Nothing About Us Without Us:

The Importance of Community-Based Participatory Research to Improve the Validity, Translation, and Impact of Clinical Research

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Professor School of Social Work, Portland State University

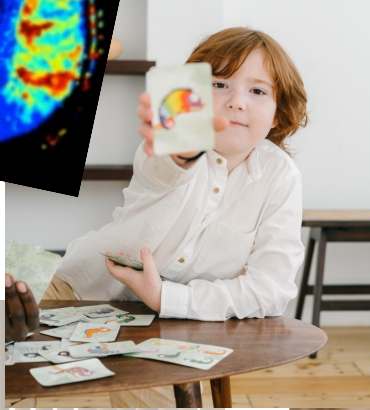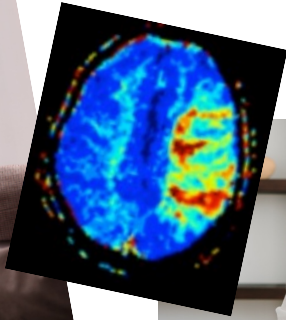Adjunct Professor, Oregon Health & Science University

Co-Director, Academic Autism Spectrum Partnership in Research and Education

Editor-in-Chief, *Autism in Adulthood*

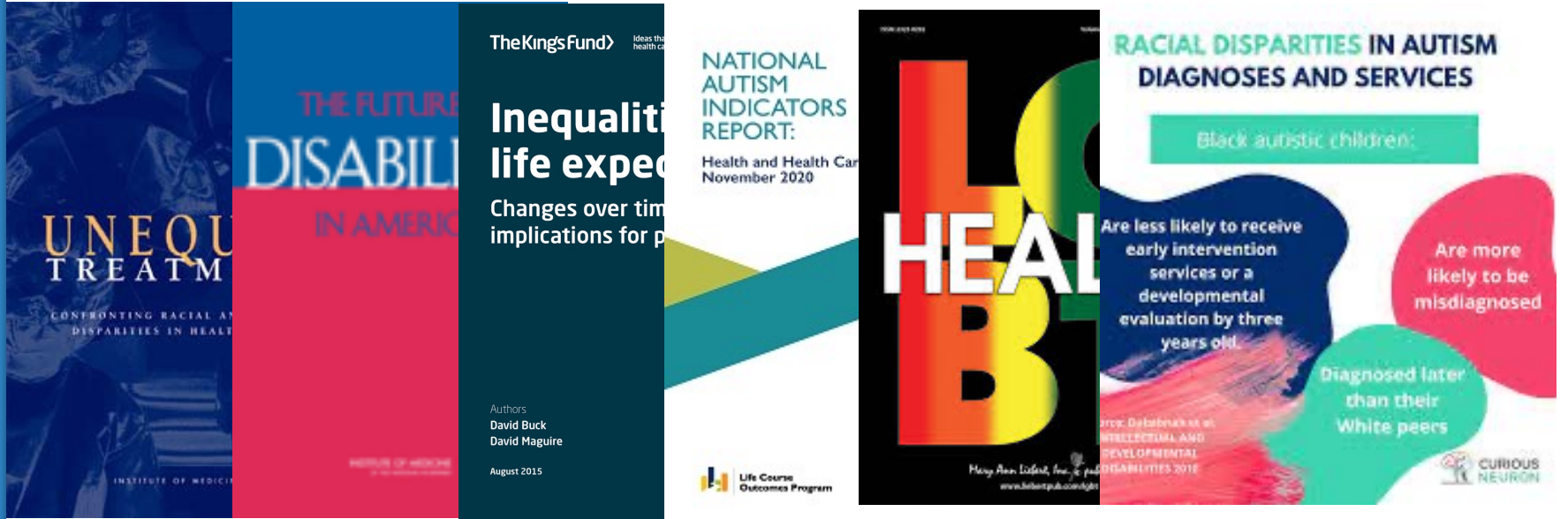ASHA Researcher-Academic Town Meeting, November 2022

Disclosures

- I receive a stipend from Mary Ann Liebert Publishers for serving as Editor in Chief of *Autism in Adulthood*.
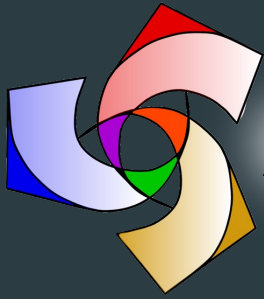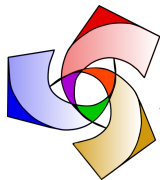
But We Don't…

CBPR and Other Participatory Research Approaches

Ways to try to increase inclusion and equity and improve the impact of research

Participatory Research Approaches

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)

- Approaches to research
- Can be used with **any** methods

And no, just getting qualitative data from study participants **does NOT count.**

2006

AASPIRE

www.aaspire.org

Academic Autism Spectrum Partnership in Research and Education

▶ Co-Founded in 2006 by Christina Nicolaidis and Dora Raymaker

▶ Autistic and non-autistic academic scientists

▶ Community partners

  ▶ Autistic adults with and without ID, speaking and non-speaking, with wide range of support needs, and other intersectional identities

  ▶ Family members, disability services professionals

▶ Community Based Participatory Research (CBPR)

Nicolaidis et al. (2011) https://doi.org/10.1353/cpr.2011.0022
Nicolaidis et al. (2019) https://doi.org/10.1177/1362361319830523

Community Based Participatory Research (CBPR)

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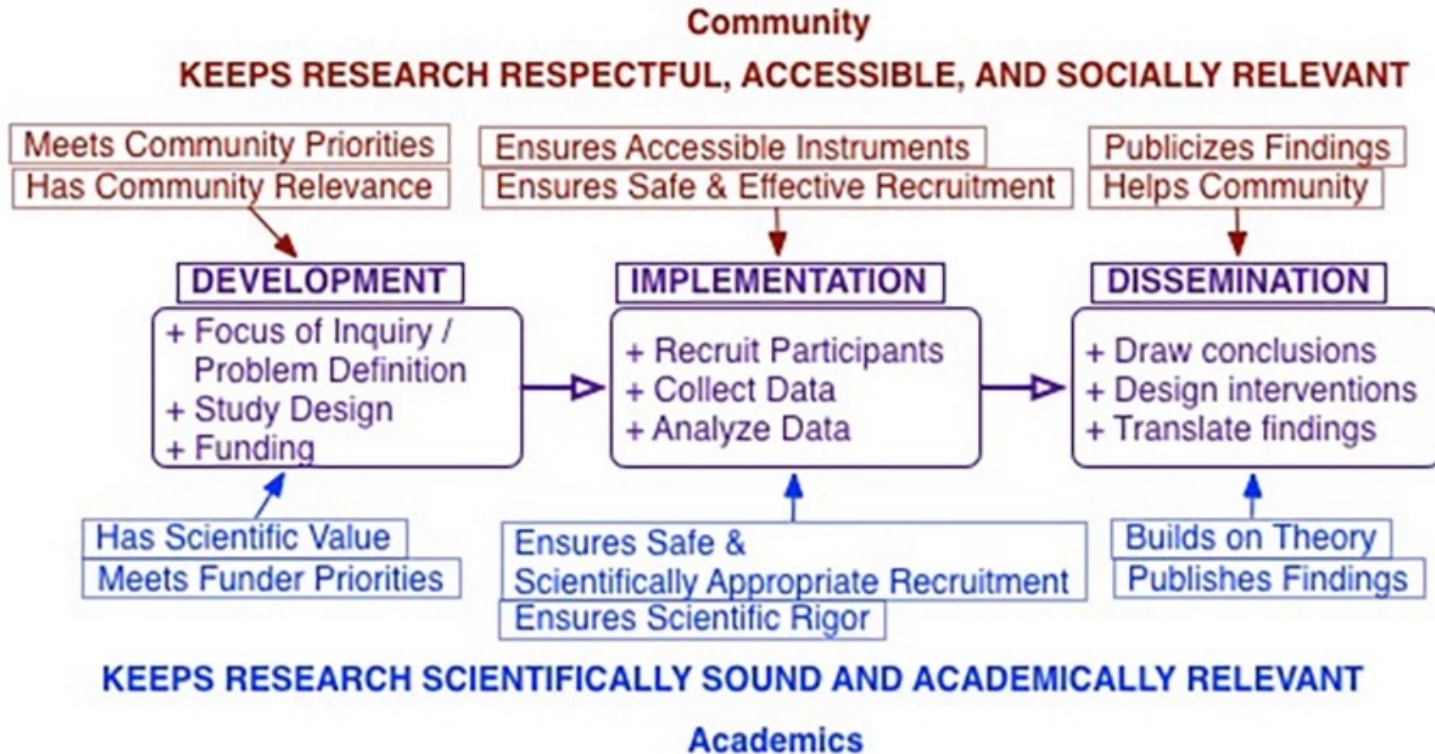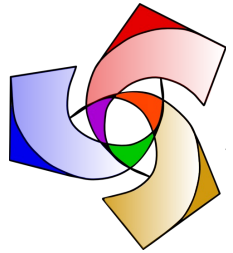
Disabled Scientists (or Scientists in Training)

- Extremely important to increase diversity - including neurodiversity and communication diversity - 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 notice their identities and biases.
- However, just including an insider researcher does not make it CBPR. (And CBPR cannot replace the need for researchers with disabilities.)
  - Disabled scientists cannot represent full range of lived experiences.
- Need to pay attention to inherent power imbalances.

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
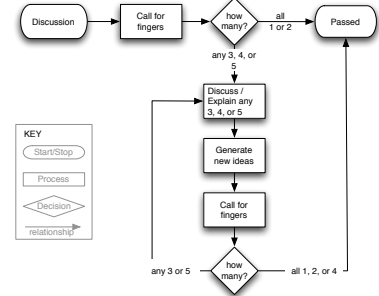
- Actively work to match theory and practice

What Does it Take to Be Equal Partners?

- True commitment to equal power sharing
  - In EVERY phase from start to finish
- Community representatives in leadership roles
- LOTS of work
  - Clearly define roles and expectations
  - Understand and meet accessibility needs
  - Build and maintain trust
- Shared Decision-Making
- Accessible Communication
  - E.g. structured email format
- Transparency
- Continuous evaluation and creative solutions!

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)

KEY
Start/Stop
Process
Decision
relationship

Discussion → Call for fingers → how many? — all 1 or 2 → Passed

any 3, 4, or 5

Discuss / Explain any 3, 4, or 5

Generate new ideas

Call for fingers

how many? — all 1, 2, or 4

any 3 or 5

Nicolaidis et al, PCHP, 2011

Keep / Change for Today's Meeting

What do you want to keep doing?

What would you like to change?

Full Team Meetings

► Far, far more thought and work than

typical team meetings.

► Preparation materials shared a week in advance

► Multiple formats (detailed, easy read, and compact)

► Optional pre-meeting to go over materials.

► Mix of slides, video, text chat, professional closed-captioning.

► Strong facilitation and clear etiquette to avoid feeling like it's "two meetings."

► Structured consensus process for all decisions.

► Survey Geek meeting (week before).
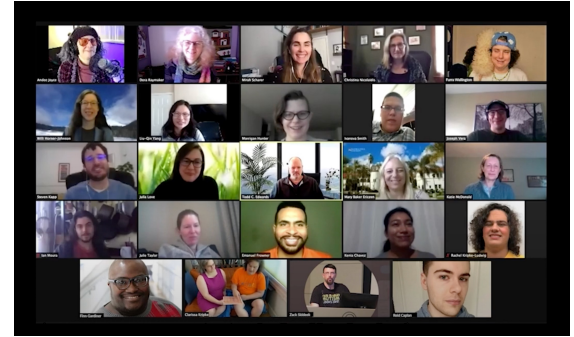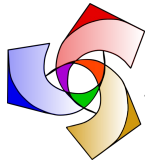
AASPIRE Guidelines

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]

Original Article

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

Christina Nicolaidis[1,2] iD, Dora Raymaker[1,3],
Steven K Kapp[3,4], Amelia Baggs[3], E Ashkenazy[3],
Katherine McDonald[5], Michael Weiner[6,7,8], Joelle Maslak[3],
Morrigan Hunter[3] and Andrea Joyce[3]

Advances in Measurement Methods

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, PhD,[4] Clarissa Kripke, MD,[3,10] Joelle Maslak, BA,[3] Morrigan Hunter, MA,[3] and Kelly Y. Zhen[1,3]

Webinars and LOTS of Sample Materials at:

https://aaspire.org/inclusion-toolkit/

Inclusion on the research team → Inclusive research

CBPR Greatly Affects the Research Itself

A Common Fallacy

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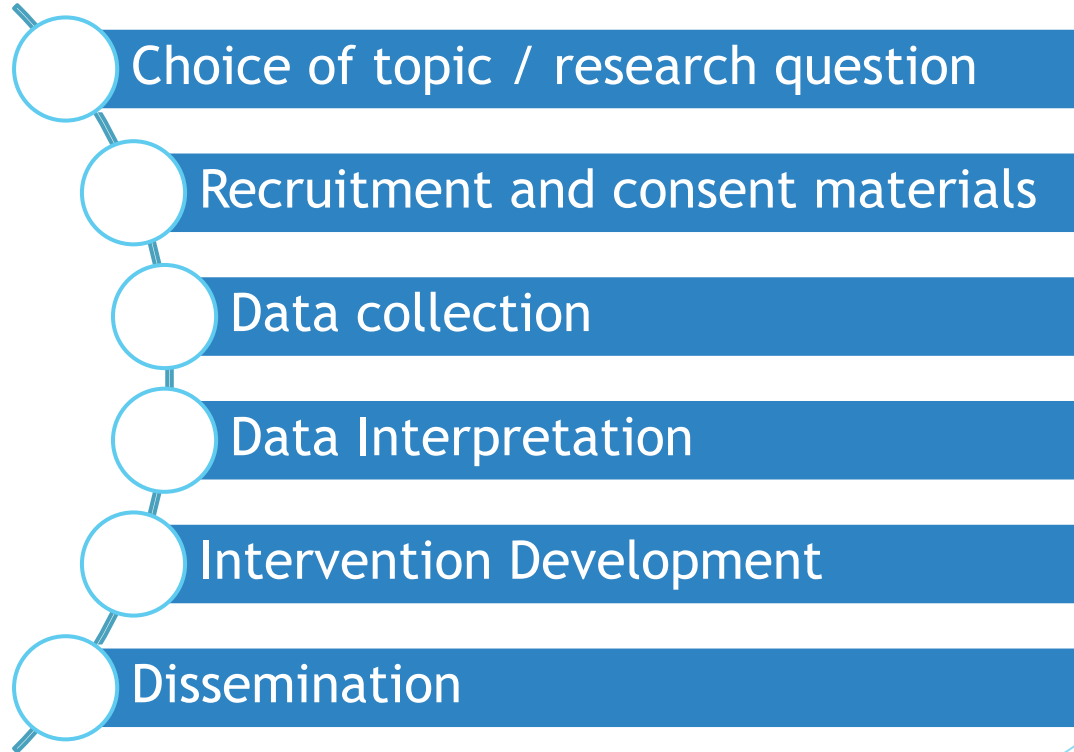
Inclusion

Scientific Rigor

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

Inclusion → Scientific Rigor → Impact

But I Would Say It's the Opposite

Partnership Affects Every Part of the Project

- Choice of topic / research question
- Recruitment and consent materials
- Data collection
- Data Interpretation
- Intervention Development
- Dissemination

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 it was totally missing from research and practice.

  ▶ Small study to define and describe autistic burnout.

  ▶ Viral response from autistic community.

  ▶ Now, lots of interest among researchers and clinicians.

Raymaker et al. (2020) https://doi.org/10.1089/aut.2018.0020

Accessible Consent

▶ Co-create materials with community partners

▶ Clear, simplified consent materials

▶ Q&A format

▶ Visual aids / white space

▶ Reduce participant burden (e.g. online consent)

▶ Time to discuss with trusted person

See https://aaspire.org/inclusion-toolkit/accessible-research/ for sample consent forms.

Accessible Consent Forms

Who may see my information?

In general, **we will not tell anyone** which responses were yours. However, **there are some exceptions**:

- **If you tell us you are being abused**, we may have to report the abuse to Adult Protective Services.

- **If you tell us that you are actively planning to hurt yourself or anyone else**, someone from our research team may ask you more questions about your safety.

    o **If you or someone else are in severe danger**, we may need to tell someone in your local emergency system so that they can help you.

- **We may have to release (give) information to others**.

    o For example, there is a chance that someone may want to check that we are doing things the way we should be. (This is called an "audit.")

    o We may need to give the information to:
        i. The group of people at our University who make sure the research is ethical (the Institutional Review Board)
        ii. The agency who pays for the study (the National Institute for Mental Health)
        iii. Other agencies that oversee research (for example, the Office of Human Research Protection)

    o If that happens, we will try not to give information that could identify you.

Study Activities

What will happen if I decide to be in the research study?

Now   Now   In 6 months   In 12 mo

We will ask you to take a **series of surveys**.
① ② ③ ④
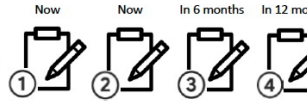
Each survey will take about **1-2 hours** to complete.   1h 2h

You can take a break or start the survey on one day and finish it on a different day.

You can complete the survey **online** by yourself or with help from someone you trust.

If you would like, you can also take the survey **over the telephone or via Zoom** with help from a research assistant.

And, YES, you can change IRB templates
(even the parts that say you aren't allowed to change)
if you offer a good argument.

See https://aaspire.org/inclusion-toolkit/accessible-research/ for sample consent forms.

Effective Recruitment

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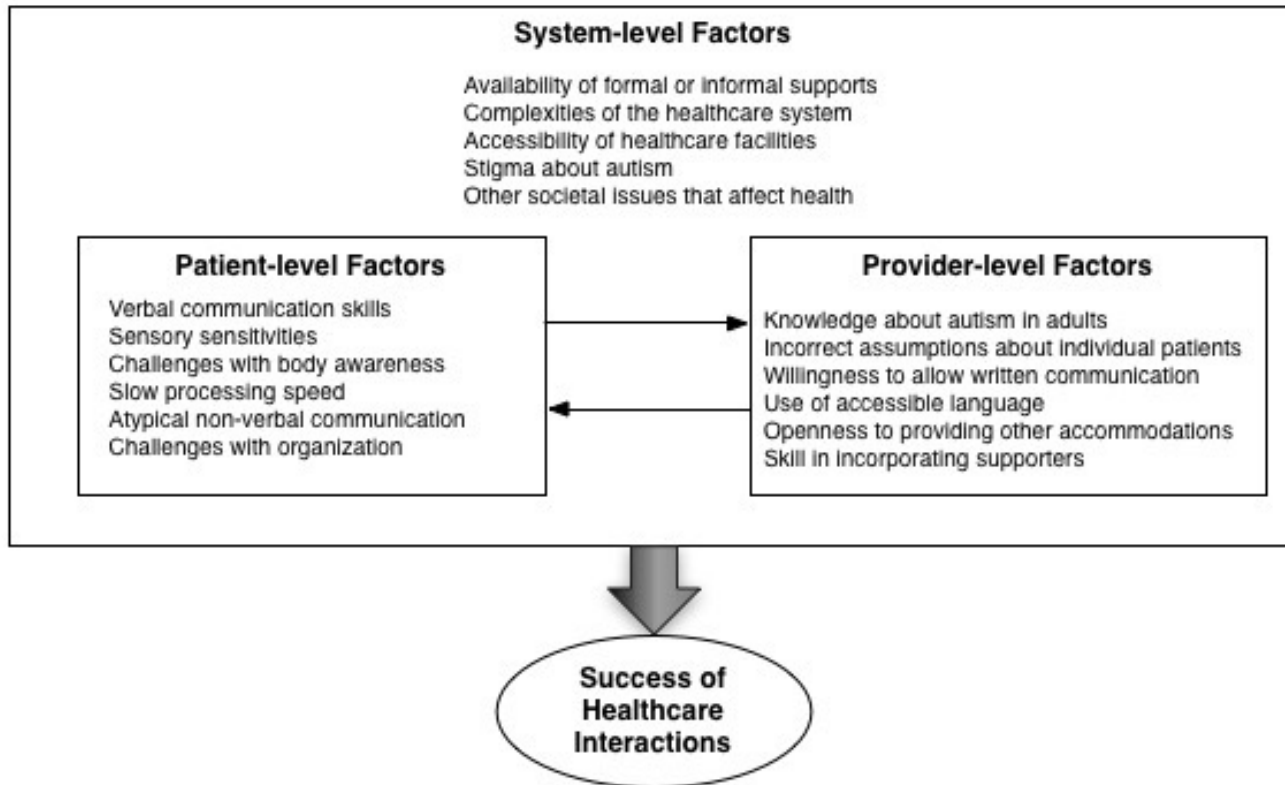- Access to community forums / events / venues
- But be careful not to abuse trust!

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 AASPIRE Inclusion Toolkit for sample interview guides

Example Qualitative Results

System-level Factors

Availability of formal or informal supports
Complexities of the healthcare system
Accessibility of healthcare facilities
Stigma about autism
Other societal issues that affect health

Patient-level Factors

Verbal communication skills
Sensory sensitivities
Challenges with body awareness
Slow processing speed
Atypical non-verbal communication
Challenges with organization

Provider-level Factors

Knowledge about autism in adults
Incorrect assumptions about individual patients
Willingness to allow written communication
Use of accessible language
Openness to providing other accommodations
Skill in incorporating supporters

Success of Healthcare Interactions

Data Collection - Surveys

Over 16 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

Nicolaidis et al. (2020) - https://doi.org/10.1089/aut.2019.0074

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

Nicolaidis et al. (2020) - https://doi.org/10.1089/aut.2019.0074

AASPIRE Outcomes Study

- ▶ 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 with CBPR approach to choose high priority outcomes
- ▶ Phase 2: Co-created or adapted instruments for each of these 15 outcomes.
- ▶ Phase 3: Large prospective cohort study to
  - ▶ Rigorously test psychometric properties
  - ▶ Identify predictors of change in outcomes over time.

https://aaspire.org/projects/outcomes/

Much more at session 4519L, Thursday 5:30pm

AutPROM Toolbox Outcomes

▶ Quality of Life and Overall Health

▶ Mental Health (Depression, Anxiety, Emotional Wellbeing, 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 **demographic, health,** and **disability characteristics, use of services, experiences of discrimination,** and a module on **gender identity and sexual orientation.**

Data Interpretation

▶ Community partners help make sense of the findings.

▶ "Confidence in Managing Health and Health Care Scale" factor analysis.

    ▶ Two factors, but not the ones we intended.

    ▶ Partners helped explain difference in two groups of questions.

    ▶ Individual Healthcare Self-efficacy (i.e., only involves your own skills).

        ▶ e.g. "How confident are you that you can bring what is needed to a healthcare visit?"

    ▶ Relationship-Dependent Healthcare Self-Efficacy (i.e., also depends on the provider and/or health system).

        ▶ E.g. "How confident are you that you can answer your healthcare provider's questions?"

Nicolaidis et al. (2021) https://doi.org/10.1177/1362361320967178

Intervention Development

► 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 / co-create intervention.

► Examples

  ► AASPIRE Healthcare Toolkit (www.autismandhealth.org)

  ► Pregnancy decision videos (www.pregnancyanddisability.org)

  ► Pregnancy Decisions App (in progress)

  ► Community Suicide Prevention Program (in progress)

www.autismandhealth.org

Nicolaidis et al. (2016) https://doi.org/10.1007/s11606-016-3763-6

Resources, Forms, and Worksheets

- Practically address patients' most pressing needs.

- Co-created by providers and autistic adults.

- Team members pilot-tested them in their own care.

- 1-month pre/post-test improvements in patient-provider communication, self-efficacy, and barriers to care.

Nicolaidis et al. (2016) https://doi.org/10.1007/s11606-016-3763-6

Autism Healthcare Accommodations Tool (AHAT)

- Patient or supporter fills out a survey

- Computer uses answers to create a personalized and healthcare provider-friendly accommodations report

Mobile app coming soon!

Welcome

A A A A 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 before making a decision.
☐ I don't need accommodations to make good
☐ I need accommodations to make good decisi
☐ I do not wish to say.

[Back] [Next] [Replay]

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.

Dissemination

- Community partners included on all scientific papers
  - Strategies to ensure they truly meet authorship criteria
- Community Briefs, Newsletters, Blogs, Social Media
- Presentations at scientific and community events
- Written guidelines from start of project

Inclusion in the Literature

Autism in Adulthood

ISSN: 2573-9581

Mary Ann Liebert, Inc. publishers

www.liebertpub.com/aut
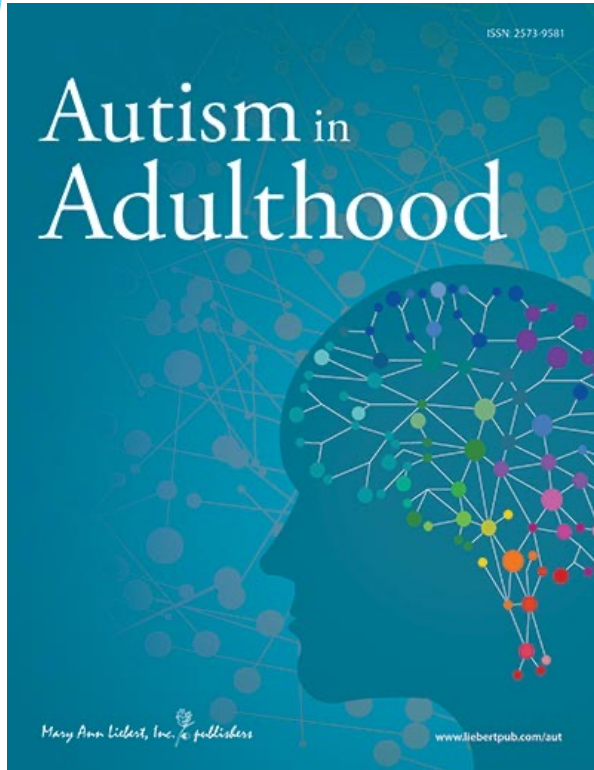
- ▶ Focuses on most pressing issues affecting autistic adults.
- ▶ Editor-in-Chief – Christina Nicolaidis
- ▶ Associate Editor – Dora Raymaker
- ▶ 12 autistic adults on editorial board (and many family members and clinicians)
- ▶ Anti-ableist Language Policy
- ▶ Each manuscript gets traditional scientific 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 people with communication disabilities 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 research is respectful, anti-ableist, rigorous, and impactful

Thank you to the AASPIRE Team

▶ Co-Directors: Christina Nicolaidis[f] and Dora Raymaker[a]

▶ Steering Committee: Co-directors and Andee Joyce[a], Mirah Sharer, Ian Moura[a], Ericka Fox[a], Anne Kirby, and Whitney Lee[a]

▶ Community Council: Andee Joyce[a] (Chair), Reid Caplan[a], Emanuel Frowner[a] , Finn Gardiner[a], Rachel Kripke-Ludwig[a], Julia Love, Joelle Maslak[a], Shannon des Roches Rocha[f], Ivanova Smith[a], Furra Wallington[a], and Zack Siddeek[a]

▶ Academic Council: Christina Nicolaidis[f], Dora Raymaker[a], Katherine McDonald, Clarissa Kripke[f], Steven Kapp[a], Anna Urbanowicz, Anne Kirby

▶ Additional Outcomes Project Co-Investigators: Julie Lounds Taylor, Mary Baker-Ericzen, Willi-Horner Johnson, Todd Edwards, Lui-Qin Yang

▶ Additional Outcomes Project Staff: Joseph Vera, Patrick Bowden, Madeline Proctor[a]

And thank you to all our other new and former AASPIRE team members, the Autistic Self-Advocacy Network, the Autism Society of Oregon, and all our study participants

a – autistic; f – family member

AASPIRE Funding

- National Institute of Health
  - R01MH121407 (Outcomes), R34MH092503 (Healthcare Toolkit Development), R34MH111536 (Healthcare Toolkit Integration), 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)

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