Accessing Healthcare

The Experience of Individuals with Autism Spectrum Disorders in Maine

A Report Prepared for the Maine Developmental Disabilities Council by the University of Maine Center for Community Inclusion and Disability Studies
Maine's University Center for Excellence in Developmental Disabilities (UCEDD)

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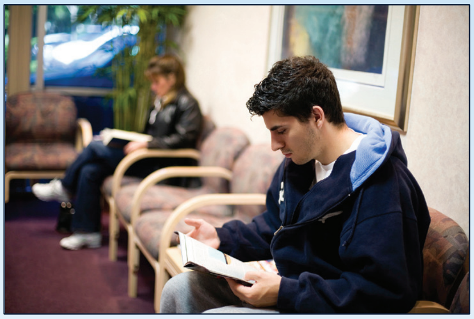

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Maine Developmental Disabilities Council

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Accessing Healthcare: The Experience of Individuals with Autism Spectrum Disorders in Maine

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Executive Summary

Introduction

Individuals with Autism Spectrum Disorders (ASD) are significantly more likely to have unmet healthcare needs and difficulty accessing healthcare services than those with other disabilities. Minority status, living in a rural location, and low income can exacerbate these disparities. Other obstacles to effective healthcare for individuals with ASD include the following: (1) severity of symptoms associated with ASD; (2) lack of knowledge or skill by medical practitioners; (3) lack of access to comprehensive healthcare supports or a medical home; and (4) lack of access to health insurance for needed supports and services. Individuals with ASD of all ages are likely to have a range of comorbid medical and psychological conditions, making the need for comprehensive healthcare imperative.

Maine has taken a number of steps in recent years to improve healthcare for persons with ASD through its Pervasive Developmental Disorders (PDD) Systems Change Initiative, including the following: (1) field-testing screening protocols for ASD; (2) designing and distributing guidance for efficient primary care provider (PCP) referrals; (3) improving effective and coordinated healthcare through an Autism Implementation Grant; (4) training providers in the use of the *Modified Checklist for Autism in Toddlers*; (5) supporting two medical practice pilots; (6) participating in the Improve Health Outcomes for Medicaid Eligible Children (IHOC) program; (7) developing a comprehensive data system to facilitate prompt screening, diagnosis, evaluation and treatment; and (8) enactment of a law in 2011 that requires insurance companies to provide coverage for the diagnosis and treatment of ASD for all children under the age of six.

Method

Two structured interview surveys were developed and field-tested: one for parents of children with ASD; and the other for adults with ASD or their guardians. The children's survey contained 83 questions and the adult survey contained 71. The parents of 85 children and 22 adults with ASD or their guardians completed the adult interviews. Most questions provided opportunities for respondents to add additional comments.

Both quantitative data and qualitative data from respondents' comments were analyzed and reported. Composite variables were created to summarize gastrointestinal (GI) issues, sleep issues, behavior, seizures, wellness, physical health and sexuality, PCP understanding of individual needs, PCP communication, and overall PCP responsiveness. Multivariate simultaneous linear regression was used to determine if any of five patient-related or four PCP-related characteristics predicted healthcare outcomes.

Results—Quality of Health

Eighty-five percent of the adults and 83% of the children were reported to be in good or excellent health. Children were reported to have a mean of 1.26 medical diagnoses in addition to ASD and adults were reported to have 1.85 additional diagnoses. Eighty-seven percent of the children and 86% of the adults were reported to have at least one sleep issue. More than 80% of all respondents reported at least one GI issue. The mean number of GI issues reported was 2.3 for children and 3.4 for adults. Seven adults (32%) and seven children (8%) were reported to have had at least one seizure. Three adults or their guardians, and three parents indicated that they discussed seizures with their PCP. Over 98% of the respondents reported at least one behavior issue. The most common PCP response to children's behavior issues was to prescribe medication (46%). In contrast, the most common PCP response to adult behavior issues was to recommend behavior assessment (33%). Parents and guardians of children and adults with ASD or their guardians expressed concerns about a number of medical issues, the most common including those related to the following: (1) nutrition, diet, weight and fitness; (2) obtaining quality medical care throughout the person's life; (3) coordination of care; (4) mental health issues and behavior; and (5) the overuse of prescription medication.

Results—Quality of Healthcare

When asked to rate the quality of care on a scale from 1 to 10, the mean score for parents and guardians of children was 7.4; and for adult respondents and their guardians, the mean score was 7.9. Access to healthcare among Maine patients with ASD appeared to be very good compared to previous research. Strengths of the healthcare system for patients with ASD included the following: (1) having a regular place to go for healthcare; (2) having a regular doctor or nurse; (3) spending enough time with the PCP; (4) relatively easy access to healthcare in rural areas; (5) effective communication with the PCP; and (6) the general perception that PCPs were knowledgeable about both ASD and the individual's unique needs. Most respondents reported that they were able to find a PCP, although several reported that it took some time. Most children (92%) had received some routine medical care within the last 12 months and 78% had received a complete physical. The majority of adults received some routine medical care within the last 12 months and 63% had received a complete physical in that time. For adults, the number of additional diagnoses was correlated with the number of routine care and screening items completed. There were some issues of concern, however, including the lack of prostate exams among adult males and difficulties that some patients had in participating in routine care. Several parents or guardians reported difficulties with their child or ward cooperating with routine care and screening procedures. Population density of the county of a patient's residence did not appear to predict difficulty finding a PCP. Among children, difficulty finding a PCP was predicted by having an ASD diagnosis other than autism and the number and frequency of behavior problems. Among adults, having additional medical diagnoses and having higher ratings of overall health were associated with difficulty finding a PCP. Finding specialists was difficult for patients in both samples, with 55% of the respondents for children and 60% of the adults or guardians reporting difficulty. Older children tended to have more difficulty finding specialty care than younger children.

It was impossible to determine, based on this data, the extent to which medical practices in Maine provided care to patients with ASD that was consistent with a medical home. Overall, respondents in both samples reported that medical practices were responsive. In some cases, medical practices provided accommodations that were requested to make appointments easier, although very few provided alternatives to the waiting room—the most requested accommodation. A number of respondents indicated in their comments that medical care was not well coordinated. In addition, there appeared to be little support for the transition from pediatric to adult healthcare, suggesting a breakdown in the continuity of care.

More than 80% of the adults with ASD or their guardians reported that their PCPs had spoken with them about “wellness-related” issues, including their likes and interests, diet and nutrition, oral health, and physical exercise. A majority of the parents of children indicated that their PCPs had spoken with them or their children about the following: safety issues, peer relationships, diet or nutrition, oral health, and physical activity or exercise. In cases in which the PCP did not discuss wellness items, parents or guardians sometimes felt that the patient with ASD would not understand. Most of the adults or their guardians reported that the PCP talked with the adults about both tobacco use and drug use. Less than 50% reported that PCPs talked with the adults with ASD about issues related to sexuality, however. PCPs seldom suggested a relationship between GI issues and behavior. Sixty percent of parents and guardians of children with ASD reported the child had accessed Complementary and Alternative Medicine (CAM), but less than half discussed CAM with their PCP. Very few PCPs were reported to have talked with children over age 11, or adults with guardians, about taking more responsibility for their healthcare or spent time alone with the patient.

Most respondents reported that the patient with ASD was covered by medical insurance including Maine’s Medicaid program, MaineCare. A number of concerns were reported about the limitations of both private health insurance and MaineCare.

Discussion and Conclusion

The median age at which children eight years and younger in this sample were diagnosed was 2.9, compared to a median age of 5.7 in a 2009 nationally representative study (Shattuck et al., 2009). This suggests that efforts to improve early identification and diagnosis of ASD in Maine have been successful. Individuals with ASD in Maine also appear to be in better overall health than those with ASD in other states. This may also reflect positively on recent efforts to improve healthcare for individuals with ASD in Maine. The rate of GI and sleep issues was slightly higher than in previous research. The percentage experiencing seizures was higher among adults than children, but similar to that reported in other studies.

Nearly all of the children and adults were reported to have at least one behavior issue. Several issues related to the treatment of behavior problems emerged in this study. They include the following: (1) the high rate at which PCPs prescribed medication for the children with behavior issues and the comparatively small number recommending behavior assessments; (2) the relatively large number of PCPs reported to have indicated that "nothing could be done;" (3) a failure of PCPs to suggest or address a possible relationship between GI problems and behavior; and (4) a lack of participation by PCPs on teams addressing behavior issues.

Most patients with ASD appeared to have regular access to healthcare and most had little difficulty finding a PCP. There were several areas of concern, however: (1) the difficulties children with more significant behavior issues, or those having an ASD diagnosis other than "autism," face in finding a PCP; and (2) the difficulties adults with additional medical diagnoses face in finding a PCP. Difficulty finding specialist care appeared to be a significant problem for individuals with ASD across the age span. Older children in this sample tended to have more difficulty in finding specialty medical care than younger children.

This research revealed a number of possible positive trends in healthcare for individuals with ASD in Maine. These included the following: (1) a much earlier median age of identification and diagnosis among the youngest cohort of children; (2) high ratings of overall health; (3) high ratings of overall healthcare; (4) satisfaction with the PCP; (5) satisfaction with the ability of the PCP to meet the patient and family's individual needs; (6) a relatively good understanding of ASD among PCPs; (6) high ratings of PCP responsiveness and communication; (7) relatively little difficulty finding a PCP; and (8) access by most patients with ASD to regular healthcare, routine care and screening.

The research points to a number of areas of concern, however. These include the following: (1) difficulty by a small number of respondents in finding a PCP who could meet their needs; (2) poor communication among some medical providers; (3) failure of medical practices to make requested accommodations, especially those related to difficulty in waiting rooms; (4) a very high rate of GI issues; (5) frequent failure of PCPs to notice or act upon a possible relationship between GI and behavior issues; (6) lack of communication with PCPs about using CAM therapies; (7) a lack of support and planning for families related to the transition to adult healthcare; (8) difficulties that some patients had with completing routine care and screening procedures; and (9) inability of some individuals with ASD to communicate pain or illness in ways that are universally understood.

Recommendations:

1. Identify strategies for improving transition from pediatric to adult care including development of a model transition planning process for use with children with ASD.
2. Families, schools, and adult providers should undertake efforts to strengthen the capacity of individuals across the autism spectrum to participate more actively in their own healthcare.
3. Provide training to medical providers on the unique needs of patients with ASD and their families.
4. Determine how PCPs can contribute to the Individualized Education Program (IEP) and person-centered planning process.
5. Improve instruction and support for individuals with ASD across the age span related to living healthy lifestyles.
6. Continue efforts to improve the quality of and coordination of healthcare for patients with ASD in Maine.
7. Explore policy changes that would allow PCPs to devote more time in office visits to persons with ASD and complex medical needs.
8. Identify policies that serve as obstacles to both children and adults with ASD receiving needed specialty care, including dental care.

Future research. A number of topics for future research emerge from this study. These include the following: (1) a more detailed investigation of the extent to which Maine children and adults receive care that is consistent with a medical home; (2) the extent to which significant behavior issues can serve as obstacles to healthcare access for children with ASD, as well as strategies for improving access to healthcare for this population; (3) specific obstacles to specialty care for patients with ASD; (4) the role of socioeconomic status and minority status on healthcare access by Maine individuals with ASD; (4) identification and testing of the efficacy of strategies for supporting medical self-determination for individuals across the spectrum; and (5) the use of

Augmentative and Alternative Communication (AAC) by individuals with ASD to communicate more effectively about pain, illness, and their healthcare needs.

Keywords: accessing healthcare, children with autism spectrum disorders, adults with autism spectrum disorders, Maine, medical home, quality of care, healthcare outcomes for individuals with ASD, patients with ASD, patient perceptions of primary care providers.

Access to Healthcare by Individuals with Autism Spectrum Disorders (ASD)

Children with developmental disabilities (DD) are significantly more likely than other children to face obstacles in obtaining appropriate healthcare (Krahn, Hammond, & Turner, 2006; Liptak, Stuart, & Auinger, 2006). Having an Autism Spectrum Disorder (ASD) further increases the likelihood that a child will have unmet healthcare needs (Carbone et al., 2012; Kogan et al., 2008; Krauss, Gulley, Sciegaj, Wells, & Taylor, 2003; Lajonchere, Jones, Coury, & Perrin, 2012; Magaña, Parish, Rose, Timberlake, & Swaine, 2012; Parish, Magaña, Rose, Timberlake, & Swaine, 2012). Children with ASD are also more likely to experience difficulty in receiving timely referrals to specialty care or in obtaining specialty services (Chiri & Warfield, 2012; Kogan et al., 2008; Krauss et al., 2003; Liptak et al., 2006). These disparities may negatively impact the health of children on the spectrum. Indeed, parents report that their children with ASD are in fair or poor health far more frequently than do other parents (Gurney, McPheeters, & Davis, 2006). Difficulties accessing appropriate healthcare can place significant financial and time burdens on the family members of these children (Kogan et al., 2008). Healthcare disparities for children with ASD are exacerbated among families who are African American or Latino (Magaña et al., 2012; Parish et al., 2012), have a low income (Liptak et al., 2008; Shattuck et al., 2012; Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011), live in non-metropolitan areas (Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007), or whose children with ASD have a more significant disability (Chiri & Warfield, 2012; Liptak et al., 2008; Shattuck et al., 2012; Shattuck et al., 2011). Children from minority, poor, and rural households are also less likely to obtain an early diagnosis of ASD from their medical provider (Liptak et al., 2008; Shattuck et al., 2009).

Little research has been conducted on healthcare access among adults with ASD (Bruder, Kerins, Mazzarella, Sims, & Stein, 2012). Existing evidence suggests, however, that healthcare disparities of adults with ASD mirror those of children with ASD. In one study, adults with ASD who could complete an online survey indicated the following: they were less satisfied with patient-provider communication; they had more unmet physical and mental health needs; they experienced lower levels of self-efficacy related to both general healthcare and the management of chronic conditions; they had lower rates of tetanus vaccinations and PAP smears; and they were more likely to use an emergency room than adults without ASD (Nicolaidis, Raymaker, Dern, Ashkenazy, & Baggs, 2012). The Centers for Disease Control and Prevention (2014) report that only 50% of adults with disabilities participate in any aerobic exercise and that this might contribute to rates of diabetes, heart disease, stroke and cancer that are about three times higher than adults without disabilities. There is also some evidence that adults with ASD, in particular, have higher levels of risk factors such as obesity and physical inactivity (Gerhardt, 2009; Iezzoni, 2011). A recent review of insurance claims of over 23,000 adults, of whom 2,108 had autism, confirms that those with ASD are more likely to experience diabetes, high cholesterol, heart failure, hypertension and obesity than those without ASD (Croen, Zerbo, Qian, & Massolo, 2014). Croen et al. suggest that the high rate for these conditions might be due to a lack of preventative care. This research indicates that other risk factors such as smoking or drinking occur at a lower level than for other adults and that cancer rates are actually lower than for the general population. Overall, however, mortality rates are significantly higher for adults with ASD than for the population in general, possibly due to difficulties faced by individuals with ASD in obtaining appropriate healthcare (Bilder et al., 2013; Emerson et al., 2011).

As with healthcare for adults with ASD, the transition of youth with ASD from pediatric to adult medical care has received little attention by researchers. There is a general consensus that healthcare transition services for youth with special health care needs (SHCN) are essential (Maternal and Child Health Bureau, 2003; Watson, Parr, Joyce, May, & Le Couteur, 2011). Such services are often minimal and difficult to acquire, making the transition from pediatric to adult medical care potentially anxiety provoking and challenging (Watson, Parr, Joyce, May & Le Couteur, 2011). Because comorbid conditions are common for children with ASD, it is especially important that transition planning for adolescents and young adults address healthcare access and support for living healthy lifestyles (Cheak-Zamora, Yang, Farmer, & Clark, 2013; Croen, Zerbo, Qian, & Massolo; 2014). Surprisingly, Cheak-Zamora et al. report that only 21% of youth with ASD have healthcare transition plans, about half the rate for youth with SHCN in general. Perhaps equally surprising, these researchers report that having multiple health conditions actually reduces the odds of a youth with ASD having a healthcare transition plan by 81%. The failure to connect youth with ASD to adult medical care providers can result in pediatricians continuing to provide care to adults with ASD well into their second, third or fourth decade of life (Johnson & Woll, 2003).

Successful healthcare transition is also important for youth with ASD because it is linked to success in other areas of adult life. The presence of comorbid medical conditions, for example, can negatively affect employment and community living outcomes for adults with ASD (Marriage, Wolverton, & Marriage, 2009). Likewise, the inability to find meaningful employment can have a negative effect on both physical and mental health (Garcia-Villamisar, Wehman, & Navarro, 2002; Holmes & Chaffee, 2007). Youth with ASD usually require services in addition to those addressing acute medical conditions, including mental health services, speech therapy, educational, employment and recreational supports, and community and social services, all of which should be integrated within a comprehensive plan for improving transition outcomes (Hendricks & Wehman, 2009). In addition to the individual with ASD and his family members/caregivers, transition planning addressing healthcare issues should include pediatricians, adult practitioners and other medical providers who are properly trained in understanding the diagnosis, multiple needs, and unique characteristics of the person with ASD (Cheak-Zamora et al., 2013; Patel & O’Hare, 2010). Such collaboration may require extensive education, capacity building, and collaboration among family members, caregivers, medical providers, community members, and young people with ASD (Stewart, 2009). Croen, Zerbo, Qian, & Massolo (2014) contend that medical providers need additional training related to the transition of youth with ASD from pediatric to adult care. Unfortunately, the Individuals with Disabilities Education Act 2004 (IDEA) makes no specific provision for healthcare transition, thus omitting an important component of adult life in the school-based transition planning process in which linkages among systems are supposed to be addressed.

Individuals with ASD have the same general healthcare needs as others, including the need for routine care, preventative care, and screenings (Bruder et al., 2012). At the same time, they often require additional care because of a high rate of comorbid medical and psychological diagnoses (Bruder et al., 2012; Gurney et al., 2006; Myers & Johnson, 2007). Estimates of the prevalence of other medical conditions vary widely. Intellectual disability (ID), for example, has been said to occur at a rate of between 18% and 70% (Matson & Shoemaker, 2009; Peacock, Amendah, Ouyang, & Grosse, 2012). Estimates for other conditions range from 9% to 70% for gastrointestinal problems (Buie et al., 2010; Myers & Johnson, 2007; Parellada et al., 2011), 6% to 39% for epilepsy (Myers & Johnson, 2007), and 39% to 80% for sleep disorders (Parellada et al., 2011; Sivertsen, Posserud, Gillberg, Lundervold, & Hysing, 2012). Additionally, as many as 70% of children with ASD have at least one comorbid mental health diagnosis, with 46% of interviewed parents communicating that they have pursued mental health services in a 12-month period (Narendorf, Shattuck, & Sterzing, 2011), although there is some evidence indicating that mental health issues are actually under-diagnosed in this population (Levy et al., 2010). There also appears to be a very high rate of psychiatric comorbidity among adults with ASD (Croen, Zerbo, Qian, & Massolo, 2014; Joshi et al., 2010). The cost of treating comorbid medical and psychiatric conditions can place a heavy financial burden on families (Kogan et al., 2008; Liptak et al., 2006). Ironically, the focus by medical providers on the healthcare needs of individuals related to their disability may result in insufficient time being devoted to standard medical care, screening, and preventative care (J. L. Johnson & Woll, 2003).

Medical providers clearly have an important role to play throughout the lifetimes of individuals with ASD. Pediatricians and other primary care providers are often who families go to first with their concerns about their child’s development, making them key in early recognition and screening for ASD as well as in making referrals for specialty services and early intervention (Hyman & Johnson, 2012; Jensen & Spannagel, 2011). Access to early intervention is especially important because of its strong association between intensive and early interventions and the amelioration of symptoms and long-term developmental outcomes (Dawson et al., 2012; Lord, Risi, DiLavore, Schulman, & Thurm, 2006). Achieving those positive outcomes is dependent, of course, on early identification through the widespread use of effective screening and diagnostic practices. Widespread screening and early identification may take on greater value given new evidence that experienced professionals can reliably diagnose ASD by age two and can sometimes identify ASD at 18 months or younger (Lord et al., 2006). The American Academy of Pediatrics (AAP) recommends that all children be screened for developmental delays and disabilities during regular well-child visits at 9, 18 and 24 months (C. P. Johnson & Myers, 2007). In addition, the AAP recommends all children be screened for ASDs during regular well-child doctor visits at 18 and 24 months.

Primary care providers for young children with ASD may be required to perform a number of other roles that go beyond screening and early identification or diagnosis, including referrals for genetic counseling, educating families and caregivers, and ongoing care and management (Myers & Johnson, 2007). As youth with ASD transition into adult life and age, physicians can play an important role in helping them attain greater functional independence, an improved quality of life, and participate more fully in their own healthcare (Bruder et al., 2012). Physicians may also play an important role in helping identify the role of underlying medical conditions or pain in explaining behavior that might otherwise be considered simply a manifestation of ASD. Problem behavior, for example, can often be a symptom of pain, especially among individuals who are limited in their ability to communicate about their symptoms in conventional ways (Carr & Owen-DeSchryver, 2007; Charlot et al., 2011). The relationship between co-existing medical conditions and the intensity of behavior usually associated with ASD is a complex one. In one recent study, researchers reported correlations among anxiety, gastrointestinal issues, and sensory over-responsivity (Mazurek et al., 2013). Sorting out the relationships among medical issues and ASD-related behavior for any individual may require the involvement of multiple medical and allied health professionals as well as coordination of the services delivered by those providers.

Obstacles to Effective Medical Care

There are a number of other factors that can act as obstacles to effective healthcare for individuals with ASD in addition to income, ethnicity, and geography. These can be divided into several broad categories: (1) individual characteristics usually associated with ASD; (2) lack of knowledge or skill by medical practitioners; (3) lack of access to comprehensive healthcare supports or a medical home; and (4) lack of access to health insurance for needed supports and services.

Individual characteristics usually associated with ASD. Absent the provision of effective accommodations and supports, a number of broad characteristics associated with the core features of ASD can serve as obstacles both to routine screening and preventive medical care. Verbal and nonverbal communication difficulties, for example, can make it difficult for a patient to talk about her symptoms or participate actively in making decisions about her own care (Buie et al., 2010; J. Murphy, 2006; Paradella et al., 2011; Scarpinato et al., 2010). Communication difficulties can also make individuals more dependent upon care providers, who may or may not have an adequate understanding of the individual's healthcare needs and history (Murphy, 2006). Even those who can communicate fairly effectively may struggle to communicate subjective symptoms or experiences (Parellada, Boada, Moreno, Llorente, Romo, Muela, and Arango, 2011), indicate they are in pain, (Buie, Fuchs, Glenn Furuta, Kooros, et al., 2010), communicate vital information in emergency situations (Scarpinato, Bradley, Kurbjun, Bateman, Holtzer, & Ely, 2010), or participate fully in their own health care (Darves, 2008). Difficulties with receptive language can make it difficult for individuals with ASD to independently follow healthcare provider instructions. Research suggests that individuals with ASD experience high rates of social anxiety (White, Kreiser, Pugliese, & Scarpa, 2012) which could make it even more difficult to communicate effectively with healthcare providers or to tolerate waiting rooms with large numbers of patients. Many individuals with ASD react badly to specific sensory stimuli, making it difficult, if not impossible, for them to enter some physical environments (Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). Individuals with

ASD also experience high rates of unusual fears and phobias including those related to specific situations and medical treatment (Canavera, Maccubbin, & Taga, 2005).

Lack of knowledge or skill by medical practitioners. Family members of persons with ASD have identified a number of barriers to effective healthcare. Many have reported that their doctor does not spend enough time with them or that they do not listen to their concerns (Brachow, Ness, McPheeters, & Gurney, 2007; Magaña et al., 2012). Parents have also expressed concerns about their primary care provider's (PCP) knowledge and skills related to working with children with ASD, often resulting in limited use of their PCP for issues related to autism (Carbone, Behl, Azor, & Murphy, 2010). Carbone et al. reported that many parents had negative experiences with their PCP although those who perceive their care as being "family-centered" are more likely to be satisfied with the physician's ability to meet the ASD needs of their child. Families report that PCPs may also ignore issues related to general health promotion because of their focus on the multiple medical problems and acute conditions faced by patients with disabilities (Johnson & Woll, 2003).

Families often feel that their physicians are slow in responding to initial family concerns about their child's development (Carbone et al., 2010; Jensen and Spannagel, 2011). This can lead to a delay in diagnosis and access to early intervention. Indeed, large workloads, time constraints, and inadequate reimbursement can also make it difficult for pediatricians and primary care providers to administer screening tools or assessments that may be necessary to obtain an early diagnosis (Hyman and Johnson, 2012). Early identification and intervention may also be delayed when primary care physicians are uncomfortable providing families with an ASD diagnosis (Jensen & Spannagel, 2011).

Families and physicians appear to have differing views about the skills of primary care providers in caring for patients with ASD. In one study, Carbone, et al. (2012) found that while doctors rated themselves as "good" in 10 of 17 areas of ASD-specific needs, parents rated these same doctors as "good" in only 3 of the same 17 areas. Physicians, themselves, have often recognized that there are significant barriers to providing effective healthcare to this population including time restrictions, a lack of expertise about ASD, and a lack of training and resources (Carbone et al., 2010; Clayton, Chester, Mildon, & Matthews, 2008; Johnson & Carter, 2011; Lajonchere et al., 2012; Parellada et al., 2011). In another study, physicians responding to a survey indicated that their training related to the care of adults with an ASD was inadequate and that they had an interest in obtaining additional training (Bruder et al., 2012). Researchers found in one study that some physicians continued to hold outdated beliefs about ASD (Heidgerken, Geffken, Modi, & Frakey, 2005). While many pediatricians and allied health professionals have received training to better understand the needs of children with disabilities and their families through LEND (Leadership Education in Neurodevelopmental and Related Disabilities) and similar programs, the same is not true for adult health and medical care providers (J. L. Johnson & Woll, 2003). Pediatricians have indicated a desire to improve services for children with ASD, but like physicians generally, they identify a lack of time, education, training and resources as barriers to improving treatment for children with ASD (Carbone et al., 2010; Golnik, 2009).

There may be steps that primary care providers can take to reduce healthcare disparities for individuals with ASD that are unrelated to time or financial limitations. Physicians, for example, may have to change their strategies for eliciting information from and for advising their patients with ASD regarding their healthcare (Mandell, 2013; Murphy, 2006; Nicolaidis et al., 2012). Mandell (2013) says, in this regard, that primary care providers should relieve patients with ASD of being solely responsible for effective communication. Parish et al. (2012) report that factors related to the quality of provider/patient interaction can mediate the negative relationship between utilization and access to healthcare by children with ASD who were Latino. These factors include time spent with the child, cultural sensitivity, and helping the parent feel like a partner in their child’s healthcare.

Lack of access to comprehensive healthcare supports or a medical home. A number of researchers have identified the need for more comprehensive and coordinated care for people with ASD (N. A. Murphy, Carbone, & The Council on Children with Disabilities, 2011; Myers, Johnson, & The Council on Children with Disabilities, 2007). Without coordinated care, people with ASD can experience redundant care, medication interactions, duplicate testing, delayed information transfer between practitioners in emergency settings, and higher out-of-pocket costs for families (Porterfield & DeRigne, 2011; Shattuck et al., 2012). Unfortunately, children with ASD are less likely than those with other special health care needs to receive such comprehensive care (Carbone et al., 2010; Carbone et al., 2012; Chiri & Warfield, 2012; Golnik, Maccabee-Ryaboy, Scal, Wey, & Gaillard, 2012; Hyman & Johnson, 2012). The most fully researched model for providing comprehensive care to children with disabilities, including ASD, is the medical home (French & Scholle, 2010; Kuhlthau et al., 2011; Waisman Center, 2009), described as a model of delivering primary medical care that is "accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective" (American Academy of Pediatrics, 2002). According to the Waisman Center (2009, p. 7), "it is especially important for children with ASD and other special health care needs requiring a wider array of specialized community services and supports than typically developing children" to have access to a medical home. The medical home has been shown to have a number of benefits for children with ASD including improved health, fewer unmet medical needs, greater satisfaction with healthcare, and a reduced financial burden on families (Golnik et al., 2012; Kogan et al., 2008). Despite the apparent benefits of a medical home, children with ASD are less likely to access a medical home than those with other special health care needs or other developmental disabilities (Brachow et al., 2007; Krauss et al., 2003). There is little research on the availability of the medical home model for adults with ASD (Bruder, Kerins, Mazzarella, Sims, & Stein, 2012). Hyman and Johnson (2012) identify a number of challenges to the provision of a medical home for persons with ASD of any age:

> [L]ack of time in a standard office visit for assessment and counseling; lack of capacity for care coordination due to the need for additional time and expense; insufficient expertise in general and in specific with behavioral management; awareness of community resources; inadequate staffing for screening and care coordination; lack of reimbursement; lack of practice guidelines; and skepticism

> by families of traditional medicine or vaccines, in addition to encountering frequent use of complementary and alternative medicine by families. (p. 1158)

Lack of access to health insurance for needed supports and services. A child's access to appropriate healthcare and services can be impacted by his family's access to medical insurance. Surprisingly, almost 98% of children with autism in the U.S. have current healthcare coverage, including 31.5% who had access to public insurance, i.e., Medicaid/state children's health insurance program (SCHIP); 47.5% who had access to private insurance, 15.2% who had both public and private insurance, and 2.5% who had other comprehensive insurance (Chiri & Warfield, 2012; Liptak, Benzoni, Mruzek, Nolan, Thingvoll, Wade & Fryer, 2008; Wang, Mandell, Lawer, Cidav, & Leslie, 2013). SCHIP and other federal and state efforts have increased opportunities for children with ASD to have access to the care they need. Increased coverage and financing alone may be insufficient, however, because families often have trouble finding appropriate services (Chiri & Warfield, 2012). Furthermore, private insurance plans have typically excluded the coverage of most ASD-specific treatments resulting in privately insured children with ASD often not receiving needed ASD-specific services (Wang et al., 2013). Fortunately, most state Medicaid programs provide healthcare services to eligible children with ASD through the Medicaid Home and Community-Based Services (HCBS) Waiver program. Wang et al. (2013) concluded that overall, children with ASD in Medicaid programs actually receive more ASD-specific and healthcare services than those with private insurance.

Systemic Healthcare Improvement Activities for Individuals with ASD in Maine

Maine has taken a number of steps to improve healthcare for individuals with ASD in recent years through its Pervasive Developmental Disorders (PDD) Systems Change Initiative, coordinated and staffed by the Maine Developmental Disabilities Council and funded by the Maine Department of Health and Human Services, Children with Special Health Care Needs Program, to improve the healthcare of Maine citizens with ASD (DHHS, 2013). In addition to examining existing systemic issues, the Initiative has worked to improve screening and early identification practices and healthcare for individuals with ASD in Maine. Activities have included the following: (1) providing six medical practices with the opportunity to field-test screening protocols for ASD for more than 3,500 children; (2) designing and distributing guidance for quick, easy, and efficient Primary Care Provider (PCP) referrals to diagnosticians and early intervention professionals in collaboration with the Maine Center for Disease Control & Prevention; (3) improving effective and coordinated healthcare through a three-year Autism Implementation Grant (AIG); (4) AIG-funded training for Head Start, Home Visiting, and Public Health Nursing Programs on using the Modified Checklist for Autism in Toddlers (M-CHAT) and on formal protocols to support families and share information with the child's PCP, as well as training to the Maine Women, Infants and Children (WIC) program on the first signs of autism; (5) building on the work of the Child Health Quality Improvement Grant through AIG to support two medical practice pilots to coordinate care within the medical home model; (6) participating in the Improve Health Outcomes for Medicaid Eligible Children (IHOC) program with the state of Vermont which is intended to promote the use of quality measures and information technology to improve health outcomes for Medicaid eligible children, thereby improving timely access to quality care; and (7) promoting the integration and support for improved communication and coordination of the medical home pilots by developing a comprehensive data system to facilitate prompt screening, diagnosis, evaluation and treatment for children with ASD. In addition, Maine enacted a public law, Chapter 635 (LD-1198), to provide coverage for the diagnosis and treatment of ASD for all children under the age of six. These steps undoubtedly are having a positive effect on access to healthcare by individuals with ASD in Maine as well as the quality of care they receive.

Method

Following a comprehensive literature review on healthcare disparities for children with ASD, the Maine Developmental Disabilities Council, Turtle Cove Consulting and the Altarum Institute collaborated on the development of two structured interview surveys: one to be administered to parents or guardians of children with ASD; and a second to be administered to adults with ASD or their guardians. A number of survey items were adapted from *The*

National Survey of Children with Special Healthcare Needs (Health Resources and Services Administration, 2014) and the *2007 Survey of Adult Transition and Health* (Maternal and Child Health Bureau, 2007). In 2012, the third author, Margaret Carr from Turtle Cove Consulting, in collaboration with the Maine Developmental Disabilities Council, field-tested the surveys with several families of both children with ASD and adults with ASD. Carr and Nancy Cronin, the PDD Systems Change Coordinator at the Maine Developmental Disabilities Council, revised the surveys based on the test results. For example, questions related to healthcare transition for children 14 years of age or over were added to the children's survey.

The final surveys contained 83 questions for parents or guardians of children with ASD and 71 questions for adults with ASD or their guardians. Survey items included yes/no questions and 4-choice Likert-style questions with opportunities to comment or elaborate on answers. Topics addressed in both surveys included the following: demographic information; ASD-related diagnosis; additional diagnoses; overall quality of health; regular contact with Primary Care Providers (PCPs); responsiveness of PCP to calls or questions; the quality of the communication with the PCP; routine care and screening items completed; sleep issues; gastrointestinal issues; behavior issues; PCP responses to medical and behavior issues; quality of healthcare; wellness topics discussed with PCP; use of alternative and complementary healthcare; PCP understanding of ASD; PCP understanding of individual needs; difficulty finding PCPs and specialists; and support for patients taking responsibility. In addition, adults with ASD or their guardians were asked whether their PCP communicated with them about topics related to physical health, mental health, sexuality, and wellness. Parents or guardians of children with ASD were asked a different set of questions regarding the PCP's communication about topics related to wellness, safety and relationships. They were also asked whether the PCP ever talked with them about their child's strengths, interests, capabilities, and likes. Parents or guardians of children aged 14 or older were asked about the PCP's support for the child's transition to adult healthcare.

Many of the survey questions contained multiple items. For example, when respondents were asked about behavior issues, they were asked to indicate whether specific behaviors occurred within five different categories of behavior (e.g., aggression, self-injurious behavior). Similarly, parents or guardians of children were asked whether the PCP had spoken with their child about a number of topics related to safety, wellness, and relationships. Thus, parents or guardians of children were asked to respond to as many as 208 different items, including demographic information. Adults with ASD or their guardians were asked to respond to as many as 214 different items. A number of the questions were conditional. For example, respondents for both children and adults were asked if they had phoned their doctor's office after-hours during the previous 12 months. If they indicated "yes," they were asked to indicate how the PCP responded. If they indicated "no," that question was skipped.

Sources of Data

Survey participants were recruited through flyers sent to contacts on the mailing lists of several parent advocacy and other disability-related organizations in Maine. The flyers were also posted on several websites. Adults with ASD, their guardians or the parents or guardians of children with ASD who were interested in participating in the survey were instructed to contact the Maine Developmental Disabilities Council. Coauthor Carr contacted those who wished to participate and scheduled the interviews.

Carr conducted all of the interviews between October 2012 and February 2013. The interviews usually lasted about two hours. However, in some instances, the length of time varied, ranging from approximately one hour for an interview with an adult with ASD, to over four hours for a parent who had more than one child with an ASD. Parents or guardians were interviewed about the healthcare of their child[ren] with ASD. All but five of the parents or guardians of children with ASD participated in face-to-face interviews. Those five families participated by phone due to scheduling issues. Two adults with ASD participated by phone because they felt uncomfortable meeting face-to-face. In several cases, parents or guardians reported on the healthcare of more than one child with ASD. In cases where the results were identical for more than one child, the results for one of the children were discarded. Survey respondents received a $20 Walmart, Hannaford, or Target gift card for their participation.

Statistical Treatment

Because the surveys contained both quantitative data and qualitative data (from the comments section for most questions), the data was analyzed using a mixed-methods explanatory design (Cresswell & Plano-Clark, 2011). Consistent with this approach, the quantitative data and qualitative data from the "comments" section of the interviews were analyzed separately. This data was then used to elaborate, explain, and in some cases, expand upon some of the quantitative results.

Demographic data was summarized for both the child and adult samples, including mean age, gender, diagnosis, the number of additional diagnoses and the population density of the Maine county in which the child or adult with ASD resided. The frequencies, percentage and standard deviations were reported for ratings of overall health, overall healthcare and whether they ever had difficulty finding a PCP or specialist.

Composite variables were created for several topics such as sleep, GI issues, behavior, and seizures. The number of respondents with specific concerns were reported along with the mean number of topics identified within each category, as well as the standard deviation. Composite scores combining answers to several related questions were calculated for each person in several areas of inquiry: wellness; physical health; mental health, physical health and sexuality; understanding individual needs; PCP and patient communication; and overall responsiveness. Some questions included both yes/no responses and Likert-style responses. In calculating these composite scores, each *yes* response was assigned a *1* and each *no* response a *0*. For Likert-style questions, the following scores were assigned: *always = 1*; *usually = 0.67*; *sometimes = 0.33*; and *never = 0*. Individual composite scores were calculated in each area by summing the scores for each of the responses and dividing by the number of questions answered. Thus, composite scores in each area could vary from 0 to 1. In addition, composite scores for routine care and screening were calculated by reporting the percentage of procedures completed for each individual.

Multivariate simultaneous linear regression was used to determine if five of the patient-related characteristics predicted several healthcare outcomes. The independent variables included the person's age, whether they had a primary diagnosis of autism, the number of additional diagnoses they had, the population density of the Maine county in which they resided, the number of behavior issues (not including those in the self-stimulation category), and their rating of their overall health. Dependent variables included ratings of the quality of healthcare, number of routine care and screening items addressed by the PCP, difficulty finding a PCP, difficulty finding medical specialists, and wellness issues addressed by the PCP. Separate regression analyses were conducted for child and adult samples. The same procedure was also used to examine whether four variables related to characteristics of the PCP predicted healthcare outcomes. Again the child and adult data were analyzed separately. The independent variables included the PCP's understanding of ASD, the PCP's understanding of the patient's individual needs, the PCP communication composite score, and the PCP responsiveness composite score. Dependent variables for both groups included overall quality of healthcare, the number of routine care and screening items completed, and physical health, mental health, and sexuality items discussed with the patient (adults only).

Most of the structured survey questions contained a "comment" section in which respondents were given the opportunity to provide an open-ended unstructured response. Three of the researchers coded those comments using open coding (Denzin & Lincoln, 2008). The researchers independently reviewed the full set of surveys and developed codes for categorizing responses based on content similarity. Researchers then met to compare coding schemes and to reach a consensus on a single list of coding categories. The themes were summarized and used, when appropriate, to explain and elaborate on some of the quantitative data.

Results

Participant Characteristics

For the 85 participating children; an adult, usually the parent, completed the interviews. Eight of the 22 participating adults answered the interview questions themselves. In one case, an adult and his mother completed the interview together. For the remaining adults, a parent or guardian answered the interview questions. Demographic information about the child and adult samples can be found in Table 1 - *Participant Characteristics*. The population density of the Maine county in which the children and adults with ASD resided is shown in Table 2 - *Population Density of Maine County of Residence*.

Table 1

Participant Characteristics

Samples	Children (N=85)	Adults (N=22)
Gender	Males 66 Females 17	Males 15 Females 7
Diagnosis	Autism - 43 PDD-NOS - 15 AS or HFA - 23 ASD - 3	Autism - 12 PDD-NOS - 2 AS or HFA - 8
Mean Age	10.06 (SD=3.88)	29.68 (SD=11.51)

Table 2

Population Density of Maine County of Residence (Number per Square Mile)

4-30		31-99		100-199		200-340	
Children	Adults	Children	Adults	Children	Adults	Children	Adults
17	5	16	3	15	8	36	3

Diagnosis

Parents or guardians of children with ASD who completed the interviews reported that 43 of the children had a primary diagnosis of autism, 23 had Asperger Syndrome or High Functioning Autism (HFA), 15 had Pervasive Developmental Disorder, not otherwise specified (PDD-NOS), 3 were described as having an ASD, and 1 indicated, "other."

Adults with ASD or their guardians who completed the interviews reported that 12 of the adults had a primary diagnosis of autism, 8 had Asperger Syndrome or HFA, and 2 had PDD-NOS. A higher percentage of the adult respondents were reported to have a diagnosis of Asperger

Syndrome or HFA than the child sample (36% and 27% respectively). The percentage reporting a diagnosis of autism was much more similar in the two samples, with 50% of the children reported to have a diagnosis of autism and 55% of adults. The mean age at which parents or guardians reported their child received an ASD diagnosis was 5.01 (SD=3.01) and the median age was 4.0. The mean age of diagnosis for adults was 15.33 (SD=15.38) and the median was 8.5. Because all the children in the survey were, by definition, diagnosed as children, a more appropriate comparison may be between children and adults who were diagnosed as children. When adults who were diagnosed as adults were excluded, the mean age of diagnosis was 7.5.

A number of parents or guardians of children with ASD indicated in the comments section that they had received multiple diagnoses. In one case, the parent stated that a neuropsychological evaluator was not able to pinpoint a diagnosis and that her child had as many as six or seven different diagnoses. Other parents and guardians also reported changing diagnoses. One parent, for example, indicated that her son was "graduating from an autism diagnosis" and was being re-diagnosed with Asperger Syndrome. In another case, the parent reported a change from PDD-NOS to autism.

Parents and guardians of children with ASD were also asked whether their child had been diagnosed with additional medical conditions. Children were reported to have a mean of 1.26 additional diagnoses, with four parents indicating their child had four or more additional diagnoses. These included Intellectual Disability (ID), Obsessive Compulsive Disorder (OCD), Attention Deficit Hyperactivity Disorder (ADHD), Anxiety, Bipolar Disorder, Depression, Epilepsy, Mood Disorder, Tourette Syndrome, Language Disorder, Chromosomal Disorders including Down Syndrome, Sensory Processing Disorders, Ataxia and Nystagmus, Fetal Alcohol Syndrome, Asthma, and Chronic Ear Infections.

Adults with ASD or their guardians were also asked whether the person with ASD had been diagnosed with additional medical conditions. Adults were reported to have a mean of 1.85 additional diagnoses, with two adults reporting to have four or more. Additional diagnoses for adults included ADHD, Celiac Disease, Post-Traumatic Stress Disorder (PTSD), Depression and Anxiety, Rett Syndrome, Tourette Syndrome, OCD, Asthma, Hypothyroidism, Allergies, Recurrent Torticollis, Down Syndrome, Intellectual Disability, Epilepsy, Traumatic Brain Injury (TBI) in infancy, and Scoliosis.

Quality of Health

High percentages of respondents, for both children and adults, indicated that the person with ASD experienced good or excellent health (85% for adults and 83% for children). Thirty-three percent of the adults and 35% of the children with ASD were described as having excellent health. Only one adult and two children were reported to have poor health. One adult did not answer the question. See Table 3 - *Quality of Health*. Eighty-six percent of adults with ASD were taking prescription medication.

Parents or guardians of children reported a number of medical concerns about their children in the comments section. These included obesity, allergies, asthma, lack of exercise, lack of mental health care, medication management, scoliosis, and bleeding ulcers. The guardian of an adult reported that it was difficult to evaluate his overall quality of health because he seldom indicated that he was sick or in pain.

Table 3

Quality of Health

Overall Health	Children (N=85) N (%)	Adults (N=21) N (%)
Excellent	30 (35)	7 (33)
Good	41 (48)	11 (52)
Fair	12 (14)	2 (10)
Poor	2 (2)	1 (5)

Sleep Issues

Eighty-seven percent of the children with ASD and 86% of the adults with ASD were reported to have at least one sleep issue. The mean number of sleep issues for children was

2.28 and 2.27 for adults. The most common issues were difficulty getting to sleep (63% of children and 59% of adults) and insomnia (54% of children and 40% of adults). See Table 4 - *Sleep Issues*. The most common response by PCPs was to prescribe medication (for 50% of the children and 27% of the adults with ASD who reported sleep issues). Forty-six percent of the adults and 58% of the children who had reported a sleep issue to their PCP were prescribed medication, referred to another physician, or referred for additional testing. Eighteen percent of the parents or guardians of children with sleep issues reported being told by their PCP that "nothing could be done." See Table 5 - *PCP Responses to Sleep Issues*.

Sleep issues appeared to be a major concern for many parents and guardians. In the comments section, several parents talked about the stress of having a child who has significant sleep issues that included getting up in the middle of the night, sleeping only a few hours, waking very early in the morning or going days without sleep. Parents attributed their child[ren]'s sleep issues to a number of causes including "being afraid to be alone," "having a brain that does not slow down," and "night terrors." Some parents reported that a number of medications or supplements had been effective including Abilify®, Chlonidine, Melatonin, Benadryl®, Zoloft® and "prescription sleep aids." Several respondents reported that they had difficulty obtaining further diagnostic evaluations related to sleep. Obstacles included resistance from MaineCare, children being too young for sleep studies, or patient difficulty participating in a sleep study. In one case, a youth had been prescribed a continuous positive airway pressure (CPAP) machine, but refused to use it.

Table 4

Sleep Issues

Sleep Issue	**Children (N=85)** *n* **(%)**	**Adults (N=22)** *n* **(%)**
Insomnia	46 (54)	9 (40)
Difficulty Getting to Sleep	54 (63)	13 (59)
Difficulty Waking Up	29 (34)	9 (40)
Sleeping Too Much	18 (21)	6 (27)

Sleep Issue	**Children (N=85)** *n* **(%)**	**Adults (N=22)** *n* **(%)**
Different Sleep Patterns	34 (40)	5 (23)
Other	14 (16.5)	7 (32)
Average number of sleep issues for individuals	**2.28**	**2.27**
Number reporting at least one sleep issue	74 (87)	19 (86)
Number of those with sleep issues who discussed with doctors	59 (68)	13 (59)

Table 5

PCP Responses to Sleep Issues

PCP Response to Sleep Issues	**Children (N=74)** *n* (%)	**Adults (N=19)** *n* (%)
Other Diagnostic Evaluations	12 (16)	2 (10)
Prescribed Medication	37 (50)	6 (27)
Suggested Counseling	7 (9)	0 (0)
Recommended Behavior Assessments	2 (3)	0 (0)
Suggested you find another doctor/ specialist	5 (6)	0 (0)
Asked for your opinion about what should happen	20 (27)	2 (10)
Indicated that nothing could be done (just part of diagnosis)	13 (18)	1 (5)
Other	8 (11)	1 (5)
Have Received Sleep Apnea Test	14 (19)	3 (14)
Number reporting sleep issues who were prescribed medication, referred to a specialist or received recommendations for further assessments	43 (58)	10 (46)

Gastrointestinal (GI) Issues

More than 80% of all respondents reported at least one GI issue. The mean number of GI issues reported was 2.30 for children and 3.40 for adults. The most common GI issues reported for children were constipation (58%) and food intolerance (46%). The most common GI issues reported for adults were food intolerance (54%), limited food choices (54%), abdominal pain and "other" GI issues (36%), diarrhea and bloating (32%), and heartburn (27%). See Table 6 - *Gastrointestinal Issues*.

Table 6

Gastrointestinal Issues

Gastrointestinal (GI) Issue	**Children (N=85) *n* (%)**	**Adults (N=22) *n* (%)**
Constipation	49 (58)	6 (28)
Food allergy	21 (25)	9 (41)
Food intolerance	39 (46)	12 (54)
Vomiting	20 (24)	2 (9)
Diarrhea	16 (19)	7 (32)
Heartburn	19 (23)	6 (27)
GERD	11 (19)	5 (23)
Abdominal pain	19 (23)	8 (36)
Bloating	24 (28)	7 (32)
Other	3 (4)	8 (36)
Total with at least one GI issue	**68 (80.0)**	**19 (86.4)**
Mean number of GI issues	**2.30 (SD=1.78)**	**3.40 (SD=2.19)**
Number with GI issues who talked to doctor about them	56 (82.3)	13 (68.4)

A large number of the respondents also reported problems related to diet including limited food choices (68% of children and 54% of adults), poor food choices (67% of children and 64% of adults), and difficulties with sensory characteristics such as the textures, smells or colors of some foods (58% of children and 64% of adults). Many of the respondents reported that their child or ward had aversions to some foods, the most common being vegetables.

In the series of questions related to GI issues, respondents were also asked about urinary tract infections (UTI). Ten parents (12%) reported that their child had UTIs and 3 adult respondents (14%) reported having them.

Survey respondents indicated that PCPs followed up in some way with reported GI issues for children 30% of the time and for adults, 32% of the time. The most common response by PCPs for both groups was to prescribe medication. Respondents indicated in the comments section that a number of medications or supplements were used to address GI issues. These included Mirilax®, Senokot® Lactaid®, antacids, Zantac®, Prevacid®, “homeopathic drops for candida,” stool softeners, and probiotics. In addition, several individuals were on special diets including gluten-free/casein-free, low-carb, and high-fiber diets. In their comments, several parents expressed frustration in their attempts to improve their child[ren]’s diet. Two parents also expressed frustration with what they felt was their PCP’s naive recommendation to simply change their child’s diet to treat the GI issue. See Table 7 - *PCP Responses to GI Issues.*

Table 7

PCP Responses to GI Issues

PCP Response to GI Issues	**Children with a GI Issue (N=68)** *n* (%)	**Adults with a GI Issue (N=19)** *n* (%)
Talked with PCP about GI Issues	65 (96)	14 (74)
X-rays	6 (9)	0 (0)
Blood work	6 (9)	0 (0)
MRI or CAT Scan	2 (3)	1 (5)
Other diagnostic evaluations	16 (25)	1 (5)
Prescribed medication	26 (40)	4 (21)
Referral to another doctor	4 (6)	0 (0)
Asked your opinion	17 (26)	1 (5)
Indicated that nothing could be done (just part of diagnosis)	11 (17)	0 (0)
Other	5 (8)	3 (16)
Total with at least one follow-up	21 (30)	6 (32)

Seizures

Thirty-two percent of adult respondents indicated that they had experienced at least one seizure and 8% of the parents reported their child[ren] had experienced at least one seizure. Furthermore, 9% of adult respondents and 17% of parents or guardians of children reported they were unsure if a seizure had been experienced. The most common issues related to seizures discussed with PCPs for both adults and children included the circumstances surrounding the seizure, length of seizure, how the person felt after the seizure and the intensity of the seizure. The mean number of types of responses for adults was 2.87, SD=2.53 and for children 2.20, SD=0.45. See Table 8 - *PCP Responses to Seizures*. Three of the adult respondents and three parents indicated that their PCP did not discuss any information related to their seizures because they discussed those issues with a neurologist.

The most common response by PCPs for children and adults with seizures were recommendations for blood work, electroencephalograms (EEGs), medication or magnetic resonance imaging (MRIs). Adult respondents indicated that medical providers shared test results related to seizures with them 71% of the time, but only 43% of parents of children with seizures indicated those results were shared. The mean number of recommendations for adults with seizures was 2.87, SD=1.96 and 2.17, SD=1.67 for children.

Table 8

PCP Responses to Seizures

PCPs Discussed:	**Children reported to experience seizures (N=7)** ***n*** **(%)**	**Adults reported to experience seizures (N=7)** ***n*** **(%)**
Length of seizure	5 (71)	4 (57)
Discussed any potential relationship to medications you/child are taking	1 (14)	1 (14)

PCPs Discussed:	**Children reported to experience seizures (N=7)** *n* **(%)**	**Adults reported to experience seizures (N=7)** *n* **(%)**
Intensity of seizure	4 (57)	4 (57)
Circumstances surrounding seizure	4 (57)	5 (71)
How do you feel/child act after the seizure	4 (57)	5 (71)
Family history of seizure	4 (57)	2 (29)
Other	0 (0)	1 (14)
Mean Number Topics Discussed with PCP	**2.20 (SD=0.45)**	**2.87 (SD=2.53)**
Recommended Tests		
Blood Work	2 (29)	5 (71)
EEG	4 (57)	5 (71)
Medication	4 (57)	5 (71)
MRI	2 (29)	4 (57)
Other Scan	2 (29)	1 (14)
Other	2 (29)	0 (0)
PCP Reviewed Tests with Patient, Parent, or Guardian	**3 (43)**	**5 (71)**
Mean Number of Recommended Tests	**2.17 (SD=1.67)**	**2.87 (SD=1.96)**

Behavior Issues

Over 98% of the respondents, parents or guardians of children with ASD, and adults with ASD or their guardians, reported at least one behavior issue. Only two respondents, one for the children and one for the adults, reported no behavior issues. The most common category of behavior reported was self-stimulatory behavior (94% of children and 86% of adults). The second most common category of behavior reported was damage to items (72% of children and 36% of adults). Over 70% of the children were reported to have aggressive behavior, but adults were reported to exhibit aggression at only about half that rate. Over 60% of children and 50% of the adults exhibited self-injurious behavior. And, 89% of the children and 91% of the adults with ASD were reported to have "other behavior," a category that included swearing, tantrums, getting angry, yelling or shouting, crying and other. See Table 9 - *Behavior Issues*.

Some of the behavior data in the survey was difficult to interpret because respondents were asked to indicate the number of times, and the time at which these behaviors most commonly occurred. Unfortunately, when multiple behavior issues were reported—as was the case in almost all instances—it was impossible to determine to which behaviors these frequencies and times referred. In several cases, parents or guardians indicated several frequencies but did not indicate to which behaviors they corresponded. Because of these problems, this data will not be reported.

Several qualitative responses, however, suggested that despite these problems, the reported frequencies might provide some insight into the behavior issues of children and adults with ASD. Several parents indicated that both the number of behaviors and their frequency of occurrence decreased with their child[ren]'s age. To test this assumption, we correlated age with the product of the *number of behaviors* and reported *frequency of behavior.* We found a strong negative correlation between age and this measure of the seriousness of behavior (t = -.320 (p=.003). In other words, the quantitative data supported the qualitative comments regarding the decline in the number and frequency of behaviors over time. In at least one instance, however, a parent reported in the comments section that behavior problems have become much more problematic with age, as her son has become bigger and stronger.

Survey respondents indicated that primary care providers responded to behavior issues in a number of ways. For children with behavior issues, the most common response by PCPs was to prescribe medication (46%). In contrast, the most common response for adults with behavior issues was the recommendation of a behavior assessment. Only 11% of the adults in this sample were prescribed medication in response to behavior problems. See Table 10 - *PCP Responses to Behavior Issues*.

A number of the respondents indicated in the comments section that they did not discuss behavior issues with their PCPs because they typically address those issues with other professionals or agencies. These other professionals or agencies included neuropsychiatrists,

psychiatrists, psychologists, occupational therapists, speech language pathologists, school personnel, staff at special purpose schools, and staff of community provider agencies. In one case, a child psychiatrist consulted with the PCP about medication. One of the parents reported that her General Practitioner felt that it was the responsibility of the residential support staff. Three parents of children reported that their PCPs said nothing could be done or that behavior issues were something that they should expect for a child with an ASD diagnosis. A number of parents indicated that they received behavior assessments through their in-home support agency, specialized schools, Applied Behavior Analyst, or a pediatric developmental behavior specialist. One parent reported that her PCP prescribed medication for ADHD for her child before the child was seen by a psychiatrist. Two parents felt that their PCPs simply did not know what to do and, as a result, offered no advice. Similarly, several of the parents felt that their PCPs did not do enough because they did not know what to do. As one parent reported, “They don’t know what to say so they don’t say anything and offer no advice at all.” Another parent criticized their PCP, suggesting that his advice of establishing a routine was “lame.”

In their comments, survey respondents identified a number of triggers or causes of difficult behavior. These included the following: frustration; lack of routine or structure; being pushed to perform tasks that are perceived to be too hard; sensory issues, including the need for “deep compression;” overstimulation; inability to communicate; not getting what s/he wants; need for attention; social anxiety; lack of sleep; unexpected transitions; PTSD; feeling that someone else is rude; puberty; constipation; and medication.

When asked if they had other medical concerns at the end of the interview, several parents expressed concerns about how their child[ren]’s behavior might be managed in the future. Many indicated that professionals needed to understand their child[ren]’s unique needs, idiosyncrasies, and communication in order to adequately address behavior issues. One parent believed that medical staff and other professionals would need to be “attuned” to her son to figure out what was underlying his behavior. She worried especially about people not understanding the “environmental causes” of his behavior - things such as the phase of the moon or the weather. A number of parents expressed concern about how behavior might be addressed if they were no longer able to manage their child's care or if their child moved into a congregate setting. The biggest concern of parents and guardians was the overuse of prescription medication. For example, one parent commented that medication should not be used to "fix or mask behaviors." Another was concerned about healthcare professionals "pushing meds" in times of crisis.

Table 9

Behavior Issues

Behavior Category	**Numbers of Responses Children *n* (%)**	**Number of Responses Adults *n* (%)**
Self-Injurious Behavior (SIB)		
Biting	18 (21.2)	5 (22.7)
Scratching	16 (18.8)	1 (4.5)
Hitting	26 (30.6)	4 (18.2)
Head Banging	24 (28.2)	4 (18.2)
Other Behavior	30 (35.3)	7 (31.8)
Total with at least one type of SIB	**57 (67.1)**	**11 (50)**
Mean Number of SIB Categories Per Person	**1.34 (SD=1.36)**	**0.95 (SD=1.32)**
Aggression/Hurting Others		
Biting	28 (32.9)	1 (4.5)
Hitting	48 (56.5)	3 (13.6)
Kicking	30 (35.3)	4 (18.2)
Scratching	30 (35.3)	2 (9.1)
Other	32 (37.6)	5 (22.7)
Total with at least one type of aggressive behavior	**61 (71.8)**	**8 (36.4)**
Mean Number of Types of Aggressive Behavior	**1.97 (SD=1.79)**	**0.59 (SD=1.21)**
Damaging Items		
Punching Walls	24 (28.2)	3 (13.6)
Throwing Things	52 (61.2)	2 (9.1)
Breaking Things	38 (44.7)	3 (13.6)
Other	14 (16.5)	5 (22.7)

Behavior Category	**Numbers of Responses Children *n* (%)**	**Number of Responses Adults *n* (%)**
Total with at least one type of property damaging behavior	**61 (71.8)**	**9 (36.4)**
Mean Number of Types of Property Damaging Behavior	**1.49 (SD=1.26)**	**0.59 (SD=.79)**
Self-Stimulation		
Rocking	28 (32.9)	7 (31.8)
Hand Flapping	29 (34.1)	2 (9.1)
Other Repetitive Motion	47 (55.3)	10 (45.5)
Other	64 (75.3)	17 (77.3)
Total number with at least one Self-Stimulation Behavior	**80 (94.1)**	**19 (86.4)**
Mean Number of Types of Self-Stimulatory Behavior	**1.98 (SD=1.02)**	**1.63 (SD=1.0)**
Other Behavior		
Swearing	29 (34.1)	4 (18.2)
Tantrums	64 (75.3)	11 (50)
Getting Angry	71 (83.5)	12 (54.5)
Yelling or Shouting	58 (68.2)	10 (45.5)
Crying	66 (77.6)	7 (31.8)
Other	33 (38.8)	9 (40.9)
Total number with at least one other behavior	**76 (89.4)**	**20 (90.9)**
Mean number of “other” behaviors	**3.7 (SD=2.35)**	**2.4 (SD=1.68)**
Mean Total Number of Reported Behaviors	**10.58 (SD=4.84)**	**6.27 (SD=4.71)**
Mean Total Behavior Minus Self-Stimulatory Behavior	**8.69 (SD=4.37)**	**4.64 (SD=4.23)**
Mean Number of Categories in Which Behavior Was Reported	**3.94 (SD=1.79**	**3.05 (SD=1.59)**
Mean Categories Minus Self-Stimulatory	**3.0 (SD=1.11)**	**2.18 (SD=1.43)**

Table 10

PCP Responses to Behavior Issues

PCP Responses to Behavior Issues	Children (N=81) *n* (%)	Adults (N=18) *n* (%)
Diagnostic Evaluation	11 (13.5)	3 (16.7)
Medication	37 (45.7)	2 (11.1)
Suggested Counseling	14 (17.3)	3 (16.7)
Behavior Assessments	10 (12.3)	6 (33.4)
Referral	5 (6.1)	0 (0)
Asked your opinion	18 (22.2)	2 (11.1)
Indicated nothing could be done	18 (22.2)	0 (0)
Other	22 (27.2)	4 (22.2)
No recommendations	15 (18.6)	0 (0)

Quality of Medical Care

Overall quality of care. When asked to rate the quality of care on a scale from 1 to 10, the mean score for parents and guardians of children was 7.4 (SD=1.79). Adult scores were slightly higher with a mean of 7.9 (SD=2.21). Ten parents rated the quality of their children's healthcare at 5 or below with one parent giving it a ranking of 1. Only one adult respondent rated their medical care at 5 or below. In that case, a guardian rated their ward's healthcare at 3.

A number of parents spoke very highly of their child's PCP in the comments section. For example, one parent described her son's doctor as one of his biggest advocates. Another parent described her child's medical care as "exquisite." The parent of an adult with ASD indicated that she was very pleased with their current doctor who "actually worries that she has to travel so far to see her." Many of the parents who highly rated the quality of care for their child also reported that this has not always been the case. For example, one parent praised all of her child's current doctors because they were "willing to learn." She contrasted them with a former doctor who "hurried, didn't listen to her, and gave her advice that she wasn't comfortable with." Another parent reported that the previous doctor did not treat her child's Attention Deficit Disorder, but instead prescribed an atypical antipsychotic medication that led to significant weight gain. The same parent described the new doctor, who prescribed Adderall®, as “a goddess.”

When overall healthcare was rated low, it was not always the PCP who was blamed. For example, one parent rated healthcare low because of the difficulty in finding a provider. Another parent blamed the PCP’s move to a “more corporate” practice for a decline in the quality of medical service.

Some parents felt that their PCP did not do enough to address their child’s autism as a medical condition. For example, one parent felt that her child’s autism was related to an underlying treatable medical condition. She complained about her child’s PCP stating: “They don’t do anything progressive. They don’t take the next step to help with this.” Another felt that “there isn’t enough attention to the biological piece; that it could be related to vitamin or mineral deficiencies that have not been looked at.”

Care consistent with a medical home. Several questions in both surveys were related to the provision of care consistent with a medical home. Survey respondents were asked about whether there was one place to seek health advice, whether there was a healthcare provider who was thought of as the child or adult’s personal doctor or nurse, whether they talked with the doctor in the last twelve months about health concerns or problems, and whether the PCP spent enough time with them. All children and 91% of adults had a regular place to go for healthcare. All but one child had a personal doctor or nurse and 91% of adults were reported to have a regular doctor or nurse. Only 72% of parents reported that they had talked with their child’s PCP in the previous 12 months about health issues, however. Adults with ASD or their guardians reported that 68% had talked about health issues with the PCP in the previous 12 months. Most of the parents, adults with ASD, or guardians who were interviewed reported that the PCP always or usually spent enough time with them—90% for children and 86% for adults. The results appear in Table 11 - *Care Consistent with a Medical Home*.

Several respondents indicated that they appreciated the time that the PCP spent with their child and the individual attention they gave him or her. For example, one parent explained that she does not mind the typically long wait times because she knows that the PCP is providing all her patients with the time they need. Another parent said that their PCP goes over his “15-minute limit” if he needs to. The parent of one adult commented favorably about the ability of their doctor to coordinate the efforts of multiple specialists. A number of families indicated that they go to other doctors, walk-in care, or the emergency room when their PCP is not available.

In sharp contrast, several parents and guardians were very dissatisfied with their child[ren]’s care. Three complained that the PCP did not spend enough time with patients. One parent explained that their PCP is “intent on having patients in and out in twenty minutes.” Similarly, the guardian of an adult reported “the PCP is not very attentive and sticks to a 15-minute limit for appointments.” The parent of a child who was described as having very complex healthcare needs felt that the PCP needed to spend more time with them than was allotted.

Although residing in less populated counties was not correlated with any healthcare outcomes, several respondents indicated that obtaining consistent medical care was hampered by their rural location. This was due in part to the frequent turnover of PCPs in the clinics they used.

One parent complained that they often have to see different doctors and that they always have to explain things each time they see a doctor. In one instance, it led to confusion about whether a medical issue was an infection or a gallbladder issue. Several parents commented on the difficulty they have navigating the healthcare system. For example, one parent described the system as “byzantine.” She explained further:

> Finding the resources, filling out forms, navigating the system, accessing the program is awful. Yet they have to re-evaluate him every year to qualify him for MaineCare and they won’t accept a doctor saying he still has a disability. It is way harder than it needs to be… And the system doesn’t help you find the resources. Case managers are overwhelmed. Healthcare people don’t talk to each other. There is no coordination of care. They don’t talk to each other and Mom has to help them to put all the pieces together.

Similarly, the guardian of an adult reported that the multiple doctors they see do not seem to be communicating with each other. She described the system as “fragmented.” Two parents also complained about medical providers and schools not sharing information.

Table 11

Care Consistent with a Medical Home

Care Consistent with Medical Home	**Children (N=85)** ***n*** **(%)**	**Adults (N=22)** ***n*** **(%)**
Place to go for Healthcare	85 (100)	20 (90.9)
Personal Doctor or Nurse	84 (98.8)	20 (90.9)
Talked with Dr. in last 12 months about health issues	61 (71.8)	15 (68.2)
Spent enough time with Dr. if they talked within last 12 months		
Always	52 (70)	8 (53)
Usually	15 (20)	5 (33)
Sometimes	2 (3)	1 (7)
Never	5 (7)	1 (7)
Total	**74 (100)**	**15 (100)**

Routine care and screening. The majority of adults with ASD received some routine medical care within the last 12 months and 63% had received a complete physical in that time. In addition, most had their eyes, throat, ears, nose, and lymph nodes examined and their height, weight, blood pressure, and pulse measured. A majority of the adults had their hearing and vision tested and had also been screened for anxiety, depression, cholesterol levels and diabetes. None of the men had a prostate exam, while 5 of the women (71%) had clinical breast exams and 3 women (43%) had screening mammograms. All of the adult women had been given a PAP test. Only two of the adults with ASD in the survey had reached the recommended age for a colonoscopy and both had undergone the procedure. Adults had a mean of 69% of routine care items completed. The results appear in Table 12 – *Adults—Routine Care and Screening*.

Table 12

Adults — Routine Care and Screening

Adults — Routine Care and Screening	*n* **(%)**	**Applicable (N=22)**
Physical Last 12 months	14 (63.6)	22
Routine Care Last 12 months	19 (86.4)	22
Immunization	12 (54.5)	22
Vision	17 (77.3)	22
Throat	21 (95.5)	22
Ears	22 (100)	22
Nose	19 (86.4)	22
Blood Pressure	21 (95.5)	22
Pulse	22 (100)	22
Blood work	15 (68.2)	22
Women: Conduct Breast Exam (out of 7)	5 (71.4)	7
Men: Prostate Exam (out of 15)	0 (0)	15
Lymph Nodes	20 (90)	22
Height	22 (100)	22
Weight	22 (100)	22
Other	1 (4.5)	22
Checked or ordered tests for any of the following.		
Anxiety	13 (59.1)	22
Asthma	7 (31.8)	22
Colonoscopy: Colon	2 (9.5)	2
Mammogram: Breast	3 (42.9)	7
PAP Test: Cervical	7 (100)	7
Skin	9 (40.9)	22
Cholesterol Level	17 (77.3)	22
Depression	15 (68.2)	22
Diabetes	13 (59.1)	22
Epilepsy	11 (50)	22
Food Allergies	11 (50)	22
Hearing Check	19 (86.4)	22
Heart Disease	4 (18.2)	22
Hepatitis B & C	10 (45.5)	22
Osteoporosis	2 (9.1)	22
Respiratory	9 (40.9)	22
Skin Allergies	9 (40.9)	22

Adults — Routine Care and Screening	***n* (%)**	**Applicable (N=22)**
Stroke	2 (9.1)	22
Vision	21 (95.4)	22
Mean Percentage of Routine Care Items Completed	**68.7 (SD=14.6)**	
Range 35.7 to 84%		

Parents or guardians of children in the survey sample responded to a smaller number of routine care and screening items than the adult respondents. Most children (92%) had received some routine medical care within the last 12 months and 78% had received a complete physical in that time. Four parents, however, reported that their child had never had a complete physical. Large majorities reported having received immunizations in the last 12 months as well as having vision, throat, ears, nose, and blood pressure checked. The mean percentage of routine care items completed for children was 84.5, but ranged from 25% to 100%. See Table 13 - *Children—Routine Care and Screening*.

Table 13

Children—Routine Care and Screening

Routine Care and Screening	**Children (N=85) *n* (%)**
Physical - Last 12 months	64 (78)
Routine Care in last 12 months.	78 (91.8)
Immunization	56 (65.9)
Vision	67 (78.8)
Throat	72 (84.7)
Ears	80 (94.1)
Nose	70 (82.4)
Blood Pressure	78 (91.8)
Mean Percentage of Routine Care Items Completed - 84.5 SD=16.7	
Range - 25 to 100	

Both parents/guardians of children and guardians of adults reported that their children/

wards had difficulty with some routine care procedures. Several parents reported that their PCPs attempted the procedures, but were unsuccessful. Four parents, for example, reported that their children tried to participate in vision exams, but could not. Three parents indicated their child[ren] had difficulty having their throat examined. A number of adults and children with ASD had difficulty having their blood pressure or pulse taken. One parent reported that all medical procedures were difficult for her child because he "won't let anyone close to him." Another explained that some procedures could be completed if they were "quick about it; he does not like anyone touching his face." Others indicated that their children had difficulty with ear and nose exams and that they cannot always complete those procedures. The parent of one child reported that their eye doctor was unable to do an adequate examination and her son received the wrong prescription as a result. Several children and adults had difficulty with having blood drawn or receiving any kind of injection. In some cases, however, it was the parents or guardians who refused to allow their child[ren] to receive vaccinations. One parent said that her child would have a chicken pox vaccination "over my dead body." Another claimed that his son's last vaccination caused his autism, while another reported that her son had a "bad reaction to vaccinations" and could not "detox" after a shot.

Parents and guardians reported a number of creative accommodations that they used to make medical procedures easier. For example, one parent said that the medical provider was able to check her son's ears when she laid on her back on the exam table and held him. Another child was examined when he was fully sedated for a dental exam. Some families reported that they were accommodated when children insisted that only particular people could complete specific procedures. For example, one child would only let the ENT (ear nose and throat specialist) and not the PCP, look in his ears while another boy would only let either of two particular nurses check his blood pressure. Adults and children sometimes needed to be restrained or sedated in order to have medical procedures completed. Sedation was most common for dental procedures.

Wellness. More than 80% of the adults with ASD or their guardians reported that their PCP had spoken with them about their likes and interests, diet and nutrition, oral health, and physical exercise. Only 22% discussed obesity and only 2 (9%) discussed being underweight. See Table 14 - *Adults—Wellness Topics Discussed with PCP*.

Table 14

Adults—Wellness Topics Discussed with PCP

Talked about with Dr. in last 12 months	**Adults (N=22) *n* (%)**
Likes & Interests	18 (81.8)
Weight - Obesity	5 (22.7)
Weight - Underweight	2 (9.1)
Diet or Nutrition	19 (86.4)
Oral Health (Dental)	18 (81.8)
Physical Activity or Exercise	18 (81.8)
Mean percent of Wellness Topics Discussed with Doctor 61.7% SD=16.2	
Range - 33.3 to 83.3	

Parents or guardians were asked if their PCPs had spoken with them or their children about ten topics related to wellness and safety. A majority of the respondents indicated that their PCPs had spoken with them or their children about the following: safety issues, peer relationships, diet or nutrition, oral health, and physical activity or exercise. As with the adults with ASD, only a small percentage talked about weight issues. Only 15% talked about bullying.

Five parents reported that their daughters had started menstruating within the last 12 months. In three of the five cases, the parent or guardian reported that the PCP talked with their daughter about “her developing body and what it means.” One parent complained in the comments section that the PCP seemed reluctant to talk about issues related to puberty and “would not even talk about taking Midol® for cramps.”

A number of parents indicated in the comments section that there would be no value in their children talking to PCPs about these topics because their children would not understand.

Others felt their children would understand, but that the PCP underestimated the child[ren]'s ability to do so. In one instance, the parents reported discussing issues related to drinking, tobacco, and the need for the Gardasil® vaccine, but indicated that they felt it was their responsibility and not the responsibility of the PCP.

Parents reported in the comments section that they were concerned about a number of wellness and safety issues. The most common concerns were bullying, peer relationships, peer pressure—especially to use tobacco or alcohol, and sexual abuse. Parents frequently indicated, however, that other service providers talked about these topics with their children. See Table 15 – *Children—Wellness and Safety Issues Discussed with PCP* .

Table 15

Children—Wellness and Safety Issues Discussed with PCP

Wellness or Safety Issue	**Children (N=85) *n* (%)**
Safety - crossing street, car seats, bike helmets, etc.	55 (64.7)
Safety - stranger danger, not getting into strange cars, etc.	23 (27.1)
Peer Relationships	49 (57.6)
Bullying	13 (15.3)
Weight - Obesity	24 (28.2)
Weight - Underweight	14 (16.5)
Diet or Nutrition	65 (76.5)
Secondhand Smoke	50 (58.8)
Oral Health - Dental	58 (68.2)
Physical Activity or Exercise	58 (68.2)
Other	3 (3.5)
Mean Number of Wellness Items Discussed with Doctor 4.84 (SD=2.31)	
Range 0 - 9	

Physical health, mental health and sexuality topics discussed with PCP. Adults or their guardians answered eleven questions related to physical health, mental health, and sexuality. Medical providers talked with 73% of the adults in this sample about both tobacco use and drug use. Only one of the adults reported being a smoker and none reported recreational drug use. The same percentage (73%) reported talking to their medical provider about alcohol use, although the percentage among those who reported using alcohol was slightly lower (67%). More than 75% discussed moods or emotions. Fifty percent or fewer indicated that they talked with their PCP about sexual abuse, sexual orientation, sexually transmitted diseases (STDs), safe sex, birth control, abuse, interactions with peers, violence or weapons. Overall, medical providers spoke with adults with ASD or their guardians on 54% of these issues. For the eleven adults with guardians who had concerns, the percentage was slightly higher at 62.%. See Table 16 - *Adults—Physical Health, Mental Health and Sexuality Topics Discussed with PCP*.

In the comments section of the survey, guardians of adults with ASD expressed a number of concerns about these issues. For example, one guardian was concerned that her son was very compliant and could easily be talked into taking drugs. Another guardian believed that her daughter did not understand the "social sexual context" and "did not have the tools to say, 'No.'" Two parents who were guardians for their adult children expressed concerns about their [child's] susceptibility to abuse. Parents of adults who were nonverbal or who were described as having significant intellectual impairments were especially concerned about potential abuse. The parent of one of these adults felt that he would tell her about something if she asked, but worried that "it could just be putting words in his mouth."

Table 16

Adults—Physical Health, Mental Health and Sexuality Topics Discussed with PCP

Topic	**Adults (N=22)** *n* **(%)**
Tobacco Use	16 (72.7)
Drug Use	16 (72.7)
Alcohol Use	16 (72.7)
Sexual Abuse	9 (40.9)

Topic	**Adults (N=22)** *n* **(%)**
Sexual Orientation	9 (40.9)
Sexually Transmitted Diseases (STDs)	9 (40.9)
Safe Sex	10 (45.5)
Birth Control	10 (45.5)
Moods or Emotions	17 (77.3)
Interactions w/Peers	11 (50)
Violence & Weapons	8 (36.4)
Abuse (physical, sexual, emotional)	10 (45.5)
Mean % of topics discussed 54.2, SD=29.7	
Range – 8.3% - 83.3%	
Mean for 11 respondents whose guardians said they were concerned about these issues: 62.1%	

Gastrointestinal issues and behavior. Parents in this sample were much more likely to notice a relationship between gastrointestinal issues (GI) and difficult behavior than the PCP. Forty-one (60%) of the parents or guardians of children with ASD who had GI issues indicated that they had noticed a relationship between those issues and their child's behavior. Eighteen (27%) of those parents or guardians indicated that their doctor had suggested a possible relationship between the two. In 26 cases, parents or guardians noticed a relationship without their doctor's suggestion. Sixteen guardians of adults were also asked whether they noticed a relationship between GI symptoms and difficult behavior. Exactly half noticed a relationship. None of the guardians of adults with ASD reported that their PCP had suggested a relationship. In cases where a relationship was noticed by the parent or guardian or suggested by the PCP, there was often very little follow-up with further diagnostic tests, prescription medication or referral to a specialist. Among children, doctors followed up by ordering further diagnostic tests in 20.8% of cases in which a relationship was suggested either by the doctor or the parents. See Table 17 – *Gastrointestinal Problems and Behavior*.

One parent commented that her pediatrician had suggested a relationship between GI issues and behavior, but that it was difficult to convince the PCP. She also reported that she had difficulty explaining things to the PCP sometimes. In another case, a PCP reportedly rejected a psychologist's suggestion about a possible relationship. Parents or guardians reported noticing an association between GI problems and behavior issues including the following: hunger and aggression; constipation and "crankiness;" the presence or absence of certain food items and behavior; red dye and aggression; and candy and hyperactivity.

Table 17

Gastrointestinal Problems and Behavior

GI Problems and Behavior	**Children with GI issues, (N=68)** *n* **(%)**	**Adults with GI Issues (Guardians Only) (N=16)** *n* **(%)**
Doctor suggested relationship between GI and Behavior	18 (26.5)	0 (0)
Parents or guardians noticed the relationship	41 (60.3)	8 (50)
Total - at least one parent/guardian or medical provider suggested relationship	53 (77.9)	8 (50)
When relationship was suggested - followed up with:		
Diagnostic tests	11(20.8)	1 (12.5)
Prescribed medication	6 (11.3)	2 (25)
Said nothing could be done	6 (11.3)	0 (0)
Referred to specialist	3 (5.7)	1 (12.5)

Complementary and Alternative Medicine (CAM). Just over 50% of parents of children with ASD discussed Complementary and Alternative Medicine (CAM) with their doctors, although 60% reported accessing it. Eighteen parents indicated that they accessed CAM for their children without talking to their doctor about it. Only 27% of the adults or their guardians talked with their PCPs about CAM and only 41% reported accessing it. Adults were more likely than children to access CAM without talking to their doctors, however. See Table 18 – *Complementary and Alternative Medicine*. Several respondents indicated that their PCP encouraged them to try new things as long as they were not harmful. In one case, a parent said that the PCP recommended some alternative treatments. In another case, a parent expressed an appreciation for her doctor's willingness to research alternative treatments that the family suggested. She added, "There is a lot of snake oil out there." Chiropractic care was the most common type of CAM treatment approach reported. Indeed one parent said that she takes her child to a chiropractor, first, and then sees a PCP if the issues are not resolved. Other types of care included magnesium supplements prescribed by a Defeat Autism Now (DAN) doctor, homeopathy, cranial-sacral therapy, massage, therapeutic horseback riding, herbal treatments, music therapy, melatonin, casein-free and gluten-free diets, sensory integration and sensory diets, neurofeedback, yoga, magnetic therapy, aroma therapy, and acupuncture.

Table 18

Complementary and Alternative Medicine

Complementary and Alternative Medicine (CAM)	**Children (N=85) *n* (%)**	**Adults (N=22) *n* (%)**
Talked to Dr. about CAM	43 (50.6)	6 (27.3)
Accessed CAM	51 (60)	9 (40.9)
Accessed CAM without talking to Dr.	18 (21.2)	7 (31.8)

PCP understanding of ASD diagnosis. All respondents were asked two questions related to their medical provider's understanding of the healthcare needs of individuals with ASD. First, they were asked a Likert scale-type question about whether they felt their medical provider was informed about their ASD diagnosis or the ASD diagnosis of their child or ward. Second, they were asked if they ever felt they had to educate their medical provider about their ASD diagnosis or the ASD diagnosis of their child or ward. A much higher percentage of parents and guardians of children with ASD felt the provider understood their child[ren]'s diagnosis than did the adults with ASD or their guardians. Sixty percent of the parents and guardians felt that their provider always or usually understood their child[ren]'s diagnosis. In contrast, only 41% of the adults with ASD or their guardians indicated this was the case. Only 9% of adults or their guardians indicated that the provider always understood their ASD diagnosis compared to 36% for the parents and guardians of children. The distribution of responses also looked very different with the adult data more closely approximating a normal distribution. The child data had more of a bimodal distribution so that more of the respondents felt that the medical provider understood their diagnosis than in the adult sample but there was also a relatively large percentage (20%) that felt that the provider never understood their child's diagnosis. In contrast, only 8% of the adult respondents felt this was the case. More than 70% of the adult respondents indicated that they had to educate their medical provider about ASD while only 41% of the parents or guardians of children indicated that this was the case. In their comments, several of the respondents indicated that when they did educate their PCP about ASD it was often related to how ASD affected the particular patient. In other cases, parents or guardians said that they shared information with the PCP about ASD that they had obtained from other medical providers. One guardian explained that educating the PCP about ASD is something she does "automatically" at each visit because she does not expect the provider to understand the point of view of an adult with ASD. See Table 19 - *PCP's Understanding of ASD Diagnosis*.

Several parents expressed an appreciation for their PCP's efforts to increase his or her knowledge of ASD by attending conferences, workshops, or by researching particular ASD-related topics. Others felt that their PCPs recognized their lack of professional expertise in this area and made appropriate referrals to other medical professionals. Several parents, however, commented that their PCP had little understanding of how to work with individuals with an ASD diagnosis, especially those with more significant intellectual or communication impairments. For example, one parent complained that her obese son was inappropriately referred to a clinic where he received counseling in portion control and getting more exercise. She believed he could not make sense of this counseling. Another parent complained that their PCP did nothing to increase his own understanding of ASD; while two other parents believed that their PCPs were not convinced that ASD was an appropriate diagnosis.

Table 19

PCP's Understanding of ASD Diagnosis

Understood Patient's ASD Diagnosis	Children **(N=85)** *n* (%)	Adult **(N=22)** *n* (%)
Always	30 (35.3)	2 (9.1)
Usually	21 (24.7)	7 (31.8)
Sometimes	16 (18.8)	8 (36.4)
Never	17 (20)	4 (8.2)
Unanswered	1 (1.2)	1 (4.5)
Reported that they sometimes had to educate provider about ASD	35 (41)	16 (72)
Mean Composite Score Understanding ASD	0.58 SD=0.39	Range = 0-1

Medical provider understanding of individual patient needs. Adults with ASD or their guardians were asked to answer two yes/no questions about whether their medical provider was meeting their individual needs as an adult with ASD. Nearly all of the adult respondents indicated that the provider understood the adult with ASD's means of communication and 82% indicated the provider treated the adult the way she or he wished to be treated. They were also asked two Likert-style questions about whether the provider was knowledgeable about their other diagnoses and whether he or she knew important information from their medical history. Most (59%) felt that the provider was always or usually knowledgeable about the adult with ASD's other diagnoses and 90% reported that the provider was *always* or *usually* knowledgeable about important information from their medical history. Two of the respondents, however, indicated the provider *never* knew important information from their medical history. See Table 19 - *PCP's Understanding of ASD Diagnosis*.

Parents or guardians of children were asked three yes/no questions and the same two Likert-style questions asked of the adult respondents. Approximately 78% of the parents or guardians surveyed reported that providers understood how their children communicate. Several spoke highly of PCPs who were willing to learn how to communicate with their child using an Augmentative and Alternative Communication (AAC) system[1]. Over 80% felt that their providers considered their children "beyond their diagnosis" and that they treated both the child and parent or guardian with sensitivity. Among parents or guardians who reported that their children had additional medical diagnoses, 83% indicated that their child or ward's providers were always or usually knowledgeable about these other diagnoses, and 81% said the providers knew important information about their children's medical history.

Although adults with ASD or their guardians were not asked explicitly whether their PCP "considered them beyond their ASD diagnosis," several addressed the issue in their comments. For example, an adult with ASD explained that the doctors "tend to cling to the term [autism] and then everything becomes about the autism." He preferred medical providers who approached medical issues as "just a problem" and did not always use "autism as a crutch."

In Table 20 below, *Medical Provider Understanding of Individual Needs* composite scores were calculated for each individual. The mean score for children was 0.578, SD=0.184. Scores ranged from 0.25 to 1.0. The mean score for adults was 0.82, SD=0.22. Scores ranged from 0.4 to 1.0.

Table 20

Medical Provider Understanding of Individual Needs

Medical Provider Understanding of Individual Needs	**Children (N=85)** *n* **(%)**	**Adult (N=22)** *n* **(%)**
Understands how patient communicates	66 (77.6)	21 (95.4)
Treats patient way s(he) wants to be treated (Adults)		18 (81.9)
Does not feel treating ASD only (Children)	69 (82.2)	
Consider beyond ASD diagnosis (Children)	73 (85.9)	
Treats parent and child with sensitivity (Children)	64 (75.3)	

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[1] According to the American Speech -Language -Hearing Association (ASHA), AAC "includes all forms of communication (other than oral speech) that are used to express thoughts, needs, wants, and ideas" (ASHA, 2014). Modes of AAC often used by individuals with ASD include sign language, gestures, pictures or symbol systems, written communication, or electronic systems.

Medical Provider Understanding of Individual Needs	**Children (N=85)** *n* **(%)**	**Adult (N=22)** *n* **(%)**
Feels provider is knowledgeable about other diagnoses		
Always	23 (27.7)	10 (45.4)
Usually	13 (15.3)	3 (13.6)
Sometimes	10 (11.8)	4 (18.2)
Never	7 (8.3)	2 (9.1)
No other diagnosis or blank	42 (49.4)	3 (9.1)
Seems to know important info from medical history		
Always	59 (69.4)	15 (68.2)
Usually	10 (11.8)	5 (22.7)
Sometimes	9 (10.6)	0 (0)
Never	7 (8.2)	2 (9.1)
Mean Composite Score Children = 0.58 (SD=0.184) Range: 0.25 - 1.0		
Mean Composite Score Adults = 0.82 (SD=0.22), Range - 0.4 - 1.0		

Communicating illness or pain. Parents and guardians reported that their children with ASD communicate that they are sick, in pain, or uncomfortable in a wide variety of ways. Parents and guardians of children who were nonverbal, for example, reported that they often had to rely on signs other than direct communication. Lethargy or sleeping was a sign of illness for several of the children. In other cases, parents and guardians reported that they did not know their child was sick until they exhibited more serious or easily observable symptoms such as vomiting, a fever, or appearing flushed. A common theme among parents and guardians of nonverbal children was that they had to rely on behavioral indicators ranging from aggression, “meltdowns,” crying or being “grumpy,” to becoming “compliant,” or, in one case, being “cuddly, snuggly, and whining.” Parents and guardians also reported that they often had difficulty interpreting some behaviors that may be associated with pain or illness because those behaviors can have multiple functions. Several nonverbal children were able to point to a body part to indicate they were in pain. The parent of an adult with ASD said that her son once put her finger in his mouth to indicate he had a headache. Only one parent reported that their child used an AAC device to indicate that she was in pain or sick and the guardian of an adult said that they are exploring the use of an iPad® to communicate body parts, feelings and emotions.

Other parents reported that even though their children were verbal, their health-related communication could be unreliable or that they communicated that they were sick in unusual ways. One parent reported that her child's verbal expressions were unreliable because they are echolalic (the automatic or stereotypical, but usually functional, repetition of words or phrases heard in the past). Another child communicated that she was experiencing nausea by asking for a bowl. Several children were able to communicate that they were sick, but unable to specify the nature of their illness or pain. In some instances, parents and guardians were able to narrow down the possibilities by reviewing a list of body parts or problems with them, however. Parents also reported having to be intuitive and using contextual factors to determine exactly what was wrong when their children indicated they were sick. One parent suggested that the inability of her child to communicate that he is sick or in pain was not simply a communication issue. She explained, "He just doesn't understand his own body." The parent of an adult reported a similar issue when she explained that her son "didn't really understand nausea until a few years ago."

Some parents and guardians also reported that their children had difficulty communicating the seriousness of their pain. For example, one child always expressed that she was sick in very dramatic terms, regardless of how sick she actually was. Another parent reported having to rely on contextual factors, such as what was going on in school, in order to know if her child's complaints constituted a "real sickness." Determining the seriousness of pain or illness for several children was also complicated by their reported high tolerance for pain. For example, one mother said that her son had a very serious ear infection before he complained. The child's doctor reportedly said it was "the worst she had ever seen and was surprised the ear drum hadn't ruptured." In contrast, other parents reported that their children behaved in ways that might be characterized as hypochondria. One parent said of her son, "When he gets sick, he wants it taken care of immediately. He wants to make sure that it is not something serious. He says that 'little things can become big things, if they are not checked early and at once."

Finding a medical provider. Sixty-seven (79%) of the parents and guardians of children with ASD indicated that they had no difficulty finding a primary care provider who was willing to treat their child. However, 55% reported that it was difficult to find specialists who would accept their child as a patient. Maine's Medicaid program, MaineCare, was frequently cited as more of an obstacle to obtaining medical care than their children's ASD diagnosis. The results were similar for adults with ASD or their guardians with 64% reporting they had no difficulty finding a PCP, but with 60% reporting that they had difficulty finding specialists. Adults or their guardians also indicated that they had difficulty finding medical providers who would accept MaineCare.

Respondents for both children with ASD and adults with ASD indicated that they had difficulty accessing a number of specialty services including psychiatrists, neurologists, neuropsychiatrists, pediatric psychiatrists, dentists, orthodontists, speech therapists, counselors, physical therapists, and behavioral specialists. Because of their rural location, one family reported having to take an overnight trip to Portland, ME in order for their daughter to be tested for Celiac disease. Some parents indicated that when they did get an appointment with a specialist, it was sometimes difficult for the provider to conduct a complete exam. One dentist, for example, said that because of the child's resistance, he would not be able to do a cleaning or take x-rays. Several respondents also indicated that they sometimes had difficulties obtaining referrals. One parent complained that the PCP's office did not understand what she was asking for and that it took several calls to get the correct referral.

Several of the respondents reported having a hard time initially finding a PCP who would treat their child. An island resident explained, "No one has ever said 'No' to having him as a patient, but [we] had a hard time finding someone on the island who was willing or interested in learning more about [child's name]'s needs and issues." Another parent indicated that a doctor simply said, "I can't see your child." The guardian of an adult with ASD reported that the doctor interviewed the parents before accepting their child as a patient, and that the mother had to "lobby to get him to take him." Another guardian reported that a medical practice agreed to take her adult daughter as a patient, but changed their minds after meeting her.

Several respondents for adults and children also indicated that they have been very selective and have changed PCPs when they felt the provider was not meeting their needs. In some cases, that has meant traveling long distances to find healthcare they considered satisfactory.

Quality of communication with PCP. Three Likert-style questions were asked of respondents related to the quality of their communication with the medical provider. These included questions about how often health-related issues were discussed in ways they understood, how often the provider listened carefully to them, and how often the provider understood and respected what they had to say. Over 75% of the adults or their guardians indicated that the PCP always or usually explained medical information in ways that were easy to understand with 55% indicating that they always understood. Seventy-three percent of the parents and guardians of children reported that they always understood when medical information was explained. Only three respondents, each a parent of a child, felt that their PCP never explained things in ways that were easy to understand. Several parents or guardians reported that they had to contact the medical practice to obtain test results.

Ninety-one percent of adult respondents and 85% of parents and guardians of children reported that their medical provider always or usually listened carefully to them. Even higher percentages for both adult respondents (96%) and parents and guardians of children (88%) felt that their medical provider always or usually understood what they had to say and treated them with respect. A composite communication score was calculated for each respondent. The mean communication composite score for adults was 0.77, SD=0.17 with scores ranging from 0.44 to 1.0. The highest possible score was 1.0. The mean communication composite score for children was 0.89, SD=0.22 with scores ranging from 0.07 to 1.0. The highest possible score was 1.0. See Table 21 – *Communication with PCP*.

Parents and guardians also commented positively on the quality of the overall interaction between the PCP and their children. One parent said, “I have never seen such a bond between two people form so quickly.” Another parent said of her PCP, “He is open and calm. He understands when she is explaining things and is having a hard time getting her point across and will ask her questions so he is sure that he understands. He really listens." Many parents appreciated the fact that the PCP usually spoke directly to their child. One parent explained that the doctor did not change the way he communicated with her child after his autism diagnosis. Others parents and guardians commented on the sense of humor shown by medical staff and the ease with which they interacted with their children. For example, one mother said that her son "is always a little nervous when he goes to the doctor, but the nurses and the doctor are very good at explaining things well, they praise him for being a good sport and they really like him." The guardian of an adult described her son's doctor as "unflappable." Another seemed to appreciate the attempts that the PCP made to communicate directly with her adult son, especially when explaining procedures, even though ultimately the parent needed to answer most of her child's questions.

A smaller number of parents and guardians expressed negative comments about the quality of interaction between the PCP and their child. Several parents complained that the PCP spoke to them rather than directly to their child. For example, one parent indicated that she usually had to explain things to the doctor. In another case, the parent complained that the PCP did not interact with the child at all and, instead, just watched and then asked the parent questions. Similarly, the parent of an adult explained that her daughter "understands everything" but that their former PCP "talked around her or through her." Others felt that the PCP was uncomfortable communicating with their child. One complained that the PCP "does not adjust his style to accommodate" her son. Several other parents felt the PCP communicated well with their children, but that other office staff did not communicate well with them.

The belief that the PCP should communicate directly with the patient with ASD was not universal. A few parents and guardians questioned the value of their PCP communicating directly with someone who they perceived as being incapable of understanding or who would be easily overwhelmed. In sharp contrast, an adult with ASD felt that he needed medical information to be provided at "a higher level—understanding the chemical pathway."

Some parents felt that PCPs questioned their credibility in reporting medical issues. The parent of one adult, for example, complained about a previous PCP who did not believe her when she said her daughter had an ear infection. In other cases, the PCP did not seem to trust the judgment of parents whose children were said to communicate pain or sickness in very idiosyncratic ways.

Most parents indicated that they followed their PCP's instructions, but several indicated that they did so selectively. For example, one parent rejected their doctor's prescription of an Attention Deficit Hyperactivity Disorder (ADHD) medication and his advice that children do not need juice or dairy. Another could not follow through with a gluten-free diet because she could not afford it.

Table 21

Communication with PCP

Communication with PCP	**Always *n* (%)**	**Usually *n* (%)**	**Sometimes *n* (%)**	**Never *n* (%)**	**Unanswered *n* (%)**
Explains health issues in ways easy to understand					
Adults	12 (54.5)	5 (22.7)	5 (22.7)	0 (0)	0 (0)
Children	62 (72.9)	9 (10.6)	10 (11.8)	3 (3.5)	1 (1.2)
Listens carefully to me					
Adults	13 (59.2)	7 (31.8)	2 (9.1)	0 (0)	0 (0)
Children	55 (64.7)	17 (20)	10 (11.8)	2 (2.4)	1 (1.2)
Respects what I had to say					
Adults	17 (77.3)	4 (18.2)	0 (0)	0 (0)	1 (4.5)
Children	64 (75.3)	11 (12.9)	9 (10.6)	0 (0)	1 (1.2)
Mean Score Adults: 0.77, SD=0.17 Range: 1.44-1.0					
Mean Score Children: 0.89, SD=0.22 Range: 0.07-1.0					

Patient control and self-determination. Parents of children over age 11 and guardians (only) of adults were asked whether their medical provider had talked with their children or wards about taking more responsibility for their own healthcare. Eleven of the 36 parents of children over age 11 (39%) reported that their provider had this conversation with their child. Only four of the 15 guardians of adults (26%) reported that this conversation occurred.

Two Likert-style questions related to the patients taking more responsibility were also asked of guardians of adults and parents of all children, although most of the parents of children under age 11 did not respond to the question or indicated that the question did not apply. In the first question, respondents were asked how often their child was encouraged to take more responsibility for his or her healthcare; and in the second, they were asked how often they had appointments in which the provider spent some time alone with the child. Of the 15 guardians of adults, 3 (20%) reported that the provider *alway*s or *usually* encouraged the adult to take more responsibility for his or her healthcare; seven (46%) reported that the provider s*ometimes* or *never* did; and 5 (33%) did not respond to the question. Of the 36 parents of children over age 11, 6 (17%) reported that their provider *always* or *usually* encouraged their children to take more responsibility for their own healthcare; 13 (36%) reported that the provider *sometimes* or *never* did; and 17 (47%) did not respond to the question. Of the 85 parents of all children, only 6 (7%) reported that their provider *always* or *usually* encouraged their children to take more responsibility for their own healthcare; 20 (24%) reported that the provider sometimes or *never* did; and 59 (69%) did not respond to the question.

In the comments section of this question, several parents indicated that the PCP had talked with their children about taking more responsibility for their diet and exercise. Others said that other people in their children's lives talked to them about taking more responsibility for their health. In some cases, this was reportedly addressed by case managers, group home staff, or in-home support staff. Several guardians indicated that the adult was already taking a great deal of responsibility, with one person making his own appointments and managing his medications. Another reminds his mother that he needs to take a pill. An adult responding to another question in the survey said that his doctor acknowledged that he had a really good handle on all his healthcare needs.

Very few respondents indicated that providers spent some time alone with their children during appointments. Of the fifteen adult guardians, only four (26%) reported that providers ever did. Of the 36 parents of children over age 11, only one (3%) indicated their provider ever spent time alone with the child. Of the 85 parents or guardians of all children, only 9 (11%) reported that the provider ever spent time alone with the child. There were very high rates of "unanswered" to this second question for each group. See Table 22 - *Provider Support for Patient Control and Self-Determination*.

For example, one parent explained that her child could only follow one-step directions and that taking more responsibility would be difficult for him. Similar themes were found in the comments of guardians of adults. Several suggested that their children or wards could not take more responsibility for their own healthcare because they did not understand or because they needed full supervision to participate in any self-care activities. For example, one guardian described a "disconnect between telling [her son] he needs to eat fruit and his understanding that it will support [his] health."

Table 22

Provider Support for Patient Control and Self-Determination

	Always *n* **(%)**	**Usually** *n* **(%)**	**Sometimes** *n* **(%)**	**Never** *n* **(%)**	**Unanswered** *n* **(%)**
Encourages child to take greater responsibility					
Adults with Guardians	3 (20)	0 (0)	2 (13)	5 (33.3)	5 (33)
Children 11 or over	5 (13.8)	1 (2.8)	2 (5.6)	11 (30.6)	17 (47.2)
All Children (*N*=85)	5 (5.9)	1 (1.2)	3 (3.5)	17 (20)	59 (69.4)
Provider spends time alone with child					
Adults with Guardians	2 (13)	0 (0)	2 (13)	6 (40)	5 (33.4)
Children over 11	1 (2.8)	0 (0)	0 (0)	6 (16.7)	29 (80.6)
All Children	3 (3.5)	0 (0)	6 (7)	25 (29.4)	51 (60)

Talked to child about taking greater responsibility
Adults with Guardians (N=15)
Children 11 and Over (N=36)

PCP discussion of children's capabilities, strengths, likes, interests and future. Fifty-seven parents of children gave a positive response when asked if their doctor ever talked to them about their child[ren]'s capabilities (such as identifying strengths, likes, and interests) or encouraged them to start thinking about their children's future. Several reported that their PCP was very positive about the future. For example, one doctor said that he thought the child would go to Massachusetts Institute of Technology (MIT), a leading research university in Cambridge, MA. A number of parents said that the PCP talked with their child[ren] about their interests and hobbies, even when they seem to be somewhat restricted. One parent said that the PCP tried but that it is difficult to talk about these things because of her son's echolalia. In sharp contrast, several parents reported that their PCP seldom made positive statements related to their child's future. For example, a parent complained that her doctor said: "She's always been autistic, she's always going to be autistic." Other parents felt that their child was too young or that they did not believe it was the PCP's role to talk to the child about his or her future.

Overall responsiveness of PCP. The majority of PCPs were reported to have *always or usually* responded to calls during office hours from both the child and adult groups. In the comments section, several parents said that the [PCP's] office always call back within an hour and, in some cases, 15 minutes. One adult and four parents of children indicated that the PCP *never* responded, however. A large majority of parents and adult respondents also indicated that the PCP *usually* or *always* responded to calls after-hours. Most respondents in both groups indicated that the PCP always followed up with them. Only three from each group indicated that the PCP sometimes or never followed up. When asked if they understood the test results, 95% of the parents and 100% of the adults indicated that they had. All of the adult respondents and 80% of the parents of children reported *always* or *usually* getting appointments as soon as needed. Three parents indicated that they never got appointments when needed, however. See Table 23 – *PCP Responsiveness*.

Several parents commented very favorably about their PCP's responsiveness. One mother reported that when she calls the doctor's office, they always get back to her quickly, even when the doctor is not there that day. The nurse makes sure the doctor receives her message. Another parent said that the PCP always gets back to her, even if he does not have an answer at the moment. The same doctor also gave the parent his home phone number. The guardian of an adult commented that the doctor called her personally to talk about low levels of Vitamin D.

Twenty-seven percent of the parents or guardians of children and 18% of adult respondents talked with healthcare providers about making appointments easier. Some parents reported that as a result of those requests, medical practices made a number of accommodations, including providing a separate room where their child could wait, adjusting the timing of appointments, and getting the child into an examination room quickly. In one instance, extra staff were made available because a child needed to be restrained for any routine care. Another parent felt that the medical practice was very responsive when they spoke with her about making changes that would make it easier to draw her child's blood. One mother praised her son's medical provider, "They took 45 minutes of unbillable time to talk about making appointments easier." She felt it provided her with an opportunity to explain who her son is, how he responds, and what he needs.

Difficulties in the waiting room were the most common issue related to healthcare appointments mentioned in the comments. One parent reported that they leave if her child is not seen within 15 minutes, while another said that they wait in the car. Several parents described waiting in very negative terms. For example, one said that her son was "out of control" when he needed to wait. Another said simply, "It's hell." Forty-five parents or guardians indicated that their child would have benefited from an alternative to the waiting room but only 11 (24%) were provided with this accommodation. PCPs for adults appeared to be more responsive in this regard. Six of the adult respondents indicated they needed a quiet place to wait. Four were *always* provided with a quiet place and one was *usually* provided with a quiet place to wait. Not all respondents indicated that waiting for an appointment was an issue and some even described it in very positive terms. The guardian of an adult said her child "loves the waiting room. They try to make sure that there are not long waits." Others spoke favorably of waiting rooms that had activities that could keep their child occupied, such as an aquarium or toys. In many cases, parents indicated that they provided their own accommodations to help their child wait. For example, the parent of an adult said that she “brings along word search puzzles and he has his iPad® with him.”

In a few cases, parents complained that their other requests were not considered. For example, when a mother asked if she could bring her child to the office prior to the appointment to acclimate her to her surroundings, she was told: “We don’t do that.” Several parents felt that the support staff at the medical practices needed some education on the needs of children with autism and their families. Parents also indicated that some medical practices did not fully appreciate the need to make accommodations for individual and family needs. For example, one parent said that she has been sometimes given the choice of bringing her child in on the day she calls or going to the emergency room. She felt that the doctor did not appreciate how difficult it was to prepare both of her children for a visit to the doctor’s office on short notice.

Parents and guardians also discussed a number of issues in the comments section related to the responsiveness of the PCPs that were not addressed directly in the structured questions. For example, a number of respondents indicated that the PCP listens carefully to their concerns and is very good at responding to their questions. One parent reported that the PCP “listens until she understands.” An adult with ASD indicated that all her doctors take her concerns seriously.

In contrast, other parents felt that their PCP did not take their concerns seriously. For example, one parent said that she does not talk with the PCP anymore about any of her “crazy ideas” because he does not know about them or does not believe that there is enough research. She gave the example of “yeast rashes” that she said her son has had his entire life. Other medical issues that parents felt were not taken seriously included ear infections, “plugged up ears” causing her son’s headaches, fibromyalgia, pain that is not displayed in typical ways, “chemical imbalances in the brain,” getting an x-ray for a broken bone (after recommendation from orthopedist in another state), “five days of constipation” and sleep issues.

The most common complaint related to responsiveness of the PCP was that they had delayed in making an ASD diagnosis or in making a referral. Some were told that their children would “grow out of it” or that it was common for boys to be more delayed than girls.

Another was told that her daughter was “compensating” for her talkative older sister. Many parents reported that it often took them years to have their medical provider or Maine Child Development Services take their concerns about development seriously. Another parent changed doctors because their original doctor was unwilling to address their son’s developmental deficits. A mother, whose two children were ultimately diagnosed with ASD, reported improvement over time saying that the doctor was “very responsive the second time around” and that she changed the way her practice responded to parents’ concerns about development.

Table 23

PCP Responsiveness

PCP Responsiveness	**Always** *n* **(%)**	**Usually** *n* **(%)**	**Sometimes** *n* **(%)**	**Never** *n* **(%)**	**Unanswered** *n* **(%)**
Responded to calls during office hours					
Adults (N=18)	12 (66.7)	4 (22.2)	1 (5.6)	1 (5.6)	0 (0)
Children (N=52)	31 (59.6)	11 (21.1)	6 (11.2)	4 (7.6)	0 (0)
Responded in timely way to after-hours calls					
Adults (N=4)	2 (50)	1 (25.0)	0 (0)	1 (25)	0 (0)
Children (N=25)	21 (84)	1 (4.7)	1 (4.7)	3 (12)	0 (0)
Followed up after tests					
Adults (N=17)	11 (64.7)	3 (17.6)	2 (11.8)	1 (9.1)	1 (9.1)
Children (N=32)	21 (65.6)	7 (21.8)	3 (9.4)	1 (3.1)	0 (0)
Saw Doctor within 15 minutes of appointment					
Adults (N=19)	7 (36.8)	9 (47.4)	2 (11.8)	1 (6)	0 (0)
Children (N=84)	18 (21.4)	36 (42.8)	15 (17.9)	15 (17.9)	0 (0)
Got appointment as soon as needed					
Adults (N=20)	17 (85)	3 (15)	0 (0)	0 (0)	0 (0)
Children (N=78)	51 (65.4)	12 (15.4)	12 (15.4)	3 (3.8)	0 (0)
Quiet place to wait for those needing it					
Adults (N=6)	4 (66.7)	1 (16.7)	0 (0)	1 (16.7)	0 (0)
Children (N=45)	10 (22.2)	1 (2.2)	3 (6.7)	31 (68.9)	0 (0)
Mean Composite Responsiveness Score (Adults) = 0.69, SD=0.14. Range = 0.34 to 0.91					
Mean Composite Responsiveness Score (Children) = 0.67, SD=0.24, Range = 0 to 1					

Transition. Thirteen children were identified as needing healthcare transition supports:

they were at least fourteen years of age; and their parents indicated that their doctor treated children only. Of those families with children needing transition supports, none reported that their PCP talked with them about making the transition to an adult provider. Two PCPs informed families about the age that their child should make the transition to adult healthcare. One offered to help the family find an adult medical provider. None of the parents reported that their doctor offered to meet with an adult medical provider or participate in the healthcare transition planning. See Table 24—*PCP Transition Support Activities*. Seven families reported that they would have liked to discuss their child's adult healthcare needs, but two did not think it was necessary. One adult with ASD and a guardian of an adult also commented about their transition experiences. The guardian explained that their doctor and case manager helped her daughter locate a new doctor when she turned 18, who would be comfortable with her as a patient. An adult with ASD complained about being abruptly dropped from the pediatric practice "when they heard he wasn't going to college."

Table 24

PCP Transition Support Activities

PCP Transition Support Activities	Children needing transition to adult healthcare **(N=13)** *n* (%)
Doctors offering to see children when they become adults	2 (15.4)
Families talked with doctors about eventually making transition	0 (0)
Informed families about the age the child should transition to adult healthcare provider	2 (15.4)
Talked with family about child's adult healthcare needs	0 (0)
Offered to help find adult medical provider	1 (7.6)
Offered to meet with adult medical provider	0 (0)
Offered to work with family in developing transition plan	0 (0)

Insurance and quality of care. The only question in the interviews directly related to insurance was for parents who were asked if anyone had ever talked to them about how their child will obtain medical coverage as an adult. A single parent reported having such a discussion. Four parents indicated that their children would be getting [Maine's Medicaid program] MaineCare. Respondents identified insurance-related themes in their comments for other questions, however. Most were related to MaineCare. A number of respondents complained that MaineCare does not cover dental services or some specialty services such as physical therapy, speech therapy, alternative treatments or, in one case, "medication for my daughter's mood swings." Others reported difficulty finding providers who will accept MaineCare. The guardian of an adult worried that the problem might be exacerbated because of increased numbers of individuals being insured under "Obamacare." While many respondents complained about the limits of MaineCare coverage, others were very pleased with it. Several people, in fact, stated that they were concerned about the possible consequences if they lost MaineCare due to budget cuts. Two parents also expressed dissatisfaction with services covered by their private insurance. One said that she is trying to have her child access MaineCare so that he can get services "not covered by their private insurance."

Other medical issues. Parents and guardians reported a number of health issues that were not addressed directly in the interview questions. The most common issue reported for both adults and children was a lack of dental care. Those interviewed reported that they had difficulty both finding dentists and paying for their services. Several parents reported that their children needed full anesthesia in order to receive dental care, a service that was often difficult to find or afford.

Among the other medical issues identified by parents and guardians of children with ASD were the following: (1) issues related to nutrition and diet; (2) obtaining quality medical care, including having medical providers who understand their child's unique needs; (3) coordination of their child's care; (4) mental health issues and behavior; (5) the availability of insurance and MaineCare; and (6) individual medical issues. By far, the most frequently cited medical concerns, other than dental care, were related to their child's nutrition and diet. In some cases, parents were concerned about their children's pickiness. In other cases, they were already concerned about their child[ren]'s weight and their risk of developing diabetes. One child, in fact, had diabetes and another was pre-diabetic. Other parents were concerned about food allergies or the child being able to maintain a healthy diet when they left home. The second most frequent concern of parents was related to their children receiving high quality medical care throughout their lives. They often equated good healthcare with very individualized care provided by professionals who know their children and their children's medical histories. The parents of children who had difficulty communicating in conventional ways were especially concerned. As one parent said, "There is a tendency to blame it all on the autism. There is a gap between what is going on with him physically and what they are seeing and what he is saying and things might get missed." Many parents also felt that coordination of care was important, especially when they are no longer available to coordinate care. Some expressed skepticism about the capacity of the service system to coordinate healthcare. For example, a parent who had worked in a group home, and who had not been impressed by the quality of medical care for consumers, worried about her son's longevity if he lived in a group home or similar setting. Several also expressed frustration with the lack of communication between medical providers and schools.

Adults and their guardians also expressed a number of concerns. The most common included the following: (1) who will look out for the person's healthcare if family members are no longer available for support; (2) weight, nutrition, and fitness; (3) threats to healthcare access because of changes to funding; (4) mental health and anxiety issues; and (5) a lack of self-determination in managing their own medical care. The most common concern of guardians for adults was that the person would not get the necessary medical care if they were not around. For example, the parent of a young man asked: "What will happen to [First Name] when we are not around to monitor his healthcare? He lives at home, not in a group home, and the only workers in his life are through his day program." Another parent explained that she has to stay on "top of things" in order for her son to get the care he needs and that she is worried about what will happen when she can no longer do that. Other parents expressed concerns about the ability of their adult children to take more responsibility for their healthcare, especially when they had difficulty communicating their medical needs effectively.

Predictors of Healthcare Outcomes

Patient characteristic predictors. Simultaneous linear regression was used to determine if a number of characteristics of the patient predicted ratings of overall healthcare. The variables that were examined are listed in Table 25 below.

Table 25

Independent and Dependent Variables Examined in Determining Association Between Patient Characteristics with Healthcare Outcomes

Independent Variables	Dependent Variables
• Age • Diagnosis (Autism or other ASD diagnosis) • Additional Diagnoses • Population Density of County of Residence • Behavior (Total minus number of self-stimulatory behaviors)	• Rating of Overall Quality of Healthcare • Difficulty Finding a PCP • Difficulty Finding Specialists • Responsiveness of PCP • Percentage of Screening and Routine Care Items Completed

Overall, the combination of independent variables related to characteristics of the patient had little value in predicting any of the healthcare outcomes. In both samples, the combination of independent variables significantly predicted healthcare outcomes only three times. For *Routine Care and Screening for Adults* the R Square was .510, F=3.124, p<.05. This was explained almost entirely, however, by the strong positive correlation between the *number of additional diagnoses* and *routine care*, Beta =.782, p<.005. *Difficulty Finding a PCP for Children* was also predicted by this combination of independent variables, R-Square =0.156, F=2.285, p<.05. In this case, two variables predicted most of the variance. *Not having a diagnosis of autism* was negatively associated with *difficulty finding a PCP*, Beta=-.270, p<.05 while the *number of behavior issues* was positively associated with *difficulty finding a PCP*, Beta = .232, p<.05. In other words, when controlling for each of the other variables, both having an ASD diagnosis other than autism and having more behavior issues were associated with difficulty finding a PCP. For adults, a number of factors were either significantly correlated with *Difficulty Finding a PCP for Adults* or they approached significance. Because of the small sample size, however, the significance of the model could not be demonstrated.

Individual variables found to be significant in these models are listed in Table 26 - *Patient Characteristics and Healthcare Outcomes*. In addition, variables that approached significance are listed.

Table 26

Patient Characteristics and Healthcare Outcomes

Outcome	**Significant Predictors**	**Factors Approaching Significance**
Quality of Healthcare (Adults)	None	Additional Diagnoses Beta = .489, p=0.10
Quality of Healthcare (Children)	Number of Additional Diagnoses, Beta = -.337, p<.05	None
Difficulty Finding a PCP (Adults)	Additional Diagnoses, Beta = .989, p<.01 Rating of Overall Health, Beta = .630, p<.05	Age, Beta = -.567, p=.07 Number of Behavior Issues, Beta = -.481; p=.07, Population Density, Beta = -.481, p=.07
Difficulty Finding a PCP (Children)	Diagnosis (having diagnosis other than autism), Beta = .270, p<.05; Behavior Issues, Beta = .232, p<.05	None
Difficulty Finding Specialists (Adults)	None	None
Difficulty Finding Specialists (Children)	Age, Beta =.303, p<.05	None
Responsiveness of PCP (Children)	None	None
Responsiveness of PCP (Children)	None	Rating of Overall Health, Beta = -.219, p=.052
Screening and Routine Care (Adults)	Number of Additional Diagnoses, Beta = .282, p<.005	None

Outcome	Significant Predictors	Factors Approaching Significance
Screening and Routine Care (Children)	None	None

PCP-related characteristics and healthcare outcomes. Simultaneous linear regression was also used to determine if a number of patient and guardian-reported PCP-related characteristics predicted selected healthcare outcomes. The variables that were examined are listed in Table 27 below:

Table 27

Independent and Dependent Variables Examined in Determining Association Between PCP-Related Characteristics and Healthcare Outcomes

Independent Variables	Dependent Variables
• PCP Understanding of ASD • PCP Understanding of Individual Patient's Needs • Communication Composite • Responsiveness Composite	• Quality of Healthcare • Routine Care and Screening • Physical Health, Mental Health and Sexuality (Adults Only) • Percentage of Wellness Items Discussed

The combination of PCP-related characteristics (as reported by parents) predicted the values of two selected healthcare outcomes for children—*Routine Care and Screening* and *Wellness and Safety Issues Discussed with Patients.* In each case, however, only one or two variables accounted for most of the variance. For *Routine Care and Screening items completed,* the R Square was .140, F=3.245, p<.05. This was explained almost entirely, however, by a surprisingly strong negative relationship with the *Responsiveness of the PCP Composite Score* – Beta = -.571, p<.005. In other words, the parent's rating of their PCP's responsiveness were negatively correlated with the percentage of routine care and screening items completed. *Wellness and Safety Items* were predicted by the combination of variables (R Square = .123, F-2.80, p<.05). The *Communication Composite Score* when controlling for the other independent variables, was strongly associated with the *number of wellness and safety items discussed* - Beta

= .35, p<.005. The responsiveness of the PCP was also positively correlated with *the number of wellness and safety items discussed*, but the relationship did not reach the level of significance.

For adults, only one independent variable was significantly correlated with a healthcare outcome. The *Communication Composite Score* was negatively correlated with *Routine Care and Screening items completed*. Individual variables found to be significant in these models are listed in Table 28 - *Patient, Parent and Guardian Reported PCP-Related Characteristics and Healthcare Outcomes* below. Variables that approached significance are also listed.

Table 28

Patient, Parent and Guardian Reported PCP-Related Characteristics and Healthcare Outcomes

Outcome	Significant Predictors	Factors Approaching Significance
Quality of Healthcare (Adults)	None	None
Quality of Healthcare (Children)	None	Communication Composite, Beta = .215, p=.10
Routine Care and Screening (Adults)	Communication Composite, Beta= -.571, p<.05	None
Routine Care and Screening (Children)*	Responsiveness of PCP, Beta = -.312, p<.005	None
Percentage of Wellness Items Discussed (Adults)	None	None
Percentage of Wellness Items Discussed (Children)*	Communication Composite, Beta = .35, p<.005	Responsiveness of PCP, Beta = .170, p=.104
Physical Health, Mental Health and Sexuality (Adults)	None	None

Discussion

Early Identification and Diagnosis

Perhaps the most encouraging finding from this study is that the median age of diagnosis with ASD for children was 4 and 2.9 for children who were 8-years old or younger at the time of the survey. The median age for adults who were diagnosed as children was 7.5. The lower median age of diagnosis in the successive cohorts suggests a substantial improvement in early identification and diagnosis in Maine over time. Furthermore, it is also nearly half the median age of 5.7 reported in a 2009 population-based study (Shattuck et al., 2009). Consistent with previous research, some parents and guardians complained that their PCP was too slow in responding to their concerns about their child's early development (e.g., Carbone et al., 2010; Jensen & Spannagel, 2011). This appears to have improved dramatically however, especially in the last eight years. Indeed, the parent of two children with ASD noted a significant improvement in her pediatrician's practices between the birth of her two children. It is reasonable to assume that these results can be attributed, at least in part, to the efforts made through the Maine PDD Systems Change Initiative to improve screening and early identification practices. Other factors may play a role, however. There is some evidence that early identification and diagnosis have improved nationwide, possibly as the result of the national Act Early network (Association of University Centers on Disability, 2014), in which Maine participated. The apparent dramatic improvements in Maine could simply reflect national trends. The results reported here must also be interpreted with caution. The children and adults with ASD for whom data was collected in this study may not have been representative of persons with ASD in Maine. There may also be differences in the child and adult samples, other than age, that could explain the differences between the groups. The same cautions apply when comparing these results with national data.

Health Issues

The percentage of individuals with ASD who were reported to be in *excellent* or *good* health was very high compared to previous research. Gurney et al. (2006) reported that in a national survey, only 57% of parents of children with autism reported that their children were in *excellent* or *good* health compared to 84% for U.S. children generally. In contrast, the 83% of the parents of children with ASD in Maine reported their children were in *excellent* or *good* health—almost identical to the rate for U.S. children in general in 2006. The rate for adults was even higher with 85% reported to be in *excellent* or *good* health. There are several possible explanations for these results. First, individuals in Maine with ASD may, in fact, be in better health than those in the earlier study. This may be an indication that existing efforts to improve effective and coordinated healthcare in Maine have been successful. Second, these results could reflect improved healthcare for persons with ASD in general since 2006 when national comparison data were collected. Again, questions about whether the samples were representative constitute a threat to external validity and limit our ability to make definitive conclusions about the overall health of individuals with ASD in Maine.

GI problems constituted one of the biggest concerns reported by participants in this research. More than 80% from both the children's and adult groups reported at least one GI issue, far greater than the highest previous estimates indicating rates as high as 70% for this population (Buie et al., 2010). The mean number of GI issues was also high, with parents indicating their child[ren] with ASD had an average of 2.3 GI issues and adults reporting a mean of 3.4 GI issues. The most common GI issue for children was constipation (58%). For adults, the most frequently identified GI issue was food intolerance (54%). These data suggest that GI problems are very common and constitute a significant medical issue for both children and adults with ASD in Maine.

Not surprisingly, nearly all respondents reported at least one behavior issue. The most common category of behavior issues was self-stimulatory behavior with 94% of the parents indicating that their child had at least one self-stimulatory behavior. The rate for adults was nearly as high with 86% reporting self-stimulatory behavior. It was impossible to determine from this data whether parents or guardians considered self-stimulatory behavior as serious as other problem behaviors such as aggression, self-injurious behavior, or property damage. The fact that there were few comments about this category of behavior in the comments section, however, suggests that parents did not consider it as serious an issue as other categories of problem behavior. Thus, its inclusion as a problem behavior in this research may have resulted in an exaggeration of the number of problem behaviors that are of serious concern to parents and guardians.

A large percentage of children also were said to exhibit aggressive behavior and self-injurious behavior, but the reported rates were much lower for adults. This points to the possibility that behavior problems tend to decline with age. This interpretation is consistent with comments made by parents who indicated that behavior issues tended to decline as their children got older. It was also consistent with the children's quantitative data where a significant strong negative correlation was found between age and the number and frequency of behavior issues. The cross-sectional design of this study made it impossible to determine with certainty if behavior issues actually declined with age, however. Only a longitudinal study examining problem behavior in individuals over time would permit such a conclusion. An alternative explanation for the lower rates of behavior issues among adults was that eight adults self-reported. Those adults may have had different criteria for "problem behavior" and may not have reported behavior that others considered problematic.

The data on PCP responses to behavior issues suggest four areas of possible concern. First, PCPs recommended behavior assessments for children at a relatively low rate, seeming to favor medication over behavior assessments. Children's PCPs prescribed medication in 45% of the cases while adults were prescribed medication in only 11% of cases. Behavior assessment, in contrast, was recommended in only 12% of the cases for children, but in 33% of cases for adults. The high ratio of medication prescription to behavior assessments in children may be explained, in part, by the fact that PCPs often address only one component of a larger behavior management strategy for a child, namely managing medication. A number of professionals—both within and outside the medical profession—may address behavior issues (e.g., a psychologist who conducts a functional behavior assessment). In addition, according to some respondents, school personnel, staff at adult agencies, or other contracted professionals may take primary responsibility for managing behavior. These individuals and agencies often conduct functional behavior assessments, making it impossible to determine, based on this data, the rate at which behavior assessments are actually utilized. The differences in the use of prescription medication for behavior between the adult and children's groups may also be related to apparent differences between the two groups in the intensity and frequency of problem behaviors. Although there was no indication in the survey responses that any of the families received pressure from schools to have their child's problem behavior treated with medication, it is possible that in some cases school personnel encourage families to obtain prescription medication for their child's problem behavior.

A second concern is that 22% of the parents reported that their child's PCP indicated "nothing could be done." This is clearly at odds with a modern understanding of ASD as a condition that, although lifelong, can be treated. Several parents also felt that their PCP could do more and did not do so either because of a lack of time or knowledge.

Third, PCPs often did not participate actively as part of a team addressing the behavior issues of persons with ASD. As our understanding of the links between medical issues, pain, and problem behavior grows, a greater role for PCPs in the management of behavior may be indicated. The PCP may play an especially important role in coordinating supports within the context of a medical home. A significant obstacle to such participation may be a lack of reimbursement to medical professionals for their participation in this kind of planning.

Fourth, over 50% of the parents and guardians suggested a connection between GI issues and problem behavior. PCPs, apparently, rarely followed up on those concerns. When PCPs of children did respond, their most common response was to order diagnostic tests, but this occurred for only 11 children (21% of those reporting GI issues and problem behavior). For adults, the most common response was prescribing medication. This limited response seems at odds with an emerging body of evidence suggesting that pain or medical issues can often be setting events for problem behavior or that they can exacerbate problem behavior (Carr & Owen-DeSchryver, 2007; Charlot et al., 2011; Walsh, Mulder, & Tudor, 2013). GI issues, especially, may play a significant role in problem behavior. In a consensus report, the American Academy of Pediatrics (AAP) states, "Individuals with ASDs and gastrointestinal symptoms are at risk for problem behaviors" (Buie et al., 2010, p.57). For patients with ASD who present with problem behavior, the AAP makes the following recommendation:

> The care provider should consider the possibility that a gastrointestinal symptom, particularly pain, is a setting event, that is, a factor that increases the likelihood

> that serious problem behavior (e.g., self-injury, aggression) may be exhibited. Sudden and unexplained behavioral change can be the hallmark of underlying pain or discomfort. Behavioral treatment may be initiated as the possible concurrent medical illness is being investigated, diagnosed (or excluded), and treated, but the behavioral treatment should not substitute for medical investigation. (p.58)

Only seven parents (8%) of children indicated that their child had at least one seizure. This is at the low end of estimates for seizure activity among individuals with ASD. In contrast, 7 adults (32%) indicated they had seizures, which was closer to the high end of estimates for this population. This was consistent with previous findings indicating that seizures become more likely for individuals with ASD as they grow older (Bolton et al., 2011). The number of respondents who were “unsure” made it difficult to compare the rates uncovered in this study with previous research. Prescribing medication was the most common response by PCPs for both groups. The majority of adults frequently had blood work done or EEGs completed. The number and frequency of various responses by medical professionals to seizures was probably underestimated because many of the respondents indicated that they see physicians other than their PCP for seizure issues.

More than 85% of the respondents in each sample reported at least one sleep issue. This was higher than previous research indicating that as many as 80% of individuals with ASD experience sleep disorders (Parellada et al., 2011; Sivertsen, Posserud, Gillberg, Lundervold, & Hysing, 2012). Overall, the sleep issues reported in both samples was remarkably consistent. The most common reported sleep issues for both groups were insomnia and difficulty getting to sleep. Large percentages in both groups also had difficulty waking up or sleeping too much. The most common PCP response to sleep issues was prescribing medication. Relatively few recommended any kind of further assessment, however.

These results must also be treated with caution. Researchers have found that subjective parental ratings of sleep for their children with ASD can be unreliable (Hodge, Parnell, Hoffman,

& Sweeney, 2012). These researchers also report that obtaining objective measures of the quality of sleep can be difficult for this population. Indeed, an inability to tolerate intrusive sleep assessments may explain why PCPs seldom recommend further assessment for individuals with ASD in this study. Regardless of the reliability of these measures, many parents and guardians report that sleep issues are a source of stress for the family.

Healthcare

Respondents rated overall healthcare highly—although a small number of parents rated their experiences as *poor*. The positive experiences were reflected in the comments section, where many spoke very favorably of their current PCP. Most indicated that they had a place to go for healthcare and had a regular doctor or nurse who they saw and whom they had talked to in the last 12 months. While most of those with ASD, their parents, and guardians appeared to be satisfied with the quality of medical care they receive, a significant minority were not. Comments suggested that for some families, dissatisfaction was largely a reflection of their difficulty finding a medical practice that could meet their needs. Several families, in fact, reported dramatic differences in their perceptions of the quality of care they received from former and current providers. Several also said that the process of finding a provider who could meet their needs was arduous.

Perceptions about the quality of healthcare also appeared to reflect varying parent and guardian perceptions of the role of medical providers in addressing ASD itself. For some providers, the bar may have been set almost impossibly high by parents who were dissatisfied with any medical care that did not lead to a cure for their child’s ASD, or at least a significant amelioration of ASD-related symptoms. The comments of several parents seemed to indicate that they believed ASD is often a medically curable condition. For example, one parent expressed concern about her child’s ability to get appropriate care “if he still has the autism” when he is an adult. Another asked, “Why do some kids outgrow ASD and others don’t?” In several cases, parents indicated that they felt the PCP was not doing enough to address the medical issues that they believed were underlying their child’s ASD.

Not surprisingly, the more additional diagnoses a child had the more likely their parents were to rate their overall healthcare as low. For adults the relationship between these appeared to be reversed. More diagnoses were associated with higher ratings of healthcare. This relationship only approached significance (p=.10), however. It was unclear why the direction of this relationship among adults may have been opposite of that among children.

Increasingly, researchers are recognizing that quality healthcare for individuals with ASD is care that is provided within a medical home model (Murphy, Carbone & The Council on Children with Disabilities, 2011). According to the American Academy of Pediatrics (2002), patients in a medical home receive care that is comprehensive, coordinated, continuous, and family-centered. Respondents were not asked specific questions about the extent to which certain characteristics of a medical home were realized in this survey. Many did address some of these characteristics in their comments, however. For example, several people thought that their medical provider did a good job coordinating care, but others complained about the lack of coordination and even a fragmentation of services. A number of those interviewed felt that there was a lack of communication among specialists and PCPs, a lack of coordination within a single practice, and that they had to provide the same information to multiple providers. It was impossible, using the existing data, to draw any firm conclusions about the overall coordination of care for persons with ASD in Maine. Respondents' comments, suggested, however, that it may be a significant issue for some individuals with ASD and their families.

There was also some evidence that continuity of care associated with a medial home can break down, especially for youth transitioning from pediatric to adult care. If the data in this study accurately reflects the experiences of youth with ASD in Maine generally, pediatricians and other PCPs have done little to prepare them for the transition to adult healthcare. The data also suggested that healthcare transition plans may be provided to children in Maine at levels below the 21% level seen for children with ASD in the National Survey of Children with Special Healthcare Needs (Cheak-Zamora et al., 2013). Although respondents were not asked specifically if their child had a comprehensive healthcare transition plan, none of the parents indicated that such a plan was in place. The only transition-related items that parents indicated PCPs had completed were (a) offering to see children when they become adults (n=2, 15%); (b) informing families about the age when the child should transition to an adult provider (n=2, 15%), and (c) offering to help find an adult provider (n=1, 8%). The reasons for this lack of support for healthcare transition were unclear. It is possible that obstacles that typically interfere with the provision of a medical home, namely a lack of time in standard office visits, reimbursement, and specific guidelines (Hyman & Johnson, 2012), also have served as obstacles to healthcare transition planning.

The adults or guardians who were interviewed indicated that most of the wellness items that they were asked about had been addressed. The only two topics that had not been addressed for a large majority of adults were “obesity” and being “underweight.” No data was collected on the patients’ weight so it could not be determined if this was a serious issue. Parents of children were asked a broader range of questions related to *wellness* and *safety*. A majority of the parents of children reported that their PCP had discussed safety issues, peer relationships, diet and nutrition, secondhand smoke, oral health, and physical activity or exercise, but they did so at a rate lower than for adults. As with adults, only a small number talked about weight issues. There were a number of possible explanations for why PCPs did not discuss some topics with patients. In some cases, the PCP or the parent may have felt that the child could not benefit from such a discussion. Many children were simply regarded as too young. In other cases, parents indicated in their comments that providers other than the PCP addressed those issues.

A majority of the adults or guardians reported that the PCP had talked about *tobacco use, drug use, alcohol use, moods or emotions, and interaction with peers*. More than 40% reported that the PCP talked to them about *sexual abuse, sexual orientation, STDs, safe sex,* and *birth control* and *abuse*. Tobacco or recreational drug use did not appear to be significant issues for the adults who participated in this study. Interestingly, the percentage of youth who talked with their PCPs about alcohol use was lower among those who actually reported using alcohol than for the sample as a whole. Perceptions about the cognitive abilities or maturity of the person with ASD may have had some effect on the *physical health, mental health,* and *sexuality* topics discussed with adults. For example, the guardian of an adult and the PCP reportedly agreed that they should talk to the adult about issues related to sexuality including abuse and the possibility of a vasectomy. They had not yet determined how to talk with him about these topics at a level he would understand, however. The parent of another adult reported that it was difficult to talk with her about these topics because of her social immaturity. The fact that PCPs talked with adult patients less often about sexual topics than substance abuse or moods and emotions may be of concern. In addition to having concerns about understanding or social maturity, it is possible that some PCPs or guardians may have felt uncomfortable addressing these topics. It is also possible that some patients were viewed as being incapable of participating in adult sexual relationships.

It was impossible to determine the extent to which conversations about wellness or living healthy lifestyles between PCPs and their patients with ASD affected patients' actual behavior. A number of parents and guardians in this study were concerned about these issues, even when PCPs had engaged their child or ward in discussions about the topics.

A mere cognitive understanding of what is considered appropriate, or even in a person's best interest, may be insufficient for many individuals with ASD who have difficulty translating cognitive understanding into behavior (Klin, Jones, Schultz, & Volkmar, 2005). It is perhaps for this reason that direct instruction in natural, community-based instruction is so effective for this population (Wehman, Lau, Molinelli, Brooke, Thompson, Moore, & West, 2012). Future research, therefore, should examine not just what PCPs are recommending to their patients with ASD regarding wellness and living healthy lifestyles; it should examine how those recommendations are being integrated into a broader program of education and support as well as the effectiveness of those programs.

Healthcare Access

Somewhat surprisingly, a majority in both the child and adult samples indicated that they had no difficulty finding a medical provider. Nationally, many individuals with ASD or their parents have indicated they have difficulty finding services (Chiri & Warfield, 2012). There were some exceptions however. For example, two adults did not have a regular place to go for healthcare or a regular nurse or doctor. Also surprising was the fact that finding a medical provider did not appear to be significantly more difficult for those residing in counties with lower population densities. Although there was a negative correlation between population density of the county of residence and difficulty finding a provider among adults, the relationship only approached significance. Previous research has indicated that individuals with ASD and their families from metropolitan areas found it easier to access medical services than those in less populated areas (Thomas et al., 2007). There are several possible explanations for these results. First, living in a rural area may have little effect on healthcare outcomes for those with ASD in Maine. Second, the sample size may have been too small to detect a significant relationship, especially with adults. Third, the measure of population density may have been too crude and may not reflect how close a family is to a population center where a wide range of medical services would be available. For example, Maine's second largest city, Bangor, is in Penobscot County, which has a relatively low population density. Much of the Penobscot County population is concentrated in the Bangor area. In addition, Bangor has two hospitals including one large medical center. The low population density of Penobscot County may not reflect the ease with which most of its residents can access healthcare. Finally, previous research examined the effects of living in a metropolitan area and not population density per se.

More than 50% in both samples indicated that finding medical specialists was difficult. Dental care was especially hard to obtain. Others commented that they had difficulty getting referrals from their PCP or having to provide multiple providers with the same information. These findings were consistent with previous findings indicating that individuals with ASD tend to have difficulty obtaining specialty services and referrals (Chiri & Warfield, 2012; Kogan et al., 2008; Krauss et al., 2003; Liptak et al., 2006) and suggest that obtaining specialist care continues to be a problem for people with ASD in Maine.

Several individual characteristics were associated with greater difficulty in finding a PCP. Children who had diagnoses other than autism, such as Aspergers or PDD-NOS, and those with a higher number of behavior issues were more likely to have difficulty finding a PCP. It is not surprising that some PCPs might be reluctant to accept a child who has a large number of behavior issues as a patient. The other finding is harder to explain. We assumed that medical providers would be less likely to accept patients with autism than those with less significant ASD-related impairments. In fact the opposite was true. Access to specialty care among children was predicted by only one variable. As children aged, they were more likely to have difficulty finding a specialist.

For adults, having additional medical diagnoses and having higher ratings of overall health were associated with difficulty finding a PCP. There were several variables that approached significance in predicting difficulty finding a PCP among adults. Surprisingly, the number of behavior issues was negatively associated with finding a PCP ($p=.07$). In other words, having more behavior issues appeared to make it easier to find a PCP—again a reversal of this relationship for children. As adults got older they were also more likely to be able to find a PCP ($p=.07$).

About 86% of adults and 93% of the children received some routine medical care in the 12 months preceding the interviews. Most had also received a complete physical in that time, although four parents reported that their child had never had a complete physical. Respondents indicated that 85% of screening and routine care items had been completed for children compared to only 36% of screening and routine care items for adults. It is difficult to make direct comparisons between adults and children, however. The routine care items list for adults was much larger and contained a number of items that a PCP might not address when there was no evidence that it was an issue. Specific issues that may be of concern for adults are the fact that none of the adult males reported having had a prostate exam and only five of seven adult women reported having a breast exam. The biggest concern related to routine care and screening emerged from the qualitative comments. Parents reported that a number of routine procedures were difficult with their children. These included relatively simple procedures such as taking a pulse, measuring blood pressure, examining an individual’s throat or ears, and in giving injections or vaccinations. Obtaining routine care may continue to be difficult for those families if strategies for completing these procedures cannot be identified. Among adults, the number of additional diagnoses was strongly correlated with the number of routine care and screening items completed by the PCP. It was unclear why this was the case. One possible explanation was that some PCPs felt additional screening and routine care items should be completed for adults with ASD who had more significant medical needs. No patient or PCP characteristics predicted the number of routine care and screening items completed in children, however.

Skepticism about traditional medicine has been found to be an obstacle to children with ASD obtaining routine care and screening (Hyman and Johnson, 2012). Such skepticism was evident when three parents indicated in their comments that they would never let their children receive vaccinations and, in at least one case, blamed vaccinations for their child's ASD. The use of alternative and complementary approaches without talking to their PCP may have also reflected skepticism or frustration with traditional medicine.

Perceptions of PCPs

In general those interviewed were satisfied with the quality of communication between the PCP and themselves. Most felt that the PCP explained things in ways that they understood and that the PCP listened to them. This stood in contrast to research indicating that families of persons with ASD were often dissatisfied with provider/patient communication (Nicholaidis, et al., 2012). These results also suggested that communication between PCPs and patients with ASD, guardians, and parents were a relative strength of the healthcare system in Maine. Several concerns were expressed in the comments section, however. The greatest concern related to communication was that some PCPs did not speak directly to the patient with ASD. In fact, over 22% of parents reported that their PCP did not understand how their child communicated. Others felt that direct communication between the patient with ASD and the PCP was inappropriate because they believed the patient was incapable of participating meaningfully in these conversations. It was possible that beliefs about the appropriateness of direct communication with a particular patient may have been tied to the PCP's or parents' perceptions about a patient's cognitive abilities or communication skills. A second concern was that some parents felt the PCP questioned their credibility. This was consistent with earlier reports indicating that many parents of children with ASD felt that PCPs did not value their opinion (Brachow, Ness, McPheeters, & Gurney, 2007; Magaña et al., 2012). Previous research also indicated that PCPs often do not spend enough time with patients with ASD and their parents or guardians (Brachow, Ness, McPheeters, & Gurney, 2007; Magaña et al., 2012). This did not appear to be a significant problem for a large majority of patients with ASD in Maine. Those who did indicate it was a problem, however, appeared to feel very strongly that they were rushed and not given sufficient time to fully address their concerns.

Overall, those interviewed indicated that the PCP was very responsive. A large percentage reported that the PCP got back to them quickly when they had a question and followed up with them after diagnostic tests. Most also reported usually seeing their PCP within 15 minutes of an appointment although 36% of parents reported that this never occurred or only occurred sometimes. Without data on wait times for others it was impossible to determine whether individuals with ASD experience longer wait times than other patients. Some families indicated in their comments that any wait was difficult. While some medical practices apparently addressed this problem by providing a quiet place for families to wait, this accommodation was provided to only 31% of the families who reported requesting it.

Parents perceptions about the ASD-specific knowledge possessed by their PCP varied widely. Most felt that the PCP was always or usually knowledgeable but a few felt they knew little about ASD. Adults with ASD and their guardians tended to be less convinced that their PCP understood the patient’s ASD diagnosis than parents of children. The differences between these two samples may have reflected greater knowledge about ASD among pediatricians, possibly due to the increasing number of children with ASD seen in their practices. Alternatively, some parents and guardians of adults have had more time to learn about ASD than parents of children. Those parents and guardians may have perceived the PCP as having less knowledge because of their own relatively advanced knowledge about the condition. Most of those interviewed felt that the PCP had a good understanding of the patient as an individual. This included understanding the person with ASD's other diagnoses, knowing important facts from the patient's history, and treating the patient with sensitivity. Furthermore, there was little evidence that medical providers ignored routine and preventative care because of their focus on ASD-related issues. This ability to "see beyond the diagnosis" was generally viewed positively.

Another relative strength of medical practices in Maine was in scheduling appointments for their patients with ASD in a timely manner. All adults or their guardians reported being able to get appointments as soon as needed and 85% of parents of children did. Only three parents reported never being able to get an appointment as soon as needed.

The responsiveness of Maine PCPs to suggestions from patients or family members about complementary and alternative care was mixed. Some families reported that their PCPs were supportive, while others apparently rejected Augmentative and Alternative Communication (AAC) out of hand. Over 60% of children and 41% of the adults were reported to have accessed some form of AAC. Only a small portion of those (21% and 31% respectively) reported that they discussed this with their PCP. This low rate of communication about the use of AAC may have been the result of parents or guardians feeling they would not be taken seriously. Given possible interactions with other treatments, the frequent accessing of AAC without talking to PCPs may be problematic.

The responsiveness and communication composite scores predicted several healthcare outcomes. The number of routine care and screening items was negatively correlated with PCP communication composite scores among adults and PCP responsiveness composite scores for children. The latter relationship was very strong. Both of these results were unexpected. It was assumed that PCPs who were more "communicative" with patients and families or who are more "responsive" would complete more routine care items. One explanation for these results is that the composite responsiveness and communication scores used here may not be valid measure of the constructs "responsiveness" or "communication." It is also possible that more routine care and screening items were necessary when PCPs were less communicative or responsive in their interactions with patients with ASD. Not surprisingly, a higher communication composite score was associated with discussing more wellness items in children. PCPs were probably more likely to discuss wellness issues with children who they felt could understand. For adults, however, a higher communication composite score was not predictive of the number of physical health, mental health, and sexuality items discussed. There were no significant patient- or PCP—related characteristics that predicted the predicted responsiveness of PCPs.

Support for Greater Patient Responsibility for Healthcare

There was very little evidence that PCPs have encouraged or supported individuals with ASD in Maine to take greater responsibility for their own healthcare. Only 17% of the parents of children over age eleven and 20% of the guardians of adults reported that this was always or usually the case. Most notable, however, was the large percentage of parents and guardians who simply did not respond to the question—47% of parents of children over 11 and 33% of the adults with guardians. It was unclear why this is the case but it may have reflected, in many cases, parent's or guardians' beliefs that their child or ward as simply too disabled to take more responsibility for their healthcare. Several of the individuals interviewed, in fact, stated explicitly that the patient was unable to either communicate effectively with medical providers or understand conversations about medical issues. Still others felt that the person with ASD would be overwhelmed by such discussions. The seven adults without guardians were not asked the question about taking greater responsibility. If they had been included, the percentage of adult encouraged to take greater responsibility would undoubtedly have been higher.

The extent to which communication impairments interfered with patients taking greater responsibility was evident in parent and guardian responses to a question about how the person with ASD communicated that she or he was in pain or ill. Parents and guardians reported that they frequently had to interpret the idiosyncratic behaviors of their child or ward that served as indications of pain or illness. Even those who could speak were often said to have difficulty specifying exactly what was wrong or the severity of a medical problem. This was consistent with the results of previous research indicating that verbal and nonverbal communication impairments often make it difficult for patients with ASD to communicate their subjective health-related experiences or symptoms (Buie et al., 2010; Parellada et al., 2011; Scarpinato et al., 2010).

It should not be surprising that parents and guardians who have had to both coordinate their child or ward's healthcare and act as an interpreter or translator would be wary about turning over responsibility to the person with autism. The idiosyncratic nature of their interpersonal communication might also make them reluctant to turn over the responsibility to others. The dependence of children and adults with ASD on others in helping them communicate with medical providers may partially explain why only 13% of the adults with guardians and 3% of children over 11 ever spent time alone with the PCP. Given the dependence of patients with ASD on parent and guardians to obtain appropriate medical care, concerns about their child or ward's future ability to access healthcare seem well-founded. Unfortunately, it appears that little is being done to increase the capacity of persons with ASD, whose communication is limited or unconventional, to communicate their health concerns or take more responsibility for their healthcare. For example, only three parents mentioned the use of AAC systems by patients with ASD to communicate health concerns.

Insurance

Issues related to insurance coverage for individuals with ASD were similar to those reported in earlier studies. None of those completing the interviews indicated that they had no insurance. But, as Chiri and Warfield (2012) reported, having healthcare insurance did not mean that all needed healthcare services could be accessed. In fact, a number of families complained that either their private health insurance or MaineCare did not cover the services they needed. Parents in Maine generally expressed satisfaction with MaineCare, however. Some parents with private insurance stated that they were trying to enroll their children in MaineCare so that they could get more services. This was consistent with Wang et al. (2013) who said that Medicaid programs tended to cover more ASD-specific services than private insurance. Some of those whose children were receiving MaineCare benefits already, worried about budget cuts that might force their children off MaineCare. Parents in this study expressed two complaints regarding how MaineCare could limit access to medical care. First, some felt that MaineCare did not cover enough services. Second, several parents reported difficulty finding medical providers who would accept MaineCare.

Conclusion

Positive Trends in Accessing Healthcare

This research revealed a number of positive trends in healthcare for individuals with ASD in Maine. Medical providers appeared to be responding earlier to parental concerns about development than in the past, often leading to the diagnosis of ASD at an earlier age. Participants in this research were also generally satisfied with the healthcare received by persons with ASD and with their overall health. Many were also satisfied with their PCP. Most felt that the PCP usually understood a patient's ASD as well as his or her individual needs. For the most part, participants in the research felt that PCPs were very responsive, respectful, and that they provided medical care in a timely manner. Individuals with ASD in Maine seemed to have little trouble accessing healthcare, although some reported that they initially had difficulty finding a provider. Many also continued to have difficulty finding specialists or getting referrals. One of the most surprising findings from this research was that parents of children living in less densely populated counties did not report significantly more difficulty finding providers for their children than those living in more populated counties. Most individuals with ASD had a regular provider and most of their routine medical care and screening addressed. Undoubtedly, current initiatives in Maine to improve access to healthcare for this population contributed to these positive results.

Healthcare Access Concerns

This research also revealed a number of possible concerns, however. First, although most of those participating in these interviews were satisfied with the healthcare the person with ASD received, a small number were very dissatisfied. For some, this dissatisfaction was related to difficulty finding a PCP or specialist who could meet their needs. For adults, those with more significant healthcare needs—as measured by the number of additional diagnoses—tended to have more difficulty finding a PCP. For children, having more frequent or more intense problem behaviors appeared to be associated with having difficulty finding a PCP. Other participants were dissatisfied because of poor communication with the provider or the responsiveness of the provider, especially when they failed to provide accommodations. The most frequently requested accommodation was for an alternative to the waiting room. Several parents and guardians also felt that their concerns were not taken seriously or that the provider did not spend enough time with them.

GI problems were reported at higher rates than had previously been reported for this population. Although PCPs responded to GI concerns in a number of ways they frequently failed to follow-up when a relationship was suggested between the patient's GI issues and behavior. This was inconsistent with recent recommendations from the American Academy of Pediatrics suggesting that medical issues, especially those related to GI problems, be investigated as possible contributors or triggers for problem behavior. PCPs were also much more likely to prescribe medication for behavior issues in children than to recommend behavior assessments. The low rate of recommendations for behavior assessments may have been due to the fact that a number of professionals usually play a role in managing a child's behavior and behavior assessments are often addressed by professionals other than the PCP.

Many parents, guardians or adults with ASD indicated that the patient with ASD accesses some type of complementary or alternative care. This frequently occurs without consulting the PCP. This may be a concern, especially in those cases where the interventions could interact with prescribed medications.

Several of the individuals interviewed reported problems with the coordination of healthcare. The most common complaint was a lack of communication among PCPs and specialists. Perhaps the most significant issue related to healthcare coordination, however, was the lack of support available to youth and their parents as children transitioned to adult medical care. In addition, very few of the participants indicated that any effort had been made to encourage youth or adults to take on more responsibility for their own healthcare—something that typically happens as youth reach adulthood.

A number of parents indicated that routine care and screening items were not addressed because their child would not tolerate them. It was not clear, however, whether parents decided that they could not be completed or whether the provider was unwilling to attempt them. In some cases, parents identified creative strategies that they used to facilitate procedures. In another case, a child was restrained so that the procedures could be completed. Patients communication impairments frequently posed a significant obstacle to specifying the nature of their pains or illnesses. Again, parents and guardians reported that they had developed accommodation strategies. These included interpreting the nuances of their children's behavior and the provision of supports to help them provide more detail. Despite the reported difficulties with communication, only three of the participants mentioned the use of AAC for reporting medical issues or engaging in discussions with medical providers.

Parents and guardians reported that they frequently had difficulty finding specialty care, especially dental care. These issues were compounded because many providers did not accept Medicaid.

Recommendations

Transition supports. Youth with ASD often have comorbid conditions that make healthcare transition planning especially important (Cheak-Zamaora, Yang, Farmer, & Clark, 2013). Steps should be taken to ensure that youth with ASD receive healthcare transition services that, ideally, include detailed healthcare transition plans. Topics addressed in healthcare transition plans should include accessing adult medical providers, support for living healthy lifestyles, and taking more responsibility for one's own healthcare.

Parents in this study frequently expressed concern about how their children's healthcare needs will be met when they are no longer available to provide support. Parents and guardians also had unique insights into their children's medical history and how they communicate their medical concerns. Healthcare transition plans, therefore, should include detailed information obtained from parents or guardians about their understanding of their child's medical history, how their child communicates she or he is in pain or sick, and a description of any accommodations and supports they provide to make medical appointments more successful.

Attempts should also be made to develop a streamlined transition planning process for PCPs to use with transition-age children with ASD. This could include the development of forms that the provider could complete that would detail not only important medical information, but some of the strategies their practice uses in meeting the unique needs of the individual patient.

Support for self-determination in healthcare. The acquisition of self-determination skills in a variety of domains has repeatedly been demonstrated to improve adult outcomes for persons with disabilities including those with ASD (Wehmeyer & Abery, 2013). This research indicates that many individuals with ASD in Maine are not acquiring the skills necessary for them to take more responsibility for their own healthcare. Efforts to strengthen the capacity of individuals with ASD to participate in their own healthcare should, therefore, be undertaken by schools, families, and adult providers. Individuals with ASD clearly have different capacities to participate in decision-making regarding their own healthcare and can benefit from different types of instruction. Even those with limited communication, however, are likely to benefit from instruction and practice with communication skills that would allow them to more reliably communicate their health concerns.

Medical provider training on the unique needs of patients with ASD. Medical providers should receive some training on the unique medical needs of individuals with ASD. This could include information on common comorbid conditions, the relationship between medical issues and problem behavior, accommodations that practices can make to make appointments easier, GI issues, effective communication strategies, and the experiences of families of children with ASD in accessing medical care.

Role of medical providers in individual planning. PCPs should be encouraged to provide some input to the teams that provide support to their patients with ASD. This might include providing those teams with information on medical issues that could be triggers for problematic behavior and on maintaining healthy lifestyles.

Living healthy lifestyles. PCPs frequently speak with their patients about wellness issues. Unfortunately, one-time or even annual talks with the PCP are unlikely to have a significant impact on the ability of many individuals with ASD to live healthy lifestyles. Some may need intensive and ongoing instruction. For many, this instruction should begin in school and continue into adult life. Effective instructional materials and strategies should be identified and shared with medical practices, schools, and adult providers.

Improving access to healthcare and coordination of care. Current efforts to improve the quality of healthcare and coordination of care for Maine citizens with ASD should continue. As part of that effort, PCPs should be encouraged to take a more active role in the life of patients with ASD. Admittedly, time limitations prevent PCPs from participating in regular team meetings, but strategies for including input from PCPs in the person's overall planning should be developed. The input of PCPs into discussions about problem behavior and living healthy lifestyles may be especially important.

Policy changes. The policies of medical practices, insurance companies, and MaineCare often limit the amount of time that a PCP can devote to an individual patient during office visits. In addition, supports that a PCP might ideally provide such as transition planning or assistance in providing a positive behavior support plan usually are not billable. Policy changes should be explored that (1) would allow PCPs to devote more time in office visits to persons with ASD who have complex medical needs, and (2) would allow medical providers to bill for activities such as contributing to healthcare transition or positive behavior support plans.

Specialty care including dental care. Efforts should be undertaken to change policies that serve as obstacles to both children and adults with ASD receiving needed specialty care, including dental care.

Limitations of this Research

Inferences from this research are limited by the fact the self-selecting samples were not necessarily representative of Maine individuals with ASD, their parents or guardians. In addition, the samples were relatively small, especially the adult sample. Although many of the findings are consistent with previous research, it is impossible to know the extent to which the healthcare experiences of individuals with ASD and their families mirror those of similar populations in other states. A number of factors, shown to exacerbate healthcare disparities among individuals with ASD, were not measured and thus not included in the multiple regression analysis. These included being members of racial and ethnic minorities and having a low income. In addition, any comparisons between the adult and child samples may be unwarranted. There is no reason to believe that the individuals with ASD in the two groups share certain characteristics that might affect their access to healthcare or the quality of their healthcare.

Recommendations for Future Research

Future research should address in greater depth the extent to which persons with ASD are provided medical care that is consistent with a medical home. Specifically, the extent to which medical services are *continuous, accessible, coordinated, culturally effective,* and *family-centered* should be explored. When examining healthcare access by individuals with ASD, future research should also look beyond the supports provided by medical providers. Support for wellness, in particular, must be integrated into a larger comprehensive program of education and support. Researchers should identify effective strategies for improving the quality of health for individuals with ASD that occur within this larger system of professional and natural supports. Researchers should also explore why youth with ASD in Maine receive so little support for the transition to adult healthcare as well as the effects of minority status and income on healthcare disparities.

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