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February 3, 2017

The Honorable Senator Richard Devlin, Co-Chair The Honorable Representative Nancy Nathanson, Co-Chair Joint Committee on Ways and Means 900 Court Street NE H-178 State Capitol Salem, OR 97301-4048

Re: 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) (OHA-PHD-17-1)

Dear Co-Chairpersons:

Nature of the Request

The Oregon Health Authority (OHA), Public Health Division requests permission to apply for the 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 for federal funds up to \$250,000 per year for three years, beginning July 1, 2017, and ending June 30, 2020 for a total of up to \$750,000.

The intent of the cooperative agreement is to implement strategies to improve the documentation of timely diagnostic follow-up and early intervention services, in order to support the early identification of deaf and hard of hearing infants and allay potential developmental delays. The funding is available through the Centers for Disease Control and Prevention (CDC), Center on Birth Defects and Developmental Disabilities. The request for proposals was received on January 5, 2017, and the application is due on March 6, 2017. This cooperative agreement funding requires no state matching funds. There is no federal requirement for maintenance of effort.

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Agency Action

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, an unfunded mandate 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. Both the core and optional expanded activities will continue to advance Oregon EHDI's ability to improve data collection, quality, and ultimately early identification and improved outcomes for infants with hearing loss. The Honorable Senator Richard Devlin The Honorable Representative Nancy Nathanson February 3, 2017 Page 3 of 4

The primary aim of the program and federal funding is to continue to improve timely screening, diagnosis and enrollment in early intervention services so that infants with hearing loss are acquiring language right from the start, along with their typical hearing peers. We will continue our improvement by aligning our data system with national functional standards for EHDI information systems to enhance surveillance 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 through this funding opportunity 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. These OHA positions include staff from the Public Health Division, Maternal and Child Health Section.

There is no expectation that the state will continue to fund the optional expanded activities at the end of the grant period. Knowledge gained in the form of data system improvements, protocols developed, and effective strategies will be integrated into the EHDI program for sustained improvement.

The OHA mission is to help people and communities achieve optimum physical, mental and social well-being through partnerships, prevention and access to quality, affordable health care. The aim of the public health system is to promote health and prevent disease and disability. 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. The Honorable Senator Richard Devlin The Honorable Representative Nancy Nathanson February 3, 2017 Page 4 of 4

Action Requested

The Oregon Health Authority (OHA), Public Health Division requests authority to accept the 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 funding from the Centers for Disease Control and Prevention if the state's application is successful.

Legislation Affected

Permission to apply for the full funding package will provide partial resources required but currently not provided with General Fund for Oregon Revised Statute 433.321-327. Without this funding, the program's ability to comply with the mandate will be severely limited.

For additional information, please contact Cate Wilcox, Maternal and Child Health Section Manager at <u>cate.s.wilcox@state.or.us</u>, or at 971-673-0299. Lillian Shirley, Director of the Public Health Division at 971-673-1229 may also be contacted.

Sincerely,

Syme Saxton

Lynne Saxton Director

CC: Linda Ames, Legislative Fiscal Office Tom MacDonald, Department of Administrative Services George Naughton, Department of Administrative Services Ken Rocco, Legislative Fiscal Office