



February 20, 2017

TO: The Honorable Senator Elizabeth Steiner Hayward, Co-Chair
The Honorable Representative Dan Rayfield, Co-Chair
Joint Committee on Ways and Means, Subcommittee on Human Services

FROM: Cate Wilcox, Manager
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SUBJECT: Request to Apply-Competitive Grant – Documentation and Use of
Follow-up Diagnostic and Intervention Services Data through the
Maintenance and Enhancement of the Early Hearing Detection and
Intervention Information System (EHDI IS)

Co-Chairs Steiner Hayward, Rayfield, and members of the committee, I am Cate Wilcox, the Maternal and Child Health Section Manager for the Oregon Health Authority.

I am here today to request permission to apply for the Centers for Disease Control and Prevention (CDC) *Documentation and Use of Follow-up Diagnostic and Intervention Services Data through the Maintenance and Enhancement of the Early Hearing Detection and Intervention Information System (EHDI IS)* Cooperative Agreement. This Cooperative Agreement will begin July 1, 2017 and provide up to \$250,000 of federal funding per year for three years, ending June 30, 2020 for a total of up to \$750,000.

The intent of the cooperative agreement is to support the early identification of deaf and hard of hearing infants and allay potential developmental delays by implementing strategies to improve the documentation of timely diagnostic follow-up and early intervention services. This cooperative agreement requires no state matching funds and there is no federal requirement for maintenance of effort.

Oregon's Early Hearing Detection and Intervention (EHDI) program sits in the OHA Public Health Division, Maternal and Child Health Section. The EHDI program was created by Oregon Revised Statute 433.321-327, to track and monitor hearing screening, diagnosis, and enrollment in early intervention services for children with hearing loss. The purpose of this law is to assure that infants with hearing loss are identified early and receive necessary services to prevent delays in language acquisition, communication, social emotional development, and to support on-time development and school readiness.

The public health, educational and personal burden for congenital hearing loss is significant. Congenital hearing loss is not rare - an estimated three in one thousand infants are born with hearing loss in the US each year. However, most infants with hearing loss are born to normally hearing parents in families with no history or experience with childhood hearing loss. Without objective screening and testing, hearing loss is invisible and easily missed by even the most attentive caregivers and providers until the child exhibits delays in speech and language. If there is a delay in identifying hearing loss, even infants with mild or unilateral hearing losses are missing sounds that are the building blocks of words and language acquisition. With early identification and appropriate services and supports, a hearing loss need not delay or limit a child's learning, opportunity and achievement.

The EHDI program provides public health tracking to: (1) collect the hearing screening status of all newborns in Oregon, (2) collect follow-up diagnostic evaluations for infants who do not pass the hearing screening, (3) collect eligibility and enrollment in early intervention services for infants with hearing loss, (4) report the incidence and trends of congenital hearing loss; (5) report information on strategies to improve timely diagnosis and enrollment in early intervention services, and (6) develop strategies to improve data collection, data quality, and access to timely services at each milestone.

This funding opportunity is one of two federal grants that together provide sufficient budget to fulfill Oregon's mandate to perform these services. Oregon has been a recipient of the CDC EHDI cooperative agreement since 2000. It includes both a core (continuing) scope of work and a new, optional expanded set of activities. The core work is to continue aligning our data system with national functional standards for EHDI information systems to:

- Enhance monitoring capacity,

- Implement training and technical assistance for EHDI partners,
- Promote and support coordination and collaboration for tracking and monitoring,
- Disseminate information about the incidence of hearing loss, trends and effective strategies, and
- Focus on continuous quality improvement.

The new expanded activities will include:

- Development of protocols for use of de-identified data,
- Analyze and identify data errors and factors related to successful receipt of timely services, and
- Identify methods to improve data quality and the reporting process.

This cooperative agreement will be implemented with existing OHA staff and will require no new positions. We will work with existing and new partners, including the State EHDI Advisory Committee to achieve grant requirements.

While we cannot prevent all congenital hearing losses, we can prevent developmental delays and promote on-time development through screening, timely diagnosis, and access to quality early intervention services. EHDI performs a critical role in tracking and assuring that infants with hearing loss are identified early so that they have the opportunity for on-time development. The funding to conduct this optional expanded set of activities would contribute to Oregon and our country's knowledge and strategies to improve timely diagnosis and enrollment into early intervention services.

Thank you for the opportunity to testify today. I am happy to answer any questions you may have.