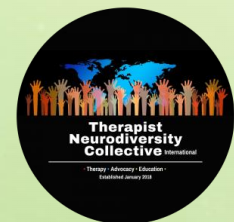


Webinar # 3R:

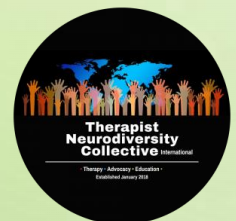
Tools and strategies for autistics and family/caregivers (monolingual, bilingual, bidialectal)

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,
aebrice@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



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

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**[®], 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)?

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

- Explore and discuss available materials that can help researchers support engagement of autistics who are culturally and linguistically diverse (CLD).

Multicultural Engagement

Banks (1989; 2009) proposes that multicultural engagement occurs when:

- (a) professionals use examples from other cultures and multiple perspectives;
- (b) professionals modify their pedagogy to facilitate learning to students from diverse groups;
- (c) professionals help students understand, investigate, determine, and use their voices in learning;
- (d) professionals accept all individuals; and,
- (e) professionals create a culture that empowers individuals from diverse backgrounds.

Multicultural Engagement

Learning to take a different perspective

Banks and Banks (1993) offer four levels of cultural engagement of material into curriculum. Here it is applied to research studies with neurodivergents, bilingual, and/or culturally and linguistically diverse (CLD) populations. Researchers need to investigate research through both a neurodivergent and multicultural focus.

1. The **Contributions Approach**. This approach focuses on surface aspects and incorporates only discrete elements (e.g., simply enrolling individuals who are neurodivergent, bilingual or CLD) into the study. The traditional study remains unchanged in structure, goals, and/or characteristics. The contributions approach is surface oriented and does not change the purpose of the study.

2. The **Additive Approach**. This approach adds content, concepts, themes from neurodivergent culturally and linguistically diverse groups.

Researchers may add a section to the study that focuses on a diverse group or specific topic.

The section is not the focus of the study but was just added on; this only adds a unit, a portion, or a section to the study.

A subgroup may be added to the study or additional analyses may be performed. The main focus remains unchanged.

3. The **Transformational Approach**. This approach offers to change the structure of the study and offer researchers the opportunity to view concepts, from a different cultural and/or linguistic perspective.

Culture is viewed not as how one group has contributed to the mainstream; however, rather on how each has contributed to the whole.

Different themes pervade the study. Bilingualism and neurodivergence drive the research design and the study.

Research is viewed from neurodivergent perspectives; research is not viewed just from neurotypical models.

4. The **Social Action Approach**. Research is viewed from neurodivergent perspectives; research is not viewed just from neurotypical models.

However, researchers take action to solve social problems.

Researchers' self examine and then take some action to solve some of society's dilemmas.

Becoming a research advocate is an example of the social action approach. Neurodivergent researchers drive research agendas.

5. ASAN (2022) in response to non-discrimination in health programs and activities stated that,

“It is essential that these services be provided in a comprehensive, non-discriminatory manner which facilitates our full, self-determined access to these aspects of our lives” (lines 24-26).

<https://autisticadvocacy.org/2022/10/asan-comments-on-section-1557/>

Culturally responsiveness from an autistic neurodivergent affirming perspective emphasizes the following:

1. Acceptance of differences among ethnic groups, individuals, and cultures as central to the human condition meaningful participatory experiences (Milton, 2012);
2. Accommodations, modifications, and supports in place (Brice & Miller, 2000; New Levine, 2009);
3. Respectful cultural responses that consider intersectionality (Cascio, Weiss, & Racine, 2021);
4. Multimodal communication choice, access, and agency (Doak 2018; 2019; Donaldson, et al., 2022; Zisk, et al.) including alternative augmentative communication (AAC) (Cage, Cranney, & Botha M 2022);

Culturally responsiveness from an autistic neurodivergent affirming perspective emphasizes the following:

5. Attempts at self-determination and self-advocacy are respected and responded to, regardless of form (Bascom, 2011);

6. Autism de-stigmatization interventions (Morris, Reilly & Nayyar 2021);

7. Fostering autistic identity and pride (Cascio, Weiss, & Racine, 2021);
and,

8. Autistic individuals have complex and fluctuating needs for levels of support that may not be immediately observable (Milton, 2012).

Neurodivergent resources

Resources to provide information that is neurodivergent appropriate

Research-specific resources

Neurodivergent Appropriate

- Neurodiversity & neurodivergent: Meanings, types, and examples. Provided by Exceptional Individuals (a neurodiverse recruitment service). This site provides definitions and examples of autism and other neurodivergent conditions.
<https://exceptionalindividuals.com/neurodiversity/>
- What is neurodiversity and why does it matter? A digital publication from the University of Washington School of Medicine
<https://rightasrain.uwmedicine.org/mind/mental-health/neurodiversity-or-neurodivergence>
- What is neurodiversity? Nicole Baumer & Julia, Frueh. Harvard Health Publishing, Harvard Medical School. Making workplaces neurodiverse friendly.
<https://www.health.harvard.edu/blog/what-is-neurodiversity-202111232645>

Neurodivergent resources

Resources to provide information that is neurodivergent-friendly

Research-specific resources

Neurodivergent-Friendly

- Around one in five people are neurodivergent. Provides programs, skills and experience to support neurodivergent students become work ready.

<https://www.neurodiversityhub.org>

- What does neurotypical, neurodivergent, and neurodiverse mean?

<https://www.medicalnewstoday.com/articles/what-does-neurotypical-mean#which-term-is-better>

- Neurodiversity and other conditions. Medical News Today. Neurotypical, neurodivergent, benefits of neurodiversity.

<https://adhdaware.org.uk/what-is-adhd/neurodiversity-and-other-conditions/>

Neurodivergent resources

Research-Specific Resources

The James Lind Alliance, a Priority Setting Partnership (UK) was initiated by Autistica (<https://www.autistica.org.uk/and>) aimed to work with all those who know and understand autism to identify the Top 10 priorities for research.

<https://www.jla.nihr.ac.uk/priority-setting-partnerships/autism/>

Neurodiverse/Neurodivergent Researchers

- Dr. Monique Botha, University of Stirling <https://www.moniquebotha.com/>
- Dr. Noah Sasson, University of Texas, Dallas <https://profiles.utdallas.edu/nsasson>
- Ari Ne'emann, Harvard University,
<https://healthpolicy.fas.harvard.edu/people/ari-neeman>
- Dr. Catherine Crompton, The University of Edinburgh,
<https://www.research.ed.ac.uk/en/persons/catherine-crompton>
- Dr. Laura DeThorne, Western Michigan University
<https://wmich.edu/speech-audiology/directory/dethorne>

Neurodivergent resources

Research-Specific Resources

Neurodiverse/Neurodivergent Researchers

- Dr. Alejandro Brice, University of South Florida, aebrice@usf.edu
<https://care.therapistndc.org/>
- Dr. D'Jaris Coles-White, Western Michigan University,
djaris.coles-white@wmich.edu , <https://care.therapistndc.org/>
- Julie Roberts, M.S., CCC-SLP, Therapist Neurodiversity Collective,
julie.roberts@therapistndc.org , <https://care.therapistndc.org/>
- Dr. Maria Resendiz, Texas State University, mr54@txstate.edu
- Dr. Siva Priya Santhanam, Bowling Green State University, sivaps@bgsu.edu
- Dr. Danai Kasambira Fannin, North Carolina Central University
dfannin@ncsu.edu,

Neurodivergent research resources

Research-Specific Resources

Neurodiverse/Neurodivergent Researchers

- Dr. Steven Kapp, University of Portsmouth

<https://researchportal.port.ac.uk/en/persons/steven-kapp>

- Dr. Damian Milton, University of Kent

<https://www.kent.ac.uk/social-policy-sociology-social-research/people/1419/milton-damian>

- Dr. Liz Pellicano, MacQuarie University

<https://researchers.mq.edu.au/en/persons/liz-pellicano/publications/>

- Dr. Kristen Bottema-Beutel, Boston College

<https://www.bc.edu/bc-web/schools/lynch-school/faculty-research/faculty-directory/kristen-bottema-beutel.html>

Neurodivergent resources

Research-Specific Resources

Neurodiverse/Neurodivergent Research Specific

- Stanford Medicine, Stanford Neurodiversity Project

<https://med.stanford.edu/neurodiversity.html>

- Eastern Carolina University Libraries Neurodiversity

<https://libguides.ecu.edu/Neurodiversity>

- Center for Neurodiversity, Landmark College

<https://www.landmark.edu/center-for-neurodiversity>

- Neurodiversity Education Resource Center and Arizona State University.
Education and workforce development for neurodivergents.

<https://neurodiversitycenter.org>

Bilingual, Bidialectal Resources

Medical Spanish

medicallspanish.com

Spanish Language Resources and the Denver Medical Society

<http://championline.org/tools-products/cross-disciplinary-resources/spanish-language-resources>

Medical Spanish podcasts

<https://docmolly.com/>

123 Teach Me. Free medical Spanish resources

https://www.123teachme.com/learn_spanish/medical-spanish

Practicing Spanish.com Medical Spanish

<http://www.practicingspanish.com/index.html>

Bilingual, Bidialectal Resources

- **ASHA Spanish**
<https://www.asha.org/public/espanol/>
- **Colorín Colorado.** A bilingual site for educators and families of English language learners.
<https://www.colorincolorado.org/resource-topic/bilingual-resources-spanish>
- **Online Resources for African American Language, University of Oregon**
<https://oraal.uoregon.edu/resources/educators>
- **The Smithsonian National Museum of the American Latino's bilingual materials.**
<https://latino.si.edu/learn/teaching-and-learning-resources/bilingual-materials>
- **Bilingual Learning, Southern California Public Radio**
<https://projects.scpr.org/bilingualllearning/>
- **Bilingualism Matters, Edinburgh, U.K.**
<https://www.bilingualism-matters.org>
- **The National Clearinghouse for English Language Acquisition**
<https://www.ncela.ed.gov>
- **Understanding Language, Stanford University**
<https://ul.stanford.edu>
- **African American English, PBS**
<https://www.pbs.org/speak/education/curriculum/high/aae/>

Neurodivergent Culturally and Linguistically Diverse Resources

Davis, R., Fletcher, S., & Digard, B. (2021). **Autistic people's access to bilingualism and additional language learning: Identifying the barriers and facilitators for equal opportunities.** *Frontiers in Psychology*, 22, 1-6. doi:

10.3389/fpsyg.2021.741182

<https://www.frontiersin.org/articles/10.3389/fpsyg.2021.741182/full>

Charting the impact of bilingualism for autistic children. The University of Edinburgh

<https://salvesen-research.ed.ac.uk/our-projects/bilingualism>

Developing bilingual autism education for SLPs to support Latinx families.

<https://leader.pubs.asha.org/do/10.1044/2021-0407-bilingual-autism-support-research/full/>

Schenker, M. (2021). **How and why to be a neurodiversity friendly SLP.**

<https://www.theinformedslp.com/review/how-and-why-to-be-a-neurodiversity-friendly-slp>

Neurodivergent Culturally and Linguistically Diverse Resources

Seach, D., Crawaford, J., Haynes, T., & Pullern, H. (n.d.). *An evidence based guide to autism and bilingualism*.

<https://schools.local-offer.org/wp-content/uploads/2022/03/An-Evidence-Based-Guide-to-Autism-and-Bilingualism.pdf>

Jones, D., Nicolaidis, C., Ellwood, L., Garcia, A., Johnson, K., Lopez, K., & Waisman, T. (2020). An expert discussion on structural racism in autism research and practice. *Autism in Adulthood*, 294, 273-281.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8992862/>

Neurodivergent Culturally and Linguistically Diverse Resources

Dr. Rachel Davis, Developmental psychologist focusing on autism, cognition and education

<https://rachael-davis.com/publications/>

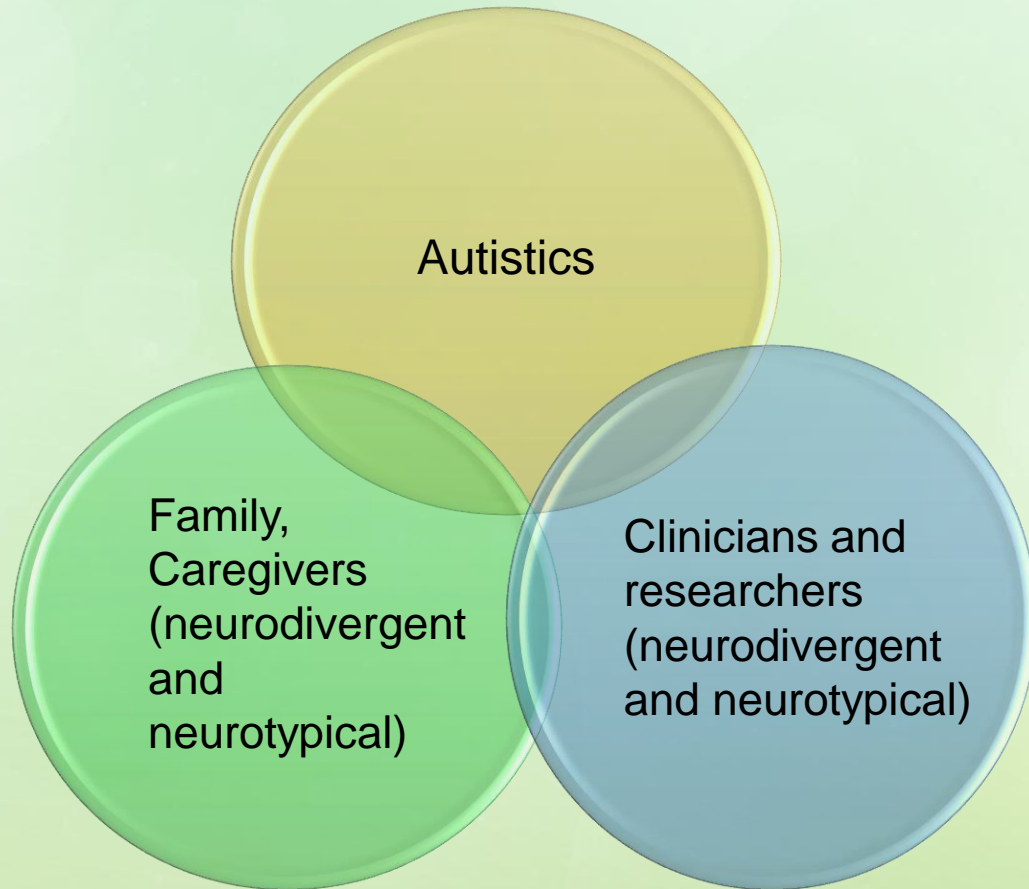
Publications include:

- Autism and bilingualism: A thematic analysis of practitioners' experiences.
- The languages that you know draw the boundary of your world: A thematic analysis of the experiences of autistic bilingual adults living in the United Kingdom.
- Why study bilingualism in autistic people.
- Autistic people's access to bilingualism and additional language learning: Identifying the barriers and facilitators for equal opportunities.
- Should we expect bilingualism to confer cognitive benefits in children with autism spectrum disorders?

Summary

- Gay (2013) referring to culturally responsive teaching states,
- “It is an equal educational opportunity initiative that accepts differences among ethnic groups, individuals, and cultures as normative to the human condition and valuable to societal and personal development” (p. 50).
- Autism is a disability and human variation.
- Autism is a fundamental core of the autistic individual. It is a part of the individual. Autism is fundamental to one’s culture and identity.
- Development for self-determined goals (Chapman & Botha, 2022).
- Engage autistic voices.

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



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<https://autisticadvocacy.org/2022/10/asan-comments-on-section-1557/>

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