

Disability Inclusion, Intersectionality, and Knowledge Translation

KTDRR's 2024 Virtual KT Conference

October 15, 16, and 18

Center on
**KNOWLEDGE TRANSLATION FOR
DISABILITY & REHABILITATION RESEARCH**

American Institutes for Research Knowledge Translation Conference

Stephen M. Shore

sshore@adelphi.edu

www.drstephensshore.com

15 October 2024

Center on

**KNOWLEDGE TRANSLATION FOR
DISABILITY & REHABILITATION RESEARCH**

Stephen M. Shore

sshore@adelphi.edu

www.drstephenshore.com

15 October 2024

American Institutes for Research

Knowledge Translation Conference

Funding and Acknowledgements

Funded by Patient-Centered Outcomes Research Institute (PCORI), Eugene Washington PCORI Engagement Award (EAIN# 4208) to Accomplish the Project Goal...

... 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.

Teal Benevides and Stephen Shore declare no financial conflicts of interest with entities who paid for the study described herein.

Listening to Autistic Voices: Participatory Research in Prioritizing Mental Health

How? Participatory Action Research Design

- Established a **Project Team** that comprises 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 setting priorities.



**Authentic Autistic
Engagement in
Research...**
How?

How? Enhancing Engagement



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 – **Presume competence!**
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 5 p.m. 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 the 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: Considerations

WHAT IS GOOD FOR THE GOOSE IS GOOD FOR THE GANDER

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

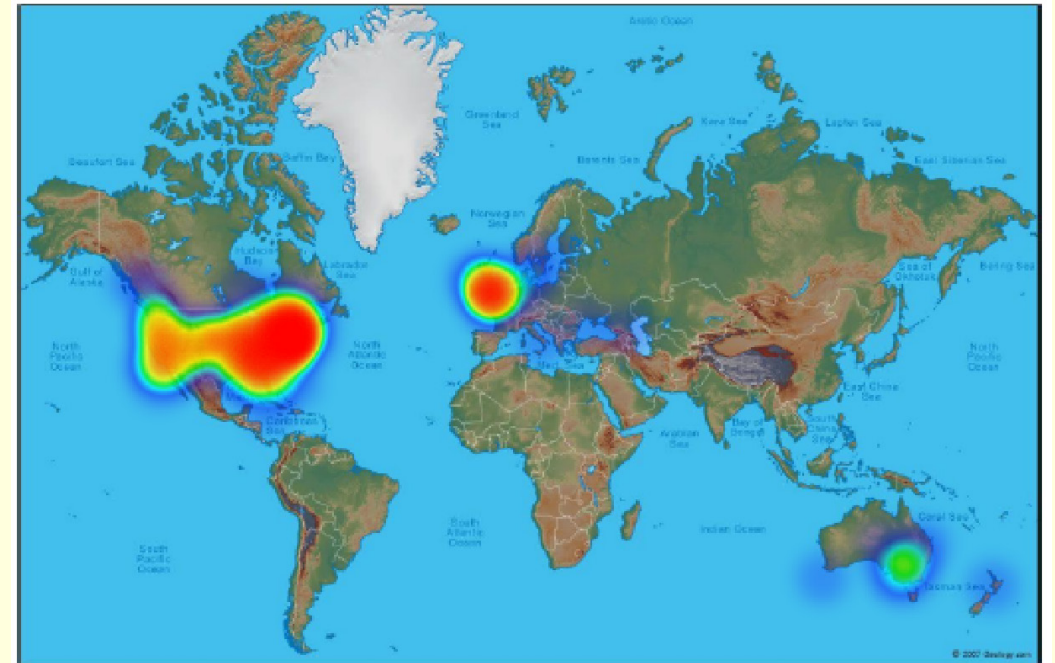




**Priority Setting for
Health Research...
Methods**

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 ($n=64$)



Analyses of our survey data by location of respondent. Unpublished.



**Priority Setting for
Health Research...
Results**

Priority Setting: Results

**Results of
priorities
revolved around
the following
areas...**

Mental health interventions and outcomes

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



Dissemination of Research



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>



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>



Autistic Adults and other Stakeholders Engage Together

Engagement & Compensation Guide

Version 2.1
December 2018

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>

Thanks for your participation!



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

Stephen Shore
sshore@adelphi.edu
www.drstephenshore.com



Q&A



ktdrr.org



ktdrr@air.org



800.266.1832