

## 1 The Autism Intervention Research Network on Physical Health (AIR-P) Research Agenda

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70

71 **Abbreviations:**

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

73 **NCC:** National Coordinating Center

74 **ARRB:** Autistic Researcher Review Board

75 **AUCD:** Association of University Centers on Disabilities

76 **HRSA MCHB:** Health Resources and Services Administration, Maternal and Child Health  
77 Bureau

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79 **Table of Contents Summary:** We outline the Autism Intervention Research Network on Physical  
80 Health Research Agenda, developed through collaborations with researchers, practitioners, and  
81 autistic individuals; literature reviews; and consensus-building.

82

83 **What's Known on this Subject:** In the United States, autistic individuals experience  
84 disproportionate physical and mental health challenges relative to non-autistic individuals,  
85 including higher rates of co-occurring and chronic conditions and lower physical, social, and  
86 psychological health-related quality of life.

87

88 **What this Study Adds:** This research agenda represents an important step forward for enacting  
89 large-scale health-promotion efforts for autistic individuals across the lifespan. It will catalyze  
90 autism research in historically underrepresented topic areas while adopting a neurodiversity-  
91 oriented approach to health-promotion.

92 **Contributors' Statement Page**

93 The AIR-P NCC and the Steering Committee created a targeted annotated bibliography of  
94 quantitative and qualitative research in identified domains and drafted the initial manuscript.

95

96 The NCC, Steering Committee, and ARRB participated in the qualitative research and reviewed  
97 and revised the manuscript.

98

99 HRSA MCHB contributed to the conception and design of the work, participated in revising the  
100 manuscript, and provided guidance and overarching feedback to this work.

101

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

104

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## Abstract

106  
107 **Objective:** In the United States, autistic individuals experience disproportionate physical and  
108 mental health challenges relative to non-autistic individuals, including higher rates of co-  
109 occurring and chronic conditions and lower physical, social, and psychological health-related  
110 quality of life. The Autism Intervention Research Network on Physical Health (AIR-P) is an  
111 interdisciplinary, multicenter research network for scientific collaboration and infrastructure that  
112 aims to increase the life expectancy and quality of life for autistic individuals, with a focus on  
113 underserved/vulnerable populations. The current paper describes the development of the AIR-P  
114 Research Agenda.

115 **Methods:** Development of the Research Agenda involved an iterative and collaborative process  
116 between the AIR-P Advisory Board, Steering Committee, and Autistic Researcher Review  
117 Board. The methodology consisted of three phases: 1) *Ideation and Design*; 2) *Literature Review*  
118 *and Synthesis*; and 3) *Network Engagement*.

119 **Results:** Six core research priorities related to the health of autistic individuals were identified:  
120 1) Primary Care Services and Quality; 2) Community-Based Lifestyle Interventions; 3) Health  
121 Services and Systems; 4) Gender, Sexuality, and Reproductive Health; 5) Neurology; and 6)  
122 Genetics. Specific topics within each of these priorities were identified. Four cross-cutting  
123 research priorities were also identified: 1) neurodiversity-oriented care; 2) facilitating  
124 developmental transitions; 3) methodologically rigorous intervention studies; and 4) addressing  
125 health disparities.

126 **Conclusion:** The AIR-P Research Agenda represents an important step forward for enacting  
127 large-scale health-promotion efforts for autistic individuals across the lifespan. This Agenda will  
128 catalyze autism research in historically underrepresented topic areas while adopting a  
129 neurodiversity-oriented approach to health-promotion.

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## **The Autism Intervention Research Network on Physical Health (AIR-P):**

### **The Research Agenda**

In the United States, autistic individuals experience disproportionate physical and mental health challenges relative to non-autistic individuals, including higher rates of co-occurring and chronic conditions and lower physical, social, and psychological health-related quality of life.<sup>1-5</sup> Funded by the Health Resources and Services Administration, Maternal and Child Health Bureau (MCHB), the Autism Intervention Research Network on Physical Health (AIR-P) seeks to establish and maintain a research network to enhance the physical health and well-being of autistic children, adolescents, and adults, particularly for underserved and vulnerable populations. The current paper describes the AIR-P Research Agenda, developed through collaborations with researchers, practitioners, stakeholders, and autistic individuals; literature reviews; and consensus-building. This Research Agenda will be iteratively revised as the field continues to advance to ensure that ongoing efforts within the Network reflect state-of-the-art research, priorities, and practice.

### **Methods**

#### **Sample**

The Research Agenda development process involved a collaborative process among the AIR-P Advisory Board ( $n = 33$ ), Steering Committee ( $n = 14$ ), and Autistic Researcher Review Board ( $n = 8$ ). The Advisory Board is comprised of researchers and practitioners across the U.S. who have expertise in autism and support research efforts within the Network. The Steering Committee is comprised of interdisciplinary researchers, practitioners, and other stakeholders with professional expertise as well as personal experience working with or caring for autistic individuals across the lifespan. The Autistic Researcher Review Board is comprised of autistic

154 researchers and scholars in the U.S., U.K., and Canada who leverage their unique personal  
155 experiences to inform research that seeks to enhance the lives of autistic individuals. The  
156 Network Engagement phase of the methodology (described below) included a sub-sample ( $n =$   
157 24) from the Advisory Board ( $n = 13$ ; 54%), Steering Committee ( $n = 6$ ; 25%), and Autistic  
158 Researcher Review Board ( $n = 5$ ; 21%). This sub-sample included individuals with diverse levels  
159 of training and education (PhD:  $n = 10$ , 41%; MD/PhD:  $n = 5$ ; 21%; MD:  $n = 4$ , 17%; students  
160 and residents:  $n = 3$ , 13%; and Master's Level:  $n = 2$ , 8%). The sample also included those who  
161 identified as autistic ( $n = 5$ ; 21%), those with an autistic family member or close friend ( $n = 12$ ;  
162 50%), and caregivers ( $n = 5$ ; 21%).

### 163 **Methodology**

164         The methodology consisted of three phases: 1) *Ideation and Design*: Through a series of  
165 planning meetings, the Steering Committee identified preliminary priority domains based on  
166 their areas of expertise and background knowledge of the literature; 2) *Literature Review and*  
167 *Synthesis*: The Steering Committee created a targeted annotated bibliography of quantitative and  
168 qualitative research in the identified domains and synthesized the findings in a literature review  
169 to refine the domains; and 3) *Network Engagement*: Experts across the Network ( $n = 24$ )  
170 engaged in a two-step process via Qualtrics surveys to identify priority research topics within  
171 each domain.

172         In the first step, the sample provided open-ended responses regarding the highest priority  
173 research topics within each of the research domains identified during the series of planning  
174 meetings and review of the literature. The open-ended responses were organized utilizing  
175 Dedoose coding software<sup>6</sup> and coalesced into six to ten priority research areas within each  
176 domain. In the second step, participants were asked to participate in a follow-up survey to

177 identify the top three priority research areas from the options within each domain, with  
178 consideration of the following criteria: 1) *Need/Urgency* (i.e., the influence of the research topic  
179 on the physical health and well-being of autistic individuals; severity of consequences [e.g.,  
180 number of autistic individuals affected by the issue]; and presence of critical gaps in knowledge);  
181 2) *Research Impact* (i.e., the ability of the knowledge gained from this research topic to translate  
182 to meaningful progress in five to ten years and the potential to lead to improvements in physical  
183 health status, quality of care, public health, or policy over the longer term); and 3)  
184 *Person/Family-Centeredness* (i.e., how well the research topic reflects the experiences and  
185 priorities of autistic individuals and their families). The research topics most frequently endorsed  
186 in participants' top three rankings across all categories were identified. Cross-cutting research  
187 domains—that is, research areas that apply to all domains and topic areas—emerged throughout  
188 all steps of the process.

## 189 **Results**

190 The AIR-P Research Agenda—along with the highest ranking research topic areas  
191 identified in the Network Engagement phase—is outlined in Table 1. The Research Agenda  
192 consists of six core research priority domains—each with critical implications for autistic  
193 individuals' physical health—and four cross-cutting priorities that applied across all domains.

### 194 **Core Research Priorities Identified**

195 **Primary Care Services and Quality.** Relative to their non-autistic counterparts, autistic  
196 children and adults have significantly more physician visits and medications prescribed and  
197 higher medical costs and total expenditures per treated patient.<sup>7–10</sup> Nonetheless, they create a  
198 smaller burden on health insurers because of their relatively low receipt of necessary treatment

199 and services.<sup>11–14</sup> In addition, there are pronounced racial, ethnic, and gender health inequities in  
200 access to quality medical services.<sup>13,14</sup>

201       Of particular concern, only half of autistic individuals receive comprehensive primary  
202 care consistent with the medical home model as recommended by the American Academy of  
203 Pediatrics. This model is defined as care from a personal provider that is preventive, family-  
204 centered, compassionate, culturally-appropriate, accessible, comprehensive, and coordinated.<sup>15</sup> A  
205 range of patient, provider, and systemic obstacles to an optimal medical home for autistic  
206 individuals have been cited in the literature.<sup>16–19</sup> These obstacles perpetuate unmet healthcare  
207 needs related to physical and mental health, prescription medications, and preventive care and  
208 increase emergency service utilization.<sup>20</sup> Specific research priorities that emerged included  
209 promoting autistic individuals' self-determination (i.e., capacity for autonomy, self-efficacy, and  
210 decision-making) in health care ( $n = 19$ , 79%), enhancing primary care provider training ( $n = 18$ ,  
211 72%), and mental health and psychiatric care ( $n = 14$ , 58%).

212       **Community-Based Lifestyle Interventions.** Although many autistic individuals  
213 experience challenges related to lifestyle—including nutrition, gastrointestinal issues, and food  
214 selectivity<sup>21</sup>; obesity and associated chronic health conditions<sup>16,22</sup>; physical activity and motor  
215 performance<sup>23</sup>; sleep<sup>24–26</sup>; stress and anxiety<sup>27, 28</sup>; social connectedness<sup>29, 30</sup>; and substance  
216 use<sup>31</sup>—these challenges are variable in the autistic population. In addition, findings on the  
217 effectiveness of interventions have been inconclusive due to reliance on small sample sizes and  
218 subsequent failure to obtain robust effect sizes on physical health outcomes.<sup>22, 25</sup> Research  
219 priorities that emerged included lifestyle interventions that promote social connectedness ( $n =$   
220 17, 71%), build self-advocacy capacities ( $n = 16$ , 67%), and engage families and communities ( $n$   
221 = 12, 50%).



222           **Health Services and Systems.** While health services and systems emerged as an  
223 important priority, a focus on transitions and coordination appeared to be particularly salient.  
224 Autistic individuals and their families characterize their experiences as a “lifetime of difficult  
225 transitions.” They report difficulty using services, lack of source of care, inadequate insurance  
226 coverage, and lack of shared decision making and care coordination. There are also a limited  
227 number of specialized service providers and resources that are often highly fragmented and  
228 governed by stringent and restrictive program and funding criteria.<sup>32-35</sup> Further, autistic  
229 individuals frequently encounter a poor person-environment fit in health care and service settings  
230 and uncertainty about the roles of parents in facilitating transitions.<sup>34, 35</sup> Transition challenges are  
231 heightened for Black and low-income youth and those with co-morbid conditions.<sup>36, 37</sup> Access to  
232 a medical home is an important predictor of receiving health care transition services, as autistic  
233 youth with a medical home are almost three times as likely to receive health care transition  
234 services as youth without a medical home.<sup>38</sup> Specific research priorities that emerged included  
235 supporting health care navigation and models of transition practices ( $n = 16$ , 67%), training  
236 primary care providers in the adult health system ( $n= 14$ , 58%), and educating individuals and  
237 families about transition care ( $n = 14$ , 58%). In recognition of the need for further research on  
238 health care transitions, the MCHB has prioritized research, performance measurement, and data  
239 analysis around transitions. As an example, they invested in the Autism Transitions Research  
240 Project (ATRP) for Youth and Young Adults with Autism Spectrum Disorders. The AIR-P will  
241 collaborate with the ATRP over the course of the grant.

242           **Gender, Sexuality, and Reproductive Health.** Mounting evidence suggests that gender-  
243 biased diagnostic and clinical criteria, along with actual sex and gender differences, may lead to  
244 the delayed recognition of autism in females.<sup>39</sup> Barriers to service access for autistic women may

245 continue into adulthood, particularly for health services related to reproductive health and  
246 pregnancy.<sup>40</sup> Autistic adults are less likely to be gender-conforming than their non-autistic  
247 counterparts. Belonging to a sexual or gender minority group is associated with higher rates of  
248 unmet health care needs among autistic people and, in turn, poorer physical health.<sup>41</sup> Indeed,  
249 autistic individuals often receive insufficient support regarding their sexuality and gender  
250 identity.<sup>42,43</sup> Further compounding these challenges, autistic individuals are at higher risk of  
251 sexual victimization and abuse compared to non-autistic people. These experiences are  
252 associated with suicidal or self-injurious behavior and psychiatric hospitalizations.<sup>44</sup> Autistic  
253 adults report less perceived and actual sexual knowledge, which may increase the risk of sexual  
254 victimization.<sup>45</sup> Specific research priorities that emerged included developing sexual health  
255 curricula for autistic individuals ( $n = 17$ , 71%), promoting sexual health education among  
256 individuals and families ( $n = 14$ , 58%), understanding intersectional identity issues ( $n = 12$ ,  
257 50%), and promoting self-determination ( $n = 12$ , 50%).

258 **Neurology.** Although autistic individuals have been found to experience motor  
259 impairments—including impairments related to gross and fine motor, postural control, and  
260 imitation and praxis—such impairments are not universal nor specific to autism.<sup>46, 47</sup> The current  
261 research base surrounding motor-based interventions has shown some promising results, but are  
262 largely based on case studies, individuals without intellectual disability, or have yielded small  
263 effect sizes.<sup>48–50</sup> Rigorous studies that include autistic individuals with heterogeneous behavioral  
264 and intellectual abilities are needed to objectively evaluate (1) motor dysfunction and (2) motor-  
265 based interventions that target fundamental motor skills, social communication, and  
266 proprioceptive awareness.<sup>51–53</sup> Specific research priorities that emerged were understanding and  
267 addressing co-occurring neurological conditions ( $n = 18$ , 75%) and neurological developmental

268 trajectories and adult outcomes ( $n = 12$ , 50%) as well as coordinating neurological care ( $n = 12$ ,  
269 50%)

270 **Genetics.** Although autism has been found to be highly heritable,<sup>54</sup> genotyping is  
271 particularly complex due to frequently co-occurring conditions. While a proportion of autism is  
272 attributable to common variants, rare copy-number variants and protein-disrupting single-  
273 nucleotide variants have also been shown to significantly contribute to the etiology.<sup>55</sup> The  
274 diagnostic relevance of genome-wide small common and rare copy-number variants continues to  
275 provide evidence of the high diagnostic yield of microarray for genetic testing in autistic  
276 children.<sup>56</sup> These findings support the utility of enhancing access to genetic testing for autistic  
277 individuals. Research priorities that emerged were genetic counseling ( $n = 15$ , 63%), identifying  
278 genes linked to co-occurring conditions or treatment responses ( $n = 13$ , 54%), and addressing the  
279 autistic community's concerns about genetics research and moving away from cure/cause  
280 research towards increasing quality of life ( $n = 12$ , 50%).

### 281 **Cross-Cutting Research Priorities Identified**

282 **Neurodiversity-Oriented Care.** The neurodiversity movement challenges deficit-  
283 oriented conceptualizations of disability, reframing the disability as a valuable minority identity  
284 that does not require corrective treatment.<sup>57</sup> The neurodiversity movement has proliferated in  
285 recent decades—primarily across college campuses — as a means to promote the success of  
286 diverse learners. However, the majority of literature on neurodiversity has been largely  
287 conceptual, with limited efforts to adapt a neurodiversity approach to health care.<sup>58</sup> This  
288 perspective encourages the promotion of self-determination, advocacy, and decision-making  
289 among autistic individuals and is informed by autistic individuals themselves.



313 well-being and thriving among autistic individuals in accordance with their self-reported needs,  
314 experiences, and priorities.

315 This agenda lays the foundation for research conducted within the AIR-P Network. Moving  
316 forward, the Autistic Researcher Review Board will collaborate with the Steering Committee in  
317 the continuous development and refinement of the overall research domains. In addition, there  
318 will be systematic efforts to catalogue research that emerged during the first year of the AIR-P to  
319 ensure that priorities are representative of the current research and emerging trends. There will  
320 also be continuous consensus-building efforts to ensure alignment within the Network.

### 321 **Conclusion**

322 The AIR-P Research Agenda represents an important step forward for enacting large-scale  
323 health-promotion efforts for autistic individuals across the lifespan. The AIR-P looks forward to  
324 addressing these critical research priorities and continuing to advance this Research Agenda as  
325 the Network spurs research and innovation.

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## Appendix

**Table 1. The Autism Intervention Research Network on Physical Health (AIR-P) Year 1 Research Agenda**

Research Priority / Top 3 Research Topics <sup>1</sup>	N (%) <sup>2</sup>
<i>Primary Care Services and Quality:</i> Research that enhances primary care models that support autistic individuals across the lifespan.	
• Autistic individuals' self-determination (i.e., capacity for autonomy, self-efficacy, and decision-making) in healthcare	19 (79%)
• Primary care provider training and specialized protocols for working with autistic individuals.	18 (72%)
• Care, and management around stress, anxiety, and/or suicidal ideation; referrals for psychiatric care.	14 (58%)
<i>Community-Based Lifestyle Interventions:</i> Research that enhances lifestyle interventions that support autistic individuals across the lifespan.	
• Lifestyle interventions that engage communities, families, children, and peers to promote social connectedness and enhance relationships	17 (71%)
• Lifestyle interventions that build self-advocacy capacities and important skills for development and independence.	16 (67%)
• Engaging families and individuals in physical activity and nutrition, increasing community supports, and strengthening the evidence-base for lifestyle interventions.	12 (50%)
<i>Health Services and Systems:</i> Research that facilitates health care services and systems, particularly transitions and care coordination for autistic individuals.	
• Health care navigation for adolescents and adults and models of effective transition practices.	16 (67%)
• Training primary care providers in the adult health care system to serve autistic individuals.	14 (58%)
• Educating families and individuals about transitions and adult care	14 (58%)
<i>Gender, Sexuality, and Reproductive Health:</i> Research that promotes sexual health among autistic individuals and address systemic barriers for women and gender non-conforming autistic individuals.	
• Developing sexual health curricula for autistic individuals and promoting awareness and knowledge.	17 (71%)
• Understanding and addressing individual, caregiver, and family education and needs pertaining to on sexual health.	14 (58%)
• Understanding and supporting youth in areas related to intersectionality, LGBTQ+ issues, and gender and sexual identity.	12 (50%)

Research Priority / Top 3 Research Topics <sup>1</sup>	N (%) <sup>2</sup>
<ul style="list-style-type: none"> <li>• Self-determination around sexual behavior.</li> </ul>	12 (50%)
<i>Neurology: Research that develops and tests the neurologic and developmental outcomes of motor based - interventions for autistic individuals.</i>	
<ul style="list-style-type: none"> <li>• Co-occurring conditions, (e.g., motor dysfunction, sensory issues, seizures, and sleep) and corresponding accommodations, supports, and interventions.</li> </ul>	18 (75%)
<ul style="list-style-type: none"> <li>• Understanding developmental neurological trajectories and adult outcomes</li> </ul>	12 (50%)
<ul style="list-style-type: none"> <li>• Neurological care coordination with other health care providers.</li> </ul>	12 (50%)
<i>Genetics: Research that facilitates access to genetic testing as a means to enhance physical health among autistic individuals and their families.</i>	
<ul style="list-style-type: none"> <li>• Genetics counseling and physician-patient communication</li> </ul>	15 (63%)
<ul style="list-style-type: none"> <li>• Identifying genes linked to co-occurring conditions or treatment responses</li> </ul>	13 (54%)
<ul style="list-style-type: none"> <li>• Addressing the autistic community's concerns about genetics research and moving away from cure/cause research towards increasing quality of life.</li> </ul>	12 (50%)

<sup>1</sup> Research topics reflect topics that were identified in the top three individual rankings. Rankings were obtained separately for need/urgency, research impact, and person/family-centeredness and the topics with the highest rankings across all categories are displayed.

<sup>2</sup> This column reflects the number and percentage of experts across the Network (n = 24) who ranked each research topic in their top three rankings of either need/urgency, research impact, or person/family-centeredness.