

Maine's EHDl Focus Increases Family and Deaf/Hard of Hearing Adult Engagement

By Amber Woodcock, GBYS Coordinator, Maine Hands & Voices and Karen Hopkins, Executive Director, MECDHH and Principal Investigator of Maine's HRSA Grant

Part of creating a holistic service for families is including family perspectives at every discussion. In 2017, Maine made an important change in the HRSA grant administration. Maine's HRSA Grant is now overseen by the Maine Educational Center for the Deaf and Hard of Hearing Governor Baxter School for the Deaf (MECDHH/GBSD). The shift from the Department of Health to MECDHH/GBSD was a conscious decision to increase family engagement and deaf and hard of hearing infusion activities in our northeastern-most state. MECDHH/GBSD had a strong history of family activities and engagement, and this grant created a path to continuous improvement in collaboration for families. Maine's EHDl team consists of representatives from MECDH/GBSD, The Maine Newborn Hearing Program, Maine's Part C Agency, and the recent addition of Maine Hands & Voices. While Hands & Voices has been instrumental to the success of Maine's grant activities, the formal addition of the Maine GYBS Coordinator to this team ensures a seamless connection and more opportunity for shared planning and shared decision making by parents.

Parents and deaf and hard of hearing adults have always been included in many aspects of the work of Maine EHDl. Parents and deaf and hard of hearing adults are represented on the EHDl Advisory Board. The EHDl Parent Consultant and Quality Improvement Specialist are parents, and both of Maine's EHDl coordinators are also parents of deaf/hard of hearing children, and one is deaf herself. The logical next step was to bring in Maine Hands & Voices/Guide by Your Side Program, to ensure Maine's Family Based Organization was more deeply involved in all aspects of the EHDl Program and could bring intimate knowledge of families served through the Guide program to the Maine's EHDl team. Maine's EHDl program is infused with parent leaders and deaf and hard of hearing adults.

Recent accomplishments

Maine's EHDl Team developed a variety of branded resources with a focus on supporting family engagement in the earliest interactions of every aspect of the EHDl Process at critical points in the journey. The most important interaction is between parent and child but adding a focus on the earliest interactions between parent and providers have proven to be successful in contributing to positive parent/child connection. Parent to parent and deaf and hard of hearing adult involvement is embedded throughout the process. Developing a statewide approach to positive early interactions with families is key.

A new website, <https://earliestinteractions.com>, creates a space for easy access to comprehensive information that engages families and professionals in a holistic and collaborative manner. In addition, the Maine EHDl app was developed to partner with the website for instant access to information for families and providers.

With this collaborative team approach and the various resources available to all, families receive the same information regardless of where they live in the state of Maine. Family engagement was a priority in the development of the materials listed below with family partners fully involved in the creation and distribution which offers an opportunity for family engagement with various providers.

- Prenatal Visit: brochure explaining newborn hearing screening

- Refer at Screening:
 - Guide for next steps, the Earliest Interactions website, Maine EHDI app, a magnet with Maine Hands & Voices information, and a baby rattle with the parent consultant's contact information
 - CMV tip sheet
- Audiology Visit:
 - Tip Sheets on audiological process that will be distributed by the GBYS Coordinator to all audiology facilities
 - Upon diagnosis, a booklet on resources related to the child's individual hearing difference and Maine's resources
- Early Intervention:
 - Welcome binder
 - Developmental Milestones and Assessment Parent Portfolio
 - Exploration of Language and Communication Process Parent Guidebook

Maine's collaborative early intervention process embeds parent to parent support (GBYS) and Deaf/Hard of Hearing Support (Deaf/HH Guides and Mentors) into the first few weeks and months of early intervention while families are journeying through the process of exploring language and communication opportunities. The Guides are offered throughout early intervention and at all transitions to ensure parent to parent support.

Annually, Camp Discover is a family favorite in Maine! Supported by HRSA grant funds, this camp provides an opportunity for families to connect over a long weekend and learn about the various communication approaches through fun, interactive activities. Deaf and hard of hearing adults and Parent Guides lead all camp activities in collaboration with professionals. There is a parent/caregiver chat every evening led by the GBYS Parent Guides that allows for shared reflections and support in a comfortable, safe environment.



One of many activities for kids, families and parents at Camp Discover, Oct. 2022

In the future, we are hoping to bring back our "Winter Island Getaway" which takes place on the beautiful Mackworth Island in Maine for a mid-winter family gathering focused on family self-care and fun!

We are currently finalizing two projects including a video supporting the exploration of language and communication opportunities with families and the creation of a family roadmap as a refrigerator magnet for easy reference about the process and showing who is who in their families' EHDI process.

This Maine team in collaboration with Maine's audiologists have developed a series of Tip Sheets describing each aspect of audiology testing and in collaboration with Maine's early intervention providers will be creating new tip sheets related to language within family routines.

Webinars are being developed that explain the various Maine Hands & Voices Programs:

- What is GBYS?
- What is a Parent Guide?
- What is a Deaf/Hard of Hearing Guide?

The Maine EHDI team is looking forward to our statewide Collaborative Deaf and Hard of Hearing Conference on March 25, 2023. This conference is a collaboration between Maine Hands & Voices, MECDHH/GBSD, and The Maine Newborn Hearing Program. Parents attend at no cost while professionals pay a nominal fee to attend. In addition, a track for audiologists is offered. Hotel accommodations are provided to families living two hours away or more making this conference more accessible to all families.

In Maine, parent engagement and deaf/hard of hearing infusion matters. Our collaborative team approach ensures families receive consistent and comprehensive information and embeds parents and deaf and hard of hearing adults throughout our process.