

Connecting Children to Early Intervention when Autism is Suspected

Introduction

- Autism spectrum disorder (ASD) affects 1 in 59 children in the United States.^{1, 2}
- Wait times for diagnostic evaluations for children with suspected ASD may exceed six months or more.³
- During the wait times, referrals for early intervention (EI) from primary care providers (PCPs) may be delayed despite being eligible for support before a formal diagnosis.^{3, 4}
- EI is effective in reducing the burden of disability, especially when initiated at the time of suspected ASD diagnosis.^{2, 4, 5}
- Families of children with suspected ASD report feeling dissatisfied with the lack of advocacy by PCPs for EI.^{3, 6}
- Primary care providers report lack of knowledge of available EI services and limited time to research options.^{6, 7}

Purpose

- Purpose:** To improve access to EI by increasing awareness and initiation by PCPs of EI for children suspected of having ASD while they are waiting for their formal diagnostic evaluations at the Developmental Center (DC) and to connect with families of these children about local EI resources.
- Objectives:**
 - Improve the time to connection between the DC and families referred for an ASD evaluation.
 - Provide in-person training for PCPs on EI.
 - Increase the number of referrals and use of EI services for children awaiting ASD diagnostic evaluations.

Methods

- The University of Iowa and UnityPoint IRBs approved this evidence-based practice project. IRB number: 201905202.
- Setting:** Anna Blank Developmental Center, Des Moines, IA
- Population:** Pediatric primary care providers affiliated with Blank Children's Hospital and a private pediatric practice in Des Moines, IA, and families of referred children.

Assessed and modified mailing practices

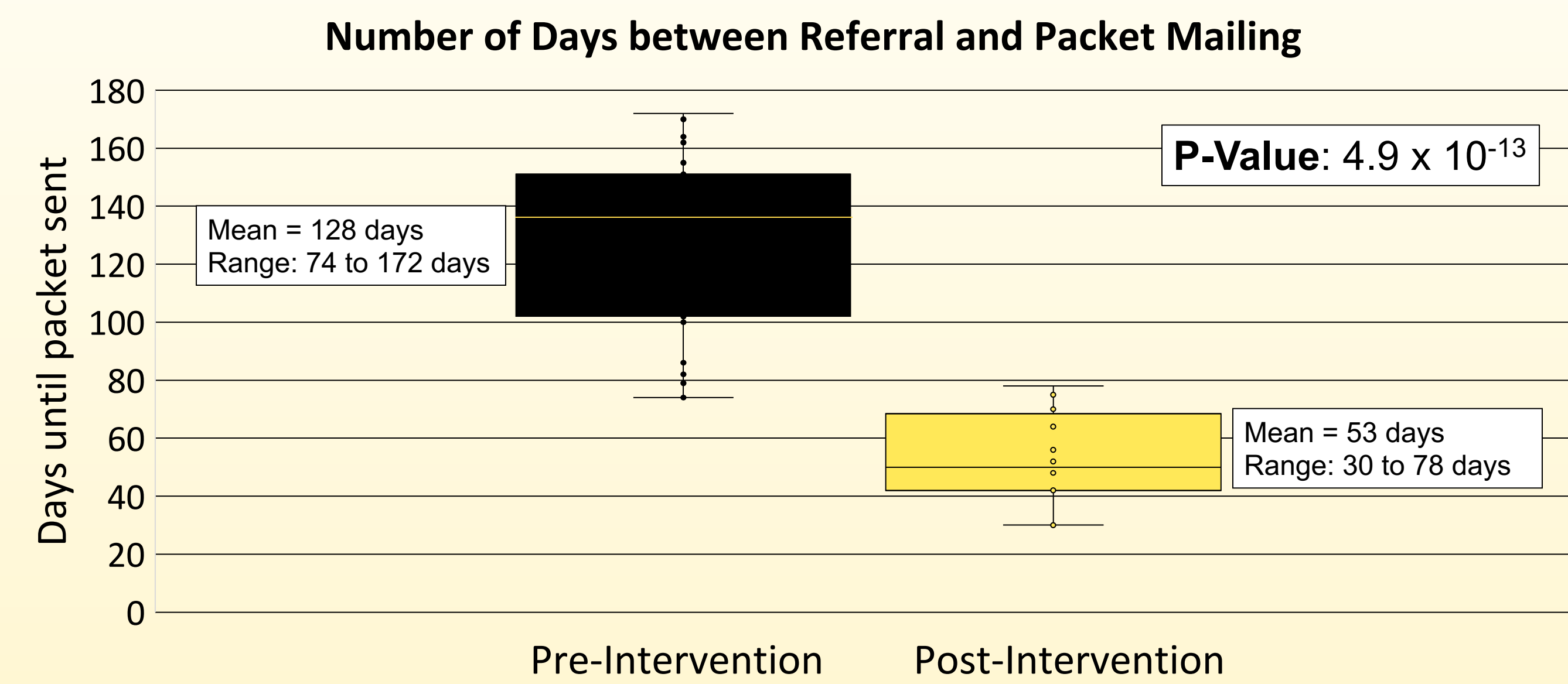
Primary Care Provider Training

Implementation and evaluation

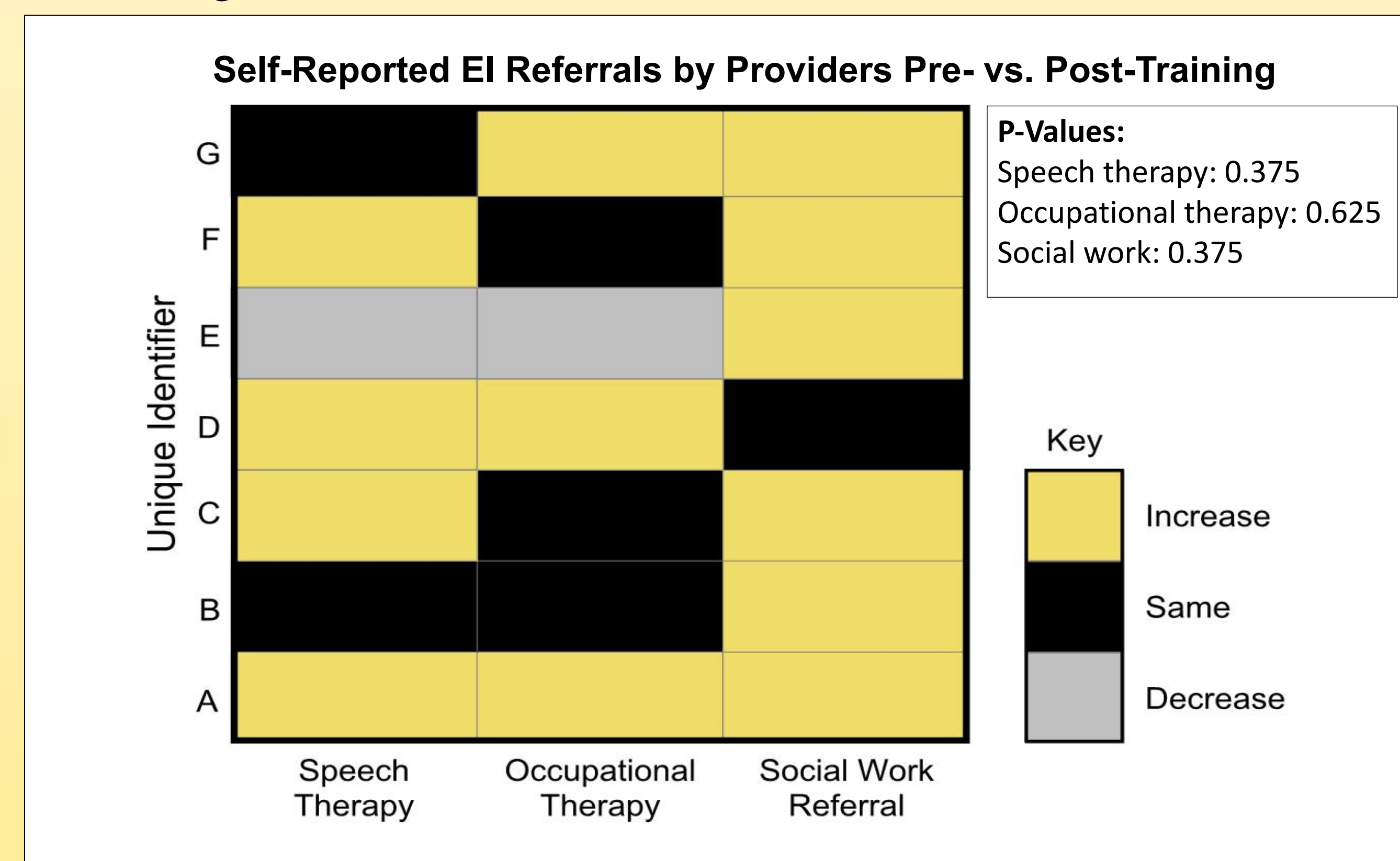
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| <p>Needs identified:</p> <ul style="list-style-type: none"> Welcome letter Updated forms Local EI resource guide Decrease time to connection with families of children waiting for ASD diagnostic evaluations | <ul style="list-style-type: none"> Worked with DC providers to create training session for PCPs about EI, comorbidities of ASD, and diagnostic codes for EI services Presented and evaluated session | <ul style="list-style-type: none"> Changed mailing practice to connect with families sooner Evaluated referrals for EI by self-report of PCPs 3-months post-training Evaluated use of EI resource guide |
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Outcomes

- The time to connection between the DC and families with referred children decreased from an average of 128 days to 53 days post-intervention.



- 100% of training session participants reported their understanding of ASD increased, and 95% agreed that their understanding of local EI resources improved.
- Self-report by PCPs of referrals for speech therapy, occupational therapy, and social work increased after training.



Evaluation

- Updated mailing practices remain in place at the DC. The time to connection was cut in half after the intervention. The DC is using updated patient intake forms and sending the new welcome letter and EI guide to families of referred children.
- 20 pediatric PCPs received training on managing children with suspected ASD. There was evidence of engagement from the PCPs and reports that the training was helpful in reinforcing strategies to manage children with suspected ASD.
- The EI resource guide provides opportunity for families to select resources with shortest wait times and closest proximity.

Conclusions

- The in-person training session was an effective format for providing updated information on ASD and EI, and in fostering connections between local PCPs and the providers of the DC. One participant wrote that the session “clarified the Developmental Center and ASD referral process and helped in identifying local early intervention resources.”
- Despite receiving positive feedback and fielding requests for additional copies of the EI resource guide from training session attendees, only 2 of the 7 providers who completed the post-training questionnaire reported using the guide.
- Limitations:** Training only offered to pediatric PCPs, inability to collect data on EI services after the mailing practice change due to the long wait times for diagnostic evaluations, and small sample of responses to compare pre-/post-training results.
- Recommendations for future research:** Evaluate data on the incidence of EI at the time of ASD evaluation for children referred after the updated welcome packet and EI resource guide were sent to families.
- Dissemination:** A poster presentation will be prepared for the 2020 conference of the Iowa Association of Nurse Practitioners.

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