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UNIVERSITY OF MICHIGAN

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INCREASING PARTICIPATION IN EARLY INTERVENTION PROGRAMS: A REVIEW OF THE LITERATURE

Authors: Anna Erickson, Robin Jacob, Katja Robinson

DATA FOR GOOD.

EXECUTIVE SUMMARY

Many children who are eligible for early intervention services do not receive them. In this literature review we explore issues for health care providers, child care providers, and parents during the identification, referral, or uptake process that may contribute to gaps in service for children.

There are a number of barriers to implementation of developmental screeners and referral to early intervention for physicians and child care providers. We find lack of staff training and time are cited as barriers to implementation of developmental screeners for both physicians and child care providers. Inadequate reimbursement and attitudes about screening were also cited for physicians and child care providers, respectively. Referral rates for physicians may vary by screening tool used as well as by age of the child and type of delay. Child care providers may be discouraged from referring because of concerns about upsetting parents or uncertainty about their role and responsibilities in referring. Families experience a diverse set of barriers to accessing and participating in early intervention services. These fall into three basic categories; logistical (e.g., lack of transportation), knowledge (e.g., inadequate health literacy), and psychological (e.g., fear of stigma).

We identify a number of best practices for increasing access and participation. For physicians and child care providers these include:

- training in and use of a standardized screening tool
- clear procedures for referral and follow up
- clear messaging for families about the value of early intervention

Best practices for families include:

- providing services in a natural setting
- peer to peer mentoring or pairing
- engaging parents as partners in the intervention
- service integration

Identifying developmental delays and providing children with early intervention during the first three years in their life can have significant impacts on their later educational, behavioral, health, and overall well-being. However, on the other end, missing the opportunity to identify and support as early as possible likely leads to unnecessary challenges to children and families later in life. Addressing the needs and barriers to participation in early intervention is therefore an essential step to prevent these avoidable challenges.

THE IMPORTANCE OF EARLY INTERVENTION

Identifying developmental delays and providing children with early intervention can have significant impacts on their later educational, behavioral, and life outcomes. Early intervention for children who are at-risk for or present developmental delays is especially beneficial because the first three years of life are a critical period of cognitive and physical development (National Research Council, 2012). Intervening during this period can be more effective and less costly than later in life. In addition to providing support for the child, early intervention empowers families by providing resources that help them support their child's development. It can also provide connections to other resources for families that might be facing food or housing insecurity or other external stressors (see Dawson et al., 2010; Hebbeler et al., 2007; National Scientific Council on the Developing Child, 2007).

Data from the National Health Interview Survey shows that an estimated 17% of children between three and seventeen have had at least one diagnosed developmental disability (Zablotsky et al., 2019). And approximately 13% of children under three have developmental delays that would make them eligible for services through Part C of the Individuals with Disabilities Education Act (IDEA) (Rosenberg et al., 2008). Yet, many eligible children do not receive early intervention services—according to McManus, Carle, and Rapport (2012), in 2006 early intervention receipt ranged from 23% to 83% across all states.

There are conflicting findings about rates of referral and participation in early intervention by demographic characteristics. Disparities in receipt of early intervention have been found for some socio-economic, racial, and ethnic groups, and for some types of developmental vulnerability (Feinberg, Silverstein, Donahue, & Bliss, 2011; McManus, Carle, & Rapport, 2012; Rosenberg, Zhang, & Robinson, 2008). For example, Rosenberg, Zhang, and Robinson (2008) found that eligible African American/Black children were half as likely as eligible White children to receive early intervention services. Feinberg, Silverstein, Donahue, and Bliss (2011) found that African American/Black children were eight times less likely to receive early intervention services based on developmental delay alone; however, no racial disparities were identified based on established medical conditions. In general, the discrepancy between the number of children potentially benefitting from services and the number of children reported to be receiving services points to possible issues during the identification, referral, or uptake process.

> "Approximately **13% of children under three have developmental delays** that would make them eligible for services."

I. BARRIERS TO SCREENING PROCEDURES AMONG HEALTH CARE AND CHILD CARE PROVIDERS

Given the importance of monitoring children's development, recommendations for implementation of developmental and behavioral screenings have been set forth by the American Academy of Pediatrics (AAP), the U.S. Department of Health and Human Services, and other experts in the field of public health and education. The American Academy of Pediatrics (Council on Children with Disabilities et al., 2006), for example, has recommended that screening for developmental delay should occur at all well-child visits. The U.S. Department of Health and Human Services has partnered with other federal programs to launch the initiative "Birth to 5: Watch Me Thrive!", a one-stop online platform that consolidates resources tailored for different settings, such as families, early child care and primary care providers, home visitors, and more (Administration for Children and Families, 2017).

As the groups of professionals that interact most frequently with young children, health care and child care providers are most likely to identify possible needs for early intervention by administering a developmental screening tool. And while implementation of developmental screening tools has increased in the last two decades, research shows that there is still room for improvement. A study conducted by Hirai, Kogan, Kandasamy, Reuland, and Bethell (2018), for example, showed that only an estimated 30.4% of children between 9 and 35 months have received a parent-completed developmental screening questionnaire from a health care professional. The same study further identified differences in screening rates based on sociodemographic characteristics—household language, educational level of caregivers, and child health status were associated with differential screening rates. Children who grew up in a household with English as the primary language, with college-educated parents, or children who have a medical home were more likely to receive a developmental screening[1]. Also, even though Medicaid programs are required to offer developmental screenings to enrolled children (see Michigan Department of Health & Human Services, 2017), data from the 2018 Core Set of Children's Health Care Quality Measures for Medicaid and CHIP show that rates of developmental screening using a standardized screening tool ranged from 4% to 76.6% (median=42.2%) for the 25 states reporting on this measure (Centers for Medicare & Medicaid Services, 2019). Michigan's rate is below the median with 37.1% of Medicaid eligible children having received a developmental screening. Identification is the first step for potentially reaping the benefits from early intervention, and therefore it is important to explore the challenges and barriers associated with it.

Health Care Providers

Despite the guidelines for screening, health care providers have not yet reached adequate screening coverage—likely missing many children who would benefit from early intervention. Studies that have explored implementation strategies within health care settings (King et al., 2010; Morelli et al., 2014; Vitrikas, Savard, & Bucaj, 2017) have identified barriers including:

- time limitations/workflow issues;
- insufficient training in administrating screening tools;
- staff capacity, including staff turnover that leads to limited available staff and gaps in capacity to screen before new staff are trained; and
- inadequate reimbursement.

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[1] The AAP defines a medical home as care that is "accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective. It should be delivered or directed by well-trained physicians who provide primary care and help to manage and facilitate essentially all aspects of pediatric care. The physician should be known to the child and family and should be able to develop a partnership of mutual responsibility and trust with them" (American Academy of Pediatrics, 2002).

Following the new AAP recommendations in 2006, a study by King et al. (2010) explored providers' approaches to implementing the new recommendations. The findings revealed that 15 out of the 17 participating providers utilized at least one parent-completed screening instrument. Most providers chose either the Parents' Evaluation of Developmental Status (PEDS), a 10-item questionnaire, or the Ages and Stages Questionnaire (ASQ-3), which comprises 30 items. Providers who expressed time concerns most frequently chose to use the shorter screening tool—the PEDS. Providers indicated that they had particular difficulties implementing the screenings tools during busy times and also indicated that staff turnover was a barrier to implementation. Staff turnover was reported to be a barrier because it led to staffing shortages and/or a gap in capacity to screen before new staff could be trained. In another study, Morelli et al. (2014) conducted focus groups with physicians at four large urban pediatric practices regarding barriers to and best practices around developmental screening. The focus groups revealed challenges to implementation, such as lack of time (similar to King et al., 2010), lack of reimbursement for implementation, and lack of knowledge/training for administering a screening tool.

Child Care Providers

More than three million children under the age of three are enrolled in non-relative child care outside their home in the U.S. (U.S. Department of Education, National Center for Education Statistics, 2016). Therefore, child care settings are another potential avenue for identifying children who could benefit from early intervention. The National Association for the Education of Young Children (NAEYC) has recommended implementing screening procedures, and states, including Michigan, have included to various degrees "screening and assessment" as a quality standard in their state Quality Rating and Improvement Systems (QRIS) (Johnson-Staub, 2014). Although requirements for screening procedures are included in the QRIS, child care centers in Michigan can still receive a five star rating (the highest rating possible) without any developmental screening in place (Great Start to Quality, 2016). While recommendations to conduct screenings have increased, there is only limited research on the implementation of developmental screening and associated barriers within child care settings (see Shahidullah et al., 2020). One study by Boh and Johnson (2018), for example, found that only 16% of 1,565 licensed child care centers and family homes reported utilizing a standardized developmental screening tool.

The research that is available (Boh & Johnson, 2018; Shahidullah et al., 2020) suggests some challenges are unique to the child care setting but also some that are similar to those of health care providers, including:

- lack of time and funding;
- lack of provider knowledge;
- attitudes towards screening; and
- beliefs about their own role and responsibilities with respect to developmental screening.

Shahidullah et al. (2020) surveyed directors and staff from child care centers who had previously participated in a workshop on the utilization of the Ages and Stages Questionnaire (ASQ) and found that while many (70%) believed child care centers should implement a universal screening for all children, only two out of five mentioned that they had used the ASQ with all children in their setting. Boh and Johnson (2018) also found, in a survey of licensed child care centers and family day care providers within one Midwestern state, that while a little over half of the respondents (54%) believed that developmental screening was part of their role as a child care provider, over 70% believed that developmental screening should be conducted outside of their child care program, pointing to some ambivalence about their role in the process. Further, child care settings where teachers believed screening to be part of their role implemented more developmental screenings compared to those where teachers did not consider it to be part of their role. Similarly, a study by Chödrön, Pizur-Barnekow, Viehweg, Puk-Ament, and Barger (2019) found that while providers believed developmental tracking with an objective checklist to be important, only 60% mentioned using one.

Shahidullah et al. (2020) identified a positive relationship between the number of children screened at child care centers and attitudes about the feasibility of the ASQ instrument (including the time and cost to implement, ease of use, perceived usefulness), center support, and their own perceived competence in using it. Over 36% of participants believed parent related issues, such as not having time or not completing the screening, to be a barrier to implementation. The narrative responses from 24 providers in the study by Chödrön et al. (2019) similarly depicted feasibility (time constraints), effectiveness (usefulness), and acceptability (children are unique and their development cannot be captured by a checkbox) as reasons for the belief that objective checklists were not important.

II. FACTORS CONTRIBUTING TO REFERRAL GAPS AMONG HEALTH CARE AND CHILD CARE PROVIDERS

Research has shown that the actual rates of referral differ from the rate of children who are identified with a potential developmental delay—this is called "the referral gap." While health care providers use screening procedures more frequently, there seems to be considerable variation in rates of referrals after children have been identified for a potential developmental delay (Jimenez et al., 2014; King et al., 2010; Lipkin & Macias, 2020). Relatively little is known about the gaps in referral for child care providers but limited evidence suggests a variety of possible sources (Branson & Bingham, 2017).

Health Care Providers

Beyond knowing about the existence of the referral gap, our review of the literature uncovered relatively little about reasons why health care providers refer some children who are identified as at-risk for developmental delay but do not refer other children.

A study by King et al. (2010) identified problems in screening and different rates of referral depending on the screening tool used. Overall, 14% of all the children in the study who were screened were identified to be at risk for having a developmental delay (ranging from 5% to 53% across providers). Rates of identification of delay were larger for providers who used the PEDS screening tool. Twenty-two percent of children who were screened with PEDS were identified as having possible delays compared to 11% of children who were screened with the ASQ-3. The authors found substantial variation in referral rates across providers ranging from 27% to 100% of children with identified delays. The average was 61%. Even though the use of the PEDS screening tool generated higher rates of identification, practices that used the PEDS showed lower referral rates compared to providers who used the ASQ-3. Forty-three percent of children identified with a delay using the PEDS were referred compared to 72% of children identified with a delay on the ASQ. Additionally, some of the providers in the study attempted to track their referral efforts. Their narrative reports indicated that many parents did not follow through with the referrals, although others emphasized that their efforts to refer children had translated into services received and had had a positive impact on children and families.

Similar to King et al. (2010), Morelli et al. (2014) also found that referral rates did not match the number of children who were identified with a possible delay—only 65% of 348 children who were identified with a possible delay received a referral, and only 128 or 51% of those who were referred actually followed through with the referral. The same pattern was identified by Jimenez et al. (2014). Fifty-eight percent of the 434 children who were identified with a developmental concern received a referral, and only 129 followed through. According to the authors, only the number of identified developmental concerns and the existence of special health care needs were associated with early intervention referral. To further explore these discrepancies in identification and referral rates, the authors conducted in-depth interviews with nine pediatricians who had at least one child with an identified concern not referred to early intervention services. The thematic analysis showed that a provider's decision for referral was impacted by parents' own views and concerns. A developmental concern brought forward by the parent was supported by a provider, and a parental wish for no early intervention was similarly respected. Other factors impacting decisions for referrals were explored by Earls, Andrews, and Hay (2009). The authors found that pediatricians were more likely to refer toddlers and preschoolers compared to infants, they were more certain in their decision when they identified concerns in multiple developmental domains or a clear gross motor skill issue (similar to Jimenez et al., 2014), and they were less likely to refer if there were issues associated with problem-solving skills or social-emotional development.

Other studies found greater referral rates when a combination of a more informal developmental monitoring and a standardized screening tool was utilized by the healthcare provider (Barger, Rice, & Roach, 2018; Barger, Rice, Wolf, & Roach, 2018). The authors explored the impact of developmental screening and developmental monitoring on early intervention receipt. Developmental monitoring is an informal strategy in which providers continuously ask questions about the development of a child. The authors used data from the National Survey of Children's Health and found that children who received developmental screening as well as developmental monitoring from their health care providers had the greatest chance to receive early interventions compared to children receiving only one of these measures.

Child Care Providers

Little is known about the referral gap within child care settings but the limited research available points to challenges that are associated with child care center policies, teacher-parent communication, and knowledge about referral agencies (Branson & Bingham, 2017; Chödrön, Pizur-Barnekow, Viehweg, Puk-Ament, & Barger, 2019; Gulsrud et al., 2019; Pellecchia et al., 2018).

Gulsrud et al. (2019), for example, explored the feasibility of screening procedures as well as the implementation of an early intervention (Joint Attention, Symbolic Play, Engagement, and Regulation, or JASPER) within an urban low-income child care center. While the authors found that access to screening was well received (about half of the families completed the PEDS and Modified Checklist for Autism in Toddlers, Revised, with Follow-Up (M-CHAT-R/F) (126 out of 252 families), less than half of eligible children subsequently participated in the intervention (20 out of 42 children).

In a study by Branson and Bingham (2017), the authors used in-depth interviews to explore screening and referral strategies of nine child care providers within one Midwestern state. The narrative data revealed that barriers to making referrals included a lack of child care center policies/procedures, a lack of knowledge of referral agencies, fear of talking to parents about developmental concerns (e.g., worries about making them sad/angry), and the self-perception that they were not qualified to make referrals. The lack of written policies about how to conduct a developmental screening, how to talk to parents about this kind of evaluation, and how to make referrals, was apparent in all centers within this study. Many providers even mentioned having received cautionary instructions from the director not to reach out to parents when concerned about the development of a child. This instruction was apparently based on fear that parents might get angry and take their children out of the child care center. Lack of knowledge about referral agencies was also mentioned in the study by Chödrön et al. (2019). In this study more than 15% of participating providers indicated they did not know where a child could be referred. The study further indicated that most providers knew to refer an identified child to IDEA Part C/Part B services—however, a smaller proportion knew about the possibility of referring a child to his/her doctor.

“**Less than half of eligible children** subsequently **participated** in the intervention.”

III. CHALLENGES AND OBSTACLES FOR PARENTS REGARDING PROGRAM UPTAKE

Parents play a critical role during the referral process and are eventually a determining factor in whether or not a child receives early intervention services. Many factors may contribute to whether or not families choose to participate in the evaluation process or continue on to receive services. Studies that have explored parental help-seeking behaviors, like initiating and/or participating in developmental screening (Jimenez, Barg, Guevara, Gerdes, & Fiks, 2012, 2013; Koerting et al., 2013; Marshall, Mendez, & Singleton, 2019; Pullmann, VanHooser, Hoffman, & Heflinger, 2010; Smith, Akai, Klerman, & Keltner, 2010), have identified barriers including:

- logistical (e.g., transportation, child care, time, insurance);
- knowledge (e.g., health literacy, child development, available services); and
- psychological (e.g., stigma around developmental delay or disability, general distrust).

A qualitative study by Pullmann, VanHooser, Hoffman, and Heflinger (2010), which focused on barriers and facilitators for parental participation in services within a rural area, found that the eight participating parents did not list "mental health" services for their children as their highest priority. Most commonly mentioned were issues around abuse, custody, relationships, poverty, and isolation (p. 218).

Issues around transportation, child care, and time constraints were mentioned by many parents in various qualitative studies (see Koerting et al., 2013). The study by Pullmann et al. (2010), for example, found that it was difficult for parents in rural areas to access services due to transportation difficulties.

One pattern that emerged from the research is the way in which health literacy and knowledge about child development impacted parental help seeking behavior. First-time mothers of infants considered high-risk, who had greater knowledge about child development, were more likely to be worried about their child's development when it was warranted (Smith et al., 2010). According to a study by Jimenez, Barg, Guevara, Gerdes, and Fiks (2013), parents with higher levels of health literacy, defined as "the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions," (p.1054) were more likely to participate in the evaluation process. Those with lower levels of health literacy reported confusion regarding the referral process and difficulty contacting the early intervention agencies. Parents also reported receiving limited support or information about early intervention and the referral process from pediatricians. Further, Jimenez, Barg, Guevara, Gerdes, and Fiks (2012) also interviewed Early Intervention (EI) providers to gauge their beliefs regarding possible barriers to uptake and they thought that parents confounded early intervention with child protective services.

A study by Girio-Herrera, Owens, and Langberg (2013) showed that many parents did not deem treatment or early intervention as important or relevant. The authors noted that many parents of children who were classified as high risk in their study did not recognize a problem in the first place. However, for parents who did recognize that their children may have a developmental delay, many felt that their concerns were not heard by providers. Some parents mentioned their wish for greater inclusion regarding their child's development, however, felt that their knowledge about their children was undervalued by pediatricians (Morelli et al., 2014). In their study, one parent, for example, said "... it comes back that she had a delay in reading. I've been complaining about it for so long; nobody would listen to me... We come in with questions like 'My child is fighting every day. My child is not being around... socializing.' You know and all you can—all they could say is, 'Oh, give them a chance.'" (Morelli et al., 2014, p. 5)

Further, early intervention and programs provided in the home may also carry a stigma that prevents parents from participating. Parents may be concerned about having their children labeled as "special education." While there is limited research about parent perceptions of early intervention services, there is certainly anecdotal evidence of negative perceptions of special education (DeWitt, 2011). The study by Pullmann et al. (2010) found that parents in rural areas often cited the close-knit community as a source for both stigma and support. On the one hand, parents feared their parenting might be judged as the cause of their children's struggles; on the other hand, they expressed the support they got from their community. The religious community was mentioned in a similar vein in the same study —it was seen as a source for emotional and often practical support, but participants were also afraid of being stigmatized. Likewise, Owens, Richerson, Murphy, Jageleweski, and Rossi (2007) found that fears of being judged by professionals and other parents were a major concern of parents considering participating in a behavioral parenting program.

Parents may also fear that conditions in their own lives, including developmental disabilities, substance abuse disorders, mental illness, or experience of intimate partner violence will negatively impact perceptions of their parenting abilities and possibly lead to a child protective services referral (National Academies of Sciences, Engineering, & Medicine, 2016).

In addition, there is little knowledge about families' perceived relationships with professionals in early interventions. A phenomenological study by Lee (2015) explored the experience of one family walking through the different stages of the Individualized Family Service Plan (IFSP) process. The family, a white, middle-class, educated family, stressed satisfaction with the overall services and the knowledge of the providers. However, they also emphasized the lack of relationship building during the initial process of evaluation and general IFSP meetings, as well as general lack of responding to parents' verbalized concerns.

These issues may be even more pronounced for families of color. Dickson, Zeedyk, Martinez, and Haine-Schlagel (2017) found in an observational study to gauge parent participation engagement in child mental health services that Hispanic/Latinx parents shared their perspective less extensively and appeared to be less enthusiastic about at-home assignments. They did not find any differences in the ways that providers engaged Hispanic/Latinx and Non-Hispanic/Non-Latinx parents. A study by Young and Rabiner (2015), which focused on racial/ethnic differences in barriers receiving mental health care for children between 9 and 13 years found, that Hispanic parents reported more practical (commute, health insurance, long waits) and stigma related barriers compared to African American and White parents. The authors noted that the Hispanic population in their sample was likely to be 80% first generation immigrants, concluding that possible language differences (which they did not explicitly explore) may have added another layer to the existing barriers.

IV. WHAT WORKS? INCREASING DEVELOPMENTAL SCREENING, REFERRAL, AND UPTAKE RATES

The literature suggests a number of possible strategies for encouraging developmental screening and referral among health care and child care providers and participation in early intervention programs for families of children with developmental delays.

Health Care Providers

The Assuring Better Child Health and Development Program (ABCD), which was created in 2000 with the goal to increase and ensure healthy development for infants/toddlers in low-income families, has identified key elements that support increased identification of children at risk for developmental delay, referral and uptake rates (Klein & McCarthy, 2009). These key elements include:

- the identification of a standardized screening tool as well as the training thereof;
- development of workflow plans to accommodate concerns regarding time;
- establishing providers' knowledge of referral agencies and building relationships;
- development of processes for tracking referred children; and
- development of working relationships with community agencies.

Since its beginning, the ABCD program has supported 27 states, including Michigan[1], and many of the participating providers within states have seen an increase in developmental screening and better care coordination (Hanlon, 2013).

For example, a pilot program at the Guilford Child Health clinic increased its screening uptake and referral rates by implementing the Ages and Stages Questionnaire (ASQ), a parent completed questionnaire, as well as hiring an early intervention specialist who assisted practices with utilizing the screening tools and making referrals. Because of these new measures the health clinics increased developmental screening rates from 7% in 2000 to 62% in 2002 to 90% in 2009 (Klein & McCarthy, 2009).

Best practices identified in the study by King et al. (2010) support the elements outlined by the ABCD study. Their findings showed the need for an office-wide implementation system that shared similar components across providers. To ease workflow challenges, responsibilities needed to be shared and assigned. Having explicit directives in place for who distributes the screening instrument (e.g., front desk), who scores the screening instrument (e.g., nurses), who is reviewing the scores with the family (e.g., doctor), and who places the referral if it is needed (e.g., social worker) can counter perceived time limitations and increase screening implementation.

Morelli et al. (2014) also point to the importance of having workflow plans in place—in fact, they found that by addressing time flow concerns up front, providers could reach screening rates of almost 85%. One of their workflow procedures included mailing the parent screening tool with instructions 15 days prior to the child's well visit. Parents also received an automated reminder call one day before their visit, and if the completed screening questionnaire was not brought to the visit, parents had the chance to complete it on the actual day of the visit and could also receive help from a designated assistant in the office. Further, implementation systems seem to evolve organically from within the setting—providers recognized the importance of continuously assessing their own implementation efforts to achieve quality improvement even though they found this work time consuming.

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[1] Michigan was one of the 19 states to participate in the ABCD Screening Academy, the focus of which was to increase the utilization of developmental screening tools. According to a personal email communication with Carrie Hanlon, a project director at the National Academy for State Health Policy, the project in Michigan improved developmental screening by improving state policy to better support developmental screening (e.g., clarifying Medicaid billing processes), improving provider practice around the use of standardized developmental screening tools (e.g., dissemination of pediatric preventive care guidelines), and sustaining and spreading the use of standardized screening tools as part of well child care from a 'best practice' to a 'standard of practice' (e.g., development of strategic spread model) (C. Hanlon, personal communication, March 26, 2020).

Child Care Providers

While there is more limited information on the factors that would increase screening and referrals among child care providers, many of the same concepts that are relevant for health care providers likely apply. In the study by Boh and Johnson (2018), teachers emphasized that receiving training about screening tools and programs would increase the likelihood of referring children to further evaluation. Addressing issues regarding workflow and time constraints, and training child care providers about how to talk to parents about the benefits of screening and referral, are also likely to be helpful. The study by Gulsrud et al. (2019) found that child care centers welcomed collaboration with university researchers and the training of their staff for implementing early intervention in their settings.

Parents and Guardians

Rigorous studies on the impact of engagement strategies to enhance parental participation in parenting interventions are still rare (Gonzalez, Morawska, & Haslam, 2018). However, findings regarding best practices for effective parenting programs suggest a few possible ways that rates of uptake and persistence in early intervention programs could be improved. Providing services in a natural setting (i.e., at home or in child care), peer pairing (i.e., partnering parents with other parents), motivational interviewing (i.e., a counseling method that helps participants find internal motivation to change behaviors), and service integration are some of the elements of effective programs that were cited frequently (Carr & Lord, 2016; National Academy of Sciences, Engineering, & Medicine, 2016; Pellecchia et al., 2018).

Pellecchia et al. (2018) conducted a review and analysis of child intervention programs to identify what strategies were effective in engaging underrepresented parents. They found that attrition was lower when services were performed at home or in the child care setting and when peer pairing was part of the model. The authors further emphasized that regular meetings within the community are likely to promote trust and reduce power imbalances between professionals and participants. As a supplement to the services provided by professionals, peer mentoring or pairing can help reduce stigma and isolation, and provides an opportunity for parents to share knowledge (National Academy of Sciences, Engineering, & Medicine, 2016).

Recognizing parents as partners in the process, acknowledging their concerns and perspectives, and tailoring interventions to the needs of the parent and child are also likely to increase engagement. Including fathers (and not just mothers) in the process can also potentially be helpful. And barriers to participation can be reduced by ensuring that services are integrated and that there is inter-agency collaboration.

Carr & Lord (2016) were able to maintain similar retention rates in an early intervention program for children with autism spectrum disorder (ASD) with a small sample of low-income families as in previous studies of families from predominantly upper-middle income, highly educated, White backgrounds. They credit a liberal cancellation policy with some of their success but acknowledge that that might not be feasible for community-based agencies who are only reimbursed for services provided.

Findings on the impact on monetary incentives on uptake and retention of parental engagement in parenting programs are mixed (Gonzalez et al., 2018). Some studies have found that monetary incentives may have an impact on the decision to enroll for the parenting program but not necessarily on attendance itself (Dumas, Begle, French, & Pearl, 2010; Gonzalez et al., 2018).

Finally, service providers may benefit from additional professional development, focused on parental engagement as well as trauma-informed care.

CONCLUSION

The benefits of early intervention for children with disabilities and possible developmental delays can be significant. Part C of the federal Individuals with Disabilities Education Act provides for these services to be made available to any child who needs them. However, the data regarding participation suggests that many children who would qualify are not receiving these services. The literature recommends a number of ways to improve identification, referral, and uptake during the early intervention process. For physicians and child care providers these include clear practices around screening within and across providers. Best practices for families include providing services in a natural setting, peer to peer mentoring or pairing, engaging parents as partners in the intervention, and service integration.

Further research could explore the ways in which demographic characteristics, particularly race and ethnicity and income, impact access to and participation in early intervention, given the relative lack of, and conflicting, evidence. And like many other social programs, further research must also consider the impacts of COVID-19 on identification for, and referral and uptake to early intervention programs. For instance, a switch to offering services virtually via video call may alleviate concerns that families may have regarding service providers entering their home. But it may also pose problems for families who do not have access to the necessary technology to participate in a virtual appointment.

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About the Authors

Anna Erickson is a senior project manager at the Youth Policy Lab. Her work focuses on early childhood and elementary programs and policy to improve educational outcomes for children.

Robin Jacob, PhD, is a faculty co-director of the Youth Policy Lab and a research associate professor at the Institute for Social Research at the University of Michigan. Her research focuses on rigorously evaluating interventions designed to improve the educational and life outcomes of youth and their families.

Katja Robinson, PhD, is a research associate at the Youth Policy Lab. Her scholarly research interests lie at the intersection of policies, practices, and well-being of children and families with an overall commitment to equity, social justice, diversity, and inclusion.

Youth Policy Lab

University of Michigan Youth Policy Lab
5201 Institute for Social Research
426 Thompson St
Ann Arbor, MI 48104

734-647-8829
@YouthPolicyLab
youthpolicylab.umich.edu

Support the Youth Policy Lab's efforts to use data for good.

The University of Michigan Youth Policy Lab helps community and government agencies make better decisions by measuring what really works. We're data experts who believe that government can and must do better for the people of Michigan. We're also parents and community members who dream of a brighter future for all of our children. At the Youth Policy Lab, we're working to make that dream a reality by strengthening programs that address some of our most pressing social challenges.

We recognize that the wellbeing of youth is intricately linked to the wellbeing of families and communities, so we engage in work that impacts all age ranges. Using rigorous evaluation design and data analysis, we're working closely with our partners to build a future where public investments are based on strong evidence, so all Michiganders have a pathway to prosperity.