

Autism Treatment Network and Autism Intervention Research Network on Physical Health

Annual Report 2020



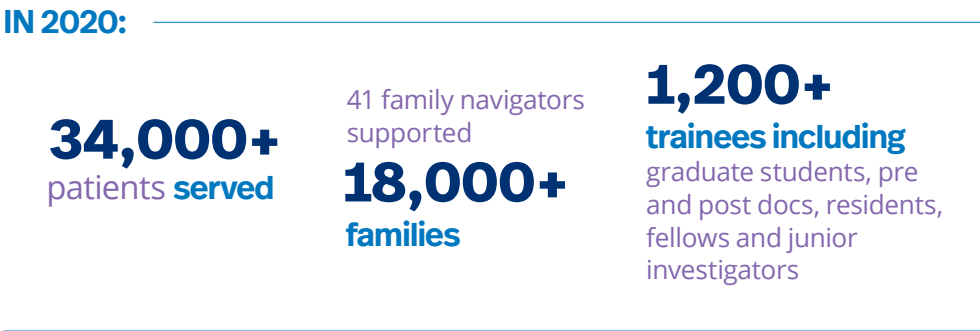
ABOUT THE Autism Treatment Network and AIR-P

Vision:
Optimal health and quality of life
for people with autism spectrum
disorders.

Mission:
Create a sustainable system
for care delivery, research and
evidence development.

For more than 15 years, the Autism Treatment Network (ATN) has made fundamental improvements in the care of children with autism and their families by linking the research focus of the AIR-P with the clinical focus of the ATN. With the support of Autism Speaks and the Autism Intervention Research Network on Physical Health (AIR-P), funded by the Health Resources and Services Administration (HRSA), the ATN brought together leading children’s hospitals and academic institutions to develop best practices in clinical care.

As the ATN/AIR-P partnership ends, we reflect upon its many accomplishments and look forward to the evolution of our work into a new kind of network to accelerate improvements in care.

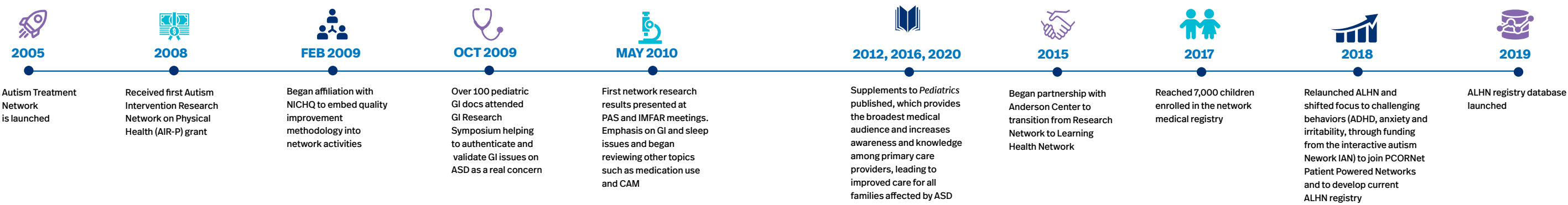


EVOLVING INTO A New Network

The Autism Learning Health Network (ALHN), the first learning network of its kind focused on autism, evolved out of the successful partnership of the ATN and AIR-P. Reintroduced as the Autism Care Network in its official launch in April 2021, the Network incorporates research and innovative quality improvement methods that are data-led and informed by patient experiences to enhance care. As a learning health system, this new network represents a significant shift in autism care by accelerating research and care improvements at speed and at scale. Using these methods built on real-time analysis of embedded clinical data and family priorities, the Network seeks to drive rapid and significant improvements in care, quality of life at scale, and reach into underserved communities.

In 2020, the Network added eight new sites, bringing the total to 20 participating centers across North America. The Network’s continued expansion will help standardize and improve care and broaden the reach of best practices.

Our Accomplishments and Highlights



* All demographic data represents Jan. 1, 2020– December 31, 2020
* All data representing Network activities covers Jan. 1, 2020 – March 31, 2021



Global Aim of the Autism Learning Health Network:

All Individuals with Autism Spectrum Disorder (ASD) will have optimal physical health, safety and Quality of Life (QOL)

Family survey data collected in 2018 by providers in the Network revealed that challenging behavior affects 93 percent of families, with 85 percent reporting moderate to extreme severity. Sixty-one percent report these challenging behaviors occur at least once a day or many times per day. Sixty-nine percent of families rated their quality of life as very good and above.

With this information, the Network identified challenging behaviors as a priority focus area and developed targets for measuring improvement – our SMART aim (a Specific, Measurable, Actionable, Realistic, and Time-bounded objective that focuses the work of the Network).

SMART Aim of the Autism Learning Health Network:

In collaboration with families, we will decrease the percentage of children* with moderate, severe or extremely severe behaviors (as reported by parents/caregivers) from 85 percent to 75 percent by April 1, 2022.

In order to better identify and reliably treat the three most common challenging behavioral domains (ADHD, anxiety, irritability) for children diagnosed with ASD, the Network aims to decrease the percentage of children with moderate or worse behaviors, leading to better quality of life and optimal health. To achieve this goal, in 2019 Network members grouped into three Learning Labs to develop clinical pathways to improve treatment for each of three commonly co-occurring behaviors - ADHD, anxiety and irritability - so that all children treated at Network sites will receive consistent, evidence-based care.

After identifying and testing treatment pathway markers, the Learning Labs shifted to Improvement Labs in 2020, bringing the focus to using data for improvement and completing small tests of change within the behavior aim.

By reviewing the medical records of participating patients, staff at network centers track the progress and treatment of behaviors and related data. Through March 2021, each of the three Improvement Labs increased completion percent on all below markers that were checked at clinic visits:

ADHD Improvement Labs
increased reliability in
6/6 markers

Anxiety Improvement Labs
increased reliability in
5/5 markers

Irritability Improvement Labs
increased reliability in
4/8 markers

CONTINUING TO Engage Family Members

The Network collaborates not only with providers and physicians, but patients and family members to improve care for people with autism. The family voice is vital to the mission of the Network and is represented across all work, research, committees and workgroups, and publications. Each of the Network Leadership sites have family representatives who serve on the ATN/AIR-P Family Advisory Council (FAC), ensuring that all Network activities are family-centered and addressing patient and family needs. The newer Network sites are actively working on recruiting and integrating family representatives into their teams.

Through the transition to a learning health network, the FAC will continue as the Family Partner Committee and will continue to be increasingly integrated into all Network projects and research moving forward.

- In 2020 and early 2021, two members of the FAC (a family member and a self-advocate) have designed a plan for the development of a self-advocate committee
- Reviewed manuscripts and over 30 lay summaries for Network publications
- Published a family-authored paper in the *Pediatrics* Supplement
- Authored a new joint tool kit: Autism Telehealth Tool Kit for Families and Providers

Grew to over **30 members**
after launching in 2008 with just one family advisor

Registry

Patient registries are a vital tool for autism research and integrating clinical data from patient visits into the registry aids in research across the Network. In 2020 and early 2021, with the help of funding from PCORI, the Network enhanced its registry in several ways, making it more user friendly and functional:

- Adapted REDCap, a medical record application, to allow sites to directly import patient data into the registry
- Updated measures to include behavioral challenge, quality of life, improvement in irritability, hyperactivity, anxiety/fear/worry
- Stratified clinical diagnoses for more precise reporting of measures

1,104 patients enrolled between
January 1, 2020 – March 31, 2021
bringing the total to **2,422**

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Studies Funded by AIR-P and conducted on the Network platform in 2020

All of the following research studies have closed to enrollment and all research data has been entered and cleaned; the research teams are conducting final analyses and working on manuscripts through August 2021

Ameliorate Childhood Obesity Risk from Newer Antipsychotics for Individuals with Autism Spectrum Disorder (ACORN)

This study will adapt and test an empirically validated pediatric weight management program (Healthy Habits for Life; HH4L) for youth with ASD who gain weight on second-generation antipsychotics.

Evaluation of a Multimedia Sleep Education Package in Children with ASD (Sleep Ed)

This study explored whether a multimedia sleep education package can be successfully provided to families and show efficacy in improving sleep habits and sleep problems, along with parenting sense of competence. The research team has published primary study findings.

Improving Participation in Dental Care and Oral Health Outcomes for Underserved Children with ASD (Dental)

This study is a randomized controlled trial to compare the established ATN/AIR-P Dental Toolkit to an alternative regimen that combines the Dental Toolkit with a parent-mediated behavioral intervention. The research team has published study findings.

Physical Exercise to Reduce Anxiety in Underserved Children with ASD (PETRA)

This study tests whether a physical exercise intervention reduces anxiety in children in underserved families.

Resiliency Program for Siblings of Children with Autism Spectrum Disorder (SibChat)

This study is a pilot wait-list controlled trial to improve resiliency in teenage siblings of children with Autism Spectrum Disorder using an eight-session virtual Mind-Body intervention.

The Emotion Awareness and Skills Enhancement Program for Youth with ASD and Intellectual Disability: A Mind-Body Intervention to Improve Sleep, Health, and Emotion Regulation (EASE-ID)

This is a research effort to extend the benefits of a previously developed mindfulness-based intervention to youth with ASD and intellectual disability and evaluate its impact on sleep and overall physical health.

Study of the impact on COVID-related restrictions on the ASD diagnostic process

A qualitative study designed to identify the strengths and challenges of virtual evaluation and tele-assessments versus in-person assessment for children with ASD particularly as these evolved during the COVID shutdown in hospital outpatient clinical services in the Network.

Autism Speaks, AIR-P, and Quadrant Biosciences co-funded in 2020:

Neurophysiologic and Cognitive Effects of Minocycline in Adolescents with ASD

This study will examine effects of short-term treatment with the antibiotic minocycline on EEGs in persons with ASD compared to a placebo and potential effects on memory, social gaze, psychophysical markers, attentional impairments, quality of life and other concerns in adolescents with ASD.

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Publications & Proceedings

Over the 11 years of the ATN/AIR-P partnership, **167 manuscripts** were published on the groundbreaking work in clinical care improvements, 56 of which used the ATN registry for secondary data analysis.

In addition, **216 abstracts** have been accepted to academic conferences, seven of which occurred during this grant period.

Despite COVID-19 related restrictions causing disruptions and influencing the ability to conduct and complete research across all Network centers through 2020, the Network published **24 studies** during this grant year.

TRAINING AND Outreach



590 community training and outreach events hosted, not including ECHO Autism clinics



3 video toolkits were developed regarding behavioral health treatment and the safe and careful use of medication



3 toolkit one-pagers were developed to align with the Network's goal of reducing challenging behaviors about behavioral health treatment, anxiety, and irritability. One-pagers were also created to aid with visual schedules and sleep



20+ lay language summaries of Network publications completed and reviewed by family partners

Find toolkits at www.autismspeaks.org/tool-kit and <http://airpnetwork.org>.

Pre- and Post-Doctoral Training

The Network supports the training of highly promising autism researchers, while advancing research that improves lives.

1,281
pre- and post-doctoral students,
residents and fellows
received training at ATN/AIR-P sites

The Network supported
**2 post-graduate fellows at the
Clinical Coordinating Center
at Massachusetts General Hospital**

EXPANDING Community Reach

Provider Training ECHO Autism

Families need access to equipped professionals in their home communities. ECHO (Extension for Community Healthcare Outcomes) Autism is a telementoring platform that helps to solve the problem of patient need outgrowing the availability of autism specialists. ECHO Autism increases specialist’s knowledge through virtual, interactive, case-based guided practice and mentorship. Providers develop local expertise to apply best practices and serve their community.

Thanks to funding from the AIR-P, in 2016, ECHO Autism launched a feasibility study across the Network. Based upon its success and a continued partnership with Autism Speaks, ECHO Autism has expanded from Primary Care clinics to a range of health professions and family support to broaden its reach in our communities.

These clinics include support for, but not limited to screening and identification, diagnostics, caregiver skills training, mental and behavioral health access:

- PRIMARY CARE

FAMILY

RUBI

NETWORK RUBI

PRIMARY CARE STAT

FAMILY ADVOCATES
- BEHAVIOR SOLUTIONS

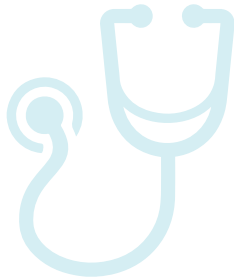
EARLY INTERVENTION

CRISIS CARE

PSYCOLOGY

MENTAL HEALTH

EXTREMISM



Through ECHO Immersion training, ECHO Autism clinic leaders “train the trainers.” Using the ECHO model, experts train local health organizations, providers and others to lead their own ECHO Autism clinics in their region, exponentially expanding the reach of autism best practices and care into local communities with trusted local expertise.

46 centers reached through ECHO immersion trainings between January 2020 – March 2021

3,596 providers trained through ECHO Autism in 2021;
862 family and community participants

=

4,458 total participants

ECHO Autism Expansion Highlights

Family ECHO launched in the spring of 2020 as a response to COVID and family/caregiver need. The clinic provides training and resources to family members and caregivers, including access to high quality professionals. Trained **701 family members and caregivers**.

ECHO RUBI is a virtual model of the evidence-based RUBI program that teaches providers how to support parents who are managing children with difficult behaviors. Launched in 2020, ECHO RUBI clinic participants include psychologists, behavior analysts, masters-level professionals and mental health practitioners. The clinic trained **189 participants** and led to the development of a Network specific RUBI in January 2021 which has trained **29 participants across 13 Network sites** to date.

ECHO Autism: Center Engagement, run by a multidisciplinary team of Network members, offers mentorship to regional centers throughout the world. This training teaches a model of care developed by the Network with a leading target of standardizing care. In 2020, the Center Engagement clinic served 20 additional sites and 86 participants, bringing the total across three cohorts to **31 centers and 161 participants**. This ECHO was instrumental in its ability to be repurposed to rapidly respond to the COVID crisis.

REDUCING HEALTHCARE DISPARITIES

Many families have struggled to access quality autism services in their local communities based on research that represents their experiences – from minority racial or ethnic groups, rural or urban areas, and families with few resources. Using data from autism centers around North America that are more representative than traditional autism research, the Autism Care Network is uniquely positioned to get this information to local providers and improve care for underserved populations.



Translated Parent Reported Outcome (PRO) measures into Spanish



Translated 1 video toolkit into Arabic, 1 into Vietnamese, and 2 into Spanish



Translated 12 tool kits into Arabic, 17 into Vietnamese, 6 into Turkish



ECHO Autism has reached nearly 4,000 providers across 15 countries (including the US and Canada)



Focused on recruiting diverse and underserved populations for research studies

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Network COVID Response

The outbreak of the COVID-19 pandemic across North America in March 2020 had a direct impact on the autism community and across all 20 Network sites. Many regular Network activities and clinic flows were directly hindered including, but not limited to: staffing shifts, disruption of research and study recruitment, limited face-to-face encounters between providers and patients, limited data collection, delays in obtaining legal and regulatory documentation, cancellation and postponement of programs and events. Based on a response to Network providers and families voicing a need for resources and services, the following efforts were put in place:

- **Compiled 90+ resources for families and providers ranging from information about COVID-19 to telehealth tips and visual supports**
- **Hosted provider and family webinars and family telementoring series to support individuals, families and providers in continuing clinical care during the pandemic**
- **Designed a study to assess how clinics perform remote diagnoses**
- **FAC members and providers authored a toolkit to address telehealth visits in the autism community**
- **Repurposed the ECHO Autism Center Engagement sessions to assist autism centers in planning for remote diagnostics and care**

LEVERAGED FUNDING:

Funds from the Health Resources and Services Administration, Autism Speaks, U.S. Department of Education, National Institutes of Health, Ontario Ministry of Health and the Missouri Department of Health supported a wide variety of projects across the Network, including:



MRI-based Presymptomatic Prediction of ASD



Screening and service program for underserved children



Network sites have leveraged over \$9.2 million in funding from external sources in 2020

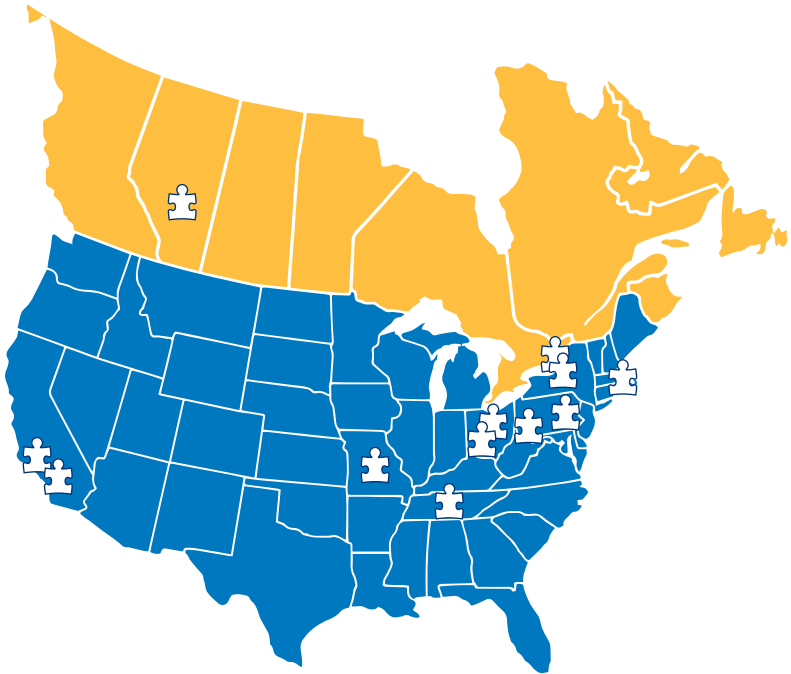


“Facing Your Fears” intervention program for children



Adapting Anxiety Intervention for Youth with Autism for Rapid Response to COVID.

In addition, the Network’s support of a pilot behavioral health intervention was leveraged into a \$190,000,000 project at Nationwide Children’s Hospital to develop a Psychiatric Crisis Department, several intensive outpatient and partial hospitalization programs, and four different inpatient units with one specifically designed for children and adolescents with ASD, though patients with ASD are treated across the full facility.



Thank You!

Network leadership would like to thank our patients, families, participating sites, providers and researchers for their dedication to advancing science and improving care, together.

- Children’s Hospital Los Angeles
- Children’s Hospital of Philadelphia
- The Kelly O’Leary Center for Autism Spectrum Disorders at Cincinnati Children’s Hospital Medical Center
- The Lurie Center for Autism at the Massachusetts General Hospital for Children
- Nationwide Children’s Hospital, Columbus, Ohio
- Holland Bloorview Kids Rehabilitation Hospital, Toronto
- University of Alberta and Glenrose Rehabilitation Hospital
- The Center for Autism & Neurodevelopmental Disorders at the University of California — Irvine
- University of Missouri Echo Autism Ready Communities
- The Center for Autism and Developmental Disorders at the University of Pittsburgh Medical Center
- The Autism Clinic at Vanderbilt University Medical Center
- The Division of Developmental and Behavioral Pediatrics at the University of Rochester Medical Center
- Phoenix Children’s Hospital
- Prisma Health Children’s Hospital-Upstate SC
- University of Nebraska Medical Center, Munroe-Meyer Institute
- University of Virginia Children’s Hospital-Division of Neurodevelopmental and Behavioral Pediatrics
- University of Wisconsin-Madison, Waisman Center
- Hospital for Special Care
- The Eunice Kennedy Shriver Center at University of Massachusetts Medical School, Center for Autism and Neurodevelopmental Disorders
- MetroHealth Autism Assessment Clinic

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AUTISM SPEAKS

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