

Primary Care Provider (PCP) Outreach: Enlisting PCPs as Integral Members of the Family Support Team



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Disclosures

Jane Stewart, MD and Jennifer Fleming disclosures

- No financial or nonfinancial relationships relevant to the content of the proposals exist.

Learning Objectives

- Participants will be able to describe the critical role of the PCP in EHDI 1-3-6 (screening by 1 month, diagnosis by 3 months, early intervention by 6 months) goal attainment
- Participants will be able to describe key aspects of our outreach program efforts
- Participants will be able to devise strategies to develop/expand their own PCP outreach program in their individual states

Primary Care Provider Defined

- Identity
 - Medical Doctor (most often)
 - Pediatrician or Family Practitioner
 - Doctor of Osteopathic Medicine (DO)
 - Physician assistant (PA)
 - Nurse practitioner (NP)
- Role
 - Provides coordinated care across wide range of health systems
 - Manages various aspects of patient health
 - Physical
 - Behavioral
 - Developmental/Social Emotional
 - Tracks milestones
 - Makes referrals to specialists
 - Trusted source throughout a child's journey

Primary Care Provider – JCIH Definition

Joint Committee on Infant Hearing (JCIH) guidelines: Role of the Pediatrician/Primary Care Provider

- Monitoring birth hearing screening outcomes
- Ensure follow-up diagnostic evaluation when indicated
- Ensure timely audiologic and medical assessment
- Partner with specialists to facilitate coordinated and comprehensive care for the infant and family (otolaryngologist, audiologist, geneticist/genetics counselor, early interventionist)
- Provide families with hearing, speech and language milestones and for ongoing developmental screening.

The Problem

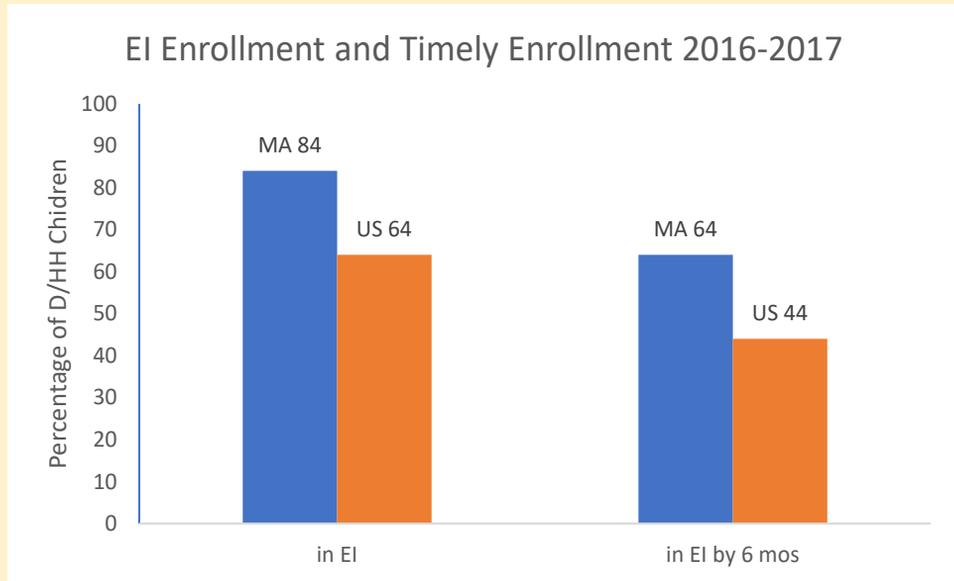
- PCP has pivotal role in achieving 1-3-6
- Hearing loss occurs in only 1-2 per 1000 children
- PCP may not currently have a child with reduced hearing in practice and may need up to date information to be comfortable providing what families need

How Can We Support These Key Team Members in Fulfilling Their 1-3-6 Role?

MA Baseline data EI by 6 months

In Massachusetts, though EI incurs no out-of-pocket costs,

- EI enrollment rate, though high, could be higher
- Enrollment by six months has been a focus



PCP Outreach Project

- Target PCPs with children newly identified with reduced hearing
- Provide PCPs with material about reduced hearing and its impact on language/child development
- Initially contact letter from EHDI program from parent of a child with reduced hearing
- Phase 2 - new letter from DPH/AAP chapter champion
 - Connecticut program successes used as benchmark
 - Data sharing agreement and legal DPH agreement developed

PCP Outreach Project

- Program initiation: June 2018
- Provide patient specific information via fax and mail
- Additional outreach to children outside of 1-3-6 window included
- Follow up directly with PCP and provider team with discretion
- Track outreach and letters sent
- Develop action items for additional outreach as needed
- 254 letters sent to date!

Sample Letter



The Commonwealth of Massachusetts
Executive Office of Health and Human Services
Department of Public Health
Tewksbury Office, Saunders Building
Tewksbury Hospital, 305 East Street, Tewksbury, MA 01876
TEL: (978) 851-7261 / FAX: (978) 840-1027

CHARLES D. BAKER
Governor
KARINE E. POLTO
Secretary

January 4, 2021

John Smith, MD
Primary Care
Boston, MA
Phone: (xxx) xxx-xxxx
Fax: (xxx) xxx-xxxx

Dr. Smith –

Our records indicate that Baby Eddie, DOB 11/11/20, was recently diagnosed with permanent unilateral moderate sensorineural hearing loss. As your MA American Academy of Pediatrics (AAP) Early Hearing Detection and Intervention (EHDI) Chapter Champion, I would like to offer you my assistance. First, I would like to provide you with some important updated information that could prove valuable in the growth, learning, and eventual outcome of your patient with any form of hearing loss.



Early diagnosis and intervention, and avoiding language deprivation are crucial to the development of speech, language, cognitive, and psychosocial abilities. The Joint Committee on Infant Hearing (JCIH) guideline is 1-3-6: screening by one month of age, diagnostic testing by three months, and early intervention (EI) services initiated by six months. The key role of EI is to provide an enriched language environment as early as possible to the infant's developing brain and promote optimal early language learning during this sensitive period of development¹.

Infants who have been diagnosed with permanent hearing loss of any degree (including unilateral losses) or with an immediately qualifying diagnosis are eligible for EI services in MA at no cost to the family. In light of these extremely difficult times, telehealth services have been approved and MA EI provider agencies are offering families support utilizing remote technology to provide services. Based on the family's Worcester address, there are several direct referral options. Two options follow:

- South Bay Community Services – Early Childhood, Worcester: 548 Park Avenue, Suite B, Worcester MA 01603. Ph. 774-823-1500 or
 - Parent EIP: 237 Millbury Street, Worcester, MA, 01610. Ph. 508-755-1288
- It is important to know that services are available from specialty service providers who have special skills and knowledge around hearing loss. Families may request more than one specialty service provider. These providers can be found on the Universal Newborn Hearing Screening Program (UNHSP) website (<http://www.mass.gov/dph/newbornhearingcreening>) along with other information and resources. Family TIES also has a family matching program in which parent families are paired with new families to offer support and information <http://www.massfamilies.org/wp-content/uploads/2019/08/P2P-MATCH-REQUEST-Form-English-Fillable-2019.pdf>. Another resource is the Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH)

MARYLOU SUDDERS
Secretary
MONICA SHANDEL, MD, MPH
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www.mass.gov/eohhs

<https://www.mass.gov/service-details/massachusetts-commission-for-the-deaf-and-hard-of-hearing-mcdhh>. Child specialists are assigned by region and offer individualized support to families.

Language development is dependent on early input to the infant's developing language acquisition center during a critical window. The initiation of language stimulation right away is very important in the long-term development of language and communication. Prompt initiation of amplification, auditory input, and language input (spoken and visual) is associated with improved long-term outcomes. Establishment of EI services is complex and decisions about the best plan for providing an enriched language environment require parent education². Essential parent information includes support in:

- Understanding the hearing loss diagnosis and results of their child's hearing diagnostic evaluation.
- Information on communication development from infancy through childhood.
- Communication choices and language exposure: this refers to all listening, spoken, and visual or signed language or combination thereof. For example, some families planning on a cochlear implant may opt to use multiple modes by initiating the use of sign language prior to receiving the cochlear implant.
- Choices in amplification.
- Educational resources and choices!

Additional information, compiled especially for primary care providers, can be found on our website <https://www.mass.gov/info-details/universal-newborn-hearing-screening-materials-for-health-care-providers#materials-for-primary-care-providers>.

Please feel free to reach out to me with any questions or concerns. I am eager to offer support to optimize outcomes for your patient.

Sincerely –

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Refs:

- ¹Wacker CJ, Hensk TK. Critical periods in speech perception: new directions. *Annu Rev Psychol* 2015;66:173-94.
- ²Yoshizawa-Jones C. Principles and guidelines for early intervention after confirmation that a child is deaf or hard of hearing. *J Deaf Stud Deaf Educ* 2016;21:646-75.
- ³Stewart J, Bentley J. Hearing Loss in Pediatrics: What the Medical Home Needs to Know. *Resist Clin N Am* 66(2019):425-436.

2

1 HEARING SCREENING
By 1 Month

3 DIAGNOSIS
By 3 Months

6 INTERVENTION
By 6 Months

1-3-6

EARLY IS URGENT!

Language delays
are a developmental
emergency

Early diagnosis and intervention, and avoiding language deprivation are crucial to the development of speech, language, cognitive, and psychosocial abilities. The Joint Committee on Infant Hearing (JCIH) guideline is 1-3-6: screening by one month of age, diagnostic testing by three months, and early intervention (EI) services initiated by six months. The key role of EI is to provide an enriched language environment as early as possible to the infant's developing brain and promote optimal early language learning during this sensitive period of development¹.

Key Content Included



- Patient diagnosis
- 1-3-6
- Language development
- Components of parent support
- EI direct referral information
- Specialty Service Providers
- Family to Family Support
- Where to go for additional information – PCP mass.gov website
- References

1 HEARING SCREENING
By 1 Month

3 DIAGNOSIS
By 3 Months

6 INTERVENTION
By 6 Months

Attachment: Visual D/HH Resource Guide



<p>Services for Children who are Deaf and Hard of Hearing</p> <p>Birth to three</p> <p>Early Intervention (EI) Team/IFSP Early Intervention services are designed to assist young children with disabilities to reach their maximum potential. Services are provided to children and their families including those who are deaf or hard of hearing. Team members work together to develop an Individualized Family Service Plan (IFSP), a written plan that states the EI services your child will receive, as well as how and when those services will be implemented.</p> <p>Speech Language Pathologist (SLP) SLPs work with children with communication and academic needs and language impairments. Some have specialized training and certification in working with children who are deaf or hard of hearing.</p> <p>Specialty Service Providers Specialty services are provided to children with specific needs. These services are provided by professionals who have specialized training and certification in working with children who are deaf or hard of hearing.</p> <p>Teacher of the Deaf (TOD) A Teacher of the Deaf is trained to teach children who are deaf or hard of hearing. They work with children of a variety of ages and abilities.</p> <p>Family Sign Language Program The goal of the Family Sign Language Program is to introduce family members to Sign Language, utilizing them to communicate with their child in the earliest age possible.</p> <p>DHH Program Consult & Assessment Individualized plans and tailored program over time.</p>	<p>Pre-school and beyond</p> <p>Preschool An educational establishment or learning space offering early childhood education to children typically ages 3 - 5. Statewide program for State children only.</p> <p>Elementary School An educational or primary school is a school in which children receive either their early education from the age of three to five to twelve, entering other preschool and before secondary school.</p> <p>Aide A person whose job is to assist someone. In a teacher's office, Certified educational assistants are available.</p> <p>Teacher of the Deaf (TOD) A Teacher of the Deaf is trained to teach children who are deaf or hard of hearing, specializing in one or more of a variety of services.</p> <p>Hearing Assistive Technology (HAT) Devices that help to overcome hearing loss. Aids are referred to as hearing learning devices. HATs can be used with the different hearing aids or cochlear implants to make it easier to hear.</p> <p>Individualized Education Program (IEP)/504 Team School staff and parents work with a specially trained team to develop and implement the student's Individualized Education Program (IEP). The team may include educational diagnosticians, special education teachers, and members of the school's special education program.</p> <p>Educational Audiologist The Educational Audiologist will focus their practice on educational settings where one deaf or hard of hearing or hearing-impaired child is attending. The student's hearing, learning and auditory processing abilities may affect their academic, social, communication abilities and developmental achievement.</p> <p>SE/PAC (Special Education Parent Advisory Council) A parent organization that works with the school system to promote communication between the school, children and special education students.</p> <p>Speech Language Pathologist (SLP) A professional who is trained to assess communication needs and implement interventions to improve communication skills and participate in working with children who are deaf or hard of hearing.</p> <p>Federation for Children with Special Needs The Federation for Children with Special Needs provides information, support and advocacy for children with disabilities, their professional partners, and their communities.</p>
<p>Health Services</p> <p>Podiatrist Podiatrists are doctors who manage the health of a child's feet, including problems, infections, and general health issues. They can be trained to diagnose and treat childhood diabetes. From some hearing problems to nerve damage.</p> <p>Otolaryngologist/ENT Otolaryngologists are trained in the medical and surgical management and treatment of patients with illnesses and disorders of the ear, nose, throat, and related structures of the head.</p> <p>Audiologist A child who professional trained to diagnose hearing loss, evaluate hearing, and provide hearing aids and/or cochlear implants. They can be trained to diagnose and treat childhood diabetes. From some hearing problems to nerve damage.</p> <p>Hearing Aids/Cochlear Implants (CI) A hearing aid is a device that is used to amplify sound. A CI is an electronic device that provides the sense of hearing by bypassing the middle ear's function. It is used for children under the age of 21. Contact your audiologist for more information.</p> <p>Ophthalmologist An ophthalmologist can eye specialist. Hearing and vision loss can occur in certain syndromes. A referral to the eye doctor is common. Hearing specialists are available.</p> <p>Health Insurance Health insurance provides coverage that pays for medical and nursing expenses.</p> <p>Geneticist A geneticist's work can be inherited. A geneticist specializes in the diagnosis and management of hereditary disorders.</p>	<p>Community</p> <p>Shared Reading Saturdays This is a weekly reading event for parents and their children who are deaf or hard of hearing. It is held at the MCDHH office. The event is held on Saturdays from 10:00 AM to 12:00 PM. The event is held at the MCDHH office.</p> <p>Religious/Community Groups Religious organizations and groups offer the local community an opportunity to connect with others who are deaf or hard of hearing.</p> <p>Parent Support Groups Parent support groups are available for children who are deaf or hard of hearing.</p> <p>Family TIES An information, referral and support network for deaf or hard of hearing children and their families.</p>
<p>Universal Newborn Hearing Screening Program (UNHSP) The UNHSP helps families get the hearing they need. Services include family support, outreach and education, parent-to-parent support, information and referral, technical assistance, educational and hearing support.</p> <p>MA Commission for the Deaf and Hard of Hearing (MCDHH) MCDHH is a state information, referral and direct service agency. It is the state's deaf and hard of hearing individuals of all ages and their families and service providers. MCDHH provides services to parents and families statewide.</p>	

Attachment: Specialty Service Providers

All Infants/Toddlers who are Deaf or Hard of Hearing in MA are eligible for Specialty Services

Specialty Service Providers – higher level of skills, knowledge, trained to work with families of children who are deaf or hard of hearing.

May include:

Teacher of the Deaf (TOD), Speech Language Pathologist (SLP), Parent Infant Programs, playgroups featuring interactions with deaf and hard of hearing peers, and parent groups.

Families can request services from more than one Specialty Service Provider.

Attachment: Bright Futures AAP Tip Sheet

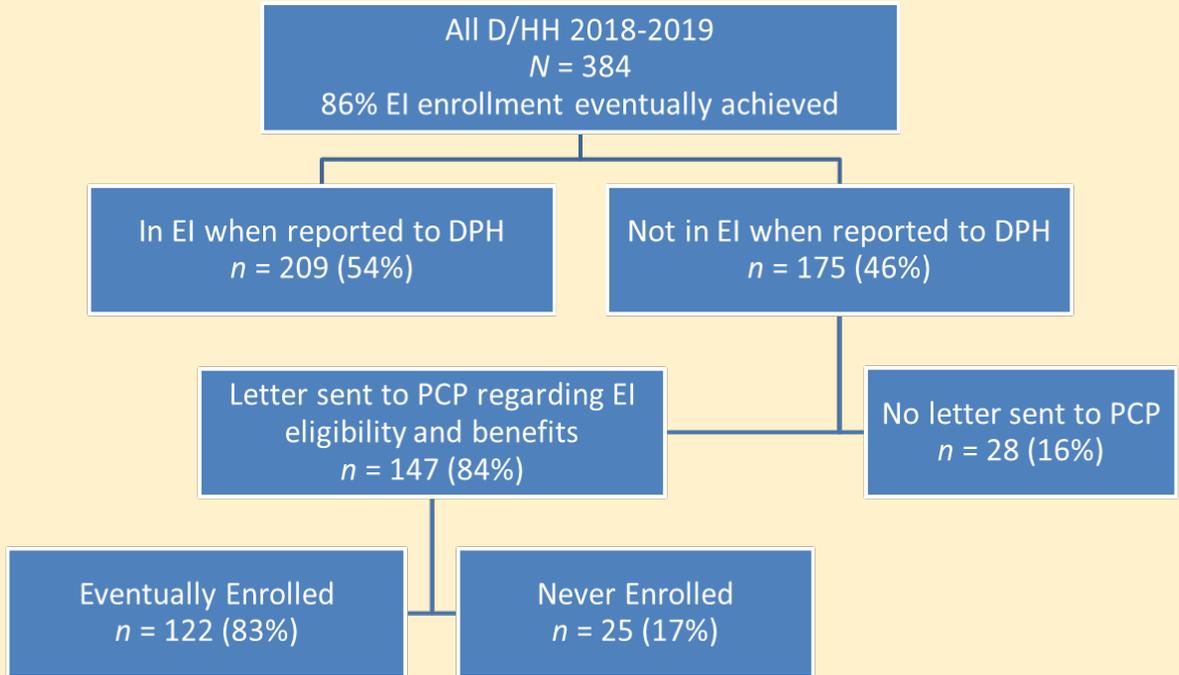
American Academy of Pediatrics (AAP) Implementation Tip Sheet



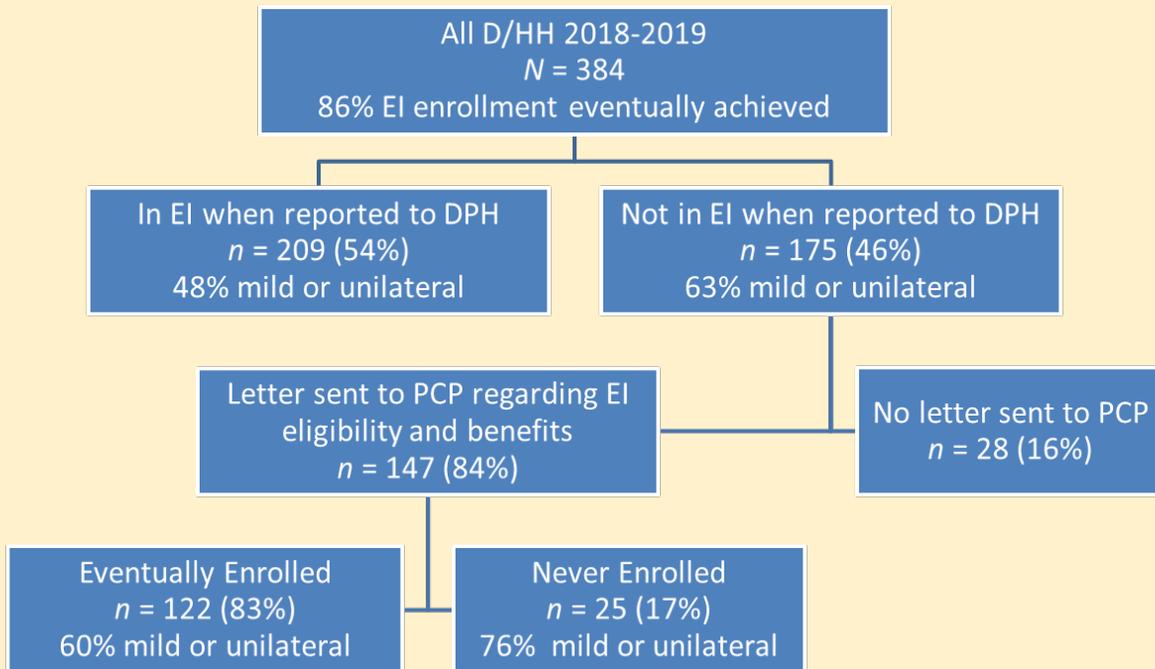
Promoting Early Hearing Detection and Intervention

https://downloads.aap.org/AAP/PDF/BF_EHDI_TipSheet.pdf

Results – EI Enrollment

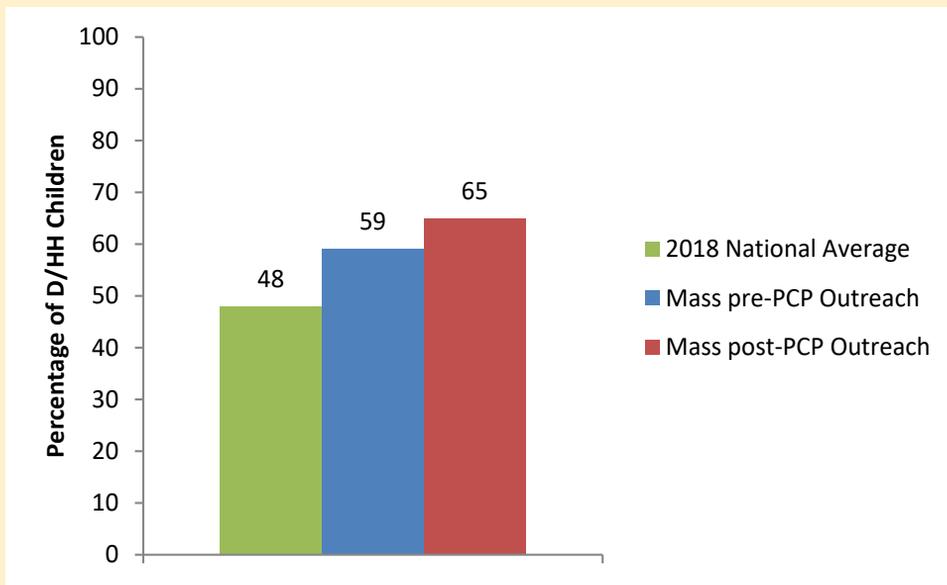


Results – EI Enrollment



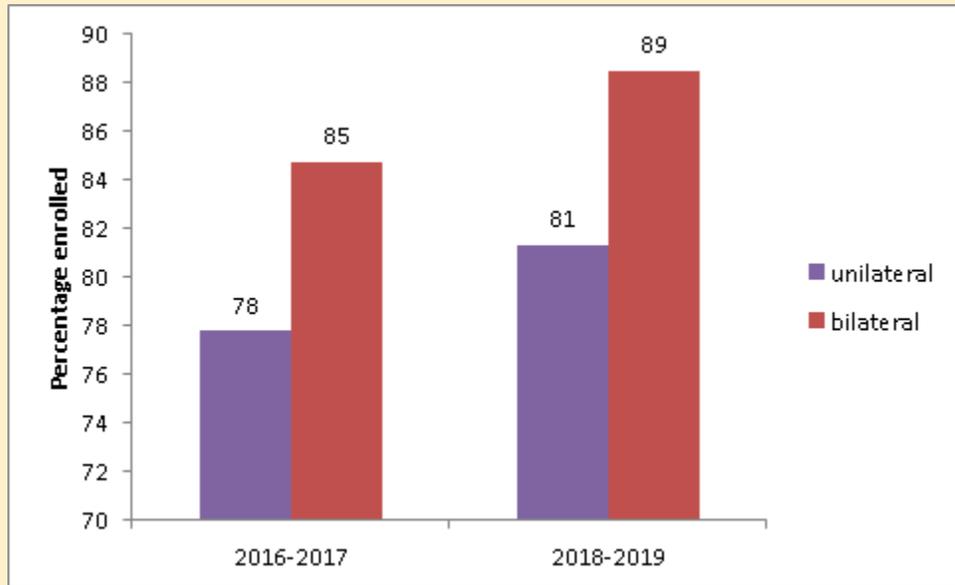
Results – EI Enrollment by 6 months

EI Enrollment by 6 months of age



Results – Unilateral vs. Bilateral

Overall EI enrollment for unilateral and bilateral cases



Results -- Summary

- Direct referrals to EI from PCPs increased dramatically
 - These referrals more often result in enrollment
- Nearly ½ of D/HH children were not in EI when HL was reported
- Children not in EI when hearing loss was reported were skewed toward mild and unilateral cases
- 83% of 147 initially un-enrolled children whose PCP received a letter were eventually enrolled in EI
- Most children who remained un-enrolled despite PCP contact had mild or unilateral hearing loss, and the reasons for not becoming enrolled were
 - Parental refusal, Lack of follow through
- Timely EI enrollment improved
- Unilateral enrollment increased
- Cases with lesser degree of loss EI enrollment improved
- Early outreach more effective

COVID-19 Modifications

- Process in place to update PCPs with up to date information
- Inform providers on EI remote enrollment
- Emails efforts and practice responses
 - Security: Limitation of non-child specific data
 - Unilateral and lesser degree of loss
 - Medically complex children with reduced hearing
 - Access to HIPPA compliant specific provider email limited
- Return to patient linked fax and letter process

PCP Feedback

- I have been in practice for 25 years and I've never had a case like this.
- Thank you so much for sharing all this information. This is what I am doing for my patient. What else can I be doing?
- It is good to know that EI services are continuing remotely right now. Thank you!
- The letter from Dr. Stewart really helped me. I had not had any children previously with hearing loss in my practice. This provided exactly the direction I needed. Thank you so much.

Conclusion

After initiation of the PCP Outreach Project, EI enrollment of D/HH children identified through the EHDI process approached 90%.

The goal of enrollment by 6 months of age has improved though at 65% still needs improvement.

Future Goals

- Based on program successes to date, continue outreach to PCPs having children with reduced hearing
- Strive for 90% successful EI referral by 6 months
- Obtain feedback from PCPs to help advise on best method of providing up-to-date information to practices.
- Expand outreach to PCP having children with risk factors for reduced hearing
- Develop focused EHDI training module/video specifically for PCPs

Contact Us!

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<https://www.mass.gov/info-details/universal-newborn-hearing-screening-materials-for-health-care-providers#materials-for-primary-care-providers->

www.facebook.com/MassNewbornHearingScreening

Thank You!