

Partnering With Autistic Adults To Improve Healthcare

Christina Nicolaidis, MD, MPH

Dora M Raymaker, MS

Academic Autistic Spectrum Partnership in Research & Education (AASPIRE)
Department of Medicine, Oregon Health & Science University (OHSU)





What Happens When They Grow Up?

- Prevalence similar in adults (1%)*, albeit many are not diagnosed
- Little research on adults
- Gaps in clinical care
 - Primary care
 - Mental health
 - Specialty services
- Few social services
- Societal marginalization
- Difficult for providers to understand/empathize

*Bruha 2009





Parallels With Research on Other Marginalized Communities

- Misalignment of research priorities
- Lack of inclusion in the research process
- Use of demeaning or derogatory language and concepts
- Threats to study validity
- Use of findings to advance agendas that oppose community values



Community Based Participatory Research (CBPR)

- Response to challenges traditional research has had in adequately addressing needs of minority communities.
- An interdisciplinary research approach involving academics and community members working together as equal partners in all phases of the research process.
- “Subjects” become part of the research team.



Who is the Community?

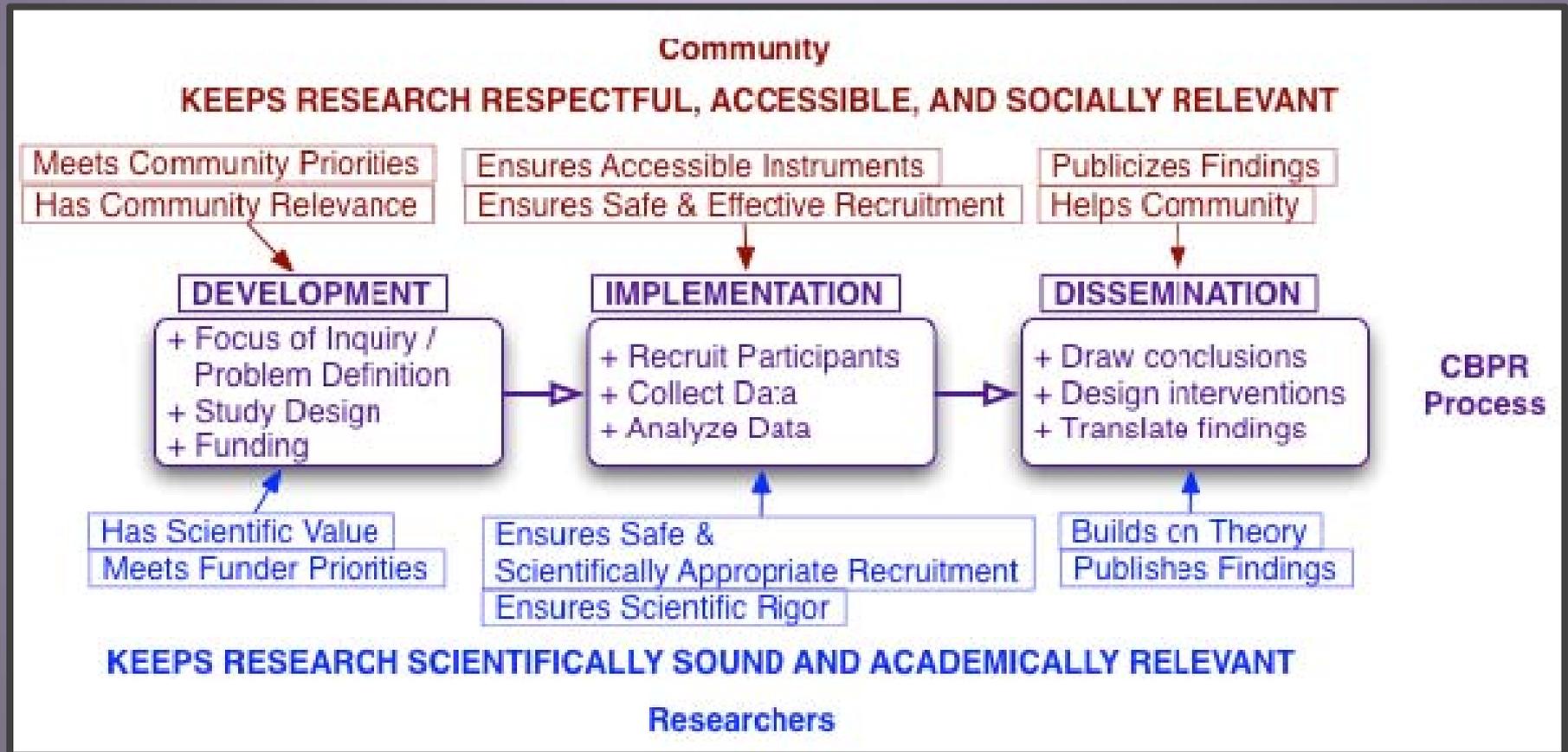
- Most minority communities follow pattern where individuals are born into families with same minority status.
- Some minority communities do not follow that pattern:
 - LGBT, Deaf, people with mental illness
 - Role of allies and stakeholders



Mission:

- To encourage the inclusion of people on the autistic spectrum in matters which directly affect them.
- To include adults on the autistic spectrum as equal partners in research about autism.
- To answer research questions that are considered relevant by the autistic community.
- To use research findings to effect positive change for people on the spectrum.

CBPR with AASPIRE





CBPR with Autistic Adults

- Is it an oxymoron?
 - CBPR relies heavily on interpersonal interactions and communication.
 - How do we effectively implement CBPR with partners whose disability is defined by atypical social interaction and communication?



Structure and Process Matters

- Academic and Autistic Co-Directors and Co-PIs
- Team meetings over IM chat
 - Agendas, moderation, visuals, etiquette
- Multiple formats for providing input (IM, email, telephone, in-person)
- Structured email format
- Clear process for coming to consensus using Finger Method
- Policies for closing (and re-opening) discussion
- Frequent “CBPR checks” and changes

AASPIRE Healthcare Survey

- People with developmental disabilities face important disparities in healthcare.
- Most studies have primarily focused on people with intellectual disabilities and/or have recruited participants through disability services or institutional settings.
- The full range of adults now recognized as being on the autistic spectrum may not be captured.
- Autistic adults who use the Internet may represent an understudied population of healthcare users who experience barriers to care.

Objective

To identify disparities in healthcare for autistic adults who use the Internet, as compared to Internet users without disabilities.

Methods - Survey

- Online survey, via the Gateway Project - an online registration system for research projects committed to inclusion, respect, accessibility and community relevance.
- Participants, 18 or older, who reside in the US and consider themselves to be on the autistic spectrum were invited to take the survey.
- Matched by age and sex with non-autistic adults with and without disabilities.
- CBPR process to adapt previously validated instruments to be accessible to autistic adults.

Methods – Survey, continued

- Analyses: Cronbach's alpha, t-tests, chi-square, logistic and linear regressions.
- Primary – self-identify as autistic.
- Secondary – only those with formal diagnosis; only those with Autism Quotient of 32 or greater.
- No differences in findings between primary and secondary analyses.

Demographics

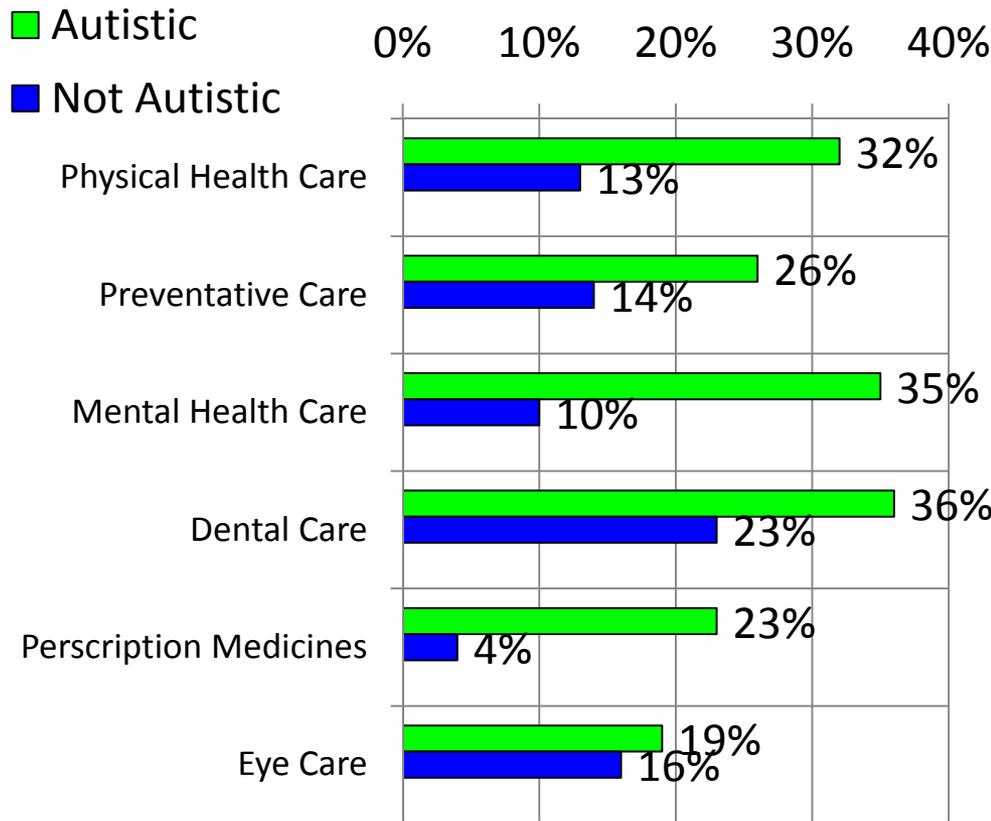
	Autistic (N=199)	Non-Autistic (160)	P-value
Age	Mean 36.9 (12.8)	Mean 38.1 (12.7)	0.40
Sex – Female	118 (60%)	103 (65%)	0.16
Non-Hispanic White	168 (85%)	141 (88%)	0.37
Education			<0.001
-High School or less	16 (8%)	10 (6%)	
-Some College	83 (43%)	30 (19%)	
-Bachelor's	53 (27%)	63 (40%)	
-Graduate	43 (22%)	55 (35%)	
Personal Income			<0.001
<\$25,000	99 (53%)	44 (29%)	
\$25-\$50K	44 (23%)	55 (36%)	
\$50 or more	45 (24%)	53 (35%)	

Demographics, ctd.

	Autistic	Non-Autistic	P-value
Insurance			<0.001
-None	26 (13%)	12 (8%)	
-Government only	40 (20%)	6 (4%)	
-Private	115 (58%)	132 (83%)	
-Other	18 (9%)	9 (6%)	
AQ Score	Mean 36.2 (7.6)	Mean 17.2 (7.4)	<0.001
Diagnosis		N/A	
-Autistic Disorder	37 (19%)		
-Asperger's	134 (68%)		
-Other	25 (13%)		
Formal ASD Dx	131 (66%)	N/A	
Realized <18 age	58 (31%)	N/A	

Survey Findings: Unmet Needs

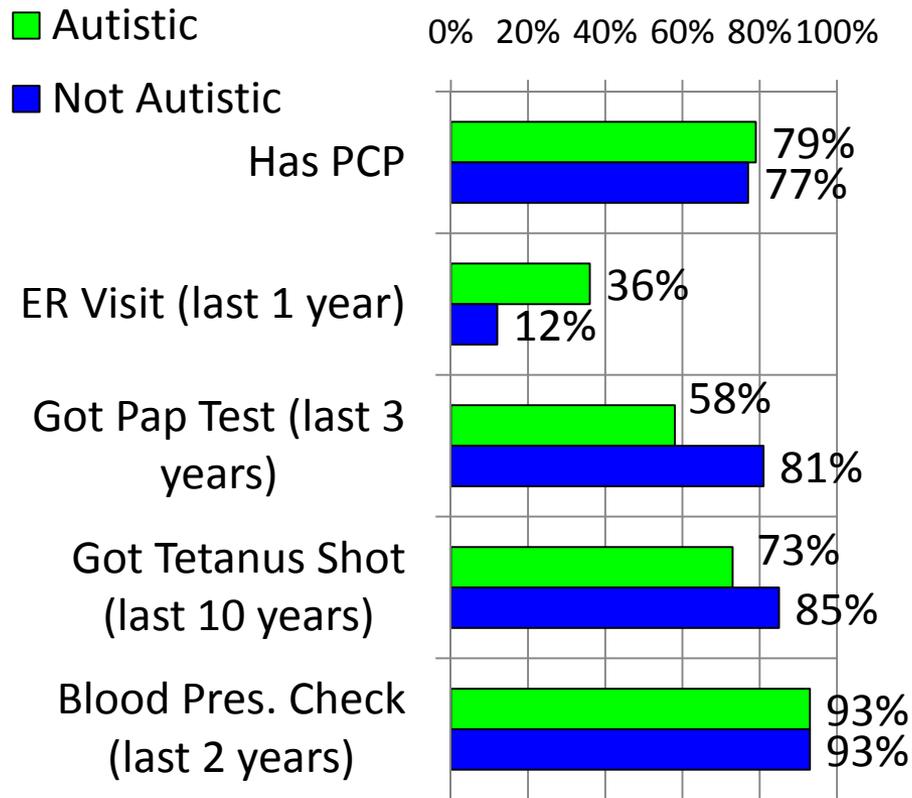
Proportion of participants who reported having unmet healthcare needs in the past year.



OR	P-value	Adj OR [¥]	P-Value
3.17	<0.001	2.42	0.02
2.21	0.005	2.10	0.04
4.68	<0.001	5.15	<.001
1.84	0.01	1.50	0.163
6.39	<0.001	4.31	0.001
1.27	0.4	1.30	0.44

¥ Adjusted for age, sex, race/ethnicity, personal education, parental education, personal income, and insurance.

Survey Findings: Healthcare Utilization

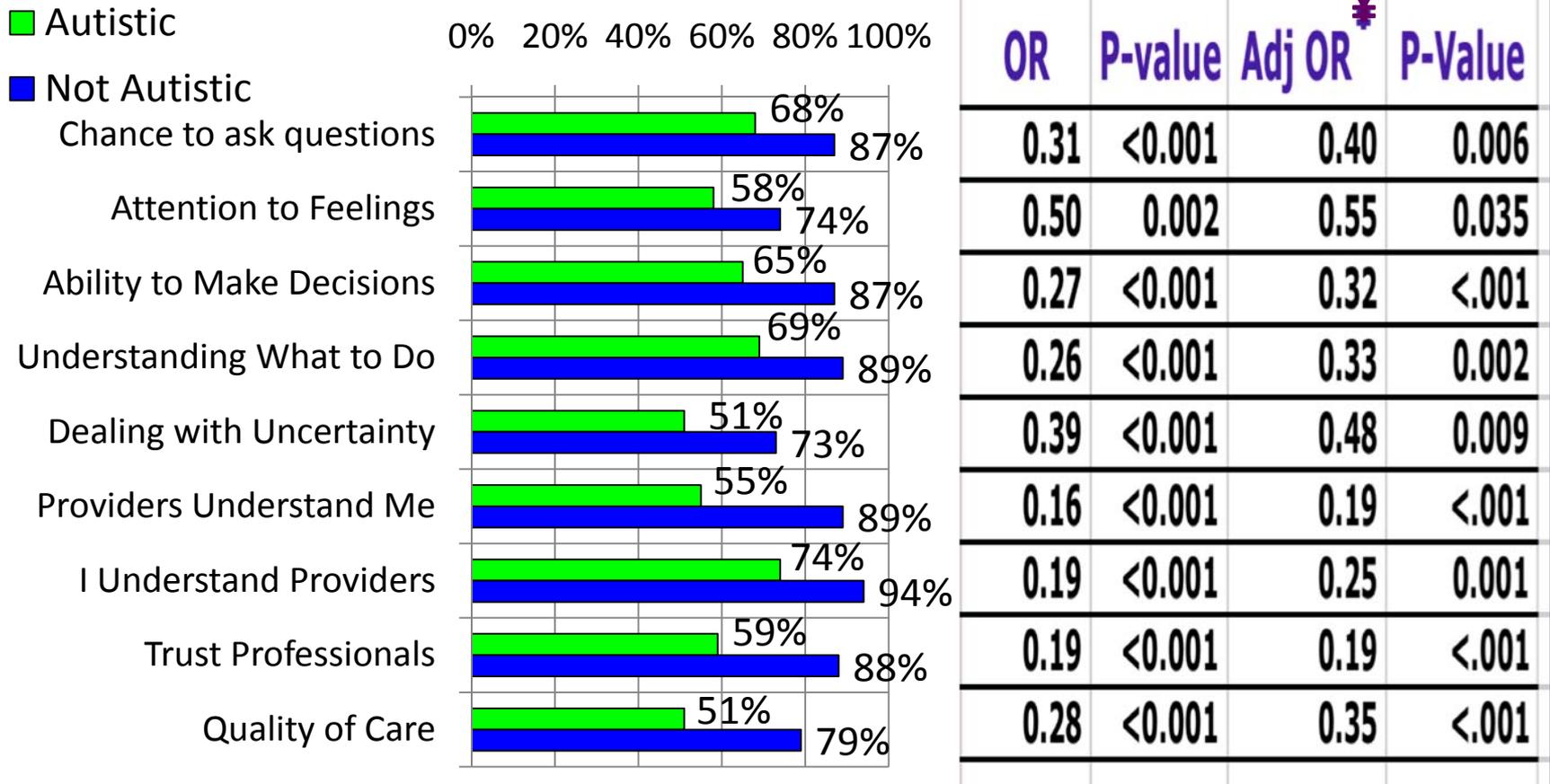


OR	P-value	Adj OR [¥]	P-Value
1.10	0.7	1.71	0.13
4.13	<0.001	3.6	0.001
0.33	<0.001	0.31	0.005
0.48	0.01	0.55	0.110
1.14	0.3	1.4	0.51

¥ Adjusted for age, sex, race/ethnicity, personal education, parental education, personal income, and insurance.

Survey Findings: Satisfaction

† Proportion of participants reporting being usually or always satisfied in the past year.



¥ Adjusted for age, sex, race/ethnicity, personal education, parental education, personal income, and insurance.



Limitations

- Self-report data from a non-random sample of Internet users.
- Correlational data – cannot imply causality.
- Only able to generalize to adults who use the Internet.

Conclusions / Implications

- Autistic adults who use the Internet report receiving worse healthcare than Internet users without disabilities.
- Healthcare providers should be made aware of potential barriers to care for autistic adults - including adults such as those in our sample, with overall high educational attainment and the communication and intellectual skills necessary to use the Internet.

AASPIRE Healthcare Interview Study

- Objective: Obtain an in-depth understanding of autistic adults' experiences with healthcare & recommendations for improving care.

Methods - Qualitative

- Purposefully sampled from survey
- 28 open-ended, in-depth, semi-structured interviews over email, telephone, or IM
- Interview guide created collaboratively
- Focus on healthcare experiences and recommendations
- Thematic analysis, using inductive approach, semantic level, essentialist paradigm

Results - Demographics

- 12 men, 16 women; 18 non-Hispanic White (64%)
- Income: 17 (63%) less than \$25,000
- Education: High school or less 3 (11%); Some College 13 (46%); Bachelors or more 12 (43%)
- Formal ASD Dx: 23 (82%); High AQ: 26 (93%)
- Autistic 10 (36%); Aspergers 16 (57%)
- Primarily use non-speech communication: 6 (21%)
- SSI/SSDI: 10 (42%)
- Insurance: Private 12 (43%); Government only 8 (29%); None 2 (7%); Other 6 (21%)

Lack of Knowledge Regarding Autism

“I thought doctors would understand my autism, I thought saying, ‘well, I have autism’ would be a suitable explanation for why I have age-inappropriate troubles with managing my healthcare, but it's not.”

“Before I was diagnosed with Asperger’s, I was told that I had depression.... Because I have difficulty talking to people and don't look at them, it is assumed that I have depression.”

Misconceptions About Intelligence

“Usually when I demonstrate a large vocabulary or some fundamentals, my needs especially around communication are then ignored. My choice is then to pretend to be less intelligent and accept their infantilism, or to be confused, frustrated, and stressed out.”

“Just because I have difficulty expressing what is going on with me doesn't mean I am stupid or that I am making things up.”

Misconceptions About Autism

“When it says ... ‘shows lack of empathy’, you get the completely wrong idea about us...Perhaps we do not show empathy, but that doesn't mean we, we aren't having it. For instance, in my case, I break into tears at the drop of a hat. So what I've learned to do is to shut down. When I'm feeling empathy, I go "Oh, no, no, you're gonna fall apart, so shut down now. Just shut down, because you don't want to look like you're a crazy woman. So shut down." So instead of looking like a crazy woman, I look like a cold-hearted bitch. When actually what is happening is I'm so overwhelmed with emotion that I just shut down.”

Difficulty with Body Awareness can Affect Ability to Report Symptoms

"I don't know my own body. ...So when I feel all these different sensations, everywhere, I don't know which is the real problem and which is just sensation."

"The problem is it is difficult for me to isolate specific sources of pain and identify duration and intensity. It's sort of like the equivalent to white noise."

Sensory Issues & Stresses Can Cause Difficulty Interacting with Providers

“...I have just traveled to the office on a very loud bus or train. The lights in the office are very bright and that is exacerbated by the white walls. Sometimes the waiting rooms are crowded and I cannot filter out the background of people talking or shuffling magazines. I feel disoriented by being led down long hallways to different rooms.... I am not able to bring up my concerns because it is all I can manage to figure out what the doctor is saying so I can respond to his questions. ”

Written Communication Not Respected by Providers

"I prefer and find it easier to communicate in text... But with every doctor I speak to, they wave away the note-card and look at me to ask the same question I have just answered and interpret my confusion as my being non-compliant with the medicine. I wish health care providers would read the notes I make for them. I wish they would be patient as I pause a lot and stutter when I am overloaded."

Need for Direct, Specific Communication

“I have a lot of difficulty with open ended questions.”

“‘How do you feel?’ Too vague. ‘Can you describe your symptoms?’ I can somewhat answer this, but not fully. It's a starting point, not end point. Specific questions related to symptoms are good: ‘Does your side hurt?’ ‘Are you keeping food down?’”

“I know that I need explicit information rather than abstractions.”

Navigating the Healthcare System

"With my autism it is very difficult for me to understand and follow all the different appointments and procedures I have to schedule and how to do it, and no one will help me since apparently people magically become competent at these things before they turn 21."

"It's like having a list of a hundred things you have to get done right a way, which you must memorize aurally in the five minutes you spend with the doctor and then execute without error, even though you don't even understand how to do half the things you need to do."

Limitations

- Small qualitative study
- Only included Internet-users

Conclusions / Implications

- Autistic adults describe important factors that may adversely affect the health and healthcare of patients on the autistic spectrum and offer concrete ideas of how to improve care.
- Healthcare providers should be open to accommodations and strategies that may improve interactions with autistic patients, and thereby positively impact health outcomes.
- We plan to use information from this study to create interactive tools to improve the primary care of adults on the autistic spectrum.

Just For You...



Communication Issues in Psychotherapy

“My wife wanted me to go to talk therapy, but I got nothing to talk about, you know... I've actually been to those sessions, and I've said to the person, what am I supposed to do? ...What do you want to hear from me? I, I don't know. what am I supposed to say? ...So that was probably not a very effective way...of treating me.”

“She asked very nonspecific questions that I found hard to answer, when I asked if she could be more specific she provided examples that still made little sense... I pretty much just let her keep talking, provided generic answers, shook my head, then left feeling a thousand times worse.”

Eye Contact

“To make matters worse [the therapist’s] eye contact was very persistent. I have enough problems making eye contact as it is, the room had nothing that I could stare at or use as an excuse for not making eye contact. Her persistence, to me, felt very demeaning.”

Adult Diagnosis Can Make a Positive Difference

“The other instance [of a good healthcare experience] that I can think of, is when I received the diagnosis of Asperger's Syndrome from my psychiatrist. You know, kind of a relief...you know to have a--to get an explanation...for a lot of things that happened in my life.”

Therapist's Role in Building Self-Awareness

“[The therapist] also pointed maybe where I wasn't right about something... I'd say that's actually a good thing because you may not see that yourself, you know... He'd say, 'Well, <name> I think maybe, maybe you shouldn't have done that or reacted that way', or you know, he pointed out how others may have perceived something.”

What Our Partners Want You to Know About Communication

- “Having trouble communicating doesn't always mean having trouble thinking. And trouble understanding what someone says doesn't mean we can't grasp the concepts.”
- “Tests that rely on language and interaction skills like the MMPI and WAIS, are not necessarily accurate for people who have atypical language and interaction styles.”
- “Autistics often take things literally that you don't expect them to.... One of the questions a psych asked me was ‘Do you hear voices that nobody else seems to?’ and of course I answered yes, because hey, hyperacusis and all that.”

What Our Partners Want You to Know About Therapy

- “I would add that a doctor needs to separate the ‘healthy autistic’ from the psychological illness the person may have additionally... Only then can they help ill autistic people become healthy autistic people.”
- “Our autistic behavior may be adaptive... [Do] not to take away things that we need to cope.”
- “Special interests are good, not bad.... Don't take them away from us.”
- “When I go to counseling, I don't just want ‘I commiserate’ - I want ideas of how they handled similar issues.”

What Else Our Partners Want You to Know

- “Autistics can have a sense of humor and an imagination. This does not rule out autistic spectrum disorders.”
- “Autistics DO have emotions! Autistic people may not exhibit emotions in the way you're used to... I have seen psychologists think that I wasn't actually upset, annoyed, etc., just because I looked calm and controlled.”
- “Autism isn't just emotional. It's also sensory. And the sensory is often a direct cause of the emotional. People don't notice the stuff that sends me into sensory overload, which puts me into a meltdown...”
- “Which works both ways: emotional stress can make it harder for me to handle sensory input and overload.”

Take Home Messages

- CBPR can improve research with minorities.
- Being on the autistic spectrum can affect experiences with healthcare.
- Autistic adults can make valuable contributions in matters that affect them, including their healthcare.

Acknowledgements

- We would like to thank our co-investigators Katherine McDonald, PhD, Elesia Ashkenazy, Cody Boisclair, Sebastian Dern, Amanda Baggs, Roberta Delaney, Rhonda Way.
- We appreciate the support of the Autistic Self Advocacy Network.
- AASPIRE receives funding from Portland State University, Oregon Health & Science University, and the Oregon Clinical and Translational Research Institute (OCTRI), grant number UL1 RR024140 from the National Center for Research Resources (NCRR), a component of the National Institutes of Health (NIH), and NIH Roadmap for Medical Research.

Please Contact Us

- Christina Nicolaidis, MD, MPH
nicolaid@ohsu.edu 503-494-9602
- Dora Raymaker, MS dora@aaspire.org
- AASPIRE <http://aaspire.org>
- Gateway Project <http://thegatewayproject.org>