

GINGER MULLIN:

This is Ginger I can hear you.

CARRIE BALIAN:

This is Carrie I can hear you as well.

GABRIELLE BIRES:

This is Gabrielle I can hear you as well.

SPEAKER:

OK that should be everybody we have captioning set up and everybody is set up and if you can share your screen Carrie in a minute we can test that out.

Perfect. And if you can carry, leave that up at least as we get a little bit closer it will help people make sure they are in the right place. Sometimes we have questions from people if they are in the right meeting.

CARRIE BALIAN:

That is fine.

SPEAKER:

One thing I did forget to mention that I touched on on Tuesday, if you have your email just disclose that (?) ahead of time -- just close that ahead of time.

WILLIAM EISERMAN:

I am going to be facilitating today's webinar. Can you hear me alright? I am assuming that what we would like to do is have you present and then once you are done, open up for questions. Is that agreeable to you all?

SPEAKER:

Yes.

WILLIAM EISERMAN:

Great the way we will do that is as questions, and you will see them but I will read them out loud so everybody has a chance to catch their breath and everybody in our audience knows what question is being responded to. Does that sound OK with everybody?

SPEAKER:

Yes.

WILLIAM EISERMAN:

Alright great. One of the questions we always get is whether the slides for today are available. I don't want you to feel like you have to share your slides with others. Everybody has their own views about the proprietary nature of their own information. We are recording today's webinar so people can view it and share it at another time. But I know that question will come up. So how would you like that responded to?

CARRIE BALIAN:

Because there is data involved, I don't know how you feel about that? I am fine but I am going to defer to you.

GINGER MULLIN:

I would ask that they contact the Department of Public Health. The information can be used with permission from the department. That way we know where it is being used versus walking in to a presentation someday and seeing our stuff up on the screen.

WILLIAM EISERMAN:

I know I have the same sensitivity around that because I have seen my own slides. With a contact you Ginger?

GINGER MULLIN:

Actually let me go ahead and put in chat... I would give them bad or my contact information. Some people might, just because I have been around an old dog for a while, I think either of those... one is a little more generic than the other. Either of those they can contact and we will get things out to them.

WILLIAM EISERMAN:

Excellent. ... Will the link go directly when people leave or when they click on the chat?

SPEAKER:

It should but it didn't last time so I will posted on the chat.

WILLIAM EISERMAN:

Maybe we can do it that way and the other is just a backup. Because once they are out it is done. OK so that's good.

Are all of you from Illinois who are presenting?

GINGER MULLIN:

Yes we are. Up north, Carrie is from that (unknown name) area and downstate Kate is from (unknown name) but works out of our Springfield office. You may be familiar with babies first which is a huge collaboration over in Decatur. I am from Lincoln, a little bit north of Springfield home of the world's largest covered wagon. And then Gabby is out of Springfield and she has the most exciting news that she was just able to start a position on Tuesday with the CDC. So she has some great adventures ahead. We will miss her but try to collaborate with her.

WILLIAM EISERMAN:

For those of you joining, welcome to the webinar titled the shift to equality and equity through direct referrals to parent to parent support. If captioning is helpful for you, you can click on live transcript. This webinar is being recorded. So if anything disrupts your full attention or participation in today's webinar, you will be able to access it in a couple of days on [infanthearing.org](http://infanthearing.org), our website. And keep that in mind if others are not able to attend live today, to refer them there as well.

For those of you who have just signed on, you are in the right place for today's webinar called the shift to equity and equality through direct referrals to parent to parent support. We will be starting at the top of the hour in three or four minutes. This webinar is being provided by the EHDI NTRC. We serve as the national technical resource Center for all of those in the EHDI community who are striving to improve early identification and intervention services for children who are deaf or hard of hearing and families.

This webinar will be recorded so if anything disrupts your full participation or today's attention -- or attention to today's webinar, you will be able to access this in a couple of days on our website which is [infanthearing.org](http://infanthearing.org). We invite you to keep that in mind if there are people that might benefit from today's information that are not attending, you can refer them to [infanthearing.org](http://infanthearing.org) to access today's recording. I will repeat all of this again in a minute and I appreciate your patience. I just want to give everybody an opportunity to get their volume adjusted to their liking. I will also do a quick audio check with each of our presenters here. When I call your name, if you could speak up for a moment and maybe say the title of today's webinar.

GINGER MULLIN:

Good afternoon.

KATE JORDAN:

Good afternoon, this is Kate and this is Equality Through Direct Referrals to Parent to Parent Support.

WILLIAM EISERMAN:

Great, Gabby?

GABRIELLE BIRES:

Hi, The Shift to Equality and Equity Through Direct Referrals to Parent-to-Parent Support.

WILLIAM EISERMAN:

Sounds good. Kerry?

CARRIE BALIAN:

Hi, this is Carrie.

WILLIAM EISERMAN:

Perfect, you all sound great. Good. Let's just take another couple of minutes while people are signing

on, and then we will get started.

Gunnar, I am going to stop sharing my screen in a moment. Do you want to start recording?

SPEAKER:

That sounds great. After he stops then Carrie, you are great to start yours.

SPEAKER:

Recording in progress.

CARRIE BALIAN:

OK, sounds good.

WILLIAM EISERMAN:

Good day, everyone. I would like to welcome you to today's webinar entitled The Shift to Equality and Equity Through Direct Referrals to Parent-to-Parent Support.

My name is Will Eiserman, and I am happy to be facilitating today's webinar. I am the Associate Director of the national assessment for hearing and assessment management. Known as NCHAM. Which also serves as the EHDI National Technical Resource Center based at Utah State University.

Today's webinar is being offered by the EHDI NTRC, and will be recorded. Which means if anything disrupts your full attention or participation in today's webinar, you will be able to access it again on our website. Which is, [infanthearing.org](http://infanthearing.org) in the next couple of days.

Keep that in mind if there are any individuals who might benefit from today's information, who are not attending today. You can direct them to [infanthearing.org](http://infanthearing.org) as well. I want to get a shout out of gratitude for our interpreters and captioners today, for helping make this meeting more accessible for those who may be in attendance.

Excuse me. We are going to have our presenters present for the next little while, and then when they are done, we will invite you to submit your questions in the Q&A field. But refrain from doing that until we invite you to do so. And then we will open up for a discussion at the end.

So, we are joined today by an incredible group of colleagues from the great state of Illinois. I will allow them to introduce themselves, I will hand it over to them now. Ginger, are you going to kick it off?

GINGER MULLIN:

Thank you so much, I sure am. I name is Ginger Mullin and I of the Illinois EHDI coordinator. I would like to everyone! I would like to welcome everybody to The Shift to Equality and Equity Through Direct Referrals to Parent-to-Parent Support.

We appreciate the opportunity to share our experience in a safe space, as we all work together towards learning and improving. Today we ask for grace as we present, at times we may use specific

terms, and they want everyone to understand that multiple terms may also be appropriate.

Some examples are, for our state we use guide by your side. We believe the information is relevant to all types of family-based organizations. Another example, could be determined hearing loss. He could also use atypical hearing, or describe the type and degree of hearing loss.

With that we will move to our next slide, and people say welcome again! I would like to introduce you to the speakers today. We have Carrie Balian, who is our guide by your side coordinator. And she has been our Guide by Your Side coordinator since 2009, she is a parent, a true professional, and advocate, and a friend.

As I said, I am Ginger Mullin, and I am an audiologist by training, I am currently at the Department of Public Health and I have been the EHDI coordinator since 2005. We also have Gabrielle Bires, she was a social service program letter at the Department of Public health and has recently taken a position with the CDC as a public health advisor for the center for surveillance, epidemiology, and laboratory services.

And Kate Jordan, she is also an audiologist and currently the vision and hearing consulted at the department, and has been part of the EHDI team for many years. Each of them may share a little bit more with you, as they present.

Our other sound beginnings leaders that are not presenting today are Andrea Marwah, Andrea Johnson. In addition, the Illinois EHDI program is supported through numerous collaborations. And the program it is supported by a total of five Illinois EHDI Department of Public Health staff. 12 Illinois guy by your side staff, and 16 hands and board members. We would like to thank The Centers for Disease Control and Prevention and the health resource service administration for their funding of our projects. Next slide.

Today we are going to address the following, which are steps in our timeline that led to direct referrals. Areas that were impacted by direct referrals, and the shift in family needs since direct referrals began. Next slide.

So, how did we get there? Illinois Sound Beginnings has been a collaboration since its inception. Originally, sound beginnings stood for the collaboration between the Illinois Department of Public Health, division of specialist care for children, and the Bureau of early intervention. Now, Illinois Sound Beginnings also includes the strong and robust partnership with Illinois Hands & Voices Chapter and -- guide by your side.

The Illinois Department is headed -- is fully grant funded. Through the years the EHDI program has strived to meet the EHDI one, three, six goals in a timely manner. We began our parent to parent support in 2005, and started our guide by your side program in 2009.

It took a lot of planning, we had many false starts. We relied on specific timing, and we required a lot of flex ability to initiate our parent to parent support for families of children with a suspected or confirmed

hearing loss.

The parent voice was needed in the Illinois EHDI program to help us understand the needs of our geographically, culturally, racially, and economically diverse state. The provision of parent to parent support which includes unbiased information, resources, and one-on-one support by transparent guides, was the beginning of our family-based organization and the states collaborative journey.

Since 2005, at least annually, both programs have reviewed goals of both the state and the family-based organization. Each audio (Audio interference) has needs, and we need to listen to one another. Collectively, we wrote of numerous proposals, goals, activities, and justifications. Unfortunately, not all of them were used but we were prepared.

We also solicited for additional partners. Our numbers dropped in the early 2010, had trouble with sustainability as well as widespread reach. The EHDI program has had increasing programmatic demands. But, we also wanted to retain our commitment to parent support. As a partnership, the two entities have had to pivot many times together. And come up with atypical solutions to keep the program viable, and expand our reach to all areas of the state. As we will explain later.

You can read more about our activities and some unique ideas in our annual reports that are posted on the Department of Public Health's website. Today, we will highlight our direct referral project which has significantly impacted our journey towards equity for all Illinois families. Next slide, please.

It is also important to remember that sometimes the right people need to be at the table. Sometimes you have to wait for someone to retire or move on before you present an idea. Or again. Also you need to have ideas ready to respond to opportunities on very short notice. Writing up ideas, even in a rough draft form, will help you embrace a time sensitive opportunities. Next slide.

Opportunities often come from hallway conversations with people who have related missions. You always have to keep in mind what each side can gain from the collaboration. Just because something is needed and could improve outcomes for everyone, – and could improve outcomes, everyone needs to feel like they are getting something for their efforts. By and needs to be sustainable and allow those involved to maximize efficiency and resources.

We need to have honest conversations about what entities define as their mission, what boundaries exist and what funding exists. In a time with limited bandwidth and resources we must be innovative so our efforts can be scalable and sustainable. Single idea programs cannot survive in the current environment. Next slide.

As I stated, the Illinois EHDI program is grant funded, and we are responsible to those of funders. We must maximize funds by leveraging resources and partnerships. Illinois hands envoy's is guide by your side currently receives grant funding from the Department of Public Health. Activities go beyond one-on-one support, and include the inclusion of parents at all stages of the EHDI program.

For activities that for outside the EHDI scope, hands and voices help with activities. Next slide.

We cannot talk about family support without mentioning FEHDI, or the family EHDI project. HRSA created the projects to increase 20% from baseline, the number of families enrolled in support programs from six months of age. At the time of initial funding definitions for family support were defined at the state level.

A grassroots workgroup was formed to identify standards for enrollment so it could be reported universally. In addition to definitions, a data entry form was created to assist in pulling child specific data from EHDI's systems. Standard data collection across EHDI programs is vital to improving the EHDI system. And meeting the needs of families we serve in an equitable manner, across the country. FEHDI definitions and information and be found@infantheating.org, or contact any of us.

These data points are critical to making success and progress. And I would like to read you a quote from one of the FEHDI participants to underline the importance of people coming together for mutual gain.

The quote reads, "I felt a sense of unity as we all came together to discuss parameters and definitions. It was refreshing to be part of something that could big reporting not only easier to figure out, but to have consistency between estates. This hopefully will allow us to see across the nation, how we are doing. Celebrate our successes, and evaluate areas to improve. I have hope that this will bring more parent partners to the table as a part of a larger team creating connections, developing rules, a sense of purpose, and a mindset of quality improvement." That is the end of the quote.

You can see that we have to make an environment that benefits many when resources are few. But if we come together, that is easy to do. Next slide.

KATE JORDAN:

Hello, this is Kate Jordan, I am an ideologist and consultant with the EHDI Illinois program. Today I would like to talk to about the day-to-day processes and the management of the direct referrals.

We began making direct referrals guide by your side in July 2020, just over two years. And hi track our EHDI information system is a flex both system and it was adapted for us to be able to make these direct referrals.

The addition of this process really is integrated into hi track, and it has been seamless and really very little extra work for us. Because along with our workflow, -- it goes right along with our workflow. This allows us to make erect referrals and follow-up communications within our stable and secure database, versus sending a lot of emails. Sending private information... About individuals. We do not have to include this, we can civilly say, "I shared a group of records with you," and then they are able to get in high track and look for themselves.

They were given access with unique groups, and tailored access. ... Some may have read only versus editing access to hide track. As new users, they have the same training as our staff had, as any users would be required to do.

For our weekly process hearing loss reports that come in through the week, they are entered into the database and we put them in a to do basket of newly diagnosed children. We checked the demographics against the diagnostic database here in Illinois and enter a note with any other information that might be useful for calling the parent. For example, the child is still a patient in the NICU or the family speaks a language other than English. Spanish speaking families can be routed directly from apparent grad -- from parent guide who is bilingual.

We can send a quick email telling them that information has been shared and after that they will have access to all the children there. So advantages have been that this routine meets our standard of making referrals within seven days. Typically the guide by your side coordinator will text families within a day and give them a heads up that the organization will be working from home and they should answer calls from unfamiliar numbers. They don't want to get stuck in a phone take circle.

The next day, the guide will follow up with a telephone call. Because they are in Hi-Track, they can immediately update demographics and enter notes from other referrals being made to other agencies such as EI which makes smoother referrals all around.

When families are contacted by other agencies they have already spoken to God by your side and hopefully they are aware of the process and this information leads them to make informed decisions. They are also able to enter appointments, or put notes in about how the conversation went. And they are able to use Hi-Track for their own processes and letters and documentation. To collect their own data. There is very little extra work, but big gains for timeliness, accuracy, and connection.

#### CARRIE BALIAN:

This is Carrie, as Ginger mentioned I am mother my child is born deaf and I am Monahan's by your site coordinator. Starting out we were cautious about how many users had access to this data system and so we started with a few users when someone was sick or on vacation there is always somebody to be used as backup. We also trained our parent guide who is Spanish-speaking so she can input data directly for family she reached out to. Getting started we knew we would have plenty of data, and having data is great but how can you make it accessible for collection? What data points you need to show for your progress? As Ginger mentioned it just so happened that we were starting our direct referral process by participating in the FEHDI process. Having data points was really helpful and that we knew what was going to be recommended to the CBC in the future for consideration of parents supporting. So we built those data points into our data boys it -- database in Hi-Track and copy this process creating special forms for each of the different specialist roles as well.

The next step after knowing which data we needed to collect was having a way to store it and collect -- having a way to store it and having a way to collect it. So we created a custom letter in Hi-Track that we would populate information onto when we received the referrals. This custom letter became her intake form. We have additional fields on it that are empty, that we complete as the family is enrolling in the program.



After a family and roles, the additional information is added into Hi-Track by one of the guys by your side program users. This is a great way to see the timeline of how the processes move along. We kept in mind that we want to have our ducks in a row before we roll out even if it meant we had to push back or start a goal. Our start date goal was July 2020, so we could start fresh at the beginning of our quarter. By July 20 we were ready and we started receiving those direct referrals. I would reach out to those who referred and complete the intake if the family chose to enroll in our program. This allowed our program to limit the number of people trained in Hi-Track, but it was also how our process was handled before our business agreement and direct referrals. I will share more later about the specialist roles at the end of our timeline.

Now we are getting to the fun part of the presentation. Gabrielle is going to share the impact that our direct referrals have had.

#### GABRIELLE BIRES:

This is Gabby and I am a program planner with Illinois EHDI. As our teammates have mentioned we have discussed so far how we got started on the processes we have created. Briefly, our partnership has allowed for all families to have an opportunity to receive support, and has helped us to meet national benchmarks for parent to parent support. It has increased parent education regarding early intervention which has led to improved enrollment and guidance by your side and early intervention. We have had some new roles and resources to meet the needs of families. In the next couple slides we will show data before and after direct referrals. Before direct referrals the timeline is July 2019 to June 2020 and after is July 2022 June 2022.

Our reach wasn't limited by only providers who shared parent parent supporter referred the family themselves. As you can see the map colored by God by your side regions we were able to reach every corner of the state from direct referrals. This is from the EHDI program to get by your side. Just to provide a quick example, if you look at the before map, you can see that no families are referred in the southernmost regions of our state and if we look at after there has been geographic expansion across the state.

The agreement also encourages racial equity as it allows God by your side to reach out to every family which in turn strengthens family empowerment because they have the option to refer to parent to parent support. This graph shows that after direct referrals, parent to parent support has been able to be provided to more racially diverse families. The greatest increase we have seen so far has been in the black African-American and Hispanic families.

The previous referred families would always have a very complicated situation, communication barriers, or their child's hearing warranted more support. This graph shows that as our partnership continues, we are able to deal with a variety of losses. The great part of this chart represents the year 2020, the peaches 2021, and the black is 2022.

Similar to these findings for the type of loss and degree of loss, this pie chart shows before direct referrals 5% of the infants that were enrolled in God by your side had a mild hearing loss and the rest

of the pie chart was split between that profound and moderate. After direct referrals we were hoping for more of a shift, and if we go to the next slide you can actually see that after direct referrals are pie chart has a much more equal percentages for the different degrees of hearing loss. So our partnerships allowed us to offer services to needs and populations with the larger variety of degrees of hearing loss.

This far we have discussed location, racial communities, and different hearing loss levels. Now we are talking about enrollment. So because of our partnership we have been able to connect with families much earlier than before. This is shown in the charts as most infants after direct referrals, are referred to parent to parent support and enrolled in that birth to six months of age category. If you compare that from before to after, the majority of infants were in that two-year and older so we are working on reaching families earlier.

Just to share some enrollments per year, in 20 2021 families were enrolled in God by your side. In 2021, 161 families and in 2022, 83 families. This only represents half a year data collection so we are on target to exceed 2021 enrollment data for this year.

Early on in our agreement, because we were serving children much younger in age than ever before, families were still learning about and navigating appropriate services. This graph shows what knowledge the family had about early intervention before and after direct referrals. Yes is when they were aware of early intervention services, no means they did not know, pending means they have received a call or paperwork but have not moved forward from there. H doubt means the child is too old for services. You can see this chart shows a dramatic differences in families in the know and pending in before or after referrals. There were simply no families in the before referrals so because of knowing this information are intakes of change. Intakes have been focused on expanding what early intervention is, the process of receiving services, and helping him was connect their local offices.

How are we doing meeting our national benchmarks of providing parent to parent support no later than six month of age? Before direct referrals, only about 12% of our families were reaching this national chart. After direct referrals we had around 67 – 68% which is really amazing.

Just to conclude with some quick stats, because we are able to reach families earlier it was really great to see that 95% of families enrolled in God by your side between the years of 2020 through 2022 became enrolled a repenting enrollment in early intervention as well. The average aid of infant enrollment after direct referrals is 6.8 months. And as I mentioned earlier, our partnerships allowed us to create new parent resources and 17 new ones have been created which Carrie will not go into more detail about.

CARRIE BALIAN:

As GAVI mentioned, other activities we have been able to do is really engage the parent voice early on. I will start by sharing our focus groups. We have assembled diverse groups of parents together feedback on the resources we use, program materials, and websites. In addition to discussing the

intake process and messaging used when serving families with children identified a part of fury. Another product of our agreement were our snippets. Serving families younger men that they were just beginning to process understanding the diagnosis. After seeing this week after week, the idea of creating out one page handout with brief bullet points and QR codes to take them traditional learning was born. When deciding what to call them, the idea of a snippet of information came to mind and so our acronym is simple and informative parent to parent education tools.

We shared how families were impacted by her switch to referrals. But how does this impact our team? One of the impacts, the biggest impact we had was understanding equality, equity, and justice. And be able to have honest and open conversations how to improve where we were. This ended up leading to another new role in our team.

This role is our diversity and equity infusion specialist. Earlier this year we discussed the idea to want more of a leadership role and the idea was perfect because we had just added on more Spanish-speaking guides that could serve the Spanish speaking families we had enrolled. We also needed support for referrals for English, Spanish, or ASL where that wasn't their first language (?).

Our diversity equity and infusion specialist, provides supporting partners for the improvement of community outcomes within disparate populations while protecting the privacy of families. Lydia has shared a quote of what it means to be in this role.

"Being a first generation Mexican-American needs more than a language barrier. Culture, ethnicity, patience and representation matters. Underserved communities need and deserve equal resources."

So, I mentioned earlier that SNIPPETS were created from the needs of earlier diagnosed families we were serving. We are going to dive a little deeper into what our team experienced serving families before direct referrals, and the shift that happened after direct referrals were in place.

The first shift was that the families we were serving had babies. Sometimes they were less than one month old, and the family had potentially just been told about diagnosis one week before we spoke. This often made us the first point of contact they were gathering information from to understand the diagnosis, and the next steps.

Because of this, you should not put a time limit on the initial call. Listen, let them share, and do not forget to be that parent. Remember what it was like and how overwhelmed you felt after your child's diagnosis. I cannot tell you how many times I have heard from a family, "I do not even know what I need to know. What will happen next?"

I connect with them by saying that I remember feeling that same way, that is what we are here for. By talking to a parent who is a bit further ahead on the journey they have a safe place to ask questions and understand those next steps.

I also encourage them to keep asking. If there is something that they asked that they are still unsure about, or maybe they forgot the answer, they should not hesitate to ask again. It is all new, and it may

take some time to get comfortable with.

What I also found is that they are unsure of who does what, and what their babies hearing test results mean. I ask if I can send them information by email. On some of the resources and organizations that will be reaching out to them, so they can better understand why those providers are calling, and how they might help their family.

By walking the family through what to expect next, you are also able to share what is typically appropriate for recommended providers, for a child who is deaf or hard of hearing. But also what to do if they do not hear from them. When they should be reaching out.

They realized that their guide is more than a person to chat with, it is someone who can help them understand services that are available to them, and where to turn when you receive mixed messages.

In the past when we were an opt in program, we would get referrals of complex families, severe losses, and potential cochlear implant candidates. Not that those are a bad thing, but I think providers only offered services to those they felt would need support. Rather than informing all families about our services.

After our direct referrals, we saw a huge variety of hearing differences. Unilateral, mild, (unknown term) conductive, and so forth. After experiencing this shift, we saw the areas where our Guide By Your Side team did have that direct experience but although they had training and resources to share, we wanted to consider adding to the team in some of these areas or updating our trainings.

When our program was and often in a model, we typically matched families with a guide in their regional area. Now we are finding that the regions do not matter as much, and we tend to match more on the diagnosis, additional health concerns, and the ages of their children.

Before direct referrals we saw very few requests for support to families where the parents were deaf themselves, or they spoke languages other than English or Spanish.

Since we received referrals for all families whose child had been diagnosed as deaf or hard of hearing, we have had to work out how to serve families who spoke other languages. I also want to point out that we have connected with more deaf parents in the last 1.5 years who have had a child diagnosed as deaf or hard of hearing than we had in our entire 13 years of our program. There are two reasons why I believe this has happened.

The first, all families are now referred to us. Providers do not assume that since the parents are deaf they do not need support. The second reason is that for those, where I see their primary language is ASL, I have a parent guide who is deaf reach out and explain what our program is. Then complete the intake if they want that ongoing support.

We find the family feels comparable communicating in their own language and supported in their choices. We also found that in helping families early on in their journey, it prepared them to pay it

forward. In our most recent call for applications 83% of those that applied previously had worked with a guide. Compared to 64% of applicants in 2020.

The beauty of all this is they have experience on the other side of the table. They have had a sneak peak of the role of the guide. I think that with this Lived experience the applicants have a better understanding of the role, and it prepares them for what to expect, which increases our retention of guides.

We have also had many newer families apply to be part of our ongoing quality improvement groups.

So, support through COVID. And I just want to point out that... All this data, all of this happened during COVID. So I think that the stats and data really speak volumes for not only the impact of the Parent-to-Parent support, but what a crucial time in our journey of parenting to need the support as well.

I have asked the team to share if there were any changes to support during COVID as compared to their experiences before the pandemic. They shared that there was a need for connections to food pantries, helping families navigate getting appointments, and rain storming the struggle of providers only allowing one person at appointments.

Now that we have all had time to adjust to navigating life with COVID, I asked the guys if parent support looked the same as before COVID or if it was different. One died shared that the focus is shifting back to hearing loss. However, there are families who have lost loved ones, or their jobs, and overall stress and support is just different now.

I mentioned earlier how, during our first year we explored other areas of support for specialist groups (?) shortly after starting our direct referrals we asked, what is next?

It may have been crazy ...but we did. In October 2020 we incorporated through a quality improvement process to the program partnerships, a specialist who follows up with families transitioning out of part C, early intervention, and into part B. US special education services under IDEA.

I had concerns that since we were serving families younger in age that they would not get referred later, when times of transition happen. They would have the perception that if they accepted the Parent-to-Parent support services now, it would not be able to access them again later.

In addition, due to COVID, I was fearful that those families who should be transitioning out of EI, would not be prepared for that change. All of these reasons prompted me to ask our Illinois EHDI team if it would be possible for us to create a transition specialist role.

Our transition specialist, Jaclyn, it's a list every month from our EHDI team of those who will be two years and six months. She then reaches out to check in with them, to see if they are aware of upcoming transition, and to send them a transition resource guide. We created to help families understand this process.

This guide has a 12 topic areas with a brief overview of the topic, and a QR Code that will take them to a link with more information. The guide was created specifically to support this role, and is also available in Spanish.

Then came another, what next moment. Enter our loss to follow-up or other LTF specialist. In February 21, the second role of loss to follow-up specialist was introduced through our COVID private project.

We were able to facilitate follow-up with families who did not make it for follow-up testing after a failed hearing screen. They would reach out to the family, answer questions, provide tips, to help them understand and increase the likelihood of a complete test.

And provide support in finding facilities through EHDI pals to go tooth for their diagnostic test. They would document their Commit occasion and results in Hi-Track. This created a connection with families, showing them that if the test did indeed confirm the hearing loss, that they would have support after the diagnosis.

Since the initial rollout, we have tweaked the process and have dedicated one guide, Kelly, to a permanent role of LTS specialist. This role was a win-win for the EHDI and Guide By Your Side program. Because the parent who transitioned into this role was beginning to question her elements as a guide. Her child was now older, and we were serving families very early on in the diagnosis.

We were able to keep on a thoroughly trained and experienced team member while helping her feel just as resourceful and relevant to the cause. She has blossomed in this role, and takes pride in her 69% connection rate, and the amazing drop in the loss to follow-up percentage that the EHDI team has seen.

Most recently, the diversity and equity infusion specialists, which I touched on earlier. The last point I want to mention is that the difference between the business approach and the squishy side of a parent approach. I believe deep in my heart that the success we have seen as a team is because as parents, we can relate, and they can relate to us.

Kelly's success in dropping the loss to follow-up rate is in her passion to serve, and to see things through. While also sharing from her heart that she also once thought that the repeat hearing test was not necessary. I am not saying that our Illinois EHDI team is not passionate, because that is far from the case! But Parent-to-Parent support is just different.

**KATE JORDAN:**

This is Kate again. And this is a visual representation of the contact efforts made by the loss to follow-up specialist. This data is just pulled from February to July 2022. The reason for the small data set is that we actually had – Hi-Track made adjustments to our data system so we were able to pull this data. That was a Hi-Track update that went into place.

In February. So, Kelly was able to contact 842 families. 59% responded. To a text or phone call. 60% of her responses were from text messages. 40% were from phone calls.

73% of the families had no response at one instance. From this we learned that it will take multiple efforts to reach families and to build trust, and not to give up. For those families that were reached and asked about why they were not able to follow-up, some of the reasons were they did not have transportation, or there were scheduling conflicts. Next slide.

I will get into talking about shared benefits. Just touching again on benefits to both the Illinois EHDI and to Hands & Voices Guide By Your Side. Next slide.

Some quick data. Text messaging was our most successful loss to follow-up contacts effort. February and March were the most responsive months for the Guide By Your Side lost to follow-up efforts. And this is really... Interesting, for us. Because, this is right after the holiday season.

And you know... Historically (Indiscernible) has had the least luck getting families who have children, who have been born over the holiday season, in December and January to seek follow-up. That was a gap, so having this come in right on that tail is just more and more helpful.

We have seen a drop from 27%, a full 10%, from 2020 - 2021. The reports are still coming in. They have solidified an underside that number. Next slide.

Just to quickly go over some of the benefits... During the COVID-19 pandemic, and even before that, at public health we were having difficulty meeting our 1/3/6 goals in a timely manner. Our partnership with Hands & Voices Guide By Your Side has helped us reach additional families in more efficient ways. We were able to take advantage of them able to use more modern communication methods. Just texting... We already talked about how beneficial that has been and how successful that route has been. These are parents living in the same community and are often more receptive interesting to focus for them. This raises the likelihood of parents to respond and take action. Hands and Voices God by your side gives parents the tools they need to make choices for what is right by their child and because they have an active education system and Hi-Track they can provide real-time updates and track their own outcomes and data. Parents worked alongside the EHDI program for growth and sustainability and they can overcome previously known barriers within the process.

GINGER MULLIN:

I know we have shared a lot already but we have a few remaining things to share. Just a reminder that our journey was supported by our great full-time and part-time support staff. Our leadership team consists of myself, Gabby and Kate at the Department of Public health, as well as carry that you have heard from today and Andrea mar why he was the director of Hands and Voices and Andrea Johnson who is the current president of Illinois Hands and Voices. Each of our Illinois team members have unique backgrounds and skills by allowing space and drawing out special skills to shine, we have been able to make the most progress during the pandemic when pivoting was essential.

So what is next? That is a question we constantly ask each other. Like many states, we do face

changes in internal and external staffing. We have threats to funding, we have fatigue, and we have competing priorities. But thankfully through our collaboration we are able to leverage opportunities when barriers and threats arrive. Very often, one of the collaborating partners can help to keep the program moving forward when others experience roadblocks. It takes flexibility, conversations outside of nine – five, and way out of the box thinking. I think Carrie receives strange text messages from me all the time saying "Hey what about this" And at our meeting we discussed those ideas.

Our current plans are in the following areas. First we would like to work on our website and social media. Our website is currently under a revamp and we want to increase access to parent materials. We have been reviewed -- revising wording so we are more culturally inclusive and we are translating all of our information into multiple languages. The website will be in Spanish and the snippets and other materials we hope to translate into the top 10 languages in Illinois. So we hope that you will still share seamlessly in those.

We are working on marketing and enhancing our specialist roles. We want to introduce the philosophy... and do some videos to examine that fostering joy. We also want to inform providers on trauma-informed care.

In the areas of continuous improvement, we will continue the health disparity analysis quantitative and qualitative. We will also do focus groups to provide a space for people to provide honest feedback, and to new ones that we plan to do are a Spanish-speaking and an African-American or black focus group. Both of these providing essays space for a unique community to provide their feedback on how we can improve the EHDI system. Will also do continuous quality improvement for increased efficiency and data documentation in our EHDI system.

Then there is always that sustainability we want to address. In the beginning we did have a business agreement. We ended up in a situation where the players in our world had changed. We were able to propose doing a business agreement and our legal department helped us write that and create that between the Department of Public Health and Illinois Hands and Voices guide by your side. Because we have been dreaming about it for many years, we had in our back pocket an outline of what we wanted it to include, so we were able to turn it around very quickly. When somebody just said "Hey maybe we could..." And we were right there with "Let's do it!". We want to go beyond that business agreement and have sustainability by embedding a lot of this into our administrative roles. Sometimes we still need to go back to our admit -- registration and our rules. We want to make sure that two-way communication is always required with all stakeholders and further define who should be reported and the responsibility and timeline of that reporting. We also want to make sure that all patient level data and privacy is adhered to, and that security for all of that is that the most important level for all of us involved. Not just the department of public health, but also our vendor guide by your side or family-based organizations.

We intend to keep working on resources for families and providers which we want to share seamlessly with everyone. We are promoting EHDI practices or the PEP materials for parents. We will continue to do the snippets which Carrie and Andrea have given birth to that idea. It has been hugely successful. We also want to look for what we can do for our deaf and hard of hearing guide in the future. We are



not done yet, we always want to ask what's next because it heaped -- because it keeps us going but also helps us redefine our efficiency and effectiveness to the community we serve. So pivoting has been the key to get through Cove it in continuing to be the key to keep us moving forward in the challenging times.--COVID

We want to thank all of you and we hope you go to our website. Know that that website is in a revamp so we hope you will go back often because there will be new things every time.

WILLIAM EISERMAN:

This is will, thank you for a great presentation. We have a few minutes for some questions so if any of you would like to post some questions to our presenters, you can type those in the Q&A box and I will read each question and invite our presenters to respond. The first question that has come in reads as follows – it has to do with potential partnering with other established parent to parent support organizations. The question reads – there is a parent to parent program in most states. Illinois is one that there is not an established program. Is there any reason for not involving the established programs in other states, in our state referrals are often done through the established program which is parent to parent.

Ginger or others, would you like to respond to that?

GINGER MULLIN:

I will ask for Kerry to join in. I think in this case parent to parent program is referring to a specific program, not the generic concept of parent to parent. In our scenario, the Department of Public Health put at grant that was discipline specific and we wanted folks that offered parent to parent support in the domain of deaf and hard of hearing. Carrie D want to add to that? Am I missing something? I think I am missing a nuance of the questions of Carrie if you could help me...

CARRIE BALIAN:

I agree, I believe the question is referring to a specific brand of family support parent to parent programs, and so you are right. We don't have that program in our state. Sometimes with those parent to parent programs, they are not discipline specific. So with that, we are fortunate enough to really understand the EHDI community and focus on the needs they have as a program. And again focus specifically on the needs with families with children who are deaf and hard of hearing. So there is the benefit to focus and partner with discipline specific. Now with that being said, I know there are other family based programs who partner with their public health systems and maybe there are more than one family-based partnerships partnering with that department. So that could be something of a consideration. The only thing I would say is that sometimes when you have multiple partnerships it gets to be difficult including all of those in the process and making sure that everyone is working towards the same goal. So there are pros and cons. Sharing the work, but then having more chefs in the kitchen I guess for lack of better phrasing at this time.

WILLIAM EISERMAN:

Here is another related question – do you know of any other states who have used your states protocols or procedures as a template for their programs?

GINGER MULLIN:

We just have the honor of being able to share this information at the national leadership conference in New York State last month. All of our information is out there and we will readily share it. Of course everything is done with federal money so there is absolutely no proprietary. We will give you anything we have. We think that some folks are starting to take some of the information we have shared. We have tried to be transparent on the calls we have been on, so we are not aware of folks in full swing of using these ideas, but we will share anything with you. We believe in share seamlessly, steel shamelessly. So get a hold of any of us.

WILLIAM EISERMAN:

Using about the expanded focus of EHDI to include children up to three years of age. How do you envision parents of children with late onset or later identified hearing loss receiving direct referrals to family supports and if that happens, will they be connected to families of other children with late onset or identified hearing loss?

GINGER MULLIN:

I can take the first part of it. Illinois state law says that any newly identified hearing loss through the age of six has to be reported to the Department of Public Health so we will follow our referral process that is laid out as a child's age dictates. Obviously we will not refer to part C for a four-year-old but we will make all the other referrals as needed. If they come through the EHDI system, those are folks that carry will work with. As we said, if there are referrals at, or families need services later on in life, that is where Illinois Hands and Voices – they serve all the kids through graduation are even beyond. They do some wonderful fundraising to be able to address those specific concerns. We also have a close connection to the Illinois school for the depth that is able to address a lot of concerns with their resources. Carried you want to comment?

CARRIE BALIAN:

We have had multiple opportunities where there was a late onset where that EHDI team it had been shared with them or the family came to us first and we are able to share that information back with EHDI so they could reach out to that audio adult -- audiologist and request that report. So it has worked both ways. We do serve those families as far as connecting them with the parents who also has a late onset. We are able to do that as well, that is just one of the things you look for when hiring for your team of parents.

WILLIAM EISERMAN:

One final question and then we will wrap it up. Before you all go, there will be a short evaluation, a link to an evaluation and a certificate generator that will appear in the chat field in a moment here if not already. If you need a certificate for today's presentation attendance, that is your way to get it. So the final question, – you have shared some great data. Have you collected any data about children with hearing loss and additional sensory loss or disability?

CARRIE BALIAN:

This is Carrie. As part of my intake process I do ask the parent. So it is parent reported. On my end. If

there are any additional needs aside from the hearing loss.

GINGER MULLIN:

This is Ginger. We, as part of our reprint of our website we are trying to do a lot more with D/Deaf and d/Deaf/blind. We feel that we need to be that Lorax who speaks for the trees for low incidence disabilities.

I hope that is an area of expansion that you will see from us as we get input. Illinois in their part C system have developmental therapists specific to hearing loss and specific to hearing -- specific to vision issues. We want to continue to partner with those, and Andrea, our Executive Director in another phase of her life, is a lot to do early intervention training sessions.

Where they have a two day conference, every June. If you are interested in that audio (Audio interference) please contact Andrea Marwah or one of us, and we will connect you with that.

As far as other disabilities, we do rely on our part C to help us address any

\*\*Audio lost\*\*

WILLIAM EISERMAN:

It sounds like Ginger got cut off. Can you still hear me?

SPEAKER:

I sure can.

WILLIAM EISERMAN:

This is will. We will wrap it up with a giant thank you to our four presenters, Carrie, Ginger, Gabby and Kate. Another shot out of gratitude to our captioners and interpreters today. And to all of you for your participation today. Ginger's email is in the chat, if you need to contact any of the presenters that is a great way to do it.

There is also the link to the evaluation and certificate generator. You will find there to click on. Remember, this webinar has been recorded. And will be on [infanthearing.org](http://infanthearing.org) in the next couple of days. So go there, share it with others.

If it is of relevance to them. Thank you everybody. I hope you have a wonderful day, and enjoy the fall!

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