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Participatory Research: Questions to Consider

- What is participatory research?
 - What implications does authentic engagement of autistic people have for reliability and validity in autism research?
 - What are some key factors indicating that successful participatory research is being accomplished?
 - In what ways can participatory research be helpful in determining health priorities for autistic individuals?
- 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 board/Delphi panels)



<https://youtu.be/1eofFWWHKM4>

12:04-18:50

Christina Nicolaidis, MD, MPH

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

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.*

[^] Identity-first language is purposefully used, as opposed to person-first language, in congruence with preferences expressed by adults on the spectrum.

Listening to Autistic Voices: Participatory Research in Prioritizing Mental Health

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-settings



**Authentic Autistic
Engagement in
Research...**

Why?

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.

Listening to Autistic Voices: Participatory Research in Prioritizing Mental Health

How? Enhancing Engagement: **Competence**

WHAT IS GOOD FOR THE **GOOSE** IS GOOD FOR THE **GANDER**

Does Paul
Kotler
have...

- communication?
- environmental awareness?
- agency?
- a voice?

<https://youtu.be/uPreKqiglgQ>



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: Considerations

WHAT IS GOOD FOR THE GOOSE IS GOOD FOR THE GANDER

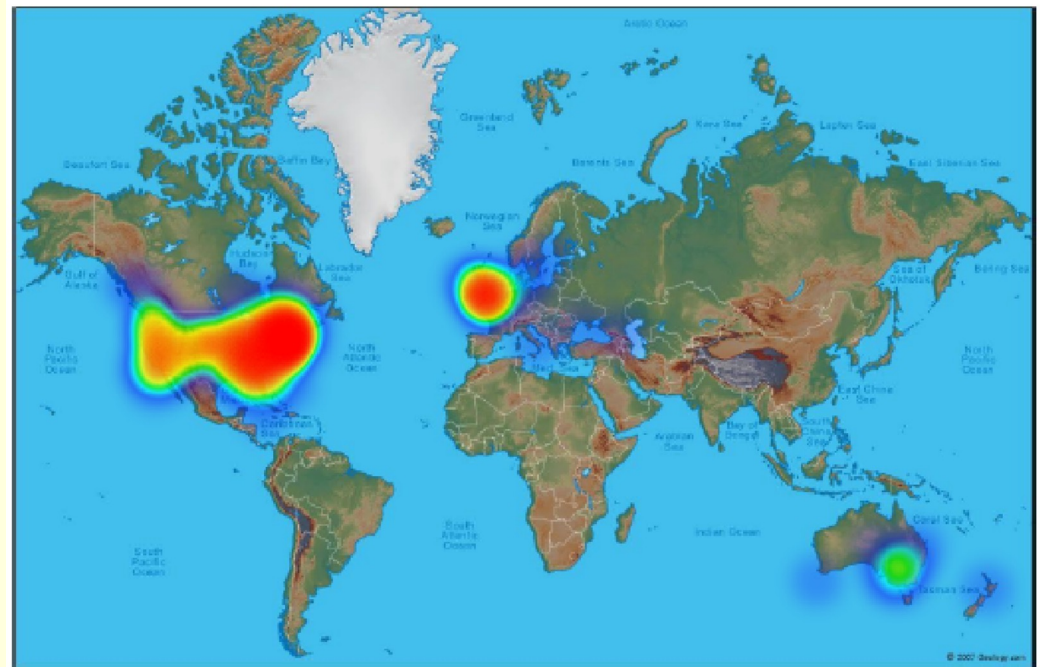
- **Include** autistics in the development, implementation & dissemination of research
- **Ensure** participation through appropriate accommodation
- **Presume competence and focus on abilities** in all interactions
- **Value** autistics as an integral part of the team (avoid tokenism)
- **Present** 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 ($n=64$)





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

**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: Summary

Mental Health Across the Lifespan



Autism
2020, Vol. 24(4) 822–833
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Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project

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



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

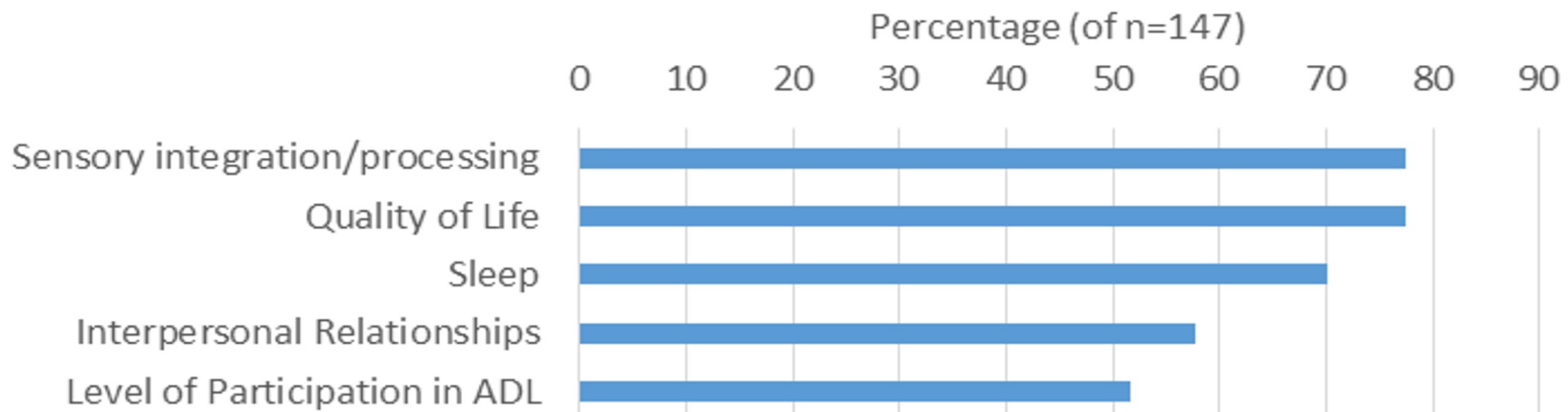
Outcome	“Yes—matters to me,” f (%)	Relative weighted rank ^a
Quality of life	130 (95.6)	1
Anxiety	122 (89.7)	2
Depression	111 (81.6)	3
Social well-being	107 (78.7)	4
Sleep	107 (78.7)	5
Interpersonal relationships	103 (75.7)	6
Suicidal ideation	92 (67.6)	7
Level of participation in activities of daily 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
2. What health professionals should be involved in future research?
3. 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
 - Migraine and headache pain
- Gut/bowel health
- Dyspraxia, mobility, joint and muscle connectivity, flexibility as aging occurs
- Stress hormones and cortisol
- Immune and autoimmune responses or conditions
- Cancer as an indicator of health

Priority Setting: 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: What health professionals should be involved in future research?

- Primary care providers
- Counselor/psychologist
- Dental professionals

Priority Setting: Access to Care Priority Topics

- 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

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.”

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?

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?”

How do 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”

Priority Setting: Summary

Physical Health Priority Outcomes:

- Sensory processing
- Quality of life
- Sleep
- Pain

Physical Health Priority Topics:

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

Priority Setting: 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

Priority Setting: Next Steps

PCORI Funded Comparative Effectiveness Research Study

Jan 2022-Dec 2027

\$9.1 million dollars

Suicide Prevention Study Overview

Study Goal

- Compare two different approaches to suicide prevention tailored for autistic youth.

Study Questions:

- Which approach results in better outcomes for autistic youth?
- Which approach leads to better satisfaction for autistic youth and their providers?
- What factors impact the effectiveness of these interventions?

PI: Dr. Brenna Maddox, PhD (UNC Chapel Hill and Dr. Shari Jager-Hyman, PhD (University of Pennsylvania)

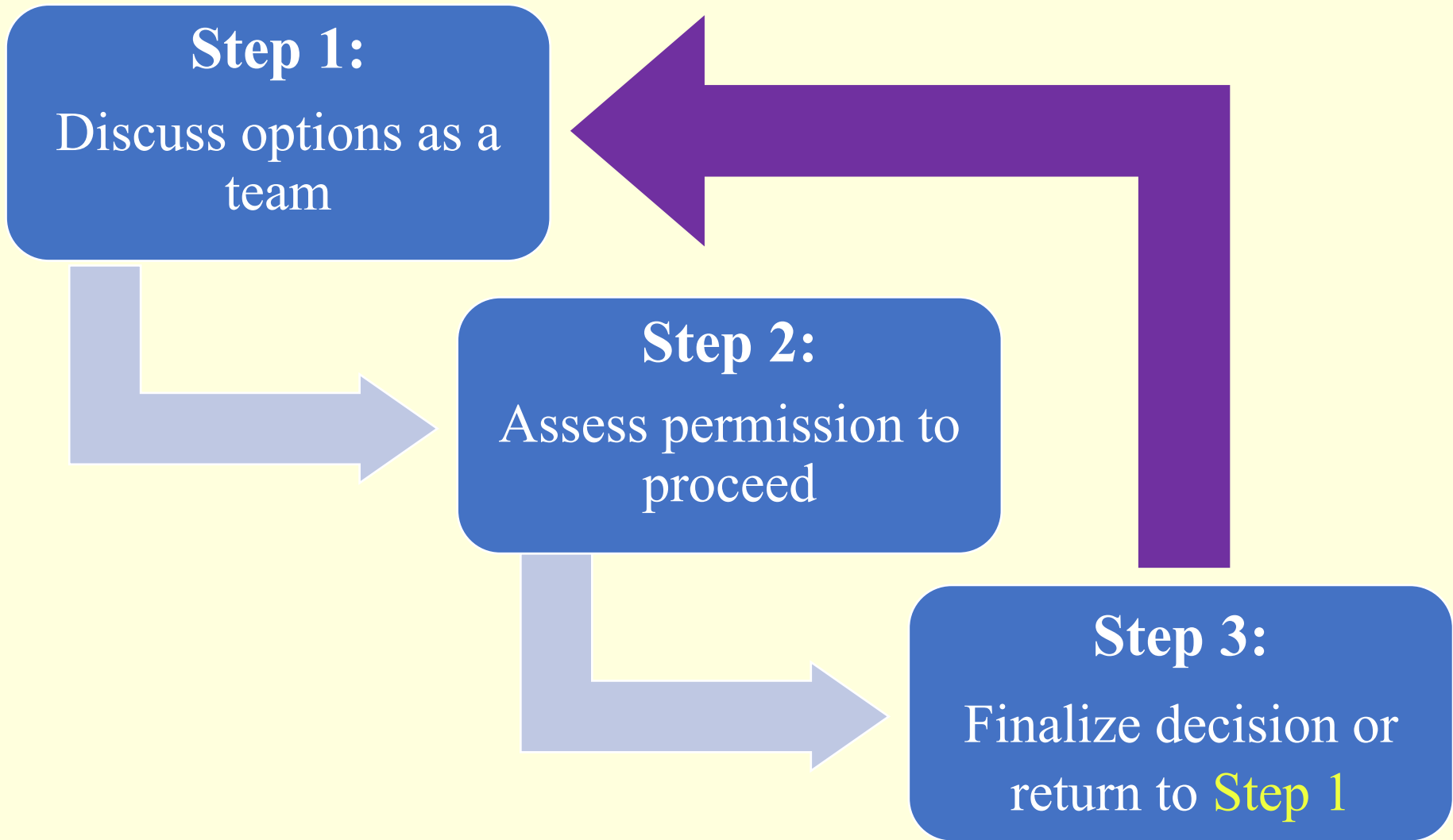
Engagement Core Leads: Benevides + Shore

AASET Members: On multiple study roles



Next Steps...
**Decision-Making
Process**

Priority Setting: Next Steps – Evolution in Decision Making Process



Priority Setting: Decision Making – Step 1

Step 1:
Discuss
options as
a team

Goal:

- To obtain input and clarify all possible options
- To determine options to eliminate

Method:

- Communication via email or virtual meeting

Example

- **Age:** Discuss various options via email or during a virtual meeting
 - 11
 - 12
 - 13
 - 14

Priority Setting: Decision Making – Step 2

Step 2:
Assess
permission
to proceed

Goal:

- To ascertain members' preferences for option

Method:

- Voting via Google Forms

Example

- Vote on whether to lower age to 13
- Vote on whether to lower age to 14

Priority Setting: Decision Making – Step 2

1. I do not have an opinion

2. I prefer for this option to move forward

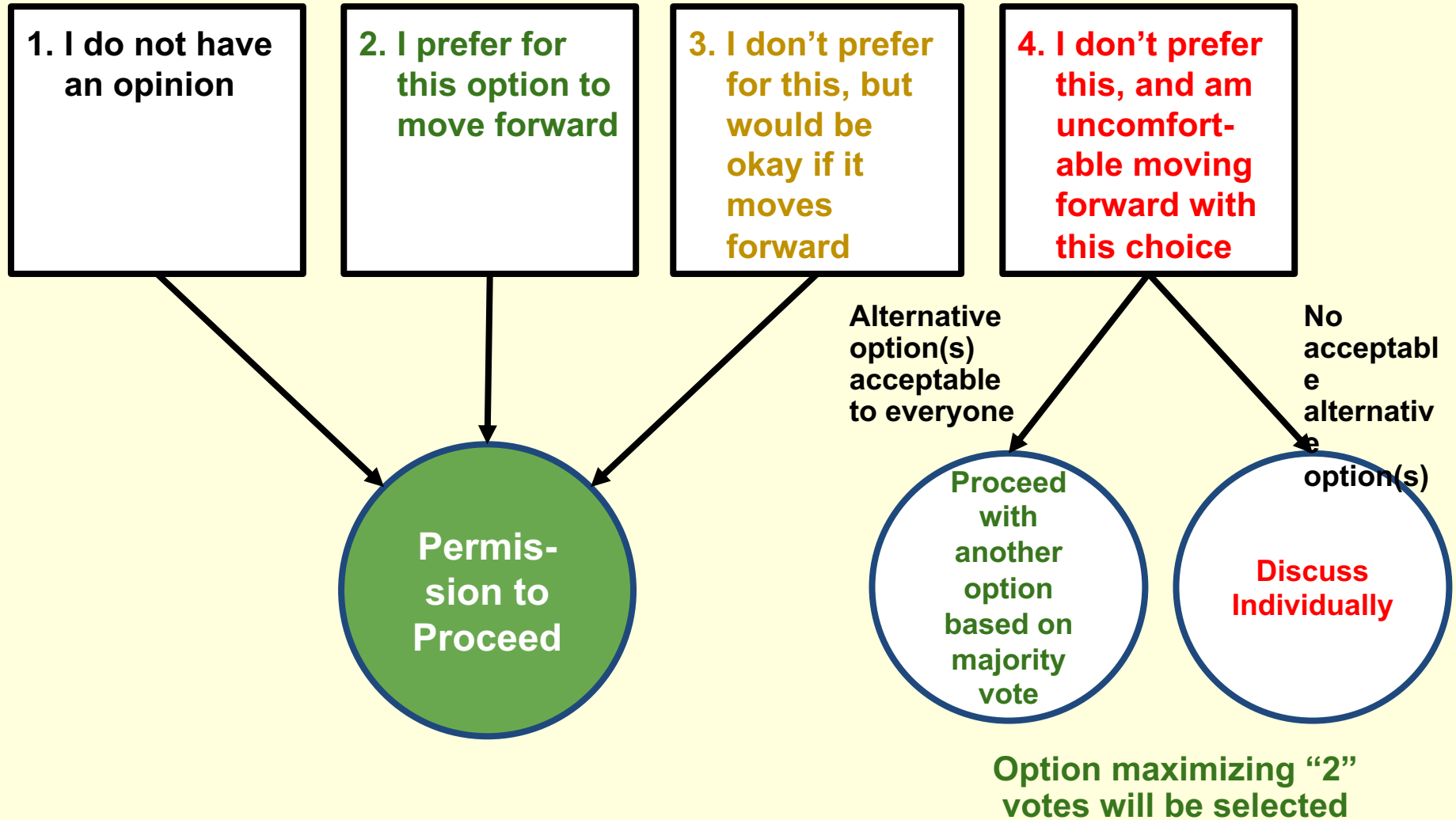
3. I don't prefer for this, but would be okay if it moves forward

4. I don't prefer this, and am uncomfortable moving forward with this choice

Examples

- Lowering the eligibility age to 13
 - 4. I don't prefer this, and am uncomfortable with this choice moving forward
- Vote on whether to lower age to 14
 - 2. I prefer this option to move forward

Priority Setting: Decision Making – Step 3



Priority Setting: Decision Making – Step 3

Step 3:
Finalize
decision or
return to
Step 1

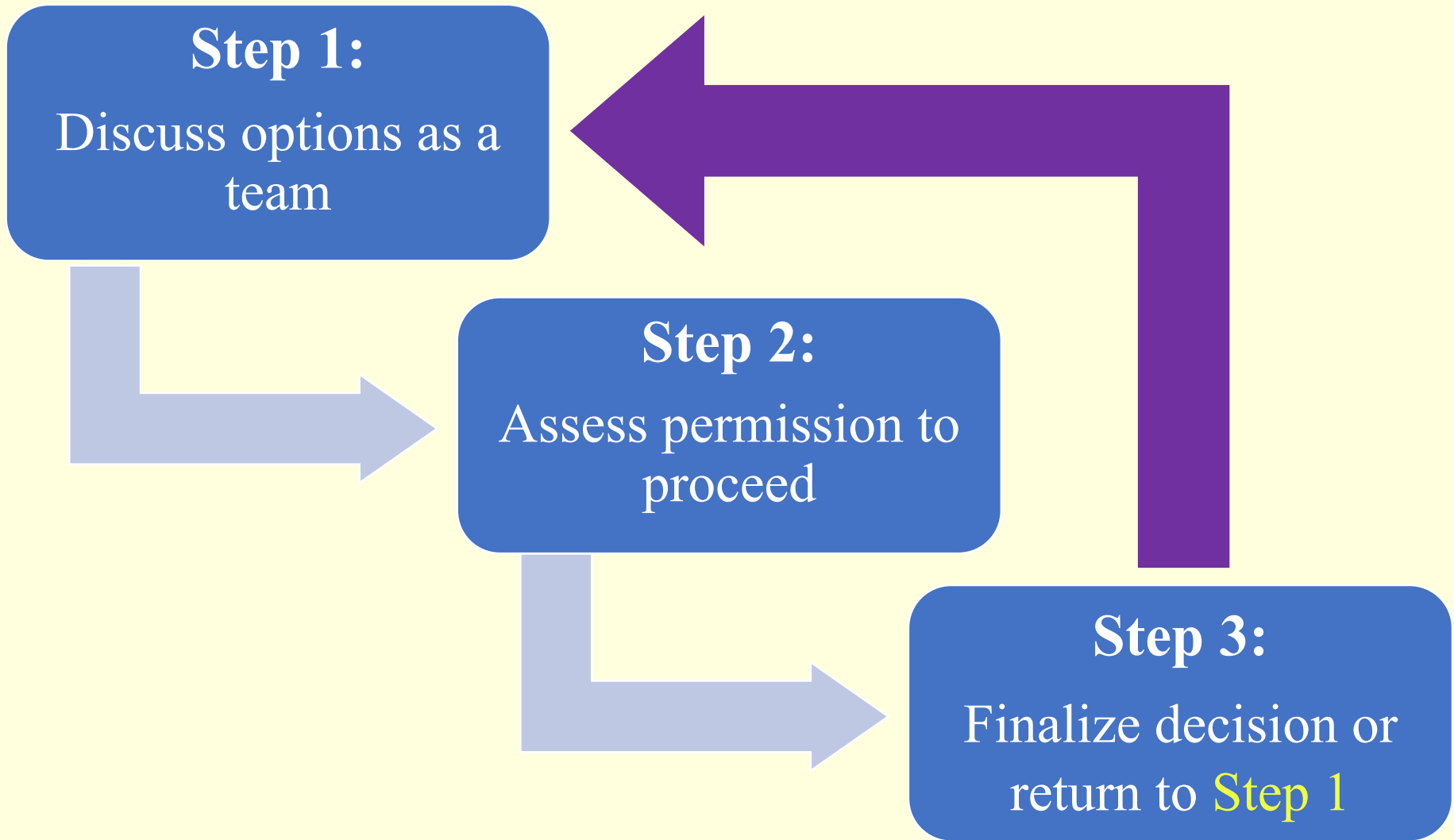
Goal:

- To select final decision or determine that is necessary to discuss other options.

Method:

- Review of Google Form by Teal & Stephen; sharing of results with Brenna & Shari
- Individual conversations, if needed

Priority Setting: Next Steps – Evolution in Decision Making Process





**Case Study
&
Discussion**

Discussion & Application for Research Methods

You are leading a research team in which there are a variety of stakeholders working to develop a shared framework for outcomes. The team has been working for several months on the framework. One member of the team feels that the framework that was discussed is not acceptable.

In teams of 2-3, discuss the following and prepare to share...

1. What are the potential sources of disagreement?
2. What are ways that you can resolve this challenge within your research team?
3. Additionally, consider methods that you could use to ensure that all stakeholder voices feel heard that you could put into place for the next project.

Discussion & Application for Research Methods

- **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.

Dissemination of Research

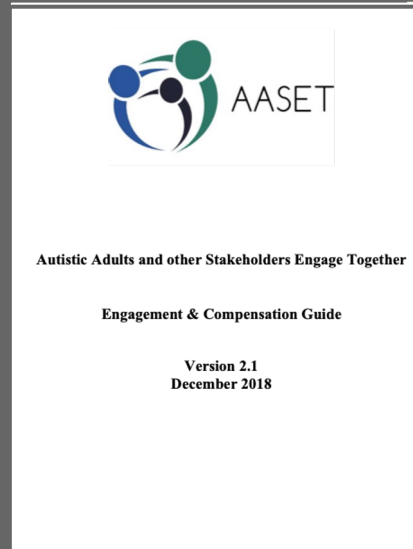


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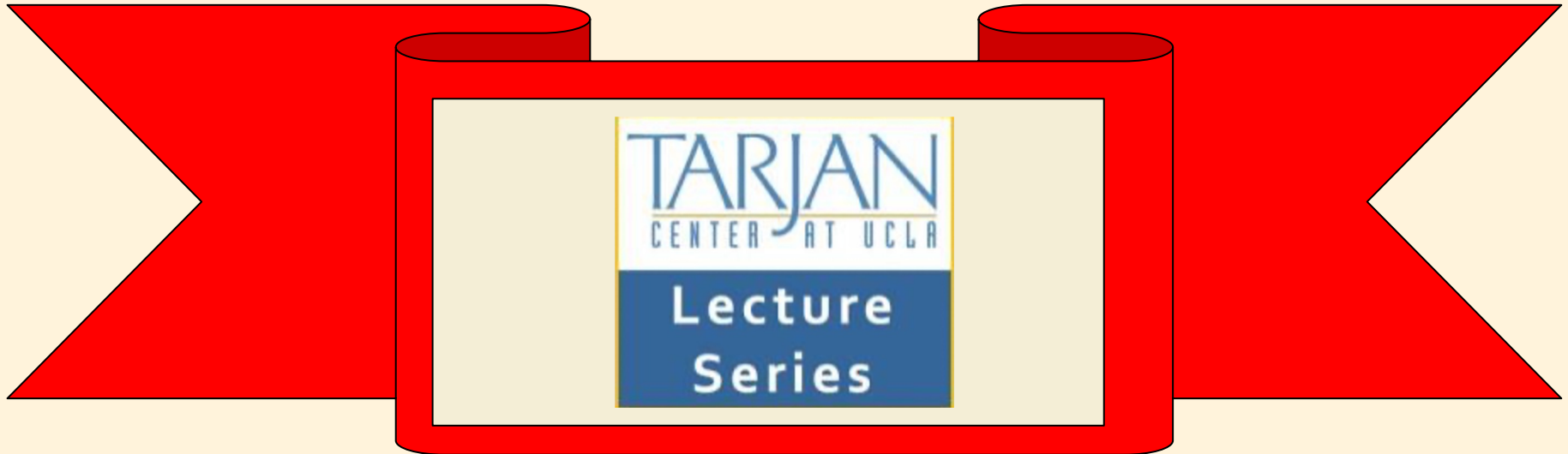


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Shore, S. & Benevides, T. (Editors) with authored contributions from Ashkenazy, E., Gravino, A., Lory, B., Morgan, L., Palmer, K., Purkis, J & Wittig, K. (2018). *Autistic Adults and other Stakeholders Engage Together: Engagement & compensation guide*.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

Thanks for your participation!

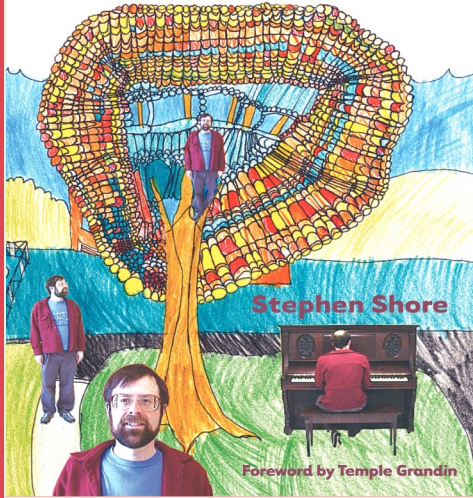


<https://www.pcori.org/research-results/2016/priority-setting-improve-health-outcomes-autistic-adults-and-other>

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Beyond the Wall

Personal Experiences with
Autism and Asperger Syndrome
SECOND EDITION



Stephen Shore

Foreword by Temple Grandin

破牆而出

我與自閉症、亞斯伯格症共處的日子

著者：史帝芬·蕭爾 (Stephen Shore)
譯者：丁凡

這座牆並沒有阻隔我與世界的溝通；
相反的，我努力突破生理障礙，終於可以與社會多一點
接觸。現在是我夢寐以求的橋樑，安全溫暖寬容的成員。
這堵巨型的牆，讓我踏上搜尋與對的感達
發掘出另一種存在……

Beyond the Wall
Personal Experiences with Autism and Asperger Syndrome

スティーブ・ショア
Stephen Shore

森由美子 [訳]

壁のむこうへ

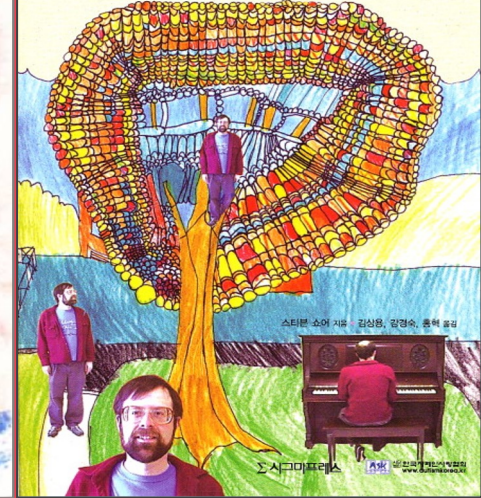
自閉症の私の人生

Beyond the Wall
Personal Experiences with Autism and Asperger Syndrome
(SECOND EDITION)

学研

벽을 넘어서

행복을 찾은 어느 자폐인의 이야기



스티븐 쇼어 지음 김성용, 김경숙, 홍혜 옮김

시크로마티스

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Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum

Foreword
Temple Grandin

Editor
Stephen M. Shore

Communicating
Through Advocacy
and Self-Disclosure:
Four Ways to Connect
Ruth Elaine Jordan-Harris

Help Me Help Myself:
Teaching and Learning
Katherine Sibley

Using the IEP to Build
Skills in Self-Advocacy
and Disclosure
Stephen M. Shore

Helping Over-Compliant
Clients
Roger N. Meyer

Building Alliances:
Community Identity and the Role
of Allies in Autistic Self-Advocacy
Phil Schwartz

Disclosure and Self-Advocacy:
An Open Door Policy
Liane Holiday Willey

"Brings unusual clarity to some of the most confusing issues
surrounding autism and its treatment." from the foreword by Temple Grandin, Author of Thinking in Pictures

Understanding Autism FOR DUMMIES

Stephen Shore, MA
Author of Beyond the Wall:
Personal Experiences with Autism
and Asperger Syndrome
Linda G. Rastelli, MA
Journalist and Editor

A Reference for the Rest of Us!

FREE eTips at
dummies.com

Living Along the Autism Spectrum

What Does It Mean
to Have Autism
or Asperger Syndrome?

Stephen Shore, Ed.D.
Federal Jacot, Ph.D.
(Foreword: Daniel Goleman, Ph.D.)

DVD

Ask and Tell • Self-Advocacy and Disclosure for People on the Autism Spectrum

自閉症スペクトラム 生き方ガイド

自己権利擁護と障害表明のすすめ

スティーブ・ショア 著 森由美子 訳 飛木穂積 監訳



Own Case
manager

Community
Identity

Opening
Door

クリエイティブ
かもめ