



The AASPIRE Healthcare Toolkit – Improving healthcare for autistic adults

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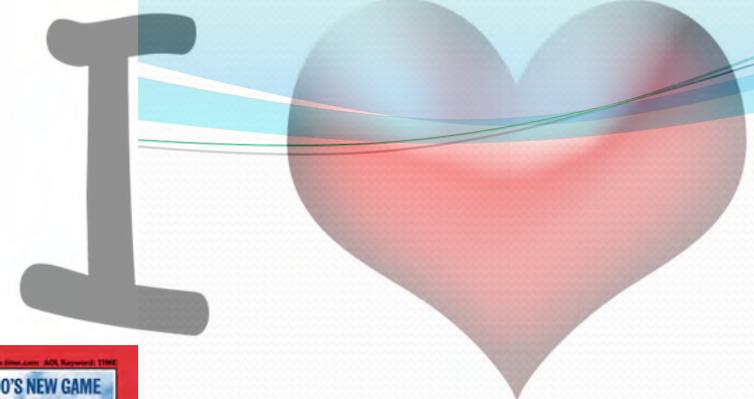
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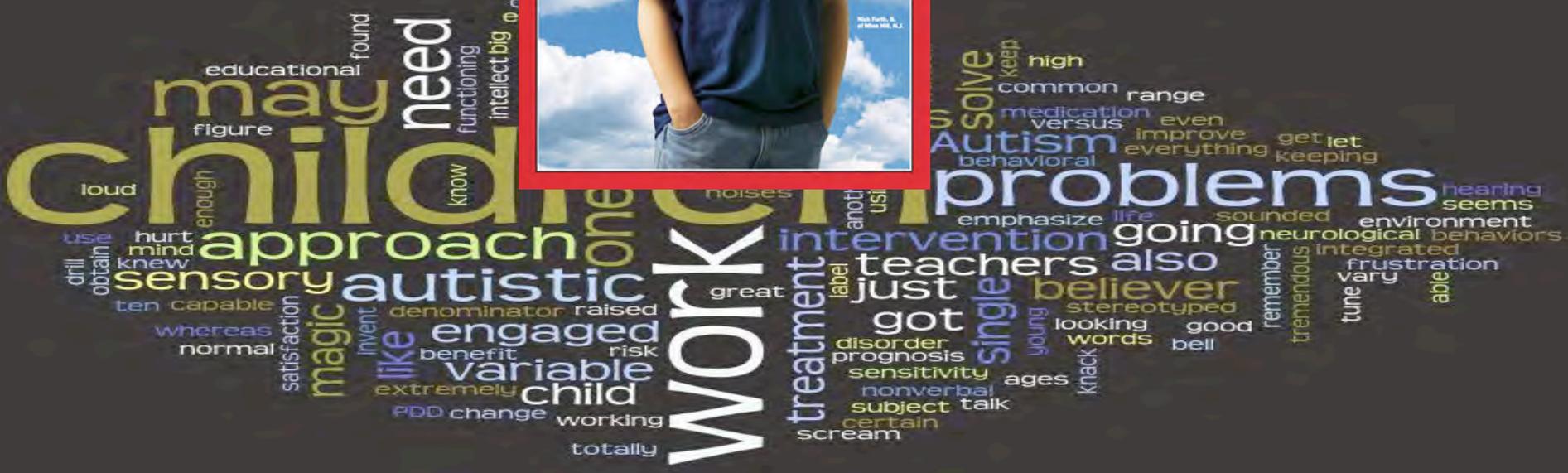
Editor-in-Chief, *Autism in Adulthood*

Community Report on Autism

2016



Autistic Children





Time to Transition to Adult Healthcare (and to Research with and for Autistic Adults)

A Few Notes

Neurodiversity paradigm

- Respect for all forms of diversity, including diversity in how our brains work
- Social model of disability

Use of language

- Ideally would use person-centered language, but can't for a presentation
- Identity-first language for autistic adults
- Person-first language for people with intellectual disability
- Alternate when talking about disability in general



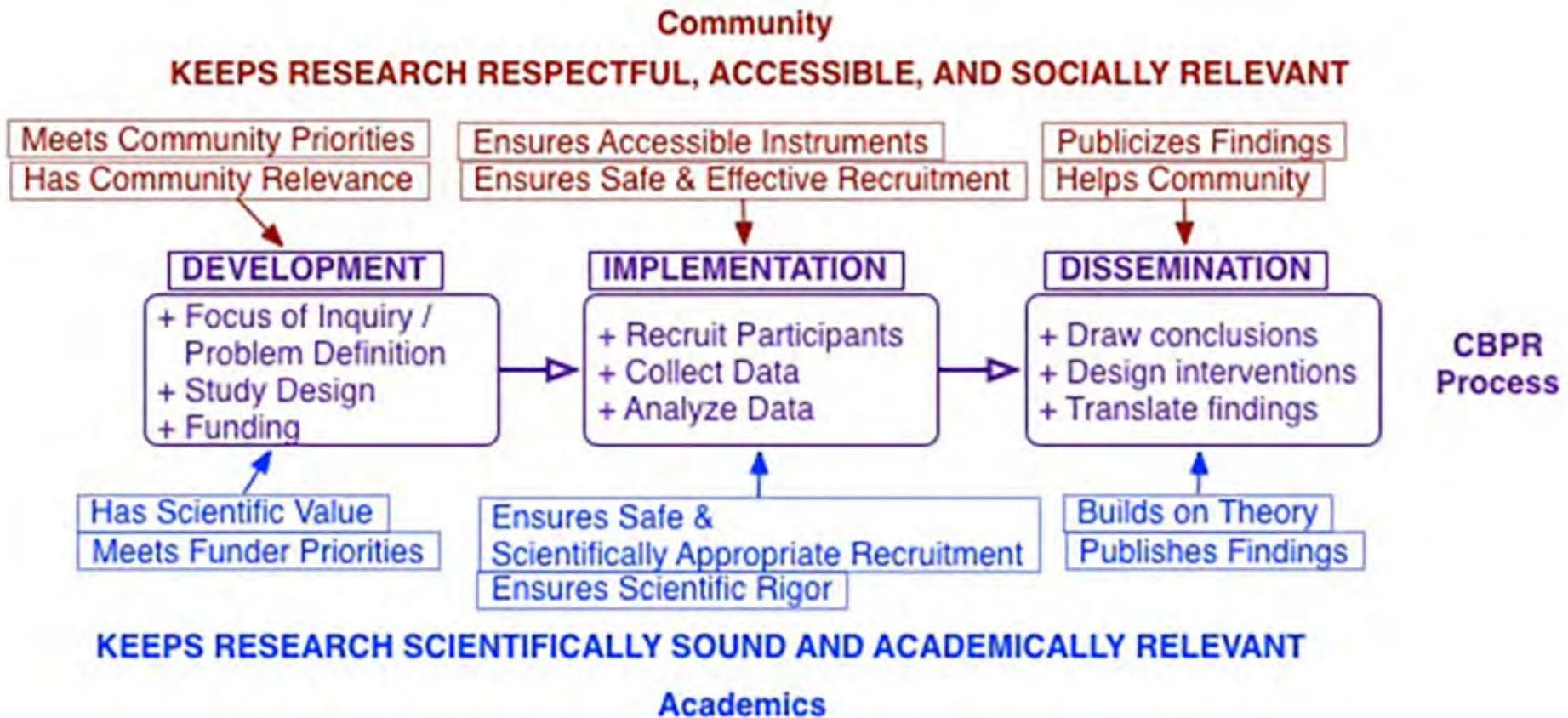
AASPIRE

- Academic Autism Spectrum Partnership in Research and Education (www.aaspire.org)
- Co-Founded in 2006 by Christina Nicolaidis and Dora Raymaker
- Autistic adults, academics, family members, disability services and healthcare providers
- Community Based Participatory Research
 - Autistic adults serve as equal partners throughout all phases of our research projects.

AASPIRE Projects and Collaborations

- Healthcare-Related Projects
 - Healthcare Survey
 - Qualitative study of experiences with healthcare
 - Development and testing of AASPIRE Healthcare Toolkit
 - Attempt to integrate Toolkit into 3 US healthcare systems
 - Hospital and ED experiences
 - Collaboration with UK researchers to create annual health check for NHS
- Other Projects
 - Outcome Measurement
 - Skilled Employment
 - Autistic Burnout
 - Interpersonal Violence
 - Pregnancy Decisions
 - Suicide Prevention

Community Based Participatory Research



Partnership Affects Every Part of the Project

- Choice of topic / research question / study design
- Study protocols
- Choice of outcomes or “constructs”
- Recruitment materials
- Consent materials
- Survey and qualitative data collection
- Intervention Development
- Data Interpretation
- Dissemination

The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants

Autism

1–13

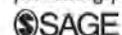
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Katherine McDonald⁵, Michael Weiner^{6,7,8}, Joelle Maslak³,
Morrigan Hunter³ and Andrea Joyce³

Abstract

As interest in autism in adulthood grows, so does the r

AUTISM IN ADULTHOOD
Volume 2, Number 1, 2020
Mary Ann Liebert, Inc.
DOI: 10.1089/aut.2019.0074

Advances in Measurement Methods

Creating Accessible Survey Instruments for Use with Autistic Adults and People with Intellectual Disability: Lessons Learned and Recommendations

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Emily M. Lund, PhD, CRC^{4,6} Sandra Leotti, PhD^{1,4,7} Steven K. Kapp, PhD^{3,8} Marsha Katz, MS ED^{4,9}
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Development of the AASPIRE Web Accessibility Guidelines for Autistic Web Users

Dora M. Raymaker, PhD^{1,2} Steven K. Kapp, PhD^{2,3} Katherine E. McDonald, PhD^{2,4}
Michael Weiner, MD, MPH^{2,5} Elesia Ashkenazy, BA² and Christina Nicolaidis, MD, MPH^{1,2,6}

Healthcare Disparities

Healthcare Disparities Survey

- Online survey comparing autistic adults (N=209) to non-autistic adults (N=228) with and without other disabilities.
- Greater unmet healthcare needs
 - Physical health needs (aOR 1.9)
 - Mental health needs (aOR 2.2)
 - Prescription medication needs (aOR 2.8)
- Greater Emergency Department use (aOR 2.1)
- Lower use of Pap Smears (aOR 0.5)
- Lower satisfaction with patient-provider communication and healthcare self-efficacy

Healthcare Disparities

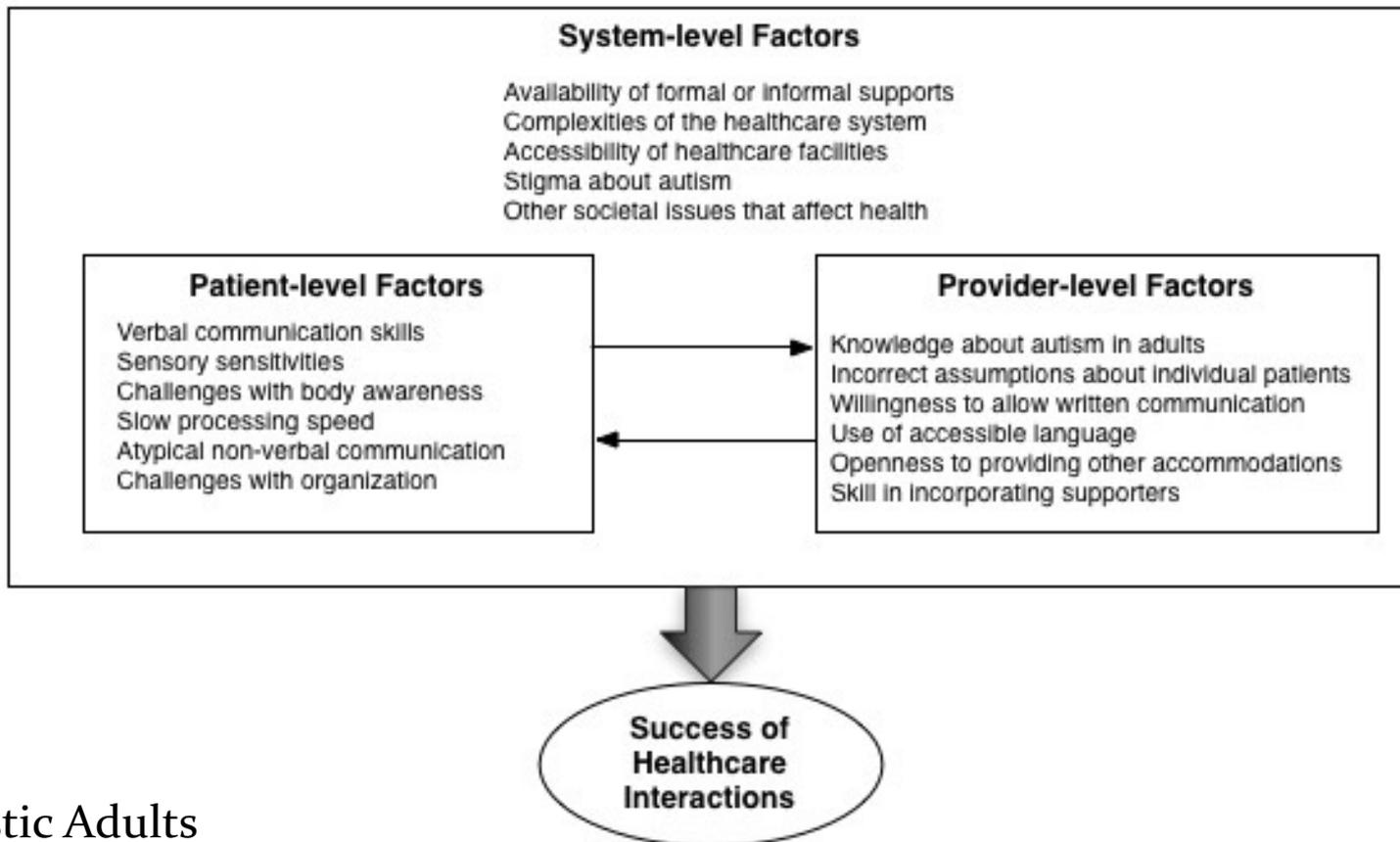
- Large Kaiser Permanente case-control study
- Compared to adults with ADHD, autistic adults had:
 - ↑ primary care visits (74% VS 67%)
 - ↑ outpt mental health visits (43% vs 33%)
 - ↑ hospitalizations for ambulatory care sensitive diagnoses (5.4% vs. 2.3%)
 - ↓ gynecology visits and cervical cancer screening (35% vs 50%)
- Differences even greater when compared with general population

Barriers to Healthcare

- People without disabilities experienced far fewer barriers to healthcare than autistic or other disability groups.
- Autistic group reported more barriers to healthcare than people with other disabilities, plus different pattern.
- Top barriers:
 - Fear or anxiety (35%)
 - Can't process information fast enough in real-time (32%)
 - Concern about cost (30%)
 - Facilities cause sensory issues (30%)
 - Difficulty communicating with providers (29%)

Patient Experiences with Healthcare

Healthcare Experiences



39 Autistic Adults
16 Supporters

Sensory Sensitivities

“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. But he refills my usual meds and I go on my way.”

Challenges with Body Awareness

- “Like when they ask if pain is shooting or stabbing or burning, it’s like, I don’t know, it just feels funny.”
- “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.”

Providers' Incorrect Assumptions

- “I have used my Alphasmart [portable communication device] when my speech is too slow or difficult to understand for medical appointments. Some of the doctors have been really great, but others have acted really condescending when I used it, also immediately assuming I couldn't be alone, had to have had parents there too ... So I try to go without, even when my speech is in a poorer shape.”
- “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.”

Communication and Openness to Accommodations

- “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.”
- “But they talk to him in the same words that they’d use if they were talking to me... If they’re gonna talk to him ... they need to say it how he can understand it.”

Decreased patient autonomy

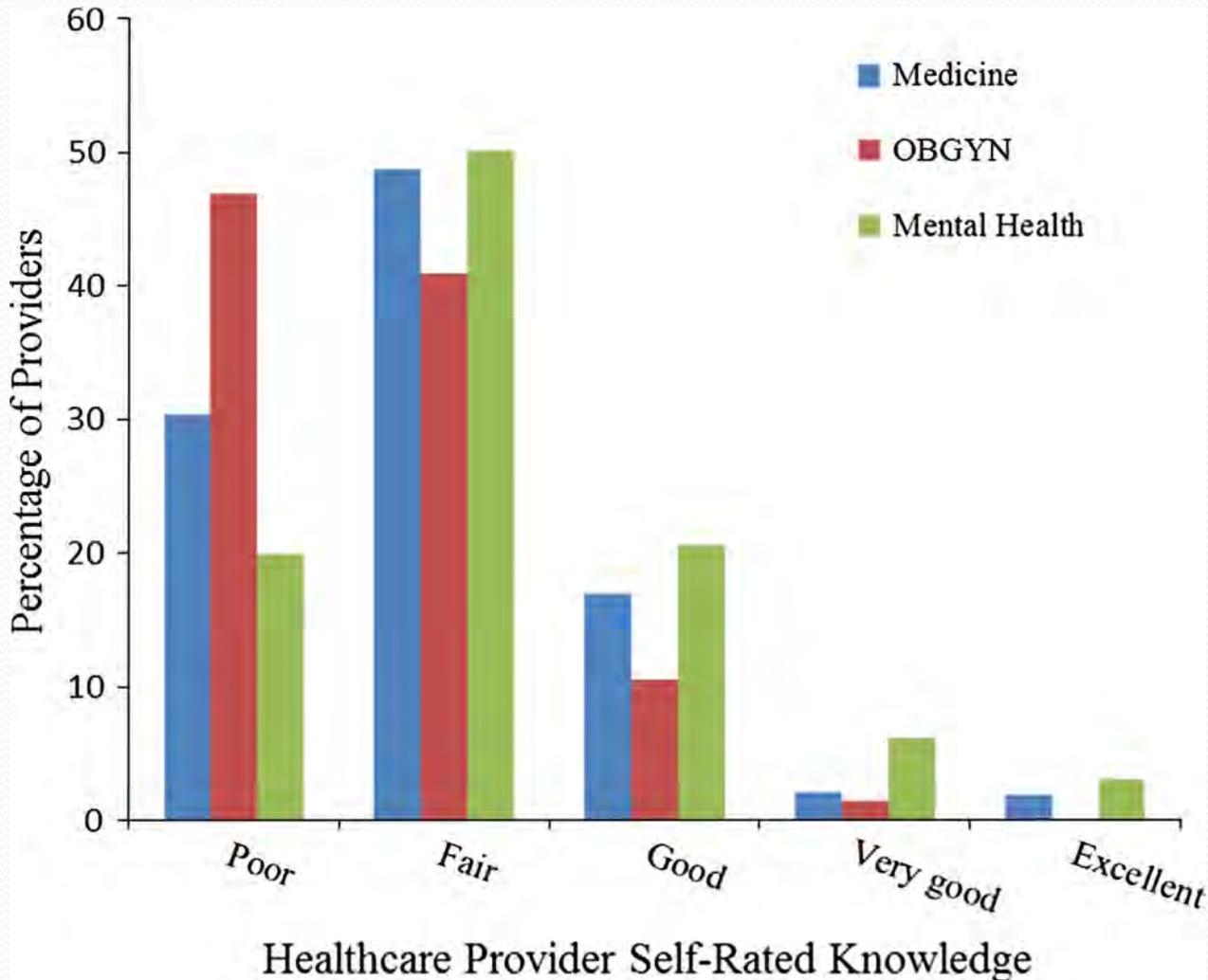
- “Just because I might need more information to understand things, it doesn’t mean they can or should just talk to me like a child or leave me without knowledge of my own health. My body is my body, and my experiences and wishes about my body are MINE TO MAKE!”

Provider Knowledge and Self-Efficacy

Early AASPIRE Inquiries

- Brief survey of 129 PCPs:
 - 73% felt uncomfortable in their ability to provide quality care for adults on the spectrum
 - 84% no plans to seek additional training on ASD
 - 88% would accept autistic adult in their practice
 - If new autistic pt, <50% would attend CME
 - 82% would search information on the Internet
 - 98% would read customized report about pt needs
 - 99% would appreciate patient's effort
- Qualitative interviews with 9 PCPs

Kaiser Survey of 922 Healthcare Providers

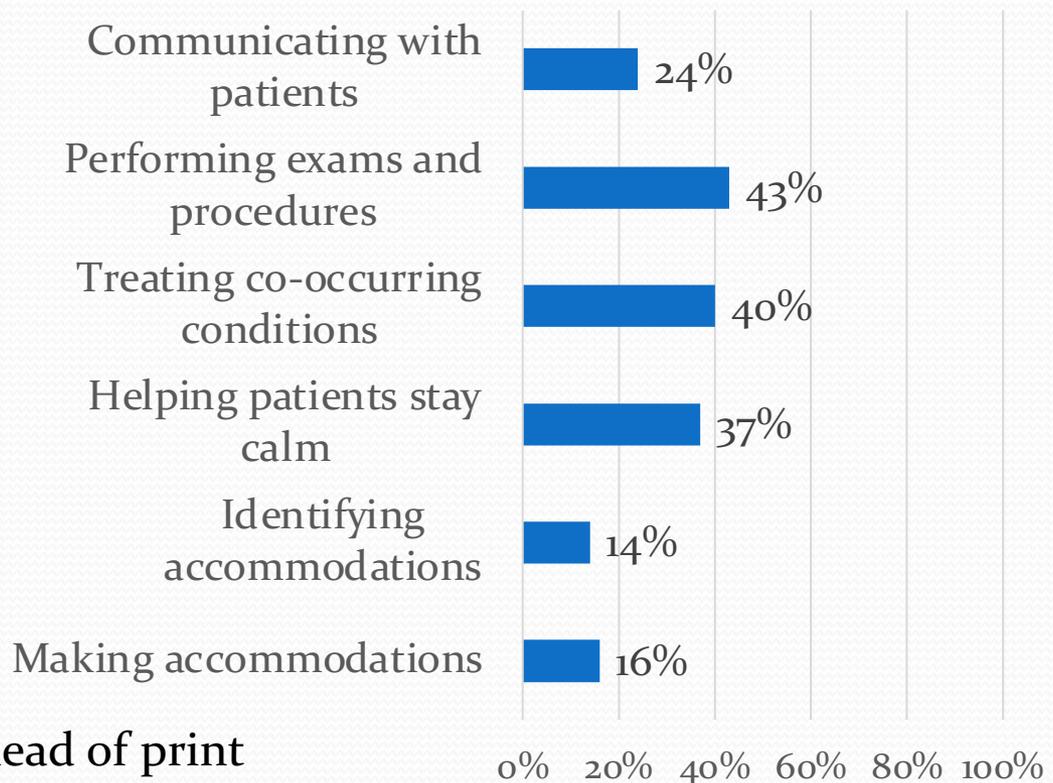


Zerbo et al, *JADD*,
2015

Provider Self-Efficacy in Caring for Autistic Adults

- Baseline survey data from current AASPIRE intervention
- 143 PCPs in 3 health systems in Northern California and Oregon

Proportion of providers who felt confident in:



Challenges with Healthcare Provider Training

- Medical / nursing school / residency curricula
 - No current training requirements
 - Crowded curricula
 - A few model programs – need to be expanded
- CME / CEU trainings for practicing adult providers
 - Many competing priorities
 - Low number of patients for any one provider
 - Not really “on our radar” yet
- Wide heterogeneity of patient needs
- Easy to fall into medical model / lack of autistic input



Very Heterogeneous Condition

“When you have met one autistic person, you have met one autistic person”

Need for individualized tools!

The AASPIRE Healthcare Toolkit



“Remember that we’re all human beings. We all deserve healthcare.... Often, we turn up with things that are more typical of people in countries without medicine, because we get so much medical neglect. That’s people with developmental disabilities in general, probably also psychiatric disabilities. Each of us is different. That’s why we did the toolkit. The toolkit helps people talk about specific issues that are different for all of us. Every time I nearly die and survive, I know that means other people didn’t survive. I wrote this so more people will survive.”

Mel Baggs

2018 Annual Meeting of the Society of General Internal Medicine



Toolkit Development

- Contents based on prior survey, qualitative research, and partner experiences.
- Community partners wrote, reviewed, and/or edited every part.
- Cognitive interviewing study with autistic adults, supporters (family members and disability service providers), and primary care providers to ensure material easy to understand and useful.
- 2-week test-re-test reliability study to ensure accommodation requests stable over time.

AASPIRE Healthcare Toolkit –

www.autismandhealth.org



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Theme: :

AASPIRE Healthcare Toolkit

Primary Care Resources for Adults on the Autism Spectrum and their Primary Care Providers

This web site has information and worksheets for adults on the autism spectrum, supporters, and healthcare providers. It focuses on primary healthcare, or healthcare with a regular doctor.

The resources on this site are meant to improve the healthcare of autistic adults. They were made by the [Academic-Autistic Spectrum Partnership in Research and Education \(AASPIRE\)](#) through a series of research studies funded by the [National Institute of Mental Health](#). AASPIRE hopes that you will find these resources helpful.

PATIENTS & SUPPORTERS



[click here](#)

Make a [Personalized Accommodations Report](#) for your healthcare provider.

This section also has information on:

- [Healthcare](#)
- [Staying Healthy](#)
- [Your Rights in Healthcare](#)
- [Autism Information](#)
- [Medical Information](#)
- [Checklists and Worksheets](#)



HEALTHCARE PROVIDERS

[click here](#)

This section has information on:

- [How Autism Can Affect Healthcare](#)
- [Tips for Successful Office Visits](#)
- [Legal and Ethical Considerations](#)
- [Autism Information, Diagnosis, and Referrals](#)
- [Associated Conditions](#)

Healthcare providers also might want share our [Autism Healthcare Accommodations Tool](#), and other [checklists and worksheets](#) with their patients on the autism spectrum.

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INDIANA UNIVERSITY



Portland State UNIVERSITY

Patient Information

AASPIRE Healthcare Toolkit for Patients & Supporters

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Theme: Light (default) : A A A search Search

Switch to: FOR HEALTHCARE PROVIDERS

HOME > PATIENTS & SUPPORTERS > HEALTHCARE > FINDING PROVIDERS

Healthcare

Finding Providers

Making Appointments Preparing for a Visit During the Visit After the Visit

Finding Providers

Content Outline

- [What is this topic about?](#)
- [How do I find names of healthcare providers?](#)
- [How do I know if I can go to a healthcare provider or clinic?](#)
- [How do I know if a healthcare provider is a good choice?](#)
- [What if a provider turns out to be a bad fit for me?](#)
- [Should I disclose my ASD diagnosis to my healthcare provider?](#)
- [Summary](#)
- [Links and Resources](#)

This topic: [print](#) [email](#) [download as pdf](#)

What is this topic about?

This section is about how to find a healthcare provider, like a doctor, nurse practitioner, or physician's assistant.

If you don't already have a healthcare provider, or if you want to change healthcare providers, this section gives some ideas about how to find a new one.

It may not be possible to follow these suggestions in a step-by-step fashion. You may need to go through the steps more than once, or in a different order, before you find a healthcare provider you like. Not all steps or suggestions in this section may apply to you.

[Back to Top](#)

How do I find names of healthcare providers?

Option 1: Get referrals from people or organizations you know and trust.

For example, you could ask:

- **Friends, family, or co-workers** - Ask people you trust if they have a doctor they like. Someone you know might be able to give you first-hand information about what a healthcare provider and his or her office and staff are like.
- **Other professionals** - If you go to other healthcare professionals, or if you use a disability service or social service agency, ask them for recommendations.
- **Autism Groups or Communities** - If you are involved with a local autism group or community either online or offline, you can ask there. These communities might be able to suggest providers with experience

Forms and Worksheets

Topic List



Forms & Worksheets



[Healthcare](#)



[Staying Healthy](#)



[Your Rights in Healthcare](#)



[Autism Information](#)



[Computer & Internet Access](#)



[Medical Information](#)



[Personalized Accommodations Report](#)



Forms & Worksheets

NOTE: These forms and worksheets are in PDF format. If you need a different format, please contact us at info@aaspire.org.

-  [Making an Appointment Worksheet](#) - This worksheet walks through the steps of making a healthcare appointment. It has lines to write in information that you might want handy while making the appointment. It also has lines to write in information the office staff might tell you, like the day and time of the appointment.
-  [What to Bring to a Healthcare Visit Checklist](#) - This is a checklist you can use when putting together the things you need to bring to a healthcare visit. It has second page with extra things to bring to a first visit, or if you haven't seen your healthcare provider in a long time.
-  [Symptoms Worksheet](#) - This worksheet covers the information healthcare providers usually want to know about symptoms. Not all questions apply to all symptoms. But thinking through some of these questions may help you better describe your symptoms or answer your provider's questions.
-  [After the Visit Worksheet](#) - Your provider may ask you to do something after the appointment. This worksheet has a page for each of the main things your provider may ask you to do:
 - Make a follow-up appointment with your healthcare provider
 - See a specialist or make an appointment with a different healthcare provider
 - Get a lab, x-ray, or other test
 - Take a medication
 - Do something to manage your health condition at home
-  [Autism Healthcare Accommodations Tool](#) - This form will guide you through the steps to create a personalized accommodations letter you can print or save and give to your healthcare provider.



Personalized Accommodations Report

Create an individualized report of ways to improve your healthcare access to give to your healthcare provider.

[Create Your Report](#)

Download Resources

PDF File Downloads

For alternate formats, contact info@aaspire.org

- [Forms & Worksheets](#)
- [Healthcare](#)
- [Staying Healthy](#)
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- [Autism Information](#)
- [Computer & Internet Access](#)
- [All Topics](#)



Provider Information

AASPIRE Healthcare Toolkit for Healthcare Providers

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Switch to: FOR PATIENTS & SUPPORTERS

Topic List

- How Autism Can Affect Healthcare
- Tips for Successful Office Visits**
- Legal and Ethical Considerations
- Autism Information, Diagnosis, and Referrals
- Resources and Links
- Patient Forms & Worksheets
- Personalized Accommodations Report

Tips for Successful Office Visits

- [Communication and Interaction](#)
- [Sensory Issues](#)
- [Body Awareness, Pain, and Sensory Processing](#)
- [Planning and Organizing](#)
- [Exams and Procedures](#)

Download Resources

PDF File Downloads
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Get ADOBE READER

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Autism Healthcare Accommodations Tool (AHAT)



- Fill out a survey
- Computer uses answers to create a personalized and healthcare provider-friendly report of accommodations

AHAT Survey

How you communicate	Ability to understand spoken language, speak, read, and write; use of alternative and augmentative communication
Communication Suggestions	Potential accommodations to help patient with receptive and expressive communication; characteristics provider should be aware of related to communication
Before the visit	Potential accommodations staff can make prior to visit (e.g. re scheduling); accommodations to help patient handle waiting room
During the visit	Potential accommodations to help patient stay calm and comfortable, handle examinations or procedures, and participate in shared decision-making; other autism-related characteristics provider should be aware of
After the visit	Accommodations to help patient understand or follow recommendations; ability to use telephone; if needed, accommodations to handle blood draws
Getting to know you	Information about patient's strengths, and special interests; information to recognize and address anxiety during office visits
Your supporters	Name and contact information for up to 5 supporters; relationship to patient and preferred role for each one; name of guardian/conservator, and/or healthcare power of attorney, if applicable
Sharing the report*	Name, date of birth, preferred gender pronoun, need for assistance with scheduling or transportation,

Sample AHAT Item

Welcome

UID: 2gWYDZB9rq3ntRgK Group: Groups Disabled

Text Only Read Text Aloud

Introduction

How You Communicate

Communication Suggestions

Before the Visit

During The Visit

After the Visit

Getting to Know You

Your Supporters

Sharing the Report

Survey Evaluation

What can help you make good decisions about your health or healthcare?

Pick up to three suggestions.

- Ask me to tell you in my own words what the choices are and what the consequences would be for each one.
- Give me extra time to make a decision, even if it means I need to come back or communicate the decision at a later time.
- Give me very blunt and concrete examples of what would happen if I did or did not follow a recommendation.
- Direct me to detailed information or resources about my health conditions.
- Give a person I trust detailed information about my health conditions and choices.
- Let me discuss my choices with a person I trust, and then come back to you.
- I don't need accommodations to make good decisions about my healthcare.
- I need accommodations to make good decisions about my healthcare, but they are not listed here.
- I do not wish to say.

AHAT Report

Cover letter

Introduction to report; need for assistance with scheduling or transportation; link to full online toolkit

Main AHAT report

Information about patient communication; recommended strategies and accommodations to help visits go smoothly, to help patient tolerate exams, to assist with shared decision-making, to help patient comply with recommendations; information to help better understand patient

Information for office staff

Recommendations for setting up appointments, helping patient tolerate wait, rooming patient, and assisting patient with blood draws

Supporter information

Name of conservator/guardian and/or healthcare power of attorney, if applicable; table with name, relationship, healthcare role, and contact information for each supporter

Sample Provider Report

Patient: Dora Raymaker



IV. Recommendations to Assist with Shared Decision Making

- Allow her extra time for making decisions (might involve communicating decision at a later time).
- Be very blunt and give concrete examples of what would happen if a recommendation was or wasn't followed.
- Give a trusted person detailed information about health conditions and choices.
- Allow time for her to discuss choices with a trusted person.



V. Recommendations to Help Ms. Raymaker Comply with Recommendations

- Write out your impressions and the plan for next steps or treatments.
- Write out detailed step-by-step instructions.
- Show pictures as much as possible.
- Show her what to do while she is still in the office.
- Have staff help with scheduling follow-up visits, referrals, or tests.

(just part of the full report)

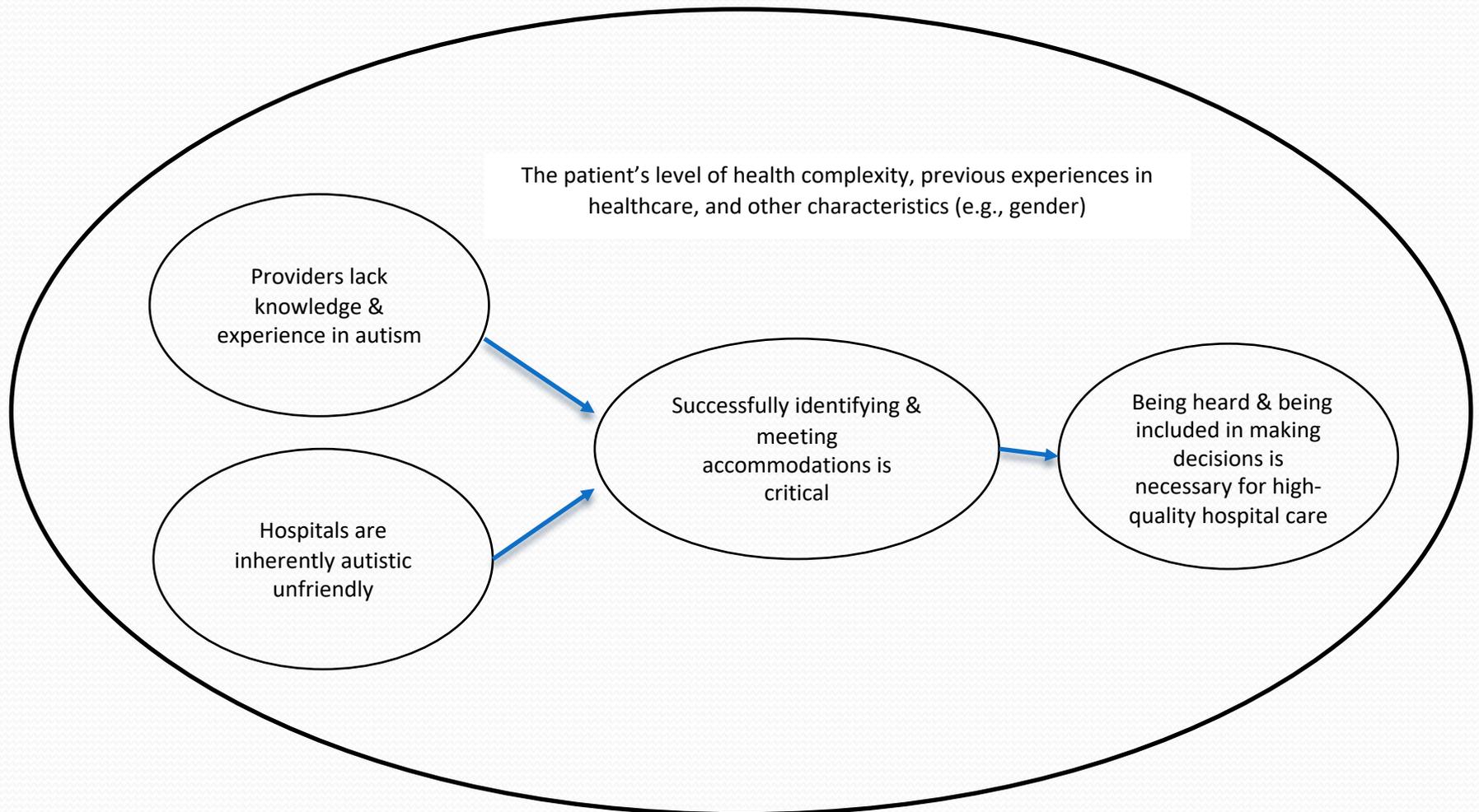
Toolkit Evaluation

- Mixed-methods, single arm, 1-month pre-post intervention study design in real-life setting.
- 170 autistic participants; 41 PCPs
- 95-97% found it easy to understand, important, & useful.
- Significant changes between pre- and post-test in
 - Number of barriers to healthcare
 - Healthcare self-efficacy
 - Patient Provider communication
- Strong qualitative themes around toolkit utility
 - Means to clarify and communicate needs
 - Validation of experience and empowerment re self-advocacy
 - Improved self-efficacy; better able to prepare for visits
 - Examples of changes in provider behaviors

Challenges Integrating the Toolkit into Healthcare Systems

- Recent NIH grant to integrate AASPIRE Healthcare Toolkit into 3 diverse health systems
 - Kaiser Permanente Northern California, Oregon Health & Science University, and Legacy Health System
- Worked with 7 intervention clinics to try to find processes that work for their workflows and settings
- Meant to compare 6-month patient and provider outcomes with those from control clinics
- But many system challenges – AHAT reports rarely made it to providers at a time that they could really use them.
- Lots of lessons learned!

Hospital Experiences Project



Lots of ideas for how to adapt AASPIRE Healthcare Toolkit to hospital... setting...

Next Steps

- Need help with dissemination of Toolkit – Available for free at www.autismandhealth.org.
- Working with Dr. Parr and collaborators to adapt toolkit for use in the National Health System in the UK.
- Working with Dr. Urbanowicz to adapt toolkit for use in inpatient settings.
- With appropriate resources, would like to:
 - Expand to other disabilities
 - Expand to mental health care, dental care, emergency care
 - Add multi-media training segments
 - Connect directly to EMRs

Final Thoughts

Take Home Points

- Autistic adults currently experience significant healthcare disparities
- Adult healthcare system is currently not equipped to manage autistic adults' needs
 - Gaps in provider knowledge and skills
 - Many barriers to care
 - Successful interactions depend on addressing patient, provider, and health system factors
- AASPIRE Healthcare Toolkit may be a small, but important step toward improving care.
- Many more solutions are needed at patient, provider, and system levels!

Funding

AASPIRE Healthcare Projects

- National Institute Of Mental Health (R34MH092503, R34MH092503)
- National Institute of General Medical Sciences via the Build EXITO Program (UL1GM118964, RL5GM118963, TL4GM118965)
- National Center for Research Resources via The Oregon Clinical and Translational Research Institute (UL1 RR024140)
- Fulbright Foundation

Other AASPIRE Projects

- National Institute of Mental Health (R01MH121407, R21MH112038, K23MH123934)
- National Institute of Child Health and Development (R21HD078830)
- National Center for Advancing Translational Sciences (KL2TR002370)
- Portland State University
- The Burton Blatt Institute and Michael Morris

AASPIRE Resources

- AASPIRE Healthcare Toolkit
 - www.autismandhealth.org
 - Autism Healthcare Accommodations Tool (AHAT)
 - Worksheets and Checklists for patients
 - Resources and information for patients, supporters, and healthcare providers
- Pregnancy Resources
 - www.pregnancyanddisability.org
 - 8 videos with and for people with IDD about pregnancy decisions
- *Autism in Adulthood*
 - www.liebertpub.com/aut
 - Peer-reviewed journal focused on the issues most important to improving the lives of autistic adults.
 - Autistic adults involved at all levels.
- AASPIRE Collaboration Toolkit
 - www.aaspire.org/collaboration-toolkit
- Inclusion Guidelines
- Accessible study materials
 - Survey instruments
 - Sample consent forms
 - Sample qualitative interview guides
- Collaboration Tools
 - Community partner recruitment/application/roles
 - Authorship and presentation guidelines
 - Consensus process

Many Thanks to...

- AASPIRE Healthcare Project Team

Christina Nicolaidis, Dora Raymaker, Lisa Croen, Maria Massalo, Mike Weiner, Katherine McDonald, Clarissa Kripke, Anna Urbanowicz, Junghee Lee, Andee Joyce, Morrigan Hunter, Reid Caplan, Joelle Maslak, Steven Kapp, E. Ashkenazy, Mel Baggs, Finn Gardiner, Mirah Scharer, Jennifer Aengst, Maria Massalo, Kelly Zhen, Gavin Schnieder

- Our many other old and new AASPIRE team members, the Autistic Self-Advocacy Network, the Autism Society of Oregon, and all our study participants