

AIR-P LEND Seminar Series: Primary Care Services and Quality

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

Research Node: Primary Care Services and Quality

Summary: In this video, the AIR-P Primary Care Services and Quality Research Node leader will discuss topics related to primary care and autism, including: (1) barriers to accessing primary care and other health care settings (2) the need for and strategies to make our health care settings more inclusive; (3) and the current research topics within the AIR-P Primary Care node.

Learning objectives:

- To review the need for all health care settings to be “Autism Friendly” while serving individual and family needs from early childhood through the life span (based on autism prevalence 1 in 44 ratio)
- To explore strategies to make our healthcare settings more inclusive (with input from individuals with autism spectrum disorder (ASD)/parents of individuals with ASD)
- To learn about current research topics within the AIR-P primary care node (eg managing needle anxiety and addressing health care needs non-traumatically)

Outline:

Section of Video	Content Outline & Talking Points	Presenter(s)	Time allotted*
General Overview	<ol style="list-style-type: none"> 1. Welcome 2. Context <ol style="list-style-type: none"> a. Overview of Node <ol style="list-style-type: none"> i. Mission of the node ii. “The overall goals of the Primary Care Services and Quality research node are to increase life span and maximize quality of life. In order to attain these goals, primary care for autistic adults needs to improve.” 3. Learning objectives (also above) <ol style="list-style-type: none"> a. To review the need for all health care settings to be “Autism Friendly” while serving individual and family needs from early childhood through the life span (based on autism prevalence of 1 in 44 ratio) 	<p><u>Presenter (Node leader):</u></p> <p>Dr. Alice Kuo, MD, PhD, MBA University of California Los Angeles, AIR-P Principal Investigator and Primary Care Services And Quality Node Leader</p> <p>Kristen Choi, PhD, MS, RN, University of California Los Angeles, AIR-P Node Leader Primary Care Services And Quality</p>	2-5 min

	<ul style="list-style-type: none"> b. To explore strategies to make our healthcare settings more inclusive (with input from individuals with autism spectrum disorder (ASD)/parents of individuals with ASD) c. To learn about current research topics within the AIR-P primary care node (eg managing needle anxiety and addressing health care needs non-traumatically) 		
Context	<ul style="list-style-type: none"> 1. Lived Experience and Parent Experience <ul style="list-style-type: none"> a. Helen Rottier to speak about her own experience accessing primary care as an Autistic Individual 2. Focus on medical phobia and the need for primary care when she broke her ankle. <ul style="list-style-type: none"> a. Vanessa Gonzalez to speak about her own experience accessing primary care for her children. 	<p><u>Presenters:</u></p> <p>Helen Rottier, MS (she/her/hers) University of Illinois Chicago PhD Candidate, Disability Studies</p> <p>Vanessa Gonzalez, Parent Advocate</p>	5 mins
Panel Discussion	<ul style="list-style-type: none"> 1. Introductions <ul style="list-style-type: none"> a. CRE leads/co-leads and panel discussants introduce AND describe themselves (see example above). 2. Structure/Facilitator notes <ul style="list-style-type: none"> a. Topic 1: Parent vs provider vs personal experience on accessing primary care services. <ul style="list-style-type: none"> i. In childhood ii. Transition to adult care iii. Adult Care b. Topic 2: What trend do you see in primary care for Autistic Individuals (and their families, if applicable) c. Topic 3: What are some common challenges that autistic children and adults often face in primary health care? d. Topic 4: How can we improve access to primary care? <ul style="list-style-type: none"> i. What is already going well that can be expanded? ii. What gaps are there? 	<p><u>Facilitator (CRE lead/co-leads):</u></p> <p>Dr. Lisa Shulman, MD, AIR-P CRE Co-Lead, Interim Director of Rose F. Kennedy Center at Albert Einstein College of Medicine, LEND Director, Children’s Hospital at Montefiore.</p> <p>Toni Whitaker, MD, AIR-P CRE Co-Lead; LEND Director University of Tennessee Center on Developmental Disabilities; Division Chief, Developmental Pediatrics at Univ of TN and Le Bonheur Children’s Hospital</p> <p><u>Panel (self-advocate/lived experience, caregiver experience, professional experience/node leader):</u></p> <p>Dr. Alice Kuo, MD, PhD, MBA University of California Los Angeles, AIR-P Principal Investigator and Primary Care Services And Quality Node Leader</p>	20min

		<p>Kristen Choi, PhD, MS, RN, University of California Los Angeles, AIR-P Node Leader Primary Care Services And Quality</p> <p>Helen Rottier, MS (she/her/hers) University of Illinois Chicago PhD Candidate, Disability Studies</p> <p>Vanessa Gonzalez, Parent Advocate</p>	
AIR-P Context	<ol style="list-style-type: none"> 1. Give context on AIR-P. <ol style="list-style-type: none"> a. Autism Intervention Research Network on Physical Health AIR-P Network (ucla.edu) b. AUCD - Autism Intervention Research Network on Physical Health (AIR-P) c. Network of researchers 	<p><u>Presenter (Node leader):</u> Dr. Alice Kuo, MD, PhD, MBA University of California Los Angeles, AIR-P Principal Investigator and Primary Care Services And Quality Node Leader</p> <p>Kristen Choi, PhD, MS, RN, University of California Los Angeles, AIR-P Node Leader Primary Care Services And Quality</p>	3-5 min
How is AIR-P addressing research gaps in this node?	<ol style="list-style-type: none"> 2. Dial in more specifically to research nodes' efforts to address the gaps in this area 3. Overview of Node/Describe the research node area (i.e., things to know about genetics as it related to the autistic community) <ol style="list-style-type: none"> a. Topic 1: Barriers to accessing high quality primary health care and preventative services throughout the lifespan. <ol style="list-style-type: none"> i. Le navigating the system, lack of "Autism Friendly" provider, etc. b. Topic 2: Promoting Autistic Individuals self-determination in health care c. Topic 3: Enhancing primary care provider training, and mental health and psychiatric care. 4. Closing Summary 	<p><u>Presenter (Node leader):</u> Dr. Alice Kuo, MD, PhD, MBA University of California Los Angeles, AIR-P Principal Investigator and Primary Care Services And Quality Node Leader</p> <p>Kristen Choi, PhD, MS, RN, University of California Los Angeles, AIR-P Node Leader Primary Care Services And Quality</p>	3-5 min

Tips to Use this Resource:

- Recruit a local autistic self-advocate to be present when you expect to review this video. This self-advocate can provide the perspective of an autistic individual for this topic.
- Recruit a local caregiver of an autistic individual when you expect to review this video to provide a family perspective.
- 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 are some reasons that an autistic individual and/or their family may have a negative experience with primary care?
2. What are some questions that an autistic individual and/or their family may want to consider asking their provider prior to making an appointment?
3. Should “Autism Friendly” providers be considered the standard of care for all

Contextual articles:

- Ayoub MC, Rava J, Lewis Hunter A, Kuo AA. Facilitators and Barriers to Care for Patients with Disabilities in Primary Pediatrics. *Pediatric Ann.* 2022 Jun;51(6):e243-e253. doi: 10.3928/19382359-20220407-07. Epub 2022 Jun 1. PMID: 35667098.
 - (Note: this one is by Alice Kuo as senior author)
 - <https://journals.healio.com/doi/full/10.3928/19382359-20220407-07>
- Lucarelli J, Welchons L, Sideridis G, Sullivan NR, Chan E, Weissman L. Development and Evaluation of an Educational Initiative to Improve Hospital Personnel Preparedness to Care for Children with Autism Spectrum Disorder. *J Dev Behav. Pediatric.* 2018 Jun;39(5):358-364. doi: 10.1097/DBP.0000000000000580. PMID: 29794887.
 - <https://pubmed.ncbi.nlm.nih.gov/29794887/>