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Improving Access to Early Developmental Evaluation in Academic Primary Care Centers

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Abstract

Introduction: Developmental disorders (DDs) affect approximately 1 in 6 children in the United States. Early identification and treatment improve developmental outcomes and child and family functioning. Disparities exist in the diagnosis of DD that leads to inequitable access to developmental services during important periods of neuroplasticity. Improve access to the developmental and behavioral pediatrics (DBP) clinic for developmental evaluation when developmental delays occur among children 3–5 years of age by increasing the percentage of children scheduled for and completing an initial visit in 90 days from 20% to 40%. **Methods:** We used the Institute of Health Improvement model, executed mapping failure modes, created a key driver diagram and conducted plan-do-study-act cycles. We plotted data over time in a statistical control chart. The key intervention was an expedited, collaborative referral and scheduling process developed, tested, and implemented by the general pediatric clinic and DBP stakeholders. Additional interventions included reminder notifications and calls to patients who missed appointments. **Results:** The percentage of patients referred to DBP who scheduled and completed their initial visit in DBP within 90 days increased from 20% to 40%. DBP clinicians suspecting that patients had global developmental delay and/or autism spectrum disorder at the initial DBP visit referred them for more extensive developmental testing with psychology and speech-language providers. **Conclusions:** Access to developmental evaluation for preschool-aged children at risk for delayed diagnosis and treatment was improved using quality improvement methodology focused on flexible and creative priority scheduling practices from within the medical home. *(Pediatr Qual Saf 2025;10:e789; doi: 10.1097/pq9.0000000000000789; Published online January 10, 2025.)*

INTRODUCTION

Developmental disability or disorder (DD) refers to a childhood mental or physical impairment or combination that results in substantial limitation to major life activities.[1] One in 6 children has DD, which includes conditions such as autism spectrum disorder (ASD), intellectual disability (ID), learning disability, attention deficit hyperactivity disorder, cerebral palsy, blindness, hearing loss, and stuttering.[2] Rates of ASD, in particular, have been increasing, with 1 in 36 children 8 years of age in the United States having this diagnosis.[3] This increased prevalence has underscored the importance of efforts to identify ASD and DD in general as early as possible to begin appropriate interventions known to improve developmental outcomes. The American Academy of Pediatrics recommends that general developmental and autism-specific screening occur in primary care for earlier identification of DD.[1,4] The guideline directs that children who screen positive be referred concurrently for early intervention, early childhood education services, and comprehensive developmental evaluation.[1]

Since the initial publication of the American Academy of Pediatrics policy statement on identifying DD in 2006,[5] surveillance and screening rates in pediatric primary practices have increased.[6,7] However, the average

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age at diagnosis of ASD in the United States is still over 4 years, with those children who are diagnosed later also having concomitant delays in initiation of intervention services.[8] DD treatment options in the United States are determined by age and medical diagnosis. Federally funded early intervention programs outlined in Individuals with Disabilities Education Act part C often include caregiver coaching strategies and assistance transitioning to preschool-based services but only serve children up to age 3. If found eligible for special education services under Individuals with Disabilities Education Act part B, children 3+ years old can access preschool classrooms specifically designed for children with DD and school-based speech, occupational, or physical therapy. Some therapeutic interventions, such as applied behavior analysis, require a medical diagnosis of ASD.

Concerningly, in the United States, there are racial and ethnic disparities in the timeliness of identification and initiation of treatment for DD.[9] Constantino et al[9] found over a 3-year lag between Black parents' first concerns and a diagnosis of ASD (average age of 5 y). They also found higher rates of ID in Black children with ASD.[3,9,10] Children with ASD from racial and ethnic minority groups and children from families with low incomes also have less access to and lower use of specialized services.[11] This lower use may be in part due to mistrust of the medical system resulting from historical and ongoing structural racism.[12,13]

With these factors in mind, the objective of this quality improvement (QI) initiative was to improve the completion of developmental evaluation for children from lower-income and historically minoritized backgrounds, following screening and referral within 90 days from the primary care setting from 20% to 40% within a year. We hypothesized that a personalized and coordinated connection from the trusted primary care medical home directly to the developmental specialist would reduce barriers to seeking timely care to evaluation.

METHODS

Setting

This QI project was a result of collaboration between the general pediatric primary care centers and the developmental and behavioral pediatrics (DBP) division with support and sponsor from the Anderson Center for Health Systems Excellence and Fisher Child Health Equity Center at Cincinnati Children's Hospital Medical Center (CCHMC) as a part of All Children Thrive Improvement learning network.

CCHMC has 4 primary care centers that were involved in this study. Sites 1, 2, and 3 are urban, and site 4 is suburban. Together, they are the medical home for more than 36,000 patients and more than 62,000 annual visits. The payer mixes across the centers are 85% Medicaid, 10% private insurance, and 5% self-pay or uninsured. The racial/ethnic breakdown of the primary care centers is 73.4% Black, 17.6% White, 2.5% Asian, 0.5% Middle Eastern, 0.2% Indian/Alaskan Native, and 5.7% mixed/other; 9.9% identified as Hispanic/Latino and 7.3% speak languages other than English (4.3% Spanish). The no-show rate for primary care centers ranges from 20% to 35% across sites. These sites train more than 200 residents and medical students annually.

CCHMC's DBP division has 3 outpatient locations, one of which is urban and receives 850 monthly referrals. Children 3–5 years of age account for 38% of all DBP referrals and are the focus age of this improvement project. The no-show rate for DBP is 15% overall and 18% for patients covered by Medicaid.

This work aimed to improve the quality of care locally. Per institutional protocols, it was therefore not seen as human subjects research and not reviewed by our institutional review board.

STUDY POPULATION AND OUTCOME

Development of Key Driver Diagram and Interventions

Our team used the Institute for Healthcare Improvement Model,[14] based on 3 fundamental questions: (1) What are we trying to accomplish? (2) How will we know that a change is an improvement? (3) What changes can we make that will result in improvement? The team created a process map (Fig. 1) to organize the workflow that can help identify issues and areas of improvement. The team also organized the theory of change using the key driver diagram shown in Figure 2. We designed interventions related to each driver and conducted plan-do-study-act (PDSA) cycles to test and adapt process changes. We plotted data on a statistical control chart to measure the percentage of 3- to 5-year-olds who completed an initial DBP visit within 90 days of their referral from primary care. The QI team met to brainstorm interventions that could impact the drivers in our systems and collected 1-year baseline data. The intervention period was from April 2021 to March 2023. We tested the following

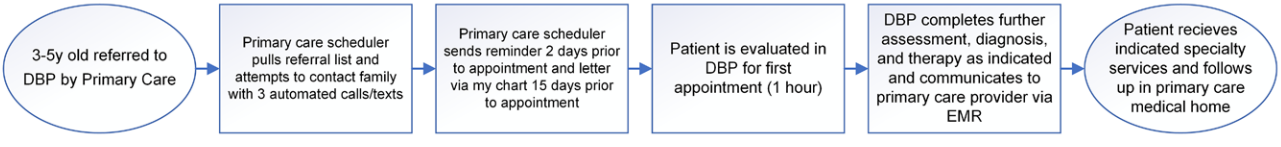

Fig. 1. Process map with the organized workflow that helped identify issues and areas of improvement.

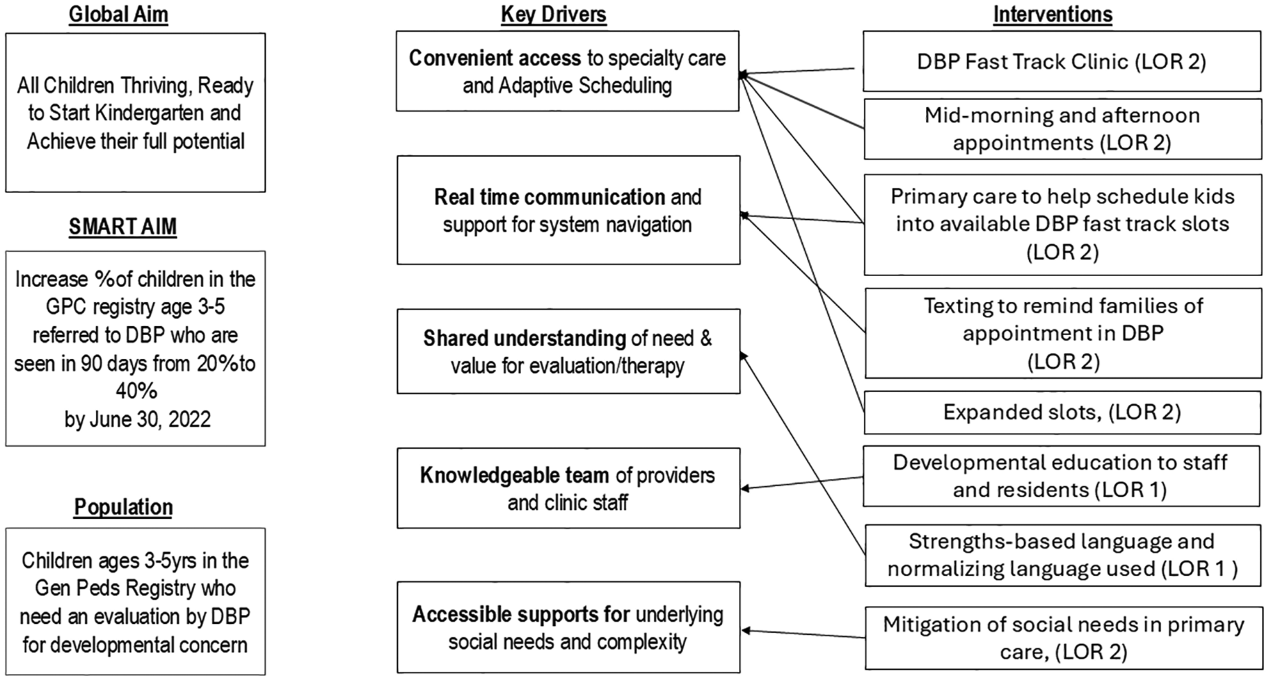

Fig. 2. Key driver diagram. Interventions are associated with relevant key drivers. LOR 2 responds to 10^{-2} performance per the Institute of Healthcare Improvement. The remaining interventions have a 10^{-1} performance. LOR, level of reliability.

interventions as part of PDSA cycles: (1) priority access visits with DBP that were only available to primary care and not to DBP clinic at large, (2) co-location of these visits in the primary care clinic, (3) scheduling of these visits by primary care staff, and (4) manual reminder calls and texts to family before the scheduled DBP evaluation visit. These interventions are described later.

For priority access visits, we reserved 2 weekly appointments for primary care patients to see a developmental pediatrician for an initial evaluation in the largest primary care clinic (clinic 1), testing a colocated DBP physician in the primary care model. Clinics 2 and 3 are a 15-minute drive from clinic 1; clinic 4 is a 25-minute drive away. The primary care scheduling staff schedules these appointments when a primary care provider refers a 3- to 5-year-old patient to DBP during a child health maintenance visit. Before the DBP appointment with the colocated DBP provider, primary care scheduling staff called the family and sent a text reminder to remind them about their DBP visit.

Due to increasing demand for the evaluation of 3-to 5-year-olds with suspected delays and the strong show rate for visits, we increased the number of available DBP appointments over several months to meet this demand. We expanded to a second location (clinic 4). All patients could choose between clinics 4 and 1 for their visit, allowing patients to choose their priority (proximity to the patient's residence or soonest next available appointment). Cumulatively, there were 12 appointments per month across 2 DBP sites of care. Clinics 1 and 4 experienced challenges in room availability, so the colocated DBP provider in clinic 1 was moved out of the clinic to the DBP department, keeping the provision of care in the same medical office building as the primary care clinic. In clinic 4 (suburban), DBP appointments were offered at a nearby DBP suburban site that is within a 15-minute drive of it. In addition to aligning geographic needs, there was an opportunity to meet the needs of Spanish-speaking families, which comprise ~20% of the suburban primary care site. The DBP provider seeing patients from the suburban location was bilingual in English and Spanish.

The scheduler from the primary care office continued to call and text families before the scheduled DBP appointments, which helped promote a strong show rate. When a family called and rescheduled, another family from the primary care fasttrack access pool offered the appointment. For no-show appointments (defined as families canceling the same day or not showing up for their appointments), the same scheduler contacted families and rescheduled their appointments. Attempts were made to fill canceled appointments using the general DBP clinic pool. They went unused if appointments could not be filled, consistent with general DBP clinic same-day cancelations. PDSA learnings indicated that early morning appointments were inconvenient for many families as most had transportation challenges or other children to send to school in the morning hours. Thus, we learned that mid-morning and afternoon appointments work best for our families. Therefore, we eliminated early morning appointments at 8 and 9 AM. After several months of testing, there was a temporary decrease in available DBP appointments due to the DBP clinician's parental leave (loss of 12 visits over 3 mo) and shifted scheduling to allow the onboarding of new clinicians.

The appointment with the DBP provider included history, observations, and a physical exam focusing on features indicative of DD in this age group, which included assessing specifically for global developmental delay, ASD, and genetic syndromes associated with DD. For families not yet engaged in developmental services (eg, speech therapy or preschool), the DBP provider offered specific recommendations of services that could be started regardless of the final diagnosis. In some cases, social workers in DBP and primary care managers helped facilitate family involvement in these services. If clinically indicated, DBP clinicians offered targeted behavioral guidance and/or medications for concerns like sleep. DBP clinicians referred all patients suspected to have DD or ASD for comprehensive developmental testing, including standardized cognitive, language, and/or autism-specific testing. The time from initial visit to comprehensive testing ranged from 1 to 4 months over the project period.

RESULTS

The control chart (Fig. 3) displays the percentage of eligible patients ages 3–5 years who DBP evaluated after referral from the primary care provider within 90 days, which improved from a baseline of 20% to 40% within 1 year. We extended the timeframe of the control chart. Statistical process control methods were used to identify significant changes in the system performance. Accordingly, the centerline (mean) was shifted when there were 8 consecutive points above the mean because this pattern has a < 1% probability of occurring by chance.[15]

Data were tracked over time (Fig. 4). Between April 2021 and June 2024, 497 distinct patients were referred from our primary care centers to DBP via the fasttrack. Of these, 250 patients (50.3%) were seen within our goal of 90 days, and 55 patients (11.1%) were seen but in greater than our goal of 90 days; 116 patients (23.3%) did not show for the appointments, 45 patients (9.1%) never scheduled, 7 patients (1.4%) had a future appointment scheduled at the time we concluded data analysis, and 24 patients (4.8%) canceled.

Our primary care scheduler attempted to contact all patients who did not show up or canceled (140 patients). Of the 116 patients who did not show up for their initial appointment, 43 completed an appointment after the 90-day goal, and 73 patients never completed an appointment. Of the 24 patients who canceled the initial appointment, 16 completed an appointment after the 90-day goal, whereas 8 patients never completed an appointment. We ran a chi-square test for patients who scheduled versus did not schedule an initial visit in the fasttrack clinic and found no significant differences in race, insurance type or language spoken.

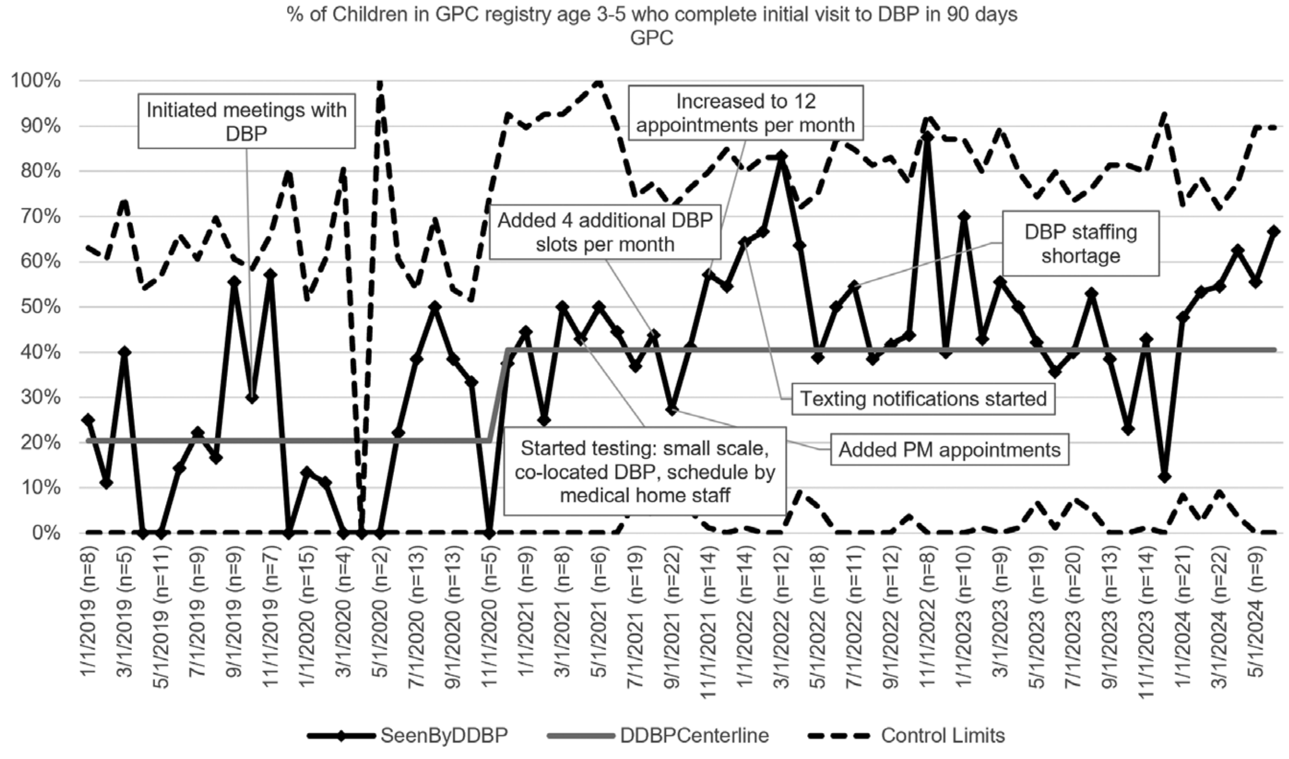

Fig. 3. A monthly annotated statistical process control chart (P-chart) depicts the percentage of all general pediatric patients referred to DBP who completed a visit within 90 days of the referral.

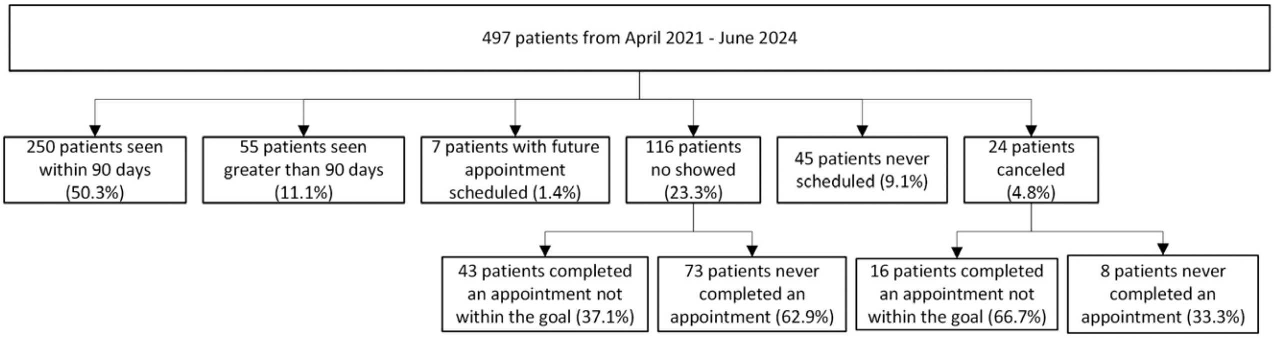

Fig. 4. Data tracked during the study period show the number of patients who were seen, canceled, did not show, rescheduled, never scheduled, and had future appointments.

To understand the final diagnosis, we conducted a chart review for a subset of patients seen for an initial evaluation with the DBP provider in the first year of this project (2021–2022). Of the 98 patients who completed an initial visit with a DBP provider in that period, 84 (86%) were suspected of DD and were recommended for further developmental testing. Of these patients, 57 (68%) completed developmental testing and 27 (32%) did not complete it. Of patients who were suspected of having DD and completed developmental testing, 41 (72%) were found to have a DD, defined as having global developmental delay or ASD.

DISCUSSION

DD is common in the pediatric population, and early identification allows for connecting to interventions, services, and resources that help children meet their full potential. The primary care clinics provide continuity of care and build trust with families over frequent visits during the children's first years. By creating priority access to developmental evaluation for Black, Hispanic, and Spanish-speaking patients who have historically been found to be at increased risk for delayed diagnosis and treatment,[16–18] we increased the percentage of patients receiving a timely developmental evaluation.

This QI project increased the percentage of at-risk patients completing developmental consultations. Research suggests that participation in early interventions and early childhood special education services can improve the language and cognitive functioning of children with disabilities.[19–21] However, children with disabilities or delays can only take advantage of these services if they are identified early and accurately. Even though healthcare providers are conducting regular screening and monitoring and placing appropriate referrals for children with suspected delays, caregivers may not follow through due to personal and system barriers. Personal barriers that prevent families from following through with appointments may include lack of transportation, lack of childcare, and difficulties with job accommodation. Family beliefs about developmental delays and early intervention vary and may contribute to evaluation and service initiation timing.[22] Distrust of healthcare systems due to racism and biases against individuals from marginalized populations are also barriers to access.[23] Additionally, system barriers such as long wait periods for developmental-behavioral providers further exacerbate challenges to prompt diagnosis.

This QI initiative showed promising results in ensuring that marginalized children receive timely evaluation and diagnosis. Our intervention, in which the primary care team staff scheduled the specialty initial evaluation, provided text reminders and colocated the specialty visit near the primary care home, may have mitigated some barriers to referral completion. For many families, the medical home is a place of familiarity that has evolved. Additionally, real-time scheduling at the time of referral, when concerns are still top of mind, may reduce some logistical barriers of asynchronous scheduling, such as family needing to respond to or initiate a call to schedule and navigate a complex health system amidst other competing demands. Furthermore, personalized medical home scheduling staff reminders may enhance the alliance between caregivers and the referring provider's office, further promoting trust.

This project was not without limitations. Numerous family factors may account for completing a developmental evaluation, including parental concern, family readiness, cultural stigma, barriers to work schedules, transportation, and other family obligations.[12,22,23] We could not establish specific reasons individual families did not schedule or complete their developmental evaluation. In addition, this study involved patients from an urban population within an academic medical setting; our findings may not be generalizable to other populations.

CONCLUSIONS

This QI intervention increased the proportion of preschool-aged children from a traditionally marginalized population who completed timely developmental evaluation. We used QI methodology to develop, test and implement successful interventions, including priority access visits within the DBP clinic and flexible and creative scheduling practices within the medical home. Through future work, we hope to continue to increase the percentage of patients who complete an initial visit and developmental testing visit in DBP and apply this intervention to children less than 3 years old in primary care clinics.

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