

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

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Only **58%** of children younger than three identified with a developmental delay receive referrals for early intervention services.

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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PolicyLab Leads

James Guevara MD, MPH

Faculty Member

Dr. Guevara was elected to the executive committee of the Council on Early Childhood for the American Academy of Pediatrics for a three-year term beginning in 2019. He has interests in the organization, financing, and delivery of health care services to children with developmental and behavioral disabilities. He has previously published on the medical expenditures and health disparities among children with chronic health conditions. Dr. Guevara is the principal investigator on three current awards. In the first (R01MD011598), he is studying the effectiveness of patient navigation on completion of early intervention referrals and child development among children with developmental delays. In the second (R61MH118405), he is testing the effects of a novel social media-based parenting program for women with postpartum depressive symptoms. In the third award funded by the Leonard Davis Institute of Health Economics, he is piloting three behavioral economic approaches to parent-child shared reading behaviors. Through these diverse research initiatives, Dr. Guevara has focused on improving the delivery of health care in primary care settings, reducing health disparities, and translating research findings into practice and policy.

Dr. Guevara received his MD from Northwestern University and also holds an MPH from the University of Washington.



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Katherine Yun MD, MHS

Faculty Member

Katherine Yun's primary interest is refugee and immigrant health, specifically the well-being of children in immigrant families in the United States. Her work has focused on the prevalence of chronic, non-communicable conditions and insurance coverage among refugees in the US, differences in primary and dental care utilization by children in different types of immigrant families, and evaluation of health care navigation and related programs for refugee communities. Current projects seek to address language barriers in behavioral health care and blunt the impact of the [COVID-19 pandemic](#) on refugees and migrants.

Dr. Yun received her medical degree from Harvard Medical School in 2006 and completed her residency in pediatrics at Yale University in 2009. Between 2009-2011, she was a Robert Wood Johnson Foundation Clinical Scholar and earned her Masters in Health Sciences Research from the Yale University School of Medicine. While at Yale, she was the supervising physician in the Yale-New Haven Hospital Pediatric Refugee Clinic, a co-recipient of Connecticut's Myra M. Oliver Award for going "above the call of duty" to support refugees and immigrants. CHOP's Refugee Health Program, led by Dr. Mary Fabio, is a recipient of the Gold Door Award from [HIAS-PA](#), "Honoring those who lead the way in support of immigrants and refugees."

Dr. Yun has also worked in Europe, where she supported research on the health impact of human trafficking, and Central Asia, where she taught middle school. From 2014-2018, Dr. Yun served on the Executive Committee of the Section on International Child Health at the American Academy of Pediatrics. She currently serves on the [Research, Evaluation, and Ethics Committee](#) for the Society of Refugee Healthcare Providers. Dr. Yun and her husband live in Philadelphia, PA.



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Team

Alexander Fiks MD, MSCE

Faculty Member

Alex Fiks is a faculty member at PolicyLab at Children's Hospital of Philadelphia (CHOP), an urban primary care pediatrician at CHOP, director of Clinical Futures at CHOP and an associate professor of pediatrics at the Perelman School of Medicine at the University of Pennsylvania. He is also the director of the American Academy of Pediatrics (AAP) Pediatric Research in Office Settings (PROS), a national research network,

medical director for the Pediatric Research Consortium (PeRC), CHOP's practice-based research network and co-director of the Possibilities Project, an initiative to innovate primary care delivery. Additionally, Dr. Fiks is a founding member of the hospital's Department of Biomedical and Health Informatics.

Board certified in clinical informatics, Dr. Fiks' research is aimed at improving outcomes for ambulatory pediatric patients through practice-based research with a focus on improving health and health care decision-making through health information technology. To achieve these goals, much of Dr. Fiks' research is focused on fostering shared decision making between clinicians and families, especially in the setting of behavioral health conditions. He is also especially interested in how electronic health record data may best be used to improve primary care, medication use and child health more broadly. As Director of AAP PROS, Dr. Fiks has been involved in building the Collaborative Electronic Reporting for Comparative Effectiveness Research (CER²), an electronic health record database designed to support pharmacoepidemiologic and other comparative effectiveness studies that currently includes >2 million U.S. children from across multiple health systems.

Dr. Fiks received his medical degree from Harvard University, and received a Master's of Science in Clinical Epidemiology (MSCE) degree from the University of Pennsylvania. He has received additional training in clinical informatics.



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Related Tools & Publications

- [Patient Navigation to Facilitate Early Intervention Referral Completion Among Poor Urban Children](#)
[Article](#)
Aug 2016

- [Overcoming Language Barriers in Mental and Behavioral Health Care for Children and Adolescents—Policies and Priorities](#)
[Article](#)
Apr 2019

- [Supporting Families with Young Children](#)
[Tools and Memos](#)
Jun 2019

- [Accuracy of Autism Screening in a Large Pediatric Network](#)
[Article](#)
Sep 2019

- [Translating Discharge Instructions for Limited English-proficient Families: Strategies and Barriers](#)
[Article](#)
Oct 2019

- [Screening Instruments for Developmental and Behavioral Concerns in Pediatric Hispanic Populations in the United States: A Systematic Literature Review](#)
[Article](#)
Oct 2019

- [Adherence to Screening and Referral Guidelines for Autism Spectrum Disorder in Toddlers in Pediatric Primary Care](#)
[Article](#)
May 2020

- [Accuracy and Equity in Autism Screening, Identification and Referral](#)
[Research at a Glance](#)
May 2020

- [Latino Parents' Experiences With Literacy Promotion in Primary Care: Facilitators and Barriers](#)
[Article](#)
Aug 2020

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