EHDI System Effectiveness: The Impact of Community Collaboration

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Abstract

Collaboration between statewide stakeholders is integral to ensuring that families who have children who are deaf or hard of hearing successfully access the resources of Early Hearing Detection and Intervention systems. However, collaboration between stakeholders takes time, resources, and common goals. The Idaho Community Collaboration (ICC) project brought statewide state and non-state agencies together to assess the Early Hearing Detection and Intervention system in Idaho through data collection and survey. With the objective data obtained from these data sources, the ICC was able to take first steps in meeting the needs of the state's family and children through collaborative decision making and resource development.

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Early Hearing Detection and Intervention (EHDI) systems include stakeholders from varying state and non-state agencies including newborn screening programs, Part C providers, educational services for the Deaf and Blind, parents, and parent support agencies. As EHDI systems strive to adhere to best practice guidelines, successful implementation depends on multiple providers and coordinated systems (Brown et al., 2019). For example, if an infant is screened at birth, successful follow-up is dependent on factors such as how the information is presented, if/how scheduling for diagnostics takes place, families' understanding of importance of diagnosis, and timeliness of assessment and initiation of intervention.

In 2009, the National Center for Hearing Assessment and Management (NCHAM) supported strategic planning activities to help state EHDI systems strengthen their programs and identify challenges (White & Blaiser, 2011), including collaboration as one key component of the strategic planning analysis. Although collaboration is often touted as an integral aspect of the EHDI system, in actuality, communication may be limited to periodic interactions about common factors and processes with little integrated engagement focused on systematic improvement of outcomes for children and families. Many factors can influence collaboration such as turf (i.e., feeling that a child *belongs* to one entity more than another), time (i.e., barriers related to caseload size, amount of time allocated to communication), and trust (i.e., a mutual feeling of respect between stakeholders). See Himmelman (1996) for a review.

Collaboration and coordination can be even more challenging in a state with substantial rural or remote areas. The state of Idaho is divided into seven public health regions used by multiple entities including the Department of Health and Welfare, containing Idaho Sound Beginnings and Idaho Infant Toddler Program (ITP), and Idaho Educational Services for the Deaf and Blind (IESDB; Figure 1). As shown in Figure 1, a substantial portion of Idaho is considered *rural*: the panhandle of Idaho (Regions 1 and 2), most of southwest Idaho (Region 3), and south central Idaho (Region 5). Region 4, while one of the most populated regions in the state (therefore counted as *suburban/urban* for the purposes of this project) still contains two counties that are classified as

rural. Similarly, in Regions 6 and 7, located in southeastern Idaho and eastern Idaho respectively, two to three of the eight counties are classified as rural. In fact, because of some of the low population density, many of Idaho's rural populations are considered *frontier* because of their isolation from population centers and services (Idaho Department of Health & Welfare, 2018). In these regions, there are limited resources specific to EHDI systems, such as pediatric audiologists, otolaryngology specialists, and early intervention providers with experience serving children who are deaf or hard of hearing (DHH). To serve families and ensure adhesion to EHDI system best practice, statewide teams must look at outcomes and processes regionally as well as statewide to better decipher the specific needs of the families who reside in more remote locations.

Figure 1

Idaho 2019 Population Estimates Based on U.S. Census Bureau 2010 Census Data

In addition to challenges faced through reduced population and access to services, Idaho is one of three states in the United States that does not mandate newborn hearing screening (NCHAM, 2020). Although there is an active newborn hearing screening advisory committee, the need for more formalized collaboration and discussion is particularly important when there is no legislation or state funding to support these processes.

A foundation grant was awarded to faculty at Idaho State University with the primary goal of improving outcomes for children who are DHH and their families across the state of Idaho through enhanced stakeholder collaboration. This paper outlines the process that was followed in developing the Idaho Community Collaboration with stakeholders who are involved with families of children who are DHH from newborn hearing screening to the child's enrollment in the Part B system.

Identify Key Stakeholders

The first step in developing the Idaho Community Collaboration (ICC) was to identify key stakeholders in Idaho's EHDI system. Although there are many entities involved with families of children who are DHH within the state of Idaho, the focus of this group was to include stakeholders who represent various aspects of the statewide systems. As shown in Table 1, five stakeholders were identified: the newborn hearing screening program (Idaho Sound Beginnings, ISB), the primary state Part C provider (the Infant Toddler Program, ITP), the state school services for the deaf and blind (Idaho Educational Services for the Deaf and Blind, IESDB), a statewide hospital system that provides clinical audiological and speech-language pathology services (St. Luke's Hearing and Balance Center), and the family advocacy and support organization specific to children who are DHH (Idaho Hands and Voices). Two faculty members from Idaho State University's Speech-Language Pathology and Audiology programs participated in the ICC with the primary roles of facilitating discussions, coordinating processes, engaging graduate students in communication sciences and disorders, and disseminating findings. There were ten participants in the meetings but many of these participants held more than one role, specifically, in addition to their professional position, they were parents of children or adults who are DHH.

Define the Process

Prior to the first meeting, each stakeholder (or stakeholder group) was asked to develop a map based on their understanding of the current process from newborn hearing screening to enrollment in Part B services. Existing examples were provided, such as the EHDI Guidelines for Pediatric Medical Home Providers (https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/PEHDIC/Documents/Algorithm1_2010.pdf). At the first meeting, each stakeholder shared their map and included questions related to their own perspectives on the strengths, opportunities, and points of clarification needed for each step of the process. As a group, each of the maps
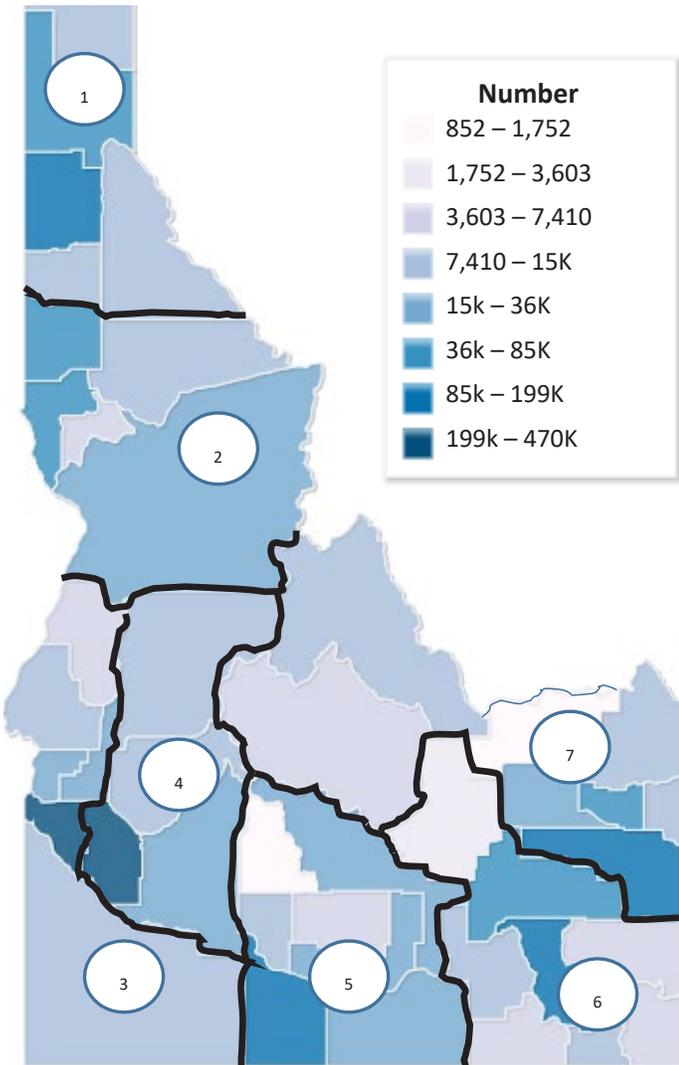
Table 1

Participants and Roles of Idaho Community Collaboration Members

Entity	Position	Role	Secondary Role
St. Luke's Hearing and Balance Center	Pediatric audiologist	Pediatric audiologist	Mother of child who is DHH
	Speech-Language Pathologist	Speech-Language Pathologist	Mother of adult who is DHH
Idaho Sound Beginnings	Administrator	Administrator	
	Parent follow-up consultant	Parent follow-up consultant	Mother of children who are DHH
Infant Toddler Program	Administrator	Administrator	
Idaho Hands and Voices	Director of Parent Support Organization	Director of Parent Support Organization	Mother of child who is DHH
Idaho Educational Services for the Deaf and Blind	Administrator, Director of Outreach	Administrator	
	Director, Part C	Deaf Educator	Interpreter
Idaho State University	Faculty member, Primary Investigator	Coordinator	Speech-Language Pathologist
	Faculty member, Co-Primary Investigator	Co-Coordinator	Audiologist

Note. DHH = deaf or hard of hearing

were discussed and compared to determine the common questions or points of clarification needed for each part of the process. As a result of these discussions, it was decided there was a need for coordinated data collection to distinguish what was actually occurring in practice and to examine the perceptions of what might be occurring at different parts of the process.

An unintended benefit of the mapping process was an opportunity for partners to learn about resources and options that were available to providers and families. For example, information about funding resources for hearing aids was not universally known across the stakeholders (e.g., IESDB and/or ITP were not aware of the same funding resources as hospital-based audiologists). Having this opportunity to discuss the processes and resources in place, as well as how they may differ from region to region was beneficial.

Gather Information

Following the stakeholder discussion, a data collection system was developed to cross-check the information between ISB, ITP, and IESDB. Existing data sharing agreements facilitated this process. The system was created and cross-referenced by administrators for each of the stakeholders (ITP, ISB, and IESDB). Based on the stakeholder maps that were created in the first step, data collected included 21 data points:

- Child identification number
- Region
- Screening date
- Screening result
- Diagnosis date
- Hearing status
- Language spoken
- Early intervention status
- Idaho Educational Services for the Deaf and Blind (IESDB) phone contact date
- IESDB assessment date
- Primary interventionist
- Discipline of interventionist
- Secondary interventionist
- Discipline of secondary interventionist
- Individual family service plan start date
- Scheduled visits
- Completed visits
- Infant toddler speech-language pathologist start date
- If closed during intake, why?
- If not in services why?
- Notes (indicate if not eligible for specific service)

In addition to the state-based system, a survey was sent to all of the families who had gone through a newborn hearing screening for a three-year period. This data was used as a way to cross-reference and compare the data that is collected within state systems and families' perceptions of the processes that had occurred.

The parent survey incorporated key concepts from Bush et al. (2014). An electronic survey via Qualtrics was distributed to 591 families via email addresses collected by ISB's newborn hearing screening form. Because of the collaboration, the email was distributed by ISB so no personal health information was shared with the investigators. Fifty surveys were returned due to wrong email addresses in the EHDI system. Surveys were

completed by families in all regions, with 116 surveys completed, yielding a 21.4% return rate. Broken down by region, 7.7% (*n* = 9) of the responses came from Region 1, 6.0% (*n* = 7) from Region 2, 12.9% (*n* = 15) from Region 4, 33.6% (*n* = 39) from Region 4, 12.1% (*n* = 14) from Region 5, 7.7% (*n* = 9) from Region 6, and 19.8% (*n* = 23) from Region 7. Having responses from each region is particularly important in Idaho, where there are regional discrepancies in terms of access to pediatric services in more urban/suburban areas (i.e., Regions 3, 4, and 6) and those in more rural/remote areas (i.e., Regions 1, 2, 5, and 7).

Of the 111 families who responded to the question, "When were you told the results of the hearing screening?" 63.1% (*n* = 70) received the results of the screening right after the screening was performed and 30.6% (*n* = 34) were told the results before they left the hospital. One family reported that they were not given the results of the hearing test. Of the 113 families who answered a related but separate question, "Who made the follow-up hearing appointment?", most families (*n* = 61, 54%) made the follow-up appointments themselves, followed by the hearing screener (*n* = 15) as part of a regional pilot program.

According to 113 responses to the question, "Were you able to follow up within 3 months of age?", 85% of the families (*n* = 97) reported that they were able to follow up within three months of age, 16 (14.1%) families reported they were not able to follow up in this timeframe (Figure 2). Distance and home responsibilities were identified as the primary factors that made follow-up challenging for families, followed by health insurance and scheduling.

Figure 2
Parent Response to "Were You able to Follow-up Within 3 Months of Age?" by Region
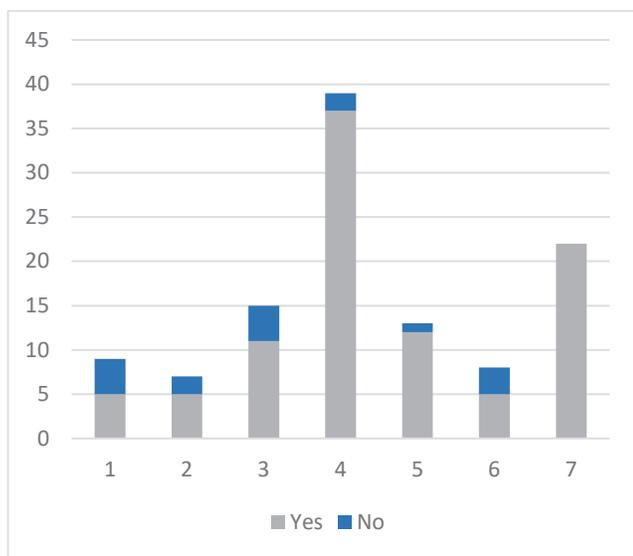
Of the 112 families who responded to the question about the importance of follow-up testing, over half of the families (56.3%, *n* = 63) felt that follow-up testing related to their child's hearing was extremely important. It is important to note that 10 families (8.9% of the sample) were unsure of the importance or thought follow-up testing was not very important. Of the 114 families that responded to the

overall survey, 45.6% (*n* = 52) had children diagnosed with hearing loss, 50.9% (*n* = 58) did not have children diagnosed with hearing loss, and 3.5% (*n* = 4) did not know if their child had a hearing loss or not. Approximately 37.5% (*n* = 42) of the 112 families who responded were told to go to an audiologist (non-specified) for the follow-up appointment, while 32 (28.6%) families were told to follow up with a pediatric audiologist. The average age of identification/diagnosis of hearing loss was 3.16 months of age; however, this varied from region to region (Figure 3).

Fit with Hearing Aids

The average age children received hearing aids was 9.86 months, with a range of 5.3 to 14 months (Figure 3). More than half (71.4%) of the 56 families who responded, reported that the amount of time required to be fit with hearing aids was what they expected (*n* = 28) or faster (*n* = 12). Approximately 19.6% (*n* = 11) of the families reported that it took longer than expected.

### Enrollment in Early Intervention

Families were asked to answer questions about who provides early intervention services and what types of services they received. According to the families who responded to "who provides early intervention services to your family" (with a check all that apply response), families reported that they receive services from IESDB (*n* = 47; 52.2%) and the ITP (*n* = 53; 58.9%) while five (5.6%) were not sure and 34 (37.8%) indicated some other service provider.

When asked what type of services their child received (with a check all that apply response), parents that responded (*n* = 85) reported audiology as the most commonly received type of service (*n* = 42; 49.4%), followed by early intervention (*n* = 38; 44.7%), and speech-language pathology (*n* = 32, 37.6%). This was slightly different than the information that was gained from the state system database. The differences between these two data sources indicates, perhaps, that families are often unsure of the types of services that they are receiving, particularly in a home-based, coaching model where a provider or multiple providers may overlap in the services that are offered (i.e., language or cognitive development). Per the state system database, 2% (*n* = 3) of families received early intervention services four times per month by their early intervention provider (Figure 4). The majority of Idaho families who are enrolled in Part C Early Intervention (EI) receive services twice per month or less (Figure 4).

Parents were asked to report the communication approaches (with a check all that apply response) used by their child. Listening and Spoken Language (*n* = 50; 48.5%) and Total Communication (*n* = 45, 43.7%) were the most commonly used communication modalities of the families who responded to the survey. American Sign Language (ASL) was used by 35.9% of families (*n* = 37) who participated in the study. It should be noted that this is a higher level of sign language/total communication use than other states typically report (e.g., Brown, 2006).
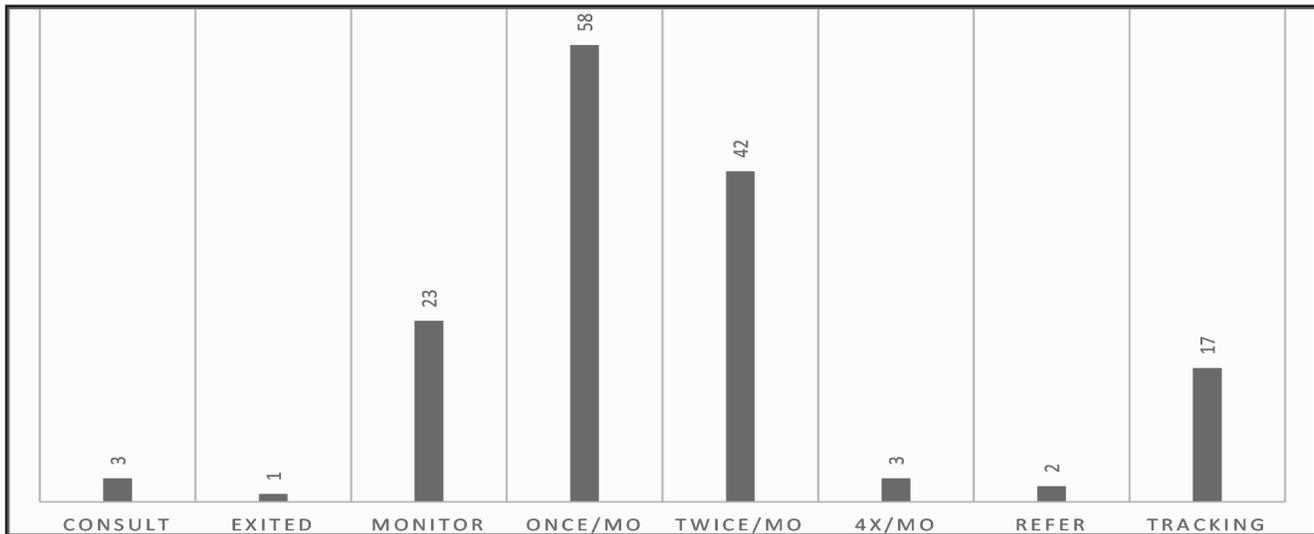
Figure 3

Average Age (in Months) of Child When the Hearing Loss Diagnosis was Made and Age (in Months) Child was Fit with Hearing Technology by Region Based on Parent Survey Results
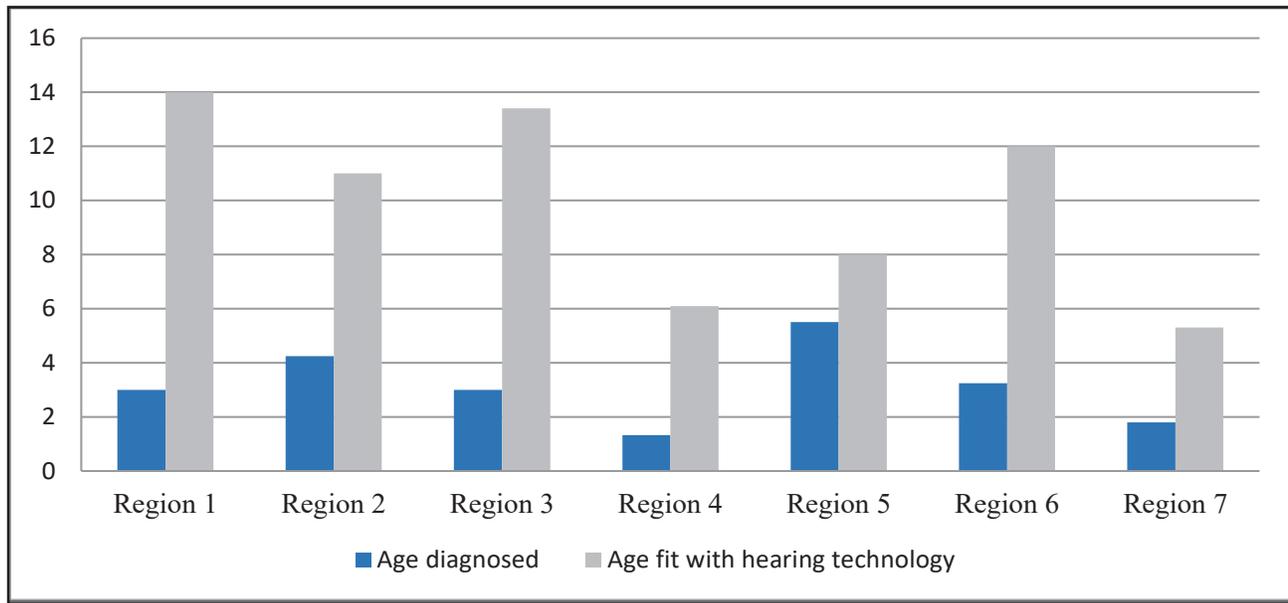
Figure 4

Amount of Early Intervention Services on Individual Family Service Plan Per Month based on Statewide Collaborative Data Tracking

Note. Consult refers to providers seeing a family on regular/consistent schedule with another provider. *Exited* refers to families who have left the system. *Monitor* refers to families who want support but not on a consistent basis. Families may have other children who are deaf or hard of hearing and only want resources or the opportunity to meet occasionally for assessment and/or strategies. *Refer* means there are concerns or providers are waiting to see if they are identified with hearing loss. *Tracking* are families who do not want services. Part C providers send newsletters, invitations to community events and check-in to see if things have changed and if they are ready for service.

Use Data to Identify Needs

The ICC met as a team on a monthly basis to discuss processes, questions, and opportunities for improvement. The parent survey results (shared here) were one aspect of data collection. This was supplemented by a provider survey (Bargen et al., 2017) and ongoing discussion of statewide needs identified by the team. These data sources and discussions lead to clear opportunities for improvement. For example, by having key stakeholders coordinate a data collection effort, it was clear that there were gaps in the communication between entities. For example, 66 children were identified as needing and wanting services who were not identified by the other partner. This gap was not a result of parents' choice or

refusal of services, but gaps in the data collection and sharing. To address this need, EI administrators from ITP and IESDB now meet on a monthly basis to ensure that all families identified as having a child who is DHH have been made aware of all of the services that exist ensuring that they have not been missed by one provider or another. In addition, a protocol and training for ITP providers was developed to ensure all providers who serve children who are DHH offer IESDB participation in the Individual Family Service Plan development process.

One of the goals of this project was to develop a collaborative process that could be shared with other states. Development and implementation of the Idaho Community Collaboration was a learning process and helped us to better identify the needs and opportunities within our state. [See Brown et al. (2019) for additional benefits of public health program collaboration]. The group has since presented the development of the ICC at the national EHDI conference, the American Speech-Language and Hearing Association (ASHA) convention, and the American Academy of Audiology (AAA) conference. Perhaps, more importantly, this information has been shared with statewide providers through the ITP, IESDB, and the statewide Pediatric Audiology Conference. Through dissemination within our state, we have found other opportunities to improve our systems and engage providers to ensure that this journey is transparent and facilitated.

The ICC used the Hogue (1994), Community Based Collaborations framework to assess the level and movement of the collaboration over the two-year collaboration period (Table 2). As the group reflected on the process of the first year, there was definite movement in the relationship of the collaborators. At the beginning of the collaboration the stakeholders were somewhere between the *Networking* and *Cooperation or Alliance* levels of collaboration (Table 2). Stakeholders collaborated and communicated, tasks were completed, processes

Table 2
Community Based Collaboration

Community Linkages - Choices and Decisions			
Levels	**Purpose**	**Structure**	**Process**
Networking	* Dialog and common understanding * Clearinghouse for information * Create base of support	* Loose/flexible link * Roles loosely defined * Community action is primary link among members	* Low key leadership * Minimal decision making * Little conflict * Informal communication
Cooperation or Alliance	* Match needs and provide coordination * Limit duplication of services * Ensure tasks are done	* Central body of people as communication hub * Semi-formal links * Roles somewhat defined * Links are advisory * Group leverages/raises money	* Facilitative leaders * Complex decision making * Some conflict * Formal communications within the central group
Coordination or Partnership	* Share resources to address common issues * Merge resource base to create something new	* Central body of people consists of decision makers * Roles defined * Links formalized * Group develops new resources and joint budget	* Autonomous leadership but focus in on issue * Group decision making in central and subgroups * Communication is frequent and clear
Coalition	* Share ideas and be willing to pull resources from existing systems * Develop commitment for a minimum of three years	* All members involved in decision making * Roles and time defined * Links formal with written agreement * Group develops new resources and joint budget	* Shared leadership * Decision making formal with all members * Communication is common and prioritized
Collaboration	* Accomplish shared vision and impact benchmarks * Build interdependent system to address issues and opportunities	* Consensus used in shared decision making * Roles, time and evaluation formalized * Links are formal and written in work assignments	* Leadership high, trust level high, productivity high * Ideas and decisions equally shared * Highly developed communication

Note. Adapted from "Community Based Collaborations: Wellness Multiplied," by T. Hogue, 1994, Oregon Center for Community Leadership and Ohio State University.

were in place, and roles were somewhat defined. Children were identified with hearing loss and there was a general process for ensuring that the partners were aware of the child, invited to meetings, and clinical audiologists were identified. Conflicts did not exist explicitly and communication was formal (generally presented in meetings). At the end of the first year, the stakeholders had moved to a *Coordination or Partnership* or *Coalition* level of collaboration, with data points to discuss and questions about effectiveness of current processes being examined. If a child is identified with hearing loss, how do we make sure that we are all aware of the child? Do providers have the resources needed to support spoken language as a choice for parents? How do we work to ensure consistency of services across regions with less access to professionals?

Informal discussions with existing partners or relying on status quo communication does not lead to systems change or meeting the collective vision of the providers. Instead, collective work on task-oriented projects was a more effective way to engage stakeholders with productive, constructive discussion. In particular, starting the collaborative with each individual's understanding of the current system was a positive way to engage in the discussion and to identify processes that were unclear or varied from provider to provider and region to region.

Collective data collection and comparison of this data was a very effective way for partners to clearly see gaps in the system as well as discuss and identify ways to address these gaps. An advantage of coordinated data collection was that ICC partners were actively engaged in the numbers and in discussing surprises when they arose. Data provided objective ways of starting discussions and was effective in dissecting perceptions that existed.

The information gained from the parent survey, paired with the information obtained from the state early intervention systems (ITP and IESDB) provides an important first-step to defining the EHDI system in Idaho. The improved collaboration and communication between entities is important for starting objective conversations about ways to address the needs of the state. It will be important to better understand why families did not receive information about their child's hearing loss, to address if and how families are getting information about a variety of communication options such as Listening and Spoken Language, and to understand and address the reasons the majority of families are getting services twice a month or less.

In the last two years, Idaho has made significant strides in terms of its EHDI services. These changes have been, in part, because collaborative partners have had increased awareness, and in turn, more engagement in statewide efforts to support families with children who are DHH. With this engagement, collaborative efforts have included:

- In 2019, Idaho passed a rule that insurance companies cover pediatric hearing aids and 45 hours of speech-language pathology visits during the first year after the child who is DHH is fit with the amplification. A team led by IESDB facilitated a change in terminology for eligibility of services (now there is one category "Deaf/Hard-of-Hearing replacing the two categories "Deaf" or "Hearing Impaired"). Collaborative members were actively engaged in these changes and participated in statewide presentations to educational providers.

- Because of the collaborative relationship, stakeholders started conversations about the comfort level and experience of providers serving families with children who are DHH. As a result, a survey was developed for EI teams asking what basic questions existed about serving young children who are DHH. The results indicated more developmental specialists needed increased understanding of hearing loss, hearing technology, how to assist with hearing aid retention, and interpretation of audiograms. In response to this need, a website was developed to share information and resources related to these specific topics. This website was developed in partnership with the pediatric audiologist and ISU graduate students and distributed to families and providers across Idaho.

- Additionally, because of the needs identified in rural areas, ICC partners are examining the role of telepractice for collaboration and to increase intensity of services to families who live in rural/remote areas. The state has also initiated a statewide early intervention assessment process to examine child outcomes and to use these outcomes as a starting point for professional development opportunities.

Lessons Learned

Student involvement was excellent, not only from an assistance perspective, but also from the opportunity to engage future professionals in the important discussions related to the EHDI system. ISU students from the audiology and speech-language pathology programs were involved in every part of the ICC process: helping with scheduling meetings, taking minutes, data collection, entry and analysis, and development and presentation of talks at regional and national conferences. This increased students' awareness of the EHDI system, challenges, and opportunities for growth and specialization.

Monthly attendance was attainable for most of the participants. Zoom (or teleconferencing software) was very helpful for connecting all participants, particularly when administrators were traveling to satellite offices or at conferences. In hindsight, occasional in-person meetings would be recommended (even on a quarterly basis), as in-person meetings did allow for more informal communication and discussion, which led to productive outcomes.

Technology applications (such as Doodle, Zoom, and Padlet) were effective tools for communicating and scheduling between stakeholders. Some of these tools were not able to be used by all participants due to firewalls within state systems; however, these were able to be

addressed by using home email addresses when needed. Having all of the partners participate was essential. After the first ICC cycle, it was felt that the right partners were involved in the process. The ICC was fortunate to have willing and engaged partners in this collaborative effort to aid the progress or accomplishments of the project.

Conclusion

Idaho is a frontier state with many families living in rural areas. There are a limited number of pediatric audiologists and newborn hearing screening is not mandated. It is surmised that the challenges discovered during this ICC process were not unique to Idaho. Collaboration between systems is challenging for a variety of reasons. Having a grant provided an opportunity to bring together stakeholders and was a driving force to initiate the group with a specific focus of collaborative development. However, once the collaboration was established, all members of the ICC realized the importance of working together to improve the EHDI system within Idaho.

The Idaho stakeholders involved with the ICC were positive, eager to participate, and willing to reflect on their own opportunities for improvement. This was seen as a significant advantage for the state of Idaho, but may limit the generalization to other states with less willing community partners. At the conclusion of the first year, the ICC partners came together to determine the vision of the group moving forward. The collective vision was summarized as:

"In five years, Idaho will be nationally recognized as a leader in DHH education, supports, resources, and partnerships. This includes:

- An easily accessible clearinghouse of information, resources, and support for providers and families

- A cohesive team and streamlined process from screening to enrollment in early intervention through transition to Part B

- Well-established use of technology to ensure access to high quality resources and support across the state."

This shared purpose and goal helped to solidify the accomplished work and create a pathway for the next steps. Given these clear goals, Idaho is better able to leverage resources, training, and support to the families and providers in the regions that demonstrate the most need.

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