AIR-P LEND Seminar Series:
Health Systems and Services

Purpose: This document corresponds with the Health Systems and Services video in the AIR-P LEND Seminar Series. It outlines the video's content and provides suggestions on how to use this resource.

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Research Node: Health Systems and Services

Summary: This video provides an overview of systems-level strategies being used to improve health outcomes for autistic youth and adults during, with the emphasis on care coordination and transitions.

Learning objectives:
- Summarize the Autism Intervention Research on Physical Health (AIR-P) Program.
- 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.

Outline:

Section of Video	Content Outline & Talking Points	Presenter(s)	Time allotted*

General Overview	1. Welcome
	2. Context
	    a. Give context on AIR-P.
	        i. Autism Intervention Research Network on Physical Health | AIR-P Network (ucla.edu)
	        ii. AUCD - Autism Intervention Research Network on Physical Health (AIR-P)
	        iii. Network of researchers
	
	The Autism Intervention Research Network on Physical Health, known as the AIR-P, is a project that establishes and maintains an interdisciplinary, multicenter research network. It is supported by the Health Resources and Services Administration (HRSA).
	
	The National Coordinating Center is located at the University of California Los Angeles and is led by Principal Investigator of the AIR-P, Dr. Alice Kuo.
	
	There are six primary research areas called "nodes" led by known researchers in the field:
		Presenter (Node Leaders):
		Lindsey Shea, DrPH, MS
			2-5 min

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

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.

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 in Colorado, which ha LEND, UCEDD, and DBP programs.

   a. Describe the video's topic. "This video will focus on AIR-P's Research Health Systems and Services Research Node."

   b. Overview of Node
      i. Describe the Health Systems and Services research node area

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. 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. 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.		

How is AIR-P addressing research gaps in this node?	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
	
	2. Inform improved access to healthcare
	  a. Medicaid enrollment and service use
	  b. National, population level data
	  c. Policy impact and catered dissemination strategies
	
	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)
	
	In the March 2022 Pediatrics Supplement, Dr. Alice Kuo, Director of AIR-P, described the prioritization of research agendas for each node.
		<u>Presenter (Node leader):</u>
		Lindsey Shea, DrPH, MS
			3-5 min

	Transitions and care coordination for autistic individuals were ranked by urgency of need, significance of research impact, and/or focus on person or family centeredness. 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		
Panel Discussion	**Questions for Panel:** **Panelist: TJ Gordon Jr. – Self-Advocate** Can you tell us about yourself and your lived experiences with navigating the different service systems to get resources you needed. Please also let us know about your experiences with coordination of your care. Have you been able to find the services you need and access them through your insurance coverage? **Possible Talking Points for Sandy:** The National Autism Indicator Reports found that, black, indigenous, people of color children with autism had lower levels of access to a usual source of care than white children with autism. Were you aware of this difference? How did it affect your services and care? How involved were your parents in your care coordination when you were younger? **Panelist: Kristen Kaiser - Parent/Caregiver** Did you understand your role as a parent in facilitating transitions for your autistic children? What roles did you take on? Did you receive education about transitions and adult care? If not, what do you wish you knew now that you didn't know then? **Possible Talking Points for Sandy:** I know you run a support group for parents of autistic children and youth. Can you please describe some of the most common themes in your group discussion?	Facilitator CRE lead: **Sandra Friedman, MD, MPH** Professor of Pediatrics, University of Colorado School of Medicine CRE co-lead: **Dina Johnson, MA** Co-Director of Interdisciplinary Training and Dissemination Director, JFK Partners Panel (self-advocate/lived experience, caregiver experience, professional experience/node leader): **Timotheus "T.J." Gordon Jr.,** Research Associate, Institute on Disability and Human Development, University of Illinois Chicago **Kristen Kaiser, MA, MPH**, Family Faculty, JFK Partners, University of Colorado School of Medicine **Node Leaders:** **Lindsay Shea, DrPH, MS**, Director of the Policy and Analytics Center at the A.J. Drexel Autism Institute	25-35 min

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Panelist: Lindsay Shea, DrPH, MS, Node Leader
As the Project Director for one of the HRSA-funded Autism Transitions Research Projects, can you share about the <u>models of transition</u> practices you have identified as effective?

Can you describe a <u>health care navigation system</u> for adolescents and adults that has been shown to be very effective?

Possible Talking Points for Sandy:
Have you seen these models interact with the healthcare system? If not, do you envision how that would be possible?

Panelist: Lindsay Shea, DrPH, MS, Node Leader
Can you share your experience with measuring the effectiveness of care coordination?

Are there promising new <u>systems of care</u> that you believe will be implemented soon to improve the quality of life for autistic adolescents and adults?

Possible Talking Points for Sandy:
Who do you consider to be key stakeholders in the development and implementation of different models of care coordination?

Closing Summary

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Tips to Use this Resource:

- Discuss the **Services Cliff** that takes place in young adulthood. See page 25.
  https://drexel.edu/~/media/Files/autismoutcomes/publications/National%20Autism%20Indicators%20Report%20-%20July%202015.ashx
- Review the **Adolescent-to-Adult Transition for Youth with I/DD** Module from the ITAC Cultural Crossroads in Disabilities to hear an interview with a Spanish-speaking mother speaks about her non-speaking daughter as she transitioned to adulthood. Video Discussion Questions and Facilitator Talking Points
- Recruit a local content expert to be present when you expect to review this video. This local content expert may help facilitate your seminar and address how the topic can be applied locally at your LEND. Schedule them now to be sure they are available to attend your seminar!

Sample discussion questions:

1. What is the "Service Cliff" that happens once youth transition into adulthood and how does it affect youth and their family?
2. What conversations can you have with transitioning youth and their families to help them navigate the "Service Cliff" time in their lives?
3. What changes need to happen in the healthcare system so that people like the Self-Advocate T.J. in this video can feel heard and have his needs met in his doctor's appointments?
4. How is transition to adult services different for diverse individuals with disabilities and what needs to change to make services more equitable?