



Detecting Autism Early- Expanding Services Throughout Southern Delaware

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Introduction

- There are few places for Autism Spectrum Disorder (ASD) services in Delaware and families are often required to travel long distances and overcome additional barriers in order to access these services.
- ASD has been increasing in prevalence, with current estimates at 1 in 59 children (Baio et al., 2018). Early identification and intervention has been shown to improve outcomes across domains for children diagnosed with ASD (Warren et al., 2011).
- Rural areas with reduced access to ASD services see fewer children diagnosed before starting school (Daniels & Mandell, 2014). On average, children with ASD in rural Delaware begin receiving services at 5.2 years, indicating that they are missing critical windows for receiving intensive, autism-specific interventions (Ekbladh & Rhoton, 2013)
- Extended wait times after initial concerns have also impacted the early diagnosis of young children and contribute to negative family experiences (Zablotsky et al., 2014)
- Concerns are often first identified by the pediatrician (Zwaigenbaum, Bauman, Fein, 2015)

Goals

1. Continue to expand access to autism services to families in Southern Delaware by providing assessments through Child Development Watch and Swank Autism Center initial appointments at Nemours Seaford.
2. CDW assessments designed to smooth the transition to school districts for families of children diagnosed with ASD
3. Providing families access to brief evaluations and connect them to appropriate services.

Method

Measures Used

- Autism Diagnostic Observation Schedule, 2nd Edition
- Autism Spectrum Rating Scales, Parent Form
- Childhood Autism Rating Scale, Second Edition, Standard Form
- Modified Checklist for Autism in Toddlers

CDW Process

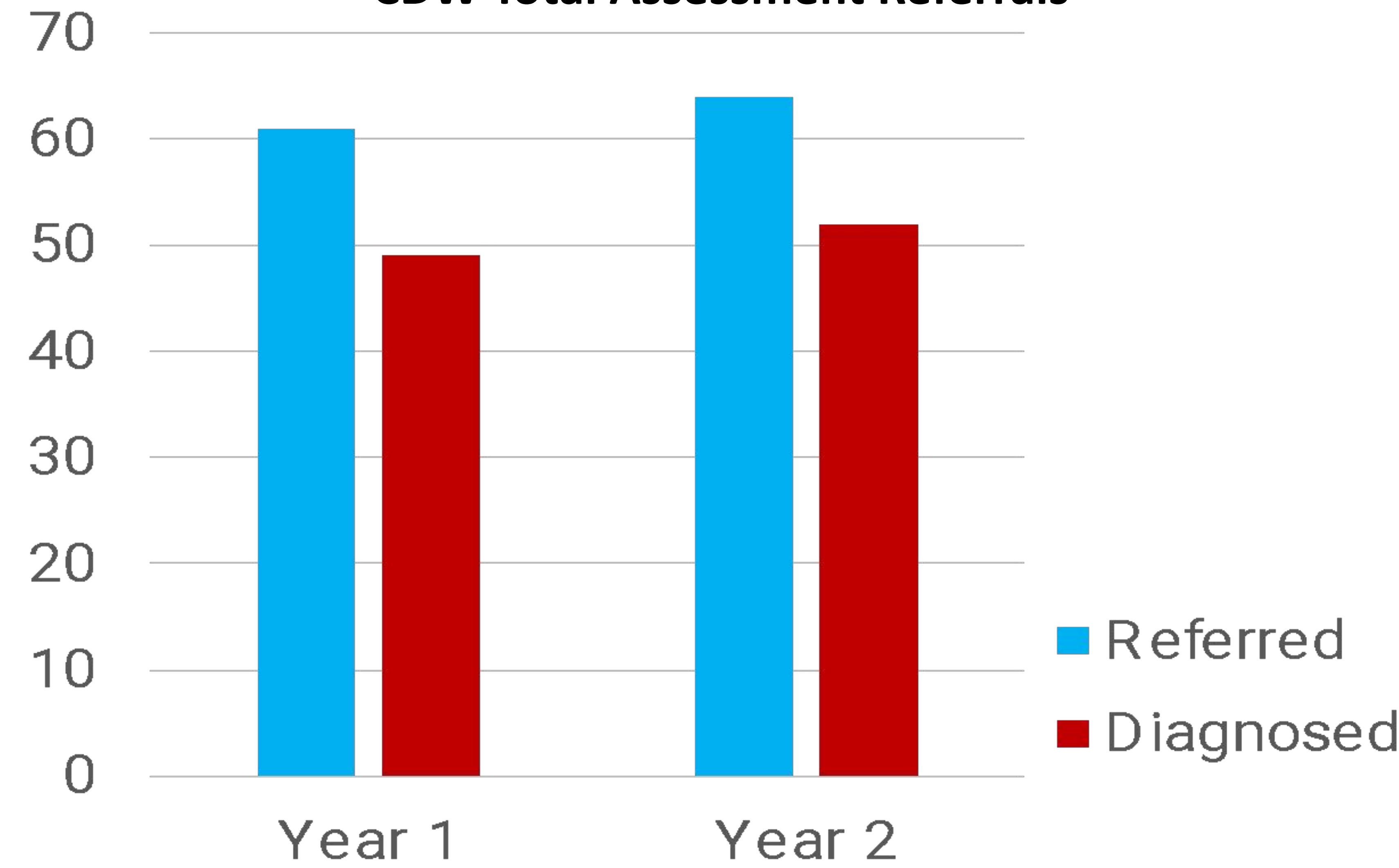
- Children referred to Child Development Watch (CDW) receive an initial developmental assessment
- Those who present with red flags for ASD are then referred to the Nemours provider completing comprehensive autism evaluations through two CDW clinics
- An evaluation can be completed through the local clinic and a follow-up parent conference is completed to provide diagnosis and recommendations, which are detailed in a report for the family
- Families who seek school district services also sign consent for the report to be shared with their local district

Swank Evaluations Process

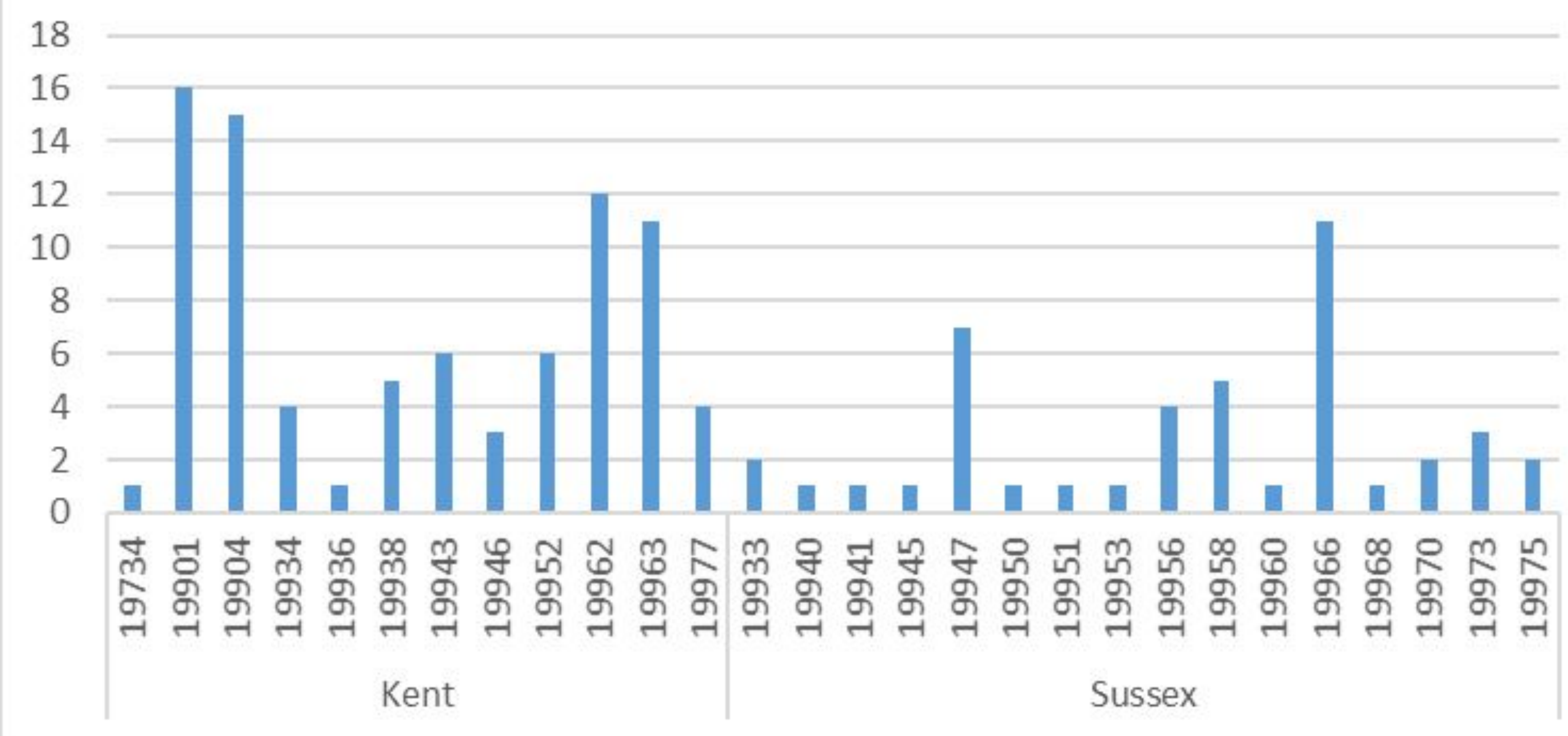
- Trainings conducted with medical staff to educate about autism and screening measures available.
- Medical staff refers patients based off parent or provider concerns identified at routine visits.
- Patients are seen for 1 hour initial visit with Swank Autism Center fellow to evaluate symptoms further and make appropriate referrals

Results

CDW Total Assessment Referrals



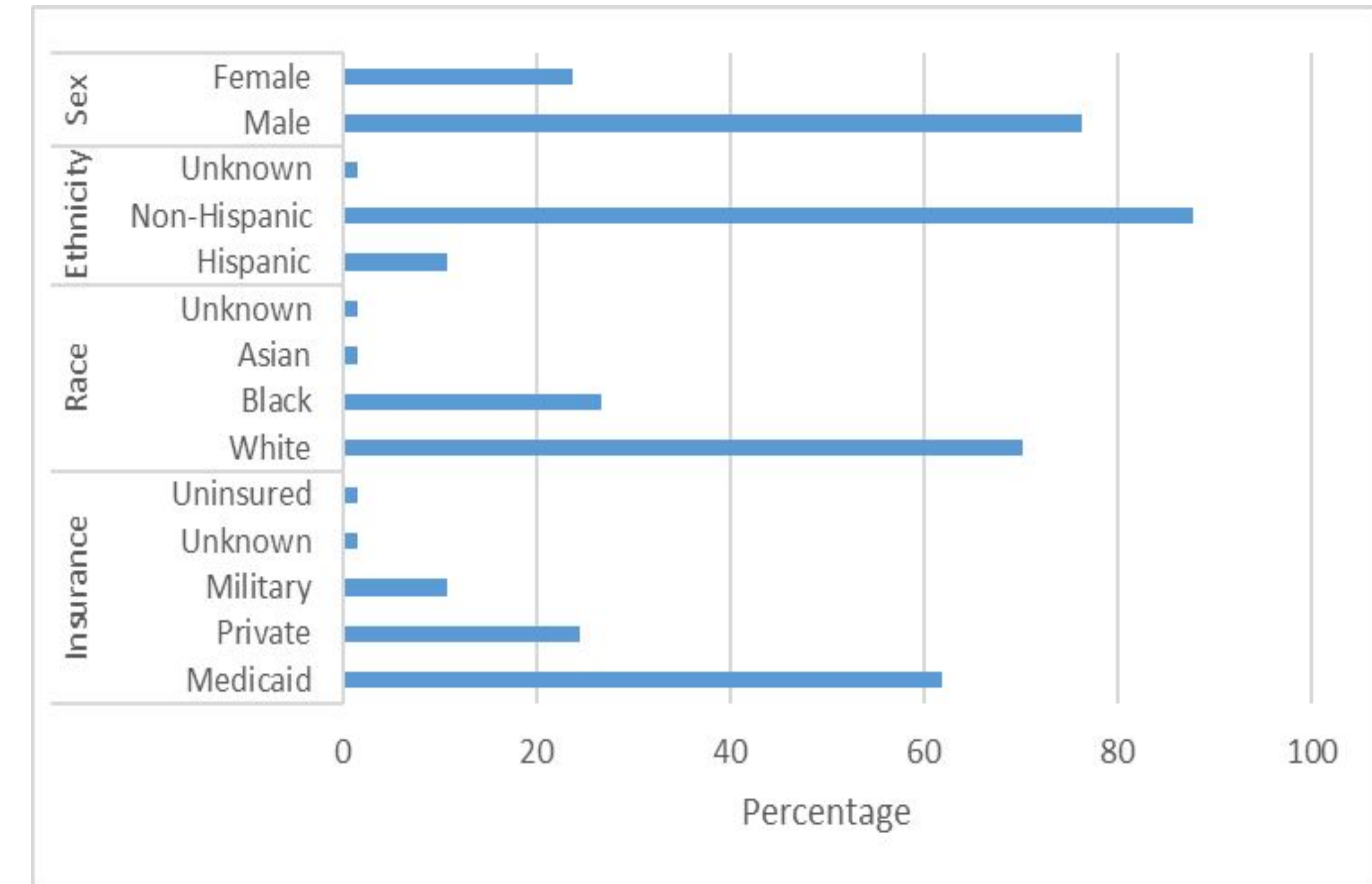
Number of Referrals Per ZIP Code



Swank Autism Initial Evaluations Outcomes

- 12 patients from two clinics referred in 5 months with 7 patients attending appointments
- 6 patients referred for further comprehensive psychological assessments
 - 5 diagnosed with autism, 1 diagnosed with ADHD
- In all cases, the referring physician's primary concern was for autism, while only two of the families identified concerns for autism.
- The average age of child referred was 5.1 years old (19 months- 12 years old), reflecting the Delaware average (5.2 years).
- Families reported positive experiences with these visits:
 - All reported being happy to have visits closer to their home
 - One family reported that they would not have gone to a similar visit if it had been in Wilmington
 - Families found it to be quicker to get scheduled than other options.

CDW Demographics



Discussion

- Over 2 years, we were able to provide 131 comprehensive assessments for ASD in Kent and Sussex counties, 107 of which resulted in a medical diagnosis of ASD.
- Further, of 7 patients seen for Swank initial visits in southern DE, 5 were diagnosed with ASD.
- The current assessment and diagnosis totals and range of locations families come from highlight the need for comprehensive ASD evaluation services throughout Southern Delaware.
- Extending services to CDW and Nemours clinics as well as training medical staff has expanded access to ASD care for families in rural and underserved areas of Delaware, thus decreasing both barriers to accessing diagnostic services and wait times for these families.
- Given the importance of targeted early intervention for children with ASD, increasing access to diagnosis at an earlier age which is also likely improves outcomes for these children
- In the future, it will be important to evaluate sustainability at both sites in order to fund a model such as this, allowing for continued provision of assessment services for families in Kent and Sussex counties.
- It may also be helpful to expand services to additional clinic locations due to the range of locations families come from. Further, it will be important to add Spanish-speaking providers in order to ensure appropriate diagnostic services for all.

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