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Improving early screening and diagnosis of autism in underserved populations

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Purpose

The purpose of this project is to determine if providing training and technical assistance on developmental delay and autism screening improves the overall timeliness of AAP-recommended well-child visit screenings and referrals in rural areas.

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This project intends to improve appropriate screening, surveillance, referral and diagnosis of ASD through training and monitoring of physicians and reducing the wait time of qualified ASD diagnostic physicians in rural and underserved areas of Arizona. Furthermore, the project will increase the number of individuals from underserved populations who are monitored, assessed, and referred for diagnosis in a timely manner. To date, three clinics in rural Arizona counties have received training. The extent to which training led to timely developmental surveillance and screening of young children will be determined when clinics are reassessed in March of 2013.

Implications

Assisting already overextended rural clinics integrate screening and referral practices into daily operations will ensure children from underserved populations receive timely diagnosis and intervention and reduce disparities typical for those groups. This project also supports physicians to follow the AAP-recommendation of early screening and referral.

About the Author

Jennifer Andrews, MBA is the Research Coordinator and primary grant writer for the AzUCD-UA and has been performing research on a variety of developmental disabilities and genetic conditions for the past 12 years.

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Introduction

Significant disparities in health care exist in many U.S. population groups, including minorities, low income families, children with special health care needs, and persons living in rural areas. Individuals of non-white heritage tend to receive diagnoses of autism and developmental disabilities at later ages than white children. In particular, ASD prevalence in Hispanic populations appears lower than ASD prevalence in the non-Hispanic White population.[i,ii,iii,iv] Improving the existing infrastructure to facilitate diagnosis and referral of high-risk children at an early age can enhance the health and well-being of these children. Providing training to physicians in underserved areas will allow them to adopt procedures proactively, maximize their current ability to screen and refer high-risk children, and reduce the disparities experienced by individuals from underserved backgrounds.

Featured Project

The project purpose is to improve the timing of screening diagnosis for children aged 0- 36 months from underserved populations, who are at risk for developmental delays and ASD, specifically minorities, low income, and rural families. This can be accomplished by increasing the number of timely developmental screenings conducted and appropriate referrals for full autism screening and early intervention services for children age 0 – 24 months in Arizona in communities with underserved populations.

Arizona Leadership Education in Neurodevelopmental and Related Disabilities (AZ LEND) program trainees provide training and collect performance data. Three clinics in Cochise, Santa Cruz, and Yuma counties participate in this project. Teams conducted in-depth interviews with each clinic to discuss process flows and determine the most feasible and least intrusive method for incorporating developmental screening into standard operating practice. Teams also trained all clinical staff to use screening instruments (i.e., PEDS and M-CHAT).

Baseline referral and diagnostic evaluation information was collected for all patients that were 0-24 months of age prior to training. These data are part of traditional reports generated by the early intervention program and can be tracked by diagnosing physicians. In March 2013, the same data will be collected to determine if providing technical assistance and training improves timely developmental screening and referral.

Best Available Evidence

This project is based on the 2006 American Academy of Pediatrics (AAP) policy statement stressing the importance of developmental screening and provision of early intervention for children with developmental delays or who are at risk for autism. AAP has determined screening to be an essential responsibility of primary care and pediatric providers.[v]

Implications for Practice

Population-based surveillance studies are most representative of the total population of affected individuals and tend to minimize problems such as referral and enrollment bias. Surveillance data are often used to make improvements in the healthcare of individuals and their families.[vi, vii] Using surveillance research techniques will provide an accurate assessment of whether or not the number of children receiving on time screening and referral increases when a developmental screening plan and technical assistance are in place.

Professional Judgment, Client, and Context

Arizona is challenged with health care professional shortages with few qualified practitioners in the state who are able to diagnose children with autism. In contrast, the state has many dedicated and expert pediatricians who serve in rural and underserved areas of the state. Many of these pediatricians are willing and able to participate in additional training allowing them to give provisional diagnoses of autism so that children can receive services. Providing a pathway to efficient screening and diagnosis will change the landscape of healthcare services for children with autism in Arizona. There is widespread support for an innovative and cost-effective solution to the challenge of providing diagnostic services in a state with a dearth of providers who can diagnose autism. This is an opportune time to implement a program that effectively utilizes state resources and provides a clear change in direction for the delivery of state services.

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