Improving Screening and Referral for Developmental Issues among Young Children in Urban Primary Care Sites

Statement of Problem

The first three years of a child's life are important for development. Unfortunately, children with developmental challenges often do not receive necessary services at this early age. The American Academy of Pediatrics (AAP) and the Maternal and Child Health Bureau (MCHB) recently recommended that clinicians use standardized developmental screening instruments to monitor a child's development. Research has shown that these tools can help identify developmental delays in children. However, there is no information about the best way to use these tools in urban pediatric practices and whether screening is effective at increasing enrollment in early intervention.

Furthermore, a substantial portion of developmental delays in young children currently go undetected, a phenomenon that disproportionately affects racial and ethnic minority communities in Philadelphia and other cities. Children in these communities are less likely to be screened for developmental delays due to cultural competency issues among medical providers and limited English skills and low literacy levels among parents. As a result, these children may be less likely to be identified with developmental delays and, if identified, less likely to access free, state-sponsored Early Intervention (EI) services. Developmental delays can lead to poor school readiness and ultimately contribute to the widening education gap between rich and poor communities.

Description

We examined the effectiveness of developmental screening strategies with and without office support at identifying developmental delays in young children to determine: 1) the feasibility of implementing developmental screening, 2) the acceptability of developmental screening by pediatric practices and families, and 3) the effectiveness of a developmental screening protocol that conforms to AAP/MCHB recommendations compared to the effectiveness of developmental surveillance alone. Factors that impacted the effectiveness of screening were assessed at the following levels: 1) referral decision at the point of completion and interpretation of developmental surveillance or screening, 2) accessibility to early intervention services, and 3) eligibility for services in early intervention programs. In a subsequent study, we interviewed families who were referred to early intervention and early intervention employees to better understand barriers to enrollment in early intervention services from their perspective. Identified barriers included parental ambivalence regarding whether early intervention services were necessary and logistical problems completing the referral (e.g. difficulty making phone contact)

Two follow-up studies aim to address barriers to accessing Early Intervention (EI) services for young children identified with delays. The first study seeks to improve rates of screening for children whose parents have limited English proficiency and low literacy by providing language translations and audio versions of the standardized developmental screening tools. In addition, this study seeks to determine the effectiveness of a

“patient navigator,” a professional who assists families with understanding and navigating health systems and treatment options, as a strategy for improving screening and referral rates. This study will have the support of a patient navigator with in-depth training in early child development, cultural competency principles, and the EI referral and service-acquisition process. She will work with families at a high-needs urban primary care practice to provide families with better information on child development and EI services and to assist families who are referred to EI to overcome practical obstacles to referral completion.

The second study aims to promote shared decision making between parents and pediatricians during early intervention referrals. This study will assess the effectiveness of a video patient decision aid in promoting informed parental decisions regarding early intervention and referral completion. The video was developed with extensive input from families, pediatricians and child development experts. It lists the pros and cons of early intervention in plain language and provides practical information on completing the referral. The video will be shown during office visits in an urban primary care practice.

Next Steps

The study team intends to strengthen public systems to address the continuum of screening to effective referral. Building off of a widely circulated evidence-to-action brief, the team recommended the following: 1) Reimbursement should incentivize screening and care coordination. 2) The federal government should support the development of public domain screening tools. 3) States and provider sites should prioritize cross-system information exchange. 4) States should coordinate the eligibility and intake processes of multiple early childhood systems to expand access to developmental services. 5) Comprehensive developmental screening metrics that address receipt of EI services are needed to inform quality improvement. These recommendations have been shared locally and nationally to facilitate increased focus on this challenge.

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Related Tools & Publications

Accuracy and Equity in Autism Screening, Identification and Referral
Research at a Glance
May 2020

Accuracy of Autism Screening in a Large Pediatric Network
Article
Sep 2019

Adherence to Screening and Referral Guidelines for Autism Spectrum Disorder in Toddlers in Pediatric Primary Care
Article
May 2020

Latino Parents' Experiences With Literacy Promotion in Primary Care: Facilitators and Barriers
Article
Aug 2020

Overcoming Language Barriers in Mental and Behavioral Health Care for Children and Adolescents—Policies and Priorities

Article
Apr 2019

Patient Navigation to Facilitate Early Intervention Referral Completion Among Poor Urban Children
Article
Aug 2016

Screening Instruments for Developmental and Behavioral Concerns in Pediatric Hispanic Populations in the United States: A Systematic Literature Review
Article
Oct 2019

Supporting Families with Young Children
Tools and Memos
Jun 2019

Translating Discharge Instructions for Limited English-proficient Families: Strategies and Barriers
Article
Oct 2019
Related Projects

The Philadelphia Human Development Project: Studying the Determinants of Early Childhood Development
Family & Community Health

Improving Developmental and Behavioral Screening for Spanish-speaking Children
Behavioral Health