

Nina C. Burruss, MD²; Isabella R. Ferrara, BS¹; Stephanie M. Morris, MD^{1,3}; Roma Vasa, MD^{1,2}

¹Kennedy Krieger Institute, Center for Autism Services, Science and Innovation, ²Johns Hopkins Hospital, Department of Child and Adolescent Psychiatry, ³Johns Hopkins Hospital, Department of Neurology

Background Information

- Children with autism have high rates of aggression and self-injurious behaviors.^{1,2}
- Pharmacological and behavioral treatments are critical for the reduction of these behaviors.³
- At Kennedy Krieger Institute, autistic children with severe behaviors can be referred to the Neurobehavioral Unit (NBU) for intensive behavioral treatment – outpatient, intensive outpatient, or inpatient services.
- Families must complete an intake packet after which they are placed on a waitlist for an NBU intake evaluation.
- Little is known about the extent to which autistic children actually receive NBU services at our institute

Purpose

To examine the extent to which autistic children with severe behavioral challenges are connected to intensive behavioral services (NBU) at our hospital.

Methods

- Sample:** EPIC data extraction: July 2019 to July 2024
- Inclusion criteria:** All patients from the Center for Autism Services, Science and Innovation (CASSI) at Kennedy Krieger Institute who were referred to the NBU via an EPIC referral during this 5-year period.
- Primary Outcomes:**
 - NBU Referral Outcome** – Proportion of children who completed treatment compared to those who did not
 - Wait Time** – Mean wait time from referral to first NBU intake evaluation
- Secondary Outcome**
 - Impact of demographics factors** – such as age, sex, race, ethnicity, and socioeconomic status as measured by the Area Deprivation Index (ADI)⁴ on primary outcome measures
- Data Analysis:** Chi-square analyses were used to examine categorical variables including NBU referral status. Wait time for patients who completed an intake evaluation were compared using analysis of variance methods.

Sample Characteristics of CASSI Children at the Time of Referral to the NBU (n = 464*)

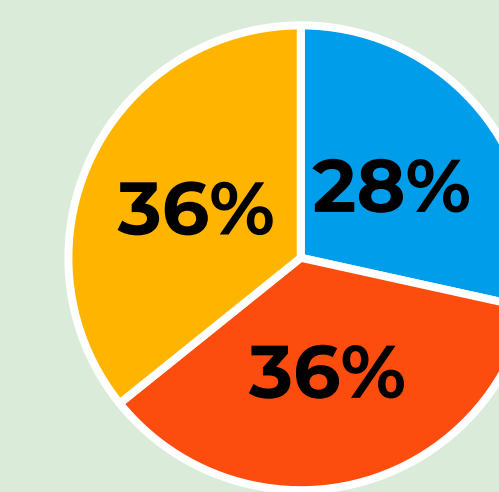
*excludes duplicates

Age in years, mean (SD)	10 (4.5)
Sex, n (%)	
Male	374 (81)
Female	90 (19)
Area Deprivation Index, n (%)	
0 – 20%	104 (23)
21 – 40%	148 (32)
41 – 60%	114 (25)
61 – 80%	56 (12)
81 – 100%	33 (7)
Race, n (%)	
Black or African American	166 (36)
White	153 (33)
Other/Unknown	80 (17)
Multiracial	46 (10)
Asian	16 (3)
American Indian/Alaskan Native	3 (<1)
Ethnicity, n (%)	
Hispanic or Latino	43 (9)
# of Psychiatric Medications, mode (range)	0 (0-8)
# Emergency Dept Visits, mode (range)	
Medical	0 (0-12)
Psychiatric	0 (0-13)

Results

Referring Discipline (n = 504*)

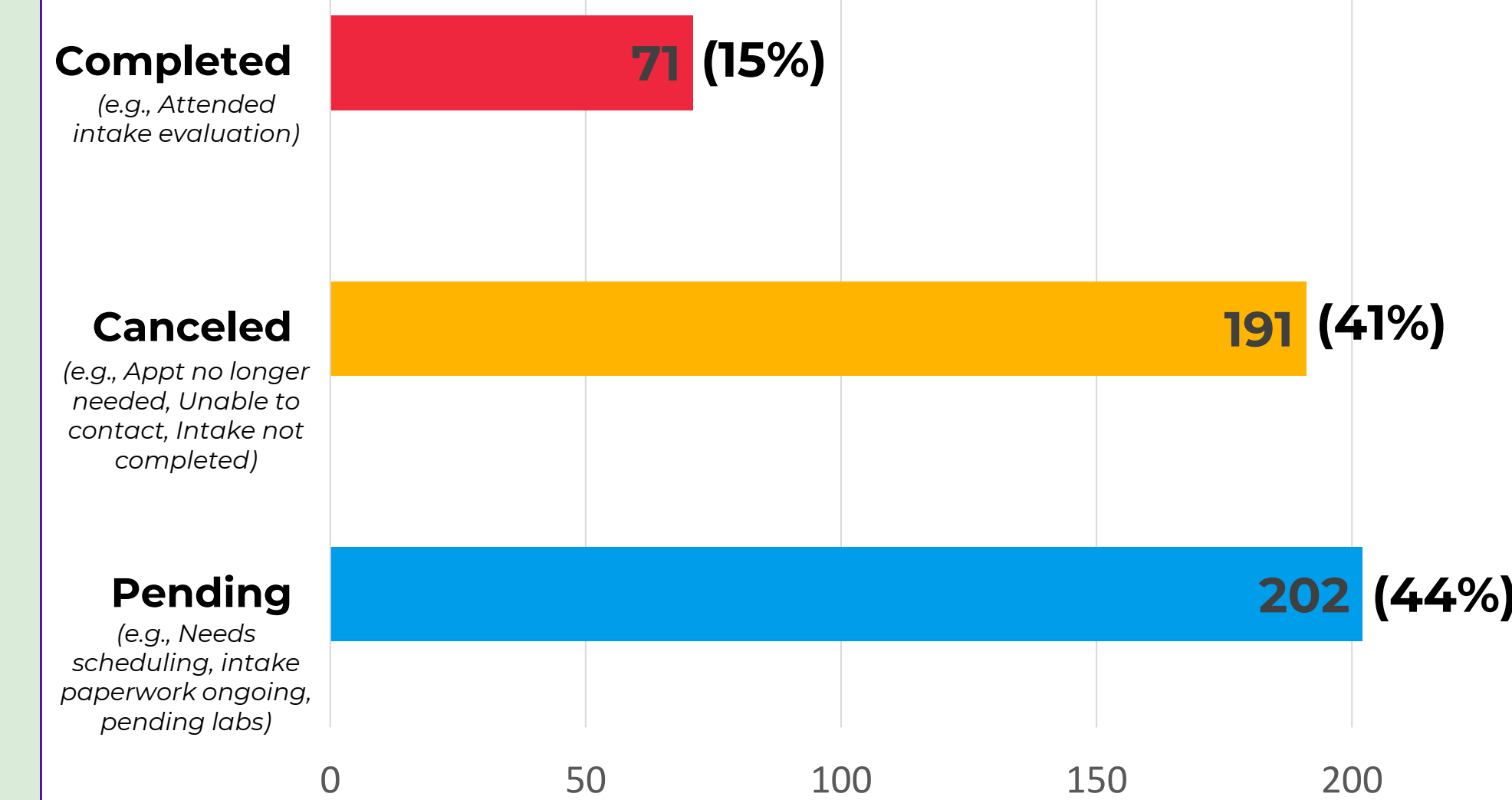
*includes duplicates



■ Psychiatrist ■ Other physician ■ Non-physician

NBU Referral Outcome (n = 464*)

*excludes duplicates



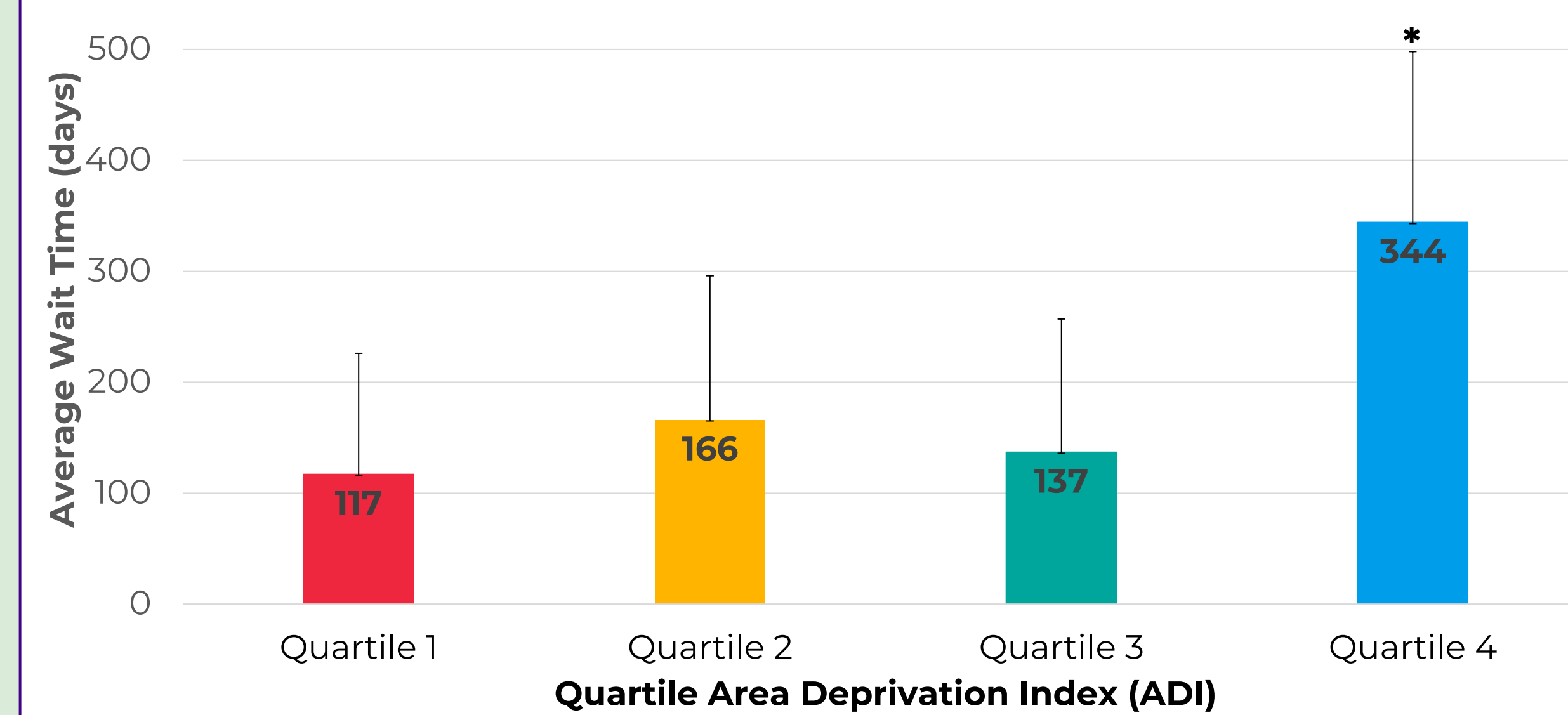
No significant differences were found for age, sex, race, or ethnicity on the proportion of completed vs canceled referrals.

Time from NBU Referral to NBU Intake Evaluation (n = 71)

Median (days)	123
Range (days)	8-1095

No significant differences were found for age, sex, race, ethnicity, or ED visits on wait time for the first NBU appointment.

Wait Time for NBU Intake Evaluation Based on ADI (n=71)



No significant difference was observed in the proportion of children who visited the Emergency Department for psychiatric concerns based on ADI ($p=0.33$).

* Patients in the highest ADI quartile, which represents the lowest SES (76-100%), had significantly longer wait times for their NBU evaluation (344 days) than those in the lower ADI quartiles representing higher SES (51-75%, 137 days; 25-50%, 166 days; 1-25%, 117 days; $p = 0.024$).



Discussion

Summary of Findings

- This preliminary cross-sectional study examines the degree to which autistic children are connected to intensive NBU services at our institution.
- We found that only a small proportion of children (15%) over the 5-year study period completed an NBU intake evaluation with a median wait time of about 4 months.
- Children with the longest wait times for NBU evaluation were those with the highest ADI (i.e. lowest SES).
- Unexplored variables that could potentially contribute to long wait times include NBU capacity (e.g., # beds, study period included covid pandemic), inpatient psychiatric hospitalization, repeat ED visits, and psychosocial stressors.

Recommendations to improve access to NBU Services

- Simplify the intake process for families (e.g., reduce the amount of paperwork required prior to intake).
- Track high-risk referrals so they are not lost to follow up.
- Consider creating EPIC dashboards for clinicians and families to monitor the referral process.
- Improve communication between the referring provider, parents, and the NBU team regarding referral status.
- Better understand the reason for canceled and pending referrals.

Study Limitations

- Some NBU referrals may not have been captured due to internal routing of referrals to the NBU (e.g., routine therapy referral was internally routed to the NBU)
- Cross-sectional view of the referral outcomes means that the pending category is fluid and demographic associations could change.
- Patient sample with predominantly middle-to-high socioeconomic status.
- Small sample sizes for demographic analyses.

Acknowledgements & Disclosures

We would like to thank Drs. Louis Hagopian, Andy Zabel, Steve Lindauer, and Ms. Marguerite Wakeman for their assistance in interpreting the data. Disclosures for Dr. Vasa can be viewed at <https://aacap.confex.com/aacap3/2024/meetingapp.cgi>. No additional disclosures. The creation of this poster was supported by the AACAP-SAMHSA Systems of Care Poster Award and Fellowship.

References available upon request