PART C EARLY INTERVENTION REFERRAL AND ELIGIBILITY FOR CHILDREN WITH DIAGNOSED MEDICAL CONDITIONS: AN EXPLORATORY STUDY IN TWO STATES

by

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Title: Part C Early Intervention Referral and Eligibility for Children with Diagnosed Medical Conditions: An Exploratory Study in Two States

Insufficient referral and participation in Part C Early Intervention (EI) services are common among children aged birth to 3 years, including those automatically eligible due to diagnosed medical conditions. States have established lists of diagnosed medical conditions to streamline eligibility determination for these children. However, there is limited understanding regarding the knowledge and utilization of the state-approved lists as well as the associated policies and referral practices, among pediatricians and Part C EI personnel. To address this gap and gather recommendations for improvement, a concurrent embedded mixed-method study was conducted in Michigan and Washington. The study involved survey questionnaire completed by 193 Part C EI personnel and 69 pediatricians, and semi-structured interviews with 45 Part C EI personnel and 22 pediatricians from both states. The findings revealed that pediatricians have significantly ($p < 0.05$) less knowledge of the state-approved lists, associated policies and referral practices compared to Part C EI personnel. There is considerable variability in how referral practices are implemented by pediatricians and Part C EI personnel, indicating a lack of common understanding. Based on these findings, recommendations are proposed. Some of the short-term recommendations include improving the state-approved lists, development of a state-wide universal web-based referral form for pediatricians and establishing a centralized fax number for efficient information transmission. In the long term, implementing an integrated

electronic health record (EHR) system and providing comprehensive training on referral and eligibility determination processes for both Part C EI personnel and pediatricians are emphasized to enhance collaboration and improve EI services.

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CHAPTER 1

INTRODUCTION

Part C of the federal disabilities law, the Individuals with Disabilities Education Act (IDEA, 2004) provides early intervention (EI) services to infants and toddlers with or at risk of developmental delays and diagnosed medical conditions that have a high probability of developmental delays or disabilities (henceforth referred to as diagnosed medical conditions). Part C EI services aim to support both children and their families. Research suggests that a vast majority of children who are likely to qualify for Part C EI services fail to enroll in the program, with estimates indicating that only approximately 10% of eligible children get enrolled (Rosenberg et al., 2008; Sices, 2007). Specifically, in 2021, 3.6% of the entire population of infants and toddlers received EI services across the United States (Early Childhood Technical Assistance, 2023). The problem of inadequate participation in the Part C EI program is also prevalent among children with diagnosed medical conditions despite their automatic eligibility for Part C EI services (Little et al., 2015; Mussato et al., 2017; Atkins et al., 2019; Kay, 2021).

Pediatricians are often the primary source of information for families during a child's first five years, serving as experts not only on health issues but also on child development. They are critical in identifying and connecting children to Part C EI services, but many children who need these services are not identified before school entry, and only a small percentage are referred to Part C EI services (King et al., 2010; Jimenez et al., 2014). The process of accessing Part C EI services according to federal guidelines involves several steps, including screening, identification, referral, intake, evaluation, and service provision, and must be completed within 45 days of receipt of referral, unless parental consent is not obtained by Part C EI agency within that timeframe (34 C.F.R.§ 303.310).

Several barriers have been identified in the literature that prevent families from accessing Part C EI services. These barriers include families declining services, ambiguous communication regarding referral purposes, inadequate communication from EI personnel and pediatricians, failure to schedule eligibility evaluations, families' reluctance to participate due to scrutiny or potential reporting to child protection or immigration services, and insufficient information reported to Part C EI from pediatricians (Kavanaugh et al., 2012; Jimenez et al., 2012; Jimenez et al., 2014; Braddock & Twyman, 2014; Little et al., 2015; Lipkin et al., 2020; Atkins et al., 2020). Despite the observed low rates of Part C EI service enrollment, little is known about the pathways to Part C EI enrollment and why young children with diagnosed medical conditions are not being referred for services. Especially important are intake and eligibility evaluation procedures (Kavanaugh et al., 2012), steps that link referral initiations from pediatricians to Part C EI enrollment.

Part C Early Intervention Eligibility Criteria

States have the authority to determine the level of developmental delay that qualifies a child for Part C eligibility, as stipulated in Section 635(a)(1) of IDEA. States also have the power to establish additional eligibility criteria for Part C services. For instance, states may choose to include infants and toddlers under 3 years of age who are at risk of experiencing substantial developmental delay if they do not receive early intervention services, as well as children aged 3 years and above who are eligible to receive preschool services under the IDEA, Part B, Section 619. Such children can continue to access these services until they qualify for kindergarten or an earlier time frame, according to the 34 Code of Federal Regulations C.F.R.§ 303.211 and IDEA, Section 632(5)(B). For this reason, states vary considerably in their Part C EI eligibility criteria, including definitions of developmental delays and diagnosed medical conditions. Evidence shows that variation in state Part C EI eligibility requirements is associated with unequal access to EI services among children, based on their geographical location and the severity of their developmental delays (McManus et al., 2009).

Additionally, federal law differentiates Part C EI eligibility for children based on developmental delay and those referred with a diagnosed medical condition. Specifically, children referred to Part C EI with developmental delay must undergo multidisciplinary eligibility evaluations to determine whether they meet the state eligibility criteria threshold (34 C.F.R.§ 303.321(a)(1)(i)), whereas children referred with a diagnosed condition receive automatic access to Part C EI services by omitting the need for multidisciplinary eligibility evaluations (34 C.F.R.§ 303.321(a)(3)(i)). The child's medical diagnosis serves as sufficient evidence of the child's eligibility for Part C EI services. It is important to note that even if a child is automatically eligible for EI services under IDEA Part C, they still receive an assessment to determine their specific needs and develop an Individualized Family Service Plan (IFSP) that outlines the EI services they will receive. However, they are not required to be evaluated by the multidisciplinary eligibility team and can move directly to programmatic related assessments, saving families and professionals valuable time and resources.

To streamline the process of identifying a qualifying medical condition at the time of the initial evaluation, individual states have compiled their own list of diagnosed conditions. Although there is no universally applicable list of diagnosed conditions, federal legislation provides a list of exemplary conditions that include chromosomal abnormalities, genetic or congenital disorders, sensory impairments, inborn errors of metabolism, disorders reflecting disturbance of the development of the nervous system, congenital infections, severe attachment disorders, and disorders secondary to exposure to toxic substances, including fetal alcohol syndrome (34 C.F.R.§ 303.21(a)(2)). A study by Barger et al. (2019) suggested that there is considerable variability in the quantity and nature of medical conditions listed across states, which may result in an unequal distribution of EI services for children with diagnosed conditions, particularly infants and toddlers, for whom associated developmental delays may not be easily diagnosed through developmental assessments alone. Moreover, there is limited understanding of the procedures and underlying rationale used by states to create a list of diagnosed conditions, as well as how states utilize this list during the referral and eligibility determination process.

Part C Early Intervention Evaluation and Assessment

The meaning of "evaluation" in Part C of the IDEA refers to the "procedure used by qualified personnel to determine a child's initial and continuing eligibility" (34 C.F.R.§ 303.321(a)(2). On the other hand, "assessment" pertains to the "ongoing procedures used by qualified personnel to identify the child's unique strengths and needs and the early intervention services appropriate to meet those needs" (34 C.F.R.§ 303.321(a)(2). According to Part C of the IDEA and the Division of Early Childhood (DEC), eligibility for Part C EI requires the use of various sources of information. These sources may include a norm-referenced evaluation tool, a child's developmental history, an assessment of the child's skills across all developmental domains, input from family members, medical professionals, social workers, and educators, and a review of medical and educational records (34 C.F.R.§ 303.321(b)).

Most children under the age of three who are referred to the Part C EI program receive an eligibility evaluation conducted by a multidisciplinary team (34 C.F.R.§ 303.24) to establish eligibility for the Part C EI program. However, if medical records indicate that a child has a physical or mental condition with a high probability of developmental delay, eligibility can be diagnosed using medical records, and no multidisciplinary evaluation is required. In such cases, children and their families omit initial evaluations and proceed directly to assessments aimed at determining their needs and strengths as well as the specific services they require (34 C.F.R.§ 3030.321(a)(3)).

In this context, "multidisciplinary" means that professionals from two or more disciplines, such as speech, occupational, or physical therapists, work collaboratively to evaluate, assess, and provide services to infants, toddlers, and their families (34 C.F.R.§ 303.24). It is also possible for a professional to meet this requirement, with qualifications in more than one discipline or profession (34 C.F.R.§ 303.24(a)). The Part C EI enrollment process requires a multidisciplinary approach in two specific areas. First, during the evaluation and assessment process, in determining whether a child is eligible for EI services and assesses their developmental needs, and second, in writing the IFSP team, which consists of experts who work with the child and their family to create an IFSP that outlines the child's goals and the services they require. IFSP teams must include parents, at least two professionals from different disciplines, and a service coordinator to assist with coordination (34 C.F.R.§ 303.340). Despite this seemingly straightforward description in Part C of the IDEA legislation, it is unclear how states implement multidisciplinary evaluations in practice for children with developmental delays and diagnosed conditions.

Furthermore, according to the federal regulations stated in CFR 34 §303.321(a)(3)(ii), if there is no evidence of developmental delay or diagnosed condition, then informed clinical opinion by qualified personnel can be used to make eligibility determinations, even when the diagnostic instruments do not establish eligibility for Part C EI services. The process involves multiple procedures and sources of information, such as a review of the child’s developmental history, parent interview, observation of the child in various settings, review of medical records, physical or neurodevelopmental examination, and assessment of the child's functioning in each developmental domain (Lucas & Shaw, 2012). Though not empirically tested, Rosenberg et al. (2008) argue that defining what constitutes a delay using informed clinical opinion is difficult; therefore, it may become challenging to determine how eligibility criteria are being applied for both initial and continued eligibility. There is a lack of clarity in the literature on how states apply informed clinical opinion, which raises uncertainty about the actual difficulty of using it in practice.

Parent Consent and Information Sharing

It is important to note that three fundamental privacy regulations are relevant to the exchange of information between Part C EI service providers and pediatricians, as well as to the process of developmental screening, referral, evaluation, assessment, and delivery of EI services to infants, toddlers, and their families. These regulations encompass the 1974 Family Educational Rights and Privacy Act (FERPA), the privacy regulation of Part C IDEA, and the 1996 Health Insurance Portability and Accountability Act (HIPPA).

Under FERPA, educational programs funded by the US Department of Education, including Part C EI service providers, are required to obtain parental consent prior to disclosing student education records (20 U.S.C. § 1232g; 34 C.F.R Part 99). However, IDEA Part C EI privacy regulations go beyond FERPA and provide additional protection than those specified in FERPA for children's personally identifiable information (US Department of Education, 2022). For instance, under Part C of the IDEA, sharing information about children's enrollment status or names with organizations that are not Part C EI service providers, such as pediatricians or hospitals, requires parental consent (C.F.R 34 § 303.414). As a result, upon receiving a referral from a pediatrician, if the family cannot be reached or has refused to give consent to share their information, the Part C EI service provider cannot provide information about the referral outcome or any other services provided under Part C EI to referral sources, including pediatricians.

Moreover, Part C EI service providers require parental consent prior to conducting developmental screenings (34 C.F.R § 303.320), as well as evaluations and assessments (34 CFR § 303.321). Obtaining medical information from parents and pediatric healthcare providers is crucial for evaluating eligibility. It is essential to note that the FERPA and Part C of the IDEA privacy regulations are applicable after a referral has been received by a Part C EI service provider. Therefore, to obtain medical information after receipt of a referral, Part C EI service providers require parental consent to request as well as to obtain medical information from the pediatric provider.

During referral, any personally identifiable information pertaining to the child and family, including the child’s medical information, is safeguarded under HIPPA. The privacy rule of HIPPA permits medical providers to use or release the child's protected health information, such as diagnostic tests and reports, to other medical providers or subspecialists for treatment purposes, without obtaining consent (45 C.F.R 164.506). However, to share the protected medical information with the Part C EI service provider during the referral process, the pediatrician must obtain parental consent.

Typically, children with complex health needs who are referred to Part C EI services are also recommended for developmental and medical evaluations by subspecialists. Nonetheless, there is scant literature regarding how Part C EI service providers solicit and obtain information from pediatricians, or the procedures prescribed for pediatricians to share protected medical information with Part C EI service providers during the referral process.

American Academy of Pediatrics Guideline and Medical Home

The American Academy of Pediatrics (AAP) has developed guidelines to help pediatric providers identify developmental delays in children and make timely referrals to the Part C EI program in their state. Since the introduction of these guidelines in 2002 and their revision in 2006, screening rates for developmental delay have significantly increased (Lipkin et al., 2020). However, despite the increase in screening, there is still a considerable gap between the number of children identified and those enrolled in Part C EI. This suggests that screening and referral alone cannot guarantee enrollment. A study by Traube and Mamey (2022) supports the notion that there is no significant association between the rate of developmental screening and the number of Part C EI enrollments.

In the same vein, AAP guidelines recommend that pediatricians schedule developmental and medical evaluations and refer children with positive screening outcomes to Part C EI agencies concurrently (American Academy of Pediatrics, 2006). A study showed that pediatric providers tend to stratify their referrals and refer inconsistently (King et al., 2010). In the absence of clear and adequate referral guidelines, pediatricians often follow a blanket rule to refer all children before a medical diagnosis is made. In some cases, children are being denied Part C EI services because they may not meet the state eligibility criteria threshold due to multidisciplinary evaluations or inadequate information provision from pediatricians at the time of referral. Evidence produced by Atkins et al. (2019) further supports this claim by revealing that several high-risk children, such as premature or low birth-weight infants who failed the Part C EI eligibility evaluation, would have qualified if their medical conditions had been documented correctly at the time of referral, highlighting gaps in the referral practices implemented by pediatricians.

Additionally, both the medical home approach in primary care (AAP, 2002) and IDEA Part C EI requirements support continued, coordinated, family-centered support to children and families. These elements are at the core of service provision, and in practice, pediatricians and Part C EI personnel are expected to collaborate and develop systems of communication and information exchange to provide continued, coordinated care (Adams et al., 2013). Although there is plenty of evidence of poor collaboration and communication between pediatricians and Part C EI, there is little research on the reasons behind this and potential models for improvement (Edwards, 2018; Sanders et al., 2022). Therefore, further research is necessary to identify gaps in the referral process related to pediatricians and referral of children with diagnosed conditions, and to explore potential solutions to improve referral processes and entry into Part C EI services.

Diagnosed Medical Condition Referral Guidelines

Although there is an extensive body of literature on many aspects of Part C EI referral gaps, there is a paucity of information about how state-established guidelines for determining EI eligibility for children with diagnosed medical conditions are developed. Each state assembles and publishes a list of approved diagnosed medical conditions that give children automatic access to EI services (henceforth referred to as state-approved list), that is, if a child’s condition appears on the state-approved list, they are automatically eligible for EI services, and do not require evaluations to go through eligibility determination. State policies and referral procedures in relation to children with diagnosed medical conditions among Part C EI personnel and pediatricians also are published with this eligibility list.

Due to the paucity of information on this process, and the critical nature of timely referral to EI services, this concurrent embedded mixed-methods study was undertaken. Mixed-methods were adopted as a way to provide novel insights into the knowledge and use of state-approved list, and associated policies and referral practices among Part C EI personnel and pediatricians. Additionally, this mixed-methods approach allowed recommendations for state leaders, policymakers, and practitioners to be formulated based on inputs from Part C EI personnel and pediatricians.

The Current Study

In view of the above, this study examined the extent of knowledge that Part C EI personnel and pediatricians have regarding the state-approved list and related policies and practices, as well as the referral practices between the Part C EI agencies and pediatricians. Additionally, the study also identified key recommendations from both Part C EI personnel and pediatricians to improve the state-approved list and referral and eligibility evaluation system for infants and toddlers. The study addressed the following research questions:

Research Question 1: To what extent do Part C EI personnel and pediatricians have knowledge of the state-approved list of diagnosed medical conditions and related policies and practices in Michigan and Washington?

Research Question 1A: Is there a significant difference in the knowledge of the state-approved list of diagnosed medical conditions across different professional groups (Part C EI personnel and pediatricians in Washington and Michigan) and training groups (academic training or residency, on-the-job experience, and no training at all)?

Research Question 1B: Is there a significant difference in the knowledge of the related policies and practices across different professional groups (Part C EI personnel and pediatricians in

Washington and Michigan) and training groups (academic training or residency, on-the-job experience, and no training)?

Research Question 2: What referral practices are currently being implemented between Part C EI agencies and pediatricians in Michigan and Washington?

Research Question 2A: What factors facilitate or impede the referral process from the perspective of Part C EI personnel and pediatricians in Michigan and Washington?

Research Question 3: What recommendations do Part C EI personnel and pediatricians have for improving the state-approved list of diagnosed medical conditions, referral, and eligibility evaluations for children with diagnosed medical conditions?

The Study Context

Data were collected in Michigan and Washington since both states maintain comprehensive lists of diagnosed conditions and have publicly accessible contact details for Part C EI coordinators and directors, which made the data collection process more manageable. It is important to note that the purpose of the study was not to make comparisons between the two states, but rather to provide a comprehensive understanding of the topic. The aim was to generate generalizable knowledge that could help these two states, as well as others, to implement essential modifications to align their systems with federal guidelines and ensure the timely delivery of EI services to eligible children and families.

Michigan

Michigan is a birth-mandate state and has been providing special education services to infants and toddlers with disabilities even before the enactment of Part C IDEA in 1986. As a birth-mandate state, Michigan maintains two different sets of eligibility criteria for infants and toddlers, one for Part C EI and the other for Part B under Michigan Mandatory Special

Education (MMSE), resulting in two distinct groups of children who are qualified for services. Children who meet the eligibility criteria for Part B under MMSE are also considered eligible for Part C EI, while those who meet the eligibility criteria for Part C EI including children with diagnosed conditions that are likely to have developmental delay, are only qualified for Part C EI. Michigan's two-tiered eligibility system leads to differences in the types and levels of services accessible to the two groups of children (Peters, 2014).

The eligibility requirements for Part C EI in Michigan include a delay of 20% or one standard deviation below the mean in one or more developmental domains. Michigan Part C EI system, Early On, serves families and their infants and toddlers who have disabilities, developmental delays, or who are at risk of delay due to certain health conditions. However, children at risk of developmental delay for reasons other than health conditions are not entitled to receive services under the Part C EI system in Michigan (34 C.F.R § 303.204; Michigan Department of Education State Board of Education, 2016). As the state lead agency, the Michigan Department of Education (MDE) works in collaboration with the Department of Health and Human Services (MDHHS) to implement and maintain the statewide coordination of Early On services.

The Early On referral system offers multiple ways to refer a child, including contacting the child find or Early On coordinator at a local lead agency by phone or through their website. Referrals are also accepted via fax. Under Part C of the IDEA child find system, the Michigan Early On public awareness contractor disseminates information to referral sources, such as pediatricians, which includes details about the availability of services and the Early On referral system (Michigan Department of Education State Board of Education, 2016).

Washington

The Department of Children, Youth, and Families (DCYF) serves as the state lead agency for implementing the provisions of the Part C EI services in the state of Washington. The Washington Early Support for Infants and Toddlers (ESIT) program offers EI services to eligible children and families until the child reaches the age of three. The ESIT program delivers EI services through a diverse range of entities, including public, private, and non-profit organizations. These entities may operate under DCYF's contract or subcontract with a community lead agency to serve a specific geographic area or a school district catchment area. Referrals are received from parents or professionals via Help Me Grow Washington Helpline, which is available in multiple languages. Moreover, the ESIT program has made referral contacts for county and school districts publicly available, and families or referral sources can directly connect with the referral contact as per the child's location.

In order to qualify for the ESIT program, a child must exhibit 25% delay or show a 1.5 standard deviation below their age in one or more developmental domains. A child may also be eligible if he or she has a physical or mental condition that causes developmental delays. Additionally, in cases where eligibility cannot be ascertained using standardized evaluation instruments and the child lacks diagnosed condition, eligibility can be determined using informed clinical opinion of a qualified professional.

In October 2018, the ESIT assembled a team of early childhood experts to compile a comprehensive list of medical and developmental conditions based on the latest research and best practices. This list was created and reviewed by the panel over a period of six months. The ESIT also created a guide for Part C EI providers on the qualifying medical conditions list to assist them in establishing eligibility criteria based on diagnosed conditions. The aim of the diagnosed conditions list was to expedite the provision of services and reduce unnecessary evaluations for children with diagnosed conditions. By enrolling eligible children promptly and avoiding unnecessary standardized evaluations, this list would lessen stress and time lost for families and allow providers to allocate their resources more effectively for necessary service provision (Washington State Department of Children, Youth & Families, 2019).

The ESIT guidance document further indicates that the program plans to conduct a one-year pilot study to test the effectiveness of the state-approved list. The primary objective of this pilot study was to establish a list and system that streamlines the enrollment process for children with qualifying diagnoses, reducing the time and effort required for enrollment and ultimately improving outcomes for infants, toddlers, and their families.

In summary, the issue of insufficient participation in Part C EI services for children with diagnosed medical conditions was explored in this chapter. The lack of research on the knowledge and utilization of the state-approved list, as well as the communication of medical information between pediatricians and Part C EI personnel were highlighted. Variations in state eligibility criteria and the state-approved list of diagnosed medical conditions, gaps in referral practices, the significance of parental consent and the relevant privacy regulations remain significant problems. AAP guidelines and the concept of medical home in relation to referral and evaluations were described. Lastly, an overview of the research context in Michigan and Washington, including the research questions, is presented. The following chapter provides specific details about the methodology employed to address the research questions.

CHAPTER II

METHOD

This concurrent mixed-method study was conducted between May 2022 and February 2023 in the states of Michigan and Washington. Data were gathered from Part C EI personnel and general pediatricians using descriptive exploratory surveys and semi-structured interviews. Both the quantitative (survey) and qualitative (semi-structured interviews) data collection methods were planned and implemented simultaneously (Creswell & Clark, 2007). By integrating these two forms of data, the quantitative results were supported and enriched by the qualitative insights, leading to more convincing and robust conclusions (Creswell & Clark, 2007). Collection, analysis, and interpretation of survey and interview data took place concurrently, with the outcomes from both methodologies combined and contrasted to answer the research questions. Equal weight was given to both the quantitative and qualitative data in the overall analysis of the study. The study was divided into two phases: a) the development and testing of the survey questionnaire through cognitive interviewing, and the development of the interview protocol, and b) the distribution of survey and conducting of interviews for data collection.

Participants

The characteristics of the overall study sample were summarized using descriptive analysis. Continuous data were expressed as means and standard deviations, while categorical data were expressed as numbers and percentages. The overall survey sample consists of 193 Part C EI personnel, and 69 pediatricians, and the overall interview sample consists of 45 Part C EI personnel and 22 pediatricians.

Sample size estimation

To ensure sufficient power to detect statistically significant differences among the groups in the study, an a priori power analysis prior to survey data collection was performed. The G*Power (version 3.1.9.7) software (Faul et al., 2007) was used to calculate the required sample size for an analysis of variance (ANOVA) with fixed effects, omnibus, one-way. With an anticipated effect size of 0.35, an alpha level of 0.05, and a desired statistical power of 0.95, the power analysis suggested a requisite sample size of 132 for comparing three groups and 148 for comparing four groups. The final sample in the study included 262 survey respondents. However, the preliminary analysis revealed that the assumption of normality was violated. As a result, a non-parametric version of ANOVA, namely the Kruskal-Wallis test, followed by Dunn's post hoc test were employed. This approach helped to yield the most accurate and robust results given the distribution of the data.

Similarly, the sample size for qualitative analysis was determined based on the principle of saturation (Guest et al., 2006). Given the vast variation within the Part C EI systems and processes highlighted in previous research, and study context which spans two states and involves two professional groups (Part C EI personnel and pediatricians), the aim was to interview between 20 to 24 individuals from each participant group (Part C EI personnel in both MI and WA, and pediatricians in same states) in order to reach thematic as well as meaning saturation (Hennink & Kaiser, 2022). As a result, the final interview sample comprised 67 participants, distributed across groups with each group containing between 8 to 22 members.

Survey Participants

As presented in Table 1, a total of 262 survey questionnaires were completed by Part C EI personnel (39.7% from Washington and 34% from Michigan) and by general pediatricians

(12.2% from Washington and 14.1% from Michigan). Most respondents surveyed were White (83.6%), worked full-time (91.6%), and were female (91.2%). Approximately 48.5% of survey respondents served in suburban areas, 24.8% in urban, and 26.7% in rural areas.

Table 1

Characteristics of the Survey Sample

Characteristics	Michigan		Washington		
	EI (n=89)	PCP (n=37)	EI (n=104)	PCP (n=32)	Total (n=262)
Gender					
Female	86(96.6)	32(86.5)	99(95.2)	22(68.8)	239(91.2)
Male	3(3.4)	5(13.5)	1(1.0)	10(31.2)	19(7.3)
Prefer not to say	0(0)	0(0)	4(3.8)	0(0)	4(1.5)
Age					
Below 35 years	20(22.5)	4(10.8)	29(27.9)	0(0)	53(20.2)
36-45 years	24(27)	9(24.3)	37(35.6)	13(40.6)	83(31.7)
46-55 years	29(32.6)	9(24.3)	26(25)	9(28.1)	73(27.9)
56-65 years	14(15.7)	9(24.3)	8(7.7)	7(21.9)	38(14.5)
Above 65 years	2(2.2)	6(16.2)	4(3.8)	3(9.4)	15(5.7)
Race/Ethnicity					
White Non-Hispanic	83(93.3)	30(81.1)	84(80.8)	22(68.8)	219(83.6)
Non-White	2(2.2)	5(13.5)	9(8.7)	6(18.8)	22(8.4)
Other	3(3.4)	2(5.4)	2(1.9)	2(6.2)	9(7.3)
Prefer not to say	1(1.1)		9(8.7)	2(6.2)	12(4.6)
Job Status					
Full time	84(94.4)	31(83.8)	99(95.2)	26(81.2)	240(91.6)
Part time	`5(5.6)	6(16.2)	5(4.8)	6(18.8)	22(8.4)

Table 1 *(Continued)*

Characteristics	Michigan		Washington		
	EI (n=89)	PCP (n=37)	EI (n=104)	PCP (n=32)	Total (n=262)
Locale					
Rural	34(38.2)	3(8.1)	26(25)	7(21.9)	70(26.7)
Suburban	37(41.6)	18(48.6)	55(52.9)	17(53.1)	127(48.5)
Urban	18(20.2)	16(43.2)	23(22.1)	8(25)	65(24.8)
[a]Role					
EI/ECSE specialist	55(61.8)		66(63.5)		121(46.2)
Occupational therapist	7(7.9)		11(10.6)		18(6.9)
Physical therapist	7(7.9)		10(9.6)		17(6.5)
SLP	16(18)		16(15.4)		32(12.2)
Psychologist	4(4.5)		1(1)		5(1.9)
[b]Practice type					
Private		10(27)		14(43.8)	24(9.2)
Multispecialty Group		5(13.5)		6(18.8)	11(4.2)
Hospital/Academic		17(45.9)		8(25)	25(9.5)
Other		5(13.5)		4(12.5)	9(3.4)
[c]Years served in state Mean(SD)	9.8(7.8)	15.8(11.3)	6.5(6.2)	18.7(10)	
[c]Years served overall Mean(SD)	15.9(10.2)	18.7(11.5)	9.8(9.3)	22.9(9.6)	

Note. EI = Early intervention personnel; PCP = Primary care provider; SLP = Speech and language pathologist. Data are presented as n(%) unless otherwise indicated.

[a] Role is applicable only to EI personnel.
[b] Practice type is applicable only to PCP.
[c] Data are presented as mean (standard deviation).

Interview Participants

All 45 interview participants in Part C EI were female (100%). The majority worked full-time (97.8%) and identified as Non-Hispanic White (93.3%). On average, they had 7.8 years (SD=6.4 years) of experience in their respective states and 13.6 years (SD=9.3 years) of experience in their profession. The largest age group was between 46 to 55 years old (37.8%), followed by those below 35 years old (28.9%), 36 to 45 years old (20%), and those above 55 years old (13.3%). They served mostly in suburban areas (46.7%), followed by rural areas (35.6%), and urban areas (17.8%).

Similarly, all 22 interviewees in primary care pediatrics were general pediatricians (100%). The majority were females (81.8%) and full-time employees (86.4%). They identified as Non-Hispanic White (72.7%) and were between 46 to 55 years old (36.4%), followed by those between 36 to 45 years old (31.8%), and those above 55 years old (27.2%), and below 35 years old (4.5%). Half served in suburban areas (50%), followed by urban areas (36.4%) and rural areas (13.6%). On average, they had 13.7 years (SD=8.2 years) of experience in their respective states and 16.3 years (SD=8.3 years) of experience in their profession.

Survey Design

For the study, a self-administered survey questionnaire was developed to investigate referral and eligibility determination practices, knowledge of the list of established medical conditions in their state, related policies, and recommendations from the perspectives of Part C EI personnel and pediatricians. The survey was developed in three phases, including item generation, expert review, and pretesting.

The first phase (item generation) comprised a review of existing literature related to referral and Part C EI eligibility determination, as well as relevant state and federal policy documents. Questions were generated based on the findings to cover content related to referral and eligibility determination practices, knowledge of the state-approved list, and related policies. This phase helped ensure that the survey was comprehensive and covered all relevant aspects of the topic under investigation. In the second phase (expert review), two experts in early intervention and developmental and behavioral pediatrics reviewed the content of the survey. This step was important to ensure that the questions and response options were valid and reliable and that they accurately captured the concepts the study intended to measure.

The final phase of the survey design (pretesting) involved employing cognitive interviewing with a small purposive sample of Part C EI personnel (N=5) and general pediatricians (N=5) in one of the Northwest Pacific states. This approach helped to understand the mental processes that participants go through when understanding, interpreting, and responding to survey questions (Silva et al., 2019; Willis & Artino, 2013; Willis, 2005) and whether any modifications were necessary. A combination of three cognitive interviewing methods--think-aloud, concurrent verbal probing, and paraphrasing--were used. Participants read the questions aloud, paraphrased the meaning, and verbalized their thought processes for their responses. A hybrid approach of scripted and free-form probes (Meadows, 2021; Ryan et al., 2012; Conrad & Blair, 2009; Beatty & Willis, 2007) was used to ensure that ambiguous terms or phrases were clarified. Participants were also asked to comment on the clarity and content of the questions and provided choices. The questions asked to the participants during the cognitive interview are given in Appendix A. The feedback from the pretesting phase helped refine the final version of the survey, making it more effective and useful. All ten participants received $20 gift cards as a token of appreciation for their time and effort. Demographic characteristics of the cognitive interview participants are given in Appendix B.

Survey Questionnaire

The final survey questionnaire consisted of 12 content-related questions, which were categorized into referral and evaluation practices (five questions), knowledge (five questions), implementation (one question), recommendations (one question), and demographic information (9 questions). In addition, two additional questions regarding clinical practices on AAP guidelines and two extra questions on demographic information were specifically included for pediatricians.

The questionnaire consisted of multiple-choice, Likert-type, and short-answer questions. The questions related to knowledge and referral practices had response options organized on a 5-point Likert scale, ranging from "strongly disagree" to "strongly agree" and "never" to "almost always."

The questionnaires were posted on-line for participants using Qualtrics (https://www.qualtrics.com), and two separate versions were administered: one for Part C EI personnel and another for general pediatricians. The questionnaire for Part C EI personnel is presented in Appendix C, while the questionnaire for pediatricians is presented in Appendix D.

Survey Procedure

A purposive sampling and snowballing method were applied to recruit the survey participants. Because of this recruitment strategy, it was not possible to calculate a response rate. Part C EI personnel whose role involved intake and/or eligibility evaluations were invited to complete the online survey via email invitations that were forwarded by the Part C EI program directors and coordinators in Michigan and Washington. The survey was sent electronically to Part C EI program directors and coordinators in the two states between July and October 2022, with a follow-up reminder email sent after six weeks. Out of the responses received, 193 were deemed complete (89 from Michigan, 104 from Washington), as responses that were over 90% incomplete were not counted.

To invite pediatricians to participate in the survey, a contact list of 200 general pediatricians providing primary care was compiled from web searches and recommendations from the Part C EI personnel in Washington as well as in Michigan. The survey was then sent to 400 pediatricians via mail between September to December 2022, which included a cover letter, survey questionnaire, and prepaid return envelope. The mailings were sent twice to non-responders, eight weeks apart, and an additional reminder letter was sent four weeks after the first mailing. Pediatricians had the option to complete the survey online or mail it in a hard copy. A total of 69 responses were received from pediatricians (32 from WA and 37 from MI), and all were fully completed.

Interview Design

The interview guide was developed based on a comprehensive review of existing research on Part C EI referral and eligibility evaluation, and a review of relevant policy documents. The interview questions were then aligned with the survey questionnaire and the research questions. The guide included both open-ended and closed-ended questions, structured to elicit information on multiple levels, including individual, organizational, and community. Questions were supplemented by follow-up and probe questions dependent on participants' responses. The guide was pilot tested with a small sample of Part C EI personnel (N=3) and pediatricians (N=2), and revisions were made based on feedback from the pilot test. It was structured to allow participants to provide detailed and comprehensive descriptions of their experiences and perceptions of the referral and eligibility evaluation system and knowledge of the state-approved list of diagnosed medical conditions, related policies and practices, and recommendations. The interview questions for Part C EI personnel and pediatricians are presented in Appendix E.

Interview Procedure

The survey participants were given the option to provide their names and contact information if they were willing to participate in an interview. Out of the survey participants, 23 individuals from Part C EI in Michigan and 22 individuals from Part C EI in Washington participated in the interviews. Additionally, 14 pediatricians from Michigan and 8 from Washington participated in the interviews. A total of 69 interviews were conducted and recorded using a videoconferencing platform, Zoom (Zoom Video Communications Inc., 2016). The interviews were transcribed verbatim. All participants provided written consent to complete the survey and participate in the interviews. A select group of Part C EI personnel and pediatricians who participated in the survey was chosen at random to receive gift cards valued at $20 and $30, respectively. All interview participants were also given an additional $20 gift card in thanks for their participation and time. The study was approved by the research compliance services at the University of Oregon and was determined to be exempt.

Data Analytic Plan

For the qualitative data, a six-stage process recommended by Braun and Clarke (2006), was employed to analyze the semi-structured interview transcripts. The lead author trained a graduate student to assist with qualitative data analysis. The initial stage involved reading the transcripts several times to note initial ideas. In the second stage, codes were systematically generated by aligning the relevance of the data with the research questions, and data were collected for each code. Disagreements and inconsistencies were resolved through discussion between the lead author and the graduate student. In the third stage, potential themes were collated from the codes. In stage four, key themes were reviewed to examine if they aligned with the coded extracts and the entire dataset. A thematic map of the analysis was then created. In stage five, the themes were reviewed to generate concise and clear definitions and names for each theme. Finally, in stage six, the key themes and related extracts were triangulated and complemented with the survey findings to provide a more comprehensive understanding of the research questions.

The quantitative data from the survey questionnaires were analyzed using descriptive analysis and inferential analysis, such as non-parametric Kruskal Wallis tests and post hoc Dunn's test. The visualizations and statistical analysis were conducted using R software (R Core Team, 2021). The integration of the qualitative and quantitative data was achieved through the comparison of the themes derived from the qualitative data with the survey results. Triangulation of findings helped to get a more complete understanding of the research questions. The analytic plan for each research question is discussed below.

Research Question 1

Part C EI personnel and pediatricians were asked to rate their knowledge of the state-approved list (five items; $\alpha = 0.92$) and related policies and practices (five items; $\alpha = 0.86$). Each item in the survey questionnaire contained response options on a five-point scale, ranging from strongly disagree (1) to strongly agree (5). The mean value was calculated for each of the five items and presented visually in a radar chart (Figure 1 and Figure 2), with each item forming an individual axis arranged radially around a point. The node on the axis represents the mean value of the item. The scale on each axis ranges from 1 to 5, with 1 indicating a strongly disagree response and 5 indicating a strongly agree response. The observations from the radar plots were compared with the thematic coding of the interview data and findings were present in integrated form.

Research Question 1A and Research Question 1B

Research Question 1A and 1B examined the difference in the knowledge of the state-approved list of medical conditions and associated policies and practices among professional groups and training groups. Given the high Cronbach alpha coefficient (Cortina, 1993), all five items were retained to compute the composite mean score for knowledge of the list of the diagnosed medical conditions as well as the knowledge of the related policies and practices. To ensure the appropriate selection of a statistical method for comparing the groups, it was crucial to examine the distribution of knowledge scores regarding the state-approved list of medical conditions as well as related policies and practices. This was particularly important due to the relatively small sample sizes of pediatricians in Michigan (n=37) and Washington (n=32).

The normality of residuals was, therefore, tested using histograms and QQ-plots, as well as a Shapiro-Wilk test, for both knowledge of the list (H=0.93, p-value <0.05) and knowledge of the related policies and practices (H=0.77, p-value < 0.05), which indicated non-normality. The homogeneity of variances was also tested using Levene's test, which showed that variances within professional and training groups were unequal (p<0.05). Therefore, a Kruskal-Wallis test (a non-parametric equivalent to ANOVA) was used to determine if there was a significant difference in the knowledge of the state-approved list and related policies and practices among the different professional groups and training groups. The results of the Kruskal Wallis test, along with post hoc Dunn's tests (a non-parametric equivalent to Tukey's test), are visually represented using a boxplot in the results section.

Research Question 2

Part C EI personnel and pediatricians were surveyed to rate the frequency of referral practices, using a five-point scale ranging from ‘never’ to ‘almost always’ across seven items. Mean values were computed for each item and presented in a radar chart (Figure 3), where each item forms an individual axis arranged radially around a central point. The node on each axis represents the mean value of the item. The scale on each axis ranges from 1 to 5, with 1 indicating a ‘never’ response and 5 indicating an ‘almost always’ response. The results of the survey were then compared with the themes that emerged from the interview data.

Research Question 2A

The facilitators and barriers to implementing the referral practices were identified as one of the emerging themes from the qualitative analysis of the interview data.

Research Question 3

Participants in the survey were presented with 10 options to select from and recommend to policymakers, state leaders, and/or federal leaders. The frequency of each option was then calculated as a percentage and displayed the data using a bar plot to show the most chosen recommendations. These recommendations were then compared with the findings from the qualitative data.

Ethical Considerations

The current study was conducted with the approval of the research compliance services at the University of Oregon and followed the ethical guidelines outlined by the institutional review board. Informed consent was obtained from all survey and interview participants. Prior to completing the survey or participating in the interview, participants were provided with an informed consent form that outlines the purpose and nature of the study, the potential risks and benefits of participation, and the participants' rights to confidentiality and anonymity. Participants were informed that they could withdraw from the study at any time without penalty.

To ensure the confidentiality of the participants, identifying information such as names and contact information were kept separate from survey and interview data. Data were stored in a secure, official One Drive account, accessible only to the researcher. Overall, the ethical considerations and practices of the current study aimed to protect the rights and well-being of the participants, while ensuring the scientific rigor and validity of the research findings.

To summarize, the research questions were addressed by employing descriptive, inferential, and qualitative analyses. The first research question focused on the mean knowledge score regarding the state-approved list, and associated policies and practices. The findings were illustrated using radar plot for both aspects. In research questions 1A and 1B, the mean knowledge score was further investigated to determine if there were significant differences in knowledge between pediatricians and Part C EI personnel in the two states. Additionally, differences were explored among groups with varying levels of training related to Part C EI referral and eligibility evaluations, including residency or academic training, on-the-job training, and no training at all. To examine significant differences, a Kruskal-Wallis test and post hoc Dunn's test were conducted. The second research question was addressed using a radar plot to illustrate the variability in the implementation of referral practices among pediatricians and Part C EI personnel in both states. To answer research question 2B, the factors influencing this variation in referral practices were explored, including facilitators and barriers. Lastly, the third research question was addressed through a descriptive analysis of survey recommendations and a thematic analysis of interview data. The subsequent section presents the findings obtained from these analyses, organized according to the respective research questions.

CHAPTER III

RESULTS

This section presents study findings, organized according to the three research questions. First, knowledge of the state-approved list of diagnosed medical conditions and related policies and practices are presented that resulted from the survey data with supplemental quotes from the interviews. Results from inferential statistics are then presented, indicating significant differences in the knowledge of the state-approved lists, and related policies and practices among four professional groups (Part C EI personnel in Michigan and Washington, and pediatricians in Michigan and Washington) and three training groups (academic or residency, on-the-job training, and no training). Next, to address the second research question, findings from the survey and thematic analysis of the interviews are presented examining existing referral and eligibility practices as well as the factors that facilitate or impede the referral process. Finally, recommendations are given based on insights derived from both the survey and interviews to address the third research question.

Research Question 1

Knowledge of the State-Approved List of Diagnosed Medical Conditions

A large majority of Part C EI personnel reported that they knew the state-approved list in their respective states (89.7%), the physical and mental conditions included (85.5%), how to access the list (84.5%), and the possibility that additional qualifying conditions existed that were not on the list (64.8%). They also reported knowing about the mental and physical conditions in the federal guidelines (66.8%). In contrast, a significant number of pediatricians reported that they were not familiar with the state-approved list (50%), the conditions included (48.4%), how to access the list (63%), and the possibility that additional qualifying conditions existed apart from the list (51.6%). They also reported not knowing about the mental and physical conditions included in the federal guidelines (63%).

Figure 1 illustrates the mean knowledge score for each item in the survey question that evaluated the knowledge of state-approved list of diagnosed medical conditions among Part C EI personnel and pediatricians. For most items, the mean knowledge score for Part C EI personnel in both states ranged from somewhat agree (4) to strongly agree (5), with the exception of two items: ‘I know that the list is not all inclusive’ and ‘I know of the mental and physical conditions included in the federal guidelines,’ which received mean scores between ‘neither agree nor disagree’ (3) and ‘somewhat agree’ (4). In contrast, pediatricians in both states had lower mean knowledge scores for each item, ranging between ‘somewhat disagree’ (2) and ‘neither agree nor disagree’(3).

The survey and interview findings were in agreement. All Part C EI interviewees were familiar with the state-approved list, primarily due to training received during job orientation, induction, or on-the-job experience. However, most pediatricians stated that they first became aware of the state-approved list when they completed the survey questionnaire. This indicates a limited understanding of the state-approved list among pediatricians in Michigan and Washington, as illustrated in this statement by a pediatrician in Michigan.

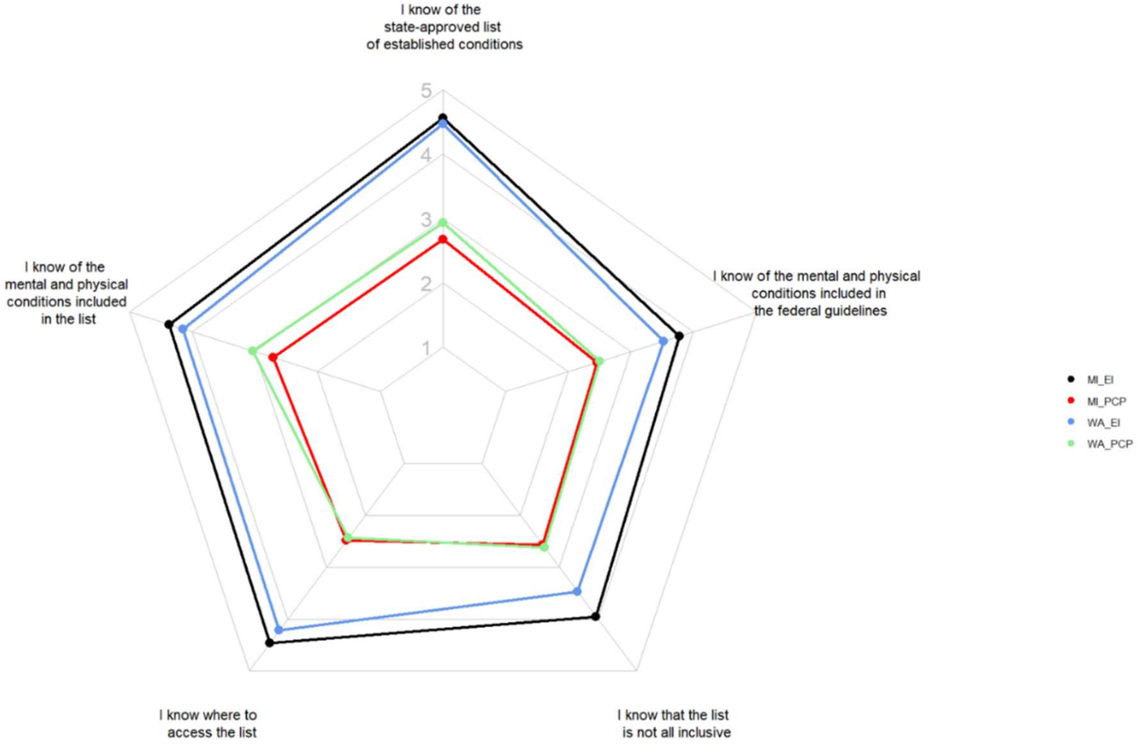
> I think when you gave the questionnaire out, I was surprised that perhaps there is a list of diagnoses somewhere that I've never seen it, under which services are automatically qualified. So, I was not aware that there are diagnoses that automatically qualify.

Knowledge of the Related Policies and Practices

Majority of Part C EI personnel agreed that they knew the state eligibility criteria (95.9%) and referral system (93.3%) for EI services, the time frame for enrolling children in EI services (95.9%) as well as that children with medical conditions with high probability of disability could automatically access EI services (81.9%), and the requirement for documenting a qualifying medical condition in child's referral record by a physician (91.7%). A lower proportion of pediatricians knew these policies and practices, with 79% reported knowing the eligibility criteria and 87% reported knowing the referral system, but fewer knew about automatic access to EI services for medical conditions likely to have disability and the time frame for enrolling a child in EI services. Specifically, 45.3% of pediatricians knew about the time frame and 56.5% knew about automatic access for children with medical conditions, while

Figure 1

Radar Plot of the Self-rated Knowledge of the State-approved List of Diagnosed Medical Conditions among Pediatricians and Part C EI personnel.



Note. The guiding question was formulated as follows: "These statements are related to the state-approved list of established medical conditions. Please indicate if you strongly agree (5), somewhat agree (4), neither agree nor disagree (3), somewhat disagree (2) or strongly disagree (1) with the following statements."

MI_EI = EI personnel in Michigan, MI_PCP = pediatricians in Michigan, WA_EI = EI personnel in Washington, and WA_PCP = pediatricians in Washington.

61.3% knew that medical conditions must be documented by a physician for automatic access to EI services.

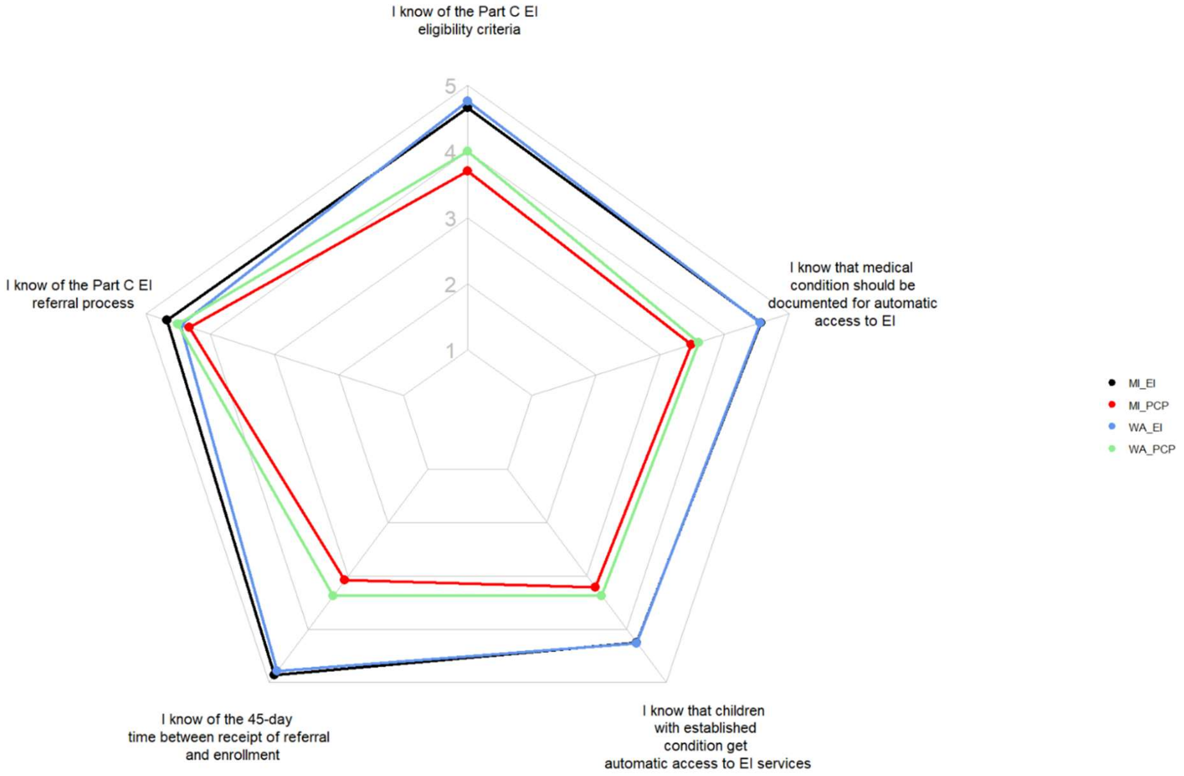
Figure 2 displays the mean knowledge score for each item in the survey question that examined the knowledge of the policies and practices among Part C EI personnel and pediatricians. For most items, the Part C EI personnel in both states demonstrated high mean knowledge score i.e., strongly agree (5). Conversely, pediatricians in both states demonstrated lower mean knowledge score across most items, ranging from ‘neither agree nor disagree’ (3) to ‘somewhat agree’ (4) with one exception: ‘I know of the Part C EI referral process,’ which received a mean score same as Part C EI i.e., strongly agree (5).

While most of the Part C EI personnel and pediatricians in the survey expressed their familiarity with the referral process in their respective states, the interviews highlighted a gap in the understanding of effective referral process among pediatricians. The following quote from a Part C EI personnel in Washington illustrates this gap.

> Sometimes we get terrible referrals. Sometimes we get referrals that don’t even have a parent name. It’s just like a one page piece of paper that says, evaluate for developmental delay. And it has the child’s name. It’s like a fact sheet in the record. And we are cold calling a family. We tried to call the pediatric provider back first, but a lot of times you’re not going to be able to get hold of a provider or records office to give you the information within the timeline we must adhere to, which is two days.

Figure 2

Radar Plot of the Self-rated Knowledge of the Policies and Practices among Pediatricians and the Part C EI Personnel



Note. The guiding question was formulated as follows: "These statements are related to policies and practices in Part C EI eligibility determination for children with diagnosed medical conditions. Please indicate if you strongly agree(5), somewhat agree(4), neither agree nor disagree(3), somewhat disagree(2) or strongly disagree(1) with the following statements."

MI_EI = EI personnel in Michigan, MI_PCP = pediatricians in Michigan, WA_EI = EI personnel in Washington, and WA_PCP = pediatricians in Washington.

Research Question 1A

Comparison of Knowledge of the State-Approved List Across Professional Groups and Training Groups

Table 2 presents the mean knowledge score of the state-approved list of diagnosed medical conditions among four professional groups: Part C EI personnel in Washington (WA_EI), Part C EI personnel in Michigan (MI_EI), pediatricians in Washington (WA_PCP) and pediatricians in Michigan (MI_PCP). The mean knowledge score was highest among Part C EI personnel in Michigan (M=4.26; SD=1.0), followed by Part C EI personnel in Washington (M=3.96; SD=1.09), pediatricians in Washington (M=2.73; SD=1.31), and pediatricians in Michigan(M=2.59; SD=2.59).

Table 2

Descriptive summary of knowledge of the state-approved list of diagnosed medical conditions among professional groups

Professional group	N	Mean	SD	SE	95% Confidence interval	
					Lower Bound	Upper bound
WA_EI	89	3.96	1.09	0.11	3.75	4.17
MI_EI	104	4.26	1.00	0.11	4.05	4.47
WA_PCP	32	2.73	1.31	0.23	2.26	3.21
MI_PCP	37	2.62	1.20	0.20	2.21	3.02

MI_EI = EI personnel in Michigan, MI_PCP = pediatricians in Michigan, WA_EI = EI personnel in Washington, and WA_PCP = pediatricians in Washington.

Table 3 presents the mean knowledge scores for the state-approved list of diagnosed medical conditions among three training groups: those who received training during academic or residency programs, those who received training at work, and those who did not receive any training. The mean knowledge score was higher for those who received training during academic/residency program (M=4.34; SD=1.04) or training at work (M=4.22; SD=0.95) compared to those who did not receive any training (M=3.07; SD=1.34).

Table 3

Descriptive summary of knowledge of the state-approved list of diagnosed medical conditions among training groups

Training group	N	Mean	SD	SE	95% Confidence interval	
					Lower Bound	Upper bound
During academic training/residency	22	4.34	1.02	0.22	3.89	4.79
Training at work	129	4.22	0.95	0.08	4.05	4.38
No training at all	111	3.07	1.35	0.13	2.81	3.33

Hypothesis Testing. Table 4 presents results of the Kruskal-Wallis test, which indicate a significant difference in the mean knowledge score of at least one pair of professional groups (H(3) = 58.12, p<0.05) and at least one pair of the training groups (H(2) = 58.08, p<0.05). As a result, null hypothesis was rejected, and post-hoc Dunn's test was conducted for pairwise multiple comparisons to examine which groups were statistically different regarding their mean knowledge score of the state-approved list of diagnosed medical conditions.

Table 4

Hypothesis testing for the knowledge of the list of state-approved list of diagnosed medical conditions

Null Hypothesis	Groups	Kruskal-Wallis test	Decision
The distribution of the mean knowledge score of the list of the diagnosed medical condition is same across the groups.	a) Part C EI personnel in WA, b) Part C EI personnel in MI, c) Pediatricians in WA, and d) Pediatricians in MI	H(3) = 64.21, $p < 0.05$, $\eta^2 = 0.25$, 95% *CI* = [0.17, 1.00]	Reject the null hypothesis and conduct Dunn's test to examine which groups are statistically different.
	Professionals who received a) training during academic or residency program b) received training at work, and c) did not receive training at all	H(2) = 52.21, $p < 0.05$, $\eta^2 = 0.20$, 95% *CI*= [0.13, 1.00]	

The Dunn's test (Figure 3) confirmed that among the four professional groups:

a) Part C EI personnel in MI and pediatricians in MI differ significantly ($p < 0.05$).

b) Part C EI personnel in MI and pediatricians in WA differ significantly ($p < 0.05$).

c) Part C EI personnel in WA and pediatricians in MI differ significantly ($p < 0.05$).

d) Part C EI personnel in WA and pediatricians in WA differ significantly ($p<0.05$).

Similarly, the Dunn's test (Figure 4) confirmed that among the three training groups:

a) Those who received training during academic/residency programs and those who did not receive training differ significantly ($p<0.05$).

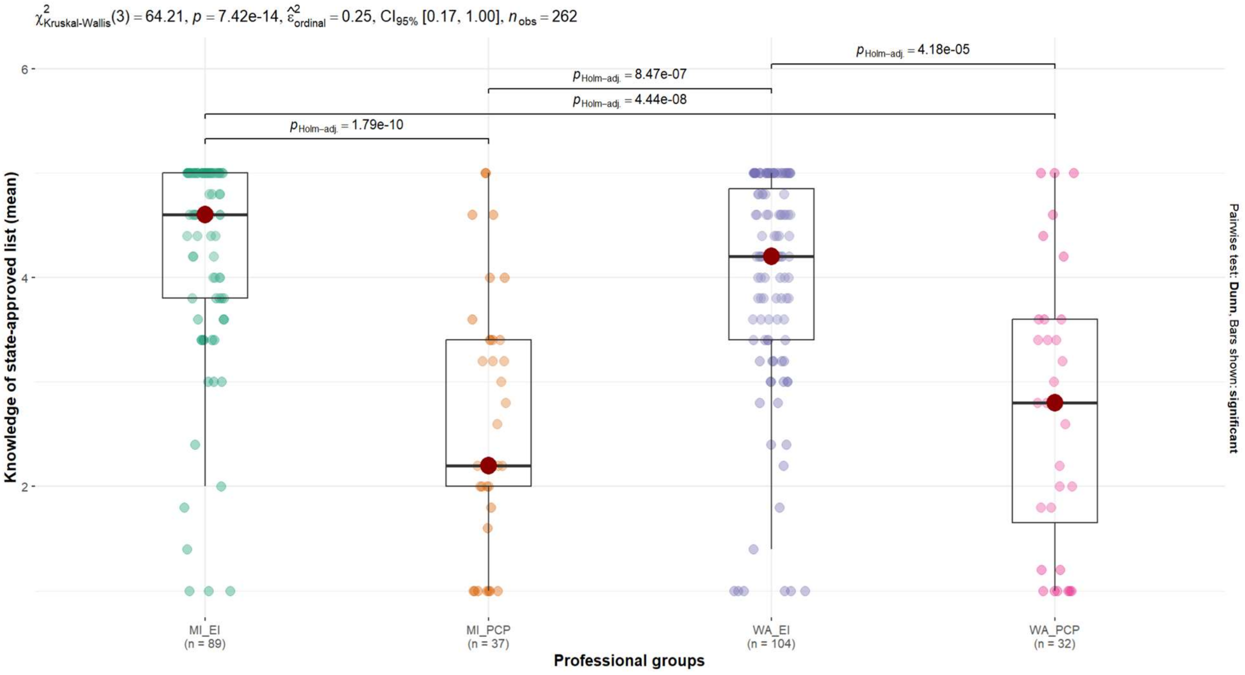
b) Those who received training at work and those who did not receive training differ significantly ($p<0.05$).

To summarize, the group membership- whether the participant was Part C EI personnel or a pediatrician- accounted for a large portion of the variability in knowledge of the state-approved list of diagnosed medical conditions, as evidenced by an $\eta^2 = 0.25$, 95% *CI* =[0.17, 1.00]. This means that group membership explains about 25% of the observed variance in knowledge of the state-approved list. Findings are illustrated in Figure 3.

Similarly, the type of training participants receive- whether during residency, on the job, or no training- also had a large effect on the knowledge of the state-approved list of diagnosed medical conditions. The effect size here, with an $\eta^2 = 0.20$, 95% *CI* =[0.17, 1.00], suggests that the type of training can account for about 20% of the variance in knowledge of the state-approved list. Findings are illustrated in Figure 4.

Figure 3

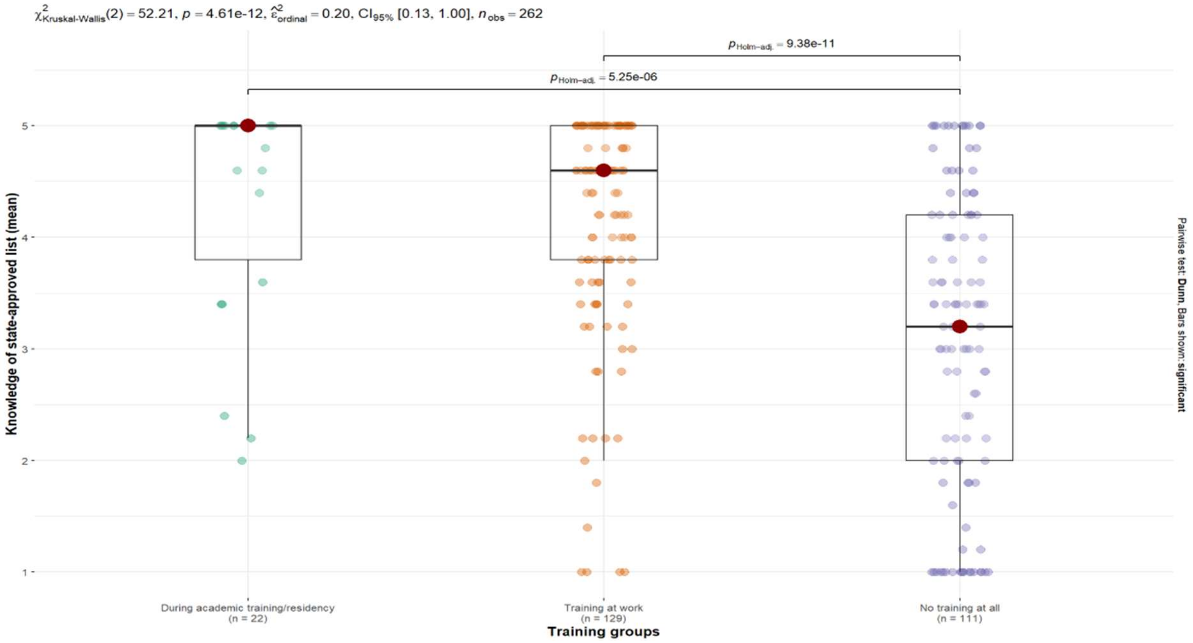
Comparison of knowledge of the state-approved list of medical conditions across professional groups.



MI_EI = EI personnel in Michigan, MI_PCP = Pediatricians in Michigan, WA_EI = EI personnel in Washington, and WA_PCP = Pediatricians in Washington.

Figure 4

Comparison of knowledge of the state-approved list of medical conditions across training groups.



Research Question 1B

Comparison of the Knowledge of the Policies and Practices Across Professional Groups and Training Groups

Table 5 presents the mean knowledge score of the policies and practices among four professional groups: Part C EI personnel in Washington and Michigan, and pediatricians in Washington and Michigan. The mean knowledge score was highest among Part C EI personnel in Michigan (M=4.60; SD=0.77), followed by Part C EI personnel in Washington (M=4.57; SD=0.75), pediatricians in Washington (M=3.77; SD=0.95), and pediatricians in Michigan (M=3.52; SD=1.02).

Table 5

Descriptive summary of knowledge of the policies and practices among professional groups

Professional group	N	Mean	SD	SE	95% Confidence interval	
					Lower Bound	Upper bound
WA_EI	89	4.57	0.75	0.07	4.42	4.71
MI_EI	104	4.60	0.77	0.08	4.44	4.76
WA_PCP	32	3.77	0.95	0.17	3.43	4.11
MI_PCP	37	3.52	1.02	0.19	3.14	3.90

MI_EI = EI personnel in Michigan, MI_PCP = pediatricians in Michigan, WA_EI = EI personnel in Washington, and WA_PCP = pediatricians in Washington.

Table 6 presents the mean knowledge scores for the policies and practices among three training groups: those who received training during academic or residency programs, those who received training at work, and those who did not receive any training. The mean knowledge score was higher for those who received training during academic or residency program (M=4.58; SD=0.70) or training at work (M=4.64; SD=0.68) compared to those who did not receive any training (M=3.96; SD=1.04).

Table 6

Descriptive summary of knowledge of the policies and practices among training groups

Training	N	Mean	SD	SE	95% Confidence interval	
					Lower Bound	Upper bound
During academic training/residency	22	4.58	0.70	0.14	4.27	4.89
Training at work	129	4.64	0.68	0.06	4.52	4.76
No training at all	111	3.96	1.04	0.10	3.76	4.16

Hypothesis testing. Table 7 represents the results of the Kruskal-Wallis test which indicate significant difference in the mean knowledge score of at least one pair of professional groups ($H(3) = 60.18$, $p<0.05$) and at least one pair of the training groups ($H(2) = 42.46$, $p<0.05$). As a result, null hypothesis was rejected, and post-hoc Dunn's test was conducted for pairwise multiple comparisons to examine which groups were statistically different in terms of their mean knowledge score of the policies and practices.

Table 7

Hypothesis testing for the knowledge of the related policies and practices

Null Hypothesis	Groups	Kruskal-Wallis test	Decision
The distribution of the mean knowledge score of the policies and practices is same across the groups.	a) Part C EI personnel in WA, b) Part C EI personnel in MI, c) Pediatricians in WA, and d) Pediatricians in MI	$H(3) = 68.30$, $p < 0.05$, $\eta^2 = 0.26$, *95% CI* $=[0.20, 1.00]$	Reject the null hypothesis and conduct Dunn's test to examine which groups are statistically different.
	Professionals who received a) training during academic or residency program b) received training at work, and c) did not receive training at all	$H(2) = 43.69$, $p < 0.05$, $\eta^2 = 0.17$, *95% CI* $=[0.09, 1.00]$	

The Dunn's test (Figure 5) confirmed that among the four professional groups:

a) Part C EI personnel in MI and pediatricians in MI differ significantly ($p < 0.05$).

b) Part C EI personnel in MI and pediatricians in WA differ significantly ($p < 0.05$).

c) Part C EI personnel in WA and pediatricians in MI differ significantly ($p < 0.05$).

d) Part C EI personnel in WA and pediatricians in WA differ significantly ($p<0.05$).

Similarly, the Dunn's test (Figure 6) confirmed that among the three training groups:

a) Those who received training during academic/residency programs and those who did not receive training at all differ significantly ($p<0.06$).

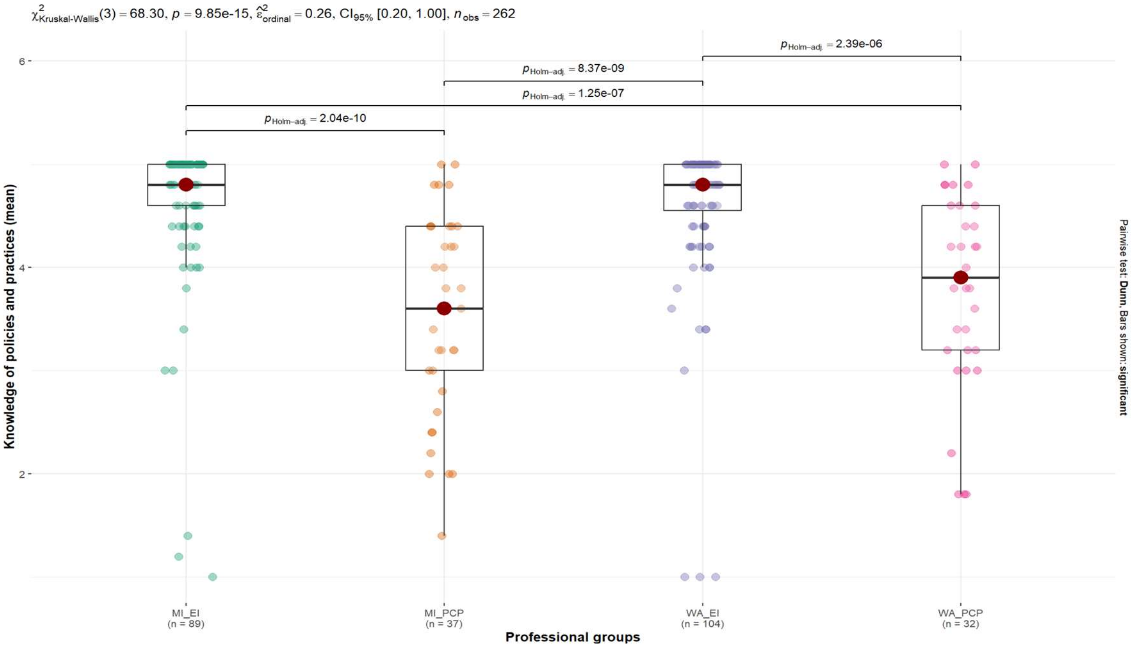
b) Those who received training at work and those who did not receive training at all differ significantly ($p<0.05$).

To summarize, the group membership- whether the participant was Part C EI personnel or a pediatrician- accounted for a large portion of the variability in knowledge of the associated policies and practices, as evidence by an $\eta^2 = 0.26$, 95% *CI* =[0.20, 1.00]. This means that group membership explains about 26% of the observed variance. Findings are illustrated in Figure 5.

In the same vein, the type of training participants receive- whether during residency, on the job, or no training- also had a large effect on the knowledge of the associated policies and practices. The effect size here, with an $\eta^2 = 0.17$, 95% *CI* =[0.09, 1.00], suggests that the type of training can account for about 17% of the variance in knowledge. Findings are illustrated in Figure 6.

Figure 5

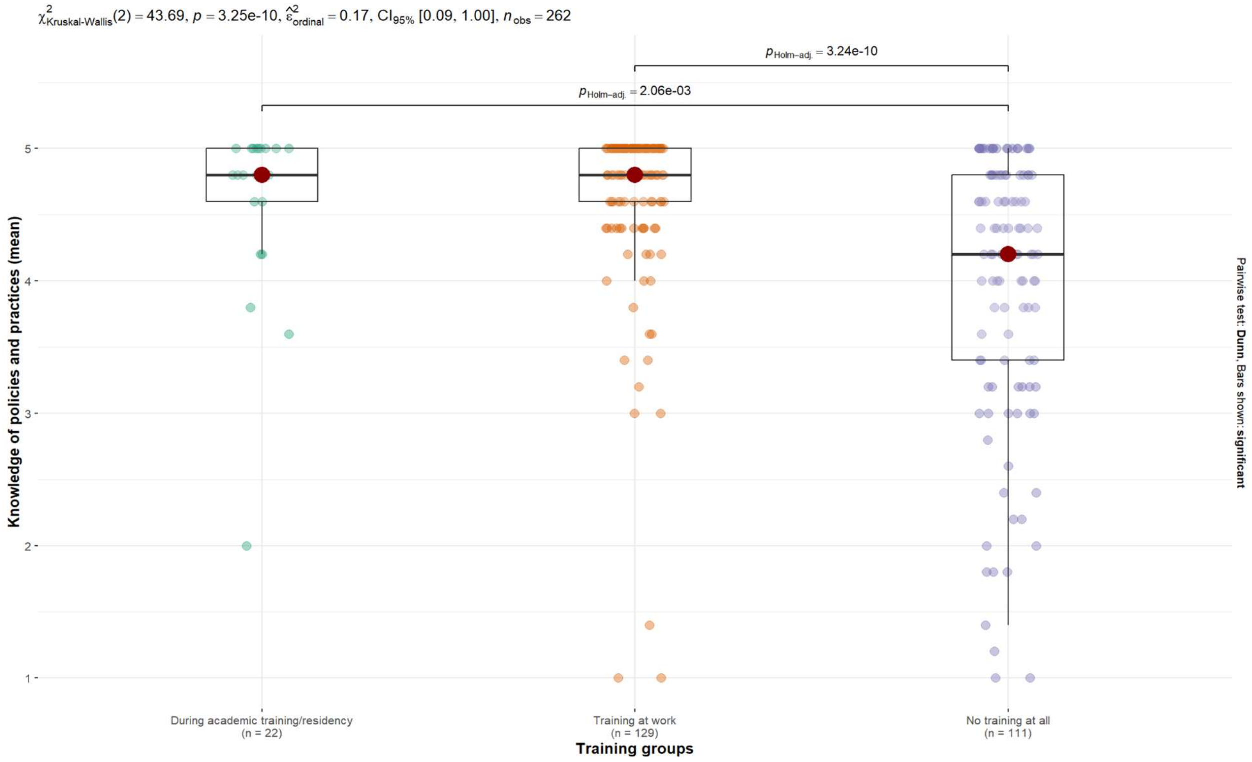
Comparison of knowledge of policies and practices among professional groups



MI_EI = EI personnel in Michigan, MI_PCP = pediatricians in Michigan, WA_EI = EI personnel in Washington, and WA_PCP = pediatricians in Washington.

Figure 6

Comparison of knowledge of policies and practices among training groups



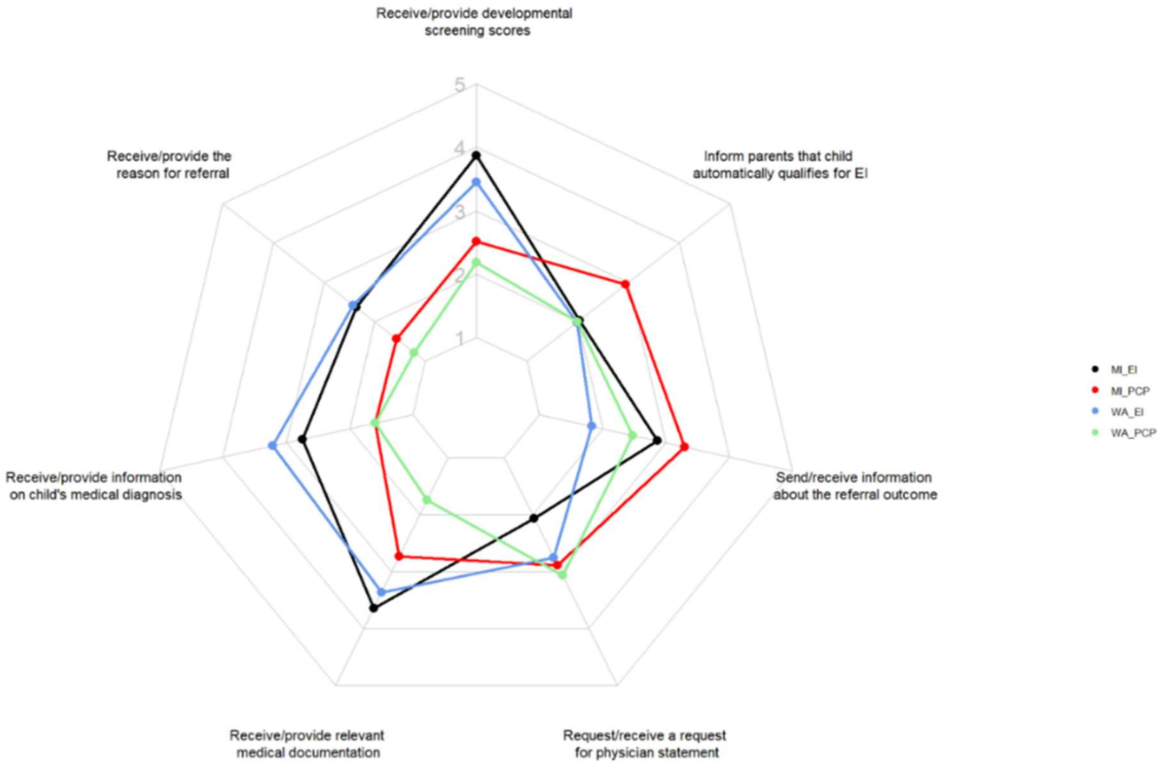
Research Question 2

Referral and Evaluation Practices Between Part C EI Agencies and Pediatricians

Part C EI personnel and pediatricians were presented with a set of seven questions pertaining to their referral practices. Figure 7 illustrates the variation in their responses, highlighting the referral practices implemented by both groups. Across all seven referral practices, inconsistent responses were obtained from Part C EI personnel and pediatricians in both states, indicating significant variability in the processes followed by two professional groups in both states. Most responses from pediatricians tended to fall within the range of ‘never’ (1) to ‘sometimes’(3), while responses from Part C EI personnel varied from ‘rarely’(2) to ‘often’ (4).

Figure 7

Radar Plot of the Self-rated Referral Practices Implemented by Pediatricians and Part C EI Personnel



Note. The guiding question was as follows: " When you receive/send a referral for a child with developmental concerns, how often do you…?". The frequency options were as follows: never (1), rarely (2), sometimes (3), often (4), almost always (5), and not applicable.

MI_EI = EI personnel in Michigan, MI_PCP = Pediatricians in Michigan, WA_EI = EI personnel in Washington, and WA_PCP = Pediatricians in Washington.

The referral practices were examined in greater detail through semi-structured interviews, which allowed for a detailed examination of specific themes. The identified themes and corresponding subthemes are presented in Table 8 and are elaborated upon below.

Table 8

Existing Referral and Eligibility Determination Practices Between Pediatricians and Part C EI

Themes	Subthemes	Referral Practices
Developmental Screening		
	Tools & Guidelines	• Tools administered: ASQ, PEDS, M-CHAT, and SWYC. • Follow AAP Bright Future guidelines and/or CDC milestones checklist.
	Wait & Watch	• Decision to refer or 'wait and watch' based on the severity of delay.
	Challenges	• Lack of resources for non-English speaking families.
Referral		
	Referral Method	• Fax, Phone, Web-based form, and Self-referral
	Parental Consent	• Verbal consent to make referral and written consent to request and release medical information, and to evaluate the child.
	Medical Reports	• Type of medical reports requested. • Timeline and secure channel to transmit medical information. • Medical reports requested for specific children versus all children referred to Part C EI. • Pediatrician to share medical reports during the referral versus only upon request
	Referral Outcome	• Enrolled, declined, no contact with family, and services received if enrolled
	Information	• Information shared with parents and Part C EI agencies at the time of referral

Table 8 *(continued)*

Themes	Subthemes	Referral Practices
Evaluation		
	Part C EI Eligibility Determination	• Multidisciplinary evaluation to determine eligibility and elicit service needs • Automatic eligibility • Informed clinical opinion
	Medical Evaluation	• Referral for medical evaluation • Waiting time
Community Outreach	Community Outreach	• Networking with popular pediatrician offices • Lack of training or guidelines on community outreach • Lack of state-level initiatives

Theme 1: Developmental Screening

Subtheme 1: Tools and Guidelines. According to most pediatricians, they take a proactive approach by conducting developmental screening for all children, without waiting for parents to express concerns. The process of developmental screening is integrated into the routine well-child visits. However, the ages at which they administer the developmental screening and the tools they use vary. The most common ages that pediatricians conduct developmental screening are aligned with the Bright Future guidelines i.e., 9, 18, 24, and 30 months. The most widely used developmental screening tools for general developmental screening among pediatricians are the Ages and Stages Questionnaire (ASQ), Parents' Evaluation of Developmental Status (PEDS) and The Survey of Well-Being of Young Children (SWYC). Pediatricians administering SWYC reported that they have built SWYC into their Electronic Health Record (EHR) system. Parents are often given developmental screening tools either via email or paper version to fill out prior to the well-child visit. However, most pediatricians shared that many parents either do not complete the screening form or never bring it back. Those who are administering SWYC via the EHR system reported that the response rate from parents was higher and it was convenient for the pediatricians to have it recorded in the electronic system directly.

Furthermore, for autism screening, most pediatricians administer the Modified Checklist for Autism in Toddlers (M-CHAT) when children reach 24 or 30 months of age. Additionally, a portion of pediatricians indicated their use of the CDC milestone checklist to keep track of children's development at well-child visits. However, Part C EI personnel noted that the most recent version of CDC milestone checklist does not include crawling as a vital milestone. As a result, some pediatricians overlook this milestone, leading to potential delay in identifying and referring children for early intervention services. A Part C EI personnel stated,

> I know the CDC milestones have recently changed for young children, and so we've had pediatricians saying crawling isn't very important or something like that to parents. Then our physical therapists are, well, crawling is very important to their development even though it's not listed as a milestone anymore.

Subtheme 2: Wait and Watch Approach. A significant portion of pediatricians reported adopting a 'wait and watch' approach when they identify developmental concerns in children. Typically, if a child exhibits a delay in one developmental domain, or parent doesn't seem to acknowledge or understand the developmental delay, pediatricians frequently recommend appropriate activities and schedule an early follow-up appointment within 1-2 months. Similarly, some pediatricians employ 'wait and watch' approach when a child's developmental performance falls within the monitoring (grey zone) zone on the Ages and Stages Questionnaire. They also consider factors such as home environment, family resources or lack of exposure to develop certain skills to decide when it is appropriate to wait and watch.

However, Part C EI personnel disagree with ‘wait and watch’ approach and indicated that pediatricians frequently delay referrals for children with speech delay, especially those from bilingual families. Some Part C EI personnel emphasized the need for training pediatricians on important signs to detect speech delay, as there is no standardized tool to measure speech delay in children, particularly those below 12 months old. Additionally, Part C EI personnel reported that pediatricians often advise families to wait and watch, in particular when following CDC milestone checklist, without realizing that it is a surveillance tool rather than a screening tool. The ‘wait and watch’ approach is further illustrated by a Part C EI personnel.

> Occasionally we will hear from families that their pediatrician told them to wait and see about a language delay, maybe if when they're 18 months and the parents had a concern. We hear, they (pediatrician) said let's wait until they're 24 months, and that would be not what we would recommend. We would recommend that they come to us as soon as they have a concern.

Subtheme 3: Challenges in Developmental Screening. Pediatricians reported several challenges in conducting developmental screening, which can lead to potential delays in identifying and referring children to Part C EI services. Language barriers and other social determinants, as well as a lack of resources such as lack of screening tools in different languages pose significant barriers to screening. Pediatricians felt that developmental screening completed by non-English speaking families may not be reliable, and limited access to interpreter services via video can be time-consuming and often overlook underlying issues. A pediatrician in Washington stated,

> I will make sure to fill out ASQ and chat with the family. But there are times that it doesn't get done. Typically, when there's not an adult present at the appointment who's able to fill out the questionnaire in the written form. And we just don't have the capacity to take the time to go through that whole questionnaire with an interpreter by video when we have 15 minutes to see the patient. Unfortunately, it (developmental screening) just won't happen.

Families from low socio-economic backgrounds, including those experiencing homelessness often miss well-child visits, particularly at crucial developmental stages like 9, 12, 18, and 24 months, which impacts screening. This is illustrated by a pediatrician in Washington who stated,

> If they don't come at those specific visits where we typically do it (development screening) as part of the workflow and sometimes, they don't. So those are the patients like sometimes I'll see at age two and a half and I'm like, oh my gosh, this kid totally has autism and a language delay.

Nevertheless, most pediatricians make efforts to engage these families early and do not wait for the next well-visit appointment. However, the absence of a formal tracking system at the state level increases the likelihood of these children missing appointments. Pediatricians agreed that having multiple professionals monitoring the development of children from birth to age 5, and encouraging families to keep up with appointments, proves effective in early detection and ensuring children receive Part C EI services. A pediatrician in Michigan said,

> So many of our parents don't utilize EI services as the first line of intervention for development unless they have a very comprehensive medical, nursing, and social work teams that each time they go to a meeting or do a virtual visit these days, or come to the doctor's office for well visit and each time one of us says, Oh, "did you contact EI did you do a developmental assessment? Is your child progressing?" So, if they hear it from me, they hear from a home visiting nurse or a social worker contacting them as well. All together they hear it several times, they feel that's more important, and they would incorporate EI in their lives.

Theme 2: Referral

Subtheme 1: Referral Method. Pediatricians commonly refer children and families to the Part C EI agency using various methods such as fax, phone, web-based form, or provide contact details to parents for self-referral when referring children and families to the Part C EI agency. This variability in the referral method results in significant differences in the quantity and type of information received by the Part C EI agency from pediatricians during the referral process.

Notably, Michigan has a state-level universal web-based referral form that is available to parents, pediatricians, and caregivers, unlike Washington. A Part C EI personnel in Washington stated,

> They're all different. That's why I said some of them have a lot of information. Some of them don't. They (pediatricians) use their own form. It would be really nice if they all had at least some basic information in the same format. It might make things faster for us instead of searching through the full document to find if there is or isn't the information we need.

In Michigan, there is a preference among Part C EI personnel and pediatricians to use the web-based form as it offers a more streamlined and systematic approach to collecting referral information; however, not all pediatricians use the web-based referral form. On the other hand, in Washington, most pediatricians typically rely on their own referral form since there is no statewide referral form in place. While some agencies in Washington have implemented their own online referral system, both states face a common challenge of lacking a dedicated web-based referral system specifically designed for pediatricians. This absence results in a lack of clarity among pediatricians regarding the necessary information to include in the referral and how to document it, thereby impacting the efficiency of the intake and eligibility determination process.

Subtheme 2: Parent Consent. Upon receiving a referral, if the parent agrees to proceed with an evaluation, they are given consent forms at the intake stage. These forms must be signed and returned before scheduling any appointments. The Part C EI agency requires parental consent for four purposes: a) evaluating the child, b) requesting medical reports, and c) obtaining permission for medical providers to release the medical reports, and d) sharing information with pediatricians, including the referral outcome.

Participants reported that in both states, the current system for obtaining parent consent to receive medical reports or share referral outcomes places the responsibility on Part C EI personnel. Part C EI personnel provide the pediatrician's office with a signed consent form to request and obtain medical information.

Moreover, most pediatricians reported lacking a formal system to obtain written consent from parents for sharing medical information with the Part C EI agency. Usually, they rely on verbal confirmation when making referrals through phone, fax, or web-based forms. As a result, most pediatricians only provide medical information when requested by Part C EI agency with a signed consent form from a parent. A pediatrician in Washington stated, "I'm obviously getting verbal consent because I'm filling out the form in front of them and telling them what (referral) I'm doing, but I don't have them sign anything."

However, Part C EI participants noted that sharing medical reports at the time of referral is a common practice among some neonatal intensive care units and local pediatricians with whom they have established close collaborations. In such cases, they typically share the written consent obtained from parents, allowing the Part C EI agency to receive the protected medical information and inform the referral outcome to the referral sources.

Lastly, while it appears that most Part C EI agencies have incorporated the practice of seeking parental consent into their workflow, obtaining consent can sometimes be a time-consuming process. As a result, acquiring parental consent and the necessary medical reports from pediatricians can pose a significant challenge in meeting the 45-day timeline for establishing the IFSP from the receipt of referral. Thus, some Part C EI personnel emphasized the importance of pediatricians and parents being aware of the 45-day timeline in order to facilitate the process by responding promptly. A quote from a Part C EI personnel in Washington illustrates this matter.

> Getting consent from parents is a process that takes a little while. Agency used DocuSign so it gets sent to parents' email and it's up to the parent to send it back. And parents do

> not always send it back in a timely fashion. Thus 90% of the time evaluations occur without any medical records because of having consent to release the information.

Subtheme 3: Medical Reports. Following a referral and intake process, Part C EI agencies commonly request medical reports prior to eligibility evaluations. The study participants mentioned two primary reasons for requesting medical reports. Firstly, medical reports are crucial for determining automatic eligibility if the child has a diagnosed medical condition that qualifies them for Part C EI services. In cases where there is no qualifying medical condition, the information gathered from medical reports is utilized, if necessary, to form an informed clinical opinion regarding the child's eligibility. Secondly, certain Part C EI personnel such as speech and language pathologists, occupational therapists, and physical therapists, rely on medical information to support and educate families, offer recommendations for effective interventions that can be integrated into the child and family's routine, and monitor the child's developmental and behavioral health. Additionally, Part C EI personnel watch for signs that may need further medical evaluation. Medical evaluation reports help them determine which evaluations have already been conducted, identify any pending medical evaluations, and determine the appropriate team members needed to support the child and their family. Without access to medical reports, they may lack these details.

However, there is a considerable variation in terms of the children for whom medical reports are requested. Most agencies in both states have a standardized practice of requesting medical information for all children, while others base it on the child's needs and concerns. Additionally, some agencies only request medical information for children referred with diagnosed medical conditions, while others request it for children whose eligibility has been established for Part C EI services. Some agencies are in the process of transitioning from selectively requesting medical information to requesting it for all children. As a result, pediatricians reported receiving inconsistent requests to release medical information, with some never receiving such requests at all.

Most participants reported that medical reports from pediatricians are generally released only upon request by the EI agency, with written consent from the parents. However, some local pediatricians and neonatal intensive care units have established collaborative relationships with the local Part C EI agency. As a result, they proactively send the medical reports during the referral process, as they are aware of the secure channels (usually fax) for sending the protected medical information.

Participants reached a consensus that medical information is typically released within a timeframe of 2 to 10 working days. However, there are instances where pediatricians either require multiple reminders or fail to respond at all, even after several reminders. When such a situation arises, it is common practice to involve parents in obtaining the necessary medical information. A Part C EI personnel from Washington expressed,

> Some of our pediatrician offices are really good and we get the medical back within two days. Some of them, we never get them back. So, then we call and follow up with them like ten days after, did they get lost in the world or did it not get there! Even after our phone call, we still don't get them all the time.

Furthermore, most pediatricians emphasized the lack of guidelines or training regarding the specific type of medical reports required, the purpose of collecting such reports, and the pediatrician’s role in providing a diagnosis and relevant medical information to facilitate a successful referral from their clinic to the Part C EI agency. A pediatrician in Michigan shared,

> The extent of my training on that (EI referral) really was 15 mins during residency, and here in Michigan it's entirely dependent on, you know, sort of what my staff tells as they have been here longer than I have.

Additionally, the absence of a secure channel for transferring medical reports poses a challenge, as pediatricians are uncertain where to send the reports until requested, thereby impeding the timely provision of medical information during the referral process or in cases where the medical condition is confirmed after the child is enrolled in Part C EI services. A pediatrician in Michigan highlighted the gap in communication system.

> No, we don’t inform or update, and the reason is that there is no way to do that back and forth because we don't know who to call or fax. So, what happens most of the time is if that information is needed, EI sends a form, and we fill in the form with the reports needed, based on whatever the form requires.

Lastly, the responses from participants indicated that a standardized set of medical reports is commonly requested, which typically includes the discharge summary (if the child was hospitalized), all well-visit notes, immunization records, hearing and vision test reports, and other medical evaluation reports if the child has undergone assessments such as neurological, cardiovascular, genetical, developmental and behavioral, and autism evaluation.

Subtheme 4: Referral Outcome. Most pediatricians reported that they usually learn about the referral outcome from parents during the follow-up well-child visits. Pediatric clinics typically lack a formal tracking system for referrals and instead make notes in the EHR system for follow up. Those who have received referral outcomes mentioned that they either received a copy of the IFSP or became aware of the referral being received when they received a request to release medical information. Pediatricians emphasized the importance of knowing whether the child is enrolled, declined, or unable to be contacted, as well as the specific services provided if enrolled. They expressed a desire to receive updates on referral outcomes for all enrolled children every six months to better support the child and family in the clinic. A pediatrician in Washington expressed the desire to receive updates stating,

> I would love to know that I'm not just sort of referring into the void and saying, hey, go forth and participate in speech therapy. I am asking, you know, having to know that they are making progress, some sort of metric.

On the other hand, most Part C EI personnel reported that they have a standard practice of faxing a copy of IFSP to the pediatrician as soon as the evaluation process is completed. However, due to Covid-19 pandemic, many Part C EI agencies have stopped sharing the IFSP unless specifically requested by pediatricians. Additionally, most Part C EI personnel agreed that sharing of the referral outcome depends on three factors. One, if pediatrician has requested the information with signed parental consent, although that is not a common practice as pediatrician usually inquire during follow-up well-child visits. Secondly, if the pediatrician has provided the requested medical information, the Part C EI agency informs them of the referral outcome as part of a good practice. Lastly, the sharing of referral outcome is parent-driven, meaning that if the parent has given consent to share information, the outcome is shared with the pediatricians. However, if there was a loss of connection with the family during the referral or intake process, no information is shared with pediatricians due to the absence of parental consent.

Subtheme 5: Information. Information given by pediatricians to parents at the time of referral varies based on their knowledge, experience, and their relationship with the local Part C EI agency. Given the constraints of 10-15 minute sessions, pediatricians are selective in the information they provide, focusing on what would be most useful for the family. Most pediatricians typically communicate three key pieces of information to families: Firstly, they share any observed developmental concerns. Secondly, they inform them that they have initiated a referral to the local Part C EI agency or provide the family with the agency’s contact details. And thirdly, they inform the family that Part C EI will reach out to them to schedule an assessment that will take place in their home. Some also explain that Part C EI is a free federal program.

Moreover, some pediatricians noted that parents are more interested in knowing how to help their child rather than the specific eligibility criteria. Most pediatricians do not inform families about automatic eligibility if a child has a diagnosed medical condition. However, pediatricians working in certain neonatal intensive care units consistently inform parents that they are eligible for Part C EI services based on the child's medical condition.

On the contrary, the intake team at the Part C EI agency usually ensures that the family is well-informed about the referral and has a clear understanding of its purpose. They provide detailed information about how the agency can assist the family, and the various services available for children and families. Furthermore, during the evaluation process, all Part C EI evaluators inform families about automatic eligibility if the child has a diagnosed medical condition. However, there is a consensus among most Part C EI personnel that pediatricians do not adequately educate families about their rights and the services offered at the Part C EI agency. This is primarily due to pediatricians lacking sufficient knowledge about the Part C EI system. Part C EI personnel have observed a difference in the information provided by pediatricians who have established connections with the agency compared to those who have no contact with them.

Similarly, there is considerable variation in the information provided by pediatricians to Part C EI agencies during the referral process. In Michigan, most pediatricians utilize the web-based universal referral form provided by the Part C EI state system. This form includes their contact details, the parent or guardian's contact information, the child's demographic information, and any concerns related to developmental delays or diagnosed medical conditions.

However, in Washington, pediatricians often use their own referral form or make referrals without a form resulting in limited information being provided to the Part C EI agency. Furthermore, there is variability among pediatricians across states in how they define developmental concerns and what they consider to be a medical diagnosis. Some provide detailed description of developmental delays, aligning with the domains in the developmental screening tools such as Ages and Stages Questionnaire, while others may describe concerns in just one sentence. Similarly, in terms of diagnosis, some pediatricians only include ICD-10 codes for specific delays (e.g., fine motor skills), while others use terms like 'suspected' to indicate their observations of underlying medical conditions that have not been evaluated. Most pediatricians in both states reported a lack of guidelines or training on good referral practices, the information required by Part C EI agencies, and their role as pediatricians in making effective referrals and ensuring that children receive the services they need in timely manner. A gap in knowledge or understanding was described by one pediatrician in Michigan.

> I feel like I'm missing some pieces of information that would probably help me do a much better job of knowing, the other things that would qualify a child not just being a premature or having been in the NICU as an infant or shaken baby or something like that, which would put them at huge risk for developmental issues. So, I guess I'm aware of the implication, but I don't know that I do everything I can do to make sure the child gets the services they need.

Theme 3: Evaluation

Subtheme 1: Part C EI Eligibility Determination. The large number of Part C EI participants reported that all children, regardless of whether they have a diagnosed medical condition, undergo multidisciplinary evaluation in both states. This evaluation involves two professionals from different disciplines and utilizing two different standardized tools to evaluate the child's developmental level. Participants emphasized that there is no differentiation between the initial evaluation and full evaluation; rather, it is considered a unified evaluation process.

This approach generates more functional information that they effectively utilize for determining eligibility, planning treatments, and establishing goals for the child and the family.

Specifically, the information gathered from the multidisciplinary evaluation helps them to determine eligibility for children with developmental delays based on the state criteria. In cases where a child's developmental delay does not meet the state's eligibility threshold and there is no automatically qualifying medical condition, but parent is concerned about the child's development, informed clinical opinion is utilized to make the child eligible for services. Similarly, if a child has a diagnosed medical condition that is not on the state-approved list and medical reports cannot be obtained, eligibility is determined based on informed clinical opinion. Additionally, informed clinical opinion is also applied if the child's medical condition is not on the list and the Part C EI personnel is not familiar with the medical condition. They conduct web searches to confirm that the medical condition has associated developmental delay and utilize the information to make the child eligible under informed clinical opinion.

Interestingly, participants in both states emphasize that state eligibility criteria hold less significance when a parent is concerned about their child's development. Parental concern becomes the decisive factor in bringing the child into services by relying on informed clinical opinion. In order to utilize informed clinical opinion, Part C EI personnel must have information gathered from the multidisciplinary evaluations. According to participants, a unified multidisciplinary evaluation approach ensures that services are not denied to any child showing signs of delay in areas that cannot be established using standardized tools.

Moreover, participants highlighted that the multidisciplinary evaluation typically lasts between 45 to 75 minutes, with the subsequent development of the IFSP taking an additional 30 to 45 minutes. The time required for the evaluation process and determining eligibility based on developmental delay, diagnosed medical condition, or informed clinical opinion remains consistent. However, participants acknowledged that when a child is referred with a diagnosed medical condition and provided associated medical reports, it expedites the eligibility determination process, enabling the utilization of information gathered from the multidisciplinary evaluation to deliver services to the child and their family.

Furthermore, while there were similarities in eligibility determination practices, Part C EI personnel also exhibited some variations, particularly regarding children with diagnosed medical conditions. Some Part C EI personnel determine a child's eligibility based on delay if their medical condition is not listed on the state-approved list. Others consider a diagnosed medical condition stated on the referral form and signed by a pediatrician as sufficient for automatic eligibility, while some require medical evaluation reports from the pediatrician's office in addition to the diagnosis written on the referral form to establish automatic eligibility.

Lastly, in Michigan, a birth-mandate state, children with significant disabilities who are eligible for Part C EI services are also evaluated for special education services under Michigan Mandatory Special Education (MMSE). The information obtained from the multidisciplinary evaluation plays a crucial role in determining a child's MMSE eligibility. Children eligible for MMSE receive more frequent services compared to those receiving only Part C EI services in Michigan. Since children with diagnosed medical condition automatically qualify for Part C EI services, their evaluation for MMSE services is conducted directly using the information gathered during the multidisciplinary evaluations including medical reports. A majority of Part C EI personnel in Michigan expressed agreement that the state should transition to a single eligibility system, as maintaining dual eligibility provides no practical advantage to children and places unnecessary burden to families.

Subtheme 2: Medical Evaluation. All pediatricians in the study expressed their commitment to referring children to the Part C EI agency as soon as they detect developmental delays. They do not wait for the child to undergo a medical evaluation before making the referral. While obtaining a medical diagnosis is a priority for most pediatricians, the decision to refer for medical evaluation depends largely on the child's age, medical complexity, and the severity of the delay. If child exhibits delay in one developmental area while progressing well in other areas and maintains good overall health, pediatricians are more likely to suggest activities that can be carried out at home or refer them solely for Part C EI services, without recommending a medical evaluation, as not all children with delays have an underlying medical condition. However, if pediatricians suspect any underlying medical conditions based on signs and symptoms such as abnormal tone or asymmetrical movement, or if the child has severe delay in multiple domains or global developmental delay, they assess and refer the child for an appropriate medical evaluation.

Furthermore, a significant challenge stated by all pediatricians in obtaining a medical evaluation is the waiting time, insurance coverage, healthcare settings, and parental stigma. Pediatricians reported that most medical evaluations take between 6 to 15 months to be completed. Children with private insurance generally have shorter waiting times compared to those with Medicaid since they rely on community resources with long waiting lists rather than hospitals. Children seen by pediatricians in academic institutions or large hospitals have faster access to subspecialists services compared to those attending private or small practices. Most pediatricians advise families to get on the waiting lists of multiple evaluation centers as they can withdraw their names if necessary. Additionally, families residing in rural areas face the obstacle of long distance travel to reach medical evaluation centers. Moreover, some families experience stigma associated with long-term diagnoses, which may delay their decision to pursue a medical evaluation.

Lastly, according to Part C EI personnel, most children who are diagnosed with medical conditions at the time of referral are typically younger than 12 months. However, there are certain medial conditions such as cerebral palsy and autism that may not be detected during infancy. The role of Part C EI personnel is crucial in assessing the need for medical evaluation and supporting families in requesting such evaluations and navigating the medical system. Therefore, Part C EI personnel emphasized the importance of being informed about any medical evaluations the child has already undergone or is currently undergoing. If a child is diagnosed with a medical condition after enrolling in Part C EI services, it is essential that this information is promptly communicated to the personnel directly by pediatricians, as parents may not always be the most effective conveyors of medical information. However, the current system is not established for two-way communication between pediatricians and Part C EI agencies to share protected medical information such as medical evaluations and medical diagnoses.

Theme 4: Community Outreach

As part of the Part C EI grant system, each Part C EI agency is obligated to engage in community outreach to provide services. This involves establishing connections with pediatrician offices and ensuring they have the information available to families and understand the EI process. Typically, program coordinators are responsible for conducting outreach on behalf of the EI agency. Most Part C EI personnel reported that they reach out to pediatrician offices, establish contact with case managers and distribute referral information and brochures to raise awareness about EI services in the local area.

However, most Part C EI personnel also reported that there is currently no systematic approach or guideline in place for conducting community outreach. Nevertheless, they often prioritize outreach to popular pediatric offices to establish referral connections. They also attend pediatricians' meetings, annual conferences, or coalition meetings when invited, in order to distribute informational materials. Some have also begun distributing state-approved lists and noted that pediatricians were previously unaware of the list. This effort has resulted in an increase in referrals. Some EI agencies and pediatricians have formed collaborative relationships due to consistent networking efforts from the EI agencies.

However, most Part C EI personnel and pediatricians have expressed dissatisfaction with the current community outreach system. They find it ineffective for several reasons such as it primarily involves one-way communication, depends on the level of interest and responsiveness of pediatricians, consumes significant resources, and takes away valuable time from EI personnel that could be spent directly serving children and families. At the state level, there is no consistent initiative or system in place for effective communication, exchange of protected medical information, organization of trainings and discussions, dissemination of system-level updates, or case consultations between Part C EI agencies and pediatricians.

Research Question 2A

Factors that facilitate or impede the referral process.

The study examined the factors that either facilitate or impede the referral processes between pediatricians and Part C EI agencies, based on the description of current practices. Table 9 provides a detailed overview of each factor that supports or hinders the referral process. The study identified three main factors that facilitate the referral process:

a) Collaboration between NICUs, local pediatricians, and Part C EI agencies encourages the sharing of medical information at the time of referral without specific requests.

b) Direct access to electronic health records (HER) by Part C EI agencies enables them to retrieve necessary medical information without relying on the pediatricians.

c) Multidisciplinary evaluation involving all children simplifies the determination of eligibility and identification of service needs.

Additionally, the study identified five factors that hinder the referral process:

a) Inconsistent efforts to seek parental consent, particularly among pediatricians, impede the sharing of information between Part C EI agencies and pediatricians.

b) The absence of a designated referral form for pediatricians, results in variations in the quantity and type of information received during the referral.

c) The lack of a consistent and secure system for sharing protected medical information leads pediatricians to release such information only when requested.

d) The absence of an established communication system between Part C EI agencies and pediatricians creates coordination breakdowns, causing the two agencies to operate in silos.

e) Long waiting periods for medical evaluation compel many children to enter the Part C EI system with incomplete information about their developmental and behavioral health.

Table 9

Facilitators and Barriers to Part C EI Referral Process

Factors	Description	Illustrative Quotes
Facilitators		
Community outreach (collaboration)	Collaboration with NICUs and pediatricians streamlines medical report receipt during referrals.	*"From the NICU, we will get that referral with usually a discharge summary. Within that discharge summary are the medical conditions." (MI, Part C EI)*
EHR	EI agency in WA accesses EHR system for direct retrieval of medical reports with parent consent.	*"We have access through EPIC to access medical records. Our medical records provider again goes into EPIC and retrieve their medical records. So, we retrieve all records from birth. (WA, Part C EI)*
Multidisciplinary evaluation for all children	Multidisciplinary evaluation for all children helps in determining eligibility and addressing service needs.	*"We do multidisciplinary evaluations for that reason so that there's always at least two sets of eyes looking at the child." (MI, Part C EI)*
Barriers		
Parental consent	Inconsistent parental consent hinders medical information sharing and referral outcome.	*"So recently, a lot of times our pediatricians are calling and saying what happened? And we're like, we can't tell you because we haven't seen the child or the family yet to get the consent so late. Now we've been asking pediatricians to provide us with a consent form if they would like to know what's going on with the referral process."(MI, Part C EI)*
Web-based Referral form for pediatricians	Varied referral methods result in information discrepancy during referrals.	*"It would be really nice if there was a universal form that had all the information, we needed on it and all of the doctors used. That would be amazing."* (WA, Part C EI)
Secure channel to share medical reports	No secure channel for pediatricians to share protected medical reports during referrals.	*One of my coworkers really needed reports because of a diagnosis, and they actually ended up showing up at the office with all of the consent, saying, 'Here it is needing this report" (MI, Part C EI)*

Table 9 *(continued)*

Factors	Description	Illustrative Quotes
Closed loop electronic (communication)	Absence of close loop electronic system for secure information exchange, referral outcomes, case conferences, and system-level updates to pediatricians.	*" Just the communication piece is tough, but I don't know if I can think of specific ways to address that. It's just sometimes a lot of phone tag and a lot of calling and trying to get information. I don't know quite how to address that."* (WA, Part C EI)
Waiting time for medical evaluation	Medical evaluation can take between 3 to 15 months.	*"Developmental evaluation tends to take 4 to 6 months to just to happen and for an autism evaluation, it's sort of 12 to 15 months." (WA, PCP)*

Research Question 3

Recommendations and Opportunities for Change

Part C EI personnel and pediatricians were presented with a randomized set of ten statements aimed at improving the utilization of the state-approved list of diagnosed medical conditions in the referral and eligibility determination processes in their respective states. Figure 8 illustrates the percentage of participants who recommended each statement. Interestingly, both Part C EI personnel and pediatricians in both states agreed on the top six recommendations. More than 75% of participants across both states recommended distributing the state-approved list to pediatricians and providing them with training on the Part C EI referral and eligibility determination processes, including information about the state-approved list. Additionally, over 60% participants suggested including the state-approved list in public awareness activities, such as community outreach events and talks attended by Part C EI personnel in pediatric settings and other community locations. It is worth noting that less than 5% of participants agreed that no changes are needed in the current state-approved list of diagnosed medical conditions.

Recommendation and opportunities for change were further explored through in-depth semi-structured interviews. Themes and associated subthemes are presented in Table 3 and details are discussed below.

Figure 8

Recommendations made by Part C EI personnel and pediatricians.

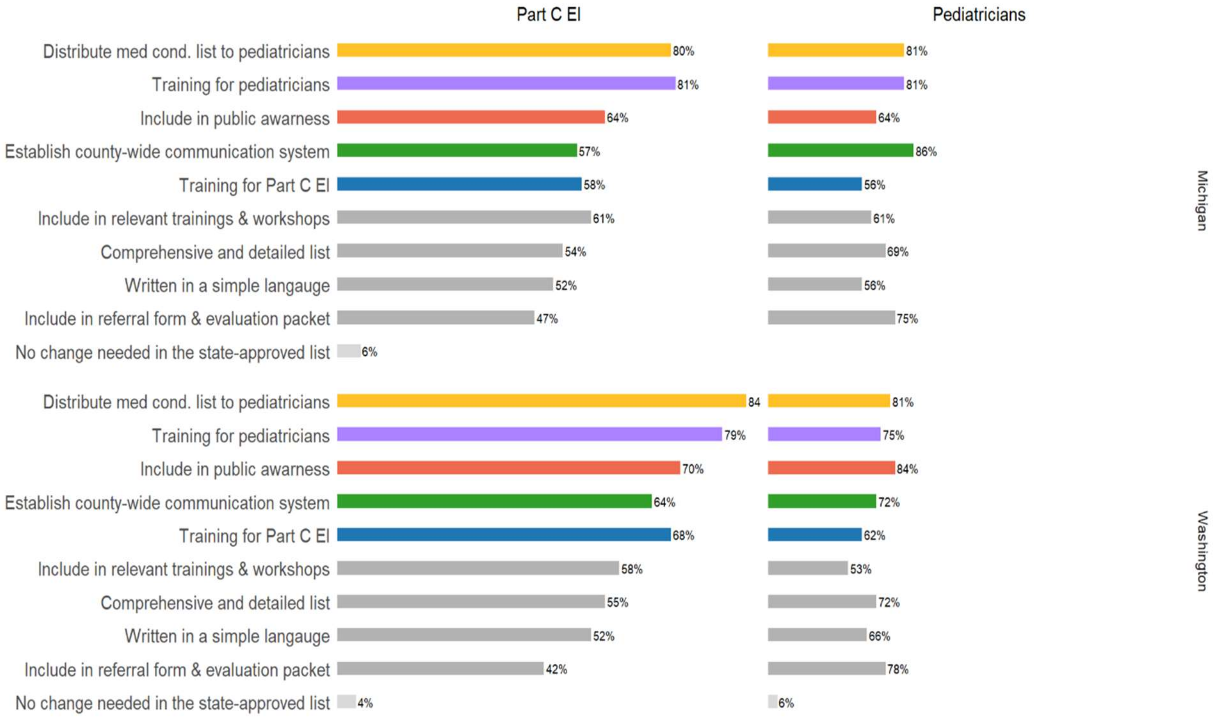


Table 10

Recommendations and Opportunities for Change suggested by Interview Participants

Themes	Subthemes	Issues to tackle	Long term/ Short term
State-approved list			
	Disclaimer	Staff overlooks that list is not all comprehensive	Short term
	Embed in the referral form	Embed in the referral form by adding a link or reference to the list so pediatricians don't miss.	Short term
	Insufficient details	Add: • Alias • Definition of medical conditions • ICD 10 code[a] • Reference to organizations that support families	Long term
	Distribution	Distribute to: • Pediatricians • Other early child providers annually and • families with children with diagnosed medical conditions	Short term
	Nation-wide database	Mass collaboration across states to create a nation-wide database of qualifying medical conditions	Long term
Referral			
	Referral form	Establish statewide web-based referral form for pediatricians. Include following in the referral form: • A link or reference to the state-approved list of diagnosed medical conditions	Long term

Table 10 *(continued)*

Themes	Subthemes	Issues to tackle	Long term/ Short term
		• A fax number and a prompt to provide medical records with the referral (as stated below) • Consent statement to release medical records from pediatricians and receive information on referral outcome	
	Medical records	Following medical records to be shared with all referrals: • All well-visit notes • Discharge summary (if hospitalized) • Developmental Screening scores • Immunization record • Hearing evaluation report • Vision evaluation report • Any other medical evaluation such as autism, neuro, cardio, developmental and behavioral or • State during referral if child is referred for medical evaluation.	Long term
	EHR system	• Establish a mechanism for Part C to have access to Electronic Heath Record (EHR) system to -receive medical records -prompt two-way communication	Long term
Training for pediatricians	Topics	• State-approved list • Guidelines to provide information to families at the time of referral. • Part C EI referral; 45-day timeline • Pediatricians' role in the referral and eligibility determination process • Information (including medical records) to include in the referral	Short term as well as long term

Table 10 *(continued)*

Themes	Subthemes	Issues to tackle	Long term/ Short term
		• When to/not to apply wait and watch approach. • Parent consent • Referral outcome • Contact person at the local Part C EI agencies.	
	State-level initiative (Method)	• Short online training with CE credits. • EI agency to organize: Lunch and learn; Breakfast over zoom sessions for pediatricians.	Long term
Training for Part C EI	Training	• Community outreach/Networking and collaborations • Referral and Eligibility Determination	Short term

Note. Long term estimates are based on the need for collaborative efforts, while short-term estimates rely solely on the initiative of the state Part C EI program.

[a] ICD-10 is the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD), a medical classification list by the World Health Organization.

Theme 1: State-approved list. This theme refers to discussions surrounding proposed changes to enhance the utility of the state-approved list of diagnosed medical conditions in the referral and eligibility determination process. Participants expressed concern that some individuals mistakenly believe that the list is exhaustive and that conditions not included are ineligible for Part C EI services. To address this, participants emphasized the importance of prominently displaying a bold disclaimer stating that the list is not comprehensive. For instance, A Part C EI personnel in Michigan said, “It would be nice for the list to more broadly clarify that this are just some of the qualifying medical conditions.”

Currently, there is a disconnection between the referral form and the state-approved list. Participants suggested that incorporating a link or reference within the referral form, directing pediatricians to consult the medical diagnosis list, would improve the accuracy of referral information and streamline the process.

The existing list primarily comprises the names of medical conditions. However, pediatricians often refer to the ICD-10 codes instead of the actual diagnosis in the referral, and sometimes a single medical condition is known by multiple terms. To address the issue, participants proposed including aliases for listed medical conditions, along with their corresponding ICD-10 codes, definitions, and references to organizations that offer support for families dealing with those specific conditions. This would transform the list into a more user-friendly resource for both families and providers.

Furthermore, the current list is not widely distributed beyond Part C EI agencies. Participants stressed the importance of widespread distribution, suggesting that the list should be annually disseminated to pediatricians and other early childhood service providers. However, they emphasized that such initiatives should be driven at the state level and necessitate collaboration between authorities such as the state Part C EI lead agency and the state chapter of the American Academy of Pediatrics. It is important that these efforts are not solely driven by local Part C EI agencies. A Part C EI personnel in Michigan shared,

> I have found that the list has been most helpful getting it out to doctors and pediatricians, because that establishes a huge clarity in our system for them to understand how we qualify kids. They can go on our website and find it, but it can be daunting if you don’t know what you are looking for and what to call certain documents.

A pediatrician in Washington emphasized the use of the diagnosed conditions list in pediatric setting by stating,

> I've never seen the list, so I can't speak to it. We could put it up in our exam rooms. That could be a trigger for the parents or a trigger for us to remember that for each of these medical diagnoses, they are automatically eligible for therapy services.

Finally, since most states have developed their own list of diagnosed medical conditions, which may not cover all possible conditions, the creation of a centralized database that integrates all the proposed changes would provide a comprehensive resource for Part C EI personnel, pediatricians, and families across the entire nation.

Theme 2: Referral. This thematic category focuses on improving the referral processes between pediatricians and Part C EI agencies. The study revealed that there are several commonalities in the referral process across agencies and across states, however variability occurs since there is a lack of statewide approach and each Part C EI agency invents its own tools and systems. For instance, the following quote from a Part C EI personnel in Washington illustrates the approach the agency is taking to establish a referral form for pediatricians.

Participants agreed that streamlining the referral system between pediatricians and Part C EI agencies could be achieved by implementing uniform referral forms, intake forms, and consent forms statewide. Participants believed that a statewide web-based referral form for pediatricians would streamline the process of receiving referrals. However, the form must include a link or reference to the state-approved list of diagnosed medical conditions, a fax number or secure email address to receive medical records at the time of referral and a consent statement that enables the release and receipt of protected information including medical records and referral outcomes, in compliance with HIPPA regulations for pediatricians, and FERPA and IDEA Part C privacy regulations for Part C EI personnel. Adding a consent statement in the referral form is critical for encouraging pediatricians to share medical reports at the time of referral since most pediatricians do not have resources or systems to obtain written consent. A pediatrician in Michigan shared,

> I'm literally in the room with them (parent) pulling up the website and filling it out. And that's an easy thing to do. But getting people to sign forms and stuff is just harder. So, in some ways I guess it's nice for me to fill out a form and then have EI to take care of all that paperwork and then tell me, it's okay for you to just send me this information now.

Participants suggested the implementation of a centralized fax number or encrypted email system for receiving medical reports, either at the county or state level. This would address the challenges faced by pediatric providers who serve multiple counties or encounter multiple Part C EI agencies within a county, making it difficult to keep track of each agency's referral system.

Furthermore, study findings indicated that Part C EI agencies typically request a standardized set of medical records from pediatrician, including discharge summaries (in case of hospitalization), well-visit notes, hearing and vision evaluation reports, immunization records, and other relevant medical evaluation reports. Consequently, it is important to inform pediatricians about the specific medical records that are expected and establish a system for them to easily share these records during the referral process. This proactive approach will not only provide crucial support for families but also streamline the referral process by saving time, effort, and resources that would otherwise be spent on requesting medical information. A Part C EI personnel in Washington recommended,

> It would be most helpful. Oh, my gosh, if I had all the medical records, I needed that the day before the evaluation, I would be happy because that would be documented and I would know what the issues are for this child or if they have a diagnosis or, you know, what their history is, it would be phenomenal. It would be awesome!

Lastly, participants from both Part C EI agencies and pediatric providers believe that the Part C EI should be granted access to the Electronic Health Record (EHR) system. This access would allow them to retrieve necessary medical records, with the consent of the parents, and facilitate two-way communication with pediatricians. Given that most Part C EI agencies request medical records for all children, it is vital to initiate conversations at the state and federal levels to set up policies and electronic systems for data sharing and communication. A pediatrician in Michigan further emphasized,

> I think it (giving Part C EI access to EHR) would be very beneficial. I think it would be a fantastic addition and I think it would really help both. I mean, I talk to visiting nurses all the time through our portal system and through our referral system. So, that helps me to have communications with them that were busy during the day. We get the messages, and we can communicate afterwards on those visits. So, I think could be very helpful with Part C EI. I think EI should have access to EHR system.

Additionally, Part C EI personnel from an agency with access to EHR system provided insights into the convenience it brings to their day-to-day operations in accessing medical records. It is worth exploring such a model to establish a mechanism that can grant Part C EI agencies access to EHR systems. A Part C EI staff member in Washington elaborated on this.

> So, what we typically do is instead of going back to the primary care provider or pediatrician and asking for more records, most of our providers are on EPIC, the electronic medical records system. We have access through EPIC care to access medical records. So, what we do is we just communicate directly with the family and have them sign a release of information using DocuSign. We do that pretty quickly and our medical records provider again goes into EPIC and retrieves their medical records. So, we retrieve all records from birth.

Theme 3: Training for pediatricians. This thematic category centered around the importance of providing training opportunities for pediatricians. Pediatricians emphasized the need for a convenient option that aligns with their busy schedules, such as a short online training course that offers continuing education credits and can be completed at their own pace.

Furthermore, the study revealed that pediatricians expressed a desire for a local contact from Part C EI agencies and in-person or synchronous information sessions held multiple time throughout the year such as lunch and learn or breakfast over zoom session four time a year. These sessions would focus on educating pediatricians about effective referral practices and their role in the process. Table 3 outlines the suggested topics to be included in the training curriculum for pediatricians.

Theme 4: Training for Part C EI. This theme highlighted the training requirements of the Part C EI personnel. Participants from the state of Michigan reported that they have robust training on referral and eligibility evaluation, including the state-approved list of medical conditions as part of the onboarding process for the new staff members. However, Part C EI participants from both states agreed that the training provided insufficient coverage of policies and practices. Furthermore, there has been a lack of training on community outreach, which is a significant and essential aspect of their work to establish collaboration and communication with pediatricians and other early childhood providers in the community.

CHAPTER IV

DISCUSSION

The issue of inadequate referral of children with developmental delays to Part C EI services has been extensively studied. One major cause is the lack of communication between EI programs and pediatric providers, highlighting the need for improved collaboration and communication (O' Neil et al., 2008; Rosenberg et al., 2008; Little et al., 2015; Sanders et al., 2022). However, it is worth noting that the problem of inadequate referral and participation is also evidenced among children with diagnosed medical conditions who are automatically eligible for Part C EI services (Little et al., 2015; Mussato et al., 2017; Atkins et al., 2019; Kay et al., 2021; Braddock & Twyman, 2014).

Previous research examining Part C EI referral and enrollment for children with diagnosed medical conditions has primarily focused on children with specific medical conditions such as prematurity (Little et al. 2015), cleft palate (Kay et al., 2021), medical risk (Atkins et al., 2019), autism (Braddock & Twyman, 2014), and hypoplastic left heart syndrome (Mussato et al., 2017). These studies, as well as more general investigations into referral and EI enrollment have overlooked the significant involvement of both Part C EI personnel and pediatricians in the referral and eligibility determination process. These professionals collaborate to deliver services to children with developmental delays and diagnosed medical conditions. Additionally, federal regulations (§303.321(b)) require the sharing of relevant medical information in the process of linking children with diagnosed medical conditions to Part C EI agencies. However, limited research has been conducted on how medical information is transmitted from pediatricians to Part C EI agencies. Furthermore, states have developed a list of diagnosed medical conditions as a reference tool to facilitate the determination of eligibility for Part C EI services. However, understanding of the knowledge and utilization of these state-approved lists among Part C EI personnel and pediatricians, as well as the associated policies and practices within the current referral system including the sharing of medical information to support eligibility determination for children with diagnosed medical conditions, remain limited.

To address these gaps, a concurrent embedded mixed-method study was conducted to investigate the knowledge and utilization of state-approved eligibility lists as well as the associated policies and practices, among Part C EI personnel and pediatricians. The study also examined the procedures followed by these professionals in referring children and determining their eligibility for services. Additionally, the study explored the factors that facilitate or hinder these practices. Furthermore, the recommendations proposed by Part C EI personnel and pediatricians were explored with the aim of establishing a more streamlined and efficient referral process for children with diagnosed medical conditions. The study was conducted in two states--Michigan and Washington.

An embedded mixed-methods approach incorporating both quantitative and qualitative data was employed due to the limited knowledge on the topic (Creswell & Clark, 2007). A survey and semi-structured interviews were conducted to gain a comprehensive understanding of the research questions. Using the two data strands together, quantitative outcomes were validated with qualitative insights, resulting in more credible and robust findings (Creswell & Clark, 2007; Clark, 2019). The survey and interview data were collected, analyzed and interpreted simultaneously, with the findings from both strands combined to answer the research questions. Importantly, the overall analysis of the study placed equal emphasis on the quantitative as well as the qualitative data.

Knowledge of the state-approved list and associated policies and practices

The study participants were asked to self-rate their knowledge regarding the five aspects of the state-approved list in their respective states, including the familiarity with the list itself, medical and physical conditions included in the list, medical and physical conditions included in the federal guidelines, where to access the list, and lastly their understanding that the list is not exhaustive. Furthermore, they were asked to self-rate their knowledge regarding five components related to policies and practices. These components encompassed state eligibility criteria, including that children with diagnosed medical conditions are automatically eligible; requirement to document the diagnosed medical condition to ensure automatic eligibility; the 45-day timeline between receipt of referral and completion of IFSP; and lastly their familiarity with the referral process in their county or state.

The findings revealed a significant difference in the knowledge of the state-approved list as well as the related policies and practices, between pediatricians and Part C EI personnel in both states. Specifically, pediatricians demonstrated a lower level of knowledge of the state-approved list as well as of the associated policies and practices compared to Part C EI personnel. Similar to studies conducted by Scot et al. (1993) and Edwards (2018), findings indicated a lack of knowledge among pediatricians regarding EI provisions and policies. In the study conducted by Scott et al. (1993), less than 50% of pediatricians were found to be aware of the EI provisions. Similarly, in the analysis by Edwards (2018), pediatric residency training directors reported only ‘minimal’ or ‘moderate’ knowledge of EI. Although Scott et al. (1993) and Edwards (2018) examined the knowledge of different components of EI services, the overall findings underscored the lack of knowledge regarding EI services among pediatricians.

In addition, participants who received training either during their academic studies, residency, or through on-the-job experience, exhibited significantly higher levels of knowledge of the state-approved eligibility list and related policies and procedures compared to those who had no training. It is important to note that the majority of participants in both training groups consisted of Part C EI personnel, as most pediatricians reported minimal or no training in EI. Edwards (2018) conducted a study with similar findings, revealing that the pediatric residency training directors reported that the EI was only briefly addressed during their residency programs.

The lack of training and knowledge among pediatricians is reflected in the information shared with families and Part C EI agencies during the referral process. The information provided to parents varied based on their knowledge, experience, and relationship with the local Part C EI agency. Due to time constraints in well-child sessions, pediatricians selectively provided information based on the family's receptivity and interest. However, Part C EI personnel noted that pediatricians do not adequately educate families about their rights and EI services. Similar conclusions were drawn by Jimenez et al. (2012), highlighting pediatricians' insufficient addressing of parents' perspectives on children's development and limited guidance on EI services during the referral process.

Furthermore, pediatricians have expressed a lack of guidance regarding effective referral practices, the necessary information required by Part C EI agencies, and their role in ensuring timely and appropriate services for children. The use of a universal referral form, as seen in Michigan, offers a structured template for pediatricians to systematically share information. However, in cases where the referral form is either not used or absent, such as in Washington state, pediatricians have reported uncertainty about which information is essential to provide, apart from the family's contact details. Consequently, there is significant variability in the information provided by pediatricians to Part C EI agencies during the referral process. This lack of knowledge and insufficient training in EI may play a role in pediatricians' reluctance to refer families to EI, as noted by families in a study conducted by Decker et al. (2021).

Implementation of Referral and Eligibility Determination Practices

Both Part C EI personnel and pediatricians were presented with a set of seven statements regarding referral practices, and they were asked to rate how frequently they implemented these practices. These questions encompassed aspects such as sharing developmental screening scores, medical reports, referral outcomes, diagnosed medical condition if known, reason for referral, and informing parents about their child's automatic qualification for EI services. The responses obtained from pediatricians and Part C EI personnel in both states displayed inconsistency across all seven referral practices, indicating significant variation in the practices followed by pediatricians and Part C EI personnel.

Developmental Screening

The research findings align with previous studies indicating that the majority of pediatricians are actively involved in conducting developmental screening utilizing standardized screening tools (Scot et al. 1993). The commonly employed general screening tools are ASQ and PEDS, while MCHAT is frequently used for autism-specific screening at 18 or 24 months by pediatricians (Lipkin et al., 2020).

Moreover, most pediatricians reported to adhere to the guidelines set forth by the AAP Bright Futures, which recommend incorporating developmental screening during specific well-child visits at 9, 12, 18, 24 or 30 months. In addition, most pediatricians conduct developmental surveillance at all well-child visits using observations, parent reports, and utilizing CDC milestone checklist. However, some Part C EI personnel expressed concerns regarding omission of crawling as a significant milestone from the current CDC checklist. As a result, some pediatricians unintentionally overlook this milestone causing delay in identification and referral to Part C EI services.

The research findings are consistent with prior studies, demonstrating that most pediatricians apply a ‘wait-and-watch’ approach. The two most common reasons for withholding a referral to EI services are delays in one domain, rather than delays in two or more domains, and pediatricians respecting parental wishes if they don’t seem ready (Jimenez et al. 2012; Jimenez et al. 2014). Additionally, some pediatricians consider additional factors including family resources, socioeconomic status, and parental acceptance of EI referral, before making the decision to refer. In such cases, pediatricians often schedule an early appointment prior to the next well-child visit to closely monitor the child’s development (Jimenez et al. 2012). Furthermore, a small number of pediatricians also adopt ‘wait-and-watch’ when child’s developmental level falls in the monitoring zone on the ASQ.

The variability in implementing ‘wait-and-watch’ approach underscores the importance of establishing clear guidelines and provision of training for pediatricians regarding its appropriate application. This is particularly relevant in the context of screening and referral for children with speech delay, especially bilingual, as emphasized by Part C EI participants in this study. They noted that most delays in referrals are observed in children with speech delay, possibly because there is a lack of screening tool and pediatricians primarily focus on the number of spoken words at age 15 or 18 months, overlooking the significance of quality of sounds produced by younger children that may indicate need for intervention.

Furthermore, despite the availability of parent-completed screening tools in at least 14 languages, pediatricians face significant challenges in conducting developmental screening for non-English and non-Spanish speaking families, highlighting persistent language barriers (Hirai et al., 2018). Pediatricians noted that the lack of access to screening tools in languages other than English and Spanish contributes to the unreliability of screening completed by these parents. Additionally, barriers related to social determinants, such as homelessness, low income, and immigration status further compound the challenges. These families often struggle to keep up with regular appointments, including well-child visits when developmental screening is typically conducted. As a result, delays in identifying developmental issues may go unnoticed, and pediatricians may need to make additional efforts to conduct screenings outside of their regular workflow. Knuti Rodrigues et al. (2016) also noted similar results, indicating that compared to English-speaking group, the non-English and non-Spanish group had lower odds of receiving developmental surveillance at 100% of well-child visits. The reason being lack of availability of standardized developmental tools in languages other than English and Spanish.

According to Knuti Rodrigues et al. (2016), the provision of high-quality language translation and interpretation resources at the point of care has the potential to address language barriers. However, this study revealed that pediatricians identified certain challenges with telephone and video translation and interpretation services, citing them as time-consuming and less effective when discussing underlying medical problems during developmental screening in real-time. Therefore, it is essential to explore the feasibility of utilizing multilingual technology platforms, powered by both human and AI assistance, for conducting developmental screening using standardized tools. An example of such a platform is ‘Talkingpoints’, which is currently being implemented to empower non-English speaking immigrant families and enhance parental engagement in school education (Park et al., 2022).

Referral Practices

Referral Method. The findings reveal that there is variability in the quantity and type of information received during referrals in the sample states. Pediatricians employ diverse methods such as fax, phone, web-based referral, and giving out contact details to parents to encourage self-referral. Unlike Washington, the state of Michigan offers a statewide web-based referral form available for parents, caregivers, and pediatricians. Both states have multiple, accepted referral methods to facilitate convenience for various referral sources including parents, caregivers, and pediatricians. These findings align with results reported by Sanders et al. (2022) who conducted surveys with state Part C coordinators and examined referral methods. Their findings indicate that referrals are received through various channels and state Part C coordinators value this diversity in methods, but eventually would like to receive referrals through websites and the EHR system.

Furthermore, many pediatricians opt for a simplified approach by giving out contact details to parents, which saves them time and effort in providing detailed information about the child and the family. However, a lack of a formal tracking system makes it difficult to ensure that parents have successfully contacted the Part C EI agency. Typically, follow-up with these families occurs during the next well-child visit, which can be 3 to 6 months after the parent received the Part C EI contact details.

Some providers may argue that giving out contact details empowers families to take control of the referral process, but research suggests that faxing a referral form to Part C EI, instead of providing a phone number to parents is associated with higher completion rate for referrals (Jimenez 2014). Additionally, a qualitative study by Decker et al. (2021) involving 30 families found that the referral process was emotionally taxing and confusing for most families. Similarly, O'Neil et al. (2008) reported that families in their study felt they were fighting for the services and were burdened with communication between Part C EI and pediatric providers.

These outcomes underscore the significance of having a designated web-based referral method for pediatricians, without which there is often confusion among pediatricians regarding the necessary information to include in the referral and how to document it. Consequently, this lack of clarity impacts the efficiency of the intake and eligibility determination process and places an additional burden on families. Therefore, there is a pressing need to establish a statewide referral system for pediatricians which incorporates a tested web-based referral form endorsed by Part C EI personnel as well as pediatricians. These findings are consistent with the conclusions drawn in the previous study conducted by Jimenez et al., 2014, in which they suggested the urgent need for state-level initiatives utilizing information technology to streamline the EI referral process and improve coordination between pediatricians and Part C EI.

Parent consent. The participation of both Part C EI personnel and pediatricians in this study highlighted the significance of parent consent in the referral process and revealed gaps in the current system. This aspect has not received much attention in previous studies that primarily focused on Part C EI referral and enrollment.

Given that federal regulations **(**§303.321(b)) assign the responsibility to Part C EI personnel for obtaining medical information from pediatric healthcare providers during the initial evaluation process, the obligation to obtain parental consent in accordance with FERPA and IDEA Part C regulations extends to the Part C EI personnel not only to conduct evaluation but also to request and receive protected medical information. Although under HIPPA, pediatricians can seek parental consent to not only make the referral but provide protected information at the time of referral. However, most pediatricians in the study reported that they do not even have the system to seek written parental consent. Most often they seek verbal consent before referring the child and the family to Part C EI. Pediatricians also highlighted that accommodating parental consent in their workflow will burden them and it is convenient for them to receive the request from EI since the request includes the parental consent.

Moreover, the lack of systematic approach in obtaining parental consent poses hindrance to sharing the referral outcome between Part C EI and pediatricians, particularly when it has not been obtained by Part C EI personnel during the intake process. This confusion surrounding the responsibility for seeking parental consent undermines effective communication and collaboration between Part C EI agencies and pediatricians. Therefore, it is important to incorporate a consent statement in the referral form that complies with HIPAA and FERPA regulations, as recommended by study participants. This will help streamline the process of obtaining parental consent at the time of referral to evaluate, request, obtain medical information, and share the referral outcome.

Sharing Medical Information. Obtaining medical information during the referral process plays a crucial role in conducting the initial evaluation to determine a child’s eligibility for Part C EI services. This study revealed the prevailing practice, wherein Part C EI personnel commonly obtain parental consent before evaluation and proceed to fax a form outlining the required medical records to the pediatrician’s office. The pediatrician then responds by fax, although the response time varies, ranging from 2 to 10 days, and sometimes even longer. It is important to note that some pediatricians require multiple reminders before responding, while others may not respond at all.

Furthermore, Part C EI personnel reported that the process of requesting medical information varies when it comes to obtaining medical records from multiple hospitals and pediatric clinics. Each hospital and clinic have its own procedures, with some accepting the request form sent by Part C EI, some having their own designated request form, while others have established systems to share the necessary medical information at the time of referral, without needing a specific request. Pediatricians who share information without being prompted often have a good relationship with the local Part C EI agency. They are familiar with the appropriate contacts and secure channel to transmit reports, such as fax number, and understand the type of medical reports commonly required to determine eligibility and provide EI services.

Previous studies have also highlighted the complexity involved in sharing medical information between Part C EI agencies and pediatricians, mainly due to the lack of access to electronic health record systems by Part C EI agencies and having to request information from multiple hospitals and pediatric clinics (O’Neil et al., 2008; Little et al., 2015). However, this study revealed that a small number of Part C EI agencies reported having access to an EHR system in the hospital from which the majority of referrals are received. Another study conducted by Sanders et al. (2022) on information transmission and referral form corroborated these findings, highlighting that some agencies in their study had access to EHR system. These agencies emphasized the convenience and efficiency of information sharing, as they no longer needed to request information from pediatricians. Instead, they had a designated person with access to the EHR system, ensuring compliance with relevant laws and regulations concerning protected medical information. For hospitals and clinics not on the same EHR system, the agencies still followed their usual process to request the necessary information. This approach of gaining access to hospital EHR systems, where feasible, alongside the usual information request process for non-integrated hospitals and clinics, could be a potential strategy to streamline the sharing of medical information.

Lastly, a critical barrier that this study highlighted is the commonality in the requested type of medical records and procedural requirements that could aid streamlining the process of sharing medical information between pediatricians and Part C EI without the need for explicit request. Most agencies highlighted the necessity of obtaining the child’s discharge summary in case of hospitalization, all well-visit notes (not just the most recent one), and any other medical evaluation reports, such as hearing, vision, neurology, and developmental and behavioral evaluations. Pediatricians expressed that disseminating this information as part of training or guidelines would facilitate making these reports available at the time of referral, which is preferred by most Part C EI personnel.

Additionally, most Part C EI personnel identified a critical piece of information that pediatricians often overlook is ongoing medical evaluation. This is significant as it is possible for a child to be declined or enrolled in Part C EI program before the completion of the evaluations. Having this information would enable Part C EI personnel to evaluate, support the family, and monitor any additional evaluation needs for the child.

Evaluation. Most Part C EI participants in both states indicated that they follow a unified system of evaluation under which there is no differentiation between initial evaluation for eligibility determination and assessment. All children, including children with diagnosed medical conditions, usually undergo initial evaluations as well as eligibility assessment since this unified process generates vital information utilized for eligibility determination, eliciting the child and family’s needs for services, and establishing goals. However, in case of children with diagnosed medical conditions, parents are informed that the child is automatically eligible for services based on the medical condition and the purpose of evaluation is to understand their needs and child’s developmental baseline. Additionally, the interaction with the child and family at the initial evaluation provides unique opportunity to Part C EI evaluators to build rapport and establish a trust-based relationship with the family. Similar views were reported by respondents in a study by Stein and Steed (2023) in which they indicated that the family-completed questionnaires and family interviews were the most useful tools for determining EI eligibility, specifically for children with social emotional difficulties. Specifically, in Michigan another reason for having a unified evaluation system is that the information acquired at the initial evaluation is required to conduct the MMSE evaluation to determine eligibility for the special educational services for children demonstrating significant delay. Although all participants agreed that in practice having a dual eligibility system in Michigan complicated the process for families and providers and needs to transition to a Part C EI only system.

Moreover, in both states, participants reported that unified multidisciplinary evaluation ensures that services are not denied to any child showing signs of delay, specifically, if parent is concerned. The presence of parent concern is a decisive factor to make the child eligible for services under informed clinical opinion even if child does not meet the eligibility under diagnosed medical conditions or developmental delay. Similar results were obtained by Solgi et al. (2022) who found that the presence of parent concern was strongly associated with EI service evaluation and eligibility outcomes.

Moreover, participants noted that even though informed clinical opinion incorporates multiple procedures, multiple sources of information, and detailed documentation in informed clinical opinion (Lucas and Shaw, 2012), the time required for this process is similar to determining eligibility based on developmental delay or diagnosed medical conditions. EI participants stated that using informed clinical opinion does not involve any additional procedural steps. However, determining eligibility based on diagnosed medical conditions that is included in the state-approved list and supported by appropriate medical reports is considered the most efficient and streamlined approach.

Nonetheless, a study conducted by Javalkar and Litt (2017) found that the reason for referral has an impact on EI service enrollment and use. Children who participated in EI based on their diagnosed medical conditions were less likely to have unmet service needs and were less likely to drop out of EI programs compared to children with developmental delay or other risk factors.

Furthermore, children identified as being at high risk during developmental screening are recommended to undergo both EI referral and medical diagnostic evaluation to determine underlying causes (AAP, 2006). While pediatricians indicated that they consider obtaining a medical diagnosis a priority, the decision to refer for medical evaluation depends on factors such as the child's age, medical complexity, and the severity of the delay. They also highlighted several significant challenges in obtaining medical diagnostic evaluations, including long waiting times, location, insurance coverage, healthcare setting, and parental stigma.

A study conducted by Monteiro et al. (2016) found that children who experienced prolong waiting time for autism evaluations were already receiving EI services based on their developmental delays, however, only 6% of these were receiving intervention specific to autism prior to receiving the autism diagnosis. Part C EI participants reported that though most children who are referred to EI with confirmed diagnosis are typically younger than 12 months, it is not uncommon for children with underlying medical conditions to go unnoticed. Therefore, they emphasized the importance of being aware of the medical diagnostic evaluations already conducted or ongoing. If any gaps are identified, Part C EI personnel can inform the parents and pediatricians to initiate a medical diagnostic evaluation. Knowing the diagnosis is valuable not only for determining eligibility but also for targeting the specific needs of the child and family.

Communication and collaboration. The study reveals that the challenges in linking children with developmental delays and diagnosed medical conditions, as well as the knowledge gap among providers, primarily stem from the lack of consistent communication and collaboration between Part C EI agencies and pediatricians. Part C EI personnel often engage with pediatric offices to distribute referral information and raise awareness about EI services. However, the absence of state-level initiatives and guidelines for networking with pediatricians' offices hinders the effectiveness of these outreach efforts, mainly due to unresponsiveness from pediatricians and time burden on Part C EI personnel.

These findings align with previous studies conducted by Spiker et al. (2000), Rosenberg et al. (2008), O'Neil et al. (2008), Little et al. (2015), and Lipkin et al. (2021), which have highlighted these issues over the past two decades. These studies also emphasize the need for electronic referral systems such as web-based referral form, integrated EHR systems, patient navigators, tracking systems, and partnerships. However, participants in this study identified three main challenges in addressing these gaps: lack of time among providers, limited resources (especially financial), and uncertainty regarding who will initiate macro-level changes. Consequently, both Part C EI personnel and pediatricians have suggested short-term actions as initial steps toward achieving long-term goals, such as making changes in the referral form including adding HIPPA and FERPA compliant consent statement, link to the state-approved list, designated fax number for secure transmission of medical reports and a list of five most requested medical reports.

Facilitators and Barriers

The study identified three factors that facilitate the referral process for children with diagnosed medical conditions. One facilitator is provision of medical reports without being requested, particularly from NICUs and local pediatricians who have established strong working relationships with Part C EI agencies. This demonstrates that if pediatricians have a secure channel to share medical information, a streamlined consent process, and clarity on which agency the children will be referred to, multiple steps in the referral process can be eliminated. However, the availability of medical reports during the referral process without being requested has not been extensively discussed in the existing literature, although all Part C EI participants in the study agreed that it will be a game-changer.

Another facilitator is direct access to an EHR system. The integrated EHR system for Part C EI has received strong endorsement not only from the study participants but also from previous research conducted by Little et al. (2015) and Lipkin et al. (2021). The third facilitator, which has also received limited attention in previous studies, is the implementation of a unified initial evaluation and assessment process for all children, including those who are automatically eligible for EI services based on their medical conditions. According to Part C EI personnel, this approach provides a more streamlined way to determine eligibility, elicit needs, and establish the IFSP. It also prevents children from being denied EI services if their delay is not confirmed by standardized tools or if they are not diagnosed with qualifying medical conditions. However, this factor also highlights a gap in understanding the policy that allows omitting the initial evaluation for children with diagnosed medical conditions. It raises questions about the practical implications of skipping the initial evaluation since it generates crucial information not only for determining eligibility but also for planning services.

Similarly, the study identified five barriers that hinder the referral process. These include inconsistent efforts to obtain parental consent, absence of designated web-based referral form for pediatricians, lack of a consistent and secure channel for sharing medical information, absence of an established communication system between Part C EI and pediatricians, and long waiting time for medical evaluations. While the first three barriers have received limited attention in previous studies, lack of communication (O'Neil et al., 2008; Little et al., 2015; Lipkin et al., 2020) and long waiting times for medical evaluation (Monteiro et al., 2016 have been extensively discussed in previous studies.

Recommendations and Opportunities for Change

The study participants put forth various short-term and long-term recommendations regarding the state-approved list, referral systems, and training for Part C EI personnel and pediatricians. The proposed suggestions related to the state-approved list have received limited attention in existing literature. They encompassed adding a bold disclaimer that the list is not exhaustive, adding a link to the list in the referral form, incorporating ICD 10 codes and other aliases for medical conditions and providing links or pop-ups with definitions of the conditions and organizations offering support to parents for specific medical conditions. Moreover, it was proposed to distribute the list to pediatricians and other early childhood providers, and in the long term, establishing a nationwide database of qualifying medical conditions would further streamline the referral and eligibility determination process.

In terms of the referral system, there are suggested short-term recommendations that aim to create a standardized referral system for pediatricians throughout the state. One suggestion is to develop a web-based referral form that all agencies can use instead of each agency developing its own referral form. It is vital to incorporate details related to the state-approved list, commonly requested medical reports, and a consent statement into the referral form.

Additionally, it is proposed to establish a centralized fax number at the county or state level, specifically for pediatricians to transmit medical information during the referral process. This centralized system would eliminate several steps in information gathering during the initial evaluation process. Furthermore, as a long-term recommendation, the study suggests developing an integrated EHR system. This system would address the communication gap and facilitate the seamless transmission of protected medical information between Part C EI and pediatricians.

Lastly, the participants recommend the implementation of a web-based training program for both pediatricians and Part C EI personnel. The training should cover various aspects of referral and eligibility determination, with a specific section dedicated to the state and local systems. It is suggested that the training for pediatricians should offer education credits to incentivize participation and should be made available both during their residency and throughout professional practice. Furthermore, pediatricians expressed the importance of local contacts and indicated that short virtual sessions held a few times per year for all pediatricians in the local area would provide valuable opportunities for networking and learning. It is worth noting that access to EHR systems and training for pediatricians have been mentioned in previous research studies (Lipkin et al., 2020) as important components for improvement.

In summary, the recommendations put forth in the study aim to enhance the referral system, improve communication, and provide necessary training to ensure a more efficient process of referring children with diagnosed medical conditions to early intervention services. However, it is not enough to merely acknowledge the gaps. Instead, it is crucial for researchers, policy makers, and state leaders to work towards bridging these gaps actively and purposefully by establishing comprehensive systems that are informed by evidence. This requires a shift away from current isolated approaches and the establishment of research-practice partnerships involving state Part C EI program, professional healthcare organizations such as the state chapter of AAP, and researchers. Through these partnerships, evidenced-informed systems and processes can be developed that are systematically and objectively tested and involve all stakeholders.

To summarize, Table 11 presents a brief overview of the significant findings from the current study, as well as relevant findings from previous studies that have examined similar areas.

Table 11

Summary of the significant findings from the current study.

Research Question	Major Findings	Previous Studies
RQ1, RQ1A, and RQ1B	Pediatricians demonstrated a significantly lower level of knowledge of the state-approved list as well as of the associated policies and practices.	Scot et al. (1993) and Edward (2018) indicated lack of knowledge of EI provisions among pediatricians.
	Participants who received training during their academic programs, residency, or through on-the-job experience exhibited significantly higher level of knowledge of the state-approved list as well as of the associated policies and practices.	Edwards (2018) revealed that pediatric residency training directors reported that EI was covered briefly during their residency programs.
RQ2 and RQ2A	Significant variation in the implementation of referral practices among Part C EI personnel and pediatricians, indicating lack of common understanding of the process.	Lack of research in this area.

Table 11 *(continued)*

Research Question	Major Findings	Previous Studies
	Developmental Screening:	
	Most pediatricians conduct developmental screening at recommended ages.	Scot et al. (1993) reported similar findings.
	Pediatricians apply the wait-and-watch approach for varied reasons.	Jimenez et al. (2012) and Jimenez et al. (2014) reported similar findings.
	Lack of developmental screening tools for non-English and non-Spanish speaking families.	Hirai et al. (2018) reported similar findings.
	Referral Practices:	
	Variability in the quantity and type of information received due to lack of universal referral form for pediatricians.	Sanders et al.(2022) reported similar findings.
	Lack of uniform system to seek parental consent to request, obtain, or release protected information and share referral outcome.	Lack of research in this area.
	Lack of streamlined system to share medical information between pediatricians and Part C EI agencies.	O'Neil et al. (2008) and Little et al. (2015) highlighted the complexity in sharing of medical information.
	Evaluation:	
	All children undergo an initial evaluation and assessment, which helps determine eligibility, baseline, elicit service needs, and if necessary, conduct an informed clinical opinion. Parental concern is a decisive factor in EI enrollment.	Solgi et al. (2022) found that parental concern was strongly associated with Part C EI enrollment.
	Inconsistent practice among pediatricians to refer children for diagnostic medical evaluation.	
	Long waiting time for medical evaluation impacts Part C EI service receipt.	Monteiro et al. (2016) indicated similar findings for children with autism.

Table 11 *(continued)*

Research Question	Major Findings	Previous Studies
	Communication and collaboration: Lack of consistent communication and collaboration between Part C EI agencies and pediatricians impact referral and sharing of pertinent medical information between pediatricians and Part C EI agencies.	Spiker et al. (2000), Rosenberg et al. (2008), Neil et al. (2008), Little et al. (2015), and Lipkin et al. (2021) reported similar findings.
RQ3	Recommendations:	
	State-approved list: Adding a bold disclaimer that the list is not exhaustive, adding a link to the list in the referral form, incorporating ICD 10 codes and other aliases for medical conditions and providing links or pop-ups with definitions of the conditions and organizations offering support to parents for specific medical conditions.	Lack of research in this area.
	State-wide universal web-based referral form for pediatricians. Incorporate details related to the state-approved list, commonly requested medical reports, a consent statement into the referral form, and a centralized fax number to transmit medical information without being prompted.	Lack of research in this area.
	Integrated EHR system.	Lipkin et al. (2015) and Sanders et al. (2022) indicated similar findings.
	Training for Part C I personnel and pediatricians during professional practice as well as residency	Lack of research in this area.

Limitations

The study has some limitations to consider, such as its limited generalizability as it only studied two states and possible sampling bias due to purposive and snowballing methods. Due to the nature of the purposive and snowballing sampling, it was not feasible to calculate a traditional response rate. Because of this omission, a representativeness of the sample could not be measured and reported, and consequently, the generalizability of the findings. The absence of a response rate also restricts assessment of the potential nonresponse bias, which is an important indicator of the quality of the data as well as the engagement level of participants in the study. However, it is important to note that while these sampling limitations do exist, the sampling strategies in the study were selected to ensure that specific and relevant population were effectively reached to gather data.

The survey questionnaire and interview guide were created based on the literature, peer-reviewed articles, policy documents, and expertise, but this may result in a narrow perspective on the referral and eligibility evaluation system as there may be pertinent questions not assessed. Lastly, the study also did not investigate the perspectives of families who use the referral and eligibility evaluation system, potentially missing important experiences and views.

Despite these limitations, the study provides valuable insights into the Part C EI referral and eligibility evaluation systems in two states, provides tangible recommendations for policymakers, state leaders and practitioners, and highlights areas for future research. The survey questionnaire and interview guide were developed using a thorough review of literature, articles and policy documents, which ensures that the study provides a comprehensive understanding of the system.

Implications

This study carries significant implications for policy, practice, and research within the field. The findings underscore that a diagnosed medical condition does not automatically guarantee the receipt of services. Rather, systemic barriers exist that involve diagnostic evaluation and the sharing of medical reports. The study sheds light on gaps in current practices related to referral and eligibility determination, particularly concerning children with diagnosed medical conditions. These insights hold relevance for state leaders, policymakers, and practitioners. While some of these gaps, such as the lack of knowledge among pediatricians and the absence of a communication system between Part C EI agencies and pediatricians, have been recognized in existing literature, this study brings attention to additional specific gaps that have received limited discussion in the literature. These include the knowledge and utilization of state-approved eligibility lists, the impact of inconsistencies in obtaining parental consent, barriers in obtaining medical information, and lack of training among pediatricians and Part C EI personnel. By addressing these gaps and implementing recommended practices, state leaders, Part C EI personnel and pediatricians can enhance existing systems. Short-term changes, such as establishing a referral form for pediatricians and disseminating the state-approved list of diagnosed medical conditions, can contribute to a more efficient process of gathering information during the referral stage.

The study also highlights a gap in the interpretation and implementation of policies related to initial evaluation, which necessitates attention from policymakers and state leaders. Currently, both Michigan and Washington require all children to undergo initial evaluation and assessment. Further research is needed to examine the practical usefulness of omitting the initial evaluation for children with diagnosed medical conditions, as it provides vital information about the child and their family. Additionally, the study underscores the need for more research to address the gaps that have been identified. For instance, state Part C EI programs or agencies currently develop their own state-approved list of diagnosed medical conditions or referral forms without clear guidelines and lack the necessary skills and resources to test these new tools or systems before widespread implementation. This study emphasizes the importance of establishing research-practice partnerships (Coburn et al., 2021) involving state Part C EI programs, pediatricians, and researchers to develop evidence-informed systems that work for all stakeholders. The initial steps towards this goal involve implementing the recommended changes to the referral form and state-approved list of diagnosed medical conditions, as well as creating online training on referral and eligibility for pediatricians and Part C EI personnel and assessing their feasibility and acceptability.

Furthermore, conducting a study with families of children with diagnosed medical conditions to examine their experiences during the transition from the pediatrician's office to Part C EI, and gathering insights on the support and information they desire at the point of care, is necessary. Lastly, the findings also highlight the need to examine new ways to provide language support to non-English and non-Spanish speaking families during developmental screenings.

Conclusion

In conclusion, this study highlights the existing gaps in knowledge and practices among pediatricians regarding the state-approved list of diagnosed medical conditions and referral procedures for children with diagnosed medical conditions. The current system lacks efficient two-way communication, streamlined parental consent, effective transmission of medical information, and training or guidelines on effective referral practices for pediatricians and Part C EI personnel. To address these issues, it is crucial to establish research-practice partnerships involving Part C EI state programs, pediatricians, and researchers. These partnerships can develop evidence-informed systems that benefit all stakeholders.

Future research should focus on the implementation and impact of omitting initial evaluations for children with diagnosed medical conditions, as well as investigate the support and information desired by families during the transition from pediatric offices to Part C EI programs. Moreover, it is imperative to develop a training program specifically targeting referral and eligibility determination for pediatricians and Part C EI personnel. It is important to evaluate the feasibility and acceptability of this training program prior to broader implementation.

Several short-term measures can be taken to address the identified issues, including revising and disseminating the state-approved list of diagnosed medical conditions; creating a statewide referral form that includes essential details such as parental consent statement, reference to state-approved list and commonly requested medical reports; and establishing a centralized fax number for secure transmission of medical reports during the referral. Lastly, considering the shift towards obtaining medical information for all referrals in Part C EI agencies, it is recommended by study participants and prior studies to establish an integrated EHR system as a long-term solution to seamless transmission of medical reports and improved communication and collaboration between Part C EI agencies and pediatricians.

Overall, this study will contribute to the existing literature by highlighting overlooked gaps in referral practices and eligibility determination for children with diagnosed medical conditions and proposing recommendations for practitioners, state-leaders, and policy makers to address the identified gaps. Through timely and coordinated early identification and referral systems for children with diagnosed medical conditions, outcomes for children and their families will be significantly improved.

APPENDIX A

COGNITIVE INTERVIEW PARTICIPANTS

Table 1

Cognitive Interview Participant Demographic Information

Participant	Profession[a]	Age	Sex[b]	Race	Job Status[c]	Community type	Years of service
P1	PCP	36-45	F	White	FT	Urban	12
P2	PCP	56-65	F	Asian	PT	Urban	27
P3	PCP	>65	M	White	FT	Urban	45
P4	PCP	>65	F	White	FT	Rural	40
P5	PCP	46-55	F	White	FT	Suburban	17
P6	Part C EI	46-55	F	White	FT	Rural	17
P7	Part C EI	56-65	F	White	FT	Rural	15
P8	Part C EI	<35	F	White	FT	Urban	9
P9	Part C EI	56-65	F	White	FT	Suburban	29
P10	Part C EI	>65	F	White	FT	Rural	41

[a] PCP = Primary Care Provider, Part C EI = Part C Early Intervention Personnel
[b] F = Female, M = Male
[c] FT = Full Time, PT = Part Time

APPENDIX B

COGNITIVE INTERVIEW GUIDE

Domains	Questions
Instructions/ Directions	What recommendations do you have to improve the clarity and ease of understanding in the instructions? You took a while to respond. Is the instruction explicit in this question? Are these instructions easy to understand and follow? Did you miss the last line of the instruction?
Items	In your own words, please describe what this question is asking? Was this question/statement easy to understand? Are there any particular words that are unclear or challenging to understand? Are these recommendation statements clear and easy to understand? Is there any additional information you would like to include in the recommendation statements? What modifications do you propose to make this question clearer? Do you recommend rephrasing this statement? What other developmental screening tools do you use that can be added as an example? Do you advise including any other statement that we have missed?
Response choices	What are your thoughts on the response choices provided? Are the response choices suitable for the question? Do these options offer a range of choices to answer? How did you determine which response option to select? Would it be more convenient to explain your response in a follow-up question where you can freely type? What is your opinion on the inclusion of the ‘Not applicable’ option in this question?
Overall	Have we overlooked asking any essential questions, or is there anything else you would like to add? What are your overall thoughts or opinions on the questionnaire? What is your perspective on the amount of time taken to complete this survey questionnaire?

APPENDIX C

SURVEY QUESTIONNAIRE FOR PART C EI PERSONNEL

Please return the completed survey in the **enclosed postage-paid envelope**	I consent to participate (check the box) ☐

A. REFERRAL AND EVALUATION

A1. When you receive an initial referral for a child with developmental concerns, how often do you

	Never	Rarely (1-24%)	Sometimes (55-74%)	Often (55-74%)	Almost always (74-100%)	Not applicable
a) first inquire or try to find out if the child has a diagnosed medical condition that has a probability of developmental delay?	☐	☐	☐	☐	☐	☐
b) receive the developmental screening or evaluation **scores** from the child's pediatrician? (E.g., ASQ or PEDS scores are written on the referral form or receive a screening form via fax, email, etc.)	☐	☐	☐	☐	☐	☐
c) receive information about the **reason for a referral** from the child's pediatrician? (E.g., 'developmental delay' is documented on the referral form.)	☐	☐	☐	☐	☐	☐
d) receive information about the **child's underlying medical condition,** if identified, as the **reason for a referral** from the child's pediatrician? (E.g., the 'actual medical condition' documented on the referral form)?	☐	☐	☐	☐	☐	☐
e) receive relevant **medical documentation,** fully completed by the child's pediatrician so that child can be **enrolled directly** without needing to go through the eligibility determination process? (E.g., medical reports and a referral form received via fax, email, etc.)	☐	☐	☐	☐	☐	☐
f)Request a **physician statement** from the child's pediatrician? (E.g., ask the child's pediatrician to document the diagnosed medical conditions on a form and sign it.)	☐	☐	☐	☐	☐	☐
g)inform the child's pediatrician about the referral outcome with parents' consent? (E.g., a child is enrolled or declined Part C EI services.)	☐	☐	☐	☐	☐	☐
h)**inform parents** at the time of intake	☐	☐	☐	☐	☐	☐

A2. If you have selected any statement 'Not applicable' in the above question (A1), please describe the reason briefly.

A3. Overall, how do you feel about the current Part C EI initial referral system for children with diagnosed medical conditions that have a high probability of developmental delay or disability?

☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ Don't know

A4. Do you have any **additional comments** or concerns about the current Part C Early Intervention (EI) **initial referral systems/processes** for children with diagnosed medical conditions?

A5. Is there a formal process in place to ensure that pediatric primary care providers and the Part C EI agency/ies in your county can communicate effectively and efficiently with each other (e.g., to exchange information, discuss a case, or for staff training)?

☐ Yes ☐ No ☐ I don't know

B. KNOWLEDGE

B1. These statements are related to **policies and practices** in Part C EI eligibility determination for children with diagnosed medical conditions. Please indicate if you **agree or disagree** with the following statements.

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree	Not applic able
a)I know of the eligibility criteria that a child must meet in order to receive early intervention services from the Part C EI agency in my county.	☐	☐	☐	☐	☐	☐
b) receive the developmental screening or evaluation **scores** from the child's pediatrician? (E.g., ASQ or PEDS scores are written on the referral form or receive a screening form via fax, email, etc.)	☐	☐	☐	☐	☐	☐
c)I know that the time between receipt of the referral and Part C EI enrollment (writing the IFSP) **cannot exceed 45 days** unless the parent has not provided consent to evaluation within that time period.	☐	☐	☐	☐	☐	☐
d)I know that the children with diagnosed medical conditions that have a high probability of disability get **automatic access** to Part C EI services without needing to go through the eligibility determination process. (E.g., **initial evaluations** are not required to decide whether the child is **eligible for Part C EI services or not).**	☐	☐	☐	☐	☐	☐
e)I know that children with diagnosed medical conditions when referred to the Part C EI program should have their medical condition **documented** (e.g., in the child's medical record or on the referral form) for them to get **automatic access** to Part C EI services without needing to go through the eligibility determination process.	☐	☐	☐	☐	☐	☐

B2. If you have selected any statement 'Not applicable' in the above question (B1), please describe the reason briefly.						
B3. These statements are related to the **Michigan state-approved list of diagnosed medical conditions** that have a high probability of disability in children. Please indicate if you agree or disagree with the following statements.						
	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree	Not applic able
a)I know of the (STATE) **state-approved list of diagnosed medical conditions** that have a high probability of disability in children.	☐	☐	☐	☐	☐	☐
b)I know of the **mental and physical conditions** included in the (STATE) state-approved list of diagnosed medical conditions.	☐	☐	☐	☐	☐	☐
c)I know **where to access** the(STATE) state-approved list of diagnosed medical conditions.	☐	☐	☐	☐	☐	☐
d)I know that there are medical conditions that may qualify for Part C EI services and **are not on the (STATE) state-approved list of diagnosed medical conditions.**	☐	☐	☐	☐	☐	☐
e)I know of the **mental and physical conditions** included in the **federal guidelines** that made infants and toddlers automatically eligible for Part C EI services.	☐	☐	☐	☐	☐	☐
B4. If you have selected any statement 'Not applicable' in the above question (B3), please describe the reason briefly.						
B5. Have you completed any **formal training or workshop** on Part C EI eligibility determination for children with diagnosed medical conditions including a state-approved list of diagnosed medical conditions? If yes, when?						

☐ During residency	☐ During residency	☐ Never had any such training

C. IMPLEMENTATION

C1. When you **do not know** if the child's medical condition is a qualifying condition for the Part C EI services, how often do you use the following sources of information?					
	Never	Rarely (1-24%)	Sometimes (55-74%)	Often (55-74%)	Almost always (74-100%)
I refer to the (STATE) state-approved list of diagnosed medical conditions.	☐	☐	☐	☐	☐
I (or my staff) perform an online search.	☐	☐	☐	☐	☐
I ask my colleagues.	☐	☐	☐	☐	☐
I ask the child's pediatrician.	☐	☐	☐	☐	☐
I ask parents' to get more information about the child's medical conditon.	☐	☐	☐	☐	☐

D. RECOMMENDATIONS AND SUGGESTIONS

A **comprehensive and detailed** list of diagnosed medical conditions is needed.	☐
The list should be written in **simple language** in order to make it easily understandable for a **non-medical person.**	☐
The list should be included in the relevant documents such as in the **referral form, and Part C EI initial evaluation packet.**	☐
Information about the list and related policies and practices should be **included in relevant training and workshops.**	☐
Common medical conditions that automatically qualify for the Part C EI services **should be part of the public awareness programs and publicity materials** such as posters and flyers.	☐
Training should be made available to **Part C EI personnel** on topics including the state eligibility criteria, related policies, and the eligibility determination process for developmental delays and diagnosed medical conditions.	☐
Training should be made available to **pediatricians** on topics including the state eligibility criteria, related policies, and the eligibility determination process for developmental delays and diagnosed medical conditions.	☐
The list should be made available **to pediatricians (General and Developmental)** so that they can show it to families and share that their child automatically qualifies for the Part C EI services if the child's medical condition is identified at the time of referral.	☐
A **county-wide communication system** should be established to update pediatricians on any changes in the Part C EI service such as eligibility criteria, and the state-approved list of diagnosed medical conditions.	☐
The current state-approved list contains **adequate information**. No change is needed.	☐

D2. What other suggestions do you have to improve the current Part C EI referral system and/or the state-approved list of diagnosed medical conditions in Michigan?

GIFT CARD
Any personal information provided in this section will be **destroyed** after the gift card distribution.

Please give your name and email or phone number to add you to a **$20 Amazon gift card** draw.

Name:	Email:	Phone:

Additionally, we invite you to participate in a **short follow-up interview**. If you are willing to participate, please provide your name and phone number or email for us to contact you. Interview participants receive an **additional $20 Amazon gift card.**

Name:	Email:	Phone:

E. **ABOUT YOU**

E1. What gender do you identify as?	E2. What is your age?
☐ Male ☐ Female ☐ Non-binary/Third gender ☐ Prefer not to say	☐ Below 35 ☐ 36 to 45 years ☐ 46 to 55 years ☐ 56 to 65 years ☐ Above 65

E3. What is your race or ethnicity?

☐ White or European ☐ Black or African American ☐ Asian or Asian American ☐ Middle Eastern or North

☐ LatinX or Hispanic or ChicanX or Puerto Rican ☐ Native Hawaiian or Pacific ☐ Multiple

☐ American Indian or Alaska Native ☐ I prefer not to say ☐ Other

E4. Do you work full-time or part-time?

☐ Full-time (30 hours or more) ☐ Part-time (Less than 30 hrs)

E5. What is your professional role in the Part C EI eligibility evaluation team?

☐ EI/ECSE specialist ☐ Occupational therapist ☐ Physical therapist

☐ Speech and language pathologist ☐ Psychologist

E6. Which of this best describes the type of area you work in?	E7. Which county(ies) do you work in?
☐ Urban ☐ Suburban ☐ Rural	
E8. How many years of service have you done as a Part C EI evaluator/intake team in STATE?	E9. How long have you been practicing in the field as a/an OT/PT/SLP/EI/ECSE specialist in the United States?

Thanks for participating in the study. I'll reach out to schedule the interview if you provided your contact information. Asha!

APPENDIX D

SURVEY QUESTIONNAIRE FOR PEDIATRICIANS

Please return the completed survey in the **enclosed postage-paid envelope**	I consent to participate (check the box) ☐

A. REFERRAL AND EVALUATION

A1. Do you screen children, using general standardized developmental screening tools such as ASQ or PEDS at recommended ages (e.g., 9-, 18-, 24-, or 30-month well visit) to identify any developmental concern that my require further evaluation> (ASQ: Ages and Stages Questionnaire; PEDS: Parents' Evaluation of Developmental Status).

☐ Yes frequently ☐ Yes occasionally ☐ No

A2. If you suspect that a child with a developmental screening may have an underlying medical condition such as Autism or Fragile X syndrome, what is the first action you most often take? <u>SELECT ONE</u>

Refer the child to Part C Early Intervention (EI) agency, and for diagnostic medical evaluation **at the same time.**	☐
Refer the child to Part C EI agency only, and **not for diagnostic medical evaluation**	☐
Refer the child for **diagnostic medical evaluation only** and **not to the Part C EI agency**.	☐
Refer the child to the Part C EI agency, and for diagnostic medical evaluation at the **same time**. Also, inform the Part C EI agency of the child's medical condition later when available.	☐
Refer the child first for diagnostic medical evaluation and **wait for the findings**. Then refer the child to a Part C EI agency with a diagnosed medical condition **documented as a reason for referral.**	☐
Varies on a case-by-case basis.	☐

A3. When you refer a child with developmental concerns to a Part C Early Intervention (EI) agency, how often do you:

	Never	Rarely (1-24%)	Sometimes (55-74%)	Often (55-74%)	Almost always (74-100%)	Not applicable
provide developmental screening or evaluation **scores** to the Part C EI team with the parent's consent? (E.g., write ASQ or PEDS scores on the referral form or send the screening form via fax, email.)	☐	☐	☐	☐	☐	☐
provide the **reason for referral** to the Part C EI team with the parent's consent? (E.g., write 'developmental delay' on the referral form.)	☐	☐	☐	☐	☐	☐
provide the child's **underlying medical condition**, if identified, as the **reason for referral** to the Part C EI team with the parent's consent? (E.g., write the 'actual medical condition' on the referral form.)	☐	☐	☐	☐	☐	☐
provide relevant **medical documentation** of the child's diagnosed medical condition to the Part C EI team with the parent's consent? (E.g., send medical documents and a referral form via fax, email, etc.)	☐	☐	☐	☐	☐	☐

receive a request for a **physician statement** from the Part C EI team? (E.g., Part C EI team asks you to write the child’s diagnosed medical condition on a form and sign it.)	☐	☐	☐	☐	☐	☐
receive information from the Part C EI team about the **referral outcome**? (E.g., the referred child is enrolled or declined Part C EI services.)	☐	☐	☐	☐	☐	☐
inform parents, during the referral, that their child will get **automatic access** to Part C EI services if the child’s medical condition is identified and has a high probability of disability?	☐	☐	☐	☐	☐	☐

A4. If you have selected any statement ‘Not applicable’ in the above question (A3), please describe the reason briefly.

A5. Overall, how do you feel about the current Part C EI initial referral system for children with diagnosed medical conditions that have a high probability of developmental delay or disability?

☐ Excellent ☐ Very good ☐ Poor ☐ I don’t know

A6. Is there a formal process in place to ensure that pediatric primary care providers and the Part C EI agency(ies) in your county can communicate effectively and efficiently with each other (e.g., to exchange information, discuss a case, or for staff training)?

☐ Yes ☐ No I don’t know

A7. Do you have any **additional comments** or concerns about the current Part C Early Intervention (EI) **initial referral systems/processes** for children with diagnosed medical conditions?

B. KNOWLEDGE

B1. These statements are related to **policies and practices** in Part C EI eligibility determination for children with diagnosed medical conditions. Please indicate if you **agree or disagree** with the following statements.

	Strongly agree	Some what agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree	Not applic able
I know of the eligibility criteria that a child must meet in order to receive early intervention services from the Part C EI agency in my county.	☐	☐	☐	☐	☐	☐
I know of the Part C EI **referral system or mechanism to make referrals** to a Part C EI agency in my county.	☐	☐	☐	☐	☐	☐
I know that the time between receipt of the referral and Part C EI enrollment (writing the IFSP) **cannot exceed 45 days** unless the parent has not provided consent to evaluation within that time.	☐	☐	☐	☐	☐	☐
I know that the children with diagnosed medical conditions that have a high probability of disability get **automatic access** to Part C EI services without needing to go through the eligibility determination process. (E.g., **initial evaluations** are not required to decide whether the child is **eligible for Part C EI services or not).**	☐	☐	☐	☐	☐	☐

I know that children with diagnosed medical conditions when referred to the Part C EI program should have their medical condition **documented** (e.g., in the child's medical record or on the referral form) for them to get **automatic access** to Part C EI services without needing to go through the eligibility determination process.	☐	☐	☐	☐	☐	☐

B2. If you have selected any statement 'Not applicable' in the above question (B1), please describe the reason briefly.

B3. These statements are related to the **Michigan state-approved list of diagnosed medical conditions** that have a high probability of disability in children. Please indicate if you agree or disagree with the following statements.

	Strongly agree	Some what agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree	Not appli cable
I know of the Michigan **state-approved list of diagnosed medical conditions** that have a high probability of disability in children.	☐	☐	☐	☐	☐	☐
I know of the **mental and physical conditions** included in the Michigan state-approved list of diagnosed medical conditions.	☐	☐	☐	☐	☐	☐
I know **where to access** the Michigan state-approved list of diagnosed medical conditions.	☐	☐	☐	☐	☐	☐
I know that there are medical conditions that may qualify for Part C EI services and **are not on the Michigan state-approved list of diagnosed medical conditions.**	☐	☐	☐	☐	☐	☐
I know of the **mental and physical conditions** included in the **federal guidelines** that made infants and toddlers automatically eligible for Part C EI services.	☐	☐	☐	☐	☐	☐

B4. If you have selected any statement 'Not applicable' in the above question (B3), please describe the reason briefly.

B5. Have you completed any **formal training or workshop** on Part C EI eligibility determination for children with diagnosed medical conditions including a state-approved list of diagnosed medical conditions? If yes, when?

☐ During residency ☐ Had training at work. ☐ Never had any such training.

C. IMPLEMENTATION

C1. When you **do not know** if the child's medical condition is a qualifying condition for the Part C EI services, how often do you use the following sources of information?

	Never	Rarely (1-24%)	Sometimes (55-74%)	Often (55-74%)	Almost always (74-100%)	Not applicable
I refer to the Michigan state-approved list of diagnosed medical conditions.	☐	☐	☐	☐	☐	☐
I (or my staff) perform an online search.	☐	☐	☐	☐	☐	☐
I ask my colleagues.	☐	☐	☐	☐	☐	☐
I ask the local Part C EI agency.	☐	☐	☐	☐	☐	☐
I refer the child to and let the Part C EI agency decide the child's eligibility for EI services.	☐	☐	☐	☐	☐	☐

I refer the child to Part C EI and document the diagnosed medical condition (e.g. on the referral form), and let the Part C EI agency decide the child’s eligibility for EI services.	☐	☐	☐	☐	☐	☐

D. RECOMMENDATIONS AND SUGGESTIONS

D1. What changes would you like to recommend improving the referral and Part C EI eligibility determination process for children with diagnosed medical conditions so that eligible children receive the Part C EI services promptly. **MARK ALL THAT APPLIES.**	
A **comprehensive and detailed** list of diagnosed medical conditions is needed.	☐
The list should be written in **simple language** in order to make it easily understandable for a **non-medical person.**	☐
The list should be included in the relevant documents such as in the **referral form, and Part C EI initial evaluation packet.**	☐
Information about the list and related policies and practices should be **included in relevant training and workshops.**	☐
Common medical conditions that automatically qualify for the Part C EI services **should be part of the public awareness programs and publicity materials** such as posters and flyers.	☐
Training should be made available to **Part C EI personnel** on topics including the state eligibility criteria, related policies, and the eligibility determination process for developmental delays and diagnosed medical conditions.	☐
Training should be made available to **pediatricians** on topics including the state eligibility criteria, related policies, and the eligibility determination process for developmental delays and diagnosed medical conditions.	☐
The list should be made available **to pediatricians (General and Developmental)** so that they can show it to families share that their child automatically qualifies for the Part C EI services if the child’s medical condition is identified at the time of referral.	☐
A **county-wide communication system** should be established to update pediatricians on any changes in the Part C EI services such as eligibility criteria, and the state-approved list of diagnosed medical conditions.	☐
The current state-approved list contains **adequate information**. No change is needed.	☐

D2. What other suggestions do you have to improve the current Part C EI referral system and/or the state-approved list of diagnosed medical conditions in Michigan?

GIFT CARD
Any personal information provided in this section will be **destroyed** after the gift card distribution.

Please give your name and email or phone number to add you to a **$30 Amazon gift card** draw.

Name:	Email:	Phone:

Additionally, we invite you to participate in a **short follow-up interview**. If you are willing to participate, please provide your name and phone number or email for us to contact you. Interview participants receive an **additional $20 Amazon gift card.**

Name:	Email:	Phone:

E. ABOUT YOU

E1. What gender do you identify as?	**E2.** What is your age?
☐ Male ☐ Female ☐ Non-binary/third gender ☐ I prefer not to say	☐ Below 35 ☐ 36 to 45 ☐ 46 to 55 years ☐ 56 to 65 years ☐ Above 65 years

E3. What is your race or ethnicity?	
☐ White or European ☐ Black or African American ☐ Asian or Asian American ☐ American Indian or Alaska Native ☐ Native Hawaiian or Pacific ☐ Multiple race/ethnicities ☐ LatinX or Hispanic or ChicanX or Puerto Rican ☐ Middle Eastern or North African ☐ I prefer not to say ☐ Other	
E4. Are you a primary care provider?	E5. Do you work full-time or part-time?
☐ Yes ☐ No	☐ Full-time (30 hrs or more) ☐ Part-time (less than 30 hrs)
E6. What is your (sub)specialty area? <u>SELECT ONE</u>	
☐ General pediatrics ☐ Developmental & behavioral pediatrics ☐ Neonatology ☐ Family physician ☐ Pediatric Resident ☐ Child abuse (pediatrics) ☐ Other	
E7. Which of these best describes your work setting? <u>MARK ALL THAT APPLY</u>	
☐ Private practice ☐ Multi-specialty practice/Group practice ☐ Federally qualified health center ☐ Hospital ☐ Long-term care facility ☐ Academic institution ☐ Research facility	
E8. Which of this best describes the type of area you work in?	E9. Which counties do you work in?
☐ Urban ☐ Suburban ☐ Rural	
E10. How many years of service have you done as a pediatrician in Michigan?	E11. How long have you been practicing in the field as a pediatrician in the United States?
Thanks for participating in the study. I'll reach out to schedule the interview if you've provided your contact information.	

APPENDIX E

SEMI-STRUCTURED INTERVIEW GUIDE

Referral	Guiding Questions	
	Part C EI Personnel (Avg time taken: 45 min to 1 hour)	Pediatricians (Avg time taken: 20-25mins)
Introduction	Introduce yourself. Talk about the aim of the research project, confidentiality, and voluntary participation. Confirm that consent has been signed and ask for permission to record. Q. Do you have any questions or comments about the study before we start? Q. Could you please talk about your role, the agency/practice that you work with, and area(s) you serve?	
Developmental Screening	None	Please tell us about the developmental screening and identification process you follow with birth to 5-year-old children. (Prompt: What standardized tools do you use and at what stages of development?
		Do you ever wait for parents to raise concern before administering developmental screening using standardized tools?
Referral	Please talk about the referral process between pediatricians and your agency.	Please talk about the referral process you follow to refer a child with developmental concern to the local Part C EI agency.
	What methods are available to pediatricians to make referral for e.g., fax, web-based form, phone or email? Follow up: Does the information provided at the time of referral differ depending on how the referral is received or the specific doctor's office that is making the referral? Do pediatricians use a standardized referral form, or do they typically use their own form for making referrals?	What methods do you use to refer a child and a family to Part C EI agency? For example, do you use fax, online form provided by EI or use yours, make a phone call, or provide contact information to parents for self-referral? Prompt: Could you share your experience with completing the online form, including the time it takes and how convenient it is?

Referral	Guiding Questions	
	Part C EI Personnel (Avg time taken: 45 min to 1 hour)	Pediatricians (Avg time taken: 20-25mins)
	What information do you receive from pediatricians at the time of referral?	What information do you provide to Part C EI agency at the time of referral?
	What information do you provide to parents at the time of referral? Prompt: Do parents receive information about the child’s automatic eligibility for Part C EI services if the child has a diagnosed medical condition?	
	Do you receive any medical documents such as hearing or vision evaluation reports, discharge summaries, or well visit notes at the time of referral without prior request	Do you provide any medical documents such as hearing or vision evaluation reports, discharge summaries, or well visit notes at the time of referral?
	Do you request to obtain medical reports from pediatrician? (Follow up: What channel do you use to make the request? Do you request to obtain medical reports prior to evaluation? Do you request it for specific children, or all children referred to you?)	Do you receive requests to release medical information from Part C EI agency/ies? (Follow up: How often do you receive requests for medical information? (Prompt: Is it for all referrals you make or some?)
	How soon do pediatricians respond to your request to release medical information? Please share your experience. Have you experienced any challenges in receiving medical reports.	How long does it typically take to release the requested medical information to Part C EI agency? Have you encountered any difficulties or challenges in releasing medical reports?
	How is the referral process for pediatricians promoted county-wide, particularly in terms of the referral form, the information required, and the submission of any accompanying documents at the time of referral?	How did you become familiar with the referral process in our county or state? Did you receive any information or attend meetings regarding the referral process from the local Part C EI agency?
Referral outcome	Do you inform pediatricians about the outcome of the referral, such as whether the child has been enrolled, declined, or could not be contacted?	Are you informed about the outcome of the referral from the Part C EI agency/ies? (Prompt: Whether the child is enrolled, declined or couldn’t be contacted)

Referral	Guiding Questions	
	Part C EI Personnel (Avg time taken: 45 min to 1 hour)	Pediatricians (Avg time taken: 20-25mins)
	Follow up: Do you provide information about the referral outcome for all children or only for selected ones? How do you provide information about the referral outcome to pediatricians?	Follow up: Do you receive information about the referral outcome for all children, or is it only provided for some of them?
	Please tell us about the eligibility determination process. Follow up: Is there a distinction between the initial evaluation and the full evaluation or assessment process? Do you omit initial evaluation for children with diagnosed medical conditions?	At what point in the referral process for EI services do you typically refer children to subspecialists for medical evaluations, such as neurology, genetics, or developmental and behavioral assessments? Follow up: Are all children with developmental delay referred for medical evaluation, or are some selected based on the signs and symptoms?
	According to the policy, the initial evaluation to determine eligibility should involve two experts representing two different disciplines. Is this requirement consistently met, or does it differ for children with diagnosed medical conditions?	None
	What happens if you receive a referral with diagnosed medical conditions but do not receive any other medical documents at the time of referral?	
	Please share your experience on how promptly pediatricians respond to release medical information. (Prompt: Have you ever not received anything despite several reminders?)	
	Is there a mechanism for pediatricians to update EI on latest diagnosis if child is already enrolled in EI?	
	Do all children undergo eligibility evaluation for dual system or some specific ones? (Only in MI)	
	Please talk about the difference in type and frequency of service under Part C and MMSE eligibility.	

Referral	Guiding Questions	
	Part C EI Personnel (Avg time taken: 45 min to 1 hour)	Pediatricians (Avg time taken: 20-25mins)
	How does the dual evaluation system work in practice? Do you have separate teams and two separate appointments required or is it a coordinated team and evaluations can be done at the same time?	
	What sort of medical documents or reports do you request or expect pediatricians to send at the time of referral? Prompt: Are there any common ones that you receive for all children?	
	Could you give an example of how medical reports help the team or the child in service provision other than establishing eligibility?	
Informed clinical opinion	Could you provide information about how and when you apply informed clinical opinion? When conducting informed clinical opinion, does it require more time or procedures compared to evaluating a child with developmental delay or a diagnosed medical condition?	None
State-approved list of established conditions	How did you learn about the state-approved list of diagnosed medical conditions? How is the state-approved list embedded in the current referral or eligibility evaluation system? Does your agency distribute the state-approved list to pediatricians and other early child providers?	Are you aware of the state-approved list of diagnosed medical conditions? Follow up: If yes, how did you learn about it, for example, through training during residency, at work, or from colleagues? How do you utilize the state-approved list in your practice? For example, do you share it with parents to inform them of automatic eligibility?
	How was the state-approved list established in your state?	None
	What happens if a child does not have any qualifying medical condition and developmental delay is not severe enough to meet the state criteria? Do you decline or	

Referral	Guiding Questions	
	Part C EI Personnel (Avg time taken: 45 min to 1 hour)	Pediatricians (Avg time taken: 20-25mins)
	have a tracking system for such children and families?	
	What do you do regarding the child's eligibility if the diagnosis you are looking for is not on the state-approved list?	
	When encountering a child with a diagnosed medical condition that is not familiar to you and is not on the state-approved list, what resources do you rely on to learn more about the medical condition?	
	Are there any state guidelines regarding credible websites that provide reliable medical information?	
Training	Have you received any training specifically related to the state-approved list, referral practices, and eligibility determination, particularly for children with diagnosed medical conditions?	Have you received any training, attended meetings, or received information from Part C EI or your clinic/hospital regarding Part C EI referral, eligibility determination (including the state-approved list), and your role as a pediatrician in the referral process? Prompt: Did you have any related training during residency?)
Recommendation	What recommendations do you have to improve the current state-approved list of established medical conditions?	
	What recommendations do you have to improve the current referral practices between pediatricians and your agencies?	
	What recommendations do you have to eligibility determination (or evaluation) system in your agency?	
	What recommendations do you have to provide training for Part C EI personnel or pediatricians?	

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