

OPINION, Q&A

Prioritizing physical health in autism: Q&A with Alice Kuo

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For the past two years, **Alice Kuo** has led the Autism Intervention Research Network on Physical Health (AIR-P), a federally funded multi-center collaboration that aims to understand and improve the physical health of autistic individuals.

Established in 2008 by the U.S. **Maternal and Child Health Bureau**, the AIR-P has long focused on addressing **autistic children's physical health issues**. When Kuo and her team took over in 2020, though, they ushered in a shift in priorities, which they outlined in a special supplement published in *Pediatrics* in April.

Under the direction of Kuo, professor of internal medicine and pediatrics at the University of California, Los Angeles, the AIR-P has plans to better **align the network's goals** with those of autistic people. They have also expanded their efforts to include **sexual and reproductive health**, **motor impairments** and the **notoriously challenging transition** from **adolescent to adult health care**.

The network's new priorities emphasize quality-of-life and health issues throughout the lifespan — not just during childhood — as well as **participatory research**, which seeks to bring autistic researchers and stakeholders into the fold to help set the research agenda.

Spectrum spoke with Kuo about this shift in focus and where she and her colleagues plan to guide the network in the coming years.

This interview has been edited for length and clarity.

Spectrum: What is the overarching goal of the AIR-P?

Alice Kuo: We have 15 collaborating research entities, mostly universities or academic research

centers, but our most significant partner is the **Association of University Centers on Disabilities**, a national network of universities and leadership programs that connects disability researchers with the community and provides training to people entering the field. We tap into their network to encourage researchers, when they think about doing research in autism, to think about doing research on the physical health of autistic individuals. So all of our activities are either toward getting new investigators to consider a career in physical health and autism, or to get existing researchers to add a physical health component to their portfolio.

S: How do the current goals represent a shift from previous ones?

AK: For 12 years, the AIR-P was based at Massachusetts General Hospital, in collaboration with Autism Speaks, and the research was built on their Autism Treatment Network. When the AIR-P was re-authorized for funding in 2019, our group put our hat in the ring to have a different perspective and to really think about autism across the lifespan and the issues facing autistic adults.

The network had been mostly focused on children, and you know, children grow up. There are all kinds of different health issues that affect autistic people through adulthood. Those aspects of our proposal may have been compelling to the government, and we were awarded this funding in 2020.

S: How are autistic people involved in setting the AIR-P's research agenda?

AK: We have our ARRB, the autistic researcher review board, and honestly, I check with them frequently on any operations of the network, the direction of our **scholars program** and the types of projects that are important to them.

Autism research should be for autistic people, so I think that they are in the best position to let us know what really should be prioritized, as far as a research agenda for autism research.

S: What are some of the priorities that have surfaced so far?

AK: It's my understanding of my autistic colleagues that these are the issues that they care about: lifespan well-being and health, sexuality and reproduction, and gender identity. All of these research priorities were formulated in conjunction with them. We're also taking their lead on some of the controversy around **genetics research in autism**, and I think our network is very much aligned with concerns about how genetic information is going to be used, and **issues of informed consent**. So I feel like if we're straying too far, they would definitely let us know.

S: Beyond just research, what are your hopes for the AIR-P?

AK: A very prominent theme in our network is to not pathologize, to not look at autism as a disorder but more of an identity, to respect autistic individuals' wishes around the use of genetic

information.

And in our primary care node, we are trying to support autistic patients in their own self-determination, their self-identity, and helping family members understand that as well. So we're really trying to change the perspective on how the world views autism and what it means to be autistic.

I have an autistic son and brother, and for me autism issues are very much social-justice issues. There has been a lot of listening and learning, and hopefully it shows in the work of our network.

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