ORIGINAL RESEARCH

Comparison of Healthcare Experiences in Autistic and Non-Autistic Adults: A Cross-Sectional Online Survey Facilitated by an Academic-Community Partnership

Christina Nicolaidis, MD, MPH[1], Dora Raymaker, MS[1,2], Katherine McDonald, PhD[3], Sebastian Dern[4], W. Cody Boisclair, PhD[4], Elesia Ashkenazy[2], and Amanda Baggs[4]

[1]Departments of Medicine and Public Health & Preventive Medicine, Oregon Health & Science University, Portland, OR, USA; [2]Autistic Self Advocacy Network, Washington, DC, USA; [3]Department of Public Health, Food Studies & Nutrition and the Burton Blatt Institute, Syracuse University, Syracuse, NY, USA; [4]AASPIRE Community Partner at Large, Portland, USA.

BACKGROUND: Little is known about the healthcare experiences of adults on the autism spectrum. Moreover, autistic adults have rarely been included as partners in autism research.

OBJECTIVE: To compare the healthcare experiences of autistic and non-autistic adults via an online survey.

METHODS: We used a community-based participatory research (CBPR) approach to adapt survey instruments to be accessible to autistic adults and to conduct an online cross-sectional survey. We assessed preliminary psychometric data on the adapted scales. We used multivariate analyses to compare healthcare experiences of autistic and non-autistic participants.

RESULTS: Four hundred and thirty-seven participants completed the survey (209 autistic, 228 non-autistic). All adapted scales had good to excellent internal consistency reliability (alpha 0.82–0.92) and strong construct validity. In multivariate analyses, after adjustment for demographic characteristics, health insurance, and overall health status, autistic adults reported lower satisfaction with patient-provider communication (beta coefficient −1.9, CI −2.9 to −0.9), general healthcare self-efficacy (beta coefficient −11.9, CI −14.0 to −8.6), and chronic condition self-efficacy (beta coefficient −4.5, CI −7.5 to −1.6); higher odds of unmet healthcare needs related to physical health (OR 1.9 CI 1.1–3.4), mental health (OR 2.2, CI 1.3–3.7), and prescription medications (OR 2.8, CI 2.2–7.5); lower self-reported rates of tetanus vaccination (OR 0.5, CI 0.3–0.9) and Papanicolaou smears (OR 0.5, CI 0.2–0.9); and greater odds of using the emergency department (OR 2.1, CI 1.8–3.8).

CONCLUSION: A CBPR approach may facilitate the inclusion of people with disabilities in research by increasing researchers' ability to create accessible data collection instruments. Autistic adults who use the Internet report experiencing significant healthcare disparities. Efforts are needed to improve the healthcare of autistic individuals, including individuals who may be potentially perceived as having fewer disability-related needs.

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Over $400 million is spent annually in the United States on autism research, the vast majority addressing autism prevalence, potential etiologies, early identification strategies, and possible treatments in children.[1] However, very few studies have focused on the priorities of adults with autism (hereafter referred to as "autistic adults"[2]), including access to high quality healthcare.[3]

Prior studies have documented that people with disabilities face disparities in health and healthcare as compared to people without disabilities.[4–20] Though some studies assessing healthcare disparities for adults with developmental disabilities have included participants on the autism spectrum, with the exception of one small study using administrative data,[21] they do not report results separately for autistic participants. Most studies also primarily include participants with intellectual disabilities, and may not be generalizable to the full range of individuals now recognized as on the autism spectrum, a majority of whom do not have an intellectual disability.[22–25]

Autistic adults who use the Internet represent an understudied population of healthcare users who may experience important barriers to care, despite often being presumed to have fewer disability-related needs. The Internet has played a very important role in the Autistic community, partly because online communication can be more accessible to individuals who find in-person and telephone communication challenging.[26–29] Though the rate of Internet use amongst autistic adults has not been studied, it is likely high, with an adage in the autistic community that "the Internet is to autistics as American Sign Language was to the Deaf."[30] Autistic adults have a wealth of information to offer about their experiences, but to our knowledge, no studies elicit information directly from adults on the autism

spectrum about their satisfaction with healthcare. Moreover, autistic adults have rarely been included as partners in autism research.

We used a community-based participatory research (CBPR) approach to adapt previously validated health services questionnaires to more accurately assess the healthcare experiences of autistic adults and hypothesized that potential disparities may exist.

METHODS

This study was approved by the Institutional Review Board at Oregon Health and Sciences University.

Community-Based Participatory Research Approach

The Academic Autistic Spectrum Partnership In Research and Education (AASPIRE, www.aaspire.org) is a community-academic partnership that includes health services and disability researchers, autistic adults, family members, and disability services providers. We used a CBPR[31,32] approach, whereby academic and community members served as equal partners throughout all phases of the research. A majority of study team members are on the autism spectrum. Community and academic partners worked collaboratively to choose the research questions, design study protocols, choose and adapt data collection instruments, recruit participants, interpret results, and coauthor this manuscript. Further details of our collaboration process are described elsewhere.[33]

Setting and Participants. We conducted this study using the Gateway Project (www.thegatewayproject.org), a secure registration system for online studies. We recruited a convenience sample of adults, age 18 or older, who have access to the Internet, by messages posted to listserves, blogs, and websites targeting autistic adults, adults with other disabilities, the broader autism and disability communities, and general Internet users. We also actively recruited participants through word of mouth and our informal network of autism and disability-related organizations and community agencies. The study was conducted in two parts. All participants first completed the Gateway Survey, which includes items about whether participants consider themselves to have a disability and/or to be on the autism spectrum (including autistic disorder, Asperger's disorder, or pervasive developmental disorder–NOS). The survey also includes the six disability items used on the US Census,[34] demographic characteristics, and the Autism Spectrum Quotient (AQ).[35,36]

We invited Gateway Project participants who were U.S. residents and considered themselves to be on the autism spectrum to take the healthcare survey, followed by a random sample of non-autistic participants, selected amongst those who matched autistic responders by sex and age group. To address the relatively low proportion of non-autistic people with disabilities in the overall pool of Gateway Project participants, we oversampled people with disabilities by also inviting all Gateway project participants who considered themselves to have a disability and answered yes to at least one US census disability item. We stopped inviting non-autistic participants to take the healthcare survey when the number of non-autistic participants exceeded that of the autistic sample. Sixty-six participants were excluded because responses did not meet data validation standards (for example, responses to item on sex differed between Gateway and Healthcare surveys). We also excluded university students who had been incentivized with extra credit points to participate in the Gateway Survey.

Instrument Selection and Adaptation. Our academic and community partners collaboratively identified which constructs to measure, chose assessment instruments, and adapted instruments to be more accessible or relevant to autistic adults. Adaptations to increase accessibility included minor modifications to wording to make language more specific or clear, addition of hotlinks with definitions of technical or ambiguous terms, and addition of prefaces with more specific instructions. In one case, we created two additional items to increase relevance. For consistency, we adapted all items to be in the first person voice. To address the anxiety some partners reported experiencing when they did not know how to answer a question with complete accuracy or did not have a way to elaborate on their answers, we added a comment box on every page.

Data Collection. We collected data on *patient-provider communication* using six items adapted from 2007 Health Information National Trends Survey (HINTS).[37–40] We added two new items on expressive and receptive comprehension, because community partners felt this was not adequately addressed in the initial scale. Participants were asked to think about their interactions with healthcare providers over the past year and rate how often their providers did each behavior. Responses used a 4-point Likert scale with anchors of "Never" to "Always". We analyzed items both individually and by summing the responses into a composite score (range 8–32; higher scores indicate higher satisfaction). The original HINTS patient–provider communication scale had a Cronbach's alpha of 0.9.[41]

We measured *healthcare self-efficacy* using the items adapted from the Chronic Disease Self-Management Studies by Lorig and colleagues.[42,43] Participants were first presented with a list of chronic medical conditions and asked to indicate which ones they had been diagnosed with by a

healthcare professional. Participants with at least one chronic medical condition then completed the Self-Efficacy for Managing Chronic Disease 6-Item Scale (which was found to have a Cronbach's alpha 0.91 in prior studies).[42] All participants were also asked to complete nine additional items about healthcare self-efficacy, selected from Lorig's original longer instrument.[43] Those items were adapted to be applicable to individuals whether or not they had any chronic illnesses. All items were rated on a scale of 1–10, with anchors of "not at all confident" and "totally confident" and summed into a composite score (range 9–90 for general healthcare self-efficacy, 6–60 for chronic condition self-efficacy; higher values indicate greater self-efficacy).

We collected data on *unmet healthcare needs* and *healthcare utilization*, using items adapted from the 2002/2003 Joint US Canada Survey[44,45] and the 2007 National Health Interview Survey (NHIS) Questionnaire—Adult Access to Health Care & Utilization.[46,47] Specifically, we measured unmet healthcare needs using the item "During the past 12 months, there was a time when I felt that I needed the following type of healthcare, but did not receive it. (Check all that apply)." Response options included six types of healthcare (e.g., "medical care for a physical health problem", "mental healthcare or counseling"). Additional items assessed whether participants had a primary care provider (PCP), the number of emergency department visits, outpatient visits, and hospitalizations within the past 12 months, and receipt of a variety of preventive care services.

We used a single item to measure *overall health status*, with response options of Excellent, Very good, Good, Fair, and Poor.[48] Results from additional instruments focusing on barriers or facilitators to care and perceptions of bias will be reported separately.

Data Analysis

Psychometric Assessment of Adapted Instruments. We used our CBPR process to ensure face and content validity. The team used an iterative process, reviewing and adapting instruments until all community and academic partners felt the survey was clear and adequately addressed the most important constructs. We assessed convergent validity by comparing responses between instruments we hypothesized would be associated with each other. We assessed the internal consistency reliability of our three adapted composite scales for each population (autistic vs. non-autistic) using Cronbach's alpha.

Demographic Characteristics and Healthcare Experiences. We conducted bivariate analyses comparing the responses of autistic and non-autistic adults for all available demographic characteristics and health services outcomes using two sample t-tests and chi-square tests. We used logistic and linear regression to assess for independent associations with dichotomous and continuous outcomes, respectively. Our main predictor was population (autistic adults vs. non-autistic adults). All models were also adjusted for age, sex, race/ethnicity (non-Hispanic White, yes/no), personal and parental educational attainment (high school or less, some college, bachelor's degree, any graduate work), income (< $25,000, $25,000–49,999, ≥ $50,000), health insurance (none, Medicare/Medicaid only, private insurance, other), and overall health status (excellent/good vs. fair/poor). Parental education is often used as an additional proxy measure for socioeconomic status (SES) in people with developmental disabilities.[49] We conducted separate analyses for each outcome measure, analyzing responses to the patient–provider communication scale and the general and chronic illness healthcare self-efficacy scales as continuous outcomes. We dichotomized the number of outpatient visits in the past year into 0–3 vs. ≥ 4, and the number of emergency department visits into zero vs. ≥ 1. All other outcomes were collected and analyzed as dichotomous variables.

Sensitivity Analyses. Primary analyses included all participants who indicated that they were on the autism spectrum. Due to changes in diagnostic criteria over time and difficulty obtaining diagnoses in adulthood, many adults who meet diagnostic criteria for autism spectrum disorder (ASD) do not carry formal medical diagnoses.[50] Moreover, screening instruments such as the Autism Quotient have limited accuracy.[35] We felt that using formal diagnoses or a screening instrument to determine eligibility would unnecessarily exclude a large number of autistic adults who may still experience healthcare disparities related to being on the autism spectrum. Sensitivity analyses limited the autistic group to those who score a 26 or greater on the Autism Quotient.[35] We also conducted a sensitivity analysis limiting the non-autistic sample to only those without other disabilities. Finally, we compared all healthcare outcomes for participants with diagnoses of autistic disorder vs. Asperger's disorder.

We analyzed data using STATA software (version 11.0, Statacorp, LP, College Station, Texas).

RESULTS

Study Sample

Two hundred and nine autistic adults and 228 non-autistic adults completed the survey. Table 1 shows participant characteristics. A majority of autistic participants were diagnosed with Asperger's disorder. Amongst the autistic sample, there was no difference in Autism Quotient scores between those with or without formal diagnoses. Fifty-five (24 %) of the non-autistic participants had a disability.

Table 1. Participant Characteristics

	Autistic Adults N=209	Non-Autistic Adults N=228
Age*		
Mean (STD)	37.3 (12.9)	39.7 (12.9)
Sex		
Female	122 (59 %)	149 (66 %)
Race/Ethnicity		
Non-Hispanic White	178 (86 %)	198 (87 %)
Personal Education**		
High School or Less	17 (8 %)	15 (7 %)
Some College	87 (42 %)	52 (23 %)
Bachelors Degree	57 (28 %)	85 (38 %)
Graduate Degree	44 (21 %)	70 (32 %)
Parental Education*		
High School or Less	24 (13 %)	40 (19 %)
Some College	43 (23 %)	32 (15 %)
Bachelors Degree	50 (27 %)	67 (32 %)
Graduate Degree	71 (38 %)	70 (33 %)
Annual Income**		
< $25,000	104 (52 %)	83 (38 %)
$25,000–$49,999	48 (24 %)	73 (33 %)
≥ $50,000	47 (24 %)	62 (28 %)
Health Insurance**		
Private	123 (59 %)	174 (77 %)
Governmental only	41 (20 %)	20 (9 %)
Other	19 (9 %)	18 (8 %)
None	26 (12 %)	15 (7 %)
Required assistance from other people in past 12 months to receive healthcare**		
Always or often	39 (19 %)	8 (4 %)
Sometimes	45 (22 %)	31 (14 %)
Rarely	44 (22 %)	31 (14 %)
Never	76 (37 %)	152 (68 %)
Disability Type(s)**		
Vision/hearing	18 (9 %)	7 (3 %)
Mobility	30 (13 %)	35 (17 %)
Learning/remembering	102 (50 %)	25 (11 %)
Activities of daily living	16 (8 %)	6 (3 %)
Leaving home alone	54 (26 %)	13 (6 %)
Working at a job	111 (55 %)	34 (15 %)
Any	137 (71 %)	53 (24 %)
Overall Health Status*		
Excellent	20 (10 %)	34 (15 %)
Very good	68 (33 %)	88 (39 %)
Good	65 (31 %)	72 (32 %)
Fair	45 (22 %)	29 (13 %)
Poor	10 (5 %)	4 (2 %)
Autism Quotient Score**		
Mean (std)	36.0 (7.6)	18.1 (7.5)
Has formal ASD diagnosis	136 (65 %)	N/A
Self-Reported ASD Diagnosis		
Autism	34 (17 %)	N/A
Asperger's	141 (68 %)	
Other#	9 (4 %)	

STD standard deviation; ASD autism spectrum disorder
**p< 0.05; **p< 0.001; std standard deviations; N/A Not applicable*
#Includes pervasive developmental disorder not otherwise specified, Rett's disorder, and ASD

Participants resided in 47 different US states (including the District of Columbia).

Psychometric Properties of Adapted Measures

All adapted measures with composite scores had good to excellent internal consistency reliability (alphas .83–.92; Tables 2 and 3). When comparing results from the autistic and non-autistic samples, the scales demonstrated slightly lower internal consistency in the autistic sample, but the differences in alphas between the two samples were extremely small (no greater than 0.03). All alphas were comparable to what has been reported in the literature for the original measures.

There was strong convergent validity, with significant correlations amongst all scales in the expected direction. For example, there was a strong correlation (correlation coefficient 0.7, $p< 0.001$) between general healthcare and chronic condition self-efficacy, and between both measures of self-efficacy and unmet healthcare needs.

Healthcare Experiences

When compared to non-autistic adults, autistic adults had significantly lower scores on each of the items on the patient–provider communication scale and the self-efficacy scales. In multivariate analyses, after adjustment for age, sex, race/ethnicity, personal and parental educational level, income, type of health insurance, and overall health status, autistic adults had lower composite scores for patient–provider communication (beta coefficient −1.9, CI −2.9 to −0.9), general healthcare self-efficacy (beta coefficient −11.9, CI −14.0 to −8.6), and chronic condition self-efficacy (beta coefficient −4.5, CI −7.5 to −1.6) than non-autistic adults (Tables 2 and 3).

Table 4 shows responses to items about unmet healthcare needs and healthcare utilization. In multivariate analyses, autistic adults had significantly higher odds of unmet healthcare needs related to physical health (OR 1.9 CI 1.1–3.4), mental health (OR 2.2, CI 1.3–3.7), and prescription medications (OR 2.8, CI 2.2–7.5). Though autistic adults were as likely as non-autistic adults to have a PCP or have their blood pressure checked, and had similar numbers of outpatient appointments or hospitalizations, they were less likely to have received a tetanus vaccine (OR 0.5, CI 0.3–0.9), and, if female, less likely to have received a Papanicolaou smear in the past 3 years (OR 0.5, CI 0.2–0.9). They also had more than twice the odds of using the emergency department (ED) in the past year (OR 2.1, CI 1.8–3.8).

Sensitivity analyses limiting autistic participants to only those with Autism Quotient scores≥ 26 reached similar conclusions as those from primary analyses. Analyses limiting the non-autistic sample to people without disabilities strengthened the magnitude of findings, but did not qualitatively change conclusions. In multivariate analyses, participants with diagnoses of Asperger's disorder were less likely than those with diagnoses of autistic disorder to use the ED. There were no differences related to diagnosis in any of the other healthcare items or composite scores assessed in the study.

Table 2. Satisfaction with Healthcare Provider Behaviors

Satisfaction with Healthcare Provider Items*	Autistic Mean (STD) N=209	Non-Autistic Mean (STD) N=228	*p*-value	Autistic participants responding usually or sometimes N (%)	Non-Autistic participants responding usually or sometimes N (%)	*p*-value
Health professionals gave me the chance to ask all the health-related questions I had.	2.9 (0.78)	3.2 (0.74)	< 0.001	148 (70 %)	157 (86 %)	< 0.001
Health professionals gave the attention I needed to my feelings and emotions.	2.7 (0.80)	2.9 (0.82)	< 0.001	124 (60 %)	132 (72 %)	0.009
Health professionals involved me in decisions about my healthcare as much as I wanted.	2.87 (0.85)	3.2 (0.79)	< 0.001	139 (67 %)	155 (85 %)	< 0.001
Health professionals made sure I understood the things I needed to do to take care of my health.	2.9 (0.79)	3.2 (0.77)	< 0.001	146 (70 %)	157 (86 %)	< 0.001
Health professionals helped me deal with feelings of uncertainty about my health or healthcare.	2.5 (0.94)	2.8 (0.88)	< 0.001	110 (53 %)	130 (71 %)	< 0.001
Health professionals understood what I was trying to communicate.	2.6 (0.72)	3.1 (0.70)	< 0.001	119 (57 %)	158 (86 %)	< 0.001
Health professionals communicated in a way that I could understand.	2.7 (0.82)	3.1 (0.71)	< 0.001	156 (75 %)	168 (92 %)	< 0.001
I felt I could trust health professionals to take care of my healthcare needs.	2.7 (0.81)	3.1 (0.71)	< 0.001	125 (60 %)	155 (85 %)	< 0.001
Satisfaction with Healthcare Provider Behavior Composite Score						
Total score	22.3 (5.1)	25.0 (4.9)	< 0.001	N/A	N/A	N/A
Internal consistency reliability (alpha)	0.90	0.92				

STD standard deviation; alpha Cronbach's alpha coefficient; N/A not applicable

**The scale was prefaced with the following statement: The following items ask about your communication with all the health professionals whom you have seen during the past 12 months. Health professionals include doctors, nurses, or other medical staff that provide healthcare. If you did not receive healthcare in the past 12 months, think about the last time you did receive healthcare. How often did health professionals do each of the following? ("Always" means around 100 % of the time. "Usually" means around 66 % or 2/3 of the time. "Sometimes" means around 33 % or 1/3 of the time. "Never" means around 0 % of the time)*

DISCUSSION

Researchers have argued that obtaining input from individuals with developmental disabilities is critical to producing scientific information that is valid, ethical, and inclusive of their perspectives.[51–55] The CBPR process allowed us to successfully adapt instruments to directly collect data from autistic individuals. To our knowledge, this is the first study to directly obtain data from autistic adults about their perceptions of unmet healthcare needs, patient-provider communication, and healthcare self-efficacy.

The literature includes multiple conceptualizations and definitions of "disparities".[56,57] We have chosen to frame our findings as healthcare disparities based on the Healthy People 2020 conceptualization, which defines disparities as differences that "adversely affect groups of people who have systematically experienced greater obstacles to health based on [a number of characteristics, including] disability".[58] Several studies have noted that people with developmental disabilities experience important healthcare disparities,[4] but most have primarily included people with intellectual disabilities and none have focused on autistic adults. Our study suggests that autistic adults who use the Internet may also experience important healthcare disparities. Future research is needed to better understand the factors that contribute to the disparity and ways to eliminate it.

Our survey found an interesting pattern of similarities and differences in healthcare utilization between autistic and non-autistic adults. The vast majority of participants in both groups reported that they had a PCP, and the two groups had similar outpatient clinic utilization. However, the receipt of outpatient care does not necessarily mean that care is effective. Additionally, providers have reported feeling uncomfortable with their level of training regarding autistic patients.[59] While it may be expected that autistic participants report worse patient–provider communication and lower patient self-efficacy, our study showed that they further report greater unmet healthcare needs, higher use of the ED, and lower utilization of some preventive services. Preventive services requiring providers to more effectively communicate or coordinate care (e.g., Pap smears) were more greatly affected than those done routinely (e.g., blood pressure measurement). Together, these findings point to the existence of a significant problem in how healthcare is delivered to autistic adults.

Table 3. General Healthcare and Chronic Condition Self-Efficacy

General Healthcare Self Efficacy*	Autistic mean (STD) *N*=209	Non-Autistic mean (STD) *N*=228	*P*-value
I can get reliable information about my health.	7.2 (2.2)	8.4 (1.5)	< 0.001
When something concerns me about my health, I can ask my healthcare providers about it.	6.5 (2.7)	7.9 (2.0)	< 0.001
When I have personal problems that may be related to my health, I can discuss them openly with my healthcare providers.	5.9 (2.8)	7.4 (2.5)	< 0.001
I can judge when changes in my health mean I should visit a healthcare provider.	6.6 (2.6)	8.2 (1.8)	< 0.001
When my healthcare providers prescribe medications, I can carry out the steps necessary to take them as prescribed. (For example, I get the prescription filled, I remember to take the medication, and I take the medication as advised.)	7.8 (2.4)	9.1 (1.6)	< 0.001
I can do something to make myself feel better when I feel sad, discouraged, or depressed.	6.2 (2.5)	7.5 (2.1)	< 0.001
I can do exercises three to four times per week (for example, range of motion, stretching, using weights, walking, swimming, or bicycling).	6.9	7.1	0.01
I can get emotional support (such as listening or talking over my problems) from friends, family, or other resources.	5.8 (3.0)	7.7 (2.5)	< 0.001
I can get help with my daily tasks (such as housecleaning, yard work, or meals) from friends, family, or other resources, if needed.	5.0 (2.9)	6.9 (2.8)	< 0.001
General Healthcare Self-Efficacy Composite Score			
Total score: Mean (std)	57.1 (15.5)	70.5 (13.9)	< 0.001
Internal consistency reliability (alpha)	0.83	0.86	
Chronic Disease Self-Efficacy**	Autistic mean (STD) N=126	Non-Autistic mean (STD) N=119	
I can keep the fatigue caused by my condition from interfering with the things I want to do.	5.7 (2.7)	6.5 (2.5)	0.003
I can keep the physical discomfort or pain of my condition from interfering with the things I want to do.	6.3 (2.6)	6.8 (2.5)	0.05
I can keep the emotional distress caused by my condition from interfering with the things I want to do.	5.3 (2.7)	6.8 (2.5)	< 0.001
I can keep any other symptoms or health problems I have from interfering with the things I want to do.	5.9 (2.5)	6.8 (2.4)	0.003
I can do the different tasks and activities needed to manage my health condition so as to reduce my need to see a doctor.	6.6 (2.3)	7.7 (2.1)	< 0.001
I can do things other than just taking medication to reduce how much my illness affects my everyday life.	6.9 (2.3)	7.8 (2.1)	0.003
Chronic Disease Self-Efficacy Composite Score			
Total score: Mean (std)	35.6 (11.9)	42.0 (12.3)	< 0.001
Internal consistency reliability (alpha)	0.88	0.91	

STD: standard deviation; alpha Cronbach's alpha coefficient; N/A not applicable

**The General Healthcare Self-Efficacy Scale was prefaced by the following statement: "The following section asks about how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time." Response options ranged from 0 (Not at all confident) to 10 (Totally confident)*

***Only participants with chronic illnesses were asked to complete the Chronic Disease Self-Efficacy Scale. It was prefaced by the following statement: "For each of the following items, please choose the number that corresponds to the confidence you feel accomplishing the specific task." Response options ranged from 0 (Not at all confident) to 10 (Totally confident)*

Our study has several limitations. The cross-sectional design precludes the ability to draw causal inferences. Our Internet-based recruitment strategy resulted in a convenience sample that may not be representative of the autistic population, the general population, or even the population of people who have access to the Internet. However, it is encouraging that non-autistic participants in our sample had rates of unmet healthcare needs similar to those found in large population-based studies.[45] Autistic individuals also had rates of preventive health utilization within the range of what has been noted in other studies of people with disabilities.[9,10,60] We had an over-representation of female participants, as is often, unfortunately, the case in online surveys.[60,61] Given the constraints of an online survey, we did not independently confirm ASD diagnoses or any other self-report variables. However, secondary analyses restricting the sample to only those with high Autism Quotient scores did not qualitatively change the results. Our study notes increased ED use in the autistic sample, but we did not collect data on the reason for the ED visits.

Our sample only included participants with access to the Internet. A majority of participants in both the autistic and non-autistic sample received at least some college education and were non-Hispanic White. Our findings cannot be generalized to adults who do not use the Internet, be it due to lack of access, socioeconomic factors, preference, or ability. Nor can they be generalized to populations with lower educational attainment or to individuals from racial or ethnic minority communities. However, we feel that the existence of healthcare disparities in this sample is still an important finding, as these individuals may otherwise be perceived as having fewer

Table 4. Unmet Healthcare Needs and Healthcare Utilization

	Autistic N (%) from *N*=209	Non-Autistic N (%) from *N*=228	OR (CI)	Adjusted OR (CI)*
Unmet healthcare needs				
During the past 12 months, there was a time when I felt that I needed the following type of healthcare, but did not receive it.				
Medical care for a physical health problem	63 (30 %)	36 (16 %)	**2.3 (1.5–3.7)**	**1.9 (1.1–3.4)**
Mental healthcare or counseling	70 (34 %)	39 (17 %)	**2.4 (1.6–3.8)**	**2.2 (1.3–3.7)**
Preventive healthcare (including routine physical examinations)**	53 (26 %)	41 (18 %)	1.6 (1.0–2.5)	1.4 (0.8–2.4)
Dental care (including dental checkups)	73 (35 %)	62 (27 %)	1.4 (1.0–2.2)	1.1 (0.6–1.8)
Prescription medications	46 (22 %)	15 (7 %)	**4.0 (2.2–7.5)**	**2.8 (1.4–5.6)**
Eyeglasses or contact lenses	39 (19 %)	37 (16 %)	1.2 (0.7–1.9)	1.1 (0.6–2.0)
Healthcare utilization				
Has primary care provider	163 (80 %)	179 (79 %)	1.0 (0.6–1.6)	1.6 (0.9–3.0)
Blood pressure checked in past year	192 (94 %)	213 (94 %)	1.0 (0.4–2.1)	1.5 (0.6–4.0)
4 or more outpatient visits in past year	80 (38 %)	83 (36 %)	1.1 (0.7–1.6)	1.0 (0.6–1.6)
Hospitalized in past year	18 (9 %)	24 (11 %)	0.8 (0.4–1.5)	0.6 (0.2–1.4)
Went to Emergency Department in past year	57 (27 %)	31 (14 %)	**2.4 (1.5–3.9)**	**2.1 (1.8–3.8)**
Pap smear in past 3 years (females only)	72 (59 %)	115 (78 %)	**0.4 (0.2–0.7)**	**0.5 (0.2–0.9)**
Tetanus vaccine in past 10 years	128 (73 %)	170 (83 %)	**0.5 (0.3–0.9)**	**0.05 (0.3–0.9)**

OR odds ratio; CI confidence interval
** Adjusted odds ratio, adjusting for age, sex, race/ethnicity, personal and parental educational level, income, type of health insurance, and overall health status*
*** The term "preventive healthcare" had a link to the following definition: "**Preventive healthcare** is healthcare that is aimed at early detection and treatment or prevention of disease. Examples of preventive healthcare may include visits where a healthcare worker performs screening tests such as pap smears, mammograms, colonoscopies; draws blood to check a cholesterol level; counsels a patient about diet, exercise, tobacco, or alcohol; or performs a routine physical examination"*

disability-related barriers to care. A recent study found that young adults on the autism spectrum whose parents reported they could perform four activities of daily living independently very well were less likely to receive medical services for diagnosis or evaluation related to disability than those who could not.[62] Our study furthers that finding, highlighting that high educational attainment does not necessarily eliminate the existence of important barriers to quality healthcare. We did not collect data on how often or in what ways participants access the Internet, nor did we collect data from participants without access to the Internet. Though one might speculate that autistic individuals who do not use the Internet may have greater barriers (e.g., due to greater communication difficulties), they also may benefit from greater support from family members, caregivers, or support staff to effectively access healthcare.

Our study has several important implications. A CBPR approach may facilitate the inclusion of people with disabilities in research, both as members of the research team and as study participants. Our CBPR process allowed us to adapt instruments to be accessible to this sample of autistic adults, primarily by increasing the clarity and precision of the language used in the instruments. Future studies are needed to further validate our adapted measures in other samples of autistic adults.

American Psychiatric Association (APA) has proposed new diagnostic criteria for the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), which includes combining autistic disorder, Asperger's disorder, and pervasive developmental disorder–NOS into one diagnosis.[63] Part of the rationale for this change is the lack of clear and consistent distinctions between diagnoses.[64] The lack of significant differences by diagnosis type in almost all reported healthcare experiences may be reflective of this issue.

Being that our study was designed prior to the announcement of the proposed changes, we did not collect data to predict whether participants will meet the revised DSM-5 diagnostic criteria. There has been considerable controversy over the proposed criteria, with some studies predicting a significant reduction in the number of people who will meet criteria, especially amongst those diagnosed with Asperger's disorder or without intellectual disabilities.[65,66] There is concern that those individuals will be deprived of services, self-understanding, and the right to accommodations, which would otherwise be mandated by the Americans with Disabilities Act. The existence of healthcare disparities in our sample, many of whom may be at risk for no longer meeting criteria, highlights these potential negative consequences, as not having a diagnosis may deprive patients and their providers of possible insights, strategies, and accommodations to try to improve healthcare experiences.

Clinicians should be both aware of the potential healthcare disparities experienced by autistic adults—including adults such as those in our sample with overall high educational attainment and access to the Internet—and open to accommodations and strategies that may

improve healthcare. Some examples of accommodations and strategies that have been useful to our team of patients and providers include: offering patients an alternative to an over-stimulating waiting room; allowing patients to communicate in their preferred mode (e.g., writing or typing); using precise, specific language; allowing extra time for patients to process information; providing very concrete, step-by-step written instructions for how to obtain necessary prescriptions, tests, or referrals; and clarifying the role of supporters. Our academic-community partnership is currently conducting a National Institute of Mental Health-funded study to better understand strategies and accommodations that improve healthcare for autistic adults, and to develop and evaluate an interactive toolkit for autistic adults and their PCPs. The toolkit will include a way for patients to generate customized accommodations reports, as well as information about health and healthcare targeted toward autistic patients, their supporters, and PCPs. Future research is needed to assess the effectiveness of such tools in improving health outcomes.

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Corresponding Author: *Christina Nicolaidis, MD, MPH; Departments of Medicine and Public Health Preventive Medicine, Oregon Health Science University, L475; 3181 SW Sam Jackson Park Road, Portland, OR 97239, USA (e-mail: nicolaid@ohus.edu).*

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