

AASPIRE

Participatory Research with Autistic Adults: Matching Theory and Practice

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A Note on *My* Use of language

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

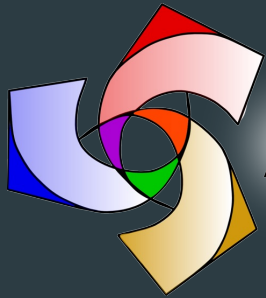
Bottema-Beutel, et al, (2021). Avoiding ableist language: suggestions for autism researchers. *Autism in Adulthood*, 3(1)18-29.

OAR Spring 2022 Webinar Series

- ▶ Today: Participatory Research with Autistic Adults: Matching Theory and Practice
 - ▶ Overview of Participatory Approaches
 - ▶ Examples from the Academic Autism Spectrum Partnership in Research and Education (AASPIRE)
- ▶ April 7th: HEARTS - A healthy relationships class for autistic people co-taught with autistic teachers
- ▶ April 20th: Autistic Adults and other Stakeholders (AASET) for Suicide Prevention

2006





AASPIRE

- ▶ Co-Founded in 2006 by Christina Nicolaidis and Dora Raymaker
- ▶ Autistic and non-autistic academic scientists
- ▶ Community partners: autistic adults and other stakeholders
- ▶ Community Based Participatory Research (CBPR)
 - ▶ Academics and community members serve as equal partners in all phases.

Academic Autism Spectrum Partnership in Research and Education



www.aaspire.org

AASPIRE Research Projects



Health Care



Outcomes



Mental Health



Employment



Pregnancy



Violence and Abuse

But Not that Long ago...

“The investigators are assuming that high-functioning individuals on the spectrum have the ability to reflect on their own experience and that they can give a valid assessment of what they need”

Grant reviewer, in 2011, as criticism of our participatory approach

Special Issue Article

Assessing the influence of researcher-partner involvement on the process and outcomes of participatory research in autism spectrum disorder and neurodevelopmental disorders: A scoping review

Jamil Jivraj¹, Lori-Ann Sacrey¹, Amanda Newton¹, David Nicholas² and Lonnie Zwaigenbaum¹



Autism
1-12
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DOI: 10.1177/1362361314539858
aut.sagepub.com
SAGE

Jivraj et al.

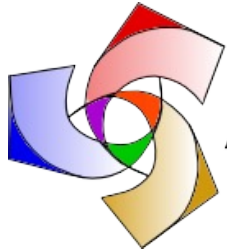
5

Table 1. Summary of breadth of participatory research studies involving individuals with ASD and other neurodevelopmental disorders.

Authors	Identifying research question	Informing study methodology and methods	Collecting data	Analyzing data	Disseminating research findings
ID	Bigby and Frawley (2010)		✓	✓	✓
	Timmons et al. (2011)		✓	✓	
	Conder et al. (2011)		✓	✓	✓
	McVilly et al. (2006)	✓		✓	
Autism	Nierse and Abma (2011)		✓	✓	✓
	Nicolaidis et al. (2011)	✓	✓	✓	✓
	Nicolaidis et al. (2013)	✓	✓	✓	✓

ASD: autism spectrum disorder.
Checkmarks indicate the involvement of partner(s) in specified stage of the study development.

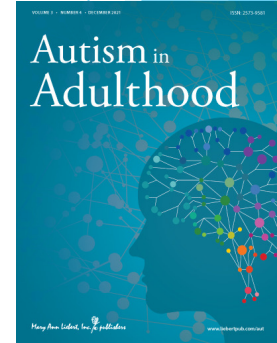
And Now....



AASPIRE



AASET



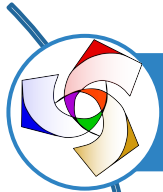
The Risk of Building Too Fast...



And the need to build a strong
foundation

What Does “Participatory Research” Mean?

Including (non-academic) community members on
the research team



Equal Power Sharing (e.g., CBPR / some PAR)



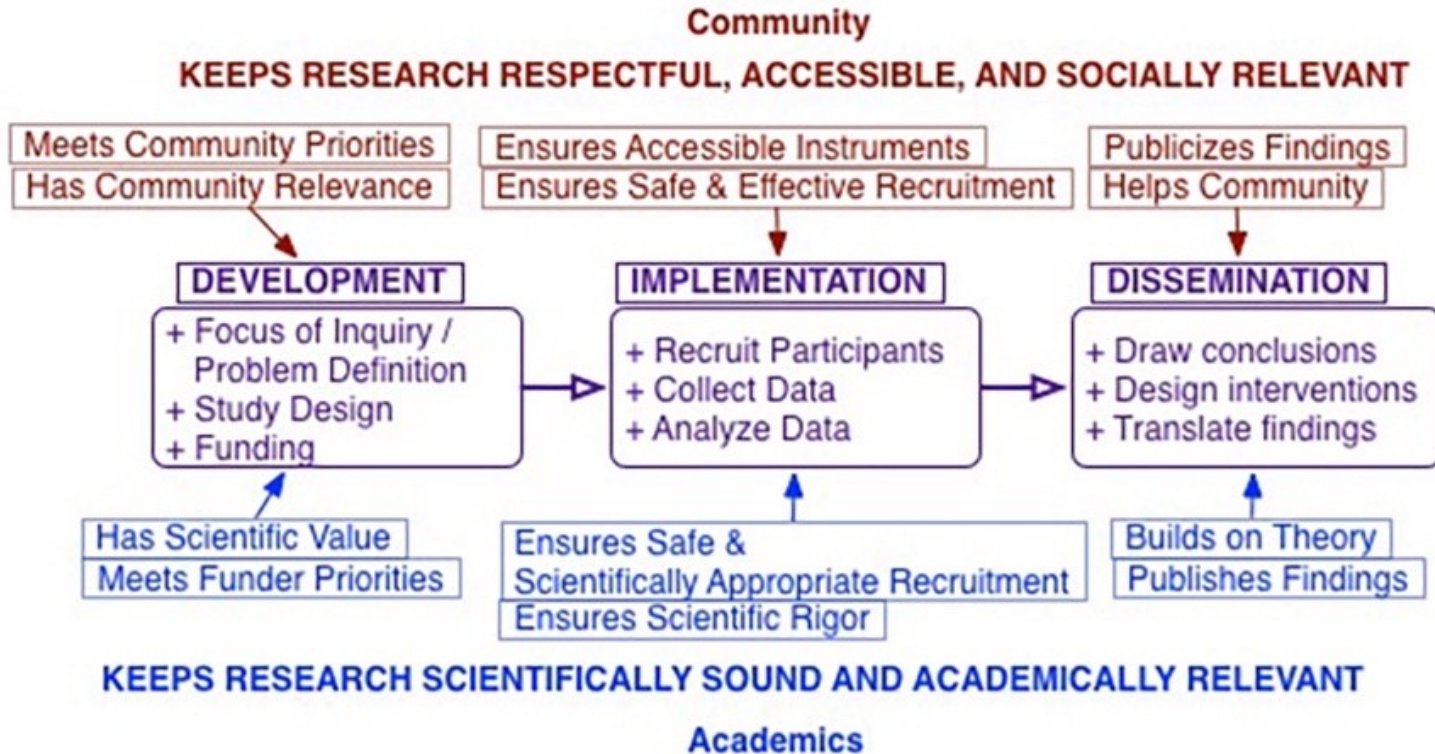
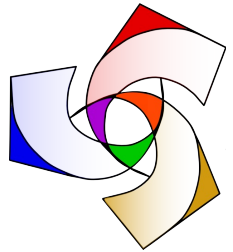
Authentic Inclusion (e.g., PCOR / Co-Production)



Consultation (e.g., Advisory Boards / Delphi Panels)

(And BTW,
just getting
data from
study
participants
doesn't
count.)

Community Based Participatory Research (CBPR)



Not All Participatory Research is (or should be) CBPR



Need to match to the context and goals of the research



Be transparent about approach and expectations



Don't pretend to be doing something you are not!



Be careful not to tokenize people



Actively work to match theory and practice

Principles of CBPR

- ▶ Acknowledge the community as a unit of identity
- ▶ Build on the strengths and resources in the community
- ▶ Facilitate a collaborative, equitable partnership in all phases of the research
- ▶ Foster co-learning and capacity building among all partners
- ▶ Balance knowledge generation and intervention for the mutual benefit of all partners
- ▶ Attend to both local relevance and ecological perspectives
- ▶ Develop systems using a cyclical and iterative process
- ▶ Disseminate results to all partners, and involve all partners in dissemination
- ▶ Commit to a long-term process and group sustainability.

Patient Centered Outcomes Research - Patient and Stakeholder Engagement Models

- ▶ Created for comparative effectiveness research related to medical illnesses
- ▶ Doesn't assume there's a community
- ▶ Isn't necessarily action research
- ▶ Expects authentic engagement with some power-sharing, but not necessarily equal partnership / ownership
- ▶ Still expects involvement of patients/stakeholders in all phases
- ▶ Still expects involvement of organizations (not only individuals)

Who is the
Community?

- Lessons from LGBTQ+

Disability impacts
on participation

- LOTS of accommodations and supports

The autism
research field

- Originally VERY resistant / still some hesitancy

Some Key Differences from CBPR
with Other Communities

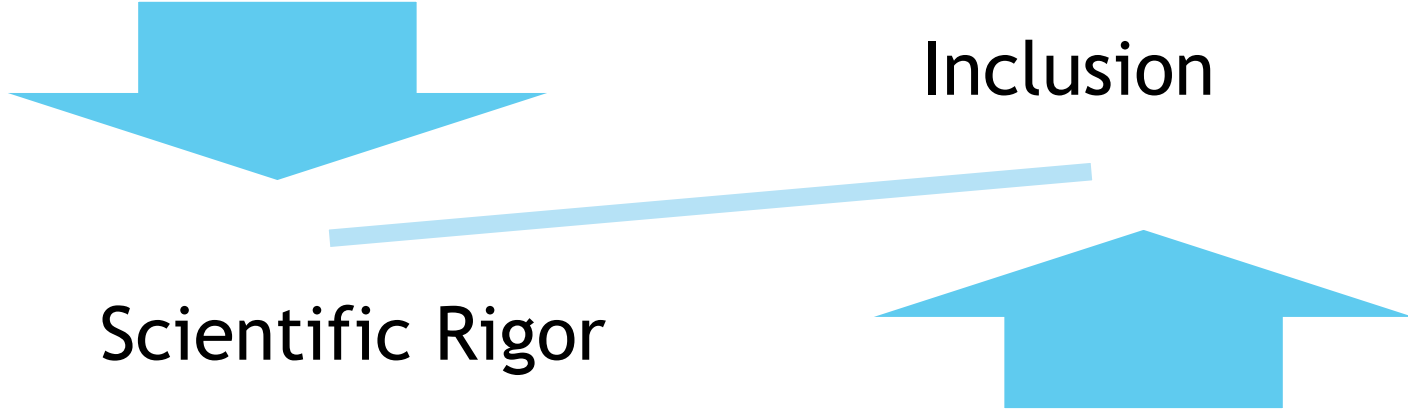
A Common Fallacy Within Autism Research

Equity * Neurodiversity * Social Justice *
CBPR * Qualitative Methods * Lived
Experience * Power Sharing

Inclusion

Scientific Rigor

Quantitative Methods * Sampling Frames
Validity * Reliability * Effectiveness *
Protection of Human Subjects





But I Would Say It's the Opposite

Other Common Misconceptions

CBPR is only for qualitative research

Participatory research is only for autistic people with low support needs, fluent speech, no intellectual disability...

Having an autistic grad student in my lab means I am doing participatory research

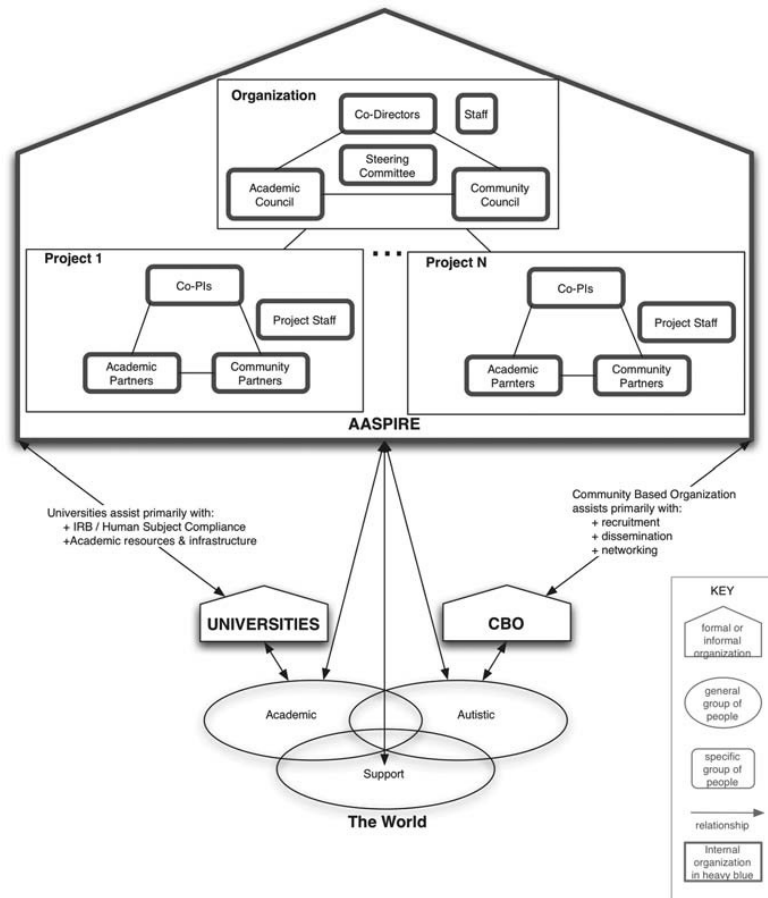
I can't use participatory approaches while in training

Autistic Scientists (or Scientists in Training)

- ▶ Extremely important to increase diversity - including neurodiversity - in academia!!!
- ▶ “Insider researchers” bring wonderful strengths and perspectives to research.
- ▶ Outsider researchers are not any more objective or less biased just because we may not see their identities and biases.
- ▶ However, just including an insider researcher does not make it CBPR. (And CBPR cannot replace the need for autistic researchers.)
- ▶ Autistic scientists cannot represent full range of lived experiences
- ▶ Need to pay attention to inherent power imbalances

Infrastructures

- ▶ Organizational level
- ▶ Project Level
- ▶ Changes over time to adjust to Dora moving from community to academic role
- ▶ New “Community Project Lead” position



What Does it Take to Be Equal Partners?

- ▶ True commitment to equal power sharing
 - ▶ In EVERY phase from start to finish
- ▶ LOTS of work
 - ▶ Clearly define roles and expectations
 - ▶ Understand and meet accessibility needs
 - ▶ Build and **maintain** trust
- ▶ Continuous evaluation and creative solutions!



Keep / Change for Today's Meeting

What do you want to keep doing?

What would you like to change?

Shared Decision-Making

▶ Challenges:

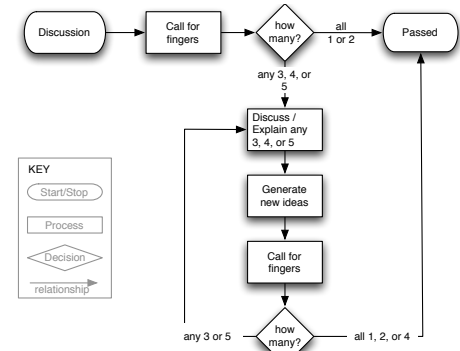
- ▶ Different levels of power
- ▶ Different communication styles
- ▶ Each person may represent important part of community - voting not ok.

▶ Formal Consensus Process

- ▶ Makes sure everyone has a say
- ▶ Encourages creative solutions to problems
- ▶ Helps us speed up process when more discussion isn't necessary or take more time when it is.

5-Finger Consensus Process

- 1 - I love it!
- 2 - It's fine.
- 3- I have more questions. (and what they are)
- 4- I don't like it, but I won't block it. (and why)
- 5- I dislike it so much I can't live with it. (and why)



Nicolaidis et al, PCHP, 2011

Email Communications

▶ Challenges:

- ▶ Large amounts of information
- ▶ Different backgrounds/skills/interest
- ▶ Balance of transparency and overwhelm

▶ Solution: Structured Email Formats

- ▶ Purpose, Actions, Deadline, Stipend, Summary
- ▶ Details in Q&A Format in Plain Language
- ▶ Clearly marked Optional sections/attachments
- ▶ Always have option to review over Zoom with assistant

PURPOSE

The purpose of this email is to brainstorm some more things to add to the Outcomes List. If you are looking for or examples of Outcomes, look in the DETAILS section of the Outcomes List.

ACTIONS

- 1) Review the attached file "outcomes_list" (.docx) or (.txt),
- 2) Offer suggestions for things to add to the Outcomes List.

DEADLINE

Please respond to this email by the end of the day **Sunday, 30 August**.

STIPEND

This is no stipend for reading or responding to this email.

SUMMARY

We are gathering more suggestions for what Outcomes to put on the Outcomes List. We will be measured by giving a survey to the individual autistic adult(s) to see if they are satisfied with the Outcomes List.

DETAILS

Please respond to this email with your ideas for the Outcomes List.

What Types of Outcomes are we Talking About?

As we have talked about before, in this project, we are going to focus on "services interventions" to improve the lives of autistic adults. We are looking for suggestions for things to add to the Outcomes List.

Think of services interventions that can happen in the healthcare system. What would we want to see such services interventions change? How would that impact autistic adults' lives? Those are the Outcomes we care about.

Should We Be Thinking About Individuals or Systems?

Group Meetings



- ▶ Original challenges (since 2006)
 - ▶ Team members all over the country
 - ▶ Partners with Auditory Processing Difficulties / non-speaking partners - could not meet by teleconference (phone)
- ▶ Original solution: text-only, real-time meetings
 - ▶ Very detailed preparation materials
 - ▶ Moderator sticks with clear agenda
 - ▶ Chat etiquettes
 - ▶ Worked well for 14 years, with meetings every other week

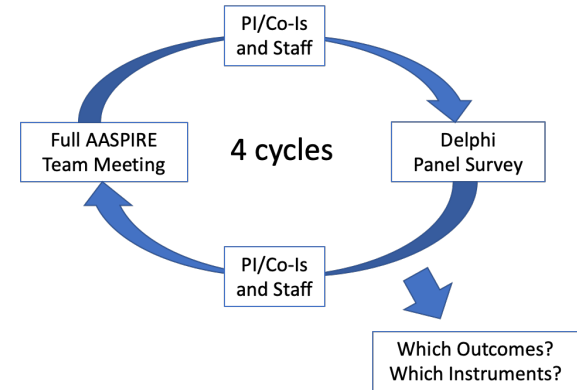
Group Meetings - Take 2!

- ▶ 2020 Team Expansion
 - ▶ Some new community partners cannot participate in text.
 - ▶ Lots of new academic partners
- ▶ New solution
 - ▶ Mix of slides, video, text chat, closed-captioning
 - ▶ Facilitation/guides to avoid feeling like it's “two meetings”
 - ▶ Preparation materials in 3 formats (detailed, easy read, and compact)
 - ▶ Optional pre-meeting to go over materials
 - ▶ Survey Geek meeting (week before)



Mixing Input from Outside Experts with our CBPR process

- ▶ Needed input outside of our own team
- ▶ Traditional "Modified Delphi Process"
 - ▶ Way to reach agreement with lots of experts
 - ▶ Normally researcher-driven.
- ▶ New "Nested Delphi Process"
 - ▶ 29 Delphi panelists (academic researchers; community leaders; leaders from services systems)
 - ▶ AASPIRE CBPR team (23 academic and community partners) met between each round to create surveys and use results to make decisions



Dissemination

- ▶ Community partners involved in all types of dissemination
- ▶ Co-authors on scientific papers
 - ▶ Explanations in comment bubbles or tables to put ideas into plain language.
- ▶ Presentations
 - ▶ Academic conferences
 - ▶ Clinician trainings
 - ▶ Community Events
- ▶ Advocacy / Policy
- ▶ Blogs, newsletters, media...



CBPR greatly affects the research itself

Some Examples from Our Work

Choice of Topics / Questions

Consent Procedures

Recruitment

Qualitative Data Collection

Survey Instruments

Choice of Outcomes

Intervention Development

Shaping the Literature

Choice of Topics / Research Question

- ▶ Team discussions about new ideas / opportunities
- ▶ Focus on high priority topics (for example, healthcare, employment, violence)
- ▶ Autistic Burnout Study
 - ▶ Autistic adults talk about it all the time, but totally missing from research and practice
 - ▶ Small study to define and describe autistic burnout
 - ▶ Viral response from autistic community
 - ▶ Now, new interest among researchers and clinicians



Accessible Consent

- ▶ Co-create materials with autistic partners
- ▶ Clear, simplified consent materials (yes - you can change the boilerplate text)
- ▶ Q&A format
- ▶ Visual aids / white space
- ▶ Reduce participant burden (e.g. online consent)
- ▶ Time to discuss with trusted person

See <https://aaspire.org/collaboration-toolkit/> for sample consent forms

What will happen if I do the study?

If you decide to do the study, you will do an interview with Marcie, the Research Assistant. During the interview, you and Marcie will go through the questions together. If you choose, you can also have someone you know be there to help you.



Your answers will be recorded on a recording machine. After the interview, a research assistant will type everything you said onto a page.

You will be able to take a break at any time. You do not have to answer any questions that you don't want to. You will be able to stop the interview at any time. It may take one or two hours to complete the interview.



How will my information be kept private?

- We will not use your name or other personal information in any public way, like when we write about the study.
- We will keep a written copy of your interview answers. We will not put your name on that copy. Instead we will use a code number to connect your answers to your name and other personal information.
- Only the researchers will be able to connect your interview answers to your name or other personal information.
- We will not ask you any questions about violence or abuse. However, if you tell Marcie you have been abused, then she may have to report the abuse to

Effective Recruitment

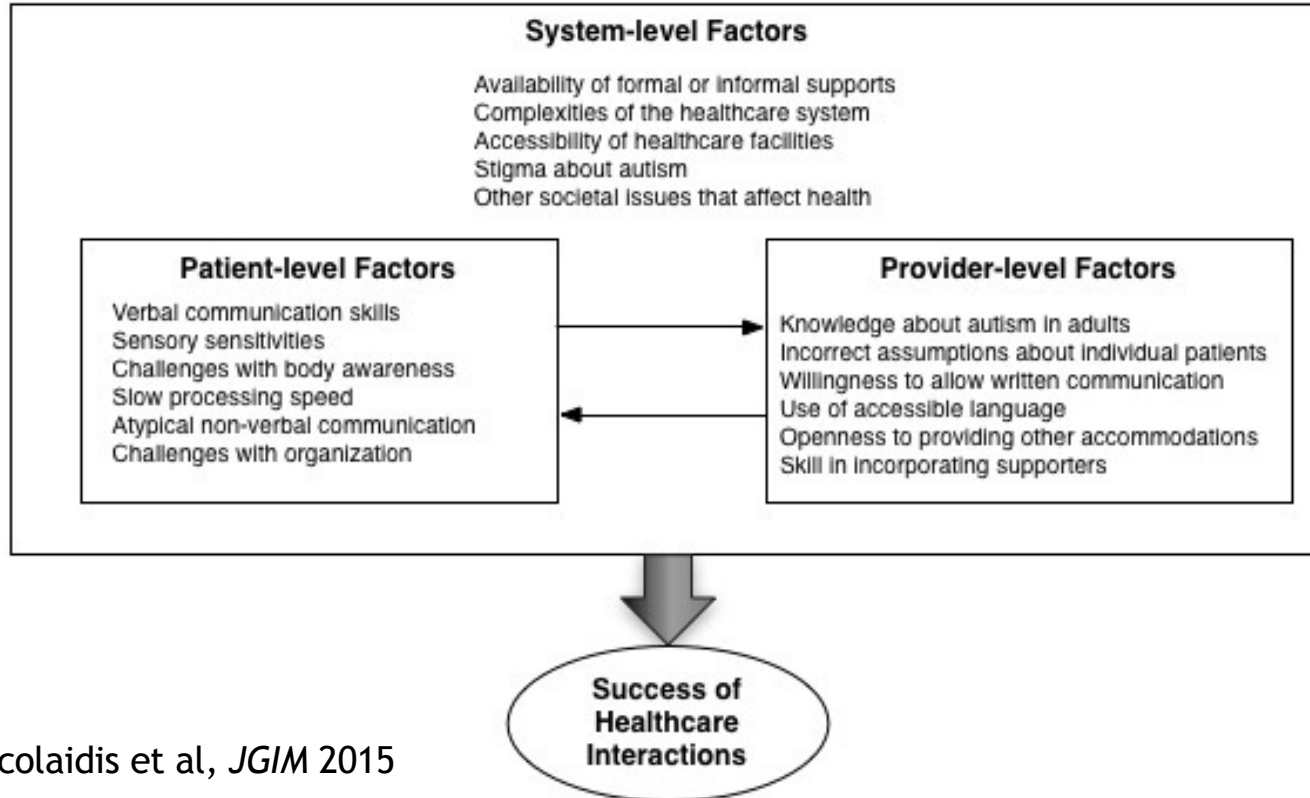
- Recruitment materials that “speak” to the population
- Recruitment via trusted community leaders
- Access to community forums / events / venues
- But be careful not to abuse trust!

Data Collection - Qualitative Interviews

- ▶ Challenges with “open-ended questions”
- ▶ Community partners help create effective interview guides
 - ▶ Instructions to help participants understand what we want
 - ▶ Make questions specific, even when they are open-ended
 - ▶ Make sure questions are concrete enough to be answered
- ▶ Partners helped us come up with good strategies
 - ▶ Show materials to participants before the interview
 - ▶ Offer lots of different ways to take part (telephone, video, IM chat, email, in person)
- ▶ Sometimes community partners collect data

See
Collaboration
Toolkit
for sample
interview guides

Example Qualitative Results



Data Collection - Surveys

Over 15 years, our community partners have reviewed LOTS of existing survey “instruments”.

Found most existing instruments to be inaccessible.

Felt they would experience significant confusion, frustration, anxiety, or anger

Stated they would offer unreliable answers, leave many items blank, or stop participating in the study

Bad Data



Wrong Conclusions



Ineffective Efforts

Common Concerns

- ▶ Difficult vocabulary, confusing terms, imprecise language, or figures of speech
- ▶ Complex sentence structure, confusing grammar, or convoluted phrases
- ▶ Response options with vague terms
- ▶ Not enough context
- ▶ Anxious if responses could vary in different situations
- ▶ They don't fully capture the idea we want to measure
- ▶ Offensive and ableist language or concepts

Common Adaptations to Survey Instruments

Prefaces	Adding or changing prefaces to increase precision or explain context
Simplifying grammar	Simplifying sentence structure; removing passive voice
Vocabulary Substitutions	Substituting difficult vocabulary words, confusing terms, or figures of speech with more straightforward terms
Hotlinks	Adding hotlinks that define problematic terms or offer examples or clarifications
Graphics	Adding graphics to increase clarity of response options
Autism-specific items	Adding new items related to autism-specific aspects of the construct

Sample Adaptation: Graphics for Vague Response Options

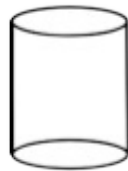
Original

7. Someone to confide in or talk to about yourself or your problems.

1	2	3	4	5
None of the time	A little of the time	Some of the time	Most of the time	All of the time

New

7. How often do you have someone with whom you can share personal information about yourself or your problems?



None of
the time



A little of
the time



Some of
the time



Most of
the time



All of
the time

AASPIRE Outcomes Study

- ▶ Builds on our prior work adapting instruments for use with autistic adults
- ▶ Large NIH grant to create and test “AutPROM Toolbox”
 - ▶ Set of survey instruments to evaluate the effectiveness of services for autistic adults.
- ▶ Phase 1: Nested Delphi process to choose outcomes
- ▶ Phase 2: Adapted or created instruments for each of these 15 outcomes.
- ▶ Phase 3: Large prospective study to test them in 3 cohorts (healthcare, disability services, community) and assess change in outcomes over time.



AutPROM Toolbox Outcomes

- ▶ Overall Health
- ▶ Mental Health (including Depression, Anxiety, Emotional Wellbeing, and Autistic Burnout)
- ▶ Self Determination / Freedom to Make Choices
- ▶ Barriers to Communication
- ▶ Community Participation
- ▶ Employment Satisfaction
- ▶ Social Support
- ▶ Quality and Satisfaction with Healthcare Services and Social Services

Survey also includes **demographics** and **disability characteristics**, experiences of **discrimination**, and a module on **gender identity, sexual orientation, and LGBTQIA+ stigma**.

Sample Changes

- ▶ Two very common instruments:
 - ▶ PHQ-9 to measure depression
 - ▶ GAD-7 to measure anxiety
- ▶ Autistic people find them very hard to answer
- ▶ Worked together to make them easier to answer
 - ▶ Added extra instructions for those who want them
 - ▶ Made beginning part of question (“stem”) more clear
 - ▶ Made response options more precise
 - ▶ Changed some items to make them more clear

Sample Changes - Question Stem

- ▶ Original (for both PHQ-9 and GAD-7)
 - ▶ Over the last 2 weeks, how often have you been bothered by any of the following problems?
 - ▶ Community partner question: how to count days?
 - ▶ Turns out it means something different when you think about depression vs anxiety.
- ▶ New for PHQ-9 (Depression)
 - ▶ Over the past two weeks, how many days did the following problems **bother you for most of the day?**
- ▶ New for GAD-7 (Anxiety)
 - ▶ On how many days did the following problems **bother you** over the last two weeks?

Sample Changes - “Double Barreled” Questions

- ▶ Sometimes partners felt it was hard to answer questions if they asked about two different things.
- ▶ Original:
 - ▶ Trouble falling or staying asleep, or sleeping too much
- ▶ New:
 - ▶ Trouble with sleep -
For example, trouble falling asleep, trouble staying asleep, or sleeping too much

Data Interpretation - Example

- ▶ Community partners help make sense of the findings
- ▶ “Factor Analysis” for our survey about Confidence in Managing Health and Health Care
- ▶ Math showed there were two factors (groups of questions).
- ▶ Partners helped explain difference in two groups of questions.
 - ▶ Things that only involve your own skills: “How confident are you that you can bring what is needed to a healthcare visit?”
 - ▶ Things that depend on doctor, too: “How confident are you that you can answer your healthcare provider’s questions?”

Intervention Development

- ▶ “Intervention” - the thing that might help
 - ▶ Program, Tool, Training, Therapy, Technology....
- ▶ Academic and community partners work together to:
 - ▶ Come up with ideas for what the intervention could be
 - ▶ Decide what it should include
 - ▶ Work out all the details
- ▶ Example - Healthcare Toolkit



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.

Autism Healthcare Accommodations Tool (AHAT)



- Patient or supporter fills out a survey
- Computer uses answers to create a personalized and healthcare provider-friendly report of accommodations

Provider Information

- PCPs and autistic adults on team helped determine content areas
- Insights from autistic adults as to what can facilitate care

AASPIRE Healthcare Toolkit for Healthcare Providers

HOME • ABOUT • SITE MAP • PARTNERS • CONTACT

Theme: Light (default) search Search

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
For alternate formats, contact info@aaspire.org

- [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](#)
- [All Topics](#)

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HOME • ABOUT • SITE MAP • PARTNERS • CONTACT

OREGON HEALTH & SCIENCE UNIVERSITY | ASAN AUTISTIC SELF ADVOCACY NETWORK | SYRACUSE UNIVERSITY | AUTISM SOCIETY Improving the Lives of All Affected by Autism | INDIANA UNIVERSITY | PORTLAND STATE UNIVERSITY

Patient Information

- Topics chosen by autistic adults
- All materials written or edited by autistic adults
- Lots of details, script, and examples

The screenshot displays the AASPIRE Healthcare Toolkit for Patients & Supporters website. The page is titled "Finding Providers" and is part of the "Healthcare" section. The navigation bar includes links for "HOME", "ABOUT", "SITE MAP", "PARTNERS", and "CONTACT". The theme is set to "Light (default)". The page content is organized into a sidebar and a main content area. The sidebar contains a "Content Outline" with links to various sections: "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", and "Links and Resources". The main content area features a "What is this topic about?" section, a "How do I find names of healthcare providers?" section, and an "Option 1: Get referrals from people or organizations you know and trust." section. The "Option 1" section includes a list of three categories: "Friends, family, or co-workers", "Other professionals", and "Autism Groups or Communities".

HOME > PATIENTS & SUPPORTERS > HEALTHCARE > FINDING PROVIDERS

HOME • ABOUT • SITE MAP • PARTNERS • CONTACT

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

Switch to: FOR HEALTHCARE PROVIDERS

← back

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.

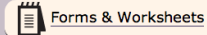
For example, you could ask:

- **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 suggest providers with experience

Forms and Worksheets

- Tools chosen to practically address most pressing needs
- Co-created by providers and autistic adults
- Team members pilot-tested them in their own care

Topic List



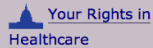
Forms & Worksheets



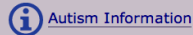
[Healthcare](#)



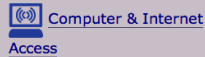
[Staying Healthy](#)



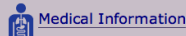
[Your Rights in Healthcare](#)



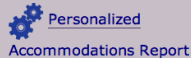
[Autism Information](#)



[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
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- [Forms & Worksheets](#)
- [Healthcare](#)
- [Staying Healthy](#)
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- [All Topics](#)



AASPIRE Guidelines

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Original Article



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SAGE

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

Christina Nicolaidis^{1,2} , Dora Raymaker^{1,3}, Steven K Kapp^{3,4}, Amelia Baggs³, E Ashkenazy³, Katherine McDonald⁵, Michael Weiner^{6,7,8}, Joelle Maslak³, Morrigan Hunter³ and Andrea Joyce³

Guidelines, Webinars, and Sample Materials at:

www.aaspire.org/collaboration-toolkit

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, BA,² and Christina Nicolaidis, MD, MPH^{1,2,6}

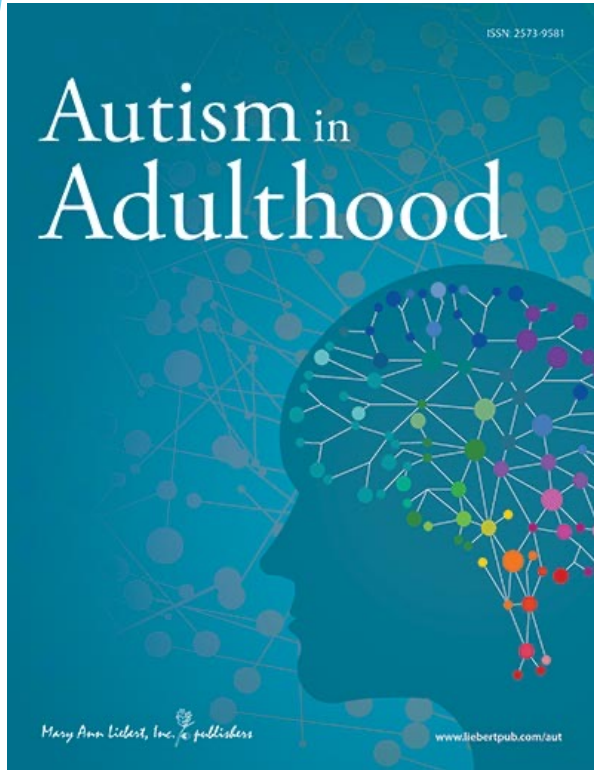
Advances in Measurement Methods

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

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

Christina Nicolaidis, MD, MPH^{1–4} Dora M. Raymaker, PhD^{1,3,4} Katherine E. McDonald, PhD^{3,5} 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} Leanne M. Beers, PhD⁴ Clarissa Kripke, MD^{3,10} Joelle Maslak, BA³ Morrigan Hunter, MA³ and Kelly Y. Zhen^{1,3}

Inclusion in the Literature



- ▶ Focuses on most pressing issues affecting autistic adults.
- ▶ Editor-in-Chief - Christina Nicolaidis
- ▶ Associate Editor - Dora Raymaker
- ▶ 10 autistic adults on editorial board (and many family members and clinicians)
- ▶ Anti-ableist Language Policy
- ▶ Each manuscript gets traditional scientific peer-reviews AND review by autistic adult
- ▶ Insights section for personal perspectives of autistic adults
- ▶ Approximately 1/3 of articles have included autistic authors so far

www.liebertpub.com/aut

Take Home Points

- ▶ Participatory research with autistic adults is possible.
- ▶ It is very hard work, but it's worth it!
- ▶ Don't pretend to do it if you aren't ready to do the work, and to mess up, and to try harder.
- ▶ It can help strengthen the rigor and impact of research
- ▶ Let's work to ensure all autism research is respectful, anti-ableist, rigorous, and impactful

AASPIRE Funding

- ▶ National Institute of Health
 - ▶ R01MH121407 (Outcomes), R34MH092503 (Toolkit Development), R34MH111536 (Toolkit Integrations), R21MH112038 (Employment), R01HD105655 (Pregnancy App) R21HD078830 (Pregnancy Qual), K23MH123934 (Suicide Prevention)
- ▶ The Centers for Disease Control (Partnering Project)
- ▶ Institutional
 - ▶ NIH via OCTRI (CTSA - UL1 RR024140) for pilot-funding, KL2TR002370 (institutional training award for Dr. Raymaker); NIH BUILD EXITO support for pilot funds and research assistants; Portland State University and OHSU (Burnout), the Burton Blatt Institute (Wellbeing)
- ▶ Foundations:
 - ▶ Fulbright Foundation (Hospital) and the Medical Research Foundation (Employment measurement)