THE INFORMATICS OF EARLY INTERVENTION REFERRALS FOR CHILDREN WITH DISABILITIES

By

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ABSTRACT

Objectives: Early identification and treatment (Early Intervention, EI) of the nearly 1 in 6 children with developmental delay can maximize their developmental outcomes and pay dividends to society. However, more than half of children who would benefit do not receive needed services. Siloed information systems contribute to this problem, widen health disparities, and reinforce cultural gaps between professional EI settings and referring parties in primary care.

Methods: To begin to address these problems, this study describes the current state of referrals of children to Early Intervention 1) through an analysis of document- and website-based referral forms for each state, and 2) through a national survey of State EI leaders about methods of referring children to EI. Three questions guided the investigation: 1) “What information is sent when referring a child for Early Intervention evaluation?” 2) “Who sends referrals of children to Early Intervention?” and 3) “How is this referral information transmitted?”

Results: Statewide EI referral forms are used by 37 states, 30 of which offer downloadable e-documents and 13 of which have web-based versions. Referral forms emphasize family contact information, reason for referral, and parental release of information. 71% of states with statewide forms offer them in English only. EI leaders from 41 states & jurisdictions (79%) responded to the survey. Leaders estimate that healthcare (45%, SD 17) is the most common source of referrals, with families second (30%, SD 16). EI agencies frequently receive referrals by phone (mean 38%), electronically (23%), email (17%), and by fax (17%). All surveyed states use statewide EI data systems but few use Health Level Seven (HL7) messaging standards (48% do not, 49% do not know). Few data systems receive structured electronic referral data (14%) and/or metadata (14%). Themes from short answer questions include a high value on centralized access to accurate data and a diversity of ways to refer children to EI. Leaders have a positive opinion of web-based referrals, an interest in system interfaces with parents’ mobile devices, and express desire to receive electronic referrals directly from Electronic Health Records.

Conclusions: Referrals of children to EI agencies vary widely in their methods and degrees of digitization. EI information systems usually do not receive discrete referral data directly from outside sources. To increase referral completion rates and work towards data integration that enables referral tracking and reduction of disparities, EI agencies should continue to provide a variety of means of access to EI, invest in web-based referral forms, enhance accessibility to communities of English language learners, collect data on race and ethnicity, and take advantage of prevalent mobile device use by parents.

INTRODUCTION

About one in six children has a developmental disability or delay.[1] Early identification and treatment of young children at risk for developmental disabilities improve their chances of maximal academic success and contribution to society as adults.[2-5] However, more than half of children with developmental delays (0.8 million children annually) do not receive developmental services in Early Intervention (EI).[6-9] Reasons for low rates of Early Intervention use include stigma, mistrust, logistical challenges, limited resources, and communication failures.[10-13] Of these, communication failures may be particularly important and amenable to intervention: In EI, information regarding children with developmental disabilities is stored across health care, educational, and other organization types. Because these organizations' information systems do not easily exchange information, it is frequently unclear to providers in both healthcare and educational systems which children are not getting needed care, and why.[14] Furthermore, gaps in professional culture and other barriers between these professional settings have historically hindered collaboration.[15-18] This study lays groundwork that contributes to better communication using information technology by answering the questions: In the United States today, "What information is sent when referring a child for Early Intervention evaluation?" "Who sends referrals of children to Early Intervention?" and, "How is this referral information transmitted?"

Early Intervention

The Individuals with Disabilities Education Act is the federal legislation that mandates access to special education for students with atypical learning needs in public schools.[19] States apply annually for funds and report outcomes data to the US Department of Education, in addition to contributing their own funds. Part C of this law, Early Intervention, is carried out by a state government agency that is often separate from public education. Part C requires states to provide treatment to eligible infants and toddlers up to age 3 not yet reaching typical developmental achievements, or those who have diagnoses with higher risk for developmental problems.[20]

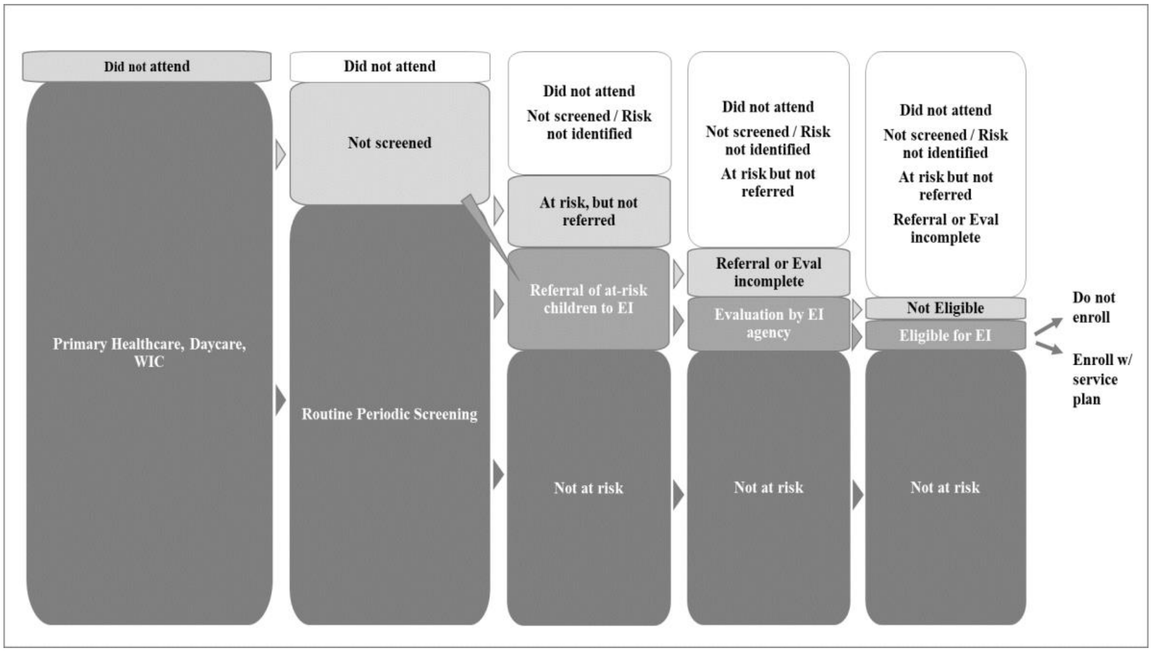
For example, a child with weakness in the muscles of his trunk might have difficulty standing or walking at the typical ages, and miss out on the developmental opportunities offered by moving about to explore his environment. Once provided physical therapy through Early Intervention, he may learn to walk across the room to the basket of stuffed animals that he has been so curious to learn more about. As another example, a 2-year-old child who does not yet speak any words gets frustrated when trying to communicate with her parent. Early Intervention could match her with a speech therapist who coaches her mother on how to accelerate her speech development, enabling the child to move on to other important developmental tasks.

Over the last 40 years, research has firmly established that high-quality Early Intervention and Early Childhood Education can improve children’s subsequent need for special education, grade repetition, and graduation rates, and can confer lifelong benefits such as better health, higher income, and lower risk of incarceration.[3,21,22] In terms of cost to society, Early Intervention pays for itself as much as 8 times over.[5] These effects are most pronounced for children of families with lower incomes, identifying it as a lever to improve equity across populations. Evidence has also shown that when developmental delays are treated early, intervention is much more effective. This speaks to early human brain plasticity, when the infant brain has great capacity to respond to and learn from external influence, a capacity that greatly diminishes by the end of the first 3-5 years of life.[23]

Barriers to Early Intervention Referral Completion

There is a limited opportunity for early treatment of infants and toddlers with delays, while their brains are most plastic and responsive. Figure 1 is a schematic of the pipeline, sometimes called “Child Find,” through which children enter Early Intervention in the United States. At each stage, lighter gray blocks represent children who do not continue in the process.

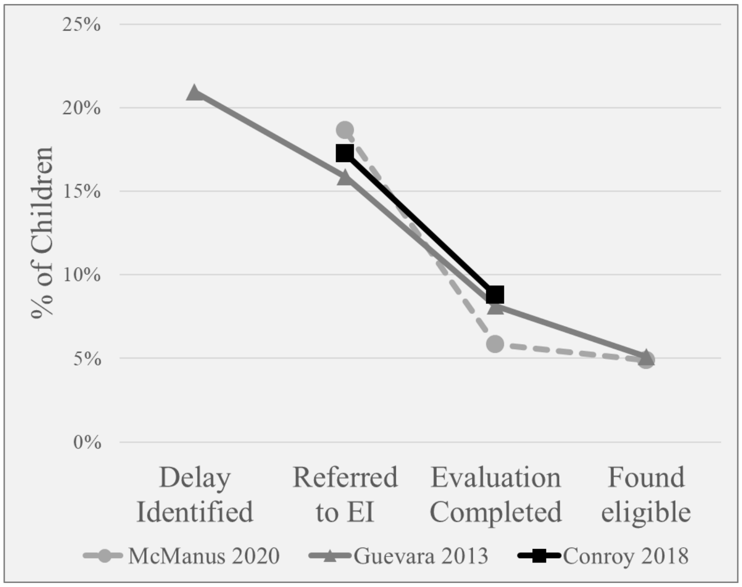
Figure 1. Early Intervention Pipeline



Children are usually identified when they come to their primary care provider, but some are not. Only a portion of children in these settings are screened for developmental delays. Only a portion of children with developmental risk are referred to early intervention based on the conversation between the parent and clinician, and informed by screening results.[24] The local Early Intervention agency contacts the family and arranges to evaluate the child's development; however, in some families, evaluations are not completed. For those that have not fallen out of the referral pipeline, once this eligibility evaluation is complete, the referral is considered complete. If the child qualifies, her family participates in developing an individualized plan to address the concern, with any combination of speech, occupational, or other services. In the final stage of the pipeline, not all children who qualify for EI services ultimately engage in them.[25]

We lack national data on the proportions suggested in Figure 1. Most states lack data on how many children are screened or referred to EI, and only have the number of referrals their EI agencies receive.[26] However, despite data limitations, it is clear that too many children are not getting services they need. To illustrate some existing data about the referral step of the pipeline, Figure 2 shows proportions of children lost to follow up once referred to Early Intervention. Rates are similar between three studies from three states, at 31% (labeled McManus 2020[8]), 51% (Guevara 2013[9]), and 51% (Conroy 2018[27]).

Figure 2. Early Intervention Survival Curve



The quantitative and qualitative literature describes five groups of barriers. One of these groups includes family and cultural factors, where, for example, a parent with lower resources or educational attainment may have difficulty navigating the EI system or advocating for their child.[28] This works against such families, as EI has sometimes been described as requiring persistence and follow through to access.[11,29] Additionally, families who do not speak English experience more barriers and receive less services.[30] Families in racial and ethnic minorities are also less likely to receive EI services.[31-33]

For example, Morgan and colleagues studied data of 9,600 children born in 2001, and their families, from the Early Childhood Longitudinal Study – Birth Cohort. They used multivariate logistic regression to incorporate 31 sociodemographic, birth, household, and behavioral variables.[30] Across four levels of covariate inclusion and at child ages 24, 48, and 60 months, children identified as Black were about 45 to 60% less likely to receive speech and language services (adjusted odds ratio (AOR) range 0.42 – 0.55). Families experiencing lower socioeconomic status were less likely to receive services, as there was a consistent dose-response pattern across income quintiles. Families whose parental primary language was not English (AOR range 0.4 – 0.43 at 48 months, similar trends at 24, 60 months were not significant) were also less likely to receive services.

Environmental and neighborhood barriers also impede access to Early Intervention. The child's neighborhood might not be safe to travel by foot, the rent might be overdue,[25] or the family might experience food insecurity. Competing priorities such as these often supersede less imminent risks to the family. Beyond that, exposure to these and other scarcities have been shown to impair our ability to look beyond immediate concerns and plan for less imminent ones,[34] for example, by following through with a referral to Early Intervention.[25]

Health care-related barriers may also play a role. Healthcare providers sometimes do not understand EI resources or child developmental risks,[35] or may suspect that the child will not receive the services. They may not refer in such cases, when otherwise they might recommend developmental supports.[36] Regarding EI workforce barriers, the EI workforce is overworked and underpaid.[37] Many of the professional credentials required to provide EI services are also marketable in the healthcare industry, which may offer higher pay. Staff working in such job conditions regularly suffer from burn-out and adopt a less service-oriented work style as a result.[38]

Lastly, system barriers such as disconnected agency processes, poor funding of EI,[39] and a lack of understanding in the general public about child development and Early Intervention all work against success. The challenge of navigating privacy regulations also plays a role. The Healthcare Insurance Portability and Accountability Act (HIPAA), the Family Education Rights and Privacy Act (FERPA), and the Individuals with Disabilities Education Act (IDEA) each contain their own signed consent requirements and associated exceptions.[40] Each act plays an important role in ensuring information privacy, and their creators intended to promote sharing of information in proper circumstances. However, in this circumstance where the sharing of private child and family information across sectors is subject to all three laws at once, they can become difficult to manage.

System Dis-integration

Early Intervention information systems are not well integrated with each other, and they usually do not link with health information systems at a state or national level. Linkage in this case means matching data between systems using common identifiers (such as a master person index), not necessarily electronic exchange of structured data between computer systems. The Early Childhood Data Collaborative's 2018 State of State Early Childhood Data Systems[41] found that about one third (29%) of states' EI data systems had child-level linkages to any other early childhood data system, and one fourth (25.5%) linked to their K-12 public school data systems. Only 16% of states linked health data systems (such as vaccine record or Medicaid billing systems) to any early childhood data system. In addition, these rates are lower than they were five years prior in their 2013 survey. This is probably related to expiration of the development grant program "Race to the Top,"[42] which aided states working to integrate their early childhood data systems.

The IDEA Infant & Toddler Coordinators Association 2013 Survey of 49 state Part C Coordinators[43] found that 88% had a centralized data system. Forty-three out of 46 states (93.5%) captured referral source in their data systems. Electronic exchange of structured data was described between EI information systems and billing systems such as Medicaid or the State Children's Health Insurance Program (SCHIP). Challenges to linking data systems included administrative separation of agencies. As this survey focused primarily on EI agencies' data capacity and data management, it did not examine information system interfaces with the healthcare industry. So, while data gathering within agencies may have progressed, data integration between early childhood agencies has not advanced a lot recently beyond a handful of states. Generally, statewide healthcare linkages to early intervention are not common, and these health data systems are not clinical information systems.

This lack of data integration appears to contribute directly to low rates of access to EI care, particularly for children in families of low income or communities of color.[25,26,44] As mentioned above, disconnected processes are described as barriers by families of low income, immigrants, those with English as a second language, and people of color, amplifying existing inequities.

The Need for System Integration

Relevant organizations call for better communication between settings caring for children with disabilities. The American Academy of Pediatrics (AAP) Council on Clinical Information Technology in 2011 wrote a policy statement supporting:

> …development, implementation, and widespread deployment of a comprehensive electronic infrastructure to support pediatric information management functions of the family-centered medical home. These functions include a) management and tracking of patient health and services over a patient's lifetime across multiple providers, b) comprehensive, efficient, and timely transfer of health data for safe patient transitions among providers, institutions, and practices…

The AAP in a 2013 Clinical Report about EI and the Medical Home states:

> Channels for concise bidirectional, 'minimum effort' communication need to be in place and familiar to both the medical home and the regional Part C Program.[45]

In 2019, the Early Childhood Technical Assistance Center described high-quality EI in its "State System Framework for High-Quality Early Intervention and Early Childhood Special Education."[46] The paper documents the increasing emphasis by the US Department of Education on accountability and quality improvement, saying, "Programs must have systems to collect the data required for accountability and to support ongoing quality improvement and improved outcomes." One of the "six interrelated components" of the framework itself is "Data System," which includes child data elements such as referral date and referral source among others.

In a systematic review of studies that contain data on children in various stages of the EI access pipeline,[44] Barger and colleagues found very few studies that tracked cohorts of children throughout. They state, "without such data, it is impossible for policy makers to make databased decisions to improve Child Find systems or judge the effectiveness of early identification systems."

Several studies document the potential of high-quality EI referral techniques to improve referral outcomes. King and colleagues documented a national demonstration project[47] shepherding pediatric clinics through use of the then-recently published 2006 AAP guidelines for developmental screening and referral.[48] Participating clinics noted that following up on EI referral results was labor intensive and revealed many incomplete referrals and family misunderstandings. However, for the clinics that accomplished referral tracking, it appeared to identify and serve more children in EI. In a more recent example, Conroy and colleagues documented a quality improvement initiative that brought their clinic's EI referral completion rates from 50% at baseline to 72% with use of EHR-based referral orders, patient navigators, and referral tracking. They cited "challenges in information sharing with individual EI sites" as a barrier to greater success and stated that "effective coordination of EI referrals is an essential function of pediatric primary care."[27]

Improvements in success rates of referral of children to EI would result in a significant increase in the number of children identified as eligible for EI services. Based on three studies[8,9,27] following children through the "pipeline" process from screening, identification of developmental concern, referral to EI, referral completion with an EI eligibility evaluation, and eligibility determination, we may estimate proportions of loss of children along the way, as seen in Figure 2. These studies and two others[49,50] suggest that a 5 to 15% improvement in referral completion rates may be achieved with interventions such as referral tracking, phone follow up with families, and direct communication with Early Intervention agencies. These interventions could be facilitated by interoperability between referral source and EI agency information systems. For example, a tracking system would aid referral sources in supporting families having trouble advocating for access to the EI system, or who may have misconceptions about the nature and benefits of EI. For a sense of effect size of such interventions, consider the following: Based on 2017 census data, population estimates of EI eligibility prevalence, and the above pipeline loss rates, a 1% improvement in referrals completed could translate to 5,700 more children per year being identified as eligible for services. If improved information system integration were to lead to a conservative 5% average improvement in referral completion rates in the United States, this would offer new access opportunities to 28,000 more children per year.

Perhaps most importantly, it may narrow disparities gaps. Brown and colleagues documented a quality improvement project focused on the completion of primary care provider referrals of children 0 – 3 to Speech Language Pathology or Audiology.[49] Scheduling at the time of referral, walk-in referrals, and phone outreach to families without scheduled appointments together increased appointments attended from a baseline of 40% to 60%. Although improvement appeared difficult to sustain overall, there was disproportionate increase in attendance for families who lived in census tracts with high rates of poverty or adults with less than a high school education.

An Opportunity

The opportunity for benefit should extend beyond improving referral completion rates. As state EI agencies, healthcare organizations and others advance their information systems, new opportunities open to address system fragmentation and health disparities exacerbated by fragmentation. Data integration between referral source and EI agency settings could create an infrastructure of information exchange. Much like a highway system, an infrastructure of information exchange would enable information to travel easily between users, enabling them to track children across settings to prevent their loss to follow-up. On a larger scale, such an infrastructure would facilitate monitoring and evaluation of programs that could answer policy questions and measure whether a change resulted in improvement.

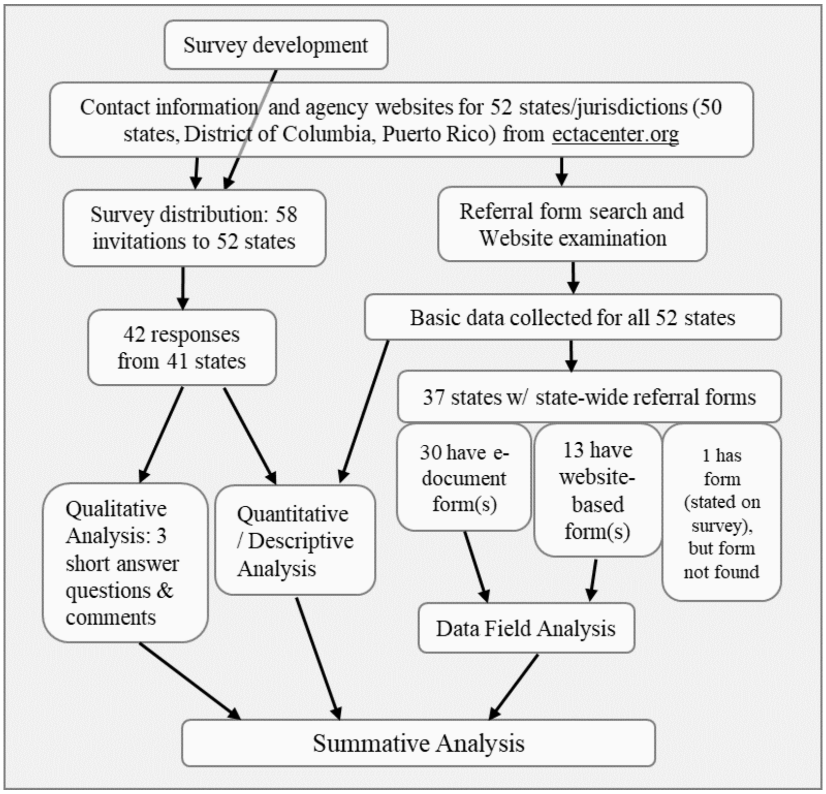
To take advantage of this opportunity, we must gather the perspectives of key stakeholders involved in the Early Intervention referral process and understand the information they exchange. These include the child and her family, the EI agency's referral coordinator, the referral source (often medical), and the organizational/regulatory entities surrounding the referral process. We may then begin to form an information model or framework that takes their views and vocabularies into account and emphasizes unmet information needs. States may then build upon such a framework to design information systems that promote higher quality referral processes.

This paper lays the foundation for this agenda by describing the organizational perspective as represented by EI agency leaders. It describes the current state of Early Intervention referral quality nationally using a survey that asks what data are sent, who sends and receives it, and how it is sent. Our mixed-method approach consists of two parts: 1) a descriptive study of states' standardized Early Intervention referral forms, and 2) a survey of state Early Intervention agency leaders on their EI referral methods.

METHODS

In the first part of this descriptive study, we collected and compared Early Intervention referral forms in the form of downloadable, printable electronic documents (hereafter referred to as "e-documents," e.g. Portable Document Format, PDF) and website-based forms with information entered directly online (hereafter referred to as "web forms"). These forms offer a snapshot of agencies' information priorities. The second part consists of development and distribution of an online cross-sectional survey to EI agency leaders (Part C Coordinators) in their respective states. The Institutional Review Board of Oregon Health & Science University (OHSU) approved this study. See Figure 3 for a schematic of study activities. Following a description of the survey are the three research questions and the methods we used to answer them.

Figure 3. Study Flow Diagram



Survey Development

We developed an electronic survey to gather data about EI referrals from Part C Coordinators across the United States including the District of Columbia and Puerto Rico. Six survey items solicited data about EI referral forms, EI referral sources and means of transmission for each respondent's state. Five questions gathered data on states' EI information systems, and three items invited free text assessments of respondents' state referral systems. We revised survey drafts with feedback from two primary care pediatricians, two informaticians, two speech pathologists, a research assistant, a physical therapist, a family medicine physician at a community health center, and a subject matter expert at the Early Childhood Technical Assistance Center.[51] These reviewers critiqued the survey for length, clarity, appropriate vocabulary, tone of language, ease of completion, and feasibility of information requested. Before national distribution, we pilot-tested the survey with four state and regional EI leaders in Oregon.

We sent email and postal survey invitations with IRB-approved information sheets to each state's Part C Coordinator. Invitations contained respondent-specific links, and postal invitations included a $2 bill as an incentive. For states that list two people jointly holding the role of Part C Coordinator, we sent invitations to both. We encouraged response with follow up by email and telephone. We used Microsoft Access 2016 to collect data, Microsoft Excel 2016 with Real Statistics Resource Pack[52] statistical software for quantitative analysis, and NVivo 12 (QSR International) for qualitative analysis. We resolved discrepancies between survey responses and/or referral form data by emails to the respective state agencies. Analysis included descriptive statistics and an evaluation of non-response bias using logistic regression.

We collected free-text survey responses from a comment section and three open ended questions ("What about [state]'s EI referral system works well?", "What about [state]'s EI referral system doesn't work well?", and "How would you make [state]'s EI referral system better?"). With input from two colleagues experienced in qualitative research as part of a related study, the author developed a codebook using this material and interview transcripts of Part C Coordinators. The primary author coded the responses and drafted initial thematic interpretations. These interpretations were refined during discussion with two career qualitative researchers (approximately 4 hours discussion) and two practicing Speech Language Pathologists with experience in qualitative research and the topic area of referrals of children to Early Intervention (approximately 3 hours discussion).

What information is sent when referring children to Early Intervention?

The referral form analysis primarily addressed this research question. The Early Childhood Technical Assistance Center[51] supplied Early Intervention agency information for all fifty states, the District of Columbia, and Puerto Rico. From this, we manually examined all 52 agency websites, searched them for referral forms, and downloaded them when available. The sample included downloadable documents (e-documents) and website-based referral forms. The number of forms considered depended on the questions being asked. For example, when inquiring about languages in which forms were available, we considered any form available for each state. For the data field analysis, we chose forms to represent 1) every state with statewide referral forms and 2) document- and website-based formats where states offered both. We then grouped data fields corresponding to categories on the Early Intervention Program Referral Form from the American Academy of Pediatrics (AAP),[53] and recorded the number of fields in each category. We counted as single fields the standard fields identified as part of an address (except county) or a person's name. When available, we also collected form attributes such as language, document file format, number of pages, presence of e-fillable fields for use on a computer, last revision date, intended role of form user, and the presence of questions about the child's race, family's preferred language, and eligibility criteria. We used descriptive statistics to summarize findings, interpreted in the context of the remainder of the study. In order to represent all sampled states equitably, we weighted state-based measures such as average number of fields against the number of forms per state.

As for the survey's contribution to this research question, one item solicited copies of referral forms for the respondents' states. Other items asked respondents about whether their agency uses a statewide referral form and how often it is used. Lastly, themes elicited from free-text responses on the survey were incorporated into results for this research question.

Who sends referrals of children to Early Intervention?

The survey solicited referral source type and frequency from Part C Coordinators. We also drew information from referral forms inferring their intended users.

How are children referred to Early Intervention?

Referral form analysis yielded types of referral forms available on agency websites. Survey items solicited which methods of sending and receiving a referral were available in the respondents' state. Respondents were then asked to estimate the proportion of incoming referrals that were received by fax, telephone call, electronic not email, email, postal mail, and in person. We asked whether the EI agency used one or more statewide EI data systems and what types of information they held. We asked whether the EI system used Common Education Data Standards and Health Level Seven, data and messaging standards used within educational and medical settings respectively. Another question clarified what Part C Coordinators mean when they answer that they receive referrals electronically.

In the following results section, qualitative themes are dispersed among headings for these three research questions.

RESULTS

Referral Form and Survey Samples

We collected 59 statewide Early Intervention referral forms from 36 states (Table 1). A 37th state's Part C Coordinator clearly indicated use of a statewide form on the survey but did not respond to requests for a copy when the form was found to be unavailable online. Forms total 59 because states with documents often had 2 to 4 versions to accommodate various user roles, Spanish language, and versions using e-fillable fields.

Table 1. Referral Forms

States with state-wide EI referral forms	Value/N (%)
States with any state-wide EI referral form*	37/52 (**71**)
States with downloadable documents as referral forms	30/52 (**58**)
States with website-based referral forms	13/52 (**25**)
States with both downloadable documents and website-based referral forms†	6/52 (**12**)
Weighted average age of form (n = 34)‡	3.6 years (range 0.5 – 9.9)

*Although the presence of a form for one state was indicated on that state leader's survey response, we were unable to obtain a copy for further analysis.

†Members of this category are shared between the previous two categories.

‡Average is weighted against the number of forms per state to represent states evenly.

Part C Coordinators from 41 states and jurisdictions (79%) responded to the survey. These leaders most often held a Master's (51%) or Bachelor's (32%) degree and held their positions for 6 years or less (Table 2). Their states represent the nation at large well with respect to region, EI eligibility criteria, lead EI agency type, and the proportion of their population that identifies as non-white. Ninety-eight percent of them consider themselves either "Extremely" or "Very" familiar with their state's referral process.

Table 2. Survey Respondents & Their States

Respondent Attribute	Value
Years in current position	Median = 4.0, Range (0.6 – 29.0)
Education	Assoc Deg or less: 7%, Bachelor's: 32%, Master's: 51%, Doctorate/prof: 10%
Years since degree	Median = 20, Range (2 – 46)

Familiarity with state's referral process	Extremely: 71%, Very: 27%, Moderately: 2%, Slightly or Not: 0%			
Survey State Attribute	**Value**			
U.S. Census Region represented	**Sample n/US Total (%)** *(Puerto Rico not designated)*			
Northeastern:	7/9 (78)			
Midwestern:	11/12 (92)			
Southern:	14/17 (82)			
Western:	8/13 (62)			
EI Eligibility Criteria	**Sample % of Total**	**Category % of US Total**		
Broad:	52.5	47.1		
Medium:	17.5	23.5		
Narrow:	30.0	29.4		
Lead EI Agency Type	**Sample % of Total**	**Category % of US Total**		
Education:	26.8	23.1		
Health:	29.3	34.6		
Other:	43.9	42.3		
Race (US population proportion quartiles in which sample states fall)	**Proportion of sample in US Quartiles**			
	1st	**2nd**	**3rd**	**4th**
Non-European American:	25.0	27.5	22.5	25.0
African American:	25.0	25.0	22.5	27.5
Asian American:	22.5	27.5	27.5	22.5

We tested non-response bias against multiple variables obtained for all 52 states using logistic regression. Response to the survey was not correlated with having a state-wide referral phone number ($p = 0.56$), having a statewide referral form whether web form, e-document or both ($p = 0.97$), whether the EI agency is part of the state's health, education, or other government branch ($p = 0.30$ and 0.47 respectively with Other as reference),[54,55] nor whether the state's eligibility criteria were classified as narrow, medium, or broad ($p = 0.61$, regression Chi-squared with log-linear $r^2 = 0.07$, $p = 0.57$).[56]

What information is sent when referring children to Early Intervention?

The referral form study provided the majority of information describing what data are sent. However, based on published literature[11,29] and free-text responses from this survey, verbal communication with the family is an essential component of the referral process. At most EI agencies, once the referral coordinator receives the initial referral information, she or he contacts the family by telephone to discuss the referral. While we do not study the content of these conversations in this project, frequent references to it by survey respondents illustrate its importance:

> *Service coordinators can, in many cases, contact the family within 48 hours after referral.*
>
> *We do not limit referrals to one form, method but rather encourage the conversation with the caretaker to explain EI.*

Nevertheless, referral forms provide an opportunity to study state information priorities. Statewide referral forms are used by 63% of states responding the survey. Another 20% use regional forms, 5% use both types, and 12% reported using neither. Similar to this is our identification of statewide forms from the EI agency websites for 37 of 52 (71%) states and territories. Of all incoming referrals, an average of 67% of them use their state's statewide form.

All statewide forms we found solicited Child-Parent information and Reason for Referral information (Table 3). After Child & Parent Contact Information, Reason for Referral often held the largest number of fields (1 to 98). Lists of qualifying diagnoses and risk conditions account for this large number, as we found them on statewide forms for 75% of states. The remainder of categories (EI program information, Feedback Requested, Release of Information, Primary Care Provider, and Agency Use Only) are absent on at least half of the forms analyzed. Across the eight categories identified, we identified 133 unique field types. When calculated to give equal weight to each state (some have more forms than others), a median of 49 (range 11 – 142) fields occur on each form. Although update data were not displayed on the web forms, the average age of revision for e-documents with such information was 3.6 years (weighted mean, Table 1), whereas in contrast at least one state changed their web form just over the six-month period of study sampling.

In comparison to the Early Intervention Program Referral Form published by the American Academy of Pediatrics (AAP, data in Table 3), numerous states' forms contained many more fields than thirteen in their Reason for Referral category, usually referencing qualifying diagnoses and risk conditions presumably related to eligibility criteria. In contrast, 25% of states with statewide forms do not directly request potential eligibility data at all on their forms.

Table 3. Categories of Fields within State-wide EI Referral Forms

	Median Number of Fields (range) *weighted for equal representation among states sampled*			**AAP EI Referral Form**[53]
Category	**All** (n = 43)	**e-Document** (n = 29)	**Online** (n = 14)	**# Fields**
Child & Parent Contact	15.0 (6 – 45)	15.0 (6 – 45)	15.0 (6 – 26)	10
Reason for Referring Child	11.0 (1 – 98)	12.0 (1 – 98)	2.0 (1 – 27)	13
Referral Source Information	6.3 (0 – 37)	7.0 (0 – 14)	6.0 (0 – 37)	6
EI Program Information	0.0 (0 – 5)	0 (0 – 5)	0 (0 – 3)	5
Feedback Requested	0.0 (0 – 24)	0 (0 – 24)	0 (0 – 0)	13
Release of Information	0.0 (0 – 22)	2 (0 – 22)	0 (0 – 1)	5
Primary Care Provider	0.0 (0 – 6)	0 (0 – 6)	0 (0 – 4)	0
Agency Use Only	0.0 (0 – 24)	1 (0 – 24)	0 (0 – 0)	0
TOTAL	48.6 (11 – 142)	50 (19 – 142)	30 (11 – 70)	48

Fields for parent signature are found almost universally on the e-document forms, and not on the website-based forms. This may indicate why images of paper documents remain part of the EI referral process even for states with web forms. For example, four of the thirteen states (31%) accepting referrals to EI through their agency website have a function to upload documents to supplement the electronically submitted data.

Qualitative Theme 1: Data Accuracy and Completeness

This theme elicited from free text survey responses is most relevant to the question "What data are sent?" The accuracy and completeness of referral data is important to Part C Coordinators, for example as reflected here in a response to the question "What about [your state]'s referral system doesn't work well?"

> *When information about the child/family from referral source is incomplete. This delays the processing of the referral.*

As paper forms and e-documents on a computer are limited in their ability to enforce data entry practices, coordinators expressed the ability or desire to improve data accuracy using web-based forms:

> *It would be nice to have an electronic method for submitting referrals. The electronic form would include required fields and the referral source would not be allowed to submit the form until it is complete.*

Other Part C Coordinators shared challenges with data entry compliance in their statewide EI data systems, for example, affecting their agency's ability to track referral sources accurately:

> *We are able to analyze all referral data, but are working on better identifying how to support common referral sources to correctly identify themselves in the dropdown selection to ensure we have accurate data.*

Who sends referrals of children to Early Intervention?

Part C Coordinators estimate that medical settings are the most common source of referrals overall (mean 44%, SD 17), followed by parents or family members (30%, SD 16), child protective services (11%, SD 11), Childcare or early childhood school settings (5%, SD 6), and a collection of other sources (10%, SD 9, Figure 4). Figure 5 uses the same data to represent variability among states. For example, note that Part C Coordinators from six states estimate that they receive more referrals from parents than from healthcare professionals.

States also varied in their intended form user. Although 25% of states with statewide forms explicitly identify healthcare providers as intended users, 14% of states with statewide forms clearly state that anyone can use the form to make a referral, and 50% do not clearly state an intended user. Healthcare professionals are usually considered to be among typical users, as reflected by the frequent appearance of requests for diagnosed conditions and medical history on these forms. Some states (17%) offer separate forms for different roles such as parent, professional, and EI staff member. This is most common among web forms (86%).

Figure 4. Mean % of EI referrals received by source (n = 36)

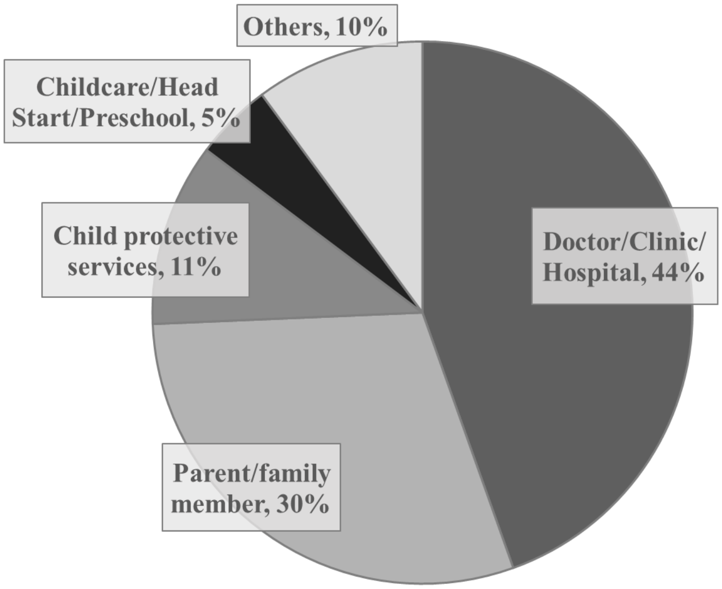
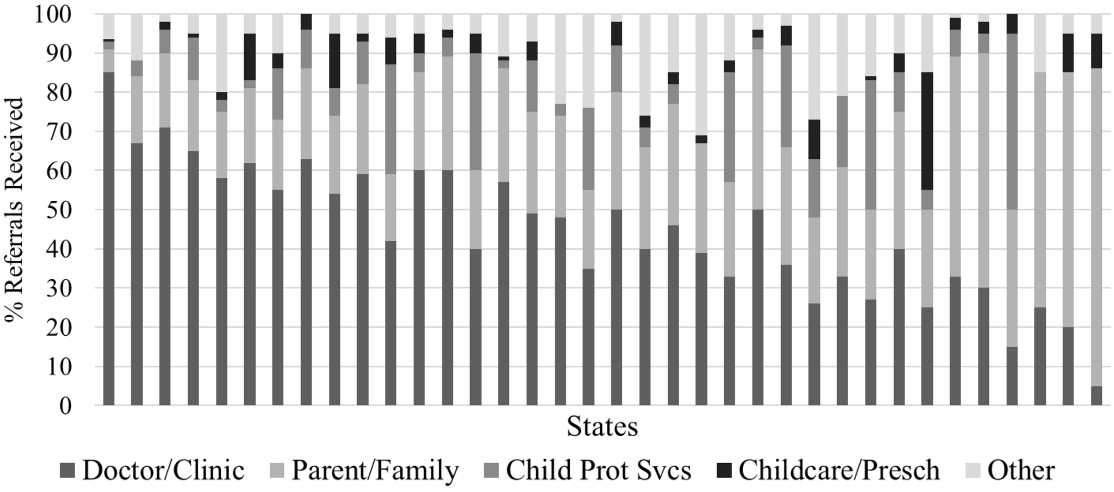


Figure 5. Percent of EI referrals received by source. (n = 36)



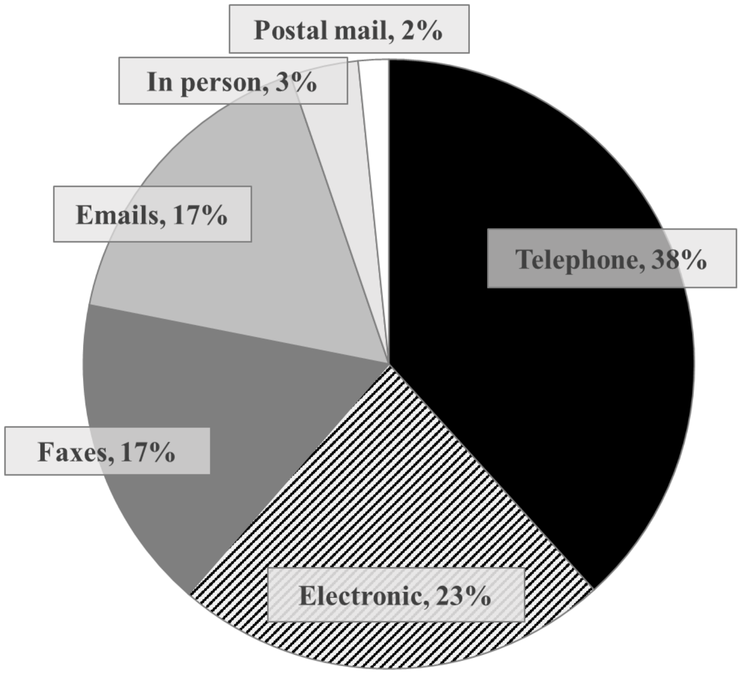
In terms of equity and inclusion, 32 of the 36 states with statewide forms (89%) have forms that solicit the preferred language of the child's family or whether an interpreter is needed. The AAP form does not ask for the child's race, however, 39% (14/36) of states with forms do. These questions are most often in the form of US Census-like categories as checkboxes. One of these states asks only whether the child is "Native American and lives on a Reservation" for purposes of directing the referral to the correct local agency. Out of the 37 states with statewide forms, 5 (14%) offer their referral form (web form or e-document) in English and Spanish, whereas only an English form was found for 73%. Another 14% of states with forms (5) offer a third-party auto-translator function within their web form that can render the text on that page in one of up to 108 languages that the user may select from a drop-down list.

How is referral information transmitted?

Although 29% (15/52) of states do not offer a statewide form, 58% (30/52) provide one or more downloadable e-documents, 25% (13/52) offer a web-based referral form, and shared between these two groups are six states (12%) that provide both e-document and web forms. EI agency leaders on average estimate they receive referrals on one of these standardized forms 67% of the time. Methods usually available to send referrals for children to EI include telephone calls, facsimile, in person, and email, although almost all states have a website available to at least find their local agency, and 34% have the capability for some referral source to send referrals electronically from a healthcare setting. Two state Part C Coordinators indicated that their states have a mobile application available to help find their local agency and even send referrals.

Eighty-five percent of states report that referrals can be sent by their source from a fax machine, although only 80% of agencies report being able to receive referrals by traditional fax machine. Upon further communication by the author, at least two states receive referrals that were initiated through traditional facsimile and then received as electronic documents through a computer-based fax system. Although many indicated that they do not collect this information and were unwilling to estimate, 18 State Part C Coordinators did estimate that the most common ways they actually receive referrals include telephone

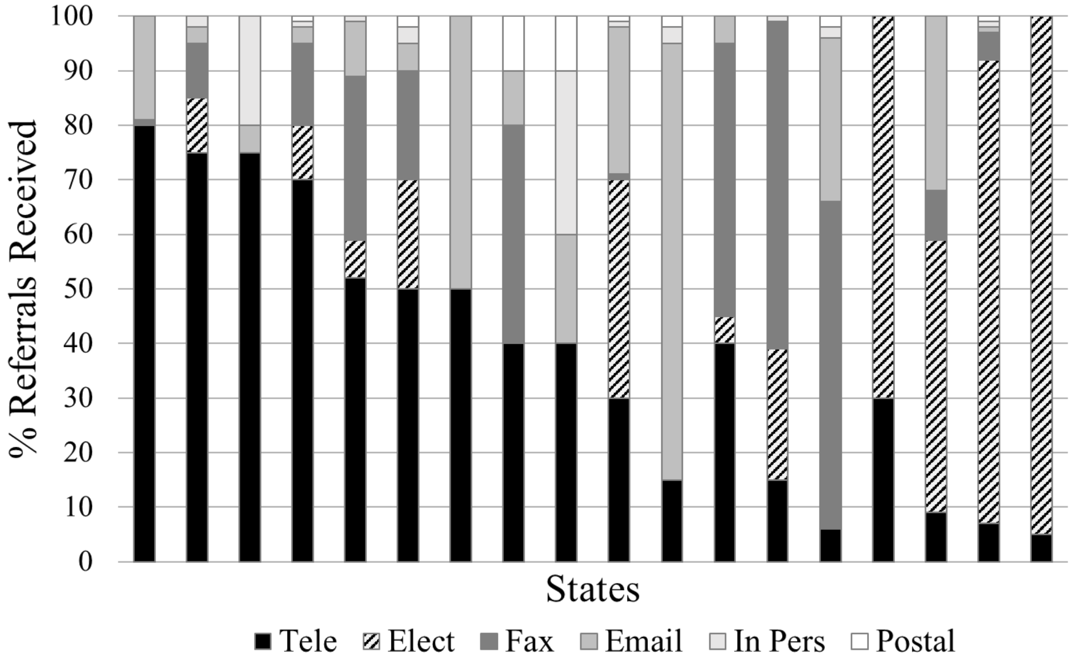
Figure 6. Mean % referrals received by method (n = 18)



(mean 38%, SD 26), electronic not email (23%, SD 32), facsimile (17%, SD 22), and email (17%, SD 21, Figure 6).

Figure 7 illustrates the wide variation in these combinations. Notably, of the 18 states responding to this survey question, none of the 4 states describing high proportions of electronic referrals had faxes as a prominent means of receiving referrals, and of the 3 states with high proportions of referrals received by fax, only one had more than 5% received electronically.

Figure 7. Estimated % of EI referrals received by primary methods (n = 18).

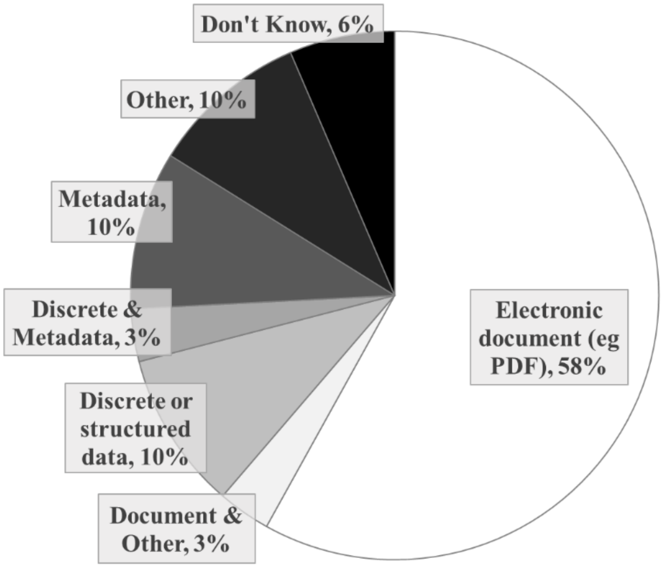


In addition to data validation with required fields and automatic translation, some are designed to be responsive to user input such as with branched logic or automatic selection of local EI agency based on the address entered. For example, 86% of website-based forms allow the user to arrive at a different form based on whether they select for example “Family” or “Healthcare Provider” on the first page. In addition, instead of updating forms every several years, online forms might be maintained with updates as frequently as needed.

All responding states use one or more statewide EI data systems. Most of these (≥ 73%) contain demographic, unique ID, and government-reporting data, along with EI program data such as eligibility, enrollment, service plan (IFSP), and service provision. To exchange information with other data systems, most of these systems (85%) do not or cannot use the Common Education Data Standards[57] supported by the US Department of Education. Health Level Seven messaging standards such as HL7 and Fast Health Interoperability Resources (FHIR)[58] used for health information exchange are mostly not available or used (92%).

As mentioned above, state leaders report that 40% (23% electronic- and 17% email-based) of referrals to Early Intervention are electronic. However, as seen in figure 8, the majority of these (58%) are electronic documents such as an online fax or PDF attached to an email. Fewer state EI data systems receive structured referral data (13%, computer system recognizes incoming data as data about the child's development) and/or referral metadata (13%, information about the referral but not its contents that is recognized by the electronic system; total for both: 23%). A region in one state enjoys electronic referrals using a locally developed online social and community services referral platform. However, it is designed for use by staff of participating organizations, and so appears not to be available to the public.

Figure 8. Format of electronic referrals received (n = 31)



Qualitative Theme 2: Ease of Referral

Ease of referral is a priority for Part C Coordinators:

> *Since we started this referral system, our child find numbers have increased dramatically and continue to grow each month. It is a streamlined system that is easy to use and effective in moving a referral forward instantaneously.*
>
> [One of our future EI data system goals is to have] *secure electronic data sharing to allow compliant referral sources to submit referrals easily.*
>
> [Strengths of our state's web-based referral system include:] • *Online accessibility in making a referral is an asset.* • *Simple to use/user friendly*

Most states with statewide referrals available offer more than one way to refer a child to Early Intervention. A typical combination of options within a state is a downloadable e-document sent to an email address/fax line and then a phone line for calling in referrals.

Qualitative Theme 3: Points of Entry

Part C Coordinators value a diversity of methods with which families and other sources may refer children to EI. Many states with web form referrals also make an e-document available, and only two states explicitly refuse e-document or fax-based referrals.

> *Relationships are strong in local communities and we accept referrals at the state and local level in a variety of formats.*
>
> *Any member of the public can access this database and make a referral for a child, or they are able to call/fax/in person a referral, which goes through the Central Referral Agency- who then will enter that into the online referral system.*

However, 15 states and jurisdictions do not offer a statewide referral form at the time of this study. While almost all have some form of a public-facing website containing contact information for the statewide EI agency, many of these 15 states and some with statewide forms direct families and referral sources to the local EI agency corresponding to the family's residence. Their websites contain labeled maps, lists, and search functions for the user to determine the correct agency themselves. Some states with state-level referral phone lines use the line to direct callers to their respective local agency to start the referral process there.

> *Most referrals are received directly by the local EI program. Local EI programs receive them through; fax, phone call and mail. Local representative [sic] would talk to the family and complete a referral form. Once a referral is received and the child is scheduled for an evaluation all the information is then stored in a statewide electronic data system.*
>
> [Our state's EI program] *does not have a standard, universal referral form for Early Intervention. Each local EI program/agency may develop their own referral form, however it is not required to be completed to make a referral. Many referrals are received by phone and do not require a referral form.*

For other states, this phone line serves as a statewide point of entry where the agency phone respondent enters referral data as they are relayed verbally to them by the referral source who calls. In some cases, the agency's own public-facing referral website serves as the data entry interface for the EI agency phone respondent.

> [Our state] *has a statewide phone number. The person that receives the call will complete a form that generates an electronic notice to the correct local EI program*
>
> *For those who call in to make a referral, the person that answers the phone then completes the online portal while speaking to them.*

Phone lines offer a personal interaction when submitting a referral that computers and fax machines usually do not. This may be particularly beneficial for use by parents and caregivers when referring a child. This may be supported by study data, as there is a weak correlation between the percent of referrals received by telephone and the percent of referrals received from the parent/caregiver (Spearman $r = 0.70$, $p = 0.007$).

Qualitative Theme 4: Balancing roles between local and state-level EI agencies

Local EI agency presence in their own communities is often the foundation for important relationships with referral sources, and statewide systems offering online referrals may not naturally contribute this local function. One state leader describes the data system as a pain point in relations with local agencies:

> [Our state's local programs] *are inconsistent in their approach to referrals with some not wishing to engage with a state-wide system.*

On the other hand, many statewide EI data systems enable state agencies to identify referral sources to whom targeted outreach is needed. How state and local EI agencies balance their roles with respect to one another is an important topic in understanding governmental influence on successful referrals of children to Early Intervention, and merits further exploration. Regardless, many Part C Coordinators value a centralized referral intake system.

> (What about your state's EI referral system works well?) *Central referral contact (phone/website) which distributes referrals to regional programs*
>
> (What would you change about your state's referral system?) *Develop centralized referral lines and locations to ensure better family engagement*

As described previously, the quality of information sent when sources refer a child to Early Intervention is sometimes inadequate. Under the federal Individuals with Disabilities Education Act (IDEA),[19] states granted funding for their Early Intervention programs must conduct outreach to families with children and potential referral sources. In addition to educating the public about EI, these activities are an opportunity for agency staff to form and reinforce relationships with potential referral sources. Part C Coordinators see these relationships as an important part of a successful program:

> (What would you change about your state’s referral system?) *With the online referral option everyone has access, however, there are still some communities unaware of the impact of EI services and are waiting too long to make referrals. We continue to work on robust public awareness activities which include the benefits of EI.*
>
> (What would you change about your state’s referral system?) *Continuous statewide technical assistance to primary referral sources regarding the type of information, the frequency of submission and the appropriate follow up for making a referral would go a long way to making the system better.*
>
> (What about your state’s EI referral system works well?) *Local agencies had made relationships with local referral sources in order to ensure appropriate referrals are being made and provide consistent ways to make these referrals.*

Qualitative Theme 5: Emerging Trends

While web forms offer relative ease for people who have computer and internet access to refer children, healthcare providers need the efficiency offered by integrating tasks into their electronic health record. Thirty-four percent of state Part C Coordinators indicate that EI referrals can be sent electronically from an EHR in their state, and 24% have non-healthcare agencies that can send referrals electronically. Based on the data presented above, this most likely takes the form of an e-document sent using email or EHR-based facsimile functions. While few state EI agencies (8%) claim use of a direct EHR-to-agency Health Level Seven-based connection for referral transmission, Part C Coordinators expressed desire for electronic system interoperability when asked “How would you make [your state]’s EI referral system better?”:

> *Integration of the online referral system to physicians EHR system would also be beneficial.*
>
> *Not linked to EHRs yet. We are in the middle of a redesign. Ask me in 6 months!*

Lastly, state EI leaders express interest in outreach to families using digital technology.

> *Something that could improve the process in the future us [sic] having the ability to receive referrals from texts or apps.*
>
> *We do miss out on some families who only want to text or e-mail and we don't have secure log in for HIPAA/FERPA compliance to accept those.*

As of April of 2020, two states offer an app for mobile devices with which parents and others may access information about referring a child to EI in their state. As the last respondent describes, data security can be a barrier to this outreach. One state’s web form referral system addresses this challenge by requiring users to register for an account and validate an email address before granting permission to access it. Once registered, the user may save and later access their own contact information, profiles of children to refer, and pending or sent referrals.

DISCUSSION

This study describes the processes of referral of children to EI from the perspective of state Early Intervention agency leaders. As reviewed in the introduction, the need for better communication and information exchange between parents, referral sources and their respective Early Intervention agencies is clear. Here we lay groundwork that will contribute to this improvement.

Anyone who aims to improve referral completion rates and access by children most in need should consider that EI referrals at a minimum need to contain family contact information, reason for referral, and referral source information. The notable absence of Release of Information for many states does not indicate that it is less important. Instead, it signals that consent documentation, usually involving a handwritten signature, presents a challenge different from the rest of the referral process. These results provide direction for future work building templates for data standards and messaging structures such as FHIR resources. For example, on an electronic universal EI referral template, the remaining fields beyond family contact, reason for referral, and referral source could be made optional or user-configurable. Documenting consent in such a template should support various methods, such as document upload or electronic authentication. Lastly, a follow up telephone conversation between agency staff receiving the referral and the parent to explain EI and discuss the parent's developmental concerns is an important part of the process. Future study of information exchanged during these calls would enhance our understanding of their role and inform new solutions to improve EI referral.

Medical professionals comprise the main group sending referrals; however, parents and families are important contributors and comprise the largest group in some states. Statewide referral forms are usually intended to include at least healthcare professionals as users, although 14% of states with statewide forms clearly state that anyone can use their form to refer a child to EI. This suggests that while EI agencies consider healthcare professionals core referral sources and referral form users, they might improve their accessibility by specifically supporting form use by other community professionals and parents. For parents and caregivers, states should accordingly put more emphasis on referral technology now more common in the home such as telephones, websites, and mobile applications.

Text on the statewide referral form appears only in English for 72% of states and territories. Again, this may reflect the fact that forms are largely designed to be used by healthcare and other professionals, most of whom are likely proficient in English. However, to the extent that parents and caregivers use these forms, this is another opportunity to improve accessibility for parents who are English language learners. Automation of form translation may be a viable solution, as five states (14%) have an auto translator installed on their web forms. Credible authorities should verify the quality of the translations. A useful area of study would be the acceptability and use rate of these drop-down translators and their effect on referrals from families of English language learners. In addition, to maximize accessibility of the process overall, forms presented in any language should include the family's preferred language as one of their requested data fields.

Race is requested on only two-fifths of statewide forms. The Individual with Disabilities Education Act requires states to report race data on children who have an established treatment plan (Individual Family Service Plan, IFSP), but not on children referred to EI.[26,59] It may be for this reason that national publicly available data on race of children at the point of referral appears to be limited to scientific studies that characterize the EI access pipeline for specific populations.[32,33,44] Since referral forms represent children at an important step in the process to access EI, race and ethnicity data should be collected on all of them and used to evaluate equitable distribution of scarce program resources. Such a practice might be encouraged by a statement from the AAP, and facilitated by conformity with standard formats such as those used by the United States Census Bureau.[60]

As to how EI referrals are received, state EI leaders reported a variety of combinations of telephone, facsimile, e-documents, web forms, and structured electronic means. While phone calls play an important role in all states, no states reported both fax and any electronic means as major components. This suggests that electronic means are taking the place of fax. However, full electronic interoperability can be resource intensive and may require legislation and additional funding to accomplish widely. In the meantime, e-documents received via email will likely persist due to their low cost and minimal technology requirements. But as a near-term improvement with potential to reduce manual data extraction, web-based referrals offer a useful combination of flexibility, accessibility, and cost. Despite a move towards more electronic referral methods, state EI leaders do value and should continue to provide multiple routes of referral to maximize access to their programs. We suggest that a move away from referrals transmitted by fax should not decrease access to Early Intervention as long as access to email and telephone remains prevalent.

Accuracy and completeness of referral data describe an important theme in Part C Coordinators' treatment of this topic. Although web forms cannot prevent all problems with accuracy and completeness,[61] Part C Coordinators appreciate and anticipate improvements in accuracy their required fields offer. Web forms may also offer automatic form translation, role-based presentation of questions, and ease of revision not found on static e-documents or paper forms. However, they likely require technical skills more advanced than email and word processing.

Perhaps most importantly, states must take electronic upgrade opportunities to address historical sticking points in the access pipeline for children and their families entering EI. This means maximizing parent engagement by adding public-facing user-centered interfaces that take advantage of mobile technology. It also means improving accessibility with support for English language learners, parents with low literacy, documentation of parental consent, and for families with limited internet access. In best cases, using an equity lens, states would develop their information system improvements in ways that incorporate the voices of all system users, with particular attention to highly impacted communities.

Limitations of this mixed-methods study include its cross-sectional nature, which limits causal inference, and that it samples perspectives of organization representatives but not others working “in the trenches” of the EI referral process. While not every state is represented here, the survey’s high response rate and negative response bias analysis should minimize this limitation. Feasibility informed the decision to consider states as the primary unit of analysis, acknowledging that it limits the sample size while appropriately representing a national sample. While using a survey limits our ability to verify respondents’ understanding of the questions, the questionnaire was developed with input from appropriate experts, and free text responses and follow up communications by email aided in interpretation. Lastly, since many of the state EI agencies participating in the survey do not regularly collect data on the way in which new referrals arrive, these results should be treated as estimations only.

Although surveys with similar content have been conducted by the Early Childhood Data Collaborative[41] and the IDEA Infant and Toddler Coordinators Association,[43] we are not aware of research that explores referral methods on a national level. Our results are consistent with these existing survey results in that most EI agencies have statewide data systems holding demographic and program data about the children they serve. Their results also describe the low proportion of EI agencies describing data linkages or exchanges with healthcare data systems, especially clinical electronic systems. They do not, however, focus on data or processes involved in EI referral. In addition, this may be the first study to describe EI referral forms themselves.

Notably relevant to this topic is the experience of Early Hearing Detection and Intervention initiatives in the United States over the last 30 years.[62] Early detection of hearing loss in infants under 3 months old became feasible in the 1990's and enabled a great push for Universal Newborn Hearing Screening. The campaign was propelled in part by its potential to minimize the effects of congenital hearing loss on child development with early identification and treatment. The 2000's saw success in making hearing screening standard practice by birthing hospitals, with more than 95% of newborns in the United States screened annually by 2010. But many of these infants were later lost to follow up. The name became Early Hearing Detection and Intervention (EHDI) to reflect all the steps of infant tracking, diagnosis, intervention, and program quality improvement. With this new emphasis and data system enhancements, the national average rate of EHDI loss to follow up went from 48% in 2006 to 25% by 2017.

This success story parallels that of Early Intervention programs beyond their both simply describing early childhood screening and treatment. Barriers for EHDI programs are similar to those identified for Early Intervention, and their approach to improvement with data systems and care coordination are similar to those we propose here.[63] EHDI organization experiences and solutions prove invaluable when applied to developmental screening and Early Intervention. As an example, Health Level Seven International's HL7 version 2.6 messaging standard includes an implementation guide for exchanging EHDI results between health and other electronic information systems.[64]

Lastly, while states have accomplished various levels of data integration with their early childhood data, one state in particular stands out. Massachusetts' Pregnancy to Early Life Longitudinal (PELL) Data System links "state birth, death, and hospital records to data on Part C referral and EI entrance"[44] and thus allows longitudinal program evaluation and observation of risk cohorts. Massachusetts' example can provide a model for similar efforts going forward, including exploration of their use of information technology to enhance referrals of children to EI.

CONCLUSION

Early Intervention can provide children the opportunity to achieve maximum academic and life success. However, too many families referred to EI in the US are still lost to follow up, denying tens of thousands of eligible children potentially life-changing services to which they are entitled. The referral pipeline is slowly transitioning towards electronic processes that could improve referral completion, but this occurs without the help of uniform data standards, federal reporting requirements, or additional funding. Until we move beyond the emails and email attachments we have used for the last fifteen years it will be difficult to make progress towards referral tracking, reduction in manual data extraction, and accessibility improvements.

Referral processes are in various stages of transition toward electronic methods, from traditional fax machines to electronic documents, to user-entered information on a website or a mobile application, to data exchanges with Electronic Health Records. Electronic communication directly between data systems may enable referral tracking and improvements in follow up, but may be cost-prohibitive. While at present most states rely on electronic documents that require manual data extraction, web-based referral forms seem to offer advantages to families and EI programs and could be a medium-term goal for state EI agencies. Offering a diversity of means for program access is important. Continuing to receive referrals by phone or mobile application and using web forms with support for English language learners or those with low literacy should provide some of this diversity. EI agencies should collect disparities data about children earlier in the pipeline in order to identify opportunities to partner with families to achieve more equitable service delivery. The experiences of Early Hearing Detection and Intervention programs offer models from which states may further develop their referral systems.

This study provides insight into ways that information technology could be used to improve referral completion. Additional research is needed to understand the perspectives of all participants in the EI referral process in order to develop and evaluate solutions that engage families, promote communication, enable data exchange across institutions, and track children throughout the EI access pipeline. In these ways, more of our most vulnerable children can be connected to the services that can help them maximize their developmental potential and life success.

REFERENCES

1. Boyle CA, Boulet S, Schieve LA, Cohen RA, Blumberg SJ, Yeargin-Allsopp M, et al. Trends in the prevalence of developmental disabilities in US children, 1997-2008. Pediatrics. 2011;127(6):1034-42. doi: https://doi.org/10.1542/peds.2010-2989.
2. Guralnick MJ. Effectiveness of early intervention for vulnerable children: a developmental perspective. Am J Ment Retard. 1998;102(4):319-45. doi: https://doi.org/10.1352/0895-8017(1998)102<0319:eoeifv>2.0.co;2.
3. Love JM, Kisker EE, Ross C, Raikes H, Constantine J, Boller K, et al. The effectiveness of early head start for 3-year-old children and their parents: lessons for policy and programs. Dev Psychol. 2005;41(6):885-901. doi: https://doi.org/10.1037/0012-1649.41.6.88.
4. Barnett WS. Effectiveness of Early Educational Intervention. Science. 2011;333(6045):975-8. doi: https://doi.org/10.1126/science.1204534.
5. Heckman JJ. Skill Formation and the Economics of Investing in Disadvantaged Children. Science. 2006;312(5782):1900-2. doi: https://doi.org/10.1126/science.1128898.
6. Rosenberg AS, Robinson CC, Shaw FE, Ellison CM. Part C early intervention for infants and toddlers: percentage eligible versus served. Pediatrics. 2013;131(1):38-46.
7. Rosenberg AS, Zhang D, Robinson CC. Prevalence of developmental delays and participation in early intervention services for young children. Pediatrics. 2008;121(6):e1503-e9.
8. McManus BM, Richardson Z, Schenkman M, Murphy NJ, Everhart RM, Hambidge S, et al. Child characteristics and early intervention referral and receipt of services: a retrospective cohort study. BMC Pediatr. 2020;20(1):84. doi: https://doi.org/10.1186/s12887-020-1965-x.
9. Guevara PJ, Gerdes M, Localio R, Huang VY, Pinto-Martin J, Minkovitz SC, et al. Effectiveness of developmental screening in an urban setting. Pediatrics. 2013;131(1):30-7.
10. Jimenez EM, Fiks GA, Shah RL, Gerdes M, Ni YA, Pati S, et al. Factors associated with early intervention referral and evaluation: a mixed methods analysis. Academic pediatrics. 2014;14(3):315-23.
11. Jimenez EM, Barg KF, Guevara PJ, Gerdes M, Fiks GA. Barriers to evaluation for early intervention services: parent and early intervention employee perspectives. Academic pediatrics. 2012;12(6):551-7.
12. Magnusson DM, Minkovitz CS, Kuhlthau KA, Caballero TM, Mistry KB. Beliefs regarding development and Early Intervention among low-income African American and Hispanic mothers. Pediatrics. 2017;140(5). doi: https://doi.org/10.1542/peds.2017-2059.
13. Twardzik E, Cotto-Negrn C, MacDonald M. Factors related to Early Intervention Part C enrollment: a systematic review. Disability and health journal. 2017;10(4):467-74.
14. Marks KP, Griffen AK, Herrera P, Macias MM, Rice CE, Robinson C. Systemwide solutions to improve Early Intervention for developmental-behavioral concerns. Pediatrics. 2015;136(6):e1492-4. doi: https://doi.org/10.1542/peds.2015-1723.
15. Shah RP, Kunnavakkam R, Msall ME. Pediatricians' Knowledge, Attitudes, and Practice Patterns Regarding Special Education and Individualized Education Programs. Academic Pediatrics. 2013;13(5):430-5. doi: https://doi.org/10.1016/j.acap.2013.03.003.
16. Sheppard ME, Vitalone-Raccaro N. How physicians support children with disabilities and their families: Roles, responsibilities and collaborative partnerships. Disability and Health Journal. 2016;9(4):692-704. doi: https://doi.org/10.1016/j.dhjo.2016.05.007.
17. Lemkin A, Walls M, Kistin CJ, Bair-Merritt M. Educators' Perspectives of Collaboration with Pediatricians to Support Low-Income Children. Journal of School Health. 2019;89(4):300-7.
18. Ritzema AM, Sladeczek IE, Ghosh S, Karagiannakis A, Manay-Quian N. Improving Outcomes for Children with Developmental Disabilities through Enhanced Communication and Collaboration between School Psychologists and Physicians. Canadian Journal of School Psychology. 2014;29(4):317-37.
19. United States Department of Education. IDEA Individuals with Disabilities Education Act: About IDEA [website]. [cited 2018 December 4]. Available from: https://sites.ed.gov/idea/about-idea/.

20. United States Department of Education. Programs: Early Intervention Program for Infants and Toddlers with Disabilities [website]. [cited 2018 December 4]. Available from: https://www2.ed.gov/programs/osepeip/index.html.
21. Campbell F, Conti G, Heckman JJ, Moon SH, Pinto R, Pungello E, et al. Early Childhood Investments Substantially Boost Adult Health. Science. 2014;343(6178):1478-85. doi: https://doi.org/10.1126/science.1248429.
22. Camilli G, Vargas S, Ryan S, Barnett WS. Meta-analysis of the effects of early education interventions on cognitive and social development. Teachers college record. 2010;112(3):579-620.
23. Shonkoff JP, Phillips DA, Committee on Integrating the Science of Early Childhood D, Board on Children Y, Families, Division of B, et al. From Neurons to Neighborhoods : The Science of Early Childhood Development. Washington, D.C., UNITED STATES: National Academies Press; 2000.
24. Sheldrick RC, Frenette E, Vera JD, Mackie TI, Martinez-Pedraza F, Hoch N, et al. What Drives Detection and Diagnosis of Autism Spectrum Disorder? Looking Under the Hood of a Multi-stage Screening Process in Early Intervention. Journal of autism and developmental disorders. 2019. doi: https://doi.org/10.1007/s10803-019-03913-5.
25. Corr C, Santos RM, Fowler SA. The Components of Early Intervention Services for Families Living in Poverty: A Review of the Literature. Topics in Early Childhood Special Education. 2016;36(1):55-64. doi: https://doi.org/10.1177/0271121415595551.
26. United States Department of Health and Human Services and the United States Department of Education. The integration of early childhood data: state profiles and a report 2016 [Available from: https://www2.ed.gov/about/inits/ed/earlylearning/files/integration-of-early-childhood-data.pdf.
27. Conroy K, Rea C, Kovacikova GI, Sprecher E, Reisinger E, Durant H, et al. Ensuring Timely Connection to Early Intervention for Young Children With Developmental Delays. Pediatrics. 2018;142(1):e20174017. doi: https://doi.org/10.1542/peds.2017-4017.
28. Jimenez ME, Barg FK, Guevara JP, Gerdes M, Fiks AG. The impact of parental health literacy on the early intervention referral process. Journal of health care for the poor and underserved. 2013;24(3):1053-62.
29. Marshall J, Adelman A, Kesten SM, Natale RA, Elbaum B. Parents' Experiences Navigating Intervention Systems for Young Children With Mild Language Delays. Journal of Early Intervention. 2017;39(3):180-98. doi: https://doi.org/10.1177/1053815117704958.
30. Morgan P, Hammer C, Farkas G, Hillemeier M, Maczuga S, Cook M, et al. Who Receives Speech/Language Services by 5 Years of Age in the United States? American Journal of Speech-Language Pathology. 2016;25(2):183-99. doi: https://doi.org/10.1044/2015_AJSLP-14-0201.
31. Barfield WD, Clements KM, Lee KG, Kotelchuck M, Wilber N, Wise PH. Using linked data to assess patterns of early intervention (EI) referral among very low birth weight infants. Matern Child Health J. 2008;12(1):24-33. doi: https://doi.org/10.1007/s10995-007-0227-y.
32. Feinberg E, Silverstein M, Donahue S, Bliss R. The impact of race on participation in part C early intervention services. J Dev Behav Pediatr. 2011;32(4):284-91. doi: https://doi.org/10.1097/DBP.0b013e3182142fbd.
33. Morgan PL, Farkas G, Hillemeier MM, Li H, Pun WH, Cook M. Cross-Cohort Evidence of Disparities in Service Receipt for Speech or Language Impairments. Exceptional Children. 2017;84(1):27-41. doi: https://doi.org/10.1177/0014402917718341.
34. Mani A, Mullainathan S, Shafir E, Zhao J. Poverty impedes cognitive function. Science. 2013;341(6149):976-80.
35. Edwards NM. The Role of Mentors in Early Intervention Referrals: Overlooked Views of Pediatric Residency Training Directors. Maternal and Child Health Journal. 2018;22(5):745-52. doi: https://doi.org/10.1007/s10995-018-2443-z.
36. Elansary M, Silverstein M. Understanding Gaps in Developmental Screening and Referral. Pediatrics. 2020;145(4). doi: https://doi.org/10.1542/peds.2020-0164.
37. IOM (Institute of Medicine) NNRC, Committee on Early Childhood Care and Education Workforce: A Workshop, Board on Children Youth and Families,. The early childhood care and education workforce - Challenges and opportunities: A workshop report. Washington, D.C.: National Academies Press; 2012.
38. National Research Council (U.S.). Committee on the Science of Children Birth to Age 8: Deepening and Broadening the Foundation for Success Board on Children Youth and Families, Allen L, Kelly

BB. Transforming the workforce for children birth through age 8 : a unifying foundation. Washington, D.C.: The National Academies Press; 2015. xvi, 689 pages p.

39. Vail CO, Lieberman-Betz RG, McCorkle LS. The Impact of Funding on Part C Systems: Is the Tail Wagging the Dog? Journal of Early Intervention. 2018;40(3):229-45. doi: https://doi.org/10.1177/1053815118771388.
40. Houston KT, Behl DD, White KR, Forsman I. Federal privacy regulations and the provision of early hearing detection and intervention programs. Pediatrics. 2010;126(SUPPL. 1):S28-S33. doi: https://doi.org/10.1542/peds.2010-0354G.
41. King C, Perkins V, Nugent C, Jordan E. 2018 State of State Early Childhood Data Systems. The Early Childhood Data Collaborative; 2018 September. Available from: https://www.ecedata.org/wp-content/uploads/2018/09/ECDC-50-state-survey.pdf.
42. United States Department of Education. Fundamental Change - Innovation in America?s Schools Under Race to the Top. 2015 November 1. Available from: https://www2.ed.gov/programs/racetothetop/rttfinalrpt1115.pdf.
43. 2013 The Status of Part C Data Systems. IDEA Infant & Toddler Coordinators Association,; 2013. Available from: https://www.ideainfanttoddler.org/pdf/2013-Status-of-Part-C-Data-Systems.pdf.
44. Barger B, Rice C, Simmons CA, Wolf R. A systematic review of Part C Early Identification studies. Topics in Early Childhood Special Education. 2018;38(1):4-16. doi: https://doi.org/10.1177/0271121416678664.
45. Adams RC, Tapia C. Early intervention, IDEA Part C services, and the medical home: collaboration for best practice and best outcomes. Pediatrics. 2013;132(4):e1073-88. doi: https://doi.org/10.1542/peds.2013-2305.
46. Kasprzak C, Hebbeler K, Spiker D, McCullough K, Lucas A, Walsh S, et al. A State System Framework for High-Quality Early Intervention and Early Childhood Special Education. Topics in Early Childhood Special Education. 2019. doi: https://doi.org/10.1177/0271121419831766.
47. King MT, Tandon DS, Macias MM, Healy AJ, Duncan MP, Swigonski LN, et al. Implementing developmental screening and referrals: lessons learned from a national project. Pediatrics. 2010;125(2):350-60.
48. Council on Children With Disabilities, Section on Behavioral Developmental Pediatrics, Bright Futures Steering Committee, Advisory Committee Medical Home Initiatives for Children With Special Needs Project. Identifying Infants and Young Children With Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening. Pediatrics. 2006;118(1):405-20.
49. Brown CM, Beck AF, Steuerwald W, Alexander E, Samaan ZM, Kahn RS, et al. Narrowing Care Gaps for Early Language Delay:A Quality Improvement Study. Clinical Pediatrics. 2016;55(2):137-44. doi: https://doi.org/10.1177/0009922815587090.
50. Nelson BB, Thompson LR, Herrera P, Biely C, Arriola Zarate D, Aceves I, et al. Telephone-Based Developmental Screening and Care Coordination Through 2-1-1: A Randomized Trial. Pediatrics. 2019;143(4):e20181064. doi: https://doi.org/10.1542/peds.2018-1064.
51. ECTA Early Childhood Technical Assistance Center. Chapel Hill: Frank Porter Graham Child Development Institute; [updated 2012-2020; cited 2020 March 23]. Available from: https://ectacenter.org/contact/ptccoord.asp.
52. Real Statistics Resource Pack software (Release 6.8). Copyright (2013 - 2020) Charles Zaiontz. www.real-statistics.com.
53. Duby JC, American Academy of Pediatrics Council on Children with Disabilities. Role of the medical home in family-centered Early Intervention services. Pediatrics. 2007;120(5):1153-8. doi: https://doi.org/10.1542/peds.2007-2638.
54. Twardzik E, MacDonald M, Dixon-Ibarra A. The Relationship Between State Lead Agency and Enrollment Into Early Intervention Services. Journal of Early Intervention. 2017;39(3):253-63. doi: https://doi.org/10.1177/1053815117708999.
55. Twardzik E. Personal Communication. Data file listing classification of states by lead EI agency type based on prior research, see Twardzik 2017 Relationship Between... ed2020.
56. IDEA Infant Toddler Coordinators Association [website]. [updated 20206/8/20]. Available from: https://www.ideainfanttoddler.org/index.php.
57. Common Education Data Standards [website]. National Center for Education Statistics; 2020 [cited 2020 May 10]. Available from: https://ceds.ed.gov/.

58. Health Level Seven International (HL7) [website]. Ann Arbor, MI: Health Level Seven International; 2020 [cited 2020 May 10]. Available from: http://www.hl7.org/.
59. Office of Special Education Programs Monitoring and State Improvement Planning Division. About OSEP & MSIP & IDEA Part B & Part C SPP APRs [6/23/20]. Available from: https://osep.grads360.org/#program/about.
60. United States Census 2020. Questions Asked on the Form [6/23/30]. Available from: https://2020census.gov/en/about-questions.html.
61. Ash JS, Sittig DF, Dykstra R, Campbell E, Guappone K. The unintended consequences of computerized provider order entry: findings from a mixed methods exploration. Int J Med Inform. 2009;78 Suppl 1:S69-76. doi: https://doi.org/10.1016/j.ijmedinf.2008.07.015.
62. White KR, Forsman I, Eichwald J, Munoz K. The evolution of early hearing detection and intervention programs in the United States. Semin Perinatol. 2010;34(2):170-9. doi: https://doi.org/10.1053/j.semperi.2009.12.009.
63. Shulman S, Besculides M, Saltzman A, Ireys H, White KR, Forsman I. Evaluation of the universal newborn hearing screening and intervention program. Pediatrics. 2010;126 Suppl 1:S19-27. doi: https://doi.org/10.1542/peds.2010-0354F.
64. HL7 Version 2.6 Implementation Guide: Early Hearing Detection and Intervention (EHDI) Results, Release 1. Health Level Seven International; 2018 September. Report No.: V26_IG_EHDI_R1_N1_2018SEP. Available from: https://www.hl7.org/implement/standards/product_brief.cfm?product_id=344.

APPENDIX: SURVEY QUESTIONS

Begin Section: **Referral forms**

Many state EI agencies have a standard EI referral form that referral sources (for instance, doctors or child care providers) can use to send you the information you need about a child. This is often a PDF or Word document than can be downloaded.

1. Does your agency (or parts of it) use one or more standard EI referral form(s)?
   Check all that apply.
   ☐ No
   ☐ Yes, a statewide form(s) (you'll have an opportunity to point us to them at the end of the survey)
   ☐ Yes, regions or agencies have different forms/versions of forms. (you'll have an opportunity…)
   ☐ Don't know/ not sure

2. Of all the EI referrals that [your state]'s EI program receives, about what **percent** are on one of these standard forms? If you are unsure, make your best guess.
   Slide the ball to indicate your answer.
   [slider ranges from 0 to 100, user adjusts position to answer]

[Comment section is presented 4 times throughout the survey.]
Comments **Comments** (Optional)
This is the same comment box throughout your questionnaire, so please note the topics you are referring to.
____

Begin Section: **Referral sources**

Most EI agencies receive Early Intervention referrals from a variety of sources.

3. Can you estimate the **percent** of referrals that each of your typical sources (e.g. parent/family vs. doctor/clinic... etc.) contribute?
   Choose one.
   ○ Sure, I'll do my best!
   ○ Our state doesn't collect this data.
   ○ Our state collects this data, but I don't have it to answer this question.
   ○ Don't know/ not sure
   ○ Other: ____

3.1. Would you like to try to estimate anyway?
   ○ Ok, I'll give it a try
   ○ Nope, it would do more harm than good. Let's keep going...

3.2. What **percent** of EI referrals does [your state] get from each of these sources? *Make your best guess or use data from [your state]'s most recent annual data if readily available. (put 0 if none)*
   - Parent/family member makes up: _______
   - Doctor/Clinic/Hospital make up: _______
   - Childcare/Head Start/Preschool make up: _______
   - Child protective services makes up: _______
   - Others: (optional specify) _______
   - Total ________

A referral to Early Intervention may be sent one way and received another. For example, a doctor might send a referral from her electronic health record (EHR or EMR) to a regular fax machine in an EI office.

4. Which methods may people use to **<u>send</u>** referrals to Early Intervention in [your state]? *Check all that apply.*
   - ☐ Fax machine: Sent from a physical fax machine. NOT including electronic/online fax sending.
   - ☐ Telephone call: giving referral info by speaking over the telephone
   - ☐ In person: speaking face to face with an EI representative to give referral info
   - ☐ Website: a person fills out referral info on a website
   - ☐ Postal mail
   - ☐ Email: referral info in message body, or as an attachment
   - ☐ Electronically from clinic or hospital electronic health record systems.
     - Examples: Epic, Cerner or other. Include faxes sent electronically from these clinics or hospitals.
   - ☐ Electronically from another agency's data system.
     - Example: foster care system or public health nursing system. Include faxes sent electronically from these agencies.
   - ☐ Apps for mobile devices: App (not a website) downloaded onto a smart phone or tablet, that sends the referral to EI.
   - ☐ Other: ____

5. As mentioned in the previous question, a referral to Early Intervention may be sent one way but received by EI in a different way.
   Which methods of **<u>receiving</u>** Early Intervention referrals are supported in [your state]? *Check all that apply.*
   - ☐ Fax machine: Received by EI at a physical fax machine, regardless of whether sent by fax or computer system. NOT including electronic/online fax receiving.
   - ☐ Telephone call: EI receives referral info by speaking over the telephone
   - ☐ In person: speaking face to face with referring adult to receive referral info
   - ☐ Postal Mail
   - ☐ Email: referral info in message body, or as an attachment
   - ☐ Electronically: EI computer systems receive the referral directly . Include referrals received electronically, whether sent using a computer system, website, mobile device app, and faxes received electronically.
   - ☐ Other: ____

6. Can you estimate the percent of referrals that [your state] **<u>receives</u>** through these different methods? *Choose one.*
   - ○ Sure! I'll do my best.
   - ○ Our state doesn't collect this data.
   - ○ Our state collects this data, but I don't have it to answer this question.
   - ○ Don't know/ not sure
   - ○ Other: ____

6.1. Would you like to try to estimate anyway?
   - ○ Ok, I'll give it a try
   - ○ Nope, it would do more harm than good. Let's keep going...

6.2. What **percent** of referrals does [your state] **<u>receive</u>** through each of these different methods? *Make your best guess or use data from [your state]'s most recent annual data if readily available. (put 0 if none)*
   - Faxes make up: _______
   - Telephone calls make up: _______
   - Emails make up: _______
   - Postal mail makes up: _______
   - In person makes up: _______
   - Electronic makes up: _______
   - Other (optional specify): _______

- Total: ________

Begin Section: **Electronic systems**

This section has questions about the electronic systems in [your state] and the data they contain. We've done our best to make them understandable to people of lots of different backgrounds. It's ok if you don't know the answer to them, but we're asking just in case you do know.

7. Is/are there one or more state-wide **data systems** that your EI agency uses to store information about children who are referred to EI or who are receiving EI services? Include data systems that are accessed using a website. *Choose one.*
   ○ Yes Please include its name (if any):______________________________
   ○ No
   ○ Don't know/ Not sure

8. What data and functions does this system contain? *Check all that apply.*
   ☐ Demographic info like sex, race/ethnicity, date of birth, address
   ☐ Unique identifiers, like Medicaid IDs, social security numbers, or another individual number that your EI program assigns
   ☐ EI Eligibility info, like whether a child qualified for EI services
   ☐ Info about the content of a child's current or past IFSP (Individualized Family Service Plan)
   ☐ Info about EI Services Delivered, like a record of services actually received by a child
   ☐ Data about participation in other programs/services from ages 0 - 35 months (for example, WIC or Early Head Start)
   ☐ EI Enrollment status as defined by IDEA regulation, or other definition
   ☐ Capability of EI reporting to State or Federal governments
   ☐ Info about a child's transition to Early Childhood Special Education (ECSE, IDEA Part B), up to and including their eligibility determination
   ☐ Info about what ECSE services a child receives after transition, or the results of her ECSE participation after transition
   ☐ Don't know/ Not sure

9. DOES this system use the Common Education Data Standards (CEDS, found at https://ceds.ed.gov/)? It's ok if you don't know the answer.

   The Common Education Data Standards (CEDS, unrelated to Common Core State Standards) are a set of commonly agreed upon names and definitions that standardize how computers handle educational data. Using these standards allows education computer systems to exchange information easily to support reporting, research, benchmark comparisons, and more. *Choose one.*
   ○ Yes, its database is based on CEDS.
   ○ Its database is not based on CEDS, but it does interface with other systems that are based on the CEDS data standard.
   ○ It CAN use CEDS or interface with other systems that are based on CEDS, but *this capability is not in use*.
   ○ No, but we are planning to make our system use it in the future.
   ○ No, we don't currently have plans to make our system do so.
   ○ Other: ____
   ○ Don't know/ not sure.

10. DOES this system use a Health Level Seven messaging/data standard, such as HL7 (versions 1-3) or Fast Health Interoperability Resources (FHIR, all found at http://www.hl7.org/)? Again, it's ok if you don't know the answer.

    HL7 and FHIR are standards for the exchange of electronic health information. They define how information is packaged and communicated from one party to another, setting the language, structure and data types required for seamless integration between systems. *Choose one.*
    ○ Yes, it does interface with other systems using either/both HL7 or FHIR.
    ○ It CAN use HL7 and/or FHIR to communicate with other systems, but *this capability is not in use.*
    ○ No, but we are planning to make our system do so in the future.

- ○ No, we don't currently have plans to make our system do so.
- ○ Other: ____
- ○ Don't know/ not sure.

11. Earlier, you may have mentioned that your state's EI program (or some part of it) can receive EI referrals electronically.
    If so, in what data type is the electronic referral received? *Check all that apply.*
    - ☐ EI referrals are NOT received electronically in my state, to the best of my knowledge.
    - ☐ Electronic Document: Usually as a PDF or Word document.
        - *Details:* a user must print or open the document and read it to know specific information about the child's development, risk factors, or questionnaire scores.
    - ☐ Discrete or structured data: Computer system recognizes incoming data as data about the child's development.
        - *Details*: Once referral received in the system, a user can electronically access and use specific system data from the referral about the child's development, risk factors, or questionnaire scores.
    - ☐ Metadata: Information about the referral (but not its contents) that is recognized by the electronic system.
        - *Details*: May include date & time referral sent, personal identifiers but NOT specific information about the child's development, risk factors, or questionnaire scores.
    - ☐ Other: ____
    - ☐ Don't know/ not sure.

Begin Section: **Strengths and challenges**

12. What about [your state]'s EI referral system **works well**?
    ____

13. What about [your state]'s EI referral system **doesn't work well**?
    ____

14. How would you make [your state]'s EI referral system **better**?
    ____

Begin Section: **Personal data**

15. What is the highest degree or level of school you have **COMPLETED**? If currently enrolled, mark the previous level or highest degree received. *Choose one.*
    - ○ Less than a college degree
    - ○ Associate's degree (for example: AA, AS)
    - ○ Bachelor's degree (for example: BA, BS)
    - ○ Master's degree (for example: MA, MS, MEng, MEd, MSW, MBA)
    - ○ Doctorate or professional degree beyond a bachelor's (for example: PhD, EdD, MD, DDS, DVM, LLB, JD)

16. What year did you complete this degree or level of school? *4-digit year (YYYY) between 1920 and 2020.* ____

17. What is your job title? _________________________

18. How long have you worked in your current position?
    Years (0-75) _________________________
    Months (0-11) _________________________

19. Overall, how familiar are you with the EI referral process in your state? *Choose one*.
   - ○ Extremely familiar
   - ○ Very familiar
   - ○ Moderately familiar
   - ○ Slightly familiar
   - ○ Not familiar at all

Begin Section: **EI referral form upload**

20. [referral form upload]

Begin Section: **We need your expertise!**

21. [seeking volunteers for interviews]