

Promoting Lifespan Health and Well-Being Through the Autism Intervention Research Network

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In 2000, the prevalence of autism was 1 in 166. Today it is 1 in 54 (1.8%), reflecting an increase of >300%, making this condition as common as red hair or green eyes in the world's population. With the recognition that a substantial proportion of the population experiences autism, a frameshift toward autism needs to occur. Similar to the growing recognition among researchers that the Latinx population is demographically diverse, autistic individuals are also diverse with unique sociocultural characteristics. These characteristics may contribute to differences in biological risk of co-occurring conditions such as cancer or cardiovascular disease across the life course. Treating all Latinx as a "pan-ethnic group" does not take into account cultural and behavioral differences among subgroups (ie, Puerto Ricans, Cubans, Mexicans, Hondurans, etc). We must begin to

recognize the diversity of subgroups within autistic populations in research. We are adopting this frameshift (presented in the current supplement) in the Autism Intervention Research Network on Physical Health (AIR-P).

The AIR-P, recently retooled under University of California, Los Angeles leadership, includes partnerships with the AJ Drexel Autism Institute at Drexel University, Kaiser Permanente, and the Association of University Centers on Disabilities to promote research on the health of autistic individuals through the life course. Most notably, in the AIR-P, we created the first ever Autistic Researchers Review Board. Composed of 8 investigators who all have the lived experience of autism as well as research expertise, the Autistic Researchers Review Board is active in all aspects of the network and ensures that our contributions

promote neurodiversity, avoid ableist language and concepts, and support equity in all intersectional identities with autism (eg, autism and race/ethnicity and autism and sexual/gender identity). The current supplement reflects this developing infrastructure composed of diverse collaborators via node-specific and intersectional commentaries, original autism research articles, and original neurodiversity research articles.

The research node commentaries from our 6 research nodes in the AIR-P represent the most pressing areas of needed research on the physical health throughout the lifespan of autistic individuals. The primary care services and quality node examines the ways in which the quality of primary care, as well as the overall primary care experience, can be optimized to support the health needs of autistic individuals, with interventions such as

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immunizations, cancer and cardiovascular screenings, and a consistent medical home. The community-based lifestyle interventions node focuses on promoting health behaviors that directly impact the quality of life of autistic individuals, such as nutrition, physical activity, and sleep. The health systems and services node addresses the development of autistic children into autistic adults, recognizing the substantial challenges for them and their families during this period because of barriers within the health care system, including service fragmentation and physician training. The gender, sexuality, and reproductive health node recognizes the importance of these biologic processes in autistic individuals and searches for improved education and intervention to support the experience of sexual debut, sexual or gender identity formation, and pregnancy. The neurology node examines common neurologic conditions that autistic individuals have, with the goal of promoting agency and self-determination for managing these conditions, and the genetics node focuses on improving access to genetic screening among autistic individuals, with the goal of empowering autistic individuals and their families to apply genetic findings to their lives.

We also present several intersectional commentaries that highlight important issues in autism and physical health and overlap with the priorities outlined across the node commentaries. These include commentaries presenting issues such as the impact of the coronavirus disease 2019 pandemic on autistic individuals, training the next generation of researchers and scientists, and how higher education can support the health and academic success of autistic individuals.

The AIR-P is poised to be highly successful on the basis of our partnership with the Association of University Centers on Disabilities and its network of 133 university centers that are now members of the AIR-P network. Our goal is to eventually create a national registry for autism, starting with smaller registries for those with genetic syndromes, to have better estimates of prevalence and support new and emerging multisite research collaborations, which will amplify the current state of research on physical health.

To lay the foundation for these research activities, the next section of our supplement presents original autism research articles. These articles reflect the developing research within the network that aligns with priorities outlined in the commentaries. These include studies on health care and services (eg, hospital inpatient stays, emergency department visits, and family perceptions on services), previously underexplored areas in the physical health of autistic individuals, including substance use and reproductive health, and studies of co-occurring health conditions among autistic individuals.

We also made a concerted effort to ensure our research reflects our theoretical orientation toward autism research. In disability communities, one is often asked whether they subscribe to a “medical model” or a “social model” of disability. A medical model is one in which the disability is pathologized (and often overpathologized) as sickness and focuses on what is wrong with the patient. A social model states that disability results from the way society is organized (eg, lack of accessibility). In AIR-P, we subscribe to a public health model of disability. In this model, public

health activities, including surveillance, epidemiology, health promotion, and prevention, should serve all individuals and, in turn, autistic individuals must be regarded as part of the general population.¹ Research using the public health model considers the entire population and examines the influence of multiple determinants, including but not limited to autism status, on health outcomes.¹ By applying a public health model to autism, we recognize the challenges of impairment that can occur at the individual level and the opportunities to address the barriers to success at the population level. This model is particularly fitting to our work given that our funder is the federal public health agency, the Health Services and Resources Administration.

The public health model of disability is reflected in several of our original neurodiversity research articles that seek to promote health in all individuals. In this supplement, these efforts focus on the transition to adulthood, a developmental period of both heightened vulnerability and opportunity for intervention. For example, we present the development of 2 potential approaches to promote the health of all young adults: a needs assessment to inform a health-promoting, college-based intervention and a qualitative assessment to inform health care transition-related curricula in residency programs. We also include 2 nationally representative studies of young adults in college with conditions that frequently co-occur among autistic individuals: ADD/ADHD and mental health diagnoses.

This supplement presents our vision for autism research and our emerging efforts to move this vision forward. We look forward to

advancing health promotion for autistic individuals through the emerging collaborations, research, and infrastructure building presented in this supplement.

ABBREVIATION

AIR-P: Autism Intervention
Research Network on
Physical Health

REFERENCE

1. Krahn G, Campbell VA. Evolving views of disability and public health: the roles of advocacy and public health. *Disabil Health J*. 2011;4(1):12–18