Parents as Detailers for Learn the Signs. Act Early.

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Category: Emerging Practice

BACKGROUND

Research shows that the early identification of developmental delays, combined with appropriate supports can lead to improved developmental outcomes for children with disabilities (King, et al., 2010) and that pediatricians are uniquely positioned to screen for and detect such delays (Earls & Hay, 2006; Honigfeld, Chandhok, & Spiegelman, 2011). Despite adoption of the 2008 Bright Futures Periodicity schedule in Georgia in 2010, the rate of developmental screening with a standardized tool among children under five is only 40.8% (National Survey of Children’s Health, 2011/2012). Nationally, barriers to physician screening have been well-documented and include time limitations, inadequate reimbursement, staff shortages, turnover, and challenges fitting formal screening into the practice workflow (Honigfeld & McKay, 2006; King, et al., 2010).

The Parents as Detailers model raises awareness and addresses the barriers to developmental screening through a novel approach - the voice of parents. First hand, physicians witness the impact that early detection has on a child and parents lives. Parent’s not only share their experiences but also provide educational materials for distribution to families to learn the significance of early detection and referrals.

PROGRAM OBJECTIVES

The overall goal of Parents as Detailers is to train parents of children with disabilities to conduct brief educational “detailing” sessions in primary care settings. The detailing process is designed to increase awareness of the importance of early screening for developmental delay and autism for physicians and staff, provide educational materials (Milestone Moments booklet developed by the LTSAE campaign or distribution to families), and to improve the understanding of Georgia’s Part C Early Intervention System along with other critical resources for parents, families, children, and physicians.

TARGET POPULATION SERVED

Parents as Detailers served 19 Georgia counties (urban and rural). Detailing sessions were delivered in 26 cities and 30 zip codes. Seven parent detailers completed 37 detailing sessions. These sessions had more than 150 attendees (an average of 4 per session) including 30 physicians (just under one per session).

PROGRAM ACTIVITIES

Parents of children with disabilities were recruited to serve as “academic detailers”. Those recruited received training in how to provide detailing visits to primary care practices. During the visit, detailers recounted their personal experiences with early screening and intervention, using both positive and negative aspects of those experiences as examples. Parent detailers also provided multiple copies of the Learn the Signs. Act Early. (LTSAE) Milestone Moments booklets, fact sheets on screening tools and outcomes, and lists of local resources.

PROGRAM OUTCOMES/EVALUATION DATA

The impact of detailing sessions was evaluated through various surveys and follow-up questionnaires. Below are the office demographics for the 37 offices that participated:
- > 220,000 pediatric patients
- 47% patients under age of 5 years
- 110 physicians
- 37 nurse practitioners
- 141 nurses
- 171 other office personnel

Of note, approximately 22% of the practices visited were located in a Medically Underserved Area (MUA), as designated by the Health Resources and Services Administration (HRSA).

Office Visit Form: A short survey completed by the presentation attendees, including physicians and office staff.
Questions focused on satisfaction of materials and presentation, acceptability, barriers, and next steps. 

Outcome- Parents received high ratings as presenters for their effectiveness and the willingness of the practice to have them return to talk about another topic.

Reflection Form- Completed by parent detailer after each visit. Information collected included practice location and contact information, number of attendees, what went well/what did not go well, and changes planned for the next detailing session. 

Outcome- The average detailing session served up to 4 attendees. Some sessions were conducted as one-on-ones with a key representative of the practice.

Follow-Up Calls- Occurred approximately one month after the detailing sessions by the project manager. Content of calls included asking about changes to the screening/referral process after the detailing session. 

Outcome- Follow-up calls were completed with 16 practices – 56% of the practitioners were unaware of the LTSAE campaign before their detailing visit; 38% of the practices said they had changed their developmental screening and referral processes as a result of the detailing session; 62% said they did not.

PROGRAM COST

The Centers for Disease Control & Prevention’s National Center on Birth Defects and Developmental Disabilities (CDC NCBDDD) funded the initial demonstration as a “proof of concept” for the Parent Detailer Model. The replication was conducted with a $15,000 grant from the Association of Maternal and Child Health Programs (AMCHP).

The estimated cost of the model requires approximately $500-750 per office visit. This amount includes support for a part-time Project Manager, stipend to parents for training and each detailing visit, lunch for the attendees, and materials.

ASSETS & CHALLENGES

Assets
Georgia adopted the Bright Futures Periodicity schedule in 2010, which may have raised providers’ awareness about the importance of developmental screening. High awareness may have been a factor in providers’ decisions to host Parent Detailers.

In addition, the center worked closely with a pediatrician who is also a mother of a child with autism on this project. This physician sent letters of recommendation to each of the practices prior to the Parent Detailers’ first phone call, which was a strong asset in gaining entry to practices.

Finally, during the time of project implementation, statewide policies addressing insurance coverage of autism-related services received significant news coverage, another asset that may have contributed to Parent Detailers’ successes.

Challenges

Scheduling detailing sessions – Although Parent Detailers were trained on negotiating appointment procedures, there were several reasons why scheduling was challenging.

- Offices resistant to cold-calling and providing information
- Resistance to schedule during lunch since that was the only break for the day
- Voicemails from Detailers often not returned
- Obtaining appointments were more challenging with larger practices than smaller practices

Overcoming Challenges

- Call logs – Parent Detailers used logs to keep track of effort in scheduling appointments
- Reflection forms – Used by Detailers to document what worked and what did not work in scheduling and executing appointments.
- Letter of recommendation or referral – Provided practices with a letter from a pediatrician who was involved with the project which helped to secure some appointments.
- Personal Touch – Some detailers visited the office with materials in hand to explain the concept and request an appointment in person.

Patience, persistence, and flexibility were the keys to success. It was also important to emphasize that the session would be short and all materials shared would be free of charge.

LESSONS LEARNED

One limitation to the impact of Parent Detailers is access to the practices for the activity. There were many practices contacted that were uninterested in hosting the parent detailers, there is no way of knowing how their rates of screening compare to the practices that did provide information.

Future work will implement a more systematic approach of outreach to practices. Partnering with the state chapter of the American Academy of Pediatrics to conduct these measures as part of a quality improvement initiative would enable Detailers greater access to practices. Future implementation would also ensure a timeline that allowed for at least 6-month follow up to measure long-term outcomes and would create a screening measure that was not solely based on self-reported screening practices.
The current practice is included as one component of a two-year Autism Implementation Grant. Under a sub-award, the P2P Project Manager from the replication will serve in that role again. She will recruit, train, and support five detailers in each year of the project, who will deliver five to ten detailing sessions to primary care practices and early care settings.

Stakeholder input was a key component of the Parents as Detailers project and included feedback from those delivering the intervention (Parent Detailers) and those receiving the intervention (physicians and office staff). The Parent Detailers model was developed as pilot project in conjunction with the CDC NCBDDD. The Milestone Moments materials used in the pilot project and in the replication of the Parents as Detailers project were developed by the CDC NCBDDD as part of their LTSAE health communication campaign, which is aimed at improving early identification of children with autism and other developmental disabilities. Parent to Parent (P2P) was also a partner during both iterations of this project. P2P is a statewide organization that offers support, resources, and referrals to people with disabilities and their families. They served as the primary recruiters of parents to serve as Parent Detailers.

A description of this practice will have been presented at the 2015 Autism CARES Grantees conference held in July 2015 in Bethesda, MD. A manuscript, describing the practice, will be submitted to *Children’s Health Care* for peer review and consideration for publication.

The *Milestone Moments* booklet was used in each of the detailing sessions. Approximately 200 copies were left in each office (a mix of English and Spanish language depending on the request of the practice). Additional resources included the outline for training and resource lists left with practices.

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