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Parent and Provider Perspectives on Early Intervention in Ohio: A Community Collaborative Approach

Jessa Reed, PhD[1]
Ursula M. Findlen, PhD[1,2]
Carrie A. Davenport, PhD[1]
Cheryl DeConde Johnson, EdD[3]
Maria Sentelik, MS[4]
Carrie Spangler, AuD[5]
Wendy Steuerwald, AuD[6]
Derek Houston, PhD[1]

[1]The Ohio State University Wexner Medical Center, Columbus, OH
[2]Nationwide Children's Hospital, Columbus, OH
[3]The ADEvantage Consulting, Leadville, CO
[4]Ohio Valley Voices, Loveland, OH
[5]Summit County Educational Service Center, Cuyahoga Falls, OH
[6]Phoenix Children's Hospital, Phoenix, AZ

Abstract

The network of early intervention (EI) for families with children who are deaf or hard of hearing (DHH) consists of multiple professionals that partner with parents. As part of a community collaborative initiative, diverse perspectives were gathered via online surveys in a state-wide needs assessment to evaluate the landscape of EI in Ohio. The qualitative and quantitative feedback were analyzed in light of the Joint Committee on Infant Hearing's (2007) goals, the 2013 early intervention supplement to those goals, and 2019 update. Care coordination and equitable access emerged as top priorities across all three stakeholder groups queried (audiologists, EI providers, and parents). Through a theory of change framework, these results offer a pathway to strengthening EI to promote the well-being of families and children who are DHH.

Keywords: early intervention, theory of change

Acronyms: ASL = American Sign Language; AVT = Auditory-Verbal Therapy; DHH = deaf or hard of hearing; EHDI = Early Hearing Detection and Intervention; EI = early intervention; PSP = primary service provider

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Correspondence concerning this article should be addressed to: Ursula M. Findlen, PhD, Nationwide Children's Hospital, 700 Children's Drive, OCC-7, Columbus, OH 43205. Email: ursula.findlen@nationwidechildrens.org; Phone: 614-722-6526.

Early intervention (EI) promotes positive outcomes for children who are deaf or hard of hearing (DHH). Language development flourishes when parents provide contingent, responsive input (Dave et al., 2018; Madigan et al., 2019; Masek et al., 2021; Olson & Masur, 2015). Because approximately 95% of children who are DHH are born to hearing parents, there is a critical need for parents to receive support in fostering their child's language development (Mitchell & Karchmer, 2004). EI providers who work with families and children who are DHH should be equipped to provide caregivers with specialized knowledge about the language and communication needs of children who are DHH so that caregivers may engage with their child in developmentally-appropriate ways (JCIH, 2019). Child outcomes benefit in both the short-term with improved vocabulary in toddler years (Yoshinaga-Itano et al., 2017) and in the long-term, reflected in stronger verbal comprehension and expressive language scores, as well as kindergarten readiness skills as children approach 5 to 6 years in age (Meinzen-Derr et al., 2020; Vohr et al., 2012). This happens most effectively when families receive evidence-based EI services from qualified providers (Kasprzak et al., 2020). Across developmental domains, EI supports the bidirectional nature of language development by empowering parents to scaffold children's emerging communication skills through responsive, age-appropriate social interactions.

Critically, the timing and quality of early intervention services modulates the effectiveness. The Joint Commission on Infant Hearing recommends a 1-3-6 timeline (JCIH, 2019). When screened by 1 month, diagnosed by 3 months, and enrolled into EI services by 6 months, children's vocabulary scores are higher relative to peers who did not meet all three recommendations (Yoshinaga-Itano et al., 2017). Likewise, children's pragmatic language skills are impacted by the timeliness of meeting all three JCIH benchmarks (Yoshinaga-Itano et al., 2020). Additionally, converging evidence from developmental psychology, speech and hearing sciences, and public health has guided the development of best practices for EI: Family-centered, coordinated and collaborative care that is evidence based provided by specialized experts. A framework that invites professionals to view parents as partners in supporting their child's language development is holistic, flexible, and based on families' goals for their child (Moeller et al., 2013; Paul & Roth, 2011; Woods et al., 2011).

The application of these principles into practice can be a challenge, however. Research has identified potential barriers and challenges that impede families during the 1-3-6 timeline (Bush et al., 2017; Jimenez et al., 2012; Shulman et al., 2010). These pinch points in the process reflect the reality that EI is nested within local communities and public health policies. Consequently, applied research addressing barriers to EI are increasingly collaborative in nature, bringing together diverse stakeholders to investigate the lived experiences of providers, families, and children within a particular context (Blaiser & Bargen, 2020; Russ et al., 2010). One way to examine the extent to which one state's Early Hearing Detection and Intervention (EHDI) program (e.g., Ohio) reflects the JCIH (2013) principles specific to early intervention in practice is to seek and understand the perspectives of parents, EI providers, and audiologists through the efforts of a community collaborative.

Community collaboratives can be effective agents of change (Burdine et al., 2010; Clancy et al., 2013). Public health initiatives such as EHDI programs consist of a vast network of providers and supports, including audiologists, speech-language pathologists, teachers of the deaf, pediatric otolaryngologists, Deaf mentors, service coordinators, pediatricians, and other parents. For a family facing a new diagnosis, navigating this network can be a challenge (Holte et al., 2012; Jackson et al., 2008; Scarinci et al., 2018). Recognizing the perspectives and priorities of various stakeholders, a needs assessment offers a starting point for change by identifying barriers and obstacles within a system, given a shared commitment to a common goal (Hickey et al., 2018). Hands & Voices, a parent-led parent-to-parent non-profit organization dedicated to supporting families of children who are DHH regardless of communication modality, in collaboration with the National Center for Hearing Assessment and Management (NCHAM; Ward et al., 2019), conducted a national needs assessment to identify both current strengths and opportunities for growth within EHDI programs. A mixed methods research design collecting both quantitative and qualitative data for analysis was used to survey parents and EHDI coordinators in addition to focus groups about the resources received/provided and desired. Parents requested access to family-to-family support and comprehensive information for families about their child's diagnosis and communication options. EHDI coordinators identified increasing family engagement in the EHDI system as a top priority moving forward. These two perspectives converge upon a shared recognition that empowering parents with the knowledge and resources to navigate the early intervention system is both necessary and desired.

The purpose of the present study was to elicit perspectives from multiple stakeholder groups about the Ohio EHDI system through a collaborative, interdisciplinary approach. A theory of change framework explicitly identifies potential causal mechanisms that might be responsible for an intervention's success (De Silva et al., 2014; Maini et al., 2018). We adopted the methodology of Ward and colleagues (2019) to conduct a needs assessment specific to the state of Ohio. This step is the first when adopting a Theory of Change framework to strengthen public health initiatives. This approach allows for a localized and nuanced lens through which potential mechanisms for change can be identified to strengthen the EHDI program moving forward, guided by the direct input of those who participate in the system in hopes of engaging more families in the periphery. These data can then inform other states' EHDI programs who are engaging in quality improvement.

Method

Overview

This project was deemed exempt from review by The Ohio State University's Institutional Review Board because no protected health information was collected. A community collaborative approach was used to guide the design and implementation of this needs assessment about Part C early intervention services in Ohio. A network of professionals and parents was formed with funding from the Oberkotter Foundation to engage in a year-long discovery period to conduct a needs assessment of the early intervention landscape across the state of Ohio. The aim was to formulate a theory of change to strengthen the early intervention system for families with children who are DHH. A core group of 22 stakeholders from diverse backgrounds were led in this endeavor by a steering committee between Fall 2017 and Summer 2018. Members included parents, pediatric otolaryngologists, speech and language pathologists, audiologists, Part C state representatives, and DHH adults. A professional facilitator ensured that all participants had equitable opportunities to share their perspectives during in-person and virtual meetings as well as through electronic surveys. To maximize engagement of stakeholders, tiered levels of participation also included regional groups who hosted the focus groups as well as a review group that provided written feedback on documents developed by the community collaborative.

Qualitative and quantitative data were gathered from three key stakeholders: parents, EI providers, and audiologists.

Surveys were conducted online using REDcap. Focus group sessions were held in person in four regions of the state. The current article summarizes the survey data.

Survey Participants

Over the course of survey data collection spanning April through August 2018, a total of 158 respondents initiated the survey. Ultimately, 82 respondents completed the survey through the last question, 22 partially completed the survey, and 54 respondents initiated the survey but abandoned it prior to answering any questions. Data from the 104 complete and partially complete survey responses were included in this analysis. Complete surveys represented answers from 14 audiologists, 33 EI providers, and 35 parents while partially complete surveys represented answers from 5 additional EI providers and 17 additional parents.

Audiologists

Audiologists who responded to the survey (*n* = 14) primarily came from the hospital setting (pediatric, non-profit, or general hospital; *n* = 10, 71.4%) and had a clinical case load between 6 and 25% (*n* = 5, 35.7%) of exclusively pediatric patients. Only one audiologist reported that their clinical caseload was 0–5% and one other reported that their caseload was 76–100% pediatrics. The top three clinical services provided by audiologist respondents included hearing evaluations/assessments (*n* = 12, 85.7%), hearing aid fitting and management (*n* = 10, 71.4%) and hearing aid technology counseling (*n* = 12, 85.7%). Additional demographic information for audiologists appears in Table 1.

Table 1
Audiologist Demographic Information

Employment Setting	***n***	**%**
Pediatric Hospital/Hospital	10	71.4
School/EI Program	2	14.3
Private Clinic/Speech & Hearing Center	2	14.3
Pediatric Case Load Percent	***n***	**%**
0–5	1	7.1
6–25	5	35.7
26–50	3	21.4
51–75	4	28.6
76–100	1	7.1
Services Provided	***n***	**%**
Hearing Evaluations/Assessments	12	85.7
Hearing Aid Technology Counseling	12	85.7
Hearing Aid Fitting/Management	10	71.4
Communication Mode Counseling	9	64.3
Cochlear Implant Management	7	50.0
Aural Rehabilitation/Therapy	1	7.1
Other (Screening and family coaching)	1	7.1

Note. Includes work setting, pediatric caseload, and clinical services provided. For clinical services, respondents indicated all services provided. EI = early intervention.

Early Intervention Providers

Table 2 provides an overview of EI providers' background and education. Early intervention providers who responded to the survey (*n* = 38) reported a variety of educational backgrounds, with the most frequently reported including speech language pathology (*n* = 10, 26.5%), elementary education (*n* = 4, 10.5%), and special education (*n* = 3, 7.9%). Respondents also noted a variety of specialty certifications, most often including: speech language pathology (*n* = 10, 26.3%), deaf and hard of hearing early intervention specialist (*n* = 9, 23.9%). Lastly, respondents reported a variety of years of experience in the EI field, with most reporting 16+ years (*n* = 15, 39.5%). EI providers reported a mean of 10.9 children with hearing loss on their current clinical caseload, with a range of 1 to 100.

Table 2
Early Intervention Provider Demographics

Educational Background	***n***	**%**
Speech-Language Pathology	10	26.3
Elementary Education	4	10.5
Special Education	3	7.9
Audiology	3	7.9
Other*	11	28.9
Not disclosed	7	18.4
Specialty Certificates	***n***	**%**
Speech-Language Pathology	10	26.3
DHH Early Intervention Specialist	9	23.9
Audiologist	5	13.2
Teacher of the Deaf	3	7.9
Educational Audiologist	2	5.3
LSLS/Auditory Verbal Therapist	2	5.3
Other**	7	18.4
Years of Experience	***n***	**%**
0–2	6	15.8
3–5	4	10.5
6–10	5	13.2
11–15	7	18.4
16+	15	39.5
Not disclosed	1	2.6

Note. Includes educational background, specialty certification, and years of experience providing early intervention services. *Other educational backgrounds included nursing, social work (*n* = 4), child & family community services, physical therapy (*n* = 2), human development and family studies, school psychology, and public administration. **Other specialty certifications included Department of Developmental Disabilities (DS), early interventionist (*n* = 2), service coordination (*n* = 3), and early childhood special education administration. DHH = Deaf or Hard of Hearing; LSLS = Listening and Spoken Language Specialist

Parents

Fifty-two parents provided answers to survey questions either in part or in whole. Parents represented families with children of varying ages with a range of birth years from 2009 through 2017 and diagnosis years ranging from 2009 through 2018. Parents who provided data related to specific hearing diagnosis related date for their children (*n* = 45) reported a mean age of diagnosis of 6.02 months with a range from 1 to 75 months and a median of 1 month. Ninety percent of the children (*n* = 47) reportedly had bilateral hearing loss (8 asymmetric) while four (7.6%) had unilateral hearing loss and one parent did not report the laterality of hearing loss. Table 3 represents the degree and configuration of hearing loss reported by each family as well as the etiology (if known), devices, and communication mode used by the children most of the time. One quarter (*n* =13) of the children presented with profound hearing loss and 55.8% reported idiopathic/unknown etiology (*n* = 29). Binaural hearing aids were worn by 55.8% (*n* = 29) and 21.2% reported using bilateral cochlear implants (*n* = 11). Total communication was reported as the primary communication mode for 46.2% (*n* = 24) and listening/spoken language was reported for 34.6% (*n* = 18). Additionally, 69.2% (*n* = 36) of parents reported their children presented with speech/language delay, but a variety of comorbid diagnoses were also reported, including: motor delay (*n* = 16, 30.8%), social/emotional delay (*n* = 16, 30.8%), reduced vision (*n* = 10, 19.2%), global developmental delay (*n* = 8, 15.4%), and autism (*n* = 3, 5.8%). Sensory processing disorder (*n* = 2), attention deficit hyperactivity disorder (*n* = 2), and dyslexia were noted for "other" developmental delays reported for children.

Lastly, families represented various races and socioeconomic status levels based on reported household income, insurance coverage, and primary caregiver education level. For race, 34 families (65.4%) identified themselves as white/Caucasian, one family (1.9%) identified as Asian, and one family (1.9%) identified as Pacific Islander. Sixteen families (30.8%) declined to answer this question. Thirty-five families reported household income with the most frequently reported income between $75,000 and $99,999 (*n* = 9, 25.7%). Health insurance coverage of the children was reported by 36 families and respondents could indicate if they had more than one source for health insurance. The vast majority of respondents reported having private insurance (*n* = 30, 83.3%), and 10 (27.8%) reported that they had Medicaid coverage. Additionally, 16 families reported that they benefited from Ohio-based supplemental insurance programs including the Children with Medical Handicaps (CMH) supplement (*n* = 14, 38.9%) and the Ohio Hearing Aid Assistance Program (OHAAP) for the purchase of hearing aids (*n* = 2, 5.5%). For primary caregiver educational level, most respondents reported having a Bachelor's Degree (*n* = 11, 31.4%).

Materials

Three surveys were developed to query audiologists, parents, and providers, respectively (available upon request). These surveys were adapted with permission from NCHAM's EI SNAPSHOT project (Ward et al., 2019) by the community collaborative so that all questions were specific to Ohio's EHDI program and resources. Although the focus of survey questions was Part C Early Intervention services, a spectrum of questions was asked to gauge the entire family journey. Therefore responses likely reflect input regarding a combination of screening, diagnosis, Part C EI and general early intervention processes in Ohio.

Table 3

Hearing-Related Demographic Data for Children of Parents who Responded to this Survey

Degree/Laterality	***n***	**%**
Profound	13	25
Moderately-Severe	9	17.3
Mild	4	15.4
Severe	5	15.4
Asymmetric	8	9.6
Moderate	8	7.7
Unilateral	4	7.7
Did not respond	1	1.9
Etiology	***n***	**%**
Unknown/Idiopathic	29	55.8
Genetic	16	30.8
cCMV	5	9.6
Other*	2	3.8
Device(s)	***n***	**%**
Binaural HA	29	55.8
Binaural CI	11	21.2
None	5	9.6
Bone Conduction Device	2	3.8
Bimodal	2	3.8
Unilateral CI	1	1.9
Unilateral HA	1	1.9
No response	1	1.9
Communication Mode (most of the time)	***n***	**%**
Total Communication	24	46.2
Listening/Spoken Language	18	34.6
No Response	3	5.8
Pointing/Grunting	3	5.8
American Sign Language	2	3.8
Cued Speech	2	3.8

Note. Includes degree/laterality, cause, device use, and communication mode. *Other etiologies reported were Cochlear Dysplasia/Mondini Malformation and prematurity. cCMV = congenital cytomegalovirus, CI = cochlear implant; HA = hearing aid(s).

Study data were collected and managed using Research Electronic Data Capture (REDCap) tools hosted at Ohio State University (Harris et al., 2009, 2019). REDCap is a secure, web-based software platform designed to support data capture for research studies, providing (a) an intuitive interface for validated data capture; (b) audit trails for tracking data manipulation and export procedures; (c) automated export procedures for seamless data downloads to common statistical packages; and (d) procedures for data integration and interoperability with external sources.

Recruitment

Survey links were disseminated via email to participating members of the community collaborative, who were invited to share the link with their colleagues and families. The link also was shared through Ohio's Early Hearing Detection and Intervention (EHDI) listserv to providers and affiliated professionals. Focus group information was shared this way as well.

Data Analysis Plan

Quantitative questions from the survey were categorized according to which JCIH goal they addressed. The community collaborative made *a priori* decisions regarding which goals to focus on when developing the survey. Specifically, the collaborative concentrated its efforts on the goals concerning access to timely services (Goal 1), resources (Goal 3), and parent-to-parent support (Goal 9). Survey questions were categorized by topic according to JCIH (2013) EI supplement goals. Whenever possible, data from multiple perspectives (i.e., parents, providers, and/or audiologists) for a particular topic are reported.

Respondents of the online survey were often asked to rate aspects of their clinical practice, process, or knowledge based on a four-point Likert scale, 1 meaning *excellent* and 4 meaning *poor*. Quantitative data were analyzed both in terms of the percentage of respondents indicating a particular rate and via mean ratings (M_{rating}) which were calculated and reported according to theme. Mean ratings closer to 1 suggest positive reports while mean ratings closer to 4 reflect negative reports.

Qualitative data from open-ended prompts on each survey (Appendix) were analyzed using content analysis to derive themes (Hsieh & Shannon, 2005; Krippendorff, 1989). First, comments were parsed to identify specific utterances that could be considered as regarding the same topic so that long-form answers from single respondents that addressed multiple topic areas could be coded individually. Each of the respondent groups were then coded for theme independently by two of three available reviewers (JR, CD, UF). A consensus process was then facilitated by the third reviewer to identify the ultimate theme(s) conveyed in the utterance. A natural filtering effect occurs in the process of sorting and identifying themes which allows for specific themes to be highlighted for each of the respondent groups, some of which ultimately overlapped across groups.

Results

Quantitative results and rankings will be discussed within the context of JCIH (2013) EI supplement goals below. For qualitative responses, after parsing for topic there were 26 utterances from audiologists, 53 utterances from providers, and 46 utterances from parents after consensus was obtained from all three reviewers (JR, CD, UF). Overarching themes present in the utterances are presented in Tables 4 and 5. Qualitative quotations will be incorporated in the discussion about quantitative data below to illustrate commonalities or disparate themes indicated across the data.

Goal 1: Timely Access to EI Services

Families must navigate the process of initial screening after birth to diagnostic testing, confirmation of hearing loss, navigating management options, and enrollment into early intervention services. The JCIH recommends that families have access to timely and coordinated entry into EI.

Parents

Eighty-five percent of families agreed with the statement that it was "easy to get information about how to enroll in EI." However, 31.1% of families felt that the process to get services for their child was confusing.

Audiologists

Audiologists reported several challenges related to timely and coordinated entry into EI. More than one-third (35.7%) reported difficulty when trying to contact Part C EI. Furthermore, 78.6% of audiologists reported that they heard from families directly about difficulties they experienced with the EI system. Almost all audiologists expressed concern that the children on their caseload were receiving inappropriate EI services (92.9%), and over half of parents (71.4%) requested information about private services from the audiologists.

EI Providers

EI providers were invited to rate their ability to assist families with various aspects of early intervention using a Likert rating from 1 (*excellent*) to 4 (*poor*). More than half of respondents (69.7%) self-reported their ability to help families learn about all communication modalities as excellent or good; the same percentage reported that they were able to adequately (i.e., rating of excellent or good) connect families with services specific to their family's communication choice. An overwhelming majority of EI providers (97.0%) felt confident in their ability to coordinate with other EI providers, with ratings of either excellent or good.

Additionally, the survey probed for EI providers' perceptions of barriers faced by families. Respondents indicated if various potential obstacles were not a barrier, a small barrier, or a large barrier. Finding out about the free, state-provided EI services was considered a small barrier by 54.4% of EI providers; 18.2% considered it to be a large barrier. Thirty-nine percent of providers did not believe that finding out about EI was a barrier at all. Enrolling into free, state-provided EI services was not considered a barrier to

Table 4

Themes and Examples

Theme	Included within theme	Examples
Care coordination	Tracking/monitoring referrals, communication among professionals, progress monitoring	"No thorough system in place to track and monitor children referred for hearing loss specifically." (Audiologist) "It would be amazing if there were a way to communicate between pediatricians and EI." (Parent) "The EI program is continually attempting to educate and encourage counties to reach out as soon as they have a child with a hearing loss, but it is not always happening. There are too many people involved with a family before they actually get involved with early intervention hearing services, leaving many opportunities to fall through the cracks. It would be great to have a system that directly notifies hearing specialists of a child with a newly diagnosed hearing loss." (Provider)
EI quality concerns	Unbiased support for all languages and communication modes, changes to state EHDI program	"Also, home based services once/month is not the same as weekly private speech therapy, and I feel like families are not counseled properly by the EI therapists on these differences." (Audiologist) "The only thing I regret is that I wish there would have been more support for us to learn ASL for our moderate to severe bilateral hearing loss child. We wanted to use sign for night times at home, bath time and summers in the water. But we were told since our child was listening and our ultimate goal was for her to speak and listen and use English, there were not ASL supporters for us." (Parent) "I would like to see a family choose a communication modality and then have the opportunity to be paired with an EI provider that supports their choice. If LSL is their choice, then working with a LSL provider through EI should be an option. If working with a family who chooses ASL, they should be paired with a provider who can teach and support the family with learning ASL." (Provider)
Equitable access	Limited access to services in regions of the state, lack of access to specialized providers, lack of training for EI providers, lack of EI curriculum, access to telehealth	"Hearing specific services are few and far between in the state of Ohio. Families that do not live in an urban area are often underserved." (Audiologist) "Could professionals with an expertise in hearing loss develop a program and curriculum that is offered to all families in Ohio?" (Provider)
Parent knowledge and education	What services are available, importance of EI, counseling on communication, resources for families	"Counseling regarding the importance of early intervention, communication mode, resources, etc." (Audiologist)
Positive experience	Quality resources available, referrals made in rural areas, in-home services available, unbiased support	"I do think families appreciate the in-home service model and those that do get timely EI services do have good things to say about the providers and the process of working with Early Intervention in general." (Audiologist) "It is without a doubt their unbiased support that also helped me think about communication methods." (Parent)

Note. ASL = American Sign Language; EI = early intervention.

families of children birth to three by 39.4% of providers. Forty-two percent felt that enrolling was a small barrier; the remaining 18.2% felt it to be a large barrier. In contrast, a majority of providers felt that "getting providers to talk to one another" was either a small (45.5%) or large (42.4%) barrier. Only 12.1% of respondents felt that coordination among providers was not a barrier at all.

Open-Ended Responses

Themes derived from the content analysis of open-ended responses are presented in Table 5. Comments related to care coordination were the most frequent, and all three groups of respondents provided feedback related to this topic. Comments related to care coordination spanned the entire EHDI process and included comments regarding provider-parent coordination as well as provider-provider coordination. Twenty-two percent of all open-ended responses addressed some aspect of care coordination. Specifically, 20.3% of feedback from providers, 10.9% of parents' feedback, and 46.2% of input from audiologists addressed topics and concerns about the process of identifying, enrolling, and navigating the EI system. Coordinated communication among professionals emerged as an area of concern, as evidenced by responses such as this quote from an audiologist, "There is also a lack of communication/training between providers on all fronts (audiologist, speech pathologist, EI provider, etc.) that leads to miscommunication or conflicting recommendations with families."

Table 5
Summary of Derived Themes from Qualitative Comments Compared across Providers, Parents, and Audiologists

Theme	Provider	Parent	Audiologist	Tally
Care Coordination	12	5	12	29
Positive Experience	0	20	5	25
Equitable Access/Equity of Services	21	1	2	24
Quality of EI Services (negative)	2	15	5	22
Policy/System Changes/ Funding	14	2	0	16
Resources	6	0	2	8
Family Choice & Family Journey	2	3	0	5

A second theme identified from the open-ended responses that aligned with the JCIH's recommendation that state EHDI programs "develop a mechanism that ensures family access to all available resources and information that is accurate, well-balanced, comprehensive, and conveyed in an unbiased manner" (JCIH, 2013; pg. e1327). This *resources* theme accounted for approximately six percent of the comments (*n* = 8). Providers mentioned this theme more frequently than audiologists, and interestingly, no parents made note of any topic related to high-quality, unbiased information. One provider expressed the desire to "Get all county programs to the same level with the same resources and knowledge" and for "a compilation of affordable resources for additional training for providers and a list of resources to refer families." Another provider posed the question of "Could professionals with an expertise in hearing loss develop a program and curriculum that is offered to all families in Ohio?"

When looking at the nature of comments across respondent groups overall, parents more often offered comments about the experience of EI while audiologists were more concerned with effective care coordination. Lastly, EI providers offered more comments about access to services and policy-related factors. Below we explore how the quantitative data and qualitative open-ended comments address the JCIH (2013) goals of interest in this study.

Goal 3: Specialized Providers Equipped with Expertise

Supporting the language development of children who are DHH has cascading effects on their later communication and literacy skills. Consequently, JCIH (2007; 2013) recommends that families have access to specialized providers with the professional qualifications to provide evidence-based intervention to children and their families following diagnosis. Specifically, JCIH recommends that families have access to "qualified providers" regardless of their communication modality (i.e., American Sign Language or spoken language).

Parents

Eight-two percent of families felt that they were provided choices related to the supports and services available to them. However, 50% of the parents who desired sign language instruction reported problems accessing such services through Ohio's EI system. In contrast, only one-quarter of families who needed Auditory-Verbal Therapy (AVT) experienced difficulties accessing AVT through Ohio's EI system.

Audiologists

Audiologists were queried about receiving information or training about Ohio's EI system. Less than one third of audiologists (28.6%) reported receiving information or training about Ohio's early intervention system.

EI Providers

The survey queried EI providers to rate their knowledge about various topics related to providing early intervention services to children who are DHH using a Likert scale from 1 to 4 (1 = *excellent*, 2 = *good*, 3 = *fair*, 4 = *poor*). Providers felt knowledgeable about the administrative aspects of their role, such as service coordination (M_{rating} = 1.82) and IDEA Part C regulations (M_{rating} = 1.94). In regard to their clinical care responsibilities, EI providers reported feeling knowledgeable about supporting families (M_{rating} = 1.85) and providing telehealth/teleintervention (M_{rating} = 1.54). In contrast, they reported feeling much less knowledgeable about topics related specifically to deafness and hearing loss, particularly assessing children who are DHH (M_{rating} = 3.03), language development (M_{rating} = 2.77), and teaching children who use either sign (M_{rating} = 2.56) or listening and spoken language (M_{rating} = 2.8).

The survey also inquired about EI providers' training through formal education, on-the-job training, and in-service/continuing education. A majority of EI providers reported receiving formal education in early intervention (75.7%), family support (91.9%), service coordination (78.3%), and IDEA Part C regulations (78.4%). However, only half of respondents indicated that they received any formal training on the assessment of children who are DHH (52.8%), teaching children using sign language (52.8%), teaching children using listening and spoken language (59.5), and teaching children who use total communication (48.6).

For a majority of EI providers, on-the-job training experiences centered on early intervention (59.5%). Almost half of respondents reported that they received on-the-job training related to assessment and teaching children who use Listening and Spoken Language as their primary communication modality (47.2% and 48.6%, respectively). Very few EI providers (< 1%) reported learning about any topic during in-service or continuing education opportunities, with the exception of pre-literacy instruction, for which 41.7% of respondents endorsed participating in continuing education or in-service training.

When asked to rate the adequacy of education and background in relation to preparedness for providing services for families and children who are DHH, 42.1% reported their background was *adequate* (n = 16), although the same percentage/number reported it was *inadequate*. Only two respondents (5.3%) reported their educational background was *very adequate* and one (2.6%) reported *very inadequate*, while three respondents (7.9%) chose not to answer.

Open-Ended Responses

Equitable access/equity of services emerged from the open-ended responses as a key theme that directly addresses Goal 3. This theme was present in comments from all three groups of respondents; 7.7% of audiologists' comments, 2.2% of parents' feedback, and 36.8% of providers' input related to equitable access/equity of services, particularly as it related to the more rural regions of Ohio. Overall, 18.6% of all comments addressed equitable access/equity of services.

The theme of equitable access/equity of services primarily consisted of two subcategories of comments: those related to equitable access regardless of geographic location and those related to a need for specialized service providers. The interrelated nature of these two themes is exemplified via provider feedback such as a desire for "more access to a variety of specialized supports for small rural counties in the state." Mirroring our survey data in which providers reported a relative lack of formal training on a variety of EI-related topics, providers inquired about a variety of possibilities to address a need for equitable access to specialized services. Ideas ranged from "a compilation of affordable resources for additional training for providers" to a more unified approach: "Could professionals with an expertise in hearing loss develop a program and curriculum that is offered to all families in Ohio?"

The qualitative analysis of comments revealed a second theme of family choice/the family journey. This theme accounted for 3.9% of the comments overall. For example, one parent remarked, "What I'd like to say to any professional listening: stop telling us you and your 'side' or 'camp' know best how to educate our child. You have valuable information and we want to hear it. We want to help our child with any strategies you know about."

Goal 9: Parent-to-Parent Support

Connecting with other families who also have a child who is DHH is both a powerful resource network and a support system for a family whose young child was recently diagnosed with a hearing loss. Shared experiences create common ground. As such, JCIH (2013) recommends the development and implementation of formally-trained parent-to-parent support systems within EHDI systems.

Parents

Access to parent-to-parent support emerged as a significant area in need of improvement. Only 47.06% of parents who answered the question agreed with the statement that "My service coordinator helped me get in touch with other parents for help and support." Furthermore, only 53.1% of families felt that the information they received about connecting with families who also had children who are DHH was excellent or good. Almost half rated that information as fair or poor, with poor meaning not mentioned at all. Less than half felt that the information that they received about AG Bell and Hands & Voices (both at the national and state level) was excellent or good, while approximately one-third of the respondents reported they received no information on these resources.

Audiologists

The survey for audiologists did not ask any questions specific to parent-to-parent support.

EI Providers

EI providers were asked to rate their knowledge of various organizations that foster parent-to-parent connections, such as Hands & Voices. Over half of respondents (52.9%) rated their knowledge of the national Hands & Voices organization as poor; 45.5% indicated that their knowledge of local Ohio chapters of Hands & Voices was poor. A similar percentage of providers (48.5%) reported that they never referred families to local chapters of Hands & Voices. However, 81.8% of EI providers rated their ability to connect families with other families as excellent or good, although they do so with varied frequency: one-third indicated that they do so sometimes, 27.3% reported doing so often. One third of providers endorsed that they always connected families with other families. Lack of family-to-family support was considered a small barrier for families by almost three-quarters of EI providers (72.7%); 18.2% considered it to be a large barrier. The remaining 9.1% of providers felt that a lack of access to parent-to-parent support was not a barrier at all.

Open-Ended Responses

No provider, audiologist, or parent response addressed parent-to-parent support.

Additional Themes

The nature of the open-ended survey questions allowed parents, providers, and audiologists to share ideas or opinions on *any* topic. Consequently, several themes emerged from the open-ended data that did not fall under a particular JCIH goal. More than a third of all responses (36.4%) expressed an explicitly positive or negative opinion. Audiologists expressed an equal number of positive and negative comments (*n* = 5 for each). Parents, on the other hand, expressed more positive (*n* = 20) than negative (*n* = 15) comments. Only 3.5% of provider comments were evaluative in nature, with two comments coded as expressing a negative experience.

Comments related to policy, including funding and systemic changes, accounted for 12.4% of all comments. EI providers were responsible for 87.5% of these comments; the remaining two comments were from parents. Providers noted that navigating the various policy changes within the Ohio EHDI system has been a challenge; specifically, the 2016 shift to a Primary Service Model was referenced.

Discussion

The goal of this community collaborative was to study the perspective of three key stakeholder groups in Ohio's EHDI program: parents, audiologists, and EI providers. Using the JCIH goals as a framework, these stakeholders were afforded an opportunity to reflect upon their lived experiences within the EI system through both qualitative (i.e., focus groups) and quantitative (i.e., surveys) methods. This design allowed for an exploration of a single topic (e.g., access to parent-to-parent support) from various viewpoints. The data revealed several points of consensus as well as divergence among and within the three stakeholder groups.

Loss-to-follow-up emerged as a critical concern expressed by providers and audiologists when considering the first JCIH goal of timely access to EI services. Given the nature of the recruitment methods employed in this study, only families who were connected in some way to EI services were queried. Nevertheless, among parent respondents, almost one-third reported that the process of enrolling into EI was "confusing." These results are consistent with previous survey data from parents who reported navigating the EHDI system as overwhelming with limited information shared for next steps to happen in a timely manner (Larsen et al., 2012). Despite significant progress in EHDI systems as a whole, many of the same concerns regarding loss-to-follow-up remain today, decades after the first universal programs were instituted.

EI providers expressed seemingly conflicting viewpoints: they felt equipped to support families. However, they were much less confident in their ability to teach children who use either American Sign Language (ASL) or spoken language. Such a discrepancy in confidence may be rooted in the changing role of the EI provider. To minimize the number of professionals working with a family in the home, a primary service provider (PSP) model has been implemented, whereby families receive EI services that are developmental, rather than deafness-specific, and delivered using a transdisciplinary approach. Theoretically, in a PSP model for families of children who are DHH, the PSP implements strategies informed by specialists in deafness and early language development. However, due to the complexity of state EHDI systems and potential for lack of qualified providers in a specific geographical location, families are not guaranteed services by a deafness-specific provider. The EI providers queried for the current study did not report backgrounds specifically related to facilitating language development in young children who are DHH. Further, a lack of confidence may also stem from a lack of training programs or variability in providers' backgrounds. Speech-language pathology training programs do not routinely include coursework and training related to the unique language and communication needs of this population. Parents reported a similar paradox: although most reported that they were given choices about their family's preferred communication modality, half of families who decided to pursue ASL had difficulty accessing high-quality services provided by the state. Collectively, these barriers to high-quality EI services due to limited qualified providers or limited service options could be addressed by improving university training through specialized DHH coursework, offering ongoing professional development to strengthen knowledge of current EI providers about the impact of deafness on development, and providing care coordination for families to navigate the often complicated EHDI system so that they can be connected with appropriate services and resources.

Although EI providers endorsed an excellent grasp of the logistics of providing EI, they concurrently endorsed feeling only good to fair in topics regarding assessment of children who are DHH and language development. One possible explanation for these findings might be due to the fact that, for the most part, the logistics of EI systems cut across disability categories; therefore, in-service training opportunities related to the EI system might be more readily available to providers than training related to assessment. The shortage of deaf education training programs (Johnson, 2004) has also created the challenge of employing EI providers with expertise in assessing young children who are DHH. Universities, policy makers, and advocates might consider opportunities for addressing this shortage given that JCIH recommends families receive services from providers with specialized knowledge. Furthermore, the refinement of research related to early language development in young children who are DHH and the effects of EI stands in contrast to the emerging nature of the nuances of high-quality EI services in practice.

Across all three stakeholder groups, parent-to-parent support emerged as a need when explicitly asked, reflecting previous research demonstrating the high value that parents of children who are DHH place on peer engagement (Haddad et al., 2019; Hintermair, 2000; Zaidman-Zait et al., 2016). In fact, parents cite parent-to-parent support as critical to their ability to navigate their child's care and an important avenue for acquiring knowledge about raising a child who is DHH (Haddad et al., 2019). Among EI providers, insufficient knowledge of parent-to-parent support organizations was reported despite providers' assertion that they consistently connected families. However, this topic did not arise in any open-response comments, suggesting that other areas may be prioritized, such as equitable access to specialized providers.

Across the three goals of timely entry, access to experts, and parent-to-parent support, a common theme emerges: There is a great onus placed on families to coordinate their care, from navigating the EI enrollment process to securing services that match their family's goals. Many families, however, do not have the time, resources, or knowledge to navigate this process with ease. All too often, the family is the hub in a multi-spoke wheel. The current Ohio EHDI system overall is not achieving what the national EHDI goals strive for based on perspectives from multiple stakeholder groups.

Through the lens of a Theory of Change framework, this state-wide needs assessment identifies several potential mechanisms to strengthen the efficacy of early intervention. For instance, converging data suggest that parent-to-parent support that equips and connects families may mediate the extent to which families advocate for and engage in the early intervention system. The identification of this (and other) potential causal mechanisms offers a pathway for future research. The needs assessment conducted by De Silva and colleagues (2014) during their implementation of a Theory of Change framework to develop a mental health intervention revealed several potential markers to measure when evaluating a pilot program. Likewise, stakeholders in Ohio's EDHI system may consider the role of parent-to-parent support when evaluating future EHDI programs.

Limitations

Several limitations need to be considered before extrapolating these results to other states' stakeholders within their own EHDI programs. First, the respondents who completed the online survey were predominantly white/Caucasian and self-reported a high level of SES. The extent to which these perspectives would apply to families from diverse race/ethnic, socioeconomic, or linguistic backgrounds is worthy of future investigation. Additionally, for many respondents, data was retrospective in nature as families reported on children who spanned 0 to 7 years old. Although the focus of this project was on Part C EI services, it cannot be ruled out that providers and parents also included other types of early intervention (e.g., speech therapy, private group or family therapies, etc.) when responding to survey questions. Finally, this project only addressed three JCIH (2013) EI supplement goals, given the particular focus of the community collaborative. Additional research that addresses the extent to which parents and professionals endorse that their lived experiences align with the recommended best practices is warranted.

Conclusion

EHDI systems are notoriously complex and often difficult for families, and sometimes providers, to navigate. How state EHDI systems function can fluctuate depending on funding, consolidation of resources (PSP model versus specialist-oriented model), and other unforeseen circumstances. However, gathering stakeholder input is one path to illuminating the difficulties and identifying potential solutions unique to families of children who are DHH and the providers who serve them. The community collaborative in Ohio was able to identify barriers to EI, including limited equitable access to specialized providers, limited information sharing and access to parent-to-parent support, and the need for care coordination to facilitate enrollment into EI. Our experience in identifying these key attributes can serve as a model for other states to evaluate their own programs to identify their unique needs.

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Appendix

Open-ended Questions Posed to Respondents

Questions for Parents:

- Knowing what you know now, what would you have done differently in obtaining Early Intervention Hearing services for your child?
- What is the most important piece of advice you would give a parent whose child has recently been diagnosed with hearing loss regarding early intervention and family supports?

Questions for Providers:

- In your opinion, what changes could be made to help early intervention work better in your state?

Questions for Audiologists:

- What challenges do families face who have an infant or toddler (0–3) who is DHH living in Ohio?
- What do you think is working well in your state for families who have an infant or toddler (0–3) who is DHH?