeting moments" in which the family "felt like a family." Harrell (2006) conducted another phenomenological study of 85 parents of children with ASD who participated in 11 focus groups. The study findings revealed the parents' need for: a) more education of pediatricians, educators, and the general public about ASD; b) networks of various professionals and parents to be accessed for support; c) support groups for parents organized by stages of their child's development and severity, as well as support groups for siblings and grandparents; d) guidance through a resource booklet to help parents navigate the diagnostic process and delivery system; and e) training in advocacy issues, preferably from a person not involved in a funding source.

Hastings et al. (2005) examined the interdependence of family members' well-being among families with children with ASD. They also studied variables such as the relationship between spouses and child, as well as the variables of depression and positive perceptions. Mothers were more affected by the child's behavior problems than fathers, presumably because the mothers report more involvement in the care of the child

(Hastings et al., 2005). Another explanation is that fathers tend to cope by avoiding the child's behavioral problems and engaging in activities unrelated to the direct care of the child (2005). Hastings et al. (2005) also found that depression in one of the marital-parental partners was a positive predictor of the other partner's stress.

Lecavalier et al., (2006) examined the effects of behavior problems of children with ASD on stress reported over time by teachers as well as parents. They found that caregivers most strongly associated stress with the child's conduct problems and lack of pro-social behaviors; these findings were consistent over a 12-month period. The study also found that parental stress, teacher stress and the child's behavior exacerbated each other. Baker et al. (2003) reported similar findings in young children with developmental delays including ASD and in children without developmental delays.

Gray (2006) conducted an ethnographic study to examine how 28 parents of children with ASD coped over time (an 8-to-10 year period). Gray found that the total number of coping strategies reported by the parents declined over time, and there was a general shift away from problem-focused to emotion-focused coping. Moreover, the parents' reliance on service providers and other family members declined over time, although the relative importance of religion and other coping strategies, such as an appreciation of their child's good qualities, had increased (Gray, 2006).

Bloch and Gardner (2007) called for health researchers and providers to view mothers of children with ASD as being vulnerable to *caregiver burden*, a term that is typically applied only to caregivers of the elderly with dementia. They cite the child's behavioral, cognitive, physical, and social impairments as requiring the mother to face a

variety of social, economic, and personal challenges. For example, many infants and children with ASD are irritable, make poor eye contact, and stiffen when held, making them difficult to manage (Bloch & Gardner, 2007). Other researchers note that providing care to children with ASD is challenging, even those who are psychologically stable and have sufficient intellectual and financial resources (Comm & Larsen, 1999; Hassall et al., 2005).

Uniformly, the literature reveals that parenting a child with autism is associated with higher levels of stress. However, a possible problem with these studies is the potential for sampling bias because most samples are clinic-referred or based on membership in an autism-related society (Montes & Halterman, 2007). The first population-based study of mothers of children with ASD was conducted by Montes and Halterman, whose study found that mothers of children with ASD had a higher level of parenting stress and were more likely to report poor or fair mental and emotional health than mothers in the general population. On the other hand, the study also found that mothers of a child with ASD were indistinguishable from mothers in the general population with respect to having a close relationship with the child, feeling angry toward the child or coping with parenting tasks. The mothers of children with ASD scored better than other mothers in the area of social skills (Montes & Halterman, 2007). Montes and Halterman conclude that the strengths in the parent-child relationship and parenting support for children with autism suggest that prior negative research reports may have stemmed from sampling bias.

THE INTERNET

The Internet originated in the U.S. military. The U.S. government established the Advanced Research Project Agency (ARPA) in 1957 to regain technical advantage over the Soviet Union who had just successfully launched the Sputnik spacecraft. ARPA's developers created ARPANET and envisioned a community of computers that would serve as a communication medium between people. ARPANET is usually regarded as the precursor to the Internet (Comer, 2000).

The Internet was a U.S. government-funded research tool during the 1970s and 1980s and was restricted to academic and military uses (Comer, 2000). The National Science Foundation developed an acceptable use policy for the Internet in the 1980s, and in 1995 the Internet was privatized and commercial use was allowed. The commercialization of the Internet coincided with the popularity of the World Wide Web (WWW), developed by British physicist, Timothy Berners-Lee. Many use the terms Internet and Web interchangeably, although the difference is analogous to the distinction between a highway system and a package delivery service that uses the highways to move cargo from one city to another. The Internet is the highway system over which Web traffic and traffic from other applications move (Comer, 2000). The Web consists of programs running on many computers that allow a user to find and display multimedia documents or documents that contain a combination of text, photographs, graphics, audio, and video (Comer, 2000). By the end of 2000, more than 80% of all traffic on the Internet came from the Web (Comer, 2000). The Internet is composed of many interconnected computer networks. Each network may link tens, hundreds or even

thousands of computers, enabling them to share information and processing power.

Unlike traditional broadcasting media, such as radio and television, the Internet does not have a centralized distribution system. An individual who has Internet access can communicate with anyone else on the Internet, post information, retrieve information, use distant applications and services, or buy and sell products (Comer, 2000). Although the terms *Internet* and *Web* are different, the following discussion and the remainder of the paper will use the terms interchangeably.

Companies, individuals, and institutions use the Internet (Comer, 2000).

Companies use the Internet for electronic commerce and for business-to-business transactions. The use of e-mail speeds communication between companies, among coworkers, and among other individuals (Comer, 2000). Online chat allows people to carry on discussions using written text. Instant messaging enables people to exchange text messages, share digital photos, video, and audio files in real time. Scientists and scholars use the Internet to communicate with one another and students, perform research, and publish papers and articles. Individuals use the Internet for communication, finding information and selling goods and services (Comer, 2000).

Originally, e-mail could only be sent to recipients by the sender in singular transactions, and only text messages (as opposed to photographs and images) could be sent (Comer, 2000). Software has been developed that will automatically propagate to multiple recipients a message sent to a single address. This software is referred to as a list server and individuals may join or leave a mail list at any time. A list server can be used to create lists of individuals who will receive announcements or to create online

discussion groups (Comer, 2000). As envisioned by the Internet's early developers, the Internet has evolved into a community of computers that serves as a communication medium between people.

THE INTERNET AND HEALTH

Traditionally, people have relied upon health professionals for health information, but in recent years the Internet has become a major source for health information (Zaidman-Zait & Jamieson, 2007). The 2006 Pew Internet and American Life Project reported that 113 million, or 80% of U.S. Internet users, seek health information online (Fox, 2006). The Pew study found that 79% of Internet users aged 18-29 years and 84% of those aged 30-49 years sought health information online. The most frequent health-related topics searched were information about specific diseases (64%), treatments (51%), and diet, nutrition, and vitamin information (49%) (Fox, 2006). To cope with the uncertainty of illnesses or the disturbing aspects of symptoms, U.S. Internet users sought emotional support provided by various types of online discussion forums, such as chat rooms, instant messaging, and asynchronous modes, such as e-mail and blogging (Jones & Lewis, 2001; Wright, 2000, 2002). Parents of children with ASD have difficulty obtaining adequate information and support to guide them in the care of their children (Huws et al., 2001). Thus, such parents may be among the demographic groups the Pew study identified as seekers of health-related information on the Internet.

Much of the research regarding the use of Internet-based health information has focused on how individuals with illnesses or other health conditions use the Internet to

obtain support and information about their conditions. Coulson (2005) examined conversations among individuals with irritable bowel syndrome (IBS) and concluded that online support groups were used to learn to interpret symptoms and to interact with healthcare professionals. Weis et al. (2003) found that informational needs of individuals with multiple sclerosis (MS) were greater than their emotional needs. Women who had had hysterectomies also sought information and advice more than emotional support. Rather than replacing non-web support, they used a designated website to augment existing support (Bunde et al., 2006). Winefield (2004) found that a few high-frequency responders to a website for people with breast cancer played a valuable role in emotionally supporting visitors to the website. Sullivan (2003) compared individuals with ovarian cancer and prostate cancer and discovered that women favored emotional support and men informational support from Internet resources.

Few studies exist about the use of Internet resources among parents of children with ASD. Mackintosh et al. (2005) analyzed sources of information and support among parents of children with ASD and found that 86% of parents used websites, e-mail, and group list serves as information sources. Huws et al. (2001) studied parents of children with ASD examined messages posted on a group e-mail list and determined that e-mail functioned as a social support mechanism as well as a way for parents to make sense of ASD. Huws et al. identified themes of searching for meaning, adjusting to changes, providing support and encouragement, and sharing experiences. Since their study did not utilize interviews to guide and solicit data in interactive conversations, the study data and conclusions were limited to observations of what parents discussed while on the website.

The credibility of health information on the Internet is an issue of concern. Bernhardt and Felter (2004) used focus groups to examine how mothers of typically developing children used the Internet to seek health information, and how the mothers evaluated the information for credibility. Most mothers sought information related to their children's acute health conditions as well as topics related to pregnancy and parenting. When asked how they had determined the credibility of information found on the Internet, the mothers responded that they had greater confidence in the content of non-profit websites ending in "edu" or "org" as opposed to for-profit entities ending in "com." The mothers also had more trust in the information if it appeared in multiple sites. Although useful in demonstrating mothers' use of Internet resources to obtain health information for "normal" children, Bernhardt and Felter's study does not elucidate the complex decision-making processes that mothers of children with complicated conditions such as ASD face when choosing among a plethora of treatments and therapies, many of which, unlike general pediatric health questions, remain unvalidated by scientific studies.

Investigators studying Internet use also are interested in the type of search techniques utilized by individuals searching for specific health information and the degree of satisfaction with the information found. The 2006 Pew Internet and American Life Project reported that 66% of Internet users looking for health information began their online session at a search engine and 27% started at a health-related website (Fox, 2006). Although many health information seekers were reassured and felt confident about the information they had found, 25% said they felt overwhelmed, 22% felt frustrated, and 18% confused. Very few respondents reported that they check the source and date of

information they find (Fox). Eysenbach and Kohler (2002) had similar findings.

Participants in their study professed they assess the accuracy of Internet information; however, when observed in a computer lab, they failed to check the “about us” section, or any disclaimers or disclosure statements on the website.

Zaidman-Zait and Jamieson (2007) reviewed the advantages and disadvantages to parents of children with established disabilities (including ASD) who sought information and support on the Internet. Advantages included the provision of anonymity, access to broad sources of information, ability to easily read about obscure conditions and clinical trials or other treatments (especially if seeking practical advice that only other parents could provide), interactive educational tutorials, and videoconferencing. Disadvantages included a concern that Internet authors were not held accountable for the quality of information that made it hard for parents to discern accuracy. Also, many parents were overwhelmed by the volume of information. Other researchers who evaluated the accuracy of information obtained from websites about depression, childhood diarrhea, and management of children’s cough found a low percentage of concurrence with quality sources of information (Lissman & Boehlein, 2001).

Another Internet resource for health-related information and support is the virtual support group, or online community. Eysenbach et al. (2004) were interested in finding out whether these groups or *virtual communities* were effective in improving health or social outcomes. They conducted a systematic review of 45 publications describing health-related support groups or virtual communities and were unable to assess the effectiveness of these groups or communities in improving health or social outcomes.

The researchers concede that such virtual communities previously had been evaluated only in conjunction with more complex interventions or involvement with health professionals. They urge more research into the effectiveness of support groups that are not moderated. Wang et al. (2007) conceptualize online communities and support groups as belonging to a new information and communications technology paradigm called *social computing*, where individuals increasingly are taking cues from one another and online communities, rather than from institutional sources such as physicians and hospitals. Although online support may be invaluable, the ability to easily and efficiently share peer-to-peer information on the Internet about treatments and other ASD-related information is positive only if the sources are accurate and credible.

Clinical and personal observations of this researcher have led to the suspicion that if any group of parents were likely to share *peer-to-peer* health information, or to take cues from one another about health-related information, it might be parents of children with ASD. These parents are motivated to find and implement therapies for their children as soon as possible. Parents have turned to the Internet for answers when their doctors have been unable to provide them (Clancy, 2006).

The parents are looking for relief or improvement in symptoms from a spectrum of disorders that is poorly understood and lacks any standard treatment protocol. Therefore, they may be more likely to seek and accept information about treatment choices from one another, or from sources that are considered less than expert by conventional standards, such as may be found on many Internet sites (Farmer et al., 2007).

Many uncertainties surround ASDs including prevalence, cause, effectiveness of

the various treatments and prevention. Although genetic research into potential causes of the ASDs has been productive and promising in the last 10-15 years, many unanswered questions remain. Genetic research will not provide help or direction to the parent trying to manage their child's behavior and needs now. Parents who find themselves with a child with ASD turn to one another for information and support. The Internet becomes an important means of connecting with others and locating information as parents work to ensure the most favorable outcomes for their children. The use of the Internet and its community of computers by parents of children with ASD has generated a phenomenon in healthcare that warranted further assessment and investigation. This study was developed to explore how parents of children with ASD use the Internet to find resources and information to help them manage their child's health, behavior, and development.

Chapter 3 reviews the concepts underpinning naturalistic inquiry and why naturalistic inquiry was an appropriate choice of methodology for this study. The chapter also describes the procedures used by the investigator to conduct the research and how these procedures contributed to the trustworthiness or accuracy of the findings. Chapter 4 presents the findings of the study. Chapter 5 reviews the findings and describes how they may be used to influence future research and improve patient care and service.

Chapter 3: Research Design and Methodology

INTRODUCTION

This chapter describes the methodology of naturalistic inquiry (NI) and how it was used in this study to explore and describe Internet use among parents of children with ASDs. There is a description of NI and an in-depth discussion providing the rationale for using naturalistic inquiry in this research. This chapter also discusses procedures used to ensure the protection of human research subjects, including presence of informed consent and participant confidentiality. Data management and data analysis procedures also are discussed followed by a description of techniques applied to ensure the rigor of the study.

RESEARCH QUESTIONS

This qualitative research study was guided and informed by naturalistic inquiry as described by Lincoln and Guba (1985). The research questions guiding the study were as follows:

1. How do parents of children with autism spectrum disorder (ASD) use the Internet in response to their needs as parents and caregivers?
2. How do parents evaluate the trustworthiness and describe the adequacy of information and support that they find on the Internet?

3. How do parents of children with ASD choose Internet-derived information about autism and how does this information influence their decisions about their choice of treatments and therapies for their child?

NATURALISTIC INQUIRY

Naturalistic Inquiry, as described by Lincoln and Guba (1985), was used to achieve the goals of this research. The naturalistic paradigm is sometimes called post-positivist or qualitative and is an alternative to the previously dominant research paradigm which may be called empirical, experimental or quantitative (Yoong, 1986). NI supports multiple concurrently existing realities, researcher involvement, and consideration of contextual factors (Lincoln & Guba, 2005). Positivists, striving to be unbiased, reliable and rational, assume one reality, and assert that the researcher's role is to explain, predict or control that reality (Gorski, 1998). NI acknowledges that there are multiple realities within the world. NI supplies the depth and richness of descriptions of observed phenomena that positivism lacks; hence, the use of NI is especially important to understanding and making sense out of the lives of others (Glesne & Peshkin, 1992; Gorski, 1998).

NI is appropriate for this exploratory inquiry because the study assumes that being a parent of a child with a neurodevelopmental disability such as autism is not a single tangible reality that can be reduced and approximated. Rather, there are multiple constructed realities held by individuals like these parents and the only way the researcher can know or understand the unknown (the parent's reality) is through sharing and understanding the beliefs or constructions of these parents (Pickard & Dixon, 2004).

Guba, an expert in the development and use of NI, comments on the importance of attending to subjective experience or subjectivity among those who wish to understand human behavior and belief systems: “Subjectivity is not only forced upon us by the human condition [but it is also] the only means of unlocking the constructions [or beliefs] held by individuals” (Guba, 1992, p. 26). Hence, subjectivity in NI research is not avoided or rejected as it is in the positivistic approach, but rather it is acknowledged and examined in ways that improve our understanding of a phenomenon of interest.

Lincoln and Guba (1985) describe NI as an interactive process in which the researcher and participant learn from each other. The researcher and the participant, like the knower and the known, are inseparable, interactive, and mutually shape each other. All entities, including the researcher and the participants, are in a state of mutual simultaneous shaping. Therefore, from the perspective of NI, cause and effect are impossible to distinguish (Lincoln & Guba, 1985).

A later work by Guba and Lincoln (1989) refers to NI as *constructivism* and further develops the concept of interdependence between researcher and participant. Schwandt (1994) notes that Guba and Lincoln assume that “the observer cannot (and should not) be neatly disentangled from the observed” (p. 128) in the activity of inquiring into constructions or representations of reality. Schwandt reviews some of the theoretical underpinnings of NI and observes that “the findings or outcome of a [NI] study are a creation or construction of the inquiry process and are resident in the minds of individuals” (p. 128). Schwandt offers a quote from Lincoln and Guba to help elucidate the subjective interplay and mutual shaping occurring between researcher and participant

in NI: “Constructions do not exist outside of the person who creates and holds them; they are not part of some ‘objective’ world that exists apart from their constructors” (Guba & Lincoln, p.143). In positivistic research, the observer and observed are a separate dyad; in NI, they are interdependent and are in a continuous process of mutually shaping each other (Lincoln & Guba, 1985).

Williams (2005) offers a simple and direct way of defining and viewing naturalistic inquiry that might help clarify the nature of NI research. He writes: “Simply put, naturalistic inquiry is *disciplined inquiry* that is conducted in natural settings (in the field of interest, not in laboratories), using natural methods (observation, interviewing, thinking, reading, writing) in naturalistic ways by people (practitioners such as nurses, teachers, or other full-time researchers and evaluators) who have natural interests in what they are studying ” (p. 2). He notes that the term *disciplined inquiry* was coined by Cronbach and Suppes (1969) to encompass different research paradigms which may differ significantly in their methods and their accepted conceptions of reality, but that each of these research paradigms or methodologies must meet certain critical standards. Williams compared NI to other research paradigms and enumerated Smith and Glass’ (1987) summary of some of the characteristics or essential standards of all disciplined research methods: 1) the researchers employ systematic, clearly described procedures so that the reader can closely follow the logic of the study and assess the credibility of their findings; 2) the researchers are sensitive to the errors that are associated with their methods and seek to control them or consider how the errors may influence the results; and 3) plausible alternative explanations are sought for results (Smith & Glass, 1987).

Naturalistic inquiry meets all of these standards of quantitative research using prescribed methods which are described later in this chapter.

Using the naturalistic perspective to explore Internet use by parents of children with ASD accommodates NI's premises of multiple realities and the interactive nature of researcher and participants. Asking how, why and in what context parents are using the Internet to obtain autism-related information can be answered by the NI approach. NI acknowledges context-specific inter-relationships that give data meaning and allow the investigator to develop and verify shared constructions among the participants. In this way, knowledge can be expanded in a meaningful manner (Erlandson et al., 1993).

Lincoln and Guba (1985) distinguish between types of studies in which the investigator "knows what he or she doesn't know" (p. 209) and therefore can project means of clarifying or solving a problem or dilemma, and types of studies in which the investigator "does not know what he or she doesn't know" (p. 209). A much more open-ended approach, such as naturalistic inquiry, is required in the latter type of study. Prior to the present study, it had not been known what parents achieve or wish to obtain by using the Internet in relation to their roles as parents of children with autism. It had been known, however, that they are stressed by parenting a child with autism, challenged by their roles as caregivers and decision-makers, eager for information about autism, and belong to the growing body of individuals who use the Internet to search for health-related information. The goal of the study was to understand *how* parents of children with ASD use the Internet, *how* they evaluate information about ASD for trustworthiness and

adequacy, and *how* the parents decide which information to use to guide their choices of treatments and therapies for their children.

In summary, NI is a post-positivist research paradigm. NI assumes the presence of multiple, context-bound realities and an interactive and mutually shaping relationship between researcher and participant. NI is holistic and employs inductive data analysis to explain and encourage insights that extend beyond the realm of measurable, discoverable facts (Gorski, 1989; Lincoln & Guba, 1985). It is appropriate for use in this study exploring how parents of children with ASD use the Internet in response to their roles as caregivers and parents.

DATA COLLECTION AND MANAGEMENT

The following section describes the procedures used to collect and manage information and data relating to the study. The section describes how interviews were arranged, conducted, documented, stored, and coded, as well as a description of sampling strategies, recruitment procedures, and how informed consent was obtained and confidentiality was protected among the participants. A description of how software was used to organize and manage data and support the coding of data is included (Bringer et al., 2007). This section will conclude with a description of strategies used to ensure the trustworthiness of the study's findings.

Interviews

The time and place of the interviews were selected by the participants and agreed to by the investigator. The time and place selected were convenient, afforded privacy and allowed for minimal interruptions. Being away from the immediate distractions of parenting gave the parent and investigator privacy and an opportunity for uninterrupted communication. Nine of the 12 interviews took place at the homes of the participants, one interview took place at an outdoor park, another took place in a private conference room in an office building and another in private room within a coffee shop.

Sampling strategies

The study employed purposive sampling (Erlandson et al., 1993) wherein the investigator selected participants because they knew the information of interest in the study, were willing to reflect on the phenomenon of interest and had the time and ability to participate (Spradley, 1979). The participants were parents of children with ASD who were able and willing to describe and express thoughts, feelings and opinions about using the Internet to seek information related to their roles as parents of children with ASD. Each participant had access to a computer with an Internet connection, either at home or at work, at least five days per week.

The first group of participating parents was recruited from clinics and networks of parents of children with ASD in the Houston area. Once data collection was underway, snowball sampling also was employed. The investigator asked participants in the study if they would recommend participation in the study to other parents (Morse & Richards,

2002). The parent who had already been interviewed gave the investigator's contact information to other parents who met study criteria. If the other parents were interested in participating in the study, they called or e-mailed the investigator to discuss the requirements of the study, and if indicated, arranged to meet for an interview.

Theoretical sampling was also used (Glaser, 1978) (i.e., where the nature of the data that had emerged during data analysis directed the investigator to select participants based on questions that had arisen from data that had been collected.) When seven participants had been interviewed, the investigator decided that an additional father (vs. a mother) and a parent with a child more recently diagnosed should be recruited and interviewed. Hypotheses or assumptions made from analysis of the earlier data subsequently were modified by data obtained from the theoretically sampled participants.

Saturation

Sampling continued until saturation was achieved. Theoretical saturation is the point at which no new information has emerged during data analysis that would develop the categories further, no new categories have emerged and no additional information arises to add to the explication of the study (Lincoln & Guba, 1985; Morse & Richards, 2002). No new categories of information emerged from the data analysis by the time the data were collected from the tenth participant (i.e., saturation had been achieved). Two additional interviews (giving a total of 12) confirmed that saturation had been achieved.

Inclusion criteria

Parents of children with autism spectrum disorder (ASD) who participated in the study met the following inclusion criteria. Participants were parents who:

1. Self-reported as a parent of a child diagnosed with an ASD
2. Had computer and Internet access in the home or at least five days a week at another site
3. Currently used or had used Internet resources to access autism-related information
4. Could speak and read English
5. Were geographically accessible for face-to-face interviews with the investigator
6. Were at least 18 years old

Although respondents were restricted to English speakers, there were no other restrictions as to race or ethnicity during initial participant recruitment for the study. No differences emerged in participants' responses to the interview questions that appeared to be related to the participant's race or ethnicity. Participants were excluded from the study if they did not meet the inclusion criteria.

Recruitment and informed consent

Information about the study and recruitment information were posted in 17 pediatric clinics and physician's offices in the greater Galveston and Houston areas. Approval of the directors of these clinics was obtained before the flyers were posted. The recruitment flyers invited parents of children with ASD to participate in interviews as

part of a research study investigating the use of Internet resources among parents seeking autism-related information. The flyers communicated the requirements that parents be 18 years or older and had access to a computer. The investigator's contact information was listed on the flyer with instructions on how to reach her for further information if they were interested in participating. (A copy of the flyer appears in Appendix B.)

The investigator returned the phone call or e-mail of the potential participant and determined whether the person met the study inclusion criteria. If he or she did meet the inclusion criteria, the investigator used a script to explain the overall study, its purpose, methodology, and timeframe. (A copy of the script used in recruitment of participants is found in Appendix C.) The investigator explained that each interview would last about an hour to an hour and a half and would occur at a place and time convenient to the participant. She reviewed the informed consent documents and the risks of the study, that included a potential minimal loss of confidentiality. She explained that participation in the study was voluntary and a participant who had entered the study could stop participating at any time without consequence. Participants also were informed during the consent process that the investigator might ask them to meet with her after their interviews had been completed to verify that what she had concluded they had said was what they had intended to say. When an individual did not meet the inclusion criteria, the investigator expressed appreciation for the individual's interest and informed him or her that because study criteria were not met, he or she could not participate.

When respondents met the inclusion criteria and continued to be interested in participating in the study, the investigator set a meeting at a time and place convenient to

the participant. Prior to initiating data collection, the investigator again reviewed the study and the consent documents with the potential participant and had him or her sign the informed consent documents. (A copy of the Subject Consent Form appears in Appendix D.) One copy of the signed subject form was given to the participant for his or her own records. The other copy was retained by the investigator. Once signed consent had been obtained, the participant was interviewed and data was collected. The investigator asked the participants questions about bio-demographical data which was handwritten onto the forms and later entered into the NVivo 7 software.

Confidentiality

The investigator protected the participants' confidentiality and identity during the conduct of the study and reporting of findings. Privacy was provided during the interview by keeping doors closed and conducting the discussions out of hearing range of others. The one interview that took place in the city park took place at a remote outdoor table 50 yards away from other seating arrangements and other park visitors. Confidentiality was ensured by assigning a code number to each participant's bio-demographic sheet, audiorecording, and transcript. The investigator stored the codebook in a locked drawer in her office, separate from the tapes and transcripts. Tapes and transcripts were coded to ensure confidentiality. Information revealing the identity of the participant was removed from the written transcripts. Findings were reported in the aggregate to prevent a breach of confidentiality.

Instruments and interviewing strategies

The primary instrument in this naturalistic study was the researcher and her senses, thoughts, intuitions, and feelings (Erlandson et al., 1993). The primary study data was the narratives of the participants. The investigator created two data collection instruments for the study: the bio-demographic data sheet and the interview guide. Bio-demographic data relating to the participants were collected using a questionnaire that includes such information as participant's age, gender, marital status, socioeconomic status, educational status, date of child's diagnosis, age of children and number of children. (A copy of the document used to collect bio-demographic data can be found in Appendix E.) Narrative data were collected during interviews with participants using a semi-structured interview guide to elicit information. (A copy of the semi-structured interview guide can be found in Appendix F.) Probes, periods of silence or requests for more information were used to clarify responses. The mean or average length of time spent in an interview was 63 minutes; the range was 40-104 minutes. No participant was interviewed more than once although it was necessary for the researcher to call one participant after the interview to clarify what the participant had said about using the Internet to locate products for her child. One interview in progress had to be rescheduled and resumed the following day when the participant's child drank cough syrup during the interview. Another interview had to be rescheduled because the parent fell asleep and did not answer the door as scheduled.

The interviews were audio-recorded so the researcher would have an accurate and complete record of what was said. A microcassette tape recorder and a digital tape

recorder were used during each interview to provide redundant or back-up recording in case one of the recorders malfunctioned.

Software for data management

Interviews were transcribed verbatim by the researcher using a notebook computer and Dragon Naturally Speaking (Version 9), a voice recognition software that types words spoken into a microphone. The investigator trained Dragon to recognize her own voice. After each interview, the investigator listened to the tapes of the interview and dictated the content of the interview into Dragon software, which produced a typed version of the interview in the investigator's notebook computer. The Dragon software produced mixed results. Sometimes it was slow; other times it was inaccurate. The use of the Dragon software was abandoned after the third interview in favor of traditional transcription which was completed manually by the investigator. The investigator saved the transcribed data to the hard drive, a thumb drive, and an external hard drive for backup. Data sets were de-identified before being stored electronically, and to further ensure confidentiality, encryption software was used to password protect data files on the flash drive and notebook computer.

QSR NVivo 7, a qualitative research management software, was used to support data management and organization in the study. This section describes how some of the features of NVivo 7 software were used to organize and store data and support the coding of data during data analysis.

The investigator purchased and downloaded N Vivo 7 (QSR, 2006) onto her notebook computer. She then attended training sessions on how to operate the software. She created a project file named “ASD” (autism spectrum disorder) for storing all data, information, and coding for the study. The investigator created and used four folders which were located in the ASD project file. These folders were: Interviews, Project Journal, Methodological Journal and Research Documents.

The investigator transcribed the first participant’s interview in Word and imported it into the Interview folder of the NVivo project file. At the completion of every subsequent interview, she transcribed each interview and imported a copy of it into the NVivo 7 ASD project file. She reviewed the content of the interview to be sure it was clear and adequately accounted for what was said in the interview before importing the data into the NVivo ASD project file. Three participant interview files required that she modify slightly the content of the interview transcript to protect the identity of the participant.

The investigator wrote her ideas, thoughts, and concerns about the study methodology and stored them in the Methodological Journal throughout all phases of the research study. The folder Research Documents was used to store the study’s research questions and any tentative coding results or schemes that had developed. When in the field or away from her computer, she used a pen to record these same items in a paper notebook and later transcribed them into her notebook computer. She placed into the Project Journal any ideas, insights, questions or possibilities about the study that arose while she was conducting and coding the interviews.

Software for coding support

This section provides a detailed description of how NVivo 7 software was used to support the analysis and coding of interview data. The coding process began when the investigator imported the interviews into the Documents folders and checked the interviews for accuracy. The investigator entered the “Node” section of the software and began the process of coding the interview transcripts. The Node section contained folders for free nodes and tree nodes. Nodes can be viewed as containers for ideas and are created to store ideas or text about related concepts together (Beekhuyzen, 2003). The investigator created new nodes by highlighting the text and typing in the name of the new node. If it were a node already in use and the investigator wanted to use the node again and associate it with another idea or piece of text, the investigator would highlight the text and use a “right click” to electronically select that pre-existing node.

The investigator used the software to move free nodes around to form tree nodes. The investigator used the “cut and paste” function to move free nodes into tree nodes. Creation of tree nodes allows the investigator to develop a form of hierarchy among the nodes. For example, when a parent mentioned a therapy for autism that she had read about on the Internet, the investigator coded that excerpt of text “chelation therapy.” A participant also mentioned ABA therapy. That text was coded “ABA.” After coding a few interviews, the investigator re-coded multiple different types of therapy for autism and placed them under one node called “Therapies.” A right click on the node would reveal all therapies that had been coded from the interviews. This node would include the participant who mentioned the therapy in her interview and enough narrative to

communicate the context of her having mentioned the therapy. A major benefit of the NVivo 7 software was that in a “right-click” the investigator could access any node, review immediately the identity of participant and be reminded of the context of the data or what the parent said and when the parent said it.

There were many other nodes that were created during this phase of the project. For example, when a parent mentioned the period of time her child was diagnosed with autism, that narrative was highlighted and coded to a node called “diagnosis.” Subsequently, other interviews were reviewed. When another parent mentioned in the transcript that her child was not diagnosed adequately, that narrative was highlighted and coded as “diagnosis.” Any other references to diagnosis were coded or assigned to the tree node “diagnosis.” Comments critical of the healthcare system arose and were coded “having to wait for appointments.” The constant comparative method (Glaser & Strauss, 1967) was used as the primary data analysis strategy in the study. For example, the node “diagnosis” and its components were reviewed regularly to look for relationships and connections to it among other data. The narrative about “failing to diagnosis in a timely manner,” having to wait for appointments” and other comments about problematic aspects of the diagnostic process for autism were re-coded and moved to the tree node “healthcare system problems.” After more interviews were completed and their data reviewed and analyzed, a theme of parents’ “searching with intensity” emerged from the data. “Searching” had once been a free node and based on the depth and richness of comments made by parents it was re-coded as a tree node and was supported by comments made by other parents who described searching the Internet with relentless

focus. At this point in the analysis, the investigator stepped back and asked, “What is going on here with this group of parents?” “What does the data say?” “Why are they searching?” A review of nodes and tree nodes revealed many comments about physicians and teachers who parents experienced as insensitive to their needs. Nodes suggested parents felt better when they knew something about autism and felt like they could do something about their child’s condition. A connection between “searching” and “needing to know” and “healthcare and education system problems” was made. Each of these categories was supported by tree nodes containing direct quotes from parents that had originated in free nodes. A coding scheme was developed that suggested parents searched the Internet with intensity and focus because they perceived the healthcare and educational systems to be insensitive to their needs. Hence, NVivo 7 was used to support the qualitative analysis rather than to perform the automated analysis itself as is sometimes erroneously assumed (Richards, 2002).

The coding and assigning of free nodes and tree nodes to data transpired over a period of several months. Most of the analysis and conceptualization of data occurred using paper copies of the interviews that had been unitized or reduced to nodes and printed from the NVivo7 ASD project file. For example, after coding two interviews using NVivo 7, the investigator reviewed with her adviser interview data that had been coded or assigned to nodes. Together she and her adviser manually coded the transcripts in the margin of the paper copy of the interviews and compared them to the NVivo 7 printouts of nodes and their contents of quotes made by parents. Differences in coding were discussed and reconciled. When necessary, the investigator returned to the ASD

project file. She opened it and made changes to coding decisions by “right-clicking” the “un-do” key. Subsequent reviews of coding decisions were made using the print-outs from the NVivo project file. These printouts contained the nodes and the supporting quotes from the participants who made them. Hence, analysis and coding of the interview data was facilitated and supported by the data organization, storage, and retrieval capabilities of the software although the analysis, conceptualization, and generation of categories and themes of data was developed using traditional qualitative research techniques.

Summary

Qualitative researchers encourage transparency and to even become literal in their description of their data analysis (Bringer et al., 2004; Fauske, 2007). Achieving and communicating the coding process with precision and transparency is difficult because the coding process is recursive (McWilliams, 2005); that is, the investigator was continually going back to the interview data and comparing it to possible emergent ideas and concepts heuristically.

Retaining and communicating transparency of the coding process was a priority. While navigating through the data in the project file, the investigator was continually looking for relationships and ways to connect the data and integrate it into a meaningful representation of what the parents had experienced. These emergent ideas and concepts were organized or stored under nodes that were named according to their content or meaning. A node may have already been created for an emergent theme, in which case, if

appropriate, other ideas or concepts (that might either be free nodes or unassigned text) would be coded to or placed under that node. Larger, broader, and more inclusive concepts were formed from these nodes and were termed categories (or themes) and subcategories. The formation of categories and themes were sometimes conceptualized using paper and print-outs of nodes. Later the nodes and resulting coding scheme or structure were recreated and imported into the NVivo 7 project file and the Methodologic notes. Hence, the project was conducted and completed as a hybrid between manual and electronic means. The electronic component was data base management software designed for qualitative research; it filed nodes under other nodes that were further developed and combined with other nodes that became higher order concepts such as categories or themes.

Data analysis strategies

The investigator used the constant comparative method of data analysis and thematic analysis recommended and described by Lincoln & Guba (1985) based on the work of Glaser and Strauss (1967). Collection and analysis of data in a NI study go hand-in-hand in a progressive, iterative and ongoing process (Erlandson et al., 1993). The most recent participant responses were compared with previous responses in a search for consistencies, discrepancies, anomalies and negative cases (Glaser & Strauss, 1967). The investigator responded to the first available data and immediately formed tentative working hypotheses that might have caused adjustments in interview questions. As a result, some interview questions were added. These were: “Where do you think you

would you be without the Internet?” and “There are many choices and controversies about treating autism. Do you use the Internet to resolve these treatment controversies, and if so please explain.” The latter question was added to gain insight about how parents both choose and reject therapies, traditional or otherwise, that are described on the Internet. New data obtained from these questions helped to confirm tentative hypotheses that had been formed. The technique of constant comparative analysis, along with a sampling strategy that sought saturation of data or a state of redundancy of data, continued until the study was concluded and the final report was written (Erlandson et al., 1993).

The investigator adhered to data analysis procedures as described by Lincoln and Guba (1985): a) data unitizing, b) emergent category designation and c) negative case analysis. Data were unitized and disaggregated into the smallest pieces of information that could stand as independent ideas relating to the phenomena of interest. A unit could be a few words, a complete sentence, several sentences and-or an entire paragraph (Erlandson et al., 1993).

Designation of emergent categories occurred as the investigator sorted the units of data into categories of ideas using the following steps: a) read the first unit of data and set it aside as the first entry in the first category; b) read the second unit and either add it to the first group or set it aside as the first unit in a second category; c) proceed in this fashion until all units have been assigned to a category; d) develop category titles or descriptive sentences, or both, that distinguish each category from the other and view

them as tentative in nature; and e) start over until all categories are exhausted (Erlandson et al., 1993).

The technique of negative case analysis was used to make the data more credible (Lincoln & Guba, 1985) and to refine hypotheses developed during analysis of data. Negative case analysis requires the researcher to look for disconfirming data in both past and future observations (Kidder, 1981). Negative case analysis is a conscious search for negative cases, cases that do not fit one's hypotheses or conclusions, and, as such, represent unconfirmed evidence that allows one to refine one's working hypotheses (Glesne, 2006). The original hypothesis was that all parents in the study were using the Internet to locate alternative therapies that might cure their children's autism or at least minimize their child's symptoms of autism. Through negative case analysis, it was determined that not all parents were looking for a cure or for alternative therapies that would provide a cure for their child's autism. For example, one mother was looking on the Internet for a communication technology to help her son tell her what he wanted and needed. The mother was not trying to "cure" or reverse his symptoms, instead, she was trying to find a way to help him function optimally. She accepted that he would retain his communication problems. Another mother used the Internet to help her understand what her son might be feeling and experiencing. She visited websites or blogs maintained by individuals with Asperger's syndrome to read their perceptions and to communicate with them so that she might understand her son's behavior. She did not try to reverse his autism. Instead, she tried to understand him and more completely understand the world that he experienced.

The technique of negative case analysis also was used to disconfirm the working hypothesis that parents in the study were active or had been at least occasional participants in online discussion boards or group e-mails. This hypothesis was disconfirmed when examination of the interview data revealed that some parents did not participate or join in online communications with other parents of children with autism-related disorders instead, they preferred only to read what others had written or discussed.

Coding strategies

The types of coding employed in the study included descriptive, topical, analytical, and thematic analysis (Morse & Richards, 2002; Richards, 2006). Descriptive coding, similar to quantitative coding, is storing information or attributes about the participants such as age or gender. Topical coding is labeling text according to the subject of the text, creating a category or recognizing a category that was created earlier. Topical coding dominated early in the project and was the first step toward interpretation of data. The codes or nodes developed using topical coding were organized in NVivo 7 software and reviewed by a faculty adviser for consistency. Although this part of the project was rote and could be viewed as straightforward, it proved to be an essential coding activity (Richards, 2006).

Analytical coding refers to coding that comes from interpretation and reflection on meaning (Richards, 2006). Analytical coding is more than storing information or naming a topic of a text, it is considering the meaning of a node or code in a context and creating categories that express new ideas about the data. Thematic analysis, which is more

pervasive than naming a topic or category, also was employed. Thematic analysis, or developing themes to convey the meaning of human behavior, was achieved by reviewing and conceptualizing the data and searching for its meaning within a broader understanding of the phenomenon of interest. In this study, a topical code was *diagnosis*, an analytical code was *problems with the diagnostic process*, and a theme (or category) was *Searching*. (A chart showing how interview data was coded using topical and analytical coding is located in Appendix G.)

STRATEGIES TO ENSURE RIGOR

The study applied the standards of trustworthiness in naturalistic research described by Lincoln and Guba (1985) and modified by Beck (1993). Lincoln and Guba designated the criteria of *credibility*, *fittingness* and *auditability* to ensure trustworthiness of qualitative studies. Each criterion and the techniques for achieving them in this study are described below.

Credibility

Credibility in qualitative research is the criterion against which the truth value of a qualitative study is measured (Beck, 1993). Credibility measures the vividness and faithfulness of the description of a phenomenon. Since vivid and faithful descriptions enhance research credibility, the investigator kept in-depth and descriptive field notes that were entered into the memo section of the NVivo software. The software also accommodated a reflexive journal or Project Journal detailing researcher-participant

relationships, as well as actions, interactions and subjective states of her and the participants and the investigator herself. An expert in qualitative research reviewed the transcripts and data analysis procedures on an ongoing basis throughout all phases of the study to guard against researcher bias and selective inattention.

Fittingness

Fittingness is the criterion against which the applicability of a study is evaluated (Beck, 1993). Fittingness measures how well the working hypotheses or propositions fit into a context other than the one from which they were generated (Guba & Lincoln, 1981). To assure fittingness in the proposed study, the investigator assessed the typicality of the respondents and adjusted the sampling procedures as needed in order to get a range of experiences among the respondents (Beck, 1993). As noted earlier, a second male (or father) was added to the participant pool and a parent of a child more recently diagnosed also was selected so that the hypothesis that parents' information and support needs are different after diagnosis could be explored and evaluated.

Auditability

Auditability is the ability of another investigator to follow the decision or audit trail of a research study (Guba & Lincoln, 1981; Beck, 1993). To provide for auditability in the proposed study, the investigator used an audio- recorder to record the interviews and field notes. The investigator accurately described all data collection, analysis strategies and recruitment procedures. All aspects of the study, including the interviews, the data,

the coding and data analysis were recorded in Word and NVivo software to ensure that others could follow the decisions made after the study began (Erlandson et al.,1993).

SUMMARY OF STUDY RESULTS

The data were analyzed and coded using the constant comparative method and the topical, analytical and theme analysis described by Richards (2006). *Searching* emerged as a theme (or category) and represented the parent's intense need to know and to find out about the causes and potential cures for autism. Parents of children with ASD spoke of health and educational systems that had failed to provide the support and information that they as parents needed to manage their child's condition. These parents of children with ASD also described using the Internet community to provide information and support to one other when they perceived that conventional sources of information and support had failed them. The next chapter will describe these findings in depth and suggest how these findings can be used to improve the care and services that .parents of children with ASD receive.

Chapter 4: Findings

INTRODUCTION

This chapter will present the findings of this descriptive exploratory study. The findings are in the form of categories that represent common meanings and interpretations of parents of children with ASD who used Internet resources to help them fulfill their roles as parents and caregivers. Specifically, the content of the categories communicate why and for what purpose parents of children with ASD searched the Internet, which sources of information about ASD the parents found trustworthy and how they determined whether it was trustworthy, and finally, how this information influenced the care they provided to their children. The three research questions that guided this study include:

1. How do parents of children with autism spectrum disorder (ASD) use Internet resources in response to their needs as parents and caregivers?
2. How do parents evaluate the trustworthiness and describe the adequacy of information that they find on the Internet?
3. How do parents of children with ASD choose Internet-derived information about autism, and how does this information influence their decisions about their choice of treatments and therapies for their child?

Seven themes or categories were inducted during the analysis of data. These categories included: 1) Searching; 2) Why the parents searched; 3) What they searched for; 4) How and where they searched; 5) Other sources of information; 6) What did they did not find; and 7) What else of value they found.

The following section presents the bio-demographic profile of the study participants, including their gender, age, marital status, education, income, occupation, and also bio-demographic information about their children. Following the bio-demographic profile, there is a description of how interview and other data aggregated into seven themes or categories which represented common meanings and experiences among the study participants.

DEMOGRAPHIC PROFILE OF STUDY PARTICIPANTS

There were a total of twelve participants in this study. There were 10 women and 2 men ranging in age from 31 to 53 years. The average age of the participants was 43. The average age of their child with ASD was 7.5 years at the time of the study (range: 4 to 13 years of age). At the time of diagnosis, the average age of the child with ASD was 3 years; their ages at diagnosis ranged from 2 years to 6 years. Ten of the parents were white and two were African Americans. Only one participant was not married. Eight participants had undergraduate degrees and four had graduate level degrees. Two of the women in the study reported being stay-at-home mothers, two were nurses, one was a college professor, one was a teacher, one was an interior designer, one was a yoga therapist/autism advocate, and one owned her own business. One of the men was a real

estate developer and the other was an engineer. The income levels of the participants were higher than average. One participant reported earning \$200,000 or higher, two reported earning \$150,000 to \$199,999, four earned \$75,000 to \$99,999, and five earned \$50,000 to \$74,999. Eight of the 12 children in the study had been diagnosed with autism disorder, three with PDD-NOS, and one with Asperger's syndrome. Six of the parents had a total of two children in their families, three parents reported only having one child, two parents reported having four children, and one parent reported having a family with three children. Four parents reported their religion as Baptist, three as Catholic, two as Christian, one as Jewish, and two reported that they had no religious affiliation. Parents were asked how much time they spend monthly on the Internet looking for information about personal interests including time spent looking up information about their child's condition. Three parents reported that they spent 10 to 30 hours on line per month and nine parents in the study reported that they spent greater than 30 hours online monthly. All had broadband access in the home.

The following describes in detail the seven categories and their related subcategories, which were developed after interview and other data were coded and inductively analyzed. (Appendix H summarizes the categories or themes.) The first category reviewed is *Searching*.

SEARCHING

A parent in the study described herself as “constantly searching for what to do next” for her child with ASD (P4: 281). Another mother of a child with autism said she

spends 15 hours per week searching the Internet for information about autism. She also maintains an electronic newsletter so she can send information to about 300 parents of children with ASD. She explained her motivation for gathering information about ASD:

The key is to know. The more I know the more I can help [my son]... the more I can help [my son], the more compelled I am to help others...I want to know. So I can sift through this information and say, 'Maybe this will work...or maybe something else' (P2: 48).

The mother of a child newly diagnosed with Asperger's syndrome expressed a similar desire to learn and to know about ASD:

The first thing I did [when my child was diagnosed] was [to] look up everything [about ASD] online. I printed it all out and tried to read everything...I drove my mind crazy trying to read it all and figure everything out (P6: 261).

Another mother reported that after her child was diagnosed she spent much of her time on-line "in non-stop researching, finding as much information as possible because the feeling of not knowing anything [about autism] is the scariest feeling...and that once you kind of feel like you have a grasp on the field...you feel more secure" (P11: 299). All parents in the study reported that they had begun the heaviest use of the Internet after they received a formal diagnosis of ASD for their child. The period following the diagnosis was an uncertain one. The parents looked for the definition and symptoms of ASD. One mother said: "I just spent hours, hours, hours, researching everything I could on the definition of autism to its symptoms...To how he could have gotten it...Everything" (P12: 472).

Despite research advances and a growth in parental advocacy and education efforts, ASD remains poorly understood. This general lack of understanding about ASD

is illustrated by the comments of a mother in the study: “I didn’t know a whole lot about autism. I wanted to know what it was, what I could do. What should I be looking for? How can I help? Is it going to get better? Is it going to get worse? Those were questions that I was just surfing the Internet to find out” (P3: 119).

Mothers of children with ASD who participated in the study researched autism-related topics on the Internet with thoroughness and intensity. One mother, who had suspected that her son was not developing appropriately, described how she began her Internet research in her efforts to understand what was going on with her child: “... I found [the Internet]...and for 22 months I just lived on it” (P9: 198). “I have gone down every rabbit trail” (P9: 191). “You get on the Internet and find out stuff and depending on how smart you are [and] how far you are in the degree you [are willing] to go... you [can] just keep going” (P9: 205).

The parents’ intense need to know and to learn about ASD had an intense or urgent quality, especially when the parents were not certain of what the problem was with their child. The parents’ constant searching was motivated by uncertainty and worry; they often turned to the Internet for answers to their questions and concerns about ASD. Another mother suspected that her son had some developmental problem, but she was not sure what it was. Once she learned of her child’s diagnosis she said, “I told my husband, ‘That’s it. Everything stops. I’m done. I’m not working. I’m not doing anything [except research autism]’ ...Then I got to the office and I stayed on the Internet literally hours, days and weeks” (P9: 189). She continued: “I thought, ‘Oh my God. You are living in a

nightmare.’ ‘I’m just nuts.’ I thought that, too. I’m going to have to figure out how I’m going to afford all of this medicine and nutritional stuff and therapy and there’s no insurance to cover it. [They/insurance] don’t cover autism because it isn’t a medical condition. And so then I went to my husband and said, ‘We have a *major* deal here.’ And so [ever since then] I have been on the Internet a *lot*” (P9: 200, 203).

All of the parents in the study expressed an intense need to learn more about autism so that they would be better able to help their children. Parents knew very little about autism before their children were diagnosed. Following the diagnosis, they searched the Internet with intensity, thoroughness, and a sense of urgency.

WHY THEY SEARCHED

Learning of their child’s diagnosis was traumatic for all of the parents who were interviewed, and unfortunately, the healthcare and educational systems did not always provide the parents with adequate information and support.

Healthcare system issues

Several parents reported that the process of getting a proper diagnosis dragged on for several months, and in some cases, years. Waiting to receive a diagnosis coupled with long waits to obtain medical and other required appointments made their encounters with the healthcare system frustrating and regrettable experiences. Three of the mothers had suspected something was wrong with their child but they had difficulty convincing their pediatrician that there was a problem. In three other instances, once an appointment was made, the physician was reluctant to make the diagnosis of ASD.

The experiences with the healthcare system during the initial period of learning that the child had ASD set a negative tone for the parents' encounters with the healthcare system and subsequent visits to providers. One mother reported that the wait for a specialist to see her child took almost three months (P4: 251), while another had to wait nine months (P12: 476). One mother revealed: "It took us so long to get in [to see a physician]...It took us like four months... which is quick compared to what it is now" (P8:44). The same participant said: "It took three months to get a speech eval and another month and a half to get the psych eval" (P8: 44). She reported that she spent nine months going to appointments with a variety of specialists before finally receiving a diagnosis for her son. She said that she remains resentful that she did not know the importance of spending more of that time getting therapy for her son rather than waiting through a series of appointments in order to obtain a diagnosis. She later learned that the early infant and childhood years are "golden neurological time" or "maximum neuroplasticity time," (P8:39) which is a general period when many developmental pediatricians believe the neurological systems of children with ASD will benefit most from therapeutic interventions.

Many of the parents' initial encounters with the healthcare system were negative. They experienced the inconvenience of prolonged waits for appointments with various healthcare providers. One mother, who had had to wait four months simply to get an appointment with a medical provider, reported that she and her child with ASD finally had arrived for the appointment where she believed the provider was located only to

discover that no one had thought to tell her the office had moved since she made the appointment: “I went to the wrong place and we were late. So we had to wait again. I had not prepared an extra snack so I’ve got this child who is out of control in the waiting room...I am having to entertain him...and there is no food in the building at all that he can eat” (P8:44). Waiting to receive an appointment from a telephone appointment scheduler and waiting to be seen by a provider in an office visit are both commonplace in any healthcare system, but some mothers of children with ASD experienced this inconvenience as unusually taxing and demoralizing. Parents of children with ASD who participated in the study reported that they initially had gone to the medical and healthcare systems seeking assistance in deciphering their child’s perplexing behaviors. Instead of receiving assistance, they were met with protracted waiting times in clinics and spent months simply to schedule appointments with various clinical disciplines, a process which ultimately culminated in receiving a diagnosis of ASD. Little, if any, concrete help or direction was provided by physicians after diagnosis. One mother said, “Getting the diagnosis was the biggest hurdle of all because it took them forever. And at the end of the process they do not have anything to offer you....They say, ‘We will get to it. We have all these kids to see. It is more important that we do a thorough evaluation...da da da da da da da da...’ But in the end, the [doctors] don’t have anything to offer you” (P8: 4). The lack of support and information from physicians and other traditional sources of health information helped to create a sense of frustration and isolation, driving the parents to search the Internet to get their information needs met. Physicians have few answers to offer parents of children with ASD, but that does not stop parents’ searching nor does it

diminish their need and intense desire to find answers that will help their children improve.

Traditionally, people facing a health issue, including parents who have a child with a health care condition, seek information from their physicians; however, several of the parents of children with ASD who participated in the study reported that they had met with a lot of frustration when they sought knowledge and information from physicians about their child's condition. The parents perceived that the physicians not only were unresponsive to their needs, but lacked information about ASD. The parents in the study found a lot of physicians unhelpful in their quest for useful information about autism:

I would be happy to find a doctor who would be even able to talk about autism."..."There are not any doctors that I have met so far who know anything about autism." (P4: 99, 123)

It is sort of sad...They [parents] don't... learn from the doctors or pediatricians." (P2: 103)

[Pediatricians] are so lacking in knowledge of autism." (P5: 86)

I very seldom go to somebody [a physician] who considers themselves an expert, unless they are a parent [of a child with ASD]. I have gotten to the point where I don't care to waste my time with any physician who does not have a child [with ASD] themselves because they so do not get it." (P8: 44)

The parents' lack of confidence in physicians was not limited to physicians' ability to manage and interpret clinical aspects of ASD. Parents also did not believe that physicians adequately use the enterprise of research and its findings to address and

manage the needs of children like theirs. One parent acknowledged the demands on physicians to treat as many patients as possible and questioned whether physicians have the capability and time to interpret ASD-related research:

What I've learned is that MDs are also not researchers...MDs are clinicians...MDs often do not know how to read research...they do not have time...(P8:54).

The parent also complained that some physicians do not take the time to learn about ASD-related medications. She questioned whether physicians “ask the right questions” about the appropriate use of medications in the treatment of ASD and speculated that instead physicians depend on “that little blurb that the marketing person from the pharmaceutical company handed them” (P8:54).

Parents in the study seemed to have had poor experiences with their child's first pediatrician, perhaps because getting the diagnosis of ASD and trying to plan related treatment and therapies was a confusing and uncertain process for parents. Only one parent in the study had been satisfied with her original pediatrician and continued to take her child to him. Two other parents were unhappy with their child's first pediatrician but reported that they were more satisfied after changing to a second pediatrician. One of the two parents who had changed pediatricians reported that the subsequent pediatrician readily complied with the parents' request to be referred to “different specialists” (P5: 136). The second parent was also satisfied with the care their second pediatrician provided because when the parent asked the pediatrician to order more speech and occupational therapies for their son, she responded by saying: “Sure...So how much does

he need?' The parents were grateful that the physician was willing to "sign off on things for her insurance" (P7: 51). The same participant also reported satisfaction with her second pediatrician because this pediatrician had noticed a discrepancy in her child's development: "The pediatrician was the one who said, 'If he isn't talking by 15 months, then we are going to have him looked at.' She was the one who was asking questions....And at about 15 months they did come and determine that he was behind. ...She is actually a really good pediatrician" (P7: 51).

Positive comments from the parents who were satisfied with their children's physicians seemed to have resulted from physicians' personalizing or individualizing the care provided. A mother of a child with autism described how her child's pediatrician helped her to feel less overwhelmed by the array of potential treatment choices available to her child. The physician suggested that she begin to address and manage her child's symptoms by starting with "something simple...like eliminating certain foods from his diet" (P6:261). Another mother appreciated a physician who would not "look at me like I had three heads" when she wanted to explore a diet elimination system to manage her child's symptoms (P4: 123).

A third mother gave another example of a physician individualizing care. A pediatric resident suggested immune-strengthening probiotic supplements rather than antibiotics for her child who had nagging gastrointestinal problems associated with ASD. Although the mother was grateful for the physician's approach, the resident ultimately did not prescribe probiotics because the family's insurance reimbursement covered only antibiotic treatment.

Parents who were satisfied with their physicians and the care received had experienced individualized, personalized and responsive care. One physician took the time to plan and review a diet for the child. Another physician “signed off” on additional speech and occupational therapies requested by the parents, while other physicians supported the parents’ request to use complementary therapies such as a diet elimination system and probiotic supplements. Parents who were unhappy with their children’s care believed that their physicians lacked expertise in ASDs and did not take the time to learn about related research, treatments and medications. Parents also were dissatisfied with care when there were lengthy waits to obtain appointments or to be seen by providers once appointments were made. Many of the parents in the study were primed by the negative experiences with the healthcare system to seek information and support from other sources. One such source was the Internet, which could be argued was a more reliable and accessible resource than the healthcare system.

All parents of children with ASD who participated in the study expressed frustration and dissatisfaction with the adequacy of direct health services for their children with ASD. Seven of the parents expressed disappointment that ASD-related research efforts were not more successful and productive. One mother commented: “Western medicine has not really found anything [about autism]. They [medical researchers] have failed, really” (P1 122). Another mother wondered: “How bad does it have to get [before more research into autism is funded]? One in 94 boys is being diagnosed” (P4: 227).

Parents in the study expressed their desire to influence what kinds of ASD-related research studies are conducted. The parents called for research focusing on current behaviors and symptoms of autism, and not just on the genetics of ASD. One parent criticized physicians whose position is: “[Autism] is a genetic disorder and [we need to prevent it through] genetic research” (P8: 56). She instead favored research into why some parents observe improvement in their children following dietary interventions such as supplements or special diets, and whether the presence of “biomedical markers,” physical differences among children with ASD at the molecular or cellular level, might explain or help explain the variance in responses to treatments. Cellular-level differences might account for why some parents note a response by their child to a particular treatment while others do not (P8: 56). The mother perceived that researchers have ignored parents’ wishes to have biomedical interventions studied, instead, pursuing investigation of genetics even though, in her opinion, identifying a gene would help only a small (“one percent” P8:58) of children affected by ASD. She wanted research into how to deal with her own living child now, rather than research directed at preventing autism in the future.

One of the mothers who participated in the study was an advocate for autism in her community and state. She reported that researchers do not take seriously parents’ wishes to influence which areas relating to autism should be pursued by the research community. She admonished researchers that they “must not assume that parents are crazy” just because parents are passionate about exploring new treatments and seeking

ways to improve their child's current functioning. She also implored physicians to "believe that parents are giving accurate reports [when they say that an intervention] is helping their kids..." (P8: 58). The mother's statement seems to reflect how parents feel marginalized and discounted by pediatricians who do not believe that it is acceptable for parents to be seeking treatments for ASD which are independent of mainstream medicine. As a result, parents of children with ASD may not share with physicians the scope and type of treatments they are pursuing for their children. This lack of communication and collaboration between the parents of children with ASD and their children's pediatricians could have a deleterious impact on the children's care as it creates an environment where parents may feel the need to suppress key information about their children to their providers. For example, one mother took her child with autism to a gastroenterologist to evaluate his symptoms of gastrointestinal distress. She emphasized that she did not mention to the gastroenterologist her concern about her son's "leaky gut syndrome," a diagnosis in alternative medicine in which it is believed toxins or the MMR vaccine may damage the intestinal wall, allowing undigested proteins to affect the brain resulting in symptoms of autism (Cass et al., 2008). She believed that because her physician was a member of "mainstream medicine" he just would not have "gotten it," that is, the physician would not have understood leaky gut syndrome nor been able to treat it (P4:111). Another mother said she had been "derided" by her pediatrician for some of the alternative therapies she had tried for her child (P8: 47). One mother described a more sympathetic exchange of information with a physician. She said a physician in her town

was willing to offer alternative therapies for autism, but only if the mother initiated the discussion and presented the idea (P9: 98).

Summary

The parents in this study were energetic and focused when seeking information about autism. Their determination showed their commitment to reversing or ameliorating their children's symptoms of autism. When actual or perceived barriers to information and support from within the healthcare or research system occurred and thwarted, the parents became frustrated and felt disenfranchised, which served as an impetus for them to seek information from the Internet. Unfortunately, the healthcare system was not the only social system viewed as problematic by parents in the study.

Educational system issues

The educational system, like the healthcare system, was described by all of the study participants as another source of frustration for parents of children with ASD. Much of their frustration appears to have resulted because services mandated by federal legislation are not adequately funded at the state and local levels. The Individual with Disabilities Education Act (IDEA) mandates that public schools provide educational services, and related services, such as speech and occupational therapies to children with disabilities, including ASD. These services are provided in order to facilitate the child's education and are not considered to be medical services. The services that are provided to

an individual child are based on an IEP or Individual Educational Plan, which many of the parents in the study said did not adequately address their children's needs.

Many of the parents in the study reported that the educational system had improperly restricted services to their child. One parent complained that the problem was compounded by the fact that the Texas Educational Association's (TEA) definition of ASD is antiquated and application of the TEA definition to her child contradicted a medical diagnosis of ASD her child had received at a large, academically-affiliated pediatric hospital. She said that she and her husband "have fought a lot" with the school district to obtain services for their child (P12: 79). Moreover, she believed that the school's inadequate services are "just a money issue." She explained: "The [schools] are having by law to give so many services [to children with ASD] now...and the money is not there to give it..." (P12: 79).

One participant in the study said that she and her husband had sued their child's school district to ensure that the child's classroom was located in a building with standards equal to other school buildings. The mother responded to another parent's assertions that the school would do what was in "the children's best interests" by countering emphatically, "No. The school will do what is cost-effective" (P7: 150). Another parent said: "Schools just don't have the resources" (P5: 48). A third mother was astonished to learn that the school system was going to give her son only one hour of speech and language therapy per week even though he had lost his language skills and needed more in-depth services (P9:91). These comments reveal the parents' lack of trust

and confidence in the educational system's ability to meet their children's educational needs. None of the parents in the study believed that their child was receiving adequate educational services. The parents also saw that behind the school system's failure was a lack of adequate funding to support the services needed by children like their child.

Some parents perceived that professionals in the school system were not well-versed in current treatment strategies for ASD. One parent noted that "the majority of families rely on school districts for information" about ASD treatment strategies, but schools and even their special education services "have so far to go" (P2: 103).

The same mother said that on her own she prepared information to send home to fellow ASD parents about various treatment strategies. However, she also believed that many parents are just "overwhelmed" by the volume of information that they receive about ASD. She noted that many families who seem to rely almost exclusively on the schools for information about ASD only know about very conventional treatment approaches, such as speech therapy, and were slowly learning about ABA and Floor Time. The mother noted that parents who rely exclusively on the school system for autism-related information seem to know much less than parents who sought other sources of information; therefore, she concluded that the school system was not on its own an adequate supplier of ASD-related information to parents (P2: 103). Another parent whose five-year-old child had a vocabulary of only two or three words, complained that the school district had "no new technology" (P12: 404) to offer her son and his language skills were not improving. She said that school officials had told her

they doubted the accuracy of the child's diagnosis of autism but nevertheless agreed to purchase for him an assistive device only when she took the initiative to do Internet research on the effectiveness of the devices. It was necessary for the mother to take the initiative to research online and develop expertise in the various speech and language assistive devices in order to get the help for her child. She did not feel supported nor did she believe that the educational system viewed her child's needs as important.

The education of children with special needs, such as ASD, is uniquely challenging to parents. Parents must reinforce at home what their children learn at school, making the relationship between the parents and their children's teachers an important one. Parents can spend a lot of time and energy maintaining that relationship and making sure their children's educational needs are met. Hence, the parents believed that it is important that school administrators attract and retain competent teachers and manage the poor performance of others.

The parents in the study were very concerned about the quality of their children's teachers. One father described the impact of teacher turnover and complained that, "When parents do find a good educator and spend time bringing them up to date on their child's progress and history, Boom! They [the teachers] are gone because [the school districts] do not pay them and it is just too much work" (P5: 86). A mother said she decided to home school her child after witnessing a teacher refusing her child's request to use the restroom and using an inappropriate technique to restrain her son. She believed the teacher's behavior was the result of inadequate teacher training (P6: 222).

One mother admitted that teaching a child with ASD is challenging and quoted an educator who said that, “A child with autism will shine a spotlight on bad teaching and will turn that situation into chaos” (P8: 198). The parents who participated in the study understood that teaching children with ASD is a challenging and complex responsibility, but they clearly were dissatisfied with the education their children were receiving in school. The mothers whose children were diagnosed with autism disorder (or classic autism) expressed more frustration about turnover of teachers and teachers’ lack of training than did the one mother of a child with Asperger’s syndrome.

Even parents who chose private education for their children with ASD reported problems or concerns about their child’s education, despite having more choices of schools available to them than other parents. One father had been surveying private schools for his child and was confounded when repeatedly confronted with what he experienced as inadequate information from the schools about their resources and approaches for educating children like his son. He said: “If you don’t [know how to] ask the right questions [of a school], you don’t get the right answers. And sometimes you ask the right questions, you get the wrong answers...You are going to have to follow your gut...and [have] that intuitive sense that if whether what you are hearing is true or not...Is it right for you? Is that something that makes sense to you? What does your gut tell you?...A lot of people don’t do that and get misdirected and end up wasting a lot of time and money and their kid is the one that ends up not getting what they need” (P10: 102). Even the most resourceful parents felt inadequate when trying to select educational

services for their children. When the father could not obtain the information about the school that he was seeking, he said he began making decisions based on “gut” or instinct. This default to emotion-based problem-solving further illustrates the difficulty of parenting a child with special needs and how important it is for parents to be able to find timely and accurate information about how to educate their child and support his or her learning needs.

All parents in the study believed that the educational system, like the healthcare system, was inadequate and insensitive to their needs and the needs of their children with ASD. Some participants found that some teachers were unhelpful and sometimes displayed callous attitudes toward their children with ASD. One parent believed that teachers “just want to frustrate you to the point where you just throw your hands up and home school the child. They don’t want to even teach them” (P5: 48). The parent went on to say: “The teachers looked at us like we were scum [because we were] trying to advocate for our child. He cannot advocate for himself” (P5:132).

The parents who participated in the study did not believe that the school system perceived their needs and their children’s needs as important. They also did not believe that the schools were willing or capable of meeting those needs. One mother recalled a meeting among herself and her husband and school system administrators to receive her son’s diagnosis. She perceived the administrators in the meeting as insensitive to parents. She said that she knew at the time of the meeting that she and her husband “were going to cry [after receiving the diagnosis of autism] while the administrators providing the

diagnosis “weren’t going to think twice about it” (P12: 324). Another mother said that “School districts [should] talk to us, but don’t talk [down] to us...I will bring my child and let you see what it is like for an hour. But don’t tell us what to do...Here is my baby...so you can see what we are going through” (P2: 312). The comments of these parents reflect their sense of isolation and perhaps abandonment by the school system. The parents reported that they were constantly searching online for information about ASD because the traditional sources of information, such as physicians and educators, proved to be inadequate. This deficit of information and support led the parents to seek information from online sources about what was going on with their children and how they as parents might help their children achieve the best possible outcomes using educational and other therapeutic strategies. The Internet was an accessible source of information about autism, including its causes and the best treatment approaches.

WHAT THEY SEARCHED FOR

ASDs are poorly-understood disorders. Symptoms vary substantially among affected children and behaviors of children with ASD can be perplexing, disruptive, and sometimes disturbing. Parenting children with ASD is taxing. Physicians and educators often do not agree with one other or their peers on the best approaches to take with these children. There is little empirically-derived data to support therapeutic interventions. As a result, many parents, in their quest to help their children, will try almost any treatment as they feel they cannot wait for research studies to be completed and published. Perhaps motivated in part by the confusion even among experts about autism, parents in the study

relied on the Internet to quickly obtain information about ASD, including how it is diagnosed, what might cause ASD, to gain understanding of their children's symptoms and to learn about possible therapies.

Confirming diagnosis

Parents in the study reported that they searched the Internet to locate a definition of ASD to see if the symptoms they observed in their child fitted a definition or description of symptoms of ASD that they found on a website. Much of their searching occurred when they had begun to suspect there were problems with their children's behavior or development. They wanted to be more informed before they consulted their physicians. One mother compared her child to developmental milestones posted on a website of a baby food company. She said, "When [her baby] wasn't rolling over, turning over [at eight months] I kind of knew [there was a problem] (P12: 424). Later, she made several visits to a children's hospital website and completed an online assessment for autism:

Every time [I completed the assessment], my son scored very high on the autism level...I brought that to the school and then to the doctor...I even brought that to the language people...I brought that to the doctor and asked her what she thought. She did not see that yet (P12: 412).

Another mother described her child's symptoms to her sister-in-law, a pediatrician who lived in another city. The sister-in-law said the child's symptoms sounded like Asperger's syndrome, so the mother immediately began to use the Internet for research. She located a website maintained by an Australian psychologist that offered

an assessment scale for ASD. She reported that when she completed the assessment she exclaimed: “Oh my God! There he [her son] is! That’s him...The tantrums, you can’t distract [or] soothe them from him...It is very weird...[He] just focuses in on something to the exclusion of all else...So when I completed the scale I got 9 out of 11” (P8: 38).

Other mothers who accessed the Internet for information about ASD expressed frustration and anger that they could about not get answers about the nature of their child’s situation from traditional resources. For example, a psychiatrist had told one couple that their child could not be diagnosed before two years of age. However, the parents went to an online version of the Diagnostic and Statistical Manual of Mental Disorders (DSM) to compare their child’s behavior to the DSM criteria. The mother stated emphatically, “You can too diagnose it at two [years of age].... I went back to the Internet and looked up the definition and I am saying to myself...‘He meets all these criteria...There is no question...He is firmly in there.’. . .The Internet really did help [us] there because we did not have a copy [of the DSM]...It is just a nice, easy checklist...So that’s great that is up there on the Web. I have sent other people there” (P7: 64). Another mother who had been struggling to make the school district provide services to her son frequently consulted the Texas Education Association (TEA) website in order to better understand the TEA criteria for ASD (P12:75).

Causes

The parents who participated in the study reported that they searched the Internet seeking to clarify and understand the causes of ASD: “I just spent hours researching

everything I could [ranging from] the definition [of autism] to symptoms...and how he could have gotten it” (P12: 472). Generally, the cause of ASD remains unknown, so no parent can be sure of the specific etiology of their child’s disorder. All explanations are merely theoretical in nature. Among the proposed causes of ASDs mentioned by the parents who participated in the study were: vaccines, mitochondrial weakness, Lyme’s disease, allergens, genetic influences, chromosomal damage, environmental toxins and various mineral deficiencies.

Four parents in the study discussed their belief that vaccines cause autism and that governmental agencies and vaccine manufacturers have colluded to hide or minimize data that would support vaccines as causal agents of ASD. One mother said, “The NIH or CDC is still trying to pin it [autism] on something other than the vaccine” (P4: 133). Another mother said that the CDC website had information for parents stating that vaccines are safe, yet the same website contained a section addressing physicians providing information that is more accurate and full of descriptions of possible reactions to vaccines. The mother said “. . .[the CDC tells physicians]; “Yes, we have these reactions [to vaccines]...[and] we are paying out these damages [monetary settlements to parents about side effects from vaccines] and you need to be worried about certain [outcomes]” (P8:77). The parents appeared to have a substantial level of distrust toward the vaccine developers and physicians who urge them to allow vaccination of their children. One parent described how a British gastroenterologist was having his license

threatened because he merely said, “I found measles in the gut of kids with autism and there is no other way it could get there except for the vaccinations” (P8:146).

A parent in the study also said she had carefully read the section on the CDC website directed to physicians where, she reported, the website outlines the contraindications for various vaccines. The mother found on the website information indicating that her child should not have received the diphtheria vaccine since the mother has a history of a seizure disorder; however, no physician had ever told her of the contraindication nor had the physicians screened the mother for a seizure disorder before administering the diphtheria vaccine to her child (P8: 78). Such apparent oversight fueled parents’ concerns and raised questions in their minds about the trustworthiness of vaccine manufacturers, the CDC, and physicians in general. The parents reported using the Internet to share amongst themselves information about the dangers of vaccines that the parents feared physicians and vaccine developers otherwise might suppress.

Not all parents blamed vaccines for their children’s disorder. For example, one mother reported that when her unvaccinated child developed autism, she “stayed on the Internet for literally hours and days and weeks” and . . .found that there’s an epidemic [of ASD] and vaccines don’t normally cause it or have to cause it...and that there could be a genetic defect, or chromosomal or genetic toxins” (P9: 190). Having convenient and rapid access to Internet-based health information and data sources helped this mother conclude what may not have caused her child’s disorder.

Some parents reported that they had entertained other theories as to the possible causes of ASD and researched these causes on the Internet. One father mentioned that he had read that some children with ASD have weak mitochondria which may increase their susceptibility to ASD. He said he had “hopped on the Internet” and started looking to see if the theory of [mitochondrial] causality of autism was “something legitimate” (P5: 133). A second parent described having being online “a lot” while searching for a possible connection between her son’s autism and Lyme disease (P9: 203). Her online ASD parent discussion groups also had been talking about a presumed connection between ASD and deficiencies in B6, iron, and various nutritional deficiencies (P9: 233). She found a lab on the Internet that conducted extensive immunological panels to find allergies that, she believed, could have contributed to her son’s symptoms of ASD (P9: 205). The parents were focused in their search for information that would lead to an improved understanding of their children’s conditions.

Understanding symptoms

The symptoms of ASD were confusing to parents in the study. One parent consulted a website to help interpret the symptoms of her child who had been diagnosed with AD (P7: 5). Her young son had become increasingly agitated when visitors arrived at the family home. The mother attempted to understand this behavior by consulting a discussion board hosted by teenagers with Asperger’s. When she asked the teenagers why they did not like visitors, she reported that the teenagers’ responses included: “Mother can’t have anyone over. This is my space,” to “Oh, she can have someone on the porch

but that's it." Fortunately, her son's aversion to visitors was short-lived, but in the interim, the mother was able to accept and respond more favorably to his behavior. The mother commented: "You can ask questions about things they (the Asperger's teenagers on the website) did as kids and they can answer you so you can understand where they are coming from" (P7: 44).

Many parents were confused by the heterogeneity of ASD symptoms and the different manifestations presented by each child. As a result of their confusion, some had difficulty interpreting their child's symptoms or behavior then choosing an appropriate response as evidenced by the following comments: "These kids are their own unique puzzle" (P8: 129). "One of the things that I share with [other] parents is... 'One size does not fit all.' You have to find out what fits your child and your family. I may send [another parent] information and [they] may say . . . this is not what I am looking for (P2: 48). "Each parent has to reinvent the wheel. Each child is so different" (P1: 81).

Many parents of children with ASD are surprised to learn that autism and its related disorders are associated with physical symptoms, including those relating to gastrointestinal system. One mother described how she had thoroughly researched the "gastrointestinal system, the central nervous system, [systems relating to one's] vision and all kinds of sensory information" in order to learn more about her child's condition (P9: 194).

Therapies and treatments

All of the parents in the study reported that they had used the Internet to search for the latest therapies for ASD. In many cases, the parents were trying to compensate for the deficiencies, described earlier, in the knowledge of their physicians or the school system about issues related to ASD. Parents used on-line discussion groups, listserves, and blogs to learn about and to evaluate other parents' opinions and experiences regarding therapies. In some cases, they searched the Internet to determine the validity of their physicians' recommendations about treatment approaches. They searched the Internet to both evaluate and locate therapies and treatments for their children, including how to access products and services relating to their child's special needs.

One treatment approach evaluated by many parents in the study was Applied Behavioral Analysis (ABA), which is a learning approach largely based on shaping behavior through the use of a punishment and reward system. Despite ABA's endorsement by the American Academy of Pediatrics (AAP), many parents in the study did not support ABA nor did they view it as effective. Five of the 12 parents in the study had researched ABA and had concluded it was an inappropriate therapy. One parent said: "[My husband and] . . . I did a lot of research [on the original ABA research study]... You have to dig to find out about it... [The method was first applied to] boys who were exhibiting feminine tendencies [who were] smacked [by those conducting the treatment]... As a result, the behaviors were snuffed out. The [boys] stopped [the feminine behavior] and that's how the ABA study worked" (P7: 42). The parents rejected

ABA therapy based on their online research that revealed disturbing accounts of how ABA had been used and its methods.

Many parents voiced negative opinions about ABA. One parent said they had avoided ABA because they did not want their child taught to “behave like a robot” (P10: 24) and obey others in a rote and rigid way. Another parent observed that autism was a communication disorder and since ABA ignores communication in favor of behavior, she did not believe ABA could be effective (P1: 154). Another mother’s doubt about ABA arose after reading discussions on websites among children with Asperger’s syndrome who talked about how much they “despised” their ABA-oriented schools (P7:47).

Parents in the study used relatively sophisticated research techniques to better understand ABA and its potential effectiveness. One mother, who had no formal scientific background or training, told how she had learned on her own over a period of several years to locate and critique online research related to ASD. She reported that she had found on PubMed an abstract of a study stating that 47% of children who had received ABA had positive results, however, when she read the entire article she concluded that the study had an inadequate sample size of 20 children (P8:120). Another mother reported that she and her husband had decided to use ABA: “The reason we chose ABA is because it works. Nine times out of ten, it works...We use studies. We use reference guides” (P6:135). A third mother said: “I take what I find in one place [on the Internet] and research it more places...Like ABA therapy...when I see success stories in more than one place, I feel better” (P12: 762). Some mothers researched a therapy such as ABA and adopted it for their children with little or no reservation, whereas others used

the Internet to research more deeply and find enough details to support their rejection or acceptance of the therapy. In either case, it is not surprising that parents of newly diagnosed children who are trying to choose a treatment plan for their child might be confused when presented with such a range of opinions, especially since some parents' opinions conflicted with the opinion of the American Academy of Pediatrics (AAP). Nevertheless, parents chose treatments and therapies even when they were not endorsed by conventional experts, such as the AAP.

Despite the plethora of information available on the Internet about ASD, it is difficult, based on the information available, for parents to choose from the multiple therapies and treatments for ASD. To compound this problem, some parents perceived that the effect of certain therapies is temporary. One father observed: "We are constantly looking [for new therapies] because no therapy lasts [is effective] very long. There is a middle and an end and a beginning [to each treatment]" (P5: 281). Some researchers believe that there is a placebo effect at play with parents of children with ASD which may contribute to the perception that there is variability in treatment effectiveness (Myers et al., 2001). The presence of a placebo effect could help explain why parents of ASD children almost constantly are stopping treatments in favor of the latest therapy. An alternative explanation is that parents are simply trying to remain hopeful when they implement and choose various untested therapies in their urgent quest to find the one therapy that will be effective for their children.

Parents in the study also used the Internet to access products, services, and therapies to meet the unique needs of children with ASD. One mother (P1:42) purchased

a weighted vest for her son to ameliorate his problems with “sensory integration,” a condition believed to exist in many children with ASD in which an individual’s proprioception, or sense of knowing where one is in space, is compromised. The pressure created on the body from wearing a weighted vest is said to comfort the child by giving him a sense of “where he is,” which some believe fosters emotional stability and self-regulation.

Many parents reported that they gave their children with ASD special diets due to the gastrointestinal symptoms such as diarrhea, cramping, and general abdominal distress associated with ASD. The gastrointestinal features of ASD were long ignored and dismissed by healthcare professionals. Recently, parents have been trying to minimize the gastrointestinal symptoms in their children with ASD by feeding their children a gluten-free casein-free diet. Although the diet’s effectiveness is debated, many parents describe the diet online and how they believe it can be used to alleviate food allergies and regulate their child’s behavior. One father in the study reported that he had used the Internet to locate recipes to assist the family in preparing the gluten-free, casein-free diet more economically. He also purchased dietary supplements tailored to children with ASD in order to encourage weight gain in his son because children with ASD are known to be “picky eaters” or have limited dietary preferences.

Parents used the Internet to locate practitioners and learn about the types of services those practitioners provide to children with ASD. One mother found the website of an interdisciplinary ambulatory pediatric clinic in central Texas that focuses solely on the care of children with ASD (P4: 208). Some of the physicians associated with this

clinic are also parents of children with ASD, while others are physicians whose work is highlighted on autism advocacy websites. This clinic's physicians diagnose and treat gastrointestinal symptoms and help parents select diet and behavioral strategies that parents want for their children but cannot find in traditional pediatric practices (P9: 266). One mother described this clinic and what it had offered her: "It is an enticing name. It is a group of doctors who come from all over...Wakefield comes from England and some other doctors...they come from all over. So they periodically see kids with autism and treat them. At the very end [of the clinic's website] they say that they do not turn any patient away based on ability to pay. They have a sliding scale. 'We will work with you, etc.' so I called them and asked them and said I would like to apply" (P4: 212). She reported that she subsequently was turned away because she did not meet the clinic's criteria of financial need.

Parents in the study used online resources to research treatments and practitioners most knowledgeable about the most recent treatments for ASD. One mother said that although she did not write or interact in on-line chat rooms, she did read what others had posted. She noted "There are doctors who are highly respected [who are invited to discuss autism in chat rooms and other online forums] and they answer questions. And they will have open discussions at such and such a time. I always want to go back and read what questions were asked" (P4: 206). Many of the therapies promulgated on the Internet are recent in nature and not widely available or perhaps not widely accepted by conventional practitioners. For example, as a result of the belief that people with ASDs have differences in their mitochondria, many parents were eager to have mitochondrial

testing done on their child. Since few providers offered this kind of testing or perhaps even knew about it or were willing to provide it, parents who wanted it for their children used the Internet to seek providers who did offer the testing. One mother (P4: 133) described her plan to have the testing conducted: “We will see what we can come up with. I have this doctor who has been able to help another child. I already have a lot of other [physicians] if she doesn’t work out...So I could go to them...I got their names off the Internet” (P4:133). The mother also described how another mother located a dentist in a chat room for parents of children with ASD. The mother needed a dentist who would accept reimbursement from CHIP (Children’s Health Insurance Program), which is government-sponsored insurance for children of working low-income families. This mother was looking for a dentist who would not use silver amalgams or fillings in her child’s teeth because many parents believe silver amalgams, which contain mercury, aggravate or even cause ASD (P4: 285).

The parents in the study used the Internet to locate therapies and services unique to children with ASD. It is unlikely that parents would find many of these services through their physicians since many of these therapies might be considered “alternative” by mainstream medicine or traditional healthcare. The parents wanted to find and implement the treatments *immediately* so their children could benefit before the children’s condition and adjustment could deteriorate further. If the child does not benefit from one treatment parents have tried, the parents move on to the next treatment. One mother added: “I look for real subtleties in change. I can tell what affects my child”

(P9:314). Another mother said: “If I had money. I would try and try and try the next thing. Until something worked” (P4:142).

Summary

The parents in the study demonstrated a committed, indefatigable attitude toward pursuing their child’s treatment. Although they took the time and trouble to research and find out about many therapies and treatments and to monitor closely their effectiveness, most did not appear to spend a great deal of time wondering why a treatment failed. They simply moved on to the next one.

HOW AND WHERE THEY SEARCHED

Parents of children with ASD in this study used a variety of methods to search for information on the Internet. Although many parents typically linked directly to trusted websites containing information about ASD, all parents reported using search engines to find information. Parents had developed their own ways to assess the trustworthiness of information that they had found on the Internet. Some parents also reported using cell phones, satellite cameras and web-based cameras as tools to help them take care of their children with ASD.

Methods of searching for information

Every parent in the study used the Google search engine to find out about autism and the other ASDs. Only one parent mentioned having used Yahoo’s search engine (P10: 36). All parents described having begun the search process by entering a word like

“autism” or “diet.” All of the parents reported using e-mail to share information with other parents of children with ASD. Some of the parents reported reading discussion boards, chat rooms or blogs. Six mentioned participating in online discussions. Group or individual e-mail was the most popular form of Internet communication among the parents, perhaps because its use was limited to individuals who are required to have identified themselves before participating.

There are several methods by which parents can obtain information on the Internet about ASD. At least four parents in the study said that they valued interacting with other ASD parents to obtain information about ASD. One mother described her on-line activities: “[It is] just parents asking me questions. Me asking parents questions. And all of us just e-mailing each other saying, ‘Hey, check out this website.’ It is really a sharing of information” (P2: 20). Another mother concluded: “Most of what [information] I have gotten [about autism] has been from other parents” (P6: 59). A father described parents in his face-to face support group who would often “go on-line” and e-mail him saying: “Hey, have you seen this? Check this out. Check out this website” (P5: 110). A mother said: “Other mothers say, ‘You know what? This has worked for my child. And maybe it will work for yours’ ” (P4: 91).

Determining trustworthiness of information

Because so many parents access the Internet for autism treatment-related information, it is important that the sources of information about ASD be accurate and trustworthy. Parents in the study were asked how they evaluated the trustworthiness of

information they had found on the Internet. Most parents said they assessed each Internet site's trustworthiness by evaluating its appearance and by noting the sponsorship of the site. Six parents said they deemed a site trustworthy if it was sponsored by or had an electronic link to a national autism advocacy or educational organization like Autism Speaks or the American Society of Autism. One mother added that the participation of leaders in autism treatment such as Bernard Rimland, whom she described as a "pioneer" in the field of autism, gave her confidence that the site contained credible information (P1:106). Another mother said she favored sites whose web addresses end in "edu" because this part of the Internet domain is given only to educational organizations. She added: "Dot coms, dot orgs, and dot nets...anyone gets them....but dot edus – only schools [get these]...So you can be sure [its information] is not tampered with" (P7: 92). She also noted that allowing readers to post their opinion or response to website content enhanced the credibility of the website (P7: 94).

Attempts to sell products or services or advertising products of seemingly questionable value on an Internet website detracted from the parents' assessment of a website's credibility. The professional nature of services advertised on a website influenced one mother's opinion of the trustworthiness of the site. She said that the presence of an advertisement for colon-cleansing procedures caused her to discount the trustworthiness of the site since she did not believe that such a procedure was credible or effective (P1: 108). Another mother said: "You have to look for the red flags - like if they are trying to sell you something...I'm good at picking out that stuff. My husband can't do

it. He will fall for everything on the Net. He can't see it when people are just trying to sell him things. He can't see it...You have to [be able to] pick out scams" (P11: 287).

Two mothers who had received education and training in early childhood development said that they relied on their own training and backgrounds to evaluate the content of Internet sources and websites. One mother offered: "I haven't run across anything yet that has been a scam... like a 'cure-all' medicine for autism...There has been pretty good, credible, decent information out there in cyberspace regarding autism. Nothing questionable yet" (P2: 295). The other mother said that she was able to trust some, but not all, information she found on the Internet. She said: "I'm no medical expert but just because of my background...seems like [certain treatments] make sense [to me]...My husband says: 'You can't believe everything you hear on the Internet.' And I say, 'I don't'" (P9: 305, 306).

Two mothers responded to the question of how they evaluate the trustworthiness of Internet sites by saying that they have had to become "medical researchers" (P12: 764; P8: 124). A third mother answered the same question by saying: "I guess it's just [having enough research] experience. I have been doing this research [on the Internet about ASD] for years" (P11: 291). The researcher asked the mothers to clarify what they did to evaluate trustworthiness of information found on Internet sites. One mother said that she looked for repetition of information or findings among multiple websites as an indicator of the trustworthiness of the information (P12:762). Another mother said she would read the actual study to "examine what they are measuring" (P8: 124). The same mother also

said she evaluated sample size of the research study and the reputation of authors (P8: 119). She said she would also ask other parents of children with ASD about their experiences to confirm whether information found on a site was trustworthy (P8: 118). She concluded: “When you read the actual study, it gives you a lot more information. The devil is in the details” (P8: 124).

Not all of the parents were confident that they could assess the trustworthiness of online information about autism. As one mother said, “[I have read] a million unproven so-called treatments for autism, and you can find parents on the Internet claiming that this or that cured their child. And you know, for a while you look at that and wonder, ‘Should we try this or should we try that?’ ...Traditional medicine says ‘No, no, no. There’s no research to prove this.’ Then the alternative side says: ‘No, no, no. We’ve cured all these kids of autism.’ So what do you do? I don’t know” (P11: 251, 279, 283).

In summary, parents who participated in the study evaluated the trustworthiness or accuracy of on-line information by assessing the features or appearance of the website or blog. A website that was sponsored or linked to a credible national educational or advocacy group was viewed as a credible information source. Commercial aspects or efforts to sell products from a website detracted from its credibility. Some mothers relied on their own training and education to give them the ability to critique website content, whereas others believed they had to develop such analytical skills as they went along. At least one mother professed to being confused when trying to choose between alternative

therapies and conventional medicine for her child, since Internet resources reported positive results and outcomes for each.

Trusted Internet sources

The parents in this study said that no physician or caregiver had ever recommended to them a website containing information about ASD. Parents found websites through the recommendations of other parents and by using search engines. Every parent in the study obtained information directly from websites by entering the website's URL in the address bar. Examples of websites of national autism advocacy and educational organizations these parents said they had regularly visited include: Autism One (www.autismone.org); Autism Research Institute (ARI) (www.autism.com); Autism Society of America (ASA) (www.autism-society.org), Autism Speaks (www.autismspeaks.org), DAN! (www.defeatautismnow.com), FEAT or Families for Early Autism Treatment (www.feat.org), and a statewide organization sponsoring a widely distributed electronic newsletter, Texas Autism Advocacy (www.texasautismadvocacy.com). Another trusted electronic source of autism information was Schafer Autism Report (SAR) (www.sarnet.org), a national online news clipping service that centralizes and distributes autism-related news to its subscribers for a nominal fee. The parents also reported visiting websites started by parents of children with ASD that offer education about autism including Kyle's Treehouse (www.kylestreehouse.org), Noah Knows (www.noahknows.org), and Autism Today (www.autismtoday.com). Parents of a child with ASD started a camp to teach children

with autism to surf and their organization is Surfers Healing (www.surfershealing.org). Another less well-known organization offering education and information about ASDs is Childbrain Development (www.childbrain.org). Some parents in the study also visited the website for The Thoughtful House Center for Children (www.thoughtfulhouse.org), a non-profit clinic offering alternative therapies. Its website provides to readers autism-related articles and other educational material. Another website viewed by some parents in this study was maintained by Tony Attwood, (www.tonyattwood.com), an Australian psychologist sharing expertise about Asperger's syndrome. WrongPlanet (www.wrongplanet.com) is maintained by individuals with Asperger's and offers commentary and education about Asperger's from the unique perspective of individuals with Asperger's syndrome. Parents in the study reported accessing WebMD (www.webmd.com), (CDC) Center for Disease Control (www.cdc.gov), and Yellow Pages for Kids (www.yellowpagesfor kids.com). The latter offers information about services and legal implications for those with developmental challenges. One parent mentioned using Passport (www.passporter.com) to help her plan her son's trip to DisneyWorld so that they could participate in Disney's special programs for children's with developmental challenges. Parents also accessed the autism center of a website of a large teaching pediatric hospital.

The parents in this study reported that they trusted and used some commercial websites. Such websites included: Southpaw Enterprises (www.southpawenterprises.com) to purchase products used to enhance the development

of a child with special needs, DynaVoxTechnologies (www.dynavoxtech.com) to research a wireless augmented communication device for a child who speaks just a few words, Gerber's Baby Food (www.gerbers.com) to compare their child's behavior to developmental milestones posted on the website, and Hilton's Heartland Wellness Center (www.hiltonsheartland.com), a wellness center offering alternative therapies and a nutritional focus.

OTHER SOURCES OF INFORMATION

Participants who were interviewed for this study were asked how they used the Internet in response to their needs as parents of children with ASD. All participants reported that they routinely accessed the Internet to search websites and send and receive e-mail using desktop or notebook computers.

Three parents in the study described their use, or planned use, of Internet or web-based technologies that did not include the use of a desktop computer. One mother used a Blackberry® to e-mail her son's teachers and to record key dates and conversations that she had had with the teachers about goals her young son had attained, and in some cases, setbacks that her son had experienced (P3: 83). The mother explained: "When you move from teacher to teacher...you get the [dates] when things have happened...so they can contact the last teacher to learn about this child instead of making mistakes somebody else has made and we have already corrected...It is a powerful tool" (P6: 83,)

The same mother also used a wireless surveillance camera to record her son's sessions with an in-home speech therapist. (These cameras are typically disguised as toy

animals and are marketed to mothers who want to monitor how their babysitters treat their children when the mother is away.) The mother in the study said: “I don’t let them know the first week [that they are being video-recorded], but the second week I tell them: ‘I just wanted to let you know that I’ve been taping you. And I like your work. They are a little shocked by it but not disturbed because they haven’t done anything wrong’” (P6: 210, 214). She had also asked for cameras at school and had developed the practice of showing up at her son’s school at random times to check on how the class was going. She explained her need to be vigilant for her child, “You have to be on your ‘A Game’ ...you have to be able to be able to walk in at any time. Those teachers need to know that this kid’s mother comes up all the time...you never know when she is coming” (P6: 186). This mother used the Internet to record and retrieve data about when and what her son with autism had learned, and she also used it to warn and control his instructors.

Two other parents reported using Internet technology in unexpected ways or in ways that were different from those reported by other participants in the study. One mother described how her husband had used the Internet to access satellite photographs of a trailer or temporary building to bring to a meeting with school administrators as proof that their son’s school had planned to put her son and his classmates in special education into classroom located in a dilapidated trailer (P7: 143). Another mother was planning a purchase of a speech assistive device for her son with autism. The device uses the web to display graphic images of a child’s typical environment. The child holds the device containing a touch screen and signals what he wants while moving through a

series of changing screens and images, so at any time he can press on an image to communicate what he wants (P12: 215). The mother described how the device works: “It’s a full computer and he can even get Internet access and send e-mail from it...It has a picture of a house and he can push the [image of the] kitchen. The kitchen opens up into a table...once he touches the table, then it will go to all the different types of food [that he can choose and communicate]” (P12: 215).

The parents who participated in the study used non-electronic sources of information in addition to online sources. They learned about ASD by attending conferences and seminars, reading books and articles about autism, and talking with other parents. One mother had attended a parenting seminar after her child was diagnosed in order “to follow-up on things that I could do [on my own to help my child]” (P3: 109). A second mother and her husband had driven to another state to attend a conference on treatment approaches to ASD when her child was first diagnosed (P1:77). A third mother described the ASD-related classes she had attended : “I may not agree with everything [the instructors] say, but every piece of information helps...[and] when I go to those different classes I ask the other parents what information they use” (P6: 47). Only two parents reported that books had been helpful in understanding ASDs (P11:63; P7:19); a third mother said she found book selection on ASDs to be very limited (P12:840). No parent found pamphlets helpful except when the pamphlet directed readers to websites for further information (P11: 63).

Every parent in the study had obtained information about ASD from other parents of children with the disorder. Five participants attended in-person parent support group meetings (P4:91; P11:76; P7:76; P5:64; P3:142) and one participant organized and led a monthly ASD parent support meeting in a pediatric clinic (P2: 28). Other meetings with parents of children with ASD were less structured and more social in nature such as meeting for lunch or coffee (P1: 85; P12: 534; P6: 318). These meetings seemed to serve as sources of information and support. One mother said she and her friend got more out of meeting for coffee than being “in a room [at a support group] feeling sorry for each other” (P6: 318).

In summary, three of the parents used the Internet to operate wireless technologies such as cell phones and web cameras in their role as parents of children with ASD. One mother operated a web camera in order to warn and control her son’s teachers. A father downloaded satellite photographs to advocate for his son and his classmates at a school district meeting. Another mother was planning the purchase of a wireless speech assistive device to help her child communicate. The use of these web-based technologies by parents of children with ASD illustrates the parents’ resourcefulness and determination to help their children achieve their fullest potential.

WHAT THEY DID NOT FIND

Parents of children with ASD were asked what information they needed but could not find on the Internet in order to fulfill their roles as caregivers and parents. Some of the responses reflected the parents’ need for intangibles such as hope and optimism about

their children's potential. For example, one mother of a five-year-old son with AD said that she would like to see websites that were "encouraging" in nature and could provide "hope" to parents and "not just focus on the fight" [against autism]. Even on the Internet, you don't see anything encouraging toward parents. That is what I wish for" (P12: 115, 804).

Other parents described a need for websites that could educate parents and help them become more effective in communicating and interacting with their children. A mother of a daughter with autism said she needed to find a website that would teach "behavioral strategies about how to interact with your own kid" (P11: 331). She said now that her daughter is speaking it is actually harder to communicate with her because her daughter "talks but is still not understanding half of what I say." The mother continued to describe her dilemma: "If [my daughter] says inappropriate things...How do I interact? What do I do when she's repeating everything I say or what do I do when she won't quit yelling 'poo poo' 'poo poo!' The teacher and behavioral therapists learn how to deal with this [behavior using] proven strategies." [I would like] a "step-by-step guide to dealing with problem behaviors. There's a lot of theoretical stuff out there to learn about autism but there's not a lot of instructions for parents...You're basically left out on your own to figure it out" (P11: 331, 363, 367, 411). Another mother wanted to be able to locate continuing education speech therapy seminars that would permit her to attend despite her lack of training and education in speech therapy. She complained: "I would read all about [the seminar and its topic] and get excited but my speech therapist says that I cannot go to that workshop" (P1: 151).

There were also comments from parents about the need to customize information according to the family's needs or circumstances. One mother said that she wished there was more information about the effects on siblings of having a child with autism in the family because in her family the sister of the child with autism would "be responsible for taking care of her brother when we [parents] are gone" (P12: 848). Another mother who has a son with PDD-NOS said she thought there should be more assistance and information provided for families whose daughters have an ASD as "there are a lot more girls with autism than people think. I think the statistic [about only boys having it] is overused" (P1: 93).

Parents in the study described their wish to find websites containing information about available services for their children in their immediate area. One parent wanted to be able to locate on one website every research study on ASDs that is being recruited for and conducted in the area so that she could evaluate whether to try to enroll her child (A5:231). Another mother she wished she could find "respite care workers [for parents] who are trained experts...experts who understand" (P8:113). The same mother continued: "You can't find appropriate services [for children with ASD] on the Internet...You can read about stuff....but that ain't going to make it happen" (P8:206). One mother wanted a directory of "governmental services by region" for children with ASD (P12:116). One parent, partly in jest, said, "I wish I could find money on the Internet" (P8:206). Another mother said she initially could not locate outpatient occupational and speech therapies for her child because the local non-profit hospital offered these pediatric therapies in their sports medicine clinic. She said: "Unless you know where to go in their [sports medicine]

website, and follow the exact links, it doesn't say they do occupational or speech therapies" (P7: 99). This same mother noted that finding local therapy services [for children with ASD] is difficult because "many [clinics] are not well-advertised unless they are extremely for-profit and some of [those] are really scary [unprincipled]" (P7:101). Another mother said she was disappointed when a website belonging to an autism advocacy organization immediately directed her to local ABA therapy providers without presenting other treatment options (P1:150). A mother of a five year old with autism wished there was a website listing "non-competitive sports programs" for children with special needs. She was looking for a gymnastics or dance program that would be non-competitive. She said she wanted to avoid "softball parents" and dance recitals where "even the moms get crazy" [overly competitive] (P11: 355).

Summary

Parents who were asked about what they thought was missing on the Internet reported a range of answers. Some parents wanted the Internet to provide instruction in behavioral strategies, speech therapy education, and gaining a better understanding of the needs of girls with ASD and siblings of children with ASD. Other parents wanted to be able to locate quality respite care services, local research studies about ASD, recreational programs and a directory of governmental or public services for children with ASD and their families. Another mother simply wanted to be able to find reputable, non-profit pediatric speech and occupational therapy providers who would accept insurance, and

whose website clearly communicated that they provided pediatric and not just sports medicine rehabilitation services

WHAT ELSE THEY FOUND OF VALUE

The Internet was a valued resource for parents who participated in the study. The parents reported that they had relied almost exclusively on the Internet for their information about ASD. One mother said: “[The Internet] is the only place that I’ve been able to [successfully] go...It is the only place that has given us information [about ASD] (P12: 832). Another mother said: “Everything that I have learned about autism, I’ve learned off the Internet” (P11: 138). Another parent confirmed the importance of the information found on the Internet to parents of children with ASD: “We did not have the Internet until 2001...We really missed it before then” (P5: 170). “When we first got online, it was ‘hit or miss.’ Now there is so much more information than there was five or six years ago. I wish we had had this back then” (P5: 118).

Parents in the study cited the convenience and flexibility of the Internet as a motivation to use it. One mother said: “You can go and turn it off...or look at [the information] tomorrow.” “I can get up when I want to...I can say ‘I can’t take this anymore...’ Another advantage this parent cited was that one could “read it in the privacy of your home” (P2: 148, 152, 156). The Internet was also described as being “helpful and less time-consuming” than other sources of information and “does not require a library trip” (P3: 193). Another mother said she appreciated the Internet when involved in online discussion groups as it allows you “think before you respond” (P6: 334).

Four parents made negative or qualified assessments of the Internet as a means of learning about ASD. One mother said: “Sometimes I find [the Internet] helpful and sometimes I do not. I sometimes find it very hard to find what I am looking for. I want to find the right thing and I had to go through all [these] pages...and [finally I] say, “No, this is not right thing. I get discouraged sometimes” (P4: 50). Another mother described how visiting the “wrong websites” had upset a mother of a newly diagnosed child. She said this mother “got freaked out” because parents [in these websites] are “doing a lot of crazy [unconventional] things [regarding their choices for their children].” She said the mother went from “website to website and chat room to chat room,” and although it seemed unlikely to others, this mother grew to believe she would need to institutionalize her child (P9: 245). A father in the study had a similar experience when his son was just diagnosed: “We went on the Internet to look at articles [about autism] and they were all so dark and gloomy [in describing the disorder] that we never really finished any of them” (P10: 20).

Most parents, however, valued the Internet as a source of information. One mother said, “It really becomes your friend...or family member...because it is not intimidating” (P2: 148). The same mother, however, noted that “a lot of families are still intimidated by the Internet. People feel warmer and more comfortable about their cell phones than they do with the Internet” (P2: 324). When asked how they would have fared without the Internet, parents had comments like the following: “[I would have felt] very lost...It is almost like an outlet. I feel like I have to have knowledge to know...[and] to

be able to take care of him. And without that knowledge, I would be lost...I can't go in a library and sit with him...I would feel like he [would not] have had the best care because I would not have known [what to do] (P12: 804). Another answered the question by saying that without the Internet, she would have been "dead" (P8: 184) due to the depression and isolation that resulted from parenting a child with autism. Another said "I wouldn't have made it" (P9: 351) and another said: "A lot of parents cannot come to meetings...so thank God for the Internet" (P2:28). The parents used the Internet to communicate with each other and to exchange information about issues affecting them as parents of children with ASD. The parents reported that they received autism-related group e-mail and regularly read websites and other on-line resources about ASDs. The parents' online resources gave them information that appeared to decrease their sense of isolation and bewilderment at some of their children's behaviors.

The Internet allowed the parents both to provide and receive support and information from parents in situations similar to their own. One mother said that she typically used e-mail to seek advice from other mothers about how to respond to a situation involving her child:

I will think about going to the computer before I will call the pediatrician. I will say to myself. 'Let me go e-mail [another parent]. or let me go e-mail another mother right quick. Let me go and e-mail someone before I think about calling the pediatrician.' [I would say to the other parent], 'Hey, what do you do [in this instance]?' (P2: 271)

Four mothers said they exchanged information amongst themselves rather than consulting their pediatricians. A mother of a daughter with Asperger's disorder commented: "I never

passed [my concerns about my child's development] to caregivers, but more to other parents on the Internet (P3:101). A mother of a boy with autism (AD) said: "I only go to other parents [for help]. It had gotten to the point where I would seek [other parents] out on the Internet...because it is very difficult when you have a child who at that time was in pain because just being in our world [was difficult] for him...He would scream at the Muzak in the grocery store (P8: 44). It was the only way I could keep my sanity because my son was at a point where he couldn't go out... He didn't want to be around other people or children. So I was cut off from other mothers...[and] from the support I needed. And I found support through the Internet with other moms there...I mean it was key for me "(P8: 110). This mother visited chat rooms to consult other parents of children with ASD in order to problem-solve a specific difficult situation with her child. She said: "If I am thinking about doing something [different], I will write [e-mail] [to the other parents], 'Please share your experiences' (P8: 75). So I would seek people out on the Internet and in chat rooms and that is where I learned most of what I know [about autism]...and truly when I go to the Internet I look for research and I look for parents' experience...I very seldom go to somebody who considers themselves an expert, unless they are a parent [of a child with ASD]" (P8: 45).

One mother read blogs written by parents of children with ASD. She said blogs were useful to her because "a lot of [the parents] will talk about the coping mechanisms that they use. The blogs are really good for stuff like that...to find out [about] other parents' experiences" (A7: 111). This mother read postings of young people with

Asperger's syndrome and learned that these teenagers had difficulty adjusting to wearing woolen fabrics during winter months. As a result, this mother felt capable of helping her young son tolerate certain textures of food and clothing. Reading the personal accounts of young adults with ASD who perceive textures in a way similar to the way her son experienced them reassured the mother by providing her with information to help her to interpret her son's behavior.

One mother of a son with severe autism described how she uses her electronic network of parents to both send and receive information. She had volunteered to manage a group e-mail or listserve that is sent to other parents of children with ASD. She also leads a monthly parent support group in a neighborhood clinic. She says: "The Internet helps to reduce isolation. It is the way I communicate with families. It has connected us. It's been a good thing. It has been a great thing. It has been absolutely great" (P2: 328). She said, "I tell the [ASD families]. 'Hey, it's okay. You are not alone' (P2: 61). 'I would share with families [some of my son's most bizarre behaviors]. How many parents want you to know that?' (P2: 61). 'So if I send that out...even if you help one mom...rather than keeping it to yourself...it has made a difference because you've reached out'" (P2:61). She said the listserve or group e-mail she maintained with other parents of children with ASD was more "intimate" and, as a result, it was perhaps easier to discuss certain topics because it is not a "chat room" or discussion board where participants are completely anonymous. The same mother described other disturbing behaviors of her child's and the positive responses she received from other parents who appreciated her

sharing information with them in their online group's discussions: "Like with my other son [who is developing typically]...He said to me: 'I wish I had autism so you would love me as much as you love L. [her son with autism]. He is crying...I e-mail a [description of his behavior out] ...and the response I get from other parents is overwhelming because they will say, "Wow. That's what's happened here. I did not know I was not the only one' (P2: 61).

Parents in this study described the Internet as flexible, convenient and a frequently used source of information about ASD. One mother was reportedly overwhelmed after misinterpreting information that she found online about her child's behavior, and another found online information to be too "gloomy"; generally, however, parents found ways to support and inform one another using the Internet and seemed to use the Internet to decrease their sense of isolation and improve their understanding of their child's condition.

SUMMARY OF FINDINGS

Parents of children with ASD who participated in this study valued the Internet as a means to search for information about ASD. The information they found helped them be effective parents of their perplexing children. They searched intensively for information about ASD that they believed the healthcare and educational systems had not adequately provided. They received online listserves and group e-mails, and read blogs, discussion boards, chat rooms and websites maintained by advocacy and educational groups, healthcare providers and vendors, other parents, and individuals with Asperger's

syndrome. They also visited a website assisting individuals making travel arrangements for children with disabilities. The parents tried to learn about the causes of autism from these sources and from one another by participating to varying degrees in online forums and communities comprised of other parents of children with ASD. The parents were interested in knowing how ASDs are defined and described, and how they could access and evaluate therapies for their children. Parents used a variety of skills and techniques to evaluate the trustworthiness of information that they found on the Internet, although not all parents were certain that what they found was credible. The parents used the Internet to provide and receive both support and information about ASD. They clearly valued the role the Internet played in helping them fulfill their parenting responsibilities.

Chapter 5 follows to provide a detailed explanation of how the findings of this study compare to current literature on the topic of how parents of children of ASD use online resources to fulfill their roles as parents and caregivers. The implications of this study, a description of its limitations, and ideas for future research will also be addressed. The chapter will conclude with a general discussion about how parents of children with ASD use the Internet.

Chapter 5: Discussion, Recommendations and Conclusions

The purpose of this study was to explore how parents of children with ASD described, evaluated and used Internet-derived information about autism, and how this information influenced their choice of treatments and therapies for their children with ASD. Semi-structured interviews with twelve parents of children with ASD were conducted using naturalistic inquiry as described by Lincoln & Guba (1985).

The following research questions were used to guide the study: 1) How do parents of children with ASD use the Internet in response to their roles as parents and caregivers? 2) How do parents of children with ASD evaluate the trustworthiness and describe the adequacy of the information that they find on the Internet? 3) How do parents of children with ASD choose Internet-derived information about autism, and how does this information influence their choice of treatments and therapies for their child?

This chapter reviews the findings that have arisen from answering the research questions and compares the findings to current literature related to the topic of the use of the Internet among parents of children with ASD. The implications of the findings of the study and the study's limitations will be addressed and followed by recommendations for future research and conclusions.

The research questions were an outgrowth of the researcher's interest in how parents of children with ASD use information technology to cope with their children's conditions. The following section will include answers to the research questions followed by a review of the study findings.

Parents in the study described searching on the Internet for information about autism with intensity and a sense of urgency, especially in the period immediately following their children's diagnosis. Many parents described having to wait for several months to receive a diagnosis of ASD for their children. They perceived inadequate support and information from physicians and the educational system; and to compensate for these deficiencies, the parents turned to the Internet.

Parents used the Internet to learn about causes, symptoms, and therapies related to ASDs. They used search engines, e-mail, and blogs, and some participated in online discussions. Parents of children with ASDs evaluated the trustworthiness of information found on the Internet by the professional nature of the website and whether the website was commercial in nature; others used their own education and training. Some parents trusted the information more if they had seen it in multiple sites or if another parent had firsthand knowledge of the legitimacy of the information.

Parents reported that they could not find hope and encouragement online; nor could they find instruction in how to handle difficult behaviors of their children, or plan for the lifelong care for their children. Some parents also wanted to find respite services for parents, local research studies about ASDs, recreational and sports programs for children with ASDs, and directories of governmental or public services for children with

ASD and their families. Other services they wanted to find online included reputable, non-profit pediatric speech and occupational therapy providers who would accept insurance and whose websites clearly communicate that they provide pediatric rehabilitation services.

Parents reported that they valued the network of parents who provided one another with online information and support. Since many therapies were untested and not validated by scientific support, parents sought and evaluated the experiences of other parents in developing and choosing a treatment plan for their children. It did not seem to matter to many parents in the study if treatments were untested or did not seem to be effective for very long. If a treatment's effects waned, the parents simply moved on to the next therapy in a tireless and focused manner.

COMPARISON OF FINDINGS TO THE LITERATURE

There are few studies in the literature about the use of the Internet among parents of children with ASD. Huws et al. (2001) conducted a grounded theory analysis of the messages sent to an e-mail group over a three-month period by parents of children with ASD. They found that the e-mail group primarily functioned as a mechanism for social support and to help the parents make sense of autism and cope more effectively with their circumstances. A similar analysis by Fleischman (2005) examined the narratives of 35 websites published by parents of children with autism. The study found that the Internet allowed parents to develop ties among themselves and helped them deal with the isolation of having children with autism. Both studies retrospectively analyzed e-mails

and websites containing conversations and narratives that had already taken place among parents of children with ASD; hence, researchers could not probe and clarify the participants' comments, responses and activities. Perhaps because of this limitation, parents' motivations for using the Internet were not as specifically or thoroughly described or explored as they were in the current study.

One of the most striking findings of the current study was the uniform dissatisfaction with the healthcare and educational systems experienced by the parents. Every parent in the study had changed pediatricians at least once and each had expressed dissatisfaction and, in most cases, resentment toward the healthcare system. Parents felt that they had been treated in an insensitive and callous manner, particularly around the time that their children were diagnosed, which as Baxter et al. (1995) discovered, was reported by many parents as the most stress-inducing life event related to their children's disability.

Some health policy researchers believe that the Internet is changing the traditional roles of patient and provider, fostering a sense of empowerment among patients or at least an increased sense of self-reliance about making health-related decisions. Some researchers have suggested that the Internet challenges previous hierarchical models of information-giving which frees patients from being the passive receiver of information and empowers them to seek answers actively (Buckland & Gann, 1997). Broom (2005) studied the impact of the Internet on the physician-patient relationship in 53 Australian men with prostate cancer, and although the conclusions of his study may not be entirely transferable to the experiences of parents of children with ASD, some parallels are

similar enough to bear analysis and comparison to the current study. He noted that some physicians may feel threatened by their patients being overly informed by material they have researched on the Internet and that physicians may use disciplinary strategies to reinforce traditional patient roles thus alienating patients who use the Internet. Other researchers have commented that some clinicians may react negatively if patients bring with them or want to discuss information that they have found on the Internet (Anderson et al., 2003; Crocco et al., 2002; Fox & Rainie, 2002). Physicians also may react negatively to information or treatment suggestions that patients bring with them if the treatment approaches are unfounded or unsupported by rigorous studies. Nevertheless, if patients believe physicians are threatened by such information because “they [the physicians] do so not get it” as one parent in the study asserted, the relationship between provider and patient suffers and the parent/patient may be propelled back to the Internet feeling alienated and perhaps more motivated to use or access therapies outside the boundaries of conventional healthcare. Three parents of children with autism in this study described being criticized and minimized by physicians for their exploration and use of complementary therapies they had found on the Internet. These parents ultimately stopped talking to their physicians about the therapies that they employed for their children. This communication breakdown is problematic; some researchers have suggested that parents are coping with their children’s disorder when they search the Internet for health-related information (Broom, 2005). Hence, it seems unwise to devalue or remove a patient’s coping mechanism, especially when there are no plans to replace it with a suitable substitute. Although only three parents in the study mentioned physician

resistance to their using Internet-derived treatment information, it is likely that the problem is more widespread. The American Academy of Pediatrics has cautioned its practitioners “to recognize when they feel threatened and guard against becoming defensive when families express their opinion in ways that challenge the professional expertise of the pediatrician” (Committee on Children with Disabilities, 2001, p.600).

Anderson et al. (2003) attempted to gain better understanding of the impact of the Internet on the patient-physician relationship. They analyzed hundreds of unsolicited e-mails to physicians by visitors to a popular health-related website and deduced that patients were shifting from being passive recipients of medical care to being active consumers of health services. Anderson et al. (2003) proposed several factors that may help to explain how the Internet has encouraged a shift in empowerment away from providers and toward patients and how it has resulted in an increase in demand for Internet-derived health information. Some of these factors are described in italics below followed by observations about the relevance of the factors to the current study:

1) *Much of the recent technological advances in medicine occurred in acute care and infection control, whereas many chronic diseases and conditions like autism are still difficult to treat and continue to negatively impact quality of life. Patients find it difficult to accept a physician’s statement that that there are few available effective therapies for a condition* (Anderson et al., 2003).

Many parents of children with ASD in this study rejected the notion that there are few available therapies for ASD and have spent hours on the Internet searching, evaluating and trying multiple successive therapies for their child in the hopes one will work or

result in some improvement. Parents of children with ASD are understandably disappointed and frustrated by the paucity of effective therapies and related research which leads to their desire to take responsibility for their child's health and functional improvement. Parents in this study were frustrated by research efforts in autism. One feeling is there is an overreliance on genetic research and not enough research into therapies that could help children now.

2) There is a perception that highly specialized care is "impersonal" and dominated by economic interests of physicians and others such as pharmaceutical companies which drives people to seek alternative approaches and information on the Internet (Anderson et al., 2003).

Many parents in this study believed that vaccines can cause autism. One mother in particular discussed at length her observation that the CDC website told parents that vaccines were safe while simultaneously letting physicians know of vaccine risks. Such a deep lack of trust would surely drive parents to seek information from unconventional sources such as might be found on the Internet.

3) It is at least perceived that physicians spend inadequate time with patients. This practice style can lead to dissatisfaction and misunderstandings, and ultimately patients turn to the Internet for their health information needs (Anderson et al., 2003).

Parents of children with ASD in this study described unsatisfactory relationships with their child's physicians, especially during the time in which they were learning of their child's diagnosis. Although parents did not attribute specifically their poor relationship with their physician to a lack of time the physician spent with them, the parents were

dissatisfied with their relationship with the physician and felt diminished by their child's physician.

4) Patients may note a lack of information retrieval skills among some physicians so in some instances physicians may not be able to appraise the Internet-derived material patients provide them or nor do they have the time to develop those skills (Anderson et al., 2003).

Parents in this study did not comment on their child's physician's online information retrieval skills; they did, however, question their physician's interest in learning or hearing about some of the topics the parents had found online.

5) A more highly educated society and a trend towards consumerism where patients are more critical and aware that doctors are not infallible also have helped to create a shift toward self-reliance and patient empowerment which has resulted in an increased demand for Internet-derived health information (Anderson et al., 2003).

The parents in this study were educated to levels above national norms and seemed to exercise self-reliance and to experience a sense of empowerment from their use of the Internet to obtain health information. Many parents had changed their child's pediatrician. Other parents voiced criticism of their physician's attitudes toward them. Based on these factors, one could assume that most parents in this study believed that physicians were not infallible.

It appears that the parents of children with ASD who participated in this study were motivated to become empowered and self-reliant health information seekers for reasons that were similar to the reasons the visitors to the website studied by Anderson et

al. (2003) were motivated to become self-reliant and empowered Internet health information seekers. Parents in the study seemed to have been motivated by distrust of the commercial interests in healthcare and the scant research efforts about ASD, and as a result, exercised self-reliance and took control of their child's condition by accessing the Internet for information.

Lemire et al. (2008) examined the presence of personal empowerment among users of the Internet for health information. Their results may help elucidate why and how parents of children with ASD access the Internet. Lemire et al. confirmed that visitors to a widely-used health information website in Montreal perceived themselves as being more competent and being more in control as a result of accessing health-related information on the website. Their study also revealed three specific ways the Internet users studied gained a sense of competence or control when accessing the website: 1) by compliance with expert advice (adopting the professional perspective); 2) by self-reliance through individual choice (by adopting the consumer perspective); 3) and social inclusion through the development of collective support (by adopting the community perspective). The professional form of empowerment was the most commonly found perspective among users of the website in Lemire et al.'s sample. The users were not questioning the authority of mainstream medicine, but rather seeking to develop a greater personal mastery of expert knowledge about a health-related topic. The consumer perspective was also prevalent in the Lemire et al. sample; the authors observed that its presence lent support to researchers such as Epstein et al. (2004) who believe that the growing use of the Internet is evidence that people are taking a more proactive role in health decisions

and questioning the prescriptive approach of mainstream medicine. Lemire et al. concluded that the presence of a community form of empowerment indicates that participation in online forums can contribute to participants' sense of personal empowerment. Nevertheless, the authors cautioned that people who favored the community perspective felt less of a sense of competence and control than did people who adopted the professional or consumer perspective.

Parents of children with ASD in the present study appeared to seek empowerment or a sense of control and competence by using the Internet in ways similar to those used by visitors to the Canadian website in the study by Lemire et al. (2008), discussed above. The parents sought information and support that was not provided to them by traditional sources such as physicians and educators. It would be reasonable to assume that the parents were gaining a sense of competence and control when using the Internet to learn about ASD therapies, treatments and causes. In contrast to the individuals who accessed the Canadian website, however, parents in this study might have been overrepresented by individuals adopting a consumer perspective, as many of the parents were seeking alternative therapies and treatments which would be considered outside the mainstream of traditional healthcare. Two mothers in the study were doubtful about the effectiveness of many complementary therapies and questioned their effectiveness. Therefore, their Internet use and motivation to exercise control and competence would perhaps have been more likely to have resulted from a professional or mainstream perspective of medicine and healthcare. At some point in the period after their children's diagnosis, all parents seemed to have used the Internet to experience social inclusion or a community form of

empowerment among other parents of children with ASD. Hence, the model developed by Lemire et al. appears to be relevant to the parents of children with ASD who participated in the present study. The parents' motivation was to gain control and competence over a disorder that is still poorly understood. Parents' use of the Internet in this study is consistent with the view that the Internet is used by many as an essential coping strategy and, specifically, a method for taking some control over a health-related condition (Broom, 2005).

Mansell and Morris (2004) surveyed extant literature on how parents of children with ASD in the U.K. reacted to the diagnosis of ASD and theorized that there are at least four stages of emotions that parents of children with ASD typically undergo. Analyzing this process may help to clarify the unique stressors that parents experience around the time that they receive their child's diagnosis of autism. It might also improve our understanding of how parents in the current study appeared to have responded to the stressors of the diagnostic process and how they might have used the Internet for information gathering and as a general coping mechanism.

Mansell and Morris (2004) conceptualized four stages in the diagnostic process: pre-diagnosis, diagnosis, post-diagnosis and a final stage of acceptance and adaptation. The *pre-diagnosis* phase lasted an average of four years (range from one to 10 years). It was characterized by confusion as to the cause of the child's behavior, feelings of self-blame among parents, and severe stresses on family relationships (Midence & O'Neill, 1997). Parents in the pre-diagnosis phase experienced frustrating delays before a diagnosis was finally received, and to aggravate the situation, some parents received false

reassurances and incorrect diagnoses, a finding which also was described by the parents in the research of Howlin and Moore (1997).

Mansell and Morris (2004) said many parents in the *diagnosis* phase, felt “mixed emotions.” They were relieved to have corroboration of their suspicions about their child’s behavior but also felt “shock and disbelief” (p. 388) that the child had been diagnosed with an ASD. Mansell and Morris recommended that during this time professionals provide appropriate information about ASD, delineate support and provide balance between realism and future difficulties.

Parents who were in Mansell and Morris’s (2004) *post-diagnosis* phase swung between feeling hope that, now that a diagnosis had been made, they might find a suitable treatment and disappointment as they grieved for the hoped-for child. The authors noted that in the period immediately following the diagnosis, parents spent most of their time searching for information about ASD and related treatments and therapies. The final stage of *acceptance and adaptation* to the diagnosis had both negative and positive consequences for the parents. Parents in the acceptance and adaptation phase at least have an explanation for their children’s behavior and the knowledge that they are not to blame for it. They also can begin to receive support from other parents, obtain treatment and a better understanding of their child’s condition. On the negative side, the parents have to come to terms with the fact that their children will “never be normal” (p.389) which creates worry about the future. Parents also feel confused and frustrated because although they have received the diagnosis, they still do not know what caused the ASD.

Parents in the present study who suspected that their child might have ASD or who received a diagnosis of ASD for their child seemed to have experienced the phases of pre-diagnosis, diagnosis, post-diagnosis and acceptance of and adaptation as conceptualized by Mansell and Morris (2004). For example, most of the parents were frustrated by delays in getting timely appointments with providers and by not receiving a timely and accurate diagnosis during the pre-diagnosis phase. The parents reported that they spent most of their time searching for information about ASD on the Internet when they were in the post-diagnosis phase. The parents had begun to accept their children's situation when in the adaptation phase, but they remained confused. Although they had received the diagnosis of ASD, they remained unsure why their child had been affected and what to do about it. Many parents in the study spent a great deal of time searching for information about causes and treatments in both the diagnosis and post-diagnosis phases where confusion and a seemingly relentless desire to learn what caused their children's autism prevailed. Deconstructing and defining this process of parental adaptation to autism as Mansell and Morris have done provides practitioners a foundation for improving the understanding of what parents in this situation are experiencing so that providers can support parents more appropriately.

IMPLICATIONS OF THE FINDINGS

Without exception, the parents of children with autism spectrum disorders in the present study believed that the healthcare and educational systems had failed to adequately serve them and their children. As a result, the parents turned to the Internet for

support and information about their children's condition. Many parents reported spending several months simply waiting to be seen by a series of healthcare providers, and many parents spent several additional months before they received a diagnosis of ASD for their children. Moreover, once the diagnosis had been made, parents felt that physicians offered no effective treatments or therapies and that physicians often discouraged and even derided some parents for pursuing complementary therapies. The educational system was as equally frustrating to parents. The parents perceived that the teachers were not adequately trained and the school systems underfunded, which resulted in teacher turnover and improper restrictions of legally-mandated services to their children.

No parent in the study mentioned the presence of, or any involvement with, a nurse at any time during their interactions with the healthcare or educational systems. Nurses can be effective in coordinating care and monitoring the timely provision of follow-up therapies and interventions. Perhaps parents of children with ASD would benefit from having a professional nurse care manager to oversee the continuum of the child's care and to ensure that there is a process in place for making sure the child and parents' encounters with the healthcare system are handled in a sensitive and coherent way. Parents whose questions about autism are answered in a timely and coherent manner during and after the diagnostic process might not feel so abandoned by educators and healthcare providers. Parents who do not feel abandoned might not default so readily to problem-solving outside of the healthcare and education systems.

It seems that "mainstream medicine" or "conventional healthcare" are quick to criticize these parents and the alternative practices that they may pursue, but are generally

slow to volunteer an alternative approach or countervailing perspective like those that are available online. Alternative therapies and practitioners offer hope and a prospect of immediate results. The conventional approach or message to parents offers future research that might prevent ASDs from occurring among other children at some time in the future, but nothing for the parents of children living with the disorders. It is clear that parents of children with ASD need hope and encouragement right now. Perhaps nurses practicing in primary care, specialty care and educational settings can play an important role in improving communication and decreasing the frustration of these parents. Parents in this study seemed to be particularly stressed and frustrated during the times that they spent getting their child diagnosed and a treatment plan formulated and implemented.

The role of the nurse in the educational setting also could be strengthened to better serve children with ASD and their parents. Some of these children receive medications to manage ADHD, seizure disorders and impulsive or self-injurious behaviors. Some may have gastrointestinal and other physical symptoms. School nurses, like community health nurses, must adapt to the increased prevalence of ASD among the children in the public school systems. Children with ASD may have difficulty processing verbal communication and school nurses should be trained and adept at communicating with them when problem-solving or evaluating their health needs. The school nurse is in a unique position to integrate the healthcare and educational needs of children with ASD, to work with the children's parents and to educate and make referrals to support groups and community resources as needed. School nurses are also in a unique position to help parents interpret the multiple complementary therapies and conventional therapies

available. Parents may perceive the school nurse as being more accessible than other clinicians; moreover, the school nurse is a part of the school but may not be perceived as being an educator. A sustained relationship between the school nurse and parents could be a real benefit to the parents and their children.

There are policy issues to consider when evaluating schools and children with ASD. Many professionals would argue that the amount of therapies many of these children receive in the educational setting is inadequate and driven by financial, rather than clinical parameters. Legislation is in place to ensure adequate therapies for children with ASDs, but many school systems lack the funding. The presence of legislative mandates that are not funded adequately represent a public policy failure. Nurses and their professional organizations should advocate publicly for improved funding for these children both in the educational and healthcare systems.

LIMITATIONS

The study is limited due to its small sample size and lack of heterogeneity of participants' educational level, income and ethnicity. Each participant held a college degree or higher and the participants reported higher than average incomes. The use of snowball sampling among parents of children with ASD who regularly accessed the Internet for health information perhaps contributed to a lack of heterogeneity. Participants were not required to own a computer or have access to one at work in order to participate in the study, yet efforts to recruit parents of lower socio-economic groups were unsuccessful. Flyers were posted at five pediatric clinics in lower income areas but

generated no interested participants. The heterogeneity of participants would have been enhanced by participation by Hispanics, participants from rural areas and individuals from lower income groups. Member checking would have improved the trustworthiness of the findings.

RECOMMENDATIONS FOR FURTHER RESEARCH

Parents of children with ASD are stressed by the uncertain and stressful nature of having a child with ASD. Parents must endure a protracted and disjointed period of diagnosis that occurs within healthcare and educational systems. Parents frequently perceive that these systems are disorganized and inconsiderate of their needs and of their children's needs. Parents also experience a research agenda and process that is insensitive to their requirements. The parents want research into interventions that will improve the quality of their life and their children's lives now, yet they perceive that most of the research efforts are devoted to sorting through the genetics of autism in order to prevent its future occurrence.

The period of time surrounding the diagnosis of autism and related disorders is particularly stressful to parents. Health services research into improving how the care and services that are provided during this time are organized and structured might improve parents' adaptation and functioning and promote a more therapeutic outcome for both parent and child. It might also help to foster a more collaborative relationship with parents if the role and involvement of primary care practitioners were stronger and

continuous and if the educational and healthcare diagnostic and treatment teams could organize themselves around the needs and conveniences of the parents and children.

The healthcare and educational services of children with ASD are controlled, provided and financed by several different organizations. Fragmentation and duplication of effort and planning of care result. Surely there are ways to optimize utilization of resources and gain efficiencies if the educational and clinical components were better coordinated and provided. What these children and their parents need most is coordination and communication among all of those who are involved in the child's care and education. A child-centered delivery model that unifies and coordinates the services of providers and educators around the child's needs versus organizational needs and constraints might be beneficial to the child and to the parents and should be evaluated and researched for cost-effectiveness.

In the meantime, perhaps the school nurse working with teachers, parents, pediatricians and psychologists can help ensure that the educational and health needs of children with ASD are integrated and well-coordinated in a multidisciplinary team approach. The school nurse could participate in much needed research or program evaluation in the school setting. There is a paucity of research evaluating the educational interventions that are used with older children with ASD; and many educational interventions that are in use are not scalable or reproducible for use in large public school settings.

Other future research might evaluate whether caregivers who are trained in the stages parents experience during the diagnostic process as described by Mansell and

Morris (2004) provide customers (or parents of children with ASD) with more favorable experiences than do caregivers who lack such an orientation or training. Researchers might evaluate whether parents adapt more readily to their child's condition if parents were assigned a care manager to help them navigate through the system of appointments and evaluations. Care managers could monitor the time and effort parents spend having their child evaluated for ASD. The objective would be to reduce unreasonable delays and the resentment many parents develop towards health system providers as a result of these delays, and most importantly, provide needed services to the child as soon as possible. Comparing parental adaptation and satisfaction levels between groups of parents whose providers recommend trustworthy and informative Internet sites about ASD to groups of parents whose providers do not recommend Internet sites and resources might elucidate the potential influence of Internet use on parental adaptation to their child's receiving a diagnosis of ASD.

Researchers have observed that, despite evidence that certain therapies are ineffective in reversing ASD symptoms, parents request and use the therapies anyway. One potentially fruitful area of research would be to examine the concept of self-reliance among the parents of children with ASD. One research question might be: Do parents gain a sense of self-reliance or competence and control by using the Internet; and specifically, is their sense of competence and control achieved by researching and using alternative therapies for their child's condition? Locating alternative therapies using the Internet might be a way for parents to cope with the uncertainty of their and their children's circumstances; hence, their uncertainty might be ameliorated or neutralized if

they were given bona fide ways to constructively participate in developing or implementing research or treatment activities.

Parents of children with ASD are in position to carefully and meticulously observe symptoms and other features of autism that might enable sub-typing across clinical groups, such as children with regressive autism or gastrointestinal disturbances (Losh et al., 2008). Researchers might consider the value of applying community-based, participatory research as it recognizes the value of including patients and advocates in all aspects of clinical research (Silverman & Brosco, 2007). Moreover, enhancements to the Internet might expand the capability of parents to participate in research. Walker et al. (2003) describe Internet2, a consortium of academic partners whose goal is to recreate the partnership among academia, industry and government that fostered today's Internet when in its infancy. Internet2 has the potential for creating partnerships that will develop new and improved opportunities for applications and interactions in clinical research, telemedicine, public health, virtual health, consumer health, education and others areas. It is perhaps noteworthy that home movies of children's birthdays were used to validate parents' assertions that their children had lost social and communication abilities between their child's first and second birthdays (Werner & Dawson, 2005). Provided that privacy and other matters relating to research ethics were addressed adequately, monitoring technology in the home or educational settings could provide evidence or clues to parents and researchers about the effectiveness of interventions. Such monitoring might allow the detailed observations necessary to identify or validate the existence of observable subclinical markers such as age at first word or phrase. The subclinical markers could be

used to define more etiological homogenous subgroups of autism, which are also called endophenotypes. Some believe that identifying and understanding endophenotypes will contribute significantly to the understanding of how autism is transmitted genetically (Losh et al., 2008).

CONCLUSIONS

Autism spectrum disorders are a significant social and health problem in the United States and appear to be increasing. Despite the innovative and collaborative research being conducted by many talented and dedicated scientists and clinicians, and the tireless and heroic efforts of the parents of these children with ASD, the causes and effectiveness of therapies of ASD are still poorly understood.

The services provided by healthcare and educational systems for these children are fragmented and underfunded, and although these systems have probably never been better, much improvement is needed. The therapeutic effectiveness of the most scientifically advanced care and education is easily diluted if the care and other services to the families affected are delivered in inappropriate and insensitive ways; hence, health services research aiming to strengthen the delivery model for care and service to this population would be helpful.

Clinicians and researchers must continue to explore and pursue ways to exploit the benefits of the Internet and all information technology as our society tries to address health-related challenges such as autism and other developmental disabilities in creative and cost-effective ways. Patient empowerment and self-reliance will rise with our

nation's standard of living and education. Health system administrators, scientists, practitioners, and educators can help patients and their families fully realize the promises of the Internet through the integration and application of research, technology, communication and collaboration among all disciplines.

Appendix A

List of Abbreviations

AAP; American Academy of Pediatrics

ABA; Applied Behavioral Analysis

AD; autism disorder

ADHD; attention deficit hyperactivity disorder

APA; American Psychiatric Association

ARI; Autism Research Institute

ARPA; Advanced Research Project Agency

ASA; American Society of Autism

ASD; autism spectrum disorder

AspS; Asperger's syndrome

BAP; broad autistic phenotype

CAM; complementary and alternative medicine

CDC; Center for Disease Control

CHIP; Children's Health Insurance Program

CNV; copy number variation

DAN! ; Defeat Autism Now

DIR; Developmental Individual Relationship-based mode

DTT; Discrete Trial Training

DPT; diphtheria, pertussis and tetanus

DZ; dizygotic

ICD; International Classification of Diseases

MMR; mumps, measles and rubella

MZ; monozygotic

RDI; relationship development interaction

SAR; Shafer Autism Reports

SCERTS; Social Communication Emotional Regulation Transaction Support

TEACCH; Treatment and Education of Autistic and related Communication-handicapped
Children

TEA; Texas Educational Agency

RT; Responsive Teaching curriculum

WHO; World Health Organization

WWW; World Wide Web

Appendix B

Recruitment Flyer

PARENTS OF CHILDREN w/ AUTISM SPECTRUM DISORDERS

I am conducting a research study about parents' use of the

Internet to:

- Find information about autism spectrum disorders
- Evaluate information about treatments and therapies
- Help them make decisions about their child's care
-

I am looking for parents who might be interested in participating in this important study by sharing their experiences with me. Please call or email me if you want to learn more about the study.

Note: Must be 18 years or older to participate in the study

Appendix C

Recruitment Script

I am Nona Fain, a doctoral nursing student in the Graduate School of Biomedical Sciences at the University of Texas Medical Branch (UTMB) in Galveston, Texas. I am conducting a study into how parents of children with autism spectrum disorders use Internet resources to guide them in making decisions about the care of their child. I also am interested in learning whether parents believe that the Internet information is adequate and helpful.

I am looking for parents of children who have Internet access at home or at work, and are at least 18 years of age. If you are a parent of a child with ASD, and have Internet access at home or at work, you may be eligible to participate.

Participation in the study is voluntary. All information about you and other participants will be kept confidential. The report describing the findings of the study will be written in a way that will protect every participant's identity. No one will know who you are or what you said to me.

Data collection for the study will involve an interview with me. The interview will be tape recorded and later transcribed and analyzed to find common themes and patterns. The interview will be arranged at a time and place that is convenient for you. The interview should take one to one and a half hours. I also may need to contact you at a later time to clarify or receive feedback regarding what you said in your interview with

me. The Institutional Review Board (IRB) at The University of Medical Branch (UTMB) has approved the study and all of its procedures.

If you would like to learn more about this study and perhaps consider participating, please call me at 000-000-0000 or e-mail me at ----- so we could schedule a time to review in detail the research study and its requirements.

Thank you for your time and attention.

Appendix D

Subject Consent Form

You are being asked to participate as a subject in the research project entitled, The Use of Internet Resources among Parents of Children with Autism Spectrum Disorder (ASD), conducted by Nona Fain under the direction of Carolyn A. Phillips, RN, PhD.

PURPOSE OF THE STUDY

The purpose of this study is to explore the use of Internet resources by parents of children with autism spectrum disorder. You are being asked to participate because you have identified yourself as a parent of a child with an autism spectrum disorder who has used or is currently using the Internet in relation to your situation.

PROCEDURES RELATED TO THIS RESEARCH

The study will consist of your completing a demographic data sheet and being interviewed about how you use the computer to find information about autism spectrum disorder. During the interview, you will be asked about how you use the Internet to find information about autism spectrum disorder, and therapies and treatments for autism spectrum disorder. You will also be asked how you judge the credibility or trustworthiness of information that you find on the Internet about autism, and whether that information meets your needs. The interview will be scheduled at a time and in a location that is convenient for you and will provide privacy so that no one can hear what is being discussed in the interview. The interview will last an hour to an hour and thirty minutes. The interview will be tape-recorded so the researcher will be sure to have an accurate and complete record of what was said. After the interview is over, the researcher may call you to be sure that she understood what you said when responding to her questions or to ask you further questions about your responses. This follow-up call to you may occur as soon as 24 hours after the interview is complete, or it may be as long as six months later.

RISKS OF PARTICIPATION

There are no physical risks involved with this study. Potential risks from participation in the study include a loss of confidentiality. To protect your privacy, a code number will be used instead of your name to identify you in all study-related materials. A code book containing all participants' names will be kept locked in a drawer in the researcher's office. Data will be reported as aggregates. In some cases, direct quotes will be used that reflect themes common to all participants; however, any part of a quote that might identify a specific individual will be masked or removed. There may also be a minimal psychological risk in that discussing your situation as a parent of a child with an autism spectrum disorder might be emotionally upsetting.

NUMBER OF SUBJECTS PARTICIPATING AND THE DURATION OF YOUR PARTICIPATION

The anticipated number of subjects involved in the study will be 20 individuals, most of whom live in the greater Galveston-Houston area. The length of time for your participation is 6 months.

BENEFITS TO THE SUBJECT

You will not benefit from your participation in the research project.

REIMBURSEMENT FOR EXPENSES

There will be no reimbursement for participation in this study.

COSTS OF PARTICIPATION

There is no cost involved with participation.

PROCEDURES FOR WITHDRAWAL

You can withdraw from the study at anytime. Though it is not required, it would be appreciated if you would let the researcher know the reason for your withdrawal.

USE AND DISCLOSURE OF YOUR HEALTH INFORMATION

Study records that identify you will be kept confidential as required by law. Federal privacy regulations provided under the Health Insurance Portability and Accountability Act (HIPAA) provide safeguards for privacy, security, and authorized access of your

records. These regulations require UTMB to obtain an authorization from you for the use and disclosure of your health information. By signing this consent form, you are authorizing the use and disclosure of your health information related to the research study. Except when required by law, you will not be identified by name, social security number, address, telephone number, or any other direct personal identifier in study records disclosed outside of the University of Texas Medical Branch (UTMB). For records disclosed outside of UTMB, you will be assigned a unique code number. The key to the code will be kept in a locked file in Nona Fain's office.

As part of the study, Nona Fain will report the results of the study that you are participating in to the faculty members of the Graduate School of Biomedical Sciences and School of Nursing at UTMB. All findings will be reported in the aggregate and you will not be identifiable from these findings.

If you sign this form, you are giving us permission to collect, use and share your health information as described in the above paragraphs. You do not need to sign this form. If you decide not to sign this form, you cannot be in the research study. We cannot do the research if we cannot collect, use and share your health information. Whether or not you agree to the research project or give us permission to collect, use or share your health information will not affect the care you will be given at UTMB or any current or future relationship that you may have with UTMB.

Your records may be reviewed in order to meet federal or state regulations. Reviewers may include, for example, the faculty at UTMB or the UTMB Institutional Review Board. This authorization for the use and disclosure of your medical information as described above expires upon the conclusion of the research study.

If you change your mind later and do not want us to collect or share your health information, you need to contact the researcher listed on the attached consent form by telephone or by letter. You need to say that you have changed your mind and do not want the researcher to collect and share your health information. You may also need to leave the research study if we cannot collect any more health information. We may still use the information we have already collected. We need to know what happens to everyone who starts a research study, not just those people who stay in it. The results of this study may be published in scientific journals without identifying you by name.

ADDITIONAL INFORMATION

1. If you have any questions, concerns or complaints before, during or after the research study, you should immediately contact Nona Fain at 000-000-0000.

2. Your participation in this study is completely voluntary and you have been told that you may refuse to participate or stop your participation in this project at any time without penalty or loss of benefits and without jeopardizing any current or future relationship you may have with UTMB. If you decide to stop your participation in this project and revoke your authorization for the use and disclosure of your health information, UTMB may continue to use and disclose your health information in some instances. This would include any health information that was used or disclosed prior to your decision to stop participation and needed in order to maintain the integrity of the research study. If we get any information that might change your mind about participating, we will give you the information and allow you to reconsider whether or not to continue.
3. If you have any complaints, concerns, input or questions regarding your rights as a subject participating in this research study or you would like more information, you may contact Dr. Wayne R. Patterson, Senior Assistant Vice President for Research, Institutional Review Board, at (000) 000-0000.

The purpose of this research study, procedures to be followed, risks and benefits have been explained to you. You have been allowed to ask questions and your questions have been answered to your satisfaction. You have been told who to contact if you have additional questions. You have read this consent form and voluntarily agree to participate as a subject in this study. You are free to withdraw your consent, including your authorization for the use and disclosure of your health information, at any time. You may withdraw your consent by notifying Nona Fain at 000-000-0000. You will be given a copy of the consent form you have signed.

Informed consent is required of all persons in this project. Whether or not you provide a signed informed consent for this research study will have no effect on your current or future relationship with UTMB.

_____ Date	_____ Signature of Subject
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_____ Date	_____ Signature of Authorized Representative (<i>if applicable</i>)
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_____	_____
-------	-------

_____ Description of Authorized Representative's Authority to Act for Subject (<i>if applicable</i>)	
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Using language that is understandable and appropriate, I have discussed this project and the items listed above with the subject and/or his/her authorized representatives.

_____ Date	_____ Signature of Person Obtaining Consent
---------------	--

Appendix E

Bio-demographic Survey

Code # _____

1.) Date of birth: _____ ID # _____

2) Gender: female _____ male _____

3) Race: White _____ Black (African-American) _____
American Indian/Alaska Native _____ Asian _____
Native Hawaiian/Other Pacific Islander _____ Other _____
Two or more races _____

4) Ethnicity: (circle one)
Hispanic or Latino (Cuban, Mexican, Puerto Rican, South or Central American)
Non-Hispanic or Latino

5) Marital status (circle one) Married Single

6) Religion _____

7) Occupation _____ Occupation of spouse _____

8) Access to computer five days per week (circle) yes no

9) Household Income (check one)

Less than \$9,999___ \$10,000-\$14,999___ \$15,000-\$24,999___

\$25,000 - \$34,999___ \$35,000 - \$49,999___

\$50,000 - \$74,999___

\$75,000-\$99,999___ \$100,000-\$149,999 ___ \$150,000 - \$199,999___

\$200,000 and above _____

10) Estimated number of hours on line (on the Internet) per month _____

11) Broadband or dial-up (circle) Broadband Dialup

12) Education level (circle) High School diploma College degree Post-graduate

13) Number & gender of children: males___ females___

14) Number of children with ASD ___ with other developmental issues___

15) Number of adults living at home _____

16) Age of child now___ Age of child at diagnosis _____

Appendix F

Interview Guide

1. As a parent of a child with ASD, what sites on the Internet do you find useful or interesting?
 - a. How do these sites compare to books or other sources of information?
 - b. How do you find information on the Internet about autism?
 - c. Do you use a search engine like Google?
 - d. What websites or non-Internet resources has your physician or other caregiver recommended?
2. What kinds of therapies and treatments (for ASD) is your child receiving now? What kinds of therapies and treatments was your child receiving previously?)
 - a. Were these therapies chosen as a result of information obtained from the Internet? Please explain.
 - b. Has the information that you have found on the Internet influenced your choices about care for your child? If so, how has it influenced it? If not, why?
 - c. Did you ever find some therapies on the Internet and suggest them to your physician? If so, please explain.

3. When did you first suspect that there was a problem with your child?
 - a. How did you go about finding information to help you solve the problem or answer questions?
 - b. Did you use the Internet more when you suspected a problem or did you use it more when you received a diagnosis?
4. Are you currently a member of a support group for parents of children with ASD? Have you ever been?
 - a. Some websites have chatrooms and discussion boards for parents of children with ASD. Have you ever participated in them?
 - b. What is your response or reaction to these chatrooms and discussion boards?
 - c. In what ways do you think they might be useful to parents?
5. What are some ways that someone could evaluate the trustworthiness of health information that they have found on the Internet?
6. There are a lot of decisions to make when parenting a child with an autism related disorders. Are there any things that you wish you had done differently? Is there information that you need but cannot find?
7. Can you think of any questions that you wished that I would have asked? Is there anything else you want to tell me or think I should know?

Appendix G

Examples of Coding

Narrative	Unit (topical coding)	Supporting narrative	Categories (analytical coding)
I. “Not so much the pediatricians. They are so lacking in knowledge of autism.” P3:56	MDs lacking in knowledge	<p>“Western medicine has not really found anything.” P1:122</p> <p>“I would be happy to find a doctor who could talk about autism.” P4:99</p> <p>[MDs say]: “We’ll get to it. We have all these kids to see. But in the end, they do not have anything to offer.” P8:39</p> <p>“Physicians don’t tell us that.”P2:77</p>	Healthcare system is inadequate

2. I think I really rely on it if I find it on More than one website.”	Relying on websites	<p>“There are certain websites that you have to think...Who is behind this? What are the pop-ups? Who is the sponsor?” P1:106</p> <p>“I think it is somewhat repetition. If I am hearing the same thing over and over...That is why I look for more than one source.” P3:172</p> <p>“I like to read the actual studies...the devil is in the details.” P8:120</p> <p>“One of the easiest is to look at the ending of the website, Dot coms. Dot orgs...P7:92</p>	Strategies to ensure trustworthiness of information
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Appendix H

Categories of Data

<i>I. Searching</i>	<i>II. Why they searched</i>	<i>III. What they searched for</i>	<i>IV. How and where they searched</i>
Urgency Intensity	Healthcare Educational	Confirming diagnosis Causes Understanding symptoms Therapies and treatments	Methods Trustworthiness Trusted sites
<i>V. Other sources of information</i>	<i>VI. What they did not find</i>	<i>VII. What else of value they found</i>	
Web-based technologies Non-electronic sources	Intangibles Instruction Programs & services	Convenience; flexibility Less isolation Way to provide & receive support	

References

- Abrahams, B.S. & Geschwind, D.H. (2008). Advances in autism genetics: On the threshold of a new biology. *Nature Reviews*, 9, 341- 355.
- Allison, C., Baron-Cohen, S., Wheelwright, S., Charman, T., Richler, J., Pasco, G. & Brayne, C. (2008). The Q-CHAT (Quantitative Checklist for Autism in Toddlers): A normally distributed quantitative measure of autistic traits at 18-24 months of age: Preliminary report. *Journal of Autism & Developmental Disorders*, 38, 1414-1425.
- (APA) American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders (4th ed.), Text Revision (DSM-IV-TR)*. Washington, DC: Author.
- Amminger, G.P., Berger, G.E., Schafer, M.R., Klier, C., Friedrich, M.H., & Feucht, M. (2007). Omega -3 fatty acids supplementations in children with autism: A double blind randomized, placebo-controlled pilot study. *Biological Psychiatry*, 61, 551-553.
- Anderson, J. G., Rainey, M.R., & Eysenbach, G. (2003). The impact of cyberhealthcare on the physician-patient relationship. *Journal of Medical Systems*, 27, 67-85.
- Asperger , H. (1944). Die autistischen Psychopathin im Kindersalter. *Archiv fur Psychiatrie und Nervenkrankheiten*, 117, 76-136.

- Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edlebrock, C. & Low, C. (2003). Preschool children with and without developmental delay: Behavior problems and parenting stress over time. *Journal of Intellectual Disability Research*, 47, 217-230.
- Baird, G., Charman, T., Baron-Cohen, S., Sweettenham, L., Wheelwright, S., & Drew, A. (2001). Screening and surveillance for autism and pervasive developmental disorders. *Archives of Disease in Childhood*, 84, 468-475.
- Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D., & Charman, T. (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames. *The Lancet*, 368, 210-215.
- Barbarese, W. J., Katusic, S. K. & Voight, R. G. (2006). Autism: A review of the state of the science for pediatric primary health care clinicians. *Archives of Pediatric & Adolescent Medicine*, 160, 1167-1175.
- Baxter, C., Cummins, R., & Polak, S. (1995). A longitudinal study of parental stress and support: from diagnosis of disability to leaving school. *International Journal of Disability, Development and Education*, 42, 125-126.
- Beck, C. (1993). Qualitative research: The evaluation of its credibility, fittingness, and auditability. *Western Journal of Nursing Research*, 15, 263-266.
- Beekhuizen, J. (2007). Putting the pieces of the puzzle together: Using NVivo for a literature review. 4th QUALIT Conference Qualitative Research in IT & IT in Qualitative Research, Wellington, New Zealand.

- Bernhardt, J. & Felter, E. (2004). Online pediatric information seeking among mothers of young children: Results from a qualitative study using focus groups. *Journal of Medical Internet Research*, 6, 1. Retrieved October 1, 2007, from <http://www.jmir.org/2004/1/e7/>
- Bettelheim, B. (1967). *The empty fortress: Infantile autism and the self*. Oxford, England :Free Press of Glencoe.
- Bishop, D. V. M., Maybery, M., Wong, D., Maley, A., Wong, D., Hill, W., & Hallmayer, J. (2004). Using self-report to identify the broad phenotype in parents of children with autistic spectrum disorders: A study using the Autism Spectrum Quotient. *Journal of Child Psychology & Psychiatry*, 45, 1431-1436.
- Bloch, J. R. & Gardner, M. (2007). Accessing a diagnosis for a child with an autism spectrum disorder: The burden is on the caregiver. *American Journal of the Nurse Practitioner*, 11, 10-17
- Bolton, P., Macdonald, A., Pickles, P., Rios, S., Goode, M., Crowson, A., Bailey, A. & Rutter, M. (1994). A case control family history study of autism. *Journal of Child Psychology & Psychiatry*, 35, 877-900.
- Bringer, J. D., Johnston, L. H., & Brackenridge, C. H. (2004). Maximizing transparency in a doctoral thesis: The complexities of writing about the use of QSR*NVIVO within a grounded theory study. *Qualitative Research*, 4, 247-264.
- Bromley, J., Hare, D. J., Davison, K. & Emerson, E. (2004). Mothers supporting children with autism spectrum disorders: Social support, mental health, and satisfaction with services. *Autism*, 8, 409-423.

- Broom, A. (2005). Virtually healthy: The impact of Internet use on disease experience and doctor-patient relationship. *Qualitative Health Research*, 15, 325-345.
- Brown, M. J., Willis, T., Omalu, B., & Leiker, R. (2006). Deaths resulting from hypocalcemia after administration of edentate disodium: 2003-2005. *Pediatrics*, 118. Retrieved July 18, 2008, from <http://www.pediatrics.org/cgi/content/full/118/2/e534>
- Buckland, S. & Gann, B. (1997). Disseminating treatment outcomes information to consumers: Evaluation of five pilot projects. London: King's Fund Publishing.
- Bunde, M., Suls, J., Martin, R. & Barnett, K. (2006). Hystersisters online: Social support and social comparison among hysterectomy patients on the Internet. *Annals of Behavioral Medicine*, 31, 271-278.
- Cass, H., Gringas, P., March, J., McKendrick, I., O'Hare, A. E., Owen, L., & Pollin, C. (2008). Absence of urinary opioid peptides in children with autism. *Archives of Disease in Childhood*, 93, 745-750.
- C.D.C. (Center for Disease Control). (2007). Autism Information Center. Retrieved July 12, 2007, from <http://www.cdc.gov/ncbddd/autism/>
- Clancy, F. (2006). Desperately seeking solutions. *Minnesota Medicine*, 89, 1-6. Retrieved June 14, 2007, from <http://www.mnmed.org/publications/MNMED2006/March/feature-clancy.htm>
- CNN. *American Morning*. 6 March, 2008. [Television broadcast].
- Comer, D. (2000). The Internet book: Everything you need to know about computer networking and how the Internet works. Upper Saddle River, NJ: Prentice Hall.

- Comm, M. & Larsen, L. S. (1999). Why no advice on autism? Effectiveness of a counseling intervention to assist family caregivers of chronically ill caregivers. *Journal of Psychosocial Nursing & Mental Health Services*, 37, 6.
- Committee on Children with Disabilities, American Academy of Pediatrics. (2001). Counseling families who choose complementary and alternative medicine for their child with chronic illness or disability. *Pediatrics*, 107, 598-601.
- Coulson, N. (2005). Receiving social support online: An analysis of a computer mediated support group for individuals living with irritable bowel syndrome. *CyberPsychology & Behavior*, 8, 580-584.
- Crocco, A., Villasis-Keever, M., & Jadad, A. (2002). Analysis of cases of harm associated with use of health information on the Internet. *Journal of the American Medical Association*, 287, 2869-2872.
- Cronbach, L. J. & Suppes, P. (1969). *Research for tomorrow's schools: Disciplined inquiry in education*. NY: McMillan.
- Doja, A. & Roberts, W. (2006). Immunizations and autism: A review of the literature. *Canadian Journal of Neurological Sciences*, 33, 341-346.
- DeGrace, B. W. (2006). The everyday occupation of families with autism: *American Journal of Occupational Therapy*, 58, 543-550.
- DelGiudice-Asch, G., Simon, L., Schmeidler, J., Cunningham-Rundles, C. & Hollander, E. (1999). Brief report: A pilot open clinical trial of intravenous immunoglobulin in childhood autism. *Journal of Autism & Developmental Disorders*, 29, 157-160.

- Dragon Naturally Speaking (Version 9). Voice recognition software [Computer software]. Burlington, MA: Nuance Communications. Retrieved November 11, 2007, from <http://www.nuance.com/naturallyspeaking/>
- Dunn, M., Burbine, T., Bowers, S. & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal*, 37, 39-52.
- Epstein, R. M., Alper, B. S., & Quill, T. E. (2004). Communicating evidence for participatory decision-making. *Journal of the American Medical Association*, 291, 2359-2366.
- Erlandson, D., Harris, E., Skipper, B. & Allen, S. (1993). *Doing naturalistic inquiry: A guide to methods*. Newbury Park, CA:Sage.
- Eysenbach, G. & Kohler, C. (2002). How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests, and in-depth interviews. *British Medical Journal*, 324, 573-577. Retrieved October 27, 2007, from <http://www.bmj.com/cgi/content/full/324/7337/573>
- Eysenbach, G., Powell, J., Englesakis, M., Rizo, C. & Stern, A. (2004). Health related virtual communities and electronic support groups: Systematic review of the effects of online peer to peer interactions [Electronic version]. *British Medical Journal*, 328, 1-6. Ret Retrieved on October 1, 2007, from http://www.bmj.com/cgi/reprint_abr/328/7449/1166?maxtoshow=&HITS=10&hits=10&RESULTFORMAT=&fulltext=eysenbach+powell&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT

- Farmer, C., Holloway, J., Kettering, T., Norris, M., Snow, A., & Witwer, A. (2007, August 20). Graduate Student Presentation. In. J. Mulick (Chair), *Outrageous Developmental Disabilities Treatments*. Symposium conducted at 2007 Annual Meeting of American Psychological Association, San Francisco. Retrieved October 20, 2007, from <http://researchnews.osu.edu/archive/fadaut.html>
- Fauske, J. (2007, June 11). The qualitative dissertation: Still hazy after all these years. Retrieved from the Connexions Web site on November 9, 2008, from <http://www.cnx.org/content/m14576/latest/>
- Filipek, P., Accardo, P., Ashwal, S., Baranek, G., Cook, E., Dawson, G., Gordon, B., Gravel, J.S., Johnson, C.P., Kallen, R.J. et al. (2000). Practice parameter: Screening and diagnosis of autism: Report of the Quality Standards Subcommittee of the American Academy of Neurology and Child Neurology Society [Special article]. *Neurology*, 55, 468-479.
- Folstein, S. & Rutter, M. (1977). Infantile autism: A genetic study of 21 twin pairs. *Journal of Child Psychiatry*, 18, 297-321.
- Folstein, S. & Rutter, M. (1997). Genetic influences and infantile autism. *Nature*, 265, 726-728.
- Fombonne, E. (2005). Epidemiology of autistic disorder and other pervasive developmental disorders. *Journal of Clinical Psychiatry*, 66, 3-8.
- Fombonne, E. (2008). Thimerosal disappears but autism remains. *Archives of General Psychiatry*, 65, 15-16.

- Fombonne, E., Simmons, H., Ford, T., Meltzer, H. & Goodman, R. (2001). Prevalence of pervasive developmental disorder in the British nationwide survey of child mental health. *Journal of the American Academy of Child & Adolescent Psychiatry*, 40, 820-827.
- Fox, S. (2006). *Online Health Search 2006*. Pew Internet & American Life Project. Retrieved July 12, 2007, from http://www.pewinternet.org/pdfs/PIP_Online_Health_2006.pdf
- Fox, S. & Rainie, L. (2002). *Vital decisions: How Internet users decide what information to trust when they or their loved ones are sick*. Washington, DC: Pew Internet and American Life Project.
- Freitag, C. M. (2007). The genetics of autistic disorders and its clinical relevance: A review of the literature. *Molecular Psychiatry*, 12, 2-22.
- Geier, D. A. & Geier, M. R. (2003). An assessment of the impact of thimerosal on childhood neurodevelopmental disorders. *Pediatric Rehabilitation*, 6, 97-102.
- Gernsbacher, M. A., Dissanayake, C., Goldsmith, H. H., Mundy, P. C., Rogers, S. J., & Sigman, M. (2005). Autism and deficits in attachment behavior. *Science*, 307, 1201-1203.
- Glaser, B. (1978). *Theoretical sensitivity: Advances in the methodology of grounded theory*. Mill Valley, CA: Sociology Press.
- Glaser, B. & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago, IL: Aldine.

- Glasson, E. J., Bower, C., Petterson, B., de Clerk, N., Chaney, G. & Hallmayer, J. F. (2004). Perinatal factors and the development of autism: A population study. *Archives of General Psychiatry*, 61, 618-627.
- Glesne, C. (2006). *Becoming qualitative researchers: An introduction* (3rd ed.). Boston, MA: Pearson.
- Glesne, C. & Peshkin, A. (1992). *Becoming qualitative researchers*. White Plains, NY: Longman.
- Goin-Kochel, R., Myers, B., & Mackintosh, V. (2006). Parental reports on the use of treatments and therapies for children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 1, 195-209.
- Goldstein, H. (2002). Communication intervention for children with autism: A review of treatment efficacy. *Journal of Autism & Developmental Disorders*, 32, 373-396.
- Gorski, P. (1998). *Race and gender identity development in white male multicultural educators and facilitators: Toward individual processes of self-development*. Unpublished doctoral dissertation, University of Virginia, Charlottesville.
- Retrieved on July 21, 2007, from <http://home.earthlink.net/~gorski/dissertation/method.html>
- Gray, D. E. (2006). Coping over time: The parents of children with autism. *Journal of Intellectual Disability Research*, 50, 970-976.
- Green, V., Pituch, K., Itchon, J., Choi, A., O'Reilly, M. & Sigafoos, J. (2006). Internet survey of treatments used by parents of children with autism. *Research in Developmental Disabilities*, 27, 70-84.

- Greenspan, S. L. & Wieder, S. (1997). Developmental patterns and treatment outcomes in infants and children with disorders in relating and communicating: A chart review of 200 cases of children with autism spectrum diagnoses. *Journal of Developmental & Learning Disorders, 1*, 87-141.
- Guba, E. G. (1992). (Ed.) *The alternative paradigm*. London: Sage.
- Guba, E. G. & Lincoln, Y. S. (1981). *Effective evaluation*. San Francisco, CA: Jossey-Bass.
- Guba, E. G. & Lincoln, Y. S. (1989). *Fourth generation evaluation*. Newbury Park, CA: Sage.
- Gupta, V. B. (2004). Complementary and alternative treatments for autism. In V. B. Gupta (Ed.), *Autistic spectrum disorders in children. Pediatric habilitation series* (pp: 239-254). New York, NY: Marcel Dekker.
- Gupta, S., Aggarwal, S. & Heads, C. (2006). Dysregulated immune system in children with autism: Beneficial effects of intravenous immunoglobulin on autistic characteristics. *Journal of Autism & Developmental Disorders, 26*, 439-452.
- Gutstein, S. E. & Sheehy, R. K. (2002). *Relationship development intervention with children, adolescents, and adults*. New York, NY: Jessica Kingsley.
- Hassall, R., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: The effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research, 49*, 405-418.

- Hastings, R. P., Kovshoff, H., Ward, M. J., Espinosa, F., Brown & Remington, B. (2005). Systems analysis of stress and personal perceptions in mothers and fathers of children with autism. *Journal of Autism & Developmental Disabilities*, 35, 635-644.
- Healy, B. (2008, May 12). *CBS News* [Television broadcast]. The “open question” on vaccines and autism. Retrieved February 18, 2009, at <http://www.cbsnews.com/blogs/2008/05/12/couricandco/entry4090144.shtml>
- Higgins, D., Bailey, S. & Pearce, J. (2005). Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. *Autism*, 9, 125-137.
- Hodapp, R. (2002). Parenting children with mental retardation. In M. H. Bernstein (Ed.), *Handbook of Parenting: Volume 1: Children and Parenting* (pp.355-381). Mahwah, NJ: Lawrence Erlbaum.
- Howard, J. S., Sparkman, C. R., Cohen, H. G., Green, G. & Stanislaw, H. (2005). A comparison of intensive behavior analytic and eclectic treatments for young children with autism. *Research in Developmental Disabilities*, 26, 359-363.
- Howlin, P. & Moore, P. (1997). Diagnosis in autism: A survey of over 1200 patients in the U.K. *Autism*, 1, 135-162.
- Huws, J., Jones, R., & Ingledew, D. (2001). Parents of children with autism using an e-mail group: A grounded theory study. *Journal of Health Psychology*, 6, 569-584.
- Hyman, S. L. & Levy, S. E. (2000). Autistic spectrum disorders: When traditional medicine is not enough. *Contemporary Pediatrics*, 17, 101-116.

- Johnson, C. P. & Myers, S. M. American Academy of Pediatrics: Council on Children with Disabilities. (2007). Identification and evaluation of children with autism spectrum disorders. *Pediatrics*, 120, 1183-1215.
- Jones, R. & Lewis, H. (2001). Debunking the pathological model: The functions of an Internet discussion group. *Down Syndrome: Research & Practice*, 6, 123-7.
- Jorde, L. B., Hasstedt, S. J., Ritvo, E. R., Mason-Brothers, A., Freeman, B. J., Pingree, W. M., et al. (1991). Complex segregation analysis of autism. *American Journal of Human Genetics*, 49, 932-938.
- Kadesjo, B., Gillberg, C. & Hagberg, B. (1999). Brief report: Autism and Asperger syndrome in seven-year-old children: A total population study. *Journal of Autism & Developmental Disorders*, 29, 327-331.
- Kanner, L. (1944). Autistic disturbances of affective content. *Nervous Child*, 2, 217-250.
- Kaptchuk, T. J. & Eisenberg, D. M. (1998). The persuasive appeal of alternative medicine. *Annals of Internal Medicine*, 129, 1061-1065.
- Karapurker, T., Lee, N. L., Curran, L. K., Newschaffer, C. J. & Yeargin-Allsopp, M. (2003). Autistic spectrum disorder in children. In *Autistic spectrum disorder in children* (pp 17-42). Madison, NJ: Marcel Dekker.
- Kidder, L. (1981). Qualitative research and quasi-experimental frameworks. In M.B. Brewer & B.E. Collins (Eds.), *Scientific inquiry and the social sciences* (pp. 43-98). San Francisco, CA: Jossey-Bass.
- Kleinman, J., Robins, D., Ventola, P., Pandey, J., Boorstein, H. C., Esser, E., Wilson, L.B., Rosenthal, M.A., Sutura, S., Verbalis, A.D. et al. (2008). The modified

- checklist for autism in toddlers: A follow-up study investigating the early detection of autism spectrum disorders. *Journal of Autism & Developmental Disorders*, 38, 827-39.
- LeCavalier, L., Leone, S. & Wiltz, J. (2006). The impact of behavior problems in caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research*, 50, 172-183.
- Lemire, M., Sicotte, C., & Pare, G. (2008). Internet use and the logics of personal empowerment in health. *Health Policy*, 88, 130-140.
- Levy, S. E. & Hyman, S. L. (2003). Use of complementary and alternative treatments for children with autistic spectrum disorders. *Pediatric Annals*, 32, 685-691.
- Levy, S. E. & Hyman, S. L. (2005). Novel treatments for autistic spectrum disorders. *Mental Retardation & Developmental Disability Research Review*, 11, 131-142.
- Lincoln, Y. & Guba, E. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.
- Lintas, C. & Persico, A. M. (2009). Autistic phenotypes and genetic testing: State-of-the-art for the clinical geneticist. *Journal of Medical Genetics*, 46, 1-8. Retrieved on February 8, 2009, from <http://jmg.bmj.com/info/unlocked.dtl>
- Lissman, T. & Boehlein, J. (2001). A critical review of Internet information about depression. *Psychiatric Services*, 52, 1046-1050.
- Lord, C. & McGee, J. P. (2001). *Educating children with autism*. Committee on Educational Interventions for Children with Autism, Division of Behavioral and Social Sciences and Education, National Research Council. Washington, DC: National Academy Press.

- Losh, M., Sullivan, P. F., Trembath, D. & Piven, J. (2008). Current developments in the genetics of autism: From genome to phenome. *Journal of Neuropathology & Experimental Neurology*, 67, 829-837.
- Lovaas, O. I. (2003). *Teaching children with developmental delays: Basic intervention techniques*. Austin, Texas: Pro:Ed.
- Mackintosh, V., Myers, B., & Goin-Kochel, R. (2005). Sources of information and support used by parents of children with autism spectrum disorders. *Journal of Developmental Disabilities*, 12, 41-52.
- Mahoney, G. & McDonald, J. (2003). *Responsive teaching: Parent mediated developmental intervention*. Baltimore, MD: Paul H. Brookes.
- Mansell, W. & Morris, K. (2004). A survey of parents' reactions to the diagnosis of autism spectrum disorder by a local service. *Autism*, 8, 387-407.
- McWilliams, R. A. (2005). Reporting qualitative studies. *Journal of Early Intervention* . Retrieved June 21, 2007, from <http://www.vanderbiltchildrens.com/interior.php?mid=2277>
- Mesibov, G. B., Shea, V., & Schopler, E. (2005). *The TEACCH approach to autism spectrum disorders*. New York, N.Y: Kluwer Academic/Plenum.
- Michelotti, J., Charman, T., Slonims, V. & Baird, G. (2002). Follow-up of children with language delay and features of autism from preschool years to middle childhood. *Developmental Medicine and Child Neurology*, 44, 812-819.

- Midence, K. & O'Neill, M. (1999). The experience of parents in the diagnosis of autism: A pilot study. *Autism*, 3, 273-285.
- Montes, G. & Halterman, J. S. (2007). Psychological functioning and coping among mothers of children with autism: A population-based study. *Pediatrics*, 119, 1040-1045.
- Morse, J. (2000). Follow your nose. *Qualitative Health Research*, 10, 579-580.
- Morse, J. & Richards, L. (2002). *Readme first for a user's guide to qualitative methods*. Thousand Oaks, CA: Sage.
- Mostert, M. P. (2001). Facilitated communication since 1995: A review of published studies. *Journal of Autism & Developmental Disorders*, 31, 287-313.
- Muhle, R., Trentacoste, S., & Rapin, I. (2004). The genetics of autism. *Pediatrics*, 113, 472-286.
- Myers, S. M. & Johnson, C. P. (2007). American Academy of Pediatrics: Council on Children with Disabilities. *Management of Children with Autism Spectrum Disorders*, Retrieved May 23, 2008, from <http://www.pediatrics.org>
- National Center for Complementary and Alternative Medicine. Expanding horizons of healthcare: Five year strategic plan 2001-2005. Washington, DC: U.S. Department of Health and Human Services.
- Newschaffer, C., Croen, L., Daniels, J., Giarelli, E., Grether, J., Levy, S., Mandell, D.S., Miller, L.A. & Pinto-Martin, J. (2007). The epidemiology of autism spectrum disorders. *Annual Review of Public Health*, 28, 235-238.

- N.I.M.H. (National Institute of Mental Health). National Institutes of Health. (2007, August 10). *Autism Spectrum Disorders (Pervasive Developmental Disorders)*. Retrieved September 4, 2007, from <http://www.mentalhealth.gov/healthinformation/autismmenu.cfm?Output=print>
- NVivo (Version 7.0). Qualitative research software [Computer software]. Victoria, Australia:QSR International. Retrieved November 11, 2007, from http://www.qsrinternational.com/products_nvivo.aspx
- Offit, P. A. (2008). Vaccines and autism revisited: The Hannah Poling Case. *The New England Journal of Medicine*, 358, 2089-2091.
- Paul, R. & Sutherland, D. (2005). Enhancing early language in children with autism spectrum disorders. In F. Volkmar, R. Paul, A. Klin, & D. Cohen (Eds.), *Handbook of Autism and Pervasive Developmental Disorders*. 3rd ed. (pp. 946-976). Hoboken, NJ: John Wiley & Sons.
- Persico, A. M., & Bourgeron, T. (2006). Searching for ways out of the autism maze: Genetic, epigenetic and environmental clues. *Trends in Neuroscience*, 29, 349-358.
- Pickard, A. & Dixon, P. (2004). The applicability of constructivist user studies: How can constructivist inquiry inform service providers and systems designers? [Electronic version]. *Information Research*, 9. Retrieved July 21, 2007, from <http://informationr.net/ir/9-3/paper175.html>
- Poling, J. (2008, August 7). Vaccines and autism revisited [Letter to the editor]. *New England Journal of Medicine*, pp. 655-656.

- QSR (2006). NVivo 7 [Computer software]. Melbourne, Australia.
- Rapin, I. & Tuchman, R. F. (2008). Autism: Definition, neurobiology, screening, diagnosis. *Pediatric Clinics of North America*, 55, 1129-1146.
- Redon, R., Ishikawa, S., Fitch, K., Feuk, L., Perry, G., Andrews, D., Fiegler, H., Shapero, M.H., Carson, A.R., Chen, W. et al. (2006). Global variation in copy number in the human genome. *Nature*, 444, 444-454.
- Reichenberg, A., Gross, R., Weiser, M., Bresnahan, M., Silverman, J., Harlap, S., Rabinowitz, J., Shulman, C., Malaspina, D., Lubin, G. et al. (2006). Advancing paternal age and autism. *Archives of General Psychiatry*, 63, 1026-1032.
- Richards, L. (2002). Qualitative computing: A methods revolution? *International Journal of Social Research Methodology*, 53, 263-276.
- Richards, L. (2006). *Handling qualitative data: A practical guide*. Thousand Oaks, CA: Sage.
- Rogers, S. J. (1998). Empirically supported comprehensive young treatments for young children with autism. *Journal of Clinical Child Psychology*, 27, 168-179.
- Rutter, M. (1968). Concepts of autism: A review of research. *Journal of Child Psychology & Psychiatry*, 9, 1-25.
- Schechter, R. & Grether, J. K. (2008). Continuing increases in autism reported to California's developmental services system: Mercury in retrograde. *Archives of General Psychiatry*, 65, 19-24.
- Schieve, L.A., Blumberg, S.J., Rice, C., Visser, S.M. & Boyle, C. (2007). The relationship between autism and parenting stress. *Pediatrics*, 119, 5114-5121.

- Schwandt, T.A. (1994). Constructivist, interpretivist approach to human inquiry. In N. Denzin & Y. Lincoln (Eds.), *Handbook of Qualitative Research* (pp.118-137). Thousand Oaks, CA: Sage.
- Sebat, J., Lakshmi, B., Malhotra, D., Troge, J., Lese-Martin, C., Walsh, T., Yammon, B., Yoon, S., Krasnitz, A., Kendall, J. et al. (2007). Strong association of de novo copy number mutations with autism. *Science*, 316, 445 - 449. Retrieved June 3, 2008, from www.sciencemag.org
- Seroussi, K. (2000). Unraveling the mystery of autism and pervasive developmental disorder: A mother's story of research and recovery. New York, NY: Simon & Schuster.
- Shattuck, P. T. (2006). The contribution of diagnostic substitution to the growing administrative prevalence of autism in U.S. special education. *Pediatrics*, 117, 1028-1037.
- Silverman, C. & Brosco, J. P. (2007). Understanding autism: Parents and pediatricians in historical perspective. *Archives of Pediatric & Adolescent Medicine*, 161(4). Retrieved May 10, 2008, from <http://www.archpedi.ama-assn.org.libux.utmb.edu/cgi/content/full/161/4/392?ijkey=5946be369b>
- Sivberg, B. (2006). Coping strategies and parental attitudes: A comparison of parents with children with autism and parents with children with non-autistic children. *International Journal of Circumpolar Health*, 6, 36-50.
- Smith, A. J. & Glass, A. (1987). *Research and evaluation in education and the social services*. Englewood Cliffs, NJ: Prentice-Hall.

- Sponheim, E. & Skjeldal, O. (1998). Autism and related disorders: Epidemiologic findings in a Norwegian study using ICD diagnostic criteria. *Journal of Autism & Developmental Disorders*, 28, 217-227.
- Spradley, J. (1979). *The ethnographic interview*. New York: Holt, Rhinehart & Winston.
- Steffenburg, S., Gillberg, C., Hellgren, L., Anderson, L., Gillberg, I. C., Jakobsson, G. & Bohman, M. (1989). A twin study of autism in Denmark, Finland, Iceland, Norway and Sweden. *Journal of Child Psychology & Psychiatry*, 30, 405-416.
- Sturney, P. (2005). Secretin is an ineffective treatment for pervasive developmental disabilities: A review of 15 double-blind randomized controlled trials. *Research in Developmental Disabilities*, 26, 87-97.
- Sullivan, C. (2003). Gendered cybersupport: A thematic analysis of two online cancer support groups. *Journal of Health Psychology*, 8, 83-103.
- Thorne, A. (2007). Are you ready to give care to child with autism? *Nursing 2007*, 37, 59-60.
- Tuchman, R. F. & Rapin, I. (1997). Regression in pervasive developmental disorders: Seizures and epileptiform electroencephalogram correlates. *Pediatrics*, 99, 560-566.
- Twoy, R., Connolly, P., & Novak, J. (2007). Coping strategies used by parents of children with autism. *American Academy of Nurse Practitioners*, 19, 251-260.
- Wakefield, A. J., Murch, S. H., Anthiny, A., Linell, J., Casson, D. M., Mallik, M., Berolowitz, M., Dhillon, A.P., Thomson, M.A., Harvey, P. et al. (1998). Ileal

- lymphoid nodule hyperplasia, non-specific colitis and pervasive developmental disorder in children. *Lancet*, 351, 637-641.
- Walker, R., Dieter, M., Panko, W., & Valenta, A. (2003). What it will take to create new Internet initiatives in health care. *Journal of Medical Systems*, 27, 95- 103.
- Wang, F., Zeng, D., Carley, K., & Mao, W. (2007, March.). Social computing: From informatics to social intelligence. *IEEE Intelligent Systems*, 22, 79-83.
- Retrieved April 23, 2007, from <http://dsonline.computer.org/portal/site/dsonline/menuitem.9ed3d9924aeb0dcd82ccc6716b>
- Weis, R., Stamm, R., Smith, C., Nilan, M., Clark, F., Weis, J. & Kennedy, K. (2003). Communities of care and caring: The case of MSWatch.com®. *Journal of Health Psychology*, 8, 135-148.
- Weiss, M. (2002). Hardiness and social support as predictors of stress in mothers of typical children, children with autism, and children with mental retardation. *Autism*, 6, 115-130.
- Werner, E. & Dawson, G. Validation of the phenomenon of autistic regression using home videotapes. *Archives of General Psychiatry*, 62, 889-895.
- W.H.O. (World Health Organization). (2000). Mental Disorders: Glossary and Guide to Their Classification in Accordance with the Tenth Revision of the International Classification of Disease. Geneva: WHO.
- Williams, D. D. (2005). *Chapter 2: Assumptions*. Retrieved October 7, 2007, from Brigham Young University. David McKay School of Education Web site: <http://education.byu.edu/ipt/williams/chapter2.html>

- Williams, K. W., Wray, J. J. & Wheeler, D. M. (2005). Intravenous secretin in autism spectrum disorder. *Cochrane Database Systematic Review*, 3, CD003495.
- Winefield, H. (2006). Support provision and emotional work in an Internet support group for cancer patients. *Patient Education & Counseling*, 62, 193-197.
- Wing, L. (1981). Asperger's syndrome: A clinical account. *Psychological Medicine*, 11, 115-129.
- Wing, L. & Potter, D. (2002). The epidemiology of autistic spectrum disorders: Is the prevalence rising? *Mental Retardation Review & Disability Research Review*, 8, 151-161.
- Wright, K. (2000). Perceptions of online support providers: An examination of perceived homophily, source credibility, communication and social support with online support groups. *Communication Quarterly*, 48, 44-59.
- Wright, K. (2002). Social support with an on-line cancer community: An assessment of emotional support, perceptions of advantages & disadvantages, and motives for using the community from a communication perspective. *Journal of Applied Communication Research*, 30, 195-209.
- Yeargin-Allsopp, M., Rice, C. Karapurkar, T., Doernberg, N., Boyle, C. & Murphy, C. (2003). Prevalence of autism in a U.S. metropolitan area. *Journal of the American Medical Association*, 289, 49-55.
- Yirmiya, N. & Shaked, M. (2005). Psychiatric disorders in parents of children with autism: A meta-analysis. *Journal of Child Psychology & Psychiatry*, 46, 69-83.

- Yoong, S. (1986). Guba as the vanguard of naturalistic inquiry: A harbinger of the future? Retrieved July 17, 2007, from <http://www.eric.ed.gov/ERICdocs/data/ericdocs>
- Zaidman-Zait, A. & Jamieson, J.R. (2007). Providing web-based support for families of young children with established disabilities. *Infants & Young Children*, 20, 11-25.
- Zollman, C. & Vickers, A. (1999). What is complementary medicine? *British Medical Journal*, 319, 693-696.

Vita

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