



Autism Intervention Research Network on Physical Health (AIR-P)

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UCLA MEDICINE -PEDIATRICS
DIRECTOR, UC-LEND PROGRAM**

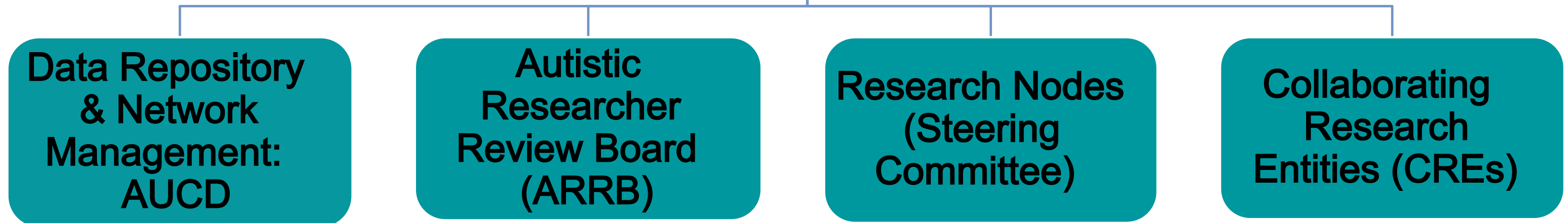


Overview

- The Autism Intervention Research Network (AIR -P) is funded by the Maternal and Child Health Bureau at HRSA.
- The purpose of AIR-P is to establish and maintain an interdisciplinary, multicenter research forum for scientific collaboration and infrastructure building.
- This Research Network will provide national leadership in research to advance the evidence base on effective interventions for autistic individuals and individuals with other developmental disabilities, with a focus on addressing physical health and wellbeing across the lifespan.



**National
Coordinating Center
(NCC):**
UCLA PI/PD: Kuo



- AIR-P Scholars program
- Autism and Physical Health research days at AUCD and CARES conferences
- Annual supplement in *Pediatrics*

Research Nodes

Primary Care and Health Care Services

Lead: Kuo

- Patient experience
- Access to care
- Health care quality
- Dental care
- Routine health maintenance

Community Based Lifestyle Interventions

Lead: Gragnani, Fernandes

- Sleep
- Physical Activity
- Nutrition
- Substance Use
- Stress Management
- Social connection

Gender, Sexual, and Reproductive Health

Leads: Croen, Massolo

- Sexual education
- Contraception
- STIs
- LGBTQ+ health
- Pregnancy
- Women's health

Health Care Transitions

Leads: Shea, Shattuck

- Emerging/young adulthood
- Care coordination
- Education & employment
- Medicaid and public benefits

Neurology

Lead: Wilson

- Managing neurological co-occurring conditions
- Seizure management
- Motor delays
- Behavioral neurology

Genetics

Lead: Martinez

- Genetic screening/counseling
- Rare/orphan diseases
- Family support
- Social networks

The AIR -P “Research Engine”

The Proposal Review



PROPOSAL CAN COME FROM ANYONE.

STEP
01

The Network



ANYONE WHO WANTS TO JOIN THE NETWORK IS WELCOME!

STEP
03

The Findings



PRESENT AND PUBLISH.

STEP
05

The Package



NCC HELPS CREATE THE "RESEARCH PACKAGE" TO DISSEMINATE.

The Analysis



MULTI-SITE DATA DOWNLOAD.



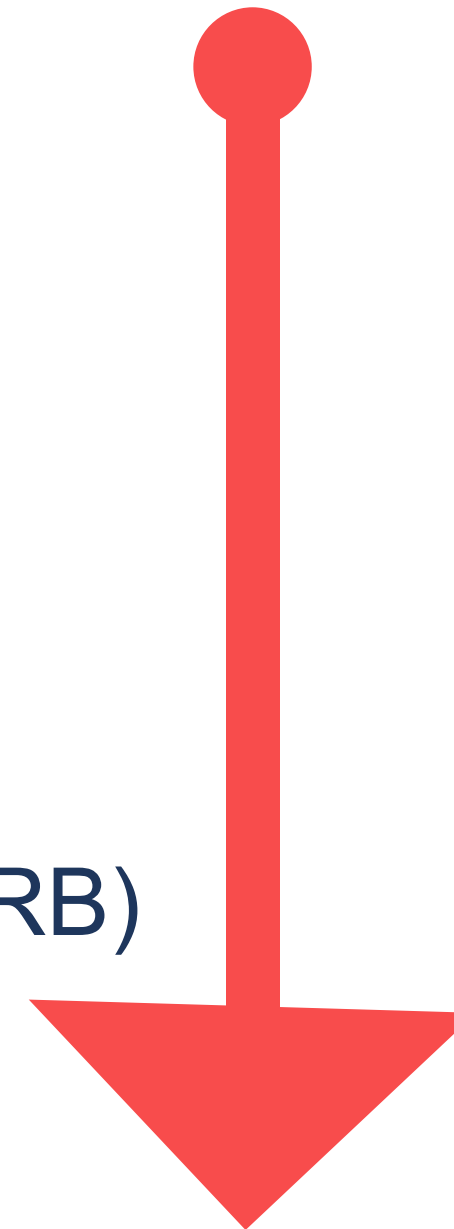
The Proposal Review

STEP
01

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- Administrative Review by the **National Coordinating Center** (NCC)
- Content Review by the **Steering Committee** (Research Nodes)
- Final Review by the **Autistic Researchers Review Board** (ARRB)



STEP 02

The Package

NCC HELPS CREATE THE "RESEARCH PACKAGE" TO DISSEMINATE.



PACKAGE INCLUDES:

- IRB Template
- Research protocol with scripts
- Templates for informed consent
- Specific methods for data collection and entry

The Network

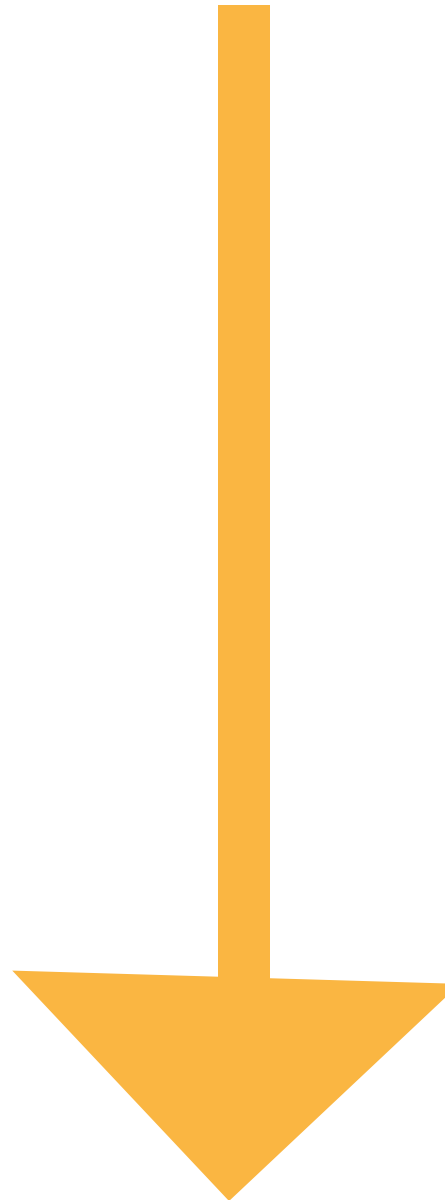
ANYONE WHO WANTS TO JOIN
THE NETWORK IS WELCOME!

- "Research Package" is loaded onto online platform
- AUCD disseminates info to network and collects data

NETWORK INCLUDES:

- 15 "official" CREs
- All entities in AUCD network (133 university -based programs)

STEP
03



STEP
04

The Analysis

DATA FROM ALL SITES ARE COMBINED.



- Multi -site data download
- Investigators analyze data
- Assistance from NCC, as needed

The Findings

PRESENT AND PUBLISH

- Findings presented at **AIR-P Research Days**
- Findings published in **AIR-P Annual Supplement**

OTHER MEETINGS:

- **CARES** annual meeting (Jul)
- **AUCD** annual meeting (Nov/Dec)

STEP
05



The AIR-P "Research Engine"

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Anyone can join the research network!

- We are especially interested in supporting doctoral students, post-doctoral fellows, junior faculty, and new investigators.
- People with lived experiences are encouraged to join.



JACKIE RYAN, MA, CPA, CMA

**AUTISTIC PHD CANDIDATE IN
REHABILITATION SCIENCE AT
THE UNIVERSITY OF ALBERTA**



PATRICK DWYER, MA

**AUTISTIC PHD CANDIDATE IN
PSYCHOLOGY AT THE UNIVERSITY
OF CALIFORNIA DAVIS**

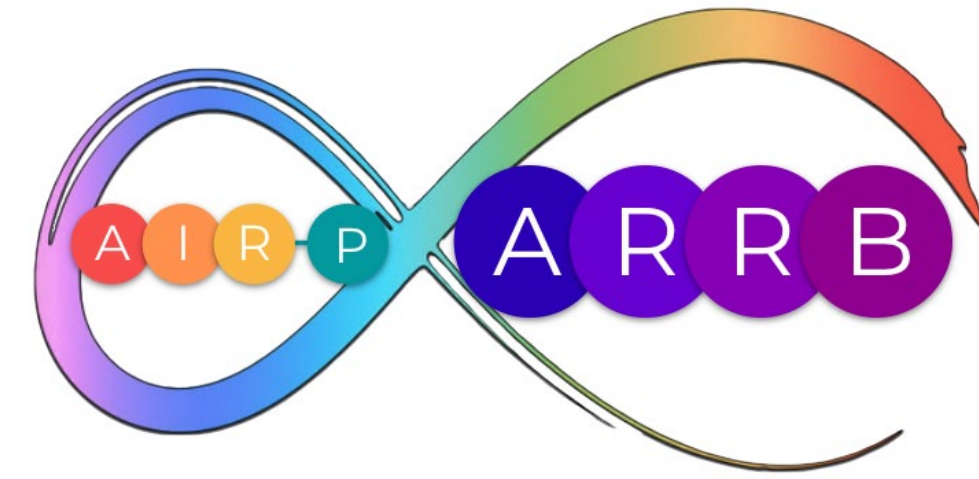
INTRODUCING





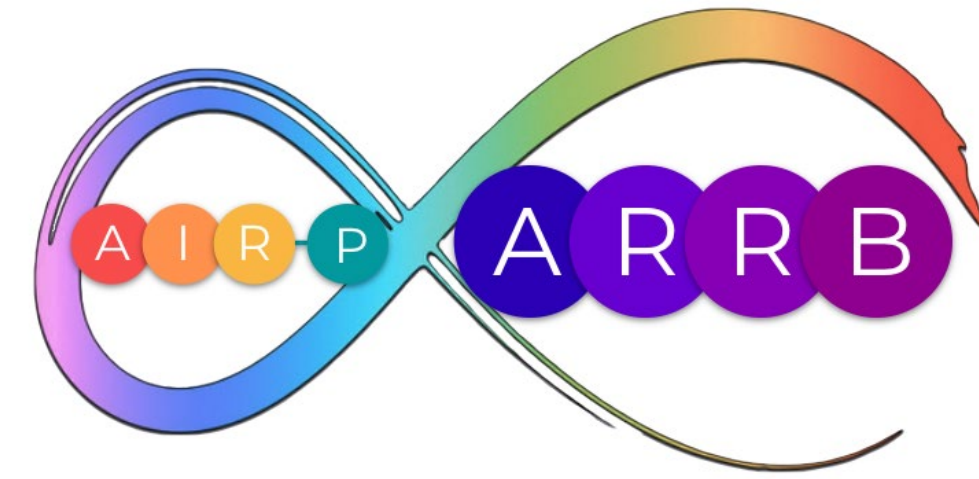
Presented by Jackie Ryan and Patrick Dwyer on behalf of:
Heather Brown, Dena Gassner, Steven K. Kapp,
Ari Ne'em an, TC Waism an, and Zachary J. William s

Who are we?



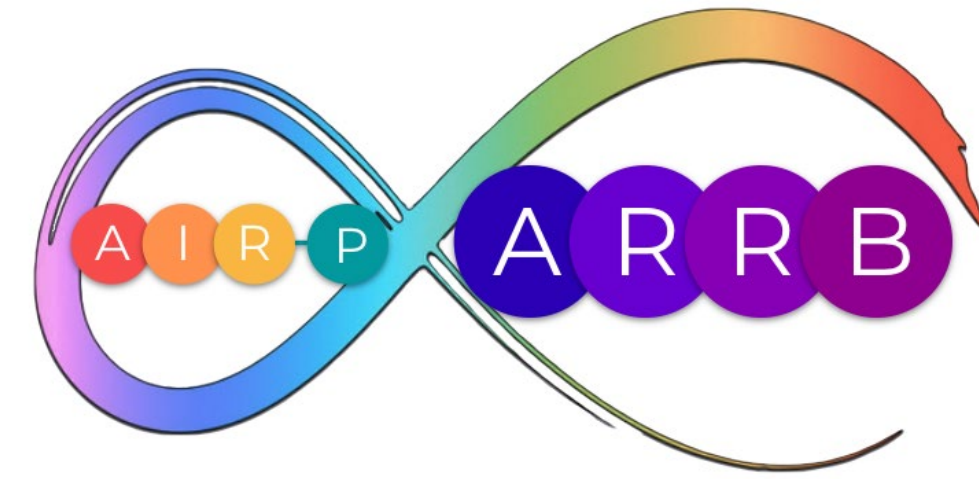
- Autistic autism researchers
- Various points in careers (grad students, lecturers/faculty, consultants)
- Combining perspectives from being researchers, from having lived experience, and from being part of the autistic community
- Helpful combination for reviewing research proposals
 - But does make us privileged and non-representative of all autistic people
 - (This is one reason we want to encourage collaborations between AIR-P sites & projects and community stakeholders - more on that later)

Neurodiversity



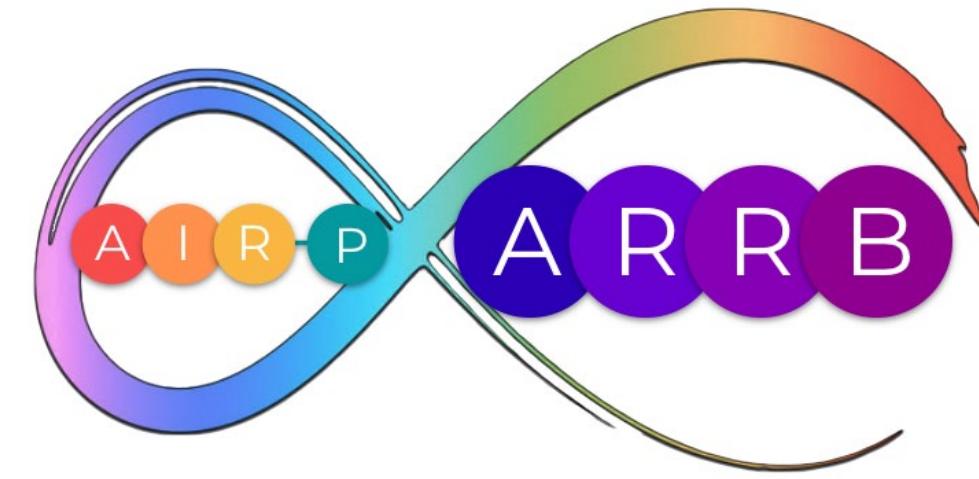
- Descriptively, means all minds/brains are different
- Prescriptively, refers to a political movement opposing cures/normalization for autism, instead advocating for acceptance, supports, respect for autistic people's own goals and objectives, and promotion of well-being/quality of life
 - Not just about autism - the neurodiversity movement also includes ADHD, learning disabilities, and many other neuro-minorities
 - The neurodiversity movement does accept teaching of adaptive skills
 - The neurodiversity movement does accept taking a medical, cure-oriented approach to co-occurring medical problems (e.g., epilepsy)

Well -Being



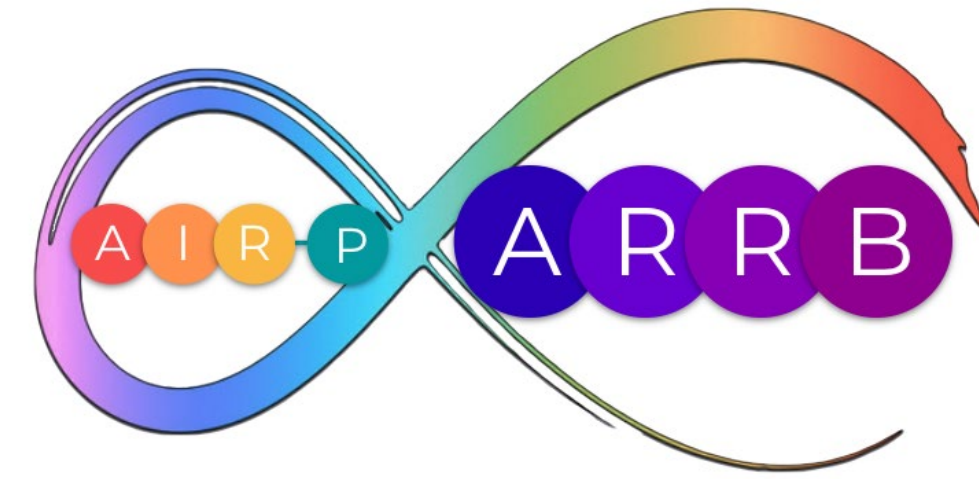
- PERMA Model, Five Pillars of Well -Being (Seligman, 2011):
 - Positive Emotions - subjective well -being
 - Engagement - flow states (relevant to autistic hyper -focus, intense interests)
 - Positive Relationships - social connectedness (note: autistic individual's goals may differ from neurotypical norms)
 - Meaning - sense that one's life has direction, purpose, and value
 - Accomplishment - feelings of competence, mastery
- The ARRB will use this framework to determine if proposed projects have potential to improve autistic people's well -being

Research Priorities



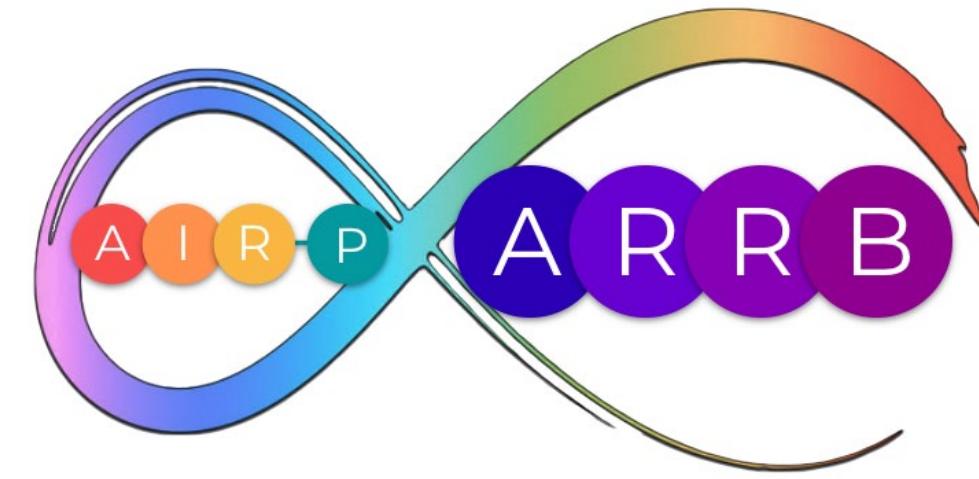
- Intersectionality
- Adults and aging
- Provider and system barriers to accessing medical care, including how autistic communication differences, interoceptive difficulties, etc., could lead to barriers in context of standard assessments and treatments
- Moving beyond description of patterns of co-occurrences and towards understanding of mechanisms at patient, provider, system, and population levels

Our Primary Goals



- 1) To use our dual perspectives as researchers and autistics to guide AIR -P research towards promoting autistic people's health & well-being
- 2) To promote an evidence base that is scientifically rigorous, inclusive of heterogeneous populations with intersectional identities, and sensitive to community needs
- 3) To inspire other research networks and organizations to use innovative models to increase autistic collaboration in all stages of research from conceptualization to dissemination

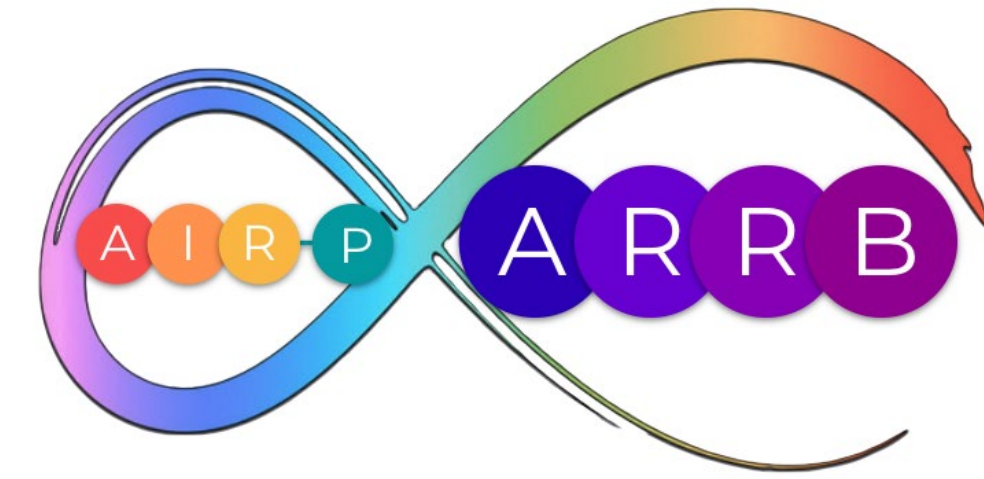
Our Primary Goals (cont'd)



4) To ensure that results of AIR -P research are communicated respectfully and in a manner that is accessible to autistic people and other stakeholders

- Consider additional media and formats such as lay summaries (see the ones in *Autism in Adulthood*), video presentations, video discussions/interviews
- Respect guidelines and autistic opinions about appropriate language such as Bottema -Beutel et al., 2020; Bury et al., 2020; Kenny et al., 2016
 - Not all autistic people agree about everything, but show our community you are making serious effort to be respectful and sensitive
 - Remember, the pathology language we use - deficit, disorder, etc. - is highly subjective and unscientific!

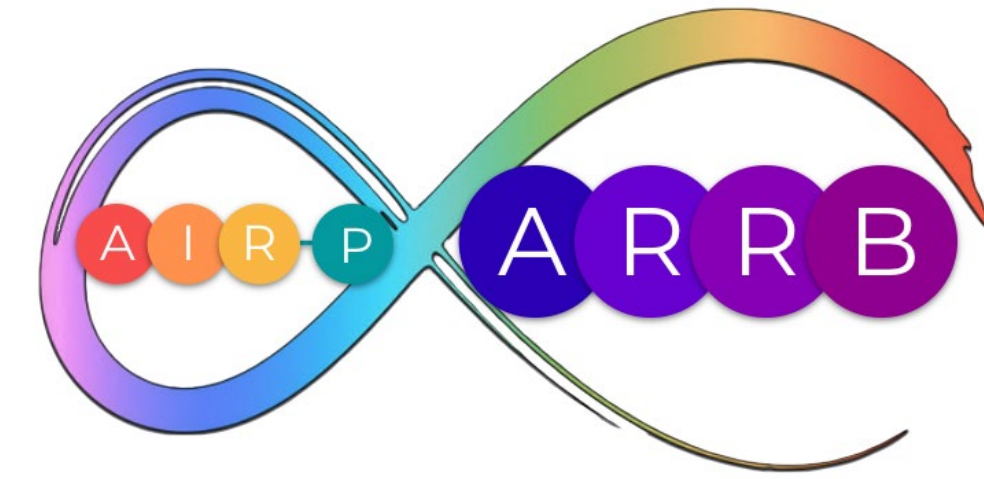
Our Primary Goals (cont'd)



5) To foster collaborations between AIR -P sites & projects and autistic people, caregivers, other community stakeholders

- Research shows information/training interventions are more effective when they are developed in participatory manner - in collaboration with communities - than otherwise (Gillespie-Lynch et al., 2021)

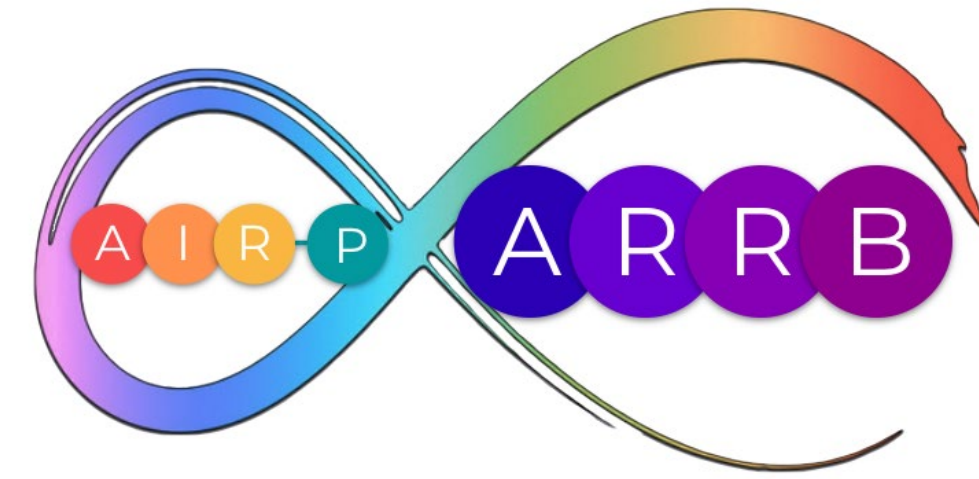
Our Primary Goals (cont'd)



5) Collaboration (cont'd)

- Community-based participatory research (CBPR) - community collaborators are equal partners from very beginning (when project is developed/conceptualized) to end (when findings published)
- Stakeholder engagement, community advisory boards, etc.

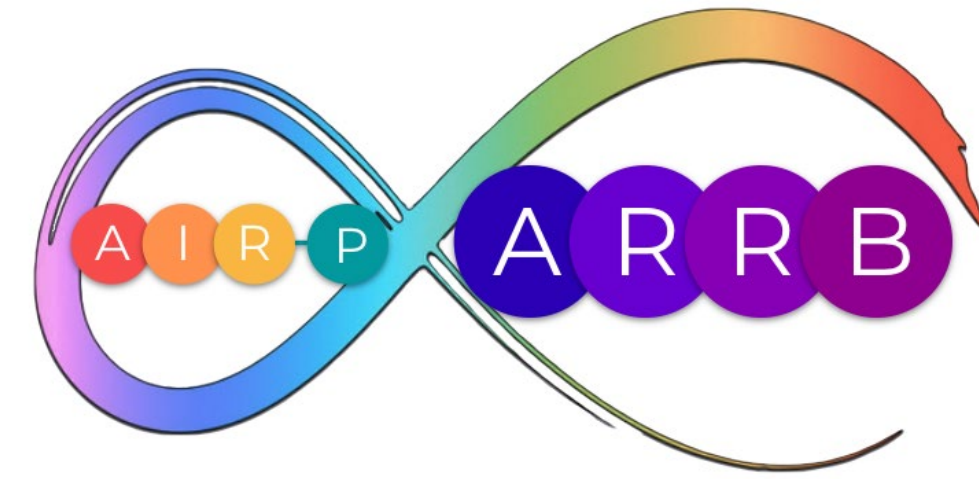
Our Primary Goals (cont'd)



5) Collaborations (cont'd): Some guidelines from Nicolaidis et al., 2019

- Consider compensation: financial, authorships, etc.
- Consider accessibility: multiple modalities for participation (verbal, text), clarity of communication, decision-making processes, etc. Assess needs.
- Consider trust:
 - Be aware of skepticism of communities towards research, and actively work to promote and maintain trust
- Don't pathologize collaborators in event of disagreement or problems

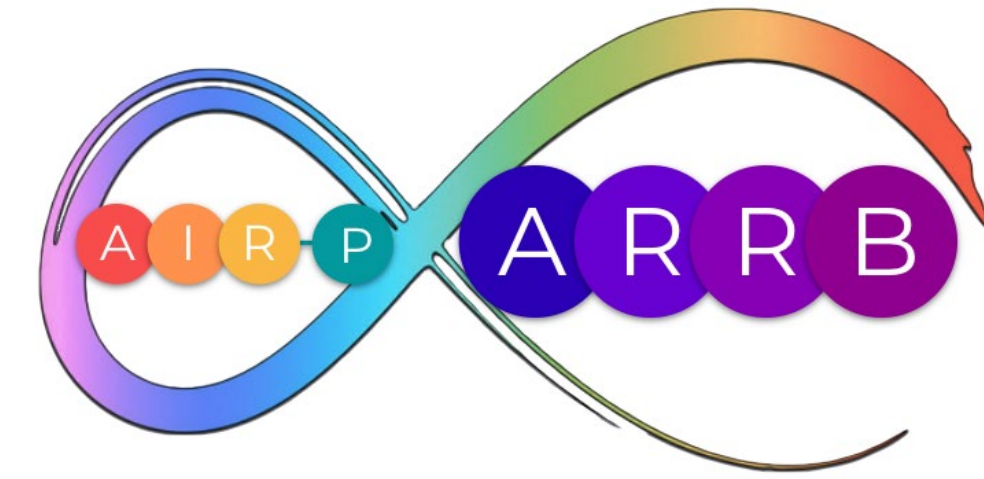
Our Primary Goals (cont'd)



5) Collaborations (cont'd) Representation considerations:

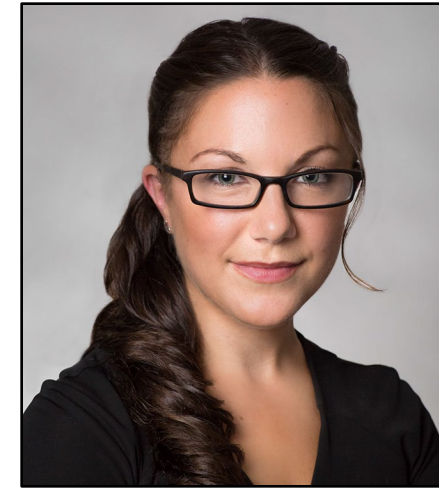
- Different types of lived experience - like content expertise
- Intersectionality
- Nonspeaking people who don't communicate fluently - are they best represented by their caregivers or by nonspeaking people who do communicate fluently? Or can they represent themselves using novel methods, such as photovoice, arts-based methods, Deep Assessment?
- Autistic children - are they best represented by their caregivers or by autistic adults? Or can they represent themselves using novel methods?

To Conclude



- We are excited by the innovative approach taken by the AIR synthesis of neurodiversity perspective and promotion of well medical approaches to co -occurring medical problems -P, trailblazing the -being with
- We are encouraged by the manner in which AIR -P has taken steps to include the autistic community in research
- We look forward to working with AIR -P sites and projects to promote research that is scientifically rigorous, clinically applicable, inclusive of heterogeneous populations, and driven by community priorities, with specific emphasis on the notion that such research will ultimately improve the health and well -being of autistic people

EMILY HOTEZ, PhD



**ASSISTANT PROFESSOR, UCLA
DEPARTMENT OF MEDICINE
PROJECT SCIENTIST, AIR-P**



AIR-P Scholars Program

- The Autism Intervention Research Network on Physical Health(AIR -P) will support an **AIR-P Scholars Program** beginning in 2021.
- **Goals/Objectives**
 - To launch the next generation of researchers seeking to promote the health and well -being of autistic individuals across the lifespan:
 - To provide pilot and feasibility funding for research projects;
 - To provide opportunities for mentorship, training, and professional development; and
 - To facilitate Network collaboration.

AIR-P Scholars Program

- **Eligibility**

- Early investigators (e.g., doctoral students, post-doctoral fellows, & early career faculty)
- Any investigator interested in transitioning into research in autism/physical health

AIR-P Scholars Program

- **Research Support**
 - One -year pilot and feasibility funding of up to \$25k
- **Mentorship and Training**
 - Applicants will apply with their faculty mentor, who will agree to provide mentorship/guidance for their project.
 - All Mentors will meet 2x/year with the AIR -P Steering Committee to brainstorm opportunities to facilitate the continued development of the Scholars
- **Opportunities for Publishing and Presenting**
 - All Scholars will present their findings at Research Days, contribute to AIR -P Supplements in Pediatrics, and engage in other Network activities.

Example Application Criteria

Significance/Merit

- Does the research have significant potential to address a gap in knowledge in autism/physical health?
- Does the proposed research align with the goals of the AIR -P/ARRB ?

Methodology/Approach

- Is the project likely to be accomplished in 12 months?
- Are the study concept and design appropriate for a pilot/feasibility study?

Investigator Qualifications

- Are the PI and other key personnel adequately trained and qualified to carry out the project?
- Is there an appropriate plan for supervision from the mentor ?

Application Timeline

RFP

January
2021

Application
Due

March
2021

NCC, ARRB,
and
Steering
Committee
Review

May
2021

Funding
Notification

June
2021

Start of
Funding

September
2021



Contact Us: airp@mednet.ucla.edu

[Feedback Survey:](#)



Thank you!



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[Feedback Survey:](#)

