AIR-P LEND Seminar Series

Health Systems and Services Research Node

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Learning Objectives

- Summarize the Autism Intervention Research on Physical Health (AIR-P) Program Health Systems and Services Node

- Identify a systems-level strategy that could improve care coordination and/or transition services

- Explain the current research agenda for the Health Systems and Services Node

Alice Kuo, MD, PhD, MBA
Principal Investigator

Autism Intervention Research Network on Physical Health

There are six primary research areas called "nodes" led by known researchers in the field:

1. Primary Care Services and Quality
2. Gender, Sexuality, and Reproductive Health
3. Neurology
4. Community based Lifestyle Interventions
5. Health Systems and Services, and
6. Genetics

Autism Intervention Research
Network on Physical Health

The AIR-P provides a **forum for scientific collaboration** and an infrastructure to **increase the life expectancy** and **quality of life** for autistic individuals, particularly for underserved and vulnerable populations.

The purpose of the AIR-P is to support innovative **life course intervention research** that promotes optimal health and well-being of autistic individuals across the lifespan.

AUCD (the Association of University Centers on Disabilities) serves a key role in managing the overall functioning of the AIR-P Network.

With AUCD's network of 143 interdisciplinary centers that bring together both university and community resources to achieve meaningful change, the AIR-P Network is poised to be highly successful in this partnership, delivering stakeholder-driven research and health promotion to autistic individuals and their families.

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The network of researchers also includes 15 **Coordinating Research Entities** (CREs), all of which have LEND programs.

The Health Systems and Services Research Node is represented by the **JFK Partners at the University of Colorado School of Medicine**, which have LEND, UCEDD, and DBP programs.

Health Systems and Services Research Node:

General Overview

Autism Intervention Research
Network on Physical Health

Autistic individuals and their families characterize their experiences as a **"lifetime of difficult transitions"** due to a limited number of service providers and resources.

Population **outcomes** among young adults on the autism spectrum are **poor** across indicators of physical health, mental health, employment, postsecondary education, community participation, independence, financial security, and **access** to needed community services.

Autism Intervention Research Network on Physical Health

Systems-level strategies for improving policy and program performance are needed among **care coordination** and **service models**.

Specific research priorities include:

- supporting health care **navigation** and models of **transition** practices
- training **primary care** providers in the adult health system, and
- educating individuals and families about **transition care**.

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For LEND trainees, the focus of this research node is more on systems and policy at the **community-based levels** rather than on individual levels such as individual assessments and services.

Health Systems and Services Research Node:

Gaps in the Research

Autism Intervention Research Network on Physical Health

The Health Systems and Services Research Node has been addressing research gaps to:

1. Improve **systems navigation** supports and opportunities for autistic youth
   a. Explore **emerging navigator** models (including peer-based navigation)
   b. Expand **existing modules** for health care navigation and skill development
   c. Use social network analysis for **measuring care coordination**

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The Health Systems and Services Research Node has been addressing research gaps to:

2. Inform **improved access** to healthcare
   a. Medicaid enrollment and service use
   b. National, population level data
   c. Policy impact and catered dissemination strategies

Autism Intervention Research
Network on Physical Health

The Health Systems and Services Research Node has been addressing research gaps to:

3. Identify **transition-specific** health care needs
   a. Emerging Conditions – at different ages of transition
   b. Supports across the Life Course
   c. Service delivery and health risk assessment models (screening tool)

Autism Intervention Research Network on Physical Health

The top three activities identified for the Health Systems and Services node included:

1. **health care navigation** for adolescents and adults and models of effective **transition practices**

2. **training primary care providers** in the adult health care system to serve autistic individuals and

3. **educating families and individuals** about transitions and adult care

Health Systems and Services Research Node:

Panel Discussion

Health Systems and Services Research Node:

Wrap-Up

Connect with folks from this seminar!

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