

The Autism Intervention Research Network on Physical Health (AIR-P) Charter

Authors:

AIR-P National Coordinating Center (NCC):

Alice A. Kuo^{a, b, c}, MD, PhD, Emily Hotez^a, PhD, Kashia A. Rosenau^c, PhD, Candace Gragnani^b, MD, MPH, Priyanka Fernandes^a, MBBS, MPH, Madeline Haley^a, BS

AIR-P Steering Committee

Dawn Rudolph^d, MEd

Lisa A. Croen^e, PhD, Maria L. Massolo^e, PhD, Laura Graham Holmes^f, PhD, Paul Shattuck^g, PhD, Lindsay Shea^h, MS, DrPH, Rujuta Wilson^a, MD, Julian A. Martinez-Agosto^a, MD, PhD, FACMG, FAAP^a

Autistic Researcher Review Board (ARRB)

Heather M. Brownⁱ, PhD, MEd, Patrick S. R. Dwyer^{j, k}, MA, Dena L. Gassner^{l, m}, MSW, Steven K. Kappⁿ, PhD, Ari Ne'eman^o, B, Jacalyn G. Ryan^p, MA, CPA, CMA, TC Waisman^q, EdD, Zachary J. Williams^{r, s, t, u}, BS

Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB)

Jessica N. DiBari^v, PhD, MHS Dana M. Foney^v, PhD Lauren R. Ramos^w, MPH & Michael D. Kogan^v, PhD

Affiliations:

^a Department of Medicine; University of California, Los Angeles, Los Angeles, CA, USA

^b Department of Pediatrics, University of California, Los Angeles, Los Angeles, CA, USA

^c Graduate School of Education and Information Studies, University of California, Los Angeles, Los Angeles, CA, USA

^d Association of University Centers on Disabilities, Silver Spring, MD, USA

^e Kaiser Permanente Northern California, Los Angeles, CA, USA

^f Boston University School of Public Health, Boston, MA, USA

^g Mathematica Policy Research, Princeton, NJ, USA

^h AJ Drexel Autism Institute, Philadelphia, PA, USA

ⁱ Department of Educational Psychology, Faculty of Education, University of Alberta, Edmonton, Alberta, Canada

^j Center for Mind and Brain, University of California Davis, Davis, CA, USA

^k Department of Psychology, University of California Davis, Davis, CA, USA

^l School of Social Work, Adelphi University, Garden City, NY, USA

^m Department of Health Sciences, Towson University, Towson, MD, USA

ⁿ Department of Psychology, University of Portsmouth, Portsmouth, UK

^o Harvard University, Cambridge, MA, USA

^p Faculty of Rehabilitation Medicine, University of Alberta, Edmonton, Alberta, Canada

^q University of Calgary, Calgary, Alberta, Canada

^r Medical Scientist Training Program, Vanderbilt University School of Medicine, Nashville, TN, USA

46 ^s Department of Hearing and Speech Sciences, Vanderbilt University Medical Center, Nashville,
47 TN, USA

48 ^t Vanderbilt Brain Institute, Vanderbilt University, Nashville, TN, USA

49 ^u Frist Center for Autism and Innovation, Vanderbilt University, Nashville, TN, USA

50 ^v Maternal and Child Health Bureau, Health Resources and Services Administration, Rockville,
51 MD, USA

52 ^w Division of MCH Workforce Development, Maternal and Child Health Bureau, Health
53 Resources and Services Administration, Rockville, MD USA

54
55 **Address correspondence to:** Emily Hotez, PhD, 911 Broxton Avenue, Los Angeles, CA 90024,
56 [ehotez@mednet.ucla.edu].

57
58 **Short title:** AIR-P Charter

59
60 **Conflict of interest disclosures:** The authors have no example conflicts of interest to disclose.
61

62 **Funding/support:** This project is supported by the Health Resources and Services
63 Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under the
64 Autism Intervention Research Network on Physical Health (AIR-P), grant #UT2MC39440. The
65 information, content and/or conclusions are those of the authors and should not be construed as
66 the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the
67 U.S. Government.

68
69 **Role of funder:** The funder/sponsor did not participate in the work for this article.

70
71 **Abbreviations:**

72 **AIR-P:** Autism Intervention Research Network on Physical Health

73
74
75
76
77
78
79
80
81
82
83
84
85
86
87
88
89
90
91

92 **Contributors' Statement Page**

93 The National Coordinating Center (Alice Kuo, Emily Hotez, Kashia Rosenau, Candace
94 Gragnani, Priyanka Fernandes, Madeline Haley) conceptualized the theoretical framework and
95 methodology in this study and led the development of this manuscript.

96

97 The AIR-P Steering Committee (Dawn Rudolph, Lisa Croen, Maria Massolo, Laura Graham
98 Holmes, Paul Shattuck, Lindsay Shea, Rujuta Wilson, Julian Martinez-Agosto) provided subject
99 matter consultation and guidance on this manuscript.

100

101 The Autistic Researcher Review Board (Heather Brown, Patrick Dwyer, Dena Gassner, Steven
102 Kapp, Ari Ne'eman, Jacalyn Ryan, TC Waisman, Zachary Williams) provided expert guidance
103 and consultation from research expertise and lived experience.

104

105 The HRSA MCHB (Jessica DiBari, Dana Foney, Lauren Ramos, Michael D. Kogan) provided
106 technical assistance, expert consultation and feedback, and additional insight on all aspects of
107 this manuscript.

108

109 All authors approved the final manuscript as submitted and agree to be accountable for all
110 aspects of the work.

111 **Background**

112 In the United States, autistic individuals experience disparate physical and mental health-
113 related quality of life across the lifespan relative to non-autistic individuals. In recognition of
114 these disparities, the Autism Intervention Research Network on Physical Health (AIR-P) seeks to
115 establish and maintain a research network to enhance the health and well-being of autistic
116 individuals across the lifespan, particularly for underserved and vulnerable populations. This
117 charter serves as the initial charter for the AIR-P—as a Network, we plan to continue to revise
118 and elaborate on the contents of this charter as our research advances and as we continue to forge
119 new partnerships and collaborations.

120 **Purpose**

121 The purpose of the AIR-P is to support innovative life course intervention research that
122 promotes optimal health and well-being of autistic individuals across the lifespan in six key
123 areas: 1) primary care services and quality; 2) community-based lifestyle interventions; 3)
124 gender, sexuality, and reproductive health; 4) health systems and services; 5) neurology; and 6)
125 genetics. The Network will establish and maintain an interdisciplinary, multicenter research
126 network for scientific collaboration and infrastructure to increase the life expectancy and quality
127 of life for autistic individuals, with a focus on underserved populations.

128 **Guiding Principles**

129 **A neurodiversity-orientation to health.** As a Network, the AIR-P aligns with the
130 neurodiversity movement and views autism as an identity akin to gender and race—not a condition
131 that requires a cure. This is reflected in our approach to promoting the health and well-being of
132 autistic individuals.

133 **A stakeholder-driven approach.** All research supported within the Network will be
134 vetted and/or co-developed by the Autistic Researcher Review Board, caregivers and family
135 members of autistic individuals, and other stakeholders.

136 **Inclusivity.** The Network will create an infrastructure for anyone—including early-career
137 investigators and investigators seeking to begin a program of research in autism and physical
138 health—to conduct research related to physical health of autistic individuals. Any individual or
139 organization may join the Network as well as access and contribute to the robust research
140 infrastructure we are developing and maintaining.

141 **Health-promotion.** Our Network seeks to advance research on physical health beyond a
142 medical model and deficit-oriented approach towards promoting the multi-dimensional health,
143 well-being, and thriving of autistic individuals and their families.

144 **Equity.** The Network seeks to address disparities in the access, quality, and utilization of
145 health-promoting services and supports for autistic individuals—particularly for underserved or
146 marginalized populations. The Network will aim to ensure that all research supported within the
147 Network benefits participants representative of low-income, racial/ethnic minority, immigrant,
148 female, Indigenous, geographically-remote, gender identity minority and sexual orientation
149 minority populations. This may require modifications to usual recruitment, data collection, and
150 analytic methods that mitigate barriers to participation.

151 **High-quality research across the lifespan,** The AIR-P seeks to advance the evidence
152 base of high-quality research for autistic individuals and their families across the lifespan. In
153 areas where there is currently no existing evidence base, the AIR-P seeks to spur innovative
154 research and engage experts across the U.S. to guide policy and clinical practice in these areas.

155

156 **Mission**

157 The mission of the AIR-P is to develop a robust research infrastructure that will foster
158 measurable improvements in optimal physical health and well-being of autistic individuals and
159 their families across the lifespan.

160 **Vision**

161 The AIR-P envisions a future where autistic individuals experience optimal multi-
162 dimensional health and well-being.

163 **Values**

164 The following values are central to all of our activities:

- 165 ● Respect, integration, and equitable access to supports and services that promote optimal
166 health and well-being for autistic individuals;
- 167 ● Self-determination and integration of autistic individuals in all facets of the Network;
- 168 ● Individualized and culturally appropriate health care;
- 169 ● Diversity within the Network, programs, and society;
- 170 ● Stewardship of public resources and measurable accountability; and
- 171 ● A commitment to helping individuals by strengthening communities and systems.

172 **Five Primary Goals**

- 173 1) Establish an interdisciplinary AIR-P Network that will lead, promote, and coordinate
174 national research activities to improve physical health and well-being across the lifespan
175 for autistic individuals;
- 176 2) Advance the evidence base for autistic individuals and their families by designing a
177 portfolio of multi-site research in six key areas: 1) primary care services and quality; 2)

- 178 community-based lifestyle interventions; 3) gender, sexuality, and reproductive health; 4)
179 health systems and services; 5) neurology; and 6) genetics;
- 180 3) Collaborate with autistic individuals in developing and carrying out research that
181 addresses their needs, experiences, and priorities and fill the current gaps in research,
182 practice, and policy;
- 183 4) Implement a pilot and feasibility funding program and corresponding scholars program to
184 facilitate the research training and mentorship of diverse new investigators and launch the
185 next generation of researchers in autism and physical health; and
- 186 5) Coordinate and facilitate the dissemination of research findings by publishing an annual
187 research Supplement, presenting at annual AIR-P, HRSA, and AUCD conferences, and
188 developing resources for families, clinicians, and other stakeholders.