



Autism Intervention Research
Network on Physical Health

AIR-P Presents:

Priority Setting to Improve Health Outcomes Autistic Adults and Other Stakeholders Engage Together

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Stephen Shore, EdD

ssshore@adelphi.edu

Assistant Clinical Professor
Department of Special Education
Adelphi University



Teal Benevides, PhD, MS, OTR/L

tbenevides@augusta.edu

Associate Professor
Department of Occupational Therapy
Augusta University



Priority Setting to Improve Health Outcomes

Autistic Adults and Other Stakeholders Engage Together

Stephen Shore, EdD

sshore@adelphi.edu

Assistant Clinical Professor

Department of Special Education

Adelphi University

Teal Benevides, PhD, MS, OTR/L

tbenevides@augusta.edu

Associate Professor

Department of Occupational Therapy

Augusta University

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... to meaningfully include and engage autistic stakeholders in identifying priorities and methods to support patient-centered outcomes research in collaboration with autistic people.

The views presented in this presentation are solely the responsibility of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute® (PCORI®), its Board of Governors, or Methodology Committee.

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Objectives of this Presentation

At the conclusion of this presentation, attendees will be able to answer the following questions:

- What **preferences for engagement** and methods are successful when incorporating autistic adults as researchers in the research process?
- What are the health **research priorities** as identified by autistic adults?

Authentic Autistic Engagement in Research...

Why?

How?

Why? Fundamental Need to Ensure Autistic Individuals Are Involved in Research

- Autistic adults[^] have multiple, chronic, and potentially preventable healthcare needs as compared to same-aged adults without ASD.
- Much of what is known about the health and healthcare needs of autistic adults has emerged from health services research without knowing the specific priorities of autistic people for addressing barriers to care (e.g. Croen et al., 2015; Zerbo et al., 2018; Schott et al., 2020).
- Approximately 2% of U.S. research funding in autism is spent in addressing adult outcomes (IACC, n.d.)
- *Noted increases in autistic involvement in research, particularly IACC and other funded studies, is promising.*

[^]We purposefully use identity-first language, as opposed to person-first language, in congruence with preferences expressed by adults on the spectrum.

How? Participatory Action Research Design

- Established a **Project Team** comprised of autistic and non-autistic individuals



Teal Benevides

Project Lead



Stephen Shore

Project Co-Lead



Alex Plank

Social Media Coordinator



Patricia Duncan

Meeting Planner

- Established a paid **Community Council** of autistic adults and other stakeholders to inform and guide patient-centered outcomes research
 - 18 Community Council members joined and contributed
 - Involved **other stakeholder individuals and organizations** in priority-setting

How? Enhancing Engagement



AASET

Autistic Adults and other Stakeholders Engage Together

Engagement & Compensation Guide

**Version 2.1
December 2018**

**Shore, S. & Benevides, T. W.
(Editors).**

***Engagement &
Compensation Guide*** for
researchers.

- Competence
- Communication
- Compensation
- Considerations

How? Enhancing Engagement: Competence

WHAT IS GOOD FOR THE GOOSE IS GOOD FOR THE GANDER

1. Non-speaking individuals should be treated as if they understand all verbal language.
2. Modify your language.
 - Instead of “sensory dysfunction”, describe “sensory differences”. The differences may impact function, but aim to not describe the problem as being the individual.
3. Teach students, family members, postdocs, and others to communicate **WITH** the person on the spectrum, even if they are a child.
 - Do not talk about the child or adult as if they are not listening - they are, and listening to deficit-based language is detrimental to a person’s mental health.

How? Enhancing Engagement: Communication

WHAT IS GOOD FOR THE GOOSE IS GOOD FOR THE GANDER

Example Email from the Engagement Guide

Purpose

- To request feedback on Conference Summary (short, 3 page summary)

Details:

- We will incorporate feedback from the Community Council prior to sharing with the attendees of the year 1 meeting.

Questions include:

- Are the materials written in a way that is understandable? Clear? Respectful?
- Is there anything missing that you would want to know?

Actions:

- Read the Conference summary
- Use track changes to share edits or comments on the content of the summary
- Send feedback to sampleperson@email.com

Deadline: Wednesday October 4, 2017 at 5pm Eastern Time

*Template developed by Elesia Ashkenazy
(AASPIRE Representative)*

How? Enhancing Engagement: Compensation

WHAT IS GOOD FOR THE GOOSE IS GOOD FOR THE GANDER

- All individuals in research and practice should be compensated for their intellectual contributions.
- Authentic alliance and respect require compensation as team members, depending on role.
- For our project, Community Council members were paid **\$50/hour** for their time in advisory roles.
- In recent CER grant applications, we have compensated at a rate of **\$100/hour** for roles such as *outcome assessor*, *intervention manual developer*, and *intervention implementer*.
- Major barrier: payment can interfere with disability benefits. This requires future work to address ***how*** to best compensate.

How? Measuring Engagement: Considerations

WHAT IS GOOD FOR THE GOOSE IS GOOD FOR THE GANDER

- Trust
 - Able to bring up differing ideas and concerns
 - Measurement: Concerns are raised and meaningfully heard
- Respect
 - Contributions are valued
 - Measurement: Equality of voices in meetings and decision points
 - Measurement: Contributions are included and recognized in process and products
- Support
 - Multiple options for remaining engaged make it easier to participate
 - Measurement: Number of people who prefer or use different options

How? Enhancing Engagement: Recommendations

1. **Include** autistics in the development, implementation & dissemination of research
2. **Ensure** participation through appropriate accommodation
3. **Presume competence and focus on abilities** in all interactions
4. **Value** autistics as an integral part of the team (avoid tokenism)
5. **Present** research results in several modalities to accommodate different communication styles
6. **Compensate** autistics for time and experience brought to the table
7. **Consult** autistics regarding priorities for research and systems change

Ways Respondents Wanted to Be Engaged In Research

- | | |
|--|-------|
| 1. Be a Research Participant | 85.6% |
| 2. Develop Research Questions | 72.6% |
| 3. Help Interpret Results with Study Team | 67.8% |
| 4. Participate in Sharing Results | 54.8% |
| 5. Recruit Research Participants | 31.5% |
| 6. Participate in Developing Grant | 27.4% |

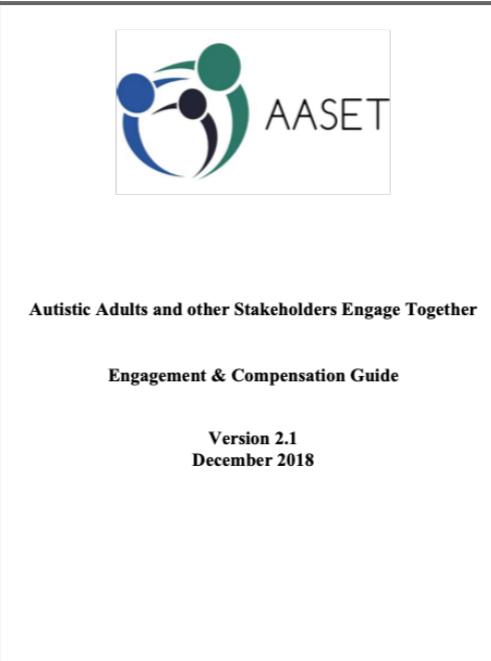
Related Publications

Benevides, T. W., Shore, S. M., Palmer, K., Duncan, P., Plank, A., Andresen, M.-L., Coughlin, S. S. (2020). Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project. *Autism*, 24(4), 822–833. <https://doi.org/10.1177/1362361320908410>.

Benevides, T. W., Shore, S. M., Andresen, M.-L., Caplan, R., Cook, B., Gassner, D. L., Erves, J. M., Hazlewood, T. M., King, M. C., Morgan, L., Murphy, L. E., Purkis, Y., Rankowski, B., Rutledge, S. M., Welch, S. P., & Wittig, K. (2020). Interventions to address health outcomes among autistic adults: A systematic review. *Autism*, 24(6), 1345–1359. <https://doi.org/10.1177/1362361320913664>

 AJOT
The American Journal of Occupational Therapy

Benevides, T. W., Shore, S. M. (2020). Engagement and compensation: Developing guidelines for researchers to inform authentic research with autistic adults. *American journal of occupational therapy*, 74(4 Supplement 1), 7411510278– [Presentation]. <https://doi.org/10.5014/ajot.2020.74S1-RP103C>

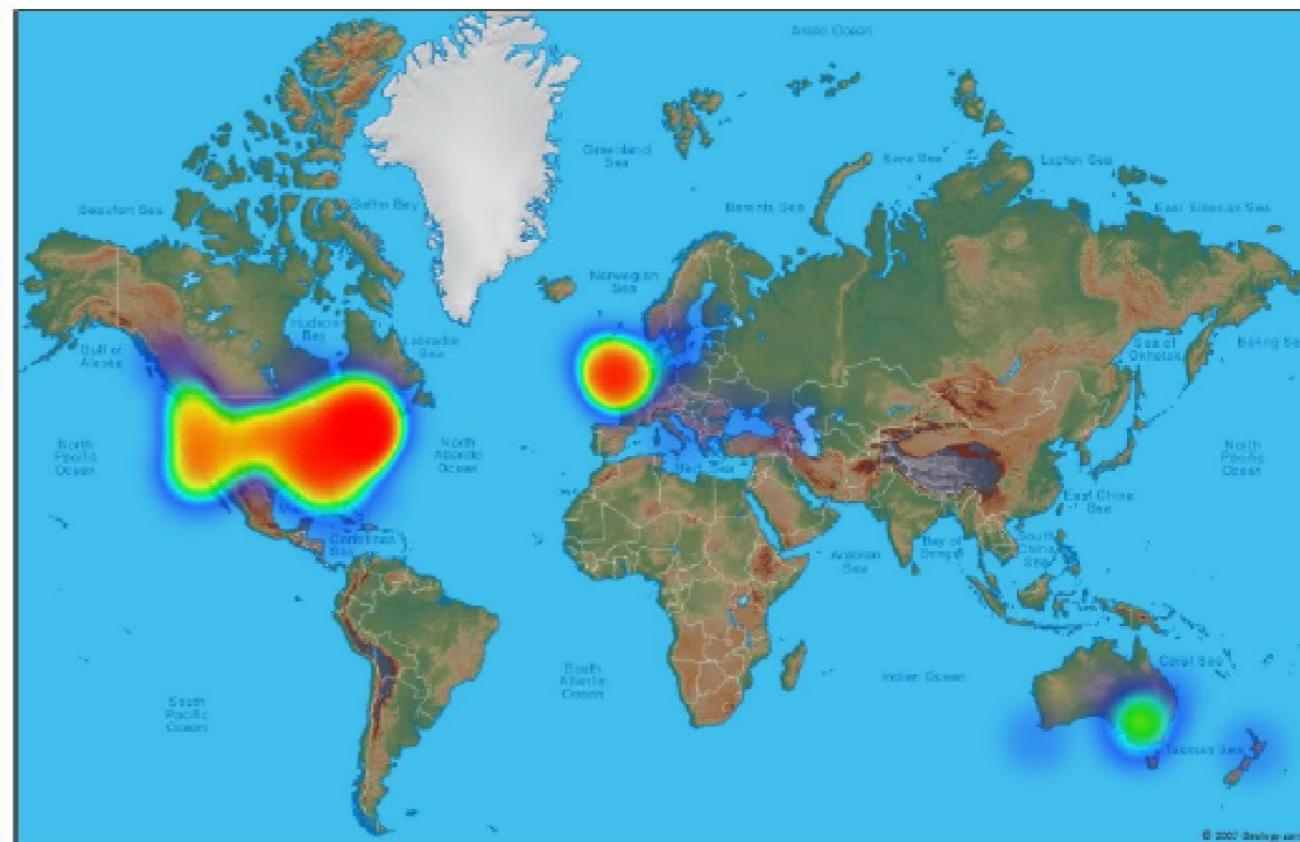


Shore, S. & Benevides, T. (Editors) with authored contributions from Ashkenazy, E., Gravino, A., Lory, B., Morgan, L., Palmer, K., Purkis, J & Wittig, K. (2018). *Autistic Adults and other Stakeholders Engage Together: Engagement & compensation guide*. <https://www.pcori.org/sites/default/files/Engagement-Guide-as-of-122018-2.1.pdf>

Priority-Setting for Health Research

Priority-Setting Methods

- Year 1 Large group stakeholder meeting
 - July 2017 ($n=51$)
- Online survey of autistic adults
 - Aug 2018 ($n=236$)
- Face-to-face focus groups of autistic adults
 - Aug-Nov 2018 ($n=26$)
- Year 2 Large group stakeholder meeting
 - November 2018 ($n=64$)



Results of priorities revolved around the following areas:

1. Mental health interventions and outcomes
 1. Access to healthcare and needed accommodations to get care
 1. Gender inequalities in diagnosis, treatment, and sexual well-being

Priority-Setting: Mental Health Priorities Summary

Mental Health Across the Lifespan



Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project

Autism
2020, Vol. 24(4) 822–833
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Table 5. Top mental health priority topics and questions.

1. What is the impact of trauma on mental health outcomes in autistic individuals, and what approaches can be used to effectively address trauma among autistic adults (e.g. trauma-informed care)? What are the best indicators or measures of PTSD, trauma, and adverse childhood experiences in autistic individuals?
2. What is the impact of social isolation, stigma, discrimination and other forms of marginalization on mental health and well-being in autistic individuals? Conversely, what is the impact of radical inclusion, such as being part of a social movement, on mental health and well-being?
3. When, for who, and under what conditions do self-managed interventions and preferred activities used to address well-being and mental health result in improved quality of life and reduced mental health symptoms? What is the effect of employing community-available approaches and techniques such as exercise/physical activity, yoga, mindfulness and meditation, tai-chi, animal-assisted therapy, art and music-based approaches to well-being?
4. What are the potential long- and short-term negative side effects or adverse outcomes of currently recommended therapies and interventions (including behavioral and pharmacological), as measured in autistic individuals across the life span?
5. How can we develop better measurement tools for autistic quality of life, depression, anxiety, social well-being, and sleep as experienced by autistic adults?

PTSD: posttraumatic stress disorder.

Priority-Setting: Mental Health Priorities Summary

Mental Health Across the Lifespan



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Table 4. Online survey participants who endorsed “This Outcome Matters to Me” and weighted rank ($n=136$).

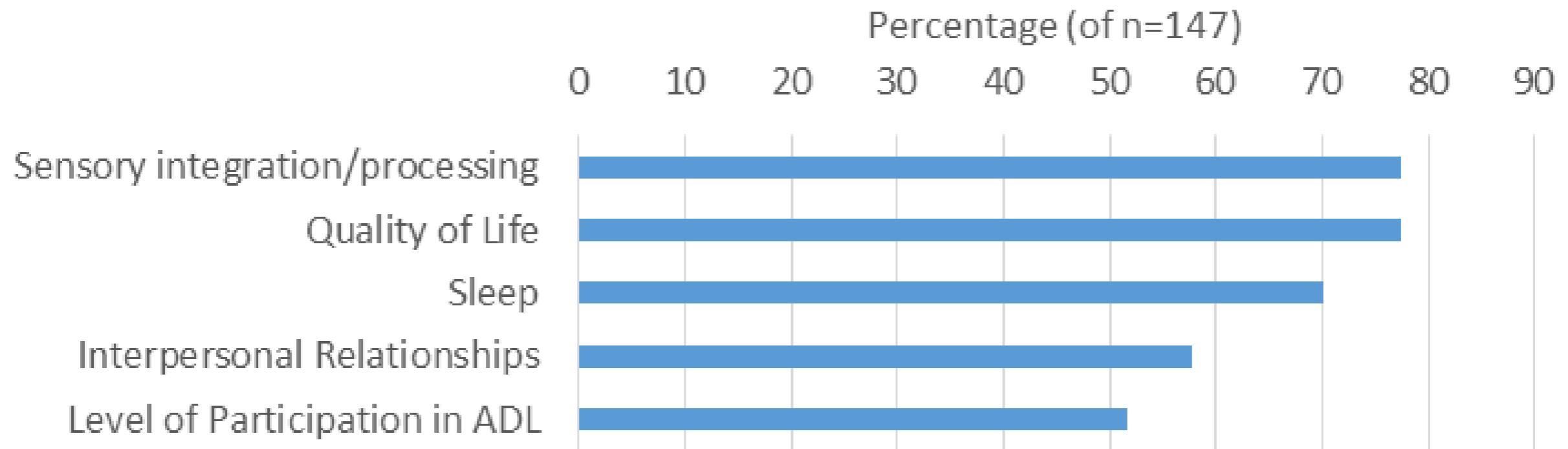
Outcome	“Yes—matters to me,” f (%)	Relative weighted rank ^a
Quality of life	130 (95.6)	1
Anxiety	122 (89.7)	2
Depression	111 (81.6)	3
Social well-being	107 (78.7)	4
Sleep	107 (78.7)	5
Interpersonal relationships	103 (75.7)	6
Suicidal ideation	92 (67.6)	7
Level of participation in activities of daily living	94 (69.1)	8
Level of participation in work	92 (67.6)	9
Suicidal attempts	87 (64.0)	10
Level of participation in your community	79 (58.1)	11
Intimacy and/or sex	76 (55.9)	12
Level of participation in leisure activities	77 (56.6)	13
Brain activity/EEG	47 (34.5)	14
Heart rate	44 (32.4)	15

^aWeighting for ranks were calculated as the sum of the number of participant responses ranking that item as “1,” “2,” . . . “15” multiplied by the weight. A rank of “1” was given a weight of 15, and a rank of “15” was given a weight of “1.”

What about Physical Health?

1. What outcomes matter to you? What does 'being healthy' mean to you?
1. What health professionals are most important to future research?
1. If you could wave a magic wand, what would you want to change about healthcare? What is a breaking news headline about autism research you would want to read?

Priority Setting: Physical Health “Outcomes that Matter To Me”



Open Ended Responses Revealed Additional Outcomes that Matter

- Pain, chronic pain, fatigue
- Gut/bowel health, irritable bowel syndrome
- Dyspraxia, mobility, joint and muscle connectivity, flexibility as aging occurs
- Migraine and headache
- Stress hormones and cortisol
- Immune and autoimmune conditions
- Cancer

Priority Setting: Physical Health “What does ‘being healthy’ mean?”

- Being healthy means absence of chronic illness, access to resources that help me stay healthy, and being physically and mentally well without pain.
- Being healthy means being able to do everyday things with little to no assistance. It means being comfortable in your abilities and being in tune with your body.
- Not being sick or in pain.
- Getting enough sleep, eating that energizes you, drinking fluids, self-esteem, low stress levels.
- Ability and well-being.
- Ability to regulate and manage body/mind systems, not being overly extreme or compulsive.

Priority-Setting: Providers

What professionals do you think are important to include in future health research in autism?

- Primary care providers
- Counselor/psychologist
- Dental professionals

Priority-Setting: Access to Care Summary

- For autistic adults attempting to access healthcare, what is the effect of **systems navigators or technology portals** on outcomes such as improved access and use of preventive and specialty services?
- Would providing autistic adults the option of **non-emergency medical transportation** (non- para network, rideshare service) at little to no cost increase their engagement with in-person healthcare services such as preventive and sick visits?
- What is the effect of implementing a healthcare tool to support **communication** between autistic patients and providers on their experience of care, engagement, and care outcomes?
- What is the impact of sensory-friendly, optimal **healing environments** on the initiation, obtaining, and sustaining of on-going medical and dental care in the autism community?

Priority-Setting: Access to Care

How can we improve the communication between health providers and autistics?

Respondent Quotes: What would you change?

- **Communication between patient and provider**
 - “Making it definitely easier to tell your doctor what's going on primarily because it's so anxiety-ridden when you go to the doctor, right?”
 - “I'll get focused on one thing that's been told to me, and they've moved on, and now whoa, we're three steps down the way. I would like a written summary at some point, word for word”
- **Provider understanding of autism, presumption of competence**
 - “I would wave a magic wand to stop doctors from treating me as a subhuman or a little child as soon as they learn I'm on the spectrum”
 - “I would love ... if doctors and clinicians understood aspects of autism.”

Priority-Setting: Access to Care

How can we improve the environments of care for autistics?

How can we reduce external barriers (transit, cost) using technology or other innovative tools?

Respondent Quotes: What would you change?

The environment of care

- “Changing the way waiting rooms work.... because waiting in a waiting room with loud noises, smells, like people wearing perfumes, lights ... It's so taxing”

Access barriers

- “I have to do everything myself because everyone has their own things to do and my parents work a lot and live 2 hours away. I do not get good care and I cannot tell if it is because I am bad at communicating and I forget a lot or if they just do not care. I say things and they don't listen and sometimes it feels like I am a child with no say in the care I get. I stopped going to the doctor because I did not get the care I needed and it was too expensive.”

Priority-Setting: Gender and Sexual Health

- How can we improve autism diagnosis in females and non-binary individuals on the spectrum?
- How do hormonal changes across the lifespan affect the skills, abilities, and sensory systems of autistic individuals?
- How can we improve gender and sexual health resources for better relationships and reducing rates of sexual abuse and trauma among autistics?

Priority-Setting: Gender and Sexual Health

How do hormonal changes across the lifespan affect the skills, abilities, and sensory systems of autistic individuals?

Research Questions Posed by Respondents

“Does menopause in women or midlife in men accelerate sensory sensitivity and executive functioning difficulties?”

How can we improve the pregnancy experience and motherhood despite overwhelming sensory and physical changes?

Does “long term use of selective serotonin reuptake inhibitors increase risk of fractures in post-menopausal autistic women?”

Priority-Setting: Gender and Sexual Health

How can we improve autism diagnosis in females and non-binary individuals?

Headlines Posed by Respondents

“Researchers confirm that higher diagnosis of boys was due to bias in diagnostic criteria”

“Autism in women just as common as men, diagnostic criteria adjusted accordingly”

Limitations to Priority Setting Activities

1. Convenience sample of self-selected adults
2. Self-reported diagnosis is not confirmable for survey respondents
3. Limited to those who have access to the internet and the ability to read and participate in an online setting (survey) or attend a focus group
4. Online survey composed more of females (65%) than males, which is not similar to current diagnostic distributions, BUT is similar to other adult studies

Future Priority Setting Activities Need to Occur With:

- Individuals who do not have the ability to consent to participate on their own in research
- Racially and ethnically diverse respondents
- Non-binary autistic adults

Summary: Priority Setting

Physical Health Priority Outcomes:

- Quality of life
- Sleep
- Sensory processing
- Activities of daily living participation
- Social participation

Physical Health Priority Topics:

- Mental health- as linked to physical health
- Access to healthcare
- Gender and sexual health

Discussion

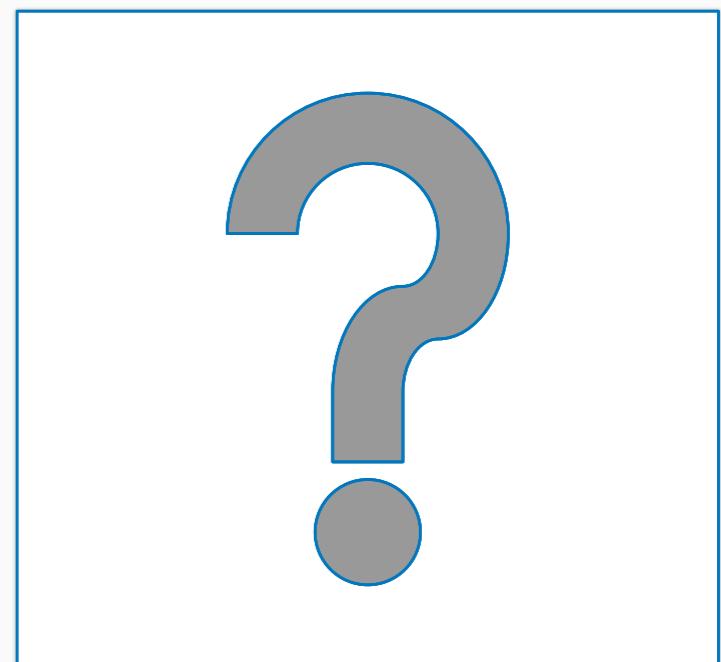
- **Share** ways that you can promote authentic engagement in your work, or ways that you have found to be successful.
- **Identify** how you can use the research priorities to tailor your own research and/or practice with autistic individuals.
- **Name** 1 thing you will do to take this information and use it in the future.

Contact Us!

Stephen Shore
sshore@adelphi.edu

Teal Benevides
tbenevides@augusta.edu

<https://www.pcori.org/research-results/2016/priority-setting-improve-health-outcomes-autistic-adults-and-other>





Autism Intervention Research
Network on Physical Health

Contact Us:
AIRP@mednet.ucla.edu
AIRPnetwork.ucla.edu



Feedback
Survey:



Autism Intervention Research
Network on Physical Health

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our
newsletter!



Thank you for attending!
A link to view the recording will be emailed to all registrants.

We hope to see you next month!

next webinar date

4:00 p.m. - 5:00 p.m. ET

AIR-P Presents –

By *Presenter names*

Brief summary

Register:

