The Autism Care Network is the first of its kind Learning Health Network for autism spectrum disorder (ASD). Made up of 20 academic institutions and children’s hospitals across the United States and Canada, the Network connects families, researchers and healthcare teams to continuously improve person- and family-centered autism care. By advancing research developments and clinical knowledge about ASD, the Network enables more personalized care and better quality of life for autistic people and their families.

The Autism Care Network utilizes person-first language (“person with autism”) rather than identity-first language (“autistic person”) in this report. In 2019, Autism Speaks polled the community about their preference and heard that there’s no “one-size-fits-all” approach. For that reason, we always recommend respecting individual preferences and using the language that feels most comfortable to the person on the spectrum.

VISION
Optimal health and quality of life for all individuals with autism spectrum disorder

MISSION
Create a sustainable system for care delivery, research, evidence development and dissemination

IMPACT
Improving clinical care
Mentoring and training
Research discoveries
Addressing healthcare disparities

SMART AIMS

DECREASE the percentage of children with moderate, severe or extremely severe challenging behaviors (as reported by parents/caregivers) from 85% to 75% by April 1, 2023

INCREASE the percentage of children whose parents report their quality of life as “very good” or “excellent” from 69% to 75% by December 31, 2023

With medical knowledge expanding rapidly, it’s more important than ever to reduce the time between the publication of new research and its application in the clinic. The Autism Care Network does this by transforming the way ideas are shared at the systems level, creating a diverse, interdisciplinary community that can distribute data, research and best practices quickly and easily.

By encouraging active collaboration between families, clinicians and researchers, the Network offers an innovative healthcare model that can achieve positive health outcomes at speed and scale.
Informing research and care through real-time data

One of the most distinctive features of the Autism Care Network is our innovative data registry. Patient and caregiver data is collected during each patient visit and shared with Network sites as part of routine clinical practice.

This digital platform allows for the same patient data to be used in clinical care, research and clinical improvement efforts. Researchers and clinicians can access this data to understand which interventions deliver the best outcomes, allowing providers to make real-time, informed decisions for their patients. The aggregated Network data is further used to shape research, identify disparities in care, develop best practices and identify what is (and what and is not) working for whom.

IN THE 2021 FISCAL YEAR

The patient registry grew by 45%

983 patients enrolled in the registry, bringing the total to 3,147

Diversity across the patient registry increased by 28%
Reducing barriers to optimal quality of life

Network registry data shows that one of the biggest barriers to achieving optimal outcomes and quality life for people with ASD and their families is the impact of behavior challenges, specifically behaviors that are harmful or dangerous to the individual or others.

These behaviors can prevent access to full participation in education and community life, and can cause harm, stress, isolation and caregiver burnout. The data also shows that the co-occurring conditions of ADHD, anxiety and irritability are the primary drivers of these behavioral challenges.

A survey of the first 500 children enrolled in the Network registry revealed:

- Challenging behaviors affect 93% of families enrolled in the Network registry.
- 85% of these families report moderate to extreme behavior severity.
- 61% report that challenging behaviors occur at least once a day or many times per day.
- ADHD, anxiety and irritability are the primary drivers of behavior challenges.
Developing clinical pathways to better care

Based on these findings and critical input from family partners, Network sites are working in three Improvement Labs and one Learning Lab to reduce the impact of behavior challenges. Their work focuses on developing evidence-informed clinical pathways to improve the identification and treatment of ADHD, anxiety and irritability.

The development, reliable implementation and testing of these clinical pathways are important steps toward standardizing care and ensuring that all children receive the same high-quality care regardless of where they are seen.

The ADHD, Anxiety and Irritability Improvement Labs aim to:

- Improve the identification and treatment of ADHD, anxiety and irritability
- Standardize care across Network sites
- Evaluate the impact of clinical pathway implementation on health outcomes

A Screening Pathway Learning Lab was also formed to develop a reliable system for early surveillance of challenging behaviors by screening for ADHD, anxiety and irritability in children with ASD. Network sites are still refining this clinical pathway and establishing its reliability.
Standardizing care for ADHD, anxiety and irritability

Each of the three Improvement Labs measures its progress in terms of reliability, or how consistently a healthcare provider is adhering to or implementing each step of a developed clinical pathway.

Reliability levels are ranked level 1 (80-90% reliable), level 2 (91-95% reliable) or level 3 (96-99% reliable). According to the James M. Anderson Center for Health Systems Excellence, systems failing to meet level 1 reliability lack standardization of care and are considered “chaotic” systems.

The Autism Care Network Improvement Labs have shown promising results in standardizing care for ADHD, anxiety and irritability. In 2021:

- **Sites involved in the ADHD Improvement Lab** increased reliability in all six markers, reaching level 1 or 2 reliability in three markers.
- **Sites involved in the Anxiety Improvement Lab** increased reliability in five out of six markers, reaching level 1 or 2 reliability in four markers.
- **Sites involved in the Irritability Improvement Lab** increased reliability in four out of eight markers, reaching level 1 or 2 reliability in seven markers.

Assessing child safety at Network sites

Reliability improved from 71% to 91% in 2021

Significant improvement was achieved across the Network this year in the area of child safety. Network providers have reached level 2 reliability in asking parents and caregivers about child safety concerns during their visits, with reliability improving from 71% to 91%.

Phase two of the Improvement Lab work will focus on improving the reliable implementation of clinical pathways across more providers, reaching Network-wide reliability across key markers, and setting up measures to evaluate the impact of clinical pathways on health outcomes.
Working hand-in-hand with families and self-advocates

The family voice has always been a vital piece of Network activities and is represented across all our improvement work, research, committees, workgroups and publications. This year, our Family Advisory Committee (FAC) shifted to the Family Partners Committee (FPC), a move meant to symbolize that our families are not only providing input but are actively collaborating with their site and the Network.

Family Partners work intimately with their Network site teams to identify opportunities for improvement, test innovations and create tools and resources both locally and nationally. With over 40 family members spanning across all 20 Network sites, the FPC works to increase the Network’s capacity to improve outcomes, value and the experience of autistic people and their families.

Though self-advocates have long been represented on the FPC, in 2021, the Network worked with several self-advocates and family partners to develop a Self-Advocate Committee. This committee consists of five Network representatives diagnosed with ASD who collaborate on Network-wide activities to ensure voices from the autism community are represented. The Self-Advocate Committee seeks to expand and have representation across all 20 Network sites.

In 2021 and early 2022, family partners and self-advocates:

- Co-authored three publications
- Co-produced a new demographics collection form and pre-visit planning materials
- Collaborated with Network staff and leadership to present data and findings at professional conferences focused on autism and other developmental disorders
- Served as subject matter experts in over six ECHO Autism clinics
- Participated as active participants on two research study design teams
- Wrote and reviewed nine lay language summaries of Network publications
- Remained ongoing members of the leadership team for two key Network studies
Expanding care in underserved communities

**ECHO (Extension for Community Healthcare Outcomes) Autism** is a tele-mentoring platform used to engage providers, disseminate findings and best practices, and increase access to autism care, knowledge and resources in underserved and rural areas. Using an “all teach, all learn” philosophy, ECHO Autism participants engage in case-based learning, ask questions and receive recommendations from a team of multi-disciplinary experts to improve and expand care and expertise.

Through the partnership between Autism Speaks, ECHO Autism and the Autism Care Network, ECHO Autism and Network leaders have the opportunity to both “train the trainers” and streamline autism care and best practices.

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**In 2021:**

- **3,454 community providers mentored** through an ECHO Autism clinic, bringing the total number of mentored providers to 7,138
- **1,495 family and community members participated** in an ECHO Autism clinic
- **ECHO Autism served providers in 16 countries** (including the U.S. and Canada) in 2021
- **Family ECHO: Autism engaged families and caregivers in all 50 states, across 37 countries, with 46 languages spoken in households, while providing live Spanish translation**
Improving provider knowledge of autism

ECHO Autism is a key component of improving provider knowledge and bridging the gap between autism specialists and community providers. To maximize the impact of ECHO Autism, the Network is engaged in efforts to make the trainings more accessible to providers around the world. We are also continuing to expand ECHO clinics across disciplines, including several clinics now educating family members and caregivers.

In 2021, Network sites ran ECHO Autism clinics on the following topics:

- Primary Care
- Family
- RUBI (parent training program for disruptive behavior)
- Network RUBI
- After RUBI
- Primary Care STAT (early diagnosis tool)
- Family Advocates
- Behavior Solutions
- Early Intervention
- Crisis Care
- Mental Health
- Psychology
- Applied Behavior Analysis (ABA)
- Extremism
- Education
- Screening, Referral Pathways and Initial Supports to Lessen ASD Disparities
- Allied Health (SLP, OT, Nursing, etc.)
- LEND: Neurodevelopmental Disabilities
**ECHO Autism Immersion Training**

**ECHO Autism Immersion Training** utilizes ECHO Autism leaders and the ECHO model to train local healthcare providers, autism centers and other stakeholders to launch their own ECHO Autism clinics. The goal is to continue to expand reach in local communities and provide deeper autism expertise and access to quality care.

- **192 participants across 53 centers trained through ECHO Autism Immersion Trainings**
- **Two booster sessions were held as ”refreshers” for ECHO Autism clinic leaders who have attended trainings in the past**

**ECHO Autism: Center Engagement**

**ECHO Autism: Center Engagement** seeks to minimize the variation in care across autism centers and aims to make care and resources more easily accessible to rural and underserved communities both within North America and internationally. The team of multidisciplinary autism experts, made up of eight leaders within the Network, uses a curriculum based on a model of care developed by the Network. Feedback from this series expressed its value in fostering relationships and community building, as well as allowing for growth and continued learning.

- **64 individuals across 15 new, non-Network centers participated**
- **Participation across four cohorts increased to 225 participants and 51 non-Network centers**
Community recruitment pilot

To respond to the gap in knowledge and quality of care between autism specialists and community and primary care providers, three Network sites came together in 2021 to create a Community Recruitment Pilot workgroup. Together, these sites have developed a process to begin integrating community providers and their patient data into the Network. The goal is to drive improvements in care and expand the knowledge and skillsets of these clinicians, giving them the tools to better diagnose and care for people with autism.

In 2021:

- The University of Missouri – ECHO Autism Communities collaborated with Canadian sites to strategically plan broader community recruitment and share learnings from previous work with community providers and the Network.
- Four community pediatricians were engaged and onboarded to the Network by the University of Alberta team and have begun testing Network data collection forms at their practices.
- Holland Bloorview developed a questionnaire to learn what health data community providers use at their practices and how this aligns with Network.

Advancing innovative research

The Autism Care Network supports research studies that advance better interventions for ASD and related conditions. Researchers have access to a robust platform for discovery and implementation as they work to improve knowledge about autism and clinical care practices.

In the first year operating as the Autism Care Network:

- 10 manuscripts were published on groundbreaking work in clinical care improvements (bringing the cumulative total number of manuscripts developed between the Autism Care Network and ATN/AIR-P to 177).
- Three of these studies used data from the previous Autism Treatment Network registry for secondary data analysis.
- 14 abstracts were accepted to academic conferences.
- Five manuscripts on Network studies are currently in development.
- Two research studies were launched with support from Autism Speaks and external funders.
Published research studies

The Autism Care Network supports research studies that advance better interventions for ASD and related conditions. Researchers have access to a robust platform for discovery and implementation as they work to improve knowledge about autism and clinical care practices.

In 2021, the Network supported the publication of 10 research studies:

Emergency department utilization of adolescents and young adults with autism spectrum disorder (DOI: 10.1007/s10803-021-04969-y)

Deficits in socialization and daily living skills associated with gastrointestinal symptoms in children with autism spectrum disorder (DOI: 10.1080/02739615.2021.1925117)

A REDCap-based model for online interventional research: parent sleep education in autism (DOI: 10.1017/cts.2021.798)

Challenges and growth: lived experience of adolescents and young adults (AYA) with a sibling with ASD (DOI: 10.1007/s10803-021-05135-0)

Facilitator reflections on shared expertise and adaptive leadership in ECHO Autism: Center Engagement (DOI: 10.1097/CEH.0000000000000395)

A cluster analysis of daily living skills in school aged children with autism spectrum disorder (DOI: 10.1080/20473869.2021.1980350)

Stakeholder informed development of the Emotion Awareness and Skills Enhancement team-based program (EASE-Teams) (DOI: 10.1177/13623613211061936)

Parent activation measure for developmental disabilities (PAM-DD) in caregivers of individuals with ASD (DOI: 10.1007/s10803-021-05263-7)

Correlates of oral health fatalism in caregivers of children with autism spectrum disorder. Special care in dentistry (DOI: 10.1111/scd.12564)

Evaluating sleep quality using the CSHQ-Autism (DOI: 10.1016/j.sleep.2021.08.022)
Enabling precision care and early diagnosis

In 2021, the Autism Care Network supported two major, groundbreaking studies.

**Precision Autism Treatment for Health (PATH) to Discovery**
*(funded by Autism Speaks and private donors)*

**GOAL:** This study aims to develop a roadmap to personalized medicine and healthcare for individuals with autism. A main goal is to build a discovery platform to understand the biology of ASD subtypes, as well as to have an ecosystem where biological discoveries can be turned into specific insights to guide clinical management.

**NETWORK SUPPORT:** Currently, six Autism Care Network sites are collaborating on this study, with a target enrollment of 100 families, including both biological parents and a child with ASD.

**FDA Validation of a Salivary miRNA Diagnostic Test for Autism Spectrum Disorder**
*(funded by Autism Speaks and Quadrant Biosciences)*

**GOAL:** With breakthrough device designation granted by the FDA, this study aims to validate Clarifi ASD as an in-vitro diagnostic for use within its intended use population, children at risk for the development of ASD. The primary goal of this work is to demonstrate that Clarifi ASD can accurately distinguish children with ASD from those without ASD.

**NETWORK SUPPORT:** Currently, 12 Autism Care Network sites and five external partnering sites are collaborating on this study, with a target enrollment of 6,604 children.

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Empowering young leaders

The Network also supports the ongoing training of promising autism researchers who help innovate in the field and make discoveries that enhance the quality of life of people with autism and their families.

**In 2021 1,763 pre- and post-doctoral students, residents and fellows received training** at Autism Care Network sites

**Over 85 trainees across over 20 disciplines** participated in the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program
Maximizing Our Investment

In 2021, Network sites leveraged over $6 million from external organizations, including Patient-Centered Outcomes Research Institute, Health Resources and Services Administration, National Institute for Health, the United States Departments of Education and Defense, NYS Office for People with Developmental Disabilities, Family Support Services and the Missouri Department of Mental Health.

This funding has supported a wide variety of projects across the Network, like:

Clinical services for home and community management of semi-acute behavioral challenges and manualized behavioral interventions for parents.

ECHO Autism Communities that support capacity building in rural and underserved communities in Missouri.

Implementation of screening for suicidality, comparing two interventions.

An interdisciplinary training program that provides services and care to improve the health of infants, children and adolescents with disabilities.

Trial of the Early Social Interaction (ESI) model using mobile technology for toddlers with autism identified from early screening in primary care.

In 2021, the Autism Care Network, through generous support from Autism Speaks, Quadrant Biosciences and private donors, was awarded $636,607 for the PATH to Discovery study and an additional $6,200,000 for the FDA Validation of a Salivary miRNA Diagnostic Test for Autism Spectrum Disorder study, for a total of $6,836,607.

The Network is continuously working to leverage the Autism Speaks investment to conduct other work in research, training and dissemination of clinical advances.
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 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