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# The Early Intervention Referral Process for Rural Infants and Toddlers with Delays or Disabilities: A Family Perspective

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## Abstract

**Introduction** Early intervention (EI) services provide essential support to families of children with delays or disabilities. Children can enter EI via a variety of routes, though all begin with a referral, and for children who require additional services, subsequent referrals are generally warranted. The referral process may be complicated by rurality, but little is known about families' experiences with EI referrals in rural areas. This study focuses on better understanding rural families' perspectives of the EI referral process.

**Methods** Families with children in Part C services throughout Montana ($N = 30$) were interviewed regarding their referral experiences. A layered analysis was used to analyze initial and subsequent referrals, and investigate families' experiences regarding the referral process.

**Results** Families' reports regarding which professionals provided referrals and who they provided referrals to were diverse. As part of qualitative content analysis three themes emerged: 1) the referral process is both challenging and complex; 2) professionals facilitate connections; and, 3) some professionals may have misconceptions or misunderstandings. Some families discussed how aspects of rurality may have exacerbated the complexities and challenges of the EI referral process.

**Discussion** Based on families' experiences, professional development related to when, how, and who to refer to EI services, and subsequent support of families during the referral process, may be of utmost importance. Furthermore, families discussed rurality in relationship to turnover rates, limited access to services or specialized knowledge, and travel distance required to receive services, demonstrating the importance of training and retaining rural EI professionals.

**Keywords** Early intervention · Referral · Rural health · Family experience · Qualitative research

## Significance Statement

Many children who are eligible for early intervention (EI) are not referred into services. Families' perspectives of the barriers faced in entering EI services have demonstrated the process is viewed as confusing and often complicated by communication issues with healthcare professionals. Little is known about the EI referral process for rural families who may experience additional, unique barriers. Our findings indicate that aspects of the EI referral process may be complicated by families' rurality. Better understanding the EI referral process can inform professional development and support higher referral rates for children, especially in rural areas, who can benefit from EI.

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## Introduction

In the United States, Part C of the Individuals with Disabilities Education Act (IDEA) is a type of early intervention (EI) program that exists to support young children who face various risk factors to their health or well-being, such as developmental delays and/or disabilities (U.S. Department of Education 2019). This EI program supports young children by identifying, evaluating, and helping meet the developmental and health needs of children and their families. As part of a metanalysis, Barger and colleagues (2018) identified very few studies that outline the entirety of EI—evaluating for eligibility through receipt of services—and also identified a need to better understand this process (Barger et al. 2018). Furthermore, the EI referral process should be investigated for families living in rural areas given that early entry into EI is critical (Barger et al. 2018), yet often challenging for families living in rural areas (Hallam et al. 2009).

The route by which children enter EI services is varied. Pediatricians are encouraged to provide comprehensive health care including administering developmental assessments, and making timely and appropriate referrals to EI programs and medical subspecialties (American Academy of Pediatrics—Committee on Child Health Financing (AAP-CCHF) 2013). Though pediatricians represent one important referral source for EI, primary sources of referral also include, but are not limited to: hospitals (Laadt et al. 2007); the child welfare system (U.S. Department of Health and Human Services (DHHS) 2018); Child Find (e.g., coordinated efforts to identify children eligible for Part C; Bricker et al. 2013); and, family self-referral (U.S. Department of Education 2019). The EI referral process is ongoing and often extends beyond an initial referral to include subsequent referrals (Bruder 2010).

The number of children eligible and enrolled in EI services varies widely throughout the United States (Rosenberg et al. 2013), but many children deemed to be high-risk or eligible for EI do not get referred to services (Clements et al. 2006; Atkins et al. 2017). For instance, only ~10% of children who may be eligible for Part C receive these services (Rosenberg et al. 2008). This low rate of receipt of Part C services is problematic given that EI can positively support overall child and family well-being (Dunst et al. 2007), and since EI services are intended to provide developmental support so that children no longer need services or are prepared to transition into special education (e.g., Part B of IDEA; U.S. Department of Education 2019).

The difference between the number of children who are eligible for EI services and those who go on to receive services may be due to a variety of factors. Previous studies have found that just over half of infants and toddlers receive developmental assessments (Halfon et al. 2004), and pediatric practices do not consistently refer children who fail developmental screenings to EI services (King et al. 2010; Marks et al. 2011). These inconsistencies may have to do with professionals' hesitancy to refer. Doctors may be less likely to provide referral information to families if the child does not have an official diagnosis, even when families share concerns about atypical development (Silverstein et al. 2006). This hesitancy may partially stem from medical practitioners' limited understanding of the EI process (Edwards 2018).

Families' perspectives regarding EI services also reflect why there may be discrepancies between the number of children who are eligible versus the number who receive EI services. Though studies regarding families' referral experiences are limited, families' perceived barriers to accessing EI services often include communication problems with their pediatrician (O'Neil et al. 2008; Jimenez et al. 2012) or therapist (Ideishi et al. 2010). Even after being referred to services, families report that the referral process is inherently confusing and can influence the timely receipt of services (Conroy et al. 2018). After initial referrals, a lack of willingness for further referrals by professionals often results in families perceiving a lack of support, further complicating services (Sices et al. 2009). Ecological systems theory (Bronfenbrenner and Morris 2006) provides a context for understanding of the importance of families' referral experiences, since what influences one aspect of the system (e.g., the family's perceived barriers for accessing EI services) then influences other aspects (e.g., the child's receipt of EI services, or lack thereof).

Lastly, there may be unique challenges for families living in rural areas, such as a general lack of services (Hallam et al. 2009). Of the limited studies that have focused on rural families' overall EI experiences, findings indicate that rural families may lack information about aspects of EI services (Bush et al. 2015) or perceive that professionals lack adequate knowledge regarding EI (Elpers et al. 2016). Importantly, these studies have not focused on how rurality has influenced the referral process specifically. In addition, 2 of these 3 studies focused on families' experiences with a child with hearing loss. Therefore, given the great variability in the needs of children served by EI (Scarborough et al. 2004), a gap in the literature exists related to the referral experiences of rural families who have a child referred to EI.

### The Current Study

The positive, influential nature of EI services cannot be understated, yet as many as 90% of children do not receive the EI services for which they are eligible (Rosenberg et al. 2008). Given the importance of EI referrals and the limited literature related to this process (Barger et al. 2018), and the dearth of literature related to families living in rural areas, the purpose of this exploratory study is to further investigate families' experiences of the EI referral process in a rural state. The overarching research question is: What were families' referral experiences as part of receiving EI services? A secondary question is: Who or what are the sources for initial and subsequent EI referrals?

## Methods

This study took place in the state of Montana. Montana is classified as a 'frontier' state, which means Montana is sparsely populated and/or requires traveling great distances to reach services such as those related to healthcare (Rural Health Information Hub 2018).

### Procedures

We used the Consolidated Criteria for Reporting Qualitative Studies (COREQ; Tong et al. 2007) to guide this study. This study was approved by Montana State University's Institutional Review Board (approval number KD041416) and was conducted in accordance with ethical guidelines for conducting human subjects research. Montana's Part C agencies sent flyers to families receiving services to invite them to participate in a semi-structured interview about their EI experiences, including interactions with their Part C Family Support Specialists who coordinate services with other agencies, professionals, and programs in order to meet the needs of children and their families. Participation included informed written consent. Interviews took place in families' homes and took approximately 1.5–2 h. These interviews about families EI experiences included questions about how and why their child qualified for Part C services, the professionals serving the child and family, and the EI services they received. This study was exploratory in nature, so no interview questions were specifically focused on rurality; we did not want questions to be leading related to what may or may not have influenced families' referral experiences.

### Sample

Thirty families with a total of 32 children participated in this study; all 30 families had received Part C services which includes working with a Family Support Specialist who is the family's service coordinator. For three families both the child's mother and father participated in the interview. Families were asked to identify the child's primary caregiver, who then provided survey information about themselves, their household, and their children. All primary caregivers identified themselves as the child(ren)'s mother and ranged in age from 21 to 63 years ($M = 32.1$); 27 were biological mothers, 2 were foster mothers, and 1 was a biological grandmother. We use the word 'families' in this manuscript when speaking to the broader sample since the child(ren)'s primary caregivers were speaking on behalf of their families' overall experiences, and we use 'parent' when referencing a caregiver's direct report. Children (20 males) were 23.0 months of age

**Table 1** Demographic information for participants

| Demographic information | % (*n*) |
|---|---|
| Primary caregiver demographics ($N = 30$) | |
| Race/ethnicity* | |
| Caucasian or white | 96.7% (29) |
| American Indian/Native American | 13.3% (4) |
| Hispanic, Latino, or other Spanish Origin | 6.7% (2) |
| Marital status | |
| Married | 80.0% (24) |
| Single | 13.3% (4) |
| Divorced | 6.7% (2) |
| Highest level of education | |
| High school or General Education Development (GED) | 20.0% (6) |
| Some college | 23.3% (7) |
| Associates degree | 3.3% (1) |
| Bachelor's degree | 43.3% (13) |
| Master's degree | 10.0 % (3) |
| Employment status | |
| Stay-at-home parent | 43.3% (13) |
| Working full time | 26.7% (8) |
| Working part time | 26.7% (8) |
| Unemployed | 3.3% (1) |
| Family demographics | |
| Annual gross household income | |
| Less than $12,000USD | 10% (3) |
| $12,000–19,999USD | 3.3% (1) |
| $20,000–39,999USD | 23.3% (7) |
| $40,000–59,999USD | 23.3% (7) |
| $60,000–79,999USD | 20.0% (6) |
| $80,000USD or more | 20.0% (6) |
| Child demographics ($n = 32$) | |
| Race/ethnicity* | |
| Caucasian or White | 93.8% (30) |
| American Indian/Native American | 21.9% (7) |
| Hispanic, Latino, or other Spanish Origin | 6.3% (2) |
| Asian | 3.1% (1) |
| Reason for initiation to early intervention* | |
| Accident | 13.3% (4) |
| Congenital medical condition | 20.0% (6) |
| Family had developmental concerns | 53.3% (16) |
| Preterm birth | 20.0% (6) |
| Professional had developmental concerns | 10.0% (3) |

*Numbers sum to more than 100% since participants listed multiple responses on average at the time of the visit (SD = 11.0 months). See Table 1 for additional demographic information.

## Analysis

We captured all information from families' interviews regarding their EI referral experiences and did not limit information to only medical- or insurance-based referrals; therefore, we captured the nuances of these experiences including referrals that are necessary in order to receive services and referrals that are more informal in nature. A layered analysis procedure was used (Vaterlaus et al. 2014). First, a descriptive qualitative approach was used to analyze aspects of the initial and subsequent referrals that families received. Second, content analysis was used to analyze families' overall referral experiences (Johnson and LaMontagne 1993; Hsieh and Shannon 2005). To complete content analysis, the data were transcribed by members of the research team. Remaining steps were completed by the first and second authors. For immersion, the researchers read and reread the transcripts and kept notes regarding emerging themes and ideas. During this step the authors highlighted exact words and phrases related to the research question. While no specific interview questions had focused on rurality, some families spontaneously mentioned rurality in relationship to information they shared about their referral experiences; therefore, when relevant to the current study, rurality was captured in this step. Next, open coding was used to create an extensive list of codes, and then the authors met to narrow and discuss how these more nuanced concepts represented an initial coding scheme. The authors then separately coded in order to determine consistent use of the codes which resulted in a kappa score of .74, indicating substantial agreement (Landis and Koch 1977). All remaining transcripts were then coded by the second author, followed by a review by the first author, after which any differences were discussed and resolved. Brackets are used in presenting quotes in order to provide context or remove identifying information.

# Results

The descriptive analysis highlighted the diversity of families' initial and subsequent EI referral experiences, and three themes emerged from the qualitative content analysis to describe families' overall referral experiences.

## Initial and Subsequent Referrals

Families reported who initially referred them into EI services and what subsequent referrals were necessary in order to obtain the care they needed for their child. Only one family was unsure of the source of their initial referral, and 4 families did not discuss any subsequent referrals. Families' reports of initial and subsequent referral sources were diverse and included many individuals and/or agencies. Families ($n$ = 26) discussed receiving a total of 61 subsequent referrals ($M$ = 2.3, SD = 1.5), each of which led to additional services (see Table 2). Most referrals were direct and did not require a chain of individuals (e.g., "[Our FSS] referred us to [our therapist]" and "The pediatrician gave me

**Table 2** Families' (N = 30) reports of initial and subsequent early intervention referrals

| Type and source of referral | % (*n*) |
|---|---|
| Initial referral (*n* = 29) | |
| Child find to Part C | 10.0% (3) |
| CPS to Part C | 6.7% (2) |
| Medical doctor to Part C | 13.3% (4) |
| Medical doctor to specialist | 13.3% (4) |
| Medical doctor to therapist | 10.0% (3) |
| NICU to other EI service | 3.3% (1) |
| NICU to Part C | 20.0% (6) |
| NICU to therapy | 3.3% (1) |
| Self-referral to Part C | 10.0% (3) |
| Self-referral to therapist | 6.7% (2) |
| Subsequent referrals* (*n* = 26) | |
| CPS to Part C | 3.3% (1) |
| Other EI service to Part C | 3.3% (1) |
| Medical doctor to other EI service | 10.0% (3) |
| Medical doctor to Part C | 16.7% (5) |
| Medical doctor to specialist | 13.3% (4) |
| Medical doctor to therapist | 13.3% (4) |
| Self-referral to Part C | 20.0% (6) |
| Self-referral to therapist | 20.0% (6) |
| Part C FSS to other Part C agency | 6.7% (2) |
| Part C FSS to Part B | 13.3% (4) |
| Part C FSS to other EI service | 10.0% (3) |
| Part C FSS to specialist | 3.3% (1) |
| Part C FSS to therapist | 46.7% (14) |
| Social media to Part C | 3.3% (1) |
| Specialist to other EI service | 3.3% (1) |
| Specialist to therapist | 3.3% (1) |
| Therapist to other therapist | 6.7% (2) |
| Therapist to Part C | 3.3% (1) |
| Therapist to specialist | 3.3% (1) |

'Other EI service' refers to a variety of individuals such as specialized preschools/schools/programs, respite nurses, audiologists, etc. 'Specialist' refers to a specialized medical doctor such as pediatric neurologists, cardiologists, geneticist, etc.

*CPS* child protective services, *EI* early intervention, *FSS* family support specialist, *NICU* neonatal intensive care unit

*Numbers sum to more than 100% since some participants listed multiple subsequent referrals the recommendation [for the Part C office]"). Many referrals, 24 of the 61 (39.3%), were based on suggestions from the family's Part C service coordinator—a Family Support Specialist (FSS).

## Families' Experiences of Services, the Process, and Professionals

Three themes emerged that described families' Part C referral experiences: (1) the referral process is both complex and challenging ($N = 30$); (2) professionals facilitate connections ($n$ = 28), and, (3) professionals may have misconceptions or misunderstandings ($n$ = 7). See Table 3 for more details.

### The Referral Process is both Challenging and Complex

All participants ($N$ = 30) reported that the referral process was both emotionally taxing and complicated. Families indicated that becoming aware of their child's exceptionalities as part of the referral process and undergoing the referral process itself was "depressing," "too hard," and incited "a lot of emotional strife." One parent detailed this emotional burden by stating, "When your child gets referred you are going through some emotional turmoil and stages of grief potentially, and uncertainty about, 'Is my kid going to be permanently disabled?'" Some families described that what added to their emotional turmoil was that their child had to be treated far from home (e.g., the specialist "was all the way in St. Paul, Minnesota") given that they live "in this rural area."

Many families discussed feeling that the referral process itself was confusing and they had "lots of questions" and "didn't really know all the ins and outs." For example, one parent stated, "[I was] left guessing, 'Am I asking too much? Am I too demanding, am I expecting too much? This is my child, is this my responsibility or is it okay to ask for help in this?'" while another questioned, "How do I know who determines that she needs [other services]?"

This lack of clarity regarding referral was often exacerbated by frequent professional turnover. Of the 20 families (66.7%) who reported high professional turnover rates, 19 reported turnover with their Family Support Specialist (FSS), specifically. This turnover rate was represented in some families' lack of familiarity with their FSS, with one individual saying, "I can't even tell you [our 4th FSS's] last name." Families reported "kids need so much consistency" and they "found it very hard losing people." More broadly, parents commented on how professional turnover may relate to the rural areas in which they lived, saying, "There's not a lot of continuity of care… it's hard to track providers in rural areas" and "Again, [in] rural Montana, good luck finding a [professional] who's going to move here."

Many families (60.0%) also discussed a perceived lack of access to services or professional knowledge regarding their children's needs which ultimately left families feeling alone during the referral process. Parents stated, "I didn't really have the support that I needed" and "What I'm lacking in Montana is support [about my child's specific condition]." Some families indicated that rurality exacerbated their ability to obtaining services or knowledge. Parents stated, "Rural Montana has its challenges, for sure," "There is no such thing as home-based services in rural Montana. You cannot get specialists who come into these communities and stay," and "We don't have an occupational therapist or physical therapist available because we live in the middle of nowhere."

Families also described a variety of other barriers that contributed to the challenging nature of referral. For example, families reported financial issues, a lack of clarity regarding transition to Part B services, a delay in entering services, and incorrect information about services provided by the individual who referred them.

### Professionals Facilitate Connections

Twenty-eight families (93.3%) identified EI professionals as advocates who provided additional supports and/or connected them with other local opportunities, demonstrating how EI professionals helped facilitate additional connections for families.

Of the 25 families (83.3%) who viewed professionals as advocates for obtaining referrals, 24 of these families viewed their FSS as the *sole* advocate for referrals, despite the fact that families were connected with a variety of professionals and programs as part of their broader EI experiences, as outlined in Table 2. Families said things like, "I really love having a go-to person" and "I appreciate [our FSS] because if there's anything that we can get approved through [other programs] she's on it." In addition, many families reported being provided with supports for getting other services or resources, examples included: Early Head Start, Medicaid, Social Security, local parenting classes or play groups, and ideas for specialized equipment to request. One parent said, "We didn't know about [our childcare options] but our FSS told us; we didn't know about the eligibility for it." Families also discussed being informed of local events and activities that may benefit their children.

### Professionals may have Misconceptions or Misunderstandings about EI

Discussions about barriers to accessing the referrals necessary for their children, which included responses from seven families (23.3%), often centered around their perceptions of hesitation by some professionals. One parent noted, "I

**Table 3** Families' (N = 30) reports of their Part C referral experiences: results from a qualitative content analysis

| Code | *n* | % | Examples |
|---|---|---|---|
| Theme 1: The referral process is both challenging and complex (*N* = 30) | | | |
| The referral experience takes an emotional toll | 23 | 76.7 | "… when they're first getting diagnosed, the parents don't know how to cope with it emotionally and they're not really allowed to go through a grief process." |
| The referral process is complicated and/or unclear | 21 | 70.0 | "One thing that would be helpful is if there was more transparency at the beginning when you enter services about what [this Part C agency] is, what it isn't, and what are realistic expectations." |
| There are high rates of professional turnover | 20 | 66.7 | "If there was one frustration it would be the turnover of Family Support Specialists, because you have to start completely fresh with every one of them. … We don't want to be shuffled.'" |
| There is very limited access to services/knowledge regarding child needs | 18 | 60.0 | "I was overwhelmed in the situation with him and I didn't really have the support that I needed. [I needed] some places to go to make contact with people that could help me, because at the time it was just way more than I could do. It still is." |
| Referral complicated by insurance or financial issues | 12 | 40.0 | "I can't afford to continue to go down to [a town hours away] for services all the time." |
| Transition to Part B is challenging and/or unclear | 11 | 36.7 | "We never even thought that would be a consideration that she wouldn't qualify for [Part B] because, I mean, there's just a lot of things that she can't do and that kids her age could." |
| Entry into services was delayed | 10 | 33.3 | "I wish I'd known about [Part C] stuff when he was born. I would have known that they did offer services automatically for [children who are] premature. … I wish they'd intervened before he started lagging. Before he stalled in his development." |
| Incorrect or unclear information provided by referrer | 5 | 16.7 | "They wanted us to give him a full-blown developmental screening. … we went [hours away] to find out that they hadn't put the paperwork in right." |
| Theme 2: Professionals facilitate connections (*n* = 28) | | | |
| Professionals are advocates for obtaining referrals | 25 | 83.3 | "The main thing that they help people with is figuring out those loops and hoops that you don't know about. How does the run of the mill person know that even exists?" |
| Professionals provided family with supports for additional services | 21 | 70.0 | "[Our Family Support Specialist] was the one that helped get the social security in order, got Medicaid in order, was telling me all about different services that were available and of course that when she found out certain things you know, she'd be like, 'Okay, well we have this resource.'" |
| Professionals connect family with local events, activities, etc. | 5 | 16.7 | "[Our Family Support Specialist] will bring me like family magazines or events going on in the community." |
| Theme 3: Professionals may have misconceptions or misunderstandings about EI (*n* = 7) | | | |
| Professionals are hesitant to refer to other services | 7 | 23.3 | "The last time I saw his pediatrician he didn't think [my child who is at risk for a neurological disorder] needed one [a therapy evaluation] at this point." |
| Professionals lack knowledge regarding Part C | 3 | 10.0 | "I asked the physical therapist, 'When is the time that I should be going to [the Part C agency]?' and she was like, 'Not yet. I don't think you should do it. … it's for kids who have more significant disabilities.' … [then] I asked the pediatrician, 'Should I refer him?' and she also was like, 'No, I think you should hold off because I don't think he has significant delays.' I could have been referred by the pediatrician." |

wouldn't get a referral if I didn't ask for it. They give it to me because I ask, but they didn't offer it or suggest it."

Though just seven families reported professional hesitancy to refer families to EI services, five of these families noted hesitancy specifically from their pediatrician. Families discussed feeling that their pediatrician was hesitant to refer to EI services. A consequence of these misconceptions was that "people aren't given the resources" necessary to obtain EI services. One parent shared:

> From the pediatrician I got, 'We'll wait, maybe we'll reevaluate at 3.' Well [that would mean], 2 months from now would be the first time he'd ever see an audiologist. He might still not even be saying 'uh oh' or 'no no,' you know? Then we'd have a real problem.

Similar to a perceived hesitancy to refer, families perceived that professionals lacked necessary knowledge regarding Part C EI services specifically, which was ultimately a barrier to referral. Comparable to the trends noted above, 2 out of 3 of the families who reported a perceived lack of knowledge regarding Part C were discussing a pediatrician. One parent shared, "My pediatrician didn't actually recommend [the Part C agency]. He was like, 'No, you already have him in audiology, you already have him in speech.'" Families' perceived hesitancy for pediatricians to refer and/or their lack of knowledge about Part C ultimately contributed to what one parent called "a huge disconnect" between professionals who can refer to services and families of children with disabilities.

## Discussion

This study provides insight into the complex nature of families' EI referral experiences. We believe this study is the first to investigate the EI referral process for families living in rural areas whose children were referred into services for diverse reasons. Families' perspectives from this study can inform both potential strengths and opportunities for growth for professionals who refer to EI services.

The various routes of initial and subsequent referrals families indicated in this study are in line with the diversity of referral recommendations represented nationally (Laadt et al. 2007; AAP-CCHF 2013; Bricker et al. 2013; U.S. DHHS 2018). Families reported viewing EI professionals, primarily their Part C FSSs, as advocates and primary sources through which they received information about other services. These findings demonstrate a strength in Montana's Part C system.

However, notions of complexity were also reported by most families in this study. Consistent with previous studies conducted in other types of geographic areas (Ideishi et al. 2010; Jimenez et al. 2012; Conroy et al. 2018), families discussed the emotionally taxing and complicated nature of the referral process. Families likely need more support as part of the referral process and entry into services. Montana's Part C program should consider creating a mechanism for greater emotional support of families who are first entering services, including a streamlined way for families to learn more about Part C services so they can feel more prepared to navigate the system and have a clearer understanding of what services may be like.

A unique contribution of this study is that we also found that the complex nature of EI referrals may have been further complicated by rurality. Importantly, no specific interview questions focused on rurality, so families' comments about rurality were based on their answers to broader questions. Families mentioned feeling as if rurality related to their experiences of high turnover rates and/or challenges with recruiting EI professionals, and a lack of access to services or professional knowledge about specific conditions, which is similar to what other limited studies have found for rural families (Bush et al. 2015; Elpers et al. 2016). Given that the studies by Bush et al. (2015) and Elpers et al. (2016) focused on children with hearing loss, our study adds to the literature in that rural families of children with diverse needs, including but not limited to hearing loss, perceive hardships to the EI referral process related to turnover, recruitment, and/or training of EI professionals. In line with the limited studies on this topic, we also found that families mentioned how rurality influenced their limited access to services (Hallam et al. 2009) and that required travel distances to access services were also a barrier (Bush et al. 2015). However, this study is the first to document these challenges related to the referral process more specifically, rather than rural families' overall EI experiences. In sum, funding and policies that focus on training and retaining EI professionals in rural areas may be an important contributing factor to families' entry into and/or experiences during EI services.

Families' responses from this study also indicate that despite national guidelines (Laadt et al. 2007; AAP-CCHF 2013; Bricker et al. 2013; Edwards 2018; U.S. DHHS 2018; U.S. Department of Education 2019), some families perceive hesitancy from professionals to refer them to additional EI services. Though this finding is concerning and in line with other studies (O'Neil et al. 2008; Ideishi et al. 2010; Jimenez et al. 2012), the majority of individuals in this study did not report such hesitancy, indicating that, based on families reports, most professionals serving the participants of this study were in accordance with recommended practices. Yet the findings of this study coupled with previous studies indicating families' perceptions of professional hesitancy or lack of clarity regarding when to refer (O'Neil et al. 2008; Ideishi et al. 2010; Jimenez et al. 2012) and/or delays in entry into EI services (Conroy et al. 2018), indicates a need for professional training and growth regarding when, how, and who to refer to specific types of EI services.

The qualitative nature of this study allowed for an in-depth understanding of families' experiences regarding the referral process but is not generalizable to a larger population. Furthermore, the families interviewed in this study were primarily Caucasian and married, and were recruited through a Part C system, further limiting the broadness with which the results can be attributed. That being said, the themes that emerged from this study could inform future research of a larger and more diverse sample. Further, this study provides insight into families' perspectives of the factors that may complicate the referral process, including rurality and perceived hesitation from or knowledge of professionals. However, this study does not provide evidence of professionals' objection to refer, nor does it offer insight into why professionals may have been hesitant to refer. Future qualitative research should investigate professionals' perspectives regarding EI referral and should seek to identify what may support appropriate referrals to EI services.

## Conclusion

EI services are shown to be positively influential to children's and families' outcomes when children face risk factors associated with their health or well-being. Despite the number of children eligible to receive services, many do not. As described in this study, families who do receive EI services describe the referral process as complex and confusing, and rurality may exacerbate the complexity or confusion for families. Many families discussed how their EI professionals were advocates for receiving additional resources or supports. Some families discussed feeling that professionals had misconceptions or misunderstandings about EI. Professional development is needed regarding when, how, and who to refer to specific types of EI services which may promote more families to enroll their children in these services and make the process easier for them to navigate.

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## Compliance with Ethical Standards

**Conflict of interest** The authors declare that they have no conflict of interest.

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