

The Autism Intervention Research Network on Physical Health and the Autism Speaks Autism Treatment Network

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abstract

Over 10 years, the Autism Intervention Research Network on Physical Health (AIR-P) and the Autism Speaks Autism Treatment Network (ATN) have collaborated to produce much of the material presented in this supplement and have been pioneers in bringing attention to the medical needs of children and adolescents with autism spectrum disorders (ASDs) and related conditions. Whereas, until recently, medical complaints (eg, abdominal pain, poor sleep, or disruptive behaviors) were typically considered part of the disorder and therefore not requiring specific attention, today clinicians throughout the country directly assess and treat these associated conditions. The combined AIR-P/ATN network has developed systematic ways to assess and treat coexisting conditions, focusing on those for which management was previously highly variable or sporadic and has shared those methods broadly with the larger parent and professional communities. The active involvement of families and young people with ASD has helped the network identify key issues for individuals and families and focus its attention accordingly. Although clinicians may have limited new, evidence-based options for treating autism directly, they now have systematic ways to evaluate and manage coexisting conditions. In turn, families

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have learned about new ways to help their children and improve their functioning and outcomes.

NETWORK HISTORY

The ATN began a decade ago with key support from private-sector philanthropy. Over the past 7 years, Autism Speaks (AS), the largest parent-led philanthropy in the field of autism, has provided substantial and critical support to the ATN. The ATN maintains a registry of enrolled children at all network sites, collects registry data, and works with sites to improve the systems and processes of care. In 2008, with funding through the Combating Autism Act (CAA) of 2006, the Health Resources and Services Administration (HRSA) and its Maternal and Child Health Bureau began a series of projects related to improving care for young people with ASD and related conditions.¹

Among the HRSA-developed CAA Initiative efforts, the AIR-P was established with a substantial commitment to conduct research to improve care, develop practice guidelines, and disseminate its work to a broad community of families and providers. The AIR-P funding greatly expanded the reach and scope of the ATN activities by leveraging the efforts of network practices and the research use of the registry data, as well as providing major support for a large number of hypothesis-driven research projects across the network. AIR-P funding allowed research and dissemination to flourish to improve the care for children with ASD and their families.

Together, AIR-P and AS funding have supported the growth of parent involvement in all aspects of the AIR-P/ATN, including parent advisors at each network site and the development of a network-wide

Family Advisory Committee. Family members participate in the scientific reviews for the network, development of research proposals, design of improvement activities, and various workgroups and committees and are part of the overall network steering committee. In 2011, the CAA was renewed, providing an additional 3 years of funding for the network. The passage of the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act in 2014 provided funding to continue network efforts for another year.

CURRENT NETWORK

The AIR-P/ATN currently includes 14 sites across North America.² All sites are based in hospitals and academic health centers, with multidisciplinary teams providing comprehensive care to children and families. An underlying principle of the network has been the commitment to high-quality care as a basis for all work on improving care, developing research, and identifying and implementing best practices. The network centers provide ongoing care to >30 000 children and youth and their families. Several multidisciplinary workgroups guide network development of reviews of specific clinical topics in their areas of excellence, as well as development of practice guidelines and toolkits for clinicians and parents. Recent work, supported by AS, has added family navigators to the multidisciplinary teams.

RESEARCH

Since 2008, the network has funded 25 clinical research projects, augmented by many additional projects supported by other private and public research programs. In turn, these collaborative projects have led to major growth in peer-reviewed publications on aspects of clinical care for children with ASD

and related neurodevelopmental conditions. Research contributions of the network have been substantial, with >80 published articles and 125 abstracts presented at various scientific meetings. Network investigations have continued to support the importance of understanding nutrition and diet,^{3,4} sleep,⁵ gastrointestinal conditions,⁶ epilepsy, and behavioral/psychiatric conditions,^{7,8} among the most promising and important areas, along with understanding more about adolescence and the transition to adulthood with ASD.^{9,10} Some network studies have addressed quality of life, health services, and health economic issues, which are areas that merit more attention and investment.^{11,12}

Nonetheless, it remains clear that there is much more to do to understand clinical conditions among children with ASD and to improve the underlying science needed to inform treatment choices. The tremendous diversity of clinical presentations and courses in ASD emphasizes how much more research is needed to guide treatment and improve outcomes. The work of the network has yielded important findings but has also identified the major gaps in research in this area.

The network has carried out its research functions in an organized fashion. The large majority of projects have arisen from internal competitions, usually with focused requests for applications from network participants, who now number >325 members. Competitions have solicited >75 research proposals, which is 3 times the number of studies that the available funds can support. All studies undergo careful scientific review from a committee that includes research faculty from the network sites and reviewers external to the network with expertise in

the project areas. Investigators of projects that pass initial review are asked to revise the project on the basis of the review before final approval and funding. This internal review process has led to strengthened proposals that have successfully competed for funding from the National Institutes of Health, the HRSA, AS, and other funders. This process has also provided important mentoring to junior investigators. A similar scientific review process applies to manuscripts from the network, all of which undergo committee review before journal submission.

CLINICAL PATIENT REGISTRY

Over the past several years, the network, mainly with support from AS, has included almost 7000 children with autism in a clinical patient registry. The registry has gathered follow-up data from increasing numbers of these children, allowing review of changes over time in some of the characteristics and health issues for children with ASD and related conditions. With strong support from the network Data Coordinating Center, the registry provides a valuable resource for research with regard to characteristics of children with ASD. The network has made the registry data available to both internal and external investigators. All use of the registry is coordinated through the Clinical and Data Coordinating Centers based at the Massachusetts General Hospital for Children, where staff members help potential investigators understand the data elements in the registry, assess proposed research questions, and provide follow-up with regard to analyses and their translation into research manuscripts. Two rounds of requests for application within the network have supported junior investigators to carry out analyses directed toward answering specific

research hypotheses. Investigators outside the network can gain access to the registry through a process similar to that used by investigators within the network. This process has led to doctoral dissertations,^{13,14} studies conducted by pediatric fellows,^{15,16} and >50 peer-reviewed publications.

APPLYING IMPROVEMENT SCIENCE TO NETWORK EFFORTS

To facilitate the use and spread of key research findings and best practices, the network implemented a major effort in quality improvement. Working initially with the National Initiative for Children's Healthcare Quality, the network identified several areas for clinical improvement: identification and management of gastrointestinal and sleep disorders, monitoring of psychotropic medication use and side effects, and access to initial diagnostic and ongoing medical care appointments. Through this process, practice teams at each center developed skills in quality improvement, including the use of data to identify needs for improvement; implementation of tests of change; engagement of staff, providers, family members, and leadership in improvement activities; and dissemination, or spread, of successful interventions. Through this improvement work, the network increased documented screenings and parent-activated care plans for insomnia and constipation, increased network-wide reliability in monitoring for side effects of atypical antipsychotic medications to >85% of children, and decreased wait times and time to third next available appointment, a common measure of accessibility. Each of these activities is replicable and has the potential to enhance access to and quality of care for children and youth with ASD.

More recently, the network has collaborated with the Anderson

Center at Cincinnati Children's Hospital Medical Center to apply improvement science across all aspects of the network, including its research and registry activities. With major design and implementation support from the Anderson Center, the network will transform into a multisite Learning Network, which will provide a collaborative laboratory for developing and testing evidence-based interventions and accelerating the adoption of effective interventions to improve care and reduce disparities. This work will enhance the current registry to inform clinical decision-making and care delivery, identify variations in care, and facilitate comparative effectiveness research. The registry will generate regular reports showing trends and variations, which allow centers to learn from one another and target improvement activities. The network is also participating in a collaborative of condition-specific networks to share innovative strategies to address common issues, such as patient and family engagement and leadership involvement. With other networks such as Improve Care Now¹⁷ as models, this work will hasten research on ways to improve clinical outcomes and to spread the adoption of best practices.

DISSEMINATION TO BROADER AUDIENCES

A main goal of the network has been to share research and clinical advances to broader clinical and family audiences. This dissemination has taken place in several ways other than the research publications noted above. First, the network has developed several evidence-informed clinical practice guidelines, 2 of which are published in this supplement (with 3 previous guidelines published in the 2012 supplement).^{5,6,18} As new research data become available, we plan to develop new guidelines and revise and update existing guidelines.

Second, the network has produced 20 toolkits addressing common challenges for families and providers, all of which are available for no-cost download at www.airpnetwork.org and www.autismspeaks.org. There have been >170 000 downloads of these toolkits as of May 2015. The network is currently surveying users about the value of the existing toolkits and the need for additional toolkits. Third, network members have carried out numerous training sessions for other clinicians and conferences for parents. Fourth, the network has had substantial presence at national research meetings, especially the International Meeting for Autism Research, the combined Pediatric Academic Societies meetings, the Society for Developmental and Behavioral Pediatrics, and the HRSA-sponsored CARES conference. Fifth, the network conducts a monthly “Advances in Autism Research and Care” webinar series covering a wide range of clinical topics, including reports on network research in progress or that has been recently completed.

CURRENT AND FUTURE NETWORK TRENDS

Overall, the network has substantially broadened the involvement of families in its research, improvement, and dissemination activities. Given recent attention to disparities in access to care for children with ASD, both in early identification and in ongoing treatment, the network has developed new strategies to enhance access to care for high-risk communities. Over the past 3 years, network sites have explored new ways to interact with their surrounding primary care community. With the high prevalence of autism and related neurodevelopmental disorders, primary care providers have a major and central role in the provision of many health services for children

with ASD and their families. Sites have identified ways to improve communication and feedback, defined shared responsibilities for aspects of care, and experimented with novel ways to include primary care providers in autism advances. One particularly innovative program has developed around the network site at the University of Missouri, in association with colleagues with Project Extension for Community Healthcare Outcomes (ECHO) in New Mexico.¹⁹ In this program, a multidisciplinary team of Missouri clinicians (developmental/behavioral pediatrician, psychologist, psychiatrist, nutritionist, and parent) use videoconferencing technology to train Missouri-based primary care providers in managing care of children with ASD. Sessions include didactic presentations and review of complex cases. This training enables primary care providers to gain enhanced skills in delivering clinical care to this population along with increased access to subspecialty consultation for complex cases. Programs like the ECHO autism efforts will help the spread of improved care for children with autism and related conditions to many underserved communities.

CONCLUSIONS

In summary, the AIR-P/ATN has made important contributions to improving the medical care of children and youth with ASD and has disseminated all of this work through numerous scientific presentations and publications. The network has had a significant impact on the conduct of intervention research on physical conditions associated with ASD, has provided mentorship to young investigators in the conduct of this research, has developed evidence for effective improvements in the delivery of care and the content of that care, and has disseminated this work through numerous scientific

presentations and publications. Network investigators are identifying new priorities for research, and the network is poised to carry these activities to new levels with its transformation into a learning network.

ABBREVIATIONS

AIR-P: Autism Intervention Research Network on Physical Health
AS: Autism Speaks
ASD: autism spectrum disorder
ATN: Autism Treatment Network
CAA: Combating Autism Act
HRSA: Health Resources and Services Administration

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