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# Getting the Most out of Healthcare as an Autistic Adult

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# Healthcare Toolkit

## Getting the Most out of Healthcare

**Dora Raymaker, MS & Christina Nicolaidis, MD, MPH**

Amanda Baggs, Cody Boisclair, PhD, Clarissa Kripke, MD, Elesia  
Ashkenazy, Katie McDonald, PhD, Kirby Erickson, and Marcie Tedlow

# Introductions

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- Dora Raymaker
- Christina Nicolaidis

# Agenda

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- I. About Community Based Participatory Research & AASPIRE
- II. AASPIRE Healthcare Studies - Results to Date
- III. Getting the Most Out of Healthcare
- IV. Resources

# Problems with Research

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- Autistic people are usually not included as part of the research team.
- Research funding priorities may not be the same as the Autistic community's priorities.
- Studies sometimes aren't designed properly to work with autistic participants.
- The results of studies sometimes aren't useful to autistic people, or are disrespectful, stigmatizing, or reinforce stereotypes.

# Community Based Participatory Research (CBPR)

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- We're not the first or only group of people to have these problems.
- Community Based Participatory Research is one response to these issues.
- In CBPR, people from a minority community become part of the research team.
- Personal life experience is valued equally with academic knowledge, and scientists and community people are expected to respect and learn from each other.

# CBPR Means...

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- Community people and university researchers together decide what is researched.
- Community people and university researchers together decide how the research is carried out and what the results of the research mean.
- Community people and university researchers together decide how the results of the research are shared with the rest of the world.
- Research is used both to advance science and to benefit the community.



# Academic Autistic Spectrum Partnership in Research & Education

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- Started in 2006 by Dora & Christina.
- Community Based Participatory Research with the Autistic community.
- Team made up of academic researchers, autistic individuals, family members, healthcare providers, and disability services professionals.
- In partnership with Oregon Health & Science University, Autistic Self Advocacy Network, Portland State University, Autism Society of Oregon, Syracuse University, Indiana University, and members of the Autistic community at large.

# AASPIRE's Mission

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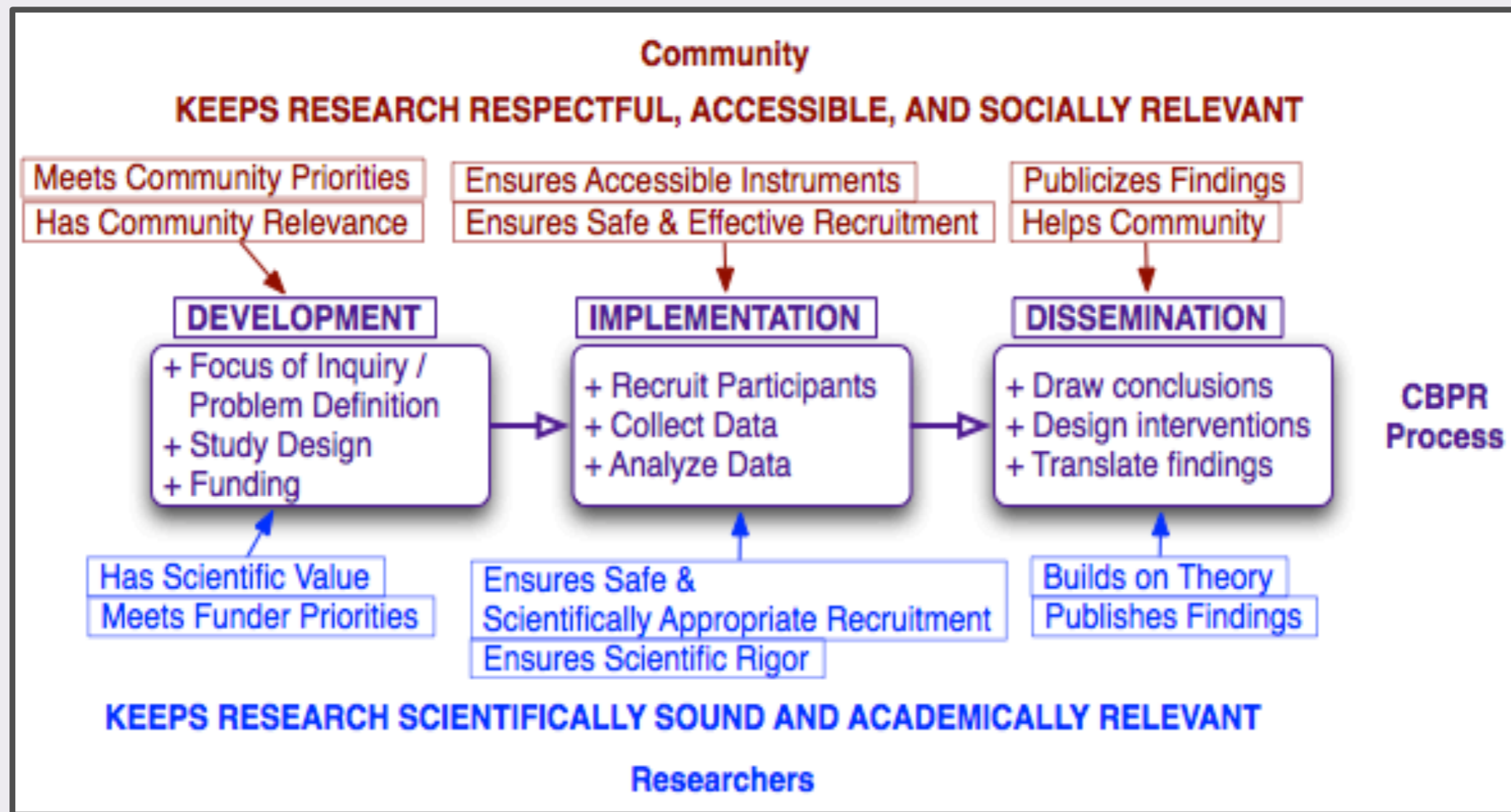
- To encourage the inclusion of people on the autism spectrum in matters which directly affect them.
- To include people on the autism spectrum as equal partners in research about the autism spectrum.
- To answer research questions that are considered relevant by the Autistic community.
- To use research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

# AASPIRE's Current Projects

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- **Healthcare Study 1** - To assess healthcare disparities & understand barriers to healthcare.
- **Healthcare Toolkit** - To develop and try out an interactive toolkit to help improve healthcare access and quality for autistic adults.
- **Internet Use, Community, & Well-being** - To examine the relationship between Internet use, sense of community, & well-being.
- Collaborations with other groups:
  - **The Gateway Project** ([www.thegatewayproject.org](http://www.thegatewayproject.org))
  - **Partnering with People with Developmental Disabilities to Address Violence**

# AASPIRE's CBPR Process



# Tools for Accessibility and Equalizing Power

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- Academic and autistic Co-Principal Investigators (Co-PIs) on all projects
- Text-based meetings in online chat
- Elist for most communication
- Often puts Autistic partners at an advantage--which is good for the non-autistics too ;-)
- Multiple formats for input--email, chat, telephone, in-person
- Agendas, moderation, visuals, e-etiquette, 5-finger decision-making process

# Check-ins, Changes, and Other Policies

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- Frequent CBPR check-ins: How are things working for you? How can things be made better?
- Changes to how we work together based on feedback
- Creation of policies together (presentations, authorship on papers, conflict resolution, closing--and reopening--old conversations)
- Private website for archiving information
- Striving to be a “learning organization”

# Questions and Comments

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# II. AASPIRE Healthcare Studies - Results to Date

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- Healthcare Survey
- Healthcare Toolkit
  - Healthcare Interviews
  - Autism Healthcare Accommodations Tool
  - Next steps: Testing the toolkit in the real-world
- Questions and Comments



# Healthcare Survey

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- Objectives:
  - To compare the healthcare experiences of autistic and non-autistic adults
  - To identify barriers to healthcare
- Study Design: Online survey via the Gateway Project
- Participants: Adult US residents who access the Internet
- Used our CBPR process to adapt previously validated survey instruments to be accessible to autistic individuals
- 437 participants (209 autistic, 228 non-autistic)

# Healthcare Survey Results

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- After adjusting for socioeconomic factors, health insurance, and health status, autistic adults reported:
  - worse patient-provider communication,
  - lower general healthcare and chronic condition self-efficacy,
  - higher odds of having unmet physical health, mental health, or prescription medication needs,
  - lower odds of receiving pap smears or tetanus vaccines, and
  - higher odds of using the emergency room.
- Autistic adults reported both different and greater barriers to healthcare than people with and without other disabilities.

# Healthcare Toolkit

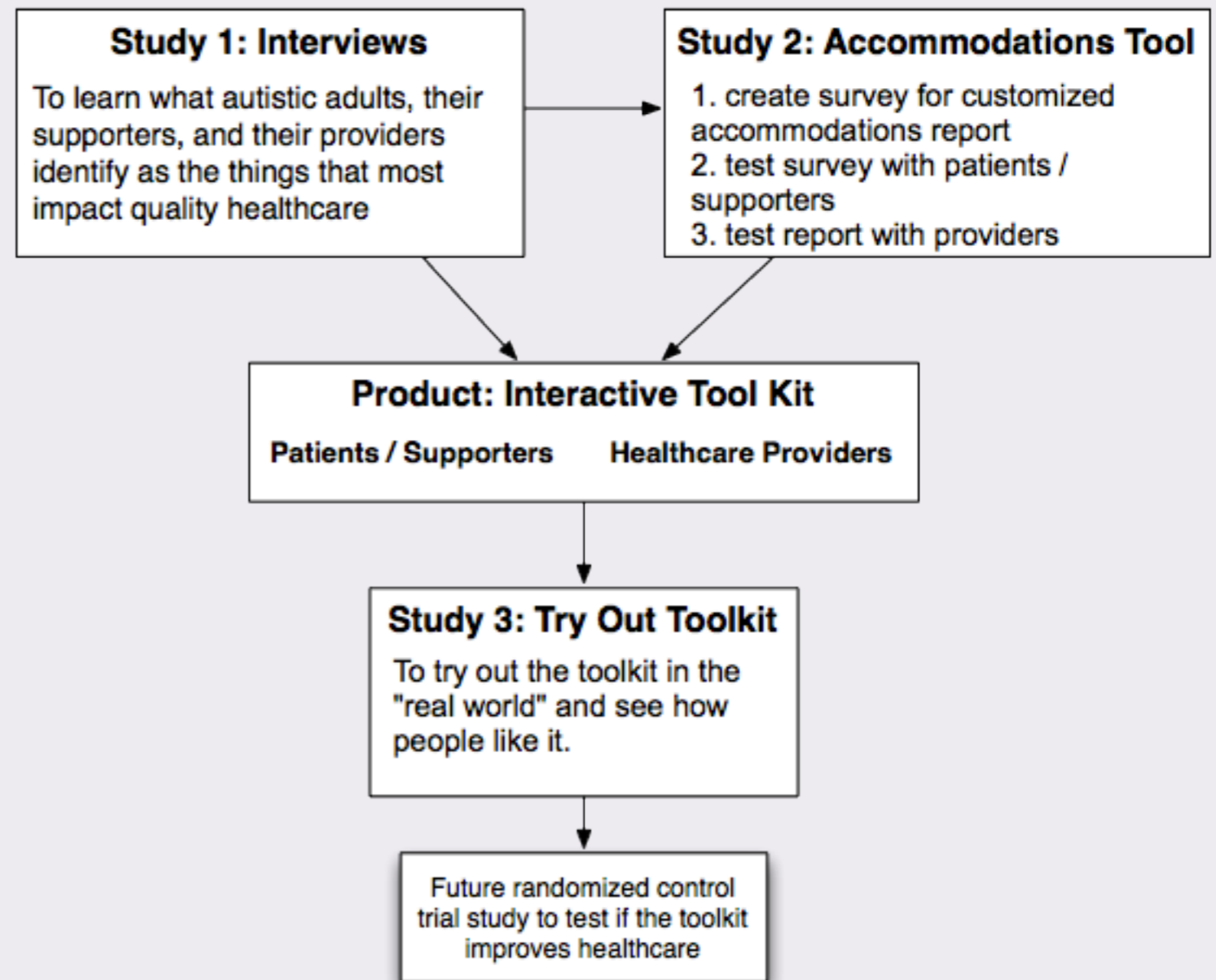
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- An interactive toolkit to improve healthcare
- Housed online and including:
  - A way to create a personalized ADA accommodations letter to give to healthcare providers (Autism Healthcare Accommodations Tool, AHAT)
  - Information for autistic adults about how to better understand, access, and use the healthcare system
  - Information for healthcare providers to help them provide better healthcare to their autistic patients
- All web site materials (except the AHAT survey) can be printed and used offline

# How We're Making the Healthcare Toolkit - 3

## Research Studies

- **Study 1:** Interviews
- **Study 2:** Autism Healthcare Accommodations Tool
- **Product:** Create Interactive Healthcare Toolkit for Patients & Healthcare Providers
- **Study 3:** Try Out the Toolkit
- **Future:** See if the toolkit improves healthcare



# Study 1: Healthcare Interviews

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- Objectives: To learn what autistic adults, their supporters, and their providers identify as the things that most impact quality healthcare.
- Study Design: Open-ended, semi-structured qualitative interviews done in-person, via email, via IM, or on the telephone
- Participants: US residents 18 and older who met at least one of the criteria:
  - Identify as autistic
  - Assisted an autistic adult with healthcare appointments in the past year
  - Provided healthcare to an autistic adult in the past year
- Used our CBPR process to collaboratively create the interview guide
- 39 autistic, 16 supporter, 9 primary care provider

# Results: Communication

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- Pragmatics - Need for direct, specific language; need for providers to be understanding about chit-chat; use of non-verbal language; issues with literal interpretation of language
- Mode - Need for communication to occur in the right mode: written, spoken, through pictures, with gestures, etc.
- Ability - Need for providers to communicate in a way the patient understands, whether that's short sentences and yes-and-no questions, or in medical jargon, and everything in between
- Communicating Symptoms - Issues around being able to communicate symptoms to providers

# Results: More Time

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- To Communicate - Providers need to allow enough time for communication to be effective
- To Process - Time is needed to understand what is happening, to make decisions, to process what the doctor has said
- To Get Used to Things - Getting used to the office, getting used to the providers, getting used to procedures, doing trial runs

# Results: Sensory Processing

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- Exams and Procedures - Sensory issues with exams and procedures
- Handling the Waiting Room - Sensory overload in the waiting room
- Identifying Symptoms - Difficulty processing sensations in a way that they can be identified clearly
- Sensory Processing and Communication - Sensory overload leading to difficulty communicating with healthcare providers



# Results: Staying Calm

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- Triggers - Meltdown triggers and avoiding them, issues with past healthcare trauma making future healthcare difficult
- Warnings Before Changes - Providing information about schedule changes, saying what will happen before doing it, having an agenda for visits
- Breaks & Other Strategies - Taking breaks, discussing things while walking, being given room to stim or pace

# Results: Role of Supporters

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- Supporters as Facilitators - Helping with appointments, helping with decision making, taking notes, helping with transportation / organization
- Supporters as Barriers - Getting in the way of self-determination, causing providers to underestimate the patient or not speak to the patient
- Healthcare Professionals Not Understanding the Role of Supporters - Confusion occurring
- Inadequate Support - Difficulty getting or following up on care because of inadequate support

# Results: Navigating Healthcare

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- Finding a Provider - Finding someone who meets needs, navigating insurance, navigating the healthcare system in general
- Scheduling - Getting an appointment, dealing with the telephone
- Transportation - Getting to healthcare visits
- Following Recommendations - Putting all the steps together to follow up on recommendations (for example, dealing with the pharmacy)

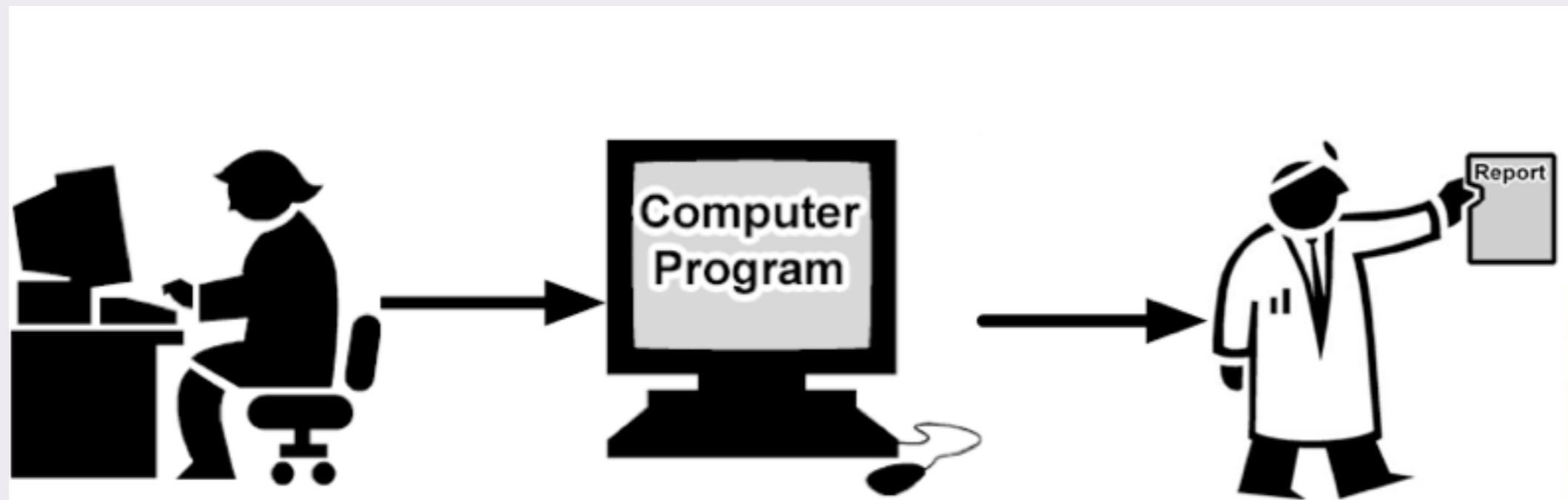
# Results: Misconceptions About Autism or Abilities

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- Over- or under-estimating intelligence and/or ability to understand
- Providers not understanding autism
- Providers making assumptions based on stereotypes or autism myths
- Providers mistaking autism for symptoms of something else

# Study 2: Autism Healthcare Accommodations Tool (AHAT)

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

# AHAT Created From

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- Information and ideas from our healthcare interviews (Study 1)
- Information, ideas, suggestions, and a whole lot of revisions from our team of autistic people, support people, researchers, and healthcare providers
- Additional input from more healthcare providers and community members

# Testing the AHAT

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- Objective: Make sure the AHAT is understandable and reliable.
- Study Design:
  - Study 2a: Show people a draft of the survey and ask them what they think it means, if we missed anything, and for other suggestions
  - Study 2b: Have people take the survey twice to see if it's reliable (in progress)
- Participants: Participants: US residents 18 and older who meet at least one of the criteria:
  - Identify as autistic
  - Assist an autistic adult with healthcare appointments
  - Are primary care providers (Study 2a only)
- Results - Study 2a
  - 20 autistic, 10 support, 10 primary care providers: No major problems, enthusiastic response; we made small changes based on feedback

# Product: Interactive Healthcare Toolkit

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- Website still in development; probably won't be fully ready for the public for another few years
- Healthcare visit worksheets and checklists are ready: get them in handouts or email Dora at [dora@aaspire.org](mailto:dora@aaspire.org) for a PDF version



# Patient Content - Topic Preview

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- Forms and Checklists
- Healthcare
- Staying Healthy
- Your Rights
- Autism Information
- Medical Information

# Provider Content - Topic Preview

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- Forms and Templates
- Autism 101
- Tips for Successful Office Visits
- Patient Narratives (from the interviews)

# Sample AHAT Item

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**What can your healthcare providers do to help you understand them better?**

- Use simple words and short sentences.
- Use very precise language, even if it means using longer sentences or advanced vocabulary.
- Be very concrete and specific.
- Show me diagrams, pictures, or models whenever possible.
- Use medical words.
- Avoid medical words.
- Avoid expressions and figures of speech (I may take them literally).
- Ask me to repeat what you said in my own words.
- Write down important information or instructions for me.
- Give me very detailed information.
- Focus only on the most important information.
- ... [more]

# Provider Report Sample

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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)

# When Will the AHAT Be Ready to Use?

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- The bad news about research is that it takes forever... It could be a few more years before the AHAT is ready to use.
- The good news is that Study 3 is to test out the website and the AHAT and we need 200 people for that! If you're interested in previewing the website, using the AHAT, showing your AHAT report to your healthcare provider, and giving us feedback, contact:
  - Marcie Tedlow
  - 503-494-1207
  - [studies@aaspire.org](mailto:studies@aaspire.org)

# Questions and Comments

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# III. Getting the Most Out of Healthcare

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- Preparing For a Healthcare Visit
  - Tips for Finding a New Provider
  - Tips for Making an Appointment
  - What to Bring
  - Understanding Types of Visits
  - Preparing What Topics to Cover
  - What Your Provider May Want to Know About Your Symptoms
- During the Visit
  - General Workflow
  - Risks and Benefits of Disclosing an Autism Diagnosis
  - Asking for Accommodations
  - Communication Tips
  - Personal Information
  - Questions to Ask Your Doctor
  - Things to Know Before You Leave

# Finding a New Healthcare Provider

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- Names of possible providers or clinics
- Can you go to this provider / clinic?
- Is this provider a good fit for you?
- Not always a simple step-wise approach (may need to cycle through questions more than once; may not answer them in this order.)
- May get information from various sources / in different ways – what works best for you? What resources and supports do you have?
- [Tips for Finding a New Provider](#)



# Making An Appointment

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- May be done by telephone, in person, or if available, secure messaging system. Other arrangements?
- Tell them what the appointment is for.
- Have your (or your supporter's) contact information available
- Know your own schedule / availability; if applicable, know availability of person who will support you.
- Things to know by the end of interaction(s).
- Special considerations if this is a first appointment.
- [Making an Appointment Worksheet](#)

# What to Bring to A Visit

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- Health Insurance Card (if you have one)
- Something fun to do in case you have to wait
- Sensory items (examples: sunglasses, chewing gum, head phones)
- A list of questions or things you want to talk about
- Completed Symptom Worksheet (if you used it)
- Any logs or diaries you keep related to your health problems
- Containers for your medications (or a list of them).
- Any instructions or paperwork you got from a different provider since your last visit (ED, hospital, specialist)
- Anything your healthcare provider has asked you to bring
- Additional things to bring if this is a first visit

- [Tips for Finding a New Provider](#)

# Questions and Comments



# Types of Visits

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- Establish care visit / New patient visit
- Urgent problem that needs to be seen in next few days
- New symptom / problem
- Follow-up from last visit
- Chronic illness management
- Consultation / second opinion
- Preventive health visit (example: pelvic exam / Pap smear)

# Preparing What Topics to Cover

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- Generally, you will only have time to go over a few things in one visit.
- Need to decide collaboratively with your provider on an “agenda”
- Start by telling or showing provider list of issues you want to talk about. (**Prepare list in advance.**) Make it clear you don't expect to do everything in one day.
- Note which ones are most important to you.
- Provider may also have his or her own priorities based on your list and your ongoing health problems.
- Avoid the “oh by the way” as the provider is ending appointment

# Preparing Information About Your Symptoms

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- What is the Symptom (or set of symptoms)?
- Location
- Severity
- Quality
- Duration
- Onset
- Frequency or Patterns
- Change From Baseline
- What Makes it Better / Worse

- Related Symptoms
- Other People
- Effect on Lifestyle or Activities
- Treatments
- Why Now?
- Your Thoughts

**Not all questions apply to all symptoms.**

**You do NOT have to have answers to each question.**

[Symptom Worksheet and Sample](#)

# Questions and Comments

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# During the Visit

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- General workflow
- Risk and Benefits of Disclosing an Autism Diagnosis
- Asking for accommodations
- Communication tips
- Personal information
- Questions to ask your doctor
- Things to know before you leave



# General Workflow

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- (Note: This is NOT always the same. May vary by provider or by visit.)
  1. Check in with front desk / receptionist (give name, insurance card). Sometimes have additional paperwork to fill out.
  2. Wait to be called.
  3. Nurse or assistant “rooms” you – checks blood pressure, weight, asks main reason for visit, asks about medications, maybe gives you a questionnaire or asks for a urine sample.
  4. Wait for provider to come in.
  5. Provider asks you questions and examines you
  6. Provider talks about what s/he thinks is going on and gives you recommendations; you ask questions
  7. Nurse or assistant may give you shots, tests, instruction, etc.
  8. You check out
  9. You may need to go to the lab, a pharmacy, make more appointments

# To Disclose or Not to Disclose?

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- Potential benefits:
  - Helps provider understand you better and provide better healthcare
  - Helps avoid misinterpretations of your behaviors or mannerisms
  - Helps avoid misdiagnoses (e.g., psychosis, malingering)
  - You can ask for specific accommodations or strategies
  - If you don't already have a formal diagnosis, can possibly help you get one
- Potential risks
  - Provider may have misconceptions about autism (though you can educate)
  - Provider may underestimate your abilities (though you can educate)
  - Provider may have negative attitude about self-diagnosis
  - Very small chance of loss of confidentiality

# To Disclose or Not to Disclose?

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- Confidentiality
  - Health information is confidential.
  - You can release information to others.
  - In rare instances, information can be legally released to others (e.g., danger)
  - In rare instances, information can be illegally obtained (e.g., hackers)

# Asking for Accommodations

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- You have a right to reasonable accommodations.
- Can present it as things that will help your visits go more smoothly, will help you better communicate, or will help you better follow recommendations.
- Focus on the things that you think will help the most – a long list is less likely to work than a short list.
- Make it a discussion – some things will be easier to do than others; you and your provider may be able to come up with solutions.

# Communication Tips

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- Make it clear that something is a disability-related need, not a preference. Example: “Even though my speech is fluent, I have a really hard time communicating verbally. May I please write down my answers instead? It will help me give you better information.”
- Explain (or ask your supporters to explain) the role of your supporters. Wide range of preferences – provider can’t guess.
- It’s ok to ask your provider to go more slowly. It’s ok to ask your provider to re-explain something or write it down.
- Be respectful of the provider’s time constraints – it may take more than one visit to address your health issue(s)
- Make sure to show your appreciation for the provider’s efforts.
- Regular preventative care or follow-up visits may strengthen relationship with provider.

# Personal Information

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- Many providers will ask you for information that may seem very personal. They do this because these things can have important affects on your health or healthcare. It's best to be honest about this stuff.
- Habits – smoking, alcohol, drugs
- Diet and exercise
- Living situation; Employment; Disability status
- Intimate relationships – men/women/both, how many partners, birth control and STD control, threats, violence, abuse
- Mental health – depression, sadness, mania, anxiety, panic attacks
- Social supports; stressors in your life
- Healthcare Power of Attorney, Guardianship, Emergency contacts

# Questions You May Want to Ask Your Provider

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- What do you think is causing my problem?
- Is there more than one condition (disease) that could be causing my problem?
- What tests will you do to diagnose the problem and which of the conditions is present?
- How good are the tests for diagnosing the problem and the conditions?
- How safe are the tests?
- What is the likely course of this condition? What is the long-term outlook with and without treatment?
- What are my treatment options? How effective is each treatment option? What are the benefits versus risks of each treatment option?
- If my symptoms worsen, what should I do on my own? When should I contact you?

(Taken from article on MedicineNet.com by William Shiel, Jr, MD <http://www.medicinenet.com/script/main/art.asp?articlekey=13683>)

# Understanding Diagnoses and Recommendations

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- Restate what the provider said in your own words to see if you got it right
- Ask a supporter who communicates well with you to re-explain it to you
- Ask the provider to write it down, or write it down yourself and have him or her check it
- If you want to, ask for the name of the condition and look it up in a credible source
- If you want to, discuss your options with a trusted person before making a decision



# Things to Know Before You Leave

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- Who do I contact if I have questions or problems after the visit?
- If you were told to make a follow-up appointment: When should I follow up? How do I make an appointment?
- If you were given a referral: Do I call them or do they call me? Who do I contact to make the referral?
- If the provider ordered labs, x-rays, or other tests: Where do I go to have them done? Do I need to do them at a special time or day? Are there special instructions? How will I find out the results?
- If the provider prescribed medications:
  - Did you fax/e-prescribe/call in the prescription or do I get a paper copy?
  - How much medicine do I take at a time? When?
  - How do I get refills?
  - What side effects should I look out for? What do I do if they happen?

[After the Visit Worksheet](#)

# Tracking Symptoms

- Your provider may ask you to track your symptoms or other information
- This could be to manage chronic medical illness or to diagnose / understand a new problem
- Many different ways to do it:
  - Diaries, charts, logs
  - Online programs
  - Smartphone applications
- Try a few to see what works best for you

# IV: Resources - Handouts from this Talk

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- Tips for Finding a Provider
- Making an Appointment Worksheet
- What to Bring to an Appointment Checklist
- Symptoms Worksheet
- Things to Know Before You Leave Worksheet
- Study Flier
- AASPIRE Flier
- Nicolaidis, C., Raymaker, D., McDonald, K, Dern, S., Ashkenazy, E., Boisclair, W.C., Robertson, S, Baggs, A. *“Collaboration strategies in non-traditional CBPR partnerships: Lessons from an academic-community partnership with autistic self-advocates.”* Progress in Community Health Partnerships: Research, Education, and Action. 2011:5(2);143-150.

# Other Healthcare Resources

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- Medical Information
  - [www.webmd.com](http://www.webmd.com)
  - [www.medlineplus.gov](http://www.medlineplus.gov)
  - [www.mayoclinic.com](http://www.mayoclinic.com)
  - [www.familydoctor.org](http://www.familydoctor.org)
  - [www.healthfinder.gov](http://www.healthfinder.gov)
- Other Checklists, Worksheets, and Tips
  - [www.healthytransitionsny.org](http://www.healthytransitionsny.org)
  - [www.developmentalmedicine.ucsf.edu](http://www.developmentalmedicine.ucsf.edu)
- Symptom Trackers
  - [www.mayoclinic.com/health/symptom-checker](http://www.mayoclinic.com/health/symptom-checker)
  - [www.symptoms.webmd.com](http://www.symptoms.webmd.com)
  - iPad/iPhone - TracknShare [www.trackandshareapps.com](http://www.trackandshareapps.com)

# Being Involved & Staying in Touch

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- Take part in testing out the online Healthcare Toolkit:
  - Email: [studies@aaspire.org](mailto:studies@aaspire.org)
  - Telephone: 503-494-1207
  - Online flier: [www.aaspire.org/healthcare-flier](http://www.aaspire.org/healthcare-flier)
- Stay in touch with us online:
  - Mailing list: [www.aaspire.org/maillinglist](http://www.aaspire.org/maillinglist)
  - Web site: [www.aaspire.org](http://www.aaspire.org)
  - 'Like' our Facebook page
- Use our data to help with your advocacy - contact us at: [info@aaspire.org](mailto:info@aaspire.org)
- Working with AASPIRE

# Thank You To:

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- The AASPIRE Team.
- The Autistic Self Advocacy Network for their support since 2007.
- All of the people who have graciously given their time to participate in our studies.
- You, for listening and sharing your thoughts with us. :-)
- AASPIRE receives funding from the National Institute of Mental Health (R34MH092503), 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.



# Contact Information

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- AASPIRE website [www.aaspire.org](http://www.aaspire.org)
- AASPIRE mailing list [www.aaspire.org/maillinglist](http://www.aaspire.org/maillinglist)
- Information about participating in AASPIRE studies [studies@aaspire.org](mailto:studies@aaspire.org)

# Questions and Comments

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