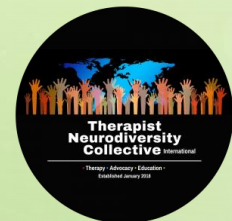


Webinar # 2R:

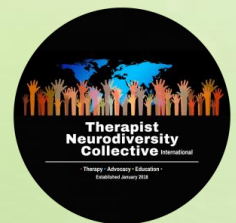
# How to involve neurodiversity in research: General models and approaches

## Project Comparative Autism Research Effectiveness (CARE)

This project is funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (Contract # EACB-25633).



# Who are we?



## Project CARE Project Lead and Co-Project Leads



Alejandro Brice, University of South Florida, Project Lead,  
[aebritce@usf.edu](mailto:aebritce@usf.edu)

PL Alejandro Brice is a Full Professor with over 35 years of clinical and research experience. Dr. Brice immigrated with his family from Cuba to the U.S. in 1960. In 2010, Alejandro sustained a subarachnoid hemorrhage (SAH- considered to be an acquired neurodivergence). As a result, he has been both a patient and person-centered outcome researcher. As a speech-language pathologist, he has worked extensively with culturally and linguistically diverse (CLD) populations with communication disorders and developmental disabilities. He was the PI for *PCORI BRIDGE Grant (EAIN-7111)*.

## Project CARE Project Lead and Co-Project Leads

D'Jaris Coles-White, Western Michigan University,  
Co-Project Lead, [djaris.coles-white@wmich.edu](mailto:djaris.coles-white@wmich.edu)



Co-PL D'Jaris Coles-White began her research investigating language in children from CLD backgrounds. Dr. Coles-White was involved in developing the *Diagnostic Evaluation of Language Variation (DELV)* (Seymour et al., 2018), designed to differentiate language differences from disorders from non-mainstream dialects. D'Jaris received a *Mentored Patient-Oriented Research Career Development Award* from NIH/NIDCD in 2001 aimed at pinpointing clinical markers for language difference from language disorder in diverse populations. Since 2005, and after the diagnosis of autism for two of her sons, Dr. Coles-White's clinical and research efforts have focused on social communication in the autistic population.

## Project CARE Project Lead and Co-Project Leads



Julie Roberts, Therapist Neurodiversity Collective,  
Co-Project Lead, [julie.roberts@therapistndc.org](mailto:julie.roberts@therapistndc.org)

Co-PL Julie Roberts, M.S., CCC-SLP, is a speech-language pathologist clinician with experience in various healthcare settings with pediatric and adult populations. Julie is a late diagnosed autistic. Ms. Roberts is currently CEO of *The Therapist Neurodiversity Collective (TNDC), an international neurodiversity-affirming therapy, education and advocacy organization*. TNDC supports individuals, clinicians, and parents who are autistic and neurodivergent. Ms. Roberts has held key healthcare leadership positions, including National Field Director of Corporate Compliance and also Multi-state Clinical Director for the nation's largest provider of rehabilitation post-acute care.

# PCORI

PCORI is the leading funder of patient-centered comparative clinical effectiveness research in the United States. From PCORI, they state the following:

- Patients deserve to know whether some approaches work better than others for certain populations, and caregivers, clinicians, and *all of our stakeholders also benefit from better information about different care options*. With health, information is power, and **PCORI funds research that allows all patients to become more empowered decision makers** [emphasis added].
- The vast majority of the research that PCORI funds is for Comparative Effectiveness Research (CER) projects, but we *also fund awards to promote engagement* in research, dissemination and implementation projects, methodology research, and the development of research infrastructure, including **PCORnet**<sup>®</sup>, the National Patient-Centered Clinical Research Network.
- The Patient-Centered Outcomes Research Institute (PCORI) is an independent, nonprofit research organization that **seeks to empower patients and others with actionable information about their health and healthcare choices** [emphasis added]. We fund comparative clinical effectiveness research (CER), which compares two or more medical treatments, services, or health practices to help patients and other stakeholders make better informed decisions.

Project **CARE** is an engagement award.

# PCORI

## Project CARE

The purpose of CARE is to connect autistics and caregivers, with researchers and clinicians to plan and evaluate comparative effectiveness research (CER).

- We will bring 50 autistics (with and without intellectual impairment), parents and family members and/or caregivers (person partners; neurodivergent and neurotypical) together with 25 researchers and clinicians (neurodivergent and neurotypical) to facilitate person-centered outcomes. In addition, to improve population health around a neurodiversity neurodivergent model of evidence-based research and practice (a first in US).
  - Teams will include autistics, family members and caregivers, autism researchers, and autism clinicians (neurodivergent and neurotypical).
  - Project CARE autism researchers and clinicians include autistics, and other neurodivergents.
- We will meet before, during, and after a complete online autism research conference. The conference is planned along with St. Petersburg College Collaborative Labs. SPC Collaborative Labs was instrumental with a previous PCORI Grant.

## **PCORI**

Project CARE will address the following Research Questions :

The CARE Project Research Questions follow those of Schaumberg et al. (2018):

1. Are the correct individuals (autistics) involved?
2. Are the appropriate supports utilized (neurodivergent appropriate) Do neurodivergents lead and guide practices?
3. Are the appropriate outcomes being studied?
4. Are the length and timing of the study appropriate?
5. Are the data sources appropriate?
6. Does comparative effectiveness research build on the data provided by evidence-based practice study designs (e.g., randomized clinical trials, pragmatic clinical research, and other relevant study designs) by evaluating clinical support in more diverse populations and in broader clinical contexts?
7. How are rigors of study methods established (i.e., Comparative Effectiveness Research, CER studies should employ designs that select new users, support and evaluate to a similar group using comparison methods)?



## **PCORI**

The three combined webinars (#1. How neurodiversity benefits research; #2. How to involve neurodiversity in research. # 3. Tools and strategies for autistics and family/caregivers) provide pre-conference information towards improving autism neurodivergent research and to be integrated as a whole.

Webinar #1/Researchers/Clinicians (R):

### **How neurodiversity benefits research:**

1. What is neurodiversity/neurodivergence in research?
2. What are the benefits of neurodiversity/neurodivergent involvement in research priorities?

At the end of this webinar, you will be able to:

- Discuss role expectations for autistics, parents, caregivers (a.k.a., person partners);
- Identify PEIR Conceptual Frameworks 3 Themes;
- Identify critical principles of plain language and neurodivergent appropriate communication;

# What do we know about including person partners into research?

Recent work has summarized knowledge from across multiple articles, presentations, chapters, and other sources to create a strong conceptual framework for engaging person partners into research.

# Meaningful Patient Engagement in Research (PEIR): A data-based conceptual framework (Hamilton et al., 2018)

- Qualitative secondary analysis of interview data of 18 experienced person partners
- Thematic analysis produced themes
- Content analysis from 18 empirical papers on person engagement in research confirmed, refuted, or supported themes
- Resulting conceptual framework is a data-based framework for person engagement in research (Hamilton et. al, 2018)

# Meaningful PEIR: Conceptual Framework Themes - 1 (Hamilton et al, 2018)

## Organizing Theme

- Procedural Requirements
- Convenience
- Contributions

## Examples

- Person partners clearly understand research
- Sufficient time; choices about how and when to engage
- Person partners want to provide their perspectives, and feel their contribution is “a good use” of their time.

# Meaningful PEIR: Conceptual Framework Themes - 2 (Hamilton et al, 2018)

## Organizing Theme

- Team Interaction
- Research Environment
- Support

## Examples

- Mutual respect and trust exists within the research team
- Person partners are treated as equal research partners
- Person partners receive adequate training and reimbursement for the project

# Meaningful PEIR: Conceptual Framework Themes - 3 (Hamilton et al, 2018)

## Organizing Theme

- Feel valued

- Benefits

## Examples

- Person partners' contributions are valued and acknowledged.
- Person partners see the benefit of their contributions.

# Role expectations: What can person-partners do?

(Wainer & Walton, 2022)

- Increase engagement with the autistic community
- Provide community involvement
- Address community concerns
- Act as cultural and community brokers
- Provide input on which topics or questions are most important to them
- Increase chances that research findings will be implemented in the “real world
- Increase relevance of research to stakeholders’ communities



# Role expectations: What can person-partners do?

- Can assist and create materials that explain your research in an understandable way (National Institute of Health Plain Language Initiative; clear concise, accurate word usage, communicating what the reader needs to know)
- Provide input on which outcome measures might be most meaningful to autistics
- Help shape research questions and ideas
- Can assist with the appropriate research design (e.g., measures, data collection procedures, etc.)
- Increase participation, buy-in from the community
- Decrease participant attrition (drop-out)
- Assist with missing data
- Increase quality and consistency (validity and reliability of data)

# Role expectations: What can person-partners do?

- Can assist to ensure that your recruitment materials and consent process are appropriate and effective (help translate into plain language, understandable language)
- Can assist to recruit
- Provide a different perspective on your data or results that you might choose to pursue
- Can provide input to your IRB application
- Can assist with qualitative data analysis and/or quantitative analysis (depending upon their knowledge base)
- Increase chances of being funded
- Listen to new perspectives

## AASPIR Practice based guidelines for the research team (Nicolaidis et al., 2019).

1. Be transparent about partnership goals;
2. Define partner roles; who needs to be included; who can make the project succeed;
3. Create a process for effective communication and power-sharing;
4. Use Plain language.

(<https://www.plainlanguage.gov/resources/checklists/checklist/>)

- Write to serve the reader's needs;
- Use headings;
- Use active voice; Use simplest tenses possible.;
- Omit excess words;
- Use shorter sentences;
- Use illustrations, lists, tables;
- Use concrete, familiar words;
- Use direct language, avoid ambiguous terms.

# Plain language

- NIH's Clear Communication program
  - Plain language
  - Cultural respect
  - Health literacy
- Clear & Simple is NIH's approach to developing easy-to-read written materials.

<https://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication>

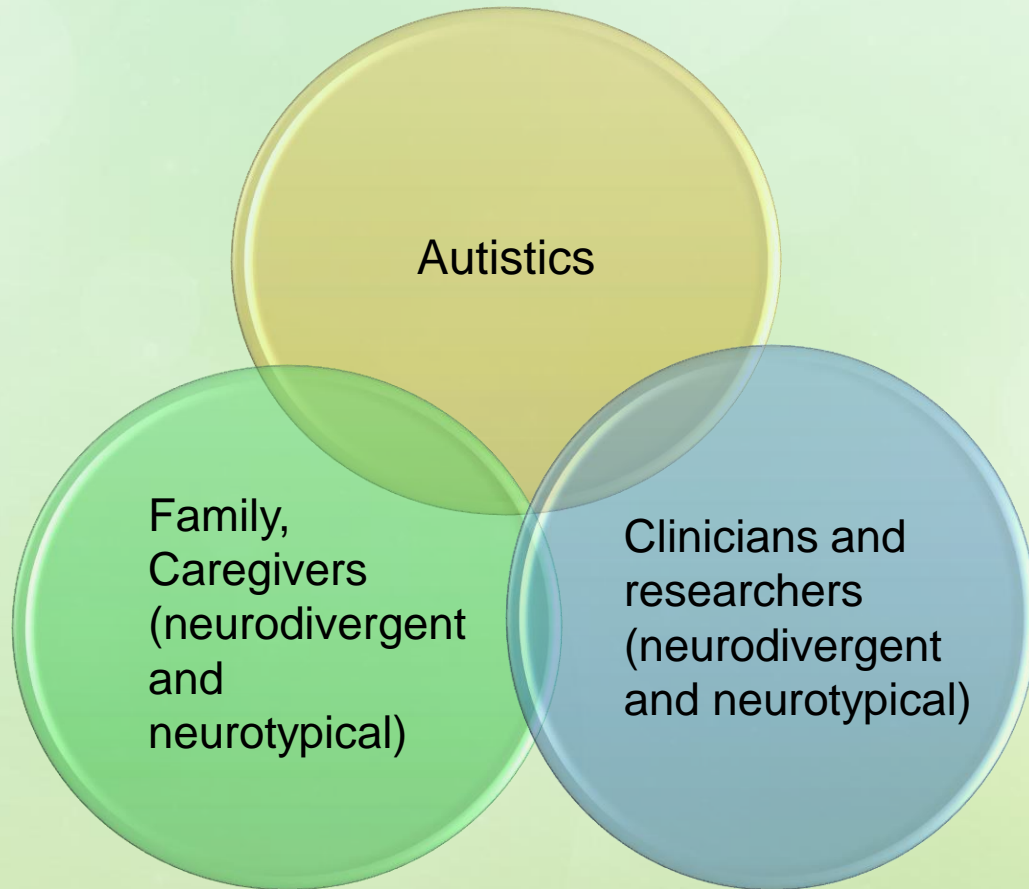
**Plain language examples** from the National Institutes of Health:

[https://grants.nih.gov/grants/plain\\_language\\_examples.htm](https://grants.nih.gov/grants/plain_language_examples.htm)

# Summary: Autistic Neurodivergent Appropriate Perspectives

- Presume competency and respect personal agency;
- Apply a strengths-based approach;
- Unrestricted alternative, augmentative communication (AAC) access;
- Every person is a human being with rights and dignity;
- Be respectful of autistic and neurodivergent differences sensory processing and other differences;
- Autism is not treated;
- Work to make sure individuals with disabilities can access what they need; providing supports, accommodations, and modifications;
- Speech-language therapy, occupational therapy, physical therapy, and/or other therapies should utilize a trauma-informed approach (Mendel, Sperlich & Fava, 2020).

# Mark your calendars for the CARE conference October 20 & 21, 2023



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