

Autism Screening for Young Children with Down Syndrome in a Primary Care Setting

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Background

- Young children with Down syndrome (DS) are at higher risk for autism spectrum disorder (ASD), with a 16% likelihood of a comorbid diagnosis of ASD compared to the national average of 1.7%.
- Children with DS receive an ASD diagnosis later than other children.
- While developmentally typical children are commonly screened for ASD at 18 and 24 months, there is limited guidance for screening children with developmental disability for ASD in primary care.
- The Modified Checklist for Autism in Toddlers, Revised (MCHAT-R) is a common measure used in primary care, partly due to its accessibility.

Objectives

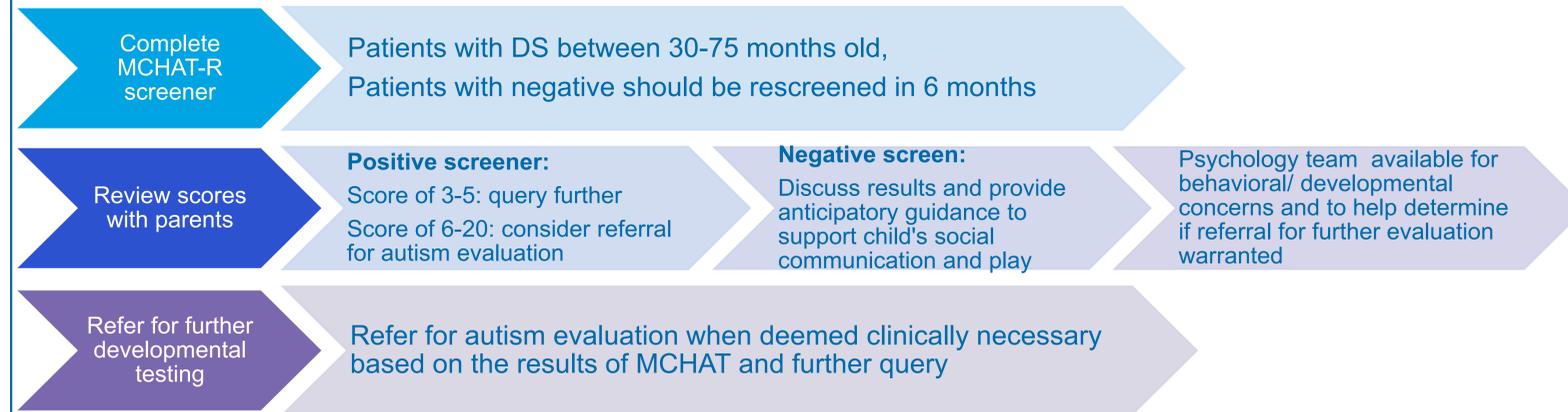
- To evaluate the feasibility of using the MCHAT-R in a population of children with DS within a primary care setting.
- To evaluate an expanded screener administration age range to account for developmental delays among children with DS.

Methods

- Children with DS were patients of a large primary care clinic for children with medical complexity.
- The M-CHAT-R screener was administered to caregivers of patients with DS age 30-75 months and scored by the patient's medical provider.
- Negative scores were discussed with the caregiver by the medical provider.
- Positive scores were discussed with a clinic psychologist who helped coordinate further developmental evaluation as indicated.

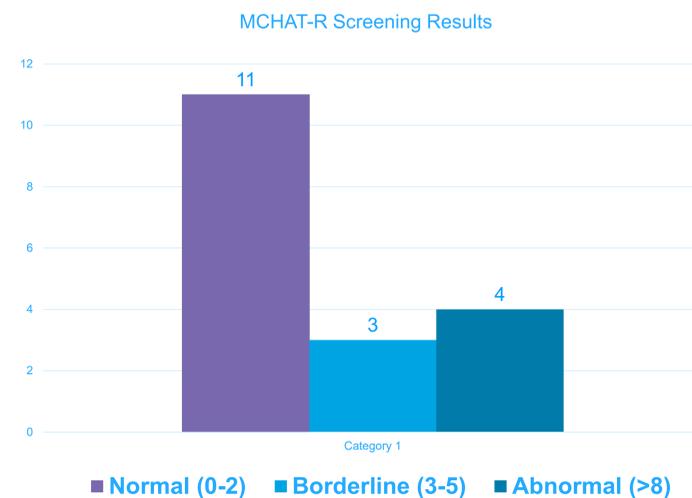
Results

Screening Process Map



MCHAT-R Screening Results

- Screening began in January 2021 and clinic providers received an implementation guide
- The clinic serves 44 patients with DS between 30-75 months of age
- As of April 2022, 18 children (41%) with DS between 30-75 months were screened, and four (22%) had a positive screener



Abnormal Results (N=4)

- One patient diagnosed with ASD
- One patient referred for evaluation
- One patient found to have severe vision impairment felt to impact MCHAT-R score
- One patient awaiting referral for evaluation

Feasibility of screening process

- Providers in primary care clinic completed survey to help determine comfort with screening process, successes and barriers to process.
- Completion rate 7/14 (50%)

| Provider opinions of what has gone well in screening process | |
|--|-----|
| Identified patients for further autism screening | 80% |
| Identified other developmental or behavioral concerns | 40% |
| Reassured parents with negative MCHAT screener | 60% |
| Nothing | 0% |
| Provider opinions of barriers to screening process | |
| Difficult for parent/caregiver to complete questionnaire during clinic visit | 20% |
| Answers difficult to reconcile given patients underlying intellectual disability | 40% |
| Parent/caregiver resistance to completing questionnaire | 0% |
| Difficulty scoring questionnaire | 20% |
| Difficulty referring patient for autism evaluation | 0% |
| Nothing | 40% |

Conclusions

- The M-CHAT-R is a free ASD screener commonly used in primary care and it can be used for young children with DS.
- A delayed and expanded age range of administration may be more appropriate than the standard AAP recommendations.
- Overall, primary care providers reported the screening process was feasible.
- By screening children with DS with the M-CHAT-R, we may be able to earlier identify children for autism evaluation

Limitations

- The MCHAT-R has been found to have limitations related to sensitivity and disparities in screening rates and accuracy.
- Lack of universal primary care provider education related to autism resulted in variable primary care provider comfort in administering the MCHAT, impacting screening rates.
- Limitations to data tracking and analysis within the electronic healthcare record impacted level of data analyses.

Next Steps

- Item analyses of the MCHAT to determine modifications needed to the screener for children with DS.
- Increased primary care provider training related to autism and autism screening.

Disclosures

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