Individual QI projects from single institutions

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Identifying Autism Spectrum Disorder in a High-risk Follow-up Program through Quality Improvement Methodology

*Christine M. Raches, PsyD*Elesia N. Hines, PsyD*Abbey C. Hines, PsyD†Emily K. Scott, MD†*

Abstract

Introduction: Children born prematurely are at increased risk for autism spectrum disorder (ASD). ASD can be diagnosed between 18 and 24 months of age, but access barriers and medical complexity can delay diagnosis. ASD screening was implemented in a high-risk infant follow-up program using QI methodology. The project aimed to screen 60% of children and refer 90% of those with positive screens. **Methods:** The team developed a standardized workflow to administer the M-CHAT-R/F to HRIF patients between the ages of 16–22 months. Telehealth ASD assessment, using the TELE-ASD-PEDS, was conducted for those who screened positive. Monthly team meetings were held to implement change cycles and review the impact of the previous month's change. **Results:** Within 7 months of program implementation, ASD screening exceeded the 60% aim. The program referred 72% of patients who screened as medium/high risk on the M-CHAT-R/F. The remaining patients were not referred per provider discretion. Twenty-seven percent of patients who received an autism evaluation received an ASD diagnosis. The average age at diagnosis was 22.5 months. **Conclusions:** An ASD screening protocol was implemented for patients enrolled in a high-risk infant follow-up program. Patients identified as at risk for ASD received an expedited telehealth ASD evaluation. The screening protocol was maintained for 13 months and is now part of the standard workflow. Screening has been expanded to other HRIF clinics, and evaluation appointments have been added to meet access needs. QI methodology is an effective tool for implementing ASD screening and referral in multidisciplinary HRIF programs. *(Pediatr Qual Saf 2024;9:e717; doi: 10.1097/pq9.0000000000000717; Published online April 3, 2024.)*

INTRODUCTION

Problem Description

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by persistent deficits in social communication and social interactions, as well as the presence of restricted, repetitive patterns of behavior.[1]

One in 36 children has been identified with ASD according to estimates from the Centers for Disease Control and Prevention Autism and Developmental Disabilities Monitoring Network.[2] Children born prematurely or requiring neonatal intensive care are more likely to be diagnosed with ASD. Estimates suggest that NICU graduates have a prevalence rate of 6%, with higher rates found at lower gestational ages.[3–5]

Despite evidence that ASD can reliably be diagnosed between 18 and 24 months of age,[6] the average age of ASD diagnosis in the United States is over 4 years.[7] The American Academy of Pediatrics recommends that autism screening occur at the 18 and 24-month well-child visits; however, studies estimate that less than half of children with ASD were screened before three years of age.[8] Screening in the preterm population may be particularly challenging for the primary care provider due to the need to adjust for prematurity in children less than 2 years of age. Primary care providers are often cautious when interpreting autism screening results in children born prematurely or those with motor, cognitive, vision, and hearing deficits, as rates of positive screens in these populations are high.[9] Other factors, including scarcity of expert evaluators and lengthy evaluations,[10] can delay early diagnosis and intervention. Early diagnosis and intervention improve developmental outcomes for children with ASD.[7]

*From the *Division of Developmental Medicine, Department of Pediatrics,Indiana University School of Medicine; and †Division of Neonatology, Department of Pediatrics, Indiana University School of Medicine.*

**Corresponding author. Address: Christine M. Raches, PsyD, Division of Developmental Medicine, Department of Pediatrics, Indiana University School of Medicine, 1002 Wishard Blvd, Suite 3120, Indianapolis, IN 46202*
PH: 317-944-4846;
Email: craches@iu.edu

Presented at the Indiana University Department of Pediatrics 4th Quality Improvement Competition, and at the Pediatric Academic Societies 2023 Meeting.

To cite: Raches CM, Hines EN, Hines AC, Scott EK. Identifying Autism Spectrum Disorder in a High-risk Follow-up Program through Quality Improvement Methodology. Pediatr Qual Saf 2024;9:e717.

Received for publication October 10, 2023; Accepted January 17, 2024.

Published online April 3, 2024

DOI: 10.1097/pq9.0000000000000717

Available Knowledge

Rationale

HRIF programs are a vital resource that provides developmental assessment, treatment planning, and ongoing support to the families of infants and young children who have graduated from the NICU. Additionally, it is known that surveillance for neurodevelopmental risks is especially important in this clinical population, and programs have become particularly interested in telehealth visits for this population during the COVID-19 pandemic.[11] Although HRIF practices are highly variable, programs typically include a multidisciplinary team conducting standardized assessments at predetermined intervals with the primary goal of helping each child develop to their full potential. Given this relationship with families, expertise in development, and frequent interactions, these programs are ideal for screening for ASD as a part of their normal clinic flow.

Specific Aim(s)

The global aim of this project was to improve the identification of ASD in an HRIF program. The SMART (Specific, Measurable, Achievable, Relevant, and Time-Bound) aim of this project was to "screen 60% of children enrolled in an HRIF program at their 18-month visit using the Modified Checklist for Autism in Toddlers- Revised with Follow-up[12] (M-CHAT-R/F) within 9 months of project initiation and to refer at least 90% of children who screened positive for further evaluation."

METHODS

Context

Autism screening (using the M-CHAT- R/F) was implemented in a multidisciplinary HRIF program supporting both level III and IV academic NICUs and several community-based NICUs. Patients are referred to the HRIF program if they are born at less than 32 weeks gestation, receive a diagnosis of moderate or severe bronchopulmonary dysplasia or complex congenital heart disease, undergo surgery as a neonate, or are discharged with a nasogastric tube or high-calorie feedings (27 calories per ounce or higher). The HRIF program is staffed by general pediatricians, child psychologists, pulmonologists and neurologists as indicated by patient need. Supporting team members include dietitians, social workers, speech therapists, physical therapists, occupational therapists, respiratory therapists, and nurse coordinators. The HRIF program is part of an academic children's hospital and is a training site for medical students, pediatric residents and neonatology fellows. The HRIF program staffs ten half-day clinics weekly in 2 locations and enrolls approximately 250 new patients yearly. Seventy percent of enrolled patients are white, 22% are black, and 6% are Asian. Twenty-three percent of enrolled patients identify as Hispanic. Due to the nature of our program, which treats medically complex children, most patients have public insurance coverage based on either income or medical qualification. The overall attendance rate for appointments within the HRIF program is approximately 81%.

Intervention(s)

An interdisciplinary team of medical providers consisting of one physician and three psychologists met to set the SMART aim and develop the key driver diagram (Fig. 1). The M-CHAT-R/F was identified as a level 1 screening measure for autism in this clinical population.[10] Baseline data were collected 6 months before program initiation in March 2022. After a review of the literature and process mapping the current clinic flow, the team developed a standardized workflow to administer the M-CHAT-R/F to patients presenting to HRIF between 16 and 22 months of adjusted age during their routine clinic visit with a medical provider to assess growth and development. A consistent approach was delineated to administer follow-up questions and refer for further evaluation by a psychologist for any toddlers determined to be at medium or high risk for autism after administration of the follow-up questions on the M-CHAT-R/F (Fig. 2). Four telehealth psychology clinic appointments (composed of diagnostic interviews and virtual play-based assessments) were created monthly and reserved for patients requiring follow-up evaluation after a medium or high-risk M-CHAT-R/F screen. Education was provided to all medical providers through a monthly staff meeting.

Study of the Intervention(s)

The interdisciplinary team of providers met monthly to review screening rates and current access to psychology telehealth appointments. During monthly meetings, the key driver diagram was revisited, and change cycles (using the Plan-Do-Study-Act methodology) were planned to improve screening rates in the HRIF program. Changes were spread clinic-wide through monthly provider meetings, daily clinic huddles with all HRIF program providers, and one-on-one coaching as needed. The following month, the impact of the change was assessed by the interdisciplinary team, and the decision was made to adopt, adapt or abandon the change. Interventions were notated on a run chart over time.

Measures

The primary aim was to screen 60% of eligible children during their 18-month adjusted age HRIF visit. Because of variability in scheduling practices, the team expanded this to all children presenting between 16 and 22 months of adjusted age. To collect data monthly for the run chart, the team looked at the total number of children presenting to HRIF each month between 16–22 months of age. A manual chart review was conducted for these children to determine if an M-CHAT-R/F was administered. This comprised the primary QI outcome.

For children who screened positive on the M-CHAT-R/F, the following data were collected: the M-CHAT-R/F score,

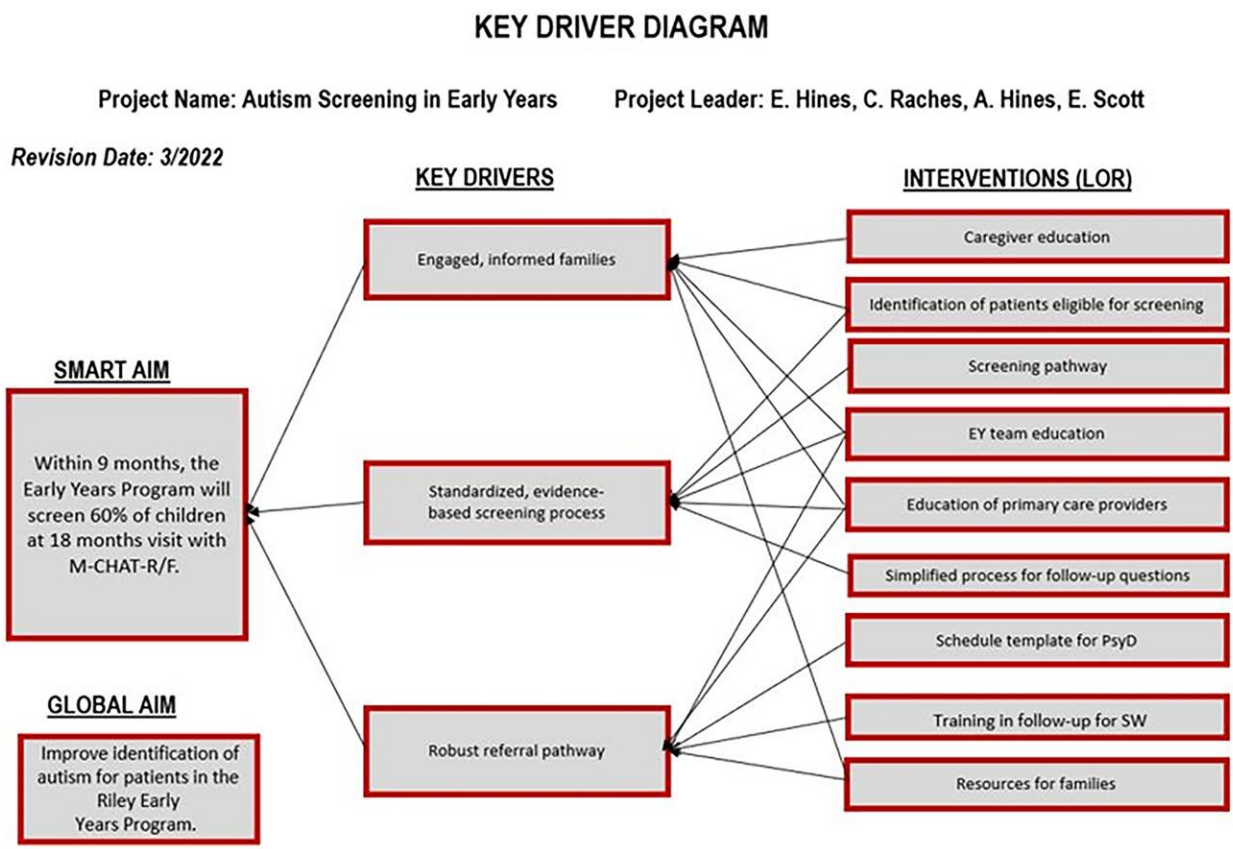

Fig. 1. Key driver diagram.

whether a psychology referral was made, the time from initial autism screening to psychology evaluation, what autism diagnostic test was administered and whether a formal diagnosis of ASD was made. For the QI initiative, lag time to psychology appointment was a particularly important metric that the team monitored frequently.

Analysis

All data were collected through manual chart review and stored on a Microsoft Excel spreadsheet housed on the university's secure and HIPAA-compliant cloud. Run charts were created through Microsoft Excel. After the project, a control chart was created using QI Macros through Microsoft Excel.

Ethical Considerations

This study was submitted to Indiana University's institutional review board and was determined to be Non-Human Subjects Research and exempt from review.

RESULTS

Baseline Data

Before the initiative kick-off in March 2022, screening for autism in the HRIF program was performed sporadically by the medical providers, most commonly if the medical provider had a clinical suspicion during the 18-month appointment or if the family raised concerns. In the 6 months of baseline data collection, only 6 of 67 patients (9%) presenting between 16 and 22 months adjusted age had M-CHAT-R/F screening performed.

Program Implementation

The autism screening initiative began in March 2022 with the roll-out of a standardized clinical workflow (Fig. 2) and provider education. That month, there was a sharp increase in screening, and the team exceeded the primary aim of 60%, as expected with the initial education push. Throughout the program's first 6 months, variability in screening rates prompted multiple PDSA cycles to achieve consistent screening rates throughout HRIF clinics. For the final 7 months of data collection, screening occurred above the project aim as the screening and referral process became more hardwired in the standard clinical workflow (Fig. 3). In the final month of data collection, 92% of eligible patients were screened.

In the 13 months after the implementation of this QI project, 111 of 168 (66%) eligible patients were screened with the M-CHAT-R/F (Fig. 4). A commonly cited reason for providers not conducting autism screening was a lack of time or an urgent medical concern that took precedence during the clinic visit. Twenty-five patients, or 23% of screened patients, had an M-CHAT-R/F score that placed

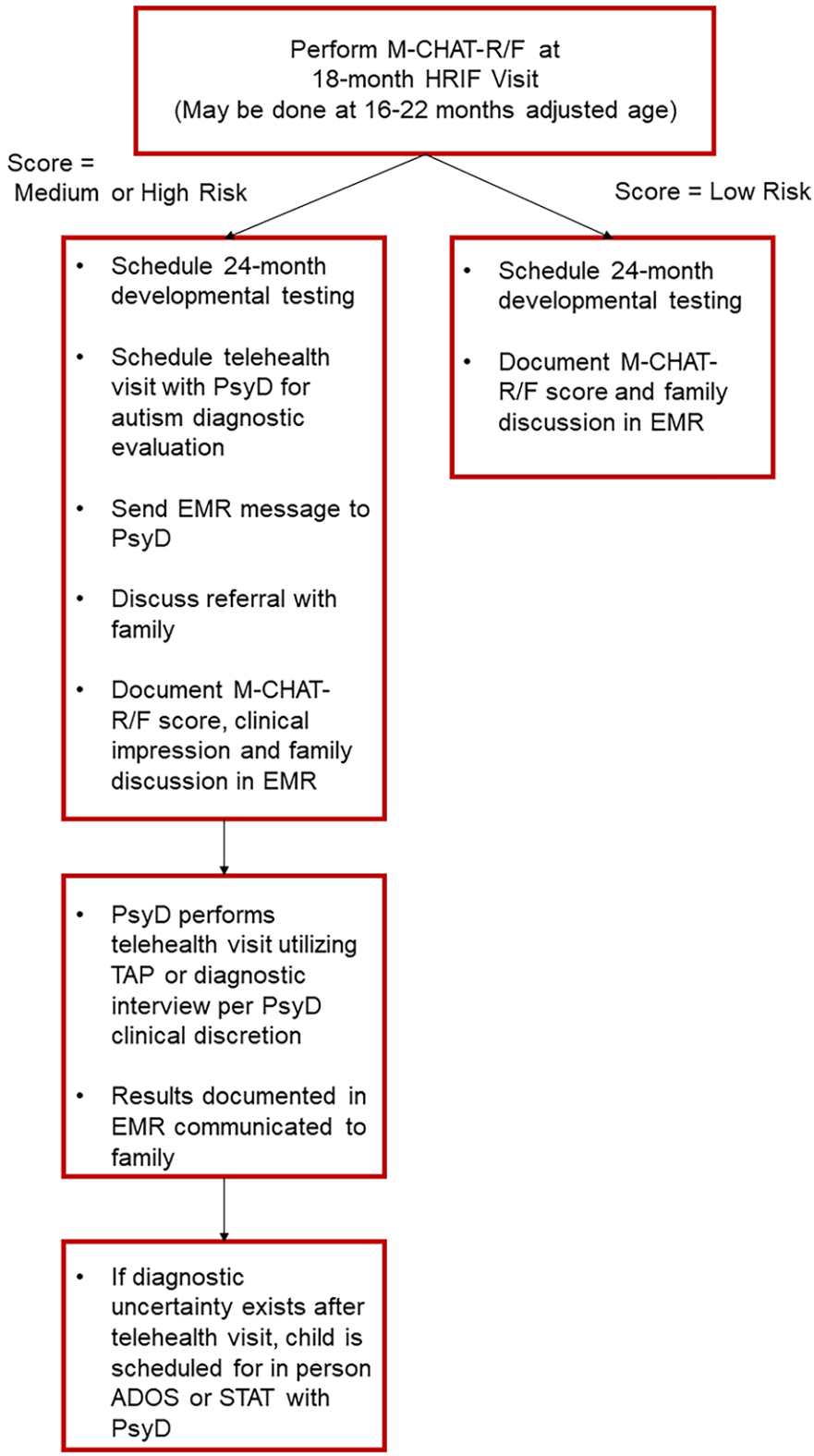

Fig. 2. Clinical pathway. The standardized workflow and decision-making used in the HRIF program depend on M-CHAT-R/F results.

them at medium or high risk for ASD. Per clinic workflow, all these patients were eligible for an autism evaluation with a developmental psychologist. Eighteen of those 25 patients (72%) were referred for an autism evaluation. The other seven patients (28%) were not referred at the medical provider's discretion. Reasons for not referring for an autism evaluation included a known, under-treated hearing loss and significant global developmental delay (such as not yet walking). Of the 18 patients scheduled for diagnostic evaluation, 15 patients (88% of those referred) attended their

telehealth appointment with a psychologist. Three of the 15 patients had a diagnostic interview alone. Twelve of the 15 patients (80%) were administered the TELE-ASD-PEDS.[13] Four toddlers (33%) were scheduled for in-person diagnostic assessment [either the *A*utism Diagnostic Observation Schedule, Second Edition (ADOS-2)[14] or the Screening

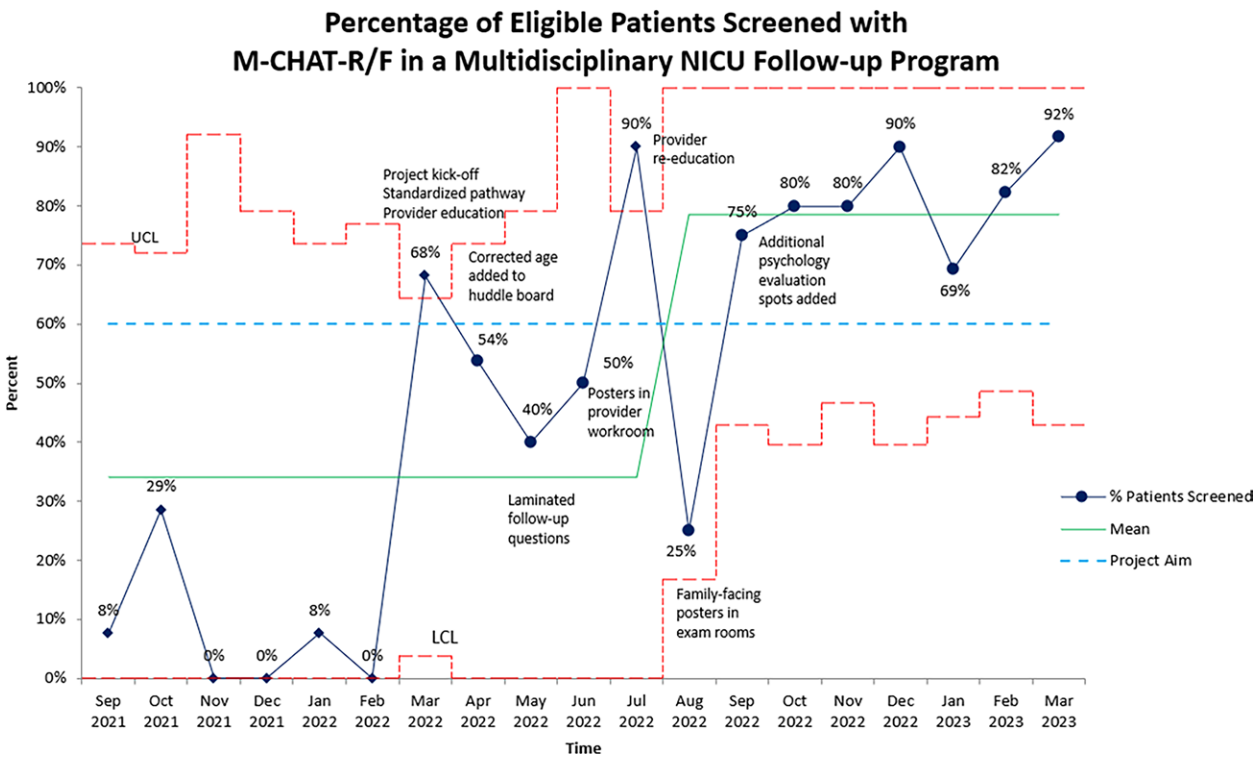

Fig. 3. Control chart. Percentage of eligible patients screened with the M-CHAT-R/F in the HRIF program. Additional information regarding these interventions is in the Results section.

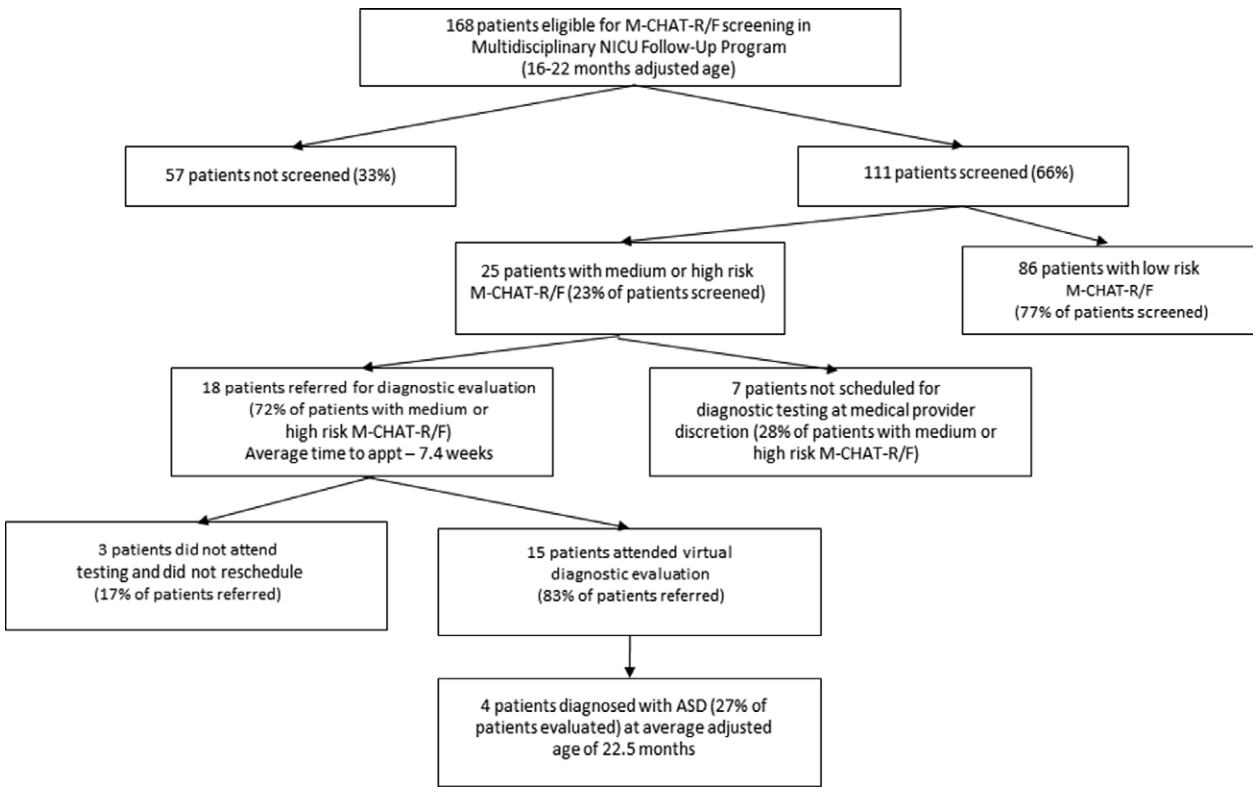

Fig. 4. Population. Outcome data for the 168 patients eligible for screening using the M-CHAT-R/F.

Tool for Autism in Toddlers and Young Children (STAT)[4] following their TELE-ASD-PEDS due to diagnostic uncertainty. Four children received a diagnosis of ASD, representing 27% of the patients receiving formal autism evaluation and 4% of the total population screened in the clinic. The average adjusted age of diagnosis was 22.5 months.

Key Interventions

Aside from a standardized workflow, key interventions included a process for easily identifying a patient's adjusted age and a method for easily administering follow-up questions for the M-CHAT-R/F. Because the clinic's medical record system identifies a patient's age as age from birth rather than their age adjusted for prematurity, patients occasionally were not identified as eligible for autism screening. During the morning clinical team meeting, a process was created to list a patient's adjusted age on the daily huddle board and immediately pull the M-CHAT-R/F screener to be given to the family upon arrival for the appointment. Adding this step to the huddle raised awareness of screening for the entire team and allowed key communication between the medical provider, medical assistant and clinic nurse. In addition, the M-CHAT-R/F has follow-up questions that should be given if a patient scores in the medium-risk category. Initially, this required the provider to return to a computer, pull up the follow-up questions and print out each additional question. During a busy clinic, this slowed workflow and decreased provider satisfaction. To combat this barrier to screening, two binders were created for each clinic containing all of the laminated follow-up questions, which could be used with dry-erase markers and reused indefinitely. This PDSA cycle was a key medical provider satisfier and streamlined screening in the clinic.

Autism Evaluation Scheduling

At the project's onset, the team anticipated that autism evaluations would be scheduled within 8 weeks of a positive screen. After the fourth month of implementation, appointment lag times for the psychology evaluations increased to 14 weeks, above the time the team considered acceptable. At that time, an additional two autism evaluations per month were added, increasing the number of available appointments from 4 per month to 6 per month. Throughout the project, the average time for autism diagnostic evaluation was 7.44 weeks.

Provider and Patient Satisfaction

A formal evaluation of provider and patient satisfaction still needs to be obtained. However, providers reported increased comfort in screening patients for ASD, knowing that they would be able to receive a formal autism diagnostic evaluation within a reasonable time frame through a simple referral process in the electronic medical record. Families appreciated the expedited evaluation through telehealth within the HRIF program in the child's home environment.

DISCUSSION

Summary

Using QI methodology, autism screening was successfully implemented as a standard of care at 18-month visits in an HRIF program. Starting with a baseline of infrequent screening at provider discretion, the team reached the goal of screening >60% of eligible patients after seven months. It maintained this screening level, or higher, for an additional six months. By nimbly responding to increased demand with increased access, the team could keep the median lag to formal diagnostic testing to less than eight weeks throughout the project. By screening patients early, reserving diagnostic spots for HRIF patients and offering a virtual option for evaluation, we overcame many documented barriers that often lead to delays in evaluation and diagnosis. The average age of diagnosis of autism in this project was 22.5 months adjusted age, which is well below the national average of over four years.

Interpretation

Of patients screening positive in the clinic, 72% were referred for further evaluation by a psychologist. The stated aim was that 90% of patients screened positive would be referred. Upon further reflection, the team acknowledges that a 90% initial referral rate was ambitious, given the degree of medical complexity and developmental delay that impact the HRIF population. Medical providers wanted to use clinical decision-making to delay psychology referral if they felt the toddler was not developmentally appropriate for autism diagnostic testing. In future work, an alternative option will allow for repeat autism screening by the medical provider at a 3-month interval coinciding with a follow-up HRIF visit to determine if referral is appropriate or autism is no longer a concern. In addition, standardized process education was provided for all team members; however, provider-specific variability was noted in the frequency of screening and referral. These provider discrepancies may be related to differences in providers' prioritization of ASD screening during a complex multidisciplinary visit.

The overall 4% rate of diagnosed ASD for this project is higher than the base rate of ASD in the general population (2.3%) but still below the 6% rate reported in other studies of NICU graduates.[4,5] This may be explained by the smaller number of patients in the sample and the short period of the project. The presence of developmental delays, sensory impairment, and behavioral challenges may complicate accurate ASD diagnosis in toddlers.[15] For these reasons, children who did not meet the criteria for an ASD diagnosis or who were not referred for an autism-specific evaluation should continue to have their social communication skills monitored.

A particular strength of this project is that the clinical HRIF program was well-suited to implement ASD screening

and diagnostic evaluation. Both clinic locations had support staff willing and able to assist with completing the screening instrument. Additionally, two clinical psychologists with training and expertise in the assessment of ASD in young children were already on the team providing parental mental health support. Before the screening project, the psychologists were embedded in and available during scheduled clinics for consultation and warm handoffs with referred parents. Following project implementation, the psychologists scheduled ASD evaluations during these clinic times. They contacted parents referred for mental health services by phone rather than initially meeting them during their children's clinic appointments. Thus, the team created a new clinical service (ie, ASD evaluations) without increased financial support by reallocating a percentage of their effort. Additionally, the ASD telehealth evaluations were billable services for the psychologists (billed as diagnostic interviews and screening), making this a sustainable practice for the clinic. Over time, this service can be generalized to other specialty clinics to meet the HRIF population's needs better.

Limitations

This study has several limitations which may impact generalizability and feasibility. This QI initiative was implemented in a small, self-contained program and thus has a small sample size. The QI project was not funded but was accomplished with existing clinic personnel resources. While telehealth ASD evaluation is considered a strength of the program, patient satisfaction data regarding telehealth visits were not collected. Furthermore, the psychologists in the clinic were already proficient in ASD evaluation and diagnosis (both traditional/in-person and telehealth evaluations). They did not require additional training to implement this project. The M-CHAT-R/F has been criticized for its lower specificity when administered to children who have an increased likelihood of having ASD.[16] Providers' knowledge of this limitation may have influenced their decision to administer the M-CHAT-R/F or refer patients who screened positive for further ASD evaluation.

Conclusions

Children seen in specialty clinics have the potential to be screened for autism in these clinics as a part of their HRIF programs. HRIF programs should regularly screen for developmental delays and neurodevelopmental risks. An ASD screening protocol for toddlers was successfully implemented and sustained in an HRIF program serving patients discharged from level III and IV NICUs. In the six months of baseline data collection, only 9% of patients enrolled in the program were screened for ASD using the M-CHAT-R/F. In the 13 months following implementation of the QI project, 66% of patients were screened for ASD. Four children received a diagnosis of ASD, representing 27% of the patients receiving formal autism evaluation and 4% of the total population screened in the clinic. The average adjusted age of diagnosis was 22.5 months. Families and providers expressed satisfaction with the expedited evaluation by developmental psychologists and follow-up with resources. The program was expanded to receive referrals from the hospital's neonatal neurology follow-up clinic and 2-year NICU follow-up developmental testing appointments in response to demonstrated need. Overwhelmingly, parents report satisfaction with telehealth appointments and increased access to specialty appointments and providers. The addition of autism screening to the HRIF program provided another venue to meet the needs of families already enrolled in the program, and the addition of autism-specific evaluations by trained psychologists improved access issues for families.

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