

Increasing Parent Engagement in Early Intervention to Impact EHDI 1-3-6 Enrollment Goals

Hilary Pamperin, RN, BSN



Michigan EHDI and Collaborative Partnerships

- Historical partnerships with stakeholders since inception in 2001
- Development of public health/community-based collaborations with universities, hospitals, providers and professionals
- Parent/EHDI program collaboration for over 15 years with evolution of 1-3-6 national goals
- Facilitate education/internships for university students and research

EHDI Goals

- **Goal 1:** All newborns are screened for hearing loss no later than 1 month of age.
- **Goal 2:** All infants who do not pass the screening will have a diagnostic hearing evaluation no later than 3 months of age.
- **Goal 3:** All infants with a hearing loss are enrolled in early intervention services no later than 6 months of age.

Parent Support

- Michigan Hands & Voices™ Guide By Your Side™ Program
- Parent 1-3-6 program
- Incorporate parent perspective



Newborns and Their Families

Provide better outcomes for Michigan newborns and young children with hearing loss. Research shows that early identification of hearing loss and enrollment in intervention services may lead to significant benefits in childhood development. Language and speech development in infants and children helps them acquire skills that are important to literacy success, which is why hearing screens are so important.

Provider/Community Development

- Implement Best Practice Guidelines state-wide
- Ensure that educational and presentation materials are available
- Collaborate with stakeholders to ensure meeting EHDI goals

www.michigan.gov/ehdi

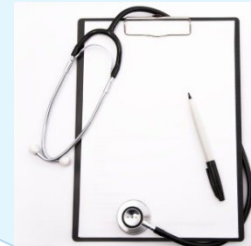
Program Outcomes

- Ensure National Goals and Objectives are being met
- Develop needs assessments
- Implement quality improvement strategies
- In 2017, 167 Michigan babies were identified with a hearing loss.



Follow-up

- Assist providers and families to ensure babies receive follow-up
- Monitor data and trends
- Provide birth hospital technical assistance



MICHIGAN HANDS & VOICES™

Guide By Your Side™

Parent Guides visit with families of identified children.



Events

Meet & Greets

Legislation

Newsletters

ASTra™

Advocacy Support & TRAINing



HANDS & VOICES™
MICHIGAN

Deaf/Hard of Hearing Guides

DHH Guides In Home Visits & Events



Parents give back meaningfully: Share Stories. Improve Systems.

The Missing Link

**EHDI quantitative reports
and best practices**



“Customer” stories



Improved medical and educational services

1-3-6 Parent Liaison Program Structure

- Recruitment and training
 - Zoom meetings
 - Sharing Our Stories training
- Building relationships with birthing hospitals, regional audiologists, early intervention programs and EHDI
- Collaborative, dynamic training for professionals
- Follow up and evaluation after parent stories

Telling the Parent Story

The Story

- Share experience of diagnosis and intervention with a brief update on where the child is today
- Share pictures to help the audience connect to the story
- Big picture - Focus on those brief moments with the audience addressing how their role impacts a family's journey



6 Month Goal

Targeting Early Intervention Professionals

- There are three types of activities that fall within this goal:
 - County-Specific Meetings
 - Systems and Outreach meetings
 - Formal Presentations.
- Two objectives for the 6 month EHDI goal:
 - 5-8 Local Inter-Coordinating Council (LICC) groups will show an understanding of the importance of Early On enrollment for all children with hearing loss, including mild and unilateral levels of hearing loss.
 - LICCs will have the resources to support families of children with hearing loss in their area.

Integration of Parents into Interagency Coordinating Councils and Great Start Collaboratives

- Presentation and continued involvement at the State level - MICC
- Presentation and continued involvement at Great Start Collaborative meetings
- Parents participated in Early Intervention meetings in six counties at over 24 meetings.
- Michigan Prenatal-to-Three Collaborative
 - Two dates for parents to participate
 - Posted the questions on our facebook page
 - Posted the link to a survey monkey version for anonymous participation
- Michigan Early On Conference
 - Two hour presentation by two parents
 - Inspired a lot of questions and conversation as well as new outreach opportunities

Parent Contribution

- *Give a good description of what MI H&V does for our communities and for families of deaf and hard of hearing children.*
- *Talked about the 1-3-6 initiative and our interest in improving early intervention. I also talked about the value of teaching empathy and inclusiveness.*
- *Discussed the importance of making families aware of resources available to them...fielded questions from professionals about state-specific resources for families.*
- *Brought up the need for reaching more families with unilateral hearing loss and getting them plugged into Early on.*
- *As a result of attending local meetings, we were able to learn about the Talking is Teaching campaign and help to develop a similar campaign to meet the specific needs of our population regarding early language development.*
- *Got out the word about how hearing loss is very hard to detect using the subjective paper tests and importance of pediatric audiology care.*

Challenges and Changes to the Program

- Identifying LICCs
 - Difficult when they are combined with other county collaboratives
 - Confusion with collaborative vs. parent coalition meetings.
 - Trial and error - thought meetings were one thing, and they were something else.
- More of a long term investment for parents
- Parent recognition of program language (Early On vs. Early Intervention vs. Special Education) - 1:1 training to help clarify and support
- Getting the right audience
- Using webinar/video options to decrease travel costs

The Future of the Program

- Increase parent representation throughout the state
 - Polling Guides to identify parent leaders
 - EHDI survey tool at 1 year old - Would you like to get involved?
- Increase passive access to parent stories through social media, video and website
- Compiling quantitative data to measure objective impact

The Future of the Program

Pre Survey

Which of the following qualifies a child for Early On services? Check all that apply. *

- Unilateral Hearing Loss
- Bilateral Hearing Loss
- Mild Hearing Loss
- Moderate Hearing Loss
- Severe Hearing Loss
- Profound Hearing Loss
- Auditory Neuropathy
- Any hearing loss as long as there is a speech delay
- Option 9

In MI, what percent of infants who have been identified with hearing loss are enrolled in Early On by 6 months of age? *

- 50%
- 74.5%
- Option 5
- Option 6
- 95%
- 36.5%

Submit

Post Survey

Which of the following qualifies a child for Early On services? Check all that apply. *

- Unilateral Hearing Loss
- Bilateral Hearing Loss
- Mild Hearing Loss
- Moderate Hearing Loss
- Severe Hearing Loss
- Profound Hearing Loss
- Auditory Neuropathy
- Any hearing loss as long as there is a speech delay

In MI, what percent of infants who have been identified with hearing loss are enrolled in Early On by 6 months of age? *

- 50%
- 74.5%
- 95%
- 36.5%

What is one thing you took from this session that you will apply to your Early On work with D/HH children? *

Your answer _____

Submit

Qualitative Results

The Impact

- Awesome feedback given - parent stories always get great follow-up questions.
- Consider the power of one family's story reaching a multitude of providers who will be with innumerable numbers of babies!
- Report on Google Forms "What did you share? What did you learn?" Reported to EHDI in quarterly reports.
- Surveying professionals at the time of presentation.

Feedback

- *Having a family that has gone through this experience was great.*
- *Very interesting. Can relate to daily work. Personal story drove message home.*
- *Personal story really accentuated the importance of follow-up.*
- *Enjoyed having a parent share her experiences.*
- *Great presentation. Loved the speaker who shared actual life experiences.*
- *Good information. Liked the added extra speaker with the story.*
- *Informative. Enjoyed hearing personal story.*
- *Very informative and appropriate, great information. Love the parent perspective. Great information and tools to help parents.*
- *Bringing parent to tell her story was excellent.*
- *Very informative. Parent was very good.*
- *Great topic with relevant information. [The parent's] story was inspiring and eye-opening.*

Feedback

- *What did you learn from this presentation?*
 - *I learned a lot about hearing loss and the impact my services have on families.*
 - *Learned more about gaps surrounding infant screenings and early support. Also learned about support and Parent Guides through MI Hands & Voices, which I had never heard about before.*
 - *Advocacy options for parents*
 - *I learned about how being HOH comes in various forms and that early detection is very important. I also learned that it is possible to test an infant's hearing at a very young age.*

Feedback

- *What was your takeaway regarding the parent's story?*
 - *Clear communication with families is key!*
 - *How important early intervention is and also the impact of support to parents who are facing a diagnosis of their child.*
 - *It helped get a parent's perspective on the need to connect.*
 - *I realized that while receiving a diagnosis of hearing impairment for a child might be difficult for a parent, it doesn't have to be a tragedy.*
- *Please share how this presentation might affect your work going forward.*
 - *I will be more mindful of the impact I have in daily practice.*
 - *MI Hands & Voices is a valuable resource, and I can share this with parents*
 - *I will connect parents with this group when needed.*
 - *I will be more aware of recommending hearing testing for all infants, as well as children who appear to have behavior problems.*

Thank you!

Hilary Pamperin

hilary.pamperin@snc.edu